HOW ARE CHILDREN AND YOUNG PEOPLE (CYP) WITH AN AUTISM SPECTRUM DIAGNOSIS SUPPORTED TO UNDERSTAND AUTISM AND THEIR DIAGNOSIS?

VOLUME 2: APPENDICES

by

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Appendix 1: Scoping review: summary of research on diagnostic disclosure

Appendix 1.1 Summary of the search criteria

	Date: December 2012	Criteria	Other information
	Databases Searched	• Science Direct • SAGE Journals • Web of Knowledge • PsychINFO • Google Scholar	
	Search Terms	1. Diagnosis: Autism and variations: Asperger Syndrome (AS)/Asperger, Autism Spectrum Disorder (ASD), Autism Spectrum Condition (ASC), High Functioning Autism (HFA) 2. Process: Disclosure; (diagnostic) interview/consultation; assessment 3. Experiences: views/perceptions/narratives/ 4. Participants: a. Child(ren)/young person; adolescent b. Parents; carers c. Adults with autism/Aspergers d. Males & females e. Professionals- paediatricians; physicians, psychologists, psychiatrist, general practitioners, occupational therapists, speech and language therapists, teachers, educators	In line with DSM V to encompass the whole spectrum Used * to reduce number of searches-eg: child*=children, child's, child autis*= autism; autistic, Search term recording grid used to ensure systematic approach
	Topics Included	• Childhood diagnostic experiences • Professional approaches • Parent experiences of autism specific diagnostic • Child experiences of autism specific diagnostic • Diagnostic experiences of adults with autism • Impact of diagnosis/disability on children • Impact of autism diagnosis • Methods used for collecting child/young person views about diagnosis and impact of diagnosis	
	Inclusion Criteria	• Date range 31st March 1979-28th December 2012 • Written in English • Views/perceptions of autism diagnosis process ○ Child ○ Parent/carer ○ Adults ○ Professionals • Views/perceptions/strategies giving a diagnosis to a child • Impact of an autism diagnosis • Views/perceptions of having an autism diagnosis • Child views/perceptions of having an illness/disability	Date limitations applied: 31st March 1979 to 28th December 2012 (Linked to concept of autism spectrum-Wing and Gould 1979) Earliest relevant research =1999
	Exclusion Criteria	Not in English language Outside of date range 31st March 1979 to 28th December 2012 Views/Perceptions not related to the impact upon the child/young person Issues related to the diagnostic criteria and/or identification, rather than experiences of the process and impact	

	Results	1. How CYP on the autism spectrum view autism diagnosis = 4 2. How CYP view having a diagnosis other than autism = 15 3. Parents' and others' views about receiving an autism diagnosis =5 4. Parents and other's views about the diagnostic process = 13 5. Parents and others' views about the impact of diagnosis = 9 6. Parents and other's views about the impact of post-diagnosis intervention = 2 7. Policy documents and research reports about sharing an autism diagnosis= 2 8. Adults with autism: views on sharing an autism diagnosis, impact = 5	- Child/young person views-receiving an autism diagnosis - Child/young person views-receiving diagnosis/impact of diagnosis other than autism - Issues and methods for collecting the views of children with autism - Parents' views of the diagnostic process for autism - Parents'/family views of the impact of the diagnosis - Adults with autism views of the diagnostic process for autism - Adults with autism views of autism, impact of the diagnosis and disclosure to others - Comparing pre/post diagnosis - Policy documents and professional research papers about sharing an autism diagnosis - Interventions to support young people, parents/families post diagnosis	- The total number of papers identified after screening titles was 138 - 83 were excluded after further reading abstracts and - Following application of the inclusion criteria 55 papers were themed and retained for review - Only 4 papers were directly relevant to children's perceptions of autism diagnosis - 1 report and 1 policy document were directly relevant - 49 papers/resources were partially relevant in providing useful information related to children's experiences of diagnosis from other perspectives: CYP with diagnosis other than autism, parents, professionals and adults with autism

Appendix 1.2 List of papers identified by the 2012 literature search

Table 1 How CYP on the autism spectrum view the diagnosis

Paper number	Reference	Country	Aims	Sample	Methods	Findings
1	Baines, A. D. (2012) Positioning, strategizing, and charming: how students with autism construct identities in relation to disability. **Disability and Society**, 27 (4): 547-561.	USA	To explore how young people with autism construct identities through social interactions at school and home	2 high school pupils with autism	Multi-sited ethnography comprising two years data including interviews and participant observation	Young people with the label of autism are capable of engaging in collective cultural practice They construct identities through social interactions to belong, compete, and participate. Nuanced efforts to distance themselves from the 'autistic' label were observed Social interactions exert power that helps to shape youth identity Young people with autism are not isolated from the sociocultural process of identity development The participants made a deliberate effort to promote a positive perception of themselves in the eyes of others Being seen as 'autistic' negatively affected how others perceived the participants
2	Billington, T. (2006) Working with autistic children and young people: sense,	UK	To encourage narratives of autistic experience that are focussed on assets	1 young person with autism across a	Observations and informal discussion with one case study participants alongside narrative	The author suggests practitioners should: - develop practices and discourses concentrate on assets rather than deficits;

Paper number	Reference	Country	Aims	Sample	Methods	Findings
	experience and the challenges for services, policies and practices, **Disability and Society**, 21 (1): 1-13.		rather than impairments or deficits 4	number of years	analysis of published studies, which were applied to the case observations	- create services that enable difficult feelings/distress to be shared; - be aware of interactionist influences and avoid placing responsibilities for behavioural change upon the child but upon also– parents and professionals; - need for more research to elicit views of CYP with autism about how they manage their 'worlds'
3	Huws, J. C. and Jones, R. S. P. (2008) 'Diagnosis, disclosure, and having autism: An interpretative phenomenological analysis of the perceptions of young people with autism', **Journal of Intellectual and Developmental Disability**, 33 (2): 99–107.	Wales, UK	To explore the retrospective accounts of young people with high functioning autism of their experience of autism from the perspective of an ''insider'' in order to highlight topics for future research.	9 young people with high functioning autism	Qualitative, Interpretative phenomenological analysis, Semi-structured interviews	Diagnosis, and the disclosure of the diagnosis of autism, were embedded in respondents' perceptions of ''having'' autism. The study identified 5 themes within the accounts: - disclosure delay - providing explanations - potential effects of labelling - disruptions and opportunities - acceptance and avoidance
4	Molloy, H. and Vasil, L. (2004) **Asperger syndrome, Adolescence and Identify: Looking Beyond the Label. London:** Jessica Kingsley Publications	UK Singapore Publication with multi-national contribution	Aim to provide 'an inside-out view' of the experiences of young people with an Asperger diagnosis.	6 life story narratives	Narrative interviews and analysis 6 case interviews: 3 in England; 2 ex-pats in Singapore; 1 from Australia living in Singapore;	The authors highlight that while young people's 'quirks' are likely to be considered as part of their unique and complex personalities, they are also likely to be viewed as symptoms. - Participants were accepting of the diagnosis - 2/6 viewed themselves as disabled and perceived this to impact socially - Views varied about the significance of AS to identity - individuals discussed more life successes were less dominated by the diagnosis - Most participants choose not to disclose their AS - 3 participants discussed misconceptions of autism being influenced by either the savant or medicalised severe disability view. - Scrutiny and linking all traits to diagnosis was also discussed - The authors highlight how trying to meet social expectations can influence low self-esteem. - The authors suggest a relationship exists between self-esteem and the extent AS was viewed as a disability

Table 2 CYPs' experiences of receiving a diagnosis other than autism

Paper number	Reference	Country	Aims	Sample	Methods	Findings
5	Baker, G.A., Hargis, E., Hsih, M.M., et al. (2008) Perceived impact of epilepsy in teenagers and young adults: An international survey. **Epilepsy and Behavior,** 12 (3): 395-401.	International	To explore the impact of epilepsy and its treatment on the quality of life, development, and opportunities for children/teenagers with the condition	212 young people with epilepsy and 507 parents or carers of children/teenagers from 16 different countries 74% -12 yrs and over 64% in mainstream schools	Questionnaires containing clinical and demographic information and perceptions of the impact of epilepsy and its treatment on aspects of daily living, including education and leisure.	More than one-third 1/3 expect the condition to hinder their lives in areas of: employment opportunities (73%), traveling and exploring (37%), education (36%) - 65% reported seizures caused them to lose, on average, 7 school days per year - 36% kept epilepsy a secret due to fears about being treated differently - 87% taking epilepsy medications Side effects included: - weight change (49%) - headaches (46%) - dizziness (41%) - shaking (33%)
6	Elliott, I.M., Lach, L. and Smith, M.L. (2005) I just want to be normal: A qualitative study exploring how children and adolescents view the impact of intractable epilepsy on their quality of life. **Epilepsy and Behavior**, 7 (4): 664-678.	Canada	To explore the impact of epilepsy on their quality of life (QOL)	49 young people with medically refractory seizures (7–18 years old).	Qualitative study using semi-structured open-ended interviews and narrative analysis	The themes reflected the negative impact of epilepsy on QOL including: —excessive fatigue as a barrier to academic and social pursuits; —intermittent emotional distress heightened by factors such as unpredictability of seizures; —profound social isolation; —discontinuous, fragmented learning Young people perceive seizures as the major barrier to their sense of normalcy and feel set apart from others. Authors suggest developing interventions and community/school-based programs to mitigate some of these negative experiences
7	Fair, C.D., Connor, L., Albright, J., et al. (2012) “I’m positive, I have something to say”: Assessing the impact of a creative writing group for adolescents living with HIV. **The Arts in Psychotherapy**, 39 (5): 383-389.	USA	To evaluate the impact of the “Teens Out Loud,” creative writing group for adolescents with HIV	6 female and 1 male adolescents with mean age of 16 years, four guardians, and five group leaders	Qualitative, interviews, grounded theory, narrative analysis	Benefits for young people were reported as: - Young people- improved confidence, communication skills, support and a desire to share experiences with others. - Guardians- improved self-expression, behaviour, and writing skills amongst their participating adolescents - Group leaders-increased openness among members and described the group as a “safe place” for adolescents talk about HIV Concerns included disclosure, discussion of sensitive topics, and balance between recreation and learning Authors suggest that creative writing groups can promote personal growth and decreased isolation of youth living with HIV

Paper number	Reference	Country	Aims	Sample	Methods	Findings
8	Forrest Keenan, K., van Teijlingen, E., McKee, L., et al. (2009) How young people find out about their family history of Huntington's disease. **Social Science and Medicine,** 68 (10): 1892-1900.	Scotland, UK	To explore young people's experiences of finding out about a family history of the hereditary disorder Huntington's disease (HD).	33 young people (aged 9–28)	Qualitative inductive method of data collection using semi-structured interviews and analysis using elements of a grounded theory approach	Findings suggest that YP want to know 'what is wrong?' and can cope with knowing from an early age. 4 types of disclosure experience were described: having always been told; being gradually told; HD was kept a secret and HD as a new diagnosis. Participants attitudes towards their family's style of communication varied. Some young people showed an understanding of parents 'disclosure dilemmas'. Young people may value the opportunity to discuss diagnosis at their own pace and when ready emotionally and cognitively. Authors highlight key times at which young people may need further information and support, while there were also circumstances where limited or even nondisclosure was supported. Being too 'open', 'overloading' young people with information and 'proactive testing', might also have a detrimental impact on young people's well-being.
9	Gray, N.J., Klein, J.D., Noyce, P.R., et al. (2005) Health information-seeking behaviour in adolescence: the place of the internet. **Social Science and Medicine,** 60 (7): 1467-1478.	UK and USA	To explore UK and US adolescents' perceptions and experiences of using the internet to find information about health and medicines, when other health information sources that are available	26 single-gender focus groups with 157 English-speaking students aged 11–19 years from the UK and the USA	Qualitative, focus group study	Many students reported that the internet was their primary general information source. Participants considered internet health information as generally salient. Its saliency was increased through active Searching and personalisation. Perceived credibility of the internet varied The internet combines positive features of traditional lay and professional, personal and impersonal sources and is an important source of health information for adolescents
10	Herrman, J.W. (2006) Children's and Young Adolescents' Voices: Perceptions of the Costs and Rewards of Diabetes and Its Treatment. **Journal of Paediatric Nursing**, 21 (3): 211-221.	USA	To explores children's beliefs about the costs and rewards of Type 1 diabetes and its treatment	17 children and young adolescents aged 8 to 15 years; mean age 10.8 years-7 boys and 10 girls	Qualitative semi-structured interviews	Determining children's perceptions was found to be valuable to influence positive diabetes-related behaviours: 'Costs' included: Having to think and count in relation to diet, Not being able to 'just eat' What can happen... Participants identified positive strategies to manage diabetes Being seen as normal and fitting in with peers is important

Paper number	Reference	Country	Aims	Sample	Methods	Findings
						Peers therefore have great impact on children's coping and diabetes-related behaviours
11	Hogan, J., Horgan, M., Glenn, S., et al. (2007) Perceptions of young people with CF on the lack of knowledge and understanding of the condition within the general public. **Journal of Cystic Fibrosis**, 6, (S1), S70: 286.	UK	To explore perceptions of young people with CF as they transition to adulthood.	8 male and 10 female CF patients aged 16−21 years.	A qualitative study using in-depth semi-structured interviews	Key themes identified were: - There is very little knowledge and understanding of CF in general population - CF receives little media attention - Lack of general understanding impacted on disclosure to peers as they found explaining the condition difficult and embarrassing. - Media information about CF tends to be inaccurate and overly negative. - Lack of understanding about CF and evokes feelings of sympathy which angered many of the young people. Participants demonstrated a positive image as people with CF who 'live their lives as normally as possible and achieve the many aspirations they have for the future'.
12	Holt, K. (2007) 'What do we tell the children?' Contrasting the disclosure choices of two HD families regarding risk status and predictive genetic testing, **Journal of Genetic Counseling**, 15 (4): 253–265.	USA	To understand the complicated process of disclosure to children, especially in the context of predictive genetic testing related to Huntington Disease (HD)	Two families with family history of HD, at least one at risk family member actively considering the use of predictive genetic testing for themselves	Qualitative Interpretative Phenomenological Analysis (IPA)	Participants considering predictive genetic testing for themselves are influenced by the dynamics of the family The desire to protect as central when parents decide not to disclose; For parents the question of disclosure is 'complicated and heartfelt, Parental worry that disclosure would cause anxiety for their child led them to avoid the topic All the YP would have preferred an open style of family communication and to be told of their genetic history and risk status from their parents early in life
13	Klitzman, R., Thorne, D., Williamson, J., Chung, W. and Marder, K. (2007) Disclosures of Huntington disease risk within families: patterns of decision-making and implications. **American Journal of Medical Genetics**, 143 (A): 1835-1849.	USA	To identify how individuals who have or are at risk for HD make these complex disclosure decisions, and what factors are involved	21 individuals with HD-eight mutation-positive, four mutation-negative, and nine not tested	In-depth interviews	Participants identified uncertainty about: - When to disclose-worried about doing so too early/late - What to tell (suspicions vs. confirmed symptoms; initiation vs. completion of testing; partial vs. indirect information), - How to disclose (planning in advance vs. ''blurting out'' information in arguments), - Whether and how to tell extended family members Reasons for disclosure: - perceived duty to foster the health of their family members, - enabling appropriate medical assessment Concerns about disclosure: - Information could burden - The 'right to remain ''in denial'' and not discuss/pursue testing

Paper number	Reference	Country	Aims	Sample	Methods	Findings
						- whether and how much to encourage family members to pursue testing
14	McIntosh, C., Stephens, C. and Lyons, A. (2012) “Remember the bubbles hurt you when you cook in the pan”: Young children's views of illness causality. **Psychology, Health and Medicine,** 18 (1): 21-29.	New Zealand	To explore four-year-old children’s everyday understandings of illness causality	5 four-year-old participants	Narrative in-depth interviews; prior to the interviews, children were asked to make their own storybooks using art materials and photographs of children experiencing illness	Two themes identified related to illness causality constructions: - “behaviour-based explanations for illness” - “illness prevention messages and behavioural rules”. Authors suggest that four-year-olds’ understanding may be more sophisticated than traditionally maintained; -illness prevention messages and behavioural rules within sociocultural contexts may significantly influence children’s conceptualisation of illness causality.
15	McMaugh, A. (2011) Encountering disablement in school life in Australia: children talk about peer relations and living with illness and disability. **Disability and Society**, 26 (7): 853-866	Australia	To identify children’s views of peer relations and living with illness and disability	24 young people with physical disability or chronic illness	Narrative, semi structured interviews on three occasions related to transition: end of Y6; early Y7 & lateY7	Common experiences of disability-related harassment and differential experiences of friendship, peer rejection and problematic school cultures were identified. Authors suggest that although children encounter and actively counter disablement in a variety of ways, it is clear that these children are also aware of the stigma, prejudices and disabling expectations
16	Singh, I. (2011) A disorder of anger and aggression: Children’s perspectives on attention deficit/hyperactivity disorder in the UK. **Social Science & Medicine**, 73, 889-896	UK & USA	To identify what ADHD means for children’s everyday lives, and what children do with this diagnosis.	150 children with ADHD diagnosis aged 9-14 from the UK & USA	Semi-structured interviews utilising vignettes, standardised pictures, a sorting & a sentence completion task	The findings highlight the influence of school culture in the UK, the researchers suggest that aggression is a central aspect of the culture that influences difficulties with behavioural self-control that children with an ADHD diagnosis display in the UK. The author contrasts this to school culture in the USA, which they suggest is where peer aggression is low but pressure to perform well in school is higher. They suggest that difficulties with self-control were more likely to be expressed in the ‘performance’ channel in the USA. The author also suggests that active moral agency can either support or compromise resilience.
17	Stewart, M., Barnfather, A., Magill-Evans, J., Ray, L. and Letourneau, N. (2011) Brief report: An online support intervention: Perceptions of adolescents with physical disabilities. **Journal of Adolescence,** 34: 795–800.	Canada	To examine influences of a pilot computer-mediated peer support	Control-group: 27 teens completed measures 22 participants- 12 males; 10 females, ages 12–18 years (Equal numbers had cerebral palsy or spina bifida	Scaled measures of loneliness, sense of community, self-perceptions, coping, and social support prior to intervention, post-intervention, and delayed post-intervention. Semi-structured qualitative interviews- perceptions of the intervention’s impacts.	Themes included: - interaction with teens with disabilities via internet - social network size and composition - loneliness and social isolation - support -seeking as a coping strategy - self-perceptions - sense of community More contact with teens with disabilities, decreased loneliness, and increased social acceptance and confidence. Significant increase in sense of community was reported from post-intervention to delayed post-intervention.

Paper number	Reference	Country	Aims	Sample	Methods	Findings
18	Taylor, S., Haase-Casanovas, S., Weaver,T. Kidd, J. and Garralda, E.M. (2010) Child involvement in the paediatric consultation: a qualitative study of children and carers' views. **Child: Care, Health and Development**, 36 (5): 678–685.	UK	To investigate child and carers' attitudes towards child involvement in paediatric consultations	Twenty families (21 children, 17 mothers and 5 fathers)	Semi-structured qualitative interviews explored child and carers' attitudes towards child involvement at different stages of the paediatric consultation process	Most families (19) felt that the child should be involved at some stage of the consultation process Views on the extent and nature of involvement varied in relation to child, family and illness characteristics, as well as on the stages of the consultation. Views varied about whether parental or doctors who should decide about the young person's involvement in the consultation process. The amount of information given to the child increased maturity of the child Some felt making a diagnosis should be a collaborative process; others solely the domain of the doctor. Some children wanted to be given the choice of being involved and some wanted their parents to be responsible for implementing the plan. Some families with a seriously ill child wanted the burden of involvement in the management plan taken away from them.
19	Wright, A., Jorm, A.F. and Mackinnon, A.J. (2011) Labelling of mental disorders and stigma in young people. **Social Science and Medicine**, 73 (4): 498-506.	Australia	To examine the association between labelling of mental disorders and stigma in youth	2802 Australians aged 12-25 years	A national telephone survey assessing responses to vignettes of a young person experiencing depression, psychosis or social phobia	No significant associations between label use and "stigma perceived in others", "reluctance to disclose" and for the most part "social distance" Most labels were associated with seeing the person as "sick" rather than "weak" Accurate psychiatric labels had the strongest effect sizes. Authors suggest that the use of accurate psychiatric labels is rarely associated with stigma Community education promoting labelling of psychosis should proceed with caution and address views about unpredictability and dangerousness

*Table 3 Parents' and *professionals' views about receiving an autism diagnosis*

(*Only two papers explored the views of professionals)

Paper number	Reference	Country	Aims	Sample	Methods	Findings
20	Bartolo, P. A. (2002) Communicating a diagnosis of developmental disability to parents: multi-professional negotiation frameworks. **Child: Care, Health and Development**, 28 (1): 65–71.	Malta	To describe how findings about four preschool children, with difficulties suspected to lie within the autistic spectrum, were negotiated with parents by two multi-professional groups, in a Medical and Education setting.	Parents of 4 preschool children 2 multi-professional groups	Narrative analysis of assessment discussions and participant interviews following the assessment	Professionals used of a parent-friendly frame, complemented by a hopeful-diagnostic-formulation frame and a defocusing-of-bad-news was found useful.
21	Brogan, C. and Knussen, C. (2003) The disclosure of a diagnosis of an autistic spectrum disorder Determinants of satisfaction in a sample of Scottish parents', **Autism**, 7(1): 31-46.	Scotland	To investigate the determinants of parental satisfaction with the disclosure interview disclosure of a diagnosis of an autistic spectrum disorder, using a self-report questionnaire	126 participants, 73% mothers; 27% fathers. 12% lone mothers; no lone fathers. Representing 96 children of which 85% male; age range 39-to 206 months. mean age 86 months. Mean age of diagnosis 55 months	Quantitative self-report scaled questionnaire based upon the work of Sloper and Turner (1993)	More than half of the participants were satisfied or very satisfied with the disclosure Those giving a more positive satisfaction rating were more positive about: 1. the manner of the professional during the disclosure interview 2. the quality of the information given at that time (including the provision of written information and being given the opportunity to ask questions) 3. their first suspicions being accepted by professionals
22	Harnett, A. and Tierney, E. (2009) Convention of hope–communicating positive, realistic messages to families at the time of a child's diagnosis with disabilities', **British Journal of Learning Disabilities**, 37: 257–64.	Ireland	To explore the way that parents are told that their child has disabilities.	1588 professionals and 584 families	Mixed methodology, involving focus groups and a parent/professional questionnaire survey	Parents and professionals agreed that there should be positive, realistic messages and hope given to parents about their child. Many parents said that they did not get nice or hopeful messages. Professionals could give realistic and hopeful messages by telling parents that there is help available. Professional could tell parents about the value and importance of every child. • Giving realistic, positive and hopeful messages to parents about their child is the start of providing good support to people with disabilities through their whole lives. Providing good support throughout people's whole lives is one of the aims of the UN Convention on the Rights of Persons with Disabilities.

Paper number	Reference	Country	Aims	Sample	Methods	Findings
23	Knussen, C. and Brogan, C. A. (2002) 'Professional practice in the disclosure of a diagnosis of an autistic spectrum disorder: Comparing the perspectives of parents and professionals in Scotland', **Journal of Applied Health Behaviour**, 4 (1-2): 7-14.		To explore the satisfaction with disclosure of the diagnosis of an autistic spectrum disorder	126 parents-73% mothers and 27% fathers; 12% single mothers no single fathers; 96 children- 85% Male/15% female Mean age at diagnosis = 55 mths 91% diagnosed within 5 yrs prior to data collection	Self-report questionnaire	55% indicated that they were satisfied or very satisfied with the disclosure 33% neither satisfied nor dissatisfied, 7% dissatisfied, and 6 % dissatisfied. Those gaining higher satisfaction scores were more likely to have: 1. been given the diagnosis of Asperger syndrome (as opposed to autism); 2. been given a definite diagnosis; 3. children who were not currently in an educational placement. Parents giving a more positive satisfaction rating were also more positive about 1. the manner of the professional during the disclosure interview 2. the quality of the information given at that time (including the provision of written information and being given the opportunity to ask questions) 3. their first suspicions being accepted by the professionals
24	Landsman, G. (2003) Emplotting children's lives: developmental delay vs. disability. **Social Science and Medicine**, 56: 1947–1960.	USA	To explore the experience of acquiring new knowledge about personhood and disability during the period of time when a woman has recently come to find that their child has a developmental disorder.	Observation of 130 developmental evaluation sessions of infants and young children. Interviews with 60 women whose children were diagnosed with a disability or developmental delay	Ethnographic research-130 observations, 60 interviews and narrative analysis	Mothers just encountering a diagnosis of disability may differ from the stories told by those who have experienced mothering a disabled child over time

*Table 4 Parents' and *professionals' views about the diagnostic process*

(* One paper explored the views of professionals)

Paper number	Reference	Country	Aims	Sample	Methods	Findings
25	Avdi, E., Griffin, C., and Brough, S. (2000) Parents' constructions of professional knowledge, expertise and authority during assessment and diagnosis of their child for an autistic spectrum disorder. **British Journal of Medical Psychology**, 3 (3): 327-38.	England UK	Explore parent views of the knowledge, expertise and authority of professionals, during assessment and diagnosis of their child for autism	11 semi-structured interviews, undertaken over 6 months with 3 sets of parents who were undergoing an assessment of their sons for communication difficulties	Qualitative interview and narrative analysis	Parents' constructions of professional expertise and authority were ambivalent and at times contradictory Suggested an ideological dilemma between professionals' equality and expertise Discourse analysis is a particularly useful tool in investigating aspects of complex parent/professional interactions in relation to the diagnostic process
26	Clarke, J. and van Amerom, G., (2008) Asperger's Syndrome: differences between parents' understanding and those diagnosed. **Social Work in Health Care**, 46: 85-106.	Canada	To investigate views of, and coping with, Asperger syndrome (AS) from the perspectives of people with a diagnosis and their parents	30 blogs by people who identified themselves with AS 30 blogs by their parents and carers	Qualitative content analysis of blogs	Parents and Carers usually accept the medical definition and seek support and/or a 'cure' for their child People with AS argue against a pathologizing and medicalising perspective. Authors' suggest they are happy with who they are. They further suggest people with AS explain they experience difficulties and due to society barriers and not those inherent in AS.
27	Gray, D. (2002) 'Everybody just freezes. Everybody is just embarrassed': Felt and enacted stigma among parents of children with high functioning autism', **Sociology of Health and Illness**, 24 (6): 734-749.	Australia	To explore 'courtesy stigma' (stigma of affiliation) and experiences of the distinction between felt and enacted stigma	32 mothers and 21 fathers were inter- viewed for a total sample of 53 parents. 21 families- both parents 11 mother only Parents of children with high functioning autism or Asperger's Syndrome whose ages ranged from five to 26	Qualitative research using in-depth semi-structured interviews	The majority of parents experienced both felt and enacted stigma Mother's reported more occurrences than fathers The majority of mothers experienced enacted stigma compared to only a minority of fathers. Enacted stigma included 'avoidance, hostile staring and rude comments from others'. Children's behaviours were related to the stigmatisation Parents of children who were considered 'aggressive' were more likely to experience stigma than the parents of 'passive' children

Paper number	Reference	Country	Aims	Sample	Methods	Findings
28	Howlin, P. and Asgharian, A. (1999) The diagnosis of autism and Asperger syndrome: Findings from a survey of 770 families. **Developmental Medicine and Child Neurology**, 41: 834–839.	UK	Comparison of the diagnostic experiences of parents of children with autism and parents of children with Asperger Syndrome.	614 parents (autism) and 156 (Asperger Syndrome) only those with single diagnosis were included	Quantitative scaled questionnaire distributed by autism charity groups.	Parents first concerned about their child- mean age in Asperger group 2.53 years and autism group 1.52 years Age when diagnosis was confirmed -autism group: mean 5.49 years and Asperger group: mean 11.13 years Very late diagnosis (20 yrs +): 2.1% of the autism and 9.8% of the Asperger group Parents in the Asperger group were significantly less satisfied with the diagnostic process than those in the autism group
29	Howlin, P. and Moore, A. (1997) Diagnosis in autism: A survey of over 1200 patients in the UK. **Autism**, 1: 135–162.	UK	To explore parent views about the adequacy of the diagnostic process and the help that resulted from this	1295 parents Average age of case 12.17 (range 2-49) 83.2 % male 16.8 female	Quantitative questionnaire Demographic data and parent satisfaction scale	Parents recognise their child's difficulties early (average 1.7 yrs); begin to seek help at average 2yrs and average age obtain diagnosis 6 yrs. Few parents were very satisfied with the process 13%; 49% not very, or not at all satisfied However, almost 20% were very satisfied and 30% were quite satisfied with the help they received- only 15% not satisfied at all.
30	Kerrell, H. (2001) Service evaluation of an autism diagnostic clinic for children, **Nursing Standard,** 15(38): 33-7.	Wales, UK	To explore parents' views about and satisfaction with their experiences at multidisciplinary autism diagnostic clinic	11 families with experience of the clinic	Structured interview-closed and open questions;	Most parents were dissatisfied with their experiences but would continue to attend and would recommend to others There is a need for improved services for parents and families of children with autism Professionals did not adequately understand potential stress levels of parents or the implications for long term coping with their child's needs Better collaboration between multidisciplinary team members is required to address the needs this group of service users
31	Mansell, W. and Morris, K. (2008) A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service: Access to information and use of services. **Autism**, 8 (4): 387-407.	England UK	1. To explore parents' views about the quality of a local diagnostic service and the use and quality of information, support, and treatment. 2. To assess the positive and negative consequences of a diagnosis and whether parents'	Parents of 100 children who had been diagnosed at the centre were sent questionnaires 55 were returned 50% completed by the mother and ½ by both the mother and the father. The mean age for diagnosis was 4–5 years,	Mixed methods-Self-report postal questionnaire with scaled and open questions	Parents obtained useful information from a range of sources, including a parents' support group, school teachers, speech and language therapists, educational psychologists, the Internet, books, and academic journals. Special units and schools were rated as the most useful source of support and treatment, Parents reported a diverse range of both negative and positive consequences of diagnosis, Many parents reported a change in their attitudes to diagnosis over time. Many expressed frustrations with: - the diagnostic process -the social, educational and health services,

Paper number	Reference	Country	Aims	Sample	Methods	Findings
			attitudes to diagnosis changed over time.	Range 2 years to over 10 years.		-the way that autism is viewed by non-professionals and other parents.
32	Midence, K. and O'Neill, M. (1999) The experience of parents in the diagnosis of autism. A pilot study. **Autism**, 3 (3): 273-85.	North Wales, UK	to investigate the experiences of parents with a child with autism and the process of diagnosis	Parents of 4 children, three boys and one girl, aged between 9 and 12 years, and first diagnosed between 3 and 7	Qualitative grounded theory, using semi structured interviews	Themes identified: -Parents' difficulties in understanding their child's behaviours and the confusion that resulted from their inability to make sense of these behaviours; -Problems in obtaining a diagnosis; -Experience of relief after the correct diagnosis Diagnosis supported: -parents understanding and acceptance of autism and the limitations imposed on their child; -improved adaptation to the condition within the family life; -fostering of more realistic expectations of their child's future
33	Moore, K., McConkey, R., Sines, D., *et al.* (1999) Improving diagnostic and assessment services for children with autistic spectrum disorders.**Early Child Development and Care**, 154: 1-11.	Northern Ireland, UK	To document the experiences of the main stake-holders (parents and professionals) to inform a credible set of principles and recommendations	34 parents at 4 focus groups Questionnaires from 15 services representatives 44/ individual professionals: medical professionals or paediatricians (N = 8); teachers (N = 8); health visitors or disability nurses (N = 8); occupational therapists/ speech and language therapists (N = 8) clinical psychologists (N = 5) consultant psychiatrists (N = 3)	Mixed methods: Focus groups, questionnaire	Principles underpinning assessment services were identified and recommendations developed for improvements: - need be provided locally as core integrated components of paediatric services - Responsive pre-school services would enhance the process - Improve access to diagnostic services and follow up support - More effective liaison between health and social services & education - Better liaison between parents and professionals - Improve skills for providing home-based supports
34	Nissenbaum, M.S., Tollefson, N. and Reese, R.M. (2002) The interpretive conference:	USA	To examine professionals' and parents' perceptions of	11 nonmedical professionals and 17 parents of	Qualitative semi structured interviews	Findings enabled a set of recommendations: Importance of professionals communicating a good understanding of autism

Paper number	Reference	Country	Aims	Sample	Methods	Findings
	Sharing a diagnosis of autism with families. **Focus on Autism and Other Developmental Disabilities**, 17(1): 30-43.		giving and receiving a diagnosis of autism	children with autism		A family friendly setting is important The needs of the family should be considered Professionals should have good communication skills Provide information about resources and interventions Provide follow-up to the diagnostic session Discuss prognosis with parents Provide positive messages and hope Recognise and prepare for the impact of giving a diagnosis on the professionals
35	Osborne, L. and Reed, P. (2008) Parents' perceptions of communication with professionals during the diagnosis of autism. **Autism**, 2 (3): 309 -24	England, UK	To investigate the ways in which communication concerning ASD, and its diagnosis, could be facilitated between parents and professionals.	15 Parent focus group interviews Age groups: -preschool -primary -secondary	Qualitative -focus groups, transcription and content analysis	Parents identified the need following improvements: • quicker and easier diagnostic process; • process needs more coherent structure and content; • more professional training about ASD; • professional require interpersonal skills training; • broad information sheets would help parents at the time of diagnosis, especially to combat negative information available via other sources.
36	Russell, G. and Norwich, B. (2012) Dilemmas, diagnosis and de-stigmatization: Parental perspectives on the diagnosis of autism spectrum disorders. **Clinical Child Psychology and Psychiatry**, 17 (2): 229-245.	UK	To explore the function of ASD diagnosis for parents, and examine whether a diagnosis affected how parents perceived ASD.	17 parents 8 parents not actively pursuing a diagnosis, despite professional indication that their child might be on the spectrum, 9 parents whose children had already received an autism diagnosis.	In-depth semi-structured interviews, which were analysed using thematic and grounded theory approaches.	Parents identified dilemmas relating to decisions about whether to try: - to retain the ‘normal’ status of the child - to ‘normalise’ the child through diagnosis and remediation Other findings - Parents of children on the spectrum became proactive in trying to reduce stigmatization of autism, - Some parents actively advocate autism diagnosis to others as positive experience - De-stigmatization of autism may lead to increased diagnosis
37	Siklos, S. and Kerns, K. A. (2007) Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders. **Research in**	Canada	To evaluate the diagnostic experiences and impact of diagnosis for parents of children with ASD in British Columbia	60 Parents with children between the ages of 2 and 18 years	Quantitative data via Postal Questionnaire Package- adapted version of The Howlin and Moore (1997) 33-item questionnaire designed to assess the problems faced by parents in obtaining a	During diagnostic process families saw an average of 4.46 professionals: 23% saw 2 professionals, 14% saw 3; 21% saw 4 41% saw 5+ and 5% 10+ before diagnosis Average wait 2 years 8 months to receive the final diagnosis Views about the diagnostic process: -51% were not satisfied.

Paper number	Reference	Country	Aims	Sample	Methods	Findings
	Developmental Disabilities, 28: 9–22				diagnosis for their children with autism	-diagnosis itself versus the diagnostic process- -----80% of respondents rated the diagnosis of an ASD as stressful -----82% reported the diagnostic process stressful.

Table 5 Parents' and *professionals' views about the impact of diagnosis

(* One paper also explored the views of professionals)

Paper number	Reference	Country	Aims	Sample	Methods	Findings
38	Casey, L. B., Zanksas, S. Meindl, J.N., Parra, G.R., Cogdal, p. and Powell, K. (2012) Parental symptoms of posttraumatic stress following a child's diagnosis of autism spectrum disorder: A pilot study', **Autism Spectrum disorders**, 6 (3): 1186-1193.	USA	An investigation of PTSS in parents experiencing their child's diagnosis	265 parents of children diagnosed with autism, 92% were female and 8% were male 87% of their children were male and over 5 years of age (85%)	A retrospective study examining the occurrence of PTSS in parents of children with autism using standardised instruments: Impact of Events Scale-Revised (IESR) and the LA Symptom Checklist (LASC). The IES-R was used for group membership (PTSS or not) and the LASC was used to determine further psychosocial ailments.	The findings from this study indicate that a subpopulation (20%) of parents with children with autism experience moderate to high levels of posttraumatic stress symptoms related to the autism diagnosis. These findings are within the reported range of 11–32% as compared to parent PTSS research across other medical conditions and disability groups. For this 20% of parents experiencing PTSS, also endorsed feelings such as intrusion or re-experiencing the events, avoidance symptoms such as staying away from the reminders of the trauma, and hyperarousal symptoms including a constant feeling of uneasiness or being easily startled
39	Lutz, H.R., Patterson, B. J. and Klein, J. (2012) 'Coping With Autism: A Journey Toward Adaptation', **Journal of Pediatric Nursing**, 27: 206–213	USA	To explore the experiences of families of individuals with autism as perceived by the mother	16 mothers' children with autism	Interview and narrative analysis	The autism diagnosis was identified as the stressor that initiated parent's process of coping and the journey toward adaptation for the mothers and families. The four main responses to the stressor that mothers experienced were: grief and anger, dis-ease and relationship strain, guilt and doubt, and disappointment and sacrifice. To cope with the stress of the child's autism, mothers used a variety of coping strategies in response to the stressors, such as seeking answers, support, socialization, and spirituality; appreciating and redefining life and multiple roles; and revising dreams and future planning.
40	Moh, T.A. and Magiati, I. (2012) 'Factors associated with parental stress and satisfaction during the process of diagnosis of children with Autism Spectrum Disorders', **Research in Autism Spectrum Disorders,** 6: 293–303	Singapore	To assess parental experiences of the process of diagnosis of ASD in the last 10 years and to explore possible factors associated with parental stress and satisfaction To explore professionals'	85 Parents: 83.3% mothers 16.7 fathers 1 grandmother 1 Special Education Therapist on behalf of a parent Children- mean age 7 yrs, 3 mths	Quantitative -scaled questionnaires and standardised measures	Parents whose children presented more severe ASD symptomatology reported lower levels of satisfaction with the diagnostic experience. The higher the number of professionals consulted and the less collaborative the relationship, the higher the reported parental stress. The number of professionals consulted did not appear to affect parents' satisfaction, but good collaborations with professionals, higher ratings of perceived helpfulness of information received and lower levels of stress were associated with higher parental satisfaction in the diagnostic process.

Paper number	Reference	Country	Aims	Sample	Methods	Findings
			reports of current ways of working to ascertain if these follow recently published clinical practice guidelines	17 Professionals 7 paediatricians, 7 2 clinical psychologists 1 ABA therapist		Parents who rated their collaboration with professionals higher also tended to rate highly the information provided to them by the professionals
41	Oprea, C. and Stan, A. (2012) 'Mothers of autistic children. How do they feel?' **Procedia - Social and Behavioral Sciences**, 46: 4191 – 4194	Romania	To identify how the diagnosis of autism affects the life of the mother and the whole family	22 mothers of children with autism	Qualitative questionnaire with open questions	The themes derived from subjects refer to: difficulty in accepting the diagnosis; impact upon parent relationships; hoping for the recovery of their child; determination to fight to get help for their child, negative attitudes of society support of relatives, friends and experts to alleviate suffering ensuring optimal conditions for the development of the child
42	Osborne, L.A., McHugh, L., Saunders, J. and Reed, P. (2008) A possible contra-indication for early diagnosis of Autistic Spectrum Conditions: Impact on parenting stress, **Research in Autism Spectrum Disorders**, 2: 707–715	Wales	The impact of diagnosis of Autistic Spectrum Conditions (ASCs) in children on parenting stress.	Parents of 85 children with Autism	Quantitative -scaled questionnaires parenting stress and standardised measures -autism and behaviour	Diagnostic severity predicted their parents' first noticing a problem, Early parental concern predicted obtaining an earlier diagnosis. Diagnostic severity of the child related directly to parenting stress. Parenting stress declined over time from the point at which the parents had first noticed a problem in their child, Parenting stress did not change by any significant degree once the diagnosis had been received. Parenting stress does not reach a floor, and remains exceptionally elevated in parents of children with autism
43	Russell, G., Kelly, S. E. Ford, T and Steer, C. (2012) 'Diagnosis as a social determinant: The development of prosocial behaviour before and after an autism spectrum diagnosis', **Social Science and Medicine**, 75 (9): 1642-1649.	UK, England Avon	To explore whether a change in the development of prosocial symptoms can be detected before and after diagnosis	Avon Longitudinal Study of Parents and Children (ALSPAC) cohort study 14,000 children born between 1991 and 1993	Quantitative- standardised measure of one core autistic symptom: social behaviour-measured this using the prosocial score from the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997, 1999)	Multi-factorial fixed effect modelling suggested that the developmental trajectory of the measure of behaviour was not significantly altered by ASD diagnosis, or the consequences of diagnosis, either for better or worse Authors suggest that results indicate that prosocial behaviours may be resistant to typical 'treatments'
44	Sansosti, Frank J. ; Lavik, Katherine B. ; Sansosti, Jenine M. (2012) 'Family Experiences through the	USA	To investigate common family experiences during the diagnostic	16 families of children aged 7 years and	Mixed methods- standardised measures- Vineland Adaptive Behaviour Scales–Second	• a 2-year lag between first noticing delays in their children's behaviour and diagnosis • delay was significantly longer for children of African American/mixed racial backgrounds

Paper number	Reference	Country	Aims	Sample	Methods	Findings
	Autism Diagnostic Process', **Focus on Autism and Other Developmental Disabilities**, 27(2): 81-92		process, and the child and family variables that may relate to different diagnostic outcomes.	younger with ASD	Edition (VABS-II) Gilliam Autism Rating Scale, Second Edition (GARS-2). Temperament and Atypical Behaviour Scale (TABS) and semi-structured interview Including closed and open-ended questions exploring satisfaction with care, services, and information received	• families whose children were diagnosed at a later age were less satisfied with the diagnostic process • Families lacked understanding of research-based interventions
45	Stuart, M., McGrew, J. H. (2009) 'Caregiver burden after receiving a diagnosis of an autism spectrum disorder', **Research in Autism Spectrum Disorders**, 3: 86–97	US	To assess family stress associated with receiving the initial diagnosis of ASD in one's child.	78 primary caregivers of children diagnosed with ASD within the past 6 months	Quantitative -scaled and standardised measures – autism severity; social readjustment and support; stressors and coping strategies	The time of initial diagnosis is stressful, although the levels of stress are moderate. Negative appraisal of caring for a child with an ASD was associated with increased burden Having a negative diagnostic experience can profoundly affect their feeling of burden across several dimensions. Higher levels of both general and contextual social support were directly related to decreased individual and family burden
46	Taylor, J. L. and Warren, Z. E. (2012) 'Maternal Depressive Symptoms Following Autism Spectrum Diagnosis', **Journal of Autism and Development Disorders**, 42:1411–1418	USA	To examine the reported symptoms and correlates of depression in caregivers of young children following ASD diagnosis.	Postal Survey-82 responses from families Responses 91% mothers	Quantitative- standardised measure of IQ; Caregiver depressive symptoms (CES-D; Radloff 1977), a 20-item self-report questionnaire indexing depressive symptoms over one-week and clinical data from the child's initial diagnostic evaluation	78.7% of mothers' retrospective reports showed clinically significant depressive symptoms regarding the week following their child's ASD diagnosis, 37.3% reported clinically significant levels of depressive symptoms at follow-up (Av. 1.4 yrs later). Depressive symptoms immediately following diagnosis were not related to initial global characteristics of child functioning, but were related to reported child problem behaviours and financial barriers

Table 6 Parents views about the impact of post-diagnosis intervention

Paper number	Reference	Country	Aims	Sample	Methods	Findings
47	Keen, D., Couzens, D., Muspratt, S., et al. (2010) The effects of a parent-focused intervention for children with a recent diagnosis of autism spectrum disorder on parenting stress and competence. **Research in Autism Spectrum Disorders,** 4 (2): 229-241.	Australia	To reduce parenting stress and increase parenting competence for families of children within 6 months of receiving an autism diagnosis	39 families who had a child aged between 2 and 4 years with a clinical diagnosis of autism	Pre-post test quasi-experimental design investigating outcomes for children (social communication and adaptive behavior) and their parents (parenting stress and sense of competence) following participation in either a professionally supported or self-directed, self-paced parenting intervention	Development in social communication was greater for children of families receiving professional support as measured by a caregiver questionnaire but not on a clinically measured behavior sample. The authors suggest that professionally supported intervention resulted in reduced child-related parenting stress and increased parenting self-efficacy relative to the self-directed intervention.
48	Papageorgiou, V. & Kalyva, E. (2010) Self-reported needs and expectations of parents of children with autism spectrum disorders who participate in support groups, **Research in Autism Spectrum Disorders**, 4 (4): 653-660.	Greece	To explore the self-reported needs and expectations that parents express according to their gender and education and according to the age and gender of their child with ASD	299 parents (72 fathers and 227 mothers) of children who were diagnosed with ASD	Qualitative-anonymous open-ended questionnaire	The needs and expectations that parents expressed differed significantly according to their gender and education, as well as the age and gender of their child with ASD- implications for organising and running support groups for parents are highlighted: • more fathers than mothers withheld that they have a child with ASD and reported greater lack of understanding and support. • parents with university education reported more acceptance in comparison to parents with secondary education who tended to withhold child's diagnosis from their colleagues • parents with secondary education expected more practical support from groups, while parents with university education expected more psychological support.

Table 7 Professional research reports that include guidance about sharing autism diagnosis

Paper number	Reference	Country	Aims	Sample	Methods	Findings
49	National Collaborating Centre for Women's and Children's Health (2011) *Autism: recognition, referral and diagnosis of children and young people on the autism spectrum.* London: Royal College of Obstetricians and Gynaecologists Press. *Available at: https://www.ncbi.nlm.nih.gov/books/NBK92985/*		Evidence review commissioned by the National Institute for Health and Clinical Excellence	Sifting reduced the initial 47,255 papers to 925 articles were examined in full text and 185 papers identified	Systematic literature searches base on clinical questions and protocol developed by GDG Reviews of the evidence published from 1990 to 11 October 2010 were undertaken	Key findings related to communicating the results of the assessment indicate that professionals should engage with parents or carers and, if appropriate, the child or young person (pp.17-18) "60 to discuss the findings, including the profile, sensitively, in person and without delay…. Explain the basis of conclusions even if the diagnosis of autism was not reached. 61 using recognised good practice when sharing a diagnosis 62 ..share information to explain: what autism is how autism is likely to affect the child or young person's development and function." "63 provide … a written report of the autism diagnostic assessment…explaining the findings of the assessment and the reasons for the conclusions drawn…" "67 For children and young people with a diagnosis of autism, offer a follow-up appointment with an appropriate member of the autism team within 6 weeks of the end of the autism assessment for further discussion (for example about the conclusions of the assessment and the implications for the child or young person)." This section of the guidance also highlights that the report and information should be shared with parental or carer consent and, if appropriate, the consent of the child or young person, with key professionals involved in the child's or young person's care, including those in education and social care to inform a needs-based management plan.
50	Finke, E. H., Drager, K.D.R., & Ash, S. (2010) Pediatricians' perspectives on identification and diagnosis of autism spectrum disorders. **Journal of Early Childhood Research**, 8(3): 254–268. https://doi.org/10.1177/1476718X10366773	USA	To describe paediatricians' experiences of autism diagnosis	5 general paediatricians	Qualitative interview	Themes identified: **Knowledge/training**: Autism Signs/ characteristics; Incidence rates; Causes Experience outside workplace; What they would like to know; Recommendations for younger doctors **Diagnosis:** Well-child exams; Firsts signs/first concerns; Wait and see; Referrals/other professionals; Giving the diagnosis Length of diagnostic process **Communication:** Comfort level/familiarity with family; Asking family questions; Addressing 5concerns and questions; Addressing family reactions to the diagnosis

Paper number	Reference	Country	Aims	Sample	Methods	Findings
						Conclusions: Autism diagnosis is a challenge for the general paediatricians due to limited number of developmental paediatricians for referral Conflict in their roles vs those outlined lack of training may contribute to feeling unqualified to make the diagnosis

Table 8 Adults with autism: views on impact of autism diagnosis and disclosing autism

Paper number	Reference	Country	Aims	Sample	Methods	Findings
51	Bagatell, N. (2007) ‘Orchestrating voices: autism, identity and the power of discourse’**,** *Disability and Society*, 22 (4), pp. 413-426.	USA	To explore the complex negotiations involved in the process of constructing identities for one young man with high functioning autism	Single case: 21-year-old college student	Ethnographic study, focussed on the process of identity construction using participant observation and interviews to construct an in-depth narrative	Emphasised struggles with identity, significant depression withdrawal into fantasy and attempted suicide. - Stress of pretending to be normal - Searching for a cure - Struggling to construct an identity - Representing self through imposed discourses of others (Holquist, 1981; Holland et al., 1998) - Voices that marginalize and become internalized - Understanding autism and a new way of understanding himself - Constructing a new life narrative by reframing experiences and behaviours. - Meet others with autism and living an authentic life - Asperger’s is integrated into an accepted self - Identity develops through participation and discourses that become inner speech - Autism as a neurological ‘difference’ - Aspie social: just sharing space and energy - Subtly coming - Negotiating identity - Orchestrating different discourses and inner voices The researcher suggests by shifting attention from deficits to social participation, individuals with autism may be better prepared to engage in the process of identity construction, leading to a full and meaningful life. The lack of meaningful services is highlighted.
52	Cousins, E. (2001) ‘Exploring the Experience of a Late Diagnosis of Asperger Syndrome and High-Functioning Autism: A Review of Relevant Theory, Research and Methodology’, unpublished doctoral thesis, University of Exeter, UK.	UK	To understand the experience of late diagnosis of autism	8 adults (over 18 years) Asperger (AS) diagnosis	Semi-structured interviews and Interpretative phenomenological analysis	Themes identified Being an outsider-early awareness of difference & self-blame Searching for an explanation- autism, concerns being dismissed, other Diagnostic revelation- sense of fit to experiences, varied emotions (surprise or anticipated) liberated from blame and uncertainty. Identity central to: -Searching for meaning- understanding themselves better, difference of mind vs neurotypical, -Support-more needed -building a framework - basis for action,
53	Davidson, J and Henderson, V.L. (2010) “Coming out’ on the spectrum: autism, identity and disclosure’, *Social*	Canada	To examine issues surrounding the management of diagnostic disclosure to others	First hand accounts and autobiographies of 45 people with Asperger (AS) diagnosis	Close reading and discourse analysis of autobiographies and personal narratives	4 repertoires were identified within the texts: -‘Keeping safe’-protective strategies in disclosure and coming out -‘qualified deception’ -the complexities of non-disclosure;

	and Cultural Geography, 11 (2), pp. 155-170.				Thematic discourse analysis	-'like resistance' -the tendency of AS authors to position their experiences of 'coming out' on the spectrum alongside coming out of marginalized groups, such as gay and Deaf communities; -'education' focusses on disclosing to support understanding and the importance of building a community to come out to.
54	Jones, G. E., (2001) 'Giving the diagnosis to the young person with Asperger syndrome or high functioning autism', *Good Autism Practice*, 2 (2): 1466-2973.	UK	Considers the potential benefits and issues and possible ways of explaining the diagnosis to the person concerned.	The views of 5 adults with autism are considered alongside academic writing and research	Qualitative analysis of biographies written by individuals with an autism spectrum diagnosis themselves.	Parents are best placed to decide whether, when and how a diagnosis should be given. Accounts explored indicated 'very strongly' that knowing they have autism has been vital. There may be instances where giving the diagnosis is not advisable. More should be written about the subject to guide both parents and professionals.
55	Punshon, C., Skirrow, P., and Murphey, G. (2009) 'The 'not guilty verdict': psychological reactions to a diagnosis of Asperger Syndrome in adulthood', *Autism*, 13(3), pp. 265-283.	UK	To examine the experiences of 10 adults receiving an Asperger syndrome diagnosis	10 adults in the processes of receiving the diagnosis	Phenomenological approach	The prior life experiences of individuals led to them developing certain beliefs about Asperger syndrome and impacted formation of each participant's perceived self-identity. Six themes were identified in the discussions: 1. negative life experiences 2. experiences of services (pre-diagnosis) 3. beliefs about symptoms of Asperger syndrome 4. identity formation 5. effects of diagnosis on beliefs 6. effect of societal views of Asperger syndrome

Appendix 1.3 How a diagnosis is viewed by children and adults with autism diagnosis and children with a diagnosis other than autism

KEY: Social experiences/influences on self-views Identity Finding out Disclosing autism Impact of diagnosis

How CYP on the autism spectrum view autism diagnosis	How CYP view having a diagnosis other than autism	Adults with autism: views on sharing an autism diagnosis, impact
Engagement in collective cultural practice (1) Belonging (1) Distancing from ‘autistic’ label (1) Societal power to shape identity (1) Promoting the positive self (1,2,) Negative (mis)perceptions of autism (1,4) Problem context (2) Self-esteem (2,4) Agency-control (2) Autism identity (2,4) Discourse (2) Having autism (3) Disclosure delay (3) Explanations (3) Labelling (3) Disruptions & opportunities (3) Acceptance/rejection (3,4) Autism, disability and social views/impact (4) To disclose or not (4) Scrutiny and autism traits (4)	Hindering opportunity (5,6) Educational impact (5,6) Treated differently (5) Side effects (5) Negative impact QOL (6) Emotional distress (6, Social isolation (6, 15, 17) Barriers to normalcy (6, 10) Mitigating interventions (6) Coping with knowing (7,8) Writing improves self-expression (7) Sharing experiences (7, 17) Personal growth (7) Decreased isolation (7, 17) Disclosure experiences (8) Parental disclosure dilemmas (7, 8, 12, 13) Emotionally and cognitive readiness (8) Openness vs overloading (8) Internet as a primary information source (9) Internet & personal accounts (9) Importance of CYP’s perceptions (10) Positive strategies (10) Being normal & fitting in (10) Peer influences (10) Poor understanding of condition (11) Lack of media attention (11) Peer understanding and disclosure hesitancy (11, 13) Negative media perceptions (11) Presenting a positive self (11, 15) Influence of family dynamics (12) Non-disclosure-protecting the child (12) Child preference for knowing and openness (12, 17) Disclosure logistics-when, how, who to (13, 17,18) Disclosure a collaborative process (17,18) Whether to seek diagnosis/testing (13)	Stress of ‘pretending to be normal’ (51) Searching for a cure (51) Struggling to construct an identity (51) Representing self through other’s discourse (51, 53) Constructing new narratives (51, 52) Integrating diagnosis into an accepted self (51,52) Experiences & participation influencing inner speech (51) Autism as ‘difference’ (51,52) Being an outsider (52) Self-blame (52) Searching for an explanation (52) Concerns dismissed (52) Diagnostic revelation (52) Sense of fit to experiences (52) Varied emotions-surprise or anticipated (52) More support services needed (52) A framework - for action (52) Aspie social: just sharing space and energy (51) Subtly ‘coming out’ (51,53) Negotiating identity (51,52, 55) Orchestrating discourses and inner voices (51) Negotiating disclosure as ‘keeping safe: to tell or not (53) Non-disclosure-‘qualified deception’ (53) Coming out -‘like resistance’ of other marginalized groups (53) Disclosure to support ‘education’: others’ understanding (53) Disclosure to build a community to come out to (53) The importance of knowing own diagnosis (54) More guidance needed for parents and professionals. (54) Benefits of knowing (54) Logistics: how, when and by whom should disclose (54) Diagnosis supports self-understanding (54) Diagnosis enables access to support groups with others with autism (54) Diagnosis supports strengths to be discussed (54) Diagnosis supports future planning (54) Not knowing & negative explanations for understanding self/behaviours (54) Experiential influences (55) Negative life experiences (55) Experiences of services (pre-diagnosis)

How CYP on the autism spectrum view autism diagnosis	How CYP view having a diagnosis other than autism	Adults with autism: views on sharing an autism diagnosis, impact
	Disclosure a duty/right (13) Underestimating CYP's understanding (14) Causal and safety-based explanations (14) Sociocultural influences on understanding (14) Disclosure to enable treatment (13) Disability-related harassment (15) Experiences of friendship & rejection (15) School cultures (15, 16) Stigma & prejudice (15) Disabling expectations (15) Agency & resilience (16, 17) Internet & social support form others with disability (17) Self-views (17) Community, acceptance and confidence (17) Labels, stigma and reluctance to disclose (19) Need for accurate psychiatric labels (19) Importance of community education (19)	Societal views impacting self-views (55)

Appendix 1.4 Summary of themes from papers about parents' perspectives

KEY: Social experiences/influences on self-views Disability, labelling & stigma Being told about the diagnosis Impact of diagnosis Accessing services Factors impacting diagnosis

Parents: receiving an autism diagnosis	Parents: the diagnostic process	Process vs outcomes	Parents: impact of post-diagnosis intervention
Parent-friendly frame (20) Defocusing-of-bad-news (20) Professional manner (21,23) Quality written information (21,23) Acceptance of parent views (21) Realistic, hopeful messages 22 Preference for definite diagnosis (23)	Mixed perceptions of professional expertise and authority (25) Ideological dilemma equality and expertise during disclosure (25) Seeking support and/or a 'cure' (26, 41) Negative and positive consequences of diagnosis (31) Parents recognise & seek help for child's difficulties early (29) Varied satisfaction with the process (29,30) Need for improved services (30;33)	Earlier diagnosis= greater satisfaction (28) Parents with autism diagnosis more satisfied than Asperger group (28) Diagnostic relief (32) Diagnosis supports understanding and acceptance (32) Parents experience posttraumatic stress (38) Avoiding diagnosis reminders (38) Diagnosis: a stressor that initiated a process of coping and adaptation (39) Feelings of grief and anger, guilt, doubt, disappointment and Sacrifice (39) Relationship strain (39,41)	Families receiving professional support reported improved social communication in their child (47) Professionally supported intervention resulted in reduced child-related parenting stress and increased parenting self-efficacy (47) Needs and expectations of parents differed significantly according gender and education (48) Needs and expectations of parents differed significantly according to age and gender of their child Fathers were more likely than mothers to withhold that they have a child with autism (48) Fathers reported greater lack of understanding and support (48)
Views about autism			

Asperger syndrome preferred, as opposed to autism (23) Perceptions change over time (24, 31) Acceptance of medical definitions (26) Against pathologizing and medicalising diagnosis (26) Acceptance of diagnosis (26, 41) Social barriers (26) Felt and enacted stigma (27) Children's behaviours & stigmatisation (27,32) De-stigmatization of autism may lead to increased diagnosis (36) Negative societal attitudes (41)	Lack of professional understanding of parental experience (30,34) Better multiagency collaboration is needed (30,33) Useful information sources (31) Frustrations with the diagnostic process (31, 35, 37) Problems obtaining a diagnosis (32) Family friendly setting is important (34) Professionals communication skills (34,35) Provision of information about resources and interventions (34,35) Diagnostic follow up needed (34) Provide positive messages and hope (34) Parental dilemmas relating to whether to 'normalise' the child through diagnosis and remediation (36) Parental proactivity in reducing stigmatization (36) Parental advocation of autism diagnosis (36)	Coping strategies research, support, faith, re-appraisal and planning (39) Social support (39,41) More severe autism symptomatology=lower diagnostic experiences (40) Quality/quantity of professional involvement impacts parental stress (40) Positive collaboration ratings=highly informative information (40) Early parental concern predicted earlier diagnosis (42) Diagnostic severity related directly to parenting stress (42) Parenting stress/depression (42, 45, 46) Developmental trajectory for behaviour not significantly altered by diagnosis (43) 2-year gap noticing behaviour and diagnosis (44) Significantly longer gap between parental recognition and diagnosis for children of African American/mixed racial backgrounds (44) Families with later diagnosed child were less satisfied with the process (44) Families lacked understanding of research-based interventions (44) Negative perception of caring for a child with autism was associated with increased burden (45)	University educated parents reported more acceptance (48) Secondary educated parents wanted more practical support from groups (48) University educated parents wanted more psychological support (48)

Appendix 1.5 Themes from the papers about views of adults with autism

Themes & subthemes: adults with autism		
Negotiating identity/self-views Stress of pretending to be normal 51 Struggling to construct an identity 51 Discourses that become inner speech 51 Asperger's is integrated into an accepted self 51 Disclosing-coming out on the spectrum 53 AS & autism identity 53 Different mind vs neurotypical 52 Not fitting in 55 Life experiences impact beliefs diagnosis and self-identity 55 Wanting/pretending to be 'normal' 55 Feeling weird and strange 55 **Identity formation 55** (Internalising others' views) framework for explanation to self & others 55 Positive framing of AS 55 Diagnosis delay- denial and stigma concerns 55 Being an outsider-early awareness of difference & self-blame 52	**Language & stigma** Voices that marginalize and become internalized 51 Orchestrating different discourses and inner voices 51 Choosing' an AS label to avoid autism stigma 53 Disclosure delay due to stigma concerns 55 Disability discourses & online identities 53 Choosing' an AS label to avoid autism stigma 53 Unofficial teacher's labels 54 Peer bullying labels 54	**Societal understanding/experiences** Family and friends not surprised by diagnosis 55 Family relief 55 Some negative family reactions 55 Positive media portrayal but concern over stereotyping 55 Lack of understanding within society 55 Problematic societal demands 55 Meeting others with AS & fitting in 55 Early access to support groups useful 54 Negative reactions to disclosure 53 Building a community to come out to 53 Aspie social: just sharing space and energy 51 Unsuccessful masking 55 Meet others with autism and living an authentic life 51 Aware others noticed differences 55 Representing self through other's discourse (51, 53) Experiences & participation influencing inner speech (51) Autism as 'difference' (51,52)

Representing self through imposed discourses of others 51 Diagnosis, a framework for self-knowledge 53		Experiential influences (55) Societal views impacting self-views (55) Orchestrating discourses and inner voices (51)
Mental health Significant depression 51 Withdrawal into fantasy 51 Attempted suicide 51 Being an outsider-early awareness of difference & self-blame 52 lifelong mental health involvement 55 Aware of/frustrated by difficulties 55 Mixed emotions: elation and relief vs loss and anger 55	**Autism knowing diagnosis** 'Very strong' indicate that knowing the autism diagnosis is vital 54 Giving the diagnosis during problematic circumstances is not advised 54 Coming to terms with the diagnosis 54 Diagnosis provides answers 54 Enables access to peers with diagnosis 54 Supports recognition of strengths and identification of successful role models with autism 54 Facilitating a more positive self-image 54 Enables informed decisions about future 54 Initial feelings of anger, denial and lack of self-worth 54 Coming out 53 Constructing a new life narrative by reframing experiences and behaviours.51 Being an outsider, early awareness of difference & self-blame 52 Searching for an explanation 52 Autism concerns dismissed 52 Diagnostic revelation- sense of fit to experiences 52 Varied emotions (surprise or anticipated) liberated from blame and uncertainty 52 Positive and negative changes 55 Framework for explanation to self & others 55 Explanation/exoneration for previous experiences 55 Access to support services 55 Searching for meaning 52 Understanding autism and a new way of understanding self 51 Different mind vs neurotypical 52 Finding out- a framework for action 52 Knowledge is power 53 **Autism not knowing diagnosis** No framework to explain symptoms 55 Misdiagnosis 55 failed interventions 55 Delayed diagnosis-poor professional understanding 55 Lack of diagnosis- caused misunderstandings when using services 55 Lack of understanding/support 52	**Disclosure: who/when/how** Parents are best placed to decide whether, when and how a diagnosis should be given 54 Delay – worries about response 54 Guidance should enable individual to their own understanding and approach to the condition 54 Disclosure decision jointly between parents and professionals 54 Feelings about the diagnosis change over time54 When to disclose tailored to individual 54 In response to asking questions/situational occurrences 54 Telling other family members -both immediate and extended 54 Peer disclosure requires consent and care 54 Parental disclosure 54 Professional support for understanding 54 Adolescents might deny diagnosis and refuse support 54 Texts by peers on the spectrum as a supportive source 54 Individualised letters from a professional to explain the diagnosis 54 Autism passports to support explanation to others 54 coming out 53 When and how to disclose 53 A methodical approach when deciding whether to disclose 53

	Feeling different 54 Trying hard but filing to fit in 54 Asking and being told there is nothing wrong 54 Qualified deception' complexities of non-disclosure 53 Searching for a cure 51 Masking difficulties 55 Knowing own autism diagnosis 53 Not knowing - no defences for keeping safe 53	

Appendix 1.6 Combining all child themes (including children with autism and children with other diagnosis)

All Child Themes (children with autism and other diagnosis)	Sub-themes	Papers
Identity & self-views	Self-views & identity (1,2,10,11,15,17) Autism & identity (2,3,4) Normalcy (6, 10) Acceptance and confidence (17)	1; 2; 3; 4; 6; 10; 11; 15; 17;
Social influences	Societal influences on identity (1,10,11,12, 14, 15,16,19) Perceptions of autism (4, 11, 13,14) Social isolation/inclusion (6, 7, 15, 17) Disability, difference, stigma, prejudice (4,5,15,19)	1; 1
Influences and impact: CYP's autism narratives	Labelling (1,3) Negative impact QOL, scrutiny opportunity (4,5,6) Processing: acceptance/rejection (3,4,6,7,8) Agency, growth & resilience (7,10, 16, 17)	
Disclosure logistics	Disclosure logistics-when, how, who to (3, 4,13, 17,18) Disclosure dilemmas (7, 8, 12, 13) Disclosure reasons (8, 13,14) Disclosure preferences (8, 12.17,18)	
Intervention/support	Interventions (6,7) Internet for information & support (9)	

Appendix 1.7 Summary of themes & subthemes

All Child Themes (children with autism and other diagnosis)	Sub-themes	Papers
Identity & self-views	Self-views & identity (1,2,10,11,15,17) Autism & identity (2,3,4) Normalcy (6, 10) Acceptance and confidence (17)	1,2,3,4,6,10,11,15,17
Social experiences/influences	Societal influences on identity (1,10,11,12, 14, 15,16,19) Perceptions of autism (4, 11, 13,14) Social isolation/inclusion (6, 7, 15, 17) Disability, difference, stigma, prejudice (4,5,15,19)	1,2,4,5,6,7,10,12,14,15,16,17,19
Impact	Labelling (1,3) Negative impact QOL, scrutiny opportunity (4,5,6) Processing: acceptance/rejection (3,4,6,7,8) Agency, growth & resilience (7,10, 16, 17)	1,2,3,4,5,6,7,8,10,15,16,17
Disclosure-how they learnt about diagnosis	Disclosure logistics-when, how, who to (3, 4,13, 17,18) Disclosure dilemmas (7, 8, 12, 13) Disclosure reasons (8, 13,14) Disclosure preferences (8, 12.17,18)	3,4,7,8,12,13,14,17,18
Intervention/support	Interventions (6,7) Internet for information & support (9)	6,7,9

Themes from adults with autism	Sub-themes	Papers
Autism: knowing/not knowing	**Not knowing diagnosis** No framework to explain symptoms 55 Searching/asking for an explanation (51, 52, 54) Misdiagnosis 55 Lack of diagnosis-service user problems 55 Lack of understanding/support 52 Feeling different/not fitting in (outsider) 52, 54 Masking difficulties (51, 55, 53) Not knowing - no explanation for understanding self/behaviours (53, 54) **Knowing diagnosis** Knowledge is power/vital (53, 54) Framework for explanation to self & others (51, 52, 53, 54, 55) Avoid sharing diagnosis in problem context (54) Coming to terms with the diagnosis [varied emotions] (52, 54) Enables access to peers/role models with diagnosis (54) Facilitating a more positive self-image (52, 54)	51,52,53,54,55

	Finding out- a framework for action (52, 54) Access to support services 55	
Negotiating identity & self-views	Construction of identity (51,52,53, 55) Self-narratives (51, 52) Integrating diagnosis into an accepted self (51,52) Self views(51, 52) Sense of fit to experiences (52) Stress of pretending to be normal (51) Normality & Difference (weird, strange, stigma) (52, 55) Framing self in relation to diagnosis (51, 53, 55 Discourses internalized (51, 55) Diagnosis delay- denial and stigma concerns (55) Diagnosis for self-knowledge (53)	51,52,53, 55
Social experiences/influences	Family relief/negativity (55) Positive media portrayal but concern over stereotyping (55) Lack of understanding within society (55) Problematic societal demands (55) Meeting others diagnosis: fitting in/sharing energy (51, 55) Early access to support groups useful (54) Negative reactions to disclosure (53) Building a community to come out to (53) Unsuccessful masking (55) Representing self through other’s discourse (51, 53) Experiences & participation influencing inner speech (51, 55) Autism as ‘difference’ (51,52) Orchestrating discourses and inner voices (51, 55)	51,52,53,55
Language, labels & stigma	Diagnosis is a pathologizing and medicalising (26) Voices that marginalize and become internalized 51 Orchestrating different discourses and inner voices 51 Choosing’ an AS label to avoid autism stigma 53 Disclosure delay due to stigma concerns 55 Disability discourses & online identities 53 Unofficial teacher’s labels 54 Peer bullying labels 54	26, 51, 53, 54, 55
Disclosure: when/who/how	Parents are best placed to decide whether, when and how a diagnosis should be given 54 Delay – worries about response 54 Guidance should enable individual to their own understanding and approach to the condition 54 Disclosure decision jointly between parents and professionals 54 Feelings about the diagnosis change over time54 When to disclose tailored to individual 54 In response to asking questions/situational occurrences 54 Telling other family members -both immediate and extended 54 Peer disclosure requires consent and care 54	51, 53, 54

	Parental disclosure 54 Professional support for understanding 54 Adolescents might deny diagnosis and refuse support 54 Texts by peers on the spectrum as a supportive source 54 Individualised letters from a professional to explain the diagnosis 54 Autism passports to support explanation to others 54 coming out 53 When and how to disclose 53 A methodical approach when deciding whether to disclose 53 Negotiating disclosure as ‘keeping safe: to tell or not (53) Subtly ‘coming out’ (51,53) Non-disclosure-‘qualified deception’ (53) Coming out -‘like resistance’ of other marginalized groups (53) Disclosure to support others’ understanding (53) More disclosure guidance needed for parents and professionals. (54) Logistics: how, when and by whom should disclose (54)	
Mental health	Significant depression 51 Withdrawal into fantasy 51 Attempted suicide 51 Being an outsider-early awareness of difference & self-blame 52 lifelong mental health involvement 55 Aware of/frustrated by difficulties 55 Mixed emotions: elation and relief vs loss and anger 55	51, 52, 55

Parent Themes	Sub-themes	Papers
Before diagnosis	Parents recognise & seek help for child’s difficulties early (29) Seeking support and/or a ‘cure’ (26) Seeing multiple professionals before diagnosis (37) Long wait to receive the final diagnosis (37) Diagnostic process is stressful (37) Parental dilemmas relating to whether to ‘normalise’ the child through diagnosis and remediation (36) Social barriers (26) Felt and enacted stigma (27) Children’s behaviours & stigmatisation (27) Lack of professional understanding of parental experience (30,34) Parents’ difficulties making sense of child behaviours (32) Problems obtaining a diagnosis (32)	26,27,29,30,32,34,37
Giving diagnosis positively	Parent-friendly frame (20) Defocusing-of-bad-news (20) Professional manner (21,23)	20,21,22,23,32

	Better understanding of child (32) Quality written information (21,23) Acceptance of parent views (21) Realistic, hopeful messages 22 Preference for definite diagnosis (23)	
Process problems	Frustrations with the diagnostic process (31) Process needs more coherent structure and content; (35) Better multiagency collaboration is needed (30,33) Varied satisfaction with the process (29,30) Need for improved services (30,33) Need for better home-based supports (33) Mixed perceptions of professional expertise and authority (25) Ideological dilemma equality and expertise during disclosure (25)	25,29,30,31,32,33,35
Positive impact of diagnosis	Earlier diagnosis= greater satisfaction (28) Parents with autism diagnosis more satisfied than Asperger group (28) Professionals communicating a good understanding of autism (34,35) Family friendly setting is important (34) Better understanding of child (32) Diagnostic relief (32) Diagnosis supports understanding and acceptance (32) Provision of information about resources and interventions (34,35) Provide positive messages and hope (34) Parental advocation of autism diagnosis (36)	28,32,34.35,36

Professional Themes	Sub-themes	Papers
Giving diagnosis:	Parent-friendly, positive, hopeful frame (20, 22, 34) Explanation based on diagnostic-formulation (20) Defocusing-of-bad-news (20, 34) Realistic messages (22) Provide a prognosis (34) Requires good communication skills (34, 40) Provide information about resources and interventions (22, 33, 34) Recognise and prepare for the impact of giving a diagnosis on the professionals (34)	20, 22, 33 34, 40
Service provision:	Should be local and core integrated components (33) Responsive pre-school services to enhance the process (33) Improved access diagnostic services (33) Provide follow-up to the diagnostic session (22, 34) More effective interprofessional practice (33, 40) Better liaison between parents and professionals (22, 33, 40)	22, 33, 40

	Improved home-based support (33) Parents whose children presented more severe autism symptomatology less satisfied (40) Too many professionals increase parental stress (40)	

Policy documents and research reports about sharing an autism diagnosis (Note: these documents are not synthesised as they already align, the policy guidance is based on the research report)	
Summary	Professionals should include parents/carers and the CYP, if appropriate, in discussion of assessment findings (49,50) Discussion should sensitively explain the autism profile & the basis of conclusions (49,50) Sharing a diagnosis should use good practice (49,50) Explanation should cover what autism is and likely impact (49,50) CYP given a diagnosis of autism should be offered a follow-up appointment for further discussion (49,50) A written report should provide an explanation of assessment findings and rationale for the conclusions (49,50) The written report should, with consent, be shared with key professionals to inform a needs-based management plan (49,50)
Who to include in the explanation	Professionals involved in the assessment (49,50) Parents or carers (49,50) Child or young person if appropriate (49,50)
What to explain	Profile related to autism diagnosis identified through assessment (49,50) The basis of the conclusions (49,50) What autism is (49,50) How autism is likely to impact the individual (49,50)
When to explain	In person during the assessment summary meeting (49,50) Through a follow up appointment (49,50) Follow verbal explanation with a written report(49,50)
How to explain	Sensitively (49,50) Following good practice (49,50)

Table 9 Summary themes from each participant group

Child Themes	Themes from adults with autism	Parent Themes	Professional Themes
Identity & self-views Social influences Influences and impact: CYP's autism narratives Disclosure logistics Intervention/support	Autism: knowing/not knowing Negotiating identity & self-views Social experiences/influences Language, labels, disability & stigma Disclosure: when/who/how Mental health	Social experiences/influences on self-views Disability, labelling & stigma Giving the diagnosis Impact of diagnosis Accessing services Factors impacting diagnosis	Service provision Giving diagnosis

Appendix 2 Systematic review undertaken in 2019

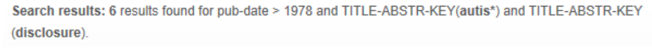
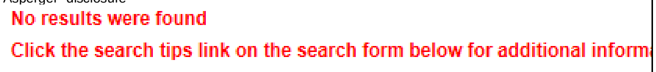
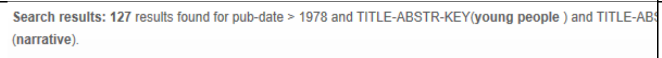
Appendix 2.1 Table showing how the search terms were combined for children’s search

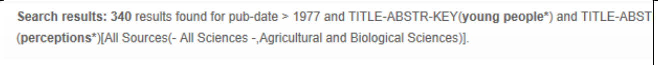
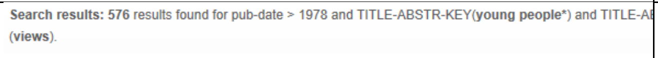
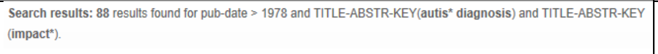
Searched G Too General	Autis*	Asperger*	Child	Young people	Adolescent
Autism*	G	G	✓	✓	✓
Asperger*	G	G	✓	✓	✓
Narrative	✓	✓	✓	✓	✓
Perceptions	✓	✓	✓	✓	✓
Views	✓	✓	✓	✓	✓
Diagnos*	✓	✓	✓	✓	✓
Disclosure	✓	✓	G	G	G
Experiences	✓	✓	G	G	G
Interview	✓	✓	G	G	G
Consultation	✓	✓	G	G	G
Impact	✓	✓	G	G	G

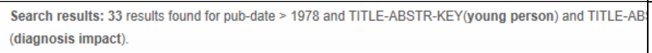
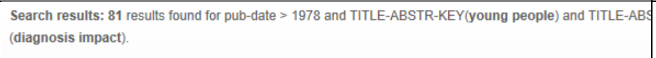
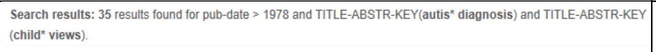
KEY:
G-search becomes to broad

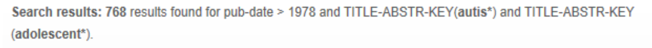
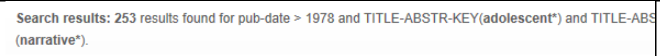
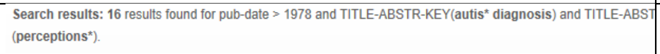
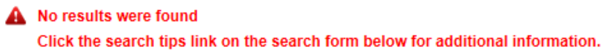
✓-search likely to produce useful results

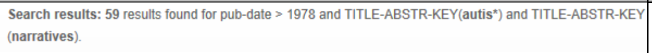
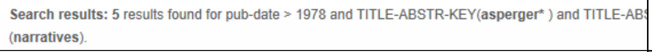
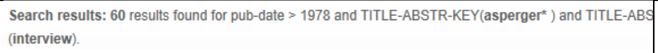
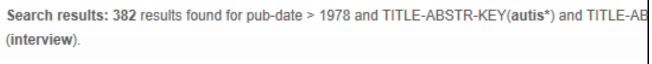
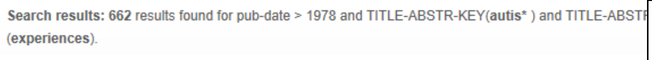
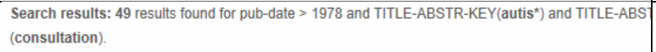
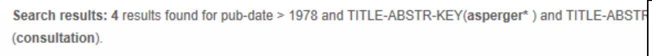
Appendix 2.2 Search results from combining search terms

Search terms & results * employed to reduce number of searches-eg: child*=children, child’s, child autis*= autism; autistic Date range: 1979 to 2019	Possibly relevant from abstract &/or title &/or key words	HR Highly Relevant or PR Partially Relevant after reading full paper
 **Search results: 6** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**autis***) and TITLE-ABSTR-KEY (**disclosure**).	Chiu, Y., Chou, M., Lee, J., et al. (2014) Determinants of maternal satisfaction with diagnosis disclosure of autism. **Journal of the Formosan Medical Association,** 113 (8): 540-548. Da Paz, N.S., Tiemensma, J. and Wallander, J.L. (2016) Written disclosure as treatment for parents of children with autism spectrum disorders: A RCT using the cortisol awakening response. **Psychoneuroendocrinology,** 71, Supplement 69.	✓ PR ✓ PR
Asperger* disclosure  No results were found Click the search tips link on the search form below for additional informa	0	NA
 **Search results: 127** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**young people**) and TITLE-ABS (**narrative**).	Dey, M., Reavley, N.J. and Jorm, A.F. (2016) Young people's difficulty in talking to others about mental health problems: An analysis of time trends in Switzerland. **Psychiatry research,** 237 159-165. Duncan, R.E., Drew, S.E., Hodgson, J., et al. (2009) Is my mum going to hear this? Methodological and ethical challenges in qualitative health research with young people. **Social science & medicine,** 69 (11): 1691-1699. Dyson, S.M., Atkin, K., Culley, L.A., et al. (2010) Disclosure and sickle cell disorder: A mixed methods study of the young person with sickle cell at school. **Social science & medicine,** 70 (12): 2036-2044. Gray, N.J., Klein, J.D., Noyce, P.R., et al. (2005) Health information-seeking behaviour in adolescence: the place of the internet. **Social science & medicine,** 60 (7): 1467-1478. Hogan, J., Southern, K.W., Cottrell, J.J., et al. (2009) To tell or not to tell – Young people's experiences of disclosure. **Journal of Cystic Fibrosis,** 8, Supplement 2 S99. Keating, D.T., Nayeem, K., Gilmartin, J.J., et al. (2005) Advance Directives for Truth Disclosure. **Chest,** 128 (2): 1037-1039. Lambert, V. and Keogh, D. (2015) Striving to Live a Normal Life: A Review of Children and Young People’s Experience of Feeling Different when Living with a Long Term Condition. **Journal of pediatric nursing,** 30 (1): 63-77. Miglani, S., Sood, A. and Shah, P. (2000) Self reported attitude and behavior of young diabetics about discussing their disease. **Diabetes research and clinical practice,** 48 (1): 9-13. Rahi, J.S., Tadić, V., Keeley, S., et al. (2011) Capturing Children and Young People's Perspectives to Identify the Content for a Novel Vision-Related Quality of Life Instrument. **Ophthalmology,** 118 (5): 819-824. Riddell, S. and Weedon, E. (2014) Disabled students in higher education: Discourses of disability and the negotiation of identity. **International Journal of Educational Research,** 63 38-46. Rowland, E. and Metcalfe, A. (2013) Communicating inherited genetic risk between parent and child: A meta-thematic synthesis. **International journal of nursing studies,** 50 (6): 870-880.	NA NA NA ✓ PR NA NA ✓ PR NA NA NA ✓ PR

Search terms & results * employed to reduce number of searches-eg: child*=children, child's, child autis*= autism; autistic Date range: 1979 to 2019	Possibly relevant from abstract &/or title &/or key words	HR Highly Relevant or PR Partially Relevant after reading full paper
	Tonberg, A., Harden, J., McLellan, A., et al. (2015) A qualitative study of the reactions of young adults with epilepsy to SUDEP disclosure, perceptions of risks, views on the timing of disclosure, and behavioural change. **Epilepsy & Behavior,** 42 98-106.	NA
 **Search results: 340** results found for pub-date > 1977 and TITLE-ABSTR-KEY(**young people***) and TITLE-ABST (**perceptions***)[All Sources(- All Sciences -,Agricultural and Biological Sciences)].	Baker, G.A., Hargis, E., Hsih, M.M., et al. (2008) Perceived impact of epilepsy in teenagers and young adults: An international survey. Epilepsy & Behavior, 12 (3): 395-401.	✓ PR
	Chew, J., Haase, A.M. and Carpenter, J. (2017) Individual and family factors associated with self-esteem in young people with epilepsy: A multiple mediation analysis. Epilepsy & Behavior, 66 19-26.	✓ PR
	Coleman-Fountain, E. (2017) Uneasy encounters: Youth, social (dis)comfort and the autistic self. Social science & medicine, 185 9-16.	✓ PR
	Feragen, K.B. and Stock, N.M. (2016) A longitudinal study of 340 young people with or without a visible difference: The impact of teasing on self-perceptions of appearance and depressive symptoms. Body Image, 16 133-142.	NA
	Hearne, A., Packman, A., Onslow, M., et al. (2008) Stuttering and its treatment in adolescence: The perceptions of people who stutter. Journal of Fluency Disorders, 33 (2): 81-98.	NA
	Herrman, J.W. (2006) Children's and Young Adolescents' Voices: Perceptions of the Costs and Rewards of Diabetes and Its Treatment. Journal of pediatric nursing, 21 (3): 211-221.	✓ PR
	Hogan, J., Horgan, M., Glenn, S., et al. (2007) 286 Perceptions of young people with CF on the lack of knowledge and understanding of the condition within the general public. Journal of Cystic Fibrosis, 6, Supplement 1 S70.	✓ PR
	McLean, K.A., Hardie, S., Paul, A., et al. Knowledge and attitudes towards disability in Moldova: A qualitative study of young people's views. Disability and Health Journal, .	✓ PR
	McNicholas, F., Tatlow-Golden, M., Gavin, B., et al. (2016) A systematic review of service transitions in people with ADHD. European Psychiatry, 33, Supplement S58.	NA
	Moreillon, J. (1992) Young people's perceptions of health and health care—World Health Organization (WHO) special session: Adolescents in our society. Journal of Adolescent Health, 13 (5): 420-423.	NA
	O'Reilly, M., Taylor, H.C. and Vostanis, P. (2009) "Nuts, schiz, psycho": An exploration of young homeless people's perceptions and dilemmas of defining mental health. Social science & medicine, 68 (9): 1737-1744.	✓ PR
	Rowland, E., Plumridge, G., Considine, A., et al. (2016) Preparing young people for future decision-making about cancer risk in families affected or at risk from hereditary breast cancer: A qualitative interview study. European Journal of Oncology Nursing, 25 9-15.	✓ PR
	Shoveller, J.A., Johnson, J.L., Langille, D.B., et al. (2004) Socio-cultural influences on young people's sexual development. Social science & medicine, 59 (3): 473-487.	NA
	Tonberg, A., Harden, J., McLellan, A., et al. (2015) A qualitative study of the reactions of young adults with epilepsy to SUDEP disclosure, perceptions of risks, views on the timing of disclosure, and behavioural change. Epilepsy & Behavior, 42 98-106.	✓ PR
	Wright, A., Jorm, A.F. and Mackinnon, A.J. (2011) Labeling of mental disorders and stigma in young people. Social science & medicine, 73 (4): 498-506.	✓ PR
 **Search results: 576** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**young people***) and TITLE-AB (**views**).	8 repeat from above searches &:	
	Cooper Robbins, S., Rawsthorne, M., Paxton, K., et al. (2011) 27. You Can Help People: Adolescents' Views on Engaging Young People in Longitudinal Research. **Journal of Adolescent Health,** 48 (2, Supplement): S31.	✓ PR
	Helgeland, I.M. (2010) What works? A 15-year follow-up study of 85 young people with serious behavioral problems. **Children and Youth Services Review,** 32 (3): 423-429.	NA
	Hiscock, A., Kuhn, I. and Barclay, S. (2017) Advance care discussions with young people affected by life-limiting neuromuscular diseases: A systematic literature review and narrative synthesis. **Neuromuscular Disorders,** 27 (2): 115-119.	NA
	Kim, S., Polari, A., Melville, F., et al. Are current labeling terms suitable for people who are at risk of psychosis? **Schizophrenia research,** (in press), 1-5. Available at: http://dx.doi.org/10.1016/j.schres.2017.01.027 (Accessed 20 May 2017).	✓ PR
	Ruck, M.D., Keating, D.P., Abramovitch, R., et al. (1998) Adolescents' and children's knowledge about rights: some evidence for how young people view rights in their own lives. **Journal of adolescence,** 21 (3): 275-289.	NA
 **Search results: 88** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**autis* diagnosis**) and TITLE-ABSTR-KEY (**impact***).	Casey, L.B., Zanksas, S., Meindl, J.N., et al. (2012) Parental symptoms of posttraumatic stress following a child's diagnosis of autism spectrum disorder: A pilot study. **Research in Autism Spectrum Disorders,** 6 (3): 1186-1193.	✓ PR
	Kozlowski, A.M., Matson, J.L. and Worley, J.A. (2012) The impact of familial autism diagnoses on autism symptomatology in infants and toddlers. **Research in Autism Spectrum Disorders,** 6 (1): 151-157.	NA
	Lutz, H.R., Patterson, B.J. and Klein, J. (2012) Coping With Autism: A Journey Toward Adaptation. **Journal of pediatric nursing,** 27 (3): 206-213.	✓ PR

Search terms & results * employed to reduce number of searches-eg: child*=children, child's, child autis*= autism; autistic Date range: 1979 to 2019	Possibly relevant from abstract &/or title &/or key words	HR Highly Relevant or PR Partially Relevant after reading full paper
	Martins, R., Bonito, I., Andrade, A., et al. (2015) The Impact of the Diagnosis of Autism in Parents of Children. **Procedia - Social and Behavioral Sciences,** 171 121-125.	✓ PR
	Moh, T.A. and Magiati, I. (2012) Factors associated with parental stress and satisfaction during the process of diagnosis of children with Autism Spectrum Disorders. **Research in Autism Spectrum Disorders,** 6 (1): 293-303.	✓ PR
	Oprea, C. and Stan, A. (2012) Mothers of Autistic Children. How do They Feel? **Procedia - Social and Behavioral Sciences,** 46 4191-4194.	✓ PR
	Osborne, L.A., McHugh, L., Saunders, J., et al. (2008) A possible contra-indication for early diagnosis of Autistic Spectrum Conditions: Impact on parenting stress. **Research in Autism Spectrum Disorders,** 2 (4): 707-715.	✓ PR
	Siklos, S. and Kerns, K.A. (2007) Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders. **Research in developmental disabilities,** 28 (1): 9-22.	✓ PR
	Stuart, M. and McGrew, J.H. (2009) Caregiver burden after receiving a diagnosis of an autism spectrum disorder. **Research in Autism Spectrum Disorders,** 3 (1): 86-97.	✓ PR
 **Search results: 6** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**asperger* diagnosis**) and TITLE-ABS (**impact***).	NA	NA
 **Search results: 33** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**young person**) and TITLE-ABS (**diagnosis impact**).	NA	NA
 **Search results: 81** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**young people**) and TITLE-ABS (**diagnosis impact**).	1 repeat from above searches &:	
	Forrest Keenan, K., van Teijlingen, E., McKee, L., et al. (2009) How young people find out about their family history of Huntington's disease. **Social science & medicine,** 68 (10): 1892-1900.	✓ PR
	Odh, I., Löfving, M. and Klaeson, K. (2016) Existential challenges in young people living with a cancer diagnosis. **European Journal of Oncology Nursing,** 24 54-60.	NA
	Olety, S. (2012) Identification and management of attention deficit hyperactivity disorders: a survey of specialist CAMHS staff perceptions, knowledge and training needs in United Kingdom. **European Psychiatry,** 27, Supplement 1 1, 313-.	NA
	Qin, P. (2011) The impact of psychiatric illness on suicide: Differences by diagnosis of disorders and by sex and age of subjects. **Journal of psychiatric research,** 45 (11): 1445-1452.	NA
	Taylor, R.M., Pearce, S., Gibson, F., et al. (2013) Developing a conceptual model of teenage and young adult experiences of cancer through meta-synthesis. **International journal of nursing studies,** 50 (6): 832-846.	✓ PR
 **Search results: 35** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**autis* diagnosis**) and TITLE-ABSTR-KEY (**child* views**).	Russell, S. and McCloskey, C.R. (2016) Parent Perceptions of Care Received by Children With an Autism Spectrum Disorder. **Journal of pediatric nursing,** 31 (1): 21-31.	NA
	Solomon, O. and Lawlor, M.C. (2013) "And I look down and he is gone": Narrating autism, elopement and wandering in Los Angeles. **Social science & medicine,** 94 106-114.	NA
	Szatmari, P. Zwaigenbaum, L. Georgiades, S. et al. (2016) "Chapter 5 - Resilience and Developmental Health in Autism Spectrum Disorder" <u>In</u> Hodes, M. and Gau, S. (eds.) **Positive Mental Health, Fighting Stigma and Promoting Resiliency for Children and Adolescents** San Diego: Academic Press. pp. 91-109.	NA
 **Search results: 5** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**autis* diagnosis**) and TITLE-ABSTR-KEY (**adolescent* views**).	NA	NA
 **Search results: 34** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**autis* diagnosis**) and TITLE-ABSTR-KEY (**child* perceptions**).	4 repeats from above searches &:	
	Keen, D., Couzens, D., Muspratt, S., et al. (2010) The effects of a parent-focused intervention for children with a recent diagnosis of autism spectrum disorder on parenting stress and competence. **Research in Autism Spectrum Disorders,** 4 (2): 229-241.	PR
 **Search results: 2** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**autis* diagnosis**) and TITLE-ABSTR-KEY (**adolescent* perceptions***).	NA	NA

Search terms & results * employed to reduce number of searches-eg: child*=children, child’s, child autis*= autism; autistic Date range: 1979 to 2019	Possibly relevant from abstract &/or title &/or key words	HR Highly Relevant or PR Partially Relevant after reading full paper
 **Search results: 768** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**autis***) and TITLE-ABSTR-KEY (**adolescent***).	3 repeats from above searches &:	
	Baixauli, I., Colomer, C., Roselló, B., et al. (2016) Narratives of children with high-functioning autism spectrum disorder: A meta-analysis. **Research in developmental disabilities,** 59 234-254.	✓PR
	Bottema-Beutel, K. and Smith, N. (2013) The interactional construction of identity: An adolescent with autism in interaction with peers. **Linguistics and Education,** 24 (2): 197-214.	NA
	Cage, E., Bird, G. and Pellicano, L. (2016) ‘I am who I am’: Reputation concerns in adolescents on the autism spectrum. **Research in Autism Spectrum Disorders,** 25 12-23.	✓PR
	Goddard, L., O’Dowda, H. and Pring, L. (2017) Knowing me, knowing you: Self defining memories in adolescents with and without an autism spectrum disorder. **Research in Autism Spectrum Disorders,** 37 31-40.	✓HR
	Locke, K.D. and Mitchell, G.E. (2016) Self-perceptions, parent-perceptions, and meta-perceptions of the interpersonal efficacy of adolescents with autism spectrum disorder. **Research in Autism Spectrum Disorders,** 31 19-29.	✓PR
	MacKenzie, J.G., Abraham, G. and Goebel, S.M. (2013) Management of Pediatric Patients With Autistic Spectrum Disorders in the Emergency Department. **Clinical Pediatric Emergency Medicine,** 14 (1): 56-59.	✓PR
	O'Brien, S. (2016) Families of Adolescents with Autism: Facing the Future. **Journal of pediatric nursing,** 31 (2): 204-213.	✓PR
	Souchay, C., Wojcik, D.Z., Williams, H.L., et al. (2013) Recollection in adolescents with Autism Spectrum Disorder. **Cortex,** 49 (6): 1598-1609.	✓PR
 **Search results: 98** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**asperger***) and TITLE-AB (**adolescent***).	Cederlund, M., Hagberg, B. and Gillberg, C. (2010) Asperger syndrome in adolescent and young adult males. Interview, self - and parent assessment of social, emotional, and cognitive problems. **Research in developmental disabilities,** 31 (2): 287-298.	✓ PR
	Matson, J.L., Dempsey, T. and Rivet, T. (2008) A comparison of Asperger symptom rating scales with children and adolescents. **Research in Autism Spectrum Disorders,** 2 (4): 643-650.	NA
	Mazefsky, C.A., Kao, J. and Oswald, D.P. (2011) Preliminary evidence suggesting caution in the use of psychiatric self-report measures with adolescents with high-functioning autism spectrum disorders. **Research in Autism Spectrum Disorders,** 5 (1): 164-174.	✓ PR
 **Search results: 253** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**adolescent***) and TITLE-ABS (**narrative***).	3 repeats from above searches &:	
	Conover, K. and Daiute, C. (2017) The process of self-regulation in adolescents: A narrative approach. Journal of adolescence, 57 59-68.	NA
	Elliott, I.M., Lach, L. and Smith, M.L. (2005) I just want to be normal: A qualitative study exploring how children and adolescents view the impact of intractable epilepsy on their quality of life. Epilepsy & Behavior, 7 (4): 664-678.	✓ PR
	Fair, C.D., Connor, L., Albright, J., et al. (2012) “I’m positive, I have something to say”: Assessing the impact of a creative writing group for adolescents living with HIV. The Arts in Psychotherapy, 39 (5): 383-389.	✓ PR
	Gregory, R.J. and Mustata, G.T. (2012) Magical thinking in narratives of adolescent cutters. Journal of adolescence, 35 (4): 1045-1051.	NA
	McLean, K.C. and Jennings, L.E. (2012) Teens telling tales: How maternal and peer audiences support narrative identity development. Journal of adolescence, 35 (6): 1455-1469.	✓ PR
	Paquet, F. (2006) Sex, drugs, and rock n’ roll: The problems of adolescent cf and asthma. Paediatric Respiratory Reviews, 7, Supplement 1 S161-S162.	NA
	Rich, M., Lamola, S. and Woods, E.R. (2006) Effects of creating visual illness narratives on quality of life with asthma: A pilot intervention study. Journal of Adolescent Health, 38 (6): 748-752.	NA
	Swain, J., Hancock, K., Dixon, A., et al. (2015) Acceptance and Commitment Therapy for children: A systematic review of intervention studies. Journal of Contextual Behavioral Science, 4 (2): 73-85.	NA
 **Search results: 16** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**autis* diagnosis**) and TITLE-ABST (**perceptions***).	2 repeats from above searches	NA
 **Search results: 2** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**asperger* diagnosis**) and TITLE-ABSTR-KE (**adolescent* views**).	2 repeats from above searches	NA
 **Search results: 98** results found for TITLE-ABSTR-KEY(**asperger***) and TITLE-ABSTR-KEY(**adolescent***).	3 repeats from above searches	NA
 **Search results: 3** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**asperger* diagnosis**) and TITLE-ABSTR-KEY (**child* views**).	NA	NA
Asperger* diagnosis & young person  **No results were found** **Click the search tips link on the search form below for additional information.**	0	0
 **Search results: 9** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**autis* diagnosis**) and TITLE-ABSTR-KEY(**young person**).	NA	NA

Search terms & results * employed to reduce number of searches-eg: child*=children, child's, child autis*= autism; autistic Date range: 1979 to 2019	Possibly relevant from abstract &/or title &/or key words	HR Highly Relevant or PR Partially Relevant after reading full paper
 **Search results: 59** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**autis***) and TITLE-ABSTR-KEY (**narratives**).	1 repeated from above searches &:	
	Cosentino, E. (2011) Self in time and language. **Consciousness and cognition,** 20 (3): 777-783.	NA
	Gray, D.E. (2001) Accommodation, resistance and transcendence: three narratives of autism. **Social science & medicine,** 53 (9): 1247-1257.	✓ PR
	Young, M.J. and Bursztajn, H.J. (2016) Narrative, identity and the therapeutic encounter. **Ethics, Medicine and Public Health,** 2 (4): 523-534.	NA
 **Search results: 5** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**asperger***) and TITLE-ABS (**narratives**).	NA	NA
 **Search results: 60** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**asperger***) and TITLE-ABS (**interview**).	2 repeated from above searches	NA
 **Search results: 382** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**autis***) and TITLE-AB (**interview**).	5 repeats from above searches &:	
	Fernańdez-Alcántara, M., García-Caro, M.P., Pérez-Marfil, M.N., et al. (2016) Feelings of loss and grief in parents of children diagnosed with autism spectrum disorder (ASD). **Research in developmental disabilities,** 55 312-321.	✓ PR
 **Search results: 63** results found for TITLE-ABSTR-KEY(**asperger***) and TITLE-ABSTR-KEY(**experi**	NA	NA
 **Search results: 662** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**autis***) and TITLE-ABSTR (**experiences**).	23 repeated from above searches &:	
	Andersson, G.W., Miniscalco, C. and Gillberg, C. (2014) Preschoolers assessed for autism: Parent and teacher experiences of the diagnostic process. **Research in developmental disabilities,** 35 (12): 3392-3402.	✓ PR
	Bademci, Ö. (2012) Working with autistic children through the spectrum of psychoanalytic concepts. **Procedia - Social and Behavioral Sciences,** 31 816-819.	NA
	Bekhet, A.K. Positive Thinking Training Intervention for Caregivers of Persons with Autism: Establishing Fidelity. **Archives of Psychiatric Nursing,** .	NA
	Bokhari, R., Alabdulaaly, M., AlSaleh, G., et al. (2014) EPA-0014 – Parents' experience about autism on youtube videos. **European Psychiatry,** 29, Supplement 1 1.	NA
	Church, C.C. and Coplan, J. (1995) The high-functioning autistic experience: Birth to preteen years. **Journal of Pediatric Health Care,** 9 (1): 22-29.	NA
	Derguy, C., Bouvard, M., M'bailara, K., et al. (2013) 2648 – Having a child with autism: What kind of needs and support expectations for parents? **European Psychiatry,** 28, Supplement 1 1.	NA
	Derguy, C., Bouvard, M., Michel, G., et al. (2014) The gap between parents' knowledge and causal beliefs about etiology of autism: A key variable to understand parents' anxiety. **European Psychiatry,** 29 (8, Supplement): 598-599.	✓ PR
	Dillon, G. and Underwood, J. (2012) Computer mediated imaginative storytelling in children with autism. **International Journal of Human-Computer Studies,** 70 (2): 169-178.	NA
	Felizardo, S., Ribeiro, E. and Amante, M.J. (2016) Parental Adjustment to Disability, Stress Indicators and the Influence of Social Support. **Procedia - Social and Behavioral Sciences,** 217 830-837.	NA
	Hoogsteen, L. and Woodgate, R.L. (2013) Centering Autism Within the Family: A Qualitative Approach to Autism and the Family. **Journal of pediatric nursing,** 28 (2): 135-140.	NA
	Kloosterman, P.H., Kelley, E.A., Craig, W.M., et al. (2013) Types and experiences of bullying in adolescents with an autism spectrum disorder. **Research in Autism Spectrum Disorders,** 7 (7): 824-832.	NA
	Lewis, L.F. (2016) Exploring the Experience of Self-Diagnosis of Autism Spectrum Disorder in Adults. **Archives of Psychiatric Nursing,** 30 (5): 575-580.	✓ PR
	McDonnell, C.G., Valentino, K. and Diehl, J.J. (2017) A developmental psychopathology perspective on autobiographical memory in autism spectrum disorder. **Developmental Review,** 44 59-81.	✓ PR
	Teti, M., Cheak-Zamora, N., Lolli, B., et al. (2016) Reframing Autism: Young Adults With Autism Share their Strengths Through Photo-Stories. **Journal of pediatric nursing,** 31 (6): 619-629.	✓ PR
	von Hofsten, C., Uhlig, H., Adell, M., et al. (2009) How children with autism look at events. **Research in Autism Spectrum Disorders,** 3 (2): 556-569.	NA
	Zalla, T. (2015) The experience of regret and the self-relevant emotions in autism spectrum disorders: A reply to Nicolle et al. **Cortex,** 66 163-165.	NA
 **Search results: 49** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**autis***) and TITLE-ABST (**consultation**).	NA	NA
 **Search results: 4** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**asperger***) and TITLE-ABSTR (**consultation**).	NA	NA
 **Search results: 1,008** results found for pub-date > 1978 and TITLE-ABSTR-KEY(**child**) and TITLE-ABSTR- (**narrative**).	6 repeated from above searches	
	Ångström-Brännström, C., Norberg, A. and Jansson, L. (2008) 'Narratives of Children With Chronic Illness About Being Comforted',	NA

Search terms & results * employed to reduce number of searches-eg: child*=children, child's, child autis*= autism; autistic Date range: 1979 to 2019	Possibly relevant from abstract &/or title &/or key words	HR Highly Relevant or PR Partially Relevant after reading full paper
	Journal of pediatric nursing, 23(4), pp. 310-316. doi:https://doi.org/10.1016/j.pedn.2007.04.006.	
	Baixauli, I., Colomer, C., Roselló, B. and Miranda, A. (2016) 'Narratives of children with high-functioning autism spectrum disorder: A meta-analysis', *Research in developmental disabilities,* 59pp. 234-254. doi:https://doi.org/10.1016/j.ridd.2016.09.007.	NA
	Bringewatt, E. H. (2013) 'Negotiating narratives surrounding children's mental health diagnoses: Children and their contribution to the discourse', *Children and Youth Services Review,* 35(8), pp. 1219-1226. doi:https://doi.org/10.1016/j.childyouth.2013.04.008.	PR
	Hilvert, E., Davidson, D. and Gámez, P. B. (2016) 'Examination of script and non-script based narrative retellings in children with autism spectrum disorders', *Research in Autism Spectrum Disorders,* 29–30pp. 79-92. doi:https://doi.org/10.1016/j.rasd.2016.06.002.	NA
	Valentine, G. (2000) 'Exploring children and young people's narratives of identity', *Geoforum,* 31(2), pp. 257-267. doi:https://doi.org/10.1016/S0016-7185(99)00047-0.	NA
	Total possible texts 102 63 repeated in searches	Total meeting inclusion criteria: 48=PR 1=HR 53=NR

Appendix 2.3 Details of the criteria for the systematic search

	Criteria	Other information
Search Terms	Diagnosis: Autism and variations: Asperger Syndrome(AS)/Asperger, Autism Spectrum Disorder (ASD), Autism Spectrum Condition (ASC), High Functioning Autism (HFA) Process: Disclosure; (diagnostic) interview/consultation; assessment Experiences: views/perceptions/narratives/ Participants: Child*(ren)/young person; adolescent; Parents; mothers; fathers; carers; families Professionals;	In line with DSM V to encompass the whole spectrum Used * to reduce number of searches-eg: child*=children, child's, child autis*= autism; autistic, Search term recording grid used to ensure systematic approach
Topics Included	Childhood diagnostic experiences Professional approaches Parent experiences of autism specific diagnostic Child experiences of autism specific diagnostic Diagnostic experiences of adults with autism Impact of diagnosis/disability on children Impact of autism diagnosis Methods used for collecting child/young person views about diagnosis and impact of diagnosis	**Search Dates:** Date limitations applied: 1979- October 2019 (Linked to concept of autism spectrum-Wing and Gould 1979) Outcome-earliest relevant research=2003
Inclusion Criteria	Written in English Views/perceptions of autism diagnosis process Child Parent/carer Professionals Views/perceptions/strategies giving a diagnosis to a child Impact of an autism diagnosis Views/perceptions of having an autism diagnosis Child views/perceptions of having an illness/disability	
Exclusion Criteria	Not in English language Outside of date range 1979 to 2019 Views/Perceptions not related to the impact upon the child/young person Issues related to the diagnostic criteria and/or identification, rather than experiences of the process and impact	**Screening:** The total number of papers 4,566 Duplicates=449 leaving 4,117 Papers through other sources=12 After initial screening-3,813 excluded= included=316 316 Abstracts screened; 157 did not meet criteria 159 Full texts screened; 130 excluded 29 met criteria; 11 x CYP; 7 x parents; 11 x professionals
Results	How CYP on the autism spectrum view the diagnosis = 11 Parents' views about explaining an autism diagnosis to their child =7 Professionals' views about sharing the autism diagnosis=11 parents/families post diagnosis	

Appendix 2.4 Systematic review results: CYP's views of autism diagnosis

	Reference	Country	Aims	Sample	Methods	Findings	Limitations
1	Baines, A. D. (2012) 'Positioning, strategizing, and charming: how students with autism construct identities in relation to disability', *Disability and Society*, 27 (4), pp. 547-561.	USA	To explore how young people with autism construct identities through social interactions at school and home	2 male high school (11th & 12th grade) pupils with autism	Multi-sited ethnography comprising two years data including interviews and participant observation	Young people with autism can: -partake in socially governed practices. - construct their identity socially to support participation, competition and belonging -distance themselves from the 'autistic' label Their social interactions were observed to exert power that helps to shape youth identity Young people with autism were not disengaged from sociocultural process related to identity Participants strove to encourage other people to view them positively. Being identified as 'autistic' negatively impacted others' perceptions	Not identified by author Author does identify the need for longitudinal, cross-context research to explore how young people with autism construct identity in and out of school.
2	Billington, T. (2006) 'Working with autistic children and young people: sense, experience and the challenges for services, policies and practices', Disability and Society, 21 (1), pp. 1-13.	UK	To encourage narratives of autistic experience that are focussed on assets rather than impairments or deficits	1 male young person with autism across a number of years	Observation and analysis of one case with interpretation based on published autistic 'insider' accounts	The author highlights the intense impact of senses on emotion and social construction of meaning demonstrated the young person with autism Author suggests practitioners should - develop practices and discourses concentrate on strengths - establish provision that facilitates difficult feelings/distress to be shared - be aware of interactionist influences and avoid assigning responsibility for behaviour change only on the child, parents and professionals also have a role - need for more research to elicit views of CYP with autism about how they manage their 'worlds'	Not identified by author Author does identify the need to search for effective ways to gain the views of children with autism about their perceptions of social interactions and other experiences.
3	Gaffney, J.G. (2017) 'It's autism, it's just a name': Exploring the impact of autism spectrum diagnosis with adolescent females using Interpretative Phenomenological Analysis.	England, UK.	To find out how girls/young women who have an autism diagnosis view their diagnosis and what can be learned from hearing their voices	Six females aged between 14 and 20. 5x mainstream education 1x young adult attending university	Interpretative Phenomenological Analysis (IPA)	Three themes were identified-each with sub-themes **Understanding Autism:** Diagnosis in a problem context; What is autism; Communication; It's my autism; Siblings with autism. **Acceptance or rejection:** Acceptance; Dissonance; Rejection. **Self and autism**: Struggling with sense of self; Stronger sense of self It is concluded that diagnosis useful, perhaps at certain times, but for some the diagnosis is unwanted and sometimes harmful to personal identity	The author acknowledges experiencing the difficulty identified by Watts (2014) of ignoring theoretical and personal views and tendencies before commencing data analysis' The author appropriately acknowledges potential for bias through the questioning activities in the interview and during analysis A limitation in meeting the recommended IPA approach for member checking (feedback on analysis and interpretation, as described by Birt *et al*., 2016) was also identified. Therefore, participants' views about researcher interpretation were omitted as a quality check.

	Reference	Country	Aims	Sample	Methods	Findings	Limitations
4	Gordon, K., Murin, M., Baykaner, O., Roughan, L., Livermore-Hardy, V., Skuse, D., & Mandy, W. P. L. (2015) A randomised controlled trial of PEGASUS, a psychoeducational programme for young people with high-functioning autism spectrum disorder. *Journal of Child Psychology and Psychiatry*, 56, 468–476.	England, UK	To design and evaluate a psychoeducation group for young people with autism [PEGUSUS], which aimed to enhance the self-awareness by teaching them about their diagnosis.	48 young people (9–14 years) high-functioning ASD 40 males (PEG18/Con 22) 8 females (PEG6/ Con 2) Aware of diagnosis; English speakers IQ over 65 Able to function in a small group	Randomised control trial	Young people with ASD reported good levels of satisfaction with PEGUSUS: quite enjoyable' (n = 4, 18.2%); extremely enjoyable' (n = 17, 77.2%). Over half (n = 12, 54.5%) found PEGASUS 'extremely helpful'; seven (31.8%) found it quite helpful. Most (n = 21, 95.5%) reported that PEGASUS increased their knowledge about ASD and supported understanding of themselves. There was no reduction in self-esteem from learning about the diagnosis Authors suggest this may reflect the focus on strengths as well as difficulties Compared to the control group, the participants' results showed greater positive change for knowledge of ASD and self-knowledge.	Authors identify that the ASD awareness measure demonstrated good reliability but cautioned that its psychometric properties had not been fully established. The management as usual (MAU) control group employed as part of the RCT methodology meant that interpretation of the findings was limited as it was not possible to identify which aspects of the programme were implicated in change in ASD self-awareness and knowledge Although some children engaged in the programme showed positive impact after taking part, the authors highlight that almost 60% of the PEGUSUS participants' scores did not show statistically reliable change. Therefore, impact was variable and the design did not support identification of possible cause in the variable outcomes.
5	Huws, J. C. and Jones, R. S. P. (2008) 'Diagnosis, disclosure, and having autism: An interpretative phenomenological analysis of the perceptions of young people with autism', *Journal of Intellectual and Developmental Disability*, 33 (2), pp. 99–107.	Wales, UK	To explore the retrospective accounts of young people with high functioning autism of their experience of autism from the perspective of an ''insider'' in order to highlight topics for future research.	9 young people with high functioning autism 3 females 6 males	Qualitative, Interpretative phenomenological analysis, Semi-structured interviews	Participants perceptions of having autism were identified to be embedded with their diagnosis and their experiences of diagnostic disclosure. The study identified 5 themes within the accounts: - disclosure delay - providing explanations - potential effects of labelling - disruptions and opportunities - acceptance and avoidance	Authors identify that only seeking perspectives of children and young people limited possible interpretations and understanding. The researchers identify that triangulation would have facilitated broader understanding of the research themes identified. For example, by exploring reasons related to the logistics of diagnosis: when and how to disclose an autism diagnosis.
6	Huws, J. C. and Jones, R. S. P. (2015) 'I'm really glad this is developmental': Autism and social comparisons – an interpretative phenomenological analysis', *Autism,* 19 (1), pp. 84–90.	Wales, UK	To explore young people's perceptions of autism	9 students 16-21 yrs with autism attending a specialist college 3 females 6 males	qualitative methodology interpretative phenomenological analysis	Making comparisons was a significant concept. Three related themes were identified: (a) Changes over time: 'I'm really glad this is developmental' (b) Degrees of autism: 'They've got it really bad' (c) Degrees of ability: 'I'm not really disabled-disabled.	A limitation in meeting the recommended IPA approach was also identified as member checking (feedback on analysis and interpretation) was not undertaken. Therefore, participants were not able to inform or challenge the authors' interpretations. However, during data collection, the interviewer's initial interpretations were checked with participants.

	Reference	Country	Aims	Sample	Methods	Findings	Limitations
7	Jones, J.L., Gallus, K.L., Viering, K.L. and Oseland, L.M (2015) 'Are you by chance on the spectrum?' Adolescents with autism spectrum disorder making sense of their diagnoses', *Disability and Society*, 30 (10), pp. 1490-1504.	USA	To provide a better understanding of how adolescents with autism identify with and make meaning of their diagnosis by examining how they construct narratives regarding their diagnosis	10 adolescents with autism 8 males 2 females Aged 13 to 20 years mean=16.24, 2 had lower verbal mental age than chronological	Phenomenological-qualitative interviews using data from a larger mixed-methods study	Themes: 1. Formation of an ASD narrative • Acknowledgment of the label • Recognition of unique behaviours and characteristics • Self-awareness and reflection 2. Social construction of the label • Distinction within the label • Pride and belonging 3. confusion regarding whether autism spectrum disorder is a disability Participants beliefs were influenced during social interactions with peers, family, and others. Language used to describe autism, as well as social stigma influences young people's views of self and their diagnosis	Sample bias was discussed by the researchers, including: • A small but fairly heterogeneous sample of participants with a broad range of diagnoses across the spectrum • geographical bias, all participants were from one area, therefore experiences that are different in other areas are not represented-e.g. adolescents in the study might have had greater or lesser access to services compared to other areas • parents of participants were involved in support groups, therefore the sample might have been biased toward those with greater knowledge of autism. Member checking (feedback on analysis and interpretation) was also identified as a limitation. Therefore participants' views about researcher interpretation was omitted as a quality check. Methodological concerns about the interview process and whether it was appropriate were also identified as depth of responses were limited.
8	Jones, R.S.P., Huws, J.C. and Beck, G. (2013) 'I'm not the only person out there': insider and outsider understandings of autism', *International Journal of Developmental Disabilities*, 59 (2), pp. 134-144.	Wales, UK	To gain an insight into how people with autism spectrum disorder (ASD) view the concept of autism and how they view society's reactions to people with this diagnosis	9 students 16-21 yrs with autism-attending a specialist college 3 females 6 males Also an expert author: a person with autism completing the analysis	Qualitative interviews followed by interpretative phenomenological narrative analysis by and expert author (a person with autism)	Themes: insider and outsider experience of autism. Results suggest that the participants had an awareness that interpersonal relationship were complex. They also demonstrated feelings of difference and a desire to fit into their peer group. a desire The authors highlighted that employing an expert author helped to reduce diagnostic overshadowing. Finding were interpreted as an interaction between age, developmental phase as well as in relation to diagnosis of autism.	Limitations were not identified by the authors. However, although an 'expert author' (an adult with autism) view was sought the interpretations was not subject to member checking (feedback on analysis and interpretation). Therefore, participants' views about the 'expert author's' interpretation were omitted as a quality check.

	Reference	Country	Aims	Sample	Methods	Findings	Limitations
9	Molloy, H. and Vasil, L. (2004) *Asperger syndrome, Adolescence and Identify: Looking Beyond the Label. London***:** Jessica Kingsley Publications	England & Singapore multi-national	Aim to provide 'an inside-out view' of the experiences of young people with an Asperger diagnosis.	6 cases-aged 12-18 yrs 3 in England; 2 ex-pats in Singapore; 1 from Australia living in Singapore; 4 male 2 female	Narrative interviews and analysis	The authors highlight that while the 'quirks' that young people without autism display are likely to be considered as part of their unique and complex personalities, 'quirks' of young people with Asperger's are likely to be viewed as symptoms. - Participants were accepting of the diagnosis - 2/6 viewed themselves as disabled and perceived this to impact socially - Views varied about the significance of AS to identity - authors suggest that individuals that discussed more life successes were less dominated by the diagnosis - Most participants choose not to disclose their AS - 3 participants discussed misconceptions of autism being influenced by either the savant or medicalised severe disability view. - Scrutiny and linking all traits to diagnosis was also discussed - The authors highlight how trying to meet social expectations can influence low self-esteem. - The authors suggest a relationship exists between self-esteem and the extent AS was viewed as a disability	Bias in narrative happens due to errors by tellers, is influenced by the accounts of others and information from other sources Life stories are only as good as the teller, the can be changed by the teller over time. As some people might not be able to 'tell their story', their voices might not be heard. Researchers might seek &/or encourage telling of stories that link with research aims Relying on stories might miss other influences that impact tellers' stories, such as social; economic; political and/or related policy decisions
10	Mogensen, L. & Mason, J. (2015) 'The meaning of a label for teenagers negotiating identity: Experiences with autism spectrum disorder', *Sociology of Health and Illness*, 37, pp. 255–269. doi:10.1111/1467-9566.12208	Australia	To learn about the lived experience of having an autism diagnosis and to facilitate direct participation in the research by people with autism	5 x teenagers 13 and 19 years with autism spectrum diagnosis 3 males 2 females	Collaborative, participatory research approach Involving photos, drawings, interviews, e-mail and communication cards	Key themes include diagnosis as - Oppressive, - liberating - facilitating control; - a positive identity; Themes also include: - Dilemma of disclosure, social identity: stereotypes and negative attitudes; - Impairment and losing control - Impairment and taking control Authors suggested that the diagnosis facilitated understanding of self; impacted individual feelings of control and agency, and impacted whether it was perceived to an advantage or disadvantage.	Limitations were not identified by the authors. Member checking (feedback on analysis and interpretation) was undertaken but only 2 out of 5 participants provided feedback. Neither the nature of the feedback nor how it informed the findings was discussed. Therefore the impact of participants' views on interpretation is unclear.
11	Rossello, E. (2015) *'I have what?' A phenomenological inquiry into disclosing a diagnosis of Asperger's disorder to adolescents* Doctoral dissertation: Chicago School of Professional Psychology.	USA	To explore the most common ways a diagnosis of autism is disclosed and positive and negative outcomes following disclosure	12 participants 4x parent sets & 4x adolescents aged13-17 who had Asperger diagnosis at least 12 months 3 females 1 male	Qualitative, semi-structured interviews	Disclosure of Asperger syndrome adolescents was identified to have a more positive than negative impact on their mental health. Three quarters of the adolescent participants wished they had known sooner. The author concludes that the more positive the adolescents' reaction to being told about their diagnosis, the more optimistic they were about their future and they were also more likely to tell others about their diagnosis.	Limitations included small sample size, which was identified to mean that the findings were not generalisable to the general population. Selection bias was also identified due to purposive recruitment from a small number of sources, described as 'good subjects' who had greater knowledge of autism as they were involved in autism spectrum groups.

Appendix 2.5 Systematic search results: parents-explaining autism to their child

Reference	Country	Aims	Sample	Methods	Findings	Limitations
Cadogan, S. (2015) *Parent reported impacts of their disclosure of their child's ASD diagnosis to their children*. MA Thesis. University of Calgary.	Canada	To explore parent-reported impacts of disclosing a child's autism spectrum disorder (ASD) identify practical implications for parents and professionals.	15 interviews with parents of children with ASD 13 x mothers only 2 x mothers and fathers	Semi-structured interviews and thematic analysis	Parental disclosure of autism to their child was identified to have discernible positive impact. Six overarching themes were identified -telling children about their diagnosis facilitated discussions about autism related differences between children and parents. - difficulties associated with autism, explanations of autism and strategies overcoming problems and problem-solving strategies were discussed -understanding autism and autism awareness - reactions and impact of autism disclosure - views and feelings associated with autism disclosure - the impact, magnitude and valiance good"-ness vs "bad"-ness of an event).	Small study size, which the author highlights might not be generalisable to or representative of all families who tell their child about an autism diagnosis. Sample bias was also discussed by the researchers, including: • The small sample, the author identified the participants as a fairly homogeneous sample which comprised ○ more mothers than fathers ○ only parents who had disclosed were interviewed ○ children discussed by parents who were mostly without cognitive impairment The researcher also acknowledged that the methodological aspects might impact the findings: • Retelling of stories might miss other influences that impact • The methodologies and interpretation of data might have been influenced by researcher bias • Qualitative approaches do not identify cause in relation to disclosure and impact
Crane, L.,Jones, L., Prosser, R., Taghrizi, M. and Pellica'no, E. (2019) Parents' views and experiences of talking about autism with their children', *The International Journal of Research & Practice*. 23 (8), pp. 1969-1981.	UK	To understand parent experiences of talking about autism with their autistic and non-autistic children	558 Parents Fathers 24 (4.3%) Mothers 533 (95.5%)	Mixed methods Survey Descriptive presentation of quantitative data and thematic analysis	Of the parent participants most had told their child about the diagnosis (n = 379, 67.9%) Just over 20% had had support or advice about disclosure to their child (n = 163, 20.4%) Parents felt satisfied with the approach they adopted (n = 319, 84.2%) Most parent who had not yet disclosed, planned to in future (n = 339, 92.4%) and confident about disclosure (n = 100, 73.5%) Qualitative themes included openness, tailoring explanations of autism and understanding the challenge of diagnosis	Authors highlighted the potential for sample bias despite the large sample, parents were mostly: • Parents of children able to talk about autism • mothers • from white ethnic background, • educated to university level (more than half) Participants were likely to be those who accepted the diagnosis Parental perspectives might not mirror those of their children
Finnegan, R., Trimble, T, and Egan, J. (2014) 'Irish parents' lived experience of learning about and adapting to their child's autistic spectrum disorder	Ireland	To understand parents' experiences of receiving the diagnosis and how parents communicated	Parents of 7 children with autism diagnosis	Qualitative Semi-structured interviews and	Age of the disclosure to the varied from 8 to 12 years. Qualitative these identified in parent views were: • -problems in accessing diagnosis and then adjusting to it • challenges accessing support	As a small study, author identified it was not designed to representative of and generalizable to all parent child diagnostic disclosure experiences

Reference	Country	Aims	Sample	Methods	Findings	Limitations
diagnosis and their process of telling their child about their diagnosis', *The Irish Journal of Psychology*, 35 (2-3), pp. 78-90.		the diagnosis to their child	aged 8 to 12 years 6 mothers 1 father	interpretative phenomenological analysis	• balancing protection of the child with disclosure to support understanding and access to provision • the need to adjust communication aid children's understanding	Potential sample related bias was discussed by the researcher including: • factors not considered such as gender, socio-economic status age, ethnicity or the nature of the diagnosis on parental experiences during diagnosis • Participants were mostly mothers, had more fathers participated, differing views might have been identified
Rossello, E. (2015) '*I have what?' A phenomenological inquiry into disclosing a diagnosis of Asperger's disorder to adolescent*s. PHD Thesis. University of Chicago.	Multi-national	To explore the most common ways a diagnosis of autism is disclosed and positive and negative outcomes following disclosure	8 parents (4x parent sets Mothers and fathers) 4x adolescents aged13-17 who had diagnosis at least 12 month	Qualitative, semi-structured interviews	Telling an adolescent about their AS diagnosis was identified to have greater beneficial than negative impact on their mental health. -No correlation was identified between the age that adolescents were told of their diagnosis and changes in mental wellbeing or behaviours - The desire to have known about the diagnosis and to have disclosed it earlier to their child was greater for fathers. Mothers' responses varied. Mothers were more likely to desire social group/online support with the process of disclosure. -There was no indication that location of disclosure (home/clinic) impacted adolescents emotional or behavioural responses. -There was no evidence that either the mother or father disclosing had a lesser or greater benefit than when both parents disclosed. -Parents who sought advice from professionals or conducted their own research led to a higher confidence level in making the disclosure	The author identified a number of limitations: • Generalisation to a larger population is restricted by the small number of participants as responses might or might not be coincidence • As the study was located in one area, their experiences might be different to those experienced by participants in other locations; • Researcher bias in topic choice and question design might have influenced results • Parental involvement in a community group that supports parents with similar needs may have skewed their experiences and the results of the study • Participants were selected from the agency where the researcher was employed, the researcher identified a strong commitment to the organization, which might have influenced both participant responses and researcher interpretation.
Smith-Demers, A.D. (2018) *The Elephant in the Room: The Lived Experience of Talking to Children with ASD about their Diagnosis*, PhD Thesis. University of Calgary.	Canada	To explore the decision-making process about whether to, and if so how and when to inform children about an ASD diagnosis	20 parent dyads (mother and father) who had disclosed & 20 parent dyads who had not disclosed	Qualitative, semi-structured interviews	Parents in the study identified: - Disclosure as gradual process that changes and develops over time - Unique approaches to disclosure that is situational for each child and family - Disclosure as important and has benefits - Discussing difficulties without naming autism prior to disclosure - Disclosure reasons: process/never thought not to disclose; part of who they are; child asking questions/aware of their differences; parents afraid they would find out - the experience of fear and deliberation throughout the decision-making process - disclosure—for some it just happened; some prepared narratives; letting the child lead was felt important; focussing on positive aspects gained attention to the discussion **Parental advice to others re disclosure:**	Potential sample related bias was discussed by the researcher, who identified that the sample was more homogeneous than planned, despite the recruitment of both disclosed and non-disclosed participants. The author identified; • No non-disclosing parents were fundamentally opposed to diagnostic disclosure, • There was limited diversity in age, cultural background, and family constellation • Participants required online access to contribute • Participation may have been limited by interest in the topic and being able to articulate and express in the English language • The study was limited to one geographical area Therefore, the views of parents who participated might differ to other and are not generalizable in different areas in this study may hold differing perspectives based on their access to resources and geographic location. parental report of a

Reference	Country	Aims	Sample	Methods	Findings	Limitations
					- Parents know their child best and should personalize approach and resources based on their knowledge of their child's interests and development; - Normalise the process by making it a shared-decisions to disclosure and how to do it; - Process and understand the diagnosis prior to disclosure - Access resources to support to disclosure process.	formal diagnosis was not verified; such verification could have improved the rigour of the study design. limited the number of participants who could participate and share their narrative around the concept of diagnosis disclosure
Smith, I. C., Edelstein, J. A., Cox, J. E. and White, S. W. (2018) 'Parental Disclosure of ASD Diagnosis to the Child: A Systematic Review', *Evidence-Based Practice in Child and Adolescent Mental Health*, 3(2), pp. 98-105.	USA	To identify articles describing the process of disclosing a diagnosis of ASD from the perspective of children, parents, or both.	5 qualitative papers identified 2x papers reported 30 Parental views included but parent gender not specified 2x papers reported Youth views 1x paper reported Youth and parent views	Systematic review	Across studies, findings suggest: - parents mostly tell their child before adolescence - varied responses to disclosure were identified - previous behaviours/symptoms were made sense of by the diagnosis Concerns reported: - delay between parents being told of the diagnoses and telling their child - processing the emotions related to diagnosis takes time. - the autism label would lead to stigma for the child Primary Themes: Delay-in 5 papers Explanation- in 4 papers Processing- in 4 papers Stigma- in 4 papers Child self-disclosure-in 3 papers Author suggested - best practice guidelines are needed to support parents with disclosure of autism - further research as it is an understudied element of the diagnostic process	Small number of studies identified. Not all studies were peer reviewed, therefore authors identify lack of sufficient evidence to enable provision of concrete, empirically supported recommendations
Ward, E. (2014) *Parental accounts of sharing an autism spectrum diagnosis with their child: a thematic analysis*. DClinPsy Thesis. University of Nottingham.	England, UK	To explore how parents share an autism spectrum diagnosis with their child	10 parents of children with autism diagnosis 2x fathers 8x mothers	Qualitative Semi-structured interviews and thematic analysis	Three main connected themes & related sub-themes: - Process of sharing: naming autism; exploring; meaning-making; acceptance and integration - Motivation to share: providing an explanation; protection - Management of sharing: preparedness (parent/child); approach and strategies; sharing as a process	- Self-selected sample of participants positive about sharing diagnosis is unlikely to reflect wider views. - Retrospective accounts were collected, parents have had time to reflect on the process, they might differ than the views of parents at other points of time in relation to explaining the diagnosis to a child. - Sample bias due to over-representation of mothers.

Appendix 2.6 Professionals’ views: giving an autism diagnosis, interventions and impact

Reference	Country	Aims	Sample	Methods	Findings	Limitations
Bartolo, P.A. (2002) ‘Communicating a diagnosis of developmental disability to parents: multi-professional negotiation frameworks’, *Child: Care, Health & Development*, 28(1), pp. 65–71	England, UK	To explore how disclosure of autism was negotiated with parents by multi-professional groups	2 tertiary, multi-professional groups in London: G1: paediatrician, clinical psychologist, speech therapist, G2: educational psychologists, psychotherapist, special needs advisor and colleagues	Case study approach Professional discussions & interviews following assessment	3 social-interaction frameworks for discussions with parents were identified: • parent-friendly frame • hopeful-diagnostic-formulation frame • defocussing-of-bad-news	Not identified by authors A small number of cases and professional groups, limits the the generalisability of the findings. A focus on giving assessment results should be included in training for practitioners
Braun, M.J., Dunn, W. and Tomchek, S.D. (2017)’ A pilot study on professional documentation: Do we write from a strengths perspective?’ *American Journal of Speech-Language Pathology*, 26, pp. 972–981.	USA	To analyse diagnostic reports for strengths-based writing	psychologists, speech & language pathologists, occupational therapists 20 patient reports (299 phrases)	Descriptive study using retrospective analysis of existing patient reports	Diagnosticians tend to write more from a deficit perspective that a strengths-based perspective Diagnostic criteria that influence diagnostic reports are based on deficits and might influence report writing	Sample of reports was from variety of interdisciplinary clinicians but only from one clinic and may not be generalisable to all diagnosticians The focus on autism diagnosticians also limits the generalisability to other interdisciplinary clinicians
Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L.A. & Hill, E. L. (2018) ‘Autism Diagnosis in the United Kingdom: Perspectives of Autistic Adults, Parents and Professionals’, *Journal of Autism and Developmental Disorders*, 48, pp. 3761–3772.	UK	To identify aspects of the diagnostic process that are working well, and areas in which improvements are needed.	10 parents 10 adults with autism diagnosis 10 professionals 8 Female;2 Male 3 clinical psychologists, 2 paediatricians; 2educators 1 educational psychologist; 1 psychiatrist; 1 speech and	Qualitative research -telephone interviews and thematic analysis	Three key themes were identified by professionals that related to: • communication about diagnosis • barriers within the diagnostic processes impacted satisfaction • support after diagnosis being inadequate	Generalisation of findings is limited due to the small study size, Sample bias was highlighted due to lack of ethnic diversity, participants were mostly white females. Rosenthal and Rosnow (1975) highlighted that women are more likely volunteer for research than men

Reference	Country	Aims	Sample	Methods	Findings	Limitations
			language therapist; 1 specialist early years practitioner			
Finke, E. H., Drager, K.D.R. and Ash, S. (2010) 'Pediatricians' perspectives on identification and diagnosis of autism spectrum disorders', *Journal of Early Childhood Research*, 8(3), pp. 254–268	USA	To describe paediatricians' experiences of autism diagnosis	5 general paediatricians	Qualitative interview	Themes identified related to: **Knowledge/training**: Characteristics and signs of autism; rate of incidence; causes; professionals' personal experiences of autism; what they wished to know and advice for junior doctors. **Diagnosis** Assessment; initial signs and concerns; a wait and see approach, referral, giving a diagnosis and related time factors. **Communication** Relationships with the family; asking questions of the family, addressing questions and concerns and families' reactions to diagnosis **Conclusions:** Insufficient number of paediatricians challenges the process. Insufficient training may cause professionals to feel unqualified to make a diagnosis	Participants demographics and roles were varied A small study, which limits the the generalisability of the findings
Fletcher, I. (2013) 'Exploring the diagnosis of Asperger syndrome with a primary-aged pupil: resources, issues and strategies', *Good Autism Practice*, 14(2), pp. 8-22.	England, UK	To review the literature on what is known about sharing the diagnosis with children with Asperger syndrome and to identify a framework to define how this might be done	Literature Review and experience of using the approach with 1 primary child	Literature review and case study to develop framework	Author synthesis of findings suggests: text resources need to be tailored for individuals -vocabulary should be unambiguous and images appropriate to support understanding - materials should be age appropriate and should include interests or characters children can identify -an interactive element is also suggested to encourage engagement and to empower the individual	None identified by the author General rather than systematic review, important factors could have been overlooked

Reference	Country	Aims	Sample	Methods	Findings	Limitations
Gray, L.A., Msall, E.R. and Msall, M.E. (2008) ‘Communicating about autism: decreasing fears and stresses through parent-professional partnerships’, *Infants & Young Children* 21(4), pp. 256–271.	USA	To provide information about developmental and behavioural perspective to guide professionals to support families throughout the diagnostic process of autism	No participants	General literature review	Review identified importance of: Listening to families concerns; comprehensive early intervention and education; considering developmental needs relating to autism; support improve social communication, promotion of adaptive skills building on strengths; ensuring parents understand autism cannot be cured. Physicians do not need to be experts but should be able to signpost parents to appropriate information and support.	None identified by the author General rather than systematic review but papers discussed are peer reviewed, nevertheless, important factors could have been overlooked
Jacobs, D., Steyaert., J., Dierickx, K. and Hens, K. (2018) ‘Implications of an Autism Spectrum Disorder diagnosis: An interview study of how physicians experience the diagnosis in a young child’, *Clinical Medicine*, 7, pp. 348-364.	Flanders Belgium	To explore the way clinicians experience ASD and an ASD diagnosis in their clinical practice.	16 physicians working children under 6 years without a diagnosis of intellectual (or other) disability but with autism (or presumed autism) diagnosis	Qualitative, semi-structured interviews & interpretative phenomenological analysis	Physicians perceive certain risks and benefits associated with autism, but felt diagnosis should be made to facilitate more effective approaches for the child Parent impact is mixed, e.g. relief, devastation but the benefits of diagnosis outweigh negative implications. Professionals mostly (5/16) relied on parents to disclose to the child. Four functions identified for diagnosis: (1) giving clear plausible explanation for parents, child, and others (2) confirming parental concerns (3) support realistic expectations (4) lifting blame from parents and child	Sample identified to be homogeneous group, however, selection bias was identified as participants were volunteers and might therefore hold particular views of diagnosis.

Reference	Country	Aims	Sample	Methods	Findings	Limitations
Jacobs.D., Steyaert.J., Dierickx,K. and Hens,K. (2019) 'Physician view and experience of the diagnosis of Autism Spectrum Disorder in young children. *Frontiers in Psychiatry*, 10, pp. 372-383.	Flanders Belgium	To gain an insight into the conceptualizations of autism of physicians working with children presumed to be on the autism spectrum but without intellectual disability	16 physicians working with preschool children without a diagnosis of (intellectual or other) disability with a (presumed) diagnosis of autism	Qualitative, semi-structured interviews	Physicians' multi-faceted and sometimes ambiguous perceptions of autism impacts autism diagnosis. 1) physicians' views link personal clinical styles and professional knowledge 2) Diagnosis of autism is seen as a descriptive element of the clinical trajectory; 3) treatment suggestions are a mix of personalised with standard approaches Physicians were found to experience difficulty defining, diagnosing, and explaining diagnosis clearly to parents.	Self-selection bias: participants volunteered and were interested in sharing views Sampling issues-focus on autism without intellectual impairment and assumed diagnosis No attempt quantify the findings or suggest generalisability as the authors identified it would require contextual translation to facilitate clinical use in other settings/cultures.
Miller, A. (2015) 'The All About Me Programme: a framework for sharing the autism diagnosis with children and young people', *Good Autism Practice,* 16 (1), pp. 79-92.	England, UK	To summarise the author's experiences of using the *All About Me Programme* to support children and young people with autism to understand their diagnosis	Views of 1 specialist advisory teacher who had utilized the programme with over 200 children	Qualitative explanation of programme inclusion and exclusion criteria and presentation of 4 case studies	Most children reacted positively to being told about autism via the programme. Important to emphasise child's strengths and talents to support difficulties to be overcome. Time to process is important, more than 3 programme sessions are likely to be needed Teaching children about autism: -is hard and never routine -is a unique emotionally charged event - requires a positive focussed, outwardly calm, confident, reassuring, and matter of fact manner - demands a good understanding of individuals and appropriate pedagogy	Programme limitations: Availability of professionals with sufficient skills Parents must also be ready for the diagnosis to support the CYP processing of information during and after sessions Not generalisable, no control group, a small number of cases presented, but discussion also informed by work with over 200 children.
Nissenbaum, M.S., Tollefson, N. and Reese, M.R. (2002) 'The Interpretative Conference: Sharing a Diagnosis of Autism with Families', *Focus on Autism and other*	USA	To examine professionals' and parents' perceptions of giving and receiving a diagnosis of autism,	11 nonmedical professionals 17 parents of children (2-5 yrs) with autism/AS diagnosis 15 mothers	Qualitative interviews	Professionals mostly described autism using negative terms Themes included: • Presentation to families ○ nonverbal communication skills ○ Being honest ○ avoiding too much information ○ highlighting the child's strengths,	Selection bias is possible as most participants were white mothers from affluent families in one county. Does not provide balance of views.

Reference	Country	Aims	Sample	Methods	Findings	Limitations
Developmental Disorders, 17(1), pp. 30-43.			2 fathers		○ Discussing the criteria & scores • Who gives the diagnosis? • When the diagnosis is given • Whether to include the child • Interventions • Positive and negative reactions to giving and receiving diagnosis	Views from others such as fathers, other parent relationships, cultures, and socioeconomic might view professional diagnosis differently
Rogers, C., Goddard, L., Hill, E. L., Henry, L. A., & Crane, L. (2016) ‘Experiences of diagnosing autism spectrum disorder: A survey of professionals in the United Kingdom’, *Autism: The International Journal of Research and Practice*, 20(7), pp. 820–831.	UK	To explore professionals’ experiences and opinions of three key areas of service: accessibility, the diagnostic process and post-diagnostic support	116 multidisciplinary professionals heterogeneous sample: psychologists, speech and language therapists, paediatricians, psychiatrists, nurses, teachers and occupational therapists	Online questionnaire Descriptive presentation of results & thematic analysis for open question responses	Most professionals were satisfied with service access but 40% indicated their service missed timescale expectations. Standardised diagnostic tools were identified helpful and used consistently Uncertain complex cases were reported to be upgraded to autism diagnosis. Concerns were highlighted about tool validity for detecting atypical autism. Professionals found disclosure of autism challenging, especially ensuring caregiver understanding, pitching information correctly, and managing distress. There was dissatisfaction with post-diagnostic provision and improvement in service provision identified as needed.	Anonymity of the online survey did not facilitate - Accuracy of responses to be checked - Provision of in-depth responses. - Sampling limitations: - Lack of ethnic (90% White). - Geographically skewed, e.g. 35% London and the South East, - Psychologists over-represented relative - to other professions

Appendix 3 Analysis of papers for the systematic search 2019

Appendix 3.1 Synthesis of themes from CYP papers

To disclose or not Themes=3 Sub-themes=0 Papers=3	Understandings & Misunderstandings Themes=4 Sub-themes=1 Papers=4	Social construction of identity Themes=6 Sub-themes=2 Papers=4	Personal construction of identity Themes=19 Sub-themes=13 Papers=8	Impact of knowing about diagnosis Themes=6 Sub-themes=8 Papers=5	Traits related to autism Themes=3 Sub-themes=0 Papers=1
Perceived negative social impact of being 'autistic' To disclose AS or not The dilemma of disclosure and social identity	awareness of the complexity of interpersonal relationships Recognition of unique behaviours and characteristics Misconceptions of autism influenced by either the savant or medicalised view of disability. Scrutiny and linking all traits to diagnosis Stereotypes and negative attitudes	Autism and collective cultural practices Social construction of identify Professional misunderstandings of autism Social construction of meaning related to autism • social construction of the label • Distinction within the label Interactions with peers, family members, and others influence beliefs about the diagnosis and themselves insider and outsider experience of autism	Distancing from the 'autistic' label Social promotion of positive self Symbolic importance of friendships/own interests to identity Understanding Autism Diagnosis in a problem context What is autism Communication It's not me, its my autism Siblings with autism Acceptance or rejection & dissonance Changes over time: 'I'm really glad this is developmental' Degrees of autism: 'They've got it really bad' Degrees of ability: 'I'm not really disabled-disabled Formation of an autism spectrum disorder narrative Acknowledgment of the label Self-awareness and reflection Confusion regarding whether autism spectrum disorder is a disability Desire to 'fit in' to a wider group Experience of being regarded as 'different' Impairment and losing control Impairment and taking control Varied reactions to diagnosis: Feelings: -"scared and a little bit angry." -confusion-wishing not to know but also glad to know-x2 -"weird and upset, then mad, now don't really care." -relieved! Things made a lot more sense"	Self and autism Struggling with sense of self stronger sense of self Improved understanding of autism strengths and difficulties =better understanding of self Perceptions of ''having'' autism disclosure delay providing explanations potential effects of labelling disruptions and opportunities acceptance and avoidance Pride and belonging Acceptance of the diagnosis Identity- self as disabled linked to social difficulties Identity- not dominated by the diagnosis when successes were the focus	Different communicative style Passive processing of information about self Emotion response and sensory defenses

Appendix 3.2 Example of approach used for synthesis with contextual information

	Study	Focus of discussion related to themes	Themes	Synthesis
1	Baines (2012)	Young people with the label of autism are capable of engaging in collective cultural practice They construct identities through social interactions to belong, compete, and participate. Nuanced efforts to distance themselves from the 'autistic' label were observed Social interactions exert power that helps to shape youth identity Young people with autism are not isolated from the sociocultural process of identity development The participants made a deliberate effort to promote a positive perception of themselves in the eyes of others Being seen as 'autistic' negatively affected how others perceived the participants	Autism and collective cultural practices Social construction of identify Distancing from the 'autistic' label Social promotion of positive self Perceived negative social impact of being 'autistic'	Personal construction of identity T= 19 ST=13 P=8 Impact of knowing about diagnosis T= 6 ST=8 P=5 Social construction of identity T= 7 ST=2 P=4 Understandings & Misunderstandings T=4 ST=1 P=4 To disclose or not T=3 ST=0 P=3 Traits related to autism T= 3 ST=0 P=1 Key: T= Themes ST=Sub-themes P=Paper
2	Billington (2006)	The author suggests practitioners should develop practices and discourses concentrate on assets rather than deficits; create services that enable difficult feelings/distress to be shared; be aware of interactionist influences and avoid placing responsibilities for behavioural change upon the child but upon also– parents and professionals; need for more research to elicit views of CYP with autism about how they manage their 'worlds'	Emotion response and sensory defenses Social construction of meaning related to autism Symbolic importance of friendships to identity/own interests Passive processing of information about self different communicative style Professional misunderstandings of autism.	
3	Gaffney (2017)	Author suggests that some participants found diagnosis useful, perhaps just at certain times, but for some the diagnosis is unwanted and sometimes harmful to personal identity	Understanding Autism Diagnosis in a problem context What is autism Communication It's not me, its my autism Siblings with autism Acceptance; Dissonance; Rejection Self and autism Struggling with sense of self stronger sense of self	
4	Gordon, Murin, Baykaner, *et al.* (2015)	Reliable change for ASD self-awareness equated to a child naming at least three more, or three fewer, ASD strengths and difficulties post-intervention compared with baseline. Most reported increased knowledge about ASD and stated this helped them to understand themselves better. PEGASUS participants did not show any reduction in self-esteem Authors suggest this may reflect the focus on strengths as well as difficulties	Improved understanding of autism strengths and difficulties=better understanding of self	

	Study	Focus of discussion related to themes	Themes	Synthesis
5	Huws and Jones (2008)	Diagnosis, and the disclosure of the diagnosis of autism, were embedded in respondents' perceptions of "having" autism. The study identified 5 themes within the accounts: disclosure delay providing explanations potential effects of labelling disruptions and opportunities acceptance and avoidance	Perceptions of "having" autism disclosure delay providing explanations potential effects of labelling disruptions and opportunities acceptance and avoidance	
6	Huws and Jones (2015)	Autism was viewed as being located along a spectrum of severities affecting individuals in different ways Participants referred to what they could and could not do- strengths and difficulties Autism was described as a type of disability and a difference Participants compared to others with autism degrees of disability	Changes over time: 'I'm really glad this is developmental' Degrees of autism: 'They've got it really bad' Degrees of ability: 'I'm not really disabled-disabled	
7	Jones, Gallus, Viering *et al.* (2015)	Adolescents' discussion of their autism-related diagnoses and identification with labels of disability seemed to reflect their personal narratives regarding their diagnosis. Interactions with peers, family members, and others influence beliefs about the diagnosis and themselves. Social stigma and the language used to describe autism impacts how adolescents view themselves and make meaning out of their diagnoses. Despite accepting the diagnosis, the author also identified participants' misconceptions related to autism	1. Formation of an autism spectrum disorder narrative Acknowledgment of the label Recognition of unique behaviours and characteristics Self-awareness and reflection 2. social construction of the label Distinction within the label Pride and belonging 3. confusion regarding whether autism spectrum disorder is a disability Interactions with peers, family members, and others influence beliefs about the diagnosis and themselves.	
8	Jones, Huws and Beck (2013)	The authors identified both insider and outsider experiences of autism. The results suggested an awareness of the complexity of interpersonal relationships, a desire to 'fit in' to a wider group, and a feeling of being regarded as 'different'. Authors suggest that use of an expert author helped avoid a 'diagnostic overshadowing' interpretation of these findings, and located them as an interaction of age, life stage, and the presence of an ASD.	insider and outsider experience of autism awareness of the complexity of interpersonal relationships desire to 'fit in' to a wider group Experience of being regarded as 'different'	
9	Molloy and Vasil (2004)	The authors highlight that while young people's 'quirks' are likely to be considered as part of their unique and complex personalities, 'quirks' of young people with Asperger's are likely to be viewed as symptoms. The authors highlight how trying to meet social expectations can influence low self-esteem. authors suggest that individuals that discussed more life successes were less dominated by the diagnosis The authors suggest a relationship exists between self-esteem and the extent AS was viewed as a disability	Acceptance of the diagnosis Identity- self as disabled linked to social difficulties Identity- not dominated by the diagnosis when successes were the focus To disclose AS or not Misconceptions of autism influenced by either the savant or medicalised view of disability. Scrutiny and linking all traits to diagnosis	

	Study	Focus of discussion related to themes	Themes	Synthesis
10	Mogensen & Mason (2015)	The meanings that a diagnosis of autism had for the young people were suggested to be indicative of the diversity and complexity of experiences with a diagnosis. Some participants described the diagnosis as being oppressive, positive or even liberating, several individuals also identified it facilitated having some control in their lives. The participants suggested lack of understanding in public attitudes, too much focus was placed on the negative connotations attached to the diagnosis typically constructing the differences in terms of deficiencies. Whether the diagnosis facilitated understanding of self, and impacted individual feeling of control and agency impacted whether it was perceived to an advantage or disadvantage.	Diagnosis as oppressive Diagnosis as liberating Diagnosis as facilitating control Autism as positive identity The dilemma of disclosure and social identity Stereotypes and negative attitudes Impairment and losing control Impairment and taking control	
11	Rossello (2015)	All adolescents were, at some level, glad they had been told about their diagnosis. The author suggested there was no indication that having been told of their diagnosis negatively impacted their views of their future. Disclosing a diagnosis of Asperger's to an adolescent was found to be more beneficial than detrimental to their mental health 3 out of 4 adolescent participants wished they had known sooner, Author concludes, the more positive the adolescents' reaction to the disclosure, the more optimistic their feelings are about their future the more likely they are to tell other people about their diagnosis	Varied reactions to diagnosis: Feelings: -"scared and a little bit angry." -confusion-wishing not to know but also glad to know- x2 -"weird and upset, then mad, now don't really care." -relieved! Things made a lot more sense"	

Appendix 3.3 Occurrence of themes across the CYP papers

Subthemes	Baines. (2012)	Billington (2006)	Gaffney (2017)	Gordon, *et al.* (2015)	Huws & Jones (2008)	Huws & Jones (2015)	Jones *et al.* (2015)	Jones, Huws &Beck (2013)	Molloy & Vasil (2004)	Mogensen & Mason (2015)	Rossello (2015)	Total number of papers in which
Autism narrative & self/identity	✓				✓	✓	✓		✓	✓	✓	7
Distancing from autism/degrees of autism	✓		✓		✓	✓	✓		✓	✓		7
Degrees of autism	✓					✓	✓					3
Emotional reactions to diagnosis			✓		✓	✓					✓	4
Diagnosis in a problem context	✓	✓	✓						✓			4
Delay/desire to have known sooner					✓						✓	2
Importance of social standing/Social promotion of positive self	✓	✓			✓	✓	✓		✓	✓		7
To tell or not to tell others	✓								✓		✓	3
Accepting/rejecting the diagnosis	✓		✓		✓	✓	✓		✓	✓		7
Social expectations, communication & self-esteem	✓	✓	✓			✓	✓					5
Labelling/disability/stigma /stereotyping					✓		✓	✓	✓	✓		5
Autism a challenge to identify	✓	✓			✓	✓	✓					5
Self-awareness			✓	✓			✓				✓	3
Levels of autism & comparisons	✓		✓		✓	✓	✓		✓			6
Understanding autism			✓	✓	✓		✓				✓	5
Diagnostic disclosure and understanding self	✓		✓		✓		✓				✓	5
Strengths/successes reduce impact of diagnosis	✓		✓	✓	✓	✓	✓		✓	✓		7
Impairment & losing control vs taking control	✓	✓	✓							✓		4
Belonging							✓	✓				2
Feeling different/desire to fit in	✓					✓		✓				3
Understanding autism as an insider							✓	✓		✓		3
Autism misconceptions							✓		✓	✓		3

Appendix 3.4 Synthesis of themes from parent papers

Parental experiences of diagnosis= 7 sub-themes identified 18 times across 5 papers	Parental preparation for disclosure to the child=24 sub-themes identified 54 times across 7 papers	Disclosing and/or communicating about autism to their child=11 sub-themes identified 38 times across 6 papers	Children's initial reaction to the diagnosis =11 sub-themes identified 43 times across 7 papers	Child perceptions and actions moving forward after disclosure 16 sub-themes identifies 55 times across 7 papers	Impact of diagnosis-8 sub-themes identified 12 times across 6 papers
Noticing differential development Diagnostic delay/diagnosis took a long time Frustration with the process Professionals not empathic Shock/surprise/negative emotional impact Confirmation/relief/hope Supported familial understanding	Pre/non-disclosure-Child/others don't notice Pre/Non-disclosure –child will not understand Pre/Non-disclosure –might impact child's self-esteem mental wellbeing Disclosure when-the child asks questions Disclosure when-child can understand Researching to prepare for disclosure Pre disclosure discussion with child about differences Parents feeling emotionally ready to disclose Parent's need/seek professional support Support from others useful or perceived to be useful Recognise the need to be open about diagnosis/ Never though not to disclose Disclosure needed/decided upon as a problem-solving tool Approached as 'everyday' neutral informative discussion/situational vs specific event Delay/desire to have known/disclosed sooner Concerns that disclosure that might have detrimental impact Worries about stigma, labelling or stereotyping	Tailoring discussion of diagnosis to individual Diagnosis in a problem or problem-solving context Disclosure to child challenges parents A learning opportunity for the child Discussion of difficulties/differences Role models with autism identified Tailored discussion to child needs/child led Focusing on positive aspects Disclosure should be as soon as possible Explanation a gradual process over time Disclosure is stressful for parents	Time to process Asking questions Accessing resources/researching Positive emotional reactions to diagnosis Accepting the diagnosis Improved understanding of self Strengths/successes reduce impact of diagnosis Relief Indifference Negative emotional reactions to diagnosis Rejecting the diagnosis	Importance of social standing/Social promotion of positive self Autism narrative & self/identity Autism a challenge to identify Acceptance of diagnosis Levels of autism, comparisons and distancing Understanding autism specific traits Impairment & losing control vs taking control negotiating autism and association with labels and stigma Understanding autism as an insider/owning the diagnosis Autism misconceptions/lack of understanding Feeling different/desire to fit in Belonging Improved self-awareness/empowering Social expectations, communication & self-esteem Disclosure to peers/associates Reluctance to disclose to peers	Negative impact Improved self-awareness More support in education following diagnosis Insufficient support Improved peer understanding Improved family understanding Experiencing stigma, labelling or stereotyping Used as an excuse

Appendix 3.5 Occurrence of themes across papers-parental experiences of diagnosis

Theme: Parental experiences of diagnosis=18	Cadogan (2015)	Crane, Jones, Prosser *et al.* (2019)	Finnegan, Trimble, & Egan (2014)	Rossello (2015)	Smith-Demers (2018)	Smith, Edelstein, Cox & White (2018)	Ward (2014)	Total number of papers in which theme identified
Noticing differential development		✓	✓		✓	✓		4
Diagnostic delay/diagnosis took a long time		✓	✓		✓			3
Frustration with the process			✓		✓			2
Professionals not empathic		✓	✓	✓				3
Shock/surprise/negative emotional impact		✓			✓			2
Confirmation/relief/hope			✓		✓			2
Supported familial understanding		✓			✓			2

Appendix 3.6 Occurrence of themes across papers-parental preparation for disclosure

Theme: Parental preparation for disclosure to the child=54	Cadogan (2015)	Crane, Jones, Prosser *et al.* (2019)	Finnegan, Trimble, & Egan (2014)	Rossello (2015)	Smith-Demers (2018)	Smith, Edelstein, Cox & White (2018)	Ward (2014)	Total number of papers in which theme identified
Pre/Non-disclosure, child doesn't see self as different					✓			1
Pre/non-disclosure-Mild others don't notice		✓			✓			2
Pre/Non-disclosure –child will not understand			✓		✓	✓		3
Pre/Non-disclosure –Label might hinder child in future					✓			1
Pre/Non-disclosure –might impact child's self-esteem mental wellbeing			✓		✓			2
Pre/Non-disclosure –child might then share inappropriately with others					✓			1
Disclosure when-the child asks questions					✓		✓	2
Disclosure when-child can understand					✓		✓	2
Disclosure due to fear child will find out					✓			1
Pre/Non-disclosure –difference of opinion in family about disclosure/diagnosis					✓			1
Researching to prepare for disclosure				✓	✓			2
Pre disclosure discussion with child about differences					✓		✓	2
Parents feeling emotionally ready to disclose		✓			✓			2
Parent's need/seek professional support		✓	✓	✓	✓			4
Support from others useful or perceived to be useful		✓	✓	✓	✓			4
Accessing physical resources				✓	✓			2
Recognise the need to be open about diagnosis/ Never though not to disclose	✓	✓		✓	✓			4

Theme: Parental preparation for disclosure to the child=54	Cadogan (2015)	Crane, Jones, Prosser *et al.* (2019)	Finnegan, Trimble, & Egan (2014)	Rossello (2015)	Smith-Demers (2018)	Smith, Edelstein, Cox & White (2018)	Ward (2014)	Total number of papers in which theme identified
Disclosure needed/decided upon as a problem-solving tool	✓	✓						2
Disclosure happened situationally					✓			1
Planning for a specific disclosure event					✓			1
Approached as 'everyday' neutral informative discussion	✓	✓			✓			3
Delay/desire to have known/disclosed sooner		✓	✓	✓	✓			4
Concerns that disclosure that might have detrimental impact		✓	✓			✓	✓	4
Worries about stigma, labelling or stereotyping		✓	✓			✓		3

Appendix 3.7 Occurrence of themes across papers-communicating diagnosis to child

Theme: Disclosing and/or communicating about autism to their child=38	Cadogan (2015)	Crane, Jones, Prosser *et al.* (2019)	Finnegan, Trimble, & Egan (2014)	Rossello (2015)	Smith-Demers (2018)	Smith, Edelstein, Cox & White (2018)	Ward (2014)	Total number of papers in which theme identified
Tailoring discussion of diagnosis to individual	✓	✓	✓	✓	✓		✓	6
Diagnosis in a problem or problem-solving context	✓	✓	✓	✓				4
Disclosure to child challenges parents		✓	✓		✓		✓	4
A learning opportunity for the child	✓	✓						2
Discussion of difficulties/differences	✓	✓	✓		✓		✓	5
Role models with autism identified		✓	✓		✓			3
Tailored discussion to child needs/child led		✓			✓		✓	3
Focusing on positive aspects	✓	✓	✓		✓			4
Disclosure should be as soon as possible		✓						1
Explanation a gradual process over time		✓			✓		✓	3
Disclosure is stressful for parents		✓			✓		✓	3

Appendix 3.8 Occurrence of themes across papers-parental views on children’s initial reactions to diagnosis

Theme: Children’s initial reaction to the diagnosis =43	Cadogan (2015)	Crane, Jones, Prosser *et al.* (2019)	Finnegan, Trimble, & Egan (2014)	Rossello (2015)	Smith-Demers (2018)	Smith, Edelstein, Cox & White (2018)	Ward (2014)	Total number of papers in which
Time to process	✓			✓		✓		3
Asking questions	✓						✓	2
Accessing resources/researching	✓							1
Positive emotional reactions to diagnosis		✓	✓	✓	✓	✓		4
Accepting the diagnosis	✓	✓	✓	✓	✓	✓	✓	7
Improved understanding of self	✓	✓	✓		✓		✓	5
Strengths/successes reduce impact of diagnosis			✓	✓	✓	✓	✓	5
Relief	✓	✓				✓		3
Indifference	✓							1
Negative emotional reactions to diagnosis		✓	✓	✓	✓	✓		5
Rejecting the diagnosis	✓	✓	✓	✓	✓	✓	✓	7

Appendix 3.9 Occurrence of themes across papers-parental views on children’s perceptions and action moving forward from diagnosis

Theme: Child perceptions and actions moving forward after disclosure =55	Cadogan (2015)	Crane, Jones, Prosser *et al.* (2019)	Finnegan, Trimble, & Egan (2014)	Rossello (2015)	Smith-Demers (2018)	Smith, Edelstein, Cox & White (2018)	Ward (2014)	Total number of papers in which theme identified
Importance of social standing/Social promotion of positive self		✓			✓	✓	✓	4
Autism narrative & self/identity	✓	✓			✓	✓	✓	5
Autism a challenge to identify		✓			✓	✓	✓	4
Acceptance of diagnosis	✓			✓				2
Levels of autism, comparisons and distancing			✓		✓	✓	✓	4
Understanding autism specific traits	✓							1
Impairment & losing control vs taking control		✓	✓					2
negotiating autism and association with labels and stigma	✓							11
Understanding autism as an insider/owning the diagnosis	✓	✓					✓	3
Autism misconceptions/lack of understanding	✓	✓				✓	✓	4
Feeling different/desire to fit in	✓					✓		2
Belonging		✓					✓	2
Improved self-awareness/empowering	✓	✓	✓	✓			✓	5
Social expectations, communication & self-esteem			✓			✓	✓	3
Disclosure to peers/associates	✓	✓						2
Reluctance to disclose to peers	✓							1

Appendix 3.10 Occurrence of themes across papers-parental views on the impact of diagnosis

Theme: Impact of diagnosis-12	Cadogan (2015)	Crane, Jones, Prosser *et al.* (2019)	Finnegan, Trimble, & Egan (2014)	Rossello (2015)	Smith-Demers (2018)	Smith, Edelstein, Cox & White (2018)	Ward (2014)	Total number of papers in which
Negative impact	✓							1
Improved self-awareness			✓	✓			✓	3
More support in education following diagnosis			✓					1
Insufficient support		✓						1
Improved peer understanding		✓						1
Improved family understanding		✓						1
Experiencing stigma, labelling or stereotyping					✓		✓	2
Used as an excuse	✓	✓						2

Appendix 4 Summary of preliminary study

Aim and context for the Kids Autism Training (KAT) programme

The main aims of the pilot study were to trial the programme and consider the impact, in addition to considering whether evaluation questionnaire used to collect the views of participants was appropriate. Polit and colleagues (2001) suggest that a pilot study can be either a feasibility study or a pre-test for a research instrument.

The **K**ids **A**utism **T**raining (KAT) Programme (Appendix 4: Summary of the KAT programme) was developed and delivered in the Autumn of 2011 by a local authority Autism Outreach Team (AOT), of which I was a member. The KAT Programme was delivered by the AOT team in the North East of England. The programme was developed to run alongside the same local authority's Parent/**C**arers **A**utism **T**raining (CAT) Programme, which had been running for 4 years prior to the development of KAT. The idea for KAT's development occurred in response to parents' views, which had been captured through evaluation of the CAT post diagnosis programme for parents. Parents suggested that a programme was needed that would support understanding of the diagnosis for the young people with autism. They felt it would be especially useful if this ran contiguously with the CAT Programme. My colleagues and I often received requests for support for young people who were finding it difficult to understand the diagnosis, from individual parents and school staff working with CYP with autism. There was also an increasing need to find more efficient ways to provide this support, due to increased demand for the AOT service. The KAT programme was designed with the aim of supporting more CYP in a way that made best use of local services. In designing the programme, the topics and activities were designed to be flexible enough to meet the needs of the individuals who attend, by providing space to focus upon individual interests, preferred activity types, and approaches to learning and social interaction, while also covering core key topics to support understanding of autism (See Appendix 4: Summary of the KAT programme for full details). The aim was to build on strategies that had already been found to be beneficial through the one-to-one work, which AOT members had been undertaking with CYP with autism for several years prior to developing the KAT **programme.**

Recruitment to the KAT pilot programme

In line with the Local Authority Autism Diagnostic Pathway, all parents/carers of young people who had recently been informed about an autism spectrum diagnosis were invited to take part in a parent information programme. Parents/carers of younger children aged 7 years and below were offered National Autistic Society EarlyBird or EarlyBird Plus training. As the programme was delivered approximately every six months, the period between diagnosis and attendance at a programme for parents usually ranged between two and twelve months following the diagnosis. KAT invitations were sent out with CAT invitations, therefore the young people who attended the KAT pilot had received the diagnosis within the previous twelve months. All young people attending the KAT programme had already been informed about their autism diagnosis.

Evaluation of the KAT pilot programme

The initial pilot study of the KAT Programme was evaluated by collecting the views of parents and professionals, and the young people who attended- who had recently learnt about an autism diagnosis. Evaluative data was collected from the young people attending KAT via a pre-programme and post-programme questionnaire, which comprised a self-esteem, anxiety and social confidence, behaviour and knowledge of autism scale. Several standardised scales were considered but none were identified which were appropriate to young people with autism. A scale was therefore developed to evaluate the young people’s self-esteem; social confidence; their view of their own behaviours and their understanding of autism.

The self-administered scale was based on Coopersmith’s (1967) self-esteem scale, which incorporated elements related to general self-esteem, social-confidence and behaviour. However, as some of the language was dated and some questions were felt to be too abstract for young people on the autism spectrum, some questions were removed and others were slightly re-phrased (Appendix 5). As this was planned to be a small exploratory pilot, the scale construct reliability was not explored; it was planned to use the data from the pilot to support analysis of the scale construct. The questionnaire was, however, tried out for ease of completion by two young people with autism. While no issues were identified with the content of the scale, both young people highlighted the need for minor alterations to formatting. Both young people identified the same formatting inconsistencies as problematic: one young person described them as 'distracting', while the second described them as 'unprofessional'. The correctly formatted questionnaire was completed by the young people with autism before they commenced the programme and after completion of the KAT programme. Qualitative feedback was also collected through comments made by young people during the KAT sessions and via a focus group at the end of the programme.

As the KAT Programme ran contingent with the programme for their parents/carers and educators, parent/carer and professional views were also collected through two focus group discussions. One focus group collected views from parents, the second from educators. Parents and professionals were asked to give their views about the impact of the KAT programme upon the young people (See Appendix 6 for focus group schedule).

Kids and Carers Autism Programme Participants

Thirty-eight invitations were sent out offering a place on both the Carers Autism Training (CAT) and Kids Autism Training (KAT) programmes. Twelve family places were accepted for CAT. As two places were offered for parent/carers within each family, the total number attending was eighteen. This included twelve mothers, two fathers, three grandparents (two grandmothers and a granddad) and a supportive family friend. Eight places were requested on the KAT programme, however, only six attended the full programme. One child place was not taken up because the child decided they did not wish to attend due to anxiety. The other child did not attend all sessions, as his parents moved house unexpectedly. All those who participated, assented to their views being included in the evaluation and the research. Invitations were also sent to the young person's school, offering a place for a key educator, either a teacher, SENCO or teaching assistant, who worked with the young people who were attending. Three educators accepted and attended the CAT programme alongside parents. As each professional was working with one of the young people involved in the KAT programme, they were asked to take part in a focus group to share their views about any impact they had observed upon the young person. Two professionals consented to sharing their views for the evaluation and research. The participants are summarised in the table below.

Table 1 Participant details for the KAT and CAT Programmes

Method of Participation	Participant Group	n	Diagnosis	Age range of children/young people with autism	Gender
Kids Autism Training	Children and young people	6	ASD=20 AS=2 A=4	8 and 13 years	1 x Female 5 x males
	Parents	8			6 x mothers 2 x fathers
	Educational professionals who work with two of the KAT participants	2		2 x teachers	2 females

Analysis of the KAT Programme

The KAT questionnaire asked child and young people to rate themselves against statements focused on: social confidence; general anxiety; behaviour; self-efficacy and also their understanding of autism. As detailed in Appendix 5 (KAT evaluation scale and participant responses), the possible responses with the score allocated in brackets were: not at all (1+/5-); rarely (2+/4-); sometimes (3); usually (4+/2-) and always (5+/1-). Child and young person participants completed the questionnaire before and after taking part in the programme to identify if there were improvements from learning more about the diagnosis. The scores are detailed below for each participant.

Table 210 Overview of participants scores before and after the KAT Programme

	Participant pseudonym					
Scale focus	Ed	Lee	Joe	Tim	Ben	Zoe
Self-esteem Pre	75	59	67	62	70	59
Self-Esteem Post	74	58	68	60	61	57
Social-Confidence Pre	14	7	18	12	12	16
Social Confidence Post	18	8	16	12	20	14
Behaviour Pre	33	26	28	36	28	21
Behaviour Post	18	31	26	35	29	24
Anxiety Pre	56	40	47	63	45	51
Anxiety Post	61	50	56	64	61	52
Pre knowledge	41	27	40	30	25	23
Post knowledge	46	38	43	29	30	25
Total Pre	219	159	200	203	180	170
Total Post	217	185	209	200	201	172

The analysis of the KAT questionnaire showed a slight improvement in the young people's knowledge of autism for five out of six participants and a reduction in anxiety for all. However, for two young people the reduction was very slight. Combined scores indicated a very slight improvement overall. Responses in terms of self-esteem, social confidence and behaviour were more variable, with some young people's responses indicating improvement and others reduction. The most consistent responses across the group was especially evident in questions related to anxiety and knowledge about autism, which indicated reduced anxiety (as scoring was inversed) and improved understanding of autism. As the responses were from a very small participant group, and the results were variable, no firm conclusions could be drawn about the impact of the programme overall. The results did demonstrate some promise in achieving the aims in supporting understanding of autism. Results from the KAT programme showed that, with the exception of one participant, there was no lowering of self-esteem. The one participant in KAT programme who reported lower self-esteem after the programme did, however, report much higher levels of social confidence and much lower anxiety levels. However, as this was a small exploratory study, no generalisations can be made.

The pilot questionnaire used for the KAT evaluation was helpful in informing further development of the online survey for the main study which followed. The key issues identified in relation to the scaled questionnaire were that there were too many questions and some questions were too difficult to understand. Therefore, improvements suggested a shorter questionnaire and further improvement in the wording for clarity of meaning.

Feedback from children's and young people's focus groups about KAT

Overall, the focus group feedback was very positive from the young people who attended, their parents and from the professionals who worked with two of the participants. As shown in Appendix 5 the young people identified a range of new learning from taking part, this included knowing more about their diagnosis, improvements in social interactions and in their ability to manage emotions. The views they shared reflected greater confidence, including feeling:

> … more confident standing up to bullies. (Appendix 5: Focus group responses, line 23)

> … How to manage anxiety and how to chat to friends. (Appendix 5: Focus group responses, line 14)

> …Having more fun, I just feel more ok when playing**.** (Appendix 5: Focus group responses, line 18)

Despite discussing the programme very positively in terms of personal impact and enjoyment, the answer to the question about any further improvements from one young person was thought provoking:

> …*I still have it***.** (Appendix 5, Child 1, Line 55)

Despite his previous positive responses**,** this final comment seemed to imply that autism is something you ‘have’ like you might have an illness. Perhaps his expectation from the programme had therefore been for a ‘cure’. While we were able to follow up with discussion of his positive personal traits, it was a reminder that coming to understand an autism diagnosis is a process.

In reflecting upon the programme and the participants’ ideas, it was noted that it was particular aspects of social and emotional development skills, which they could relate to their specific circumstances that the participants found easiest to discuss. The emotional response that most of the young people shared was about feeling more confident in specific, tangible skills. While the skills identified were varied, the notion of being more confident in relation to specific skills, or self-efficacy (Bandura, 2006), was apparent. This was an especially useful finding, which led to self-efficacy being employed as a concept for the online survey that followed to explore young people’s experiences of the diagnosis.

While the focus group was a time efficient approach to gain some useful data about the programme, it was noted that some young people who took part did not contribute much information. It was felt that their contributions might have been impacted due to their social needs, their communication was more inhibited than had been observed in one-to-one discussion with both peers and adults. Furthermore, when asked to identify anything they felt would improvement programme for the future, one of the children suggested:

> …*more one-to-one talking…* (Appendix 5: Focus group responses, line 31)

Two participants agreed to this suggestion. Suggestions from other participants were for more games and group activities that linked to the main programme topics. In planning the programme, games and practical activities were key elements of all sessions. Care had been taken, however, not to overload the content with activities requiring constant social interaction. Therefore, as the group of participants usually found social interaction problematic and anxiety provoking, this was considered to be a very positive outcome.

Feedback from parent focus group about KAT

Parents also reported positive outcomes in relation to the KAT. Five out of the parents identified that the programme had a positive outcome. Their child's increased confidence in their own abilities was a theme in parent responses:

> …it definitely helped XXXX to recognise his strengths (Appendix 6a, line 39)

Another parent indicated the KAT had supported his child in the following ways:

> … XXXX has made new friends, understands ASD better, and the confidence factor has improved (Appendix 6a, lines 42-43)

All the parents/carers of the young people who participated in KAT indicated that they would recommend it to other parents.

The two professionals who were working with two of the young people in an educational setting, indicated they felt that taking part in the KAT programme had achieved its aims in supporting the young person to understand the diagnosis positively. They identified the following as benefits they were aware of in school:

> The visuals he made at the sessions have been brought in and used in school. It helped talking to each other, with the parents. (Professional 1, Appendix 6b, lines 28-29)

> XXXXX is more accepting of ASD. Calming strategies used for range of children in school not just children with ASD…
> (Professional 2, Appendix 6b, lines 42-43)

Both professionals also agreed they would you recommend the KAT programme for other children on the autism spectrum, identifying:

> *… it has made such a difference.* (Professional 2, Appendix 6b, lines 83-84)

> Yes, for all others. I think it would be good to bring this type of work into school more. (Professional 1, Appendix 6b, lines 85-86)

The idea of bringing the programme into an educational setting was not something that had been considered previously, we reflected afterwards as a team, how as part of PSHE, it might be a useful approach to combine support for young people to understand their diagnosis and could incorporate peer awareness.

Learning from KAT

In reflecting on the overall outcomes and learning from the KAT programme the following aspects were most beneficial:

- Young people understanding of autism improved.
- Young people found it easiest to discuss issues related to their diagnosis in terms of key tangible skills, especially strengths and difficulties that were specific to them.
- The young people especially valued making a scrap book about themselves, which focussed on their strengths, many of which related to traits associated with autism. Having something to take away to reflect on was important and appeared to be valued by them.
- The emotional management strategies activities and learning, supported by resources that the young people made to take away for ongoing use, had impact across settings.
- Ongoing impact for the children and young people was also indicated. For example, one parent discussed his child’s willingness to plan to

make improvements and his continued use of the ‘Good Things about Me’ scrapbook, created as part of this process.

- Focusing to be on positive traits but also considering difficulties as part of planning improvements appeared to be key to the benefits of the programme that were identified. Discussing difficulties was also something the young participants really valued, they seemed to appreciate the opportunity to compare with peers on the spectrum. They seemed to find comfort from learning that they were not the only person who found things difficult. Hearing about other successes was also appreciated and was useful to motivate participants to plan for improvement.
- Sharing feedback on progress between sessions was effective and the group were encouraging of each other when feeding back each week**.**

Key limitations and improvements were:

- The questionnaire was too long. Children and young people suggested a shorter questionnaire and improved wording for clarity for some questions.
- The children and young people found it easier to discuss their feelings and the autism diagnosis in relation to confidence related to specific tangible skills and interactions.
- A short-term intervention will not fully support a young person’s understanding of an autism diagnosis, or their acceptance.

Knowing about autism

The analysis of the KAT questionnaire showed a slight improvement in the young people’s knowledge of autism for five out of six participants and a reduction in anxiety for all. However, for two young people the reduction was very slight. Combined scores indicated a very slight improvement overall. Responses in terms of self-esteem, social confidence and behaviour were more variable, with some young people’s responses indicating improvement and others reduction. The most consistent responses across the group was especially evident in questions related to anxiety and knowledge about autism, which indicated reduced anxiety (as scoring was inversed) and improved understanding of autism. As the responses were from a very small participant group, and the results were variable, no firm conclusions could be drawn about the impact of the programme overall. The results did demonstrate some promise in achieving the aims in supporting understanding of autism. These variable findings are similar to Gordon et al.’s (2015) PEGUSUS programme, which also aimed to develop children and young people’s understanding of autism. The PEGUSUS study also found that most young people enjoyed the programme and some of the young people reported positive impact, more than half did not show statistically reliable change. Furthermore, results from the KAT programme showed that, with the exception of one participant, there was no lowering of self-esteem, which is also similar to the PEGUSUS study. The one participant in KAT programme who reported lower self-esteem after the programme did, however, report much higher levels of social confidence and much lower anxiety levels. However, as this was a small exploratory study, no generalisations can be made.

Appendix 4.1 Kids Autism Programme: Post course questionnaire for children

Please write your age: ____________

Gender, please circle: Male Female

We ask you to complete these questions to find out if you found this KAT Course helpful. If you have said it is ok for Julie Prentice to use your questionnaire information for research, she will use the information to help her to work out if the KAT Course is useful and how she could make it better. She will then write a project about what she has found out. Sometimes research projects are published in special magazines (like the one Julie showed you) but she will make sure that she does not use your name or details. If you change your mind about me using your information, just tell your parents. They have a special note to send me if this happens. It will not be a problem if you decide that you do not want Julie to use your information.

ID Code: ____________________ ______________ Below is a list of sentences that describe how people sometimes feel. Make a tick to show if you feel the same as the sentences:	Never X	Hardly Ever X	Some-times --	Often ✓	Always ✓
1. I often wish I were someone else.					
2. I get upset easily at home.					
3. I don't like to be with people I don't know well.					
4. I am usually happy.					
5. I worry about other people liking me.					
6. People think I'm boring.					
7. I am nervous.					
8. I follow my mother or father wherever they go.					
9. People tell me that I look nervous.					
10. I always do the right thing.					
11. I am proud of my school work.					
12. I am popular with children my own age					
13. I worry about sleeping alone.					
14. I worry about not being as good as other kids.					
15. I don't feel that I have anything to be proud of.					

ID Code: ____________________ ____________ Below is a list of sentences that describe how people sometimes feel. Make a tick to show if you feel the same as the sentences:	Never X	Hardly Ever x	Some-times --	Often ✓	Always ✓
16. I understand my diagnosis (Autism/ASC/Aspergers, etc)					
17. I get scared if I sleep away from home.					
18. Other people who are my age think I'm odd.					
19. I feel that I am often successful.					
20. I am never unhappy					
21. I am happy to talk to people about my diagnosis					
22. I worry about going to school.					
23. Having an Aspergers or Autism diagnosis is rubbish					
24. I often feel useless.					
25. I worry about things working out for me.					
26. I find it very hard to talk in front of the class					
27. I am a positive person.					
28. I get really frightened for no reason at all.					
29. I like to be different					
30. I am afraid to be alone in the house.					
31. I enjoy chatting with people I don't know well.					
32. There are a lot of things about myself I would change if I could					
33. People tell me that I worry too much.					
34. I am a lot of fun to be with					
35. I can make up my mind without too much trouble					
36. I always have to ask people what I should do next.					
37. I feel shy with people I don't know well.					

ID Code: ____________________ ____________ Below is a list of sentences that describe how people sometimes feel. Make a tick to show if you feel the same as the sentences:	Never X	Hardly Ever X	Sometimes --	Often ✓	Always ✓
38. It takes me a long time to get used to anything new					
39. I think that having Autism or Aspergers can be a good thing					
40. I often find new things difficult because of my Autism or Aspergers					
41. I give in very easily.					
42. I wish I didn't have an Autism or Aspergers diagnosis					
43. I am never unhappy					
44. I worry about how well I do things.					
45. My parents expect too much of me.					
46. I understand Autism and Aspergers very well					
47. Things are all mixed up in my life					
48. I like most things about myself					
49. No one pays much attention to me					
50. I never get told off at school					
51. I often get rewards/points/merits from the teacher					
52. Having Autism or Aspergers makes me different in a good way					
53. I often wish I was the same as everyone else					
54. I never swear.					
55. I sometimes get into trouble for hurting other people.					

ID Code: ____________ ____________ Below is a list of sentences that describe how people sometimes feel. Make a tick to show if you feel the same as the sentences:	Never X	Hardly Ever X	Sometimes --	Often ✓	Always ✓
56. I always do what my parents ask me to do.					
57. My behaviour is good.					
58. I would like my behaviour to be better in school.					
59. I feel like I never get things right.					
60. My parents are proud of me.					

KAT Programme- Questions for after you have finished the course (An adult will help with these)

Please also answer the questions below:

1. Did you want to attend the KAT course? Yes/No/Don't know

2. What do you think you have learnt from coming to the KAT course?

3. Please tell us about anything that you feel you are better at because of the KAT course:

4. Tell us about any **changes** you think we could make **to make the KAT course better**?

5. What do you feel has been **the most enjoyable** part of the course:

6. What do you feel has been **the most helpful** part of the course:

7. Please tell us about **anything that you don't like** about the KAT Course:

8. Any other comments or suggestions:

Thank you for your assistance.

Appendix 4.2 Analysis of KAT Questionnaires-Pre and post KAT programme

Participant	P1	P2	P3	*P4*	*P5*	*P6*	*P1*	*P2*	*P3*	*P4*	*P5*	*P6*
Self-esteem scale	*Before KAT*						*After KAT*					
1. I often wish I were someone else.	5	5	5	*4*	*2*	*3*	*5*	*3*	*4*	*4*	*2*	*4*
4. I am usually happy. +	4	3	4	*3*	*3*	*3*	*4*	*3*	*4*	*3*	*3*	*3*
5. I worry about other people liking me.	4	2	3	*4*	*4*	*2*	*4*	*3*	*4*	*4*	*4*	*3*
6. People think I'm boring.	5	1	5	5	5	5	5	4	5	3	5	5
11. I am proud of my school work.+	4	3	4	3	5	3	3	2	3	4	4	1
12. I am popular with children my own age+	2	3	3	2	4	3	5	1	2	2	4	3
14. I worry about not being as good as other kids.	5	4	3	3	3	3	4	1	4	2	4	2
15. I don't feel that I have anything to be proud of.	5	4	4	4	5	3	3	4	2	3	4	3
19. I feel that I am often successful. +	4	3	3	2	4	3	3	3	3	3	4	3
20. I am never unhappy+	1	4	2	3	4	3	3	4	2	3	2	2
24. I often feel useless.	4	4	3	3	2	3	5	3	4	3	2	3
27. I am a positive person. +	5	3	3	2	3	3	3	3	4	3	3	2
32. There are a lot of things about myself I would change if I could	2	2	4	3	1	1	5	3	5	3	1	1
43. I am never unhappy+	3	3	3	3	3	4	3	3	3	3	2	3
45. My parents expect too much of me.	5	2	4	4	5	4	4	3	3	4	3	5
48. I like most things about myself +	4	4	4	3	3	3	4	3	4	3	3	3
49. No one pays much attention to me	4	1	3	3	5	4	4	3	4	2	3	3
59. I feel like I never get things right	5	3	4	4	4	2	3	4	4	4	3	3
60. My parents are proud of me +	4	5	3	4	5	4	4	5	4	4	5	5
Self-Esteem Sub-Scale Total	75	59	67	62	70	59	74	58	68	60	61	57
Self-Esteem Pre	75	59	67	62	70	59						
Self -Esteem Post	74	58	68	60	61	57						
Social Scale												
3. I don't like to be with people I don't know well.	4	1	5	3	2	3	1	2	4	3	5	2
18. Other people who are my age think I'm odd.	2	2	4	3	5	2	5	2	3	2	5	2
31. I enjoy chatting with people I don't know well. +	2	1	2	2	1	2	4	1	1	2	1	3
34. I am a lot of fun to be with +	4	2	4	1	3	5	5	1	5	3	4	5

Participant	P1	P2	P3	*P4*	*P5*	*P6*	*P1*	*P2*	*P3*	*P4*	*P5*	*P6*
Self-esteem scale	*Before KAT*						*After KAT*					
37. I feel shy with people I don't know well.	2	1	3	3	1	4	3	2	3	2	5	2
Social confidence Total	14	7	18	12	12	16	18	8	16	12	20	14
Social Confidence Pre	14	7	18	12	12	16						
Social Confidence Post	18	8	16	12	20	14						
Behaviour scale												
2. I get upset easily at home.	4	2	3	4	3	2	2	1	3	5	2	2
10. I always do the right thing.+	3	4	3	4	3	3	3	5	3	4	3	3
50. I never get told off at school +	3	5	3	5	1	4	1	3	3	5	3	5
51. I often get rewards/points/merits from the teacher +	2	1	4	2	4	2	3	3	3	2	3	3
54. I never swear. +	3	2	1	3	1	1	3	5	2	2	3	2
55. I sometimes get into trouble for hurting other people.	5	2	4	4	4	2	1	3	4	5	4	2
56. I always do what my parents ask me to do. +	4	4	3	4	3	3	1	4	2	4	3	3
57. My behaviour is good.+	4	4	4	5	4	3	3	4	4	4	3	3
58. I would like my behaviour to be better in school.	5	2	3	5	5	1	1	3	2	4	5	1
Behaviour Sub scale totals	33	26	28	36	28	21	18	31	26	35	29	24
Behaviour Pre	33	26	28	36	28	21						
Behaviour Post	18	31	26	35	29	24						
Anxiety Scale												
7. I am nervous.	2	1	2	3	1	3	2	2	4	3	2	2
8. I follow my mother or father wherever they go	3	1	1	4	1	4	3	2	4	5	4	5
9. people tell me that I look nervous.	5	4	2	5	3	5	5	3	5	4	5	5
13. I worry about sleeping alone.	5	2	3	5	5	5	4	5	2	5	5	4
17. I get scared if I sleep away from home.	5	3	2	5	3	4	5	3	3	5	5	5
22. I worry about going to school.	5	2	3	4	1	3	1	1	2	4	1	1
25. I worry about things working out for me.	3	3	2	3	3	3	3	4	3	3	1	3
26. I find it very hard to talk in front of the class	3	1	1	2	2	2	3	3	3	4	4	4
28. I get really frightened for no reason at all.	2	2	5	5	3	3	4	4	4	4	4	1
30. I am afraid to be alone in the house.	4	4	1	4	3	3	5	5	2	5	1	5
33. People tell me that I worry too much.	3	3	4	3	2	5	5	2	5	4	5	3
35. I can make up my mind without too much trouble +	2	4	4	4	4	1	3	3	2	3	4	2

Participant	P1	P2	P3	*P4*	*P5*	*P6*	*P1*	*P2*	*P3*	*P4*	*P5*	*P6*
Self-esteem scale	*Before KAT*						*After KAT*					
36. I always have to ask people what I should do next.	4	1	3	2	3	3	5	3	3	2	4	3
38. It takes me a long time to get used to anything new	2	1	4	3	3	2	3	3	3	3	4	1
41. I give in very easily.	2	3	3	4	5	2	3	2	4	4	5	3
44. I worry about how well I do things.	3	2	4	3	1	2	3	2	3	2	3	4
47. Things are all mixed up in my life	3	3	3	4	2	1	4	3	4	4	4	1
Anxiety scale totals	56	40	47	63	45	51	61	50	56	64	61	52
Anxiety Pre	56	40	47	63	45	51						
Anxiety Post	61	50	56	64	61	52						
Understanding autism												
16. I understand my diagnosis (Autism/ASC/Aspergers). +	3	2	4	3	5	3	5	4	4	3	5	3
21. I am happy to talk to people about my diagnosis +	4	1	2	3	2	2	5	3	4	1	3	2
23. Having an Aspergers or Autism diagnosis is rubbish	5	3	5	3	4	2	5	5	5	4	3	3
29. I like to be different +	4	3	3	3	2	1	3	3	5	4	3	3
39. I think that having Autism or Aspergers can be a good thing +	4	4	5	3	2	3	5	5	5	3	3	2
40. I often find new things difficult because of my Autism or Aspergers	3	3	3	3	1	1	4	3	3	2	1	2
42. I wishI didn't have an Autism or aspergers diagnosis	5	3	5	4	3	3	5	4	5	3	3	3
46. I understand Autism and Aspergers very well +	3	3	4	2	2	3	5	4	4	3	4	2
52. Having Autism or Aspergers makes me different in a good way +	5	3	4	3	3	3	5	4	5	3	3	2
53. I often wish I was the same as everyone else	5	2	5	3	1	2	4	3	3	3	2	3
Total	41	27	40	30	25	23	46	38	43	29	30	25
Pre understanding autism	41	27	40	30	25	23						
Post understanding autism	46	38	43	29	30	25						
Overall	Se	W	JL	Sh	T	B						
Total Pre	219	159	200	203	180	170						
Total Post	217	185	209	200	201	172						

Appendix 4.3 KAT Focus Group –Responses from children and young people

Interviewer: Did you want to attend the KAT course?
Child 1 Yes
Child 2 Yes
Child 3 Yes

Child 4 (F) Not at first
Child 5 No
Child 6Yes

Interviewer: What do you think you have learnt from coming to the KAT course?
Child 1 ---
Child 2 More about my Aspergers
Child 3 ---
Child 5 How to manage anxiety and how to chat to friends
Child 6 How autism is different from normal life

Interviewer: Please tell us about anything that you feel you are better at because of the KAT course
Child 1 Having more fun, I just feel more ok when playing
Child 2 Controlling my anger and calming myself better
Child 3 Not really
Child 4 (F) No
Child 5 I can keep myself calmer
Child 6 More confident standing up to bullies
Interviewer: Why?
Child 6 They don't bother me now so they go away.

Interviewer: Tell us about any changes **you think we could make** to make the KAT course better**?**
Child 1 Nothing, more games
Child 2 Bit less work, more games
Child 3 What causes ASD. Liked opportunities to talk in a small group
Child 4 (F) More games and more one to one talking. Fun things were good and I got to know the autism outreach team.
Child 5 Yes, more talking
Child 6 More outside play and talking

Interviewer: **What do you feel has been** the most enjoyable **part of the course?**
Child 1 Games, Annie, Julie and Viv
Child 2 Games, Annie, Julie and Viv
Child 3 More scientific information
Child 4 (F) ---
Child 5 Doing the activities
Child 6 The games

Interviewer: What do you feel has been the most helpful **part of the**

course?
Child 1 Learning about Aspergers
Child 2 Yes, I know more about Aspergers now
Child 3 ---
Child 4 (F) ---
Child 5 ---
Child 6 Learning what other people with autism are like
Interviewer: Do you mean the other children who came?
Child 6 The famous people are cool

Interviewer: Please tell us about anything that you don’t like **about the KAT Course?**
Child 1 Aspergers, I still have it
Interviewer: But look at all these amazing things about you in your scrapbook, Aspergers is part of the reason you can do all of those great things
Child 2 Your really cool XXXXXXXX
Child 3 ---
Child 4 (F) ---
Child 5 ---
Child 6 ---

Interviewer: Any other comments or suggestions:
Child 1 I loved everything
Child 2 Learned about Aspergers and how to control my anger. I loved everything too
Child 3 ---
Child 4 (F) Good to know what diagnosis we all have. More about feelings would be good. I laughed a lot. No it was a waste of time, rubbish-only joking.
Child 5 No
Child 6 nothing else

Appendix 4.4 Parent and carer interview schedule and responses:

Interviewer: Thank you for meeting with us today. We'd like to ask your views about the CAT/KAT Training Program including the impact of taking part, benefits, drawbacks and ideas for improvement. Please be reassured that you can answer honestly, no names will be recorded.

Interviewer: The object of the CAT Programme is to help parents, carer's and educators of children newly diagnosed with an autism spectrum disorder to understand the child's difficulties and to provide them with autism friendly strategies for supporting the child. Do you feel that the CAT Programme has achieved these aims?

Parent 1 Yes

Parent 2 Yes

Parent 3Yes

Parent 4 Yes

Parent 5 Yes I feel like I know more

Parent 6 Yes, could see relevance to own child

Parent 7 Yes

Parent 8 Yes

Interviewer: Participants often have their own expectations from attending training. Did you have any other expectations about the programme?

Parent 2 No, so much depth

Parent 1 More 1:1 time

Parent 5 It was as I expected, I learnt a lot and met people experiencing the same issues as we are. Meeting the TA has been invaluable.

Interviewer: If yes, what were they?

Parent 2 I had hoped that staff would attend from XXXX's school

Parent 4 I would like some more information about how to stop XXXX over eating

Interviewer: Were your personal expectations met?

Parent 3 Yes, I met other parents with similar issues

Parent 2 I would have like to have more information about educational rights

If not why do you think they were not met?

Parent 3 I would have like to hear more from people with autism speaking

Interviewer: The object of the KAT Programme is to help young people who have been recently diagnosed with an autism spectrum disorder to

understand their diagnosis, to be positive about their strengths and to provide them with some problem solving strategies. Do you feel that the KAT Programme has achieved these aims?
Parent 6 Yes, it definitely helped XXXX to recognise his strengths
Parent 5 Yes
Parent 7 No, but it was my fault, I missed anxiety session
Parent 1 Yes, XXXX has made new friends, understands ASD better, and the confidence factor has improved

Interviewer: Did you have any other expectations about the KAT programme?
Parent 5 No
Note: Other parents shaking their heads

Interviewer: Were your personal expectations met?
Parent 4 Yes
Parent 2 No, it worked really well for my child
Note: Other participants nodding in agreement.

Interviewer: Do you believe that you have benefited from taking part in the CAT training project, and if so, how?
Parent 2 Yes, more confident dealing with problems, when J is upset
Parent 1 Learnt lots to help son, makes for a happier family
Parent 3 I understand XXXS better and I'm calmer as a result
Parent 7 I feel reassured about when XXXX is older, it can be ok
Parent 5 Explaining about autism to my child, I've learnt a lot and reel better about answering her questions now

Interviewer: Do you believe your child has benefited from taking part in KAT, and if so, how?
Parent 2 Yes, recognising strengths.
Parent 1 Yes, that has been great for XXXXX too
Parent 7 Yes, I agree too, it has made such a difference to us all as a family focussing on that.
Parent 4 Yes
Note: Other participants nodding in agreement.

Interviewer: Do you think that your family as a whole has benefited from the CAT programmes, if so, how?
Parent 1 Yes, we talk things through more, taking autism into account.
Parent 2 I agree

Parent 8 Yes
Parent 5 Yes, it makes understanding now better
Parent 3 My work colleagues have read some of the information, and are more understanding now
Parent 6 Yes, understanding is better
Parent 8 Yes, we found the strategies helpful and are seeing a gradual improvement

Interviewer: Do you think that your family as a whole has benefited from your child taking part in the KAT programmes, if so, how?
Parent 2 Yes, just getting on better, hard to explain
Note: Some other participants nodding in agreement. No more comments.

Interviewer: Can you think of anything that you would have liked the course to cover that has not been included?
Parent 1 Yes, more on educational rights would have been useful
Parent 5 How to handle aggression in meltdown
Parent 8 More one to one time with the team to ask for specific advice

Interviewer: Do you think that any parts of the course should have been left out? Why?
Parent 8 No
Parent 1 Only parts not personally relevant but I know they were useful to others
Parent 2 Yes, I can see why all included but not all relevant to my circumstances
Note: some nodding in agreement

Interviewer: Did you find the course content easy to understand?
Parent 1 Yes
Parent 2 Yes
Parent 3Yes
Parent 7 Yes
Parent 4 Yes, it has been nice using my brain again
Parent 8 Yes

Interviewer: Was the language used easy to understand?
Parent 3Fine
Parent 7 Fine
Parent 8 Yes
Parent 1 Yes, it was fine, you always explained the tricky words
Parent 2 Fine

108. Interviewer: Was technical language always explained sufficiently well?
109. Parent 6 Yes, isn't that the same question
110. Interviewer, yes it is quite similar isn't it. Was everyone else ok with the
111. technical language?
112. Parent 2 Yes
113. Parent 3 Yes
114. Parent 8 Yes
115. Parent 7 Yes
116. Interviewer: Have you found the course booklet useful? Please explain
117. why if you have:
118. Parent 1 Yes, I've used it to re-cap things
119. Parent 8 Yes, I've shared it with the family. His grandma found it really
120. useful.
121. Parent 7 Yes-read all the time
122. Parent 2 Yes
123. Parent 4 Yes
124. Parent 3 Yes
125. Parent 7 Yes
126. Parent 8 Yes-read it all the time

127. Interviewer: Were the session slides clear and easy to understand?
128. If not, please explain the problem and give ideas for improvement:
129. Parent 1 Yes
130. Parent 2 Yes
131. Parent 3 Yes
132. Parent 8 Yes
133. Interviewer: Were the materials for specific strategies in the course booklet useful?
134. How have you used them?
135. Parent 3 Social behaviour maps are being used regularly-they really help
136. Parent 2 Me too
137. Parent 8 ~I'm going to but haven't yet
138. Note: some nodding from others

139. Interviewer: Would you recommend the CAT Course to other Parents and carers?
140. Parent 2 Yes
141. Parent 3 Yes
142. Parent 6 Yes
143. Parent 8 Yes
144. Parent 7 Yes
145. Parent 4 Yes
146. Parent 1 Yes
147. Parent 5 Yes

Interviewer: Would you recommend the KAT Course to other Parents and carers?

Parent 2 Yes

Note: nods from all

Parent 6 I think it is more appropriate for Asperger type kids though. Some children with autism might find it too difficult

Interviewer: Is there anything else that about the courses that you feel it would be useful for us to know?

Some sessions too intense, too much information

Can't think of anything, just want to say thank you. It has made a massive positive impact upon us all

Internet safety not as relevant-kids get it anyway-schools do this anyway

Appendix 4.5 KAT Educator interview schedule and responses:

Interviewer: Thank you for meeting with us today. We'd like to ask your views about the CAT/KAT Training Program including the impact of taking part, benefits, drawbacks and ideas for improvement. Please be reassured that you can answer honestly, no names will be recorded

Interviewer: The object of the CAT Programme is to help parents, carer's and educators of children newly diagnosed with an autism spectrum disorder to understand the child's difficulties and to provide them with autism friendly strategies for supporting the child. Do you feel that the CAT Programme has achieved these aims?
Professional 1 Yes
Professional 2 Yes
Interviewer: Participants often have their own expectations from attending training. Did you have any other expectations about the programme? If yes, what were they?
Professional 1 As expected
Professional 2 To be honest I don't think I really thought about it.

Interviewer: Were your personal expectations met?
Professional 2 Resources useful
Professional 1 Yes

Interviewer: If not why do you think they were not met?
Professional 2 More practical strategies would have been useful, for in school they were too general. There was perhaps too much info.

Interviewer: The object of the KAT Programme is to help young people who have been recently diagnosed with an autism spectrum disorder to understand their diagnosis, to be positive about their strengths and to provide them with some problem solving strategies. Do you feel that the KAT Programme has achieved these aims?
Professional 1 The visuals he made at the sessions have been brought in and used in school. It helped talking to each other, with the parents

Interviewer: Did you have any other expectations about the KAT programme?
Professional 1 Not sure
Professional 2 Yes, I wasn't sure either

Interviewer: Do you believe that you have learn new skills and strategies while taking part in the CAT training project,
Professional 2 Yes
Interviewer: Which have been most useful?
Professional 1 Visual resources provided
Professional 2 Yes, I agree

Interviewer: If the child you support has taken part in KAT training, do you believe they have benefited from taking part, and if so, how?
Professional 1 Helped talking to each other, with the parents. Liaison with parent
Professional 2 XXXXX is more accepting of ASD. Calming strategies used for range of children in school not just children with ASD.
Professional 2 I also found the calming strategies really useful, they have been used for range of children in school not just XXXXX

Interviewer: Do you think that strategies and knowledge acquired from the KAT programme have had a beneficial impact upon the young person's behaviour at school? If so how?
Professional 1 XXXXX's behaviour has improved in school

Interviewer: Can you think of anything that you would have liked the course to cover that has not been included?
Professional 1 No
Professional 2 No-I'm being more flexible, I've tried new things, I'm also sharing ideas with colleagues

Interviewer: Do you think that any parts of the course should have been left out?
Professional 1 No
Professional 2 No
Interviewer: Did you find the course content easy to understand?
Professional 1 Yes
Professional 2 Yes
Interviewer: Was the language used easy to understand?
Professional 1 Not a problem
Professional 2 Yes
Interviewer: Was technical language always explained sufficiently well?
Professional 1 Yes
Professional 2 Yes
Interviewer: Have you found the course booklet useful?
Professional 2 Yes
Professional 1 I've shown it to colleagues at school

Interviewer: Were the session slides clear and easy to understand? If not, please explain the problem and give ideas for improvement:
Professional 1 Yes
Professional 2 Yes, comfortable enough to ask questions. Good to have parents and school, different perspective. Yes, other teachers have asked for advice

Interviewer: Were the materials for specific strategies in the course booklet useful? How have you used them/Do you plan to?
Professional 1 About to use 5 point scale

Interviewer: Would you recommend the CAT Course to other educators who work with children on the autism spectrum?

Professional 2 Yes
Professional 1 Definitely

Interviewer: Would you recommend the KAT Course for other children on the autism spectrum?
Professional 2 Yes, if they were ready to learn about it. It has made such a difference
Professional 1 Definitely again. Yes, for all others. I think it would be good to bring this type of work into school more.

Interviewer: Is there anything else that about the courses that you feel it would be useful for us to know?
Professional 1 I think we have covered everything.
Professional 2 I can’t think of anything else either.
Interviewer: *Thank you for your help, it really makes a difference to helping us to continue to make improvements to the course in the future. We will provide you with a summary of our findings once they are completed.*

Appendix 5 Analysis of documentary and related conference paper

Autism Education Trust video transcription and analysis

Name	Transcript	Themes	Converging Themes and **Broad topics**
Video 1 Aspergers D 12	Hi my names XXXX, at the age of 12 I was diagnosed with Aspergers syndrome as well … I had a lot of problems when I was at secondary school as well because I was in the lowest class, teachers put me down a lot. I didn't have faith in myself that I was going to do well. Basically my mum and dad found me a school, ….this school is in *place name, *school name, I felt great this looks like an amazing school, you know, I've got an open opportunity for myself, you know a fresh start you know. Doing the cbt made me realise you know it makes you think about you know what the situation is you know how bad it is , is it bad, is it good….and…it just made me realise, it made me put things into perspective what I was worrying about you know irrational things. This cbt is a good tool to have cause now I can, I'm thinking straight about things, I'm doing my exercise which is helping me to keep stable ehm and I'm trying to think positively.	Diagnosis Problems at school Feeling less able than peers Feeling put down by others Poor self-efficacy New school following diagnosis Positive about new school Diagnosis provide a fresh start Access to mental health support Confused/uncertain about impact Provides a new perspective on worries Irrational worries Mental health Support valued Exercise-self-help strategies Positive thinking- self help strategy	**Autism traits** • Irrational worries • Difficulties with eye-contact • Communication and literal understanding • Sensory differences hardest to cope with • Terrific memory **Impact** • New school following diagnosis • Positive about new school • Diagnosis provide a fresh start • Confused/uncertain about impact • Provides a new perspective on worries • Accepting support • Improved self-efficacy Making sense of past experiences • Self as different • Improved self-awareness • Access to the right support

Name	Transcript	Themes	Converging Themes and **Broad topics**
	21. I write, I have a diary in fact, em, since year 10	Diary-self-help strategies	• Specialist provision • Self-awareness developed over time • New school with specialist provision • Better understood • Disclosure so college tutor's recognised needs • Diagnosis is a first step • Diagnosis was confusing • Denial for a time • Negatively obsessed by diagnosis • Sought help to understand diagnosis • Diagnosis leads to support **School** • Problems at school • New school following diagnosis • Positive about new school • Aware of specialist provision • Asked for access to specialist provision • School staff didn't understand • Specialist provision
	22. I've been writing a diary, I've been writing		
	23. every day, how my days been and I've been		
	24. writing how, when I've been feeling bad and	Taking control of thinking	
	25. sometimes how I've turned it around which has		
	26. made me think, good feeling I was having cause		
	27. you know cause I've read it out on paper I've	Diary-self-help strategies	
	28. got my feelings out…and…I've..and I can now		
	29. look back and reflect on it and say yeah I've you		
	30. know this day I've really thought I've had a		
	31. really bad morning but I've turned it, I've	Taking control of thinking	
	32. turned it around.		
	33. There's people by your side, that can help, they	Positive support from others	
	34. give you that little lift, that extra nudge and you		
	35. know if you start taking on board things you	Taking control	
	36. know you will be fine, you'll get, you be a	Leads to improved self-efficacy	
	37. success, you'll start to feel happy in yourself,		
	38. you'll start to believe more.		
	39. Basically it's all about evidence. As the weeks		
	40. go by and you start taking on help, you'll start	Positive evidence	
	41. to see that evidence and you start to see the	Accepting support	
	42. changes and them changes will go from ok		
	43. changes to really good changes and that's what		
	44. matters.	Improved self-efficacy	
Video 2 Autism	45. Before I knew I had I didn't actually think I was	Didn't feel different	
	46. any different from anyone else em because at		
	47. my old school there was I don't know if it was	Aware specialist provision	
	48. an actual autism resource base but it seemed		
	49. like it, also one of those attached to the school,		

Name	Transcript	Themes	Converging Themes and **Broad topics**
	which I actually for some reason once asked if I could go to and I went there and sort of fitted in with everyone else em that might have been one of the reasons where they thought em I might have had had autism.	Asked for access to specialist provision Fitting in with peers with autism	• New school with specialist provision • Better understood • Improved self-efficacy Difficulties at school **Post diagnostic support** • Access to mental health support • Mental health Support is beneficial • Mental health Support valued • Positive support from others • Accepting support • Access to the right support • Specialist provision • Involved in planning support • Disclosure so college tutor's recognised needs • Sought help to understand diagnosis • Diagnosis leads to support **Taking control strategies** • Exercise-self-help strategies • Positive thinking- self help strategy
	I understand that now and I understand why I was like that and why I fitted in I know that I am different now, I know why I got angry, why I get angry, I supposed it's something to blame for all my problems.	Making sense of past experiences Understand self as different Improved self-awareness	
	Well I get em, I get the proper help that I need em for work and things cause before I didn't nobody really knew why I was like that and didn't know how to help me so they couldn't really help me cause it was just a mainstream school.	Access to the right support Lack of self awareness before diagnosis School staff didn't understand	
	Not much will change, especially outside of school nothing will really change, like at home nothing will change…… at all really but at school you will go to, probably go to a ,you'll probably go to a hub. To a unit and depending what level like how autistic you are, then, or how bad it is, then you might be like a friend of mine is pretty much independent in mainstream, just is autistic and has a desk and that at the unit and sometimes does 1 or 2 lessons at the unit but does most of his lessons in mainstream.	Things don't change after diagnosis Specialist provision Levels of autism Autism and able/ independent	

Name	Transcript	Themes	Converging Themes and **Broad topics**
	Concentration isn't a problem for all autistic people, I sometimes do have, em, concentration problems and keeping up with the work as well but I do I do get most of what em like in science I get most of what they're talking about and I em understand all the questions em most of them and I can em I do really well in some the classes others I don't. Ah! a lot of the time I take things more serious like ah I take things a bit more literally and like if em not like so literally like if someone said oh it's raining cats and dogs I wouldn't think that it's actually doing that I would em I would know what they meant by that, but some other things like em I would believe I believe a lot more of what people say. If you think you have autism, I would say the easiest thing would not be to run straight to your parents and say I think I have autism em what I do, what not what I've done, what I've think would be a good, what I've heard like what people do with things like medical things is not to go straight to the doctor is to quickly look on the internet em and see if there are any signs and if you think you might be then confront your parents or a doctor em not confront, em like you know talk to your parents or a doctor and see if you are or you aren't.	Compares self to peers with autism Recognises autism differences Concentration impacts learning Recognises strengths and weaknesses Comparison to peers Communication and literal understanding Recognises own communication differences Better to know about autism Advises other to seek diagnosis if they think they have autism	• Diary-self-help strategies • Diary-self-help strategies • Taking control of thinking • Taking control leads to improved self-efficacy • Correct communication aid enabled participation • Taking control-food tolerance • Own research about autism supported acceptance • Taking control-sought help to understand diagnosis • Taking control by focus on autism strengths and tackling weaknesses **Mental wellbeing-before** x3 • Feeling less able than peers • Feeling put down by others • Poor self-efficacy • Irrational worries • Lack of self-awareness before diagnosis • Aware of own anxieties **Mental wellbeing-after** X4 • Aware of own anxieties

Name	Transcript	Themes	Converging Themes and **Broad topics**
	Is there anything else I have on this topic is there anything else I wish to add to this concoction of research, no		- Confused/uncertain about impact - Provides a new perspective on worries - Self-awareness developed over time - Sensory differences hardest to cope with **Autism diagnosis** - Diagnosis provide a fresh start - Diagnosis hard but over time accommodated - Enjoys and accepts diagnosis as part of self - Autism provides opportunities - Autism brilliant brain - Different perspective - Better to know about autism - Proud of different interests - Proud of/accepts diagnosis as part of self - Positive autism role models - Public perceptions - Positive autism identity
Video 3 14 years Aspergers	XXXX's film Hello, my name is …….., peace and love and I live in …… I'm 14 years old and I have high functioning Aspergers. I do sometimes give bad eye sight to people if, no, I mean eye contact. Like, you look at people while you talk. I'm not that bad but I find it a bit hard. My doctor told me just look at the eyes for about 10 seconds, look away for 10 secs more, it's like that he said. Although I've got Aspergers….em it can give you addictive to something. It can make you addictive to something you really like em I'm really addictive into the Beatles… but a load of people say that I am the youngest beetle fan. I'm proud of it. I'm not even 15 yet. I like the Beatles I've got all their CDs even the Beatles rock band and the game inside PS3, even some DVDs, even some posters and pictures on my wall. Lots over there and over there. In the future I do hope that I will be a train driver, I'm working on that for ……. Railway centre. …..I'm going to go after my future hopefully by getting a good em a good, erm	Links self with able autism Difficulties with eye-contact Autism specific advice Autism interests/ enthusiasms Proud of different interests Future ambitions	

Name	Transcript	Themes	Converging Themes and **Broad topics**
	…..reports in school and loads of good qualifications and hopefully enjoy. Go after your dream, it it don't matter, if you've got Aspergers your still equal to everyone. You are born with it and proud of it, like me	Positive Self efficacy Proud of/accepts diagnosis as part of self	- Things don't change after diagnosis - Recognises autism differences - Worried about diagnosis - Own research about autism supported acceptance - Diagnosis is a first step - Diagnosis was confusing - Denial for a time - Negatively obsessed by diagnosis - Diagnosis not negative - Diagnosis leads to brilliant things - Diagnosis leads to support **Relationships with peers** - Compares autistic self to peers - Comparison to peers - Didn't feel different **Before self-efficacy** - Didn't feel different **After self-efficacy** - ~~Improved self-efficacy~~ - Fitting in with peers with autism
Video 4 15 yrs old Autism	**XXXX's film** My name is XXXX, I'm 15 years old and autistic, I use communication aids to speak and I am speaking to you with my super cool iPad. **XXXX's Mum** I'm XXXX's mum and actually XXX had a very early diagnosis she was diagnosed when she was only 3 and she's 15 now and I think things were quite different then. Err I first noticed that she was a different sort of baby from a very young age. I come to the conclusion when that she started nursery that would be when I would really know if she was going to shape up and be like regular kids or whether she was always going to be a bit different. So when she went to nursery, after a couple of months in nursery it was pretty evident that she wasn't going to be like the other kids. She wasn't going to start talking, she wasn't going to play with them, and she was going to prefer the company of adults and all	Communication aid viewed positively Only analysing themes from the young people	

Name	Transcript	Themes	Converging Themes and **Broad topics**
	kinds of other things that she'd show me.		- Recognises strengths and weaknesses - Recognises own communication differences - Future ambitions - Positive Self efficacy - Autism interests/ enthusiasms - Good skills-positive self-efficacy - ~~Improved self-efficacy~~
	XXX I don't remember much about my diagnosis because I was only 3 but I do remember some things. It went on for a long time and at one point I hurt myself on a piece of furniture and the doctor stopped my mum from comforting me because she wanted to see if I would go to my mum because apparently that's what a normal kid would do. I can't remember if I did or not.	Early diagnosis Vivid memory of event from diagnosis	
	XXXX's mum It was quite, quite, tiring erm a lot of the questions. I couldn't work out why she was asking them at the time. An awful lot of questions about family history and health and things like that as well that I couldn't answer, and at the end of it she just said "well I like to call a spade a spade, you're an intelligent woman the child's got autism" and I just thought oh right and I think some people wouldn't like that kind of diagnosis but to me it was a relief.		
	XXXX After I was diagnosed with autism, a lot of meetings took placed and mum always talked to me about what was going on so I grew up with the knowledge of being autistic. We also talked a lot about the sort of things that might be useful and help me live the kind of life I wanted and as	Involved in the diagnostic process Grew up with diagnosis Involved in planning support	

Name	Transcript	Themes	Converging Themes and **Broad topics**
	I was able to type on communication aids by the time I was 4, I was able to take part in meetings myself. **XXXX’s mum** It meant that we could go to the borough, we could get support for her in nursery, so she could have one to one support err we could start looking at communication aids for her because she wasn’t showing signs of speaking err and I saw it as a way of opening doors to money, basically. It meant that there was funding there and we could now access it. **XXXX**When I was diagnosed it didn’t mean much to me but as the years went by I understood more about my autism and learned how to enjoy my differences and how to help myself when I get sensory overload because that’s the hardest thing to cope with. **XXX’s mum** She’s hypersensitive in sound and when she was about 3 she had a hearing test, all that proved was she had hearing that seemed to be fine. It didn’t actually give us any idea of how hypersensitive she was and that caused quite a lot of problems for her and still does. So… that didn’t really become apparent till she was about 6. **XXXX** Autism and me get along quite fine	Correct communication aid enabled participation Self-awareness developed over time Sensory differences hardest to cope with Enjoys and accepts diagnosis as part of self	

Name	Transcript	Themes	Converging Themes and **Broad topics**
	most of the time but because I know myself really well it makes it easier to cope with and enjoy the lovely aspects of autism. I get to do amazing things sometimes and get some opportunities that I might not get otherwise' I also adore having a brilliant autistic brain that seems to give me a different perspective on things and I have a terrific memory and that's really useful for school. **XXXX's mum** The thing to do is to look at how you overcome the barriers and to stay really positive and work through those. Technology is so advanced now, there are so many different types of support, and it is possible to do really well with autism. Make yourself an expert in your own child then you'll know what to ask for. **XXXX** I've recently met some young adults with autism and that was inspiring as they are moving onto work and university degrees. I think the more autistic people stand out in the public eye the better it will be for all us with a diagnosis and we can show we are a force to be reckoned with.	Autism provides opportunities Autism brilliant brain Different perspective Terrific memory Positive autism role models Public perceptions Positive autism identity	
Video 5 Autism	My interests include drawing, I'd show you but its copyright, erm video gaming, erm playing with toys and Lego,	Autism interests/ enthusiasms	

Name	Transcript	Themes	Converging Themes and **Broad topics**
	erm I’m good on the piano and em……also a good comedian. The experience is hard but erm… well in time you get used to it. In particularly the situations easily get scared, very, very nervous when we got caught in a flood, in a ten hour drive. I was travelling to wales at the time, yeah I thought we’d never make it err that night. Don’t freak out. I’m fussy over food, long time ago I used to hate carrot. I’ve got better over the years though erm the past few years I’ve had to erm eat them with potato so they taste better. Recently erm getting used to it and just decide to try and eat the whole thing in one go to get that over with. Believe it or not I hate pizza. The pepperoni, the melted cheese, the tomato ketchup, so yeah I don’t like pizza also. I can also say that there are somethings that erm a erm a erm autistic kid can’t stand were as a mainstream kid can. I’m not too fond of classical music, I’m into video game music………. Were as a mainstreamer are more interested in human you know music from BBC radio2. I keep thinking that life is like a game…yeah…it’s based on points…and….take for example I love. I	Good skills-positive self-efficacy Diagnosis hard but over time accommodated Aware of own anxieties Sensory differences and food Taking control-food tolerance Compares self to peers Different interests Escape into fantasy?	

Name	Transcript	Themes	Converging Themes and **Broad topics**
	like... the right side so much and I hate the left side. When I eat something, I make it eat on this side (he points to right side of mouth) and when I try to step on something which is much larger, I step on with my right foot and smaller stuff with my left. If I don't do stuff that I want to something might come after me, something bad might randomly happen, (interviewer's voice, and do you keep calm). Godzilla, keep calm don't ask their parents immediately (like he said) erm just wait patiently until the answer comes.	Anxiety based behaviours Difficult to interpret-perhaps waiting patiently is keeping calm?	
Video 6 Diagnosed at 10 years Autism	Hey, my name is XXXXX. I want to ….. I'm going to tell you about my experiences and how it… well, helped when I was diagnosed. **XXXXX's mum** I was nearly 40 when I had XXXX and I didn't know much about kids, any sort of kids really. So I assumed that most babies where the same really and I had XXXX and I must admit at the time I never really understood why parents would have more than one. Because he was incredibly challenging really difficult as a baby and then when he was put alongside his peers. I, I, think it was at that point I realised how	Diagnosis has helped	

Name	Transcript	Themes	Converging Themes and **Broad topics**
	very different he was. I happened to take XXXX to a doctor’s appointment that I had got for myself and the district nurse happened to be there and XXXXX as usual was having a meltdown. I was trying desperately to sort of cope and have a conversation with somebody and try and manage XXXX and took him off me and came back into the room and said “ sorry, I didn’t, I didn’t realise your son was autistic” **XXXX** This nurse came up to my mum she, I was waiting in the waiting room for a hospital appointment and a nurse came up to my mum and said “oh is that your son” she said “yes” and um she said “oh um, he looks, he’s a lot like my son, my son’s autistic” and my mums like what, he can’t be autistic. **XXXX’s mum** Within a week we, we got a diagnosis. He was aged 10 **XXXX** Apparently it worries a lot of people when they’re diagnosed it didn’t do that. I, I, was slightly worried, I was slightly you know……….phh what that not me but as soon as read a lot of books on myself well on autistics it all seemed like me . **XXXX’s mum** If I could sort of ………offer any ….I don’t know any ideas or advice to	Vivid memory about diagnosis or a story told? Worried about diagnosis Own research about autism supported acceptance	

Name	Transcript	Themes	Converging Themes and **Broad topics**
	other parents who have just got a specifically a late diagnosis because I think that's where the problems come is when you have a late diagnosis. Erm is not to panic, you know it's erm it's not the end of the world, its actually the start of a new world and a much , much better world because you can have understanding and I have certainly formed a much closer relationship with XXXX than ever I had before much, much more positive. **XXXX** My new school is brilliant, it has a SENCO, erm it has a whole department dedicated to erm special needs, it's just got a lot better erm, erm I'm not getting into any of trouble. I'm top of my classes sometimes erm I'm kind of not very good at maths you know but apparently I'm very 'creative'… erm, you know, in brackets I don't know. **XXXX's mum** There will always be problems there will always be the difficulties that are associated and there will always be prejudice erm there will always be people who frown.	New school with specialist provision Better understood Improved self-efficacy	
Video 7 Aspergers	Hello this is XXXXX talking on behalf of the Autism education trust, with regards to a erm Aspergers diagnosis erm I was diagnosed with a Aspergers	Diagnosed Aspergers	

Name	Transcript	Themes	Converging Themes and **Broad topics**
	syndrome in 2009, in the March of 2009. I went to an Aspergers social group which was in Oxford, I spoke to a specialist in Aspergers and I explained to him my difficulties erm such as at school and in the work place, which I've also done a video about and he gave me a statement of education because I was at college at the time and I gave the statement to the	Difficulties at school	
	appropriate people, persons at the college and that was my recognition and diagnosis of Aspergers.	Disclosure so college tutor's recognised needs	
	The diagnosis is very important, it's what one would term the first port of call, which is the first step to recognition of Aspergers through a diagnosis.	Diagnosis is a first step	
	A diagnosis is a very confusing time… it can be.	Diagnosis was confusing	
	For me personally I did unfortunately go down the route of denial, and I done this for many, many months	Denial for a time	
	erm and I kept going on and on about Aspergers in a very erm sort of obsessive, negative way and this went on for many, many months.	Negatively obsessed by diagnosis	
	And I eventually came out to my parents I said, "I am in denial about this and I'm not accepting this"	Taking control-sought help to understand diagnosis	
	and this is a thing that can happen I assume it's common.	Recognition others have similar experience	
	It's not a negative thing to be diagnosed. It can lead onto so many brilliant things.	Diagnosis not negative	

Name	Transcript	Themes	Converging Themes and **Broad topics**
	If you want to get into a job or if you want to pursue an interest, it’s not necessarily, Aspergers or autism that you feel that you can get the support that is needed then I feel that, that is one of the greatest aspects of the diagnosis. You focus on your strengths, through the diagnosis you will get an idea of what your weaknesses are erm and you can build upon them as much as you can but please just focus on the strengths.	Diagnosis leads to brilliant things Diagnosis leads to support Focus on autism strengths Taking control to tackle weaknesses	

Summary of themes evident within the young people's views shared through the Autism Education Trust (2012) Autism: Receiving and understanding a diagnosis

Autism traits	**Impact**	**School**	**Post diagnostic support**	**Taking control**	**Mental wellbeing**	**Autism Diagnosis**	**Self-efficacy**
Irrational worries Difficulties with eye-contact Communication and literal understanding Sensory differences hardest to cope with Terrific memory	Diagnosis was confusing Denial for a time Negatively obsessed by diagnosis Sought help to understand diagnosis Confused/uncertain about impact Diagnosis is a first step Diagnosis provide a fresh start Provides a new perspective on worries Making sense of past experiences Self as different Improved self-awareness Self-awareness developed over time Better understood Disclosure so college tutor's recognised needs Diagnosis leads to support New school following diagnosis New school with specialist provision Positive about new school Access to the right support Specialist provision Accepting support	Problems at school X2 School staff didn't understand Positive about new school Aware of specialist provision Asked for access to specialist provision Specialist provision New school with specialist provision Better understood Improved self-efficacy	Access to mental health support Mental health Support is beneficial Mental health Support valued Positive support from others Accepting support Access to the right support Specialist provision Involved in planning support Disclosure so college tutor's recognised needs Sought help to understand diagnosis Diagnosis leads to support	Exercise-self-help strategies Positive thinking- self-help strategy Diary-self-help strategies Diary-self-help strategies Taking control of thinking Taking control leads to improved self-efficacy Correct communication aid enabled participation Taking control-food tolerance Own research about autism supported acceptance Taking control-sought help to understand diagnosis Taking control by focus on autism strengths and tackling weaknesses	**Before diagnosis** Feeling less able than peers Feeling put down by others Poor self-efficacy Irrational worries Lack of self-awareness before diagnosis Aware of own anxieties **After diagnosis** Aware of own anxieties Confused/uncertain about impact Provides a new perspective on worries Self-awareness developed over time Sensory differences hardest to cope with	Diagnosis provide a fresh start Diagnosis hard but over time accommodated Enjoys and accepts diagnosis as part of self Autism provides opportunities Autism brilliant brain Different perspective Better to know about autism Proud of different interests Proud of/accepts diagnosis as part of self Positive autism role models Public perceptions Positive autism identity Things don't change after diagnosis Recognises autism differences Worried about diagnosis Own research about autism supported acceptance Diagnosis is a first step Diagnosis was confusing Denial for a time Negatively obsessed by diagnosis Diagnosis not negative Diagnosis leads to brilliant things Diagnosis leads to support	**Before self-efficacy** Didn't feel different Feeling less able than peers Feeling put down by others Low self-efficacy **After self-efficacy** Improved self-efficacy Fitting in with peers with autism Recognises strengths and weaknesses Recognises own communication differences Future ambitions Positive Self efficacy Autism interests/ enthusiasms Good skills-positive self-efficacy Improved self-efficacy

Appendix 5.1 Conference paper

Autism diagnosis and impact: a work in progress

Julie Prentice

Abstract

Background *Although a diagnosis of autism is likely to have psychological ramifications, there is little evidence related to good practice in supporting young people to understand their diagnosis.*
Method *The published accounts of six young people with autism were analysed using narrative analysis.*
Results *A range of both positive and negative themes were identified.*
Conclusion *An autism diagnosis is recognised as beneficial by some young people. However, the influence of a deficit, medical model of disability is also evident when discussing diagnosis. This could negatively impact upon self-esteem. Greater consideration from the perspective of young people about the processes surrounding diagnosis is required.*
Keywords: *autism, concrete, diagnostic disclosure, disability, disability models, interpretative phenomenological analysis, identity, impairment, labelling, realisation*

Introduction

While providing outreach support for young people with autism, the researcher noted that many young people with autism found it difficult to understand and access appropriate information about their diagnosis. Their educators and parents were concerned that if support was not provided appropriately, the process might prove detrimental rather than beneficial to the young person.

Despite the growing array of literature and research evidence relating to many aspects of autism, research undertaken by the National Institute of Clinical Excellence (NICE, 2011) was unable to identify evidence related to good practice in supporting young people to understand their autism diagnosis. Nevertheless, understanding and coming to terms with a diagnosis is likely to have psychological ramifications (Ruberman, 2002). Attwood (2006) identified the four most common reactions to diagnosis as depression, denial and arrogance, escape into the imagination, and imitation of typical peers. A wider range of possible, reactions has been suggested from analysis of personal accounts. These psychological ramifications range from potential improvements in self-esteem (Jones, 2001) through to suicidal feelings (MacLeod and Johnston, 2007).

This paper presents the initial part of a wider piece of research. This very small scale, initial research explored the published accounts of young people who describe how they came to understand their autism diagnosis.

Background

The World Health Organisation's (WHO, 1993) diagnostic criteria is used by the National Health Service (NHS) within the UK; it defines autism as a form of developmental disorder with abnormal functioning in the three areas: reciprocal social interaction; communication; and restricted, stereotyped, repetitive behaviours (WHO, 1993, section 84:0). The autism spectrum (Wing, 1988) incorporates the whole range of autism diagnoses, from people with autism and significant intellectual impairment, through to those with autism and average or above average intellectual ability.

The Autism Education Trust (2012) has highlighted a difference of opinion amongst people with autism about the medical terminology used in relation to autism. Some people with autism value the diagnostic terminology, as it summarises the difficulties that they experience; while others object to terms such as deficit and disorder, as they believe that such terms can be stigmatising, demoralising and cause problems with self-identity and self-esteem. To respect the views of people with autism, this paper follows the approach taken within the National Standards for educators (Autism Education Trust, 2012) by using the terms autism or the autism spectrum, unless discussing the research of others.

Currently, no single biological or medical test exists that can support a speedy diagnosis of autism; diagnosis can therefore be delayed, especially for those with autism and average, or above average intellectual ability, who are frequently not diagnosed until late childhood when their self-identity is already established (Howlin and Asgharian, 1999). Rhodes *et al.* (2008) highlight that following a diagnosis, an individual may have to accept that other people view them as ‘disabled’, while continuing to refuse to accept it as part of their own self-identity. The indistinct biological evidence has led some people to find the very concept of the autism diagnosis as problematic (Armstrong, 2011), and to suggest that an approach that is much wider than provision of information specifically related to understanding the diagnosis is important (Jack 2011; Timimi 2011).

Research by Howlin and Asgharian (1999) found that while the average age at diagnosis was 5.5 years for autism, it was 11 years of age for more able young people with autism. The age of diagnosis is important in identifying the age at which diagnostic disclosure is most likely to happen, as the approach and materials used will need to be appropriate to the developmental level of the individual (NICE, 2011). However, it has been found to be around 9 years of age when the majority of children on the autism spectrum began to demonstrate their desire for a better understanding by beginning to ask questions related to it (Wilkner Svanfeldt *et al*., 2000).

However, research by Huws and Jones (2008) identified that several of their participants experienced a delay between the time when they were diagnosed and when their diagnosis was disclosed to them. The participants who experienced this delayed diagnosis revealed feelings of ‘*shock, disappointment and disbelief*’ and also feelings of marginalisation from the diagnostic process, from their parents, and from the health professionals involved in the process (Huws and Jones, 2008, p. 104). Furthermore, and contrary to the information available from adults with autism, the young people investigated did not suspect that they might be on the autism spectrum prior to disclosure. The participants’ reactions to their diagnosis also varied with some participants feeling that it helped them to make sense of earlier experiences, while others described feelings of anger and the perception that the diagnosis might be used as a discriminatory label.

Whitaker (2006) highlighted a number of difficulties to take into account when discussing a diagnosis with a young person, these include: the 'autistic way of thinking'; the continuing debate about the name of the condition; and the medical model of autism which describes it as a disease, disability or difference. Emotional understanding has also been identified as an area of difficulty for children with autism, for example, displaying fewer facial expressions (Hobson *et al.,* 1998). Such differences in emotional responses could make it difficult to make an accurate interpretation of the emotional impact of diagnostic process for the young person.

Bagatell (2010) highlights that the identities of people with autism are not an underlying element to be exposed, but they are also constructed through interaction in the social world. Thomson (1997) highlights that society's attitudes are passed on through the media and 'codes of literary convention, these codes construct the image of 'the disabled' (p. 9). While the ideology of the norm is also strongly embedded, inability to meet the "normal" standards of health and functioning can have a negative influence (Becker, 1997). Research evidence has been available for some time relating to parental experiences following their child's autism spectrum diagnosis; many parents reporting feelings of relief (Brogan and Knussen, 2003). However, the findings of Huws and Jones (2008), although limited by the small number of participants, has highlighted how young people's views can differ significantly to those of parents, emphasising the importance of seeking their views.

Research about autism diagnosis has tended to focus upon collecting the views of parents, rather than the individuals themselves, due to the practical difficulties in obtaining information from individuals with verbal, cognitive and developmental difficulties (Huws and Jones, 2008). Thus, it could be argued that a medical view of autism, which has focussed upon the impairment, is implicated in the gap in the empirical evidence base (NICE, 2011). Article 23 from the United Nations Convention on the Rights of the Child 1981(United Nations International Children's Emergency Fund, 2012) emphasises that children with disabilities should have the same rights afforded to other groups. Furthermore, Article 12 indicates that children's views should be respected and taken into consideration when making decisions that affect them.

A critical realist approach has been adopted for this research because it accepts that reality exists independently of thoughts, while also recognising that reality is developed and described through language and interpretation within social context. Acknowledging the ‘autistic way of thinking’ (Whitaker, 2006) and putting this at the centre of the research process was considered essential in order to understand the diagnostic experiences through the unique social and cognitive constructs of those young people with autism who have experienced it.

Methods

The most significant consideration in choosing research methods is that they are practically and ethically suited to provision of the most useful information about the concept under consideration (Robson 2002). Therefore, this stage of the research drew evidence from the population whose views it seeks to explore (Huws and Jones, 2008), interrogating the published accounts of young people with autism. Using grounded methods the complexity of experiential data was systematically analysed through rigorous, systematic analysis that enabled interpretation to be developed around the participants’ experiences (Strauss and Corbin, 1998).

Participants

The accounts of six young people with autism who had published their thoughts about the diagnostic processes, either in texts (Armstrong, 2011) or to camera (Autism: Receiving and Understanding a diagnosis, 2012) were explored. The sample included five males and one female.

Data collection and analysis

The published text and DVD material was transcribed into a format that would support the analysis. The transcripts were analysed in detail and significant points, connections and interpretations annotated. The emerging themes and the initial notes were condensed, possible connections identified, clustered together and a master-list of themes produced. To avoid preconceptions the researcher progressively reanalysed and linked codes to enable identification of themes, which were selected by both prevalence and upon the richness of the accounts and how themes connected with the account (Smith, 1999; Corbin and Strauss, 2008).

Results

A number of converging themes relevant to perceptions of autism emerged from the analysis, including difference, deficit and impairment, success and resilience. Although the converging themes were selected on the basis of the richness of the accounts and the insight offered into perceptions of autism, themes are presented below in order of prevalence alongside excerpts from the transcriptions as exemplars of the views in context.

Difference, Deficit and Impairment

As in the research of Huws and Jones (2008), five of the six accounts took the diagnosis to mean that there was something fundamentally 'wrong' with them as a person:

> '*It seems to imply that you can be affected in any and every possible way… It can feel like the most sabotaging and limiting beliefs have been installed and diagnosis has a potentially negative confirmation effect on behaviour and can make things worse…'* (Andrew)

> *And know I'm different now… …* depending on what level, how autistic you are, then, or how bad it is. …'(Brett)

Where the themes impairment, deficit and difference (Attwood, 2006) were most strongly articulated, links to identify, disassociation and emotional turmoil were evident:

> *One of the disadvantages is … that it can cause you to think negatively, so to speak. And eh, and eh, when you have a diagnosis that is one of the worst things you can do, cos all of a sudden you've got all these negative ideas about yourself and that you are never going to achieve anything*. (Jonathan)

Identity Crisis

As indicated in the research of Rhodes *et al.* (2008), several of the accounts revealed anxiety about the impact of the diagnosis upon their identity, their view of self was shaken by the revelation:

> *…you feel that you don't have autism or you don't want to have a diagnosis …* (Robyn)

> *… it can cause you to think negatively, so to speak. And … when you have a diagnosis that is one of the worst things you can do, cos all of a sudden you've got all these negative ideas about yourself and that you are never going to achieve anything.* (Jonathan)

Labelling and Diagnosis

The accounts revealed anxiety similar to that suggested by Becker (1997) viewing the diagnosis of autism as a label that stigmatised:

> *…you don't want to be labelled…* (Robyn)

> uHowever, the diagnosis was also identified as an important factor in enabling appropriate support to be put in place:

> … *Also having a diagnosis is important because it can allow you to get support, so in the future, if you need support, then you'll be able to get it far easier with a diagnosis than without.* (Robyn)

The Diagnostic Catalyst and Support

Diagnosis was highlighted as a catalyst for support by some young people (Huws and Jones, 2008). Some young people found the strategies they were able to access after diagnosis as highly valuable.

> *…the diagnosis put the support in place that I needed to complete the jigsaw,* (Robyn)

> *But it did provide a team of people that almost provided me with a side route to getting that diagnosis…* (Dean)

Inappropriate strategies

Unfortunately, a number of the accounts also described being provided services following their diagnosis that they felt were inappropriate to their needs.

> *…my own experience in the UK was the above meeting which potentially involved years of therapy, tinkering with a myriad of external "symptoms" (AKA individualism) in one to one sessions. This sounded like many painful and time consuming months were to be spent discussing issues I didn't even think existed or I could attend AA like groups with other people who were probably equally confused and in many cases dislike group social experiences.* (Andrew)

The Concrete and Evidence

While some accounts revealed frustration that the diagnosis had been explained in a vague way that did not support their understanding. The frustration and negative result of intangible information appeared to link to disassociation in some accounts.

> *I didn't even know what ASD was and all I got told was a vague, unclear and ill-defined restatement of the symptoms because there is no disease, as such, of autism. All of this can make someone highly confused from being told of Aspergers without adequate information about what it really is.* (Andrew)

However, where support had been perceived to provide concrete evidence, a more positive discourse was evident:

> *Well, I understand it now and understand why I was like that and why I fitted in. And know I'm different now, I know why I got angry, why I get angry, I suppose it is something to blame for all my problems. Well, I get, I get, the proper help that I need for work and things.* (Brett)

Skills, Success and Resilience

The most positive aspects of the accounts revealed evidence associated with resilience, achievement and positive involvement in activities that are respected:

> *Being autistic simply means that your brain is physically different, it means that you think in a different way to other people, and that can be very useful for whatever your special interest.* (Robyn)

> *I'm twenty-four; I have Asperger's syndrome and work as a specialist trainer teaching people about Asperger's syndrome. Also mentor people on the autism*

> *spectrum, do non-clinical consultancy and I’m also an artist and a musician.* (Robyn)

Conclusion

This study aimed to analyse existing evidence from the literature in order to provide useful starting points for a forthcoming mixed methods research project incorporating both narrative research and online surveys. The analysis revealed a number of themes, as what on first consideration appeared to be positive explanations by confident young people with autism, revealed underlying elements that reflected negative influences from what might be considered to be a medical view of disability (Morris, 1996; Oliver, 1996; Thomas, 1996). The analysis highlighted the influence of the medically focussed language used to describe autism and its related features (Whitaker, 2006). Negatively phrased language was used within some of the young people’s narratives, which suggested that their views of themselves were shaken by the diagnostic revelation (Thomson, 1997), which could reveal problematic influences upon their self-esteem. However, the narratives also revealed positive experiences and outcomes that could influence greater resilience, these positive features included a focus upon their own abilities and achievements and involvement in activities that are respected by others.

Greater consideration from the perspective of young people with autism, into the processes surrounding diagnosis, is required in order to understand factors that influence their views upon their diagnosis both negatively and positively (NICE, 2011). Such information could be used to inform the processes and support offered during the diagnostic procedures, in order to maximise the positive aspects and to minimise the negative in order to improve outcomes.

Outcome

Findings from this research have informed development of a survey and semi-structured interview, which will be used to collect views from a greater number of young people with autism to inform identification of successful approaches to diagnosis and related processes.

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Appendix 6 Focus group procedures and findings

Appendix 6.1 Letter to headteacher

Understanding My Autism Diagnosis

A Research Study

An Invitation for Children to Take Part

Dear Head Teacher,

I am currently employed as a Senior Lecturer for the Childhood Studies Department at [redacted] University and I am undertaking a research-based PhD qualification at the University of Birmingham. My research aims to explore children's and young people's views about how they were informed about their autism diagnosis and how they have been supported to understand it. I write to ask you to consider allowing children at your school to take part.

The Guideline Development Group (GDG) for the National Institute of Clinical Excellence (NICE) has identified evidence of both immediate and longer term benefits from the provision of 'accurate, appropriate and sympathetic information' for young people following an autism diagnosis (NICE, 2011, p. 184). They also identified evidence that highlights the importance of the information being tailored to the specific developmental needs of the individual. However, a gap in the evidence base, relating to young people's views upon how they are supported to understand their diagnosis, was also identified.

The aim of this study is to explore the views and experiences of young people with autism, related to how they were told about an autism diagnosis and how they have been supported to understand it. It is anticipated that understanding the views of young people will support the identification of useful starting points for those who are charged with the responsibility of helping young people on the autism spectrum to understand their diagnosis.

The first phase of the study will seek to ensure that the research materials are appropriate for young people with autism and request that you consider allowing children within your provision to take part in a focus group for this purpose. If you feel it is appropriate for the children within your school to take part, I would be grateful if you would consider providing their parents with information about the research so they can decide whether they would like their child to take part. The information for parents includes separate information for the children, so that parents can help their child to make the decision about whether to participate. I have provided a copy of the information and consent forms for parents and children with this letter for your information.

This research has been fully considered and agreed by the University of Birmingham, ethics committee. Appropriate protections have been taken to enable young people to take part safely. Research reports will not identify individuals who take part.

In addition to my academic qualifications (M.Ed. Children with Autism), I have over ten years of experience of working closely with children and young people with autism, including six years of experience working for a local authority as a specialist teacher for children and young people with autism. In undertaking this latter role, I regularly undertook one to one interviews with children and young people with autism for assessment purposes, initiated therapeutic approaches to support the development of their emotional understanding, and provided specialist support in both one to one and group situations to help them to understand their diagnosis. I hope that you feel confident that I have the appropriate experience to ensure this is a positive experience for the young people who take part.

In addition to seeking publication of the research to disseminate findings to professionals; I will provide seminars to feed back the research findings to the groups who took part in the research project. The seminars will dissemination information about the appropriate approaches to support understanding of autism directly to the parents of young people who contributed. In addition to the parent/guardian seminars, I will also offer appropriately accessible presentations for the young people who took part.

Thank you for taking the time to consider this request. Please do not hesitate to contact me, if you require any further information (Contact details). My research supervisor is Dr K. Wittemeyer, she can be contacted at the University of Birmingham (Contact details).

Yours sincerely

Julie Prentice

(Contact details).

<u>Reference and link to the NICE guidance, for your information:</u>

National Institute for Health and Clinical Excellence (NICE) (2011) **Autism: recognition, referral and diagnosis of children and young people on the autism spectrum: NICE Clinical Guideline** [Online]. London: National Collaborating Centre for Women's and Children's Health. Available:
http://www.nice.org.uk/nicemedia/live/13572/56424/56424.pdf

Appendix 6.2 Focus group research information for CYP and parents

Parent research information and consent for the focus group pilot study

Understanding My Autism Diagnosis-A Research Study

Information for parents

Dear Parent/Carer,

I am currently employed as a Senior Lecturer for the Childhood Studies Department at [redacted] University and I am undertaking a research based PhD qualification at the University of Birmingham. My research aims to explore young people's views about how they were informed about their autism diagnosis and how they have been supported to understand it.

The National Institute of Clinical Excellence's (2011) has identified a gap in the evidence base, relating to young people's views upon how they are supported to understand their diagnosis. It is anticipated that understanding the views of young people will support the identification of strategies, which those helping young people understand their diagnosis can employ. In this first stage of the research, I am asking children with autism to look at and discuss a research questionnaire, in small groups, and to tell me what they think about questions. I will use the children's ideas to make improvements to the questionnaire.

This invitation to take part in the research has been sent to you, as a parent or guardian of a child with autism, so that you can consider whether it is appropriate to ask your child whether he/she want to take part. In order to take part, it is essential that your child already knows that they have an autism diagnosis. If you child does not already know about their diagnosis, **please do not feel that you should inform them so that they can take part in this research**.

It is very important that parents tell their child about their diagnosis when they feel the time is right. This is often when the child becomes aware of differences from peers and starts to ask questions. However, the right time will vary from child to child, some parents tell their children about their diagnosis when they are quite young (primary school age), other parents choose to wait until their child is older because they feel they will understand the diagnosis better. I have included some links to sources of helpful information about autism diagnosis and telling a child about their diagnosis. If your child does not know about their diagnosis, you might find the information useful when you feel the time is right to tell them.

I have full clearance for working with young people. This information has been checked by the university and it will also be checked by your child's school. In addition to my academic qualification, Master of Education (Children with Autism) and teaching experience, I have over ten years of experience of working with children and young people with autism, including six years of experience as a specialist teacher for children and young people with autism. In undertaking this latter role, I regularly undertook one to one interviews with children and young people with autism for assessment purposes, initiated therapeutic approaches to support the development of their emotional understanding, and provided specialist support in both one to one and group situations to help them to understand their diagnosis. I hope that you will be reassured that my experience will ensure that taking part is a positive experience for your child.

During the group activity in school, children will have the opportunity to test the questionnaire and discuss it. I will use visual information to support children's thinking and discussion. As the children discuss the questionnaire, in addition to making written notes, I will make an audio recording of the session in order to ensure that I do not miss any important contributions. This information will be transcribed into a written text to support my analysis.

I will provide you with information about the next phase of the research in case you and your child also wish to take part in the main survey. After completion of the main phase of research, I will actively seek opportunities to publish it in order to make it available to people who care for, educate and support children and young people with autism. However, no information that could be used to identify the people who take part will be included within the research write up. Following completion of the research, interview data must be preserved for ten years and accessible to my supervisor and for academic audit. However, it will be stored safely in a secure area. This is guaranteed within the ethics code of the University and the Data Protection Act of 1998. While information collected for the research will be kept confidential, in line with safeguarding requirements, any disclosures of harm will be discussed with the appropriate safeguarding professionals.

Thank you for taking the time to consider this request. Please complete the attached consent forms and return them to your child's teacher, if you are happy for your child to take part. You are very welcome to contact me if you require any further information (Contact details). My research supervisor is Dr K. Wittemeyer, she can be contacted at the University of Birmingham (Contact details).

Yours sincerely

Julie Prentice
(Contact details)

Note: The NICE (2011) report can be accessed at the following link:

- http://www.nice.org.uk/nicemedia/live/13572/56424/56424.pdf

A useful source of information about autism and telling a child about their diagnosis is available from the National Autistic Society at the following link:

- http://www.autism.org.uk/about-autism/all-about-diagnosis/diagnosis-the-process-for-children/after-diagnosis.aspx

Information and support for parents after diagnosis is available at the following links:

- http://www.nhs.uk/Livewell/Autism/Pages/Thediagnosisofautism.aspx
- http://www.youngminds.org.uk/for_parents/worried_about_your_child/living_autism?gclid=CJ6soN_6xLMCFW_KtAod6CcArQ
- http://www.mencap.org.uk/all-about-learning-disability/information-parents-carers-and-familyhttp://www.mencap.org.uk/all-about-learning-disability/information-parents-carers-and-family

Understanding My Autism Diagnosis-A Research Study

Parental Consent

Would you like to take in the research? Yes ☐or No☐

Please print your name: ____

What is your relationship to the child: ___________________________

Child's name:

____

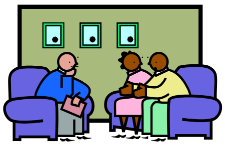
Please sign your name below **<u>if you consent to your child taking part</u>**

Signed:

____

Date: ___________________________

Child and young person research information and consent for the focus group pilot study



Understanding My Autism Diagnosis

A Research Study-Interview Information and Consent

I am doing some research to try to find out what young people think about how they found out about their autism. I would like to invite you to take part in my research.

I am asking a group of children from your school to try out my research questionnaire and discuss it with some other children from your school. When you discuss it, I will ask you to think about whether you found it easy or hard to complete, if you think I need to change anything and whether you have any other ideas about things I should include.

As you might have lots to tell me, I will make some written notes and record the words you say on a digital voice recorder. I use a voice recorder as it can be difficult to write down everything that is said. I will use the information that you and the other young people tell me to make the questionnaire better. The improved questionnaire will then be made available for children to complete through a website.

I will be writing a report about the findings from this research and hope the report will be published in a research magazine. This will help other people who work with young people with autism. When I write my report, I might include some of the things you tell me, but I will not use your name so people will not know that the information came from you.

You do not have to take part if you don't want to. If you decide to take part, the written information with your name on it will only be seen by my university tutor and me. When I am not using the information it will be locked away. I will have to keep the information in a safe place for 10 years. This is in case the information could be useful to other researchers; if other researchers do wish to look at the information, they will also have to follow the rules above.

If you would like to take part, please complete the form on the next page.

Thank you

Julie Prentice

Understanding My Autism Diagnosis-A Research Study

Young Person Assent

Would you like to take in the research? Yes ☐

or No ☐

Please sign your name below **<u>if you would like to take part</u>**.

Young person's signature for agreement to take part in the research:

____

Parent/Guardian, please sign on the line below if you give consent for your child to take part:

____

Date:_________________________

NOTE: All images from http://office.microsoft.com/en-us/images/

Appendix 6.3 Focus group schedule

Pre-focus group- research information and consent

I am doing some research to try to find out what young people think about how they found out about their autism.

I understand that you and your parents have agreed you would like to take part in my research.

I will ask you to try out my research questionnaire and we will then discuss it. I would like to know whether you found it easy or hard to complete, if you think I need to change anything and whether you have any other ideas about things I should include.

As you might have lots to tell me, I will make some written notes and record the words you say on a digital voice recorder.

I will make notes on this sheet so you can see if I have understood you correctly. (Show the visual prompt)

I use a voice recorder as it can be difficult to write down everything that is said. I will use the information that you and the other young people tell me to make the questionnaire better. The improved questionnaire will then be made available for children to complete through a website.

I will be writing a report about the findings from this research and hope the report will be published in a research magazine. This will help other people who work with young people with autism. When I write my report, I might include some of the things you tell me, but I will not use your name so people will not know that the information came from you.

You do not have to take part if you do not want to. It is fine to change your mind.

If you decide to take part, the written information with your name on it will only be seen by my university tutor and me. When I am not using the information, it will be locked away. I will have to keep the information in a safe place for 10 years.

This is in case the information could be useful to other researchers; if other researchers do wish to look at the information, they will also have to follow the rules above.

Would anyone like to change their mind about taking part?

I would like you to complete the first section of the questionnaire with information about yourself, first.

You will also make your own secret identification code for the research. This helps to keep your information anonymous.

We will then have a chat about that section.

We will do the same for each of the sections of the survey questionnaire.

In each of the next sections, you have to rate some statements using this scale- (identify the scale)

Were the statements easy to understand?

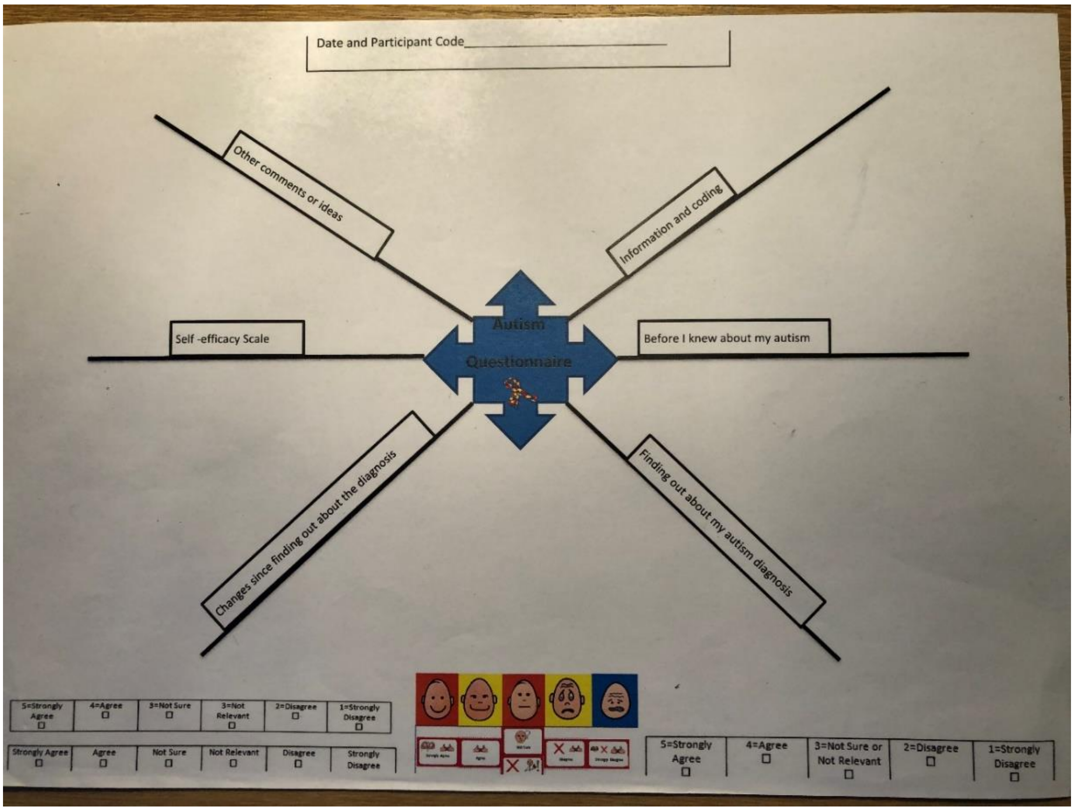
Did anyone think any statements would be easier to understand if worded differently.

After each section ask:

Was the information easy to understand?

Did you understand how to make the code?

Appendix 6.4 Focus group visual prompts and recording sheet



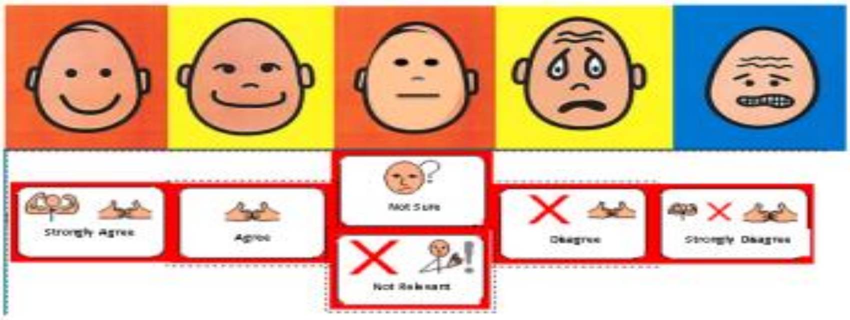
The above prompt was used for recording discussion points visually for young people. My notes on the above visual prompt were shared with them to check I had understood them correctly. Other visual prompts created for both interviews and focus groups are below. However, school staff advised they were not needed for the able students who attended the focus groups:

Prompts list 1:

Feeling	**School-subjects**	**Relationships**
		Teachers
Confident	English	Friends/Classmates
Worried	Maths	Mother
Calm	History	(Mum; Mom; Mam)
Normal	Georgraphy	Father
Anxious	Science	(Dad; Pop; Daddy)
Happy	Art	Brother
Different	Design Technology	Sister
Sad	Physical Education	Granddad
Fine	Languages-French;	Grandmother
Confused	German; Spanish	Aunty
Good		Uncle
		Cousins

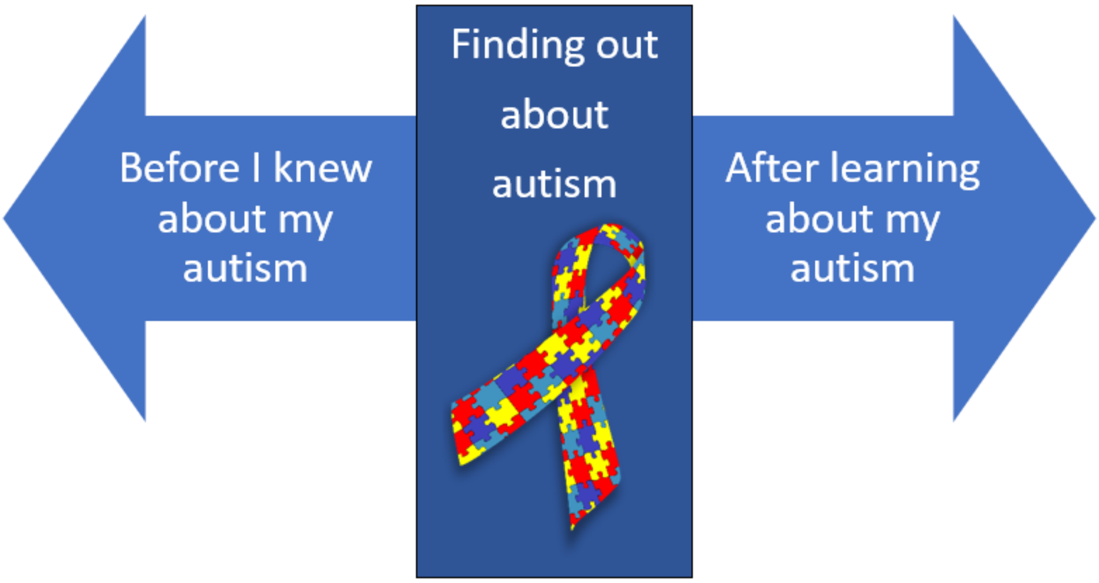
Interests/activities	**Interests/activities**	**Other**
Groups: guides; scouts; cubs; youth clubs Sports: swimming; football; running; team games; gymnastics; dancing Art: paining; drawing; sculpture; Music Movies	Cooking Crafts IT/Computer Social media Gaming	Future Career Home Academic achievements Friends Romantic relationships

Sorting statements for participants needing greater support with communication. The visual scale options below created to use with the visual prompts above:



Close up of the visual scale from the prompt above. This was also designed to use with the Talking Mat prompts if they had been used during the interviews with young people.

Visual prompt for the points of discussion in relation to autism:



Appendix 6.5 Focus group transcript

Focus group transcript 1

Q. So this is the questionnaire, it just starts of by telling people what the research is about. So this will be for people doing it on line and what will happen is that the online survey…, Have you ever done an online survey?

H. Shakes head.

Q. So, what it does,

H. Survey Monkey?.

Q. Yes, like that. You get a different page and you click next, rather than being on paper it will be on screen and the first thing you get is this page, on screen, with the information and the boxes to tick if they still want to take part. And then on this bit here, what I have done to enable people to take part anonymously is to make their own code for the questionnaire rather than giving their name. So shall I read through or would you like to read the information about the questionnaire and code.

H. Err, I'm ok, I don't mind.

Q. Ok I'll let you read it, if there is anything tricky or anything that you do not understand, let me know and I'll write down your ideas so I can make it easier for others.

H. Looks up to indicate he has finished reading.

Q. So you can do it as if you are really doing the questionnaire and that will make it easier To comment on. So the first one, if you want to take part, then if your parents agree. And I know everyone's, your parents have already sent the agreement back, so you will be able to tick those ones won't you? Right do you understand that, what you have to do to make your own code?

H. so for me it will be (completes the code without hesitation)

Q. So you didn't feel that was too complicated?

H. No, I just did whatever, I was going to do 16 but that is my birthday but I realised.

Q, Right, ok you just had to think about it. And it is just straight forward on that one. Ok, so from that first page, what do you think? Is it complex or will people of your age understand it?........ Was it too complicated, will they be put off by anything?

H. Well I was put off by 'it' (a typing error on the first page).

Q. You know, as you were reading it, I thought there is a random 'it' there, a proof reading error, it would annoy people wouldn't it, so what I do is I'll have to check very carefully for things like that. I'll just write that down so I don't forget it was an in/it wasn't it. Other than that, was it simple enough?

H. nods head in agreement.

Q. and do you think you understood that bit about what the research was about? That bit at the top where it tells you what the research was about.

H. um hum. (nods head) then shakes it. Looks at the sheet next to him with the focus group aims on it.

Q. Well it might be confusing today, as your helping me with the questionnaire. But the main research is different, it will be about finding out about what young people think about their autism, whereas today, we will do that as well, but one of the main aims is to find out what you think about the questionnaire. So it is slightly different in that way isn't it. Do you want to read it again or have you done?

H. That solved it.

Q. Phew that's good. So you didn't have any questions about it now?

H. shakes head

Q. Now the main bit, not everyone will be able to do all of the sections as it will depend when they found out. Some people find out about their autism really early on and some people much later. So people who find out about their autism really early on sometimes do not remember. They just feel they have known all their lives. Whereas some people find out slightly later and so they can remember before the diagnosis. Can you remember before you were diagnosed?

H. I don’t know when I was diagnosed.

Q. That is not unusual, can you remember when you found out? Was it before this school?

H. eee…

Q. how long have you been at this school?

H. 4.5 years

Q. did you know before you came here?

H. Yes.

Q. Well it might have been when you were at primary school.

H. I can’t remember what year but I do know it happened at that school. Well, you know they did a lot.

Q. Thinking about that point in primary school, as that seems to be when you found out. Perhaps you can answer the questions with that in mind. It sounds like it might have been just before you came here from what you said. So there is a scale, on the computer you will just click on it, on this copy just tick the box. The scale goes from strongly agree to strongly disagree. Now in the middle, if you are not sure, or you do not think it is relevant for you, you can tick that one. Does that make sense?

H. It needs two boxes for not sure and not relevant- it would be better set out like this as two boxes. Cos not sure is you don’t know, and not relevant is like………

Q. Yes, not apply to you. Do you think it would be better as two?

H. I’d rather have that one, the one with the two boxes.

Q. right, do you think the numbers matter? Would it matter if there were two number 3s or would it be better to take the numbers away?

H. It doesn’t matter.

Q. but definitely the boxes-(showing the possible versions). Shall I let you go through that section and answer the questions, up to there (pointing), and let me know if there is anything you don’t understand. I’ll just let you read them.

H. What do you mean by that, I was very confident about myself and my ability?

Q. So all of these questions are about before the diagnosis so if you think about that period at primary school.

H. I didn’t read that heading bit.

Q so maybe I need to put colour in that box it might highlight it to them? Yellow or something?

H. maybe bigger text so they see it. Otherwise it just blends in.

Q. Yeh, good idea. This is why it is so important to go through as all the little issues come up. So just give it a go. Oh, there was this bit, so how did you feel about yourself, you know how good you were at things and your ability when you were at primary school in those early days before people understood that you were on the autism spectrum. So how confident were you.

H. so confident about interacting with other people?

Q. yes, well it is about yourself, confident with other people and your ability. So do I need those as two questions? Do I need to ask people about their confidence then their ability?

H. Yes ability. Their confidence at interacting with other people.

Q. What do you think? Do I need those as two separate questions? I think that is what you are saying to me-is it?

H. I feel confident about myself with other people is there as well.

Q. So if we just had about my ability, would that make sense there? If it was like that?

H Well my ability in lessons makes more sense.

Q. Right, if we had ability in lessons, I’ll just write it on here.

H. I didn’t know anything at all about autism

Q. That is fine. Do you think you were good at your lessons?

H. That is what I'm trying to figure out? …. I know I was good at maths, as I am now. English, maths ok. History, Geography, I didn't do any language. So I'm going to say agree

Q. Ok, that is good. …. So were you worrier at that time?

H. Hmm difficult, an e.g. here…

Q. some examples?

H. Yes,

Q. So it could be things like friendships….. It could be things like timetable changes…

H. I don't think people would change the timetable, it seems unlikely…

Q. OK, so if I give some examples, if I put things like friendships, different staff maybe, changing staff maybe that might be more appropriate… changing staff?

H. Nods…………. By average do you pretty much mean all of this together?

Q. Yeeh… because for some people they might have ticked that everything was fine all of the way through so it just confirming really that everything was fine. So, if looking back you felt that you were generally quite happy, so there were not worries of things like that…

H. Technically 6 & 7 are the same I never worried about anything and everything was fine …

Q. Yes, well that is because in questionnaires you sometimes have to do that because you have to do that in questionnaire, you have to do the same question in different ways-just in case somebody misunderstands one questions so you can misunderstand the other. Don't worry if you see any overlap, there is usually overlap, asking about similar things. …… Ok that is great, is there anything else in that section or did the rest seem straight forward-once you got into the swing of it?

H. it seemed straight forward.

Q. That's good, and then the next bit is about finding out about the diagnosis. Some people remember it quite distinctly and some people, depending on the age-some people are quite young so they don't remember it very well and if they did see any specialists they don't know what is was for. It just depends when you found out. So the next bit is about how you found out about your diagnosis, for some people that is from parents, from some people that is doctors when they were going through the assessment. There are various different ways that people find out. So some of it might not be relevant to you again, some of it you might think yes I remember things like that and then again just let me know whether you agree with what the statement says or not. From strongly agree to strongly disagree.

Q. Can you remember a meeting with the doctors or specialists or anything?

H. Specialists, some of them…

Q. did any of them give you any information?

H. I can't remember that. They probably gave my parents a lot.

Q. Well, yes, but this is about you-the questionnaire is about young people. So if you don't think they gave you information, you would be going towards the disagree-or at least not strongly agree.

H. They probably did give me information because they would probably have to…

Q. Possibly but it didn't feel so important to you at the time…

H. Or perhaps I was doing other things at the time. And as your brain is young and it is just developing, perhaps you just don't remember everything.

Q. Yes, that is right, the older you get, the less you remember about longer ago. So don't worry if you cannot remember, you are not sure, you have always got that one to tick.

Q. Did your parents talk to you about it, tell you about it?

H. I never really asked any questions so no one told me. I’m sure my parents would have told me after we went to the doctors-gave me information.

q. After the diagnosis-ok.

H. that question makes no sense…

Q. Go on then.

H. It was a real surprise to me, I didn’t realise anyone thought I had autism.

Q. Some people it comes as a real surprise as they did not know anything about autism or that anyone thought they had it. But if that is not relevant to you…

H. So technically, all of these questions relate to that (pointing to the section header)

Q Yes, so again if we highlight that..

H. Well, yes, pretty much all of the questions really…

H. It was not really difficult for me just long process of going to doctors and consultants.

Q. Well, so not difficult just long…

H. Well, it might be different for different people. So you should make that 2 questions really…

Q. What number is that one?

H. 22

Q. 22, so it is 2 questions you feel?

H. Yes cos if it was a long process, but you might find it easy you couldn’t really answer it.

Q. Yes, that is good. So still thinking about finding out about the diagnosis-all of these still relate to that.… So on the computer these will all come up on one page…

H. I think at the beginning you should have some different questions: I found out when I was young or I found out when I was older, because this question if you were young you wouldn’t be able to look into it would you-24?

Q. So you are suggesting putting that at the beginning are you.

H. Yes, perhaps 2 questions about age group.

Q. Yes, so that is really useful, it is all of these type of things that are really helpful ideas.

H. Maybe understand autism-perhaps understand autism

Q. Do you know whether your diagnosis is autism or Aspergers?

H. I’m not really sure, don’t know.

Q. That is fine, to be honest many people think there is not much difference. It is just some specialists prefer to use the term autism and some prefer the term Aspergers.

H. I know some facts now-as I did a PowerPoint on it last year.

Q. Did you; did you do it for the younger ones, or for people in other bits of the school?

H. I mainly did about autism.

Q. Right so you did it specifically about you.... Did you enjoy doing that?

H. That question doesn’t have any boxes.

Q Right, I’ve missed them out

H. Right that is a new section.

Q. Yes, it needs to be bigger and in bold doesn’t it? It is about afterwards-after finding out.

H. I think you should get rid of the numbers and make new boxes to agree and disagree so there are some things good about and some things bad.

Q. Right, so which one? Is it just this one or do you mean generally?

H. Well there are some of them that are negative and some that I’m positive. So I could just tick that one.

Q. So it is 44 isn't it?

H. Maybe you could do it for all of them ones….Then everyone could just tick that box and some that are good and some that are bad.

Q. So, if I just – let me look at that question...so you think it needs splitting into two questions.

H. Or you could just have agree/disagree on all of them and that would do.

Q. Ok right.

H. I'm on to this bit.

Q Ok this bit is different, it is a scale for, I'm wondering whether to have this word included, self –efficacy. What self-efficacy means is how good you feel you are at something…so hopefully that-the scale- helps you to explain how good you feel you are at the things in the following statements.

H. I can read but I don't like it…

Q. Mmmmmmmmm but this is not about whether you like it but how good you think you are. But I can see what you are saying.

H. Writing, what do you mean by writing?

Q. Hmmm, just the process of writing. Some people feel quite confident when writing,

H. Just things you have to write down.

Q. Yes, anything that involves writing things down. Do you think, my handwriting's terrible. Or my arm aches, or do you just write and you do it without it bothering you at all?

H. I guess by computing you mean in the ICT suite and that, in school?

Q. Yes, just generally anything to do with computing do you feel quite confident in.

H. Well, I can play games on them, that's the main thing. I can't make any games myself. You should do, how good do you think you are at the following in school. That would make more sense.

Q. So if I have two questions here. ??????????????

H. So concentrating, you mean doing work and em.. yeh…

Q. Yes, just being able to concentrate on things you are doing for your work.

Q. is that one difficult?

H. Well, I do not do cricket, so I just crossed it out.

H. I think there should be a button so you can cross certain things out.

Q. Right.

H. Emmm, if it like one of these… so you can cross off sports that you do not do well in. I do basketball but don't do cricket.

Q. So do you think if I just said taking part in team sports without giving the examples. Would that be better?

H. Or just, allowing people to cross out certain things, certain words or something. Then they'll be set to what you think.

Q. Ok

H. Making friends. I've got them on x box not so much in real life.

Q. That is a good idea, putting a question about gaming and friends online.

Q. One more page-you seem as though you are whizzing through this bit is this easier.

H. Yeh, its easier….. There should be a box saying not relevant…

Q. Do you think some of these are not relevant?

H. Yes, in case you do not do it so I can't really tick anywhere.

Q. have you added something I've missed out there- not sure. So there should be a not relevant and not sure.'

Q. So thank you for doing that. You have given me lots of ideas there. Is there anything else I’ve not asked about, anything that comes to mind.

H. The gaming one, mainly cause a lot of people game.

Q. Yes, gaming, I’ve written that one down. Let’s check what I’ve written down:
Asking the question at the beginning about the age at diagnosis
The proofreading thing about the extra it.
The titles and font sizes, and that is for all of them isn’t it.
Changing the phrasing for number 2 to make it clear we are talking about lessons, ability in lessons for that one.
Examples for number 3: types of worries, changes to staff.
You mentioned, parents telling you after doctors so it might be useful to have something at the beginning about that.
Question 22, you thought would be better as two questions. As there were two concepts-it wasn’t difficult but a long process.
Then there were some boxes missing.
Number 44, you felt it would be better to have just disagree/agree

H. Well for all of them you could have just an agree/disagree box

Q. so did you feel that you didn’t want to go strongly either way?

H. Yes. Not sure, where you feel like you agree/disagree at the same time. An agree/disagree box for all.

Q. Yes. ……box for all. ….. When we looked at the scale-that one for reading you felt comfortable saying you were good at it but perhaps something about whether perhaps people like doing it or enjoy it? And maybe the computers, having a question about formal use of the computer at school and something about your own time-gaming and that type of thing.

H. Yes, so its own section/question.

Q. And maybe ad opportunity to be specific about the sports maybe to cross out or actively select specific sports. And maybe add something about the online friendships.

H. Yes in the gaming section. Yes, in the gaming section cause that is where they get them.

Q. And you feel you need the not sure boxes in that section would help. Ok. That is great. You found it ok to do the code didn’t you, you didn’t have any problem with that? That is really useful. Oh, one of the other things I was going to ask-someone suggested, putting more pictorial things on the scale, but I was worried that it was going to be for people of your age and possibly younger people from about Y7 upwards. Do you feel that would be too young if you have a visual scale with it?

H. I’m not really sure.

Q. You seem to feel confident about your diagnosis having done a presentation about it. Is there anything, after talking about it today that you feel you would like to know more about? Do you feel you know as much as you need to know?

H. Well I could find out more but…

Q. Ahh, so if you did want to find out more, would you go to the internet and look it up?

H. Yes, as it is quicker than looking through a book.

Q. So have you ever done that, did you do it for your talk or was it something you just look up out of interest?

H. Me, I just did it for my talk. I don’t often do it.

Q. That is a good idea that, it might be a really useful way to sort of help people to explore it themselves, actually finding out about their diagnosis to tell other people about it. Did you enjoy doing it?

H. The questionnaire. Not really.

Q. Thank you very much. Well I found it was really helpful. What I'll do; is let you know when it is up and running and online. Then if you want to you can take part on line and see the changes.

Focus group transcript 2: M=Michael, I= Ian; & C=Carl (Pseudonyms)

Q. It is turned on now. So was the information clear and the instructions on that front first page alright Carl- when you had had a read through it?

C. It was a bit complicated.

Q. It was a bit complicated was it?

C. No, it just wouldn't work for some cases.

Q. Why? Perhaps there is something I haven't thought of?

C. If it is single digit months.

Q. Yes, if it is up to September-which is the ninth month, you would put; 01 for January, 02 for February. But I think you are right, I need maybe to put an extra sentence there to explain that. Do you think that would make it easier.?

C. Yes.

Q. Ok-months 1-9 further explanation. This first bit, it depends when you found out about the diagnosis-some people remember really well and some people don't remember much at all, depending on how young they were when they found out. What you do is look at the statements and think about how much you agree or disagree with the statement. So first bit, this bit at the top is about before you knew about your diagnosis, perhaps when you were younger. Can you all remember when you actually found out? How old were you?

I: 10 and ½

Q. You were 10and ½. Carl, can you remember?

C. No.

Q. So have you known for a long time, can you almost not remember a time before you knew. Have you always known?

C. No I just can't remember the actual dates and times.

Q. That is fine, so you might vaguely be able to remember before you knew even if you cannot remember the actual date? That is fine.

Q. What about you Michael, what about you can you remember when you found out?

M. Well, I didn't know at first, cos I was a baby at the time.

Q. Right, so you got your diagnosis really early.

M. Well most babies, as I'm sure you know, talk really early but I didn't so Mum and dad I suppose took me to the hospital. Of course I cannot remember this, and they probably found out I've got Aspergers then and there. Of course I found out much later but I can't really remember when.

Q. Right, so for you then, the questions, if you try to think about before you actually found out about it rather than before your parents found out. Does that make sense? An then all you do is say whether you strongly agree, so if before the diagnosis, you didn't know anything about the diagnosis you would strongly agree. If you had already found out about it, for example if you know something else with Aspergers, for example, you might disagree or strongly disagree. If you really can't remember that you can tick number 3 which is not sure or not relevant. Someone has already suggested to me, one of the people who have tried it out, that I should actually separate that into 2 boxes not one-not sure and not relevant. So you can say exactly which one you mean-you can choose not sure or not relevant. Do you think that would be best?

I, C. Yes.

You could be not sure, but it could still be relevant.

Q. Yes, so that is one of the things I think I'll do. That seems to be something important. Do you think you will be able to go on and do that section, up to number 13?

ICM. Yes

Q. if there is anything you are not sure about or anything you think needs changing, do let me know.

C. Number 9, doing not sure.

Q. Right although there is not a box next to not sure, you can tick next to that to show which it is.

C. I'll underline not sure.

Q. Yes, that is a good idea or you could circle, not sure or not relevant. But what I'll do when I set it up online is to have two boxes so you can chose not sure or not relevant.

C. What if you don't agree or disagree?

Q. Erm, so do you think I need something like, not sure not relevant neutral? Something like that? Do you think that term neutral would be clear enough? Or that statement that you suggest: neither agree or disagree? I've seen that in things before. What would be clearer to you do you think?

C. Probably, I don't know, neither is clearer.

Q. Neither agree or disagree?

C. Yes.

I: With 11, does it mean doing well academically or doing well with others.

Q. For that one, it's thinking academically, generally how things are going at school rather than things like friendships.

I: I wasn't doing really well but I was doing well so would that be agree?

Q. Yes. Whatever, I think one of the things about these type of questionnaires is it is hard to get a statement that matches everything-so you have to go with the one you feel is closest. But do let me know if anything doesn't work because I might be able to know if there is anything Know if there is anything you feel, cause I could maybe change the statement. Do you think if the statement said: I was doing well at school. Would that would be easier to answer?

I Yes, I think so.

I do we carry on with 14?

Q. Em, yes the next bit is just about when you found out about your diagnosis. Now some people that will be from the specialist who made the diagnosis, if they were older. Sometimes, they leave it to your parents, after talking with parents, parents sometimes feel that they are better to talk to you about it. So it just varies. So yes, if you feel you are ready to move on to that section, yes, go right through to 34 it goes to this section. So that is all about finding out about your diagnosis. So it might be one event or over a period of time. It just varies from person to person.

I My parents told me but they didn't tell me when I started to ask questions, they just told me one day. So do I agree or disagree with that statement.

Q. Em so, just circle the bit of the sentence that applies to you. What I might do is to separate that into two sections on the questionnaire. But you just base it on the bit you have circles. This is why it is so important to try it out. You think you have sorted it out. Did you spot something Carl that wasn't in the correct tense?

C. Yes this one, 13.

M number 30, there are no boxes, Do I just put the ticks in the boxes anyway?

Q. yes, well spotted.

M. I'll put them in.

Q. Yes, just where they would be.

C. Number 30, when did we move onto that.

Q. We have just started talking about that next bit now.

C. Have we? When did that happen.

Q Perhaps you were still thinking about that one. We are talking about finding out about the diagnosis now. Sometimes that is from specialists, some from parents, some it is a combination.

I do not understand 20.

Q. 20. Some people, this is one of the things I got from the book that I read. Some people felt that the name either Aspergers or autism was applied to them to label them. They felt like they had been labelled as Aspergers or Autistic and that is not how they feel. They didn't feel like it was them and how the label was applied to them. I might need to do some clarification of that.

C What does it mean by empowered in number 25.

Q. Empowered, it made you feel able to do things better, more confidently, and you know-sort of enabled. All of these things are things that people have said about finding out about the diagnosis. So, for some people it is very positive and for some people it is just ok, for some people they find it upsetting. That is why there are various types of statements.

Q Do you understand that section ok? It is just I notice that you have moved on to changes since finding out. Why don't you have a break and eat your lunch…. One of the things I was wondering about M, on the questionnaire, I've used the term autism all of the way through. Do you think it would be better to put autism/Aspergers, or did it not really bother you?

M. It didn't really bother me to be honest-I'm not worried about that.

Q. Ok.

I I agree with 34 except the word most at the end.

Q. Ok. ……Have you spotted the change after 34? That is about after the diagnosis. I've just realised that it is not in bold. I'll have to change that. So I need to put that in bold don't I.

C. Number 32, it seems to be 2 parts.

Q. Right. Let me see.

C. but only one set of answers.

Q. that is a really good point, let me see. If you want to answer it as two separate answers, you could mark in the boxes for the first half and under for the second half. But that is a good point.

I I only slightly agree with 39.

Q. 39… ok so we may be possibly thinking about slightly agree. What about you M, did you feel at any point that you needed a slightly agree or slightly disagree or did the scale work for you?

M. It works for me. I'll just go and put this away.

C. there seems to be a lot of these (finding out). Some of the things just didn't happen. I didn't actually read any books.

Q. So does not relevant cover that, if that question is not relevant to you?

C. Not relevant will mean it is not relevant to someone else possibly. Possibly a clearer explanation of not relevant.

Q. I'm just trying to think what would work.

C. Not applicable or NA.

I: With number 47, the Aspergers diagnosis has not changed my confidence, I've just never had any anyway.

Q. Right, I would say that is a strongly disagree then.

I: Perhaps change the wording to changed my confidence would help.

Q. or boost my confidence, would that work?

I With 48, I agree with understanding but I disagree with not argue as much.

Q. So again I might need 2 questions there…. That is really helpful. ……. The scale I. Do you feel that not relevant is fine or do you feel not applicable is a better term?

I I think you still need not sure and not applicable as you might be not sure or it might not have happened to you.

Q. so do you think I not sure, not relevant and not applicable?

I Maybe.

Q the last bit is about how you feel about yourself now. It is called self-efficacy. It is like self-esteem. How successful you feel you are at the things it says in the list there. Some of it is about interacting with other people, asking teachers or friends for help and so on. Some of it is about subject knowledge-how confident you are feeling.

1 & 2 it depends on the teacher or person.

Q. So we might a….

I I can answer them I'm just saying.

Q. it is useful to think about that though.

C Why has it got that

Q. Which one? 43.

C It would imply you did get angry and you might not have.

Q does that need to be a separate question?

C. No I think it just needs to be worded differently.

Q. Right reconsider the wording.

C. I got angry more often than other people would be a good way to put it.

Q. Yes

I: with 26, it depends where I am. My personality changes when I'm with different people.

Q. 26? I've got controlling my temper.

I Yes, well I control my temper better when I'm with some people than others, it depends where I am.

Q. Oh right, ok.

I So I act differently at home than I do at school. In a taxi compared to when I see my gran.

Q. So that is a bit like the other one isn't it?

I I'll put developing skill as that makes sense.

Q. Situation dependent…. It is one of those things if I split too many things it will get too long.

C I'm struggling with it this long.

Q. that is why I don't want to split to many.

C there are a lot that are.

Q I think on line it feels easier as each section is on a page and I think it feels quicker to complete because you swap between one page and another.

Q. How did you find that M.

M I found it quite easy to be honest.

Q. Did you that is good. Was there anything that you wanted to point out to me?

M Friends, this is something that I'm discretely worried about at the moment because I'm struggling to make friends. Mr .. says it takes time to make friends. There a few people I know, and I try to invite them and they don't always talk to me, not always, but I did make a lot of friends at primary school in my year. I find it hard to stay in touch via e-mail a lot of them went to other schools, it is just me that came from …..the majority went to ……. which is a school in …………

Q. Did that happen to either of you, did you find that friends went to other places?

I I came with 2 other people from my school, none of which were my friends. One of them is in my class and one of them isn't.

Q so did you find the same as M when you first came?

I now I have 3 friends but until last year I didn't have any. I had 1 in primary school.

So it took you a while. That is one of the things that can be more difficult for people who have autism or Aspergers. Interacting with other people can be most difficult. Getting that right, because it is a, one of the most complicated skills we do. It is not straight forward, it takes a lot of watching and looking to see, trying to work out if they are interested in what you are saying or if they look uninterested to change what you are talking about. So it can be very difficult. It is difficult for all young people so you will find you are not the only ones. Do you do anything here about developing friendships?

M well I do chat to a few people and play games on the computer.

Q. so there are things set up to encourage you to make friends.

I There a three or four friends that I have who come up and we play on the computer or watch a video.

M. there is one person who is one of the kids from base but he hardly comes up, probably because he has friends from his other school who he likes to spend time with, but he probably has some other form of autism so it is easier for him.

Q have you asked him if you can join him and his friends?

M. Well I hardly go outside, I'm quite happy spending time in here.

Q. Well, maybe someone will join the school next year or even part way through who you will get on with. What really helps is to find someone who likes the same things as you because then you have things to talk about to develop the friendship. Thank you m. Are you waiting to get off somewhere.

M Yes.

Q. I thought you were. Thank you so much that was really helpful M.

I with 30, my parents are always proud of me. My parents are always telling me they are but I don't really think they are. So what do I put for that?

Q. well this isn't about what your parents think, this is what you think so…

I I don't know because they constantly say that they are but I don't feel they are.

Q. You don't feel convinced-so you may be slightly agree?

That is a good idea. What do you think I.

I I think it is ok as it is.

Q. ok so we have a mix for that one. One of the things they will be on the online survey is a box to type other ideas into after each section. Therefore if anything doesn't work for you, you can type in the box to explain. Do you think that will help?

I Yes you could clarify technicalities.

Q. would that help you.

C. It would be helpful.

Q. One of the other things I'm doing is I'm going to actually go and talk with young people and get them to just tell me about their experiences. So there will be the online questionnaires and interviews.

Q. What I will do, it is up to you whether you want to but I'll let Mr … know it is all done so if you want to go to do the finished one, you can go and do it. You might want to just go to look to see what has changed or you might want to take part, that is fine too. Is there anything else that strikes you or that you feel I've missed out, that you feel that been important in understanding the diagnosis, just let me know.

Q do you know what your diagnosis is?

I Aspergers, I think, I'm not entirely sure. I'm pretty sure it is.
Q. As I said to M, did it matter to you that it said autism, would you prefer it to say aspergers/autism?
I I'm happy as it is, isn't Aspergers a type of autism?
Q. Yes it is; it is all on a spectrum. Some people feel it would be easier to say high functioning autism. So you are able but also on the autism spectrum. It is considered very close. Therefore some people feel we should just use autism and say how much the impact is to help others to understand. So it doesn't seem to be an issue for you?
I No.
Q Well it is up to you, you can wait for you friend or if you want to go…
I Well I haven't had lunch yet…
Q. Oh, well, you go and get your lunch, thank you so much for all of your help, it has really been great. Thank you.
I bye
Q. Bye.
C. done.
Thank you very much. Was there anything else?
C. No
Q. Thank you very much C. Did you bring anything with you, your bag. Bye have a good day.

Appendix 6.6 Annotated draft survey from focus group feedback

Young Person Survey for Focus Group

A Research Project About Finding Out About Autism

This research questionnaire aims to find out what children and young people think about their autism diagnosis and the support they have had to understand their autism. It contains a selection of statements; for each statement you select an option to show how the statement relates to your own experiences. You can also type your own ideas into the text boxes if you would like to add anything.

You don't have to take part if you don't want to; you won't get in to trouble if you don't take part. It's not like a test - there are not any right or wrong answers. You change your mind part way through you can simply stop. Your information will not be used if you do this. If you take part, your answers will be kept strictly confidential and you will not be identified by name. ~~It~~

Note: Annotations from focus group feedback in yellow boxes. Small errors highlighted in red font colour

If you have read the information about the research and you want to take part, please tick this box: ☐

It is also important that you discuss taking part with your parents and they agree that it is ok. Tick this box if your parents are in agreement with you taking part: ☐

If you have not discussed this with your parents, you must discuss it with them and make sure they say it is ok before completing the questionnaire.

To make your own special code for the questionnaire, please enter the first two letters of your last name, a 2-digit number for the month in which you were born and last 2 digits of the year you were born.

Note 1. Needs an example of the code so it makes sense.

Note 2. Month number needed

Are you male or female? (Please click on the boxes to make your selection)

Male ☐	Female ☐

Part 1-You and Your Autism

Note 3. Heading font size needs to be bigger

Before I knew about my autism diagnosis:					
1. I didn’t know anything about autism	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
2. I was very confident about myself and my ability					
3. I worried about many things	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
4. I knew I was different to other young people	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
5. I didn’t have much faith in myself	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
6. Everything was fine	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
7. I never worried about anything	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
8. I struggled to get on with other people	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
9. I had no idea that I had autism	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
10. Nothing ever seemed to work out as I hoped	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant	2=Disagree ☐	1=Strongly Disagree ☐
11. I was doing ~~really~~ well school			☐		
12. I felt that no-one understood me	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
13. I had always fit in with everyone else, I felt ‘normal’	5= Strongly	4=Agree	3=Not sure	2=Disagree	1=Strongly Disagree ☐
Finding out about my autism diagnosis:					
1. The doctors and other specialists were able to tell me lots of helpful information	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐

Note 4. Consider -splitting -self-confidence and confident in lessons

Note 5: Really too subjective-remove it-What if they are not doing well?

Note 6: Tense? Needs rewording.

Note 7: autism/Asperger diagnosis- C diagnosis is

2. My parents told me about my diagnosis when I started asking questions	5 ☐	Note 8. Two parts, needs	☐	e	1=Strongly Disagree ☐
3. Helped me to put my experiences into perspective	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
4. I was given lots of helpful information leaflets	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
5. Was a real surprise to me, I didn't realise that anyone thought I had autism	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
6. Has been a very positive experience	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
7. Made me feel like I had been labelled	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
8. Provided me with what felt like a fresh start	Note 9 might need explaining or ☐		relevant ☐		1=Strongly isagree ☐
9. Was a very long and difficult process that involved many assessments and meetings	5= Strongly Agree ☐ Note 10 Perhaps reword -add finding out phrase	4=Agree ☐	3=Not sure or not relevant	2=Disagree ☐	1=Strongly Disagree ☐
10. I felt that I didn't have autism, I thought they had got it wrong	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
11. I felt that I needed to look for information myself, I used the internet to research information about autism	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
12. I felt empowered, I was helped to understand the autism and to recognise all the things I'm good at	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
13. Helped me to see the evidence about who I am	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
14. All I've been told was about the negatives about having autism	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
15. Accessing websites/blogs/tweets created by other young people with autism has	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐

been really helpful in coming to terms with my diagnosis					
16. Knowing the facts about autism has really helped me	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
17. Reading the information about the diagnosis was like creating a big mental list of things that I struggle with	Note 11. Boxes				
18. It was reading information books about autism that has helped me to understand	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
19. All I was told about the diagnosis was a vague, unclear information, it made me feel highly confused	5= Strongly Agree ☐ Note 12. Two parts, two questions better	4=Agree ☐	3=Not sure or not relevant	2=Disagree ☐	1=Strongly Disagree ☐
20. The doctor/autism specialist helped me to understand the autism, to feel confident in myself and to understand there is no such thing as a 'normal' person	5= Strongly Agree ☐	4=Agree ☒	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
21. Reading books written by other people with autism has helped me to understand the autism ~~most~~	5= Strongly Agree ☐ Note 13. Most not needed	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
Changes you have notice since finding out about your autism.	Note 14. Style not right needs to be bold like the other				
1. I've been able to get the support that I need in school/college	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
2. None, it has not made any difference to me	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
3. I've been able to access support from a specialist to help me to understand what the diagnosis will mean for me	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
4. Nothing has changed at all at home	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not	2=Disagree ☐	1=Strongly Disagree ☐

			relevant ☐		
5. I feel like I've been labelled and the label becomes a source of attention	5= Strongly	4=Agree	3=Not sure	2=Disagree	1=Strongly
6. I notice all the things that I'm good at and I know that my autism is what gives me these strengths	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
7. I feel that I have something to blame for my problems	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
8. The teachers/tutors give me more help	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
9. I understand it now, I know why I'm different and why I got angry	5= Strongly Agree	4=Agree ☐	3=Not sure or not	2=Disagree ☐	1=Strongly Disagree ☐
10. I get these negative ideas about myself, I sometimes think I'm never going to achieve anything	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
11. Now I've accepted it, I realise that it is not the end of the world, it is just a different way of thinking	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
12. I feel like a valuable individual	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
13. It has really helped my confidence	5= Strongly	4=Agree	3=Not sure ☐	2=Disagree	1=Strongly
14. My family are more understanding and we do not argue as much	5= Strongly	4=Agree	3=Not sure ☐	2=Disagree	1=Strongly
15. I feel that I can be a success and I'm happier in myself	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
16. I know that I think differently and that this is the reason for my strengths	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant	2=Disagree ☐	1=Strongly Disagree ☐

Note 15. Suggested idea for scale-consider adding slightly agree

Note 16. Reconsider wording

Note 17. Add: …to boost my confidence

Note 18. Two parts, two questions better

Note 19. Scale- need a not applicable option

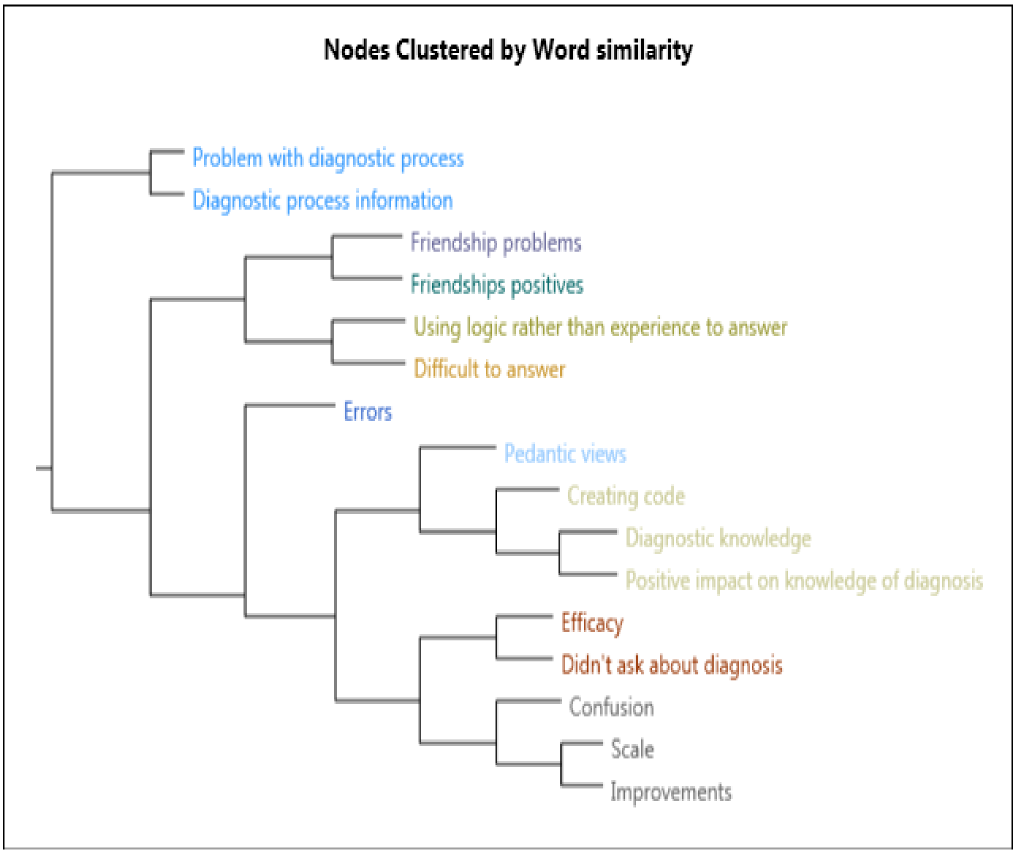
Appendix 6.7 Summary of key considerations and changes made based on the suggestions from CYP via the focus group.

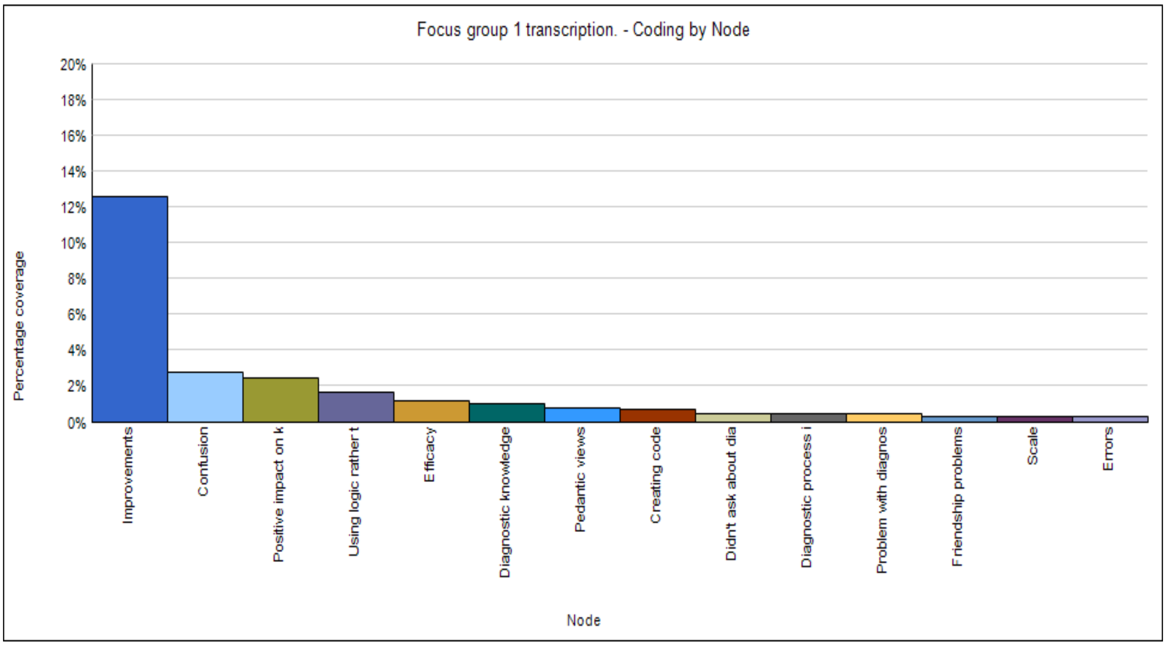
1. Unfortunately, there were some proofreading errors on the trial questionnaire. These were distracting for the young people who contributed. Very careful proofreading was undertaken to eliminate such errors before launching the online version.
2. Participants managed the code well but felt it would have been easier with an example and month numbers provided. The code is the only way to link the online surveys if parent child dyads participate. Therefore, an example of how to create the code was added and to the final version of the survey to increase the likelihood of this being provided accurately.
3. Sections headings were emphasised to ensure the change between before/finding out/after diagnosis sections were clear for children and young people.
4. Asperger was added to the headings so that they read ‘my autism/Asperger diagnosis. The young people who had this diagnosis felt this was important so people with an Asperger syndrome diagnosis would know the survey was also for them.
5. The scale was altered to include an ‘other’ section as the young people in the focus group found it frustrating. The not relevant/not sure sections were separated as young people were concerned that they were too different. One young person suggested adding slightly agree, but the other children felt that was not needed.
6. Some of the questions were slightly reworded for clarity.
    a. In the before diagnosis section, question 2 was divided into two questions, one focussing on ability and the second social confidence. Question 6 ‘faith in myself’ was changed ‘to confidence in myself’ for clarity. Question 11, the word really was removed, and a second question added so there was a question about doing well at school, or school was difficult (12 & 15 in the final questionnaire)
    b. In the finding out section, question 2 was reworded, the end part edited. The first 3 questions were reordered to focus on parents first then professional explanation of diagnosis. Several questions were rephrased at the start to remind young people the section was about finding out about the diagnosis.
    c. There were fewer adjustments to the after-diagnosis section. Question 13 had boost added: ‘helped to boost my confidence’. Question 15 was split into two sections. Question 21 was rephrased.

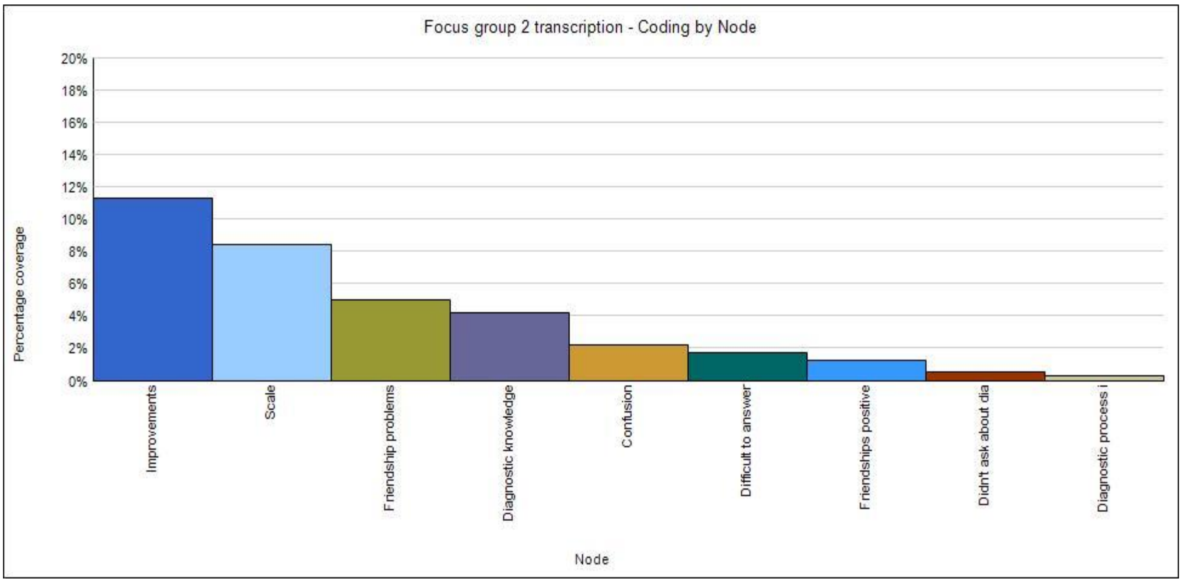
Other general notes on focus group:

- The discussion mostly focused on the draft survey. The participants were very focussed on this, taking their role very seriously. Attention to detail and purpose was very good.

- Discussion beyond the survey mostly focussed on the young people’s social experiences and friendships. The is a central concern of all children in adolescence. It is therefore understandable this is also so for young people with an autism diagnosis.
- Most were unsure about the diagnosis, but one participant was keen to emphasised Asperger syndrome rather than autism. This seems to be his preferred diagnosis.
- The participants did not have much knowledge about their diagnosis, or the processes related to it. Information about this might need to be mostly from parents.
- The young people all knew about their diagnosis and seemed confident to discuss it. They attend a specialist provision and have been supported positively in relation to the diagnosis. A high achieving school, so expectations for them are also high. Despite this, they were aware of problematic public perceptions of autism.
- Summary visuals from NVivo below. However, simply reading and highlighting the key points in the transcript was more useful.


Nodes Clustered by Word similarity


Focus group 1 transcription. - Coding by Node
Percentage coverage
20%
18%
16%
14%
12%
10%
8%
6%
4%
2%
0%
Improvements
Confusion
Positive impact on k
Using logic rather t
Efficacy
Diagnostic knowledge
Pedantic views
Creating code
Didn't ask about dia
Diagnostic process i
Problem with diagnos
Friendship problems
Scale
Errors
Node


Focus group 2 transcription - Coding by Node
Percentage coverage
20%
18%
16%
14%
12%
10%
8%
6%
4%
2%
0%
Improvements
Scale
Friendship problems
Diagnostic knowledge
Confusion
Difficult to answer
Friendships positive
Didn't ask about dia
Diagnostic process i
Node

Appendix 7 Online survey for children and young people

Diagnosis of Autism/Asperger Syndrome: Young People's Survey

For confidentiality reasons, you are not asked to give your name, however, you are asked to create your own survey code. This will enable you to ask for your survey information to be withdrawn if you change your mind after completing the survey.

It will also enable me to link your survey information with your parents' information if you both take part.

To create your own survey code, in the box below, please enter the first two letters of your last name, a 2-digit number for the month in which you were born and last 2 digits of the year you were born.

For example: John Drake born in July of 1999 would enter DR0799. Angela Smith born in November 2003 would enter SM1103.

Month guide: January: 01; February 02; March 03; April 04; May 05; June 06; July 07; August 08; September 09; October 10; November 11; December 12.

You will find it useful to write down this code so you remember it. If you later change your mind and do not want your information to be used, the code will make it possible to identify your information so it can be withdrawn.

However, even if you cannot remember the code, please get in touch as it might still be possible to withdraw the information if you provide some additional details. You can e-mail me at [redacted] to ask me to delete your information.

About you:

Your gender: Male; Female; Other (Please give details)

Where do you live?

North East; North West; Yorkshire and the Humber; East Midlands; West Midlands; East of England; Northumberland; Durham; London; South East; South West; Other (Give details below); Not sure.

If you know what your diagnosis is, please select from the list below or type an alternative into the box at the bottom of the list:

Autism; Childhood Autism; Autism Spectrum Disorder; Asperger Syndrome; Pervasive Developmental Disorder-not otherwise specified; Not Sure; Other

This section is about the time before you knew that you had autism.

Before my autism diagnosis:

Statement	**Strongly Disagree**	**Disagree**	**Not sure**	**Agree**	**Strongly Agree**	**Not relevant**	**Other- Please specify:**
I didn't know anything about autism							
I was confident about my ability							
I was confident when chatting with people in my class							
I worried about many things							
I knew I was different to other young people							
I didn't have much confidence in myself							
Everything was fine							
I never worried about anything							
I struggled to get on with other people							
I had no idea that I had autism							
Nothing ever seemed to work out as I hoped							
I was doing well at school							
I felt that no-one understood me							
I felt 'normal'							
I was finding school difficult.							
In your own words, please tell me what things were like for your before your autism diagnosis.							

This section is finding out about your autism diagnosis:

Statement	Strongly Disagree	Disagree	Not sure	Agree	Strongly Agree	Not relevant	Other- Please specify:
My parents told me about my diagnosis							
My parents explained the diagnosis very clearly							
A doctor or autism specialist told me about my diagnosis							
The doctor or other specialist was able to tell me lots of helpful information							
Going through the diagnostic process helped me to put my experiences into perspective							
I was given lots of helpful information leaflets							
Finding out was a real surprise to me, I didn't realise that anyone thought I had autism							
Finding out has been a very positive experience							
When I found out, it made me feel like I had been given a label							
Being told I had autism provided me with what felt was like a fresh start							
Finding out about autism was a difficult process, which involved many assessments and meetings							
When they told me, I thought they had got it wrong							
When I found out, I felt that I needed to look for information about autism so I understood what it meant							

Statement	Strongly Disagree	Disagree	Not sure	Agree	Strongly Agree	Not relevant	Other- Please specify:
I used the internet to research information about autism							
When they told me about the autism diagnosis, I felt empowered							
I was helped to understand autism and to recognise all the things I'm good at							
Finding out, helped me to see the evidence about who I am							
All I was told was about the negatives related to autism							
Accessing websites/ blogs/tweets created by other people with autism has been really helpful in coming to terms with my diagnosis							
Knowing the facts about autism has really helped me							
Reading the information about the diagnosis was like creating a big mental list of things that I struggle with							
It was reading information books about autism that has helped me to understand							
All I was told about the diagnosis was vague, unclear information							
When I was told I had autism, it made me feel highly confused							
The doctor/autism specialist helped me to understand the autism, to feel confident in myself and to understand there is no							

Statement	Strongly Disagree	Disagree	Not sure	Agree	Strongly Agree	Not relevant	Other- Please specify:
such thing as a 'normal' person							
Reading books written by other people with autism has helped me to understand autism more than anything else							
Tell me in your own words about your experiences of finding out about your autism diagnosis.							

This section is about changes you have noticed since finding out about your autism:

Statement	Strongly Disagree	Disagree	Not sure	Agree	Strongly Agree	Not relevant	Other- Please specify:
I get more support at school/college							
None, it has not made any difference to me							
I've been able to access support from a specialist to help me to understand what the diagnosis will mean for me							
Nothing has changed at home							
I feel like I've been labelled and the label becomes a source of attention							
I notice all the things that I'm good at and I know that my autism is part of what gives me these strengths							
I feel like I have something to blame for my problems							
The teachers/tutors give me more help							

Statement	Strongly Disagree	Disagree	Not sure	Agree	Strongly Agree	Not relevant	Other- Please specify:
I understand it now, I know why I'm different and why I get so upset							
I get these negative ideas about myself, I sometimes think I'm never going to achieve anything							
Now I've accepted it, I realise that it is not the end of the world, it is just a different way of thinking							
I feel like a valuable individual							
I feel different but in a good way, I don't want to be just like everyone else.							
It has really helped to boost my confidence.							
My family are much more understanding.							
15b We don’t argue as much							
I feel that I can be a success and I'm happier in myself.							
I know that I think differently and that this is the reason for my strengths.							
Tell me in your own words about what has happened since you found out about your autism diagnosis. For example: Have you had any extra help? Have you noticed anything different about yourself and how you feel about yourself?							

Statement	Strongly Disagree	Disagree	Not sure	Agree	Strongly Agree	Not relevant	Other- Please specify:
Have you noticed any differences in the way people behave towards you?							
Anything else: If there any other information that you would like to tell me, please write in the box below: Please note, this is your last opportunity to provide information.							

Appendix 7.1 Information for webpage managers-Understanding my autism diagnosis: A research study

An Invitation for Child to Take Part

Dear Website Manager,

I am currently employed as a Senior Lecturer for the Childhood Studies Department at [redacted] and I am undertaking a research based PhD qualification at the University of Birmingham. My research aims to explore children's and young people's views about how they were informed about their autism diagnosis and how they have been supported to understand it.

The Guideline Development Group (GDG) for the National Institute of Clinical Excellence (NICE), recently identified evidence of both immediate and longer term benefits from the provision of 'accurate, appropriate and sympathetic information' for young people following an autism diagnosis (NICE, 2011, p. 184). They also identified evidence that highlights the importance of the information being tailored to the specific developmental needs of the individual. However, a gap in the evidence base, relating to young people's views upon how they are supported to understand their diagnosis, was also identified.

The aim of this study is therefore to explore the views and experiences of young people with autism, related to how they were told about an autism diagnosis and how they have been supported to understand it. It is anticipated that understanding the views of young people will support the identification of useful starting points for those who are charged with the responsibility of helping young people on the autism spectrum to understand their diagnosis. While the research is focused upon the views of young people, I am also asking their parents to take part in order to gain the most complete picture of the impact of the diagnostic process and an autism diagnosis.

I write to ask you to consider putting the advertisement to take part in the research on your website, or to send out the attached information, via your e-mail group, to parents of young people with autism so that they can consider whether they and their child would like to take part.

This research has been fully considered and agreed by the University of Birmingham, ethics committee. Appropriate protections have been taken to enable young people to take part safely. Research reports will not identify individuals who take part.

Thank you for taking the time to consider this request. Please do not hesitate to contact me, if you require any further information (Contact details). My research supervisor is Dr K. Wittemeyer, she can be contacted at the University of Birmingham (Contact details).

Yours sincerely
Julie Prentice
(Contact details)

Reference and link to the NICE guidance, for your information:

National Institute for Health and Clinical Excellence (NICE) (2011) **Autism: recognition, referral and diagnosis of children and young people on the autism spectrum: NICE Clinical Guideline** [Online]. London: National Collaborating Centre for Women's and Children's Health. Available: http://www.nice.org.uk/nicemedia/live/13572/56424/56424.pdf

Appendix 8 Online survey for parents

Appendix 8.1 First draft of online survey for parents with revision annotations

Note: Annotations from parents/supervision feedback in yellow boxes
Smaller annotations in red font
Only feedback from parents who trialled the survey was an error in Q19 in the finding out section. Therefore, notes on improvements are from discussion about refinement with GJ during supervision.

A Research Project About Finding Out About Autism

This research questionnaire aims to find out what parents think about their child's experiences of finding out about an autism diagnosis and the support they have had to understand their autism. The second part of the questionnaire aims to understand the possible impact of the diagnosis, and the process related to it, by considering how the young person might be feeling about their ability and future prospects.

Your answers will be kept strictly confidential; participants will not be identified by name. If you would like to take part, please enter the first two letters of **your child's last name**, followed by a 2-digit number for the month in which your child was born and then the last 2 digits of the year in which your child was born.

Above paragraph needs rewording to explain more clearly: highlight that code is created for confidentiality reasons.

For example John Drake born in July of 1990 would enter DR0790. Angela Smith born in November 2003 would enter SM1103

Month numbers to be added as children's survey

What is your relationship with the child?

Mum	X	Dad		Other	

Is your child

(Please put X in the relevant boxes)

Male		Female	X

Demographics, discussed adding ethnicity-not needed
Areas of country needed for sampling purposes. This might highlight differences in provision

Scale change to match scale in CYP survey-separate not sure/not relevant – add other option with free-text box for details

Part 1-You and Your Autism

Before my child knew about their autism diagnosis:					
1. They didn't know anything about autism	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
2. He/she was very confident about his/her self and his/her ability	☐		☐		

1. Maintain consistent pronoun throughout: use S/he
2. Split Q 2 into 2 section ability/social as children's survey

3. He/she worried about many things	5= Strongly Agree ☒	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
4. My son/daughter was always asking why they were different to other young people	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
5. He/she didn't have much faith in myself	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
6. Everything was fine	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
7. My son/daughter never worried about anything	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
8. He/she struggled to get on with other people	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
9. My child had no idea that I had autism	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
10. Nothing ever seemed to work for my child	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
11. He/she was doing really well at school	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
12. He/she felt that no-one understood me	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
13. My son/daughter had always fit in well with everyone else	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
My son/daughter's experienc of finding out about their autism diagnosis:					
1. The doctors and other specialists were able to tell him/her lots of helpful information	5= Strongly	4=Agree ☐	3=Not sure or not	2=Disagree	1=Strongly Disagree
2. I/we told him/her about the diagnosis when he/she started asking questions	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
3. Finding out seemed to help him/her to put his/her experiences into perspective	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
4. My child was given lots of helpful information leaflets	5= Strongly Agree ☐	4=Agree ☒	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐

Structure of questions is different-rephrase: Rate your child's experiences of finding out about their autism diagnosis

Add an extra question-some parents might disclose straight away

5. It ~~appeared to~~ come as a real surprise to my child~~, he/she didn't realise that anyone thought he/she had autism~~	5= Strongly	4=Agree ☐	3=Not sure or not	2=Disagree e	1=Strongly Disagree
6. Has been a very positive experience	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree e ☐	1=Strongly Disagree ☐
7. Has made them feel labelled ~~or stigmatised~~	☐		☐		
8. Provided him/her with what felt like a fresh start	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree e ☐	1=Strongly Disagree ☐
9. Was a very long and difficult process that involved many assessments and meetings	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree e ☐	1=Strongly Disagree ☐
10. My child felt that they ~~didn't~~ have autism, they thought everyone had got it all wrong	5=	4=Agree	3=Not sure	2=Disagree	1=Strongly
11. My son/daughter has searched for information about autism on the internet	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree e ☐	1=Strongly Disagree ☐
12. The diagnosis has helped to empower my child as they were helped to understand the autism and to recognise ~~all the things he/she is good at~~	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree e ☐	1=Strongly Disagree ☐
13. Helped him/her ~~to recognise the evidence who he/she is~~					
14. My child has only been told the negative aspects of having autism	Agree ☐		relevant ☐	☐	☐
15. Accessing websites/blogs/tweets created by other young people with autism has been really helpful for my child ~~in coming to terms with their diagnosis~~	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree e ☐	1=Strongly Disagree ☐
16. Knowing the facts about autism has really helped him/her	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree e ☐	1=Strongly Disagree ☐
17. Reading the information about the diagnosis seemed to highlight all the problems to my child					
18. It was reading information books about autism that has helped him/her to understand	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree e ☐	1=Strongly Disagree ☐

5-Rephrase: It came as a real surprise to my child.

7-remove or stigmatised

10-Rephrase: When my child was told the have autism, they thought it was wrong.

12-Rephrase: just needs their strengths at the end
13. Rephrase end: …to understand experiences and difficulties
15. Rephrase end: …to understand the diagnosis

19. All he/she was told about the diagnosis was vague, unclear information, it made me feel highly confused	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
20. The doctor/autism specialist helped my child to understand the autism. This helped his/her confidence and helped him/her to understand there is no such thing as a ‘normal’ person	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
21. Reading books written by other people with autism has helped my child to understand the autism	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
Changes you have notice since your child has known about their diagnosis:					
1. ~~My son/daughter~~ has been able to get the support that he/she needs in school/college					
2. None, it has not made any difference to him/her					
3. He/she has been able to access support from a specialist to help him/her to understand what the diagnosis will mean for him/her					
4. Nothing has changed at all at home	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
5. ~~He/she~~ feels they have been labelled ~~and that they get attention they do not want because of the label~~	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
6. ~~He/she~~ is better at noticing all the things that s/he is good at and knows ~~that having autism is what influences these strengths~~	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
7. My child feels that they have something to blame for my problems	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐
8. The teachers/tutors give him/her more help	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagree ☐	1=Strongly Disagree ☐

<Rephrase so it leads into the statement: Since finding out I have noticed my child:
This means the beginning of statements can be reduced as below:

1. Has more support at school/college.
2. Has not changed at all.
3. Has been able to access specialist support to aid understanding of diagnosis.
4. Is just the same as they were pre-diagnosis.
5. Feels they have been labelled
6. Is better at noticing what they are good at and knows these strengths are part of the autism.
7. Feels that autism is part of the problems they experience.
8. Gets more help from teachers/tutors.

9. My son/daughter understands it now, they know why they are different to their peers	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagre e ☐	1=Strongly Disagree ☐
10. My child thinks negatively about their future. He/she thinks they will never achieve anything	5=	4=Agree	3=Not sure	2=Disagre	1=Strongly
11. ~~Now my child~~ accepts the diagnosis, ~~they have realised that it is not the end of the world, it is just a different way of thinking~~					
12. ~~My child~~ feels like a valuable individual					
13. It has really helped my son/daughter's confidence					
14. The whole family are more understanding and we do not argue as much					
15. My child feels they can be a success and generally seem happier	Agree ☐		relevant ☐	☐	☐
16. My child understands that they think differently and that this is the reason for all of their strengths	5= Strongly Agree ☐	4=Agree ☐	3=Not sure or not relevant ☐	2=Disagre e ☐	1=Strongly Disagree ☐

Statement 9-rephrase Understands why they are different to peers.

Statement 10-split into two: Thinks negatively about their future. Also add a question: Thinks they are never going to achieve anything

Statement 13: Has a greater level of confidence.

Statement 14: Is better understood by the whole family. Also add a question about having fewer disagreements with family members.

Statement 15: Feels they can be a success and are happier

Statement 16: Understand that they think differently and that is the reason for many of their strengths.

Appendix 8.2 Summary of key considerations and amendments to the parent survey

The survey was trialled by three parents. All reported the survey seemed appropriate, they felt able to answer it in light of their child’s experiences.
Two parents mentioned there was and an error in Q19 in the finding out section.

I sought further feedback through supervision as I was worried parents might not have felt they could highlight issues, despite reassurances and explanation that this was the purpose.

Therefore, possible improvements were discussed and improvements suggested by GJ through the PhD research supervision process. The following key considerations and improvements were discussed:

    1. The survey introduction was discussed but not changes identified. Parents had all accessed the information about the survey prior to accessing the survey so it had been kept brief.
    2. The explanation about the identification code was reworded to explain the reason for creating the code more clearly. It was re-worded to highlight that code is created to facilitate confidentiality/anonymity. Month numbers were also listed, as added to the children’s survey to reduce possibility of error.
    3. Demographics discussed and felt sufficient. Adding ethnicity was considered but GJ advised can be off-putting for some people. However, areas of the country were anticipated to be useful. They were needed for sampling purposes and might highlight differences in provision.
    4. The scale was improved to match the scale in the CY’s survey. Therefore a not sure/not relevant were separated to allow specific selection. The option of ‘’other’ was also added with a free-text box for details.
    5. In the **before diagnosis** section. The pronoun use was discussed and altered so it was consistent a number of different phrases in the draft version were felt to be confusing, therefore, **s/he** was used wherever phrasing allowed. Eleven statements were slightly rephrased (1; 2; 3; 4; 5; 6; 7; 8; 9; 11; 12; 13), as shown in the annotation in Appendix 7.1 above.
    6. As for the children and young people’s survey, the first question was separated into two questions, one about ability and one social experiences.
    1. In the **Finding out about diagnosis** section, as the structure of questions was different, the introductory phrase was altered to: Rate your child’s experiences of finding out about their autism diagnosis. An extra question-was added so that parents could indicate if they told their child about the diagnosis straight away. Eight statements were slightly rephrased (5; 7; 10; 11; 12; 13; 15; 19), as shown in the annotation in Appendix 7.1 above.

1. In the after-diagnosis section, the lead in phrase was altered to read: Since finding out I have noticed my child: This enabled the beginning of the statements in the final section to be simplified, as shown in the annotation in Appendix 7.1 above. Also, Statement 10-split into two: Thinks negatively about their future/Thinks they are never going to achieve anything. Fourteen statements were slightly rephrased (1; 2; 3; 4; 5; 6; 7; 8; 9; 11; 12; 13; 14; 15), as shown in the annotation in Appendix 7.1 above.

Appendix 8.3 Final version of the online survey for parents

Diagnosis of Autism/Asperger Syndrome: Parent Survey

This research questionnaire aims to find out what parents think about their child's experiences of finding out about an autism diagnosis and the support they have had to understand their autism. The second part of the questionnaire aims to understand the possible impact of the diagnosis, and the process related to it, by considering how the young person might be feeling about their ability and future prospects.

For confidentiality reasons you are not required to provide your name. However, you are asked to create your own survey code. This is so you can inform me how to identify your survey responses, if you change your mind about your information being used and wish to withdraw it. It will also enable me to link the information provided in parent surveys with the information in the young persons' survey.

Create your own survey code:

To do this, in the box below, please enter the first two letters of your child's last name (oldest child if you have more than one child), a 2 digit number for the month in which your child was born and last 2 digits of the year they were born.

For example John Drake born in July of 1999 would enter DR0799. Angela Smith born in November 2003 would enter SM1103.

For a birthday in January put 01; February=02; March=03; April=04; May=05; June=06; July=07; August=08; September=09; October=10; November=11; December=12.

You will find it useful to write down this code so you remember it. If you later change your mind and do not want your information to be used, the code will make it possible to identify your information so it can be withdrawn.

However, even if you cannot remember the code, please get in touch as it might still be possible to withdraw the information if you provide some additional details.

You can e-mail me at [redacted] to ask me to delete your information. Please note, I will only be able to delete information within 30 days of your completion of the survey.

Where do you live?

For example: North East England; North West England; Yorkshire and the Humber; East Midlands; etc.

Your child's gender: Male; Female

I have more than one child with autism (Please give details if you have more than one child)

For the rest of the survey, tell me about your oldest child's experiences

What is your relationship to the child?

Mother; Father; Other: (Please state)

My child's diagnosis is:

Autism; Childhood Autism; Autism Spectrum Disorder (ASD); Asperger syndrome; Pervasive Developmental Disorder-not otherwise specified (PDD-NOS); Not sure; Other (If you selected Other, please specify)

This section is about the time before your child knew about their autism.

Rate you child's experiences **before their diagnosis**:

Statement	Strongly Disagree	Disagree	Not sure	Agree	Strongly Agree	Not relevant	Other- Please specify:
S/he didn't know anything about autism							
S/he was very confident around other children							
S/he was very confident about his/her ability							
S/he worried about many things							
S/he was always asking why s/he was different to other people							
S/he didn't have much confidence in him/herself							
Everything was fine							
S/he never worried about anything							
S/he struggled to get on with other people							
S/he had no idea s/he had autism							
Nothing ever seemed to work out for my child							
S/he was doing really well at school							
S/he felt that no-one understood							

Statement	Strongly Disagree	Disagree	Not sure	Agree	Strongly Agree	Not relevant	Other- Please specify:
S/he felt 'normal'							
S/he was finding school difficult							
In your own words, please tell me what things were like for your child before the autism diagnosis.							

Finding out about the autism diagnosis:

Rate your child’s experiences **of finding out about their autism diagnosis**

Statement	Strongly Disagree	Disagree	Not sure	Agree	Strongly Agree	Not relevant	Other- Please specify
The doctors and other specialists were able to tell him/her lots of helpful information							
I/we told my child about their diagnosis as soon as it was confirmed							
I/we told my child about their diagnosis when they started asking questions							
Finding out seemed to help him/her to put his/her experiences into perspective							
My child was given lots of helpful information by the specialist							
Finding out about the autism diagnosis came as a real surprise to my child							
Finding out has been a very positive experience for my child							
When s/he found out about the diagnosis, s/he felt like s/he had been labelled							
Being told s/he had autism provided him/her with what felt like a fresh start							
Finding out about the diagnosis was a difficult process that involved many assessments and meetings							
When my child was told about the diagnosis, s/he didn't believe they had autism							
When they found out, s/he felt the need to							

Statement	Strongly Disagree	Disagree	Not sure	Agree	Strongly Agree	Not relevant	Other- Please specify
look for information on the internet							
The diagnosis has helped to empower my child, as they were helped to understand the autism and to recognise all their strengths							
Finding out, helped him/her to understand their experiences and difficulties							
My child has only been told about the negative aspects related to autism							
Accessing websites/blogs/tweets created by other people with autism has helped my child to understand the diagnosis							
Knowing the facts about autism has really helped her/him							
Reading the information about the diagnosis seemed to highlight all the problems related to autism to my child							
It was reading information books about autism that has helped him/her to understand							
All s/he was told about the diagnosis was vague, unclear information,							
Finding out about the diagnosis made my child feel highly confused							
The doctor/autism specialist helped my child to understand the autism.							

Statement	Strongly Disagree	Disagree	Not sure	Agree	Strongly Agree	Not relevant	Other- Please specify
Finding out about the diagnosis from the doctor/autism specialist has helped increase his/her confidence							
Information about the diagnosis highlighted that there is no such being as the 'normal' person							
Reading books written by other people with autism has helped my child to understand the autism							
Tell me in your own words about your child's experiences of finding out about their autism diagnosis							

Changes you have noticed since your child found out about their autism:

How do the statements relate to your child's experiences since finding out about the diagnosis?
Since finding out about their autism, I have noticed that my child:

Statement	Strongly Disagree	Disagree	Not sure	Agree	Strongly Agree	Not relevant	Other- Please specify
Gets more support at school/college							
Has not changed at all							
Has been able to access support from a specialist to aid understanding of the diagnosis							
Is just the same at home as they were before the diagnosis							
Feels that they have been labelled							
Feels that they have been labelled							
Is better at noticing all the things that they are good at and know these strengths are part of the autism							
Feel that the autism is the cause of all of their problems							
Gets more help from teachers/tutors							
Understands why they are different from peers							
Thinks negatively about their future							
Thinks they are never going to achieve anything							
Accepts the diagnosis							
Has realised they just have a different way of thinking							
Feels like a valuable individual							
Has a greater level of confidence							

Statement	Strongly Disagree	Disagree	Not sure	Agree	Strongly Agree	Not relevant	Other- Please specify
Is better understood by the whole family							
Has fewer disagreements with other family members							
Feels they can be a success and are happier							
Understands that they think differently from peers and that this is the reason for many of their strengths							
Tell me in your own words about what has happened since your child found out about their autism diagnosis. For example, have they had extra help? Has their behaviour changed? Are they more positive? Have you noticed any differences in the way people behave towards them? Tell me about anything else that you have noticed.							
Anything else							
Is there anything else that you would like to tell me? This is your last opportunity to provide information.							

Appendix 9 Interview schedule for children

Read or re-cap on the main points from the information sheet and ask whether the participant would still like to take part.

Remind the participant that they can stop the interview or withdraw their data from the study at any time prior to publication. Remind them how to do this-as indicated on the information sheet. Give a contact sheet with a reminder of how to get in touch.

Explain that you need to ask a few general information questions before the main interview questions. We'll do these first. In total there are 15 questions but I might give you other prompting ideas or questions to help you to think about the question.

Explain that you will be analysing the things that you are told and creating a type of summary that highlights what I hope are your key experiences. It can be really helpful to researchers if the people who provide the information look at the summary and comment upon the researcher's information. Would CHILDNAME and their parent like me to revisit them to show them my summary and give me their thoughts upon it? (record the response)

Participants name:

*Explain that when you write the report you will use a pseudonym (explain what this is)-do they have a preference about what pseudonym is used***. *Note this*:**

1) Note gender: Male or Female
2) How old are you?
3) Who do you live with? Mum; dad; brothers; sisters; grandparents; other
4) Do you know what your diagnosis is?

Prompts: Autism; Aspergers syndrome; Pervasive Developmental Disorder not otherwise specified; High Functioning Autism-Other.

Main questions:

Explain that giving as much detail as they can to the following questions will be appreciated as this is likely to give me a greater understanding to help with the report I will write.

5) Tell me about your interests and the things you like to do: sport; games; music; movies; art; etc**.**
   (Note this is simply to put the young person at their ease in allowing to talk about a topic they are comfortable with prior to discussing the diagnostic process, etc.)

6) Do you remember the time before your diagnosis was made? **If no** go on to question 8e.

If yes, allow the participant to tell you using their own words-- use the following prompts as needed:

  a) Tell me about what things were like for you before you were diagnosed.
  b) What about the family-did everyone understand you? Did you get on well together?
  c) Did teachers understand? How did they show this?
  d) Describe your experiences at school/college before you were diagnosed.
  e) Tell me about friendships before your diagnosis
  f) Did you have lots of friends? What types of things did you do together?
  g) Tell me about your feelings in the few months before you were diagnosed?

7) Please tell me about your experience of finding out about the autism or autism diagnosis
  a) Tell me about your feelings at this time/meeting.
  b) Where were you?
  c) Who was there?
  d) Did you have any idea what was going to happen?
  e) Since you have known about your diagnosis, what type of information has been provided: leaflets; chance to ask questions; books; dvds; an explanation from someone
  f) Who has provided information
  g) Did you have to ask for the information?
  h) Was the information available useful?
  i) What has been the most useful information
     Tell me why it has been particularly useful

8) Do you feel that other people knowing about the diagnosis has altered the way other people have treated or interacted with you?
  a) Is anyone more or less understanding?
  b) Teachers
  c) Parents
  d) Siblings
  e) Wider family-aunties, uncles, grandparents, cousins
  f) Friends
  g) Do your friends know about your diagnosis? Who told them? How did they react?

9) Tell me about any help you have received to understand the diagnosis.
  a) Meetings with a doctor/nurse/psychologist/autism specialist
  b) Opportunities to attend groups
  c) Were you given any choice about the type of support?
  d) Informal support from family and friends
  e) Self- help-have you done any research yourself about autism-internet; library, etc.
  f) What has been the most/least helpful?

10) Has the diagnosis altered or impacted upon the way you feel about yourself?
  a) More positive or less positive
  b) Differences or difficulties
  c) Your future aims/hopes dreams ambitions

11) Tell me about any extra help you have had since finding out about your diagnosis
  a) From family
  b) At school/college
  c) From friends
  d) Community-guides; cubs; sports/art/music clubs, etc.

12) Tell me about your feelings about your autism diagnosis now
  a) Mostly positive or negative
  b) Has it helped you understand yourself

13) How do you feel people with autism can be best helped to understand their autism?
  a) What would your advice be for:
    a) Doctors or psychologists
    b) Nurses or Autism specialists
    c) Parents
    d) People with autism
    e) Friends of people with autism

15. Tell me about your ambitions for the future:

  a) An interest you would like to follow;
  b) A future career;
  c) Your home
  d) Your academic achievements
  e) Your friends
  f) Your relationships

Appendix 10 Interview schedule for parents

Read or re-cap on the main points from the information sheet and ask whether the participant would still like to take part.

Remind the participant that they can stop the interview or withdraw their data from the study at any time prior to publication. Remind them how to do this-as indicated on the information sheet. Give a contact sheet with a reminder of how to get in touch.

Remind the parent/carer that the research is focused upon the impact for the individual with autism rather than the impact upon them.

Explain that you need to ask a few general information questions before the main interview questions. We'll do these first. In total there are 15 questions but I might give you other prompting ideas or questions to help you to think about the question.

Participants name:

*Explain that when you write the report you will use a pseudonym-do they have a preference about what pseudonym they would like you to use***. *Note this*:**

1) What is your relationship to the focus child?
2) Describe your family situation: Partner/siblings, etc
3) Ask the parent carer to confirm their child's age and diagnosis.

Prompts: Autism; Aspergers syndrome; Pervasive Developmental Disorder not otherwise specified; High Functioning Autism-Other.

4) At approximately what age was the diagnosis made?
5) When was your child made aware of the diagnosis?
6) How and by whom were they informed?

Main questions:

Explain that giving as much detail as they can to the following questions will be appreciated as this is likely to give a greater understanding.

a) How were things going, generally, for your child prior to the diagnosis?

b) What about the family-did anyone have concerns about CHILD NAME?
c) What about teachers-did they share any concerns about CHILD NAME?
d) How was CHILD NAME doing at school/college before they were diagnosed?
e) Did they have any/many friends prior to diagnosis?
f) How did CHILD NAME seem emotionally in the 6 months before they were diagnosed?

7) Please tell me about CHILD NAME’s experience of finding out about the autism diagnosis
    a) How was CHILD NAME feeling on the day/at the meeting.
    b) Where were they when they were told?
    c) Who was there?
    d) Did CHILD NAME have any idea what was going to happen?
    e) Since CHILD NAME has known about the diagnosis, what type, is any information has been provided: leaflets; chance to ask questions; books; dvds; an explanation from someone
    f) Who has provided information
    g) Did you have to ask for the information?
    h) Was the information available useful?
    i) What has been the most useful information?
    Tell me why it has been particularly useful

8) Do you feel that other people knowing about the diagnosis has altered the way they have treated or interacted with CHILD NAME?
        h) Is anyone more or less understanding?
        i) Teachers
        j) Yourself and your partner (if appropriate)
        k) Siblings
        l) Wider family-aunties, uncles, grandparents, cousins
        m) Friends
        n) Do your friends know about your diagnosis? Who told them? How did they react?
9) Tell me about any help CHILD NAME has received to understand the diagnosis.
        g) Meetings with a doctor/nurse/psychologist/autism specialist
        h) Opportunities to attend groups
        i) Was any choice given to CHILD NAME about the type of support?
        j) Informal support from yourself or other family and friends
        k) Self- help-has CHILD NAME done any research about autism-internet; library, etc.
        l) What has been the most/least helpful support?

10) Do you think the diagnosis has altered or impacted upon the way CHILD NAME feels about him/herself?
    a) More positive or less positive
    b) Differences or difficulties
    c) Future aims/hopes dreams ambitions
11) Tell me about any extra help CHILD NAME has had since finding out about the diagnosis
    a) From family
    b) At school/college
    c) Other professionals
    d) From friends
    e) Community-guides; cubs; sports/art/music clubs, etc.

12) How do you think CHILD NAME feels about the autism diagnosis now
    a) Mostly positive or negative
    b) Has it helped CHILD NAME understand him/herself

13) How do you feel young people with autism could be best helped to understand their autism?
    What would your advice be for:
    f) Doctors or psychologists
    g) Nurses or Autism specialists
    h) Parents
    i) People with autism
    j) Friends of people with autism

15. Tell me about CHILD NAME's ambitions for the future:

    g) An interest s/he would like to follow;
    h) A future career;
    i) Where CHILD NAME would like to live
    j) His/her potential academic achievements
    k) His/her friends
    l) His/her relationships

16. This is the last question: Is there anything else you think is important about how your child learn about their autism that you think it would be useful to add?

Thank you for sharing your views and your time.

Appendix 11: Online survey for professionals

How professionals support young people to understand an autism diagnosis

1 In order to take part anonymously and to withdrawn if you wish to later, please make an ID code below by entering

- The first two letters of your last name
- A two digit number for your month of birth
- The last two digits from the year you were born

E.g. John Drake born in July of 1999 would enter DR0799.Angela Smith born in November 2003 would enter SM1103.

2a. What is your current role?

- •Specialist Teacher (Autism)
- Specialist Teacher (Other-please give further details below)
- Specialist Support Practitioner (Autism)
- SENCO
- Primary Teacher
- Secondary Teacher
- Teaching Assistant
- Mental Health Professional (Please give details below)
- Speech and Language Professional (Please give details below)
- Occupational Therapist
- Social worker
- Other (please state)

If you wish to give further details about your role or you selected 'Other', please give details here

2.b Which area of the country do you live in?

- North East
- North West
- Yorkshire
- Humberside
- Midlands
- East Midlands
- West Midlands
- East of England
- London
- South East
- South West
- Wales

- Scotland
- Other (Please state)

2.c Approximately how many young people with autism have you supported to understand their diagnosis in the last year.:

- 0
- Fewer than 5
- 5-10
- 11-15
- 15-20
- 20 or more

2.d Please give the age range of the young people you support (Please select all that apply):

- 0-4 years
- 5-10 years
- 11-15 years
- 16-18 years
- Over 18 years

2.e Please explain if there is anything about your role that you did not get chance to explain.

3 Please indicate the type of general advice and support that you regularly provide in relation to children and young people with autism (Please select all that apply)

- Advice/support for school staff
- Advice/support for parents
- Training for professionals
- Training for parents/carers
- Interventions for young people
- Mentor role
- Counselling for young people
- Diagnostic work
- Therapeutic interventions
- Other (Please give details)

3.b Please explain about the work that you do that helps young people with autism to understand their diagnosis (this might include work directly with the young person, of those who educate or care for them)

- 3.c Please select the types of resource that you use (or advise others to use) to help young people to understand their autism diagnosis (If you use or advise a specific resource, please give the name in the box below).
  - Film clips
  - Non fiction/information books about autism
  - Fiction texts about autism
  - Autobiographies/biographies about people with autism
  - A published workbook about autism
  - Leaflets
  - Websites
  - Blogs
  - Social media
  - Bespoke resource created by yourself (Please describe it below)
  - Other (Please give details)
  - If you use or advise a specific published resources, please give the names in the box below).

3.c.ii It would be particularly helpful if you gave the name of the resource that you feel would be particularly useful in helping young people to understand their diagnosis.

3.c.iii How skilled do you feel when helping young people with autism to understand their diagnosis or when providing advice about how to do this?

- Not at all
- Slightly
- Somewhat
- Moderately
- Extremely

3.c. How often have you been able to access training in order to support you to help young people with autism to understand their diagnosis?

- Never
- Rarely
- Occasionally
- Regularly
- Very often

3.d. When helping a young person to understand their diagnosis, what topics would you usually include or advise others to include? (Please list the topics in the box below)

3e. Please explain below if there is anything else about the support or advice that you provide that you have not had chance to explain:

4 What do you feel are the 3 most important factors that support a young person to accept and/or feel positive about their diagnosis? (Please write your answers in the box below)

5. What do you feel contributes to the autism diagnosis having a negative impact upon a young person? (Please write your answers in the box below)

6. Please explain the main circumstances which would usually trigger an intervention to support a child or young person to understand an autism diagnosis?

7. Please explain how you involve parents in the support you provide to help Children/young people to understand their autism spectrum diagnosis.

8. Please describe any barriers you have identified that can prevent a child or young person accessing support to understand an autism spectrum diagnosis.

9. Please explain about any factors that serve to promote access to support with understanding an autism diagnosis for a child or young person.

10. Please explain how you liaise with other professionals in relation to the work you undertake to support children and young people to understand an autism spectrum diagnosis.

11. Please describe how you evaluate the impact of the work you undertake to support young people to understand their diagnosis.

12. Please share any other thoughts about promoters or barriers for supporting children/young people to understand an autism spectrum diagnosis.

13. If you would like me to send you a research summary of the research findings, please provide your e-mail address below. If you provide your e-mail address, it will only be used to provide you with the research summary.

Appendix 12 Interview schedule for professionals

1. Please tell me about your role.
2. Please could you explain how you are involved in supporting young people with autism to understanding their diagnosis, or in supporting their parents with this process.
3. Have you had any training that you feel has helped you with work relating to supporting young people with autism to understanding their diagnosis?
4. Do you feel confident when undertaking this work? m
5. How is it decided whether the young person will be supported to understand their diagnosis, or whether their parents receive advice to provide this support?
6. Have you noticed any specific signs or behaviours that you feel indicate that the young person might be struggling to understand or accept the diagnosis?

    a) What impact can this have upon the young person and those around them at home or school?

7. What do you feel are the most important factors that support a young person to accept and/or feel positive about their diagnosis?
8. What do you feel contributes to an autism diagnosis having a negative impact upon a young person?
9. Please could you tell me how you usually prepare and deliver your advice or intervention.
10. Could you tell me about the resources that you use most often to support your work around the diagnosis.
11. Have you ever undertaken work related to the diagnosis that you feel has had a detrimental impact?

    a) Could you tell me in what way it was detrimental?
    b) How did this impact upon you and any subsequent work?

12. Could you tell me about a specific intervention you have undertaken in relation to understanding of the diagnosis that you feel it has gone especially well?
13. Please describe how you evaluate the impact of the work? (This might involve formal or informal methods)
14. Please share any other thoughts that you feel are important when considering about how young people are supported to understand their autism diagnosis:

Appendix 13 Extracts from research journal notes

Pseudonyms are used throughout all of the research diary extracts for people, places and organisations, as outlined in the ethical agreement, in order to provide anonymity and to maintain confidentiality.

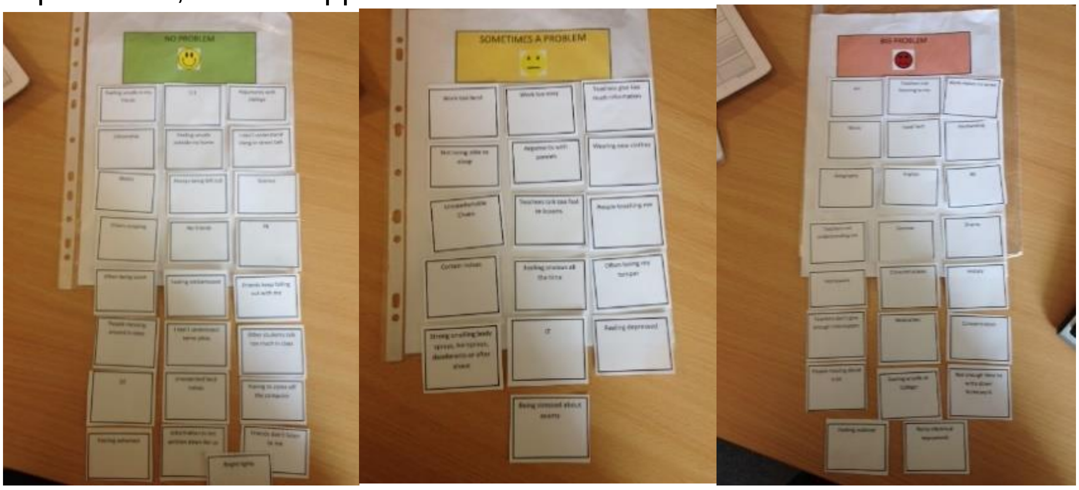
This is a small selection of journal notes to serve as illustrative examples:

Extracts from diary relating to research methods:

3.11.2013

Development of scale for interview that can be used if volunteers have communication needs/benefit from visual prompts.

The statements are general statements abouts interaction, academic experiences, etc. to support individual discussion.



Does the scale need to be closer to that used in the survey. I'm not repeating the survey, I'm aiming for greater depth, it is just to support discussion. Offering a selection might be useful. However, the statements are too negatively focused. If this is used, I need to improve statements, more positive school interactions:
For example: I have lots of good friends; I have a few friends; I have a good friend; I prefer to be on my own. I feel ok when chatting with friends; I am popular; etc. Teachers support me well; I enjoy school; teachers explain things well; I'm doing well at school; etc.

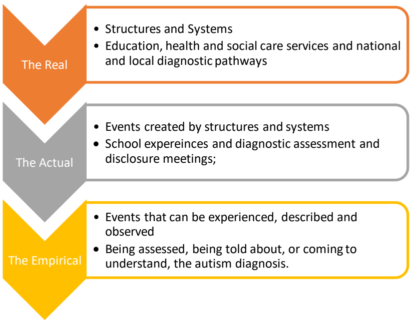
Discussed during supervision-too many statements. Perhaps just focus on topics, without statements so they are fully neutral. This seems a better approach.

There is the possibility of the special school provision sending out information to parents. Therefore, a second version was thought useful, with images for children who also have intellectual impairment and/or whose communication is best supported with visual prompts/symbols. Use Communicate in Print or Makaton.

Date	Reflections on methods	Reference to specific data source if applicable
June 2014	Participation seems to be low so far for the survey. Sending out more requests though. Also conference later this month will be an opportunity to advertise to professionals, who might be willing to disseminate. Concerned about sampling and participants- while a representative sample was hoped for, it is looking problematic, despite sending out lots of requests, participation is still low Sampling is often made largely on pragmatic considerations: Note Murphy, et al 1998) highlight that this is often the case in quantitative research. Stewart and Shamdasani (1990, p.53) convenience sampling can be employed as long as the group consists of a representative sample of the larger population. For the preliminary study, an opportunity sample was necessary, demographics were considered to ensure that it was a representative of the population under consideration, the responders comprised a range of ages, socio-economic groups and genders. Although there were more mothers than fathers attending the training, this is typical for parent programmes and parent training.	NA
October 2014	Parent Interview 1 It became apparent soon after the interview began that [redacted] had not been told about her autism diagnosis. I was surprised as I had discussed the research purpose with her mother when organising the interview. When this was first revealed, I was worried the interview would not be useful. However, it became apparent that although [redacted] mum had not discussed autism with her, she was discussing differences with her. She was using the notion of ‘a different brain. Therefore, the interview was actually very useful, many parents are likely to discuss differences before introducing the specific diagnosis. However, while this interview was useful, when arranging future interviews, it will need to be much more explicit about the child’s knowledge of the diagnosis.	Parent Interview 1 Transcript 2
August 2014	**Beginning analysis of first data** Need to focus on diagnostic experience rather than experience per se. Focus upon the meaning of the experience (event-process-relationship) to the participant.	

	Remember-participant and researcher are interpreting-double hermeneutic Aiming to consider each contribution/participant then–then consider convergence and divergence across the data set. Things to consider: 1 What are the experiences at particular times, which are relevant to the diagnosis 2. identify the services and interventions etc. that impact positively 3. Are there related findings from conventional research-but after my analysis, don't let other research influence. 4. situate and understand people in their socio-cultural context-what contributed/detracted 5. evaluate and reflect upon the role played by therapeutic/family support 6. re-evaluate existing theory	
November 2014	NVivo used for the focus group analysis. I think this was not helpful. For this type of information, it was better just to read and note key points. NVivo was helpful when looking at the transcript from the documentary DVD about young people's experiences, comparing analysis undertaken in NVivo and by hand was useful, the methods seem to support thinking in different ways. Also the automatic coding is a useful first step in NVivo, I think I'll continue with the main data, however, the hand coding is when I really getting a 'feel' for the data. I think I will always need to do this as the main approach.	Appendix 5.7
December 2014	Parent Interview 2 Another useful interview. What was apparent through this interview is that Xs mother was still questioning the diagnosis. She had been told so many times her son does not have autism, she is now doubting the diagnosis. What is surprising is that X's dad already has an Asperger diagnosis, yet the doubts are very evident. I found this very surprising, It was apparent that despite her husband having autism, X's mum had not had any support to understand autism. The impact of the professional's who had not recognised her concerns about X was also clear. However, it was apparent from X's mother that their attempts were probably to reassure her but the long-term impact was not anticipated	Transcript 4
January 2015	Systematically going through the search terms again although time consuming was useful, notes were	Literature search-Appendix 1

	taken about the process itself, which was useful as I didn't do this when I undertook the main research. The work undertaken on this search and analysis so far has taken a significant amount of time. I think it is likely that it will make a chapter in its own right. I think that I will find it beneficial to my thinking to write this section soon possible. It is only when I start writing that I am really able to engage with thinking about the implications and the relevance to the research I am carrying out. Still little from young people about their experiences. Also I think parents do most of the work around supporting children's understanding. There is still very little research exploring exactly how they approach the work though. Research with parents does focus on the impact on them, so little on the child or how they help them to understand the diagnosis. **Thoughts from work on the literature review: How has diagnostic disclosure been explored by other researchers**: Scaled measures of loneliness, sense of community, self-perceptions, coping, and social support prior to intervention, post-intervention, and delayed post-intervention; Semi-structured qualitative interviews Narrative analysis of biographies. **The key factors outlined as helpful to the process by the research:** Giving realistic, positive and hopeful messages is the start of providing good support More contact with others with the same diagnosis decreased loneliness, and increased social acceptance and confidence Young people feel it was important to maintain their position as knowledgeable individuals within the process of support Quicker and easier diagnostic processes improve outcomes Good interpersonal skills of professionals involved in the process impact upon outcomes By shifting attention from deficits to social participation, individuals with autism may be better prepared to engage in the process of identity construction The importance of put greater emphasis on the child perspective when developing and using self-report measures	

	Young people might answer questions regardless of their understanding of the question. Important to consider this in any further interviews. The importance of using factual language	
July 2017	Child interview. Interview today with XXXXX. Having spoken with his mother, she indicated that he disliked visual supports and was very able, so I did not need to use any visual support for the interview with him. I followed her advice; however, I feel he would have benefitted from developmentally appropriate visual support. Building trust with participants is important though. There were times during the interview when I felt visuals would have made such a difference. I think in future child interviews I will always have the visuals I have created with me; I think if I had introduced the visuals as a usual part of the interview, they would not have been problematic for XXXXX. In my day job, my advisory work, I would not have made a visit without a range of resources in my bag to support discussion. I need to apply this knowledge to the interview, The visuals that I usually use make such a difference to my communication with children. I must not underestimate the importance of this in future.	Transcript 3
October 2017	When writing the research methods chapter, I noted that I seem to need to do things in specific orders I was rethinking the ontological layers based on the diagram I created previously:  It occurred to me that parents do not really appear here- this might be just my conceptualisation, but I need to go back to the NICE Pathways to consider this against the findings, this seems to be a possible approach to consider the research data against.	Bhaskar's (1975; 2008) Ontological Layers Applied to Diagnostic Pathways for Autism (NICE, 2017)

<table>
<tr><th colspan="2">Redacted to ensure confidentiality

Fieldwork Notes: examples of reflections on pertinent practice-based work specifically related to autism diagnosis that have informed my thinking while undertaking this study.</th></tr>
<tr><th>Notes from practice and context</th><th>Reflections in relation to research</th></tr>
<tr><td></td><td></td></tr>
</table>

Appendix 14 Confirmation of ethical approval numbers

Appendix 14.1 Approval number for Kids Autism Training Research:

Ethical Approval ERN_11-0332

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for your project, subject to the Committee's satisfaction with your response to the following conditions:

- Please confirm whether any of the research has already commenced
- Please confirm how the researchers will become aware of children that have recently been diagnosed with Autism Spectrum Disorder
- Please clarify how voluntary consent/assent is to be obtained from the children if their parents have had to 'coerce' their children to attend the sessions
- Please consider amending the parent information sheet so reference to the wording 'coerce' is changed to sound more appropriate. For example, the phrase "Your child may need encouragement and support to attend the classes" may be more appropriate to use
- Please clarify whether it will be possible to link up data from the child, parents/carers and teachers so that the identity of the child will be known
- Please ensure that safeguarding requirements regarding disclosure of harm are included in all participant information
- Please include information about how discoveries of harm will be handled
- Please make clear on all participant information sheets that the study will initially be a pilot to determine how best to design, deliver and evaluate a training programme for carers of children diagnosed over the age of eight
- Please be aware of the data storage and retention requirements in the University's new Code of Practice for Research (available at http://www.as.bham.ac.uk/legislation/docs/COP_Research.pdf). In particular, please note that following completion of the research, data should normally be preserved and accessible for ten years. Data will also need to accessible to the supervisor and for academic audit, so please ensure this is accurately reflected in all participant information
- Please confirm that necessary permissions have been obtained to use Simpsons characters in participant information (if relevant)
- Please ensure that details of how to withdraw from the study are included in all participant information
- Please include the supervisors contact details on all participant information
- Please ensure that any abbreviations (e.g. CAT/KAT) are explained on all participant information
- Please confirm that the researcher's colleague who will be co-delivering the training will be fully informed of the research and what is required in terms of questionnaire administration.

Appendix 14.2 Confirmation e-mail for main study-survey and interview

Ethical Review ERN_13-0961 is the approval number for the main study:

"How are young people with Autism supported to understand and come to terms with diagnosis?"

Thank you for your application for ethical review for the above project, which was reviewed by the Humanities & Social Sciences Ethical Review Committee. The study was granted conditional ethical approval on 3rd October 2013.

On behalf of the Committee, I can confirm the conditions of approval for the study have now been met and this study now has full ethical approval.

Approved amendments following recommendations from Humanities and Social Sciences Ethical Review Committee:

Application for Ethical Review ERN_13-0961: "how are young people with Autism supported to understand and come to terms with diagnosis?"

I have carefully considered and attended to each point as summarised below and where appropriate have attached the amended documents:

1. Please clarify if parents are able to participate in the questionnaire even if their child is not.
   Response: Yes, it will be possible for parents to participate through the online questionnaire even if their child does not. As it is possible to identify paired parental/child data from the codes, the data sets for this analysis can be analysed comparatively, while the data from parents can be analysed as a discrete set. However, due to both time constraints and to meet the identified methodological constraints, the interviews will only be undertaken when both a parent and their child wish to participate.

2. Please clarify when confidentiality will be breached in relation to safeguarding concerns that may arise, and include this in both the information sheets. Please also clarify the procedure to be followed in such circumstances.
   Response: I have read the University of Birmingham, Code of Practice for Research (2013 to 2014) and understands the requirements. I have taken note particularly of section 3.6 and of of 10.1.6 Breach of any relevant Duty of Care. I have also consulted the ethical standards for educational research (British Educational Research Association, 2011, p. 8) and is fully aware of the safeguarding requirements as set out in the latest national statutory guidance: HM. Government (2013) *Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children.* London: Department for Education (DfE). Available at: http://media.education.gov.uk/assets/files/pdf/w/working%20together.pdf

   If a safeguarding concern is encountered through the research process confidentiality will be breached if a child or young person discloses an issue that is illegal, detrimental to their safety, health or wellbeing. In these circumstances, if disclosure takes place within an educational setting or charitable organisation, the issue will be discussed with the relevant named person with responsibility for safeguarding, so that the settings established procedures can be followed. This is the most appropriate way to respond in these circumstances, as the named person would be aware of any previous concerns or disclosures, or background information such as whether the Child Assessment Framework (CAF) process has been initiated for the child or young person, and any other information that might be relevant to the individual's circumstances. As identified within the research information, the participants will be informed that safeguarding issues might require confidentiality to be breeched prior to their participation. Written notes will be carefully maintained with regards to disclosures in such circumstances, relating to the details of the disclosure and the procedures followed. The Humanities and Social Sciences Ethical Review Committee will also be kept informed and consulted with, as appropriate to the situation. The participant and/or their parent/guardians will be advised of the intention to break confidentiality in relation to disclosure, if this is not likely to place the child or young person at further risk or interfere with the safeguarding procedures. Where there is uncertainty with regard to the safety or procedural implications of informing the participant, and/or their parent/guardian, that confidentiality relating to a disclosure might be breached by contacting the relevant authorities, this will be discussed with the named person and/or the local safeguarding officials first.

However, it is recognised that as some of the parent networks might be more informally organised, it might not always be possible to raise the concern through a settings named person for safeguarding. In these situations the local area safeguarding procedures will be followed. These are available through the Local Safeguarding Children Board arrangements, which are available via local authority websites; the researcher will ensure she is aware of the relevant local area details prior to working with participants. The Statutory Guidance (HM. Government, 2013, p. 14) highlights that:

"Anyone who has concerns about a child's welfare should make a referral to local authority children's social care. For example, referrals may come from: children themselves, teachers, a GP, the police, health visitors, family members and members of the public".

In Kent for example, the following public facing webpage contains relevant contact details: http://www.kscb.org.uk/worried_about_a_child.aspx

The researcher is also aware that she has a duty to follow through a referral relating to safeguarding, if she is not satisfied that a named person within an organisation will follow up the concerns raised correctly. The statutory guidance makes this clear:
"…no professional should assume that someone else will pass on information which they think may be critical to keeping a child safe. If a professional has concerns about a child's welfare and believes they are suffering or likely to suffer harm, then they should share the information with local authority children's social care". (HM. Government, 2013, p.16)

3. Please amend the information sheet to read … '*so that you can consider whether it is appropriate to ask your child whether he/she want to take part'* instead of the current sentence reading 'so that you can consider whether it is appropriate for your child to take part.' as this makes it clearer that the child has to give consent, independently of the parent.
   Response: The wording has been changed as advised. Amended documents attached.

4. Please provide copies of the consent forms for parents for both the interview and the questionnaire.
   Response: Consent forms for both are attached. They were within the same document in the original application. I have put them into individual documents for ease of identification.

5. Please confirm what safeguarding mechanisms will be used to ensure that parental consent is obtained prior to a child accessing the online survey link, if this to be published on various websites.
   Response: The British Psychological Society (2010) highlights that anonymous at source collection methods reduce the risk for participants. It is also planned that invitations will go to parents and guardians, who will be able to make an informed decision about whether it is appropriate to pass the participation request on to their child. The organisations where

the survey is being advertised will be asked to send the invitations via their e-mail groups, to ensure that the invitation goes to parents/guardians.

It had also been planned to ask the charity to advertise the questionnaire on their website on a section of the site aimed at parents rather than children. However, it is acknowledged that the nature of an internet questionnaire can make it very difficult to ensure that parents have always given consent. Therefore, the information and the research purposes will also be provided before the online questionnaire and participants will be asked to speak with their parents/guardians about the research to get their permission to take part, if they have not already done so, before they complete the questionnaire. This is an approach that has been considered by some to be ethically appropriate and is used by large organisations such as the BBC for their Newsround and Ouch disability blogs and surveys, who ask children and young people to contribute online:

http://www.bbc.co.uk/newsround/24394725

http://www.bbc.co.uk/news/blogs/ouch/

http://www.autism.org.uk/news-and-events/news-from-the-nas/survey-about-autism-teams.aspx

http://www.autismeducationtrust.org.uk/Global/News/My-way-2.aspx

The Economic and Social Research Council (2010) does not give guidance specific guidance on online research but suggests consulting the British Psychological Society (BPS) (2007) guidance. The BPS guidelines (2007) highlight a number of issues concerning Internet Mediated Research (IMR) relating to the verification of identity and ‘real’ informed consent. The nature of online data means that it is difficult to ensure informed consent, as it cannot be certain that participants read the information provided before giving consent. Furthermore, it is not possible to guarantee the age or identify of the person completing the survey. However, the guidelines suggest that IMR should still be possible with children and young people as long as additional steps in place to reduce the above risks. In this case the most problematic issue is finding a suitable way of addressing of the issue of identify and consent. After reconsidering the above concerns, it is felt that the above issues could best be mediated by ensuring that the invitations to participate are only sent out through existing e-mail groups to members, rather than publishing the survey on a website. This will ensure that they go directly to parents (or legal equivalent) so that consent can be obtained before children take part.

References

British Psychological Society (BPS) (2007) **Conducting Research on the Internet: Guidelines for ethics practice in psychological research** [Online]. Available at: http://www.bps.org.uk/sites/default/files/documents/conducting_research_on_the_internet-guidelines_for_ethical_practice_in_psychological_research_online.pdf (Accessed 05 October 2013).

Economic and Social Research Council (2010) **Research Ethics Framework** (Updated 2012)[Online]. Available at: http://www.esrc.ac.uk/_images/Framework-for-Research-Ethics_tcm8-4586.pdf (Accessed 05 October 2013).

6. Please use the UoB logo on the information sheet and invitation letter to be sent to participants, as the research is being conducted on behalf of the university.
   Response: The logo has been attached to all documents. See attached.

7. Please be aware of the data storage and retention requirements in the University’s new Code of Practice for Research (available at

http://www.as.bham.ac.uk/legislation/docs/COP_Research.pdf). In particular, please note that following completion of the research, data should normally be preserved and accessible for ten years.
Response: I have accessed the University of Birmingham, Code of Practice for Research (2013-14) and I am aware that data should be preserved and accessible for ten years.

Additional suggestion from the committee:

- Please consider an alternative/additional way of recording the codes for participants in case they withdraw from the process, as practicalities of the vulnerable individuals recording this information for themselves may be a struggle.
  Response: It is acknowledged that some individuals might find recording this information difficult; however, this approach enables the participant's anonymity when taking part. On balance, this was felt most important. However, as the code is not randomised, if participants could not remember their code, it would still be possible for them to enable me to identify their questionnaire, if they got in touch and provided their family name, month and year of birth. Perhaps the statement at the top of the questionnaires could be changed to the following:

  For example John Drake born in July of 1999 would enter DR0799. Angela Smith born in November 2003 would enter SM1103. Please keep a record of this code for yourself; if you later change your mind and do not want your information to be used, the code will make it possible to identify your information so it can be withdrawn. However, even if you cannot remember the code, please get in touch as it might still be possible to withdraw the information if you provide some additional details.

Appendix 14.3 Approval number of ethical renewal for the main study

Application for Ethical Review ERN_13-0961R

Appendix 15 Research information for parents and children and young people

Appendix 15.1 Information for children

I am doing some research to try to find out what children and young people think about how they found out about their autism. I would like to invite you to take part in my research.

If you wish to take part, I will ask you some questions about yourself and your autism. I would like you to tell me as much as you can about finding out about your autism diagnosis. This not a test and there are no right or wrong answers. Many of the questions are about your feelings.

As you might have lots to tell me, I will make some written notes and record the words you say on a digital voice recorder. I use a voice recorder as it can be difficult to write down everything that is said.

After the interview, I will write down the words you say. You can have a copy when I have finished writing them down. I will also think very carefully about the things that you tell me and try work out the most important parts to write in my report.

If you agree, I would like to show you this so you can tell me if I have picked out the most important things. To do this I would have to come back to see you.

I will be writing a report about the findings from this research and hope the report will be published in a research magazine. This will help other people who work with young people with autism.

When I write my report, I might include some of the things you write or tell me about, but I will not use your real name so people will not know that the information came from you. You can choose a pretend name for me to use in the report, if you would like to.

Please do not feel that you have to take part, if you don't want to.

If you decide to take part, the written information with your name on it will only be seen by me and my university tutor. When I am not using the information it will be locked away. I will have to keep the information in a safe place for 10 years. This is in case the information could be useful to other researchers; if other researchers do wish to look at the information, they will also have to follow the rules above.

Would you like to take in the research?

Yes or

No

Please sign your name below **<u>if you would like to take part</u>**.

Young person's signature for agreement to take part in the research:

Parent/Guardian, please sign on the line below if you give consent for your child to take part:

____

Date:______________________

NOTE: All images from http://office.microsoft.com/en-us/images/

Appendix 15.2 Information for parents

Dear Parent/Carer,

I am currently employed as a Senior Lecturer for the Childhood Studies Department at [redacted] University and I am undertaking a research-based PhD qualification at the University of Birmingham. My research aims to explore children's and young people's views about how they were informed about their autism diagnosis and how they have been supported to understand it.

The National Institute of Clinical Excellence's (NICE) recently published guidance called 'Autism: recognition, referral and diagnosis of children and young people on the autism spectrum'. This report identified evidence of both immediate and longer-term benefits from the provision of 'accurate, appropriate and sympathetic information' for young people following an autism diagnosis (NICE, 2011, p. 184). They also identified a gap in the evidence base, relating to young people's views upon how they are supported to understand their diagnosis.

The aim of this study is to explore the views of young people with autism about how they have been supported to understand their diagnosis. It is anticipated that understanding the views of young people will support the identification of strategies, which those helping young people understand their diagnosis can employ.

This invitation to take part in the research has been sent to you, as a parent or guardian of a child with autism, so that you can consider whether it is appropriate for your child to take part in a research interview. It is essential that your child is under 18 years of age and that they already know that they have an autism diagnosis. If you child does not already know about their diagnosis, **please do not feel that you should inform them so that they can take part in this research**.

It is very important that you tell your child about their diagnosis when you feel the time is right. This is often when the child becomes aware of differences from peers and starts to ask questions. However, the right time will vary from child to child, some parents tell their children about their diagnosis when they're quite young (primary school age), other parents choose to wait until their child is older because they feel they will understand the diagnosis better. I have included some links to sources of helpful information about autism diagnosis and telling a child about their diagnosis. If your child does not know about their diagnosis, you might find the information useful when you feel the time is right to tell them.

I have full clearance for working with young people (CRB Certificate); this will be shown to parents/guardians prior to the interview. In addition to my academic qualification, Master of Education (Children with Autism), I have over ten years of experience of working with children and young people with autism, including six years of experience as a specialist teacher for children and young people with autism. In undertaking this latter role, I regularly undertook one to one interviews with children and young people with autism for assessment purposes, initiated therapeutic approaches to support the development of their emotional understanding, and provided specialist support in both one to one and group situations to help them to understand their diagnosis. I hope that you will be reassured my experience will reduce the likelihood of causing any upset for your child and will ensure the appropriate response can be provided should any upset in discussing their diagnosis arise.

At the interview, in addition to making some brief written notes, I will make an audio recording of the session. This information will be transcribed into a written text to support analysis. If your child is happy to meet with me again, I will explain my analysis to them and ask for their opinion. This helps me to identify whether I have understood their meaning correctly.

After completion of the research, I will actively seek opportunities to publish it in order to make it available to people who care for, educate and support children and young people with autism. However, no information that could be used to identify the people who take part will be included within the research write up. Following completion of the research, interview data must be preserved for ten years and accessible to my supervisor and for academic audit. However, it will be stored safely in a secure area. This is guaranteed within the ethics code of the University and the Data Protection Act of 1998. While information collected for the research will be kept confidential, in line with safeguarding requirements, any disclosures of harm will be discussed with the appropriate safeguarding professionals.

Thank you for taking the time to consider this request. Please contact me if your child would like to participate. Also, do not hesitate to contact me if you require any further information (Contact details).. My research supervisor is Dr K. Wittemeyer, she can be contacted at the University of Birmingham (Contact details).

Yours sincerely

Julie Prentice

(Contact details)

Note: The NICE (2011) report can be accessed at the following link:

- http://www.nice.org.uk/nicemedia/live/13572/56424/56424.pdf

A useful source of information about autism and telling a child about their diagnosis is available from the National Autistic Society at the following link:

- http://www.autism.org.uk/about-autism/all-about-diagnosis/diagnosis-the-process-for-children/after-diagnosis.aspx

Information and support for parents after diagnosis is available at the following links:

- http://www.nhs.uk/Livewell/Autism/Pages/Thediagnosisofautism.aspx
- http://www.youngminds.org.uk/for_parents/worried_about_your_child/living_autism?gclid=CJ6soN_6xLMCFW_KtAod6CcArQ
- http://www.mencap.org.uk/all-about-learning-disability/information-parents-carers-and-familyhttp://www.mencap.org.uk/all-about-learning-disability/information-parents-carers-and-family

Appendix 16 Research information and consent for professionals

Understanding An Autism Spectrum Diagnosis-A Research Study

Information for professionals considering taking part

in a semi-structured interview

This research aims to explore how children and young people are supported to understand an autism spectrum diagnosis. In order to investigate this process, I am exploring the views of young people with an autism spectrum diagnosis, their parents and professionals who work with them. This research is being undertaken as part of a research-based PhD programme at the University of Birmingham.

The National Institute of Clinical Excellence's (NICE) published guidance which identified evidence of both immediate and longer term benefits from the provision of 'accurate, appropriate and sympathetic information' for young people following an autism diagnosis (NICE, 2011, p. 184). They also identified a gap in the evidence base, relating to how they are supported to understand their diagnosis.

The aim of this study is to identify strategies which those helping young people understand their diagnosis can employ. I will, therefore, actively seek opportunities to publish the research in order to make it available to people who care for, educate and support children and young people with autism.

If you agree to take part in an interview you will not be asked to provide any information that will enable your employer or the young people you work with to be identified. If you change your mind at any point during the interview we can stop immediately and your information will not be used. You can also ask for your information to be withdrawn from the study for up to 3 months afterwards by sending me an e-mail requesting withdrawal. In addition, no information that could be used to identify the people who take part will be included within the research write up. Following completion of the research, data must be preserved for ten years and accessible to my supervisor and for academic audit. However, it will be stored safely in a secure area. This is guaranteed within the ethics code of the University and the Data Protection Act of 1998.

The interview will focus upon aspects of the work you undertake which is focused upon helping young people with autism to understand their diagnosis. This might include work undertaken directly with young people, or with parents, carers or educators in order to provide them with advice about helping a young person to understand their diagnosis.

The interview will be recorded using a small audio recorder. And will be transcribed in full afterwards. I will also take notes of key points during the interview as this can be helpful if any issues arise with the audio recording. You will be asked a series of open questions about the work related to diagnosis that you undertake so that you can provide as much detail as you feel comfortable to provide.

Thank you for taking the time to consider this request. Please do not hesitate to contact me, if you require any further information (Contact details). My research supervisor is [redacted], she can be contacted at the University of Birmingham (Contact details).

Yours sincerely

Julie Prentice

(Contact details)

Useful sources of information:

The NICE (2011) report can be accessed at the following link:

- http://www.nice.org.uk/nicemedia/live/13572/56424/56424.pdf

A useful source of information about autism and telling a child about their diagnosis is available from the National Autistic Society at the following link:

- http://www.autism.org.uk/about-autism/all-about-diagnosis/diagnosis-the-process-for-children/after-diagnosis.aspx

Information and support for parents after diagnosis is available at the following links:

- http://www.nhs.uk/Livewell/Autism/Pages/Thediagnosisofautism.aspx
- http://www.youngminds.org.uk/for_parents/worried_about_your_child/living_autism?gclid=CJ6soN_6xLMCFW_KtAod6CcArQ
- http://www.mencap.org.uk/all-about-learning-disability/information-parents-carers-and-familyhttp://www.mencap.org.uk/all-about-learning-disability/information-parents-carers-and-family

Understanding An Autism Spectrum Diagnosis:

A Research Study

Consent to take part in a semi-structured interview

Do you agree to take part in the research described over the page?

Yes ☐or No☐

Please sign your name below **<u>if you would like to take part</u>**.

Signed:

____

Date:______________________

Appendix 17 Recruitment Activities

Appendix 17.1 Short summary of research for National Autistic Society and Research Autism websites.

Autism/Asperger Diagnosis and the Impact on Young People

This research is being undertaken by Julie Prentice a PhD Student at the School of Education, University of Birmingham.

This research will use online surveys and interviews to explore children and young people's views about how they have been helped to find out about their autism/Asperger diagnosis, in order to inform people developing strategies in the future. Information about the process and impact on the child is also sought from parents/carers in order to gain the most complete picture.

Children and young people aged between 7 and 19 years old who have an autism spectrum diagnosis can access the survey at: **Survey link**

The Parent/carer survey can be accessed at: Survey Link

I will also be undertaking a small number of in-depth interviews with children, young people and their parents/carers. Interviews can be face to face, by telephone or by Skype. If you would like to participate in an interview, please contact Julie Prentice: (Contact details).

Appendix 17.2 Confirmation of advertisement on website

Research Autism
@ResearchAutism

Birmingham University recruiting participants for study into
Understanding an #Autism Spectrum/#Asperger Diagnosis researchautism.net/take-part-in-a...

3:34 pm · 8 Jun 2017 · Twitter Web Client

Subject: RE: Application to advertise research on website.

We have now posted your study online on the Research Autism website at http://www.researchautism.net/take-part-in-autism-research where it will remain for the next 3 months. We have also posted it on the Research Autism social media channels (Twitter https://twitter.com/ResearchAutism , Facebook https://www.facebook.com/ResearchAutism , and Google+ https://plus.google.com/106232069643803503278) which have a combined reach of more than 10,000 followers.

Appendix 17.3 Online Survey- request to participate and to share information with parents

Date	Area	Type of contact	Contact detail removed to maintain anonymity	response
23.05.14	Kent	Kent Autism Trust	Contact for a number of parent groups in the area	Sent out at the beginning of July Agreed to advertise
23.05.14	Bristol	Parent support group		No response
23.05.14	Avon	Parent support group		No response
19.06.14	Kent	School with autism provision		No response
19.06.14	Kent	School with autism provision		No response
19.06.14	London	Outreach Team		No response
19.06.14	London	School with autism provision		No response
20.06.14	Kent	School with autism provision		Unable to distribute
19.06.14	Kent	School with autism provision		No response
20.06.14	Oldham	School with autism provision		Distributing to parents of children from her provision and the wider school
19.06.14	Oldham	Outreach Team		Distributing to parents she meets as part of her role and via a local parent group

Date	Area	Type of contact	Contact detail removed to maintain anonymity	response
20.06.14	Kent	School with a range of autism provision		
19.06.14	Stockton-on-Tees	Outreach Team		Yes, will send out in their area
20.06.14	London	School with autism provision and Outreach team		
20.06.14	Sunderland	Outreach Team		Forward to manager for approval
20.06.14	Sunderland	School with autism provision and Outreach team		No response
20.06.14	Leicestershire	Outreach Team		No response
07.07.14	Staffordshire	Outreach Team		No response
07.07.14	Brent London	Outreach Team		Manager AOT Replied sending out with caseworkers on team in September and adding to local group newsletter
07.07.14	Northhampton-shire	Outreach Team		No response
07.07.14	Peterborough	Outreach Team		No response
	Somerset	Outreach Team		No response
07.07.14	Greenwich	Outreach Service		Sent to 420 Families Living with Autism in Greenwich via newsletter

Date	Area	Type of contact	Contact detail removed to maintain anonymity	response
07.07.14	Dudley	Autism Outreach Service		No response
07.07.14	London Borough of Hounslow	Autism Outreach Service		No response
07.07.14	Norfolk	Autism Outreach Service		No response
07.07.14	Essex, Suffolk and Cambridge-shire	Autism Outreach Service		No response
07.07.14	Hampshire	Autism Outreach Service		No response
07.07.14	Bristol	**NAS Bristol branch**		No response
07.07.14	Avon	**NAS Avon branch**		No response
07.07.14	Online	**Support group**		No response
07.07.14	Devon	small charity for parents of children with autism		No response
07.07.14	Barnet	**NAS branch**		No response
07.07.14	Bexley	**NAS branch**		No response
07.07.14	Camden	**NAS branch**		No response
07.07.14	Enfield	**NAS branch**		No response
07.07.14	Greenwich	**NAS branch**		No response

Date	Area	Type of contact	Contact detail removed to maintain anonymity	response
07.07.14	Haringey	**NAS branch**		No response
07.07.14	Kingston	**NAS branch**		No response
07.07.14	Lambeth	**NAS branch**		No response
07.07.14	Newham	**NAS branch**		No response
07.07.14	Richmond	**NAS branch**		No response
07.07.14	Southwark	**NAS branch**		No response
07.07.14	Sutton	**NAS branch**		No response
07.07.14	West London	**NAS branch**		No response
01.07.17	Hertfordshire	**Outreach Team**		Yes will disseminate
01.07.17	Yorkshire	**Outreach Team**		Yes will disseminate
01.07.17	Anglesey	**Outreach Team**		Yes will disseminate
01.07.17	Northamptonshire	**Outreach Team**		Yes will share information
01.07.17	Newport	**Outreach Team**		No response
01.07.17	Gwent	**Outreach Team**		No response
01.07.17	Caerphilly	**Outreach Team**		Yes will share information with colleagues and parents
01.07.17	Southwark	**Outreach Team**		No response
01.07.17	Freemantles, Surrey	**Outreach Team**		No response
01.07.17	Leicestershire	**Outreach Team**		No response
01.07.17	Aberdeen	**Outreach Team**		No response
01.07.17	Coventry	**Outreach Team**		Yes will share information
01.07.17	Bristol	**Outreach Team**		Yes will share information with colleagues
01.07.17	Peterborough	**Outreach Team**		Yes will share information with colleagues and parents

Appendix 18 Results from children’s and young people’s survey

Appendix 18.1 Survey statements from children and young people: Scores calculated for children’s responses to each section of the online survey

	Before diagnosis	Before %	Finding out about diagnosis	Finding out %	After diagnosis	After %
1. F	56	74.66	75	60	60	66.66
2. F	37	49.33	78	62.4	59	65.55
1. M	26	34.66	77	61.6	58	64.44
2. M	30	40	85	68	72	80
3. M	33	44	63	50.4	34	37.77
4. M	32	42.66	113	90.4	76	84.44
5. M	28	37.33	84	67.2	51	56.66
3. F	23	30.66	84	67.2	59	65.55
6. M	28	37.33	109	87.2	52	57.77
7. M	40	53.33	89	71.2	68	75.55
4. F	29	38.66	102	81.6	67	74.44
Mean	32.91	43.87	87.18	69.75	59	66.26
Median	30	40	84	67.2	59	65.55
Mode	28	37.33	84	67.2	59	65.55
Max	56	75	113	90	76	84
Min	23	31	63	50	34	38
Range	33	44	50	40	42	46

Appendix 18.2 Online Survey: Before diagnosis-CYP’s scaled responses

	Survey Statement	5 Strongly Agree	4 Agree	3 Not Sure	3 Not Relevant	3 Other	2 Disagree	1 Strongly Disagree
1	I didn't know anything about autism	4	4	0	1	1	1	0
2	I was confident about my ability	1	2	0	1	1	4	2
3	I was confident when chatting with class peers	0	3	0	0	1	3	4
4	I worried about many things	7	0	0	2	0	2	0
5	I knew I was different to other young people	5	2	0	1	0	2	1
6	I didn't have much confidence in myself	5	3	0	2	0	1	0
7	Everything was fine	0	2	0	1	0	4	4
8	I never worried about anything	0	1	1	0	0	1	8
9	I struggled to get on with other people	5	4	0	0	0	2	0
10	I had no idea that I had autism	6	3	0	2	0	0	0
11	Nothing ever seemed to work out as I hoped	1	5	3	1	0	1	0
12	I was doing well at school	1	1	2	0	0	3	4
13	I felt that no-one understood me	5	5	0	0	0	1	0
14	I felt 'normal'	0	2	0	3	0	2	4
15	I was finding school difficult	8	2	1	0	0	0	0

Appendix 18.3 Online Survey: Finding out-CYP’s scaled responses

Finding out about my autism diagnosis statements	5 Strongly Agree	4 Agree	3 Not Sure	3 Not Relevant	3 Other	2 Disagree	1 Strongly Disagree
1. My parents told me about my diagnosis	7	2					1
2. My parents explained the diagnosis very clearly	2	3	3			1	1
3. A doctor or autism specialist told me about my diagnosis	4	3	1			2	
4. The doctor or other specialist was able to tell me lots of helpful information	2	2	3	1	1	3	
5. Going through the diagnostic process helped me to put my experiences into perspective	3	4	4				
6. I was given lots of helpful information leaflets			1	3		4	2
7. Finding out was a real surprise to me, I didn't realise that anyone thought I had autism	2	3	1	1		3	1
8. Finding out has been a very positive experience	5	2	2	1	1	1	
9. When I found out, it made me feel like I had been given a label	2	1	2	1	1	3	1
10. Being told I had autism provided me with what felt was like a fresh start	1	3	2			4	1
11. Finding out about autism was a difficult process, which involved many assessments and meeting	3	3	3			1	1
12. When they told me, I thought they had got it wrong			4	1	1	3	2
13. When I found out, I felt that I needed to look for information about autism so I understood what it meant	2	1	2			4	1
14. I used the internet to research information about autism	2	2	1	1		3	1
15. When they told me about the autism diagnosis, I felt empowered	1	3	3	1		2	1
16. I was helped to understand autism and to recognise all the things I'm good at	2	5	1			3	
17. Finding out, helped me to see the evidence about who I am	3	5		2		1	
18. All I was told was about the negatives related to autism	1					8	2
19. Accessing websites/blogs/tweets created by other people with autism has been really helpful in coming to terms with my diagnosis	2	3	2	2		1	1
20. Knowing the facts about autism has really helped me	5	4	1			1	
21. Reading the information about the diagnosis was like creating a big mental list of things that I struggle with	4	2	3			2	
22. It was reading information books about autism that has helped me to understand	3	2	1			4	1
23. All I was told about the diagnosis was vague, unclear information	1		1			4	5
24. When I was told I had autism, it made me feel highly confused	1	1	3			3	3
25. The doctor/autism specialist helped me to understand the autism, to feel confident in myself and to understand there is no such thing as a 'normal' person		3	2	1		4	
26. Reading books written by other people with autism has helped me to understand autism more than anything else	4	1				5	1

Appendix 18.4 Online Survey: After diagnosis-CYP's scaled responses

After diagnosis statements from the survey		Strongly Agree	Agree	Not Sure	Not Relevant	Other	Disagree	Strongly Disagree
1	I get more support at school/college	4	3	1	1	1	2	1
2	None, it has not made any difference to me	1	1	2	0	0	3	4
3	I've been able to access support from a specialist to help me to understand what the diagnosis will mean for me	0	3	2	0	0	7	0
4	Nothing has changed at home	2	3	0	0	1	6	0
5	I feel like I've been labelled, and the label becomes a source of attention	1	1	2	0	0	4	3
6	I notice all the things that I'm good at and I know that my autism is part of what gives me these strengths	3	2	3	0	1	2	0
7	I feel like I have something to blame for my problems	2	4	1	0	1	2	1
8	The teachers/tutors give me more help	3	4	0	1	1	2	1
9	I understand it now, I know why I'm different and why I get so upset	5	6					
10	I get these negative ideas about myself, I sometimes think I'm never going to achieve anything	5	1	2	0	0	3	0
11	Now I've accepted it, I realise that it is not the end of the world, it is just a different way of thinking	3	4	1	1	1	2	0
12	I feel like a valuable individual	3	3	2	1	0	2	1
13	I feel different but in a good way, I don't want to be just like everyone else	3	3	3	0	1	1	0
14	It has really helped to boost my confidence	1	3	3	0	1	3	1
15	My family are much more understanding	2	6	1	0	1	2	1
16	We do not argue as much	1	2	3	1	1	2	2
17	I feel that I can be a success and I'm happier in myself	3	3	2	0	1	0	2
18	I know that I think differently and that this is the reason for my strengths	4	4	1	0	1	0	1

Appendix 18.5 Analysis of qualitative survey data from children's and young people's survey

ID & Dem	Views Shared	Themes	Converging Themes		Broad Topics
1. Rob M	**Impact:** My life at home has changed very little because many people within my family are also autistic, despite this we do argue much less now. I feel happier in myself knowing why I am different, but despite this I don't get much support whatsoever.	- Autism-family trait - Improved self-awareness & happier - Lack of support	G HP E	A. Social difficulties (13) -i B. School issues (4)-ii C. Self-efficacy(4-/4+)-i D. The diagnostic catalyst (7)-ii E. Difficulty accessing support (2) -iii F. Developing own understanding (4)-vi G. Autism traits (2)-iv H. Post diagnostic improvements (4)-ii I. Emotional disequilibrium/mental health (9)-v J. Lack of control (2)-i K. Support strategies (3) vi L. Finding out (-4+4) -iii M. Identity (7)iv N. Awareness and understanding=support (10)-iii O. Strategies and self-help (15)-vi	i. Self-efficacy = +4 -19 ii. Diagnostic catalyst=28 iii. Increased awareness and support=29 iv. Identity=21 v. Mental health=9 vi. Resilience builders = 30
2. Brogan F	**Impact:** When I get angry and don't know why, I have a code word now and say it to my friends and they leave me alone. As I get older I am finding some differences between my friends and I. I don't always understand why they do or say something but I will tell them that I don't understand why they do/say them and they will usually try and explain to me. I haven't done any research on Asperger's because mum told me all I need to know for now and maybe when I am older I will do some if I feel I need to then. I don't think my Asperger's really affects me at the moment as I am clever and can understand most things. I do struggle to concentrate though and if I am allowed to fidget whilst the teacher	- Peer awareness enabling strategy implementation - Feeling different - Poor social understanding overcome by cognitive strategies - Peer awareness enabling strategy implementation - Diagnostic conversation with parent - Diagnosis is not a problem - Positive view of self	N M O K L + P CP O		

ID & Dem	Views Shared	Themes	Converging Themes		Broad Topics
	talks to the class then I can hear her and take in what she is saying. If she tells me to sit still, then I have to concentrate so hard on sitting still, then I don't listen to her. Then I get told off for not listening which can make me feel cross and I do tell the teacher this. Mostly she lets me fiddle with something so I can listen. I do get angry feelings for no reason and I have learnt that it is ok to feel like this and as long as I use my code word, my friends leave me alone and when I feel calm, they let me join back in playing as if I didn't even leave. I am very lucky and we came up with this ourselves. My mum knows about this and so do my friends parents and they were all very happy about it as it means we can all stay friends and have fewer arguments now. I don't have these feelings at home but I know it would work the same at home if I do ever feel angry. I do lots of swimming as I am good at it and I do at least one activity a day after school as I have a lot of energy and it all helps with my coordination. If I don't have an activity because it has been cancelled for a day then mum takes me to run and	• Awareness of self-help strategies • Lack of understanding/patience by teachers • Coping strategies and self-efficacy • Peer awareness enabling strategy implementation • Home/family=safe place/understanding • Coordination & Energy: the importance of physical activity • Rules and routines as imposed supportive strategies	Q O N R O K	P. Diagnosis acceptance (5)-vi Q. Poor awareness: lack of support (4)-iii R. Safe place (1) vi S. Acceptance (4)-ii T. Diagnosis and confusion or disappointment (6)-ii U. Language of deficit (2)-iv V. Feeling different (-5 +5)-iv W. Disclosure and perceptions (4)- ii X. Diagnostic delay (3)-iii Y. Life goes on (1)-vi Z. Positive relationships crucial (4) vi	

ID & Dem	Views Shared	Themes	Converging Themes		Broad Topics
	play in the park or play on the trampoline, otherwise I won't go to sleep until at least 1 in the morning. As it is, I am allowed to read until I fall asleep which is usually about 11 now. I stay in bed as that is the rule or mum will turn my light off and I am not allowed to read anymore. I am allowed to go to the toilet however.	- Coordination & Energy: the importance of physical activity - Rules and routines as imposed supportive strategies	O O		
3. Karl M	**Before:** I thought I was unintelligent and slightly insane **Finding Out**: I was happy because I knew it would allow my parents to understand me better, but sad for myself because it didn't make me feel better about being different **Impact**: I haven't accepted my diagnosis yet so I'm unsure of how to feel, however I always got support from school before I was diagnosed because it took months to be formally diagnosed – My teachers help me a lot to complete work **Other:**	- Low self-efficacy and difference - Relief that others understood - Diagnosis, difference and inferior - Challenge of diagnosis and feelings of uncertainty - School-support without diagnosis	CM N T T N		
4. Kai F	**Before:** I did not understand people and did not know why. I often got in trouble for things I did not understand. People	- Social Confusion	CA		

ID & Dem	Views Shared	Themes	Converging Themes		Broad Topics
	82. reacted in ways that had no explanation. 83. Everybody was equal for me- I treated 84. adults and peers the same (as peers). 85. This was often why I got in trouble. 86. **Finding Out:** I did some tests and at the 87. end of it was told that I had Asperger's. I 88. don't think I was paying attention to it 89. until then. After that it did not explain 90. others but it explained why they could 91. not be explained. 92. **Impact:** I started looking into how 93. people work socially. It's taken a long 94. time. Gradually I started to be able to 95. observe changes in people, then I 96. started to associate behaviours with 97. change, then started looking into 98. patterns and making predictions, 99. comparing predicted behaviour with 100. actual behaviour. Over time I have 101. been able to get more and more 102. accurate (never 100%). I assume my 103. outward showing of my own 104. feelings has improved at the same 105. time (along with learning what I do 106. has which effects on others- this 107. took a long time too, and had a few 108. rocky patches). I think it's less 109. people behaving differently to me	• Lack of knowledge of social hierarchy • • Misunderstood by others • Lack of understanding of the process • Disassociation • Disclosure and partial understanding • Diagnosis as a trigger to improve social knowledge • Use of cognitive ability to improve social understanding • Emotional development, self awareness and self-efficacy • Disclosure to counter issues with peers	A Q L- L- T D O F N M		

ID & Dem	Views Shared	Themes	Converging Themes	Broad Topics
	(apart from once or twice when we've had to tell them I've got the condition to get them to stop teasing, a long time ago) and more me recognising behaviour and reacting accordingly, leading them to react differently to me. I've had better social success which makes me feel better about myself. I have had a LOT of extra help, almost indispensable. **Other:** How I think is who I am- how I interpretate memories and react to events, which thoughts make up my consciousness. Asperger's is part of this- I find it indispensable in how I exist and react to the world, if a barrier to social activities. Others are alien and unknown- difficult to understand and interact with easily, more so to do so positively. However, this makes successful friendships and bonds that much more valuable. A friend to me is one I would stick with through thick and thin (almost an Ally)- I am not fickle when it comes to	• Having to change to fit in with neuro-typical expectations • Improved social understanding leading to improved self-efficacy • Support indispensable • Aspergers traits and identity inseparable • Social barriers persist-self-efficacy • Friendships difficult to establish but valued more as a result	O N GM AC- Z	

ID & Dem	Views Shared	Themes	Converging Themes		Broad Topics
	relationships. Yet I am hopeless in a social situation in which I have no previous experience of on which to base predictions of others on- although this does not immobilise me, it regularly makes for unpleasant (or unwanted) outcomes. An actual social interaction is less a conversation than more me attempting to pick the best response from many that my brain is throwing at me- in a few seconds I will imagine a response several ways, each time predicting what the expected outcome of taking that path would be. I'll go through many different scenarios before settling on something to say or do...usually. Sometimes I skip this and come out with something anyway, often stupid or ill-thought of (sometimes thinking it through half-way through and attempting to salvage the situation in a clunky manner) and can make a social interaction severely awkward. If there was a "cure" to autism, I would never consider it.	- Social faux pas challenge self-efficacy - Use of cognitive ability to improve social understanding - Social faux pas challenge self-efficacy - Uncomfortable acceptance - Use of deficit language	AC- O AC- S U		
5. Adam	**Before:** I felt different to everyone, I was the odd one out! **Finding Out:**	- Feeling different - Marginalised	V- M		

ID & Dem	Views Shared	Themes	Converging Themes		Broad Topics
M 12	166. **Impact:** 167. **Other:**				
6. James M	168. **Before:** I had depression I was at 169. *mainstream. The new school 170. with smaller classes and a better 171. environment for me as mainstream 172. school was tough. 173. **Finding Out:** I feel like I belong 174. somewhere even if to others it is a 175. weird place I have one. 176. **Impact:** I have made friends with 177. ASD and also I have finally made a 178. group of friends who all know I have 179. Asperger's and they are super sweet 180. about it. All of us have our own 181. issues which makes it easy to be 182. honest and open about things which 183. is useful. I don't hide away from my 184. Asperger's; I don't blurt it out 185. instantly but I feel fine to mention 186. it. Sometimes I worry about how 187. others will feel rather than myself 188. though. 189. **Other:**	• Negative emotions • Importance of the right environment • Uncomfortable acceptance • Difference • Uncomfortable acceptance • Peer awareness and acceptance • More comfortable relationships with others of similar need • Uneasy balance between disclosure and perceptions	I B S V- S N N W		
7. Claire	190. **Before:** Before my diagnosis, I was 191. angry, lonely, and constantly 192. anxious. I was only 11 when my	• Negative emotions	I I		

ID & Dem	Views Shared	Themes	Converging Themes		Broad Topics
F	mental health collapsed. I was depressed, and it made me do and say things that I regret to this day because they were the words and actions of a person who I categorically am not. I'll never be able to shake the labels I picked up in the days before anyone had any understanding of why I thought and behave the way I do, and they're all negative. I'm growing up now, and I'm moving on, and I'm learning, but I'll never forget the pain of those times, and I'll never get over the suffering my own fear and pain caused my family. **Finding Out**: I was told at the same time as my parents that I had an autism spectrum disorder. I was twelve years old. I remember looking at both my parents, and thinking my mother might have been relieved. I don't think she was shocked. I looked to my father second. I just remember thinking he looked disappointed. I wanted to cry. I know he loves me and is extremely	• Impact on mental health • Regret and disassociation • Negative labelling • Development and improvement • Regret and guilt • Disclosure by professionals and parents • Disclosure and the impact of others reactions/disappointment • • Negative emotions	I U F I L + CW CI		

ID & Dem	Views Shared	Themes	Converging Themes		Broad Topics
	proud of me, but he knew me for so long without an autism diagnosis that it's still hard for him to accept that part of who I am. When I was told it was a relief. Looking back, none of us know how diagnosis took so long. I tick almost every box for being on the spectrum. Being a bright, articulate girl is probably what left me undiagnosed for so long. I sometimes think about how much easier things might have been if we'd known sooner, and then I remember that kind of thinking is pointless, so I stop. When I went home after diagnosis, I went right back to my normal routine. I went on my laptop and I went back to school the next day, although I only did part time lessons then. I spent the next few weeks finding out everything I could about autism and what it meant. I think maybe those few weeks helped. **Impact:** After I was diagnosed I began to get more help at school. I began to behave better. I managed nine GCSE's, in the end. Now I'm at	• Diagnostic delay- a challenge to acceptance • Disclosure a relief • Diagnostic delay • Late diagnosis, gender and ability • Coping strategies and self-efficacy • Life goes on • Self-study about the diagnosis beneficial Diagnosis as a trigger for self-improvement	T P X CX CO Y F D H		

ID & Dem	Views Shared	Themes	Converging Themes		Broad Topics
	*college there is much more support for my autistic side.	- Increased support post diagnosis			
	My father is quietly supportive, I think. My mother is actively supportive. She advocates for me whenever I need it (and sometimes when I don't), and she'll always explain to anyone I can't explain to, and she doesn't often make me do things I don't want to.	- Parental support and advocacy	N		
	My brother's good about it too. He knows good stims and bad stims and when I'm anxious or when I'm happy, and when it's OK to tease and when I just can't deal with him. He's mostly good.	- Benefit of sibling understanding	N		
	Also, if it hadn't been for my diagnosis, I wouldn't have met the person who started out as an acquaintance, became a friend, then my best friend, and now my boyfriend.	- Relationships with others of similar need	Z		
	He has Asperger's Syndrome. He's less spectrumy than me,	- Comparison to others on spectrum			
	but he understands me better than anyone else I've ever known, and we care about each other so much.	- Spectrum relationship supports understanding	M Z		
	I feel things for him I've never been able to feel for anyone	- Positive relationship			

ID & Dem	Views Shared	Themes	Converging Themes		Broad Topics
	else. We want to get married in a few years. He, without a doubt, had been the best part of being diagnosed. **Other:** Autism is a fucking mental wankfest. That is probably the least articulate thing I've ever said or written, but it's true. I'm getting better at navigating life, but it's not easy. I still have problems with anxiety and sudden unexpected changes in setting and routine, and I have a ridiculous number of sensory issues, but I'm learning all the time. Sometimes now I think I might actually get somewhere significant. It's all been about learning and being patient and just realising that sometimes you have to take a deep breath, accept things are not what you thought or hoped they would be and start over. I'm getting better at that. I make sure to do things I enjoy, and I'm learning to talk about my problems. It's going to be OK.	• Autism makes life difficult but getting better • Use of cognitive ability to improve social understanding • Improving self-efficacy • Use of cognitive ability to improve social understanding • Diagnosis, difference and inferior • Use of cognitive ability to improve social understanding • Improving self-efficacy	HZ T O C+ O T O C+		
8. Chris M	**No open responses**				

ID & Dem	Views Shared	Themes	Converging Themes		Broad Topics
9. Aaron M	**No open responses**				
10. John M	Before: Alls I can remember is *school, I hated the place, it had horrible teachers who where always in your face and shouting, and a horrible bully who just lashed out at me and talked crap to me. Finding Out: I can't remember(I have bad memory),but right now I feel happy, I mean I don't mind being unique, and I can't even think of being a normal person. Impact: I feel good about being autistic. Always trying to fit in can severely scar your personality. I've had a lot of help from my parents, helping me understand my condition and helping me evolve. Other: It may put a few obstacles in my way, but I love being autistic. I mean, I'm sick of people abusing the word and using it as an insult, autism makes you unique, quirky, and different. it's not a bad thing, like social media users make it out to be. #SupportAutism	• School is difficult • Lack of understanding/patience by teachers • Bullying/Social difficulties • Self-aware, unique and happy • Comparison to normal person • Positive acceptance • Negative impact of conforming • Parental support important -positive understanding • Uneasy balance between disclosure and perceptions • Positive acceptance • Uneasy balance between disclosure and perceptions • Positive acceptance	B Q A CV+ V- V+ V- L+ W- V+ W- V+		

ID & Dem	Views Shared	Themes	Converging Themes		Broad Topics
11. Sally F	Before: I was bullied and generally misunderstood. I knew I was different but couldn't understand why. I struggled to cope at school and at home. I had social issues and struggled with severe anxiety, which caused major difficulties at school. Finding Out: Although it was a long-winded, exhausting process to be diagnosed, I was relieved. I was on the path to self-discovery. My emotions started to make sense. I began to research the condition endlessly. Impact: I was withdrawn from *mainstream secondary and transferred to a *specialist school for people with severe anxiety, received one to one support. I also received support from a residential training facility, but no additional support from mainstream college. I have accessed one to one support through the *Specialist Service. I understand why I sometimes find social situations daunting and exhausting. I understand why other people may perceive things	• Social difficulties/bullying • Lack of understanding • Awareness of difference • Life/School is difficult • Social difficulties/bullying • Anxiety at school • Diagnostic process draining • Disclosure a relief • Positive acceptance • Self-study about the diagnosis beneficial • Access to specialist provision • Increased support post diagnosis • Lack of support from some • Increased support post diagnosis	A Q V- B AC L- X S H P CV + D H D O		

ID & Dem	Views Shared	Themes	Converging Themes		Broad Topics
	357. differently to me. People tend to be 358. more supportive. 359. Other: My main difficulties include 360. social interaction with peers my 361. own age, accessing the community i 362. ndependently and understanding 363. and managing my emotions.	- Improved social understanding leading to improved self-efficacy - Increased support post diagnosis - Ongoing social anxiety - Ongoing emotional needs	D CA I		

Appendix 19 Results from the parent survey

Appendix 19.1 Individual scores relating to the positivity of their child’s experiences at different points relative to the autism diagnosis

Parent	Before Scores	Before %	Finding Out	Finding Out %	Post Diagnosis	Post Diagnosis%
1. 1	26	34.66	91	72.8	72	75.79
2.	39	52	79	63	66	69.47
3.	42	56	73	58.4	60	63.16
4.	25	33.33	86	68.8	74	77.89
5.	23	30.66	86	68.8	54	56.84
6.	39	52	83	66.4	78	82.11
7.	29	38.66	79	63.2	72	75.79
8.	31	41.33	77	61.6	65	68.42
9.	40	53.33	68	54.4	56	58.95
10.	35	46.66	63	50.4	52	54.74
11.	29	38.66	75	60	43	45.26
12.	23	30.66	91	72.8	71	74.74
13.	23	30.66	73	58.4	53	55.79
14.	43	57.33	94	75.2	75	78.95
15.	41	54.66	66	52.8	64	67.37
16.	30	40	83	66.4	68	71.58
17.	50	66.66	80	64	67	70.53
18.	38	50.66	84	67.2	58	61.05
19.	49	65.33	75	60	58	61.05
20.	42	56	54	43.2	49	51.58
21.	35	46.66	76	60.8	68	71.58
22.	28	37.33	84	67.2	65	68.42
23.	32	42.66	80	64	57	60
24.	43	57.33	86	68.8	73	76.84
25.	37	49.33	58	46.4	66	69.47
26.	23	30.66	75	60	85	89.47
27.	20	26.66	93	74.4	82	86.32
28.	56	74.66	59	47.2	66	69.47
29.	39	52	74	59.2	76	80
30.	39	52	98	78.4	87	91.58

Appendix 19.2 Before diagnosis: parent views of their children’s experiences

Statement	Strongly Agree	Agree	Not Sure	Not Relevant	Other	Disagree	Strongly Disagree
1. S/he didn't know anything about autism	20	3	2	0	0	3	2
2. S/he was very confident around other children	0	5	1	0	0	8	16
3. S/he was very confident about his/her ability	3	5	4	1	0	8	9
4. S/he worried about many things	14	7	4	0	0	4	1
5. S/he was always asking why s/he was different to other people	4	4	4	1	1	6	10
6. S/he didn't have much confidence in him/herself	11	6	3	0	1	7	2
7. Everything was fine	0	1	1	0	0	12	16
8. S/he never worried about anything	1	3	0	0	0	8	18
9. S/he struggled to get on with other people	14	8	4	2	1	1	0
10. S/he had no idea s/he had autism	22	3	2	0	0	1	2
11. Nothing ever seemed to work out for my child	8	10	3	1	0	6	2
12. S/he was doing really well at school	1	3	3	2	0	6	15
13. S/he felt that no-one understood	8	8	6	1	0	4	3
14. S/he felt 'normal'	2	3	9	0	0	6	10
15. S/he was finding school difficult	16	7	2	0	2	1	2

Additional comments from parents who selected other or wished to provide further details-before diagnosis:

1. Q5. S/he was always asking why s/he was different to other people
2. Parent 3: sometimes
3. Q6. S/he didn't have much confidence in him/herself
4. Parent 3: sometimes
5. Q9. S/he struggled to get on with other people
6. Parent 6: Sometimes
7. Q15. S/he was finding school difficult:
8. Parent 3 socially not academically
9. Parent 9 Play school

Appendix 19.3 Finding out about the diagnosis: parent views of their children's experiences

Statement	Strongly Agree	Agree	Not Sure	Not Relevant	Other	Disagree	Strongly Disagree
1. The doctors and other specialists were able to tell him/her lots of helpful information	0	2	2	2	2	15	8
2. I/we told my child about their diagnosis as soon as it was confirmed	11	7	1	1	2	5	3
3. I/we told my child about their diagnosis when they started asking questions	4	7	2	10	2	4	1
4. Finding out seemed to help him/her to put his/her experiences into perspective	8	9	2	2	2	6	1
5. My child was given lots of helpful information by the specialist	0	3	1	2	1	13	10
6. Finding out about the autism diagnosis came as a real surprise to my child	2	3	10	5	0	5	5
7. Finding out has been a very positive experience for my child	6	7	6	3	3	4	1
8. When s/he found out about the diagnosis, s/he felt like s/he had been labelled	1	2	7	4	0	9	7
9. Being told s/he had autism provided him/her with what felt like a fresh start	3	7	11	3	1	3	2
10. Finding out about the diagnosis was a difficult process that involved many assessments and meetings	10	7	1	4	1	5	2
11. When my child was told about the diagnosis, s/he didn't believe they had autism	2	1	5	6	0	8	8
12. When they found out, s/he felt the need to look for information on the internet	0	1	5	8	0	7	9
13. The diagnosis has helped to empower my child, as they were helped to understand the autism and to recognise all their strengths	5	11	2	3	1	7	1
14. Finding out, helped him/her to understand their experiences and difficulties	6	12	5	2	1	3	1
15. My child has only been told about the negative aspects related to autism	1	0	2	3	0	12	12
16. Accessing websites/blogs/tweets created by other people with autism has helped my child to understand the diagnosis	1	7	8	8	1	3	2
17. Knowing the facts about autism has really helped her/him	5	9	7	3	0	5	1
18. Reading the information about the diagnosis seemed to highlight all the problems related to autism to my child	4	10	8	3	0	3	3
19. It was reading information books about autism that has helped him/her to understand	2	4	6	2	1	11	4
20. All s/he was told about the diagnosis was vague, unclear information	2	9	4	4	1	7	3
21. Finding out about the diagnosis made my child feel highly confused	0	3	9	3	1	7	7
22. The doctor/autism specialist helped my child to understand the autism.	0	3	3	4	0	10	10
23. Finding out about the diagnosis from the doctor/autism specialist has helped increase his/her confidence	4	3	4	5	1	7	6
24. Information about the diagnosis highlighted that there is no such being as the 'normal' person	5	3	8	7	0	5	2
25. Reading books written by other people with autism has helped my child to understand the autism	1	9	6	5	1	6	3

Additional comments from parents who selected other or wished to provide further details- finding out about the diagnosis:

Q1.The doctors and other specialists were able to tell him/her lots of helpful information

Parent 18: only specialists were any help

Parent 26: I was given a book list. I told my son myself within days that he was "different", not "wrong". The key was when he met others like him, when I set up autism support group, * Group Name.

Q2. I/we told my child about their diagnosis as soon as it was confirmed

Parent 4: He was told age appropriate information

Parent 15: Not immediately, I had to process it first

Q3.I/we told my child about their diagnosis when they started asking Questions

Parent 4: we expanded the information we had told him

Parent 28: We don’t give him any excuse not to do things! He just doesn’t know the full extent of his diagnosis. Just that he has extra help in class. We work hard to ensure that he has that help.

Q4.Finding out seemed to help him/her to put his/her experiences into perspective

Parent 3: yes, but it took a while.

Parent 8: beginning to but as she's young it’s a process to help her understand

Q7.Finding out has been a very positive experience for my child

Parent 3: positive in that it was necessary

Parent 8: Mixed. She's been v upset about it but is starting to feel more positive

Parent 28: No, not really. He tries to use it as an excuse, but it doesn't work!!

Q9. Being told s/he had autism provided him/her with what felt like a fresh Start

Parent 4: finding out provided us an answer as well as a way forward

Q10. Finding out about the diagnosis was a difficult process that involved many assessments and meetings

Parent 4: depends, including CAMHS fiasco, over 2 years, diagnosis waiting time once requested-2 months and then diagnosis in a day

Q13.The diagnosis has helped to empower my child, as they were helped to understand the autism and to recognise all their strengths

Parent 4: all along as he has been told age appropriately continually after diagnosis

Q14.Finding out, helped him/her to understand their experiences and difficulties

Parent 4: all along as he has been told age appropriately continually after diagnosis

Q16.Accessing websites/blogs/tweets created by other people with autism has helped my child to understand the diagnosis

Parent 4: all along as he has been told age appropriately continual after diagnosis

Parent 8: Newsround tv programme

Q19. It was reading information books about autism that has helped him/her to understand

Parent 4: all along as he has been told age appropriately continually after diagnosis

Parent 8: she was told nothing by professionals its been left to us

Q21. Finding out about the diagnosis made my child feel highly confused

Parent 3: a bit at first

Q23.Finding out about the diagnosis from the doctor/autism specialist has helped increase his/her confidence

Parent 4: all along as he has been told age appropriately continually after diagnosis

Q25. Reading books written by other people with autism has helped my child to understand the autism

Parent 8: but probably will in future

Appendix 19.4 Parent survey responses about changes for their child after an autism diagnosis

Statement	Strongly Agree	Agree	Not Sure	Not Relevant	Other	Disagree	Strongly Disagree
1. Gets more support at school/college	17	5	1	1	1	1	2
2. Has not changed at all	4	7	3	3	1	9	4
3. Has been able to access support from a specialist to aid understanding of the diagnosis	6	4	4	4	0	8	4
4. Is just the same at home as they were before the diagnosis	8	9	0	0	2	6	5
5. Feels that they have been labelled	0	4	8	2	1	6	14
6. Is better at noticing all the things that they are good at and know these strengths are part of the autism	3	9	9	2	1	5	2
7. Feel that the autism is the cause of all of their problems	1	2	9	2	1	10	4
8. Gets more help from teachers/tutors	14	4	5	1	0	5	1
9. Understands why they are different from peers	7	14	6	1	1	2	0
10. Thinks negatively about their future	3	5	5	3	4	8	5
11. Thinks they are never going to achieve anything	2	5	4	2	2	9	6
12. Accepts the diagnosis	10	12	2	2	1	2	1
13. Has realised they just have a different way of thinking	9	14	4	2	0	1	0
14. Feels like a valuable individual	4	10	7	2	1	7	0
15. Has a greater level of confidence	4	10	5	2	1	6	2
16. Is better understood by the whole family	9	16	0	1	1	4	0
17. Has fewer disagreements with other family members	4	8	3	4	1	9	1
18. Feels they can be a success and are happier	4	8	8	1	2	7	1
19. Understands that they think differently from peers and that this is the reason for many of their strengths	8	9	7	1	1	5	0

Additional comments from parents who selected other or wished to provide further details-changes after diagnosis:

Q1. Gets more support at school/college

Parent 10: At primary yes, at secondary help is poor

Q2. Has not changed at all

Parent 17: Except he does realise that his reaction to events may not always be the same as those around him.

Q4. Is just the same at home as they were before the diagnosis

Parent 3: no, but mainly due to age and hormones

Parent 10: we understand him more now

Q5. Feels that they have been labelled

Parent 4: He will say "sometimes" by others more then his friends or family

Q6. Is better at noticing all the things that they are good at and know these strengths are part of the autism

Parent 4: though lack of understanding in junior school has knocked self-esteem and confidence greatly

Q7. Feel that the autism is the cause of all of their problems

Parent 4: when feeling down, he will say "sometimes"

Parent 28: He tries, however, we won't hear of it. Then he blames NF1 instead!! [Note: neurofibromatosis type 1=NF1]

Q9. Understands why they are different from peers

Parent 13: Sometimes

Q10. Thinks negatively about their future

Parent 3: He thinks negatively about everything

Parent 4: more of a confidence and self-esteem issue currently

Parent 13: Sometimes

Parent 28: Not at all, he knows he can spot details others don't. He wants to work in cyber-security

Q.11. Thinks they are never going to achieve anything

Parent 3: he thinks this way anyway. He doesn't blame his autism.

Parent 4: again, more of a confidence and self-esteem issue currently

Q12. Accepts the diagnosis

Parent 28: Doesn't really think about it, except when he's trying to get out of something!!

Q13. Has realised they just have a different way of thinking

Q14. Feels like a valuable individual

Parent 4: Sometimes

Q15. Has a greater level of confidence

Parent 3: No, but I don't think this is linked to his awareness of his autism diagnosis.

Q16. Is better understood by the whole family

Parent 4: bar some relatives

Q17. Has fewer disagreements with other family members

Parent 5: He can disagree with fresh air

Q18. Feels they can be a success and are happier

Parent 3: I'm not sure he's capable of feeling this way

Parent 4. More of a confidence and self-esteem issue currently

Q19 Understands that they think differently from peers and that this is the reason for many of their strengths

Parent 4: Currently working on it.

Appendix 19.5 Parental responses to open question-children's experiences before an autism diagnosis

ID	Please tell me what things were like for your child before the autism diagnosis	Themes	Converging	Broad themes
Parent 1 F 18.11yrs Nwest AS	Very difficult as she believes she was doing things wrong and was therefore 'stupid' for not being able to get it right. Although I gave her explanations without a professional diagnosis she felt very alone and under pressure to be 'normal' which left her exhausted and anxious.	Life was difficult 1.A Feeling inferior/unintelligent 6. D Felt doing things wrong 8. A Feeling alone/different 9. D Parent providing explanation 21.I + Pressure to conform 11. D Lack of diagnosis impacted negatively 16. G Heightened emotions 12.E	**Overall Converging Negative Themes (125)** 1. Life was difficult (7) =A 2. School was difficult (8) =A 3. Not self-aware (5) =B 4. Seeks isolation (7)= C 5. Social difficulties/bullying (11) = C 6. Feeling inferior/unintelligent (6) =D 7. Comparison/recognition of difference to peers/sibling (15) =D 8. Doing things wrong/blame (3)=A 9. Difference (6) =D 10. Differential diagnosis-related to traits (3)=H 11. Pressure to conform/seeking acceptance (2) = D 12. Heightened emotions (11) =E 13. Increasing social difficulties (5)=C 14. Traits problematic/different (4) =D 15. Academically Able vs social difficulties (3) =F 16. Unmet needs/impacting wellbeing/behaviours (9) =G 17. Lack of understanding (4) =G 18. Professional understanding/support (6) =G 19. Diagnosis problematic/delayed (8) =H 20. Late diagnosis (4) =H **Overall Converging Positive Themes (35)** 21. Parent understanding, support/seeking diagnosis (12)=H 22. Confident in own abilities (2)=B	A. Ability/Difficulties Pos= 7/Neg=18 B. Self-views Pos= 2/Neg=5 C. Social experiences Pos= 3/Neg=23 D. Identity/Difference Pos=0 /Neg=27 E. Feelings Pos=3 /Neg=29 F. Uneven profile Pos=0 /Neg=3 G. Understanding Autism Pos=8 /Neg=19 H. Diagnosis Pos=15 /Neg=15 I. Support/Understanding Pos=4 /Neg=2
Parent 2 13.11 yrs M SE ASD	My son sometimes found it difficult to go into school or into his classroom and hard to join in everything. He found it very difficult to go into assembly.	School was difficult2. A Difficulty joining in 9.D		
Parent 3 17.7 yrs M AS London	He was 12 when he was diagnosed and academically extremely able. Before that both I and his school acknowledged he most likely was ASD and he received support for his social skills Socially he struggled more as he got older and he became more aware of his differences. His traits have also become more obvious with age so I felt a formal diagnosis was something that would help him to understand his condition.	Late diagnosis 20. H. Academically Able vs social difficulties 15/27. A +/- Parent anticipated & sought diagnosis 21. H+ Professional Awareness/ Support26.I Increasing social difficulties 13. C Feeling alone/different 3.D Traits becoming more obvious 13. D Parent anticipated & sought diagnosis to improve life 21. H+		
Parent 4 Mother M ASD 13.6yrs	My child was diagnosed at 5 years old. We had always known that he needed some	Early diagnosis 28. H+		

ID	Please tell me what things were like for your child before the autism diagnosis	Themes	Converging	Broad themes
London	support but had no idea what and had been under the "care" of CAMHS and being told that he "may have ADHD" but that most likely his "behaviour" was my fault regardless of having an older neurotypical child that was seen as the "perfect child". We were told that it was because my husband and I were adopted. Meanwhile my child was diving under furniture, in fight or flight mode from the age of 2 until diagnosis. We finally persuaded CAMHS to allow us to go for a diagnosis after I researched Aspergers. My child was then diagnosed Autism Spectrum in one day by a multidisciplinary professional team.	Parental recognition of needs but not suspecting autism 7. D Professionals not understanding needs 18. G Parents blamed/ 8/7/18.G Different traits/problematic behaviours 14. D Heightened emotions 12.E Late diagnosis 20. H+ Parent anticipated & sought diagnosis 21.H + Diagnostic struggle/delayed process of diagnosis 19. H Diagnostic process 20. H	23. Positive peer awareness/acceptance (3)=C 24. Identification increased understanding (4)= G 25. Positive communication re ability/diagnosis (2) =G 26. Professional understanding/support (2)=G 27. Academically Able (5)=A 28. Early Diagnosis (3) =H 29. Improving skills (2)=A 30. Parent Providing explanation/support (4)=I **Feelings attributed to young people** • Stupid x2 • Anxious x2 • Exhausted • Emotionally fragile • Isolated • Distressed x2 • Angry • Frustrated x2 • Struggling • Withdrawn • Thick • Retard • Labelled • Unsettled Negative = 18 • Happy x2 • Confident Positive = 3	
Parent 5 ASD SE 13.7yrs Male	He was significantly behind his peers academically and socially pretty much at every mile stone of his life, it was obvious to anyone who spent time with him. He wasn't bothered about making friends and perceived everyone to be bullying him who didn't agree with his views or like what he liked. He was known as the kid who was obsessed with Doctor	Comparison/recognition of difference 7.D social difficulties/bullying 3/7. C/D Different traits 9.D		

ID	Please tell me what things were like for your child before the autism diagnosis	Themes	Converging	Broad themes
	Who! I felt like I was constantly having to make excuses for him, I felt like everyone else seemed to be sailing along in this parenting malarkey, and we were really struggling. When his sister was born 4 years later it was obvious that he had some thing "wrong" with him.	Comparison /struggling 7/8. A Comparison /recognition of difference 7/9. D Perceived to have something wrong 7. D		
Parent 6 SE ASD F 15 yrs	My child was emotionally fragile, prone to 'meltdowns' and struggled to understand the world. Communicating verbally caused my child to feel frustrated.	Heightened emotions 12.E Life was difficult-to understand 1.A social difficulties 5.C.		
Parent 7 SE F x2 ASD 10.6 yrs	It was like a never ending pass-the-parcel from school, speech & language, paediatricians etc.. I spent most days going in to school to sort problems etc and the rest of the time, consoling, explaining, calming children.	Seeing range of professionals for related traits 10.H Problematic diagnostic process 19.H Lack of understanding of needs/parent advocate 17.G/21.I+ Parents managing/ heightened emotions 21.I/ 12.E		
Parent 8 SE ASD F 7.3 yrs	She wanted to be like everyone else as she saw it and to have friends, but was increasingly aware she couldn't cope with things as well as the others, isolated herself at school, and began to get extremely distressed about school. She was very self-critical about things like her sensory sensitivities, and	Comparison/recognition of difference 7.D Seeking acceptance 4.C Feeling inferior/unintelligent 6.D Social difficulties 5C Managing heightened emotions 12.E		

ID	Please tell me what things were like for your child before the autism diagnosis	Themes	Converging	Broad themes
	104.couldn't understand why she 105.was the only one to find things 106.so hard, and blamed herself, 107.even hitting her own head in 108.frustration. She was very angry 109.and explosive at home.	Feeling inferior/unintelligent 6.D Managing heightened emotions 12.E		
Parent 9 SE ASD F 6.6yr	110.My daughter still doesn't 111.understand autism she just 112.says mummy my brain is 113.different to my Friends	Self-aware/not of autism 3B Comparison/recognition of difference to peers 7.D		
Parent 10 Mother SE AS M 13.10 yrs	114.My child and I had no idea 115.about autism. He seemed to 116.be happy at school but 117.complained being bullied by a 118.specific child and his group of 119.friends, they had all known 120.each other before school, my 121.child was a new comer to the 122.area. School had always 123.reported that my child was 124.happy and got on with a wide 125.range of children. So when 126.they suggested there was an 127.issue with friendships after 5 128.years of primary school this 129.was quite surprising to us. 130.My child had issues around 131.food since about 20 months, I 132.had often queried this with my 133.GP. 134.When finally we got referred to 135.the paediatrician when he was 136.aged 6, nothing was 137.mentioned 138.about ASD. She eventually 139.discharged my son after 18	Not self-aware/ of difference 3.B Happy at school 22.A+ Social difficulties/bullying 5.C Feeling different 9.D Professionals not understanding needs 31/18. G Professionals not communicating concerns 7/18.G Different traits 14.D Professionals not recognising/ communicating concerns 7/18.G Seeing range of professionals for related traits.		

ID	Please tell me what things were like for your child before the autism diagnosis	Themes	Converging	Broad themes
	months with no mention of ASD. He then saw a dietician for a further 18 months who then suggested something underlying (ASD still not mentioned). He finally received a diagnosis when he was 10.	7/18.G Problematic diagnostic process 19/20.H Late diagnosis 20.H		
Parent 11 F Male 12.5 SE AS	hard to make and keep friends. would not listen to any one else point of view	Social difficulties 5.C Traits problematic 14.D		
Parent 12 Male SE Autism 13.10yrs	My child found it very difficult to cope at school. Although he already had a statement for Dyspraxia it was only for fifteen hours a week. He could not focus, sit or concentrate for any length of time and was always running out of class.	School difficult 2.A Differential diagnosis-related to traits 10.H Unmet needs/impacting behaviours 16.A		
Parent 13 Male 10.7yrs SE ASD	My son was always in trouble at Home/school. He didn’t have any friends. He has been misunderstood by most.	Unmet needs/impacting behaviours 16.A Social difficulties/lack of friends 5.C		
Parent 14 Male 15.5yrs SE ASD	He struggled to express what he felt and couldn't often find the right words or make sense of what he felt. He got angry and vented this by punching himself, hitting his head against a wall and tearing/damaging things. He blew up at sister and me and we felt quite intimidated by him. He was unable to cope	Communication/social difficulties 5.C Managing heightened emotions 12.E Unmet needs/impacting behaviours 16.E		

ID	Please tell me what things were like for your child before the autism diagnosis	Themes	Converging	Broad themes
	174. with his anger. He was very 175. quiet and shy in school/groups 176. and rarely engaged in group 177. discussion or put his hand up 178. to answer a question. He felt 179. confident in his own abilities 180. but unable to come across as 181. confident. He struggled with 182. social interaction and "small 183. talk". He became very insular 184. and unhappy, crying daily 185. before school.	Managing heightened emotions 12.E Academically Able vs social difficulties 15/27.A/F+ Confident in own abilities 22.B Academically Able vs social difficulties 15/27.A/F+ Communication/social difficulties 5.C Managing heightened emotions 12.E		
Parent 15 Male 8.6yrs ASD SE	186. He was a 'handful', treated as 187. naughty and uncooperative. 188. Sanctions didn't work as he 189. was ambivalent to them, if he 190. couldn't have a certain toy, 191. perceived as a favourite he 192. would move to something else. 193. He was surprised by the 194. consequences of his actions, 195. and therefore caused things to 196. happen that he didn't really 197. intend. He still played 198. alongside other children rather 199. than with them. Due to some 200. physical differences, 201. syndactyly and cleft lip and 202. palate, some of his 'not fitting 203. in' was put down to this.	Unmet needs/impacting behaviours16.E Difficulty understanding social & behaviours expected 16.C Social difficulties 13.C Differential diagnosis-related to traits 10.H Feeling alone/different 4./9. C		
Parent 16 F SE Autism 19.1 yrs	204. She struggled socially and with 205. her peers. She's always been 206. immature compared to her 207. peers and found people didn't 208. understand her.	Social difficulties 5/13.C Comparison/recognition of difference 7.D Lack of understanding of needs 17.G		

ID	Please tell me what things were like for your child before the autism diagnosis	Themes	Converging	Broad themes
Parent 17 M SE ASD 13.6yrs	Our son was becoming more isolated in class. This had happened gradually over some years but became obvious in Year 3.	Isolated 4.C Increasing social difficulties13.C		
Parent 18 Male SE ASD 16.8yrs	HE ALWAYS FOUND LIFE VERY HARD NOT ABLE TO MAKE FRIENDS, BULLED, ECT LIKES TO BE ON HIS OWN, DID NOT LIKE TO TAKE PART IN ANY SPORTS GAMES, ALWAYS PLAYED ON HIS OWN AND WOULD SHUT HIMSELF AWAY IN HIS BEDROOM.	Life was very difficult 1.A Seeks isolation 4.C Increasing social difficulties 13.C Seeks isolation 4.C		
Parent 19 17yrs SE Autism Male	Quite oblivious to his difference - no speech from 2-6 yrs so not sure how he really felt - he would wander off all the time, not sleep or eat much. Spent the first term at primary school under the table, but the other children were lovely to him & he has always felt he's had lots of friends – he has a birthday party every year & he loves it! He was very unpredictable & challenging as a child but as his communication improved it became easier to understand his distress & anticipate his moves!	Not self-aware/ of difference 3.B Comparison/recognition of difference to peers 7.D Unable to cope with school/unmet needs/impacting behaviours 2/16.A Positive relationships with peers-accepted despite differences 23.D + Traits problematic/different 13.A Improved communication & understanding over time 29.C +		

ID	Please tell me what things were like for your child before the autism diagnosis	Themes	Converging	Broad themes
Parent 20 SE Autism 16.10.yrs	243.Well he was very young, he 244.got bullied at school and cried 245.every single day, pleading not 246.to be sent.	School was difficult/unmet needs 2/16.A social difficulties/bullying 5.C		
Parent 21 Male 5.3yrs AS SE	247.Constantly picked upon by 248.bullies, with the school 249.claiming our child was the bully 250.- he was retaliating to the 251.bullying received. Climbing 252.under chairs, hiding behind 253.parents, avoiding people 254.contact was normal.	social difficulties/bullying 5.C School was difficult/unmet needs 2/16.A		
Parent 22 F 14.7yrs SE ASD	255.She was 'different' to her peers 256.and would become distressed 257.and withdrawn	Comparison/recognition of difference to peers 7/4. D Isolated 1/4. A		
Parent 23 SE ASD Male 12.6yrs	258.I knew that something wasn't 259.quite right but couldn't 260.understand what, whether it 261.was just developmental delay 262.or just that my son was a very 263.different character from my 264.older son. There was about 5 265.years when I knew about his 266.diagnosis before we decided 267.the time was right to tell him.	Parental recognition of needs but not autism 22.H+ Comparison/recognition of difference to sibling 7.D Delay between parental awareness of diagnosis and telling child 19.H		
Parent 24 WMids ASD 2 x M 4 & 7.6yrs	268.Eldest got diagnosis at 2.5 269.before the diagnosis we 270.weren't sure why he was doing 271.the things he was or why he 272.wasn't talking yet. We are 273.awaiting diagnosis for my other 274.son who is 4. It's hard not 275.knowing for sure.	Early diagnosis 28.H Parental recognition of needs but not autism 21.H Diagnostic delay & uncertainty 19.H Diagnostic delay & uncertainty 19.H Early diagnosis 28.H		

ID	Please tell me what things were like for your child before the autism diagnosis	Themes	Converging	Broad themes
		Diagnostic delay & uncertainty 19.H		
Parent 25 Lond F ASD 15.6 yrs	276.Significant difficulty in making 277.friends; difficulty in 278.concentrating in class; 279.some disruptive behaviour, 280.especially so by year 5. At 281.home, frequent fighting with 282.her (neurotypical) twin brother.	Increasing social difficulties 13.C School & Home difficult/impacting behaviours 1. A Managing heightened emotions 7/12.E		
Parent 26 Oxford M AS 16 .3 yrs	283.He called himself "thick" and 284."stupid". When my son asked 285.me what a “retard” was, I 286.realised he was being labelled 287.as one. therefore decided 288.that an official label would 289.potentially discredit any other 290.unofficial ones that were being 291.attached to him. He was 292.diagnosed in the closing days 293.of year 6 and I told him within 294.days that he was different – 295.not wrong.	Feeling inferior /unintelligent 5/6.C Diagnostic struggle/delayed process of diagnosis 19.H Late diagnosis 20.H Immediate positive disclosure by parent 21/25.H		
Parent 27 SEast ASD 20/12/96 Male 10/08/99 Female 09/12/70	296.Educational system 297.unbearable.	School was difficult/unmet needs 2.A		
Parent 28 Father York & humb M ASD 12.11 yrs	298.We had asked his teacher 299.what was wrong with him & his 300.teacher said he was wily and 301.knew how to get out of doing 302.any work. He found the 303.academic work quite tricky, 304.(and still does) however he 305.had some good friends who	School difficulties/Professionals not understanding needs 2/18.A/I Academically Able vs difficulties 7/27. A		

ID	Please tell me what things were like for your child before the autism diagnosis	Themes	Converging	Broad themes
	had been through nursery with - he is still friends with them now - so he enjoyed going. (and still does). No one has ever told him he cannot do something, so he has to get on with things.	Positive relationships with peers-accepted despite differences 23.C Positive expectations 25.B		
Parent 29 Wales 15.3 M x2 Autism	At times, our life felt like a living hell. It occasionally still does but I feel that now we have a better understanding of why things go wrong for us.	Life was/is very difficult 1.A Improved understanding over time24/29. G.		
Parent 30 SE 18yrs M & 1 x male adult ASD	Lots of highs and lows repetitive games behaviours constant asking questions and seeking reassurance. Hated loud noises food textures strong smells Couldn't settle at night Didn't like me to leave him at nursery High levels of anxiety	Coping roller coaster 1/24. A Different traits/problematic behaviours 14. D Heightened emotions 12.E Attachment 2. A Heightened emotions 12.E		

Appendix 19.6 Parental responses to open questions-finding out about an autism diagnosis

Name	What were your child's experiences of finding out about the autism diagnosis	Themes	Converging	Broad themes
Parent 1 F 18.11yrs Nwest AS	it came after years of CAMHS meetings and discharges when she was 16. We left the diagnosis meeting and she laughed and smiled and felt a great sense of relief. She stopped trying to hide from her autism and started making positive decisions about her life.	Long process=1 Delayed diagnosis=1 Young person included in the process=16 Post-diagnosis relief=15 Pressure to conform=6 Diagnostic catalyst for positive change=18	**Overall Converging Negative Themes** 1. Diagnostic timescales x6/A 2. Diagnostic process problematic/not explained/not right time x6/A 3. Autism difficult to understand/ explain x2/C 4. Feeling different x10/H 5. Disassociation/disinterest x13/A 6. Conforming x2/H 7. Emotional impact/struggling x1/G 8. Lack of professional support with diagnosis/diagnostic explanation x7/E	A. Diagnostic Processes Neg x25 Pos x25 B. Resources Neg x2 Pos x5 C. Explanation & Understanding Neg x3 Pos x28 D. Engagement Neg x0 Pos x6 E. Support Neg x12 Pos x5 F. Skills Neg x0 Pos x14 G. Impact Neg x1 Pos x9 H. Identity Neg x22 Pos x13
Parent 2 Mother 13.11 yrs M SE ASD	My son seemed not terribly interested but was taking in what was said. The Doctor left it to me and my husband to explain the diagnosis to our son and emphasised that we needed to tell him straight away,	Young person included in the process=16 Not interested=5 Explanation process handed to parent=19 Immediate explanation=21		

Name	What were your child's experiences of finding out about the autism diagnosis	Themes	Converging	Broad themes
Parent 3 17.7 yrs M AS London	The assessment was very easy in that it only took one (long) meeting to confirm his diagnosis. He found the whole experience very confusing, however, as its purpose was not explained to him by any of the doctors or specialists and I only talked to him after the diagnosis was confirmed. As far as I am aware he has never discussed his condition with a doctor. He was aware prior to the diagnosis that he was 'different' and I explained the condition to him as best I could. I encouraged him to ask questions and research himself but I'm not sure he ever has. It has taken a while but five years on he does accept that he has high functioning autism, although he refuses to let it define him and he has actively disliked any other high functioning ASD children he has met, simply I think because they are too similar to him.	Assessment straight forward process=22 Young person included in the process=16 Confused by diagnosis=3 Process not explained by professionals or parents =2 Parental explanation =19 Lack of professional support related to understanding the diagnosis=8 Pre-diagnostic awareness of difference =4 Parental explanation=19 Encouraged to research the diagnosis=20 Acceptance a process =35 Not defined by autism=34 Rejection of those with similar features=5	9. Comparison to peers x5/H 10. Self-awareness/self-esteem/self-efficacy x5/H 11. No awareness pre-diagnosis x1/C 12. Inappropriate resources/views x2/B 13. Poor peer awareness x1/E 14. Lack of professional support/understanding x4/E **Overall Converging Positive Themes** 15. Realisation & Relief x7/G 16. Young person included x5/D ~~17. Interest in diagnostic explanation/process~~ 18. Diagnostic catalyst x2/G 19. Parent aware/explained diagnosis x15/C 20. Strategies to support understanding x4/C 21. Advice about explaining x1/E 22. Diagnostic process supportive/accepted x9/A 23. Quality of information/resource x2/B	
Parent 4 M ASD 13.6yrs London	As my child was diagnosed at 5(he is now 13) he has been told age appropriately about his Autism Spectrum continually after diagnosis to this day	Early diagnosis=36 Explanation an ongoing process=35		

Name	What were your child’s experiences of finding out about the autism diagnosis	Themes	Converging	Broad themes
Parent 5 ASD SE 13.7yrs Male	Even though we told him and still continue to talk about his autism he doesn't really understand. He does tell people he has autism if he thinks they need to know. But mostly he just talks about why he isn't as clever as other kids, and why he has 1-2-1 lessons. His self -esteem is a much bigger issue than the autism.	Parental explanation=19 Explanation about autism an ongoing process=35 Understanding autism is difficult=3 Explanation to others important to young person=27 Negative comparison to peers=4 Questions support=4 Poor self-esteem=10	~~24. Individualised information~~ 25. Books x3/B ~~26. People involved in explanation~~ 27. Diagnosis understood by/explained to others x3/C 28. Engagement with the diagnosis x1/D 29. Access to support/specialist supportx4/E 30. Skills and strategies x10/F 31. Comorbid/related needs x1/A 32. Improved skills/ self-efficacy x4/F ~~33. Fitting in better~~ 34. Self-awareness x8/H 35. Explanation/Acceptance over time x13/A 36. Early diagnosis x2/A 37. Focus on positives when discussing autism x6/C	
Parent 6 SE ASD F S 15 yrs	We read a book called 'I have Autism... What's that?' And without any prompting my child recognised that the book was about 'someone like me'. We spoke about the ways autism affects my child specifically, both positively and negatively. She ultimately accepted that her condition provided her with a different view of the world and some difficulties that we address as a family.	Parental explanation=19 Book supported explanation=25 Recognition of features in self=34 Information about autism tailored to the individual=23 Acceptance a process=35 Self-awareness=34 Focus on strategies rather than difficulties =30		

Name	What were your child's experiences of finding out about the autism diagnosis	Themes	Converging	Broad themes
Parent 7 SE F x2 ASD 10.6 yrs	I told both my daughters about their diagnosis of ASD. The doctor that diagnosed was lovely but he did not tell them of their diagnosis. I explained what ASD is & that is why they are how they are. They really took it well & it answered many questions for them I.e. they no longer think they are "weird" (as branded by other children), they know there is a reason for their ways & feelings. And also the added bonus of not being passed about from one specialist to another.	Parental explanation=19 Lack of professional support with explanation=8 Explanation of autism linked to individual=24 Acceptance of diagnosis=28 Explanation and realisation=15 Different and weird =4 Explanation and realisation=15 Continuity of professional involvement=29	38. Positive comparison to peers x3/H 39. Role models x2/H	
Parent 8 SE ASD F 7.3 yrs	Our child was told nothing at the assessment appointment, so it's been left to me to research ASD and the best time and way to tell her and give her the relevant information, positive and negative in a way that would preserve self-esteem etc. She already felt different as she'd noticed she was the 'only one who's scared of noises' and was very down on herself because of this, actually saying she hated herself at the age of 5. Post diagnosis I've been able to explain more about why, and that her way of thinking and processing is not less, just a bit different. Though she's found it hard at times and wishes she was like everyone else, she's slowly starting to see the positives such as original thinking.	Lack of professional support=8 Young person included in the process=16 Parent had to research to support explanation=8 Parental explanation=19 Giving positive and negative information about autism=37 Recognition of the possible impact on self-esteem=10 Feeling different=4 Comparison to peers=9 Difference emphasised rather than problems=20 Comparison to peers=9 Understanding and accepting diagnosis an ongoing process=35 Positive features/skills emphasised=37		

Name	What were your child's experiences of finding out about the autism diagnosis	Themes	Converging	Broad themes
Parent 9 SE ASD F 6.6yrs	She still is unaware of her diagnosis and has never questioned why she sees doctors etc I have explained some of it to her and she hasn't made any comments about it	No awareness of diagnosis=11 Medical involvement not questioned =2 Parental explanation=19 Lack of response=5		
Parent 10 Mother SE AS M 13.10 yrs	He didn't listen at the appointment with the diagnosis. I discussed it with him later. It made him feel less "mad" and we explored ASD together with various aged related books. He found a lot of books to childish, he wouldn't use social stories. Now at secondary school he seems more able to accept it, but finds other children quite cruel or disbelieving, or just plain rude to him. On the whole I would say it's been a negative experience, apart from he understood at the time of diagnosis why he felt so mad and out of synch with his peers. SPD is the biggest problem as it affects so much of his education and how other children treat him.	Didn't listen=5 Parental explanation=19 Post-diagnosis relief=15 Book supported explanation=25 Inappropriate resources=12 Acceptance a process=35 Peers lack understanding=13 Diagnosis a negative experience=2 Diagnosis and self-awareness=10 Difference & Comparison to peers=4 Social difficulties =10		
Parent 11 Male 12.5 SE AS	no comments			
Parent 12 Male SE Autism 13.10yrs	I think he found it a relief that there was a reason why he felt as he did and that through help he could find ways around the difficulties he experienced every day.	Diagnosis relief=15 Diagnosis provides explanation=22 Strategies to overcome difficulties=20		

Name	What were your child’s experiences of finding out about the autism diagnosis	Themes	Converging	Broad themes
Parent 13 Male 10.7yrs SE ASD	My Son only knows what we have told him. The information we were given was limited by the consultants. We have had to do a lot of research to enable us to inform him. We feel that the resources in mental health are not enough and need a lot more money injected into it to be able to support the children and their families.	Parental explanation=19 Lack of professional support related to understanding the diagnosis=8 Parent had to research to support explanation=8 Not enough mental health support=14		
Parent 14 Male 15.5yrs SE ASD	It opened the way for him to feel ok about his behaviours, feelings and actions. It also empowered him to take control of his anger, learn coping strategies to deal with anxieties around animals and food. His social skills have improved immensely. He is self-confident and able to make contact with new people (eg work experience) without me. He is so much happier. He has far less angry outbursts and is able to communicate his frustrations quite clearly and not let his feelings control him. He feels he has a reason for "odd" behaviours and rather than making him odd, it explains exactly who he is. It's the best thing for him. He feels normal by being told he is different!	Explanation and realisation=15 Taking control=30 Focus on strategies =30 Improved social understanding=32 In control of emotions =32 Diagnosis supports self-awareness=34 Different 4 Normal/self-awareness =34		

Name	What were your child's experiences of finding out about the autism diagnosis	Themes	Converging	Broad themes
Parent 15 Male 8.6yrs ASD SE	He's 8, and only diagnosed 5 months ago. We are on a steep learning curve, and one I am scaling first. When I understand certain of his behaviours I explain to him, or in the case of stress responses I ask different questions to what I would have done before. He only knows what I've been able to tell him, although I don't go on about labelling everything as being 'his autism'. I say, 'I understand why you want to make as much noise as possible right now, please go into the garden/room and be noisy there'. I'm doing more adapting than he is, but our lives are calmer as a result, as I know not to pressure him. He probably wouldn't tell anyone about his autism, not because of any stigma, but because it's irrelevant to him. We are aware it's a reason for his behaviour not an excuse. So we focus on the unwelcome behaviours, and alternatives.	Recent diagnosis=1 Parents need to process and understand diagnosis first=35 Focus on strategies rather than difficulties =30 Parental explanation=19 Diagnosis alters parent =30 strategies/supports understanding=20 Acceptance a process=35 Diagnosis reduces stress =22 Not interested==5 Improves parental understanding=22 Focus on strategies rather than behaviours=30		
Parent 16 F SE Autism 19.1 yrs	She was happy to know what it was she had and not bothered with the details really after that.	Diagnosis supports self-awareness=34 Not interested=5		

Name	What were your child’s experiences of finding out about the autism diagnosis	Themes	Converging	Broad themes
Parent 17 M SE ASD 13.6yrs	We were told about the diagnosis and this was I recall then told to our son by a specialist consultant, who explained the condition. There was though no follow up with our son after the diagnosis. We post diagnosis have endeavoured to highlight the positive sides to this diagnosis and to this condition. Overall I fell it has been helpful for him to know that he has this condition. He can see that is why his reactions to some events or his interest in certain topics are not the same as peers or others around him.	Young person included in the process=16 Professional explanation=26 No post diagnostic follow-up=14 Positive features/skills emphasised =37 Diagnosis supports self-awareness=32/22 Difference=9		
Parent 18 Male SE ASD 16.8yrs	I am still not sure what he feels but it is a great help to us so that we can guide him and understand his problems which we have still much to learn, I think he knows a little about his problems and he does take his police ASD card when he goes out.	Diagnosis supports understanding=22 Understanding a process=35 Support strategy=30		
Parent 19 17yrs SE Autism Male	Still unaware, despite going to an autistic unit & his peers talking about their autism - he just is who he is. He has sometimes asked why other people aren't good like him - in reference to the naughty boys & bullies at school - so if he sees a difference it is a positive one & he is the superior being!	Lack of association with others on spectrum=5 Positive self-view=34 Comparison to peers=38 Difference=38 Positive self-view=34		

Name	What were your child's experiences of finding out about the autism diagnosis	Themes	Converging	Broad themes
Parent 20 Male SE Autism 16.10.yrs	He only now age 16, realises that he 'might'(his words) have Aspergers. He is more not bothered about it when I found out i also have it age 56!! So when he was younger didn't really understand and wouldn't read books. He was in denial, still is a bit. As he is able to act Neuro typical quite well when with people outside the home.	Acceptance a process=35 Impacted more by parent diagnosis=5 Disassociation =5 Denial=5 Conforms to others=6 expectations		
Parent 21 Male 5.3yrs AS SE	As our son was only 5 years old it didn't matter much to him, only that we as parents understood partially what he was struggling through. The diagnosis (and a new school) mean that adults are trying to help him, rather than label him as a bully etc. He has very little sense of self. He has now decided that we are trying to help him overcome his physical, emotional and school difficulties and he is motivated to lessen the impact.	Disinterest=5 Diagnosis supports understanding=22 Lacks self-awareness=10 Focus on strategies rather than difficulties=30		
Parent 22 F 14.7yrs SE ASD	She wanted to know if she could have an Autism Assistance dog like her big sister, but otherwise took it in her stride!	Linked to a positive interest=37 Parent explained=19 Acceptance of diagnosis=22		

Name	What were your child's experiences of finding out about the autism diagnosis	Themes	Converging	Broad themes
Parent 23 SE ASD Male 12.6yrs	I think it made sense in that he felt he was different to other children and found certain things difficult that other children found easy. We presented it very positively and tried to focus on what it meant to him and his life rather than the limitations or difficulties it may cause him in life. He doesn't talk about it much as he doesn't talk about anything much so it is sometimes difficult to know what he's feeling and if you ask him, he finds it difficult to put it into words too.	Diagnosis supports understanding=22 Difference=4 Comparison to peers=9 Positive features/skills emphasised=37 Difficult to articulate view of diagnosis= 5?		
Parent 24 WMids ASD 2 x M 6 & 7.6yrs	He was 2.5 at the time so we are only just talking about it to him now at 6, he understands what it means and he's happy we have told him and he enjoys telling others about his different brain and explaining how every Brain is different.	Early diagnosis & explanation=36 Parent explained diagnosis=19 Enjoys disclosure=27 Difference is shared=38		
Parent 25 Lond F ASD 15.6 yrs	Didn't really register at first; diagnosis came at the end of year 6 so the focus was on secondary transition. Found it very difficult to accept process as she had/has a strong desire to be the same as everyone else.	Time to process the diagnosis=35 Late diagnosis=1 Came alongside another life stress=2 Acceptance of diagnosis difficult=5 Desire to fit in=4		

Name	What were your child’s experiences of finding out about the autism diagnosis	Themes	Converging	Broad themes
Parent 26 Oxford M AS 16 .3 yrs	I was given a book list. I told my son myself within days that he was "different", not "wrong". The key was when he met others like him, when I set up autism support group, * support group name My son knew he was different. He believed what I said. He listened to the doctor but nothing really resonated until he met others like him at *the support group. Subsequently, I won a place for him at a specialist Asperger's school which has revolutionised his self-esteem and understanding of being a person with autism.	Booklist=25 Parental explanation=19 Difference not wrong=38 Meeting others with diagnosis=39 Proactive support-29 Difference=4 Acceptance of diagnosis=35/39 Time to process=35 Specialist provision=18 Being understood improves self-esteem & acceptance=32		
Parent 27 S East Female 09/12/70	She waited for years and was denied it due to negligence via education and professionals via salt team. I knew she had it and she was statements and 14 before diagnosed.	Delayed diagnosis=1 Problematic process=2 Parental recognition but not professional=14		

Name	What were your child's experiences of finding out about the autism diagnosis	Themes	Converging	Broad themes
Parent 28 York & humb M ASD 12.11 yrs	We weren't really told very much, however, he was also diagnosed with NF1 at the same time. It was a bit of a relief as we knew that he was finding school difficult and was getting left behind his peers academically. I have learnt things as I have gone along. I now work in an EBD school and if I had known at diagnosis what I know now things would have been very different, especially with regard to his statement. WE have never given him the opportunity to "get out" of things because of his diagnosis and chose not to tell him for about 4 years. We are bringing him up to be independent and to make a useful contribution to society. He attends a mainstream school of 1,500 and he manages with TA support.	Lack of professional support related to understanding the diagnosis=8 Comorbid diagnosis=31* Diagnosis relief=15 School was difficult=7 Comparison to peers=9 Understanding a process=35 Concern about diagnosis as an excuse=12 Delayed disclosure=1 Independence encouraged=30 Educational support=29		
Parent 29 Wales 15.3 M x2 Autism	We were informed of my son's diagnosis via a letter from the paediatrician. We have been unable to see a health professional face to face to discuss the diagnosis as we were unable to attend the original appointment date and have not been offered another. Very frustrating!!! The NHS is a shambles!!!!	Informed by letter=2 Lack of professional support related to understanding the diagnosis=14 Problematic process=2		
Parent 30 SE 18yrs M & 1 x male adult ASD	We told our son when he was 10 and able to understand what it meant and did do in a very positive way telling about all the things he could do and not focusing on the difficulties but explaining why he had these difficulties and teaching him strategies to overcome them	Parental explanation=19 Positive features/skills emphasised=37 Focus on strategies rather than difficulties=30		

Appendix 19.7 Parental responses to open questions-children's experiences after diagnosis

	What has happened since your child found out about their autism diagnosis?	Themes	Converging +Positive theme =Neutral theme -Negative theme	Broad topics
Parent 1 F 18.11yrs Nwest AS	Moved to college a year early and then was able to access the disabled students allowance when starting her degree, which gave her a mentor for her first year at least. Was assessed as having dyslexia which gave her access to more time for assignments. Tutors try to be understanding and differentiate work for her	Understanding enabled positive change-a Practical support became available c X 3 Recognition enabled full consideration of YP's development -d Needs were met more appropriately –b	a-Diagnosis enabled positive change +12 (3) b- Needs were met more appropriately +7 (3) c- Support became available +17 (3) d- Understanding of others improved +20 (2) e- Positive impact on young person's skills +1 (4) f- No change =8 (3) g- Negative impact on young person -2 (4) h- Identity +1 =2 -3 (4) i-Acceptance of diagnosis/recognised positively +4 (4) j- Processing/Disassociation from autism =9 (4) k- Others lack of understanding -19 (2) L- Problematic emotions -3 (4) M-Mistreatment -2 (2) N- Parent/own approach to resolve difficulties =1 (2) O-still unable to access correct support -7 (3) P=family support important +1 (2) Q = Explaining to others/ disclosure =1 -1 (2) R=Autism used as excuse -1 (4) S=Nature of autism problematic -1 (4) T=ambitions +2 (4)	1. Skills and strategies Pos=13; 2. Understanding of others Pos=23; Neutral=9; Neg=22 3. Diagnosis as a catalyst for change Pos=40; Neutral=8; Neg=7 4. Self-views (awareness/ efficacy/identity) Pos=8; Neutral=9; Neg=7
Parent 2 13.11 yrs M-SE-ASD	Seems uninterested in hearing about autism and others on the spectrum	Disinterest in the diagnosis- processing/disassociation/or is it just processing/emotional style?- j		
Parent 3 17.7 yrs M AS London	The most positive aspect of the diagnosis is a greater understanding of the people he is in contact with on a daily basis. Since he hit puberty (after his diagnosis) he has become more negative and anxious in general but I don't think this is because he is aware of his condition, more that he has the condition.	Better understanding by important people-d Emotional impact of puberty -h Not the knowing but the having that is the issue-h		
Parent 4 M ASD 13.6yrs London	Things and life for my child did become simpler, though years 3-6 were, we realise now more difficult and had more of an impact then we realised. the junior school didn't understand autism as the infant school had and my child was branded "difficult" and at times bullied and treated virtually abusively (he was locked in a classroom by himself during a meltdown). I was constantly in the school, being called to the school and bringing in the Autism Advisory Teacher to the school. It was not until late year 5 that things changed for the better, but by then he had made up his mind about the school and I do not blame him. He is currently entering year 9 at a mainstream HS with an Autism Resourced Provision that I can not speak highly enough	Things become simpler/easier-a Problems caused by lack of understanding by important people-k Branding-h Bullying and abuse-M Emotional disequilibrium=L Lack of understanding causing conflict and negative impact=k Able to call on specialist support=c Lack of understanding -k Young person disillusioned by lack of understanding =g Access to staff with positive understanding and provision improves outcomes=c Recognition of own strengths=e		

	What has happened since your child found out about their autism diagnosis?	Themes	Converging +Positive theme =Neutral theme -Negative theme	Broad topics
	about! He is now learning about himself as well as academically what he is very good at and the self-esteem and confidence is increasing.			
Parent 5 Mother ASD SE 13.7yrs Male	His behaviour didn't change. He was 8 when he was diagnosed. The school were quick to put extra support in place for him, although they were treating him like he had it before the diagnosis. My mum and husband went on a course to help them understand why my son does what he does, some aspects of autism just can't be helped! he always had a very negative view of life before the diagnosis anyway, but as he has got older he becomes more negative	No change in behaviour=f School staff recognised need and made adjustments=d/a Access to training improves understanding of family members=d Young person increasingly disillusioned =g		
Parent 6 SE ASD F 15 yrs	My child has been to ASD specific support groups to address emotional regulation and social skills. School have provided extra support. My child has grown in confidence, made good progress academically and succeeds in maintaining friendships.	Provision of additional support for young person's social and emotional development=c Extra support for learning=c Extra support led to increased confidence good progress and positive relations with peers=e		
Parent 7 SE F x2 ASD 10.6 yrs	Behaviour has not changed, but my daughters now have an understanding (to a point) of why they do what they do. Family members now realise that there is a reason why my children have not ever spoken to them & realise that they are not just rude or ignorant. As for school, they did not receive extra help after diagnosis but some teachers would put in extra effort to encourage & help, others will just be oblivious to their problems.	No change in behaviour=f Self-understanding=h Diagnosis improves understanding of family members=d Some increased understanding in education=d Some educators still do not understand=k		
Parent 8 SE ASD F 9.3 yrs	Unfortunately because our child is of average intelligence and able to mask her difficulties to a degree, school staff continued to feel not much support was needed (as do extended family) which meant school continued to be extremely difficult, school refusal worsened till we decided	Able with autism still not understood=k Support needs not recognised by educators or family=k School refusal= L		

	What has happened since your child found out about their autism diagnosis?	Themes	Converging +Positive theme =Neutral theme -Negative theme	Broad topics
	the only way to preserve mental and emotional wellbeing was to home educate.	Home education felt necessary as child not understood=N		
Parent 9 SE ASD F Amy 6.6yrs	I feel that at school she is let down by her teachers as she Is academically good they seem to ignore the fact that her social skills need attention and that she has high emotional needs	Able with autism still not understood or supported=k/O		
Parent 10 Mother SE AS M 13.10 yrs	He had more help at primary school and the teaching staff were more understanding. He still had his core friends, but others in his year still treated him poorly and bullied him. Secondary school has been mixed. The SENCO knows about ASD yet practically has done nothing positive and expects him to "mature" and cope. He is in a high achieving grammar school, and they expect a certain level of behaviour and seem to be unable to allow for ASD in this. His anxiety levels are high, he has had suicidal ideations and continues to do so. He knows I have his back and is extremely close to me. I think his father is undiagnosed aspergers, and his brother also has aspergers and ADHD. This causes some friction at times. He can be very negative about himself and things that go wrong. He is coping though, but I am sure things could be better with the correct intervention.	School staff recognised need and understood=c/d Negative peer interactions=M Problems caused by lack of understanding by important people=k Able with autism still not understood or supported=k/O Anxiety and unmet mental health needs=O Parental support important =P Family members also on the autism spectrum Young person negative self-image=h Could be better if understood and supported appropriately=k/O		
Parent 11 Male 12.5 SE AS	No comment			
Parent 12 Male SE Autism 13.10yrs	He has had extra hours on his statement so he has help throughout school day. He is now able to do a full school day. People now try to understand his difficulties and adapt their own behaviour to help him.	Diagnosis enabled extra support=c Understanding enabled positive change=e School staff recognised need and made adjustments=d/b		
Parent 13	Since my sons diagnosis not a great deal has	Not much change=f		

	What has happened since your child found out about their autism diagnosis?	Themes	Converging +Positive theme =Neutral theme -Negative theme	Broad topics
Male 10.7yrs SE ASD	changed. His support at school has increased but he's attitude towards this is one of a hindrance. He is embarrassed that he receives additional support, he doesn't like to stand out. I believe the educational system needs re-educating, not all teachers in mainstream school understand Autism. When my son has one of his melt downs this is often interpreted as him refusing to cooperate. My son needs aren't always being met outside the home and this is frustrating for us and him.	Increased support but hindered by young person's acceptance=j Support impact young person's identity=h Educators lack understanding=K Behaviours misunderstood=k Parents frustrated by lack of understanding =k		
Parent 14 Male 15.5yrs SE ASD	He was offered a speech and language assessment which identified areas for improvement re social interaction, small talk, confidence in groups, expressing self and understanding what can be expected in classes like English where he does struggle. He also saw a trainee therapist to improve his animal anxieties-exposure/desensitising therapy. Very successful. Some friends have noted how much more mature and self-assured he is. Some have noticed an improvement in his overall communication skills since several years ago.	Provision of additional support for young person's social development=b Provision of additional support to meet young person's emotional needs=b Additional support has positive impact=e Communication skills have improved=e		
Parent 15 Male 8.6yrs ASD SE	We have only really shared with school, the label is less important, since I am forever hearing in social media support groups, that I've found for myself, that if you've met a child with autism, you've met one child with autism. Therefore, telling anyone that your child is autistic, means little to them, due to their own perception and knowledge, and tells them little about how it affects your child. There is also a stigma about perceived over diagnosis, and any old misbehaviour is labelled as autism. As before, I don't want to use it as an excuse, but it's of little explanation to others either, so I tend to withdraw	Limited disclosure = Q Specific diagnosis not important due to individual presentation =h Telling people about autism doesn't support understanding=Q Stigma and over diagnosis=J? Autism not considered an excuse=Q		

	What has happened since your child found out about their autism diagnosis?	Themes	Converging +Positive theme =Neutral theme -Negative theme	Broad topics
	135.from tricky situations. I find other parents very 136.aggressive at times when I have seen what 137.happened, and their child is the instigator, my 138.child is the (over) reactor, but not the instigator. 139.In these instances, I'd look like I would be trying 140.to justify my son's behaviour, and would garner 141.little if no understanding from the other party, so 142.we don't bother mentioning it. He has received 143.more help in school, but that might be to do with 144.the changes to funding, and so they now have to 145.spend the money on him. The SENCO has been 146.more supportive than the school management, I 147.sometimes feel they have different 148.understandings, and the school heads are less 149.accepting, tolerant of him. Sometimes it feels like 150.he is too much trouble for a mainstream school.	Reactions of others problematic =K General lack of understanding from others=K Additional support =c Understanding not consistent in school=d/k He is too much trouble to include=K		
Parent 16 F SE Autism 19.1 yrs	151.Getting a statement of special educational needs 152.was the key in getting the help she needs and 153.deserves. People we know are more 154.understanding and make more allowances. She 155.is not badly behaved but has odd behaviour 156.which hasn't got any better or any worse. If we 157.are out though and she displays these behaves 158.in front of strangers they don't understand.	Diagnosis as a catalyst for support=c Diagnosis improves understanding and enables adjustments=b/d No change in the child's behaviours=f No impact on views of general public=k		
Parent 17 M SE ASD 14.2yrs	159.Since the diagnosis there was some extra 160.understanding at Primary School but rather little 161.extra practical support. The Secondary School, 162.especially Year 7, was excellent at giving extra 163.help. This has reduced over time (he is now in 164.Year 9).	Diagnosis improves understanding=d Little additional support offered=O Support given and reduced=c		
Parent 18 Male SE ASD 16.8yrs	165.help has now started and we are still finding new 166.ways to help him from support groups. he has 167.changed to move himself away from problems to 168.control his frustration	Diagnosis enabled extra support =c Access to support improves understanding of family members=d Diagnosis improves own understanding and strategies=e		

	What has happened since your child found out about their autism diagnosis?	Themes	Converging +Positive theme =Neutral theme -Negative theme	Broad topics
Parent 19 17yrs SE Autism Male	169.Obviously it helped with his schooling. 170.Occasionally I feel the need to explain to others 171.about his condition if they find his behaviour or 172.conversation strange, but I don't feel comfortable 173.having to excuse him as he won't have done 174.anything wrong & I wish other people were less 175.judgemental	Diagnosis enabled extra support=c Feel the need to explain behaviours to others=Q People make judgements=k		
Parent 20 Male SE Autism 16.10.yrs	176.It was a total fight to get any help. Never really 177.got help from anywhere. Had to take him out of 178.the primary school he hated and get 7 charities 179.to pay for private education, which thankfully 180.they did till July this year.	Lack of understanding and support=K/O Problems caused by lack of understanding by important people=K Support only available from charity=c		
Parent 21 Male 5.3yrs AS SE	181.We get extra help from school, occupational 182.therapist, after school clubs. He has now 183.decided he wants to work to make things less 184.difficult for himself. When he behaves in "odd" 185.ways I see people's reaction and try to make him 186.feel by my words and actions that there is a 187.rational explanation for many of his behaviours. I 188.hope he gets strength from this. The extended 189.family are now more accepting after initially 190.denying any issues. We as parents are 191.constantly looking for ways to lessen the 192."deviant" behaviour and try to make him "fit in" 193.more, plus we are trying to ensure he is not 194.victimised by bullies and that his teachers try 195.hard to get him to work to his best ability.	Diagnosis enabled extra support=C Diagnosis as a trigger for self-improvement=e Parent tried to explain odd behaviours in relation to diagnostic explanation=Q Diagnosis improves understanding of family members=d Parents encourage changes in behaviour to aid fitting in and avoid bullying=i/h Parents need to encourage teacher understanding=O		
Parent 22 M 14.7yrs SE ASD				

	What has happened since your child found out about their autism diagnosis?	Themes	Converging +Positive theme =Neutral theme -Negative theme	Broad topics
Parent 23 SE ASD Male 12.6yrs	He sometimes uses his autism as a reason why he isn't good at something like friendships. He isn't treated differently at school as he was already getting the appropriate help via his statement at a special needs school	Autism is used as an excuse=R No change as support/Statement already in place=f		
Parent 24 WMids ASD 2 x M 6 & 7.6yrs	School have not offered anything more with the diagnosis than without it but family members understand him better and he understands himself. It's not just for now but for his future so he will always know why he might struggle with certain things or why he's really good at others.	No extra support at school=f Diagnosis improves understanding of family members=d Diagnosis puts context to strengths and needs=i		
Parent 25 Mother Lond F ASD 15.6 yrs	Things have improved since she moved to a specialist school in year 9 with very individualised teaching by staff who understand the needs of people on the spectrum. Her disruptive behaviour (including self harm) was helped by a further diagnosis of ADHD and appropriate medication which helped her settle down at school and stay in lessons, since when she has achieved considerably in her studies.	Change of school for staff to recognised need and make adjustments=k Recognition of other needs also enables appropriate strategies/medication =a Right support has been settling and enabling to achieve= a/e		
Parent 26 Oxford M AS 16 .3 yrs	My son's sense of humour has come to the fore; he laughs at himself but in a good way. He also recognises autistic traits in others; again in a good way. He laughs at his creation of neologisms; in fact, revels in them. Asperger's Syndrome is a visually intangible condition. My boy has striking looks being half-Persian/half-English and he has really improved in his ability to approach people such as famous footballers and pundits and... ask for selfies! In large family gatherings at home, and social events at school, he is now able to socialise.	Sees the funny side of differences=e/i YP can now recognise positive traits=i Interest/skill-e Invisible nature of autism=s Confidence has improved=e Now able to socialise=e		

	What has happened since your child found out about their autism diagnosis?	Themes	Converging +Positive theme =Neutral theme -Negative theme	Broad topics
	Two short years ago he would sit with his head on a table and hands over his ears. He is now confident that he can contribute socially at least in short bursts. Phenomenal!	Difficulties improved quickly after diagnosis=a Post diagnosis increased confidence=a Contribute to society T		
Parent 27 Mother SEast ASD Mother Male 18yrs	Not at all, he knows he can spot details others don't. He wants to work in cyber-security Doesn't really think about it, except when he's trying to get out of something!! He has 1:1 support at school, however the LA don't fund this the school does. He can be incredibly stubborn, believing he is always right and he can fairly argue with his dad.	No change in YP=f Positive ambitions=T YP disinterested=j School provide support=c Problematic behaviours/emotions=L		
Parent 28 York & humb M ASD 12.11 yrs	Teachers are a lot more understanding however, through the SENCO, we have had to arrange an awareness raising session for teaching staff as some were very critical of my son's behaviour- e.g. they couldn't understand why he couldn't answer a question when put on the spot, why he would be tired in class!	Understanding enabled positive change=a Access to training improves understanding=d Lack of understanding causing negative impact=k		
Parent 29 Wales 15.3 M x2 Autism	More support at school and college, extra time for exams	School staff recognised need and made adjustments=d/b		
Parent 30 SE 18yrs M & 1 x male adult ASD	No comments			

Appendix 19.8 Parental responses to open question- anything else

	Is there anything else that you would like to tell me?	Themes	Converging	Broad topics
Parent 1 F 18.11yrs Nwest AS	Getting a diagnosis for a very able girl who did not cause her school any 'difficulties' was a long drawn out process. I told my daughter she thought differently to others and about autism but she needed to hear it from a professional before she would agree. The diagnosis changed all our lives and she is now building a successful independent life where once we thought I would have to be on 24 hour call for ever. I have returned to work and although she often needs my help she is developing many other strategies to get the most out of life and use her amazing strengths. She is very open about her autism and a great advocate.	Invisible nature of those who are able with autism Need confirmation to accept/understand Diagnostic catalyst for positive change Strategies based on strengths	**1. The Diagnosis** Invisible nature of those who are able with autism x4 Variable impact of autism x3 Differential diagnosis x5 Need confirmation to accept/understand Diagnostic catalyst for positive change Time to process Related needs become apparent Progress beyond predicted Ability highlights inability Not disabled enough Difference and disability The label helps/prevents other labels Diagnosis is helpful Autism an excuse **2. Understanding of others** Poor peer understanding of difference-2 Positive peer relations-2 Poor understanding from professionals **3. Right Advice/information** Useful information but difficult to apply Wading through the information/signposting needed Searching for answers/the right approach Waiting for the lightbulb moment **4. Moving on**	1. The Diagnosis x23 2. Understanding of others x5 3. Right Advice/information x4 4. Moving on x11 5 Strategies x4 6 Traits x7 7.Support x11 8 Process x3 9. Parenting x2
Parent 2				
Parent 3				
Parent 4	my son experiences "exposure anxiety" as per Donna Williams so this whole section can be difficult for him.			
Parent 5				
Parent 6				
Parent 7	My children have a good	Positive peer relations		

SE F x2 ASD 10.6 yrs	small set of friends that accept them & their ways. Making new friends is virtually impossible. They like their school friends to be in school, but have difficulty speaking to them outside of that environment. To very close family members they are very chatty & friendly, but there are aunts/uncles & cousins that they have never spoken a word to. I would like to add that both children were diagnosed as selective mutes long before ASD diagnosis, so this may add to the problem	Home school separation Confidence and familiarity Differential diagnosis	Letting go Independence Making progress Independence vs safety Worries about the future-4 Reluctant acceptance Strengths recognized/pride Pride **5 Strategies** Strategies based on strengths- Strategies for success x2 Conforming **6 Traits** Home school separation Confidence and familiarity Emotional impact x2 Change difficult Skills Rules **7.Support** Right support difficult to access x7 The right setting Charitable support Professional support for mental health supported acceptance of diagnosis Professional support **8 Process** Poor/Let down x2 Seeking private diagnosis due to lack of understanding **9. Parenting** Parenting is different/difficult Feeling helpless	
Parent 8 SE ASD F 7.3 yrs	The school related questions refer to when she was in school. She's been home educated since January this year, half way through year 2, due to finding school very stressful as needs not understood or met, and sensory issues	Just clarity		
Parent 9				
Parent 10 Mother SE AS M 13.10 yrs	I think SPD has a big impact on his life, he has scored highly with this. NT children know when someone is a little different, some of them can be very cruel about this indeed. He is in an all boys school, and I wonder how beneficial this is to his social skills. I would have liked easier sign posting to help, and easier	Differential diagnosis Poor peer understanding of difference The right setting Let down		

	access instead of months of waiting for an initial appointment and then ages till a decision is made and then only being offered minimal help. I feel he is let down on lots of fronts.			
Parent 11				
Parent 12 Male SE Autism 13.10yrs	Although my child is at the lower end of the spectrum and has an extensive vocabulary when upset he will then go up the spectrum as he is unable to communicate what he is feeling or thinking. This is when he runs off and hides to get back in control. Finds change very difficult to deal with.	Variable impact of autism Emotional impact Change difficult		
Parent 13				
Parent 14 Male 15.5yrs SE ASD	Although we waited a year and a half for the referral to child and mental health services, we were seen for anger management in the meantime, which had a really effective result in helping my son to remain calm more often. Once we were finally in therapy it took about a year for the therapist to acknowledge he wasn't connecting to my son and referred him to a trainee. This worked well and my son engaged well. His animal and food anxieties were tackled well and have had quite a	Mental health support Positive impact of mental health support		

	114.lasting impact. My son is not 115."cured" but he can be in the 116.same space as a dog, for 117.example, which was 118.impossible 3 years ago. He 119.has the thought processes in 120.place to understand his 121.reactions and try and manage 122.them. He realises he needs 123.to develop coping strategies 124.to deal with things in life.	Agency in developing own strategies		
Parent 15 Male 8.6yrs ASD SE	125.As the diagnosis is recent 126.and he is obviously not 127.'severe' as it has not been so 128.blindingly obvious as with non 129.verbal, uncommunicative 130.children, it feels like it has 131.come quite late. I sought my 132.own preliminary diagnosis 133.through the psychologist 134.attached to the South 135.Thames Cleft Service, as I 136.was getting nowhere fast with 137.other people. This incomplete 138.assessment was for ADHD 139.and possible ASD and ODD, 140.but gave me something to get 141.the GP to base the referral for 142.formal assessment locally. 143.The appointment was 7 144.months later, and reversed 145.the earlier one, no ADHD but 146.definitely ASD. At that 147.appointment we we're given 148.the diagnosis, a prescription 149.for melatonin, and a list of 150.local resources and national 151.organisations, and they said 152.they'd see us in a year....! 153.After a two hour appointment,	Invisible nature of those who are able with autism Seeking private diagnosis due to lack of understanding Differential diagnosis No follow up support Time to process		

	it's like shell shock, you have no immediate questions, or rather you have a million and one, and don't know where to start. I attended the autism awareness day on all aspects of the condition, I didn't even know we had an autistic diet, but we do! This was informative, but general, applying it in real life is harder, except that at least as parents we are more understanding. We are booked to attend the Early Bird Plus course, which will be more tailored to us, but this is for children under 8 and there is a waiting list of a year, so he will be 9 before this comes around. I think we have more trouble because we are in the middle of the spectrum (I'm guessing, since there is no longer a diagnosis of anything but ASD) and therefore sometimes things go well, and sometimes things don't, it's all very unpredictable, nothing is consistent. He has no fears, so doesn't seek predictability in those, but is spontaneous and impulsive, but usually crosses the road well, but not always..! So, it's hard for him to be allowed independence for his own safety. I have recently seen an occupational therapist and completed a	Useful information but difficult to apply Right support difficult to access Understanding the range of needs Variable ability problematic Independence vs safety Related needs become apparent		

	sensory questionnaire as this looks likely to providing him with stimulus, coping strategies etc that we weren't aware of at all, this was through school. Didn't even know about this before they mentioned it, and when we went to the appointment I thought it would be about helping him in school and what he can be helped with, but he wouldn't do the tests go ended up having a great time on a swing in the OT room throwing bean bags around rather than doing any writing at all. I'm hoping this will unlock other benefits in time. I'm also seeking an ASD friendly martial arts class, for stimulation and focus. It has all been me doing the searching and considering the options though. I have accessed some local charitable services, who have trained me in passive restraint, as this was becoming a problem. Still all very new, and there is so much 'out there' to read, some of relevance, some not, it's time consuming and hard work and just a little bit frustrating!	Differential diagnosis Lack of follow up support Charitable support Wading through the information/signposting needed		
Parent 16				
Parent 17				
Parent 18				

Parent 19 17yrs SE Autism Male	233.*Child name is now 17 & in 234.supported learning at college 235.- he also has learning 236.difficulties. He is very artistic 237.& likes to make animations. 238.He loves dinosaurs & 239.SpongeBob. In general he is 240.now a very calm & content 241.boy but I think he is getting 242.more anxious about 243.becoming an adult. He 244.follows rules to the letter & 245.does not like exceptions to 246.rules - he wants to be a good 247.sensible boy. While I was told 248.he may never talk again I 249.have tried not to have 250.expectations or limitations. 251.Instead I prefer a 'who 252.knows', 'wait & see' & a 'don't 253.know till you try' approach! 254.He has come a long way, but 255.although it sounds strange, 256.as he becomes more able his 257.inabilities become more 258.noticeable too.	Autism and LD Skills Worries about the future Rules Conforming Progress beyond predicted Ability highlights inability		
Parent 20 Male SE Autism 16.10.yrs	259.One thing is that Aspergers 260.can be such a hidden 261.condition.If you are able to 262.mask the extreme anxiety 263.that comes with trying to act 264.normal ,the general public 265.think you are ok. Somehow 266.Teachers and people in 267.Authority need to believe 268.children when they say they 269.don't understand or don't do 270.what they are supposed to. 271.The whole process of getting 272.your child diagnosed.....and	Invisible nature of those who are able with autism Poor understanding from professionals Problematic diagnostic processes		

	273.actually Adults is totally 274.flawed its takes absolute 275.ages to get an appointment 276.anyhow.....although 277.my sons was done about 8-9 278.years ago I believe it is still 279.the same. No back up help 280.either. Social Services said 281.he wasn't Disabled 282.enough!!Things need to 283.change...the word Disabled 284.should change too for people 285.on the spectrum, it's a 286.horrible word, and just 287.because our brains are wired 288.differently which causes 289.anxiety, we really are not 290.Disabled in that sense. 291.I am willing to meet up with 292.you if you wish to help. But 293.my son is still not happy 294.about talking about the fact 295.he has Aspergers ,but it is 296.slightly better since I got a 297.diagnosis around a year 298.ago....although I was told I 299.definitely have it ...but you 300.cant tell! He couldn't give me 301.a definite on paper as my 302.parents would have had to 303.say what I was like from their 304.view but they died along time 305.ago.	Not disabled enough Difference and disability Invisible nature of those who are able with autism		
Parent 21	306.			
Parent 22	307.			
Parent 23 SE ASD Male 12.6yrs	308.It is very difficult as a parent 309.to support my child's 310.emotional and mental stability 311.And development when they 312.are autistic as all the	Parenting is different/difficult		

	instinctive things we do as a parent as offer a cuddle or a chance to talk are the very things that cause my son the most anxiety and that can leave you feeling very helpless so you just do what you can, read books, go to support groups, try different theories and ideas to try and stay positive but knowing that it is never enough and just hoping that someday there will be a 'light bulb' moment when he will find something that he is good at, makes him happy and takes away his daily diet of anxieties. My son generally sleeps well (even though he worries that he doesn't get any sleep at all) so at least in his sleep he is happy.	Feeling helpless Searching for answers/the right approach Waiting for the lightbulb moment Emotional impact		
Parent 24 WMids ASD 2 x M 4 & 7.6yrs	My 4 year old is still awaiting assessment and the not knowing is very stressful for the family. The label helps us all understand and help better, without it the child gets other labels such as naughty. In my experience though schools don't give any more help or support with a diagnosis as they just go on a need basis rather than a diagnosis one. Def don't regret the label and it's definitely helped my 6 year old to understand himself and he knows his brain works	Stressful wait for diagnosis The label helps/prevents others Doesn’t impact support Diagnosis is helpful		

	353.differently to others but that 354.doesn't upset him and he's 355.great at explaining his autism 356.to others. However he does 357.have a tendency to use it as 358.a excuse for naughty 359.behaviour which is def not 360.asd related and will say 361.things like "I can't help it, it's 362.my different brain"	Autism an excuse		
Parent 25 Mother Lond F ASD 15.6 yrs	363.She was also helped 364.considerably by sessions at 365.the *service name (the 366.Forensic Mental Health for 367.Young People team) which 368.gave her strategies for 369.dealing with her anxiety 370.issues and paved the way for 371.her to come to terms with her 372.diagnosis. She has shifted 373.fairly recently from outright 374.denial to a reluctant 375.acceptance and seeing that 376.there might be advantages 377.for her - e.g. It explains her 378.strengths and weaknesses in 379.particular areas.	Professional support for mental health supported acceptance of diagnosis Reluctant acceptance		
Parent 26 Oxford M AS 16 .3 yrs	380.Letting go as a parent of 381.someone with autism is 382.extremely hard. The first time 383.that my son travelled 384.independently, by train, 385.about 18 months' ago was 386.both a thrilling and nerve- 387.wracking experience for me. 388.A few days before he was 389.due to travel, I gave him 390.instructions as to how to 391.research his potential journey 392.and he duly planned his	Letting go Independence Strategies for success		

	route. Success! Other notable developments in independence within a similar time-frame include ordering his provisional driving license online; giving an articulate and detailed statement to the local police station following being attacked by a gang of youths; calling an ambulance when an elderly gentleman collapsed outside our house; engaging with 1:1 sessions with a CAMHS psychiatrist and developing a trusted relationship to discuss his worries and anxieties to alleviate tendencies to self-harm. Just writing this now has reignited my pride in my son.	Making progress Professional support Pride		
Parent 27	NC			
Parent 28 York & humb M ASD 12.11 yrs	We have learnt as much from him as he has from us. When you do your questionnaire can you make the different options always visible at the top - I kept having to flick up and down to see the column headings.	Learning from the child		
Parent 29 Wales 15.3 M x2 Autism	I feel that there's a big gap in the support available to families of individuals with ASD - we should be offered training on how we can best support a person with ASD (e.g. Coaching & motivating, managing behaviour etc.). Peer support/mentoring for person with ASD so they	Support gap Parental support needed Support for the young person		

	433.don't feel alone.			
Parent 30 SE 18yrs M & 1 x male adult ASD	434.By doing something lots of 435.times with our son we have 436.found he can then do this by 437.himself ie getting a flight 438.overseas which we have 439.done many times to and from 440.the same airport so he is now 441.confident to make that 442.journey on his own and meet 443.us there He is amazing at 444.housework and likes 445.everything clean and tidy so I 446.no longer pay a cleaner but 447.let him do this job which he 448.does better than any cleaner I 449.have ever employed!	Strategies for success Strengths recognized/pride		

Appendix 20: Results from professionals’ online survey

Appendix 20.1 Online survey: information about professional roles

What is your current role?	If you wish to give additional information about your role, or if you selected 'Other', please give details here:	Which area of the country do you live in?	Approximately how many young people with autism have you supported to understand their diagnosis within the last year?	Age range of the young people supported
1. Specialist Teacher (Autism)		Yorkshire	Fewer than 5	0-4 years,5-10 years,16-18 years, Over 18 years
2. Specialist Teacher (Autism)		South East	Fewer than 5	0-4 years,5-10 years,11-15 years,16-18 years
3. Specialist Support Practitioner (Autism)	Academic and practical mentoring for students at ks5.	South East	20 or more	16-18 years, Over 18 years
4. Specialist Teacher (Autism)		Not given	20 or more	0-4 years,5-10 years,11-15 years,16-18 years, Over 18 years
5. Specialist Teacher (Autism)		Northern	5-10	5-10 years,11-15 years,16-18 years, Over 18 years
6. Other (please state)	Autism social worker	Wales	20 or more	11-15 years
7. Specialist Support Practitioner (Autism)		Wales	Fewer than 5	0-4 years,5-10 years,11-15 years,16-18 years, Over 18 years
8. Other (please state)	Home school link worker (attendance and behaviour)	South East	5-10	0-4 years,5-10 years
9. Specialist Teacher (Autism)		North East	20 or more	11-18 yrs

Appendix 20.2 Online survey: type of support professionals provide in relation to children with autism

Participant	Please indicate the type of general advice and support that you regularly provide in relation to children and young people with autism (Please select all that apply)	3.a. If you selected Other, please specify:
1	Advice/support for school staff, Training for professionals, Training for parents/carers	
2	Advice/support for school staff, Advice/support for parents, Training for professionals, Training for parents/carers ,Interventions for young people	
3	Advice/support for school staff, Advice/support for parents, Training for professionals ,Interventions for young people, Mentor role, Counselling for young people, Other (Please give details)	Academic support; Organisational strategies; Managing stress;
4	Advice/support for school staff, Advice/support for parents, Training for professionals, Training for parents/carers, Interventions for young people, Diagnostic work, Therapeutic interventions, Other (Please give details)	Theraplay; Nurture groups; Peer support; Youth work
5	Advice/support for school staff, Advice/support for parents, Training for professionals, Training for parents/carers, Interventions for young people, Counselling for young people ,Therapeutic interventions, Other (Please give details)	Peer awareness
6	Advice/support for school staff, Advice/support for parents, Training for professionals, Training for parents/carers, Interventions for young people, Mentor role, Other (Please give details)	Social work interventions- child protection;, LAC
7	Advice/support for school staff, Advice/support for parents, Training for professionals, Training for parents/carers, Interventions for young people, Therapeutic interventions	Communication

8	Advice/support for school staff, Advice/support for parents, Counselling for young people	
9	Advice/support for school, Advice/support for parents, Training for educators, Training for parents/carers, Interventions for young people, Other (Please give details)	

Appendix 20.3 Online survey: information about the specific support professionals offer that helps children understand diagnosis

Participant	Please explain about the work you do that helps young people with autism to understand their diagnosis	Please select the types of resource that you use (or advise others to use) to help young people to understand their autism diagnosis	Type of resource 'Other'	Name of the most useful resource for helping young people to understand their diagnosis:
1	Direct support practitioner to complete interventions such as 'All About Me' Work with parents to enable them to support children's understanding	Film clips Non-fiction/information books about autism, Fiction texts about autism A published workbook about autism, Websites		
2	Discussing with parents how to share diagnosis. 1-1 work with primary age child to explain diagnosis. Providing literature to support understanding.	Non-fiction/information books about autism Autobiographies/biographies about people with autism, Bespoke resource created by yourself Other (Please give details)	Strengths and difficulties work book, with info tailored to the individual. Also signposted to talks by Dean Beadle, which helps parents and children to see a more positive side to their diagnosis. He is an inspirational adult with ASD who gives talks locally and wider afield.	Not necessarily the most helpful but 'My book of Autism Heroes' parents have found helpful to share with their child.
3	An introduction to autism programme that I have written to help them self-advocate. Training for teachers, both general and student specific ie "he hates flies and wasps and should not sit near an open window"	Film clips, Non-fiction/information books about autism, Websites Bespoke resource created by yourself	I have put together an introduction to autism presentation that I use for students and teachers	National Autism Society you tube clips. The series of 4 involving an adult male.
4	Direct work with parents families and other professionals Write programmes - guidance	Film clips, Non-fiction/information books about autism Fiction texts about autism, Autobiographies/biographies about people with autism, A published workbook about autism Leaflets Websites, Blogs, Social media, Bespoke resource created by yourself		
5	Training for professionals and parents including experience of diagnosis and presentation of it in a positive way. Difference not deficit model consistently promoted and key positive role models highlighted. Explanation of reasons for difficulties alongside strategies to deal with them.	Film clips, Non-fiction/information books about autism Fiction texts about autism Autobiographies/biographies about people with autism A published workbook about autism, Leaflets, Websites Bespoke resource created by yourself	I usually take aspects of a variety of published materials such as I am Special and adapt to the specific needs of the young person.	I haven't found a one size fits all as all out YP are different so always take what's useful.
6	Direct work with some individual to explore the core differences of living with autism and how this presents for them and then how people can best support them	Film clips, Non-fiction/information books about autism, A published workbook about autism, Leaflets, Websites, Bespoke resource created by yourself (Please describe it below)	Autism STAR - 5 core differences and how this presents for the individuals	I am Special Peter Vermeulen has proved very useful But I usually pick and mix
7	I support and provide resources for parents/carers to use with their children to support their understanding of autism.	Film clips, Non-fiction/information books about autism, Fiction texts about autism, Autobiographies/biographies		

Participant	Please explain about the work you do that helps young people with autism to understand their diagnosis	Please select the types of resource that you use (or advise others to use) to help young people to understand their autism diagnosis	Type of resource 'Other'	Name of the most useful resource for helping young people to understand their diagnosis:
		about people with autism, Leaflets, Websites		
8	I often find teachers don't get how a child with autism sees the world despite their teaching qualifications	Non-fiction/information books about autism		10 things every child with autism wishes you knew
9	Advice for parents about discussing diagnosis I work directly with young people and create resources to support this	Film clips, Non-fiction/information books about autism, Fiction texts about autism, Autobiographies/biographies about people with autism, Bespoke resource created by yourself (Please describe it below)		

Appendix 20.4 Online survey: professional’s skill level-supporting understanding of diagnosis

Participant	How skilled do you feel when helping young people with autism to understand their diagnosis or when providing advice about how to do this?	How often have you been able to access training in order to support you to help young people with autism to understand their diagnosis?
1	Moderately	Regularly
2	Somewhat	Never
3	Extremely	Very often
4	Extremely	Regularly
5	Extremely	Very often
6	Somewhat	Never
7	Somewhat	Rarely
8	Extremely	Never
9	Moderately	Occasionally

Appendix 20.5 Topics professionals use when supporting a young person to understand a diagnosis or when advising others about this work

	When helping a young person to understand their diagnosis, what topics would you usually include or advise others to use? Please list the topics in the box below	Please explain below if there is anything else about the support or advice that you provide that you have not had chance to explain.
1	focus on differences teaching practical strategies can use themselves	
2	Strengths and difficulties. Focusing on the scientific angle for a child who was interested in that aspect. How they experience their ASD. How others might experience ASD. Focusing on positive aspects and strengths. That it continues throughout life, but making sure they are not scared or misunderstand and think they might be medically unwell. Giving them the opportunity to think/talk things through with a trusted person regularly. Get their views on what they think about their diagnosis. Signposting to further support.	
3	I explain that autism is a different operating system, like pcs and macs. I refer to fight/flight and explain that we who are autistic have bucket loads of trigger hormone, whereas the others have just a little. I explain that we are logical and systematic, and that the others emotional vagaries are hard for us to understand.	I am able to understand the autistic student, mentor them, and advocate on their behalf because I am autistic. I have the benefit of a degree in autism (BPhil In Autism from Uni of Birmingham) and I am a parent of 2 grown up children with spectrum conditions.
4	No topics entered	
5	Four areas of difference and their impact in individual Sex and relationships Puberty Emotional recognition and regulation Sensory differences Asking for help,	
6	Core differences Sensory differences Being different is ok	
7	Communication and social interactions.	
8	I advise others to look at NAS website	
9	-Identify the young person's strengths, interests -4 areas of difference and the positive aspects of these traits -Strategies	

Appendix 20.6 Factors when learning about autism that professionals feel impact young people positively and negatively

	4. What do you feel are the 3 most important factors that support a young person to accept and/or feel positive about their diagnosis? Please write your ideas in the box below:	5. What do you feel contributes to an autism diagnosis having a negative impact upon a young person? Please give your ideas in the box below:	12. Please share any other thoughts about promoters or barriers for supporting children/young people understand an autism spectrum diagnosis:
1	positive links to others with ASC emphasising difference over difficulty providing practical strategies & exemplifying ways in which pupil has made progress so pupil can relate to these	lack of understanding of those surrounding pupil late diagnosis focus upon difficulties associated with ASC	early intervention key peer awareness & promoting idea that all learn in different ways from early age key
2	Positive role models Focusing on the individua'ls positive characteristics and strengths A positive attitude from parents and carers	Negative attitude of those around them. Negative experiences from others regarding their strengths and challenges Being 'abandoned' after diagnosis	Debate as to whether it is best for parents or another adult to share info. In my role I often don't know the individual very well so I feel my impact can be limited by this.
3	1. It has benefits- Dedication, loyalty, completion of tasks, etc 2. Unique. Vive la difference! 3. Others with autism have been hugely successful. I have a famous faces montage on my office wall.	Parents thinking that it limits a child. Poor support causing stigma in schools, leading to bullying. Not properly explaining to a child. One student thought he had a brain tumour and was going to die because no one told him why he was different.	All children should be autism aware. And deaf aware. And dyslexia aware. And VI aware...I could go on. Ignorance is the biggest barrier.
4	That it's a difference not a deficit That others have been successful That is only part of their identity not all of them	Negative delivery Lack of support following diagnosis and looking for information e.g trawling the internet	
5	positive role models highlight strengths different not less	negative parental views often voiced when child present feeling misunderstood despite diagnosis adjustments not being made to enable the YP to engage	
6	their own level of understanding parent support Level of anxiety	Society understanding Parent acceptance Individual's understanding	
7	Being accepted in a school environment, autism awareness within schools and the education system, having a social network	Not being heard and considered at school due to lack of autism awareness.	
8	Never discuss it in a negative context Play to their strengths Celebrate their successes however small	Adults lack of understanding	
9	Timing-diagnosis and disclosure not too late. Also at a time when they are not experiencing any other pressures or mental health needs. Generally a focus upon positives and possibilities.	The opposite to when it works well- late diagnosis can be problematic but not for all. People around them are also important for positive reassurance so if that isn't provided, it can be problematic.	

Appendix 20.7 Service provision to support young people's understanding of diagnosis

	6. Please explain the main circumstances which would usually trigger an intervention to support a child or young person to understand an autism spectrum diagnosis:	8. Please describe any barriers you have identified that can prevent a child or young person accessing support to understand an autism spectrum diagnosis:	9. Please explain about any factors that serve to encourage children/young people to access to support with understanding an autism diagnosis	11. Please describe how you evaluate the impact of the work you undertake to support young people to understand their diagnosis. Please include formal or informal evaluation methods.
1	low self-esteem/anxiety resulting in behaviour which challenges the setting	Reluctance to appear different Lack of early intervention - by time difficulties become apparent, low self-esteem can have become quite embedded	peer awareness & appreciation/tolerance Understanding of difference in setting by staff & peers	pupil voice monitor frequency of incidences of behaviours which challenge
2	Request from school or parent for my support	Parents not wanting them to know. Individual lacking sufficient language or cognitive ability to understand diagnosis fully.		Informally - by getting feedback from parents/teachers. Individual work book includes section asking for pupils' views on whether they have found session/s helpful and what they have learned from them.
3	I speak to all those who come to me. They must learn to self-advocate as no one will do it for them! They are going on to university or employment and need to complete UCAS forms within a few months.	I have not found anything yet that I cannot work around. Sometimes language has to be used that the student understands. Like pc vs mac. Or CD vs DVD. They look the same but are made differently, they do different things. One is better than the other for some things and vice versa	NAS website is helpful.	I talk to them!
4	Emotional wellbeing Response to school requests Parents requests My own assessment	Parents not wanting them to know Schools not acknowledging a problem Young person not wanting to engage Cognitive ability Age e.g. Too much for some under 5s	Good understanding of their self Hearing from someone with a diagnosis- e.g. Dean Beadle	Regular report writing and follow up Track children through key stages and onto university Information from parents Links with SENCOs etc
5	Presentation of YP as confused and unhappy, frustrated, a late diagnosis when teens question themselves and their sense of self, impact on learning and life	low mood and therefore a CBT approach to overcome initial negativity and encourage ability to engage with sessions regarding diagnosis, parents don't want child to know or keep it a secret from others	Parent training offer Parent support groups regional and national organisations publicity so less stigma attached support from other parents	No specific baseline, observed behaviours, raised confidence and self-esteem, sometime use psychological assessments Talk to child, parents and professionals
6	Diagnosis	Their own denial or that of parents Just not ready Ability to understand	Acceptance Knowledge of autism by supporting adults	Don't do this formally Mostly by reviewing how the child is doing in general - care plan reviews
7	Low self-esteems, Anxieties around school.	The child or parents/carers being ready to discuss and accept.		Discussions with the child/young person and their parents/carers, supervision with line manager.
8	Their unusual behaviour	The barriers are usually thinking children are naughty rather than autistic	NAS	I evaluate with parents and teachers to see how my suggestions to manage behaviours is going

	6. Please explain the main circumstances which would usually trigger an intervention to support a child or young person to understand an autism spectrum diagnosis:	8. Please describe any barriers you have identified that can prevent a child or young person accessing support to understand an autism spectrum diagnosis:	9. Please explain about any factors that serve to encourage children/young people to access to support with understanding an autism diagnosis	11. Please describe how you evaluate the impact of the work you undertake to support young people to understand their diagnosis. Please include formal or informal evaluation methods.
9			Being involved with a service who recognises the importance	We set objectives for the work we do and it would be against the targets we are working towards with the young person. Feedback from parents and teachers and well as the young person contributes to evaluating the progress.

Appendix 20.8 Liaison with others about work to support young people to understand the diagnosis

	7. Please explain how you involve parents in the support you provide to help children/young people to understand their autism spectrum diagnosis:	**10. Please explain how you liaise with other professionals in relation to the work you undertake to support children/young people to understand an autism spectrum diagnosis.**
1	Parent training to support u/st of differences & practical strategies to help	advise schools how to deliver interventions training promote peer awareness activities
2	Discuss how/when to bring up the topic. Suggest literature which might support or explain. If I am working with the child, give parents information on what I am going to do with their child and provide feedback and the opportunity for the parent to speak/meet with me to discuss further.	Discuss approach with colleagues or with teachers who have requested support
3	I rarely involve parents. The students I work with are academic students and all over 16. I refer to the information we have in our files, supplied by parents and the feeder school. Occasionally we have reports from the Ed Psych team. Some students have EHCPs.	I sometimes have telephone contact or written information from the local Ed Psych team.
4	Joint planning Sharing information Training	Role out training Connect with professionals Network with others in the field
5	ensure they have access to training, leaflets, websites, share materials so consistent approach with all involved with YP	telephone calls, multi-agency meetings EHCP advise and planning Share resources and advise professionals and settings
6	Share the information with professionals as well as parents (with consent)	MDT
7	By setting up training/workshops parent to parents support Resources and time to talk things through.	Multi agency working with consent from parents/carers and/or child/young person
8	Talk to them Lend them books on autism Share my own experience of my son who is autistic	Meetings with staff and Senco attend appointments with families
9		Feedback through meetings and reports.

Appendix 21 Interview the interviewer analysis of the process

Appendix 21.1 Interview the interviewer-Parent Interview: Discussion with colleague

The full parent interview was undertaken. A colleague followed the interview schedule beginning by going over key research information and consent process, then by the asking all the main questions. The question prompts were used as necessary to ensure all possible topics were covered by the researcher in response.

Researcher: How did that feel as the interviewer? Did you spot any problems?

Colleague Interviewer: I felt that there were a few places, as the interviewer that the questions didn't flow. I felt it was like changing the topic and it might feel like too much of a jump for participants. How can I explain, it might make them feel that their last contribution was not as… as expected?

Researcher: Can you remember which ones?

Colleague Interviewer: It was towards the end. Well really it was just that last question about recruiting participants. It is not the right time after they have been pouring out their heart.

Researcher: Yes, it was quite emotional for me. Sorry did I go on?

Colleague Interviewer: No, I don't mean that. You need the participants to 'go on' for your research. That is the rich data you will need. What I mean is that last question suddenly changed from about the child and their experiences to, what was it: that last one about how might more young people be encouraged to participate? You can ask parents that at different times away from the interview, we work with them enough? Also, the support groups we have contacts with as well?

Researcher: Yes, I see what you mean, I don't know why I put that. It was just in my Masters research I really struggled for participants and the survey isn't recruiting well. I'm just a bit desperate I think. Yes, I think you're right. I'll take that out completely. You said questions, which other questions didn't work well?

Colleague Interviewer: Let me look back…… Actually, no the rest of the questions were fine from my perspective as the interviewer. The other thing that I was thinking at the end is that the interview just stopped. I mean, I know you'll say thank you and so on but it just seemed to end.

Researcher: Yes, in my mind I would be asking them if there was anything they felt was relevant that they wanted to add. I need it in the schedule don't I so I don't forget. Was there anything else about the content?

Colleague Interviewer: No, I think the rest were fine and worked well. I did reorder slightly to make the interview flow though. You covered some of the later questions…… Well, you often talked ahead. I asked all the questions but there were a few times where I felt we'd covered them that I still asked them… as we had to try them out.

Researcher: Yes, I see what you mean. I did go off at a tangent, didn't I? I'm glad it was a while since I created the schedule, I wasn't at all thinking about what was coming next. Do you think I should give the parents a copy of the questions?

Colleague Interviewer: You could. Might it distract though?

Researcher: Yes, I think it might constraint their ideas as well. I'll have a think about that.

Colleague Interviewer: I don't think it mattered that you spoke ahead. I just made sure I kept checking the schedule to make sure you didn't miss anything out. It might just mean that some of the information comes differently ordered. Will that matter for your analysis?

Researcher: No, no, I don't think it will. I'm doing thematic analysis anyway and from the way I've tried with the qualitative information from the survey, which is much more tightly organised, they don't always answer exactly as the question is asked. I'm theming it, so the analysis is not necessarily organised sequentially when I discuss it, it will be by themes.

Researcher: Was there anything else about the content?

Colleague Interviewer: No, well, you asked for clarity a few times to check you had understood the questions. I think that was just part of the thought process though. There wasn't anything specific I can remember? Were some questions upsetting though, for you? You know, you spoke as if… well as if you were thinking you could have done things differently at times. Is that what you were thinking?

Researcher: Well, I was thinking we have done lots of talking about his epilepsy and perhaps not enough on the social side of things-the autism bit I suppose. I suppose there was some of that … guilt coming through.

Researcher: I find that in work with parents generally, you listen for it and reassure as it occurs. I think that is what I'll do when interviewing. I was also thinking, even though the volunteer's child will already know about the diagnosis, it might make volunteers self-check… think about whether they have told their child enough. I put a few links in the research information. I think I'll put a pack of information together with some ideas about discussing diagnosis with book list and useful links etc. Then I can offer it at the end, just in case so they have something to follow up with if they do feel like that.

Colleague Interviewer: That's a good idea. I didn't know half of this, you don't usually talk about *your child at work.

Researcher: Don't I? Perhaps we are too busy talking about work… But you are right. I wonder why? No, I'm being vague, I'm repressed, what can I say? I'm being flippant now. I know exactly why, it is that being a professional thing… It's like when I went into school, I tried at all costs not to let his teachers know that I was a teacher when he was little. It changes their attitude towards you. Not always for the best. Anyway, I'm not making much sense, am I? I just know that some professionals have certain views about parents of children with disabilities; it's that… 'them and us' mentality, which I hate. It might be just my insecurities, my opinion and usually not justified, I just feel it changes people's attitudes and it can interfere with professional relationships. I don't hide it, I just don't talk about him very much. When I was at Uni doing my teaching training, there was a parent of a child with a disability she used to contribute all the time and was always bringing things up about her child, you would see people's eyes roll! I think on a personal level that is something for me to think of.

Researcher: What about how you felt during the interview, did it impact on you? Emotionally I mean.

Colleague Interviewer: Well, it made me think about what I've been through recently with my dad. I know it is totally different thing, someone who is old and ill, but it made me think of some of our experiences with medical professionals. You do feel talked down to at times, not listened to, dismissed.

Researcher: Oh, sorry, I didn't think about that…

Colleague Interviewer: Its fine, empathy, sharing experiences is good. It just made me think, it happens across the medical profession.

Researcher: Do you think it is just the medical profession?

Colleague Interviewer: Now that is a question. I don't know. No, I think it is to do with specialisms. I even feel it at the garage when they try to explain what they have done with the car and I try to query things.

Researcher: Yes, too true.

Researcher: Thank you this has been so helpful. I'll ask one last time, just to make sure, anything else occur to you?

Colleague Interviewer: Well there is one thing, I'm not sure how to put it… Well, your son, his ability, his cognition has changed. Were all the questions as relevant for parents of children who are … less able?

Researcher: Don't worry, I know what you mean. Actually, that is one of the issues, most research related to autism focus on those without additional learning needs, well the research that takes views of participants. Something to think about though. And it would be good if parents of children with more complex needs also took part. So many children have more than just autism-comorbidity, etc.

Researcher: Thank you again, this has been so helpful.

Colleague Interviewer: I've just remembered something else, not sure it is important. It is just, towards the end, I became really conscious how long it had taken. Had I managed the interview well enough, I suppose I was just worried, as I know you have an appointment soon.

Researcher: No that is really helpful, something to think about in organising times etc., definitely. I need to make sure parents know the time frame, over-estimate rather than under estimate. I don't want them feeling it has gone on too long, or being worried they are going to miss an appointment or be late somewhere. It would also impact on perhaps what they contribute. Also, I'll make sure I leave enough time for me, not try to squeeze in between appointments, I don't want to be rushing them either. I need to be able to listen to the emotional impact for them, and ethically it is important that they feel valued.

I think I’ll make sure I have all my most useful information, that I usually take to parents’ appointments-the first home visit after diagnosis pack and the other useful leaflets. Then if something does come up, emotional impact, lack of support, etc. I’ll have something concrete and useful to offer, As well as thank you, of course.

Researcher: Thank you, this took longer than we both thought I think, I hope I haven’t taken up too much of your time.

Colleague Interviewer: It’s fine, I’d set the time aside and I did find it interesting to do. Good luck with it all…

Conclusion from the parent ‘interview the interviewer‘ process:

The final question in the draft interview schedule was removed as it was felt too divergent in topic to the rest of the questions. The question that was removed was:

16. I am also considering what might help more young people to participate in research about their autism. What do you think might have encouraged your child to participate?

A final question was added to the interview schedule to enable the parents to add anything they felt was relevant that they hadn’t been asked about:

> 16. This is the last question: Is there anything else you think is important about how your child learn about their autism that you think it would be useful to add?

As participants might sometimes provide information related to questions that have not yet been asked. It was identified important to enable them to continue to maintain their flow. However, the question would still be asked just in case there was anything else related to the topic they wished to add.

As the interviewer, I would make sure I just kept checking the schedule to make sure no questions were missed out.

Ensuring that appointments were well planned so that the participant did not feel rushed, or the interviewer, as this might impact the quality of the information provided. When making appointments, parents will be advised how long the interview usually takes to support this.

Appendix 21.2 Interview the interviewer-Professional interview: Discussion with colleague

The full professional interview was undertaken. A colleague followed the interview schedule beginning by going over key research information and consent process, then by the asking all the main questions. The question prompts were used as necessary to ensure all possible topics were covered by the researcher in response.

Researcher: Thank you for agreeing to do that, sorry it took so long.

Researcher: Did you feel there were any issues with the interview or questions as the interviewer?

Colleague Interviewer: No, it seemed fine. The questions made sense and the prompts made it easy if you didn't fully answer the question.

Researcher: Sorry, I went off on a tangent at times, didn't I?

Colleague Interviewer: Yes, but I don't think it mattered. From my experience in interviews, that often happens. The schedule made it easy to spot this and to throw in a prompt at an appropriate time.

Researcher: You mean when you could get a word in edgeways?

Colleague Interviewer: Well, when there was a space, I was able to give a prompt to get you back on track.

Researcher: Were there any other problems or did you feel there were any gaps.

Colleague Interviewer: No, it did really seem to cover everything and all of the questions made sense to me. Sorry, I can't think of anything.

Researcher: No that's fine. It is good news if it works well.

Researcher: How did it feel as the interviewer? Were there any emotional or ethical aspects that occurred to you?

Colleague Interviewer: No, I think the information covers that. I suppose professionals might not like being asked if their work ever had a negative impact or if they felt confident in undertaking the work but I can see that could be a useful thing to consider.

Researcher: Do you think I should consider taking the questions out or rephrasing them.

Colleague Interviewer: You could think about it. That said, as professionals, we get asked questions like that all the time as part of supervision and … What is it called, that thing we do every year, self-evaluation for the job?

Researcher: Oh, you mean Performance Management?

Colleague Interviewer: That's it! I really don't think you need to take them out, it is good to reflect on these things and our practice. You could run it by your supervisors.

Researcher: Actually, they have already seen the schedule and didn't raise any concerns about it.

Colleague Interviewer: Definitely leave them in then, I think they will be useful questions for your research.

Researcher: Thank you for all of your help with this. If anything else does occur to you later, just let me know.

Conclusion from the professional 'interview the interviewer' process:

Although it was acknowledged that the questions about whether the professionals' work with a young person had ever not gone well, and about the way they evaluated the impact on young people were challenging questions, they were felt important for research processes. Also, it was felt that professionals would be accustomed to questions like this through the supervision process or performance management processes. They were also provided anonymity to reduce any worry employers judgment about performance, therefore**, no changes were deemed necessary to the interview schedule.**

Appendix 22 Example of interview transcript, and analysis process and feedback

Speaker	Transcript	Analysis	Feedback from participant
INTERVIEWER	Okay. So are you happy for me to start on the interview?		
PROFESSIONAL 3	Yeah.		
INTERVIEWER	I'll ask you all the questions so I don't miss anything out. But if you think anything's not relevant and sometimes as we get towards the end people have pre-empted some of the questions. But we'll tackle each…I'll say each one and then if we think, "We've covered that," we'll just move on. Does that make sense?		
PROFESSIONAL 3	Yeah. Usual sort of semi-structured.		
INTERVIEWER	So first of all, would you tell me about your role or your recent role where you were working with young people around the diagnosis.		
PROFESSIONAL 3	Yeah, until 2 years ago, for 10 years before that I was working in a local authority as the sort of autism advisory teacher. And I was acting deputy head of one of the services. That was with children and young people in local	Autism advisory teacher and service deputy Local authority role Primary and secondary support	

Speaker	Transcript	Analysis	Feedback from participant
	24. authority schools primary and secondary **25.** in the sort of South East.		
INTERVIEWER	26. That's brilliant. Thank you.		
PROFESSIONAL 3	27. And that included with work with around 28. 250 children to explain their diagnosis to 29. them with them and their parents in 30. schools.	250 children & their parents	
INTERVIEWER	31. That's a huge amount. I know that from 32. a lot of people I've spoken to there's not 33. a lot of that work going on. Was there a 34. reason in your authority that you 35. particularly picked up on that aspect of 36. the work?		
PROFESSIONAL 3	37. Yeah. I mean that's why I anonymised. I 38. actually took it out of the book to avoid 39. misconceptions, but the authority wasn't 40. doing what it should do because it was. 41. Because this is obviously an issue 42. everywhere for children that just didn't 43. know why people coming in to work with 44. them, why they were being supported, 45. why I was there, why they had the 46. difficulties. At the same time, there 47. were parents who didn't know how to go 48. about telling their child and schools as 49. well. There was an anxiety around the 50. whole thing, how would we explain it,	Work anonymised to support misconceptions and lack of authority focus Support for the individual to understand their own difficulties and support provided Parents and educators not sure how to support children's understanding Anxiety about child understanding and reactions	39' but' should be 'that' 3rd column first sentence should say 'Work anonymised to avoid potential misconceptions of there having been lack of LA focus

Speaker	Transcript	Analysis	Feedback from participant
	how might the child react, what the effect might that have on their future relationships.	Worries about relationships lacking understanding	
INTERVIEWER	Yeah. And did you find that that was across parents and professionals or did you find it was more parents that identified it?		
PROFESSIONAL 3	I think probably having…this is sort of not scientifically measured in any way. It's probably going to be more parents because they need to actually do it at some stage. They know that that's something that's got to be tackled or avoided. But yeah, I mean, schools also, we're very keen to refer children for the work.	A particular focus for parents to understand Some educators also recognise the importance of supporting understanding	
INTERVIEWER	Yeah, okay. Thank you. And in terms of how you worked with the young people, could you sort of explain about the work that you did specifically with young people and the parents or anybody else if you did work specifically with professionals as well?		
PROFESSIONAL 3	Yeah. Basically, the key to it was about what you did for preparation. A lot of time is put into preparatory work, finding out about the child and their	Importance of learning about the individual and their diagnosis to support preparation for work about diagnosis	

Speaker	Transcript	Analysis	Feedback from participant
	circumstances and how they learn. And their own medical explanation of autism as well because it's different for everybody. So it will have to be explained differently for everyone. And that involves meeting the young person, observing them, meeting them, getting their views without mentioning autism unless they knew about it and then trying to found out what they picked up. But also in those sorts of meetings, the semi-structured interviews with them because getting children to talk on the autism spectrum about themselves can be difficult. But from that also, we were able to sort of have a understanding as well about how to engage with those children. We needed to know what their interests were as well. Then meeting with parents and school staff to find out further information about the child and this is all in the book. There's a whole section on what you need to find out or what I think anybody would need to find out first and how to go about doing it.	Professional observation and meeting individual crucial When individuals know about the diagnosis, understanding their views is important Learning how to interact with the individual is crucial Understanding interests Meeting parents and educators supports understanding	
INTERVIEWER	That's going to be really useful I		

Speaker	Transcript	Analysis	Feedback from participant
	think.		
PROFESSIONAL 3	So I devised the interview forms for collecting data from children and then from adults. The adults obviously would make the decision on whether to go ahead and how. So part of the meeting with the parents would be to discuss what the work entails and listen to any of their concern and then reach decisions on A) Whether they want to go ahead at that time whether they feel the child's ready or B) And if so, how to go about doing it. And the main method that I used was to create an all about me booklet with the child which over three one-hour sessions with the child and at least one of their parents there because they needed to carry this one afterwards. So it's like an apprenticeship approach. Usually what would happen is somebody from the school will be invited to the last session when the child presented with the book. So basically, the main delivery tool	Interview paperwork supports information about the individual Parental consent crucial Parental ideas about the right approach important A differentiated booklet about the child created with parent and child Educator involved to support understanding	

Speaker	Transcript	Analysis	Feedback from participant
	is a differentiated template for a booklet and working through that in session one where we look at the child's attributes so they find out about themselves and who they are as a person and their strengths and their challenges. And then in the second session, we go back over that, emphasising all the time the person's good at lots of things and an able person. They're a good person and the people around them love them. And then what we do is using an overall summary of their key strengths and challenges that's used to **frame** the diagnosis and explain it in the second session when the rest of the booklet is made. Then the booklet is given to the child within the final session and it's read through. School and parents can continue it afterwards.	Booklet about child's strengths and challenges Abilities and skills are re-emphasised in subsequent sessions Positive personality traits emphasised too Individual strengths and challenges used to frame diagnosis Booklet provided so parent and school can continue to support the child's understanding over time	
INTERVIEWER	So it's three sessions then, sort of three sessions of the actual		

Speaker	Transcript	Analysis	Feedback from participant
	focused? Obviously, you've done all your prep as well?		
PROFESSIONAL 3	Yeah. So the meetings carry on in between the sessions as well. So at the end of each sessions leave with the parents and preps. Anybody that wasn't sure sharing information deciding at the end of the first session whether to go ahead. And then it's what the child will be told about autism or having autism means for them sort of headline sentence. Because each child is given a headline sentence in the booklet. And then also sharing that with the school staff so that they're aware of what the child's being told. And then you choose and also, I have the sort of approach working with them in the meantime, how to answer questions that might come up.	Decision about disclosure can be made after initial session Where disclosure happens, a headline sentence is included in booklet Support provided for school staff about how to respond to children's future questions	
INTERVIEWER	Okay. It sounds like a really thorough approach that you've been using.		
PROFESSIONAL 3	Yeah. But the key to it is the preparation, knowing the child,	Knowing the child is crucial for disclosure	

Speaker	Transcript	Analysis	Feedback from participant
	being qualified to – in my view – being qualified to teach people with autism and having done this programme with other children doesn't necessarily qualify you to do it with the next person, you still have to find out about them. And again, in the book I've done sort of a job description for the person, for the person leading the work.	Qualified to support/teach children with autism is also crucial Published a book to support understanding of how to support a child to understand the diagnosis	
INTERVIEWER	Oh, that's good. That's a really good idea.		
PROFESSIONAL 3	And in different circumstance. So in some it may be that it's got to be a professional no matter what because you might need to be doing…a specialist professional because you might need to be using things like teach techniques or behaviour management strategies because at the end of the programme, it's not just limited to children that in a particular area on the spectrum. The aim is to maximise who can be involved, so	Created guidance to be differentiated Professional understanding of appropriate strategies crucial	

Speaker	Transcript	Analysis	Feedback from participant
	there are differentiated levels of the templates as well. So that could be from children working at a very literal level. Also, has got some sort of language that communicates and understand the very basic concept right up to sort of adults who are ready to go to university.	Language is simple to support understanding	
INTERVIEWER	Right. I didn't realise that you'd covered that huge range.		
PROFESSIONAL 3	Yeah, 6 to 18 are being covered, yeah.	Differentiation supports approach use for a wide age range	
INTERVIEWER	So that must've been a huge amount of differentiation in terms of what you've….		
PROFESSIONAL 3	Well there's a whole chapter on that point that makes the differentiation when the aim…. Including children as well without those interventions would not meet the criteria because there's a whole set of criteria or involvement, one of which is you've got to be able to participate and probably have an adult-led agenda for longer. So a lot of the work maybe needs to be done with some	Differentiation related to development and autism related needs	

Speaker	Transcript	Analysis	Feedback from participant
	children on structured teaching and rewards and things like that. Or brining in sensory time to meet the needs of children that's got hyposensitivity, not just the ones with hypersensitivity.		
INTERVIEWER	(laughter) Yeah. Yeah, they often get missed, don't they?		
PROFESSIONAL 3	What I came to find in my own career towards the end of it is only when I understood that that I knew why a lot of children had the behavioural issues. particularly lower functioning children in places like the special school where I worked who couldn't remain seated for more than a few minutes at a time.	Understanding of individual needs crucial to support right level of engagement and attention	
INTERVIEWER	And just what huge difference it makes I think when people make that connection and they start to be able to put some sensory diet, activities in for them, doesn't it? So it's been really comprehensive….		
PROFESSIONAL 3	Quite practical.		
INTERVIEWER	Yeah, yeah. (laughter) No, that's		

Speaker	Transcript	Analysis	Feedback from participant
	fine. So in terms of…I mean, you know it's incredibly comprehensive what you've done. Do you feel that you had any training around this?		
PROFESSIONAL 3	Well. I used earlier models. So work by **Carol Grey**, I don't know if you're familiar, you must know about social stories?	Social Stories (Gray, 1996)	
INTERVIEWER	Yes, yeah.		
PROFESSIONAL 3	There are copies available on the **Carol Grey** website.		
INTERVIEWER	Okay. Yeah, but I do know that. We had that at one of the….		
PROFESSIONAL 3	From the morning news, 1996, wasn't it? (laughter) Then there was Peter Vermeulen's book. I mean, I started in 2004, so it was the first edition of that book. But also, I mean, the first thing I did was go to NORSACA conference where Jude **Welton** who explained how she did it, how she taught her child. And it's based on those sorts of approaches really in the context of…. And basically, the booklet contains personalised narrative about the child, who they are and	Vermeulen (2000) I am Special Welton at NORSACA conference explained how she explained to her child Autism explained as part of the individual	

Speaker	Transcript	Analysis	Feedback from participant
	then **that's how** they've got autism and it's explained in that context, it's been just a part of who they are as an overall person. So they followed sort of that…. And then basically, personalised and getting on and doing it.		
INTERVIEWER	Yeah. I presume learning from when it went well and when it went…the times when it didn't. Did you feel confident when you were doing it? Did it increase over time or did you feel confident from starting out with it?		
PROFESSIONAL 3	Well, what I felt of it it's a massive responsibility. You're telling somebody else's child and that's going to be life changing in a lot of cases for the child and the parent. And the anxiety, I think it's important that you're anxious about every single case that you were leading it. Because just because you did successfully before doesn't change that. I've been fortunate not a lot has gone wrong here, but fortunately it's always been	Explaining an autism diagnosis is a big responsibility Anxiety/important to not become complacent as impact will vary for individuals Hasn't gone wrong but aware it might not always go well	

Speaker	Transcript	Analysis	Feedback from participant
	manageable. But there could always be the next case. So just because you've done 200 doesn't mean 201 is going to go well. And I've made that point very clearly in the book, the massive effects of individual differences, well in my own research. There's always that potential that you could have somebody who has a major meltdown or doesn't like it. So I think it's healthy to have that to make sure that you're adequately prepared. Preparation counts. The other thing that I have found through personal experience is that people like…a lot of adults are worried about the actual telling and the impact that will have on their child. And in most cases- in a lot of cases in fact, children react totally indifferently, it doesn't have the same meaning for people with autism as it would for typical people. And what I found is that the biggest issue is the child being able to understand and internalise or	Important to be prepared to support individual if the impact is problematic Preparation crucial Adults worry about explaining an autism diagnosis Children with autism are often indifferent Understanding and processing the diagnosis is the biggest issue	

Speaker	Transcript	Analysis	Feedback from participant
	possibly accept what they've been told. That's more of an issue really. And I think a programme like this is actually, it's only a starting point on the journey for the child which will probably be lifelong, they learn to live with it. They're learning to feel it's okay to have autism.	Programme is a starting point, coming to understand diagnosis is a lifelong process	
INTERVIEWER	Have you noticed any difference in terms of across age ranges? I mean obviously every young person's different, but did you notice whether age had an impact on how well the work went or how you needed to approach it?		
PROFESSIONAL 3	I think basically but my own work as a researcher I've looked into seem to indicate…and the views of people with autism as well like you were saying to me, they all hint that the longer it's left, the harder it's likely to be, the more likely you're going to have less…let's not say negative, but a less positive outcome. And it's often because children have already found out what autism is. Or it can be that they feel they weren't told	Earlier disclosure might lead to more positive outcome	

Speaker	Transcript	Analysis	Feedback from participant
	the truth before. And there a lot research seems to back that up but mostly with more able children.		
INTERVIEWER	Yeah. Have you looked at specific research?		
PROFESSIONAL 3	Yeah. It came out the year before or the year after. Which one was it, the not guilty verdict? That was Huws' and Jones's, wasn't it?	Huws, J.C. and Jones, R.S. (2008) Diagnosis, disclosure, and having autism: An interpretative phenomenological analysis of the perceptions of young people with autism. *Journal of Intellectual and Developmental Disability*, *33*(2), pp.99-107.	
INTERVIEWER	No, I don't think…		
PROFESSIONAL 3	No, it may have been Punshon et al…	Punshon, C., Skirrow, P. and Murphy, G. (2009) The `not guilty verdict': Psychological reactions to a diagnosis of Asperger syndrome in adulthood. *Autism*, 13(3), pp. 265-283	
INTERVIEWER	Yeah. I might be wrong. Yeah. When you've been looking at them so long they sometimes start to merge into one, don't they? Where were we? Oh yes, it was age.		
PROFESSIONAL 3	Age seems to be a factor, yeah. And the other possibility is that obviously the younger you do it, the harder it might be for the child to understand. But then again, you tell them less and you tell them more over time. You tell them less at the	Can be difficult for younger children to understand Younger children can be told less in information built on over time	

Speaker	Transcript	Analysis	Feedback from participant
	beginning and build on that. So the programme basically has got a baseline level of what children need to be told and be able to sort of understand (overlapping background noise). And then that's increased upon according so where the child is developmentally and cognitively.	Baseline differentiated in programme Information has to be developmentally and cognitively appropriate.	
INTERVIEWER	Which actually brings me to the next question, because that was the next question, how is it decided? And I know you've sort of said some about that already about the meetings and you've just mentioned about the baseline. Is there anything else around that about of how it's decided when the young person needs that support?		
PROFESSIONAL 3	Yeah. Again, one of the other- I mean, there's a whole range of issues that are just about the child readiness, when the circumstances arise. If a child's going through a particularly a bad time, we might want to consider leaving it. But I think one of the big issues there	Readiness in lots of personal factors Avoid disclosure at problematic times for the individual Accidental disclosure can be an issue if delayed	

Speaker	Transcript	Analysis	Feedback from participant
	though is the possibility of accidental disclosure. That in the meantime the child finding out. I mean, the main criteria that I've got around the child is being able to understand how people are different as well.	Possibility of child finding out accidentally criteria for disclosure being needed Child needs to understand difference	
INTERVIEWER	That's it, that's a very logical reason.		
PROFESSIONAL 3	Yeah. Again, in the book there's a whole section on how to identify when children are ready as well as which children and then another section on which children the programme is more appropriate for, suitable for all. But it's not the child not being suitable to the programme, it's the programme not being suited to them.	Programme must be right for the child rather than visa-versa	
INTERVIEWER	Have you noticed any specific sort of signs or behaviours where that's led you to believe that a young person is struggling with the diagnosis?		
PROFESSIONAL 3	I will say that from my own professional work, one of the biggest problems was I didn't have the luxury in always going back and following it up in the way that I	Evaluating impact can be difficult due to workload demands	

Speaker	Transcript	Analysis	Feedback from participant
	described in the book. Because when you've got large caseloads, you can't be going back to 300 children over a 10-year period. Sorry, the question was about?		
INTERVIEWER	Did you notice any signs or signals, behaviours that might indicate that a young person was struggling to understand or come to terms accept the diagnosis?		
PROFESSIONAL 3	Yeah. I mean, again, one of the other problems with children with autism is the fact that it's not always possible to detect the behaviours. Sorry, detect outward behaviour that anything is wrong. So I mean, one of the key things I do is advise parents and schools after the diagnosis has been given, to make sure that they monitor the child for changes in the behaviour. That might indicate they could be distressed. So I think it's basically being aware who have shown negative reaction. Of those, there's been no report of cases of any of the more severe,	Identifying signs can be problematic Monitoring is important as a follow up Noticing changes in behaviour is important No severe problems reported after disclosure programme	

Speaker	Transcript	Analysis	Feedback from participant
	long term effects of the work on disclosure. I think sometimes children- one of the things…I think a ig sign of it is… and this tends to be with older and high functioning children on the spectrum, is around them trying to excuse the behaviours and being in denial of the facts that when people give examples where do you this in this situation they’ll say yes, that was because. And if you keep loading things in like more and more examples, they come up with more and more ways sort of to try to explain it off as being a one off. But again, I mean, that’s with brighter and older children. And it’s actually only the children I’ve worked with who had already been told had autism but not done the programme in virtually every case because they found out without a full explanation.	Giving excuses might indicate problematic understanding More likely to happen with able children who haven’t had a full explanation	
INTERVIEWER	And that leads me to one of the other questions in terms of…. So we talked about in reaction to the		

Speaker	Transcript	Analysis	Feedback from participant
	work. Before the work's been initiated, has anybody identified a young person to take part in the work because they felt their emotional wellbeing is being impacted by not having a good understanding?		
PROFESSIONAL 3	Yes, that's definitely happened on a number of occasions where children…where their emotional wellbeing or their acceptance of support and things like that. Yeah.	Emotional wellbeing or acceptance of support can be a sign support needed to understand diagnosis	
INTERVIEWER	Okay. Thank you. And in terms of the work that you've carried out, has any of the young people that you've worked with refused to take part?		
PROFESSIONAL 3	No, actually. Nobody's ever fully refused. I mean, in any of the cases where the work has not been completed when started and we're talking about a handful of cases, it's never been because of anything on behaviour on the part of the child. If the child had started to show some signs of being in difficulty there have been a few times when a	No refusals to participate Sometimes time needed to process being told	

Speaker	Transcript	Analysis	Feedback from participant
	session has been curtailed, it's usually the second one where we're talking about the autism. And the aim has been to reconvene a week later and try and pick it up from where it was at. So far, every child that's got to the point of being told about the diagnosis has gone on to complete the programme. It's only been…and I think there's very few children where we've stopped at the session one but in those cases it was just obvious that the child had no understanding what we're teaching and they weren't ready, so we went off and considered further work that needed to be done first. So it wasn't like you're not getting the programme, that's it. What do we need to do to bring the child to a state of ready? But clearly, there are some children that this work wouldn't be appropriate for in the first place just because they've got severe learning difficulties.	Reconvened when ready Every child has completed the programme Only cases when child was not understanding at session one has caused to work to be halted Readiness is crucial Programme not appropriate for children with severe learning difficulties	
INTERVIEWER	It's funny I mean, that's one of the things I'm conscious of in my		

Speaker	Transcript	Analysis	Feedback from participant
	research. It is always most difficult to work with people who've got more significant learning difficulties, isn't it? I know in the future I was thinking that was one of the areas that I would like to look in the future. But I think I need to get through this first. (laughter)		
PROFESSIONAL 3	Because I'm retired I've thrown everything into one book basically and sort of get that out there and then just get on with my life.		
INTERVIEWER	I'm sure it's going to sell really well because it is such a need. Well, no, actually the next question doesn't apply. Because there was a question about where young people have refused what impact did it then have upon the people around them but it doesn't really apply because it doesn't sound that that's happened. From your experience, what do you think are the most important factors that have supported the young person to accept or feel positive?		

Speaker	Transcript	Analysis	Feedback from participant
PROFESSIONAL 3	Well, the things that I've tried to aim for right at the moment…. First of all, preparing the child for the disclosure because of that whole session about themselves and who they are. And that's got to be done positively so that by the end of the first session they're aware of who they are as a person, that they're a good person so they're aware of their personal traits, things like whether they're hardworking, quiet, not loud, tidy, untidy, all those things that make up who they are and reach the conclusion that they're good person who's loved by the people around them. And we look at their interests and skill. So we try to list up to 10 attributes of the child related to their personality. And then up to 10 strengths the child's got and we look for an overall pattern in that as well. So they're good things like, so it could be working with things and objects or computers or doing things that you actually, you don't	Preparation crucial Supporting understanding of self as a good person and positive traits is important Listing attributes and strengths	

Speaker	Transcript	Analysis	Feedback from participant
	need to interact to much with other people. And then looking for a handful of their key autism related challenges and explaining that we all have things that are difficult and that that's okay. So at the end of that session they've got that sort of picture and they've got a pattern of the things they find challenging that's unique to them, so it could playing and joining in with other children. It's also made clear to them that's part of this of this process of making them feel it's okay, that other people have strengths and weaknesses. But the child's difficulties are reciprocal therefore, it's not just them that has difficulty playing with the typical children around them as an example, rather the other children find it difficult to know how to play with that child who needs some help. And then the next step is to make sure that when giving the diagnosis to the child in the follow up session that we go back to that	Recognise challenges related to autism but also that this is ok Others have needs is highlighted	

Speaker	Transcript	Analysis	Feedback from participant
	and that's useful for actually calming the **adults then**. That everybody is aware of…all the adults are aware of how they need they behave in the session. It's going to be stressful especially for parents. And to speak very slowly at that point, not pressuring and just speaking with a firm, calm approach, sort of using matter of fact language. Being matter of fact, calm and collected, having a script ready so that you know exactly what you're going to say at the moment that the diagnosis is given. So for example, in my case it would be telling the child we found out all these things about you last time and we'd go through some of those. And then I'd say to the child, we're about to show the child, they would have a schedule so they'd know what's coming but they wouldn't know obviously on their schedule having autism because you can't put that even though that's what the session is about. So	Ensuring parents and educators understand how to respond in the session Preparing parents is crucial as it can be stressful for them Getting the language and communication right: calm and matter of fact Revising their key strengths and needs from previous session Providing a visual schedule	

Speaker	Transcript	Analysis	Feedback from participant
	actually put a letter A or AS for Asperger's syndrome on the schedule and say, "We're now going to talk about- I'm going to tell you something new and interesting about yourself and will be okay. And it's about this thing called A or AS that you've got. And it's literally reading from the script in the child's booklet template what we've completed and I just read that bit off then. You have autism. It's okay to have autism and I'm going to tell you a bit about that in a minute. But first of all, we're going to talk about some famous people with autism. So after we get to the last diagnosis the next thing to do, and I found that this order has helped because we used to then go on to tell them to explain the diagnosis, give them an account, a personalised account and then later on talk about famous other people having autism and some of them being gifted and talented and famous. So we go straight into that	A or AS on the schedule to signal the point of disclosure of something new and interesting about you A script You have autism, it is ok, there are famous/successful people with autism Order supports understanding Explanation of autism is tailored to the individual	

Speaker	Transcript	Analysis	Feedback from participant
	actually, straight after the diagnosis because I found that children engage far better in the sessions when that happens. And that included children with stereotype behaviours, like sitting, rocking on the chair, moving side to side, not looking. Suddenly, they attended to the session they’re presented with pictures of other people with autism. There are millions of people like them in the world, it’s just they’re spread out a bit thin. And I’ve seen children sort of change for that part of the work and then revert back to how they were again afterwards. And even children who have no idea who the famous people are that you presented them with, just to be given a page full of pictures and photographs of people that they’re told are like them. You just see kids get absorbed with that, go quiet and have a real careful look at the screen. And this isn’t always cognitively able children as well. But then when going on to give	Autism role models support children’s engagement and interest Even children with more significant needs respond to role models Pictures and photographs of the famous people they are like supports engagement	

Speaker	Transcript	Analysis	Feedback from participant
	them the explanation of what the diagnosis means, the next step is to tell them first of all some basic facts about it including what it doesn't mean. And that's sort of been the main way into telling children and then they seem to calm after that. Ones that were a bit anxious feel calmer when they're told that there are famous people with autism out there, children that were quite but when they found out that their favourite computer game was designed by somebody that could've been on the autism spectrum then suddenly it's not so bad. Finding someone with autism linked to their interest as well.	Children respond well and seem to accept the diagnosis calmly Even children who are initially anxious are calmed by examples of positive role models	
INTERVIEWER	So, you mentioned what it doesn't mean. Could you just sort of like give some…a few of those things?		
PROFESSIONAL 3	Yeah. So, in a child's booklet there's a series of facts they're given, facts about autism. It's just if I open up the booklet, then I could just show them. And I hope this makes sense afterwards when you're listening to		

Speaker	Transcript	Analysis	Feedback from participant
	it on the tape because it's a bit different when you're speaking on the phone.		
INTERVIEWER	No, no. It's all making perfect sense.		
PROFESSIONAL 3	Oh, good. Yeah I'll open a copy as we are speaking Let's see. Right. Okay. It has opened up the wrong thing- I've got so many copies.		
INTERVIEWER	I'm like that with my research. I've got so many copies of it. And then sometimes I forget which was the last bit I was working on.		
PROFESSIONAL 3	And one of the other things I always do is e-mail it to myself		
INTERVIEWER	Yeah, I do that as well.		
PROFESSIONAL 3	Right. Okay. If I take the generic level one which is the level two booklet. So I've got to the three levels basically. Right. People have autism. So what does having autism mean? So even though it's called what does it mean, it's actually telling what it doesn't mean. So number one thing, it is okay to have autism. I'll come back to that	Explaining what it does not mean is important Ok to have autism	

Speaker	Transcript	Analysis	Feedback from participant
	because that's what was said throughout all of the programme, but it's about proving it to the child and not just say it's okay and that's the end of it. Having autism does not mean I'm sick or I'm healthy. I'm a fit, healthy, and intelligent person. It does not mean someone is a bad person. I am a good person. I've already established this in the previous session. It means that my brain works in a different way to most people's brains. People with autism think in a special, different way to most people.	Autism isn't an illness People with autism can be intelligent Individual is good Brian works differently in a special way	
INTERVIEWER	That's great.		
PROFESSIONAL 3	So they told that, and then it's just giving the matter of fact explanation of what…a headline explanation, and I found that this became important in this particular page in the booklet because children weren't able to express what it meant at the end of the programme to others. So they've got a page which has got their own personalised headline sentence of	A simple headline explanation as a first step Personalised headline to support individual understanding	

Speaker	Transcript	Analysis	Feedback from participant
	saying what autism is. So it will always begin with having autism described to someone like me who might be good at. And then we'd complete that sentence based on what they're good at. So in this example, working by themselves with things and objects like computers. And then the second half of the sentence would be 'And can find it hard to make friends and join in with other people."	Headline sentence includes what they are good at Also a sentence about key challenges	
INTERVIEWER	Right. So there's that balance, yeah.		
PROFESSIONAL 3	So there's that sentence. But also, the language, the choice of words is really important. So the word 'but' and 'although' they are not used. I've managed to eliminate this out of the programme. Instead we just have 'and'. Because if you're saying "I'm good at this but…." And also, using the word harder, not hard or challenge rather than difficult. So a lot of time has gone in over the years to refining the language to reach a point where there's no hidden messages for children with	Keeping language, such as conjunctions, simple to support understanding Language has bee refined to build on learning from implementing the approach	

Speaker	Transcript	Analysis	Feedback from participant
	autism. And also, checking the booklets at the end that there's nothing that can be misinterpreted from an autistic view before you give it to the child.	Final check of the booklet is important to avoid misunderstanding	
	And then the other thing is it's come to make it as a positive is to have a section at the end for good things about autism which is related to their special interests and they get some picture for that.	Images and information about positive elements	
	So basically, they're told although autism makes some things harder, especially people things, there are good things about autism that, topics they are interested in, and can really enjoy doing, can learn to do very well, then we list them.	Supporting a balanced understanding of strengths and needs	
	So in this booklet a girl called *Sue is good at using her interest of clothes and designing clothes.	Strengths based interests build on	
	And the last page in the book has a who am I, again, with some positive bullet points about the child which includes that they have autism. But also, when they going through the things they find harder, it's again reiterated in that	Final page a brief recap to support understanding	

Speaker	Transcript	Analysis	Feedback from participant
	explanation that these things are harder for typical children to do with them. And, so like we're all in this together. And that often fits in very well with peer work later. So	Includes a reminder that people without autism experience difficulties too	
	then again to help the child sort of becoming accepted. Afterwards, I think what we have to do is prove to them overtime constantly that	Linking to peer work useful	
	having autism can be okay. I think that's a point Peter Vermeulen made in his 2013, 'I Am Special'.	Continually reinforcing that having autism is ok	
	There's no good telling people with autism that they're okay if their daily lives are not okay. Furthermore, some of them might anyway have already…might	Got to be realistic as Vermeulen (2013) explained	
	straightaway attribute everything negative in their life to their diagnosis. So it's about helping them to see all these positive things, referring them to the booklets in the future, developing the booklet	Might have to counteract previous negative links made to diagnosis	
	later. But apart from that, giving them opportunities to succeed, emphasising when they're doing things positively, and also offering	Helping the individual to see the positives and as an ongoing basis	

Speaker	Transcript	Analysis	Feedback from participant
	them…making sure they have plenty of opportunities in their lives to do the things that they enjoy doing and gain pleasure from and that they succeed in.	Ongoing identifications of successes to build the positive evidence	
INTERVIEWER	Yeah. So it does have that really positive focus, doesn't it? That's really good.		
PROFESSIONAL 3	Yeah. The whole thing is a holistic thing. It's about preparing them for it knowing…picking the timing, preparing- know when the child's ready, preparing to do the work effectively, preparing the child to be told, telling them in a matter of fact way and then following it up with an ongoing lifelong explanation almost but then proving that they can have a good life and that there are other people like them. I went back to the other people with autism as well. One thing I did find was that some children thought that they would automatically become rich and famous themselves when they saw that page. So a sentences is also put in there making it clear that it	Holistic approach crucial Preparation important Mater of fact disclosure Ongoing process to support understanding Revisiting positive role models Realistic about role models and not everyone with autism will be rich and famous but can be happy and fulfilled	

Speaker	Transcript	Analysis	Feedback from participant
	doesn’t mean they’re going to be rich and famous, but what is does mean is they can have a happy and fulfilling life. And I think that becomes more important with the older kids , especially children who are like 15, 16 have said they think their life’s ruined because they’ve got to that point where having autism hasn’t been good.	Seeing a positive future is crucial, especially later diagnosis or disclosure because the initial diagnosis can be seen a problematic for their future	
INTERVIEWER	Yeah. And I think the adolescence is particularly hard, isn’t it? All of that difficult friendship.		
PROFESSIONAL 3	Yeah. And if you’ve had exclusions from the school and bad outcomes in relationship with peers.	School issues and exclusion can be problematic Peer relations can be problematic	
INTERVIEWER	Okay. In terms of sort of what you’ve used I mean, I’ve got that you’ve explained that really well. I just wondered, do you ever bring in sort of resources from anywhere in particular? Just you mentioned pictures and things like that. Have you got…or famous people? Do any		

Speaker	Transcript	Analysis	Feedback from participant
	of those resources come from elsewhere?		
PROFESSIONAL 3	Well, they come from the internet, they're pasted into the booklet of the page. Now the electronic versions with the book, what I've done is only to put people with a confirmed diagnosis in that one but make the point because there are other people in the internet that you could may have and suggest that people look for pictures of individuals that might be relate to the child. There is a bit of an issue around that with copyright and things like that when you're making publish resources where....	Internet used for images for resources People/images of someone the child relates to important Copyright can be an issue	
INTERVIEWER	Yeah. I could imagine because I've done quite a bit of work with individual children as well about diagnosis. What you're doing has been very similar. So it reassures me to hear that.		
PROFESSIONAL 3	Well, that's a major point that I made in the book to avoid getting into trouble with anybody else. I made it quite clear from the		

Speaker	Transcript	Analysis	Feedback from participant
	beginning that other people use this attributes approach and all I'm doing is sharing my experience with other people rather than claiming ownership of it.	Sharing and building on others professional knowledge important	
INTERVIEWER	Yeah. No, but I think it is that pulling it together. I think for confidence, for other people, you know, from the research, people just do not feel confident. And I think your book will really helped with that.		
PROFESSIONAL 3	Yeah. I mean for me, what's really- I didn't feel the children knew why I was working with them. And then coupled with that, all the adults around them and other people had a key piece of information that that child never had about themselves perhaps acknowledge what's missing and helping children take up their rights to a voice in decision making without having the full information. And then on the same sort of level. I mean again, the book cover has a picture of a child's face with a jigsaw, I don't know if you've	Sometimes children not told why a professional is involved Children don't have the knowledge about themselves to support their thinking and decision making Own book a published resource Miller, A. (2018) *All About Me A Step-by-Step Guide to Telling Children and Young People on*	

Speaker	Transcript	Analysis	Feedback from participant
	980. seen that from Jessica Kingsley's 981. site. But the reason why I asked 982. them do a couple like that with a 983. jigsaw puzzle with one piece with 984. the child face on was by going all 985. about me giving them that missing 986. piece. That sort of goes back your 987. first question about why.	*the Autism Spectrum about Their Diagnosis*. London: Jessica Kingsley Publications Diagnosis is the missing piece of their personal puzzle	
INTERVIEWER	988. Yeah. No, it's really interesting. 989. And I think from people I've spoken 990. to, there are some of sort of 991. common themes that come through 992. in terms of why and just seem to 993. be….		
PROFESSIONAL 3	994. I mean, a lot of that comes from the 995. literature from the accounts of 996. people with autism and their 997. experiences, people like John 998. Vincent. A video he did, it was on 999. TV. He said that it was only after he 1000. was given his diagnosis as a 1001. teenager that things made sense 1002. but by which time he'd had a mental 1003. breakdown and he'd ended up 1004. finishing his education on the 1005. psychiatric ward.	Insider accounts useful: John Vincent Diagnosis helped things make sense Lack of self-awareness can impact mental health	997-8 Should read John Simpson
INTERVIEWER	1006. Yeah. And I've worked with, in my		

Speaker	Transcript	Analysis	Feedback from participant
	most recent role. I worked children with complex needs and circumstances who were out of education. And it was a key theme that came through. Anyway….		
PROFESSIONAL 3	The probably one thing that missed out when you were talking about the making things positive for the child is that, who else you tell really and how and involving the child in that- how would you involve the child in that process. And the booklet actually is quite a good tool for that.	Giving the child agency in decisions about disclosure to other is important	3rd column: 'Giving the child agency in decisions about disclosure to others and their participation in doing it is important.'
INTERVIEWER	And did many of the young people that you worked with want to go on and tell peers or…?		
PROFESSIONAL 3	It was mixed really. I mean, that was one of the issues I highlighted because I've got a second chapter in the book is it basically looks at the pros and cons of telling or withholding. I forgot what I was we saying now.	Benefits and issues to consider in disclosing to others	
INTERVIEWER	I've mentioned whether any of the young people wanted to go on and tell peers.		

Speaker	Transcript	Analysis	Feedback from participant
PROFESSIONAL 3	Oh, yes, yeah. I mean, that was one of the concerns, that's one of the key issues parents and other adults often have been have beforehand is that the child might also go on and tell others. And in actual fact, I found that's very rare. It's usually by children that get very excited and a lot of them wouldn't tell anyone else themselves because it involves communicating, right? Or may not have many people that they feel they can talk to or be friends with and that's one issue. And then a lot have said, "I don't want other people to know." But I've always…again, I've done a lot of peer work to follow this up properly in about a quarter of the cases an autism awareness lesson afterwards with the child's class but only after the child's wanted me to do it. In some cases, we may have had to wait for a long time before we got there. But that's the good thing about the All About Me book is that can be incorporated into a	Parents and educators sometimes worry about the child disclosing Self-disclosure rare due to communication needs, friendship issues and not wanting others to know When they do disclose it is usually through excitement When thy do disclose, useful to follow up with peer training Important that the child wants this to happen and for it to be at the right time Child's presentation about self can be a starting point	

Speaker	Transcript	Analysis	Feedback from participant
	presentation for a class. So this presentation they're giving is also about the child and autism. That's the beginning of a journey as well for them.		
INTERVIEWER	Yeah. No, that's really good. Sort of building that understanding…		
PROFESSIONAL 3	Yes, there are templates for that in the book, an example presentation.	Resource templates	
INTERVIEWER	We've sort of covered this but just because it's one my questions, were there any times where things didn't go well? You've said there hasn't been many with the children. But what about the family or professionals where you felt it had an impact?		
PROFESSIONAL 3	I mean, in terms of parents and professionals I mean, it's having that dialogue beforehand is really important so that they're clear about what's going to happen and that they're in agreement. So it may be…I mean, I've actually said at the end of the day it's the parent's decision and we have to respect that even if we think it's wrong. But	Dialogue and agreement important to support work positively Parents might need time to process and support to prepare	

Speaker	Transcript	Analysis	Feedback from participant
	we’ve got to find ways to help prepare them **and again** with the whole section in the pre-intervention chapter that suggests ways that…the processes that parents might need to go through first and what the professionals around could do to support them while they’re working through those processes. Most of the things don’t cost very much other than time to listen and to talk. But also, just before the session where the diagnosis is disclosed to the child there’s always an opportunity i immediately before that for the parents to say, “I’ll have a brief meeting with them beforehand to remind them what we’re going to do, how it’s going to be said, how we’re going to behave as a group.” And at that point the parents still have the option of turning around and saying, “Actually, I don’t want to do this.” And again, might not be what we all want but we have to respect that. There have been a	them, so they are ready for it to happen Providing time to discuss with parents beforehand is useful Final check about readiness is crucial and willingness to delay if not	

Speaker	Transcript	Analysis	Feedback from participant
	couple of times where that's happened and we've delayed for a while and come back to it later.		
INTERVIEWER	Yeah. And is there one case or one time when you've gone through this process with a young person that particularly stands out for you because it's gone really, really well?		
PROFESSIONAL 3	I actually think there isn't one It's really odd because while I've been doing the book, writing the book, the resources that I made and described in it were about fictional children and then I actually felt like I've been with those children by the end of it because they were sort of an emergent version of best practice across the whole thing. No, I think the times when it's gone best for me when it's been most rewarding is when there was a lot of anxiety beforehand on the part of the parents. And there was also in my opinion a good chance the child might not like what they hear where at the end of the programme everybody in the family is using the	Resource is emergent version of best practice across experiences When disclosure goes well, the positive impact and acceptance after disclosure can enable the whole family to move on	

Speaker	Transcript	Analysis	Feedback from participant
	word autism. And that they don't…then that the family can move on. It's an important moment for a lot of parents that I think because the child being told can sometimes be for parents the last piece in their own acceptance. They've got…it's real, once the child knows it's real. Autism it's something they might not have wanted but they're able to use the word, they're able to talk about it. And when they realise that their child doesn't get really upset and angry and actually is okay about it. I mean, I think in most cases that's want parents want. They're not too worried if the child doesn't have a good understanding at the beginning. I mean, I taught a lot in this programme but the intention is that don't…it's not intended that they'll remember everything but the parents will have the tools to continue.	Disclosure to the child is the last step in parents' acceptance of disclosure Able to accept and use the word That the child does not get upset or angry is positive for parents, even though understanding might take longer Disclosing the diagnosis is only the first step to understanding	
INTERVIEWER	Yeah. And I think the idea of doing it alongside parents, that's the key,		

Speaker	Transcript	Analysis	Feedback from participant
	isn't it? Because they're going to be there in the future taking it forward. Okay. So the next question, and I don't know whether you can answer it or whether you've already answered it is, on those occasions was there a reason that you think it went so well?		
PROFESSIONAL 3	Well, I think in every case where it's gone well, the best case has been where the preparation was thorough. The pre-programme worked. By the time they've been ready the child was familiar with me, familiar enough and comfortable enough because they are used to me, it can often work. It might only be down in the context of having one or two visits beforehand -the reality of local authority case load ratios. So when it all comes together and runs through smoothly from start to finish and it's been differentiated to meet the child's needs. The child…any behaviour issues they've had have been sort of	Preparation for disclosure is crucial Child being familiar with the professional and vsv is important Time to tailor the work for the child is crucial	

Speaker	Transcript	Analysis	Feedback from participant
	overcome, it hadn't stopped the child from completing the work. Just that really, having…just planned it right, got all the right resources. And I think in a lot of cases it does need somebody that's familiar not just with the child, not just for their autism but with good autism practice and they can then apply it to that child. And I think they're the best cases where that's worked out well through careful preparation. And that's not just about the person- me leading the work, that's about the quality of information I've been able to get from those around the child even if they've been anxious.	Planning enables potential difficulties to be identified and planned for Professionals should be experienced with autism and the child to facilitate the most appropriate adjustments Best practice is build on preparation and information from all key people	
INTERVIEWER	Yeah. No, that's a really good point. And do you think as well in terms of that where you know that you're passing it on, so for example to a person in the setting, in the school, in that last session where they've got a good understanding, do you think that's a factor as well or good autism practise?		

Speaker	Transcript	Analysis	Feedback from participant
PROFESSIONAL 3	Yeah. I think it's not so much necessarily their understanding. I think it's their preparedness to be flexible to the child really, to accommodate the child. It's about their attitudes towards inclusion I think. I don't think you have to know a lot about autism to be able to learn to work well with children on the spectrum. We've all probably worked with some people that were highly qualified in the field but weren't suited to it.	Flexible support for the child crucial too Good inclusive attitudes	
INTERVIEWER	Yes. It's amazing, isn't it? Sort of where you come…. And then you come across people who would say they know nothing but are just brilliant in terms of the work.		
PROFESSIONAL 3	And I'll take the person…anyone involved with the child's needs. Again, with school setting with their staff it's got to be their acceptance, their understanding of the child's needs. Again, that's a point I made in the book is around the fact that sometimes when children have been making progress, the adults,	Supporting those involved with the child to support them moving forward is important	

Speaker	Transcript	Analysis	Feedback from participant
	parents often but sometimes school staff can help to reinforce the strategies. They may have felt that the autism is going away and maybe they don’t need to do this work after all. Or in situations where the child’s difficulties are masked by the behaviour and the people around them, so…. And I’m sure you will have come across children where the other children in the class go out of their way to include the child to such a level that unless you know what you’re looking for, it would appear everything is fine. No, it’s only fine at playtime, it’s not all of the time. He’s part of…well, no, he’s not. He’s not joining in and doing it for them. So it’s on being able to take that on board as well. And also, them being prepared to say things that might upset the child or the parent, but which are true. I think that is a really important point. If you’re going to do this work with the child then it’s important that their	Helping others to see that support might be needed even when not obvious is important Being honest and realistic with parents, even when discussion is difficult Identifying challenges and support for challenges is important	

Speaker	Transcript	Analysis	Feedback from participant
	challenges are raised and you don't try and mask the difficulties to spare the feelings on that. But going through their challenges doesn't have to be…it might not be a positive experience but it doesn't have to be a negative one either.		
INTERVIEWER	Yeah. Well, thank you. You'll be glad to hear we're nearly there. The next question is about how you've evaluated the impact of the work-it can also be informal as well.		
PROFESSIONAL 3	Yeah. Again, I mean globally I've evaluated it through my dissertation, the retrospective study of the first 10 years of doing that work which w as a suggestion that I did that actually. I was going to do something else more about parents if I remember rightly, or how children respond/how people who have followed the work up. But it was suggested it would be a good point write up all this work with	Retrospective study	

Speaker	Transcript	Analysis	Feedback from participant
	children. Write that up. So that actually helped my practice. Because having spent time reflecting over it for a whole year and writing the dissertation, it then started to reflect more closely I think and it's become more evaluative. The best way to evaluate it is to do it as going along I think and that's around your questioning techniques with the child. Ideally, I would suggest this, the best way to find out the whether a child with autism has understood something is to get them to explain it in their own words. But obviously, a lot of people with autism can't do that. So then you might get them to draw a picture or something like that, or you ask them a series of closed questions. So trying to assess how much of it they understand as they go along and then listening to their questions and their responses. I mean, I've often picked up that children haven't accepted their	Reflective practice Gauging the child's understanding through questions and interaction during the intervention Sometimes need to adapt the communication to support the child's communication-e.g. visual	

Speaker	Transcript	Analysis	Feedback from participant
	diagnosis- that accepting of the diagnosis even when they haven’t said that directly. It’s just things like a child that every time it was asked during join programme can you explain what having autism means, he would say, “Well, it means I can’t socialise as well with other people.” And then he would say, “So I’ve been told.” So, then you’re thinking, right, you’re not recognising this in yourself, are you? Or again, I might have got that wrong. I mean, it’s actually going back and checking whether we’ve understood what they say probably, not for them what might be called neurotypical projections. And then there are…so that sort of checking process and monitoring their behaviour for signs of changes, listening to their questions. I think there was one child as well who said right at the end of the very last session I asked him to say what he thought about having autism because I’ve taken…one of the tools	Checking child’s communication and responses Observation for behavioural signs	

Speaker	Transcript	Analysis	Feedback from participant
	that I have is the one to five emotions rating scale that I get them to say how they're feeling about it. At various points throughout the work I think you've constantly got to be checking how they're feeling if they can't tell you outright. But at the very end of the last session he just said "Well I think actually it means I'm disordered. And I looked up disordered. I was told it's a disorder and I've looked up disorder in the dictionary and it mean- an example sentence I saw was a computer that is disordered does not work properly." So he'd sort of picked that up, "Okay, my brain doesn't work. It's disordered, it's broken." But it's good that he said that.	Feelings scale to monitor change Monitoring for misunderstanding continuously so they can be addressed as they happen	
INTERVIEWER	Yeah, because then it's something you can pick up then, isn't it?		
PROFESSIONAL 3	Yes.		
INTERVIEWER	Yeah. the disordered seems to be processed and internalised?		

Speaker	Transcript	Analysis	Feedback from participant
PROFESSIONAL 3	And actually, the child’s understanding of the words they use to describe themselves with. Again, it’s in my book and I think it was in the GAP article actually. There’s a child I’ve put in there who is called Ricky but that’s not his real name, who said that he was a loving person. So we gave him a series of attribute cards to choose from with symbols to help him select. And then what I’ve learned is it’s so important to check that the child knows how these things apply to them and that they genuinely believe it, otherwise, it’s going to have little meaning for them. And we’ve just say to him “Right, okay. Can you tell us something that you do that’s loving?” And his mum was expecting him to give her a cuddle, and he said, “Loving? Wearing glasses. I love wearing people’s glasses.” glasses on. And then other things like the really obvious stuff, like the first parts of the booklet you take a photograph of	Words used to describe themselves are useful Attribute cards and ensuring the child understand them and believe them Children’s explanations might be individual and need interpretation	

Speaker	Transcript	Analysis	Feedback from participant
	the child to begin with that goes on the cover and on the first page. We discussed the idea about everybody having this unique face, a unique appearance and no two people looking the same. And that particular boy, he didn't get that so now everyone's got two eyes, a nose and a mouth. But then he did go on to start categorising us. He put me in the group, I'm the head teacher of a group of people that were grandparents. But he didn't see that the features, he just saw it as a whole. And then of course, you've got kids with prosopagnosia as well.	Different media can help to support unpicking of child's understanding Different perception needs to be considered	
INTERVIEWER	Yeah. I think your pronunciation of it is better than mine.		
PROFESSIONAL 3	To them faces they don't pay attention to or can't read them. So even familiar children, even familiar people they don't recognise them based on appearance if they come with a different hairstyle.		
INTERVIEWER	Yeah. And I used a video by Luke Jackson, and I think he must've		

Speaker	Transcript	Analysis	Feedback from participant
	been 15 when he did it. And he talked about learning everybody's face and different expression as separate entities, and I thought that was an interesting way to think about understanding your emotions.		
PROFESSIONAL 3	I don't think I properly answered the question about other resources. So apart from things sort of- I think I possibly mentioned things like learning support materials like symbols, et cetera, or cue cards, schedules. Every child has a schedule of some form. Usually it's a bit in list for this work, but I've also used symbols on Velcro.	Resources: symbols, cue cards, Schedules (different formats- lists and symbols)	
INTERVIEWER	And you said the five scale, I added that.		
PROFESSIONAL 3	Yeah. And also including on that, there's another scale which is the easiness scale rather than difficulty rating scale which children can be given when they're not sure. When they can't come up with the list of their own skills and things or challenges, then an adult could put	Easiness/difficulty rating scales	1465: 'write' should be 'rate'

Speaker	Transcript	Analysis	Feedback from participant
	it to them, could give them some examples and still giving the child ownership of it by asking them to write themselves out of five how easy is it. And if they get a score of four or five being in difficult, then that would…one or two meaning it' very easy would go on count to their list and vice versa with the challenges. And also, they do get cards when needed with lists…for sorting activities with lists of things they might find easy or difficult. But then I think the thing that I meant to say, to go back to this question was that you mentioned the Luke Jackson video, I've used that in the past with some children.	Scales linked with contextualised examples Sorting activities Luke Jackson video	1477/8 Video was by Roy Hoy
INTERVIEWER	Yeah. That's another really good one, isn't it? Yeah.		
PROFESSIONAL 3	Yeah. That's good with peers, that one as well. But what I tend to do is take in a selection of resources for parents to look at, take to the final session and give them a list but advise them strongly that they need to look at the resources themselves	Provide a section of resources to support the child to identify those useful for them	

Speaker	Transcript	Analysis	Feedback from participant
	so they could judge whether they’re going to be useful for their child or not. And that can include a whole range of things like information books, books by people with autism, Jude Welton’s books, ‘Can I Tell You About Aspergers?’ the autism one. For old, more able children there’s that one by…who wrote it? It’s edited by Tony Attwood and, I forgot her name who did it? The one about the Aspie …. Let me get a copy off the bookshelf then I can tell what it’s called. It’s this very good self-help book for older teenagers and young adults. I have to look in the bibliography. I can’t find it on the shelf.	Books by people with autism Jude Welton: Can I Tell You About Aspergers Tony Attwood: The Complete Guide to Asperger's Syndrome Or Exploring Depression, and Beating the Blues:A CBT Self-Help Guide to Understanding and Coping with Depression in Asperger’s Syndrome?	
INTERVIEWER	I’m just trying to think if I can…. Is it quite…? I’m saying quite recent, is it about three years?		
PROFESSIONAL 3	Yeah. And in fact, he’s made some shorter version, a collection of books that are coming out on JKP website. Just trying to find this.		

Speaker	Transcript	Analysis	Feedback from participant
INTERVIEWER	I think I might know the one you mean actually. It came out about two or three years ago I think. But I can't think who it's by. Who did you say it was by?		
PROFESSIONAL 3	I said it's by **Tony Attwood** and…I'll give you the full reference. I've just got to wait for 200 pages to load.		
INTERVIEWER	Oh, sorry about that. (		
PROFESSIONAL 3	Probably the end of the manuscript.		
INTERVIEWER	Well, we are finished. That was the last question. Unless there's anything…. The only other thing is if there's anything else I haven't asked about that you think is important for me to know.		
PROFESSIONAL 3	I think the other thing is that I don't treat the work as being an intervention. But it's not the intention to intervene with the child's autism or to make them normal. I prefer initiative more. I mean, the last service I worked for, we didn't talk about teaching children about…call it diagnosis work, we called it teaching children	Diagnosis work is learning rather than intervention	

Speaker	Transcript	Analysis	Feedback from participant
	about their Autism. Let's see, Tony Attwood. Where's it gone? Into the B's going backwards. Yeah, it's called the complete- no, it's not, sorry. Yeah, it's by Tony Attwood, somebody Evans, I can't remember who that was, Been there, Done that, try this, an Aspie's Guide to Life on Earth. That's Jessica Kingsley. And basically, I think it's the top 10 issues or 12 issues or something like that that affect children- people with autism that stress them. So it takes several issues, so one of them could be anxiety, another one is socialising and so on. And then you get a series of essays by Aspie Mentors so successful people on the Autism spectrum…	Resource: Edited by Tony Attwood, Craig R. Evans and Anita Lesko (2014) An Aspie's Guide to Living with Personal Management Issues Been There. Done That. Try This!	
INTERVIEWER	That sounds really good. No, I haven't seen this one.		
PROFESSIONAL 3	…how they've dealt with the problem. And then **Tony Attwood** summarises it at the end, he comes up with some generic sort of hints for people. And I've noticed that on		

Speaker	Transcript	Analysis	Feedback from participant
	the JKP website now there are some shorter books rather than you buying the whole thing in one book. Some books are about 50 pages long or so that just take one issue and again use the experiences of his group of Aspie Mentors.	Experiences of those with autism useful to draw on as mentors	
INTERVIEWER	Right. Oh, I'll have a look at that. I've missed that one. Yeah, I'll have a look at that one.		
PROFESSIONAL 3	Have you seen the Autism Education Trust video as well?	Autism Education Trust video of positive role models	
INTERVIEWER	Yes. I've actually analysed that video as part of my research. I transcribed it and I've included it in particularly in my earlier research when I was looking at what I needed to look at, if that makes sense. But yes, it is really good and I've used that in work with young people as well. Because I think there's some really positive role models on there, isn't there?		
PROFESSIONAL 3	Yeah. Well, the young woman that talks with the communication aid, Helen.	Range of examples of people with autism useful	
INTERVIEWER	Yes, yeah.		

Speaker	Transcript	Analysis	Feedback from participant
PROFESSIONAL 3	I mean, I've cited her as an example of how having the diagnosis can enable you to engage in discussing your support and making decisions about the future where as a child and she was in meetings they didn't even know why she went to special school.		
INTERVIEWER	Yeah. There are so many cases, aren't there, where they just don't…isn't revealed and they don't have that information and it must be a really difficult world to understand I think if you don't have the knowledge of sort of why, what are those decisions being made for.		
PROFESSIONAL 3	Another thing probably an important issue that include, another thing that can influence how a child responds is they're aware of their difficulties beforehand. And children that hadn't realised and we're talking about quite able children as well. I think Huws and Jones may have talked about this where autism was basically an absent presence in their	Autism as a absent presence-child might have the awareness of difference if not the diagnosis	

Speaker	Transcript	Analysis	Feedback from participant
	life. So it was there, but they didn't know it and they weren't aware. Children like that can be confused or upset whether sort of actually you find it quite hard to get along with other people. This could be kids, able kids, but they've not realised actually when things do go wrong it's because of what they're doing something inadvertently that provoke the situation or make matters worse. And I think children like that, that's why it's important to ascertain beforehand exactly what the child knows about themselves including their awareness of their differences and challenges. If necessary, if they don't know, people need to start labelling those for them in the context of everyday life so that they can come along with that and they don't have to get into denying and saying, no, that's not the case. I've had one little boy who said he was surprised by that and then had that destabilising effect that he wasn't aware that	Difficulties understanding self can impact negatively on relationships Lack of understanding of the difficulties being experienced can exasperate them Identifying what they understand about themselves and their own needs before disclosing is important Pre-work to support the child to recognise difficulties they might need to tackle is useful	

Speaker	Transcript	Analysis	Feedback from participant
	there was anything wrong with what he was doing. And that can also lead to the child then not being…not accepting the diagnosis or finding it difficult to talk about. But…yeah.	If children do not have a sense of difference, it can impact acceptance	
INTERVIEWER	Yeah. It’s so easy, isn’t it? And there should no surprises in terms of what we know about some of the differences that they have in terms of understanding the world, but that interpretation as you say and how problematic it can be. One of the reasons actually why I first started looking at it was because a young man, so talking to him, he did know about his diagnosis. Somebody, I don’t know whether it’s his parents or somebody else had told him, and he was talking about it. And it was only in talking about it that he related it to somebody else he knew, that his parents knew who had autism and complex needs. And he had this image that he’d somehow…. I think his perception was almost like a disease. He’d		

Speaker	Transcript	Analysis	Feedback from participant
	been told he'd now got autism and I think he thought there was going to be a progression for him to deteriorate and become like this person he knew with really significant complex needs who also had autism.		
PROFESSIONAL 3	Yeah. No, I've had that. Yeah, as well. So basically, I mean it's that encountering negative images or examples of autism before they find out about they've got it themselves. That was actually a key issue that came up in my research around late diagnosis children finding out about it later. And I don't know if you're familiar with the research that was done by Cassidy in Coventry I think a couple years ago. Presented it at the NAS mental health conference, it was on suicidality amongst people with autism.	Negative images and perceptions of autism can impact how they view autism and their subsequent acceptance Suicide as a risk for late diagnosis: ? Cassidy, S., Bradley, L., Shaw, R. et al. (2018) Risk markers for suicidality in autistic adults. *Molecular Autism,* 9, 42. https://doi.org/10.1186/s13229-018-0226-4	
INTERVIEWER	No, I haven't seen that.		
PROFESSIONAL 3	Well, one of her key findings was that more likely suicidal behaviour is not necessarily but are more likely in adults with late diagnosis. She		

Speaker	Transcript	Analysis	Feedback from participant
	did a message to the over a 100, maybe 200 people with self-reporting questionnaire.		
INTERVIEWER	Yeah. Well, I'll have a look at that.		
PROFESSIONAL 3	I can put that as an example of what children need to be told.		
INTERVIEWER	Yeah. There was some research previously that I have looked at in my research which related to suicide but it wasn't Cassidys or…I'll have a look at that as well. That's really useful.		
PROFESSIONAL 3	I think it's available on…I think there's been access to it in the internet.		
INTERVIEWER	Is there?		
PROFESSIONAL 3	Yeah.		
INTERVIEWER	Right. I'll have a look at that. Thank you.		
PROFESSIONAL 3	Or a summary of it, yeah. That's a good one that one.		
INTERVIEWER	Yeah. I will definitely have a look at that, thank you. That's really helpful. Well, that's all of the questions and you've been incredibly helpful and given me		

Speaker	Transcript	Analysis	Feedback from participant
	some other bits of literature to look at that I haven’t come across yet. So that’s really great. And just it’s so comprehensive the information you’ve provided so I’m really grateful for you to take this time.		

Appendix 22.1 Summary of themes from professionals to each question

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
Role	Specialist teacher Wide ranging role Parent training Multi-professional training Training beyond the authority Run as a business Focus on children with most complex needs Support for mental health needs CBT-specific intervention One to one for complex cases	Independent professional -also on the autism spectrum himself Working with organisations, individuals, families Provides training, mentoring, counselling and diagnostic work	Autism advisory teacher and service deputy Local authority role Primary and secondary support	Specialist Teacher Role Referral through local processes Through parent training Training for professionals Focus mostly on parental understanding Support to identify the right time Parental understanding readiness seen as a important. Supporting communication and continuity between home and school Multi-agency working-TAC approach	Role details-Speech and Language Therapist 12 years of experience Specialist autism service-RI Early intervention-autism specific School -based Multi-disciplinary therapy, assessment and diagnosis
Helping young people with autism to understand the diagnosis	Specific parent training Parent experience of diagnosis covered	Families important to diagnostic work Work needs to be with parents and	250 children & their parents Work anonymised to support misconceptions and lack of authority focus	Focus mostly on parental understanding	Assessment role sometimes

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
	Sharing experience Parent experience of sharing diagnosis with child Processing the diagnosis Grief and emotions Peer awareness has positive impact on child with diagnosis Re focus on difference, not deficit Changing societies perceptions Actual disclosure not part of the role Diagnosis work tends to be for older age group Social interaction difficulties and bullying Late diagnosis impacting self-identity Focus on mental wellbeing first or positive diagnosis focus on strengths and strategies Approach/role wide-ranging Positive role models crucial Difficulties also explored Strengths and interests and where these can lead	whole family as well as the child Family can provide the supportive environment Neurodiversity perspective Disclosure is not the end point All work post diagnosis and integral and holistic rather than diagnosis specific Focus on positive outcomes of being on the spectrum. Peer awareness Draws on own understanding as a example of an adult with autism to support awareness Developing ways of communicating	Support for the individual to understand their own difficulties and support provided Parents and educators not sure how to support children's understanding Anxiety about child understanding and reactions Worries about relationships lacking understanding A particular focus for parents to understand Some educators also recognise the importance of supporting understanding Importance of learning about the individual and their diagnosis to support preparation for work about diagnosis Professional observation and meeting individual crucial When individuals know about the diagnosis, understanding their views is important Learning how to interact with the individual is crucial Interview paperwork supports information about the individual Parental consent crucial	Support to identify the right time Parental understanding readiness seen as a important Signposting for parents to information Supporting preparation for specific aspects of development Parent training Parent focus Not the right time-too young Parent training has positive impact Understanding enables agency for strategies Similar impact for children and parents Role models children can relate to	Post diagnosis service? Parent focussed training: Early Bird; Hanen: More than Words; social stories; social skills Support focussed on family needs Collaborate planning Providing information Parental needs differ Relationships important Needs vs availability Well resources and flexible provision Parental support through school Health role Service collaboration A point of readiness Parental permission

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
		English for people with autism is a second language The world needs explaining in an appropriate way Typical people often do not explain accurately Positive impact on children's self-awareness Typical people have the communication problem not people with autism Bringing the school and family together is important Programme was able to cater for a range of needs Holistic approach to ensure child is understood in all environments Supporting the school to understand the child holistically	Parental ideas about the right approach important Educator involved to support understanding Explaining what it does not mean is important Ok to have autism Autism isn't an illness People with autism can be intelligent Individual is good Brian works differently in a special way	Concrete examples of the spectrum useful	Role for social worker Social and emotional support Diagnostic discussion and developmental appropriateness Time for parental processing of diagnosis Diagnostic disclosure focussed work comes later Parent agency regarding disclosure Varied readiness of parents for child disclosure Child awareness of difference as a trigger for disclosure Parental requests for advice regarding disclosure Parents knowledge of best approach Respecting relationships

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
					Supporting professionals understanding of autism and supportive approaches Transition a focus for support Educators varied levels of understanding Collaborative support
Resources	Specific poem: A different place (Parents) Individualised Vermeulen (2013) I am Special Workbook Too much focus on difficulties Resources personalised to individual and to emphasise positive Individuality is good Difference Different strengths and difficulties Developmentally and situationally specific Person-centred Based on formative assessment	Bespoke work No single resource or course right for everyone Some courses problematic and support inappropriate understanding/ Intervention Case studies useful to draw out ideas. The value of a more experienced person with autism supporting a young person. Focus on long term outcomes can be too distant to support engagement	Bespoke booklet about child's strengths and challenges Abilities and skills are re-emphasised in subsequent sessions Positive personality traits emphasised too Individual strengths and challenges used to frame diagnosis Booklet provided so parent and school can continue to support the child's understanding over time Created guidance to be differentiated Language is simple to support understanding Published a book to support understanding of how to support a child to understand the diagnosis Internet used for images for resources People/images of someone the child relates to important	EarlyBird for parents Autism and Me-Rosie BBC Documentary Huws, J.C. and Jones, R.S. (2008) Diagnosis, disclosure, and having autism: An interpretative phenomenological analysis of the perceptions of young people with autism. Journal of Intellectual and Developmental Disability, 33(2), pp.99-107. Punshon, C., Skirrow, P. and Murphy, G. (2009) The `not guilty verdict': Psychological reactions to a diagnosis of Asperger syndrome in adulthood. Autism, 13(3), pp. 265-283	Specific resources to develop social and emotional understanding: social stories; Incredible 5 point scale Strategies adapted for the individual Appropriate videos signposted-e.g. A for Autism Learning from/with others with similar experiences Meeting and discussing autism with other parents is supportive for parent processing

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
	Individualised approach crucial No published approach would be right for everyone	Positive self-awareness is crucial Creating the right environment is the real key	Copyright can be an issue Luke Jackson video Jude Welton: Can I Tell You About Aspergers Tony Attwood: Exploring Depression, and Beating the Blues A CBT Self-Help Guide to Understanding and Coping with Depression in Asperger's Syndrome Resource: Edited by Tony Attwood, Craig R. Evans and Anita Lesko (2014) An Aspie's Guide to Living with Personal Management Issues Been There. Done That. Try This! Autism Education Trust video of positive role models		Group activities to facilitate discussion Focus on difference in explaining to peers individual needs Supporting the child to connect with peers Peer awareness raising Liaison with teachers/sharing materials for them to implement Parent programmes support parent understanding: EarlyBird
Training	No specific training=supporting understanding of diagnosis Masters in autism Learning from professional speakers, parents and own research Combination of learning sources Lack of general information about how to support understanding Left to parents and professionals to do own research	Psychologist ADI-R Trained PhD Philosophy (Autism) AS Diagnosis so also able to draw on personal experiences Strengths & limits of particular viewpoint Parent of child with autism diagnosis	General autism Own research: Welton at NORSACA conference discussing how she explained to her child Social Stories (Gray, 1996) Vermeulen (2000) I am Special	Masters Level autism focussed qualification Taught and self-study Inclusion focus Confident because of personal connection to autism Empathy with parents is important	No disclosure specific training Lots around autism and approaches to draw from Own experience from multi-disciplinary team Role specific rather than disclosure SALTs might not have autism diagnosis focussed training

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
	Approaches inconsistent National strategy guidance needed Parental needs can create difficulty knowing how to access guidance Gap between support children will receive well-educated parents and those without a good education Technology can help but not the ideal solution Parental lack of awareness of the SEND system problematic Late diagnosis especially problematic				Diagnosis makes a difference Understanding of disclosure through work with other professionals Learning psychology colleagues Observing and working with other professionals crucial Interpersonal skills crucial
Confidence supporting understanding of diagnosis	Complex role makes it difficult to be confident Individual nature of autism means there is never one approach Continually learning and listening to individuals to ensure right support CBT training Combination of understanding individual with autism and interpersonal skills crucial	Drawing on personal experiences Strengths and limits of particular viewpoints Parent perspective understood	Explaining an autism diagnosis is a big responsibility Anxiety/important to not become complacent as impact will vary for individuals Hasn't gone wrong but aware it might not always go well Important to be prepared to support individual if the impact is problematic Preparation crucial	Confident because of personal connection to autism Personal experience of autism crucial Empathy with parents is important	Able to draw on general professional skills from training Confident Young people can articulate strengths and needs Different needs and strengths Unexpected questions about diagnosis can shake confidence

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
	Difficult to access supervision due to the specialist nature of the work Complex and responsible role Anxious to get it right Weight of responsibility can cause stress Working with significant mental health needs Supervision requested and being organised		Adults worry about explaining an autism diagnosis Children with autism are often indifferent Understanding and processing the diagnosis is the biggest issue Programme is a starting point, coming to understand diagnosis is a lifelong process		Readiness important for the professional Relationship is crucial Confidence varies depending on individual Children ask questions about differences Particular types of insight from young people
How is it decided whether a young person needs support to understand the diagnosis	Parents usually request, might be from parent but through school Parents signposted to support groups and training Letter from diagnostic clinic provides basic signposting Signposted to materials and national organisations such as the National Autistic Society Lots of parents do not want child to know about diagnosis	Combination of things that make the difference	Decision about disclosure can be made after initial session Where disclosure happens, a headline sentence is included in booklet Support provided for school staff about how to respond to children's future questions Readiness in lots of personal factors Avoid disclosure at problematic times for the individual Accidental disclosure can be an issue if delayed Possibility of child finding out accidentally criteria for disclosure being needed Child needs to understand difference	Usually not direct involvement with diagnostic disclosure Although not the focus, parents sometimes asked for advice about whether to tell. Child beginning to ask questions or identifying feelings of difference. Self-awareness Child identifies with others with needs	Flexible service so no particular criteria Long waits for service Flexible support Interdisciplinary and person-centred discussions Regular planning review Regular reviews and family contact enable the topic to come-up when needed Not specifically advertised

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
	Age is a factor Younger children, celebrating difference is the focus Improvement in peer awareness When child struggling and not understanding the diagnosis Important that the young person knows at the right time Can be a relief for child to be told, when handled positively Supports understanding of self Recognition of support and possible strategies Concerned if parents don't want to disclose to older children Professional debate raised concerns about diagnosis problematic if on a CV.		Parents and educators sometimes worry about the child disclosing Self-disclosure rare due to communication needs, friendship issues and not wanting others to know When they do disclose it is usually through excitement When thy do disclose, useful to follow up with peer training Important that the child wants this to happen		Trusting relationships facilitates requests for support Shared planning the approach support identification of work on diagnosis as a need Family and care plan to inform preparation for disclosure Research about impact needed Lack of professional understanding means they would struggle to explain the diagnosis Knowledge of child in different environments useful to inform disclosure preparation Person-centred multi-professional approach crucial Relationship with the child is crucial Professionals wanting to work with the family Aim to match parents and professionals if possible

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
	Young people can be angered by late diagnosis Young people are concerned about impact on future career prospects Overwhelmed by college Environmental factors-Support not right in education Strengths Environmental factors-problematic home factors Problem solving-moving forward Complex nature of overlapping needs Diagnosis concern about impact on careers Problematic when young person doesn't accept diagnosis Child concerned difficulties elate to homelife				
Specific factors that suggest a young person might be	Behaviour change Unpicking issues with the young person	Combination of things that make the difference	Identifying signs can be problematic Monitoring is important as a follow up	Focus mostly on parental understanding	Child observed difficulties might signal need to discuss diagnosis

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
struggling to understand/ accept a diagnosis	Time to do this is important Time for reflection and developing strategies Relationships crucial Awareness raising crucial to support understanding/ empathy	Different in each case Work needs to be tailored to the individual. Needs to be developmentally appropriate Professional has to have the ability to personalise it.	Noticing changes in behaviour is important No severe problems reported after disclosure programme Giving excuses might indicate problematic understanding More likely to happen with able children who haven't had a full explanation No refusals to participate Sometimes time needed to process being told Reconvened when ready Every child has completed the programme Only cases when child was not understanding at session one has caused to work to be halted Readiness is crucial Programme not appropriate for children with severe learning difficulties	Support to identify the right time Parental understanding readiness seen as a important.	Parent might highlight needs that professional interprets the child need help to understand diagnosis Good relationship enable discussion of diagnostic disclosure Emotional disequilibrium as a sign Behavioural changes Problems as a sign they need to know Disclosure is a sensitive issue Parent needing time to process diagnosis themselves before disclosing to child Parental acceptance supports disclosure to child. Autism is a stigma for some Might not be disclosed to wider family Has to be processed by parent before explained to others

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
When young people are experiencing difficulty around accepting the diagnosis, what impact do you think it has on the young person	Emotional, frustration and denial Blaming others Lack professional understanding Invisible nature of autism impacts understanding Strategies not accepted Fluctuating nature of sensory emotional presentation Confusion about self-identity Identity confusion Emotional turmoil and wellbeing impacted Anger/confusion at being assessed but not diagnosed sooner Signs there but missed Anger because of the impact due to lack of recognition	Lack of understanding of the spectrum and vast range of impacts The individual should be the focus but sometimes work is focussed on important others in their life Programme was able to cater for a range of needs Holistic approach to ensure child is understood in all environments Supporting the school to understand the child holistically Parents try to liaise with the school but concerns not always understood Lack of understanding by educators when difference in behaviour at home and school Intermediator role between parent and	Diagnosis is the missing piece of their personal puzzle Insider accounts useful: John Vincent Diagnosis helped things make sense Lack of self-awareness can impact mental health Difficulties understanding self can impact negatively on relationships Lack of understanding of the difficulties being experienced can exasperate them	Not appropriate as work not directly with young person	Some parents against disclosure Working around the diagnosis would still happen without actually discussing autism Work to support child self- awareness if not diagnosis Can be worked on without mention of autism

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
	Feeling the unfairness of experiences due to lack of recognition	school to support shared understanding			
The most important factors that support the young person to move towards that positive understanding of the diagnosis	Positive successful role models with autism Positive focus to move forward Positive perhaps different future Learning from others' experiences Future potential Ups and down are normal life experiences	Discussion with the young person to gain understanding of them is the key resource. Textbooks might lead to misperceptions as not accurate for all Individual cases valuable- autobiographies as role models Importance of example being appropriate and applicable Professional understanding of autism might be better than knowledge from one person with autism Depth of understanding is crucial to employ resources and autism perspectives appropriately	Professional understanding of appropriate strategies crucial Knowing the child is crucial for disclosure Qualified to support/teach children with autism is also crucial Preparation crucial Supporting understanding of self as a good person and positive traits is important Listing attributes and strengths Recognise challenges related to autism but also that this is ok Others have needs is highlighted Ensuring parents and educators understand how to respond in the session Preparing parents is crucial as it can be stressful for them Getting the language and communication right: calm and matter of fact Revising their key strengths and needs from previous session Providing a visual schedule	Not appropriate as work not directly with young person	Parents supported to understand the need for self-awareness Careful explanation important Parents want the best for the child Early intervention for self-awareness Broader strategies all support that awareness raising Advice about what to say Parents know child best, therefore best placed to disclose. Advice to boost their confidence to support disclosure Parents get it right when they do disclose.

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
			A or AS on the schedule to signal the point of disclosure of something new and interesting about you A script You have autism, it is ok, there are famous/successful people with autism Order supports understanding Explanation of autism is tailored to the individual Autism role models support children's engagement and interest Even children with more significant needs respond to role models Pictures and photographs of the famous people they are like supports engagement Children respond well and seem to accept the diagnosis calmly Even children who are initially anxious are calmed by examples of positive role models Preparation for disclosure is crucial Child being familiar with the professional and vsv is important Time to tailor the work for the child is crucial Planning enables potential difficulties to be identified and planned for		

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
			Professionals should be experienced with autism and the child to facilitate the most appropriate adjustments Best practice is build on preparation and information from all key people		
Where diagnosis has a negative impact, what factors link to that?	Work focused on emotional wellbeing sometimes raises diagnosis issues Peer and their parent awareness important in school setting Positive peer awareness has positive impact Difficult to organise due to interest but can have positive impact Negative response caution about similar work in future	Training poor quality for professionals Not enough professional understanding of young people's experiences. Frustration that parents are not supported to understand diagnosis sooner Lack of immediate support post diagnosis Society view of autism as a deficit Lack of understanding about emotions and processing of people with autism Understanding is the crucial element rather than awareness	Dialogue and agreement important to support work positively Parents might need time to process and support to prepare them, so they are ready for it to happen Providing time to discuss with parents beforehand is useful Final check about readiness is crucial and willingness to delay if not Difficulties understanding self can impact negatively on relationships Lack of understanding of the difficulties being experienced can exasperate them Identifying what they understand about themselves and their own needs before disclosing is important Pre-work to support the child to recognise difficulties they might need to tackle is useful If children do not have a sense of difference, it can impact acceptance diagnosis Negative images and perceptions of autism can impact how they view autism and their subsequent acceptance	Parents need time to process Parental support to recognise child strengths	Parental acceptance of support impacts child Service issues can impact willingness to engage Support for parents is support for the child Not about the professional but processing the diagnosis Parental engagement supports child development Passive disengagement Is more problematic When the diagnosis is given or sought? Diagnostic experiences can impact processing and understanding

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
		Shift to a truly empathic understanding of autism needed Terminology is important to change as it sets the expectation National charities perspective is sometimes problematic and perhaps concern if this is challenged Important to highlight issues with perceptions of autism Problematic language used by national charity in the name of the organisation Stereotyped portrayal of autism problematic Surface level adjustments Autism impacts people differently, therefore adjustments need to be individual	Suicide as a risk for late diagnosis: ? Cassidy, S., Bradley, L., Shaw, R. et al. (2018) Risk markers for suicidality in autistic adults. Molecular Autism, 9, 42. https://doi.org/10.1186/s13229-018-0226-4		Diagnostic process is sometimes reported to be problematic. Lack of knowledge of the diagnostic process might led to confusion for parents Diagnosis might not be accepted if parents do not have faith in the process Parents reasons for seeking diagnosis for the child vary Parents who actively seek the diagnosis experience relief. When the diagnosis is wanted it can be a relief For some an unexpected surprise More difficult if unexpected More difficult to explain the diagnoisis/give diagnosis if unexpected

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
		Tokenistic involvement of people/person with autism Single/few viewpoints might be used to justify decisions inappropriately			Diagnostic process and delivery have a huge impact Empathy is crucial Professional manor Delay and problematic diagnostic experience causes anger. Parents might do own research and might be misinformed Parents can be vulnerable if not signposted appropriately Lack of information can lead to misunderstanding Partial understanding Media portrayal can be problematic Preservice experiences can impact Parent experiences impact child

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
					Parents might search for a solution Realisation there is no cure is hard for parents Importance of professional signposting and advice Lack of professional training about interpersonal skills Professional attitude can be problematic Viewpoints can be difficult to alter Professional assumptions based on one student can be difficult to overcome Lack of understanding of the system of support and provision can cause upset for parents Negative emotional experience for parents/all concerned Misunderstanding provision

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
					Negative emotional experience for parents/all concerned Information about service provision difficult to negotiate for professionals and parents Some parents will find this more difficult to negotiate than othes Different service provision in different countries Empathy due to personal experiences Coordination of services is problematic
What has a positive impact in understanding diagnosis positively?	Relationships and mutual positive regard Listening and giving time to the young person Unpicking issues with them Supporting individuals to understand the difficulties so strategies make sense Behaviours can have serious impact	One programme is not going to be right for everyone. Knowing the individual and family is crucial to enable successful personalisation Focus on autism as part of individual make-up Support focused on emotional	Keeping language, such as conjunctions, simple to support understanding Language has bee refined to build on learning from implementing the approach Final check of the booklet is important to avoid misunderstanding Images and information about positive elements	Advice Focus on Strengths Negative school experiences impact introspection on negative experiences Highlighting strengths to the young person	Good support enables parental agency to implement approaches/discuss diagnosis Might have siblings with autism Parenting a child with autism can be difficult Good relationship with key person

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
	Working with an individual over time to address their related needs systematically Can’t separate diagnosis work from the rest of the support for the young people	development and self-awareness Insider perspective important to understand the experience Approach has to consider family dynamics Combination of things that make the difference Different in each case Work needs to be tailored to the individual. Needs to be developmentally appropriate Professional has to have the ability to personalise it.	Supporting a balanced understanding of strengths and needs Strengths based interests build on Final page a brief recap to support understanding Includes a reminder that people without autism experience difficulties too Linking to peer work useful Continually reinforcing that having autism is ok Got to be realistic as Vermeulen (2013) explained Might have to counteract previous negative links made to diagnosis Helping the individual to see the positives and as an ongoing basis Ongoing identification of successes to build the positive evidence Holistic approach crucial Preparation important Matter of fact disclosure Ongoing process to support understanding Revisiting positive role models	Successful role models An improving openness about autism diagnosis Online content can be useful	Right interpersonal skills crucial Providing the key information supports parental agency around decision making Judging readiness is important Parent and professional working as a team Previous negative experiences impact working relationships in future Diagnosis can be the problem Professional commitment to make a difference Professional satisfaction Can feel like a one way relationship if parental experience/impact not understood Empathy & understanding are crucial Trying to understand to facilitate the right approach

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
			Realistic about role models and not everyone with autism will be rich and famous but can be happy and fulfilled Seeing a positive future is crucial, especially later diagnosis or disclosure because the initial diagnosis can be seen a problematic for their future Resource is emergent version of best practice across experiences When disclosure goes well, the positive impact and acceptance after disclosure can enable the whole family to move on Disclosure to the child is the last step in parents' acceptance of disclosure Able to accept and use the word That the child does not get upset or angry is positive for parents, even though understanding might take longer Disclosing the diagnosis is only the first step to understanding		Able to positively impact lots of cases Good multi-professional working was a factor Support for child's self-awareness Support for other professions to understand child's needs Support for family to understand child's needs Good communication crucial Key worker to coordinate services Time of intense emotions for the carers Getting communication right was the key factor Good planning Each profession supporting other profession's knowledge Learning from each other Good planning

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
					Autism specific strategies Importance of everyone understanding and being flexible Good multi-agency work and understanding the child
How do you evaluate the work around the diagnosis, specifically?	Observing and listening to young person Psychological assessments of self, used but less valuable Child behaviours and communication best guide Formative assessment Formative decisions about when child ready to discharge from support Observing and listening to young person Looking for signs of positive or balanced view of self Relationships and knowing the individual crucial for good formative assessment	Professional observations of change Outcome measured as a more robust approach to life Seeing positive change in self-perceptions Improved resilience Able to move on from previous experiences? Improved self-awareness and resilience? Can be difficult to measure What makes the difference for those who do well?	Retrospective Study Reflective practice Gauging the child's understanding through questions and interaction during the intervention Checking child's communication and responses Observation for behavioural signs Feelings scale to monitor change Checking child's communication and responses Observation for behavioural signs Feelings scale to monitor change Monitoring for misunderstanding continuously so they can be addressed as they happen Words used to describe themselves are useful Attribute cards and ensuring the child understand them and believe them	Not appropriate as work not directly with young person	Smart goals regularly reviewed in a person-centred way Professional supervision Good communication

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
		Focussing on strategies that make a difference positively? Resilience is important rather than measurement?	Children's explanations might be individual and need interpretation Different media can help to support unpicking of child's understanding Different perception needs to be considered Words used to describe themselves are useful Attribute cards and ensuring the child understand them and believe them Children's explanations might be individual and need interpretation Different media can help to support unpicking of child's understanding Different perception needs to be considered Resources: symbols, cue cards, Schedules (different formats-lists and symbols) Easiness/difficulty rating scales Scales linked with contextualised examples Sorting activities Luke Jackson video		
Anything else I haven't asked that you feel is important?	Families need better support and signposting following diagnosis	Nothing else to add	Autism as a absent presence- child might have the awareness of difference if not the diagnosis	Not enough support	Understanding the individual child crucial

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
	What they get now isn’t sufficient Lack of understanding by educators can impact whether current needs identified and support accessed Follow-up appointments needed after diagnosis More in-depth guidance for parents In-depth information for the young person (books or online) Parent groups might not be right for all Support needs to be tailored more to the individual child and parent Child might or might not be at diagnostic meeting-is that right for everyone? Person-centred approach crucial Large meetings can be traumatic for young people		Experiences of those with autism useful to draw on as mentors Provide a section of resources to support the child to identify those useful for them Books by people with autism Experiences of those with autism useful to draw on as mentors Autism as a absent presence-child might have the awareness of difference if not the diagnosis	Something needs to go wrong to access support Being ready to access support is important Readiness is crucial	Professional training for interpersonal skills Balancing child trust to discuss in confidence with keeping parents informed Clinical judgement Not trained in interpersonal skills Parents do all the work with child after diagnosis More support needed for parents pre-diagnosis Work focusses on parents when child too young Diagnosis has a huge impact on parents Emotional reactions differ Trading up to diagnosis to support access to services Dealing with misdiagnosis problematic for parents Trust needed Pre-training useful for parents

Interview focus	Professional1	Professional 2	Professional 3	Professional 4	Professional 5
					Parents own research The impact of professional communication Care needed to avoid misunderstanding Miscommunication can cause ongoing mistrust of professionals Diagnosis comes before relationships so difficult to get it right Time needed to develop relationships Drawing on personal experiences supports empathy Questions from children come at unexpected times Impact of getting it wrong can be far reaching for mental health

Appendix 23 Member Check Record

Parents	Response
1	That all seems fine. Thank you for sending it on.
2	Yes, happy with that. I'm sorry, I did go on a lot about myself in places rather than Child Name. I hope it was still useful. *Response sent to reassure parent of the usefulness of the interview*
3	Telephone response Yes, everything was as I remember it.
4	I am more than happy with the transcripts. I feel it is an accurate representations of our discussions.
5	Yes, I've had a look at the interview notes and they all look fine. Sorry, they were so long, it must have taken you ages to type up, I talk far too much!
6	No response
Professionals	
1	Sorry for my delayed response. Following a restructure work is absolutely manic That is all absolutely fine.
2	Whilst my memory is not quite what it used to be, my recollection is that this is an exceptionally accurate reflection of what I said and how I said it! What I would like to thank you for is: • The integrity and accuracy in your questioning and reporting; • The insight and sensitivity in your analysis of my intentions; • Revealing to me that I say, 'you know' and 'I mean' far to often and for no real purpose. Thank you and all the very best
3	Thank you for forwarding the interview transcript to me. It must have taken you hours to write this up! I have just finished reading through it. I have made a few minor notes in the righthand column as requested and they are in the copy attached to this email.
4	Yes, thank you for sending it through, it is an accurate transcript. I am really interested in the colour coding and need to find out more about thematic analysis! I have not added anything further on the forms.
5	No response

Appendix 24 Synthesis of data across CYP, parent and professional participants

24.1 Online Survey: Before diagnosis-CYP's and Parents scaled responses

KEY	More than 2/3 agree	More than ½ agree

	CYP Survey Statement	5 Strongly Agree	4 Agree	3 Not Sure	3 Not Relevant	3 Other	2 Disagree	1 Strongly Disagree	Parent Survey Statement	Strongly Agree	Agree	Not Sure	Not Relevant	Other	Disagree	Strongly Disagree
1	I didn't know anything about autism	4	4	0	1	1	1	0	S/he didn't know anything about autism	20	3	2	0	0	3	2
2	I was confident about my ability	1	2	0	1	1	4	2	S/he was very confident around other children	0	5	1	0	0	8	16
3	I was confident when chatting with class peers	0	3	0	0	1	3	4	S/he was very confident about his/her ability	3	5	4	1	0	8	9
4	I worried about many things	7	0	0	2	0	2	0	S/he worried about many things	14	7	4	0	0	4	1
5	I knew I was different to other young people	5	2	0	1	0	2	1	S/he was always asking why s/he was different to other people	4	4	4	1	1	6	10
6	I didn't have much confidence in myself	5	3	0	2	0	1	0	S/he didn't have much confidence in him/herself	11	6	3	0	1	7	2
7	Everything was fine	0	2	0	1	0	4	4	Everything was fine	0	1	1	0	0	12	16
8	I never worried about anything	0	1	1	0	0	1	8	S/he never worried about anything	1	3	0	0	0	8	18
9	I struggled to get on with other people	5	4	0	0	0	2	0	S/he struggled to get on with other people	14	8	4	2	1	1	0
10	I had no idea that I had autism	6	3	0	2	0	0	0	S/he had no idea s/he had autism	22	3	2	0	0	1	2
11	Nothing ever seemed to work out as I hoped	1	5	3	1	0	1	0	Nothing ever seemed to work out for my child	8	10	3	1	0	6	2
12	I was doing well at school	1	1	2	0	0	3	4	S/he was doing really well at school	1	3	3	2	0	6	15
13	I felt that no-one understood me	5	5	0	0	0	1	0	S/he felt that no-one understood	8	8	6	1	0	4	3
14	I felt 'normal'	0	2	0	3	0	2	4	S/he felt 'normal'	2	3	9	0	0	6	10
15	I was finding school difficult	8	2	1	0	0	0	0	S/he was finding school difficult	16	7	2	0	2	1	2

24.2 Online Survey: Finding out-CYP’s and Parents’ scaled responses

KEY	More than 2/3 agree	More than ½ agree

CYP Statements: Finding out about my autism diagnosis statements	5 Strongly Agree	4 Agree	3 Not Sure	3 Not Relevant	3 Other	2 Disagree	1 Strongly Disagree	Parent Statements: Finding out about my autism diagnosis statements	5 Strongly Agree	4 Agree	3 Not Sure	3 Not Relevant	3 Other	2 Disagree	1 Strongly Disagree
27. My parents told me about my diagnosis	7	2					1	I/we told my child about their diagnosis as soon as it was confirmed	11	7	1	1	2	5	3
28. My parents explained the diagnosis very clearly	2	3	3			1	1	I/we told my child about their diagnosis when they started asking questions	4	7	2	10	2	4	1
29. A doctor or autism specialist told me about my diagnosis	4	3	1			2		Finding out about the diagnosis from the doctor/autism specialist has helped increase his/her confidence	4	3	4	5	1	7	6
30. The doctor or other specialist was able to tell me lots of helpful information	2	2	3	1	1	3		The doctors and other specialists were able to tell him/her lots of helpful information	0	2	2	2	2	15	8
31. Going through the diagnostic process helped me to put my experiences into perspective	3	4	4					Finding out seemed to help him/her to put his/her experiences into perspective	8	9	2	2	2	6	1
32. I was given lots of helpful information leaflets			1	3		4	2	My child was given lots of helpful information by the specialist	0	3	1	2	1	13	10
33. Finding out was a real surprise to me, I didn't realise that anyone thought I had autism	2	3	1	1		3	1	Finding out about the autism diagnosis came as a real surprise to my child	2	3	10	5	0	5	5
34. Finding out has been a very positive experience	5	2	2	1	1	1		Finding out has been a very positive experience for my child	6	7	6	3	3	4	1
35. When I found out, it made me feel like I had been given a label	2	1	2	1	1	3	1	When s/he found out about the diagnosis, s/he felt like s/he had been labelled	1	2	7	4	0	9	7
36. Being told I had autism provided me with what felt was like a fresh start	1	3	2			4	1	Being told s/he had autism provided him/her with what felt like a fresh start	3	7	11	3	1	3	2
37. Finding out about autism was a difficult process, which involved many assessments and meeting	3	3	3			1	1	Finding out about the diagnosis was a difficult process that involved many assessments and meetings	10	7	1	4	1	5	2
38. When they told me, I thought they had got it wrong			4	1	1	3	2	When my child was told about the diagnosis, s/he didn't believe they had autism	2	1	5	6	0	8	8
39. When I found out, I felt that I needed to look for information about autism so I understood what it meant	2	1	2			4	1	NA							
40. I used the internet to research information about autism	2	2	1	1		3	1	When they found out, s/he felt the need to look for information on the internet	0	1	5	8	0	7	9
41. When they told me about the autism diagnosis, I felt empowered	1	3	3	1		2	1	The diagnosis has helped to empower my child, as they were helped to understand the autism and to recognise all their strengths	5	11	2	3	1	7	1
42. I was helped to understand autism and to recognise all the things I'm good at	2	5	1			3		Finding out, helped him/her to understand their experiences and difficulties	6	12	5	2	1	3	1
43. Finding out, helped me to see the evidence about who I am	3	5		2		1		Information about the diagnosis highlighted that there is no such being as the 'normal' person	5	3	8	7	0	5	2
44. All I was told was about the negatives related to autism	1					8	2	My child has only been told about the negative aspects related to autism	1	0	2	3	0	12	12
45. Accessing websites/blogs/tweets created by other people with autism has been really helpful in coming to terms with my diagnosis	2	3	2	2		1	1	Accessing websites/blogs/tweets created by other people with autism has helped my child to understand the diagnosis	1	7	8	8	1	3	2
46. Knowing the facts about autism has really helped me	5	4	1			1		Knowing the facts about autism has really helped her/him	5	9	7	3	0	5	1

47.	**Reading the information about the diagnosis was like creating a big mental list of things that I struggle with**	4	2	3			2		Reading the information about the diagnosis seemed to highlight all the problems related to autism to my child	4	10	8	3	0	3	3
48.	**It was reading information books about autism that has helped me to understand**	3	2	1			4	1	It was reading information books about autism that has helped him/her to understand	2	4	6	2	1	11	4
49.	**All I was told about the diagnosis was vague, unclear information**	1		1			4	5	All s/he was told about the diagnosis was vague, unclear information	2	9	4	4	1	7	3
50.	**When I was told I had autism, it made me feel highly confused**	1	1	3			3	3	Finding out about the diagnosis made my child feel highly confused	0	3	9	3	1	7	7
51.	**The doctor/autism specialist helped me to understand the autism, to feel confident in myself and to understand there is no such thing as a 'normal' person**		3	2	1		4		The doctor/autism specialist helped my child to understand the autism.	0	3	3	4	0	10	10
52.	**Reading books written by other people with autism has helped me to understand autism more than anything else**	4	1				5	1	Reading books written by other people with autism has helped my child to understand the autism	1	9	6	5	1	6	3

24.3 Online Survey: After diagnosis-CYP's and parents' scaled responses

KEY	More than 2/3 agree	More than ½ agree

	After diagnosis statements from the CYP survey	Strongly Agree	Agree	Not Sure	Not Relevant	Other	Disagree	Strongly Disagree	After diagnosis statements from the Parents' survey	Strongly Agree	Agree	Not Sure	Not Relevant	Other	Disagree	Strongly Disagree
1	I get more support at school/college	4	3	1	1	1	2	1	Gets more support at school/college	17	5	1	1	1	1	2
2	None, it has not made any difference to me	1	1	2	0	0	3	4	Has not changed at all	4	7	3	3	1	9	4
3	I've been able to access support from a specialist to help me to understand what the diagnosis will mean for me	0	3	2	0	0	7	0	Has been able to access support from a specialist to aid understanding of the diagnosis	6	4	4	4	0	8	4
4	Nothing has changed at home	2	3	0	0	1	6	0	Is just the same at home as they were before the diagnosis	8	9	0	0	2	6	5
5	I feel like I've been labelled, and the label becomes a source of attention	1	1	2	0	0	4	3	Feels that they have been labelled	0	4	8	2	1	6	14
6	I notice all the things that I'm good at and I know that my autism is part of what gives me these strengths	3	2	3	0	1	2	0	Is better at noticing all the things that they are good at and know these strengths are part of the autism	3	9	9	2	1	5	2
7	I feel like I have something to blame for my problems	2	4	1	0	1	2	1	Feel that the autism is the cause of all of their problems	1	2	9	2	1	10	4
8	The teachers/tutors give me more help	3	4	0	1	1	2	1	Gets more help from teachers/tutors	14	4	5	1	0	5	1
9	I understand it now, I know why I'm different and why I get so upset	5	6						Understands why they are different from peers	7	14	6	1	1	2	0
10	I get these negative ideas about myself, I sometimes think I'm never going to achieve anything	5	1	2	0	0	3	0	Thinks negatively about their future	3	5	5	3	4	8	5
	NA								Thinks they are never going to achieve anything	2	5	4	2	2	9	6
11	Now I've accepted it, I realise that it is not the end of the world, it is just a different way of thinking	3	4	1	1	1	2	0	Accepts the diagnosis	10	12	2	2	1	2	1
12	I feel like a valuable individual	3	3	2	1	0	2	1	Feels like a valuable individual	4	10	7	2	1	7	0
13	I feel different but in a good way, I don't want to be just like everyone else	3	3	3	0	1	1	0	Understands that they think differently from peers and that this is the reason for many of their strengths	8	9	7	1	1	5	0
14	It has really helped to boost my confidence	1	3	3	0	1	3	1	Has a greater level of confidence	4	10	5	2	1	6	2
15	My family are much more understanding	2	6	1	0	1	2	1	Is better understood by the whole family	9	16	0	1	1	4	0
16	We do not argue as much	1	2	3	1	1	2	2	Has fewer disagreements with other family members	4	8	3	4	1	9	1
17	I feel that I can be a success and I'm happier in myself	3	3	2	0	1	0	2	Feels they can be a success and are happier	4	8	8	1	2	7	1
18	I know that I think differently and that this is the reason for my strengths	4	4	1	0	1	0	1	Has realised they just have a different way of thinking	9	14	4	2	0	1	0

24.4 Synthesis of themes across the three participant's groups

	CYP Themes	Parent Themes	Professional Themes
Before diagnosis Self-efficacy/self-views Identity Social experiences /awareness School difficult Poor awareness: lack of support Emotional disequilibrium/mental health needs Appropriate strategies/ understanding Language of deficit/disorder Accessing professional support	Self-efficacy Identity Social difficulties School difficult Poor awareness: lack of support Emotional disequilibrium/mental health needs Appropriate strategies/ understanding Language of deficit/disorder	Ability/Difficulties Self-views Social experiences Identity/Difference Feelings Uneven profile Understanding of Autism Diagnosis Support/Understanding **Interview** Differences to peers apparent but misunderstood and stigmatised Parent and child feeling alienated and problematised Lack of professional or family understanding and support Problematic social and emotional experiences	**When and how do they get involved to support understanding of autism diagnosis?** Child struggling and not understanding diagnosis Linked to work about social and emotional development Parents or professionals ask for advice or help with disclosure Commissioned by local authority Interdisciplinary and person-centred discussions Regular multi-disciplinary reviews and family contact enable the topic to come-up when needed Parents and educators not sure how to support children's understanding Anxiety about child understanding of autism and emotional reactions Worries about child's relationships Child lacking understanding of self
Finding out about the diagnosis Identity: negative emotions; comparisons; self-views; acceptance > rejection of diagnosis Range of emotional impacts: relief - disassociation	Relief and understanding Comparison and difference Problematic emotions/disassociation Diagnostic delay Self-views and strategies Levels of acceptance	Diagnostic Processes Resources Explanation & Understanding Engagement Support Skills Impact	Autism is part of the person Having autism is ok What autism is not Difference/brain difference Individuality is good Neurodiversity

	CYP Themes	Parent Themes	Professional Themes
Impact of disclosure processes/experiences: others understanding; support; catalyst for change Factors linked to outcomes: how autism is framed; strategies; CYP engagement; positive focus on skills; peers & role models; other's reactions; support; self-study Understanding/framing autism Disclosure resources & strategies	Researching the diagnosis Impact of disclosure processes	Identity **Interview** Problematic diagnostic processes and child not actively involved Positive disclosure experience and positively focussed explanation CYPs varied engagement Immediate impact positive & negative Framing autism **Tell me about any help your child has received to understand the diagnosis** General/other support rather than specific to understand diagnosis Parent/child supported by charitable group to understand diagnosis No support for child to understand the diagnosis Lack of time/capacity/involvement from professional to explain diagnosis to child Discussion/support for parent re diagnosis Parent provided explanation/support for child's understanding of diagnosis Research about autism undertaken by child Being with peers with autism supports understanding	Different strengths and difficulties Strengths and interests and where these can lead Positive role models-biographies Developmentally and situationally specific Person-centred Based on formative assessment Individualised approach crucial Holistic Knowing the individual Bespoke resource or booklet Information or images of people with autism the child shares an interest with Autism Education Trust videos of positive role models Luke Jackson video Welton (2003) Can I Tell You About Aspergers Evans & Lesko (2014) An Aspie's Guide to Living with Personal Management Issues Been There. Done That. Try This!

	CYP Themes	Parent Themes	Professional Themes
			Vermeulen (2013) I am Special Workbook Social stories Scales linked with contextualised examples Attributes cards Session schedule and cue cards Sorting activities Presentation about the child
After diagnosis Skills and strategies Understanding/expectations of others Diagnosis as a catalyst for change Self-views (awareness/ efficacy/identity) Support/training Peers with autism - role models/friendships Whether to tell others Perceptions of autism Emotional understanding/responses Problematic diagnostic experiences Preparation/readiness	• Improved self-awareness & happier • Lack of support • Peer awareness enabling strategy implementation • Feeling different • Poor social understanding overcome by cognitive strategies • Diagnostic conversation with parent • Diagnosis is not a problem • Positive view of self • Awareness of self-help strategies	Skills and strategies Understanding of others Diagnosis as a catalyst for change Self-views (awareness/ efficacy/identity) • Diagnosis enabled positive change • Needs were met more appropriately • Support became available • Understanding of others improved • Positive impact on young person's skills • No change • Negative impact on young person • Identity • Acceptance of diagnosis/recognised positively	**Factors leading to negative impact** Problematic diagnostic experiences Unexpected autism diagnosis Diagnosis not accepted if parents do not have faith in the process Parents not being supported to understand diagnosis sooner Parents need time to process-readiness Parental support to recognise child strengths Lack of/poor information about autism leading to misunderstanding Training poor quality for professionals Not enough professional understanding of young people's experiences

	CYP Themes	Parent Themes	Professional Themes
	• Lack of understanding/patience by teachers • Coping strategies and self-efficacy • Peer awareness enabling strategy implementation • Home/family=safe place /understanding • Coordination & Energy: the importance of physical activity • Rules and routines as imposed supportive strategies • Coordination & Energy: the importance of physical activity • Diagnosis, difference and inferior • Challenge of diagnosis and feelings of uncertainty • School-support without diagnosis • Diagnosis as a trigger to improve social knowledge • Use of cognitive ability to improve social understanding	• Processing/Disassociation from autism • Others lack of understanding • Problematic emotions • Mistreatment • Parent/own approach to resolve difficulties • Still unable to access correct support • Family support important • Explaining to others/ disclosure • Autism used as excuse • Nature of autism problematic • Ambitions	Lack of immediate support post diagnosis Society view of autism as a deficit Lack of understanding about emotions and processing of people with autism **Factors leading to positive impact** Positive successful role models with autism Positive focus to move forward from Learning from others' experiences Understanding that ups and down are normal life experiences Approach/factors are individual and developmentally appropriate Professional has to have the ability to personalise it Supporting understanding of self as a good person and positive traits is important Recognise challenges related to autism but also that this is ok Ensuring parents and educators understand how to respond to discussion around disclosure Getting the language and communication right: calm and matter of fact Explanation of autism is tailored to the individual

	CYP Themes	Parent Themes	Professional Themes
	• Emotional development, self-awareness and self-efficacy • Disclosure to counter issues with peers • Having to change to fit in with neuro-typical expectations • Improved social understanding leading to improved self-efficacy • Support indispensable • Uncomfortable acceptance • Peer awareness and acceptance • More comfortable relationships with others of similar need • Uneasy balance between disclosure and perceptions • Diagnosis as a trigger for self-improvement • Increased support post diagnosis • Parental support and advocacy • Benefit of sibling understanding		Best practice is built on good relationships, preparation and information from all key people

	CYP Themes	Parent Themes	Professional Themes
	- Relationships with others of similar need - Comparison to others on spectrum - Spectrum relationship supports understanding - Positive relationships - Positive acceptance - Negative impact of conforming - Parental support important - positive understanding		

24.5 Identifying themes from open survey questions from CYP with autism and parents of CYP with autism

Synthesis across participants and colour key (CYP; parents & professionals)	CYP Converging Themes & Broad topics	Parents Converging Themes	Parents Broad Topics	Parental Interview Themes
Before diagnosis Self-efficacy Identity Social difficulties School difficult Poor awareness: lack of support Emotional disequilibrium/mental health needs Appropriate strategies/understanding Language of deficit **Finding out** Relief and understanding Comparison and difference Problematic emotions/disassociation Diagnostic delay	**Broad Topics** I. Self-efficacy = +4 -19 II. Diagnostic catalyst=28 III. Increased awareness and support=29 IV. Identity=21 V. Mental health=9 VI. Resilience builders = 30 **Converging Themes Before diagnosis** - Low self-efficacy /negative self-views - Feeling different - Social Confusion - Lack of knowledge of social hierarchy - Misunderstood by others	**Before diagnosis** 1. Life was difficult (7) =A 2. School was difficult (8) =A 3. Not self-aware (5) =B 4. Seeks isolation (7)= C 5. Social difficulties/bullying (11) = C 6. Feeling inferior/unintelligent (6) =D 7. Comparison/recognition of difference to peers/sibling (15) =D	**Before Diagnosis** J. Ability/Difficulties Pos= 7/Neg=18 K. Self-views Pos= 2/Neg=5 L. Social experiences Pos= 3/Neg=23 M. Identity/Difference Pos=0 /Neg=27 N. Feelings Pos=3 /Neg=29 O. Uneven profile Pos=0 /Neg=3 P. Understanding Autism Pos=8 /Neg=19	**How were things going, generally, for your child prior to the diagnosis?** Differences to peers apparent but misunderstood and stigmatised Parent and child feeling alienated and problematised Lack of professional or family understanding and support Problematic social and emotional experiences

Synthesis across participants and colour key (CYP; parents & professionals)	CYP Converging Themes & Broad topics	Parents Converging Themes	Parents Broad Topics	Parental Interview Themes
Self-views and strategies Levels of acceptance Researching the diagnosis Impact of disclosure processes **After diagnosis** Skills and strategies Understanding/expectations of others Diagnosis as a catalyst for change Self-views (awareness/ efficacy/identity) Support/training Peers with autism - role models/friendships Whether to tell others Perceptions of autism Emotional understanding/responses	• Feeling different • Marginalised • Poor mental health and negative emotions • Importance of the right environment • Negative emotions x2 • Impact on mental health • Regret and disassociation • Negative labelling • Development and improvement • Regret and guilt • School is difficult • Lack of understanding/patience by teachers • Bullying/Social difficulties • Social difficulties/bullying • Lack of understanding • Awareness of difference • Life/School is difficult • Social difficulties/bullying • Anxiety at school **Converging themes-Finding out** Relief that others understood Diagnosis, difference and inferior Lack of understanding of the process Disassociation Disclosure and partial understanding Uncomfortable acceptance Difference Disclosure by professionals and parents Disclosure and the impact of others reactions Negative emotions Diagnostic delay- a challenge to acceptance Disclosure a relief Diagnostic delay	8. Doing things wrong/blame (3)=A 9. Difference (6) =D 10. Differential diagnosis-related to traits (3)=H 11. Pressure to conform/seeking acceptance (2) = D 12. Heightened emotions (11) =E 13. Increasing social difficulties (5)=C 14. Traits problematic/different (4) =D 15. Academically Able vs social difficulties (3) =F 16. Unmet needs/impacting wellbeing/behaviours (9) =G 17. Lack of understanding (4) =G 18. Professional understanding/support (6) =G 19. Diagnosis problematic/delayed (8) =H 20. Late diagnosis (4) =H **Overall Converging Positive Themes (35)** 21. Parent understanding, support/seeking diagnosis (12)=H	Q. Diagnosis Pos=15 /Neg=15 R. Support/Understanding Pos=4 /Neg=2 **Finding out** I. Diagnostic Processes Neg x25 Pos x25 J. Resources Neg x2 Pos x5 K. Explanation & understanding Neg x3 Pos x28 L. Engagement Neg x0 Pos x6 M. Support Neg x12 Pos x5 N. Skills & strategies Neg x0 Pos x14 O. Impact Neg x1 Pos x9 P. Identity Neg x22 Pos x13 **After diagnosis** 5. Skills and strategies Pos=13; 6. Understanding of others Pos=23; Neutral=9; Neg=22 7. Diagnosis as a catalyst for change	**Please tell me about your child's experience of finding out about the autism diagnosis** Problematic diagnostic processes and child not actively involved Positive disclosure experience and positively focussed explanation CYPs varied engagement Immediate impact positive Immediate impact negative Framing autism **Do you feel that other people knowing about the diagnosis has altered the way they have treated or interacted with your child?** Understanding of others remains problematic Positive impact on familial understanding Positive support or impact on professional understanding Lack of support for understanding diagnosis Invisible nature of autism leads to misunderstanding Diagnosis not fully accepted by parents-linked to problematic

Synthesis across participants and colour key (CYP; parents & professionals)	CYP Converging Themes & Broad topics	Parents Converging Themes	Parents Broad Topics	Parental Interview Themes
	Late diagnosis, gender and ability Coping strategies and self-efficacy Life goes on Self-study about the diagnosis beneficial Self-aware, unique and happy Comparison to normal person Diagnostic process draining Disclosure a relief Positive acceptance Self-study about the diagnosis beneficial **Converging themes-After diagnosis** Poor social understanding overcome by cognitive strategies Awareness of self-help strategies Coping strategies and self-efficacy Coordination & Energy: the importance of physical activity Rules and routines as imposed supportive strategies Use of cognitive ability to improve social understanding Emotional development, self-awareness and self-efficacy Peer awareness enabling strategy implementation Lack of understanding/patience by teachers Having to change to fit in with neuro-typical expectations Peer awareness and acceptance Benefit of sibling understanding Positive relationships Negative impact of conforming	22. Confident in own abilities (2)=B 23. Positive peer awareness/acceptance (3)=C 24. Identification increased understanding (4)= G 25. Positive communication re ability/diagnosis (2) =G 26. Professional understanding/support (2)=G 27. Academically Able (5)=A 28. Early Diagnosis (3) =H 29. Improving skills (2)=A 30. Parent Providing explanation/support (4)=I **Feelings attributed to young people** - Stupid x2 - Anxious x2 - Exhausted - Emotionally fragile - Isolated - Distressed x2 - Angry - Frustrated x2 - Struggling - Withdrawn - Thick - Retard - Labelled - Unsettled	Pos=40; Neutral=8; Neg=7 8. Self-views (awareness/ efficacy/identity) Pos=8; Neutral=9; Neg=7 **Anything else** 1. The Diagnosis x23 2. Understanding of others x5 3. Right Advice/information x4 4. Moving on x11 5 Strategies x4 6 Traits x7 7.Support x11 8 Process x3 9. Parenting x2	assessment and concerns about stigma **Tell me about the help your child has received to understand the diagnosis** General/other support rather than specific to understand diagnosis Parent/child supported by charitable group to understand diagnosis No support for child to understand the diagnosis Lack of time/capacity/involvement from professional to explain diagnosis to child Discussion/support for parent re diagnosis Parent provided explanation/suppose for child's understanding of diagnosis Research about autism undertaken by child Being with peers with autism supports understanding **Do you think the diagnosis has altered or impacted upon the way you child feels about him or herself?** Diagnosis a catalyst for positive change

Synthesis across participants and colour key (CYP; parents & professionals)	CYP Converging Themes & Broad topics	Parents Converging Themes	Parents Broad Topics	Parental Interview Themes
	Peer awareness enabling strategy implementation Diagnosis as a trigger to improve social knowledge Improved social understanding Diagnosis as a trigger for self-improvement Improved self-awareness & happier Feeling different Diagnosis is not a problem Positive view of self Diagnosis, difference and inferior Challenge of diagnosis and feelings of uncertainty Uncomfortable acceptance Positive acceptance Lack of support Diagnostic conversation with parent Home/family=safe place /understanding School-support without diagnosis Support indispensable Increased support post diagnosis Parental support and advocacy Parental support important -positive understanding More comfortable relationships with others of similar need Relationships with others of similar need Comparison to others on spectrum Spectrum relationship supports understanding Disclosure to counter issues with peers Uneasy balance between disclosure and perceptions	Negative = 18 • Happy x2 • Confident Positive = 3 **Finding out** **Overall Converging Negative Themes** 40. Diagnostic timescales x6/A 41. Diagnostic process problematic/not explained/not right time x6/A 42. Autism difficult to understand/ explain x2/C 43. Feeling different x10/H 44. Disassociation/disinterest x13/A 45. Conforming x2/H 46. Emotional impact/struggling x1/G 47. Lack of professional support with diagnosis/diagnostic explanation x7/E 48. Comparison to peers x5/H 49. Self-awareness/self-esteem/self-efficacy x5/H 50. No awareness pre-diagnosis x1/C 51. Inappropriate resources/views x2/B 52. Poor peer awareness x1/E		No changes noticed Further support needed to aid understanding Negative impact on view of self Understanding of diagnosis supports positive view of self Being with peers with autism supports understanding Diagnosis linked to strategies/problem solving **Tell me about any extra help your child has had since finding out about the diagnosis** Good support organised or provided by professional No support for family members to understand Lack of support following diagnosis Parental search for support Services pressures & funding issues Improvement in support but still not sufficient Support from family

Synthesis across participants and colour key (CYP; parents & professionals)	CYP Converging Themes & Broad topics	Parents Converging Themes	Parents Broad Topics	Parental Interview Themes
		53. Lack of professional support/understanding x4/E **Overall Converging Positive Themes** 54. Realisation & Relief x7/G 55. Young person included x5/D ~~56. Interest in diagnostic explanation/process~~ 57. Diagnostic catalyst x2/G 58. Parent aware/explained diagnosis x15/C 59. Strategies to support understanding x4/C 60. Advice about explaining x1/E 61. Diagnostic process supportive/accepted x9/A 62. Quality of information/resource x2/B ~~63. Individualised information~~ 64. Books x3/B ~~65. People involved in explanation~~ 66. Diagnosis understood by/explained to others x3/C 67. Engagement with the diagnosis x1/D		**How do you think your child feels about the autism diagnosis now?** No changes noticed Rejection of diagnosis Association with peers with autism supports understanding Understanding of self has improved confidence Problematic view of self/poor self-efficacy Recognises self as different Strengths linked to positive view of self **How do you feel young people with autism could be best helped to understand their autism?** Wanting to know/interest is crucial/right time Peers/role models with autism Linking autism with strengths Understanding the spectrum of needs Understanding linked to strategies/problem solving Right person- a known trusted adult

Synthesis across participants and colour key (CYP; parents & professionals)	CYP Converging Themes & Broad topics	Parents Converging Themes	Parents Broad Topics	Parental Interview Themes
		68. Access to support/specialist supportx4/E 69. Skills and strategies x10/F 70. Comorbid/related needs x1/A 71. Improved skills/ self-efficacy x4/F ~~72. Fitting in better~~ 73. Self-awareness x8/H 74. Explanation/Acceptance over time x13/A 75. Early diagnosis x2/A 76. Focus on positives when discussing autism x6/C 77. Positive comparison to peers x3/H 78. Role models x2/H **After Diagnosis** a-Diagnosis enabled positive change +12 (3) b- Needs were met more appropriately +7 (3) c- Support became available +17 (3) d- Understanding of others improved +20 (2) e- Positive impact on young person's skills +1 (4) f- No change =8 (3) g- Negative impact on young person -2 (4)		Right setting Visual or individualised approaches **What are your child's ambitions for the future?** Positive future ambitions Ambitions linked to strengths/interests Romantic relationship Financial security Work experience and workplace understanding Uncertainties linked to perceived difficulties **Anything else you feel would be useful to share about the diagnosis?** Lack of understanding of female presentation of autism impact diagnostic experiences Family friendly services Importance of recognition of differential development early Timely access to assessment and support Parental frustration with professionals/the system

Synthesis across participants and colour key (CYP; parents & professionals)	CYP Converging Themes & Broad topics	Parents Converging Themes	Parents Broad Topics	Parental Interview Themes
		h- Identity +1 =2 -3 (4) i-Acceptance of diagnosis/recognised positively +4 (4) j- Processing/Disassociation from autism =9 (4) k- Others lack of understanding -19 (2) L- Problematic emotions -3 (4) M-Mistreatment -2 (2) N- Parent/own approach to resolve difficulties =1 (2) O-still unable to access correct support -7 (3) P=family support important +1 (2) Q = Explaining to others/ disclosure =1 -1 (2) R=Autism used as excuse -1 (4) S=Nature of autism problematic -1 (4) T=ambitions +2 (4) **Anything else** **1. The Diagnosis** Invisible nature of those who are able with autism x4 Variable impact of autism x3 Differential diagnosis x5 Need confirmation to accept/understand Diagnostic catalyst for positive change Time to process Related needs become apparent Progress beyond predicted		Positive support from charity sector

Synthesis across participants and colour key (CYP; parents & professionals)	CYP Converging Themes & Broad topics	Parents Converging Themes	Parents Broad Topics	Parental Interview Themes
		Ability highlights inability Not disabled enough Difference and disability The label helps/prevents other labels Diagnosis is helpful Autism an excuse **2. Understanding of others** Poor peer understanding of difference-2 Positive peer relations-2 Poor understanding from professionals **3. Right Advice/information** Useful information but difficult to apply Wading through the information/signposting needed Searching for answers/the right approach Waiting for the lightbulb moment **4. Moving on** Letting go Independence Making progress Independence vs safety Worries about the future-4 Reluctant acceptance Strengths recognized/pride Pride **5 Strategies** Strategies based on strengths- Strategies for success x2 Conforming **6 Traits** Home school separation		

Synthesis across participants and colour key (CYP; parents & professionals)	CYP Converging Themes & Broad topics	Parents Converging Themes	Parents Broad Topics	Parental Interview Themes
		Confidence and familiarity Emotional impact x2 Change difficult Skills Rules **7.Support** Right support difficult to access x7 The right setting Charitable support Professional support for mental health supported acceptance of diagnosis Professional support **8 Process** Poor/Let down x2 Seeking private diagnosis due to lack of understanding **9. Parenting** Parenting is different/difficult Feeling helpless		

24.6 Brief summary of parent interview themes across participants

Question	Parent 1-Mother Rosie Age at interview-6 Diagnosed-6 Disclosure-in the process	Parent 2-Mother Stephen Age at interview-13 Diagnosed-9 Disclosure-a few months later at 10 years	Parent 3-Mother Peter Age at interview-15½ Diagnosed-13 almost 14 years Disclosure-straight away	Parent 4-Mother Robbie Age at interview-15 Diagnosed-4yrs Disclosure-between 10-11years	Parent 5-Mother Jasmin Age at interview-11 yrs 6 months Diagnosed-7 ¾ Disclosure-straight away	Parent 6-Father Michael Age at interview-12 yrs Diagnosed-7 ½ Disclosure-straight away
How were things going, generally, for your child prior to the diagnosis? Differences to peers apparent but misunderstood and stigmatised Parent and child feeling alienated and problematised Lack of professional or family understanding and support Problematic social and emotional experiences	Labelled as naughty-people worry about the label but do humans need a diagnosis to label? Othering goes on without this Parent notice difference from an early age Behaviour is the focus of labelling Awareness of others' observations Problematic reaction to people's attention Difficulty understanding emotions	Felt like an overprotective mother Family problems/house and area move Social difficulties Lack of friends Mother feeling isolated Passive child Parent didn't feel comfortable to join local social opportunities Parental recognition of differential development Problems with processes Parent recognised immaturity Improved with an understanding teacher SENCO unable to fulfil her role-needs not recognised Suggested just immature by professionals	Prior to diagnosis problematic Family trauma caused sudden house move Immediate change in behaviours Mental health needs before diagnosis Secondary transition problematic and experienced bullying School were unsupportive regarding the difficulties Parent worried about labelling and him being judged Extreme anxiety response during cooking due to sensory needs Discussed with school services but they didn't believe parent Masking in school, school didn't recognise issues School dismissive of the issues	Difficult pre-diagnostic experiences Made to feel like a bad parent Differences to other children highlighted by others Parent feeling alienated Mother recognised differences Older family members dismissive of potential needs Mother made to feel identification of need would have negative impact SALT involvement from early age Paediatrician involved Parent recognising difference but hoping it wasn't the case	Going through a bad time at school prior to and when diagnosed Lack of professional understanding Child masking needs Invisible nature of autism/child looking fine so teacher lacked understanding Peers recognized differences/bullying experienced Even when school knew about the diagnosis, they didn't recognize needs due to being a girl with autism Negative view of differences as weird Father not accepting/denial of diagnosis Don't like to play on the diagnosis. Disclosure if needed to support understanding.	Lack of professional recognition of needs Battling for support Child experiencing anxiety Anxiety behaviour misunderstood by professionals Parents felt blamed by professionals Problems with the process and lack of consistency

		Autism information led to recognition of traits in child	Criticised for fine motor difficulties	Focus on educational processes for support rather than needs Generally happy But distressed by certain situations Child's father lacked awareness of needs	Don't want autism to be an excuse or to undermine child's relationships	
Please tell me about your child's experience of finding out about the autism diagnosis Problematic diagnostic processes and child not actively involved Positive disclosure experience and positively focussed explanation CYPs varied engagement Immediate impact positive Immediate impact negative Framing autism	Too young to understand others' views Experiences with medical profession for operations added to anxiety in relation to diagnostic process Assessment linked to problematic behaviours Not interested to discuss afterwards Brain difference Identifies with another young person on the spectrum Explains to others that her brain is different	Problematic diagnostic processes Early professional recognition Lack of explanation of the process Initial assessment didn't provide diagnosis. Parent with Aspergers Involved in diagnostic process/ Not aware of the purpose though Accepted diagnosis straight away Asked questions Never seemed worried about the diagnosis Disclosure shortly after - as dyslexia diagnosis to explain Felt the right time & right information	Positive self-efficacy Nearly fourteen when diagnosed and told straight away. Aware of purpose of assessments Parent highlighted possible autism-based traits at CAMHS appointments	Some support for child to understand the diagnosis as an adolescent Emotional management-linked to autism traits Positive impact on responding to situations	Private diagnosis Child involved in diagnostic discussion Parent explained more at home immediately Didn't understand Film/documentary-Meet Saffron Responsive-similar traits, same gender similar to daughter Difference but just as clever Attentive, asks questions Different processing Xbox/playstation film analogy most useful Relating traits to skills important Discussed diagnosis from beginning Provided visual positive affirmations about strengths	Told him straight after the diagnosis Initial upset Brain difference Identifies difference with others with needs Neurodiversity and difference Ups and downs-child's experiences vary across environment and time

					A shared ongoing process	
Do you feel that other people knowing about the diagnosis has altered the way they have treated or interacted with your child? Understanding of others remains problematic Positive impact on familial understanding Positive support or impact on professional understanding Lack of support for understanding diagnosis Invisible nature of autism leads to misunderstanding Diagnosis not fully accepted by parents-linked to problematic assessment and concerns about stigma	Daughter identified as high functioning Autism is invisible at first Others lack understanding of more subtle presentation Other people’s understanding is continually problematic- even after explanation given. Parental understanding helped by diagnosis Difficulties not recognised as child is placid in school Helpful that staff recognised and understood Support from key member of staff positive impact Parental concern about continuation of support and understanding Comparison to others on the spectrum Recognition of differential presentation of autism	Diagnosis changes everything and this is unexpected when autism is suspected Not a shock but upsetting Mixed feelings about the diagnosis Worried about impact on child of autism being identified But also feels it would have been picked up anyway Wanting to make child’s life easier Relief at first when told about didn’t meet the criteria Cannot be there to protect them all the time Society is the problem Diagnosis not fully accepted by parents-linked to problematic assessment Mother questioning diagnosis due to recognition of others emotions	Sister views diagnosis negatively-- view of ‘labelling’ Feels allowances are made because of diagnosis Blends in at school/masks autism traits Anxiety comes out at home. Sister doesn’t understand changes in his behaviour between school and home. No professional support for sibling understanding Lack of information for young people following diagnosis Mixed response from family to diagnosis Some lack of understanding from extended family Helped other members of the family understand Awareness changes the way his mother interacts with him Parent doesn’t want to label children	Supported mum’s understanding and explanation to others People needed to understand to identify solutions Supported immediate family understanding and approach to support him Less impact at school Outwardly father articulated acceptance Expected conformity though Wanted him to be the same/expected child Father also looked for information Time needed to process Father still struggling to accept diagnosis Some autism awareness training at school A consistent teaching assistant made positive difference Good understanding of his specific needs	At first school professional support/understanding didn’t change after diagnosis Only girl with autism, professionals lacked understanding Environment not supportive School ignored professional advice Anxieties rose and dealt with inappropriately Excluded from primary school Even basic understanding lacking Parent felt school setting her up to fail	Parental concern about labelling Views influenced by professional knowledge Diagnosis useful to access specialist setting Negotiating the emotional conflict acknowledging child’s differences and whether to seek assessment Anxiety behaviour misunderstood by professionals Wanting others to understand Impact of society perception on the child

	Individual nature of autism Support was available before the diagnosis from class TA General support in school rather than specific for her daughter Coincidental that she is educated alongside other with autism	Showing understanding of emotions in people he knows well. Concern about behaviours in front of others		Individualised understanding		
Tell me about any help your child has received to understand the diagnosis General/other support rather than specific to understand diagnosis Parent/child supported by charitable group to understand diagnosis No support for child to understand the diagnosis Lack of time/capacity/involvement from professional to explain diagnosis to child Discussion/support for parent re diagnosis Parent provided explanation/suppose for child’s understanding of diagnosis Research about autism undertaken by child	Focus teaching time offered Individualised approaches offered No support for child to understand the diagnosis Social and emotional strategies offered Fear about consistency of support for the future No suggestion to seek formal assessment of support needs as child identified as academic Parent remains concerned about social and emotional development Parent remains concerned about development in relation to toileting	Lack of time to discuss diagnosis on the day- Not discussed with child Discussion with parent afterwards Discussion of diagnosis with parent initiated by child Recognition of being like his father with Aspergers diagnosis Diagnosis in child easier to accept than husbands’ Seen father’s mental health needs impact him. Mum protects children from father’s mental health needs Child asked if he would be like his dad Seeking mental health support for child to pre-empt problems later. Has had some mental health support.	Child hasn’t been given support from professional to understand the diagnosis Parent able to access support Child asking for advice Parent told none available for child Parents worked out how to tell him themselves Access support through local parent group Child accesses support through local group for social development Child taking positive skills development opportunity Volunteer placement difficult to organise due to sensory needs Volunteers for local group	No support for child to understand the diagnosis Has done own research Being with peers with autism has been supportive Peers have same diagnosis and point of development	No professional support Parents have been open about needs/diagnosis Autism a hidden disability can mean other don’t understand Accessing the same as other children just in a different environment Supportive services in place if needed	Not much involvement in the process In the room but not involved Strengths related to autism traits recognised Friendships are the main concern Use of role play with figures to support understanding Some support from special school Asking for help Social needs continue to be main need and recognized by child Social differences and lack of understanding impact child and family friendships

Being with peers with autism supports understanding	Concern about behaviours Parent feels supported by local charitable group	Experiences frustration and anxiety No support for child to understand the diagnosis Being able to ask questions of professionals would be useful- Some professional advice for parent Parent provided book linked to interests Hearing from a professional might support belief –about positive messages from parent Agency in the process for child suggest to be useful	Agency in deciding-volunteers at group and loves it despite sensory needs Mentors younger children			Lack of understanding support from education A friend on the spectrum=acceptance
Do you think the diagnosis has altered or impacted upon the way you child feels about him or herself? Diagnosis a catalyst for positive change No changes noticed Further support needed to support understanding Negative impact on view of self Understanding of diagnosis supports positive view of self	Parent feels that diagnosis hasn't impacted on her child. No changes noticed Anticipation of support needs in future to understand the diagnosis	Autism often associated with difficulties Negatively impacts self-efficacy Parents encourage recognition of strengths Child links difficulties with diagnosis Parental recognition of difficulties Child recognises difference from peers Physical play differences less obvious	Diagnosis a catalyst for positive change The answer to move forward from Diagnosis not a label a source of understanding Understanding of self supports positive view of diagnosis and self.	Mostly knowledge of his autism diagnosis helps	Autism doesn't occur in conversation for child due to being in a school with other with autism Not them and us, just us Focus is on developing strategies and understanding Occasional discussion of autism to support siblings understanding Autism not a focus for discussion-just accepted part of her identity. Different processing is main focus for understanding.	Recognition of strengths supports positive thinking most: brave, caring and helping others

Being with peers with autism supports understanding Diagnosis linked to strategies/problem solving		Peers are maturing ahead of child This increases child's awareness of differences from peers			Refocusing her on the positives Focus discussion of issues on problem solving Can get negative about self on a bad day-parent needs to be there to 'catch the fall'	
Tell me about any extra help your child has had since finding out about the diagnosis Good support organised or provided by professional No support for family members to understand Lack of support following diagnosis Parental search for support Services pressures & funding issues Improvement in support but still not sufficient Support from family	No support for siblings to understand the diagnosis also considered important. Siblings misunderstand behaviours Lack of understanding causes upset Siblings find behaviours difficult to understand Siblings view different approaches as parental favouritism Difficult to explain to siblings. No support to help other family members to understand Extended family find diagnosis difficult to understand/accept Invisible nature of autism means others lack understanding	Further diagnosis being sought No support for child until he was eleven Parent has to seek support Lack of funding impacts provision-Concern that publication of services might increase demand Having to fight for services Professionals are stretched and make parents aware. Professionals under pressure	Good professional support for anger –management-visual and tailored to his needs. Emotional management much improved-Can now discuss his feelings Doing well at school Some changes in school since made aware of diagnosis but parent feels not consistent Memory and attention is problem and unsupported in school Solution suggested problematic In the process of looking at new strategies SENCO now supportive Improvement happening but still not consistent	No support Confident in his mother's support Confident that the support will be there. Previous experience supports this. Naïve about future realities Secondary school professionals tried to support	Close family bonds Understanding enable adjustments within interactions Extended family supportive Child unaware of father's views Father makes adjustments in activities to engage child	Support services lacking

	Lack of understanding impacts wider family acceptance Lack of support/information for siblings and wider family to support understanding		Access arrangements to be provided for exams Mixing with others with similar diagnosis is perhaps supportive for him			
How do you think your child feels about the autism diagnosis now? No changes noticed Rejection of diagnosis Association with peers with autism supports understanding Understanding of self has improved confidence Problematic view of self/poor self-efficacy Recognises self as different Strengths linked to positive view of self	Doesn't know fully about diagnosis Parent feels that diagnosis hasn't impacted on her child. No changes noticed	Empathy is shown by child to others with same needs Child doesn't want others to know about diagnosis Peer issues Child horrified at the thought of Asperger disclosure to peers Positive recognition of peers with similar needs Child beginning to recognise traits in others Identifies with dad's needs Identified lack of understanding in those without diagnosis Low self-esteem continues Academic is better but variable	Mixing with others with similar diagnosis is perhaps supportive for him Positive role model through volunteer work Therapy support has been good. Parent has attempted to discuss diagnosis but not interested Diagnosis is viewed as a positive difference by child, a strength Relaxed about who he is now Socially becoming more confident Relaxed about who he is now Socially becoming more confident More outgoing	Mostly knowledge of his autism diagnosis helps Being with peers with autism has been supportive Peers have same diagnosis and point of development	Can get negative about self on a bad day Being there to 'catch the fall' Focus discussion of issues on problem solving. Refocusing her on the positives	Strengths recognized but not built on by school- Strength-a way with animals Child discusses future career linked to strengths

		Better when able to use computer for English Seeing he can do it improves self-view/self-efficacy Different interest to peers	Has friends at school More self-confident			
How do you feel young people with autism could be best helped to understand their autism? Wanting to know/interest is crucial/right time Peers/role models with autism Linking autism with strengths Understanding the spectrum of needs Understanding linked to strategies/problem solving Right person- a known trusted adult Right setting Visual or individualised approaches	Visual support is anticipated to be helpful. Inquisitive/asks questions and full answers required. She has to be interested to pay attention. Fine with adults outside of family once she has relationship with them. Communication with people not known can be problematic The right person will be important	Professional to answer questions But perhaps not the right people to help Not in a clinical setting-in the home Peer awareness raising useful Video of children the same age used to support understanding Support to understand the range of autism needs Gender difference less helpful though Positive role models useful-cool role models	Would need to tailor work about diagnosis to individual Like the 10 week parent course would be useful An abridged version of the parent course-tailored for young people Important to discuss differences and how to manage them Awareness no good without the strategies, that is what child asked for Positive role model linked to academic strengths Recognising the strengths related to autism diagnosis	The time is right Diagnosis at the right time developmentally When diagnosis early no later follow up for understanding Explanation about diagnosis left to the family. Sometimes parent programmes are not early enough	Positive school and respectful educators make key difference Good academic and social and emotional support at school	Autism only comes up when difficulty experienced Autism as a reason/excuse so problem solving as focus of discussion Autism cafe triggers discussion of own traits. Child’s perception of own traits impacting others – compounded by difficulty reading emotions Continual family support to understand autism and self Use of video sharing experiences of a person with autism Understanding of self through recognition of similar traits presented differently Specific incidents provide opportunity to discuss autism in context

							Feeling the need to meet people stereotyped understanding Awareness of stereotyped views
Tell me about your child’s ambitions for the future. Positive future ambitions Ambitions linked to strengths/interests Romantic relationship Financial security Work experience and workplace understanding Uncertainties linked to perceived difficulties	Positive future ambitions Ambitions link to interest Perhaps some awareness of relationships being difficult? Recognition of positive autism traits that are also strengths for Rosie	Has positive future ambitions Needs to be interest based to motivate Education and structured appreciated Things he is confident about/has high self-efficacy with Emotional and communication issues still cause difficulties Parent anticipates ongoing improvement Doing well boosts his wellbeing Embarrassed by handwriting Wants romantic relationship Wants financial security-Interested by high earnings On bad days negative about future	Positive future ambition to be an architect Opportunity for good work experience Interests drive ambitions	Trying to help him find a pathway for his skills Different skills not recognised A pathway for his skills and strengths Concern about understanding in the workplace Nurtured Trying to balance developing experience with protection due to vulnerabilities	NA- Uncertain	Owning a reptile shop A strength-child has a way with animals Child discusses future career linked to strengths Recognition of building on strengths to support success

		Worries about family difficulties impacting his outlook/ambitions Wants to change policy. Wants to tell politicians about issues Changing ambitions Lacks autonomy - Parents still worry about independence and problematic behaviours				
How might other young people be encouraged to participate in research to share their views?	Children more likely to volunteer if friends do Understanding exactly what is being asked is important Once activity understood, more willing to volunteer Knowing the person is important	Understanding the outcome Knowing he will be listened to Agency to contribute Doing it a way that works for the child	Young people might be motivated by an incentive to take part Survey was too difficult Getting the context right is important Right time and an incentive important Accepting of support and professionals Needs to be interest motivated to take an interest Visuals to support emotional vocabulary	NA	NA	NA
Anything else you feel would be useful to share about the diagnosis? Lack of understanding of female presentation of autism impact diagnostic experiences	Lack of understanding of female presentation of autism impact diagnostic experiences Services and training aimed at boys	Earlier professional support would have been useful for parents Don't want to be judged by professionals The diagnostic process is difficult to navigate	Diagnosis a positive difference	Left to family to develop his resilience and understanding Would benefit from professional support Neutral view beneficial at times	Not having to endure the lack of understanding Nightmare school experience Understanding and empathy needed earlier	Lack of services are the main concern The future-what happens if parents not there? Wanting others to understand

Family friendly services Importance of recognition of differential development early Timely access to assessment and support Parental frustration with professionals/the system Positive support from charity sector	Timing a factor-family friendly services Even charity-based information is aimed at boys Teacher didn't recognise autism due to lack of understanding of female presentation Training specifically about girls made a positive difference Teacher later able to make the link to examples provided at subsequent training Previously understanding was experience based on male presentation More awareness needed for professionals about girls and autism Diagnostic professional knowledge of more difficult to diagnose in girls Personal autism diagnostic experience positive, despite female presentation Parental recognition of differential development early	Passing between services is problematic Holistic assessment needed Early recognition to avoid the child failing Still mixed feelings about the value of the diagnosis Recognition from professionals of differences not early enough. Not getting support can impact long term Not the early diagnosis that it is important but the support coming with the diagnosis. It all needs to happen earlier and together-a more joined up assessment system More support needed Professionals need more empathy Professional attitudes cause stigma Negative attitudes from professionals problematic for child self esteem		Impacts willingness to engage with strategies Significance of impact on parent perhaps not understood Grief for parent No support to deal with the emotions Need time to process Diagnosis given by letter No preparation for parents for emotional impact Counselling would be useful for parents Tough trying to identify solutions Leaflets are not enough As a teacher, understanding better than many parents	Early negative experiences/lack of understanding can negatively impact mental health	Providing an insider perspective Strengths related to autism traits recognised Impact of society perception on the child

		Professionals should focus more of positives to support children's positive self-esteem Advice from charity sector useful Advice from parent about managing child not acted on by professionals Parental frustration with the system				

Appendix 25 A brief research summary for parents and professionals

Children and young people's experiences of an autism diagnosis: what do we know and how can we support their understanding of autism?

Acknowledgements

This research summary briefly outlines key learning from a series of systematic literature reviews and research undertaken during my PhD studies. This summary has been compiled to inform those who participated in the study about the research outcomes. I am grateful to all participants who shared their enlightening personal and professional stories. I would also like to acknowledge the researchers of the papers reviewed for their dedication to ensuring that the views of children and young people with autism and their parents are heard. The professionals who participated were also immensely generous in sharing their experiences and advice about discussing autism with children and young people. Thank you.

Introduction

Autism is neurodevelopmental in nature, with differential development experienced in the areas of social communication and information processing, which can present in people with a range of communicative and intellectual skills (World Health Organization, 2018). Literature suggests that an autism diagnosis can have positive and negative psychological ramifications, which range from improvements in self-esteem (Jones, 2001) to extreme depression and even suicidal feelings (MacLeod and Johnston, 2007).

The overall aim of this study was to understand the impact of autism diagnosis for children and young people (CYP), through the perspectives of those most closely involved in the experience, to identify factors that are most likely to influence a positive impact. This summary presents two key strands of research related to this aim, the first strand involved a systematic exploration of the literature, the second strand employed a mixed-methods research study.

Strand One: The systematic literature reviews

For strand one, three systematic reviews were undertaken, in line with the PRISMA protocol (Moher et al., 2009), to explore the existing evidence base about the perspectives of the key stakeholders in the diagnosis of autism in children: CYP with an autism diagnosis; parents of children with an autism diagnosis; and professionals involved in diagnosis and post diagnostic support. The papers meeting the search criteria included eleven papers informed by the views of CYP about their diagnostic experiences; seven papers that explored parental views about their children's diagnostic experiences; and eleven papers that explored professional's views about sharing an autism diagnosis with children and their parents. With one exception, the papers explored this topic using qualitative methods, therefore, the findings from the qualitative studies were synthesised using thematic analyses across the papers related to each of the key stakeholders.

Strand One: Findings

A common theme identified by all three key stakeholders is the impact of the autism diagnosis on CYP's self-identity, which was especially influenced by their social experiences and the communication they heard about autism. There was agreement in the literature that it was parents who were more likely to support children's understanding of the diagnosis than professionals, and that discussion of an autism diagnosis with CYP should include a focus on their key strengths related to autism diagnostic traits.

Strand Two: A mixed-methods study

The views of the same three key stakeholders were collected for strand two through a mixed-methods study, which utilised online surveys and interviews. This aimed to enable CYP's experiences of learning about their autism diagnosis to be understood in relation to the conversations and interactions that parents and professionals had with them. Participation was lower than anticipated, overall, twelve CYP with an autism diagnosis participated; thirty-five parents and fifteen professionals. Fortunately, those who participated provided rich accounts of their experiences related to how CYP learn about and develop their understanding of autism diagnosis, and about their experiences related to autism.

Strand Two: Findings

Although there was some variation about the impact of the diagnosis, most CYP with autism and parents of CYP with autism, identified that post-diagnostic experiences were more positive than experiences before the diagnosis; furthermore, knowing about the diagnosis appeared to be a resilience boosting experience for some young people, as the new knowledge about their diagnosis enabled them to make connections with strategies suggested by others, or with strategies they identified for themselves. Parents' and professionals' views about disclosure were aligned, suggesting that discussion of diagnosis should be developmentally tailored for the individual, it should focus on strengths related to autism, which are contextualised to the individual's experiences. Positive role models with autism were also highlighted to support positive perceptions. The findings highlight that, in addition to positive conversations about the diagnosis, processing and coming to understand what an autism diagnosis means for the CYP is a process that takes time, which is best supported by ensuring that the social contexts that CYP experience, at the point of diagnosis and beyond it, reflect a positive understanding of the differences that are experienced in relation to autism.

What this study findings suggest will best support CYP to develop a positive understanding of their autism diagnosis

Drawing on the perspectives of the key stakeholders involved in an autism diagnosis for CYP enabled a comprehensive insight to be gained. In addition to the general overview provided by the responses to the main survey statements, the participants who took part in the online surveys and the interviews for this study provided rich accounts regarding children's learning about their autism diagnosis. Together, these differing perspectives enabled a holistic understanding of children's and young people's experiences in relation to an autism diagnosis, and about how parents and professionals can support CYP to understand their diagnosis.

As identified by parents in the study by Crane et al. (20019), the findings from this study suggest that, for CYP with autism, learning about an autism diagnosis is a process that takes time, which is influenced by many conversations and experiences. These findings are supported by the previous research related to CYP with autism (Huws and Jones, 2008); parents of CYP with autism (Cadogan, 2015; Rossello, 2015) and professionals who work with them (Nissenbaum, Tollefson and Reese, 2002; Jacobs et al., 2018). The views of the study participants highlighted key points of social interaction between CYP with autism and others, which can be of influence when CYP are learning about their diagnosis. The findings also point to the key role of professionals at each stage during CYP's diagnostic journey; these crucial points of influence show where parents and professionals could positively or negatively influence CYP experiences and perceptions of their autism diagnosis.

Before diagnosis, children described feeling different and of struggling to understand their differences. Parents discussed how other people did not understand their child's differences, this led to problematic experiences for CYP and to parents feeling judged by others, because of the differences in development that their child displayed. As a result of their experiences, before diagnosis, CYP with autism described poor self-efficacy and mental wellbeing due to problematic learning experiences and social interactions, especially with peers. These problematic social experiences were also identified by the parents within this study and within the literature (Baines, 2012; Huws and Jones, 2008; Jones et al., 2015). Parents also discussed raising concerns about their child's development with teachers and other professionals, however, their concerns were not taken seriously because professionals did not recognise the difficulties their children were experiencing. A lack of understanding from family members, professionals, and the child's peers had an impact on both parental wellbeing and CYP's wellbeing. Therefore, CYP with autism and parents of CYP with autism, often experience the autism diagnosis within a problem context, as also highlighted (Gaffney, 2017). Across the three key stakeholders, these findings point to the significance of interactions with others, to shape outcomes in relation to having autism and learning about an autism diagnosis, which are supported by the findings relating to parental perceptions, and those of professionals. When these key stakeholders' views are considered alongside the wider research about issues such as self-efficacy (Flammer, 2001), autism and identity (Cooper, Smith and Russell, 2017); and peer awareness (Campbell et al., 2004; Smith and Williams, 2005; Campbell and Barger, 2011), possible factors are illuminated that might explain the experiences described by CYP and their parents within this study.

The parents and professionals who participated in this study advocated a positive strengths-based approach when discussing autism with CYP with autism and their parents, which is also advocated in wider research exploring parents (Crane et al., 2019) and professional's views (e.g. Bartolo, 2002; Gray, Msall and Msall, 2008; Jacobs et al., 2018). However, the professionals who participated in this study were mostly specialists in autism and might therefore be expected to advocate this positive good practice. Research studies that consider the perceptions of professionals with a wider range of relevant roles, but with less specialist knowledge of autism, tended to use deficit-focused language in their reports and their communication with parents (Nissenbaum, Tollefson and Reese 2002; Braun, Dunn and Tomcheck, 2017). Therefore, some parents might experience explanations about their child's autism diagnosis, which are negatively focused.

This study, like that of Crane et al. (2019), identified parents as the main sources of information for the child about their autism diagnosis. Therefore, if parents base their explanation on those provided by professionals, which focus on negatively focused language related to diagnostic criteria, it is likely that explanations of autism for some children will also draw on negatively focused explanation. Furthermore, as the NICE (2011b) clinical guidance for diagnosis of autism advocates inclusion of the children within the diagnostic conference, children might also hear deficit focused explanation from professionals (Nissenbaum, Tollefson and Reese 2002; Braun, Dunn and Tomcheck, 2017). Some parents in this study, and the wider literature (Lutz, Patterson and Klein, 2012), describe responses such as grief, guilt, anger and disappointment upon learning about their child's diagnosis. If children are present at this time, their observations of such reactions in their parents, as highlighted by a few children in this study, might influence the perceptions of autism that they take forward from this experience.

Following the autism diagnosis, most participants indicated improved understanding by others, including by peers (Campbell, 2004). These improved social experiences, combined with better understanding of self that learning about the diagnosis brought (Jones et al., 2015; Crane et al., 2019) appeared to boost their self-efficacy (Flammer, 2002). This improved self-efficacy led to increased agency and engagement with self-help strategies (Cadogen, 2015; Mogensen and Mason, 2015), which provided a boost to CYP's resilience and their general wellbeing (Cooper, Smith and Russell, 2017). However, as also identified by Huws and Jones (2008), while most young people described improvements following the diagnosis, some participants discussed themselves and their diagnosis less positively. As suggested by Mogensen and Mason (2015) and Flammer (2002), when CYP's views about autism and themselves were less positive, they were more likely to view the diagnosis negatively. Views shared by parents and professionals for this study, also highlight CYP's problematic interactions with peers, linked to lack of peer awareness, which can influence negative self-perceptions (Smith and Williams, 2005; Campbell and Berger, 2011). Furthermore, as highlighted by Whitaker (2006), negatively focussed discussion and language related to autism diagnosis can influence CYP to develop negative perceptions of autism (Huws and Jones, 2008), which can lead to lower self-efficacy (Flammer, 2001).

What this study suggests is important for positive outcomes for children with an autism diagnosis before they are diagnosed

The findings from the CYP with autism, parents of CYP with autism, and the professionals who work with them, point to a range of factors that might positively impact children's experiences of an autism diagnosis, and the way they are supported to understand the diagnosis, these are:

- Early identification, supported by more training for professionals across childhood services, to improve understanding about the range of ways that autism might present in individuals.

- Improved peer awareness of autism, or neurodiversity more generally, which could be supported by the development of good quality diversity and equality teaching and learning materials for all school children. Materials that follow a spiral curriculum to ensure regular engagement with the topic and progression to develop understanding across childhood are likely to be most effective.
- Autism friendly educational environments, facilitated through training for professionals about strategies and adjustments than can be implemented when developmental differences are identified, to ensure that early years, school-based and other childhood settings are inclusive.
- Good signposting to sources of good quality information, support, and guidance for parents of children demonstrating differential development

What is important to improve positive outcomes during the diagnostic process?

- Better preparation of parents about the process and the emotions they might experience when their child receives a diagnosis (and if they do not). This should include information to help them to consider whether they will be emotionally ready for the child's inclusion in the meeting when they are first told the outcome of the assessment.
- Guidance for parents with children undergoing assessment about support they might access and strategies they might implement for children with social communication difficulties, this should include the importance of positive communication about the child's strengths and regular praise.
- Professional communication with CYP about the purpose of assessment, which is appropriately differentiated to the CYP's development.
- Professional guidance for parents and/or communication with CYP about the autism diagnosis, which is appropriately differentiated and focusses on the strengths that are identified during assessment, as well as immediate guidance about how the child might make improvements in relation to any difficulties that are identified.

What is important to positive outcomes when parents and professionals are communicating with children about their autism diagnosis?

- Parent and child emotional readiness for discussion of autism.
- When a professional is involved, time to develop a relationship with the young person, and to develop understanding of their strengths, interests, and their needs.
- A person-centred approach to ensure explanation about autism is developmentally appropriate and draws on specific contexts and interests related to the individual.
- Preparatory work, before disclosure of the diagnosis, to the help the CYP understand that difference is a positive facet of human development and that diversity is positive (If a child is not developmentally ready to learn about autism, this could be a focus of support until they are ready).
- An approach for discussion of autism that employs a strengths-based focus that draws on positive role models, which makes links between the individual's strengths and their specific interests.
- An emphasis on problem-solving, when discussing the differences in development, and challenges that young people experience related to their autism diagnosis.
- Calm, clear delivery of information about autism (Parents and professionals might benefit from preparing a script of key points they wish to say, including how key points will be phrased).
- Developmentally appropriate approaches for the individual, such as: visual prompts to support communication of key ideas, visual prompts to provide a structure; a list of discussion points; and emotional scales to support discussion of feelings.
- Information for parents and CYP about appropriate websites, blogs, documentaries, or books that contain accurate, positive information about autism and/or positive role models with autism.
- Parents should be included in sessions when diagnosis is delivered by a professional, and information should be shared with the child's setting, to

ensure consistent information and views are shared with the young person.

What is important to positive outcomes beyond the diagnosis?

- The opportunity for the child or young person to revisit information, to ask questions, and to raise uncertainties with a trusted adult, who is aware of the information that has been shared with the child.
- Signposting to further good quality information, support, and guidance.
- Support for the young person's social and emotional development
- Good signposting and referral systems should further professional support be needed.

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Other sources of information and guidance

National Autistic Society Guide (no date) *A short guide to this complex condition and how the National Autistic Society can help*. Available at: https://www.autism.org.uk/shop/products/books-and-resources/understanding-autism-leaflet (Accessed 17 August 2020).