

AUTISM SPECTRUM DISORDERS, FAMILY LIFE AND SHORT BREAKS: AN  
INVESTIGATION INTO THE EXPERIENCE OF FAMILY LIFE AND SHORT BREAKS  
OF FAMILIES THAT HAVE CHILDREN WITH AUTISM SPECTRUM DISORDERS IN  
AN ENGLISH COUNTY

By

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## **Abstract**

Research was undertaken in an English shire county, investigating the experience of families that have children with autism spectrum disorders (ASD) regarding daily life and their attitudes and experience concerning short breaks ('respite care'). The research comprised three phases: a postal survey of 256 families, a survey of 27 social workers, and semi-structured interviews carried out with mothers, fathers, siblings and children with ASD from 14 families.

The research identified the significant impact of ASD on family life. Differing key themes emerged within mothers', fathers', siblings' and children with ASD's narratives. Benefits and shortcomings of short breaks were identified and quality indicators were suggested in a number of key areas: organisational, environmental, staff-, child- and family-related and psychological. Factors associated with short breaks use included family attitudes and values, information, service shortfall, family adaptation, child's age, diagnosis and school placement and allocation to a social worker. Social workers were identified as having inconsistent and at times incorrect understandings of ASD; the factors associated with access to services were mediated by the views of the social worker involved. An interactive, systemic model, derived from the analysis, is suggested as helpful in understanding interplay between families, social workers and service providers.

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## Table of Contents

<b>1.</b>	<b>Introduction to the thesis .....</b>	<b>1</b>
1.1.	Introduction .....	1
1.2.	Rationale and researcher's background .....	2
1.3.	Overall aims of the research .....	4
<b>2.</b>	<b>Review of the literature .....</b>	<b>9</b>
2.1.	Family systems theory: an overview .....	9
2.1.1.	Origins of systems theory .....	9
2.1.2.	The family system .....	11
2.1.3.	Family structure .....	12
2.1.4.	Family interaction .....	15
2.1.5.	Family functions .....	17
2.1.6.	Development over time .....	19
2.1.7.	Modes of family adaptation .....	21
2.1.8.	The social ecology model – the family in context .....	24
2.1.9.	Criticisms of family systems theory .....	26
2.2.	Reviewing the literature .....	28
2.3.	Review of the literature regarding the impact of ASD on the family .....	29
2.3.1.	Living with a child with ASD .....	29
2.3.2.	What helps families cope? .....	33
2.4.	Review of the literature regarding short breaks .....	36
2.4.1.	Short breaks: an overview .....	37
2.4.2.	Short breaks and families of children with ASD and other developmental disabilities .....	42
2.5.	Critical Review of research literature .....	45
2.5.1.	The impact of ASD upon families .....	46
2.5.2.	Focus on parental experience and needs in studies of short breaks .....	47
2.5.3.	The views of children with ASD about short breaks .....	48
2.5.4.	Lack of whole family focus .....	51
2.5.5.	Lack of the service-provider's perspective .....	51
2.5.6.	Quality in short breaks for children with ASD .....	52
2.5.7.	Methodological concerns .....	54
2.6.	What do we need to know? The research questions .....	56

<b>3.</b>	<b>Overall methodology and research design .....</b>	<b>58</b>
3.1.	Epistemological and theoretical underpinnings.....	58
3.2.	Linking theory and methodology .....	61
3.3.	Combining methods: the overall research design.....	65
3.3.1.	Case study.....	65
3.3.2.	Combining methods.....	66
3.4.	Outline of the research project.....	68
3.5.	Ensuring reliability, validity and trustworthiness.....	71
3.6.	Generalisability.....	73
<b>4.</b>	<b>Survey of families with children with ASD .....</b>	<b>75</b>
4.1.	Families with children with ASD, family life and short breaks .....	75
4.2.	Outline of method.....	76
4.2.1.	Description of sample.....	76
4.2.2.	Survey instrument.....	76
4.2.3.	Survey design .....	77
4.2.4.	Methodological considerations.....	78
4.2.5.	Question design .....	80
4.2.6.	Actions to maximise response .....	82
4.2.7.	Pilot study .....	83
4.2.8.	Main survey .....	85
4.2.9.	Data analysis.....	87
4.3.	Results .....	89
4.3.1.	The child with ASD.....	90
4.3.2.	The family .....	92
4.3.3.	Dependence level of the child with ASD .....	93
4.3.4.	Child's behaviour .....	100
4.3.5.	Informal support .....	102
4.3.6.	Formal support.....	103
4.3.7.	Future needs.....	109
4.3.8.	Attitudes towards short breaks .....	110
4.3.9.	Testing the hypotheses .....	113
4.4.	Analysis .....	114
4.4.1.	Comparing the dependence level of children with Robinson and Stalker's study .....	114
4.4.2.	Variation between users and non-users of short breaks .....	115
4.4.3.	Factors associated with use or non-use of short breaks.....	116

4.4.4.	The attitudes of non-users towards short breaks .....	119
4.4.5.	High dependence within users and non users.....	122
4.4.6.	‘Re-slicing’ the cake: considering those families that do not wish to use services, those that use services and non-users by default .....	122
4.4.7.	Factors associated with families’ identification of needing short breaks.....	124
4.4.8.	Attitudinal differences between families that accessed short breaks, those that wished to access short breaks and those that did not wish to use such services .....	126
4.4.9.	Factors associated with the use or non-use of short breaks where families wish to access such services .....	128
4.5.	Discussion.....	132
<b>5.</b>	<b>Survey of social workers .....</b>	<b>137</b>
5.1.	Introduction and research questions addressed .....	137
5.2.	Reviewing the literature.....	138
5.2.1.	Social work and disabled children.....	138
5.2.2.	Research from other professions .....	142
5.2.3.	Implications .....	143
5.3.	Accessing services for disabled children and their families within the local authority in the study .....	144
5.4	Outline of method.....	146
5.4.1.	Sample group.....	146
5.4.2.	Survey instrument.....	147
5.4.3.	Survey design .....	147
5.4.4.	Undertaking the survey.....	151
5.5.	Results .....	153
5.5.1.	Causes of ASD .....	153
5.5.2.	Diagnosis .....	154
5.5.3.	General understanding of ASD.....	155
5.5.4.	Characteristics of ASD .....	155
5.5.5.	Treatment of ASD .....	156
5.6.	Analysis .....	158
5.6.1.	Factual inaccuracies.....	158
5.6.2.	Confusion about the characteristics of ASD.....	160
5.6.3.	Confusion about scientific terminology .....	163
5.6.4.	Attitudes towards methods of service delivery.....	163
5.7.	Discussion.....	165

<b>6.</b>	<b>The family interviews .....</b>	<b>168</b>
6.1.	Reviewing the literature.....	169
6.1.1.	Interviewing families.....	169
6.1.2.	Ascertaining children's views .....	172
6.1.3.	Ascertaining the views of children with ASD .....	175
6.2.	Outline of method.....	179
6.2.1.	Data collection.....	179
6.2.2.	Interview schedules .....	182
6.2.3.	Ethical considerations.....	184
6.2.4.	Coding .....	186
6.2.5.	Accessing the families .....	187
6.2.6.	Trialling and piloting.....	188
6.2.7.	Data collection process.....	189
6.2.8.	Data analysis.....	194
6.3.	Family life .....	197
6.3.1.	Experience of family life – mothers .....	197
6.3.2.	Experience of family life – fathers .....	204
6.3.3.	Experience of family life – siblings without ASD .....	208
6.3.4.	Experience of family life – children with ASD.....	212
6.4.	Informal support .....	216
6.5.	Formal support: social workers .....	218
6.5.1.	Uncertainty about role .....	218
6.5.2.	Stigma.....	219
6.5.3.	High turnover.....	220
6.5.4.	Variability of service .....	220
6.6.	Formal support: short breaks .....	222
6.6.1.	Factors associated with use.....	222
6.6.2.	Factors associated with non-use .....	224
6.6.3.	Contact with services.....	226
6.6.4.	Functions of short breaks.....	227
6.6.5.	Positive and negative factors: families .....	230
6.6.6.	Positive and negative factors: children with ASD.....	237
6.6.7.	Service shortfall and areas for development.....	241
<b>7.</b>	<b>Answering the research questions.....</b>	<b>247</b>
7.1.	What can we learn of whole families' experiences of living with ASD?.....	247
7.1.1.	Family composition .....	248
7.1.2.	Parental employment .....	248
7.1.3.	The child with ASD's dependence .....	248
7.1.4.	The need for and availability of support.....	249
7.1.5.	Range of experience .....	250



7.1.6.	Difference of experience between family members .....	251
7.2.	What can we learn of whole families' attitudes to and experience of short breaks? .....	254
7.2.1.	Shortfall in service availability .....	254
7.2.2.	Families' stated reasons for short breaks use and non-use .....	254
7.2.3.	Functions of short breaks .....	255
7.2.4.	Positive attitude towards ASD-specific services .....	256
7.3.	What factors are associated with quality in short breaks by whole families? .....	257
7.3.1.	Generic quality indicators in short breaks .....	258
7.3.2.	Quality and ASD .....	260
7.4.	What factors – within and outside the family – are associated with whether or not families access formal support through short breaks? .....	265
7.4.1.	Hypotheses from the literature .....	265
7.4.2.	Range of factors .....	268
7.5.	Systemic factors and short breaks .....	268
7.5.1.	Family structure .....	269
7.5.2.	Family interaction .....	276
7.5.3.	Family functions .....	279
7.5.4.	Family adaptation .....	279
7.5.5.	Family life cycle .....	283
7.5.6.	The family in context .....	283
7.6.	Families and their social workers: different understandings of short breaks? .....	284
7.6.1.	Short breaks in legislation .....	285
7.6.2.	Perceptions regarding different models of service delivery .....	286
7.6.3.	Cost and availability .....	288
7.6.4.	Differing perceptions of social workers and families .....	289
7.6.5.	The family and short breaks providers .....	290
7.7.	Towards a model for understanding short breaks use and non-use .....	290
<b>8.</b>	<b>Concluding comments .....</b>	<b>298</b>
8.1.	To what extent have the research questions been answered? .....	298
8.2.	How much confidence can be placed on these findings? .....	303
8.3.	Original contribution .....	304
8.3.1.	Contribution towards understanding of family life in families affected by ASD .....	305
8.3.2.	Contribution towards understanding of factors associated with short breaks use and non-use .....	305

8.3.3.	Contribution towards understanding of quality indicators in short breaks services for families with children with ASD .....	306
8.3.4.	Contribution towards understanding of social workers' perceptions of ASD .....	306
8.3.5.	Contribution to the knowledge base regarding methods of consulting with children with ASD .....	306
8.4.	Things I would have done differently.....	307
8.5	Challenges and key areas of learning .....	308
8.5.1.	Problems on the way .....	308
8.5.2.	Developing the research tools with parents .....	310
8.5.3.	Consultation with children with ASD .....	310
8.5.4.	Conducting research interviews .....	312
8.6.	Areas for further research .....	313
8.6.1.	Researching within a different population .....	313
8.6.2.	Researching the service provider's perspective.....	314
8.6.3.	Researching the impact of short breaks on family stress.....	314
8.6.4.	Research into coping strategies of the three subgroups.....	314
8.6.5.	Testing the model .....	315
8.7	Postscript .....	315
8.7.1.	Developments in social care .....	316
8.7.2.	Short breaks in context .....	318
8.7.3.	The importance of assessment.....	319
8.7.4.	Underpinning principles .....	320
<b>References.....</b>		<b>322</b>
<b>Appendices .....</b>		<b>350</b>
<b>1.</b>	<b>Research Timeline .....</b>	<b>350</b>
<b>2.</b>	<b>Letter to parents of children with ASD .....</b>	<b>353</b>
<b>3.</b>	<b>Questionnaire for parents of children and young people with autistic spectrum disorder.....</b>	<b>354</b>
<b>4.</b>	<b>Questionnaire for social workers .....</b>	<b>361</b>
<b>5.</b>	<b>Family interview schedules.....</b>	<b>366</b>
<b>6.</b>	<b>Family interviews: initial codebook .....</b>	<b>371</b>

<b>7.</b>	<b>Family interviews: first letter to survey respondent .....</b>	<b>373</b>
<b>8.</b>	<b>Family interviews: letter to older child with ASD .....</b>	<b>375</b>
<b>9.</b>	<b>Family interviews: letter to younger siblings .....</b>	<b>377</b>
<b>10.</b>	<b>Ascertaining the views of children with ASD: practicalities and problems .....</b>	<b>380</b>
	A10.1. Introduction .....	380
	A10.2. The children .....	381
	A10.3 Issues regarding consent .....	382
	A10.4. Data collection .....	384
	A10.5. Initial visit .....	385
	A10.6. The interview visit .....	387
	A10.7. Observation .....	394
	A10.8. Triangulation .....	394
	A10.9 Issues and problems in researching the views of children with ASD .....	394
	A10.9.1. Difficulties arising from impairments in social interaction .....	396
	A10.9.2. Difficulties arising from anxiety at communicating .....	398
	A10.9.3. Difficulties regarding use of language .....	398
	A10.9.4. Difficulties regarding preferences and emotions .....	399
	A10.9.5. Poor personal memory and overselectivity .....	400
	A10.9.6. Issues concerning visual supports .....	401
	A10.9.7. Parental influence on the child's answers .....	402
	A10.9.8. Importance of triangulation .....	403
	A10.10. Concluding comments .....	403
<b>11.</b>	<b>Family interviews: final codebook .....</b>	<b>405</b>
<b>12.</b>	<b>Family interviews: matrix of siblings' responses .....</b>	<b>407</b>
<b>13.</b>	<b>Adaptation modes of the families interviewed .....</b>	<b>412</b>

## Figures

Figure 2.1	Social ecological model (after Bronfenbrenner, 1979).....	24
Figure 2.2	Factors associated with the use of short breaks services by families that have children with ASD: model derived from the literature .....	43
Figure 3.1	Design of the research study .....	70
Figure 6.1.	Example of transcript being code using NVivo.....	196
Figure 7.1	Factors associated with the use of short breaks services by families that have children with ASD: model derived from the literature .....	267
Figure 7.2	Factors associated with short breaks use and non-use: a systemic model .....	294
Figure A10.1	Andrew’s schedule for the afternoon of his interview.....	388
Figure A10.2	Peter’s mat for identifying preferences.....	391
Figure A10.3	Ian’s sorting task .....	391
Figure A10.4	Michael’s work system .....	392
Figure A10.5	Amanda’s work system.....	393

## Tables

Table 2.1	Darling's typology of adaptation among parents of disabled children .....	22
Table 2.2	The research questions .....	57
Table 4.1	Postal survey: details of respondent where known (n = 85) .....	85
Table 4.2	Comparison between children about whom responses were made and whole population on register.....	86
Table 4.3	Year of birth of child with ASD (n = 155) .....	90
Table 4.4	Diagnostic information .....	91
Table 4.5	Educational placement of child with ASD.....	91
Table 4.6	Adults in household (n = 150) .....	92
Table 4.7	Number of children in household .....	93
Table 4.8	Dependence of children with ASD .....	94
Table 4.9	Number of areas in which children were dependent.....	99
Table 4.10	Medical conditions affecting children with ASD .....	100
Table 4.11	Comparison of parents' descriptors of their child's behaviours .....	101
Table 4.12	Total sources of informal support.....	102
Table 4.13	Sources of informal support: whole sample.....	102
Table 4.14	Does the child stay away from home overnight?.....	103
Table 4.15	Do you have a current need for short breaks?.....	104
Table 4.16	Sources of formal support.....	108
Table 4.17	Correlation between child's dependence and number of formal services used .....	108
Table 4.18	Number of sources of formal support per family.....	109
Table 4.19	Do you think you may need to use short breaks in the future?.....	109
Table 4.20	Attitudes towards short breaks.....	110

Table 4.21	Can the needs of children with ASD be met within generic short breaks services? – users’ opinions .....	112
Table 4.22	Comparative levels of informal social support .....	114
Table 4.23	Comparative levels of dependence (10 point scale) .....	114
Table 4.24	Comparison between levels of dependence .....	115
Table 4.25	Comparison of users and non-users of short breaks .....	116
Table 4.26	Age of children: short breaks users and non-users .....	117
Table 4.27	Child’s diagnosis: short breaks users and non-users.....	117
Table 4.28	School placement: short breaks users and non-users.....	118
Table 4.29	Does the child have an allocated social worker? .....	119
Table 4.30	Families’ stated reason for non-use of short breaks.....	120
Table 4.31	Child’s dependence: users and non-users of short breaks .....	122
Table 4.32	Comparison of families by short breaks use or desire for short breaks .....	123
Table 4.33	Comparison of families that do not wish to access short breaks with current and would-be users .....	124
Table 4.34	Sources of informal support: comparison of families that do not wish to access short breaks with current and would-be users .....	125
Table 4.35	School placement: comparison of families that do not wish to access short breaks with current and would-be users.....	125
Table 4.36	Dependence level of child: comparison of families that do not wish to access short breaks with current and would-be users .....	126
Table 4.37	Social worker involved: comparison of families that do not wish to access short breaks with current and would-be users .....	126
Table 4.38	Comparison of responses to attitudinal question: users of short breaks, would-be users and families that do not wish to use a service .....	128
Table 4.39	Comparison of users of short breaks and non-users who wish to access services.....	130
Table 4.40	Does the child have an allocated social worker? Short breaks users and non-users who want to use short breaks .....	130

Table 4.41	School placement: short breaks users and non-users who want to use short breaks .....	131
Table 4.42	Age of child: short breaks users and non-users who want to use short breaks .....	132
Table 4.43	Child's diagnosis: short breaks users and non-users who want to use short breaks .....	132
Table 5.1	Age of social workers .....	152
Table 5.2	Experience of working with disabled children .....	152
Table 5.3	Experience of working with typically-developing children.....	153
Table 5.4	Experience of working with disabled adults.....	153
Table 5.5	Potential causes of ASD.....	154
Table 5.6	At what age does ASD become fully present in the child?.....	155
Table 5.7	Social workers' perceptions of the characteristics of ASD .....	156
Table 5.8	Social workers' perceptions of potential benefits of specialised provision .....	158
Table 5.9	Comparison of social workers' and teachers' perceptions of the characteristics of ASD .....	161
Table 6.1	Consultations carried out with members of families that have children with ASD .....	190
Table 6.2	Details of families interviewed .....	192-3
Table 6.3	Details of mothers interviewed .....	198
Table 6.4	Details of fathers interviewed .....	205
Table 6.5	Details of siblings without ASD interviewed .....	209
Table 6.6	Details of children with ASD interviewed.....	213
Table 7.1	Quality indicators for short breaks identified by parents and children in Mitchell and Sloper's generic study (2002).....	260
Table 7.2	Factors associated with quality in short breaks services by children with ASD and their families.....	263

Table 7.3	Comparative levels of dependence: users and would-be users of short breaks .....	267
Table 7.4	Adults in household: users and non-users of short breaks .....	269
Table 7.5	Perceived need for short breaks: single and two parent families of children with 7+ dependence .....	270
Table 7.6	Socio-economic status of principal wage earners in family survey .....	271
Table 7.7	Adults in household in employment .....	271
Table 7.8	Positioning the families using Darling's typology of modes of adaptation .....	279
Table 7.9	Factors identified as associated with short breaks use or non-use in the family survey .....	291
Table 7.10	Factors identified as associated with short breaks use or non-use in the family interviews .....	292
Table 8.1	What can we learn of whole families' experiences of living with ASD? .....	299
Table 8.2	What can we learn of whole families' attitudes to and experience of short breaks? .....	300
Table 8.3	What factors are associated by families with 'quality' in short breaks? .....	301
Table 8.4	What factors, both within and outside the family, are associated with whether or not families access formal support through short breaks? .....	302
Table A10.1	Details of participants .....	383
Table A13.1	Positioning the families using Darling's (1979) typology of modes of adaptation .....	412



## Terminology

Throughout this thesis, for the sake of brevity, the terms *child*, *children*, *girl* and *boy* are used to refer to all children and young people up to the age of eighteen years included in the study. This is in no way intended as demeaning.

As the above point illustrates, all terminology relating to groups of people is value-laden, and loaded with connotations and implications. These connotations and implications are ever-shifting, and language that is intended as positive in one place or time can hold different values in another, or to other groups. Therefore an explanation is required regarding the terminology used regarding disability and autism.

A debate is ongoing about the language of disability. Those espousing a ‘people first’ perspective argue that, for example,

“...*learning disability is a label, people with a learning disability are people first.*” (Northfield, 2004, p1)

However other disabled groups resist such terminology. They argue that disability does not belong to the individual; rather they consider that people with impairments are disabled by society’s inability or reluctance to accommodate them. Therefore they consider themselves disabled. This argument is consistent with the social model of disability, which informs current legislation and practice, and the term *disabled children* is used with legislation, policy guidance and the service setting, within policy guidance. Therefore, within this thesis, the term *disabled children*, rather than *children with disabilities*, is used throughout.

The language relating to autism is similarly contentious. Following the language used in Kanner's original research (1943), children were first described as *autistic*. Wing (1996), writing from a 'people first' perspective, introduced the term children *with autistic spectrum disorders*. Others, also employing people first terminology, describe those with *autism spectrum disorders*.

Some people on the autism spectrum reject such people first terminology.

*"We are not people who 'just happen to have' autism; it is not an appendage that can be separated from who we are, nor is it something shameful that has to be reduced to a sub-clause."* (Sainsbury, 2000, p11)

The terminology of disorder is also rejected by some, arguing from a perspective of 'neuro-diversity', and the term *autism (or autistic) spectrum condition (ASC)* is now often used by those on the spectrum, by researchers and in policy (Baron-Cohen, 2008; Department of Health, 2009).

In my own practice I now follow the convention used within the Autism Centre for Education and Research at the University of Birmingham, and refer to people *on the autism spectrum*. However during the period in which this research was undertaken (2003-2005) the term in general use was *autism spectrum disorder (ASD)*, and this was the wording used within the project. In recognition of this, the term *autism spectrum disorder (ASD)* is used throughout to refer to conditions on the autism spectrum.

## **Publications derived from this thesis**

### **Publications in peer-reviewed journals**

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- Preece D. & Jordan, R. (2007) Social workers' understanding of autistic spectrum disorders: an exploratory investigation, *British Journal of Social Work*, 37, 925-936.
- Preece, D. (2009) Effective short breaks services for families with children with autism spectrum disorders, *Practice: Social Work in Action*, 21, 159-174.
- Preece, D. & Jordan, R. (2010) Obtaining the views of children and young people with autism spectrum disorders about their experience of daily life and social care support, *British Journal of Learning Disabilities*, 38, 10-20.

### **Publications in conference proceedings**

- Preece, D. (2005) Negotiating differing agendas: designing a research tool through collaboration with parents of children with autistic spectrum disorders. In C. Bhaowises, D. Evans, E. Mariou, N. Muhammad & L. Sousa de las Heras (Eds) *Proceedings of the 4<sup>th</sup> Research Student Conference, School of Education, University of Birmingham, June 4<sup>th</sup> 2005*. Birmingham: University of Birmingham.
- Preece, D. (2006) "Different ways of knowing and doing": using mixed methods of data collection and analysis within the same PhD study. In C. Corcoran, D. Evans & C. Nicholson, with N. MacNab, A. Taysum, G. Everleigh, J. Georgeson & M. English (Eds) *Papers from the Student Conference, Researching Education: Different Ways of Knowing and Doing, University of Birmingham, July 1<sup>st</sup> 2006*. Birmingham: University of Birmingham.
- Preece, D. (2007) Factors associated with the use and non-use of short breaks (respite care) services by families with children with ASD. In "A World of Possibilities": *Proceedings of the 8<sup>th</sup> International Congress Autisme-Europe, 31 August – 2 September 2007, Oslo, Norway*. Oslo: Autisme-Europe.
- Preece, D. (2009) Respite care for families with children with autism spectrum disorders. In *Proceedings of International Conference – Rain Man is among us: Contemporary forms of support for autistic persons – a systems approach, Kraków, 27-29 November 2008*. Kraków: Katedra Psychologii Uniwersytet Pedagogiczny.

## **Chapter 1: Introduction to the thesis**

*Within this introductory chapter I identify the factors that led me to undertake doctoral research concerning the life experience of families with children with autism spectrum disorders (ASD) and factors associated with their use or non-use of short breaks support. I situate myself in terms of my professional role and experience, and the research in terms of its potential to influence practice. I introduce and outline the research topic and some of the key issues relating to it, identifying the originality and timeliness of this study. Finally I describe the overall shape of this thesis.*

### **1.1. Introduction**

This thesis describes an investigation undertaken into the experience of children with autism spectrum disorders (ASD) and those who live with them – their mothers, fathers, sisters and brothers. The field work was carried out within an English shire county between 2003 and 2005. This research identifies the impact of autism across whole families, and for the first time within the literature investigates how this is experienced by all family members. The interface between families that have children with ASD and the brokers and providers of formal social care support – social workers and short breaks (respite care) services – is examined; and, again for the first time, whole families’ experiences of using short breaks and whole families’ opinions regarding factors associated with quality in such services, are identified. Finally, factors associated with the use and non-use of short breaks services by families that have children with ASD are discussed, and an original theoretical model to describe service use or non-use is suggested. This model is derived from the analysis of the

three phases of this study and is consistent with my epistemological position and the theory underpinning my research.

## **1.2. Rationale and researcher's background**

Autism spectrum disorders are pervasive developmental disorders, with an estimated prevalence rate of approximately 1 per 100 (Baird *et al.*, 2006). They are characterised by a triad of impairments in social and emotional understanding, communication and flexibility of thought and behaviour (Jordan, 1999a; Wing, 1996), each of which can occur with differing severity (Lord and Risi, 2001). The cumulative effect upon the individual and the family can significantly affect functioning.

It has been shown (see 2.3 -2.4 for a fuller discussion) that ASD can cause higher levels of parental anxiety and tension than other disabling conditions (Gray, 1994), and the presence of autism within families can have a significant impact on parents (Duarte *et al.*, 2005; Gray, 2002), siblings (Rivers and Stoneman, 2003) and individuals with ASD themselves (Grodén *et al.*, 1994). The need for appropriate formal social care support is highlighted in a number of studies (Tarleton and Macaulay, 2002). Short breaks have been shown to be an important part of the range of such formal supports used by families that have children with ASD (Beresford, 1994; Factor *et al.*, 1990; Geall, 1991) and as such a topic worthy of study.

This doctoral research follows on from earlier studies that I have undertaken investigating the attitudes of parents of children with ASD towards short breaks (Preece, 2000; 2001) and children with ASD's experience of using such services (Preece, 2002). The rationale for this research is closely and strongly related to my professional role and experience. I have worked

with disabled adults and children and their families for almost thirty years. After practising in the fields of learning disability and physical disability, I began working primarily with children and young people with ASD in the early 1990s. Since 1993 I have developed and managed local authority social care services for children with ASD and their families within the county where I live and work. These include ASD-specific short breaks (Preece, 2003, 2009), a group home (Preece, 2008) and a family advisory team (Howley *et al.*, 2001; Preece and Almond, 2008).

These services are underpinned by the TEACCH (Treatment and Education of Autistic and related Communication-handicapped Children) structured teaching approach (Mesibov *et al.*, 2005), developed at the University of North Carolina and now widely regarded as good practice in ASD (Autism Working Group, 2002). I was involved in introducing this approach to services in the UK (Preece *et al.*, 2000), continue to have close links with the University of North Carolina (regularly presenting papers at their international in-service conference, most recently in 2005 and 2009) and I utilize aspects of this approach in consulting with children with ASD.

I am both a practitioner working daily with children with ASD and their families, and the manager responsible for social care provision to this group in a shire county with a population of over 650,000. These services have been identified as effective (Social Services Inspectorate/Audit Commission, 1999) and as exemplars of good practice (Carlin *et al.*, 2004; Gray, 2006). The ASD-specific residential short breaks home which forms part of this provision has been rated as outstanding at its last three Ofsted inspections. I have consulted to government-funded Regional Partnership Strategic Development Teams developing social

care provision for children with ASD in a number of local authorities, and I am currently acting as a consultant on a project, funded by the European Commission and carried out in conjunction with Autisme-Europe, to establish autism-specific short breaks services in Eastern Europe. I have presented papers on service provision in this field in the UK and worldwide, and published in academic and social care journals. As a result, I have opportunities to influence policy and practice concerning service development beyond the confines of my county.

It is crucially important to me that families with children across the whole autism spectrum are adequately supported, with services appropriate and fit for purpose and that children's and families' views and priorities should help shape these services. However, before commencing this research, I knew that only a minority of families that have children with ASD – both within my own local authority and more widely – access social care support services such as short breaks. I was further aware, from anecdotal evidence and my previous research, that many families find it difficult to access appropriate services – or any at all. I felt the reality concerning this area of activity was more complex than I was at that time aware of and I strongly believed that a better understanding of the situation could enable positive changes in the experience of families that have children with ASD to be brought about both in my own local authority and more widely.

### **1.3. Overall aims of the research**

The overall aims of my doctoral research were therefore to investigate the experience of day to day life and social support of families that have children with ASD, to identify and investigate the factors associated with use and non-use of short breaks services by these

families and to identify factors associated with quality in such services. This study was timely and relevant when I began planning it in 2003 and it has become even more so during the period since then. The identified population with ASD has steadily risen as diagnostic criteria have widened and awareness of the condition has increased. It is now estimated that as many as 1% of the population may have an ASD (Baird *et al.*, 2006). This increase in the identified population has been reflected within the county surveyed. When I carried out the family survey, which comprises the first phase of this study, the estimated number of children with ASD in the county was between 350 and 400; by 2007, this had risen to just under 600 (Whitaker, 2007).

Bebbington and Beecham (2007), analysing data from the 2001 Children in Need Survey (National Statistics/Department of Health, 2002), suggest that children with ASD comprise around 4 per cent of all children in need in the UK, and that local authority expenditure on this group may be equivalent to £100m per year. PriceWaterhouseCoopers (2007) argue that effective short breaks can reduce the long-term costs of intervention and support and the recent government initiative “*Aiming High for Disabled Children: Better Support for Families*” (HM Treasury/Department for Education and Skills, 2007) concludes that effective and appropriate short breaks services are needed by families with disabled children, and that children with ASD face particular problems in accessing existing services.

This rings true with my own experience. Working as a consultant has shown me that in many local authorities children with ASD are placed with children with a range of disabilities (such as learning and physical disabilities) in generic short breaks services. Such placements frequently break down, sometimes resulting in family breakdown and extremely costly



placements in specialist residential schools. Even where specialist services exist, demand often outstrips availability.

However, attempting to identify what actually comprises effective and appropriate short breaks for those with ASD and their families, what services should be provided and what would indicate quality within those services, is problematic. Though a significant body of research in education has identified the benefits to children with ASD of differentiated provision or approaches (Autism Working Group, 2002; Jordan and Jones, 1997a), the social care needs of these children and their families remain under-researched. Research into short breaks has paid little attention to the specific needs of children with ASD and their families, focusing instead on a presumed homogeneous group of ‘disabled children’ (Minkes *et al.*, 1994; Prewett, 1999). Moreover, the literature on ‘short breaks’ is contradictory, with some authors stressing the merits and values of these services while others argue that they are abnormal and segregating (see 2.5.2 – 2.5.3).

Similar problems arise when considering the identification of the views and priorities of children with ASD and their families. “*Aiming High for Disabled Children*” requires local authorities to engage with disabled children and their families so they can be fully involved in the way services are planned, commissioned and delivered; disabled children and their parents should be consulted about how to improve services and should be involved in service evaluation (HM Treasury/Department for Education and Skills, 2007). This imperative to consult with children as well as their parents has been a constant within national and international legislation, policy and good practice guidance over recent years. It is enshrined in, to name but a few examples, the *United Nations Convention on the Rights of the Child*

(United Nations, 1983), the *Code of Practice on the Identification and Assessment of Special Educational Needs* (Department for Education and Skills, 2002) and the *Children Act* (Department for Education and Skills, 2004).

Though considerable research has been carried out with the parents of disabled children, much less has been undertaken with the children themselves, and only a handful of studies have investigated the experience of children with ASD (Beresford and Tozer, 2003; Beresford *et al.*, 2004; Jones *et al.*, 2007; Preece, 2002). Furthermore, my literature search found no studies which have sought to identify the experience and needs of whole families where there are children with ASD, including their non-disabled siblings. This study, therefore, adds to the knowledge base by addressing significant limitations in the existing literature. It explores for the first time the experience of as close as possible to a whole population, and of whole family units from within that population. It explores for the first time social workers' understanding of ASD. It further addresses the tendency of research into the experience of families living with ASD and their use of short breaks to have privileged the needs and experiences of parents, and to have neglected either seeking the views of the children with ASD or considering families as units. In this research, consultation was undertaken with parents, children with ASD and their siblings, enabling a picture of the whole family's experience, attitudes and opinions to be constructed. For these reasons this is a worthwhile study, which adds to the knowledge base and in which I undertake novel and original research.

This thesis is structured as follows. In Chapter Two I present an overview of family systems theory, the theory underpinning my research, then review the literature regarding the daily

lives of families with children with ASD and their experience of short breaks, identifying and defining the research questions. In Chapter Three I present the overall research design, linking methodology explicitly to theory and to my epistemological position. Chapters Four to Six report on the three distinct phases of this research project: an initial survey of families with children with ASD in one local authority, a further survey investigating how social workers serving this population conceptualised autism, and finally a qualitative investigation of the experience and attitudes of parents, siblings and children with ASD. In Chapter Seven I return to the research questions, synthesising the findings of the three phases of the project, and suggest a model for conceptualising short breaks use and non-use within this population. In Chapter Eight I summarize the original contribution made by this project, identify limitations and weaknesses and suggest areas for further research. A short postscript within this chapter comments on developments that have occurred within the sphere of formal social care support since the data was collected in 2003-5, and discusses implications for local authority service providers arising from this study.

This text is followed by a list of references. Finally the thesis is supported by appendices containing the research tools, examples of documentation sent to participants, evidence supporting analyses and methodological information concerning the process of consulting with children with ASD.

Having introduced the research topic, and having outlined the structure of the thesis, I shall in the next chapter move on to present an overview of family systems theory and to review the literature concerning short breaks and families that have children with ASD.

## **Chapter 2: Review of the literature**

*In this chapter I present an outline of family systems theory, the theoretical framework underpinning my thesis. I describe how the experience of families with disabled children is understood within this theoretical approach, discuss criticisms of this theory and present my rationale for its use. I then review the literature regarding families' experience of living with ASD and regarding short breaks. This literature review identified areas where further research was required to add to the knowledge base, and it is from this literature review that the research questions are derived. Finally in this chapter I introduce the four research questions that are addressed in this study, presenting evidence to support the worth of this study.*

### **2. 1. Family systems theory: an overview**

Within this research, my conceptualisation of families that have children with ASD, their needs, and the means by which support is provided is underpinned by family systems theory. It is therefore essential to discuss this theory in some depth. In this section, I introduce this theory, at first generally, then moving on to look at its application to families with disabled children and such families' interaction with wider society. Finally I discuss weaknesses of the theory, whilst arguing why I consider it a valid and appropriate tool to use in investigating my research topic.

#### **2.1.1. Origins of systems theory**

The use of systems theory regarding provision of, and research into, social care derives from the work of von Bertalanffy (1971), who developed general system theory in the 1920s. Von

Bertalanffy observed that all organisms are systems, composed of sub-systems, and in turn comprising parts of super-systems. Thus individual humans are made up of, for example, circulation, respiratory and skeletal systems. In turn these humans are part of larger systems: families, groups and societies. The point was made that the interaction between the various parts of these systems creates characteristics not contained within the separate entities.

As the caring professions developed through the twentieth century, the focus of attention was upon the individual, with psychological/psychodynamic approaches dominating within psychology, health and social care (Kemp *et al.*, 1997). In the 1960s, social work theorists identified the need to focus upon both psychological and social aspects in assessment and intervention, suggesting the development of a psychosocial perspective (Woods and Hollis, 1999).

Pincus and Minahan (1973) explicitly applied systems theory in a social care context. They argue that the quality of people's lives is largely dependent upon systems in their immediate social environment, suggesting three kinds of systems that can support people: informal or natural systems (e.g. family, friends, colleagues), formal systems (e.g. community groups, trade unions) and societal systems (e.g. hospitals, schools). People experiencing problems may not be able to access these supportive systems for a variety of reasons. They may not have informal support systems; they may not know about or wish to use more formal supports; or the system's policies may be problematic for them. The task of supporting agencies can therefore be considered as being to identify those elements in the interaction between the individual and the environment that are causing problems, and to intervene to ameliorate the situation (Payne, 1997).

### 2.1.2. The family system

Within this social systems perspective, the family is perceived as a social unit embedded within other informal and formal social units and networks (Dunst *et al.*, 1988). Each family has a family system: the way the family has developed to cope with the day to day realities of living together as a unit within society.

*“(The) method created by the family to be whatever it is being.”* (Ogden and Zevin, 1976, p6)

The family system develops over time, as individual family members interact with each other and with the outside world. These interactions and patterns of behaviour are built up over the family's lifetime, incorporating what has been learned from previous generations (Gorell Barnes, 1984). Patterns of behaviour differ from family to family, and are not rigidly defined but gradually evolve (as the patterns and behaviours of the family members are repeated and reinforced) to make up the family system, maintaining the family, and giving it balance and definition.

*“Such norms represent the sum total of all the years of conflict, compromise and concern.”* (Jordan, W. 1972, p14)

Manor (1984) identifies a number of important points about the family system. Families are systems that have a sense of their own identity. Members are aware of the family boundary – who is inside the family and who is not. Boundary changes – to include new members (e.g. step parents) or exclude others (e.g. the ‘black sheep’) – can occur, but only with considerable stress. Each family system contains sub-systems, such as the marital pair or sibling group. At the same time, the family is itself a sub-system of other systems (the extended family, the neighbourhood, wider society). Families vary in the extent to which they operate as ‘closed’ or ‘open’ systems. Some are much more involved with the community, friends and

neighbours than others: however, no family systems are entirely closed. Finally, families vary in the pace at which they are able to adapt to change.

As well as providing a conceptual basis for social care practice, family interventions have been developed in fields such as health care (Doherty, 1985; Turk and Kerns, 1985) and within psychology and psychiatry (Ogden and Zevin, 1976). Ann Turnbull and her associates at the Beach Center on Disability, University of Kansas (Turnbull *et al.*, 2006; Turnbull and Turnbull, 1990) and Seligman and Darling (1997) in Pennsylvania, have undertaken research linking family systems concepts to the experience of families with disabled children, and to cross-disciplinary interventions.

Turnbull and Turnbull (1990) suggest that most family systems comprise a number of characteristic structural components: family structure, family interaction, family functions and family life cycle. These components are discussed in detail below.

### **2.1.3. Family structure**

Family structure comprises the variety of factors that make families unique: these include membership characteristics, cultural beliefs and ideological style.

#### ***Membership characteristics***

A considerable body of research has investigated the impact of a disabled child upon families and family life. One effect of this has been to identify such families as a unique population, defined by the effects of this impact (Byrne and Cunningham, 1985). However even within this population there is much diversity, and, as Ainge *et al.* (1998) point out, families with

disabled children cannot be considered as a homogeneous group. Families differ with regard to numerous membership characteristics: they may comprise single-parent families; they may be extended families (with members residing either in the same household or geographically separated); and there can be great variation with regard to income, physical and mental health issues (Seligman and Darling, 1997). Membership characteristics change over time, as individuals exiting or entering the system; and each change affects the family's communication and relationship patterns.

### *Cultural beliefs*

A family's cultural beliefs play a major role in shaping its interactional patterns (both within the family and with individuals or agencies outside it) and in determining its functional priorities (Turnbull *et al.*, 1986). Furthermore, cultural values and beliefs also impact upon the way in which families adapt to a disabled child, and can influence the families' usage and trust of caregivers and external agencies (Chamba *et al.*, 1999; Dyson, 2000; Shah, 1992).

### *Ideological style*

A family's ideological style is based on its beliefs, values and coping behaviours, and is further influenced by its cultural beliefs (Seligman and Darling, 1997). Beliefs and values may be handed down from generation to generation, influencing how family members interact with one another, with other families and with external agencies, such as schools and social services. Shah (1992), for example, found that some Asian families emphasise cohesion and respect, with all important decisions being taken by the head of the extended family.



The family's response to a child with a disability is influenced by ideological style, but having such a child may also influence the family's values, beliefs and coping behaviours. The family has to confront its beliefs about people who have disabilities; and if a disabled child is born into a family that is prejudiced towards disability, this can result in both practical and psychological problems (Marshak and Seligman, 1993). The family must also address its beliefs about whether responsibility for the management of the disability lies with themselves, in the hands of others (for example, 'experts' or 'God') or is a matter of chance. Rolland (1993) has found that the family's ideological style will impact upon its interpretation of events related to the disability (e.g. whether someone is to blame, feelings of guilt), the approach to care-giving and whether or not, and how, family members seek help.

Ideological style also influences the family's coping strategies, both as a unit, and with regard to its component parts. Potentially dysfunctional coping strategies – such as withdrawal or avoidance – have been identified both in fathers of children with ASD (Houser and Seligman, 1991; Gray 2002a) and in mothers (Hastings *et al.*, 2005), and have been shown to impact upon sibling relationships (Rivers and Stoneman, 2003). McCubbin and Patterson (1981) suggest that family coping styles comprise internal and external strategies. Internal strategies include acceptance and planning (Carver *et al.*, 1989) and reframing (making attitudinal adjustments in order to address the situation constructively, emphasising its positive aspects) (Hastings *et al.*, 2005), as well as more negative strategies such as mental or behavioural disengagement (Carver, 1997) and withdrawal (Gray, 1994; Sivberg, 2000). External strategies include spiritual support and religious coping (Poston and Turnbull, 2004; Tarakeshwar and Pargament, 2001) and the use of emotional or practical social support (from informal or formal sources).

Turnbull *et al.* (2006) consider the term ‘coping’ inappropriate when discussing families caring for a disabled child, both because the word is often viewed negatively by families (e.g. as in ‘a parent who cannot cope’) but also because ‘coping’ typically refers to how a family or individual deals with a crisis, whereas the challenges involved in living with disability occur daily for a protracted period of time. They suggest that the term ‘life management skills’ (Scorgie *et al.*, 1999) is a less stigmatising and a more accurate descriptor. However, as ‘coping’ is the term generally used in family systems literature, I use this term throughout this thesis.

#### **2.1.4. Family Interaction**

Disabled children do not exist and function in isolation. They live within a context (usually the family) and as Ellman (1991) describes, the family can be likened to a mobile – when something happens to one family member, all others are affected in some way. Turnbull *et al.* (1986) suggest that the family interactional system comprises four elements: subsystems, cohesion, adaptability and communication.

##### ***Subsystems within the nuclear family***

The nuclear family is composed of four basic subsystems: the marital subsystem (husband/wife); the parental subsystem (parent/child); the sibling subsystem (child/child) and the extra-familial subsystem (interaction with extended family, friends, neighbours, professionals). The composition of these subsystems is affected by the family’s structural characteristics (e.g. single parent, number of children, size of extra-familial network) and by the life-cycle stage of the family. Seligman and Darling (1997) urge professionals to be cautious and aware when intervening in families since, for example, an intervention designed

to improve the bond between a mother and child may have implications for the mother's relationships with her husband and any other children.

### ***Cohesion and adaptability***

While subsystems identify *who* will interact, cohesion and adaptability relates to *how* those family members interact. Cohesion is concerned with the concepts of enmeshment and disengagement (Seligman and Darling, 1997). These can be considered as poles on a continuum. Highly enmeshed families have weak boundaries between subsystems, and can be viewed as overprotective and over-involved (Minuchin, 1974). Seligman and Darling (1997) suggest that such families can negatively impact on a disabled child, suffering anxiety at 'letting go', and restricting the child's independence. Negative outcomes, such as social withdrawal, may also impact upon the family as a whole (Gray, 1994). At the other pole, disengaged families are characterised by rigid subsystem boundaries and can be seen as under-involved (Minuchin, 1974). In such families, involvement results in anxiety; and disengaged families seek to avoid anxiety. Consequently, though a disabled member may be free to act independently, they may feel unsupported in these activities or unloved. Well-functioning families are considered to strike a balance between enmeshment and disengagement: subsystem boundaries are clearly defined but allow for both close bonding and the development of autonomy.

Adaptability concerns the family's ability to react and change in response to a stressful situation (Olson *et al.*, 1980). As with cohesion, adaptability can be considered as a continuum, with poles of chaos and rigidity. Chaotic families are characterised by inconsistent change and instability: they have few rules to live by, and those they have frequently change

(Seligman and Darling, 1997). The family has no 'leader', with family life consisting of endless negotiations and frequent role changes (Turnbull and Turnbull, 1990), as the family see-saws between disengagement and enmeshment. Adjusting to caring for a disabled child and meeting his /her needs in such an environment would be difficult. It would also be difficult to adjust to caring for a disabled child in a rigid family, where roles and behaviours do not change in response to stressors. Seligman and Darling (1997) provide an example of a rigid patriarchal family. In such a family, the father's perceived role as 'head of household' would not allow him to help with domestic tasks and childcare (which would be viewed as 'woman's work') thus putting significant pressure upon the mother. She in turn – due to the effort put into caring for the disabled child – will have little time or energy for her husband, her other children, or for external interaction. Such a family may well become dysfunctional and socially isolated. As with cohesion, healthy families are seen as those that interact functionally, maintaining a balance between reacting to change and maintaining stability.

### ***Communication***

Effective communication is an essential in a healthy, functioning family. Where communication breakdowns occur, this can be understood as a systemic problem: as Turnbull and Turnbull (1990) argue, communication problems exist in the interactions between individuals, rather than in the individuals themselves – and can come about as a result of different factors, depending upon the situation.

#### **2.1.5. Family Functions**

Family functions can be understood as the outputs or products of family interaction. Different families place different emphases and priority upon different functions; and the family

member(s) who carry out these functions may vary between families. Turnbull *et al.* (2006) suggest that the family fulfils seven basic functions. It has an *economic* function, providing income to support the family, paying its bills and planning for future need. It provides *daily care* to its members (cooking, laundry, providing transport, meeting minor health needs and undertaking medical visits to meet greater health needs). It enables family members to pursue *recreational* activities, individually and as a group, and to develop hobbies and interests. It provides opportunities for *socialisation* and the development and enjoyment of interpersonal relationships. It has a function relating to *self-esteem*, enabling individual family members to recognise their strengths and weaknesses, and providing a safe accepting sense of belonging. It is a source of *affection* and a setting in which intimacy and nurturing are experienced. Finally it has an *educational/vocational* function, supporting children in undertaking homework, helping develop skills and work ethic, and supporting career choices (in some families, an eighth function of *spirituality* – meeting family members' spiritual and religious needs – may be an important consideration).

The presence of a disabled child can impact greatly upon the family's ability to carry out these functions. Some impacts may be negative, or problematic. For example, disabled children may generate greatly increased demands (e.g. regarding domestic and health care issues) and may create an extremely restrictive environment for the other family members. The presence of such a child may also change the family's self-identity, reduce its ability to generate income, constraining its social and recreational opportunities and limiting career choices. Conversely, some impacts may be positive. Turnbull *et al.* (1985) note that for some families, a learning-disabled member contributed positively to the family in terms of affection and self-definition. More recent studies support this finding, identifying families strengthened

by the presence of disability, and where disabled children are viewed as impacting positively on the lives of their parents and other family members (Hastings and Taunt, 2002; Risdal and Singer, 2004; Taunt and Hastings, 2002). Fleischmann (2004) further shows that some parents of children with autism experience this as a positive challenge which they feel empowers them as parents and makes them better people.

Time is a major factor in addressing family functions. Almost two thirds of employed parents with children under eighteen in the USA feel they have too little time to meet their children's needs (Families and Work Institute, 1994). The presence of disability can mean that time is even more constrained. In some cases the stress experienced by families is exacerbated by the number of tasks which professionals ask the parents to carry out regarding the disabled child (Brotherson and Goldstein, 1992; Laborde and Seligman, 1991). This can sometimes be overwhelming, and placing such pressure on families that they have insufficient time or energy to adequately address the different aspects of functioning which the family needs to meet.

#### **2.1.6. Development over time**

Families are not static entities. They change and develop as new members are born, grow up, leave home, introduce new family members through long-term relationships, and eventually die. Theory suggests that, with some variation within and across cultures, families tend to pass through predictable stages. However, as well as these predictable, *on-cycle* changes (Turnbull *et al.*, 2006), unpredictable, *off-cycle* changes may occur, such as divorce, unemployment, serious accidents and untimely death. When changes occur, the family changes and its characteristics, interactions and functions are affected.

### ***Family Life Cycle***

Though different authors (Carter and McGoldrick, 1999; Olson *et al.*, 1980) suggest differing life cycle stages, six stages typify the family life cycle: formation of the new couple and marriage/partnership, child-bearing and infancy, families with young school-age children, families with adolescent children, ‘launching’ children and families in later life

A child’s disability can bring additional stressors to the family within all but the initial stage. Seligman and Darling (1997) identify a number of these. During *child-bearing and infancy*, stress can be caused by the effort expended to get an accurate diagnosis, as well as the need to make emotional and practical adjustments to the situation, and to inform other family members. When children are of *school age* potential sources of stress include interaction with the education system, dealing with the reactions of the child’s peer group, other parents and professionals and arranging child care and out-of-school activities. With the arrival of *adolescence*, the family must learn to cope with the continuing nature of the disability, as well as issues concerning physical maturation and sexuality, peer isolation and rejection and planning for the child’s adult life. At the *launching* stage, when typically-developing children would be moving towards independence, the family may need to adjust to a future of continuing responsibility, as well as dealing with restricted socialisation opportunities or considering the potential need for future residential placement. In *later life* come the stresses involved in re-establishing the spousal relationship (if child has been successfully ‘launched’), and interacting with care providers. If the child has not been ‘launched’, the family must adjust to the stresses of continuing to provide care whilst aging. In either case, further stressors may result from the need to care for their own elderly relatives, or each other, and from the need to plan for the future.

### ***Developmental transitions***

Developmental transitions – the process of moving from one life stage to another – are particularly challenging periods for families, characterised by significant change, and can cause stress and dysfunction (Falicov, 1988; Seligman and Darling, 1997). Challenges can be exacerbated where there is a disabled child, as transitions may be delayed or not occur at all: for example young disabled adults may remain in the parental home until they themselves are elderly and their parents can no longer care for them (Essex *et al.*, 1999). Some transitions may also occur earlier than expected, such as when the disabled child is placed in a living situation outside the home, either for short periods of time (for example, when attending short breaks) or permanently (in a residential placement or substitute family). These situations can also be significant stressors. Baker and Blacher (2002) have shown that moving a child into a residential placement creates an array of emotions, ranging from relief to stress and burden; and Chan and Sigafoos (2001) suggest that for some families short breaks use, and attendant concerns such as transport issues and quality of care, can create, rather than reduce, stress.

#### **2.1.7. Modes of family adaptation**

Seligman and Darling (1997) identify a range of modes of family adaptation, suggesting that *normalization* – the ability to lead as ‘normal’ a lifestyle as possible within societal norms – is the goal of most families. Components of a normalized lifestyle vary according to location, class and culture. However for western families with school-aged children these might typically include employment for either/both parents, sufficient finances to maintain a basic lifestyle, appropriate school placements for children, adequate housing, social relationships with family and friends, leisure time, and freedom of movement and access (Seligman and Darling, 1997). They suggest that – regardless of the child’s disability or the parents’ coping



abilities or styles – the most important factor determining a family’s level of normalization is the availability of appropriate social support, informal or formal.

Though normalization is the most common type of adaptation throughout childhood, achieving such a lifestyle is difficult for many families with disabled children, particularly if the child’s impairments, or the behaviours they present, make accessing social supports difficult. Darling (1979) suggests a four-mode typology of adaptation among parents of disabled children (see Table 2.1 below). Darling stresses that that these modes are approximations only, not intended to stereotype families; moreover families may move between categories as circumstances change.

**Table 2.1      Darling’s typology of adaptation among parents of disabled children**

<b>Mode of adaptation</b>	<b>Type of integration <sup>1</sup></b>	
	<b>‘Normal’ society</b>	<b>Disability subculture</b>
Normalization	+	-
Altruism	+	+
Crusadership	-	+
Resignation	-	-

<sup>1</sup> + = integration achieved; - = integration not achieved or withdrawn

In Darling’s model, all parents have access to two societal structures: ‘normal’ mainstream society and the smaller disability subculture (parent support groups, advocacy organisations and local and national disability organisations). Parents with equal access to both structures will generally choose a *normalization* mode, and this is the most common mode of adaptation. However, some families who have achieved normalisation remain active within the disability subculture, becoming *altruists*. Reasons for altruism can vary. Some individuals are particularly caring; some have a strong sense of justice; some are guided by religious beliefs; others enjoy the social aspects or the prestige of involvement. Altruists often perform

leadership roles in national charities or organisations, or choose a career within disability, utilising their skills to help other families (Klein and McCabe, 2007; Wickham-Searl, 1992). They are those who choose to associate with those with disabilities though they have access to 'normal' society.

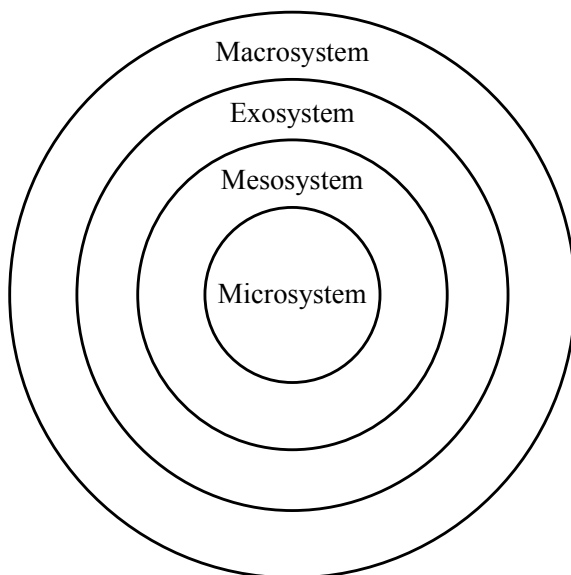
Other parents have difficulty accessing 'normal' society. A subset of these may adopt a *crusadership* mode. Such individuals strive for social change, trying to improve opportunities for their own and other people's families and children. Some may become heavily involved in local or national organisations and support groups; others may wage legal battles against local authorities, or challenge educational and care services. The literature suggests that those in this subset are more likely to be middle- to upper- income, more educated, married suburban and white (Mandell and Salzer, 2007; Powell, 1987).

Finally, there are some families who, despite being unable to achieve normalization, do not enter the disability subculture of support groups and disability organisations. In some cases this is due to lack of information. Others cannot access the subculture, due to isolation, poor health, lack of transport or other issues. These families are typified as being *resigned*. Some parents may become fatalistic, while others may have mental health problems as a result of the stress they endure. The literature suggests this group is more likely to include poorer, less educated urban and rural residents, as well as those from minority ethnic backgrounds (Mandell and Salzer, 2007).

### 2.1.8. The social ecology model – the family in context

The discussion so far has centred upon the family. But, as stated in 2.1.2, the family is a system embedded within other systems. Considering the family within this social ecological context was pioneered by Bronfenbrenner (1979), who suggests that the ecological system comprises a number of subsystems: the microsystem, mesosystem, exosystem and macrosystem (Figure 2.1).

**Figure 2.1** Social ecological model (after (Bronfenbrenner, 1979))



Mitchell (1983) and Hornby (1994) have applied this model to the study of families with disabled children. They conceptualise the *microsystem* as comprising the pattern of roles, functions and interpersonal relations experienced by the family: in essence, the family as discussed in this chapter so far. The family (the *microsystem*) functions within a *mesosystem*, the range of settings within which it actively participates. This might comprise the extended family; friends and neighbours; medical and health care, education and social care professionals; work colleagues; other parents and support groups; and the local community as

a whole. Various facets of this subsystem can impact greatly upon the family in a range of ways. Extended family may accept or reject the disabled child, either providing or withholding informal social support. Neighbours and work colleagues may be supportive or stigmatising to the family. Professionals may be humane and helpful or act as impersonal gatekeepers of services. Furthermore, there can be considerable variation regarding the availability of and coordination between services from area to area (for example between affluent and poor areas or urban and rural communities).

The *exosystem* comprises settings in which the family is not directly involved, but which nonetheless impact upon the family, such as the mass media, and the healthcare, social welfare and education systems. The mass media can affect general societal attitudes regarding disabled people and how they are portrayed: for example, as helpless, innocent and incapable, or as menacing and undesirable. Health, education and other governmental supports (local and national, financial and practical) are also of vital importance to families with disabled children.

Finally the *macrosystem* reflects the values inherent in social institutions. These include ethnic, cultural, religious and socioeconomic values, which affect how disability is viewed both by family members and the wider society (for example, whether disabled people should be included in or segregated from society), and can impact upon how families choose to interact with education, health and social care services. Economic and political factors, both at a local and national level (such as the health of the economy, and the importance and funding allocated to disability issues) will also impact upon these families.

As previously identified, the underlying tenet of the ecological model is that a change in any part of the ecological system affects subparts of the system, necessitating adaptation. Furthermore, consideration must be given to the permeability of the family in interacting with the other subsystems in the environment. Some families are highly permeable, readily seeking support and assistance from other family members or formal services. Others however are impermeable, resisting support and withdrawing inwards.

### **2.1.9. Criticisms of family systems theory**

Despite its influence on the conceptualisation of practice within social care and other caring professions, a number of criticisms have been made of family systems theory, and problems identified. Mune (1979) has argued that weaknesses exist at the very core of the theory, in that there is a lack of clarity about what precisely constitutes a system, where its boundaries lie, and what its attributes precisely comprise. Emancipatory and feminist perspective have asserted that focusing on function and exchange within and between systems ignores factors such as structural injustice, abuse of power and societal inequities with regard to age, gender and class (Healy, 2005; McNamee and Gergen, 1992; Wakefield, 1996a, 1996b). Greene and Blundo (1999) write that family system's functioning is often dependent on the exploitation of women's labour; and that macro- and micro-political, economic and cultural influence within the helping agencies and individual professionals also impact upon the family system and its functioning. It is further argued (Wakefield, 1996b; Greene and Blundo, 1999) that the focus on systemic interactions and networks, the assumption that

*“...each family will experience a life of predetermined stages or developmental cycles within which they incur assumed tasks to meet the changed needs of each stage of a prescribed cycle of life.”* (Greene & Blundo, 1999, pp93-94)

can lead practitioners and researchers towards a rigid and mechanistic understanding of family life, detracting from them focusing on, and addressing, the uniqueness of the individual.

Despite these caveats, the family systems model offers a number of benefits as a conceptual tool. Its use is consistent with my realist epistemological position (see 3.1) (May, 2001; Robson, 2002; Sayer, 2000): it offers a model by which the complex stratified social world can be understood, and through which the structures of social relations impacting on families' daily lives and underlying their experience of informal and formal support can be interpreted. Family systems theory offers further advantages in conceptualising the experience of families with a child (or children) with ASD. It provides a framework for understanding and responding to people within their environments, rather than considering them as if in a vacuum. And the focus on the family prevents both the pathologisation of the disabled child (in which they are seen as the 'problem' in the family) or the narrow focus on the disabled child (to the exclusion of other family members) that is prevalent both in social care provision for disabled children and adults in general (Grant, 2003; Grant and Ramcharan, 2001), as well as in literature and practice regarding children with ASD (Beals, 2003; Hastings and Symes, 2002). Instead, consideration is necessarily given to analysing the interactions within and across systems (Healy, 2005). Overall, a family systems perspective offers

*“...a way of seeing complex phenomena (the person and their environment) in their interconnected and multilayered reality, to order and comprehend complexity and avoid oversimplification and reductionism.”* (Mattiani and Meyer, 2002, p4)

As such it forms part of the inherent structural framework of this thesis, as well as of my understanding of ASD and disability and my wider practice.

## 2.2. Reviewing the literature

Having presented the theoretical framework underpinning this thesis, I will now move on to discuss the initial literature review, undertaken to identify current knowledge regarding the research topic, and to help identify the research questions. May (2001) writes that before undertaking research it is essential to

*“...spend time reading around the topic of interest to see what theories other researchers have held and indeed what research has already been carried out.”*  
(p96)

At the start of this project, In 2003, I carried out an initial literature search using bibliographical analysis (Hart, 1998) of publications since 1980: this underpinned the study as a whole as well as informing the initial family survey. The search focused on key areas associated with the topic of use or non-use of short breaks by families that have children with ASD. These comprised research into the life experience of families living with a child with ASD; research concerning what helps families cope (including both informal and formal sources of support); and research into short breaks use by families that have children with ASD.

As the research proceeded, further literature reviews were conducted, relevant to the second and third phases of the study. Regarding the second phase, the literature regarding social workers and ASD, and professionals' perceptions about ASD and disability was reviewed. With regard to the final phase, the literature concerning interviewing families, children and children with ASD was reviewed. These later reviews are detailed in Chapters 5 and 6. The literature reviews were undertaken by searching the following databases: British Education

Index, Ingenta Connect International Bibliography of the Social Sciences National Autistic Society: Autism Research Database, Social Science Information Gateway and SwetsWise.

## **2.3. Review of the literature regarding the impact of ASD on the family**

### **2.3.1. Living with a child with ASD**

ASD is a pervasive developmental disorder, affecting about 1% of the population (Baird *et al.* 2006). The disorder is characterised by a triad of impairments in social and emotional understanding, all aspects of communication and inflexibility in thinking and behaviour (Jordan, 1999a; Wing, 1996). Each of these impairments can occur with differing severity (Lord and Risi, 2000), and the cumulative effect can be significant upon the family and its functioning.

Many studies have been undertaken investigating the life experience of families that have children with ASD (Koegel *et al.*, 1992; Marcus, 1984; Randall and Parker, 1999). Although some recent studies have reported positive experiences and perceptions of family life with a developmentally disabled child (Hastings and Taunt, 2002, Taunt and Hastings, 2002), the overwhelming majority have identified that the deficits of ASD can have a significant negative impact upon the family and its functioning, as well as causing significant stress to the children with ASD themselves (Abbeduto *et al.*, 2004; Ghaziuddin and Greden, 1998; Groden *et al.*, 1994; Milgram and Atzil, 1988). The child's obsessions and narrow interests can impose extreme restrictions upon the family's social, leisure and recreational opportunities (Koegel *et al.*, 1992); and family adaptability and cohesion may be so affected as to fall outside healthy norms (Higgins *et al.*, 2005).



### ***Impact on parents***

ASD can cause greater parental anxiety and tension than other disabling conditions (Gray, 1993, 1994; Holmes and Carr, 1991; White and Hastings, 2004; Wolf *et al.*, 1989), and a high level of stress is reported as characteristic of parents of such children (Hastings and Johnson, 2001; Koegel *et al.*, 1992). Gray (1993) reports that parents may feel stigmatised as a result of the child's behaviours. A number of stressors have been shown to impact upon parents: the child's cognitive impairments (Bebko *et al.*, 1987; Koegel *et al.*, 1992); their linguistic impairments (Bebko *et al.*, 1987; Gray 1994; Koegel *et al.*, 1992); behavioural problems, particularly in areas such as toileting, eating and sexual expression (Abbeduto *et al.*, 2004; Bromley *et al.*, 2004; Gray, 1993; Sharpley *et al.*, 1997). A wide range of sleep problems may occur in ASD, and problems such as difficulty falling asleep, not falling asleep in their own bed, early morning awakening and multiple night time arousals can all impact significantly on families (Hering *et al.*, 1999; Williams *et al.*, 2004).

The principal caregiver for the child with ASD (as with children with disabilities in general) is predominantly the mother, who may consequently experience chronic fatigue and stress (Duarte *et al.*, 2005; Holmes and Carr, 1991; Milgram and Atzil, 1988; Tunali and Power, 2002). Fitzgerald *et al.* (1997) found that over a third of mothers of children with ASD in the Irish Republic report being constantly tired, and that mothers of children with more behavioural difficulties were in poorer health than others. The mother's wellbeing seems to be negatively associated with the challenging behaviours of the child with ASD (Abbeduto *et al.*, 2004; Hastings, 2003a), which can lead to social stigmatisation (Gray, 2002a). Tomakin *et al.*, (2004) report that the increased care-giving demands resulting from the impairments of ASD, particularly with regard to the child's lack of self-care skills, are associated with maternal

stress, and suggest that mothers may experience a number of negative consequences, including depression, feeling restricted to the role of mother/carer, and conflict with their spouse.

Fathers are generally less involved in the direct physical care of their children with ASD than mothers, often due to being the family's only wage earner (Holmes and Carr, 1991). Their lower level of direct involvement may account for them reporting lower levels of stress than mothers (Gray, 2002a; Hastings, 2003a; Wolf *et al.*, 1989), though it is clear that they too experience significant feelings of stress and stigmatisation (Gray, 1993, 2002b).

### ***Impact on siblings***

It is sometimes assumed that the presence of ASD will negatively impact upon the life experience of siblings (Fitzgerald *et al.*, 1997); and indeed some studies have identified negative associations. Gold (1993) found siblings of boys with ASD to be significantly more likely to experience depression than the general population. In addition to psychological problems, exhaustion may affect siblings who are responsible for domestic tasks and physical care; and problems can arise when increased parental expectations are not accompanied by increased parental attention or time (Harris, 1994; Rodrigue *et al.*, 1993).

Other studies suggest the picture is less clear. McHale *et al.*, (1986) found sibling relationships to be generally positive, and only slightly less cohesive than in families where ASD was not present; while a number of studies have found the majority of siblings to be well-functioning (Pilowsky *et al.*, 2004) and no more vulnerable to adjustment problems than the general population (Kaminsky and Dewey, 2002; Rodrigue *et al.*, 1993; Verté *et al.*,

2003). Moreover, where social or affective problems occur, their causation may be ambiguous. A genetic association has been identified between depression, obsessive-compulsive disorder, social problems and ASD, and such difficulties may be regarded as expressions of the broader autism phenotype rather than a result of having a sibling with an ASD (Hansen and Hagerman, 2003).

In some studies, the positive adjustment of the siblings may have been affected by external factors, such as the impact of formal support (Hastings, 2003b), attendance at autism-specific support groups (Kaminsky and Dewey, 2002; Mates, 1990) or a sibling education programme (Mates, 1990); Roeyers and Mycke (1995) identified an association between the sibling's understanding of autism and the sibling relationship. This relationship is also subject to the impact of other problems within the family: Rivers and Stoneman (2003) found that both stress within the marital relationship in parents of children with ASD, and high levels of family stress necessitating the use of formal support services, were associated with less positive sibling relationships.

### ***Impact of other stressors***

Koegel *et al.* (1992), comparing 55 mothers of children with ASD across a number of ages, functioning levels, cultural settings and geographical locations, suggest that a relatively consistent stress profile can be identified as characteristic of families with a child with ASD. However more recent studies seem to indicate that stress levels and profiles vary between families, and that the presence of significant behavioural problems and high levels of dependence are more important than the child's condition in determining parental stress (Floyd and Gallagher, 1997; Hastings, 2003a; Hoare *et al.*, 1998). Furthermore, it seems clear

that the stress that a family perceives within itself is subject to a wide range of variables, including not only child characteristics but also factors such as finances, housing, mutual support within the nuclear family, spirituality and belief systems and adjustment to the reality of the condition of the child with ASD (Bristol and Schopler, 1983; Gray, 1994; Marcus, 1984). Konstantareas *et al.*, (1992) argue that ASD is but one potential stressor among many, and suggest an interactive model of family stress and coping, including factors such as specific child characteristics, the personality characteristics of the parents, parental coping styles and the resources and supports available to the family.

### **2.3.2. What helps families cope?**

Families that have children with ASD deal with the pressures and stresses of life in their own individual ways. Some coping strategies may be dependent on cultural factors or the resources locally available. Marie Bristol has undertaken a number of studies within North Carolina (Bristol, 1984, 1985, 1987; Bristol *et al.*, 1993; Bristol and Schopler, 1983) where the TEACCH approach underpins the state's services for children and adults with ASD (Mesibov *et al.*, 1983). This research highlights the importance of local cultural norms and services. Membership of a church, and belief in God, were identified as important supports to parents in North Carolina, a region where religion plays an important role in society; also involvement with the TEACCH programme, and belief in its efficacy, were shown to be important in helping parents cope (Bristol, 1984; Bristol *et al.*, 1993).

However in studies undertaken in Brisbane, Australia, David Gray (1993, 1994, 1998, 2002a, 2002b) found far less importance placed upon either adherence to one particular approach or religious belief. Here support from within the family was identified as important and social

withdrawal was extensively used as a coping mechanism, enabling the nuclear family to avoid the difficulties inherent in social interaction. These strategies also fit in with the region's predominant culture, in that self-reliance and independence are societal norms (Gray, 1994).

Some factors that help families cope are less closely associated with geographical location or culture. Where specific intervention approaches are being used, belief in the intervention's effectiveness has been identified as an important coping strategy. This is equally true of families undertaking Applied Behavioural Analysis (ABA) early intervention programmes (Hastings and Johnson, 2001) and those using the TEACCH approach (Bristol, 1984). Sivberg (2000) found that different parents employ different coping strategies, such as distancing or escape, while Raif and Rimmerman (1993) found a strong sense of family coherence to be important in helping parents remain positive. Milgram and Atzil (1988) found that parents of children with autism report reduced stress levels when the 'burden of parenting' is reduced. This is supported by Gray (1994) who states that, though families may use a wide range of coping strategies, help with, and relief from, the day-to-day pressures of parenting the child with ASD – either through informal or formal support – are the most successful for a substantial number of families. Therefore, in this next section of this review, consideration is given to the impact of informal and formal support.

### ***Informal support***

Wolf *et al.* (1989) identify that parents of children with ASD are generally under greater stress than those of children with other disabilities and that social support moderated its impact. This buffering effect is also reported in other studies (Bristol, 1984; Gill and Harris, 1991). The most common source of social support is the partner or spouse of the main carer:

and studies clearly identify the importance of this spousal relationship to successful coping. Bristol (1985) suggests there is a strong relationship between paternal support and successful family adaptation; while Fitzgerald *et al.* (1997) argue that the state of the marriage/relationship is an important factor regarding maternal stress. Wider informal social support is also important (Bristol, 1984), and Raif and Rimmerman (1993) found a strong informal support system to be significantly associated with parents feeling able to continue caring for a child with developmental disabilities.

The literature identifies a number of significant points concerning informal support. Boyd (2002) argues that it is more successful than formal service provision in reducing the impact of stress within the family, and that parents who receive effective informal social support relate more positively to their children. It may be that experiencing others interacting with their child, and accepting their condition, helps parents accept and relate to their child. Boyd further suggests that low levels of social support are a strong predictor of maternal depression and anxiety in families that have children with ASD. Studies have also suggested that how parents perceive informal social support – from family, friends and community – may be a crucial factor. Weiss (2002) makes the point that perceived social support is as important, if not more, than actual practical help; this is supported by White and Hastings (2004) who identify that the perceived helpfulness of informal support is of greater importance in affecting parental wellbeing than the number of sources of such support.

However, it is clear that many families that have children with ASD receive only extremely limited social support (Gray and Holden, 1992; Konstantareas and Homatidis, 1989; Sanders and Morgan, 1997). This situation can lead parents to withdraw from the larger community,

because of the negative events they experience as a result of others' reactions to their child's condition; this withdrawal can then in turn exacerbate the parents' stress. In such circumstances many families turn to statutory services in search of more formal support.

### ***Formal support***

External support is clearly identified as a major benefit to families of children with ASD, and dependence upon assistance from outside agencies is a common coping strategy (Gray, 1994). Appropriate and effective educational provision can be extremely supportive, and satisfaction with the child's school placement has been shown to reduce family stress (Carpenter and Herbert, 1994; Oberheim, 1996). Another helpful formal support is parent training: positive outcomes have been identified both with regard to coping skills training (Ergüner-Tekinalp and Akkök, 2004) and to psychoeducational and parent management training (Bristol *et al.*, 1993; Shields, 2001; Shields and Simpson, 2004; Sofronoff and Fabko, 2002; Sofronoff *et al.*, 2004). In many cases, however, more direct support is needed; and some of the most common – and important – forms of formal support are short breaks services. I will now move on to review the literature regarding such services.

## **2.4. Review of the literature regarding short breaks**

In this section I will initially present a brief historical overview, situating models of service delivery in their historical and societal context, before discussing the literature concerning short breaks, at first with regard to families with disabled children in general, and then concerning those that have children with ASD.

### **2.4.1 Short breaks: an overview**

#### ***Historical perspective***

Formal short breaks have been known by many names over the sixty year period that they have been provided: relief care, respite care, short-term care and short breaks. The terminology has changed as service provision has been reconceptualised: originally understood as providing parents with relief from the burden of caring for a disabled child, it is now recognised as needing to provide positive opportunities for the disabled child as well as the rest of the family. Services for families that had children with learning disabilities began shortly after the Second World War, where children were admitted to hospitals to provide their families with ‘relief care’ (Oswin, 1984). Health services remained the main provider of short breaks for many years. Policy documents issued during the 1970s acknowledged parents’ and carers’ needs for regular breaks, advocating the development of ‘respite care services’ (Department of Health and Social Security, 1971; National Development Group for Mental Handicap, 1977; Committee of Enquiry into Mental Handicap Nursing and Care, 1979). As a result, service development began within local authority social care settings, initially comprising residential services, with the first family-based schemes emerging in 1979 (Stalker, 1996). Nationally, a wide range of services now exists, within local authority, health, voluntary and private sectors, providing both residential and family-based short breaks to disabled children and their families.

Short breaks have been identified as a key support for families with children with ASD (Beresford, 1994; Bristol and Schopler, 1983; Factor *et al.*, 1990; Geall, 1991; Preece, 2000). The two main models of short breaks services outlined above are the most common types of provision. In family-based services, generally known in the UK as Family Link, the family of



the disabled child is linked to another family, or families, who provide short periods of care for the child ranging from a few hours to a few nights at a time (Prewett, 1999). The Link Family is paid a small amount of money per session: the national average is £44 per 24- hour overnight period (Cramer and Carlin, 2008); however, becoming a family link carer is largely understood as an altruistic gesture (Prewett, 2000). In residential care services, short periods of care, ranging from one to several nights at a time, are provided in a residential home employing care staff. Other services that may be provided include sitting services and ‘befriending’ schemes (Prewett, 1999), holiday schemes (McGill, 1996) and short breaks provided in the service user’s own home (Olsen and Maslin-Prothero, 2001).

In general, all of these services are free to families assessed by local authority social workers as requiring such support. The range of short breaks services provided (and who provides services), eligibility criteria regarding access to services, length and frequency of stays, staffing levels and activities on offer all vary between local authorities; there are no set patterns or models required. However all short breaks services where the child stays away from home overnight are regulated by Ofsted and have to comply with national minimum care standards (Department of Health, 2002a, 2002b). I will now move on to discuss these models of service provision more fully.

### ***Models of service provision***

Family-based short breaks are generally provided by local authority social care services or voluntary care agencies, and are identified as having a number of advantages due to the domestic, non-institutional nature of the provision. The child is guaranteed a high level of one-to-one care and interaction, and communication between the child’s own family and the

host family is generally good. In a number of studies, parents and siblings report that they can enjoy a break, confident that the disabled child is being well looked after (Bradley and Aldgate, 1996; Hughes and Hind, 1989; Robinson and Stalker, 1989); and this type of service is generally viewed positively by both parents and professionals (Stalker and Robinson, 1994). However some caveats are raised. Robinson (1987a) suggests that children considered 'easier' or more likeable are more readily placed; and Cramer and Carlin (2008) show that teenage boys with ASD or 'challenging behaviours' are the most difficult to place. Bradley and Aldgate (1996) report that some parents fear that such services may undermine family relationships and integrity, and also that some families have experienced many disruptions. Furthermore Cramer and Carlin (2008) suggest that the availability of family-based short breaks seems to be shrinking, with the total number of children using services reducing from 7521 to 6761 between 1999 and 2008.

Residential short breaks are also provided by a wide range of agencies, including local authority social care and education departments, health care services and voluntary organisations. The trend over the past twenty-five years has been a reduction in residential services, as family-based services developed. This change has occurred for a number of reasons, ranging from the philosophical, such as the impact of the concept of normalisation (Wolfensberger, 1972) on social work policy and practice (Dalley, 1992), to the financial: residential care is more expensive than family-based care or other models of family support (Netten, 1996). Nevertheless, residential short breaks continue to perform an important function (Dowling and Dolan, 2001a). Family-based services tend to be used by more affluent families, or those with less demanding children (McConkey and Adams, 2000): thus residential services are of particular importance to families from low socio-economic groups,

or those who have children for whom it is difficult to recruit carers, such as those with challenging behaviours or high levels of dependence (McConkey and Adams, 2000; Orlik *et al.*, 1990) and from minority ethnic communities (Shah, 1992).

Research comparing users and non-users of short breaks identifies that stress levels – particularly in mothers – appear to be lowered where short breaks are available (Chan and Sigafoos, 2001; Factor *et al.*, 1990; Gray, 1994). Many parents who receive satisfactory short-term care consider it significant in enabling them to continue caring for their child (Beresford, 1994; Preece, 2000). However, not all findings in this area have been positive. Hartrey and Wells (2003) found that the use of short breaks and the resultant experience of separation caused guilt and stress in mothers. Aniol *et al.*, (2004), examining the impact of short breaks on reducing the potential of child abuse, found that short breaks alone did not result in either significant decreases in the potential for abuse or improvement in family relationships. Hoare *et al.* (1998) suggest that the use of short breaks per se is indicative of underlying carer distress, while Chan and Sigafoos (2001) voice concerns that positive time spent separate from the disabled child may lead to parental alienation.

Dowling and Dolan (2001b) suggest a need for alternatives to the two prevailing models of short breaks, and alternative models of service provision – such as ‘sessional’ or ‘befriending’ services, where a young adult is paid to ‘befriend’ a disabled youth in order to support their accessing mainstream leisure activities – exist in many areas. However few developments have been evaluated and only a handful of studies have researched alternative short breaks models. McGill (1996) studied a pilot summer play scheme for disabled children. He reports that families viewed this positively; and moreover that a need was identified for specialist day

time and evening activities to be developed for disabled youngsters, in addition to short breaks and play schemes. Olsen and Maslin-Prothero (2001) have evaluated a small service providing short breaks, in the family's own home, for families with children with complex health care needs. In this model, professionals come in and support the child, enabling one or both parents to take a break. The reaction to this service was mixed, and problems were identified concerning lack of flexibility and where families needed more immediate and responsive support.

The local authority in which this research was undertaken provided a range of short breaks services. The county's Family Link service had about 80 Family Link carers working across the range of disabilities, offering periods of care ranging from a few hours to two nights at a time. In addition, specially trained 'contract carers' had been recruited to work with 'hard to place' children, such as those with physical disabilities or those with autism. At the time of this study there were two autism-specific contract carers, each providing 182 days of care per year. Residential short breaks provision comprised a six-bed service for children with physical and multiple disabilities; a six-bed service for children with learning disabilities and associated challenging behaviours; and a six-place ASD-specific service. Each of these services was open 360 days per year, offering 2160 nights care. The maximum period of care offered in the residential homes was four nights at a time. The number of nights an individual child might receive in the ASD specific service during one year ranged from 12 to 84 nights, the average package of support being 48 nights per year (4 nights per month).

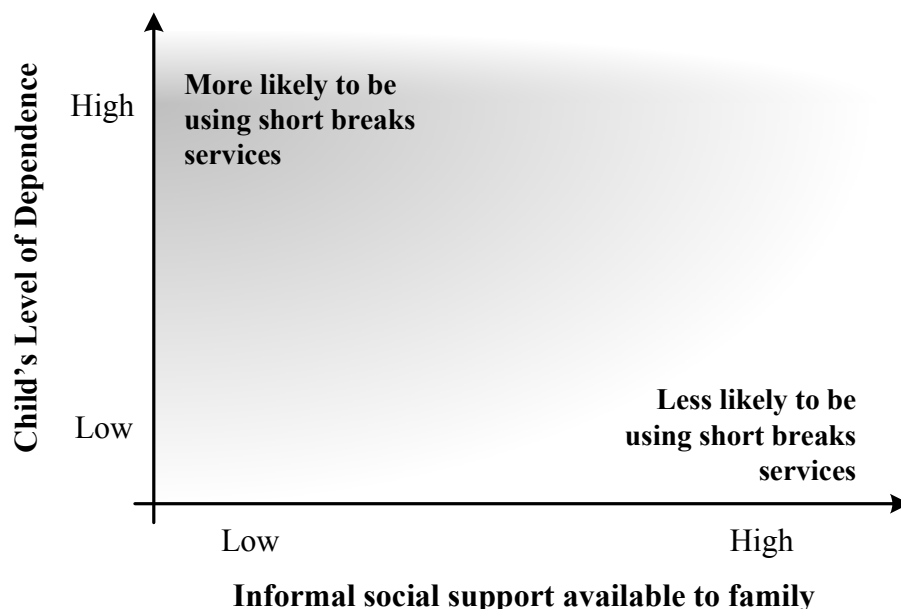
#### **2.4.2. Short breaks and families of children with ASD and other developmental disabilities**

Despite the caveats identified above, it is generally acknowledged that successful and appropriate short breaks help prevent family breakdown and children being placed out of the home (Abelson, 1999; Boyd, 2002). Numerous studies have researched the characteristics of families who access such services. This research has predominantly been carried out within a positivist paradigm, using positivist research designs. As Porter and Lacey (2005) suggest, this reflects the heavy influence of psychology in this field. Factors suggested as being positively associated with short breaks use include the child's gender and age (Jawed *et al.*, 1992; Salisbury, 1990), parental age (Grant and McGrath, 1990), family size (Robinson and Stalker, 1993), and the family's socio-economic status (Grant and McGrath, 1990). Many of these are identified in only one or two pieces of research. However two are widely supported within this body of literature as being strongly identified with short breaks use.

Firstly, it is suggested that short breaks tend to be used more by families that have limited informal social support (Boyd, 2002; Cohen, 1982; Factor *et al.*, 1990; Randall & Parker, 1999). Secondly, it is argued that families who use – or wish to use – short breaks services tend to have children who are more dependent, or who have more serious behavioural problems, than non-users (Boyd, 2002; Chadwick *et al.*, 2002; Factor *et al.*, 1990; Marc and MacDonald, 1988). This body of literature suggests that a model such as the one below (Figure 2.2) might be used to conceptualise short-break use. Within such a model, those families more likely to be using short breaks could be expected to have children with higher dependency and lower informal support. Those less likely to use such services could be expected to have children with lower dependency and a greater availability of informal support.

However, there is also a large body of research – predominantly carried out within interpretative/constructivist paradigms, and investigating the subjective experience of parents of children with ASD – which suggests that, on the contrary, it is those families that have the most dependent and disabled children, or those who exhibit the most challenging behaviours, who have the greatest difficulty in accessing short breaks. This finding has been identified regarding children with complex health needs (Shared Care Network, 2003), children with profound and life-threatening disabilities (Redmond and Richardson, 2003) and children who exhibit challenging behaviour (Trenenan *et al.*, 1997). Considerable evidence suggests access is also an important issue to families that have children with ASD, and a number of studies have been identified concerning the use of short breaks by this population.

**Figure 2.2** Factors associated with the use of short breaks services by families that have children with ASD: model derived from the literature



### ***Family-based short breaks***

The generic literature highlights family-based short breaks as a preferred source of support, and as one with many advantages. However, while experience of such services is considered positive for most children and parents, this may not be the case with regard to children with ASD and their families and a number of problems have been identified concerning the appropriateness and effectiveness of this service model. Appropriate carers are often unavailable. Prewett (1999) identified a national shortage of carers for specific groups of disabled children, such as teenagers, those with complex health needs, and those with challenging behaviour. Almost a decade later, Cramer and Carlin (2008) found the situation unchanged. This lack of carers means that families can be on waiting lists for services for years without ever receiving any service (Oberheim, 1996; Sargent, 1995). The behaviours exhibited by many children with ASD – such as self-injury and smearing faeces – can preclude a family-based placement even being an option (Barson, 1998) with carers unwilling to accept these behaviours in their own homes. Where children with ASD are linked to other families, these links have been found to break down more frequently than the norm (Barson, 1998). The development of ASD-specific family-based care services may be a way forward (Preece, 2003; 2008), but such schemes have not yet been formally evaluated, and recruitment may be an issue.

### ***Residential short breaks***

As with family-based services, the literature regarding residential short breaks for children with ASD is primarily one of dissatisfaction. Research shows that service criteria for residential services often exclude children with ASD. Reasons given can include the impact of their challenging behaviours on other service-users, and the disruption they can cause

(Sargent, 1995; Van Bourgondien and Elgar, 1990). Where residential short breaks are accessible, these services tend to be provided for a generic clientele of 'disabled children', and parents of children with ASD often find services inadequate or inappropriate. Research shows residential care staff to be often considered unskilled and lacking in knowledge or understanding of ASD (Barson, 1998; Forrest, 1994; Hand, 1994). Further problems can arise for a variety of reasons, including service-user mix, the types of activities on offer, ecological factors (volume levels, space, safety and security), and staffing levels and training (Barson, 1998; Oberheim, 1996; Leadbeater, 1999; Sargent, 1995).

Writing of short breaks in general, Tarleton and Macaulay (2002) suggest almost a third of children on waiting lists in the UK have ASD. Moreover, more able children with ASD, such as those who have Asperger Syndrome (AS), may be deemed not to have a disability by service providers, and thus fail to qualify for a service (Oberheim, 1996). Overall, the literature suggests that there are not enough short breaks services available to families with children with ASD in the UK. Brady (1998) reports that 55% of families with children with ASD in Great Britain consider lack of short breaks a problem, while Barson (1998) surveying residential short breaks services in Wales, found that only 7% of families were able to access such services.

## **2.5. Critical Review of the Research Literature**

It can be seen from the above review that the literature regarding both how ASD impacts on families' experience of daily living and concerning the use of short breaks by families of children with ASD, is complex confusing and in places seemingly contradictory. Factors contributing to this situation are outlined in this section.



### **2.5.1. Research on the impact of ASD upon families**

The literature on the experience of families with children with ASD has been shown to be problematic in some areas, with sometimes contradictory perspectives being offered. Moreover, the literature provides only a partial picture of family experience. In most of the literature discussed above (except where explicitly focusing on, for example, the experience of siblings) our understanding of family life is based upon research carried out with adults – mothers and fathers. Moreover, assertions are often made about *families* based upon data drawn solely from mothers (for example, Bristol (1987) on family coping, and Henderson and Vandenberg (1992) on family adjustment). Even when statements are made concerning *parents* these are sometimes based solely on maternal report, as in Hastings and Symes' (2002) study on parental self-efficacy. It is questionable whether it should be taken for granted that such maternal reports are necessarily indicative of their spouse's experience or that of their typically developing children, let alone that of the child with ASD (who is surely part of the *family*).

Though numerous studies have been undertaken into the experience of parents and siblings, the experience of children with ASD themselves remains under-researched. Studies have long identified that disabled children experience situations differently from their parents (Garth and Aroni, 2003; Raviv and Stone, 1991), but only a handful of published studies investigate the life experience of young people with ASD (Humphrey and Lewis, 2008; Jones *et al.*, 2007); and – as with the growing number of personal accounts of living with ASD (e.g. Gerland, 2003; Jackson, 2002; Sainsbury, 2000) these tend to concentrate on more able individuals. It has been argued that where the child's ability to communicate is severely impaired by incapacity or age, parents are of key importance, providing the context by which meaning can

be attributed to the child's experiences and actions (Case, 2000). This has sometimes led, even where studies focus on the child's experience, to research being carried out almost exclusively with parents and carers (Case, 2000; Gerard, 1990a).

A handful of studies have compared the experience of adult disabled individuals with that of other adult family members (Grant and Ramcharan, 2001; Ramcharan and Grant, 2001) and that of disabled children and their typically-developing siblings (Connors and Stalker, 2003). However, nowhere in the literature about the experience of families that have children with ASD have I been able to identify studies where the experience of parents, siblings and children with ASD within the same family have been investigated. This seems a significant gap in our knowledge and understanding of how ASD may differently impact, and an area in which research would be timely and appropriate.

### **2.5.2. Focus on parental experience and needs in studies regarding short breaks**

Similar concerns apply concerning the literature upon short breaks. Parental priorities have been identified with regard to short breaks, which are reported as being common across families with disabled children (Russell, 1995, 1996), and high on this list of priorities are appropriate and high-quality services. However, defining appropriateness and quality in such services can be problematic (see 2.5.6.), not least due to the very nature of short breaks. Such services have two recipients: the family (often meaning the parents) requesting a service, and the child with ASD who goes to the service setting. The needs, wishes and perceptions of the families (as defined here) and the children with ASD will be separate but interconnected and potentially conflicting (Grant and Ramcharan, 2001; Ramcharan and Grant, 2001). Achieving a balance in supporting both *carers* and *cared for* is an important aspect of short breaks, but

historically this balance has often been neglected. Research has predominantly taken a parental focus (Barson, 1998; Brady, 1998; Oberheim, 1996; Preece, 2000; Sargent, 1995), with parents as the main respondents and parental satisfaction as the main measure of service quality. The potential problems here are the same as those regarding the over-reliance on parental reports in the construction of our view of how ASD impacts on families. The privileging of parents' views and interpretations can minimise consideration of the child's perspective (Shakespeare *et al.*, 1999) and distort our understanding.

### **2.5.3. The views of children with ASD about short breaks**

This tendency to neglect the child's perspective has been criticised by emancipatory authors such as Middleton (1999) and Cocks (2000) who, arguing from within a social model of disability, are highly critical of short breaks. They suggest that such services stigmatise the disabled child, reinforcing their status as a problem for the family, and segregating children in preparation for a life of separation as an adult.

Middleton (1999) considers services provided within the child's own family home to be, from a philosophical standpoint, the most positive for disabled children. MacDonald and Callery (2004) suggest that the impact of the social model of disability upon social work training has been such that social workers now tend to perceive services that remove disabled children from their families (even for short breaks) negatively. Therefore they seek to provide services that do not remove children from their parents. This position is supported by research such as that undertaken by Radcliffe and Turk (2007). In their study of children attending a residential short breaks service in London, conducted by surveying parents using the service ( $n = 37$ ), over half the children were described as reacting negatively to service use, with 37% showing

strong negative reactions lasting several days. However, parents still value services that provide them with overnight breaks (MacDonald and Callery, 2004; McConkey et al, 2004; Preece, 2000) while their reaction to in-home services has been mixed (Olsen and Maslin-Prothero).

Other authors, though not arguing against the provision of short breaks, assert that disabled children should be more closely consulted and involved in service planning and research into service efficacy (Beresford, 1997; Morris, 1998a; Russell, 1998; Ward, 1997). Participation of disabled children and young people in decision-making is an emerging area (Cavet and Sloper, 2004; Franklin and Sloper, 2004; 2009) with only a handful of studies directly researching the experience of disabled children concerning short breaks (Anderson, 1996; Marchant *et al.*, 1999; Minkes *et al.*, 1994; Prewett, 1999). Within this literature, the difficulties inherent in accessing the opinions of some disabled children are clear (Beresford and Tozer, 2003; Ware, 2003). Problems can occur when children have cognitive or communication impairments (Minkes *et al.*, 1994) and it can be difficult both to ensure validity, and trustworthiness (Lewis, 2002; Preece, 2002), and to deal effectively with ethical dilemmas, such as consent (Lewis, 2002; Morris, 1998b). These studies vary considerably in scale and focus – from a local survey in Dundee (Anderson, 1996) to a national survey (Prewett, 1999) – but there is generally congruence between the findings. The majority of children report that they enjoy their short-term breaks, and like both the staff and other service users; a minority have negative experiences, and are unhappy either about the standard of care or being away from home.

In the main, results of generic research on disabled children's experiences of short breaks are generally positive. But are these results applicable to children with ASD? Though some children with ASD were included within these studies, none had an autism focus, or adapted their design to take account of the characteristic impairments of ASD. Instead, they consulted across a broad range of disabilities. The children consulted in Anderson's (1996) study for example, comprised one child with muscular dystrophy, one with severe autism, one with learning and physical disabilities and nine with learning disabilities; Minkes *et al.* (1994) carried out seventy-seven interviews with young people with physical and learning disabilities ranging from mild to severe – the number of young people with ASD is not specifically identified.

Focusing specifically on consultation with children with ASD concerning their experience of short breaks, Preece (2002) found that the characteristic impairments of ASD impact on their ability to participate in social and communicative processes such as consultation. Though small in scale – comprising three case studies – this study highlights a number of difficulties in carrying out consultation with this group, suggesting that generic methods of consultation may be inappropriate for such children. It is argued that the characteristic impairments of ASD – their social and communication difficulties, their desire for sameness and routine – may lead them to experience short breaks differently from other children. Some questions, such as those concerning playmates and friends, seemed to lack relevance for the children. This study concludes that further research is needed in this area.

#### **2.5.4. Lack of whole family focus**

Difficulties arise within the literature as a result of the tendency to focus on either the *family* (which, depending on the study, may mean the mother, or the mother and father, or mother, father and siblings – but which rarely includes the disabled child’s perspective) or the *child* in isolation. Wehmann (1998) suggests that the needs of developmentally disabled children living at home can only be fully understood within the context of their family – yet often an artificial separation is made between the needs of the family and the disabled child, both by professionals (Widdows, 1997) and in research (Grant and Ramcharan, 2001). Within the literature reviewed in this chapter only a handful (e.g. Bristol, 1984, 1985) explicitly conceptualise families as interactive systems and greater focus on the needs of the family as a whole is needed (Poston *et al.*, 2003).

#### **2.5.5. Lack of the service-provider’s perspective**

Some studies, particularly those carried out within an interpretative paradigm focusing on parental perspectives and experiences, are written as if unlimited service provision is – or should be – a given, advocating for services on demand, increased choice and localised services (Russell, 1995, 1996). However, services are not provided within a vacuum, and it is important to identify the perspective of service-providers. This includes those who indirectly provide services – national and local government, facing competing demands from different user groups, other areas of public spending, and financial constraints – as well as those engaged in direct service provision. The costs of supporting disabled children are high, and research identifies the need for cost-effectiveness studies regarding short breaks (Beecham *et al.*, 2002, Gerard, 1990b). However, in the literature on social care services for children with ASD, the issue of cost has been given little consideration and research has tended to focus on

overall spending rather than the effectiveness of models of service delivery (Bebbington and Beecham, 2007; Järbrink and Knapp, 2001; Järbrink *et al.*, 2003; PricewaterhouseCoopers, 2007).

Franck (2004) suggests that short breaks potentially provide

*“...the perfect environment for conflict and dissatisfaction or, perhaps worse, compromise that results in services that do not meet anyone’s needs well.”* (p289)

It is therefore imperative that the different perspectives of parents, families, children and service providers are explicitly acknowledged and stated to enable understanding of the differing viewpoints and negotiation to achieve appropriate outcomes to occur.

#### **2.5.6. Quality in short breaks for children with ASD**

Mention of outcomes takes us to the next issue. Research on short breaks in general has focused on the ‘soft’ outcome of parental satisfaction, rather than addressing more quantifiable outcomes (such as improved family functioning, improved child functioning or reduction in disabled children placed in residential schools or accommodated by the local authority). Grant and Ramcharan (2001) highlight the lack of longitudinal studies; and the paucity of studies considering the effectiveness of services is noted by a number of authors (Fortune and Proctor, 2001; Logan, 1999). McNally *et al.* (1999), reviewing twenty-nine studies on short breaks service, are critical of the methodology of many studies, suggesting there is little evidence that short breaks provide consistent or enduring benefits to carers.

Within the field of ASD, studies have measured quality and outcomes in early intervention with children with ASD (Hayward *et al.*, 2009; Luiselli *et al.*, 2000; Salt *et al.*, 2002;

Vismara, 2009) and the effectiveness of different educational and therapeutic approaches (Jordan *et al.*, 1998; Owens *et al.*, 2008; Reynhout and Carter, 2006; Stephens, 2008) and a range of quality indicators are suggested, including the child's cognitive and social development, social and communicative functioning, and parental satisfaction. By contrast, only limited research has evaluated outcomes in social care provision for people with ASD, primarily within residential services for adults (Matthews, 2000; Van Bourgondien and Reichle, 2001; Van Bourgondien *et al.*, 2003). Quality evaluation tools have been developed both for services for individuals with ASD (Druce and Reynolds, 1996; Morgan and Reynolds, 1996; New York State Education Department, 2001; Van Bourgondien *et al.*, 1998) and for generic short breaks services (Robinson *et al.*, 1996). However only limited research has focused on the validity and reliability of these tools (Beyer, 2003), and though first results are promising, significant gaps remain in the literature in this area.

Dempster and Donnelly (2002) identify that ethical, financial or operational concerns can impact upon the quality of research upon outcomes; and McConachie (1999) identifies the difficulty of evaluating the efficacy or impact of individual services upon disabled children and their families when multiple factors affect outcomes, and there are often a multiplicity of services involved with the family and child. Law *et al.*, (2008) further identify that families that have children with ASD may use a wide range of interventions (dietary, medication, behavioural, cognitive and physical) at any given time ( $n = 5,662$ , mean = 5.2, range = 0 – 68). As these interventions will be in use (and changing) at the same time that families are using social care supports and services, the picture is inevitably even further clouded.



Nonetheless, as Sloper (1999) asserts, it is necessary to move on from merely identifying problems to proposing solutions. This is particularly important given that current health and social care policy seeks to develop and define clear quality standards with regard to service provision (Department of Health, 1999; Department of Health/Department for Education and Skills, 2004; HM Treasury/Department for Education and Skills, 2007). Mitchell and Sloper (2002) identify parents' and children's quality indicators for a range of provision including generic short breaks services. A further step in the right direction – though still a measure of 'soft' outcomes – might be to seek to deepen our understanding in this area by identifying factors associated with quality in short breaks by whole families of children using short breaks: not only parents, but also siblings and children with ASD.

#### **2.5.7. Methodological concerns**

Further limitations result from methodological concerns, such as the provenance of the research, populations and sample sizes. Research on short breaks and ASD highlighting service shortfall has predominantly been carried out by or on behalf of the National Autistic Society (NAS) (Barson, 1988; Brady, 1998; Leadbeater, 1999), local societies (Oberheim, 1996) or short breaks organisations (Tarleton and Macaulay, 2002). The research is generally published by these organisations (which have a campaigning focus, generally demanding more or specialist services) without being subject to any process of peer review. As a result, it might be argued that the findings of these studies are those that the organisations concerned might wish to identify.

It is identified in 2.4.2. that a significant body of research has been undertaken, within both positivist and interpretative paradigms, focusing on parental stress in ASD, and studying the

users and non-users of short breaks. However, such studies have generally been carried out with small or potentially unrepresentative samples: Factor *et al.* (1990) for example, considering users and non-users of short breaks, surveyed only 36 two-parent families; while Gray (1993) researched the experience of 33 families in Australia. The results of studies with populations or sample sizes of this nature are not necessarily externally generalisable or applicable. Many UK studies concerning the short break needs of families that have children with ASD also have small or otherwise potentially unrepresentative samples. Barson (1998) surveyed just fifty-three families – all of whom were NAS members – to report on the situation across Wales. Brady's (1998) study also is based on a population comprising only NAS members.

Tarleton and Macaulay's UK-wide study (2002) is illustrative of problems inherent in this literature. Their 154-page study was published by the Shared Care Network, an organisation which campaigns for increased short breaks services. This study is described on its cover as 'thorough and persuasive' by a senior NAS manager; and national and local recommendations are made, based upon the study's confirmation of the 'overwhelming and lifelong need' for short breaks for families that have children with ASD (Tarleton and Macaulay, 2002). However, close scrutiny identifies severe limitations in this study. Only six adults with ASD were consulted, four of whom were members of an NAS Asperger Syndrome (AS) pub group known previously to one of the researchers; only two of this six had ever attended short breaks. Service provider responses ranged from 61% in residential short breaks services down to only 8% in sitting services. Again, the only parents surveyed were NAS members, with a response rate of only 15%. The research does not identify how many parents of children with ASD nationally are NAS members; however it seems questionable that 15% of NAS members

can be considered representative of the whole population of families with children that have ASD in the UK.

## **2.6. What do we need to know? The research questions**

From this review of the literature it can be seen that information is still needed concerning many areas relating to this topic. Four specific questions stand out as key, and comprise the research questions addressed within this thesis (Table 2.2).

The first of these is what can we learn of whole families' experiences of living with ASD? Other studies have focused largely on parental (predominantly maternal) experiences, while a few have looked at the experience of siblings or children with ASD themselves. However none have looked in an integrated way at the experience of whole families, comparing and contrasting the views of different members within the same families.

Secondly, what can we learn of whole families' attitudes to and experience of short breaks? Again our understanding of short breaks comes predominantly from a parental (usually maternal) perspective, and more information about how short breaks are conceptualised and experiences by whole families would add to the knowledge base.

Thirdly, more information is needed regarding what whole families (mothers, fathers, siblings and the children with ASD themselves) consider to be important in short breaks services for children with ASD, and what factors are associated with 'quality' within short breaks.

Finally, more information is needed with regard to what factors, both within and outside the family, are associated with whether or not families access formal support through short breaks? The literature on this topic is contradictory, and the model of use/non-use suggested by the majority of the literature (Figure 2.2) seems overly simplistic, and is contradicted not only by my experience as a practitioner with almost three decades of experience in this field, but also by some published studies.

**Table 2.2      The research questions**

- |  |
|--|
| <ul style="list-style-type: none"><li>• <b>What can we learn of whole families’ experiences of living with ASD?</b></li><li>• <b>What can we learn of whole families’ attitudes to and experience of short breaks?</b></li><li>• <b>What factors are associated by whole families with ‘quality’ within short breaks?</b></li><li>• <b>What factors, both within and outside the family, are associated with whether or not families access formal support through short breaks?</b></li></ul> |
|--|

These are the research questions addressed within this thesis. In the next chapter I will go on to describe the overall methodology and research design used within this study to answer these questions.

### **Chapter 3: Overall methodology and research design**

*In this chapter I describe and discuss the overall methodology and research design used within this doctoral research. I relate the choice of methodology to the context in which the research was carried out, to the theoretical and epistemological underpinnings of the overall study, and to the research questions. I describe how a case study approach, using multiple and mixed methods of enquiry, was identified as the most appropriate to address the research questions, and outline the shape of the overall study, which comprised three discrete phases.. This chapter does not outline or discuss the methods used in each discrete phase of the research: these issues are discussed in Chapters 4, 5 and 6 with regard to each phase individually.*

#### **3.1. Epistemological and theoretical underpinnings**

As I have explained, it is important to me – at a local level, with regard to my day-to-day work– that the short breaks services I manage are appropriate to, and meet the needs of, both children with ASD and their families, and that children’s and parents’ views and priorities should have a part in shaping these services. It is also important to me – within wider research and practitioner communities – that the voices of children with ASD and their families are heard, their views and needs are sought and identified, and that services are developed that address these needs.

These tenets are consistent with my epistemological position, which is informed by realism (Bhaskar, 1975; Danermark *et al.*, 2002; May, 2001; Sayer, 2000), in particular by Robson’s (2002) model of realism. Before undertaking this doctoral research, my approach to research –

both understanding it and undertaking it – was essentially pragmatic, seeking methodological approaches that fitted best with the research method at hand. In my initial undergraduate studies in Medieval and Modern History I had used qualitative, interpretative methods in my dissertation, while also developing an understanding of how mixed methods, and evidence from different sources and indeed disciplines (archaeology, carbon dating) can increase knowledge about the same phenomenon. In my Masters research in special education I undertook both quantitative and qualitative studies (Preece, 2000, 2002) and the ‘paradigm wars’ of quantitative methods being positioned as opposed to qualitative methods (Gage, 1989; Oakley, 1999) seemed illogical. With regard to particular epistemological standpoints, I found it easier to identify what mine was not. Whilst acknowledging the value of positivist approaches in the natural sciences, ‘pure’ positivism seemed to me unsuited to researching social phenomena.

At the same time, relativist approaches seemed inadequate as a way to conceptualise the experiences and understanding gained in thirty years of working in personal social services with severely disabled children and their families. For example, it is clear that ‘autism’ is a social construct: a strong reason behind the increasing numbers of people identified with autism is that the diagnostic criteria have shifted over time. Before the 1940s, when Kanner (1943) first described autism as a condition, it did not exist as a recognised entity. Since then, numbers have increased dramatically as the parameters have widened and autism has been conceptualised as a spectrum disorder. In the past, within European cultures, children on the autism spectrum might have been viewed as ‘changelings’ (Leask *et al.*, 2005; Waltz, 2009). Corbett and Perepa (2007) show that still today many languages and cultures have no word – or concept – for autism; and children with ASD are still dying during attempts to exorcise evil

spirits blamed for causing their condition (BBC News, 2003). Nonetheless beneath these varied ways of understanding the world lies the hard reality of impairment, which exists independent of theoretical beliefs or concepts about its nature.

Moreover the devaluing of both quantitative and qualitative methods associated with pure positivist and relativist standpoints seemed unhelpful to me. It seemed to me equally appropriate that ethnographic methods should be used to shed light upon the experience of working-class women at home (Hobson, 1980) and that randomised, controlled trials should be used to test flu vaccines (Munoz *et al.*, 2009). The flexibility offered within a realist perspective fits well with my 'natural' stance and with my position with regard to using the appropriate methods and tools to do the task at hand.

May (2001) suggests that the function of social scientific research within a realist paradigm is to identify the structures and mechanisms of the social world, to

*“...uncover the structures of social relations in order to understand why we then have the policies and practices that we do.” (p12)*

This social world is complex and stratified, incorporating individual, interactive, institutional and societal layers: the role of a realist research study to engage and address these different layers of reality. Realism asserts that the knowledge and understanding people have of the social world in which they live affects their behaviour. Moreover, although people's understanding about the social world may be incomplete or partial and they may not be directly aware of the underlying mechanisms of the social world, these mechanisms nevertheless affect their experiences (May, 2001). This fits well with my reading of social concepts such as 'hegemony' (Gramsci, 1998), where social structures (such as how public

services are understood and delivered) and ‘common sense values’ are seen as transient and ideologically created (Hall, 1980) (for example, within my working lifetime there has been a shift from a general understanding that the state should provide welfare support towards a culture of choice and individualisation which has been philosophically and politically driven). The task of realist scientific enquiry within a social scientific context is to develop theories to explain the real world, to test these theories by rational criteria, seeking to explain how actions and mechanisms, within specific contexts, produce events. Knowledge about and within this social world must be viewed as a social and historical product, which may be specific to a particular time, place and culture (Robson, 2002).

My research is further informed by family systems theory (Seligman and Darling, 1997): instead of considering ‘parents’ or ‘disabled children’ separately, families are considered as interactive units comprising discrete yet interdependent individuals, with individual and group needs. Family systems theory is discussed in detail in 2.1.

### **3.2. Linking theory and methodology**

These theoretical imperatives – that realist research within a social context must be concerned with critical interpretation, and that research informed by family systems theory should take account of whole families’ experiences – underpin this research. Using a three-phase approach, I seek to interpret how daily life is experienced by all members of families that have children with ASD; how the condition of ASD and its impact are variously interpreted by families and by social workers, the gatekeepers to formal social support, and how the social practice of ‘short breaks’ is experienced and interpreted by the members of families that have children with ASD. Finally I synthesise the findings of the three phases of my



research to construct a model describing the inter-systemic processes and interactions associated with short breaks use or non-use.

As identified above, it is necessary to identify and interpret what this practice means to the various individuals and organisations that interact within it. Participants may hold differing assumptions and beliefs dependent upon the role they play in the practice and the tradition that exists within that role (e.g. parent, child with ASD, social worker) within the specific time and place in which the research is being carried out. The impact of these assumptions and beliefs can be far-reaching and deeply-felt. Children with ASD and their families experience significant stress and social exclusion both because of the inherent problems of autism, and due to oppressive and restrictive conditions and mechanisms within society (for example, the value placed by society on disabled people, and on meeting their needs and the needs of those that care for and live with them). This study's research questions are clearly linked to both the results of the literature review and to my epistemological position: that a social practice such as 'short breaks' can be explained only through interpretation, and that research should not only collect observations, but also examine the mechanisms that affect choices and inform or inhibit the actions of the researched.

Similarly, the overall methodology and the research methods selected to answer these research questions are clearly linked to my realist position. It was important to me at the outset of this research to identify the many ways in which I differ from the families who are the subjects of my research. I am a practitioner/researcher in my early fifties; the parents in the study were mostly aged between their late-twenties and forties, with children aged from toddlerhood to young adulthood. I have thirty years working experience of short breaks across

health and social care settings; families will have a more limited experience as service-users, if they have any experience of service use at all. I have over fifteen years' experience of working with numerous children across the autistic spectrum, from those with severe learning disabilities to individuals with Asperger Syndrome; families' experience will vary from a few years to eighteen years and will be with fewer children, but will be of constantly living with autism. I trained as a teacher in the late 1970s and as a social worker in the early 1980s and have experienced how services have changed and developed over time; families may never have considered these services until they needed to use them, and their perspective may focus solely on their problems, needs and wishes in the here and now.

All these points show how as an experienced practitioner I inevitably hold a number of pre-understandings (Usher, 1996) about 'short breaks' and social care support, arising from my training, my experience and my personal leanings. These pre-understandings may be inconsistent not only with those of the families who are the subjects of the research, but also with those of other researchers. It was therefore vital to me that the research was grounded within the experience of families with children with ASD as well as within the literature. For this reason the research tools used to investigate the experience of families with children with ASD were designed in collaboration with families. In the first phase of the research, surveying families through the use of a questionnaire, the survey tool was designed in conjunction with parents of children with ASD from an adjoining county. In the third phase of the study, where interviews were carried out with whole families, the initial interview schedules were trialled with parents who had previously used short breaks; and the tools and visual supports used to aid consultation with the children with ASD were developed through discussion with their parents, siblings and in some cases the children with ASD themselves.

This decision, arising from my theoretical and philosophical position, impacted on the research design. For instance, the literature suggests an association between family stress and short breaks use (Chan and Sigafoos, 2001; Factor *et al.*, 1990; Guralnick *et al.*, 2008). This initially led me to consider using a formal tool such as the Coping and Stress Profile (CSP) (Olson and Stewart, 1995) or the Coping Health Inventory for Parents (CHIP) (McCubbin *et al.*, 1983) to formally assess levels of family stress within participants. However this did not sit comfortably with my desire to develop the research with “the researched”, and in conjunction with my supervisor I decided that incorporating such a formalised measure would be inconsistent and inappropriate, and that formal investigation of family stress levels fell outside the parameters of this study.

Similarly, acknowledgement of my professional role precluded investigation of some areas the literature identified as deserving further inquiry. The literature review identifies a paucity of research regarding service provider perspectives (2.5.5.). Within the local authority under scrutiny, I manage staff providing direct services to families that have children with ASD. I have also written much of the documentation and policy regarding these services. My pre-understandings (Usher, 1996) about short breaks would colour my analysis. Working day to day in this field I am inevitably impacted by my perceptions of “how things are”. However these perceptions are only anecdotal. They have not been obtained scientifically, and potential for self-deception exists in such situations (Gilovich, 1993). Furthermore, there are inherent issues of role conflict as well as dangers of my role affecting the data collected. I strongly believe this aspect of “short breaks provision” is worthy of study; I equally believe it would be inappropriate for me to do this in this research setting.

### **3.3. Combining methods: the overall research design**

The research questions that I address in this study, arising out of my review of the literature and experience as a practitioner, are as follows. What can we learn of whole families' experience of living with ASD? What can we learn of whole families' attitudes to and experience of short breaks? What factors are associated with quality in short breaks services by whole families? What factors, both within and outside the family, are associated with whether or not families access formal support through short breaks?

To address these questions it was first necessary to define the study geographically and with regard to size. Limitations of previous research identified in the literature review included small sample size and concerns about the representativeness of samples. It was therefore decided to seek to undertake this research with as close to a whole population (within a given area) as possible. As the research was supported by the local authority within which I worked, thus facilitating accessibility to the population, it was decided to locate the study within this area. Therefore the overall study would be a case study researching family life and short breaks use/non-use by families that have children with ASD, within this local authority.

#### **3.3.1. Case study**

Case study research is often associated with research with a small number of subjects (perhaps just one) and assumed to carry implications that data will be unstructured and that analysis will be qualitative (Gomm *et al.*, 2000). However, Edwards and Talbot (1999) helpfully define case study research as being involved with the study of a unit of analysis and that this unit may be

*“...an individual, a family, a work team, a resource, an institution, an intervention.”* (p51)

In planning this study, it was the intervention, short breaks, which I identified as the unit of analysis. The boundaries of the case are clearly defined both geographically – by location within the local authority – and by diagnostic criteria and age – families must have children with a diagnosis on the autism spectrum no older than 18 years at the start of the study.

### **3.3.2. Combining methods**

Edwards and Talbot (1999) further identify how rigour can be built into case study research through the use of triangulation. Among the methods they discuss are gathering information from a range of participants and utilising several methods to address the case. Volkmar *et al.* (1997) criticise the tendency of researchers in the field of ASD to consider data such as observation or parental comments in isolation, and consider such approaches open to challenge. Cohen and Manion (1994) suggest that using multiple methods in researching human behaviour can help minimise the distortion and bias that can result from relying exclusively upon one method or source of data. Within this study a combined methods design – using both quantitative methods (surveys) and qualitative methods (semi-structured interviews and observations) is used to address the research questions. Such a design may seem problematic to researchers who believe that ‘quantitative research’ and ‘qualitative research’ represent two separate paradigms (Clarke, 1999; Sale *et al.*, 2002). However as Kushner (2002) writes

*“...this is a false distinction...Paradigms are based on value positions, not on choice of methods.” (p257)*

Combining methods in this way to gather data from a wide range of complementary sources is consistent with a realist perspective. Realism acknowledges that social phenomena are varied and complex and that different methods may be appropriate to different aspects of an enquiry.

*“The social phenomena that we study ‘on the ground’ in the real world are unarguably complex, dynamic and contextually diverse... We need to marshal all of our multiple ways of knowing, and their associated multiple ways of valuing, in the service of credible and useful understanding. We need to adopt a mixed-method way of thinking about evaluation, especially social and educational program evaluation.” (Greene et al., 2001, p25)*

This reinforces advice from the British Educational Research Association which states that

*“...it is important to emphasise that there is no one strategy which is always going to be appropriate for every piece of research undertaken. It is very much a matter of...fitting the method or technique to what is being investigated.” (Campbell et al, 2003, p5)*

Gorard and Taylor (2004) and Greene *et al.* (2001) argue that combining quantitative and qualitative methods can result in more coherent, rational and rigorous research, bringing about a deeper understanding of the social phenomenon under scrutiny. Among the potential benefits of combining methods are the production of more comprehensive findings, greater validity; and the development of more credible and insightful inferences. I also felt that it would be beneficial to me – as a student researcher – to undertake research that enabled me to develop skills in using both quantitative and qualitative methods.

It was clear to me at the outset that I needed to use those methods that would most fruitfully and effectively enable me to generate data to answer the research questions. At that point, the only definite research method identified was the use of a questionnaire, to gather initial quantitative and qualitative data from as close to the whole population as possible. Though the nature of the research questions was such that I had identified that I would carry out interviews with families at some point, I had at that time no idea of with whom these would be carried out, how many interviews, or what their exact content would be. I intended the direction of the research to be data-driven, and therefore research design, as well as its analysis, was an iterative process.

### **3.4. Outline of the research project**

I wished initially to obtain quantitative and qualitative information from as close to the whole population of families that had children with ASD as possible, regarding the four research questions (to identify their experience of living with ASD, their attitudes towards and experience of short breaks (including levels of service use and the types of services used) and factors associated with use or non-use of such services and with quality). I also wished to test hypotheses regarding factors identified within the literature as strongly associated with service use or non use. In order to do this I decided to construct a questionnaire in conjunction with a group of parents of children with ASD from a neighbouring local authority (so that their experience was similar to that of the population being researched, but they were not part of that population). The method used in this phase of the research is described and discussed in full in Chapter 4 (4.2.1-4.2.9). This was posted in late 2003 to as close to the whole population that it was possible for me to identify, eliciting 155 responses (a 61% response rate. This good response rate gave my findings strength, validity and credibility (it is acknowledged that responses generally reflect the viewpoint of the major caregiver – predominantly the mother).

Data analysis from this large-scale survey of parents suggested two areas of study that may shed further light on the research questions: a relatively small-scale examination of social workers' understanding of ASD and a larger investigation, consulting directly with whole families about daily life and short breaks.

Having an allocated social worker is identified in the first phase of this study (4.4.4 and 4.4.10) as an important factor in short breaks use. Information about how social workers

understand ASD was identified as important in answering the research question focused on identifying factors inside and outside the family associated with short breaks use or non-use. To elicit this information, I again used a questionnaire to collect data; in this instance the questionnaire was adapted from a previously published tool. It was circulated to the whole population of social workers working with families with children with ASD within this local authority during autumn 2004. The response rate was 96% (n = 23), or almost the whole population. The method used in this second phase of the research is fully outlined and discussed in Chapter 5 (5.3.1-5.3.4).

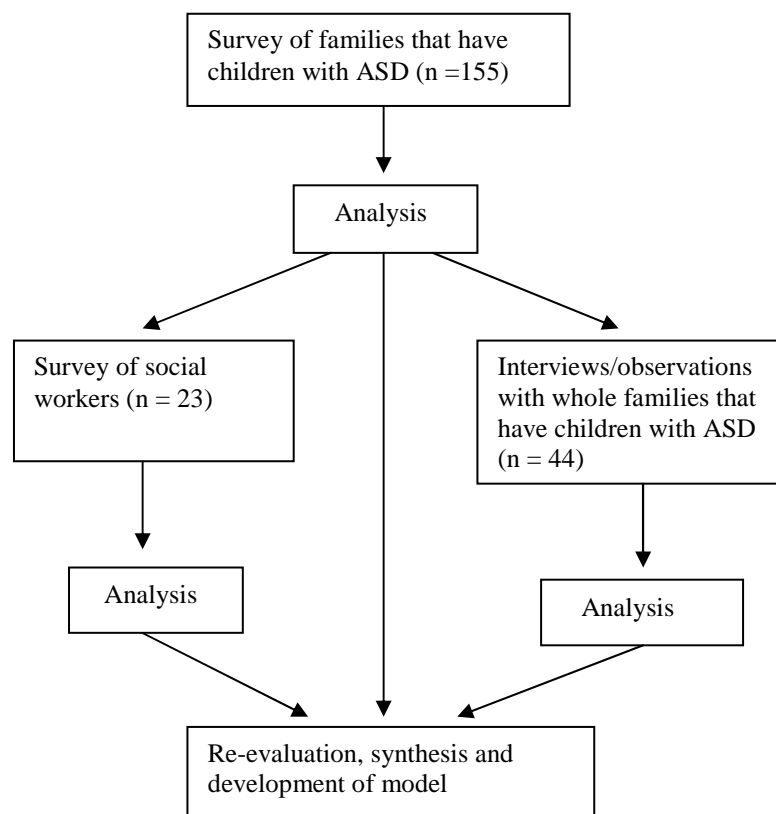
Analysis of the family survey identified that the sample could helpfully be considered as three subsets: families using short breaks, families that wished to use them (but were not doing so), and those that did not wish to use such services. To obtain deeper and richer qualitative data regarding whole families' experiences of living with ASD, whole families' attitudes to and experiences of short breaks, factors associated with short-breaks use and non-use, and factors associated with service quality, I consulted directly with whole families from these three subsets. Forty-two semi-structured interviews were carried out during the spring and summer of 2005 with members of fourteen families. In two families, parents were interviewed but did not wish their children to participate. In two further cases, children could not participate in the interview process due to their profundity of impairment; they were instead observed in both home and short breaks settings. Where parental permission was given, visual tools and supports maximised the reliability of the children with ASD's responses. Interview data were supported by the use of documentary evidence, including policy documents, social work assessments, and children's files and daily notes from the short breaks settings, facilitating triangulation within this phase of the research, and contributing to triangulation overall



(Robson, 2002). The method used in this third phase of the research is fully outlined and discussed in Chapter 6 (6.2.1-6.2.8).

The analysis of the data from each phase of the study and its re-analysis in the light of the findings from the other phases enabled me to answer the research questions and to develop a model illustrating families' use or non-use of short breaks. Figure 3.1 below shows the overall design of the project as it developed; Appendix 1 provides a detailed timeline of the research.

**Figure 3.1 Design of the research study**



### 3.5. Ensuring reliability, validity and trustworthiness

Reliability is concerned with

*“...the consistency or stability of a measure; if (the study) were to be repeated, would the same result be obtained.”* (Robson, 2002, p93)

As such, the concept of reliability is generally understood in terms of replicability. However, obtaining such reliability when researching in a social context, as in this study, is impossible. Data is dependent on respondents' interpretation of the questions. This can change due to personal or environmental factors. For example, a parent's response to the same question might change if their child's behaviour deteriorated, if services decreased or ceased, or even as a result of being in a different frame of mind. How social workers might answer the same question could vary as a result of a number of factors, such as undertaking training or working with different families, or with children with different needs.

Within this study as a whole, reliability is sought through the use of mixed methods and multiple sources of data. This enables triangulation to be undertaken, providing multiple perspectives upon the phenomena of living with ASD and short breaks, and increasing rigour. The robustness of the family survey tool was tested by piloting and carrying out the main research in two separate counties. These counties have some similarities though there are significant differences (the pilot county has more urban areas and a higher ethnic minority population), which could potentially impact upon replicability. However,

*“...reliability in terms of consistency cannot...always be a goal. Reliability in terms of getting the best information available and building up as rich and complex a picture should be.”* (Edwards and Talbot, 1999, p.83)

Robustness within the survey of social workers was tested by piloting the research tool with another group of social care professionals who worked with the same population of children.

## The concept of validity

*“...concerns the accuracy of the questions asked, the data collected and the explanations offered...It refers to the quality of data and explanations and the confidence we might have that they accord with what is true or what is real.”*  
(Denscombe, 2002, p100)

Validity is crucial to research design, and Robson (2002) stresses the importance of ‘construct validity’ – ensuring that the design meets its purpose. This was addressed in the three-phase study by a number of actions. The design within each phase was piloted and amended as necessary to ensure that the questions asked were fit for purpose to provide good data in the areas I wished to explore to address the research questions. I checked for ‘face validity’ or reasonableness by comparing the data to that produced in the pilot study, and with my own pre-understandings and experience. Within the two surveys, I used as large a sample group as possible. The response rate in the family survey was 61%, and comparison with the county’s special needs register identified the sample as corresponding closely to the whole population (see 4.2.8 and Table 4.2). The response rate for the survey of social workers was 96%. As such, the samples obtained can be considered as representative and the design as appropriate (Edwards and Talbot, 1999). Within the family interviews, the underlying design – seeking the views of different members within the same families – and the use of purposive sampling to identify the families interviewed, as well as the overall number of interviews undertaken (42 within 14 families), all strengthen validity. I designed the family survey, and designed and trialled the interview schedules in conjunction with families with children with ASD. I adapted the social workers’ questionnaire from a previously published and validated tool (Mavropoulou and Padelidu, 2000). Furthermore, as discussed with regard to reliability, triangulation was undertaken, using multiple data sources, and the whole research design is driven by the data and the literature.

Lewis and Lindsay (2000) highlight the need to ensure that the data are valid, and accurately reflects the perspective of the child, whether simply at that time, or on a more permanent basis. They highlight that this can be negatively affected by questioning techniques that inhibit the child's expression, or by failing to adapt the research tool to take account of the child's age and developmental level. In the family 'interviews', the tools used to consult with the children with ASD were individualised and adapted to suit the children, using my skill and expertise as a practitioner working within this field who delivers training to other professionals regarding communicating and consulting with children with ASD. In the same way, I used the skills gained in thirty years of working with children to ensure that the interviews with siblings were appropriately pitched.

To further maximise validity, I ensured there was transparency and explicitness about all aspects of the methodology and procedure of the research; and the validity of qualitative analyses throughout the study was tested by externally rating samples of data and checked for inter-rater reliability.

### **3.6. Generalisability**

External generalisability cannot be claimed for either the whole study or the parts thereof, for the opinions and experiences both of families and of social workers in different areas are shaped by many factors, including the level and types of service provision available (for example, ASD-specific care services had been established in the county used for more than a decade). Moreover, social and demographic factors (the county is largely rural, with a low ethnic minority population) would make direct comparison untenable with areas such as inner cities (even within other local authorities in England and Wales where the same legislative

framework governs service provision). My complete PhD research is in effect a large case study of a ‘singularity’ (the experience of these families with children with ASD) within a stated boundary (this county at this time). Acknowledging the study’s limitations, it is suggested that the findings may have value, permitting statements of ‘fuzzy generalization’ (Bassey, 1999) to be made. Both Bassey (1999) and Griffiths (1998) suggest study of singularities such as this might have more general relevance, in that the findings show

*“...that something has happened in one place and that it may happen elsewhere.”*  
(Bassey, 1999, p.52)

As such, ‘fuzzy generalization’ therefore offers others the opportunity to see if similar findings can be drawn elsewhere.

Such then is the overall design of the research reported on within this thesis. In the next chapter I shall move on to discuss the first phase of this research study: the survey of families within the local authority area.

## **Chapter 4: Survey of families with children with ASD**

*In this chapter I describe and discuss the first phase of my doctoral research in which I surveyed, as far as possible, the whole population of families with children with ASD within one local authority with regard to their experience of daily life and short breaks. I investigate three of the four research questions: those concerning families' experience of living with ASD, their attitudes to, and experience of, short breaks and factors both within and outside the family associated with short breaks' use. Quantitative and qualitative data were collected and analysed to explore how the impact of ASD was perceived and what services were being used across the population. It was accepted that the data elicited would be partial and exploratory, as only parental perspectives would be accessed, and in the main that of the principal respondent only. Information about the perspectives of other family members on these questions, and information about the fourth research question, concerning perceptions of quality, were collected through the interviews discussed in Chapter 6.*

### **4.1. Families with children with ASD, family life and short breaks**

The literature review concerning everyday life in families with ASD (2.5.1.) and their experience of short breaks (2.5.2, 2.5.3) presents no clear conclusions. Furthermore, the review identified methodological limitations within the literature, with many studies having small or potentially unrepresentative samples (2.5.7). Therefore, this survey was designed to elicit data from as close as possible to a whole geographically-defined population of families with children with ASD, investigating their experience of living with ASD, their attitudes to, and experience of, short breaks and identifying factors within and outside the family associated with short breaks' use.

## **4.2. Outline of method**

### **4.2.1. Description of sample**

Acknowledging that the sample should be as representative of the whole population as possible (Edwards and Talbot, 1999) I wished to include as close as possible to all families that had children with ASD in the county. Fortunately my employers (the county council) supported my research. This helped both in regard to access to the sample group and in meeting costs associated with the research.

The potential population comprised all families that have children diagnosed with ASD in this county who were registered on the local authority's register of disabled children at the time the survey was carried out in autumn 2003 ( $n = 278$ ). This register had been widely promoted, and comparison with Health Authority and Local Education Authority databases suggested that 70-80% of families had registered. However 'hard to reach' families who did not want any contact with services would not be included in the potential population.

### **4.2.2. Survey instrument**

A self-completion postal survey was selected as the most appropriate data collection tool to answer the research questions. Such surveys offer significant benefits when undertaking exploratory studies such as this. They are the most effective way of obtaining information about a large set of people, they quickly provide large amounts of standardised data, they are relatively unobtrusive, which can help response rates, and they can ensure anonymity, maximising frankness and validity (Edwards and Talbot, 1999; Robson, 2002). Potential disadvantages include low response rates and misunderstanding the questions; actions taken to address these issues are discussed in 4.2.6.

### **4.2.3. Survey design**

As discussed in 3.2 I was aware of my potential pre-understandings and prejudices regarding short breaks, and therefore wished to ground the research not only in the literature but also the experience of ‘the researched’: families that have children with ASD. Findings from the review of the literature are discussed in Chapter 2. To engage with the researched, survey design was undertaken in collaboration with parents of children with ASD. To ensure these parents were similar to the research sample, but not from the same population, I contacted a neighbouring county’s local ASD charity; this group supported me in contacting parents to collaborate on survey design and in piloting the survey. The county was comparable to the research site in terms of size, population and in that its social care services included both ASD-specific and generic services.

#### ***Parental involvement in the design process***

The parent group comprised mothers and fathers, both from families using short breaks and those that did not. Two meetings were held. At the first, in July 2003, I presented them with a number of issues for discussion (e.g. ‘respite care’, ‘issues for families’). I facilitated and recorded the discussion, noting their points on a flipchart. After the discussion, to maximise reliability (Silverman, 2001), the families confirmed the accuracy of the recorded information, and the data were collaboratively classified into general themes. These themes (*information, individualisation, inequality, availability, understanding of what services were for, and choice*) informed the questionnaire design. A draft questionnaire was taken to a further ‘pre-test’ meeting with the parent group in October 2003. The group reviewed each question’s wording, clarity and potential responses, and amendments were suggested and made. Changes were also made regarding the coding of responses.



### ***Areas of questioning and hypotheses***

The literature review, parental collaboration and my professional experience led me to decide that the survey would need to provide descriptive information about the child with ASD, the family, and their experience of and attitudes towards informal and formal support. The literature review also suggested that limited informal social support and high child dependence were associated with short breaks use. This suggested two hypotheses that could be tested through the survey: that families who use short breaks had more limited informal social supports than non-users and that users of short breaks had children with higher levels of dependence than non-users.

#### **4.2.4. Methodological considerations**

##### ***Gaining access to the sample group***

Registration on the county's database of disabled children was voluntary: no details were held without consent. All families were aware this database was used to provide information for planning and service development and had consented to be contacted to take part in research at the point of registration. This research was undertaken with local authority approval and adhered to its research governance procedures. Therefore it was possible to gain access to this group of families. In the questionnaire, families were asked if they would be willing to participate in further research. Thus this initial sample identified the population for the interviews carried out later in the project.

### *Survey size*

Survey size was determined by the population with ASD on the county's register of disabled children. When planning this research in early 2003 this stood at 278, which was estimated to be 70-80% of the total population of such children in the county.

### *Ethical issues*

All research studies are impacted by ethical concerns. The study complied with BERA Guidelines (British Educational Research Association, 1992) and with the University of Birmingham's Code of Conduct for Research (University of Birmingham, 1999). Ethical approval was obtained from the School of Education and from the local authority where the research was undertaken. When the study began, formal research governance procedures had not been developed: approval was obtained by submitting a research proposal to senior managers within Children's Services. Specific ethical issues are discussed below.

### *Consent*

Consent was obtained from the local authority to undertake the research and to use its resources (register coordinator's time, printing, and postage) and from the autism charity in the neighbouring county for its database to be used to support the questionnaire design and piloting and pilot study. Consent within the design group, pilot study and the family survey was interpreted by response to the questionnaire. In both the pilot study and the full family survey, a letter explaining the research and seeking the family's consent to participate in the study accompanied the questionnaire (see 4.2.6. and Appendix 3).

All documentation clearly stated that the research fulfilled two functions: to audit families' opinions, and to fulfil the requirements of my doctoral study. To prevent false hopes being raised, documentation explicitly stated that the survey would not lead to immediate service developments.

#### *Anonymity*

Anonymity was guaranteed as my only means of identifying children was by their unique registration number. Names were only made known to me after families had consented to take part in the case studies. In this thesis, all names have been changed, and no families are identifiable from quotations.

#### **4.2.5. Question design**

Whilst collaborating with the parent group, I reviewed published tools used to investigate families' experience and short breaks (e.g. Robinson *et al.*, 1994; Stalker and Robinson, 1991a). A draft questionnaire was designed, based upon the survey tool designed by Stalker and Robinson, which they successfully used to survey non-users of short breaks (Stalker and Robinson, 1991a). The original questionnaire was generic rather than ASD-specific, and was outdated in its terminology: for example, it referred throughout to 'relief care'. I adapted the questionnaire to make it ASD-specific rather than generic, and relevant to service users as well as non-users. It comprised an introduction (providing instructions and return details) and questions concerning the child and family, current use of short breaks, future/unmet needs and attitudes to short breaks. As identified in 4.2.4 this draft was shared with the parents and amendments were made regarding questionnaire wording and coding. This initial pre-testing was followed by a pilot study.

### *Dependence scale*

To identify respondents' perceptions of each child's dependence, they were asked to identify if their child needed help in ten areas (e.g. washing, toileting, communication). Responses were plotted on a scale (e.g. if a child was identified as dependent in three areas, their dependence level was three, and so on). This scale was developed by Robinson and Stalker (Robinson and Stalker, 1990) and successfully used in a large scale, multi-site study researching the experience of families with disabled children regarding short breaks (Robinson, 1987b; Robinson and Stalker, 1989, 1990, 1991; Stalker and Robinson, 1991a, 1991b). Using this scale enabled comparisons to be drawn between their generic study and this one.

### *Attitudinal scale*

I wanted to identify whether opinions voiced in previous research were shared and endorsed by parents in this population, and whether attitudinal differences existed between distinct groups of parents, such as users and non-users of short breaks. Five attitudinal statements concerning short breaks (e.g. 'Using respite care services emphasises the difference between disabled children and others') were taken from Stalker and Robinson's (1991) survey tool. Discussion with my supervisor led to agreement that their five-point scale was appropriate, as the mid-point ('not sure') might accurately reflect some respondents' attitudes. Two further statements relating to overnight breaks and the suitability of generic short breaks services were added as these issues were identified as issues by the parent group collaborating in the design process.

## ***Coding***

While developing the questions I began categorising and coding potential responses in preparation for computer analysis.

*“The coding process...constitutes the first step in mapping our observations into data.”* (Rose and Sullivan, 1996, p 38)

Respondents were identified by their unique Disability Register registration number. Each question was identified by a unique code, beginning with a letter to ensure the data could be analysed both in Excel and SPSS (Nelson, 2002; Pallant, 2001). Potential responses were assigned a numerical code. Although I attempted to identify all potential responses, it was acknowledged that coding responses may be an iterative process, and that the appropriateness and utility of codes would be tested in the pilot study.

### **4.2.6 Actions to maximise response rate**

As a major potential weakness in postal questionnaires is low response, actions were taken to maximise the response rate. The questionnaire was designed to be easy to read and to complete. Language use throughout was informed by the parent group and the questionnaire was worded to be jargon-free and understandable to non-professionals: for example “respite care” was used rather than “short breaks”. To ensure anonymity, questionnaires were distributed by the county’s disability register coordinator. Questionnaires (numbered with each family’s registration number) were posted out with an initial return deadline of three weeks. A signed covering letter (Appendix 3) explained the purpose of the research, gave return details and identified that the survey was anonymous unless families were willing to be available to participate in later interviews. The return date and address were clearly stated, and each letter was signed by the researcher. As the questionnaires were numbered, it was possible to identify where follow-up letters were required. The disability register coordinator

was told which numbered questionnaires had been received; further questionnaires and follow-up letters were then sent to those families whose registration numbers she had not been given, stressing the value of response, and requesting return within seven days.

#### **4.2.7. Pilot study**

Gorard (2003) states that an effective pilot study should be seen as a ‘dress rehearsal’ for the whole research process including negotiating access with respondents, delivering the questionnaire, coding responses and analysing data. Having amended the questionnaire and codebook, the pilot questionnaires and covering letters were printed. The covering letter differed from that used in the final survey in that it identified the purpose of the pilot study as being to ensure the fitness for purpose of the final questionnaire, that respondents had been randomly selected, that the study was totally anonymous and that aggregated information from the pilot study would be shared with the local charity. Edwards and Talbot (1999) suggest pilot studies of about 10% of the overall population. Thus this questionnaire was sent to thirty families, selected at random from the autism charity’s membership, but excluding those who had collaborated in design. Questionnaires were circulated on 7 October 2003. Ten responses were received. Three further envelopes were returned as address unknown (1) or addressee not known at this address (2). Thus the response rate from possible respondents was 10/27 or 37%.

Minor amendments were made to the questionnaire; changing wording and increasing space for responses to open questions (see Appendix 4 for the final version of the questionnaire). The most significant amendment arose from the data analysis process. Parents at the pre-test meeting had felt that ‘medical issues’ should be included in the areas used to identify

dependence, increasing their number from ten to eleven. Analysis of the pilot data showed this was superfluous, as medical problems led to dependence in other areas (e.g. sleep problems, need for constant supervision). Furthermore, amending the scale made direct comparison with Robinson and Stalker's study impossible. Thus I reverted to the original ten areas of dependence in the main study.

The low response rate was disappointing but I understood that for many respondents helping design a survey for use elsewhere may be a low priority. It was also possible that the most engaged families had participated in the design process and were consequently excluded from responding. The issue of incorrect data on the register (affecting 10% of the sample) was also noted.

This questionnaire's purpose was to provide data to enable me to test my hypotheses concerning the use and non-use of short breaks, and to identify factors impacting upon this. It generated both quantitative data and qualitative data (the text responses to the open questions). An essential facet of piloting was ensuring the data were analysable. Within this study both Excel and SPSS were used to analyse quantitative data. It was identified that creating the dataset in Excel and coding such data numerically would facilitate analysis (Gibbs, 2002; Pallant, 2001). Data were entered into Excel as they were returned, facilitating ongoing testing of the appropriateness and utility of codes and again amendments were made. Though the response rate was too small for meaningful statistical analysis, I learned that the dataset was fit for purpose and that data analysis would be practicable.

#### 4.2.8. Main survey

Two hundred and seventy-eight questionnaires were distributed on 20 October 2003. Families that had not returned them by 14 November (known to me only by their registration number) were sent a follow-up letter and further questionnaire by the register coordinator, with a return date of 26 November.

In twenty-two cases the family had moved out of county, the young person was nineteen or older, or the child did not have ASD. Thus the true population was actually 256. One hundred and fifty-five responses were received, a response rate of 60.5%. It was pleasing to receive such a high response rate from a postal survey as this would strengthen the study's findings.

Though respondents could return the questionnaire anonymously, sixty percent of respondents ( $n = 90$ ) provided names and contact details. From this information it was identified that five sets of siblings were included in the sample. Therefore although the population of children was 155, they came from a maximum of 150 families (85 of which had supplied names and contact details). It was impossible to ascertain whether more families with multiple children with ASD were included in the sample; therefore, a figure of 150 families is used throughout. In the overwhelming number of cases where the respondent is indicated, questionnaires were completed by the child's mother (79%). Details of respondents are shown in Table 4.1 below.

**Table 4.1      Postal survey: details of respondent where known ( $n = 85$ )**

<b>Respondent</b>	<b>No</b>	<b>%</b>
Both parents	11	13
Father	5	6
Mother	67	79
Did not indicate male or female	2	2



### ***Description of sample***

The county's special needs register database held statistical information about all families that had disabled children within the county. The questionnaires returned were compared with the information on the database regarding families that had children with autism to ascertain the sample's representativeness (Table 4.2). This identified the sample as generally representative. The gender split of children was almost identical (80% boys to 20% girls in the sample, 79% to 21% in the database. Within the sample and the database, 26% of families used short breaks. Ninety-five per cent of respondents were of White European ethnicity, compared to 94% of families on the database. Children aged under-11 were slightly under-represented (38% in the sample, compared to 44% on the database) as were children in mainstream settings (34% in the sample, compared to 39% on the database). However, in all areas compared, the two groups were within 6% of each other. Furthermore the response rate of 155 from a population of 256 gave an accuracy of +/-5% at 5% significance (Malec, 1993).

**Table 4.2      Comparison between children about whom responses were made and whole population on register**

	<b>Children in sample (n = 155)</b>		<b>Population on register (n = 256)</b>	
	No	%	No	%
Gender of child with ASD: male	124	80	202	79
Gender of child with ASD: female	31	20	54	21
Age of child: under 11	59	38	114	44
Age of child: 11 and over	96	62	142	56
School placement: mainstream	52	34	100	39
School placement: special unit in mainstream school	33	21	41	16
School placement: special	70	45	115	45
No support services used	72	46	121	47
Short breaks used	41	26	67	26
Services other than short break used	42	27	68	27
Ethnicity of family: White European	147	95	240	94
Ethnicity of family: Black, Afro-Caribbean or Asian origin	3	2	9	3
Home area: north of county	61	39	105	41
Home area: south of county	94	61	151	59

#### **4.2.9. Data analysis**

Quantitative and qualitative methods were used to analyse the data generated by the questionnaire.

##### ***Summary descriptive statistics (simple analysis)***

All numerical information captured by the questionnaire was expressed in tabular form. Frequencies and percentages of respondents within the specific categories defined within the questionnaire were compared and contrasted with regard to each question. Some questions in the survey (e.g. age, gender, child's school placement, use of short breaks) were included on the disability register registration form. Comparison between questionnaires returned and the disability register database enabled the sample's representativeness to be ascertained (see Table 4.2 above). This was crucial, for to ensure validity it is necessary that the sample is closely related to the whole population (Robson, 2002).

Simple analysis also provided basic information about the whole sample, such as the number of adults in the household, the child's age and diagnosis. This was analysed by categorising respondents – e.g. users of short breaks, non-users of short-breaks – and comparing subgroups to identify similarities and differences. This analysis of the raw data provided the figures to test my hypotheses though statistical tests were required to ascertain statistical significance. Means and deviations were calculated to compare subgroups within the sample. This provided important information (e.g. the mean levels of dependence of children of users and non-users and the standard deviation from these means, identifying the range of dependence within each category). Moreover, as Robinson and Stalker's study identified mean levels of dependence for the children of users and non-users of short breaks, simple analysis allowed comparisons to be drawn between their study and this one.

### *Statistical testing*

Statistical tests were used to go beyond merely presenting the data, and move on to analysing patterns within them, and differences between subgroups. To test the hypotheses, categorical data were analysed. Given the number of responses ( $n = 155$ ), chi-square was identified as an appropriate test and data were subjected to chi-square testing using a software package (Tall, 2002.) Chi-square is a relatively simple test, and was thus my first choice of test. If the results were significant, then they would also be significant when using a more powerful, but harder to use test. If the data had closely failed to reach significance using chi-square then a more powerful ordinal test, such as the Mann-Whitney U or Kolmogorov-Smirnov tests (Field, 2000; Robson, 2002) could have been used to compare groups and clarify any small differences observed.

### *Analysis of text*

Content analysis was undertaken regarding the text responses to open-ended questions. This technique consists of establishing a series of categories, then counting frequencies within those categories. Categorisation must be precise, so that different coders analysing the data can achieve the same results. Silverman (2001) identifies two factors as vital in content analysis: ensuring categories are applied consistently by different researchers, and ensuring counts are accurate.

Two methods of content analysis were used in this study. Robinson and Stalker used parents' descriptions of their children's usual behaviours (allowing up to three descriptors per child) to analyse and categorise their main behavioural characteristics. This same procedure was followed here – using the same categories – to identify differences between the two groups

regarding the types of behaviour that parents felt to be characteristic of their children. A fifteen per cent sample of parents' descriptions of their child's characteristic behaviours was rated independently by an external auditor to assess the reliability of my categorisation. Cohen's Kappa (Bakeman and Gottman, 1986) was used to identify inter-rater reliability. The commonly applied criterion is that an obtained Kappa of greater than 0.7 indicates that inter-rater reliability is satisfactory. In this case,  $K = 0.9$ , which shows the analysis to be reliable.

In undertaking content analysis based on a given set of categories, attention may be deflected away from data that cannot be fitted in (Silverman, 2001). There were clear reasons for using preordained categories regarding the children's behavioural characteristics. Elsewhere a more open type of content analysis was used. For example, to establish reasons for non-use of services, I first identified in the text all statements made regarding non-use. These statements were grouped into categories, which were then collated into key themes. Responses were re-analysed, to ensure no valid categories were ignored. Again, an independent auditor analysed a sample, to ensure reliability and validity, and Cohen's Kappa was again used to measure inter-rater agreement ( $K = 0.87$ ).

#### **4.3. Results**

Respondents to the survey were asked to provide information about their family; the child with ASD and their dependence, informal support; formal support; and their future needs. I shall begin by summarising the findings concerning the whole sample under these six headings. I will then go on to test the hypotheses suggested by the literature review against this data and the results of this analysis will be discussed in the light of the research questions.

#### 4.3.1. The child with ASD

##### *Age of child*

Children's ages ranged from 3 years 7 months to 18 years 9 months, with a mean age of 10 years and 9 months (SD = 3.9) (see Table 4.3).

**Table 4.3** Year of birth of child with ASD (n=155)

Year	No	%	Year	No	%
1985	3	2	1993	18	12
1986	8	5	1994	8	5
1987	8	5	1995	10	6
1988	18	12	1996	17	11
1989	4	3	1997	18	12
1990	8	5	1998	7	4
1991	9	6	1999	4	3
1992	13	8	2000	2	1

##### *Sex*

124 of the children (80%) were boys, and 31 (20%) girls. This is consistent with typical prevalence rates, where the ratio of males to females is around 3 or 4 to 1 (Mesibov *et al.*, 1997).

##### *Diagnosis*

Parents were asked to give details of their child's diagnosis, and almost three-fifths of the children in the sample were reported as having a diagnosis of autism or autistic spectrum disorder (ASD). Just fewer than a quarter had a diagnosis of Asperger Syndrome, while the remainder were reported as having severe learning disabilities with ASD or, in about 6% of the sample, 'autistic tendencies'. In all cases but one, this latter diagnosis was not used for children born since 1991. This may indicate greater diagnostic accuracy, or it may be related

to the development of services specific to ASD and the subsequent requirement of clarity of diagnosis. A summary of diagnostic information is shown in Table 4.4.

**Table 4.4 Diagnostic information**

Diagnosis	No	%
Autism/Autistic Spectrum Disorder	89	57
SLD/ASD, SLD with autistic tendencies	28	18
Asperger Syndrome, Asperger Syndrome + any other condition	38	25

### ***Educational placement***

The local authority in which the study was carried out has, since 1990, developed a wide range of ASD-specific classrooms, in both mainstream and special schools, based upon the TEACCH approach (Preece *et al.*, 2000), and almost two-thirds of the children within the sample were educated either within special schools or in ‘designated special provision’ (DSPs) attached to mainstream schools. Over a quarter of the children were fully included in mainstream settings. Further details regarding school placement can be seen in Table 4.5.

**Table 4.5 Educational placement of child with ASD**

	No	%
Mainstream	40	26
DSP in mainstream	33	21
Special school	70	45
College	8	5
Residential school	2	1
Not at school (excluded from mainstream)	1	1
Nursery	1	1

### **4.3.2. The family**

Five respondents indicated that there were two children with ASD in their families. Therefore, although data were collected regarding 155 children, these children came from (at most) 150 families. More families may have had more than one child with ASD; however, this was not

indicated on the response to the survey. Therefore, throughout this thesis, the total number of children is taken to be 155 and the total number of families to be 150.

### ***Ethnic origins of parents***

In 142 (95%) of the families, both parents were of White European origin (this is consistent with the ethnic make-up of the population within the local authority. According to a national census carried out in 2001 (National Statistics Online, 2001) the White European population of the county is 95%).

### ***Number of adults in household***

In 105 families (70%) both parents were in the household; in 11 households (7%), one parent plus a partner were present; in 34 families (23%) only one parent or person with parental responsibility was present (see Table 4.6).

**Table 4.6      Adults in household (n = 150)**

	<b>No</b>	<b>%</b>
Mother and father	105	70
Mother only	31	21
Father only	2	1
Grandparent	1	1
Mother and stepfather/partner	9	6
Father and stepmother/partner	2	1

### ***Adults' employment status***

Only 15 families (10%) contained two adults working full time. In 57 families (38%) there was only one income, with 16 families (10.7%) containing just one adult working part time. Twenty-nine families in total (19%) contained no adult in employment. In single parent

families (n = 34) only three adults – one father and two mothers – worked full time. In 53% of these single-parent households (n = 18), the parent was not in paid employment.

### ***Children in household***

The number of children in the household (including the child with ASD) ranged from 1 to 5, with a mean of 2.3 (SD = 0.9). Almost three quarters of the respondents (116 families) had two or three children; and five indicated that they had two children with ASD. In all but six families, the child with ASD was resident in the family home; two children were placed in residential school, two were living in a residential home for children with ASD, and two were living in other settings. Further details concerning the number of children in the household are shown in Table 4.7.

**Table 4.7      Number of children in household**

	<b>No</b>	<b>%</b>
One child	24	16
Two children	74	49
Three children	37	25
Four children	12	8
Five children	3	2

### **4.3.3      Dependence level of the child with ASD**

#### ***Areas of dependence***

To identify the parents' subjective interpretation of the dependence of their child, and to enable comparison both between children and between the areas of dependence, to be made, parents were asked to identify whether their children needed help in ten areas: washing, dressing, toileting, eating and drinking, managing behaviour, occupying self, getting around, communicating, need for constant supervision, and sleeping problems.



It is acknowledged that a child's dependence is affected by a number of factors, not least the child's age: the younger the child, the more dependent they might be expected to be. Robinson and Stalker (1990) did not make any adjustments to allow for the disabled child's age in their study, and therefore, to facilitate comparison, nor do I in mine. However, as is shown in 4.3.1, the mean age of the children in this study was 10 years 9 months, and only 6 of the children (4%) were aged below 5 years. Furthermore, the results showed that difficulties were experienced in all these areas of dependence by many children with ASD, across the whole age range; even the least problematic (eating/drinking) was one in which almost 60% of the children were dependent. Almost 90% of respondents reported that help was needed to enable their children to get out and about and to manage their difficult behaviour and over 80% of parents felt that their children needed help in the areas of communication and washing (see Table 4.8). Parents reported different levels of dependence within these areas, and employed differing strategies to deal with their children's needs. These are discussed in the following section.

**Table 4.8      Dependence of children with ASD**

<b>Area of dependence</b>	<b>No</b>	<b>%</b>
Managing behaviour	136	88
Getting around	136	88
Washing	128	83
Communicating	125	81
Dressing	118	76
Constant supervision	110	71
Occupying self	96	62
Sleeping	93	60
Toileting	93	60
Eating and drinking	92	59

### *Managing behaviour*

This was one of the two areas identified as problematic for the greatest number of children – 88% of the sample. Many parents described their children as exhibiting severe behavioural problems, including self-harm, aggression to others, swearing, shouting, destruction of property and smearing faeces.

*“Very destructive. Becoming quite aggressive. No sense of danger at all - climbs everywhere, tips drinks over, hangs off curtains.”* (Parent of 4 year old boy)

*“Can become very upset, biting himself and banging his head.”* (Parent of 8 year old boy)

Respondents describe a range of strategies that are used to help manage the child’s behaviours. In some cases, parents use elements of the TEACCH approach (Schopler *et al.*, 1995) to reduce the child’s confusion about what is happening, in a manner consistent with that used in schools in the county. Other parents make use of ‘social stories’ (Gray and Garard, 1993), a method of teaching appropriate behaviours and social rules to children with ASD, which initial studies are identifying as beneficial (Norris and Dattilo, 1999; Smith, 2001). Many parents managed their child’s behaviour by avoiding situations which they knew to cause the child distress, and adjusting how the family lived to fit in with the child.

### *Getting around*

Getting around was also identified as an area in which almost 88% of children were dependent. The level of support needed ranged from only slightly more than typically developing children to total support. In some cases the child’s dependence and reluctance to go out and about places severe restrictions on the family. Again, families used a wide variety of strategies to enable them and their child to get out and about, ranging from the use of TEACCH schedules (Schopler *et al.*, 1995) to the use of restraints.

In eleven cases (7%), respondents reported that they used buggies or pushchairs to get out and about with the children, even though the children were able to walk and had no physical disabilities:

*“Has to use special needs pushchair - can walk but resists. We try short journeys, then he just sits on the ground.”* (Parent of 4 year old boy)

*“If out in busy places needs use of major buggy as is very good at wandering off. Behaviour is more manageable in buggy as feels safe in own space.”* (Parent of 7 year old boy)

### *Washing*

Children were identified as dependent in the area of washing in 83% of cases. There was a wide range of dependence, from children who required supervision or prompting to those who were totally unable or unwilling to wash themselves and who required total support. Children's attitudes towards personal cleanliness varied widely, from some who had no interest in this area to others who were obsessively clean. Other problems associated with washing and bathing included children having difficulties understanding the sequence of activities involved in bathing to concerns about safety and hygiene.

### *Communicating*

Dependence in this area was reported in 81% of cases. Almost 20% of children were reported as having minimal or no speech. Even where children could speak their parents reported that they were often reluctant to do so, or experienced problems in communicating with others. Finger pointing and signing were strategies reported by parents in aiding communication, as was the use of the Picture Exchange Communication System (PECS) approach (Frost and Bondy, 2002), a visual system for encouraging communication in children with ASD.

### *Dressing*

Over three quarters of the children were dependent in the area of dressing and undressing. With regard to the process of dressing/undressing, the level of help needed ranged from children requiring assistance with buttons, zips and laces, to children who needed help with sequencing or putting clothes on the right way round, to children who required dressing completely. Some children were reluctant to wear clothes at all, while others had a restricted range of clothing, or dressed inappropriately.

### *Need for constant supervision*

Seventy-one per cent of respondents felt that their children required constant supervision. In some cases this was because of the child's lack of initiative but more commonly constant supervision was viewed as necessary to keep the child safe.

### *Occupying self*

Sixty-two per cent of respondents felt their children were unable to occupy themselves effectively without adult help. A range of problems was identified, from children who had limited attention to others who would engage in a limited range of activities. Parental participation was reported as being necessary in many cases if purposeful activities were to be undertaken.

### *Toileting*

Toileting was an area of dependence for 60% of children. Twenty one children (14%) were still in nappies, 22 (14%) were incontinent both by day and night and 23 (15%) needed a parent to wipe their bottom after going to the toilet. Other areas of difficulty included children

who did not go to the toilet unless reminded, children who were afraid of the toilet, children who needed supervision and prompting to complete the task in the right sequence. Even when children were able to use the toilet, further problems arose due to their being restricted with regard to which toilets they would use.

### *Sleeping*

Sleeping was also an area of dependence for 60% of the children (n = 93). Thirty children (19%) were reported as not going to sleep till very late at night, 28 (18%) were reported as waking several times in the night and 15 children (10%) woke very early in the morning. Some children suffered panic attacks on waking while others still slept with their parents. Further difficulties included children needing to undertake bedtime rituals or requiring a parent to remain with them until they had fallen asleep.

### *Eating and drinking*

Finally, eating and drinking were reported as being an area of dependence for just under 60% of children. Ten children (6%) were on special diets (e.g. gluten-free, dairy-free) as their parents reported that they had food intolerances. Many children had problems understanding 'table manners' and tended to eat with their fingers rather than cutlery; others could use a knife and fork but needed their food cutting up. Problems concerning food intake ranged from children who could not recognise they were full to others who did not recognise when they needed food or drink. Many children had a restricted diet and respondents also reported other restrictive behaviours concerning food and drink.

### *Levels of dependence*

The data were then investigated to ascertain how many children needed help in how many areas (see Table 4.9). It can be seen that very few children need little support. Over two thirds of the children were reported as dependent in 7 or more areas ( $n = 104$ , mean = 7.25, SD = 2.6), with over 40 % of children being reported as dependent in 9 or 10 areas, and almost a quarter being dependent in all areas. Within Robinson and Stalker's research (1990) the mean level of dependence across their whole sample was 6.4. The elevated level of dependence across this sample supports the findings within the literature that children with ASD have greater levels of dependence than those with other disabilities, thus placing greater levels of stress upon families (Chadwick *et al.*, 2002; Factor *et al.*, 1990).

**Table 4.9      Number of areas in which children were dependent**

	<b>No</b>	<b>%</b>
No help necessary	2	1
One area	2	1
Two areas	6	4
Three areas	7	4
Four areas	9	6
Five areas	12	8
Six areas	13	8
Seven areas	20	13
Eight areas	18	12
Nine areas	29	19
Ten areas	37	24

### *Medical issues*

Medical issues affect 45 children (29%) in the sample. Epilepsy is the most common medical condition reported, affecting 24 children (15% of the sample). Though the most common condition noted here, the incidence across the sample group is slightly lower than that reported as existing across the whole population with ASD, where incidence figures are reported as being between 18-29% (Kielinen *et al.*, 2004). The next most common conditions

were bowel and digestive problems (n = 9: 6%) and asthma (n = 6: 4%). Nine children (6%) had multiple medical conditions in addition to their diagnosis of ASD: the others had one medical problem in addition to their ASD. Full details are shown in Table 4.10.

**Table 4.10 Medical conditions affecting children with ASD**

Medical condition	No	%
Epilepsy	24	15
Bowel/digestive problems	9	6
Asthma	6	4
Visual impairment	2	1
Hydrocephalus	2	1
Obesity	2	1
Hearing loss	1	1
Ear infections	1	1
Obsessive Compulsive Disorder	1	1
Cerebral Palsy	1	1
Orthodontic problems	1	1
Eczema	1	1
Diabetes	1	1
Tourette's Syndrome	1	1
Heart disease	1	1
Urinary tract infections	1	1
Chronic lung disease	1	1
Dyspraxia	1	1

#### 4.3.4. Child's behaviour

Respondents were asked to describe their child's general demeanour and behaviour. Many highlighted the complexities of trying to describe what was 'usual' and illustrated the difficulties and stresses facing the child with ASD and the whole family.

*"That's a difficult one! Naomi can be very happy or very distressed. Naomi became very upset at school at Easter and it took her 3 months (screaming constantly) before she calmed down, but has been much happier since the school holidays. She is very quick tempered and does bang herself against objects when cross - but generally happy and cheerful."* (Parent of 10 year old girl)

Several respondents were very positive about their children with ASD, but nonetheless were clear about the problems caused by the condition, and the limitations that it placed on the child and family.

*“My child is great fun but can be very draining and unpredictable.”* (Parent of 11 year old boy)

As discussed in 4.2.9, parents’ descriptions of their children’s typical behaviours were compared with Robinson and Stalker’s study to ascertain any differences between the two populations (see Table 4.11).

**Table 4.11 Comparison of parents’ descriptors of their child’s behaviours**

	<b>Robinson and Stalker (1987-1991) generic study</b>		<b>This ASD-specific study</b>	
	Users of short breaks	Non-users	Users of short breaks (n = 41)	Non-users (n = 114)
<b>Behaviour</b>	<b>%</b>	<b>%</b>	<b>%</b>	<b>%</b>
Sociable, easy going	44	42	13	14
Passive, introverted	9	13	2	25
Active	20	23	15	11
Anti-social	26	22	50	37

Parents in this ASD-specific study (both users and non-users of short breaks) reported much higher levels of anti-social and introverted behaviours from their children, and much lower levels of sociable and easy going behaviour. Furthermore, families who used short breaks reported that their children exhibited more anti-social behaviours (e.g. aggression, tantrums, self-harm, running off) and active behaviours (short attention span, noisiness, over-activity, constant chatter) than non-users.



#### 4.3.5. Informal support

Respondents were asked about the sources and the levels of informal support that they received. The mean level of informal support available was 2.0 (SD = 1.0), with 7.1% receiving no informal support at all, and only the same number of families receiving support from more than three sources (see Table 4.12).

**Table 4.12 Total sources of informal support**

	No	%
No sources	11	7
One source	35	23
Two sources	59	39
Three sources	33	22
Four sources	10	7
Five sources	1	1

The most frequent source of support was the main carer's spouse/partner (81%), followed by grandparents (39%) and other children within the nuclear family (37%). Support from beyond this immediate family network was minimal. Little support appeared to be available from friends (15%) or neighbours (5%). This highlights the level of social isolation that can result due to the presence of ASD in the family (Gray, 1993). Full details regarding sources of support are shown in Table 4.13.

**Table 4.13 Sources of informal support: whole sample**

	No	%
Partner	121	81
Grandparents	59	39
Other children	55	37
Other relatives	29	19
Friends	23	15
Other	9	6
Neighbours	7	5

Over half of the children had rarely or never stayed away from the family home overnight (see Table 4.14). Slightly more than a quarter stayed overnight periodically with close

relatives, such as grandparents or ex-husbands; however only 4 children (3%) had ever stayed with friends or at a ‘sleepover’. Whether or not children stay away from home is influenced by many factors, including, of course, the child’s age: however, of the 86 children who had rarely or never stayed away from home, 29 (34%) were aged 11 years or over.

**Table 4.14 Does the child stay away from home overnight?**

	No	%
Frequently	30	19
Sometimes	38	24
Rarely/never	86	55
No answer	1	1

Over half the respondents (n = 89: 59%) were satisfied with the level of informal support that they received. However, just over a third (n = 52: 35%) were dissatisfied with the available support.

*“We hardly ever go out as a couple and find it awkward to ask relatives as they have their own families. Our parents are elderly and our son will not settle with others.”* (Parent of 11 year old boy)

#### **4.3.6. Formal support**

##### ***Assessing formal support***

To access formal social support, it is necessary to have a social worker undertake an assessment of need within the Framework for Assessment of Children in Need and their Families (Department of Health/Department for Education/Home Office, 2000).

Fewer than half the children (n = 73: 47%) were allocated social workers. Nonetheless in more than two thirds of the sample, parents (n = 104: 67%) reported that using short breaks had been suggested to them. While social workers were the most frequent source of information about short breaks (n = 53: 34%) the use of short breaks was also suggested by a

wide range of other sources, including other parents, friends, teachers, doctors and other professionals. When asked how they would find out more about short breaks, families' responses suggested a lack of clarity and information about services. While 46 families (31%) stated that they would contact Social Services, a further 10 families (7%) said that they would contact either their child's school or the local autism charity to be signposted. Over 20% of families (n = 31: 21%) had no idea how to go about accessing short breaks.

### ***Need for formal support through short breaks***

Respondents were asked whether they felt that they currently needed formal support in the form of short breaks. Responses from both parents were similar, though mothers expressed a slightly greater need (see Table 4.15).

**Table 4.15 Do you have a current need for short breaks?**

	<b>Female adult in household (n = 148)</b>		<b>Male adult in household (n = 115)</b>	
	<b>No</b>	<b>%</b>	<b>No</b>	<b>%</b>
No	61	41	54	47
Yes	87	59	61	53

In total, almost 60% of families expressed a current need for short breaks (n = 88: 59%). Despite this, only a quarter of families actually received this type of support. Forty-one children (26%), from 39 families, attended short breaks, with 26 children (17%) attending residential settings only, and 13 children (8%) going to family-based short breaks only; 2 children (1%) attended both types of service. The low figure for family-based care, the preferred source of short breaks support in the literature, may result from the difficulties identified by previous research in identifying families willing and able to provide this type of

service for children with ASD. This is supported by comments from respondents who had found it impossible to access family placements.

*“Social Services could not find anyone suitable because of his height, weight and age. He needs male carers and they had no one.”* (Parent of 17 year old boy)

Where families accessed residential short breaks, packages of support below 5 nights per month (60 nights per year) were most common (n = 18, 64%); only 4 families (14%) reported packages of support higher than this. The level of support received from family-based services was not identified: this is an aspect of the questionnaire that I would amend if I were carrying out this study again.

Where families were able to access short breaks, respondents spoke of the benefits that the whole family gained from this service. Comments indicated the perceived value to parents –

*“Time to be a couple again. To be able to talk. To de-stress. To cope better.”*  
(Parent of 7 year old boy)

*“Able to sleep, think, eat in peace; read the paper or a book; go out for a walk; go out for an evening.”* (Parent of 15 year old boy)

– to siblings –

*“Time to relax and spend time with the other two children, who do miss out on attention. A chance to recharge our batteries, and spend quality time with the other children on their interests.”* (Parent of 10 year old boy)

*“It gives the rest of us a break from him – particularly his brother, who is regularly attacked by him.”* (Parent of 11 year old boy)

– and to the children with ASD themselves (particularly with regard to becoming more independent from their parents).

*“We believe our son has developed/extended his life skills, particularly in areas such as communication and social interaction, alongside developing and increasing his independence and confidence. This is all very encouraging for our family.”* (Parent of 16 year old boy)

Short breaks were felt to provide families with opportunities to undertake activities which could not be carried out while the child with ASD was present and to be of significant importance in helping maintain the family unit, and enabling the parents to keep the child with ASD at home.

*“Without respite we would not be a family. Respite care allows me to meet his needs and care for my son properly without becoming exhausted and ill.”* (Parent of 6 year old boy)

*“Time to do what ‘normal’ families do. Watch TV or video with no interruptions. Go to bed without him. Have a bath or shower without him. Go shopping. Have friends round.”* (Parent of 11 year old boy)

*“Able to go to places our autistic son can’t cope with: shops, visiting relatives, cinema. Our lives are extremely limited whilst caring for our son and this is a much needed piece of freedom.”* (Parent of 14 year old boy)

It is clear that users of short breaks perceived a range of benefits that could result from short breaks, for parents, siblings and the child with ASD alike. These feelings were shared by some non-users of services, who felt that short breaks would be beneficial to their families:

*“I might get a night’s sleep for once, and I could treat my daughter to an outing.”* (Mother of 10 year old boy)

However not all families felt positively about short breaks. Some respondents, who had previously used short breaks but no longer did so, identified problems that had arisen after using short breaks

*“A couple of years ago Tommy was referred to the (generic short breaks unit). Unfortunately he became very agitated the few times he went there. I think he found some of the physical disabilities of the other children a little overwhelming. Also most of them were more severely disabled than Tommy, and he retreated into himself instead of joining in.”* (Parent of 17 year old)

Others spoke of how they felt emotionally torn by their need to use such services and of their concerns about their children:

*“I find the decision to use respite very difficult, as I feel caring for Dan is my responsibility.”* (Parent of 8 year old boy)

Parents also voiced concerns over what they perceived as shortfalls in service, in particular with regard to more able children and those with Asperger Syndrome. Their views concerning the limitations of available provision concurred with the literature (Oberheim, 1996).

*“Whilst there is provision for children with autism, there is little available for children and young adults with Asperger Syndrome. The provision needs to be appropriate – respite, but also social groups, youth clubs, etc. Social workers do not acknowledge Aspergers as a disability and therefore do not offer support.”*  
(Parent of 13 year old boy)

The range of comments elicited in this section of the survey highlights the tensions and stresses that exist in using short breaks services, and the range of issues that families and service providers need to consider. These issues are investigated more fully within the family interviews (6.6.5); and findings from the whole study are synthesised in 7.2.

### ***Other sources of formal support***

As well as short breaks, other sources of formal support were provided within this local authority, many of which were accessed by a number of families. For example, almost a third of the children (n = 49: 32%) attended holiday play schemes (further details are given in Table 4.16). However, as with short breaks, there were differing attitudes towards these services, and a number of problems were reported both with regard to the availability and appropriateness of support.

**Table 4.16 Sources of formal support**

	<b>No</b>	<b>%</b>
Residential short breaks	28	18
Residential school	2	1
Family based short breaks	15	10
Sitting service	11	7
Childminder	4	3
Domiciliary care	1	1
Play group	1	1
Holiday play scheme	49	32
Sessional/befriending	25	1
Other	2	1

Use of Pearson's Rho (Gorard, 2003) identified a correlation (.369, significant at 0.01\*\*) between the child's level of dependence and the number of formal support services accessed by that child. Higher dependence correlated with more services being used (see Table 4.17).

**Table 4.17 Correlation between child's dependence and number of formal services used**

		<b>Dependence</b>	<b>Formal Services</b>
<b>Dependence</b>	Pearson correlation	1.000	.369**
	Sig. (2-tailed)	.	.000
	N	155	155
<b>Formal services</b>	Pearson correlation	.369**	1.000
	Sig. (2-tailed)	.000	.
	N	155	155

\*\*Correlation is significant at the 0.01 level (2-tailed)

Nonetheless, the mean number of sources of formal support available per family was only 0.7 sources (SD = 0.8), and – though a few families were provided with 3 or more formal support services – almost half (n = 69: 46%) received no formal support whatsoever (See Table 24.18). Of these 69 families, 47 (68%) indicated that they did not wish to access services. Nonetheless 22 families who felt a need for short breaks were in receipt of no formal support whatsoever.

**Table 4.18** Number of sources of formal support per family

	No	%
None	69	46
One	43	29
Two	26	17
Three	10	7
Four	1	1
Five	1	1

#### **4.3.7. Future needs**

As reported above (see Table 4.15) just less than 60% of the respondents stated that they currently need support via the medium of short breaks. However, when families were asked if they felt they would need to access short breaks services at some point in the future, almost two thirds of families identified such a need (n = 98: 65%) (see Table 4.19).

**Table 4.19** Do you think you may need to use short breaks in the future?

	No	%
Yes	98	65
No	39	26
Don't know	6	4
No answer	7	5

Respondents felt that as they, and their children grew older, they would need increasing levels of support, especially as current sources of informal support became unavailable (as grandparents grew elderly and became unable to manage the child with ASD, or as siblings grew up and left home). Some voiced their concerns about what support and provision would be available for them and their children when their children became adults:



#### 4.3.8. Attitudes towards short breaks

Parents were asked to indicate to what extent they agreed or disagreed with seven statements concerning short breaks (see Table 4.20). Three points attracted the most agreement. The first was that short breaks could be beneficial to children with regard to developing their skills and abilities. 99 respondents (66%) agreed with this statement, and only 5 (3%) disagreed.

**Table 4.20 Attitudes towards short breaks**

	Strongly agree		Agree		Not sure		Disagree		Strongly disagree		No answer	
	No	%	No	%	No	%	No	%	No	%	No	%
Using short breaks emphasises the difference between disabled children and others	17	11	37	24	33	21	41	26	9	6	18	12
Short breaks can prevent children being received into long-term care	25	16	42	27	45	29	23	15	4	3	16	10
Parents should always be responsible for looking after their own children	24	15	36	23	17	11	47	30	13	8	18	12
Short breaks can improve a child's skills and abilities	36	23	66	43	33	21	3	2	2	1	15	10
Short breaks are only useful if they include overnight breaks	8	5	7	5	24	15	86	55	12	8	18	12
There is not enough information available about short break services	40	26	43	28	37	24	20	13	2	1	13	8
The needs of children with ASD can be met within general short breaks services	5	3	22	14	62	40	27	17	26	17	13	8

The second area of consensus concerned the statement that short breaks were only beneficial if they included overnight breaks. Almost two thirds of respondents disagreed with this statement (n = 96: 64%): this is an important point as historically short breaks provision (both within this local authority and nationally) has been predominantly based upon models of

service where children receive overnight stays. However, some respondents strongly felt that short breaks services must, of their very nature, provide overnight care, and that other models of service delivery were not fully 'short breaks'.

*"I have always understood the social services definition of 'respite care' meant overnight breaks; and I believe it should be offered consistently to families where a child has ASD because of the continual pressure all of these families are under. Sitting services, play schemes, etc. are very valuable but not strictly 'respite' because they are too short to provide a proper break and because organisation, transport etc. eats into the free time."* (Parent of 12 year old girl)

It was clear that individual families conceptualised 'short breaks' in different ways, some more narrowly and some with a wider definition.

The third point which attracted the most agreement concerned the paucity of appropriate information about short breaks. Over half of the families (n = 82: 55%) agreed with this statement, reflecting comments made in responses elsewhere:

*"I think that a lot of the services available to children and families living with autism are kept secret and therefore people can't use them properly and sometimes these services are lost due to poor attendance. I would like to know more myself both for my family's benefit and that of my child."* (Parent of 11 year old boy)

*"Would like to know how respite care would help a disabled person. Would like to know how many people looking after them. What is there for them to do? Do they have own room? Do they go out? Will they be safe? Does it help them to make friends and join in, feel comfortable to be with people very much like themselves?"* (Parent of 15 year old boy)

*"All respite services should be made widely known after diagnosis. My daughter was diagnosed at 3 years but it's taken till she is 7 years for any mention of respite care being an option."* (Parent of 7 year old girl)

Respondents were most likely to hold a definite opinion, either agreeing or disagreeing with the statement, concerning whether or not parents should always be responsible for their own children. Only 11% expressed uncertainty with regard to this issue (n = 17) while the numbers

who agreed and disagreed were both around 40%. Fifty-seven respondents (38%) agreed with the statement while 59 (39%) disagreed.

The area of greatest uncertainty was whether the needs of children with ASD could be met within generic services. Forty per cent of respondents (n = 60) were uncertain about this. The number of parents who agreed with this statement (n = 27: 18%) was just over half that of parents who disagreed (n = 51: 34%). However, scrutiny of the responses of parents who used short breaks revealed that almost four times as many disagreed with this statement as agreed with it, suggesting that –to families using short breaks – an autism-specific service was important (see Table 4.21).

**Table 4.21 Can the needs of children with ASD be met within generic short breaks services? – users’ opinions**

Agree	7
Not sure	7
Disagree	24

This was supported by comments made by parents about the need for, and importance of, autism-specific services:

*“Respite for my child would only be positive in a TEACCH environment with autism-trained staff who can acknowledge and appropriately manage my child’s special needs.”* (Parent of 10 year old boy)

*“ASD children have specific needs which need specific services.”* (Parent of 11 year old boy)

Though this expressed preference among service users seemed to fit well with the literature regarding the difficulties children with ASD can experience in generic short breaks settings, it can be argued that if parents have only received specialist short breaks, then they have no experience on which to base this preference. This seemed to be an area requiring further study, and therefore was investigated in more depth in the family interview phase of the study

(6.6). The overall findings of this section showed that, among the sample as a whole, there was a firm belief concerning the benefits to children of short breaks; parents did not feel that overnight stays were a prerequisite in short breaks services; there was a belief that information about services was inadequate; many parents were unclear whether the needs of children with ASD could be met in generic services, while many others firmly believed that they could not.

#### **4.3.9. Testing the hypotheses**

Having outlined the general findings of the survey I will move on to consider the hypotheses derived from the literature review (2.4.2).

##### ***Hypothesis A – Informal Social Support***

The first hypothesis was that non-users of short breaks services would have greater levels of informal social support than users. Potential sources of this support included spouses/partners, parents, children, other relatives, neighbours and friends. The results of this study showed that non-users had on average 2 sources of informal social support, compared with 1.8 sources available to users of short breaks. Chi-square analysis was undertaken, applying Yates' correction where the number in any category within the sample was less than five (Lieberman, 1971). Here and throughout this thesis, statistical significance was set at  $p = .05$ .

Analysis identified that though users had slightly fewer sources of informal support, the difference between users and non-users was not significant ( $\chi^2 = 2.27$ ,  $df = 3$ ,  $p = .70$ ). More complete details are given in Table 4.22. Therefore this first hypothesis suggested by previous research was not supported by the results obtained within this study.

**Table 4.22 Comparative levels of informal social support**

	<b>n</b>	<b>Mean</b>	<b>SD</b>
Whole sample	150	2.0	1.0
Users of short breaks services	39	1.8	0.9
Non-users of short breaks services	111	2.0	1.0

**Hypothesis B – Child’s level of dependence**

The second hypothesis was that the children of short breaks users would be more dependent than those of non-users. Chi-square analysis of the data regarding dependence showed the difference between the two groups to be significant ( $\chi^2 = 6.41$ ,  $df = 2$ ,  $p = .05^*$ ). Full details are shown in Table 4.23. Therefore this second hypothesis derived from the literature was supported, with children of users of short breaks being reported as dependent, on average, in 8.2 of the 10 areas, compared to 6.9 areas for the children of non-users.

**Table 4.23 Comparative levels of dependence (10 point scale)**

	<b>n</b>	<b>Mean</b>	<b>SD</b>
Whole sample	155	7.4	2.7
Users of short breaks services	41	8.2	1.9
Non-users of short breaks services	114	6.9	2.7

**4.4. Analysis**

Having presented the results of this survey, I will move on in this section to analyse them, with regard to the initial hypotheses (4.3.9), with regard to other studies undertaken, and in terms of their significance.

**4.4.1. Comparing the dependence level of children with Robinson and Stalker’s study**

Use of Robinson and Stalker’s dependence scale enabled comparisons to be drawn between this population of children with ASD and the generic population of disabled children within their research (undertaken in the late 1980s, within three local authorities, with a total sample

of 586 families). Within that study, the mean dependence level across the whole sample was 6.4. Children of non-users of short breaks had a mean dependence of 5.1, and users' children had a mean dependence of 6.7. It is noteworthy that dependence levels within this current study are higher in all areas and that the mean dependence of children of non-users within this ASD-specific study is higher than that of children attending short breaks within the generic study (Table 4.24).

**Table 4.24 Comparison between levels of dependence**

	<b>Robinson &amp; Stalker (1990): generic study</b>	<b>This study (2004): ASD- specific study</b>
Whole dataset	6.4	7.4
Non-users of short breaks	5.1	6.9
Users of short breaks	6.7	8.2

#### **4.4.2. Variation between users and non-users of short breaks**

Analysis of Hypotheses A and B shows the child's level of dependence to be a significant variable between families using short breaks and those who do not, significant at  $p = .05^*$ ; however, differences regarding informal support are statistically insignificant. At this point the data were subjected to chi-square analysis to seek to identify any other areas where there was significant variation between users and non-users of short breaks. The categories were selected based on factors suggested in the literature and from my professional experience, and included demographic (where the family lived), educational (the child's school placement), family (number of adults and children in the home, age of main carer, parents' employment and socio-economic status) and support factors (availability of social work support). The results of this analysis are shown in Table 4.25 (details of informal support available and the child's dependence are included).

This analysis shows that though the availability of informal support is not a significant factor associated with use/non-use of short breaks, there are five factors, including the child's level of dependence, where differences between users and non-users are statistically significant. Three of these are more highly significant than the child's dependence. These other factors are the child's age (also significant at .05\*), the child's diagnosis, the child's school placement and whether the family has a social worker (these last three being significant at .001\*\*\*). These factors are described more fully below.

**Table 4.25 Comparison of users and non-users of short breaks**

<b>Factor under consideration</b>	<b>Chi-square</b>	<b>p-value</b>
Father working	.043 (df = 1)	.9
Age of main carer	.27 (df = 2)	.9
Number of children in household	.95 (df = 3)	.9
Number of adults in household	.92 (df = 1)	.8
Sex of child	.013(df = 1)	.75
Number of sources of informal support	2.27 (df = 3)	.7
Area of county where the family lives	3.45 (df = 3)	.5
Socio-economic status	3.5 (df = 3)	.2
Mother working	1.97 (df = 1)	.2
Dependence level of child	6.41 (df = 2)	.05*
Age of child	4.73 (df = 1)	.05*
Diagnosis	18.18 (df = 2)	.001***
School placement	19.52 (df = 2)	.001***
Allocation to social worker	28.72 (df = 1)	.001***

#### **4.4.3. Factors associated with use or non-use of short breaks**

The perceived dependence of the child has already been discussed above. In this section I will consider the other four factors identified by this analysis.

##### ***Child's age***

Across the whole population (155 children), 53% (n = 83) were under 11 years old, while 46% (n = 72) were over 11 years, with a mean age of 10 years 9 months (SD = 3.9). The

children of those families not using short breaks tended to be younger, with a mean age of 10 years 1 month (SD = 4.0). By contrast, almost 60% of children attending short breaks were 11 or over, with a mean age of 11 years 7 months (SD = 3.7). This is consistent with the findings of other studies, which indicate that short breaks use peaked between 11 and 16 years of age (Robinson and Stalker, 1993). The data is shown in Table 4.26.

**Table 4.26 Age of children: short breaks users and non-users**

	Short breaks users		Non-users	
	No	%	No	%
Under 11 years	17	42	67	59
11 years and over	24	58	47	41
Total	41	100	114	100

### *Diagnosis*

The child's diagnosis appears to be highly significantly associated with short breaks use (see Table 4.27). Children with a diagnosis of ASD/Autism were in the majority in both the users and non-users groups. However, only one child (2% of users) had a diagnosis of AS, while 32% of non-users had AS. In total, 48% of families with children who had SLD and autism (or autistic tendencies) used short breaks, almost 30% of families with children with a diagnosis of ASD/Autism used short breaks, but only 3% of families with children with AS were in receipt of such services.

**Table 4.27 Child's diagnosis: short breaks users and non-users**

	Short breaks users		Non-users	
	No	%	No	%
ASD/Autism	26	64	63	55
SLD + ASD/autistic tendencies	14	34	14	13
Asperger Syndrome	1	2	37	32
Total	41	100	114	100



### ***Child's school placement***

There was great variation between the school placements of those children whose families used short breaks and those who did not (see Table 4.28). Only 7% of children attending short breaks were educated in mainstream settings, whereas over 40% of non-users attended mainstream schools. In total only 7% of children educated in mainstream settings attended short breaks. This is clearly a highly significant factor associated with use or non-use.

**Table 4.28 School placement: short breaks users and non-users**

	Short breaks users		Non-users	
	No	%	No	%
Mainstream	3	7	49	43
DSP	9	22	24	21
Special school	29	71	41	36
Total	41	100	114	100

With regard to diagnosis and school placement, it was important to check the extent to which these factors were correlated. Scrutiny of the data identified that of the 38 children diagnosed with AS, 24 children (64%) were educated in mainstream settings, 7 (18%) were in DSPs and 7 (18%) were in special schools. Of the 52 children in mainstream settings (including nurseries and colleges), 24 (46%) had a diagnosis of AS, a further 24 (46%) had a diagnosis of ASD/Autism, and the remaining 4 children (8%) were diagnosed with SLD and autism (or autistic tendencies). It was clear that diagnosis did not determine the type of school placement, and that significant numbers of children with AS were in settings other than mainstream. Therefore both of these factors were worthy of identification.

### ***Social worker***

The vast majority of children attending short breaks (over 80%) had an allocated social worker (see Table 4.29). This is not in itself surprising, as social workers are the 'gatekeepers'

to accessing local authority short breaks. By contrast, almost two thirds of children whose families did not use such services had no social worker. Allocation to a social worker is clearly another highly significant factor associated with using short breaks.

**Table 4.29 Does the child have an allocated social worker?**

	<b>Short breaks users (n = 41)</b>		<b>Non-users (n = 114)</b>	
<b>Social worker?</b>	<b>No</b>	<b>%</b>	<b>No</b>	<b>%</b>
Yes	34	83	39	34
No	7	17	75	66

#### **4.4.4. The attitudes of non-users towards short breaks**

This analysis identifies a number of factors that are more strongly associated with whether families access short breaks or not than either the level of informal support available to them or their child's level of dependence. As well as the quantitative data analysed above, qualitative data were collected and these too were analysed to identify what factors families themselves identified for not using short breaks. Families who did not use short breaks services were asked in the questionnaire to identify their reason(s) for this. Ninety-three responses were made to this open-ended question, and the text data obtained were subjected to qualitative analysis. The responses were grouped into nodes, which were then categorized into key themes. Again, a percentage of the data was externally analysed, to ensure reliability of categorization. The families' responses clustered into four thematic categories - family attitudes and values, issues concerning the child, service shortfall, and lack of information (Table 4.30). In part these reflect Stalker and Robinson's (1991) findings in their study of non-users of generic short breaks services, where the main reasons for not using services were lack of perceived need, insufficient information, inaccessible services and a preference to keep childcare responsibilities within the home. Other issues, such as concerns about the

impact of short breaks use on the child, are more strongly stated within this study, perhaps reflecting the characteristic impairments of ASD. The parents' responses and these thematic categories are discussed more fully below.

**Table 4.30 Families' stated reasons for non-use of short breaks**

	<b>No</b>	<b>%</b>
Family attitudes and values	40	37
Service shortfall	30	27
Impact on child	21	19
Lack of information	18	17
Total	109	100

NB Some responses included comments in more than one category

### ***Family attitudes and values***

Forty responses (37%) indicated that families did not wish to use short breaks due to their attitudes and values. These families preferred to look after themselves without external support, and did not feel help necessary or desirable, or were mistrustful of others to provide appropriate care.

*"I wouldn't want him to miss out on anything that the rest of the family do. He is part of our family and that is where he belongs."* (Parent of 10 year old boy)

*"I would not like to leave him with strangers...I have to trust people to leave my children with them. And if I don't know them, how can I?"* (Parent of 14 year old boy)

*"We feel that our child will develop better by not being treated as a disabled person."* (Parent of 9 year old boy)

### ***Impact on child***

Concern for the impact on the child with ASD of using short breaks was voiced in twenty-one responses (19%). These concerns centred on the child's inflexibility, potential confusion, and the potential impact on the child's self esteem.

*“He is painfully aware that he has Asperger Syndrome. I feel that awareness on his part that ‘special help’ was being given to give mum and dad the odd break would be detrimental to his emotional well-being.”* (Parent of 15 year old boy)

*“He gets distressed when away from me for long periods of time other than at school.”* (Parent of 8 year old boy)

### ***Service shortfall***

Comments about service shortfall were made in thirty responses (27%). These centred upon the inappropriateness of services; being assessed as not needing services; and problems – such as length of time on waiting lists, or transport difficulties.

*“We wanted to use Family Link. But after waiting so long we were told there was no way we would find a family as our son was too old...”* (Parent of 16 year old boy)

*“What respite? The services available are not appropriate to the needs of children with Asperger Syndrome.”* (Parent of 11 year old boy)

*“We were told his condition was not serious enough for respite care.”* (Parent of 17 year old boy)

### ***Lack of Information***

Eighteen responses (17%) centred on a lack of information about services, in particular with regard to eligibility criteria, access to services and potential costs (all short breaks services are in fact free to families).

*“We don’t know about any services and could not afford to pay a lot.”* (Parent of 11 year old boy)

*“I didn’t think I was eligible. I can’t afford it. It could be too far away.”* (Parent of 6 year old boy)

*“I have no idea of what help is available to me at the present time or in years to come. No one has discussed this with me in any detail.”* (Parent of 11 year old boy)

#### 4.4.5. High dependence within users and non-users

Testing the data has shown that the children of non-users of short breaks have lower overall levels of dependence than those of families who use such services. However, it appeared that many such families still have children with significant levels of dependence. Data were re-examined to identify the number of children in the two original groups – users and non-users of short breaks – who were identified as having a high level of dependence. This was defined as children who were dependent upon adults in 7 or more of the 10 areas of dependence. The results are shown in Table 4.31 below.

**Table 4.31 Child’s dependence: users and non-users of short breaks**

Dependence	Users		Non-users	
	No	%	No	%
0-3	1	2	16	14
4-6	6	15	28	25
7-10	34	83	70	61
Total	41	100	114	100

Although the percentage of highly dependent children was lower in the non-users group (61%: 70/115 children) than in the users group (83%: 34/41 children), it was still clear that over 60% of families who did not access services had highly dependent children (61%: 68/111 families).

#### 4.4.6. ‘Re-slicing the cake’: considering those families that do not wish to access services, those that use services, and non-users by default

As shown by the families’ comments discussed in 4.4.4., many non-users of short breaks services do not access these services because they simply do not want to. Either their families are able to access appropriate support from within their informal support networks, or their ‘ideological style’ (Seligman & Darling, 1997) is such that, regardless of the informal support

they receive, they choose to live their lives without seeking outside help from statutory service providers. However it was also clear that some non-users were non-users by default, in that they wished to access short-breaks but could not. Simply dividing the sample into *users* and *non-users* of short breaks was overly simplistic. It was felt that it would be more helpful, and would potentially identify key issues more clearly, if further analysis and research focused not simply upon these two subsets but upon three: families who accessed short breaks, those families who chose not to use such services and those who wished to access short breaks but could not. The comparative numbers in these groups are shown in Table 4.32.

**Table 4.32 Comparison of families by short breaks use or desire for short breaks**

	<b>No</b>	<b>%</b>
Families currently accessing short breaks	39	26
Families that wish to access short breaks	49	33
Families that do not wish to access short breaks	62	41

Dividing the sample in this way showed, as discussed in 4.3.6 previously, that 87 families (59% of the sample) identified a current need for short breaks, while 61 families (41%) did not identify such a need. At this point the quantitative data were interrogated to compare those expressing a need for short breaks (both users and non-users) with those who did not want to access short breaks services. Significant factors were identified (see Table 4.33).

**Table 4.33 Comparison of families that do not wish to access short breaks with current and would-be users**

<b>Factor under consideration</b>	<b>Chi-square</b>	<b>p-value</b>
Sex of child	.034 (df = 1)	.9
Father working	.019 (df = 1)	.9
Number of adults in household	.33 (df = 1)	.9
Area of the county where the family lives	1.37 (df = 3)	.75
Age of child	2.18 (df = 3)	.7
Number of children in household	2.44 (df = 3)	.5
Number of children in household	2.44 (df = 3)	.5
Diagnosis	3.15 (df = 2)	.25
Mother working	2.53 (df = 1)	.2
Number of sources of informal support	10.02 (df = 3)	.02*
School placement	8.36 (df = 2)	.02*
Dependence level of child	6.65 (df = 1)	.01**
Allocation to social worker	46.6 (df = 1)	.001***

#### **4.4.7. Factors associated with families' identification of needing short breaks**

Comparison of families expressing a current need for short breaks with those who did not want services identified four areas where there were statistically significant differences between the data collected from the two groups. These were the number of sources of informal support available to the family (significant at .02\*), the child with ASD's school placement (also significant at .02) the child's level of dependence (significant at .01\*\*) and whether or not the family was allocated a social worker (significant at .001\*\*\*). These four factors are discussed below.

##### ***Informal support***

Although Hypothesis A – that non-users of short breaks would have more sources of formal support than users – was not supported, it can be seen that, within this sample, families that do not wish to access services do have more sources of informal support than current and would-be users of short breaks. Over 40% of these families have access to support from three or more sources, as compared to 20% of users and would-be users (see Table 4.34).

**Table 4.34 Sources of informal support: comparison of families that do not wish to access short breaks with current and would-be users**

No of sources	Families that do not want short breaks		Users and would-be users	
	No	%	No	%
0	3	5	9	10
1-2	33	53	61	69
3-4	26	42	17	19
4+	0	0	1	1
Total	62	100	88	100

### *School placement*

Almost 60% of families with children in mainstream schools did not wish to access short breaks. By comparison over half the families with children in DSPs and almost 70% of families with children in special schools either accessed or wished to access short breaks (see Table 4.35)

**Table 4.35 School placement: comparison of families that do not wish to access short breaks with current and would-be users**

School placement	Families that do not want short breaks		Current and would-be users		Total
	No	%	No	%	
Mainstream	24	58	17	42	41
DSP	14	44	18	56	32
Special school	24	31	53	69	77

### *Child's dependence*

The dependence level of children in families that do not want a service was lower (mean = 6.24, SD = 2.61) than that of children in families that use or wish to use short breaks (mean = 7.93, SD = 2.31); and the proportion of less dependent children in these families is almost twice that found in current or would-be service users (see Table 4.36). Nonetheless, it is noteworthy that almost 55% of these families still have children with a dependence level of 7/10 or above.



**Table 4.36 Dependence level of child: comparison of families that do not wish to access short breaks with current and would-be users**

	Families that do not want short breaks		Current and would-be users	
Dependence	No	%	No	%
0-7	28	45	22	25
7+	34	55	66	75
Total	62	100	88	100

### *Social worker*

The final and most significant factor associated with differences between families that do not want short breaks and those that are using or want this type of support is whether or not a social worker is allocated to the family. Almost 70% of families using or wishing to use short breaks have a social worker. By contrast, only 13% of families that do not want short breaks have dealings with a social worker (see Table 4.37).

**Table 4.37 Social worker involved: comparison of families that do not wish to access short breaks with current and would-be users**

	Families that do not want short breaks		Current and would-be users	
Social worker	No	%	No	%
Yes	8	13	61	69
No	54	87	27	31
Total	62	100	88	100

### **4.4.8. Attitudinal differences between families that accessed short breaks, those that wished to access short breaks and those that did not wish to use such services**

When the responses of the three subgroups to the attitudinal questions in the survey were analysed, this further revealed that the groups held attitudes that sometimes differed significantly from each other (see Table 4.38). Statistically significant differences were revealed in their responses to three of the attitudinal statements.

*Parents should always be responsible for looking after their own children* ( $\chi^2 = 9.96$ ,  $df = 4$ ,  $p = .05^*$ )

Just under half of those families who either used or did not wish to use short breaks disagreed with this statement (46% and 45% respectively). By contrast only 26% of those who wished to access short breaks felt that parents should not always be responsible for their children. As the analysis of the numerical data has shown that families that did not want services had more sources of informal support (Table 34) it may be that families either using short breaks or not expressing a need were more used to their children spending time away from them and home, and were more comfortable about giving up this responsibility from time to time.

*Short breaks are only useful if they include overnight stays* ( $\chi^2 = 10.98$ ,  $df = 4$ ,  $p = .05^*$ )

Twenty per cent of current users felt that short breaks were only useful if they included overnight stays. However only 4% of those wishing to access short breaks saw overnight stays as essential, as did 6% of those families not wishing to access short breaks.

*The needs of children with autistic spectrum disorders can be met within general short breaks services* ( $\chi^2 = 23.71$ ,  $df = 4$ ,  $p = .001^{***}$ ).

Over 60% of current users of short breaks disagreed with this statement, with fewer than 18% either agreeing or expressing uncertainty. In comparison, almost 40% of would-be users expressed uncertainty, with this figure rising to almost 55% with regard to non-wanters.

Variation between the groups with regard to their answers to these attitudinal questions suggests they may hold different understandings regarding the responsibilities of parents, the nature of short breaks and of how children's needs can be met within services.

**Table 4.38 Comparison of responses to attitudinal questions: users of short breaks, would-be users, and families that do not wish to use a service**

	Users of short breaks (n = 39)			Would-be users of short breaks (n = 49)			Families who do not want short breaks (n = 62)		
	A	U	D	A	U	D	A	U	D
	%	%	%	%	%	%	%	%	%
Using short breaks emphasises the difference between disabled children and others	49	13	36	37	36	36	23	23	34
Short breaks can prevent children being received into long term care	44	31	23	50	20	20	40	32	11
Parents should always be responsible for looking after their own children	42	10	46	53	8	26	40	15	45
Short breaks can improve a child's skills and abilities	82	10	5	70	20	2	52	29	3
Short breaks are only useful if they include overnight stays	21	5	69	4	18	70	6	19	55
There is not enough information available about short breaks	49	36	13	69	16	10	47	23	16
The needs of children with autistic spectrum disorders can be met within general short breaks services	18	18	62	20	39	37	16	55	15

Not all respondents answered every question

**A = Agree**  
**U = Unsure**  
**D = Disagree**

#### **4.4.9. Factors associated with the use or non-use of short breaks where families wish to access such services**

As shown in Table 4.32, the data revealed that 49 of the 111 families that did not access short breaks (44%) expressed a current need for this type of support. The mean level of dependence of their children was 7.7 (SD = 2.5). This was appreciably higher than the mean level among non-users as a whole (6.9). The presence of this high level of dependence, plus the desire to use short breaks, makes it surprising that they are not receiving this service. Moreover, although 27 of these families (55%) were in receipt of some kind of formal support – such as holiday play scheme support during summer holidays – 22 families (45%) received no formal

support whatever. These 49 families who wished to access services but could not outnumbered those families that were actually receiving services. As Table 4.31 shows a total of 88 families expressed a current need for short breaks. Of these 88 families, 39 (44% of those families expressing a current need) were receiving such a service; but over 55% of them were not (n = 49: 56%).

It was concerning that over half of those families who wished to access short breaks were ‘non-users by default’ – though they felt a need for this service they were not receiving it. In order to identify factors that might militate against accessing short breaks services, the data regarding users of short breaks (n = 39) and non-users who expressed a current need (n = 49) was subjected to chi-square analysis, using the same categories that were used in the previous analyses (see Table 4.39). This analysis revealed four factors to be significantly associated with whether families received short breaks. These are the same factors that were identified as significant when comparing short breaks users and non-users (4.4.4 above): whether the family has a social worker (significant at .02\*); the type of school attended by the child; the child’s age (both significant at .005\*\*); and the child’s diagnosis (significant at .005\*\*\*). These factors are discussed below.

**Table 4.39 Comparison of users of short breaks and non-users who wish to access services**

Factor under consideration	Chi-square	p-value
Number of children in household	0.27 (df = 3)	.95
Number of sources of informal support	0.85 (df = 3)	.9
Sex of child	0.03 (df = 1)	.9
Number of adults in household	0.38 (df = 1)	.7
Father working	0.31 (df = 1)	.7
Socio-economic status	1.33 (df = 2)	.7
Mother working	0.49 (df = 1)	.5
Dependence level of child with ASD	2.58 (df = 2)	.3
Age of main carer	2.53 (df = 3)	.3
Area of county where the family lives	2.74 (df = 1)	.1
Does the child have an allocated social worker?	5.99 (df = 1)	.02*
School placement	11.43 (df = 2)	.005**
Age of child with ASD (under/over 11)	9.45 (df = 1)	.005**
Diagnosis	17.93 (df = 2)	.001***

### ***Social worker***

The vast majority of children accessing short breaks had an allocated social worker (see Table 4.40). As identified above, this is unsurprising, as assessment by a social worker is necessary if a family is to access local authority short breaks. It was notable however that the children of over 40% of non-users who wished to access short breaks did not have a social worker – this is more than double the level among users. Nonetheless, the children of almost 60% of would-be users were allocated a social worker. This suggests that other factors may be impacting more significantly upon use/non-use.

**Table 4.40 Does the child have an allocated social worker? Short breaks users and non-users who want to use short breaks**

Social worker	Short breaks users		Would-be users	
	No	%	No	%
Yes	34	83	29	59
No	7	17	20	41
Total	41	100	49	100

### ***School placement***

The children receiving short breaks predominantly came from within the special school population (29/41: 71%). Only three children using short breaks (7%) were placed in a mainstream classroom. By contrast, 37% of would-be users' children were in mainstream settings. Being placed within a mainstream setting clearly seems to be a variable that impacts negatively on short breaks use (See Table 4.41). It may be that such children are perceived as less disabled than their peers in special educational settings, and that their families are less in need of short breaks. However, school placement may be influenced by parental preference, or academic ability. It does not necessarily reflect the level of functional impairment that the child experiences in daily living or the impact of the child's ASD on family functioning.

**Table 4.41 School placement: short breaks users and non-users who want to use short breaks**

	Short breaks users		Would be-users	
	No	%	No	%
Mainstream	3	7	18	37
DSP	9	22	10	20
Special school	29	71	21	43
Total	41	100	49	100

### ***Child's age***

Examination of the data concerning the ages of the children was also revealing (Table 4.42). Almost 60% of children attending short breaks services were 11 years old and above; in contrast, only slightly more than a quarter of the children of would-be users were over eleven. The average age of children within the short breaks group was 11 years 7 months (SD = 3.7), compared with 9 years 5 months (SD = 3.4) in the would-be users group. The child's age is clearly a significant variable with regard to accessing services.

**Table 4.42 Age of child: short breaks users and non-users who want to use short breaks**

	Short breaks users		Would-be users	
	No	%	No	%
Under 11 years	17	41	36	73
11 years and over	24	59	13	27
Total	41	100	49	100

### *Child's diagnosis*

Finally, the child's diagnosis seems to be linked with receipt of short breaks. Children with a diagnosis of ASD or autism were the majority in both the users group (63%) and would-be users (55%). However, almost all of the remainder of the users group (34%) comprised children who had severe learning disabilities (SLD) in conjunction with a diagnosis of ASD or 'autistic tendencies'. Only one child attending a short breaks service had a diagnosis of Asperger Syndrome. In contrast, 35% of the children of would-be users had a diagnosis of Asperger Syndrome (Table 4.43).

**Table 4.43 Child's diagnosis: short breaks users and non-users who want to use short breaks**

	Short breaks users		Would-be users	
	No	%	No	%
ASD/Autism	26	63	27	55
SLD + ASD/autistic tendencies	14	35	5	10
Asperger Syndrome	1	2	17	35
Total	41	100	49	100

## **4.5. Discussion**

This exploratory study has identified a number of key points with regard to the families within the county and their use or non-use of short breaks. It has identified a number of significant factors impacting on family life and short breaks use. In terms of the sample as a whole, in over 80% of families the child with ASD has at least one sibling. In a quarter of

families, only one adult is present in the household. The children with ASD have significant needs: over two thirds are dependent in at least seven areas, with over 40% dependent in nine or ten. Over half of the respondents stated that they had a current need for short breaks, and almost two thirds felt that they would need such services in the future: however only about a quarter of families currently received short breaks. Finally, short breaks were identified as offering benefits to parents, siblings, children with ASD and the family unit, by users and non-users alike. However a number of shortcomings were also identified, particularly with regard to lack of appropriate services and information.

The literature (Barson, 1998; Oberheim, 1996; Sargent, 1995) suggests that generic services are often inappropriate for children with ASD, and that ASD-specific provision would be of greater benefit to these children and their families (Preece, 2003; Wall, 1990). The attitude of service users supports this, and parents clearly felt that ASD-specific services provide more positive experiences for children. However, further study is needed to identify outcomes for children in this area of research to ascertain whether ASD-specific short break services have any qualitative impact in the lives of children with ASD and their families.

The testing of the hypotheses suggested by the literature review, and their further consideration in the light of the different ways that the sample could be divided, provided significant findings. The hypothesis that families who do not use short breaks have greater levels of informal social support than short breaks users was not proven. Within this sample, the difference between the mean levels of informal support available to both groups was insignificant. Both groups received only a low level of informal support, rarely extending beyond the immediate family. The hypothesis that the children of short breaks users would



exhibit higher levels of dependence upon adults than those of non-users was supported. However, there was no significant difference between the dependence levels of children who attended short breaks services and those who accessed other services, such as play schemes. Moreover, comparison with other generic studies revealed that the children's mean dependence levels were elevated across the board within this ASD-specific population. As a result, the mean dependence of the children of non-users within this study was higher than that of the children of short breaks users in other generic studies.

A number of factors in addition to the child's level of dependence were identified which seemed to be associated with use or non-use of short breaks. These were the child's age, their diagnosis, their educational placement, and whether they had a social worker. These same factors were significant both when comparing short breaks user with all families who did not use such services, and when comparing users with those families who wished to use services but did not. In summary, families using short breaks were more likely to have a older child, with a diagnosis of ASD/autism, possibly with severe learning disabilities (but not AS), and educated outside a mainstream educational setting. They were also much more likely to have a social worker than those who did not.

The level of significance differed across the analyses, except for the matter of the child's diagnosis, which was highly significant ( $p = .001^{***}$ ) in both cases. To summarise the situation with regard to those families who wished to use services, the research suggests that parents who felt they need short breaks seem more likely to receive this support if they had a social worker, and if their child was in a special educational setting, over 11 years of age and had a diagnosis of ASD or autism (possibly with severe learning disabilities). By contrast,

parents seemed less likely to receive such support if they did not have a social worker, and/or their child was in a mainstream educational setting, aged under-11, and diagnosed with Asperger Syndrome.

This analysis suggests that the situation regarding the use of short breaks by families with children with ASD is more complex than the literature suggests, and that other variables may be more significantly associated with short breaks use or non-use than informal social support and the child's level of dependence. Moreover, further questions that require investigation were raised by this study.

It was clear from this analysis that many non-users felt a need for short breaks, but were not accessing them: over half the families wishing to use short breaks were unable to do so. Parental comments suggested that reasons for this included lack of information about services, concerns about the impact of service use on the children and lack of appropriate services. This last factor is telling, given that the local authority in which this study took place has developed a range of ASD-specific provision. All of this provision, however, is located within its 'Services for Disabled Children': it may be that, as Jordan (2001) suggests, a wider spectrum of services needs to be provided to meet the differing needs of children with ASD. This suggested that further research needed to be carried out, with the families of children with ASD and the children themselves, to identify the impact of ASD on family life, to identify the factors that family members felt were indicative of appropriate services, and to identify the types of services that they felt would most appropriately and effectively meet their needs. This was identified as an important area of further research that would be investigated within this project.

Whether or not a family was allocated to a social worker was identified as an important variable throughout this study. Under the Children Act 1989, the legislation that governs the provision of social care to disabled children in England and Wales (Department of Health, 1991); it is the local authority that is responsible for decisions made about both the range of short breaks services provided and the eligibility criteria that define who can access them. Finance will inevitably have an impact on the range and level of service provision available but, at the level of the individual family, the role of the social worker assessing their situation is crucial. Whether a child is eligible for a service, what level of service should be provided, whether there is even a need for the family to receive social work support; all of these matters hinge upon the decisions made by the social worker. The results of the initial part of the research showed that having a social worker was a significant factor in accessing services, but also that many would-be services users, despite having an allocated social worker, were not in receipt of short breaks. This suggested that investigation into the attitudes of social workers towards ASD and their understandings of the condition would be helpful, and this was identified as another area into which further research would be undertaken within this doctoral study. In the next chapter I shall discuss this research into social workers' attitudes and understandings.

## **Chapter 5: Survey of social workers**

*This chapter reports on a study undertaken to ascertain the understanding of social workers regarding ASD. How social workers perceive the condition will inevitably impact on how they assess the needs of such children and their families, and upon the types of services or interventions they seek to provide to meet those needs. Using a research instrument designed by Mavropoulou and Padelidu (2000), I surveyed all of the social workers who worked with this population within the local authority ( $n = 27$ ). The results showed that, though many social workers had a good understanding of some aspects of the condition, there was also confusion about some key facts concerning ASD and scientific terminology, an inaccurate understanding of intervention approaches, and a more positive attitude towards the ability of generic services to meet need than was supported by the literature or was reflected within the family survey.*

### **5.1. Introduction and research questions addressed**

The initial survey of families identified areas and directions for further study. After discussion with my supervisor, it was decided that research would be undertaken in two further areas. These were to explore how social workers conceptualize and understand ASD and to undertake deeper research with families, exploring their experience of daily living and their attitudes to and experience of short breaks and social work support.

In this section of the thesis I describe the investigation undertaken with social workers. The specific focus of this phase of the research was to identify the understanding of social workers in this local authority concerning ASD (causes, main behavioural features, and related issues)

and to identify their opinions regarding intervention methods and service provision for families with children with ASD.

## **5.2. Reviewing the literature**

To carry out this phase of the research a further literature review was undertaken, using the methods and sources identified in 2.1 above. The family survey identified social workers were significantly associated with the use of short breaks. It was therefore important to ascertain how they conceptualised the condition. It seems a given that social workers' understanding of ASD will impact upon how they perceive these children and their families, how they assess their needs and what types of interventions and services they consider appropriate. However, when I reviewed the literature to identify what research had discovered about social workers' perceptions of ASD, I failed to identify any studies that addressed this topic in even a limited way. Nonetheless, the literature clearly identified the problematic nature of social work with disabled children. This is discussed below.

### **5.2.1. Social work and disabled children**

Until the 1960s, social support to disabled children and their families was provided largely by voluntary organisations and special schools (Baldwin & Carlisle, 1994). Social work as a profession, and the creation of social services departments, emerged as a result of the Seebohm Report (Seebohm Committee, 1968); however, disabled children received little practical help or social support from social services departments during the following two decades (Philip and Duckworth, 1982). In this period social work developed as a generic service (Baldwin and Carlisle, 1994): the specialist expertise and knowledge needed by

disabled children and their families did not exist within local authority social services departments.

Not until the Children Act (Department of Health, 1989) were disabled children brought within the mainstream of children's legislation and service provision. This legislation placed a number of duties upon local authorities. They were required to provide information about services provided by themselves and others, to maintain a register of disabled children, and to safeguard and promote the welfare of children in need, which included all children defined as disabled. Children in need were defined as

*"a) those unlikely to achieve or maintain, or have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision of services;*

*b) those whose health or development is likely to be significantly impaired, or further impaired, without the provision of such services; and*

*c) those who are disabled."* (Department of Health, 1989, Section 17 (10))

Using the same definition of disability that was used over 40 years earlier in the 1948 National Assistance Act, a child was defined as disabled

*"if he is blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed."* (Department of Health, 1989, Section 17 (11)).

Middleton (1996) argues that the wording of this definition gives local authorities significant scope for interpretation of what comprises a disability, and identifies that the use of the word '*substantially*' had led to some authorities rationing access to services by

*"limiting their availability to those with severe disability, in medical terms, whatever the individual needs of the families may be."* (Middleton, 1996, p6)

The Act, in Schedule 2, Part 1(6) required local authorities to provide services to minimise the effect of their disability on such children, enabling them to lead lives '*as normal as possible*'.

In practice, this was largely translated into the provision of short breaks services, to provide support to their parents and families.

Research carried out on behalf of the Department of Health a decade after the Children Act (Robinson *et al.*, 2001) identified that, although progress had been made in service provision, significant challenges remained. Westcott and Cross (1995) showed that adults may believe they cannot communicate with disabled children, and that this then becomes a self-fulfilling prophecy; numerous studies have identified the lack of direct contact between disabled children and social workers (Bamford *et al.*, 1997; Beresford, 1994; Mencap, 1997). Specific problems identified concerning social workers' involvement with disabled children included a paucity of staff training, lack of consultation with children about their wishes and feelings, and poor inter-agency working (Robinson *et al.*, 2001). Middleton (1996) further argues that the adoption of a care management model within social care services, has led to social workers becoming little more than the brokers and monitors of 'service packages', and that their role as service providers (of advocacy, for example, or counselling) has been lost.

Middleton further identifies (1998) that many social workers working with children with disabilities feel unconfident in their own abilities and unclear about their role. This may in part arise from a lack of appropriate training about disability (Westcott and Jones, 1999), leaving them feeling deskilled when working with professionals from other agencies – such as paediatricians, nurses and teachers – who have undertaken specialist disability training. This statement is supported – particularly in the field of autism – by research undertaken with parents. A consistent complaint is that social workers do not understand the nature of autism, and that they therefore misjudge or underestimate the needs of such children and their

families, and lack the skills to work with them (Carlin *et al.*, 2004; Hand, 1994; Jones *et al.*, 1997; Oberheim, 1996). It takes time to develop understanding and skills: however, Kennedy and Wonnacott (2003), surveying social work teams across the UK, identified that social workers in disabled children's teams carry high caseloads, often in excess of that carried in other areas of child care, with an average caseload of almost 40 cases per social worker. Due to the nature of disability, these are likely to be both diverse and to require social work input for a longer time than many 'mainstream' cases (often to transition to adulthood and beyond). All of this militates against the development of meaningful relationships and effective understanding. Further potential problems have been highlighted by Peterson and Quarstein (2001) who identify that professionals working with those with disabilities can become inured to their hardships and desensitised to their situations.

While no research was found with regard to social workers' understanding of ASD and its impact, research undertaken with regard to social workers' perceptions in other areas has identified that the impact of how workers conceptualise those with whom they are working and their situation impacts significantly upon both how they interact with service users and their families and the types of intervention they consider appropriate. Adams (1999) identified a continuum of attitudes among social workers working with drug-using parents: some were supportive, some ambivalent and some held negative views. Those who held more supportive views were more positive about potential outcomes, while those who held negative attitudes were more likely to act in a discriminatory way towards these parents. Similar patterns have been identified with regard to how workers conceptualise disability. Johnson *et al.* (1998), researching social workers' attitudes to the parents of children with mental and emotional disabilities, also identified widely divergent views. A slender majority of social workers held



positive attitudes towards parents, while almost half had parent-blaming beliefs. These attitudes impacted on how they worked with families, with those who were more positive towards parents being also more positive about information sharing and working in partnership. Moreover, those social workers who believed that clinical research should inform practice and who felt that medical journals were useful sources of information held more positive attitudes towards both open information-sharing between agencies and families and towards medication. Conversely, those who saw the child as the identified ‘patient’ in a dysfunctional family were less open, and held negative views towards the use of medication.

Heenan (2005), reflecting on experiences of teaching social work students in Northern Ireland, identified that stereotyping disabled people could lead to oppressive practice; the fact that there are relatively high levels of dependency on disability benefits in the province has led to widespread assumptions about fraud within the social security system and the stereotyping of many in receipt of these benefits as ‘dishonest, malingering scroungers’. Stereotypical views were held by many social work students and Heenan highlights the damaging effect that such stereotyping from those in a position to impact on the services they receive can have on disabled people.

### **5.2.2. Research from other professions**

Heenan’s findings are mirrored in studies focused on professionals working in other fields. Raine *et al.* (2004) found that general practitioners attitudes towards two medical conditions (chronic fatigue syndrome and irritable bowel syndrome) affected both how they perceived their patients and how they treated them. The GPs held more negative views about chronic fatigue syndrome. This led to them viewing patients with the condition as having ‘undesirable

traits' and to conflict over treatment and management. Referral for mental health interventions, which have been identified as potentially helpful with regard to both conditions, was discounted by many participants either because they were unaware of such interventions, felt them unnecessary or because they believed them to be unavailable. Overall it was identified that doctors' beliefs could act as barriers to patients receiving appropriate services, due both to negative stereotyping and to lack of awareness of what research has identified as good practice.

Research from other disciplines, including health visiting (Halpin and Nugent, 2006) and education (Helps *et al.*, 1999; Mavropoulou and Padeliadu, 2000) has shown that there is wide variation in professionals' knowledge about ASD. Studies of teachers have shown that many lack a basic theoretical understanding of ASD and that they may hold outdated views or misconceptions regarding the condition (Helps *et al.*, 1999; Mavropoulou and Padeliadu, 2000; Stone and Rosenbaum, 1988). Teachers have been shown to often overestimate the cognitive abilities of these children, perceiving the child differently to his or her parents, and underestimating the difficulties caused by ASD (Helps *et al.*, 1999; Stone and Rosenbaum, 1988; Szatmari *et al.*, 1994). On the other hand, teachers with a better understanding of ASD, and commitment to a proven and effective way of working, have been shown to have higher self-efficacy, to be less prone to burnout and to be more confident in their work (Jennett *et al.*, 2003).

### **5.2.3. Implications**

Three aspects of this literature review seem particularly significant. The first is that the topics not only of social workers' understanding of ASD but of their understanding and

effectiveness regarding children with disabilities and their families on the whole is under-researched, and that this study is both timely and necessary. The second is that how professionals perceive and understand those with whom they work can impact greatly on the services they receive. Thirdly it has been shown, across professions, that there is wide variation in workers' knowledge and understanding of ASD and that professionals can view these children, and the impact of their ASD, very differently from their families.

### **5.3. Accessing services for disabled children and their families within the local authority in the study**

Before moving on to discuss the research undertaken with these social workers, it is necessary to identify how social work services for children and families were organised and accessed within this local authority. Generic fieldwork teams were organised into 4 areas (north, south, east and west), each having a referral team, a family support team and a child protection team. Social work support for disabled children and their families was provided by two teams, one covering the north and east of the county, the other the south and west. Provider services for disabled children comprised the county's Family Link service, a residential short breaks service for physically and learning disabled children, services for children with autism (residential short breaks, a residential home and a family advisory team) and the 'development' team, which managed the county's register of disabled children, provided information and supported play schemes. All of these services for disabled children were managed by one service manager.

Services were limited within the county. The residential short breaks service for children with physical and learning disabilities had 16 beds; the autism-specific short breaks home had 6 beds; the autism family advisory team had four part-time workers. Therefore, in order to seek

access to services, families had to undergo a number of assessments, in which they had to stress the negative impact of living with disability on their lives.

All families that felt a need for support had initially to contact their local generic children's social services referral team. If the family was unable to refer themselves, a referral could be made on their behalf by their doctor, community nurse or other relevant professional. A worker from the referral team undertook an initial assessment to identify whether the child and family were 'in need' and eligible for a service under the county's eligibility criteria (which were taken from the Children Act, 1989, see 5.2.1 above).

If the child was judged as 'disabled', the case was passed on to the appropriate Disabled Children's Team. A further in-depth assessment would be undertaken by a social worker from one of these teams, to identify both the family's needs and what package of support would be appropriate to support them. Supports such as befriending, play schemes, childminding or small amounts of equipment could be provided through discussion with their team manager, who held a budget for such expenditure.

Requests for more significant packages of care, including all requests for overnight family-based or residential short breaks, had to be taken to the monthly Disabled Children's Service Resource Allocation Panel. This panel was chaired by the service manager in charge of the Disabled Children's Service, and comprised managers from both fieldwork and provider services. This panel decided which, if any, services would be allocated to the family, and in what amount. Family members could not attend this panel; instead, the social worker made a presentation, and was questioned about the request.

All services provided were subject to review, usually annually. The purpose of this review was to identify whether the level of service provided remained appropriate to meet the family's needs, or whether the package of care needed to change. As Kennedy and Wonnacott (2003) identify, it was rare for families that had been accepted as 'open cases' to be closed before transition, with most families transferring to Adult Services at the child's eighteenth birthday.

#### **5.4. Outline of method**

As outlined in 4.2. above, the analysis of the data from the survey of families identified having an allocated social worker as an important factor in short breaks use, and information about social workers' understanding of ASD was identified as an important part of the jigsaw in answering the research question focused on those factors inside and outside the family associated with short breaks use or non-use. I will now move on to discuss the method used to obtain data regarding this topic.

##### **5.4.1. Sample group**

The population under scrutiny in this part of my PhD research comprised those social workers within the local authority who worked with children with a diagnosis of ASD. In this local authority, providing social work support to children with a diagnosis of ASD and their families fell within the remit of two specialist disabled children's teams, sited in the north and south of the county. In total, twenty-seven staff potentially worked with these families. This comprised a service manager (who was responsible for all social care services for disabled children and their families, including field social work teams, family-based short breaks, residential services and sessional support and befriending services), two team managers, two

principal social workers, fifteen social workers and seven assistant social workers (these latter staff not having a social work qualification).

#### **5.4.2. Survey instrument**

The specific focus of this aspect of the research was to investigate how these social workers conceptualised ASD and the types of intervention methods and service provision they felt appropriate for families with such children. To investigate this topic, it was again decided that an anonymous, self- completion postal survey would be the most appropriate data collection tool due to such a tool's ability to be quick and unobtrusive (which seemed important when surveying busy professionals) and anonymous (which was important as the researcher was known to all of the respondents – and indeed was managed by one of them).

#### **5.4.3. Survey design**

Having identified the sample and the appropriate method of enquiry, the next step was again to design an appropriate questionnaire to answer the questions. The literature review identified that Mavropoulou and Padelidu (2000) had developed a questionnaire to investigate teachers' understanding of ASD, based on earlier research (Stone and Rosenbaum, 1988; Szatmari *et al.*, 1994). Their tool was used to examine the perceptions of mainstream and special education teachers in Greece about ASD, and focused upon the same issues (albeit with a different population) that I wished to address. Discussion with my supervisor led to the decision to adapt Mavropoulou and Padelidu's questionnaire (2000) for this study. The reasons for this were threefold. Firstly, their survey instrument was designed to gather data on the same topics that I was seeking to address, and had been successfully used in a study published in a peer-reviewed journal. Undertaking further research using this tool might help

identify if this was a reliable research instrument, and highlight any shortcomings in the instrument. Moreover, using this tool would enable comparisons to be drawn between Mavropoulou and Padeliadu's group of special education teachers and the social workers in this local authority. Finally, there was no readily available 'like population' with whom I could design a research instrument, in the way that I had with the parental survey questionnaire. Social work teams in neighbouring counties were differently configured – and in some cases worked with differently defined populations of disabled children. Residential care workers in the county who worked with children with ASD received significantly different training from field social workers (while most social workers had undergone no specific ASD training, all residential care workers working with this population attended first a half-day ASD awareness training during their induction, then a 3-day TEACCH seminar, then participated on a 5-day TEACCH workshop) and their understanding of ASD might be very different.

Mavropoulou and Padeliadu's questionnaire asked respondents their opinions regarding the causes and diagnosis of ASD, their general knowledge regarding the condition, its characteristics and its treatment (including the use of specialised provision). The decision was made to retain their overall design and wording, while making some small amendments to make the tool applicable to a group of social workers rather than teachers, and also changing some terminology to make it appropriate to a UK context (e.g. 'learning disability' for 'mental retardation'). A limitation of this stage of the study is that the attitudes of individual social workers towards short breaks were not investigated within the survey. It would have been very useful with hindsight to have asked the social workers for their views on the purpose and benefits of short breaks and about service allocation. I did not do this as a result

of not wishing to make significant amendments to Mavropoulou and Padelidu's tool, which could preclude comparisons being drawn between the teachers in their study and the social workers in mine. However in retrospect, I regret not having done so.

### ***Methodological considerations concerning the survey***

#### *Gaining access to the sample group*

All social workers within the sample group were employees of the local authority, which was supporting the research. There were no barriers to access.

#### *Size of the survey*

The size of the survey was again predetermined by the size of the population: as described above, this comprised the 27 social workers within the local authority who worked with children with a diagnosis of ASD.

### ***Ethical issues***

This survey was compatible with both the University of Birmingham's and the local authority's codes of conduct concerning research. Specific ethical concerns are outlined below.

#### *Consent*

The local authority for which I work gave its consent for the research to be undertaken and for its resources (social workers' time, printing and use of internal post) to be used. Consent within the sample group was interpreted by response.



### *Anonymity*

All questionnaires were identical and as they were returned to the researcher in the local authority's internal post system it was not possible to identify responses, either in terms of worker or team. However, due to there being questions regarding age, gender and experience, it might in some cases have been possible – given the small population – for me to establish who had completed which questionnaire.

To address this issue the questionnaires were sent out with a letter clearly stating the reason for the survey – to catch a picture, at this moment in time, of social workers' perceptions and understandings of ASD. It was further stated that analysis would not seek to identify who had completed which questionnaire, and that no attempt would be made to guess the identity of respondents. Acknowledging this issue challenged the research; however to ensure ethical integrity, it was necessary to do so.

### *Coding and analysis*

A codebook was prepared as with the survey of families. Analysis of both quantitative and qualitative data was carried out in the same manner, as described in 4.2.9 above.

### *Actions to secure a good response*

Given the small total population, it was essential to maximise the rate of response. To do this the questionnaire was designed to be easy to read and complete. The wording of Mavropoulou and Padeliadu's questionnaire (2000) was used, but with some amendments to make it relevant to the target population. Throughout, the word 'autism' was replaced by 'autistic spectrum disorder' as this is the term in general use within the local authority, with 'autism'

referring to a subgroup of the spectrum. References to teaching experience and special education were replaced by social work experience and specialised interventions and services. A covering letter explained the purpose of the survey and that it would take less than 15 minutes to complete.

#### ***Pilot study and issues arising***

The questionnaire was piloted with five residential social workers who worked at a group home for children with ASD, selected at random. This identified the length of time it took to complete the questionnaire, the codebook's robustness and identified the need for some final changes to the wording (see Appendix 4 for a copy of the questionnaire).

#### **5.4.4. Undertaking the survey**

I gave the questionnaires, covering letters and addressed envelopes to the service manager and the team managers of the two teams on 5 October 2004; the team managers then handed the packs out at their team meetings. Respondents were asked to send the completed questionnaires back by 5 November. At this time two social workers and one assistant social worker were on long-term sick leave. Thus the total possible number of responses was 24.

By 1 November, I had received eleven completed questionnaires (46% of the possible responses). A follow up letter was circulated on 5 November, acknowledging the pressures of work the social workers were under, thanking those who had already returned the questionnaires, and asking those who had not done so to reply by 15 November. This time each letter was personally addressed and signed (again with a questionnaire and an addressed

envelope to be used in the internal post) and posted to the individual social workers. By 15 November, 23 respondents (96%) had replied

### ***Description of sample***

Nineteen respondents were female, three were male, and one did not indicate their gender.

Ages ranged from 21 to 56, with a mean age of 44.1 years ( $SD = 8.2$ ) (see Table 5.1).

**Table 5.1      Age of social workers**

<b>Age</b>	<b>No</b>	<b>%</b>
Under 25 years	1	4
26-35 years	1	4
36-45 years	9	39
46 years or older	9	39
No answer	3	14

Workers' experience in working with disabled children and their families ranged from under a year to 28 years, with a mean experience of 9.4 years ( $SD = 7.4$ ) (see Table 5.2).

**Table 5.2      Experience of working with disabled children**

<b>Age</b>	<b>No</b>	<b>%</b>
2 years or less	3	13
3-10 years	10	44
11-20 years	6	26
21 years or more	3	13
No answer	1	4

Sixteen workers (70%) had previous experience of working with typically developing children, ranging from a year to 16 years (mean = 6 years,  $SD = 5.0$ ), and nine workers (39%) had previously worked with disabled adults for periods ranging from a year to 20 years (mean = 2.9 years,  $SD = 3.0$ ) (see Tables 5.3 and 5.4).

**Table 5.3 Experience of working with typically-developing children**

Age	No	%
None	6	26
2 years or less	3	13
3-10 years	10	44
11-20 years	3	13
21 years or more	0	0
No answer	1	4

**Table 5.4 Experience of working with disabled adults**

Age	No	%
None	13	56
2 years or less	2	9
3-10 years	6	26
11-20 years	1	4
21 years or more	0	0
No answer	1	4

Other experience included working within psychiatric social work (n = 2) and as a foster carer (n = 1).

## **5.5. Results**

Respondents were asked for their opinions with regard to 4 areas: the causes and diagnosis of ASD; their general knowledge regarding ASD; the characteristics of ASD; and the treatment of ASD, including the use of specialised provision. In this section I will summarise the findings under these headings, before going on to discuss these findings.

### **5.5.1. Causes of ASD**

Social workers were asked to rank five ‘possible’ causes of autism (brain damage, lack of mother’s emotional response to the child, social causes, heredity and ‘other’), with 1 representing the most significant and 5 the least. These rankings were then aggregated, and

means were derived. Thus if all workers felt one ‘possible’ cause to be the most important, its mean score would be 1; likewise, if one ‘possible’ cause was felt to be insignificant by all respondents, its mean score would be 5. The results are shown in Table 5.5.

**Table 5.5 Potential causes of ASD**

Potential cause	Total scores	Mean score
Heredity	55	2.4
Brain damage	60	2.6
Other	68	3.0
Lack of mother’s emotional response	102	4.4
Social causes	104	4.5

It is clear that it was not generally thought that ASD was caused either as a result of maternal behaviour or due to social causes. However, two respondents ranked maternal coldness as the second most important factor in causing ASD and one respondent ranked social causes as the second most important factor. Heredity and brain damage were identified as the most important causes, though neither scored particularly highly (2.4 and 2.6 respectively). Five respondents (22%) believed mumps, measles and rubella vaccine (MMR) inoculations to be a cause of autism, with three (13%) considering it the main cause. Three further workers felt that the causes were not yet understood (with 1 suggesting possible unspecified environmental causes), while one worker felt that

*“autism lies dormant in the young person, then a shock to the system can activate it.”*

### **5.5.2. Diagnosis**

Respondents were asked whether they believed that a diagnosis of ASD could be carried out mainly by neurological examination, or by psychiatric examination of the child’s behaviour. Five respondents (22%) stated that neurological examination was the main diagnostic method,

with the remaining eighteen (78%) identifying diagnosis as being carried out through psychiatric examination of the child's behaviour.

### 5.5.3. General understanding of ASD

All the social workers (n = 23) agreed that ASD was more prevalent in boys than girls, that ASD could be accompanied by learning disability, that ASD was not an early form of schizophrenia and that people with ASD did not suffer a reduced lifespan as a result of the condition. However, there was no such consensus with regard to the age of onset of ASD. One worker felt that autism became present before the end of the first year of life, with over 40% believing it became apparent before the age of two and over 56% believing that ASD was not fully developed in a child until after the age of 3 (see Table 5.6).

**Table 5.6 At what age does ASD become fully present in the child?**

Age	No	%
From birth to the end of the first year	1	4
From the second to the third year	11	48
From the third year onwards	13	56
No answer	1	4

Some respondents gave more than one answer

### 5.5.4. Characteristics of ASD

Respondents were asked to rank twenty-two statements with regard to whether they considered them to be characteristic of ASD (see Table 5.7). Wide divergence was displayed with regard to this question, with some respondents identifying all twenty-two statements as being characteristic of ASD, while one worker believed only eight to be characteristic (mean = 14.7, SD = 3.7). Full agreement between all twenty-three workers was achieved with regard to only 3 statements: that the child wants to keep his or her environment the same; that he or she avoids change in his or her daily routine; and that he or she has obsessions.

**Table 5.7 Social workers' perceptions of the characteristics of ASD**

<b>Statement</b>	<b>No</b>	<b>%</b>
Wants environment the same	23	100
Avoids change in his/her daily routine	23	100
Has obsessions	23	100
Doesn't understand the feelings of others	22	96
Overreacts to noise	22	96
Does not seek the company of others	22	96
Does not make eye contact	21	91
Seems distant	21	91
Engages in stereotypical behaviour	20	87
Has problems in his/her eating routine	20	87
Has temper tantrums	19	83
Has sleeping problems	18	78
Does not seek physical contact with others	16	70
Does not get attached to a person	14	61
Makes clumsy movements	11	48
Does not have self-care skills	10	43
Does not play with objects	8	35
Does not develop speech	7	30
Presents problems in his/her physical appearance and health	7	30
Has hearing problems	6	26
Does not have feelings	3	13
Has hallucinations	3	13

#### **5.5.5. Treatment of ASD**

With regard to the treatment of ASD, 87% of respondents indicated a strong belief in the effectiveness of specialised interventions. It was clear that there was a particularly favourable attitude towards the TEACCH structured teaching approach (Schopler *et al.*, 1995). This approach underpinned service provision within this local authority, and was used within schools and social care services.

*“...a consistent approach with structure, use of TEACCH schedules, an understanding of how the person perceives the world (as far as this is possible) can be very helpful.”*

*“Interventions such as TEACCH are very effective.”*

Favourable comments were also made about the National Autistic Society's EarlyBird programme (Shields and Simpson, 2004), a parent training model which had been running at a local general hospital.

*"(EarlyBird) can be very effective – especially when there is early intervention with preschoolers."*

There was far less agreement with regard to the asking whether psychotherapy could be an effective treatment method with regard to ASD. Seventeen point per cent of respondents believed such approaches to be of no value, while 35% felt that such approaches could be of value to some.

*"Cognitive behavioural therapy is helpful in adapting undesirable/unwanted behaviour".*

Almost 50% of respondents did not answer this question or stated that they did not know.

With regard to the potential benefits of specialist provision to children with ASD, respondents focused on the development of practical skills, such as developing self-care skills and independence; these were viewed as areas where specialist intervention could make a difference by over 85% of respondents (see Table 5.8). Overall, social workers had a very positive attitude towards the benefits of specialist services, with the majority of the sample believing that they could be of benefit in nine of the ten suggested areas. Whilst considering specialist services and interventions beneficial, 65% of workers (n = 15) also believed that it was possible to successfully integrate children with ASD within a generic disability service; 30% felt this was not the case.



**Table 5.8 Social workers' perceptions of potential benefits of specialised provision**

Area	No	%
Develop basic self-care skills	22	96
Complete an activity independently	22	96
Reduce his/her tendency to self-injury	21	91
Get relief from anxiety and emotional tension	20	87
Reduce his/her repetitive behaviours	20	87
Develop emotional relationships with others	17	74
Read and write	17	74
Play with other children	15	65
Express his/her desires using speech	15	65
Understand the feelings of others	11	48

## 5.6. Analysis

Although the sample size was small, the study identifies a number of pertinent issues regarding social workers' understanding of ASD. These are discussed below.

### 5.6.1. Factual inaccuracies

It was shown by the results that all respondents had an accurate understanding of many issues regarding ASD, such as ASD being more common in boys than girls, and the facts that ASD can be accompanied by learning disability, that individuals with ASD do not have a reduced life span and that ASD is not an early form of schizophrenia. However, a number of respondents held inaccurate beliefs about the condition. Over half of the social workers felt that ASD became fully present after the age of three years. In fact, the onset of ASD is early, always occurring before three years, excepting the very rare condition Childhood Disintegrative Disorder (Ozonoff and Rogers, 2003), and many children can be successfully diagnosed as early as two years (Lord and Risi, 2000). It is possible that some respondents may have interpreted the question "*At what age does autism become fully present in a child?*" as meaning at what age does the child's ASD become apparent or is it diagnosed: if this is the

case, then their responses may also be indicative of the confusion shown regarding ‘scientific’ terminology and language, discussed further below.

There was also confusion regarding how ASD is diagnosed. Neurology has made a major contribution towards the understanding of autism, with neuroimaging showing deviations from the normal in many areas of the brain (Courchesne *et al.*, 2001). However, Tharp (2003) has shown that such studies do not identify any ‘signature abnormality’ that is diagnostic of ASD. Diagnosis of the condition is made by the use of psychological diagnostic tools such as the Childhood Autism Rating Scale (CARS) (Schopler *et al.*, 1988) and the Autism Diagnostic Observation Schedule (ADOS) (Lord *et al.*, 2000). Despite this, over a fifth of the social workers considered neurological examination to be the main method used in diagnosing the condition.

Further confusion was identified with regard to the causes of ASD, with some social workers believing the condition to be linked to maternal coldness or social causes, and over a fifth believing there to be a causal link between MMR and autism. The theory that autism was a response to ‘refrigerator’ mothering was prevalent in the 1960s and 70s (Bettelheim, 1967) but has long been disproved: ASD is now considered a pervasive developmental disorder with a biological basis (Mesibov *et al.*, 1997). The study suggesting a link between MMR and autism was much publicised (Wakefield *et al.*, 1998). However, by the time of this survey (autumn 2004) a large body of research had been published identifying that there was no evidence of any causal link (see, for example, Chen *et al.*, 2004; Farrington *et al.*, 2001; Kaye *et al.*, 2001). Nonetheless, these social workers retained this false belief. Finally there was

some confusion about what actually comprised ASD, with one respondent believing that Attention Deficit/Hyperactivity Disorder (AD/HD) was part of the autistic spectrum.

### **5.6.2. Confusion about the characteristics of ASD**

Two points of interest arise from the social workers responses with regard to the list of ‘characteristics’ of ASD. The behaviours presented in the list are specific instances of the ways in which the triad of impairments may manifest themselves. They are not an exhaustive list, and there are individuals with ASD who may display very few of these behaviours. Thus a significant number of the behaviours or issues that many respondents believe to be ‘characteristic’ of ASD are not, and may or may not be present in an individual. There may be a danger that if a child fails to exhibit these behaviours or traits – such as over-reacting to noise or failing to make eye contact, which are viewed as fundamental to ASD by over 90% of respondents – then the child’s ASD and subsequent difficulties, and the families resulting needs, may be underestimated by their social worker.

The social workers’ perceptions of the characteristics of autism were compared with the responses made by special education teachers who had attended 20 hours of training regarding ASD, which were discussed in Mavropoulou and Padelidu’s original study. It is notable that there are significant differences between the two groups’ understanding of the characteristics of ASD (see Table 5.9).

**Table 5.9** Comparison of social workers' and teachers' perceptions of the characteristics of ASD

	Current study of social workers (n = 23)		Mavropoulou & Padelidiadu (2000) (n = 29)		
Statement	No	%	No	%	Chi-square
Wants environment the same	23	100	18	62	11.06 p = .001***
Avoids change in his/her daily routine	23	100	25	86	
Has obsessions	23	100	7	24	30.24 p < .001***
Doesn't understand the feelings of others	22	96	25	86	
Overreacts to noise	22	96	9	31	22.25 p < .001***
Does not seek the company of others	22	96	25	86	
Does not make eye contact	21	91	15	52	9.43 p = .005**
Seems distant	21	91	28	96	
Engages in stereotypical behaviour	20	87	26	90	
Has problems in his/her eating routine	20	87	1	3	37.15 p < .001***
Has temper tantrums	19	83	19	65	
Has sleeping problems	18	78	0	0	34.71 p < .001***
Does not seek physical contact with others	16	70	20	69	
Does not get attached to a person	14	61	8	27	5.82 p = .02*
Makes clumsy movements	11	48	18	62	
Does not have self-care skills	10	43	7	24	
Does not play with objects	8	35	2	7	6.42 p = .02*
Does not develop speech	7	30	7	24	
Presents problems in his/her physical appearance and health	7	30	7	24	
Has hearing problems	6	26	0	0	8.55 p = .005**
Does not have feelings	3	13	7	24	
Has hallucinations	3	13	2	7	

Social workers felt far more behaviours to be characteristic than did the teachers; ten behaviours were considered characteristic by more than 85% of the social workers, while only five were considered characteristic by the same percentage of the teachers. A number of the behavioural traits were more strongly associated with ASD by the social workers than the teachers. With regard to five of these – that the child wants the environment to stay the same, that the child has obsessions, that he or she overreacts to noise, that he or she has problems with regard to eating and that the child has problems sleeping – the contrast between the two groups was highly significant ( $p \leq .001^{***}$ ). In the case of two traits – that the child does not make eye contact and that he or she has hearing problems – the contrast was significant at  $p = .005^*$  and with regard to two further potential characteristics – that the child does not get attached to a person and that he or she does not play with objects – the significance was  $.02^*$ . It may be that the social workers are more aware of issues such as the child's obsessions, overreactions of problems regarding eating and sleeping as these could be major stressors upon families, and could lead them to seek social care support from statutory services. However, as was indicated above, some children with ASD may exhibit few, if any, of these 'characteristics'.

A further issue arising from the analysis of social workers' perceptions regarding these potential 'characteristics' is that there is little consistency across the teams with regard to the presentation of ASD. With regard to all but three of the statements, there were divergent views; behaviours that were identified as fundamental to ASD by some workers were not by others. This variation may arise from the individual worker's experience of working with children with ASD, with their conceptualisation of ASD being based upon the children with ASD that they have known, and their pre-understandings of the disorder's characteristics. It

may on the other hand simply reflect a misunderstanding of the meaning of the word *characteristic*; so that some workers may have been just ticking off any and all behaviours that they might see in a child with ASD, rather than thinking of the defining characteristics (Hindsight suggests that it might have been helpful to have rephrased some questions; however doing so would have precluded comparisons being drawn with the teachers in Mavropoulou and Padeliadu's study). Whatever factors may be causing it, this inconsistent understanding of ASD and the characteristic behaviours associated with the condition might well lead to inconsistency in understanding and responding appropriately to the needs of the child and their family.

#### **5.6.3. Confusion about scientific terminology**

It appeared that some respondents were confused by scientific terms and concepts. Some respondents did not link the concept of heredity with genetics, or brain damage with brain formation. This may be because of a lack of understanding regarding 'scientific' terms, or because of assumptions or pre-understandings, based on their previous professional experience. For example, the term 'brain damage' might be considered to refer solely to the impact of some post-birth trauma or non-accidental injury. It is also possible that some respondents answers to the question regarding how diagnosis is made may reflect a lack of understanding regarding terms such as 'neurological' and 'psychological'.

#### **5.6.4. Attitudes towards methods of service delivery**

Some respondents had an inaccurate understanding of approaches being used with children with ASD within the county, for example writing of

*"...communication systems such as TEACCH are highly beneficial".*

Although communication is addressed within the TEACCH approach, and is a fundamental consideration within it, it is not a communication system. This structured teaching approach was used consistently within schools, social care settings and within the community in this local authority (Preece *et al.*, 2000; Preece and Almond, 2008) and it is concerning that some social work staff did not understand it. With regard to the potential benefits of specialist interventions, it is interesting that the only area where fewer than half the respondents felt these could benefit individuals with ASD was in learning to develop social and emotional understanding. This is the focus of 'social stories' (Howley and Arnold, 2005) and there is a developing body of research to support their efficacy (Moffat, 2001; Swaggart *et al.*, 1995).

With regard to the feasibility of effectively integrating children with ASD within generic disability services, about two thirds believed this possible, while a third felt it was not. Overall, their attitude is more positive than the research would suggest is warranted. Studies over many years have shown that many families that have children with ASD find it hard to access generic disability services, and that often such children may be excluded due to the impact of their behaviours (Sargent, 1995; Van Bourgondien and Elgar, 1990), viewed as too able to meet eligibility criteria (Oberheim, 1996) or may simply sit on a waiting list without receiving a service (Tarleton and Macaulay, 2002). Moreover, ASD-specific social care support services (including residential and family-based short breaks, and family support services) had been specifically developed in this local authority in the 1990s in response to the inability of local generic disability services to meet the needs of these children and their families (Howley *et al.*, 2001; Preece, 2003).

This was a clear point of divergence from the views of families. As stated above, two thirds of social workers felt it was possible to integrate children within generic social care disability services. By contrast, less than a fifth of families surveyed felt that children with ASD could be integrated effectively in generic short breaks settings. Families using short breaks that felt that specialist services were necessary outnumbered those who felt their children could be included in generic 'disability' settings by four to one.

## **5.7. Discussion**

Previous research has identified that social workers who work with disabled children sometime lack confidence in their skills (Middleton, 1998), which may in part arise from a lack of appropriate training about disability (Westcott and Jones, 1999). Where social workers do receive training regarding disability issues, the predominant paradigm is the 'social' model of disability (Finkelstein, 1980). This was developed as an alternative position to what was viewed as the medicalisation and pathologisation of disability. It argues that the individual's impairment and their experience of disability are separate, and that the latter arises out of social factors such as discrimination and prejudice.

Some recent writers have suggested that, though helpful in creating a more sensitive perspective on the implications of disability (Oliver and Sapey, 1999), the model is inadequate for those with profound impairment (Brett, 2002) and others whose experience does not fit the model (French, 1993), and that it fails to take account of the impact of disability upon the family around the disabled individual (Case, 2000; Brett, 2002; Dowling and Dolan, 2001b).



Writers with ASD (e.g. Sainsbury, 2000, Sinclair, 2005) have identified the profound sense of alienation from the ‘normal’ world felt by individuals with ASD. This alienation and the difficulties such individuals experience do not occur solely as a result of external discrimination and prejudice (though these clearly affect them, especially when the impact of their ASD is underestimated). As Sinclair (2005) writes,

*“...autism isn’t something a person has, or a shell that has a person trapped inside. There is no normal child hidden behind the autism. Autism is a way of being. It is pervasive: it colors every experience, every sensation, perception, thought, emotion and encounter, every aspect of existence. It is not possible to separate the autism from the person...”* (p2)

Research has also shown that the beliefs that social workers hold about disability and disabled individuals, and the values that underpin those beliefs, have a profound impact upon how they perceive disabled individuals and their families, how they assess their needs, and how they feel those needs can and should be met. Where beliefs and understandings are inaccurate, this can lead to unhelpful and discriminatory stereotyping, negative attitudes towards parents and incorrect assumptions about what types of intervention are appropriate (Heenan, 2005; Johnson *et al.*, 1998).

This phase of the research suggests that social workers who are responsible for assessing families that have children with ASD in this locality, and for making decisions about service provision for them, can have widely differing understandings of ASD and that in many instances their understandings will contain misunderstandings and inaccuracies. The implications of these misunderstandings and inaccuracies can be far-reaching, and may impact upon whether they consider families as in need of services, or even as being eligible to receive services. In the next chapter I shall go on to present the final phase of the research:

the interviews carried out with whole families including children with ASD to investigate their experiences of daily living, of social support and of short breaks.

## **Chapter 6: The family interviews**

*As identified in Chapter 4, analysis of the initial survey suggested two areas for further study. The first was the subject of Chapter 5 and the second was to explore how families that have children with ASD experience their lives, looking in particular at why some seek formal support and others do not, and to consider the types of support that families find helpful and appropriate. Within this phase of the research I sought to address four specific research questions. What can we learn of whole families' experience of living with ASD? What can we learn of whole families' attitudes to and experience of short breaks? What factors, both within and outside the family, are associated with whether or not families seek formal support? What factors are associated with quality in short breaks services by whole families?*

*In this chapter I discuss the interviews and associated activities undertaken to ascertain the views of parents, siblings and children with ASD themselves from fourteen families about these issues. I summarise the literature with regard to interviewing families, interviewing children and interviewing children with ASD. I outline the design of the research tool and the research process, and I present and analyse the results of this process. The families' experience of family life is discussed, and the main themes from the narratives of mothers, fathers, siblings and children with ASD are identified. I then move on to report on families' experience of informal support and formal support through social workers and short breaks. I identify the reasons families give for service-use or non use, the functions they ascribe to services, and factors that they view as positive or negative within services. Finally, I outline areas where the families feel that there are gaps in provision.*

## **6.1. Reviewing the literature**

Analysis of the family survey identified that it would be helpful to gather deeper, richer data regarding families' conceptualisation of daily life and short breaks. Having decided to conduct interviews, and acknowledging as problematic the privileging of parental views and lack of family focus within the literature, I was committed to consulting with all family members where possible: mothers, fathers, siblings and the children with ASD themselves. To inform this process, I undertook a third literature search, focused on three areas: literature regarding interviewing families, literature regarding ascertaining, through interviews, the opinions of children and finally literature regarding ascertaining the views of children with ASD.

### **6.1.1. Interviewing families**

Research on interviewing families has a long history, stretching back to Cavan and Ranck (1938). More recently, studies have been published focusing specifically upon methodological issues in conducting qualitative research with families using data collection tools such as semi-structured interviews (Gilgun *et al.*, 1992; Sussman and Gilgun, 1997; Whall and Fawcett, 1991). Key issues regarding interviews with families can be drawn from this literature.

#### ***Defining the family***

How families are conceptualised varies between studies. Åstedt-Kurki and Hopia (1996) define a family as a coherent unit of people united by biological, social and legal ties; Whall (1993), contrastingly, considers it a self-identified group of two or more people who may or may not be related biologically or legally, but have a special relationship.

### **Gaining access to the family and its environment**

Elwood and Martin (2000) suggest that there are no neutral sites in which to conduct interviews, as all environments are laden with layers of spatial relations, power and meaning. Some authors favour interviewing families in their own homes, feeling this places family members in their natural environment and may increase willingness to participate and speak freely (Thalman Boyd, 1996). Daly (1992), however, suggests the researcher's presence may be an intrusion into a private space, and that problems may arise regarding privacy or in discussing sensitive topics. Even when the interview site has been negotiated, challenges remain regarding gaining access to the family's experience and Daly (1992) suggests this will always be limited; some private facets of family life will always be inaccessible, while other aspects will be hidden due to being taken for granted by interviewees.

### ***Parts and wholes***

Families present further challenges to researchers as the unit of analysis – the family – is composed of multiple individuals and the family may contain multiple and contradictory perspectives. The family may have a 'spokesperson' (usually the mother) who presents the family's reality to the world. However, although using this single informant can make data collection easier and less costly (Uphold and Strickland, 1993), this can lead to gate keeping and misrepresentation (Åstedt-Kurki *et al.*, 1999). It has also been the case that men's perspectives on family experience are under-researched in families with disabled children (Quinn, 1999). The literature suggests that accessing the perspectives of multiple members is beneficial and presents a broader and richer perspective on the family unit (Daly, 1992).

Family members may be interviewed concurrently or sequentially. Individuals interviewed separately may more openly express their feelings and perceptions (Thomas, 1987), and the researcher can compare family members' thoughts and feelings (Anderson and Anderson, 1999); however, the opportunity to observe inter-member interaction is lost (Åstedt-Kurki *et al*, 2001).

### ***The role of the researcher***

Interviewing families creates tensions and raises questions about how researchers both present and maintain their role. Researchers must decide how to present their motives for undertaking the research, how structured interviews will be, and how they will participate in the interview process.

Daly (1992) suggests that families being interviewed easily confuse the researcher role with that of 'expert helper' – particularly if the researcher has a professional role separate to the research they are undertaking – and states that the research process will almost certainly be of less interest to the participants than access to the researcher, whom they may view as a professional with resources and answers. Oakley (1981) writes that researchers should endeavour to develop non-hierarchical relationships with the researched, and that research relationships should be based upon principle of fair exchange. Requests for information and advice should be expected, and before interviews begin researchers should identify how they will manage this potential role confusion, and how they will respond.

The researcher is responsible for creating the interview relationship. They are the research instrument in this process (Gillham, 2000) and must pay attention to issues such as their

timekeeping and appearance and what this may convey, and any equipment being used and their ability to use it. Looking careless or inept may impact negatively on the interview. They should be attentive and responsive to participants' verbal and non-verbal communication, and must pay attention to what interests the family. Morgan (1995) writes that interviewees can become frustrated if the interviewer is felt to be pushing the interview forward while they still want to talk about the current topic.

Finally, the researcher must structure the interview, introducing and developing the interview, bringing it to an end both socially and in terms of the data collection process, and ensuring that the family has access to the researcher and the data after the interview is over (Gillham, 2000).

### ***Ethical considerations***

As well as the ethical issues already discussed in this section (such as respecting family privacy, limiting intrusiveness and managing role conflict), researchers undertaking family interviews must attend to issues of informed consent and of unanticipated self-exposure (Daly, 1992; Mauthner *et al.*, 2002). These are discussed more fully in 6.2.2 below.

#### **6.1.2. Ascertaining children's views**

In recent years there has been an increasing emphasis upon obtaining children's views about issues that impact on their lives. Article 12 of the United Nations Convention on the Rights of the Child states that all children have the right to speak about things that affect them, and requires adults to listen to them (United Nations, 1983). Within UK legislation, the Children Act (1989) (Department of Health, 1991) requires all local authorities to take account of

children's wishes and feelings, involving them in decisions about service provision. Listening to children is a key principle across many government policies and initiatives, including the Quality Protects programme (Department of Health, 1998a), Sure Start partnerships (Department for Education and Employment, 1988) and the Framework for Assessment of Children in Need and their Families (Department of Health, 2000).

These imperatives are reflected in the developing literature on ascertaining and researching children's views. Some authors argue that children cannot provide valid research data due to their suggestibility and immaturity (Ennet *et al.*, 1991; Qvortrup, 1994). Alderson (1995), however, suggests this position is short sighted, and that even inaccurate responses offer insight into children's experiences, illustrating the impact of their feelings, imagination and memory. More recently, authors have explored how to effectively elicit children's views and thoughts (Christensen and James, 2000; Docherty and Sandelowski, 1999; Lewis and Lindsay, 2000; Mauthner, 1997; Woodhead and Faulkner, 2000). This literature highlights a number of key points, which are discussed below.

### ***Methods of gaining children's views***

Lewis and Lindsay (2000) argue that although a study's methods should be determined by the research questions, and strongly influenced by ethical considerations, practical considerations will also inevitably impact. They note that interviews are a common technique in researching children's perspectives, and that this method of data collection, if carried out carefully and rigorously, can be interpreted as methodologically safe. Conversely, quantitative techniques such as questionnaires, though common in children and teenagers' magazines, may be unreliable (Lewis and Lindsay, 2000). Indirect techniques - such as drawing, model-making



and analysis of diaries – can be used (Jones and Tannock, 2000), but interpretation of such data requires a high degree of inference. Dockrell *et al.* (2000) argue that the more the child's perspective is inferred indirectly (rather than being explicitly and directly reported) the greater is the risk of research facing charges of misinterpretation or over-interpretation.

### ***Ethical considerations***

The literature concerning research with children identifies a number of key issues with regard to ethical considerations relating to power, consent and disclosure. These are discussed in 6.2.3 below.

### ***Negotiating interview privacy***

Even when access to the children and consent has been obtained, it can be hard to negotiate privacy to conduct the interview. Obtaining separate interview space may prove difficult for a range of reasons. Living conditions may be such that there is little private space in which to conduct interviews and adults may see themselves as protecting children, or might not consider the child's need for privacy (Brannen and O'Brien, 1995). Moreover, as Mauthner (1997, p18) points out, the family may not share

*“...mainly white middle class researchers' conception of children's rights to privacy, confidentiality and autonomy.” (p18)*

When it is possible to interview children privately, different results can emerge than when families are interviewed together; interviewed alone, teenagers can disclose feelings or concerns not usually discussed within the family. It is harder for researchers to obtain the views of very young children, as parents usually wish to be present during interviews, and may control the child's responses. Furthermore, children can impact on interviews with

parents, by demanding their time and attention, or restricting the conversation simply by being in the same room (Mauthner, 1997).

### **6.1.3. Ascertaining the views of children with ASD**

A growing body of literature has been published concerning the experience of disabled children, and methods of involving them in research (Beresford 1997; Connors and Stalker, 2003; Morris, 1998a; Russell, 1998; Ward, 1997). More recently, articles have focused on practical issues in interviewing children with cognitive impairments and learning and other disabilities (Garth and Aroni, 2003; Lewis, 2002, 2004a; Lewis and Porter, 2004; Porter, 2003; Stalker and Connors, 2003). Further studies have identified approaches to – and the difficulties involved in – eliciting the views of children who are unable to participate in interviews (Cameron and Murphy, 2002; Germain, 2004; Porter *et al.*, 2001; Taylor, 2007; Ware, 2003, 2004).

Within this developing area of study, little published research directly addresses the experience of children with ASD. Only a handful of children with ASD have been included in studies; Prewett (1999), for example, included just one teenager with AS. Connor and Stalker's (2003) study included one child with ASD. They report that he used facilitated communication, with his mother as facilitator, to give his responses, stating

*“...this enabled the inclusion of a child who would otherwise have been excluded from the study. Facilitated communication remains controversial, however.”*  
(p32).

Rather than being “controversial”, Facilitated Communication (first developed by Crossley (1992) in Australia and Biklen (1990) in the USA) is discredited, its claims of effectiveness

shown as unsupported by evidence (Konstantareas, 1998; Mostert, 2001; Schreibman, 2005). Consequently it is impossible to ascertain the validity of ‘views and comments’ attributed to this young man.

Two recent studies have, by contrast, focused specifically on the issues involved in attempting to ascertain the views of children with ASD through consultation.

***Preece (2001, 2003) Consultation with children with autistic spectrum disorder about their experience of short-term residential care***

This formed part of my MEd studies at the University of Birmingham (Preece, 2001); an abridged article was later published (Preece, 2003). I had identified that research had not considered how the characteristic impairments of ASD – difficulties in social interaction, difficulties in communication and restricted interests and a need for routine – might affect children’s ability to participate in consultation processes. To identify if and how these characteristics impacted, and to attempt to discover whether meaningful consultation could be carried out with such children, I examine the process of consulting with three children with ASD and learning disabilities (aged 7 to 14) about their experience at a residential short breaks service. Individualised consultation processes were developed for two children; the third was non-verbal and had extremely restricted communication so he was observed at the service. In all three cases, consultation/observation was undertaken by their class teacher, as a known, familiar, and trusted adult uninvolved with the service. Multiple data collection techniques were used to facilitate triangulation (Robson, 2002).

ASD impacts on the consultation process in many ways. Regarding social interaction, the children demonstrated autistic aloofness and social anxiety. Interaction was difficult, and it

was hard to identify whether responses were accurate or were made out of acquiescence or a desire to end the interaction. Further, though the children expressed clear preferences about concrete subjects such as food, questions concerning liking or disliking people, or having friends, were problematic. Their communication impairments affected the process. Where answers were obtained, it often remained difficult to gauge their validity; language use was sometimes bizarre and idiosyncratic and simple, closed questions were more effective in eliciting answers than open ones. Further concerns about the validity of the responses resulted from the phenomenon of recency, whereby children with communication problems may just echo the last option offered (Rodgers, 1999). Finally, all children exhibited some degree of discomfort and nervousness in communicating. The need for routine and resistance to change raised a significant and fundamental issue: if children reported that they liked something, did this indicate a real preference or merely that it had become part of their familiar routine? Similarly, was 'dislike' of a new experience indicative of a true dislike, or merely that something was unfamiliar? Further difficulties were caused by the children's poor personal event memory. However all children responded better when consultation was supported by concrete tools such as photographs or schedule cards

This study had significant limitations. It was carried out with a small group, over a brief period. Furthermore, as Jordan (1999b) points out, awareness of taking part in a 'special' intervention may influence children's responses. It is therefore inappropriate to seek to draw generalisable conclusions from the results. Nonetheless it constitutes a first, exploratory attempt to address methodological issues.

***Beresford and Tozer (2003) Finding out about outcomes of social care for children and young people with autistic spectrum disorders; Beresford, Tozer, Rabiee and Sloper (2004) Developing an approach to involving children with autistic spectrum disorders in a social care research project***

These papers report on research carried out at the University of York, concerned with identifying outcomes of social care services desired by children with ASD. This was one of four projects focused on the needs of different groups of 'hard to reach' children and direct participation by these children was a key aim.

This research draws on multiple data sources, including interviews with the child, parents and other informants (usually teachers), as well as informal observations of the children carried out in their school setting. Twenty-six families with children that have a diagnosis of autism or AS were recruited to the project. However, parental permission to engage children directly in consultation was obtained in only five cases (19%): one child with AS and four children with autism (none of whom had severe learning disabilities) aged 6-14. The researchers identify parental unwillingness as the main barrier to children's participation, often based on fear the child would become anxious. Other barriers included parents fearing that children would not understand the questions or that the severity of the children's ASD and communication difficulties would prevent their participation.

Of the five 'interviews', one was unproductive, in that the child refused to participate. The other four were considered more successful in that the children seemed to find the process enjoyable and some relevant data were elicited. Parents were surprised at the length of time the children spent in the process and two children were reported to have responded to abstract questions about likes and dislikes.

A number of points are made concerning research with children with ASD. As in my earlier study, triangulation is shown to be valuable. Further it is identified that research design must be flexible in order to include these children. In this study the researchers had to revise their research questions so that the children's participation, and the data collected, could be meaningful. As the study continued, it was necessary to redefine and adapt the project to accommodate the needs and abilities of the children participating in it. This had cost, time and resource implications, but was necessary for the research to be meaningful. As a result,

*“...different research questions and methods were used with the children with autistic spectrum disorders compared with the other groups of children...Taking this approach can feel like going against all that is taught about the qualities of ‘good research’, where consistency of method and research tools within a research project is advocated. However there is a balance to strike between ‘methodological rigour’ and facilitating the direct participation in research by the groups who are the focus of the research.” (Beresford et al., 2004)*

This literature review highlights the issues and challenges regarding undertaking interviews with whole families, including children and children with ASD, and identifies significant factors that had to be considered in the planning of this phase of the research. I will now move on to discuss the initial methodological decisions concerning the interviews.

## **6.2. Outline of method**

### **6.2.1. Data collection**

To address the research questions, a semi-structured interview format was identified as the most appropriate data collection tool. This format offers a number of advantages (Edwards and Talbot, 1999; Gillham, 2000; Robson, 2002). These include 100% response rate, the fact that meanings and interpretations can be probed and explored in a more flexible and individualised manner than is possible through questionnaires or fully structured interviews and that such interviews yield rich, deep and potentially illuminating and insightful data for

qualitative analysis. Possible disadvantages include the potential for intrusion and distress and concerns about reliability arising from the lack of standardisation inherent in the interview process. Steps taken to address these issues are discussed in the sections on ethical issues and analysis respectively.

Where children could neither be interviewed nor give informed consent, due to their cognitive impairments, I included them by undertaking structured observations, recording data in the same areas covered by the interview schedule. This approach had been used successfully in my earlier research in this area (Preece, 2002).

Volkmar *et al.*, (1997) criticise researchers in the field of ASD for using parental comments or observational data in isolation, and consider such approaches open to challenge. Cohen and Manion (1994) suggest that using multiple methods in researching human behaviour may help minimise the distortion and bias that can result from relying exclusively upon one method or source of data.

In this phase of the research the understandings of the individual family members are investigated. I wanted to know where differences of perception occurred, and to maximise the validity of the interview data (Cohen and Manion, 1994). Therefore, where possible, I used sources of supporting data. In all families I triangulated the responses of different family members. Where short breaks were used, I observed the children within these settings, referred to documentary evidence including initial social work assessments, care guidelines and review reports and interviewed short breaks' carers regarding the child's presentation and behaviour.

### *Sample group*

Analysis of the survey (4.4.7 - 4.4.9 above) identified the need to investigate the experience of families that accessed short breaks, those that wished to access such services but were unable to, and those families that did not wish to use such services. Therefore after consultation with my supervisor I set about identifying families within these three discrete groups to interview. Almost 60% of survey respondents had indicated they were willing to participate in interviews. Thirty-seven respondents were willing for the child with ASD to be interviewed, and forty-two for siblings to be interviewed.

As shown in 4.3.3 above, the dependence level of children with ASD in the sample varied from some needing little support to those who were dependent in most or all the areas identified by Robinson and Stalker (1990). To ensure that I was exploring the experience of families whose children had broadly similar – and significant – levels of dependence, I considered only families where the respondent had rated the child's dependence at 7/10 or above. A dimensional sampling approach (Robson, 2002) was used to select families for interview. Three primary dimensions were considered. These were: the discrete group into which the family could be categorised (whether the family used short breaks, wished to use short breaks, or did not wish to use short breaks), the child's dependence level being 7/10 or higher and the fact that the family was willing to be interviewed.

Within the three discrete groups, secondary dimensions were considered. These included the factors identified within the family survey as strongly associated with short breaks use/non-use: whether or not the family had a social worker, the child's school placement, age and diagnosis. Other dimensions were associated with family characteristics. These included the



number of adults, children (in total) and children with ASD in the household and the family's ethnicity. Finally, where possible, I sought to include families where I could interview siblings and children with ASD. Many families clustered into similar categories (for example, a quarter of service users could be categorised as White British, father absent, one to two siblings, child with ASD in special school). Where clustering occurred, tertiary dimensions were considered - where the family lived (to include urban and rural experiences), school attended (to include a range) and social worker (again to maximise diversity). Consideration of these dimensions identified seventeen potential families to interview: seven using services, six who wished to use a service and four who did not.

The method used to obtain the sample is not based on statistical theory, but on purposive sampling criteria (Curtis *et al.*, 2000). The selection of the sample was conceptually driven by both the theoretical framework underpinning the research and the emerging theory arising out of the data. I have explicitly identified the rationale for case selection, and acknowledge that there are ethical and theoretical implications arising from the choices made to include some families and exclude others. The sample is designed to make possible analytical generalisation (Miles and Huberman, 1994), in that careful sample selection can provide the opportunity to select and examine the generic processes that are vital in understanding the phenomenon under investigation, but it is acknowledged that statistical generalisation is impossible.

### **6.2.2. Interview schedules**

The topics investigated within the interviews were determined by the overall research questions and by analysis of the earlier phases of the study. Families were questioned about day to day family life, informal and formal support, their experience of and attitudes towards

short breaks and what other supports would help. Specific questions investigated families' attitudes concerning responsibility and others looking after their children, their understanding of the functions of short breaks and their attitudes concerning specialist and generic short breaks services. These were areas where statistically significant differences had been noted between the three groups within the survey.

Three interview schedules were developed – for parents, siblings and children with ASD – covering these topics. Each child with ASD's interview schedule/consultation tool was developed after an initial meeting with the family and discussion with parents. Where possible, with regard to the choices and wishes, the children were asked "*If you could have a magic wand and wish for anything in the world, what would you wish for?*" This was asked of the disabled children in Connors and Stalker's (2003) study, and it was hoped that comparisons could be drawn with the responses of children with ASD in this study. Parents' and siblings' schedules comprised five or six questions under each topic heading. For example, questions for parents under the heading '*What is family life like?*' included "*What is a typical weekday like?*" "*How has having a child with ASD impacted on your life?*" and "*What do you do together as a family?*"

Questions were open-ended, which are advantageous in semi-structured interviews, as they are flexible, allow for in-depth discussion, help build trust and rapport, enable researchers to more accurately assess respondents' beliefs and opinions, and can yield unanticipated and unexpected answers (Robson, 2002). Prompts were developed for each question and strategies to use as probes were identified (See Appendix 5 for the interview schedules).

### **6.2.3. Ethical considerations**

#### ***Consent***

As well as the ethical issues already discussed (e.g. respecting family privacy, limiting intrusiveness and managing role conflict), attention must be paid to issues of informed consent and of unanticipated self-exposure (Daly, 1992; Mauthner *et al.*, 2002). Due to the emergent nature of the interview process, it may be impossible for researchers to fully inform families of what they are consenting to beforehand. Therefore, as suggested by Miller and Bell (2002,) consent was considered as an ongoing process, both during and after the interviews.

Lindsay (2000) argues that researchers have extra responsibilities when children participate in research, and should ensure that they fully understand the short- and long-term implications of participation (such as being part of a case study in a journal article). Factors to be considered in ensuring that the child is adequately informed about the process include their age, cognitive ability, life experience and emotional state. Within this study, letters were written to the individual children explaining the research. This was followed up by an initial meeting where the research was explained to the family. A number of writers (Goodenough *et al.*, 2004; Mauthner, 1997; Mayall, 1994) argue that unequal and age-related power relationships exist between adult researchers and child subjects, making it hard for children to refuse consent, and limiting their ability to influence the research process (Alderson and Mayall, 1994). To address this, children were explicitly informed that they did not have to participate even where other family members were doing so, and that consent could be withdrawn at any time.

Due to the potential for acquiescence in individuals with learning disabilities (Rodgers, 1999) I treated each child with ASD's level of engagement in the initial visit and the opinions of their parents and siblings about their responses as secondary indicators of consent. I recognise that this meant that consent sometimes hinged on interpretation by other family members; however, this was a necessary decision in seeking to involve these children. As with other family members, consent was treated as a continuous process rather than a one-off agreement (Marchant *et al.*, 1999), and consultation sessions stopped when the children wished or if they showed distress.

Two children (Natalie and Patrick) had no speech, could not read or write, found social interaction extremely stressful, and had limited intentional communication, largely restricted to motoric gestures or the use of pre-symbolic objects (Ockelford, 1993). Middleton (1999) and Morris (1998b) suggest such children are practically and ethically best included in research by 'being with them': therefore 'participation' comprised my observing them at home and in their short breaks settings. Observation of Patrick at home ended within ten minutes, as he was distressed to find me there on his arrival home from school; by contrast, he accepted my presence in his family link placement without demur.

### ***Disclosure***

It was also recognised that disclosure of painful material or of abuse might occur in such interviews. Potential causes of disclosure might be the power imbalance between interviewer and interviewee, causing the interviewee to feel obliged to answer (Daly, 1992), the informal atmosphere of being interviewed in their own surroundings, or the rapport established by the interviewer (Duncombe and Jessop, 2002). Disclosure of abuse presents a clear dilemma to

researchers, and particularly practitioner researchers (Bell and Nutt, 2002). As a practising and registered social worker, I have clear professional responsibilities if abuse is identified. Furthermore I must adhere to the Code of Practice for Social Care Workers (General Social Care Council, 2002). Therefore, I made clear my professional responsibilities before each interview and further identified that if interviewees did not wish to discuss any area of questioning they did not have to and that interviews could stop at any time. Throughout each interview I regularly checked out the interviewee's comfort level. In the event, no disclosures occurred.

#### **6.2.4. Coding**

The coding system was developed before the pilot stage. A provisional 'start list' of codes (Basil, 2003, Miles and Huberman, 1994) was derived from the study's conceptual and theoretical framework, the research questions, and from problem areas and key variables identified in the survey (see Appendix 6). One group of codes was explicitly linked to the theoretical framework of the family systems model: family structure, family interaction, family functions and family lifecycle stages. Coping strategies were coded in accordance with the Brief COPE measure (Carver, 1997). These codes could all be applied when using NVivo, the qualitative data analysis software package with which I would be carrying out my data analysis (Bazeley and Richards, 2000; Gibbs, 2002). It was acknowledged that these codes were provisional, and that some might become redundant whilst others would be added during analysis. The coding process is discussed further in the outline of the data analysis process below.

### **6.2.5. Accessing the families**

A research governance group was established in the local authority in January 2005 and permission for the study to be undertaken was obtained from this body. All the families had previously given permission to be contacted, providing their addresses and contact details on the questionnaires. One family was fostering a child with ASD from another local authority; in this instance the research proposal was submitted to, and permission was obtained from, that local authority's research governance group.

It was important that initial overtures towards potential interviewees were appropriately managed, to maximise the sample group and to enable families that had changed their minds about participation to withdraw without distress or discomfort. I also recognised the potential distress that children with ASD might experience if asked to participate in something unusual or unexpected. Beresford *et al.* (2004), for example, cite the children and young people's unwillingness, based on anxiety, as a major factor affecting the recruitment of families for interview in their research. To address these issues and maximise participation I used the following process.

Initial letters were sent to the seventeen respondents who had completed the survey the previous year, asking if the family still wished to participate in interviews, explaining the research, obtaining consent and requesting a contact telephone number (see Appendix 7). Three families chose to withdraw at this stage (I did not ask why, as this might have seemed intrusive). On receipt of telephone numbers from the other fourteen, I made contact, setting a date and time for an initial visit. This call was followed by a further letter to the parents and letters to the children. The letters to the parents confirmed the date and time that I would be

making the initial visits and gave the parents contact telephone numbers. Where parental consent had been obtained for children's participation, letters explaining the research to the children (based on those used in Connors and Stalker's 2003 study) were attached. Two versions were prepared for children with ASD (for younger and older children) and two for siblings (see Appendix 8 for a letter to an older child with ASD and Appendix 9 for one to a younger sibling). Individually addressed letters introduced me to the children, explained the study's purpose and about participation and anonymity, and sought consent. Children were not promised full confidentiality as at this time I did not know if they would be interviewed in private or with other family members. A consent form was attached, to be signed either by the child or on their behalf. This was collected at the initial visit.

#### **6.2.6. Trialling and piloting**

At this point, I was also engaged in trialling and piloting processes. Gillham (2000) suggests that trialling – like piloting – should be carried out in conjunction with an individual (or individuals) with similar characteristics to, but distinct from, the sample group. Whereas the emphasis in piloting is on testing out the whole data collection process (access, data collection, transcription, coding and analysis), trialling focuses on refining the questions, and grants an opportunity to check things out with someone similar to the researched. My interview schedule was trialled with the mother of a child who had attended short breaks for five years before moving for educational reasons to a residential school. Minor amendments to prompts were made, but the schedule was not significantly altered.

As identified in 6.2.1 above, the dimensional sampling process identified seventeen potential families for interview. Piloting was essential, to ensure that the data collection and analysis

processes were fit for purpose, and that I was confident regarding my role (Gillham, 2000; Sampson, 2004). My supervisor and I decided to pilot the consultation process with one of the families using short breaks, and to seek to interview the other sixteen families in the study. The pilot family comprised mother, father (later diagnosed with AS) and two sons (one with AS and one with classic autism).

The pilot was carried out in accordance with the data collection process described in 6.2.7 below. The family were positive about the process, finding it enjoyable and non-threatening. Transcription highlighted two particular difficulties inherent in consulting with children with ASD: dealing with unclear speech and the need to use visual supports. I was clear myself that I would have to type all transcripts, not only because of confidentiality, but also because only I knew when the augmentative supports had been used and could accurately transcribe them. However, coding the interviews was successful, and my supervisor and I decided to include the pilot data within the final study as the interview schedule was not amended afterwards.

#### **6.2.7. Data collection process**

In addition to the pilot family, thirteen families were interviewed. Some had moved category since the survey; one family had started using short breaks; another no longer felt the need for a service. The fourteen families interviewed comprised six using short breaks, four that wished to use them and four that did not want such a service. Two did not permit their children to be interviewed; and two children with ASD were non-verbal with severe learning disabilities: they were involved in the consultation process by observing them at home and in their short breaks settings (see 6.2.1 and 6.2.3). In total, forty-four consultations were carried out in a number of different combinations (see Table 6.1).



**Table 6.1 Consultations carried out with members of families that have children with ASD**

	<b>Present during consultation</b>					<b>Total</b>
<b>Family member</b>	Alone	With child with ASD present part of the time	With at least one parent present	Together	Observed only	
Mother	9	3	N/A	N/A	N/A	<b>12</b>
Father	6	N/A	N/A	N/A	N/A	<b>6</b>
Parents together	N/A	N/A	N/A	2	N/A	<b>2</b>
Children with ASD	5	N/A	7	N/A	2	<b>14</b>
Siblings	7	N/A	3	N/A	N/A	<b>10</b>
<b>Total</b>	<b>27</b>	<b>3</b>	<b>10</b>	<b>2</b>	<b>2</b>	<b>44</b>

Data collection was undertaken using a two stage process. Initial visits were carried out in spring 2005. I met the families, discussed the research and the interview process, and checked they still consented to participate (all did). I identified how families were to be interviewed (all agreed to be tape recorded), in what combinations, and what adaptations were needed to make the process accessible for children with ASD. In four cases, parents did not wish visual supports to be used, or they felt their child did not need them. In these cases, the parent(s)' wishes were respected. In the other eight cases, visual supports, work systems, schedules or structured tasks were designed to support the consultation process (a full discussion of the consultation process with the children with ASD – and of the problems and issues encountered – is provided in Appendix 10). Finally I collected children's consent forms, arranged the interview date(s) and briefed the families about the interview areas, giving them a written outline of the interview structure. This was done to maximise their comfort and confidence, and to ensure that they had time to think about the topics under consideration.

## ***Interviews***

Interviews were undertaken between March and early June 2005. Interview length was determined by the interviewee. Interviews with parents lasted from 20 minutes to 2 hours, with an average length of about 45 minutes. Interviews with siblings lasted from 5 minutes to 40 minutes, with an average length of about 20 minutes. Finally, interviews with children with ASD lasted from 15 minutes to 40 minutes, with an average length of about 25 minutes (Details of the families interviewed, and how individual members were interviewed, are given in Table 6.2). Though younger siblings and children with ASD were provided with opportunities to draw to illustrate their answers, none chose to – though one child with ASD presented me with a drawing of a train. Two children with ASD strongly disliked drawing, and their parents told me that they did not ever draw. This was a major point of difference from many research projects with children with severe learning disabilities, where drawings are often an effective means of eliciting children's views (Marchant *et al.*, 1999; Marchant *et al.*, 2001). On the other hand, photographs and visual supports were extensively used in the process of interviewing the children with ASD (see Appendix 10 for a full discussion of this topic). After each interview I ascertained whether the interviewee wanted a copy of the tape and/or a transcript and informed them that I would later send them a brief summary outlining my main findings. One interviewee followed up receipt of their transcript with further written notes.

**TABLE 6.2 Details of families interviewed**

<b>Name</b>		<b>Age</b>	<b>Occupation</b>	<b>How interviewed</b>
<b>Families currently using short breaks</b>				
Family A	Mother	39	Autism family advisory worker (p/t)	Individual interview
	Father	39	Stock controller (f/t)	Individual interview
	Child with AS	14		Individual interview
	Child with ASD	12		Individual interview
Family B	Mother	48	Hairdresser (p/t)	Individual interview
	Partner	55	Car salesman (f/t)	Individual interview
	Child with ASD	16		Individual interview
	Sister	24	Office worker	Individual interview
Family C	Mother	43	Not in employment	Individual interview
	Child with ASD	7		Observation
Family D	Mother	43	Not in employment	Individual interview
	Father	40	Motor racing team manager (f/t)	Individual interview
	Child with ASD	13		Observation
	Brother	10		Individual interview
Family E	Mother	45	Autism charity office manager (p/t)	Individual interview
	Child with ASD	15		Individual interview
	Child with semantic-pragmatic disorder	13		Individual interview
Family F	Mother	36	Not in employment	Mother and stepfather interviewed together
	Stepfather	29	Not in employment (disabled)	
	Child with AS	11		Did not interview
	Sister	16		Did not interview
<b>Families who wish to use short breaks</b>				
Family G	Mother	43	Factory worker (p/t)	Mother and father interviewed together
	Father	50	Factory owner (f/t)	
	Child with ASD	18		Interviewed with parents present
	Brother	9		Interviewed with parents present
Family H	Mother	40	Hairdresser (p/t)	Individual interview
	Child with ASD	15		Interviewed with mother present
	Sister	18	Office worker (f/t)	Individual interview

Family I	Mother	38	Shop supervisor (p/t) Flying instructor (f/t)	Individual interview
	Father	42		Individual interview
	Child with ASD	8		Interviewed with mother present
	Sister	16		Individual interview
	Sister	15		Individual interview
Family J	Mother	38	Education liaison officer/interpreter	Individual interview
	Child with ASD	9		Interviewed with mother present
	Brother	16		Individual interview
	Brother	14		Individual interview
	Sister	10		Interviewed with mother present
Families who do not wish to use short breaks				
Family K	Mother	36	Fingerprint expert	Individual interview
	Child with AS	10		Individual interview
Family L	Mother	34	Payroll manager (f/t) Golf professional (f/t)	Individual interview
	Father	35		Individual interview
	Child with ASD	7		Did not interview
	Sister	8		Did not interview
Family M	Mother	44	Not in employment	Interviewed with children present
	Child with ASD	12		Interviewed with family present
	Sister	18	Shop assistant (f/t)	Interviewed with family present
Family N	Foster mother	63	Foster carer Foster carer	Individual interview
	Foster father	66		Individual interview
	Child with ASD	16		Interviewed with foster mother present

### ***Observations***

Two children with ASD (Natalie and Patrick) had no speech, could not read or write, found social interaction extremely stressful, and had limited intentional communication, largely restricted to motoric gestures or the use of pre-symbolic objects (Ockelford, 1993). Middleton (1999) and Morris (1998) suggest that such children are both practically and ethically best included in research by 'being with them'; thus they participated through the first author observing them at home and in their short breaks settings. During these observations I remained in the background, and did not attempt to interact with the child being observed, other children present or with staff/carers present. An observation schedule – based upon the interview format – was used to record my observations; and at the end of each observation session the data obtained was checked out with adults present who knew the child well – e.g. parent, family link carer, key worker – for accuracy. The observation sessions typically lasted between twenty to forty minutes.

### **6.2.8. Data analysis**

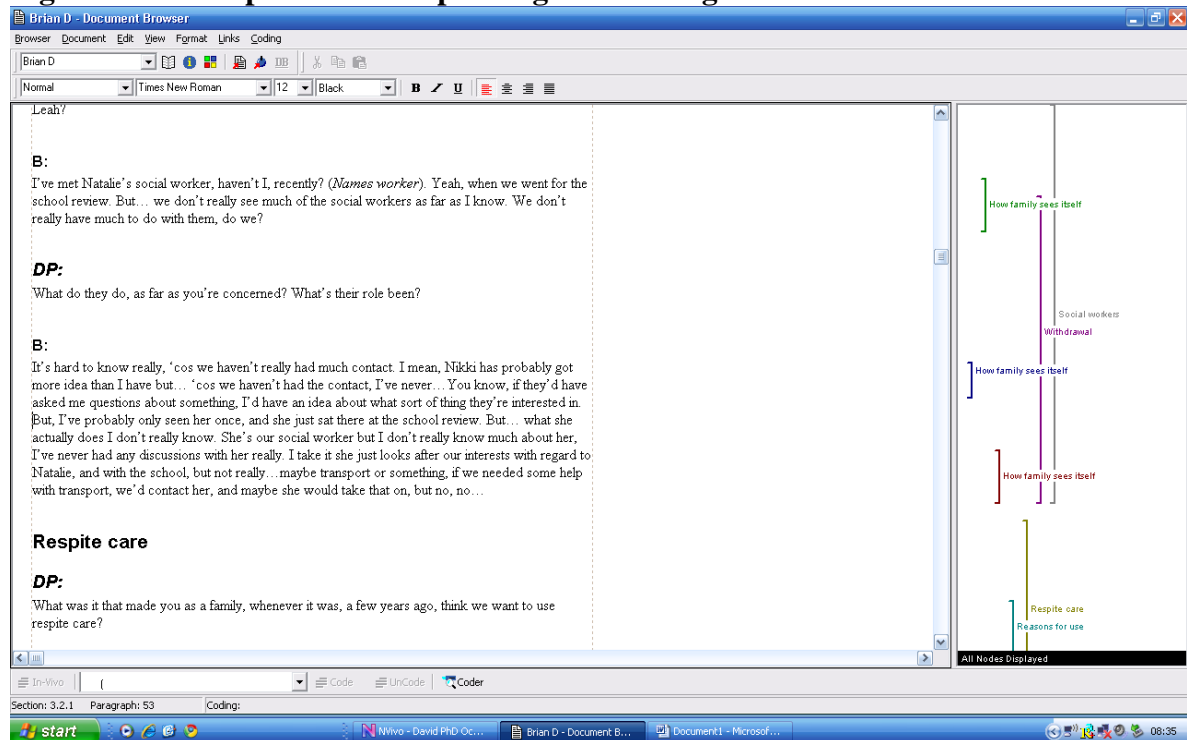
After transcription I had 182,580 words (907 pages) of interview data. To manage this large amount of data, I used a computer-assisted qualitative data analysis software (CAQDAS) package: NVivo 2.0. Lee and Esterhuizen (2000) and Gibbs (2002) suggest that CAQDAS can be a helpful tool with regard to the management of data, in particular with regard to storage, coding and retrieval. These programs include both word processing and database-creating facilities. This enables the researcher to select chunks of text and apply codes to them, and also to retrieve all similarly coded text without losing any information about where it came from, allowing coded sections to be viewed within their context (Gibbs, 2002). Lewis (2004b) identifies NVivo as being an appropriate and effective tool in analysing interview

data. Though initially challenging to learn and use, NVivo allowed the text to be managed and analysed with relative ease, and proved an invaluable tool given the large amount of data concerned.

### ***Template approach***

The interviews were transcribed, formatted so that the interviewer's questions, the respondents' answers and the different subsections of the interview would be recognised by the program, and imported into NVivo. Data were analysed using a 'template' approach (Robson, 2002). A provisional set of key codes (Basil, 2003, Miles and Huberman, 1994) – both derived from the theoretical framework underpinning the research, and related directly to the key variables identified within the initial survey – was drawn up (see 6.2.4.) and entered into NVivo as 'tree' or 'free' nodes. These codes/nodes served as a template for the data analysis. Coding was an iterative process, and the template changed frequently during the initial stages of the process of analysis, as I went through the transcripts line by line, identifying and coding each interviewee's substantive statements (Gillham, 2000) and as further themes and patterns emerged. An example of a section of text being analysed is shown in Figure 6.1. After coding (and re-coding) ten interviews I achieved 'coding saturation': from this point the codes remained consistent (see Appendix 11). After coding all of the interviews, I then re-read each transcript, ensuring no valid categories had gone unrecognised, and that there were no key substantive statements to which a code could not be applied. A sample of the transcripts was externally audited using the final codebook.

**Figure 6.1. Example of transcript being coded using NVivo**



The example above shows part of Brian D's interview being coded using NVivo. The interview transcript is on the left. On the right, 'coding stripes' show which extracts of text were coded under each category. Running a report enabled all extracts categorised under the same code to be collated.

Data were then further reduced into matrices, condensing the key themes and statements. Matrices were constructed for families as a whole, and for mothers, fathers, children with ASD and siblings separately (see Appendix 12 for an example). As with the transcripts, a completed matrix was externally audited – using printed reports showing all data coded under each heading in the matrix, and any supporting sources of data used for triangulation – to ensure reliability.

### **6.3. Family life**

#### **6.3.1. Experience of family life – mothers**

##### ***The mothers***

Thirteen mothers (and one foster-mother) were interviewed (see Table 6.3). They were aged 34 to 63 (mean = 42.1 yrs, SD = 7.2 yrs). Nine (64%) were in employment – 6 (43%) were working part time and 3 (21%) were in full time employment; five mothers (36%) were not in paid employment. Six (43%) were single parents, and all but one (93%) were the main carer in their family. One mother felt that – though undiagnosed – she may be on the autism spectrum, or that she at least displayed characteristics of the broader autism phenotype (Micali *et al.*, 2004; Piven *et al.*, 1997).

Five consistent themes emerged from the mothers’ description of family life. These are acceptance of the impact of ASD on their lives, isolation, the experience of stigma, concern about the impact of living with ASD on their other children and the lack of a template for the future.

##### ***Acceptance of impact of ASD on themselves***

Across all three sub-groups, almost all mothers accepted the impact of having a child with ASD upon themselves. This was clearly illustrated in their descriptions of daily life. Mornings typically followed set routines (getting up, washed, dressed, breakfasted and to school) coordinated to fit in with school transport taking the children with ASD to school. Most had established methods of negotiating this period of time successfully. However, some identified school day mornings as “*traumatic*” and “*a struggle*”.



**TABLE 6.3 Details of mothers interviewed**

<b>Name</b>	<b>Age</b>	<b>Occupation</b>	<b>Family composition</b>
<b>Families using short breaks</b>			
Andrea A	39	Autism social care worker (p/t)	Lives with husband (undergoing diagnosis for AS) and 2 children: 14 year old son with AS and 12 year old son with ASD
Jacqui B	48	Hairdresser (p/t)	Divorced. Lives with partner and 16 year old son with ASD
Alison C	43	Not in employment	Unmarried. Lives with 7 year old son with ASD
Nikki D	43	Not in employment	Married. Lives with husband and 2 children: 13 year old son and 10 year old daughter with ASD
Marie E	45	Autism charity office manager (p/t)	Divorced. Lives with 2 children: 15 year old son and 13 year old daughter, both with ASD
Gwen F	36	Not in employment	Married, lives with children's stepfather (who is physically disabled) and 2 children: 11 year old son with AS and 15 year old daughter
<b>Would-be users of short breaks</b>			
Maggie G	43	Factory worker (p/t)	Married. Lives with husband and 2 children: 18 year old daughter with ASD and 9 year old son with diabetes
Sandra H	40	Hairdresser (p/t)	Divorced. Lives with 2 children: 15 year old son with ASD and 18 year old daughter
Sam I	38	Shop supervisor (p/t)	Married. Lives with husband and 3 children: 2 daughters (aged 16 and 15) and 8 year old son with ASD
Asma J	38	Education liaison officer/interpreter (f/t)	Divorced. Lives with 4 children: son 16, son 14 with learning difficulties, son 9 with ASD and 10 year old daughter
<b>Families who do not wish to use short breaks</b>			
Donna K	36	Fingerprint expert (f/t)	Unmarried. Lives with 10 year old daughter with AS
Megan L	34	Payroll manager (f/t)	Married. Lives with husband and 2 children: 7 year old son with ASD and 8 year old daughter
Stella M	44	Not in employment	Divorced. Lives with 2 children: 12 year old son with ASD and 18 year old daughter
Kath N	63	Foster carer	Married. Lives with husband, 16 year old foster-son with ASD and 2 other foster sons, both with emotional and behavioural difficulties

Many mothers then had to go to work, either full or part time. Those not in paid employment still reported their days were full, either due to meetings with professionals or having to undertake as many domestic and family tasks as possible while the child was at school. As soon as the child returned home, the mother's focus was on meeting their needs. Often the child returned hungry, and in many families the child with ASD, mother and any siblings ate their evening meal as early as four or four thirty in the afternoon. After the meal, mothers were largely occupied in full-time interaction with the child.

*"And then he comes home at 4-ish, and then it's hard work really, 'cos he's quite demanding in that he wants things all the time."* (Alison C)

After the child with ASD was bathed and ready for bed – which often required the mother's complete support – the process of preparing the child for bed began. This often took hours and in some cases, to settle the child, the mother had to go to bed along with him/her.

*"I have to go upstairs, and physically lie with him in the bed, or else he won't go to sleep. If I don't, he's just up all night."* (Stella M)

Weekends and school holidays were considered even more stressful by some mothers, particularly by lone carers.

*"Awful! Awful! Because that's when it's difficult on your own, because you're having to watch him every minute. It drives you crazy..."* (Alison C)

Some considered weekends and holidays more relaxed: generally because the child followed his/her own preferred routine with which mothers fitted in.

*"She knows I'm not going to force her to get dressed, I'm not going to make her brush her teeth or whatever immediately. She sort of knows it's a relaxed sort of lazy time."* (Nikki D)

In general, mothers accepted their situations and resignation was commonly stated.

*“Am I happy? Well...um...you always hope your kids are going to, like, grow up, get married, leave home, but he’s not going to do that, so...just have to accept it really, don’t I?” (Sandra H)*

However, some mothers fantasised about escaping their situation.

*“Most times I’m all right but sometimes like this morning, I said, ‘Oh I might leave home later and not come back’ (laughs). I’m sort of half-joking and half-meaning it.” (Stella M)*

They spoke of curtailing their career and life aspirations in general in order to cope with the day to day demands of having a child with ASD.

*“I stopped beating myself up about a lot of things, and just thought, no, the focus is the children and...that’s annoying sometimes, and is limiting on my life, but I can’t see any other way of doing it.” (Marie E)*

Their children exhibited many unusual behaviours, and most mothers accepted the restrictions they placed upon their lives, including being unable to sleep in their own beds, being unable to “pop out” to the shops, and being unable to make appointments at, for instance, the dentist’s or hairdresser’s.

*“I went for about three years without being able to get my hair cut, because I didn’t have anywhere that I could leave her.” (Donna K)*

Others, however, struggled with these behaviours, viewing each day as a battle, experiencing a chronic burden of care, and expressing their need for professional support.

*“If I haven’t had help for a while, things start going down, ‘cos of my mentality. It’s psychological as well as practical help, physical help.” (Alison C)*  
*“It’s a fight... hard work.....a continual fight.” (Sam I)*

### **Isolation**

All mothers stated that they experienced feelings of isolation; only the foster-carer was an exception.

*“You’re totally isolated really.” (Marie E)*

*“I always feel ...even (when) I’m miles away, gone for a weekend somewhere completely different, I don’t have the children, don’t have the home, don’t have Peter...I’m still on the periphery.” (Andrea A)*

These feelings began within the marital dyad. Half were single parents, receiving no day to day support from the father. In most cases, the father provided no support at all, having little or no contact with the family. In others, more amicable situations existed, where fathers provided informal breaks.

*“His dad has him every other weekend, Friday to Sunday lunch...” (Stella M)*

Even where mothers were married or had partners, husbands/partners were generally distanced from the direct care of the child (only one father had an active direct caring role). Most worked long hours, and/or had hobbies that occupied much of their spare time. Nikki D’s husband worked for a motor racing team and was away from home for months on end, leaving Nikki as sole carer of their two children. Asma J’s sense of isolation was heightened by having no relatives in the United Kingdom (her family was from Pakistan) and by her experience of racism as a devout Muslim within a shire county with a low minority ethnic population.

*“I’ve seen fear on their faces...If somebody is scared of me or Ibrahim...I don’t know what their feelings are, but I can see the expressions on their faces, and I think that makes it doubly difficult for me as a parent.” (Asma J)*

Other research suggests that Asma’s sense of isolation, compounded by racism, is not exceptional (Hatton *et al.*, 2004; Shah, 1992). Where the child with ASD had siblings, these children often provided support and care; this is discussed in the sections concerning mothers’ concern about the impact of ASD on their children and the experience of siblings.

Isolation from the wider family was commonly reported, although some mothers described the wider family, particularly grandparents, positively (see the section on support from the extended family). Friendships and relationships with neighbours were also negatively impacted by ASD, compounding mothers' feelings of isolation.

*"I was cut off from the middle class perfect family neighbours who didn't understand us. I had a lot of problems in that way. Like neighbours complaining about the school bus parking so they couldn't get out to work for two minutes, and getting a petition up. Can you believe it? Knowing I was a single parent, and I had enough problems. I just don't get that at all really, don't understand that."*  
(Alison C)

A recurring theme among was the loss of the friendships and relationships formed before the child with ASD was born. Instead, their friendships tended to be with other parents of children with ASD, formed through their children's schools or in support groups. While offering support, these relationships also enhanced their sense of isolation and separateness from the rest of society.

*"I used to have quite a big circle of friends. Then we had had Ian and I'd got this Tasmanian Devil thing in a buggy, and you lose an awful lot of friends awfully quickly, particularly when you say he smears poo! They don't want to know you any more."* (Andrea A)

*"I feel like that. I always feel that people define me by being the parent of autistic children."* (Marie E)

### ***Experience of stigma***

Stigma was another recurring theme in the mothers' interviews. Negative attitudes of neighbours have been described. Mothers also experienced hurtful and judgemental comments in the street and other public places, with members of the public assuming their child was misbehaving and criticising their parenting. However, some mothers living in rural settings believed the child's behaviour was more accepted, and their own situation ameliorated, by living in small communities where the family's situation was known and understood.

*“There’s Jack, the old boy over the road, he’s really good with her... because he is so loud, she does always answer him, she makes a point of her answering him...” “Bye-bye”, or whatever... Yeah, most people are really good....” (Nikki D)*

### ***Concern about impact of ASD on their other children***

While most mothers accepted the impact of ASD on themselves, they worried about its impact on their other children. Some had other children with special needs – such as diabetes or learning disabilities – whose needs and difficulties were not treated with sufficient priority due to the demands of the child with ASD. Where the child with ASD had younger siblings, mothers wanted these siblings to experience as “normal” a childhood as possible.

Where there were older siblings, mothers were acutely aware of the impact of living with ASD, and often felt guilty about their reliance on these siblings for care and support.

*“They find it quite hard, and I think it has affected them. They get quite stressed at times with it... Sometimes I think I might rely on them too much (but) there isn’t really anybody else who I’d want Andrew to be with, or trust with him. Or who I’d know would feel comfortable with him.” (Sam I)*

### ***Lack of template for the future***

The final theme was the absence of a template that could help them to think about and plan for the future.

*“You learn...quite quickly when your child’s just diagnosed, that things are not going to be the way you expected they were going to be.” (Gwen F)*

Mothers expressed a fear of looking ahead, and were often afraid of what the future held for them and their children

*“I worry about the future. ‘Cos I mean, (his sisters) are not going to be here for ever, either...” (Sam I)*

*“We’d like to think his sister will be there for him but we don’t want her not to have her own life.” (Megan L)*

Some stated that they tried to live their lives on a day by day basis, giving little thought about what the future may hold. Others reported treating family life as an educational experience, and focused their lives on maximising their children's skills.

*“Otherwise we would just live in autie world, where Susan would be off doing her funny autie activities, Benjamin would spend forever on the Gameboy, until he got himself into a complete fury...and we'd have no kind of family life. That's just not what I want.”* (Marie E)

### **6.3.2. Experience of family life – fathers**

In eight families (57%), the birth father no longer lived in the family home. Five birth fathers were interviewed, as were one step-father, one foster-father and one partner (see Table 6.4). They ranged in age from 29 to 65 (mean = 44.5 years, SD = 11.9 years). Six were in full-time employment outside the home, one was unemployed due to disability and one was a full-time foster-carer. In three single parent families, the mother felt that her ex-husband may have had an ASD; where fathers were present, one was awaiting a diagnostic interview for AS (which was subsequently confirmed) and another felt that, if not diagnosable, he had characteristics of the broader autism phenotype.

As discussed above, only Simon L, a golf professional, shared caring tasks with his wife. The other fathers and partners had little involvement with the hands-on physical care of the children with ASD.

*“I don't usually see him in the morning...then after work I normally get in about half six, seven, something like that.”* (Philip I)

Five main themes emerged in the narratives of the fathers and partners. These were withdrawal, minimising the difficulties, the use of humour to address their situation,

uncertainty about the future, and considering their family as being in particular need of professional support.

**TABLE 6.4 Details of fathers interviewed**

Name	Age	Occupation	Family composition
<b>Families using short breaks</b>			
Peter A	39	Stock controller (f/t)	Married. Lives with wife and 2 children: 14 year old son with AS and 12 year old son with ASD. Undergoing assessment for AS himself at time of interview – subsequently diagnosed
Floyd B	55	Car salesman (f/t)	Single. Lives with partner and her 16 year old son with ASD
Brian D	40	Motor racing test team manager (f/t)	Married. Lives with wife and 2 children: 13 year old son and 10 year old daughter with ASD
Bob F	29	Not in employment (disabled)	Married, lives with wife and 2 step-children: 11 year old son with AS and 15 year old daughter
<b>Would-be users of short breaks</b>			
Arthur G	50	Factory owner (f/t)	Married. Lives with wife and 2 children: 18 year old daughter with ASD and 9 year old son with diabetes
Philip I	42	Flying instructor (f/t)	Married. Lives with wife and 3 children: 2 daughters (aged 16 and 15) and 8 year old son with ASD
<b>Families who do not wish to use short breaks</b>			
Simon L	35	Golf professional (f/t)	Married. Lives with wife and 2 children: 7 year old son with ASD and 8 year old daughter
Harold N	66	Foster carer	Married. Lives with wife, 16 year old foster-son with ASD and 2 other foster sons, both with emotional and behavioural difficulties

### ***Withdrawal***

In almost 60% of families interviewed fathers were no longer present and in half of these they had minimal or no contact with their ex-wives and children. Where present in the nuclear family, they tended to withdraw both from the day to day childcare and from contact with the professionals involved with their child, such as schools and social workers (see the section on



formal support below). Harold N followed a county cricket team. Bob F was undertaking a counselling course. Philip I was a flying instructor, on weekdays leaving home at 7 a.m., returning at 7 p.m. His evenings were spent aero-modelling in the loft or on the computer and his weekends were spent running a flying club. Brian D, the manager of a motor racing team, worked abroad from December to February, then for one week a month during the remainder of the Grand Prix season. While at home, he worked eleven-hour days, often including weekends. Arthur G, who ran his own company, worked

*“...a normal office day, plus probably three quarters of an hour in the morning, and (I) nearly always go back in the evening, plus Saturdays and Sundays.”*  
(Arthur G)

Some fathers acknowledged that they behaved in this way consciously.

*“To be honest, I’d rather spend a day at work than traipsing round school with him.”* (Philip I)

Wives and partners were sensitive to the impact of ASD in the family on their husbands, and chose not to challenge them or to seek more support from them.

*“Philip was different then, when Andrew was a baby and we didn’t know he was going to be autistic. He was a lot more of a hands-on family man...I think the girls look back and they see it as the good times. I think a lot of it, why he goes flying at weekends, is because he does find it hard, the impact of Andrew. And it’s sort of his way of shutting off from it. I sort of understand that: I think it has affected him greatly.”* (Sam I)

No fathers had attended support groups or sought contact with other families in similar situations. They were more likely to seek information in impersonal ways, such as using the internet.

### ***Minimisation of difficulties***

Whereas mothers strongly expressed how ASD had impacted negatively on their families and themselves, fathers tended to minimise the difficulties that their family faced as a result of the condition.

*“I don’t think we have any real problems, to be honest.” (Simon L)*

*“It’s no hardship at all.” (Arthur G)*

### ***Humour***

Whereas mothers spoke of feeling stigma and isolation, fathers were more likely to use humour to deal with the problems they faced in living with a child with ASD.–

*“I can’t be embarrassed. I just laugh.” (Arthur G)*

When talking to others outside their families about life with ASD, they tended to present family life in humorous terms.

*“All my workmates know about Andrew, but don’t necessarily understand his condition...and I don’t really see much point in explaining... I’ll go into work and say (laughs) ‘Guess what he did yesterday? Trod on the hamster!’ (laughs)...And they just laugh, and I laugh too... Some of the things he does...it’s a bit comical.” (Philip I)*

All of these behaviours – withdrawal, minimising difficulties and humour – can be understood as coping strategies in dealing with the presence of ASD.

### ***Uncertainty about the future***

Despite the themes outlined above, many fathers – like the mothers – expressed fear and uncertainty about what the future held for them and their children. Some dealt with these feelings by seeking to live one day at a time while others sought control by carefully planning out their future.

*“When he was first diagnosed as autistic...you spend the next six months worrying yourselves to death about it, and what’s going to happen to him in later life...but...you’ll just kill yourself if you do that. So I came to a decision where I wasn’t going to worry too much about it. As long as he’s happy today, and we’re happy today, then we’ll work on tomorrow when tomorrow comes.” (Philip I)*

*“I’ve worked my life around this, being able to pack up and spend time with Sarah, sort of semi-retirement – I might just work a couple of days a week – and if Sarah hasn’t got a job or whatever, or can’t do anything, I’ll have the time...I’ll have all the time in the world then.” (Arthur G)*

### ***Conceptualisation of own family as particularly needy***

While many fathers minimised the difficulties their family experienced, others felt their situations were more difficult than those faced by other families that have children with ASD. Fathers often assumed other families had wider informal support networks than their own, and that their family was more isolated than others – perhaps due to their own limited contact with other families that have children with ASD

*“I think, other families of autistic kids probably don’t need the more help, because they’ve got help from families. So in between the respite they’ve got mum, and brother and sister and that popping over to help look after her for the afternoon; or drop her off here and I’ll...you know, that’s one luxury we haven’t got, so...we’re probably unique in that way.” (Brian D)*

### **6.3.3. Experience of family life – siblings without ASD**

Four brothers and six sisters without ASD were interviewed (see Table 6.5). They were aged from nine to twenty-four (mean = 15.3 yrs, SD = 4.3 yrs). All but one still lived in the family home. Five major themes emerged in the interviews with the siblings. These were their acceptance of the impact of ASD as normality, the restriction of their opportunities, the closeness of the sibling bond, embarrassment, and stress.

**TABLE 6.5 Details of siblings without ASD interviewed**

Name	Age	Status	Family composition
<b>Families using short breaks</b>			
Hannah B	24	Office worker (f/t)	Lives alone. Grew up in home with mother, sister and brother with ASD
Carl D	13	At school	Lives with mother, father and 10 year old sister with ASD
<b>Would-be users of short breaks</b>			
Tom G	9	At school	Lives with mother, father and 18 year old sister with ASD. Has diabetes
Caroline H	18	Office worker (f/t)	Lives with mother and 15 year old brother with ASD
Jane I	16	At school	Lives with parents, sister aged 15 and 8 year old brother with ASD
Linzi I	15	At school	Lives with parents, sister aged 16 and 8 year old brother with ASD
Yusuf J	16	At school	Lives with mother and 3 siblings: brother aged 14 with learning difficulties, brother 9 with ASD and 10 year old sister
Imran J	14	At school	Lives with mother and 3 siblings: brother 16, brother 9 with ASD and 10 year old sister. Has learning difficulties
Layla J	10	At school	Lives with mother and 3 siblings: brother 16, brother 14 with learning difficulties and brother 9 with ASD
<b>Families who do not wish to use short breaks</b>			
Cindy M	18	Shop assistant	Lives with mother and 12 year old brother with ASD

### ***Acceptance of the impact of ASD***

All of the brothers and sisters interviewed accepted the presence of ASD within their family as being that family's 'normality'.

*"He's just normal to me..."* (Cindy M)

As in other studies (Hannah and Midlarsky, 2005; Howlin, 1988), siblings often took responsibility for the child with ASD, providing their parents with support. They carried out direct physical care, prepared meals, bathed and prepared the child for bed, took them out and about and babysat. Sisters in particular took on a caring role regarding their disabled sibling, which restricted and limited their own opportunities for socialisation and achievement.

*“Sometimes I can’t attend competitions ‘cos I have to look after my brother – ‘cos my mum and dad are at work. I’m a bit unreliable to the school because of that, and that’s why I missed out on my opportunity to get into the county team.”*  
(Linzi I)

Siblings felt they had a good understanding of ASD, which they often researched for school projects. The literature suggests that such an understanding is helpful both regarding the sibling’s relationship with the child with a disability and to positive outcomes for the sibling in general (Roeyers and Mycke, 1995; Williams *et al.*, 2002).

*“I’ve read books and articles, and watched TV programmes – everything on TV about autism I’ll watch – so, I’ve kind of just taught myself everything, really.”*  
(Hannah B)

Linzi I had positively reframed her situation and felt that her experience of living with ASD had been beneficial.

*“It’s made me stronger inside because it’s given me something hard to cope with at a young age. So difficulties that I face later on will, I guess, be easier to get over...”* (Linzi I)

### ***Restriction of opportunities***

Despite their acceptance of their situation, the presence of ASD in their families restricted opportunities available to the siblings, both socially and educationally; older siblings spoke of how they had missed out while growing up.

*“If I wanted to do something, it would always be, someone had to look after George...someone always had to be there for George.”* (Caroline H)

As well as being unable to do things outside the home, siblings often could not have friends come to the home, either because the child with ASD would not tolerate their presence or because they were scared of the child’s behaviours.

*“If friends try to have a conversation with me they’re interrupted and slapped. I think it’s the aggression that makes it hardest for my friends. They can cope with the shouting, but they’re just not expecting that.” (Jane I)*

Regarding educational issues, siblings spoke of homework being destroyed, or situations where they could not do homework due to the child with ASD’s behaviour. Jane I wanted to go to university, but was concerned about how she would perform in her GCSEs.

*“If I’ve got to write something, he’ll come and like ruin the work and start ripping it up, or just crunching it...And if I want to go on the computer, and do internet research, or go on any of the revision websites, or anything like that, he’ll just hit me till I get off there.” (Jane I)*

### ***Sibling bond***

All siblings identified things they liked about the child with ASD, and it was clear they felt a close bond with the children with ASD.

*“Sometimes he can be really, really sweet, and he can be quite funny as well.” (Hannah B)*

*“He’ll have days when he’s really touchy feely, and he’ll cuddle you, which I like, when he cuddles... and we tickle, you tickle him and he’ll scream the house down, but then he’ll want you to do it again... which is funny. I like him for things like that.” (Cindy M)*

### ***Embarrassment***

Despite this generally positive attitude towards their brothers and sisters with ASD, siblings were often embarrassed by their behaviour.

*“It’s quite hard, like, going out places with him...’cos it can be pretty...it can be embarrassing sometimes, ‘cos he shouts a lot and all that.” (Linzi I)*

*“It’s a bit difficult sometimes. The thing I don’t like is when people stare...’cos its obvious to me, obviously, there’s something wrong with him...’cos of the things he does, and ...I just don’t like people staring.” (Caroline H)*

Only a few older siblings had become more hardened in their responses to potentially difficult situations.

*“Yeah, you sometimes get people looking at her if she’s making a load of noise or something...but I’m not like, really defensive. I just don’t mind that much.” (Carl D)*

### ***Stress***

All siblings reported that living with ASD caused difficulties and stressful situations in day to day family life. Problems arising from the restriction of social opportunities, difficulties doing homework and embarrassment have already been identified. Further stressors included their siblings’ frequently aggressive behaviour towards them and the lack of respect shown to their personal space and possessions. It was clear that day to day family life was often very difficult for these siblings of children with ASD.

*“She hits, pulls hair, bites and makes noises.” (Tom G)*

*“He sometimes breaks my stuff and nicks things.” (Jane I)*

### **6.3.4. Experience of family life – children with ASD**

Fourteen children with ASD were consulted. In two cases, this was through observation and discussion with other family members and short breaks carers. The other twelve children were interviewed, either separately or with other family members, and with differing levels of structure and supports (A full outline and discussion of the consultation process with the children with ASD is provided in Appendix 10. In this Appendix I describe in detail how consultation was undertaken, providing examples of the tools used, and identifying the difficulties and barriers that can occur in consulting with such children). Children were aged from seven to eighteen (mean = 12.5 yrs, SD = 3.3 yrs). Details are given in Table 6.6.

Four significant themes emerged from the consultation process. These were the children's generally positive view of family life, isolation, a lack of awareness of the impact of ASD on the family and the presence of problems at school.

**TABLE 6.6 Details of children with ASD interviewed**

<b>Name</b>	<b>Age</b>	<b>Diagnosis</b>	<b>Family composition</b>
<b>Families using short breaks</b>			
Michael A	14	AS	Lives with parents (father diagnosed with AS) and 12 year old brother with ASD
Ian A	12	ASD	Lives with parents (father diagnosed with AS) and 14 year old brother with AS
Peter B	16	SLD/ASD	Lives with mother and her partner
Patrick C	7	ASD	Lives with mother
Natalie D	10	ASD	Lives with parents and 13 year old brother
Benjamin E	15	Semantic pragmatic disorder	Lives with mother and 13 year old sister with ASD
Susan E	13	ASD	Lives with mother and 15 year old brother with semantic pragmatic disorder
<b>Would-be users of short breaks</b>			
Sarah G	18	ASD	Lives with parents and 9 year old brother
George H	15	ASD	Lives with mother and 18 year old sister
Andrew I	8	ASD	Lives with parents and 2 sisters (aged 16 and 15)
Ibrahim J	9	ASD	Lives with mother, 2 brothers and sister
<b>Families who do not wish to use short breaks</b>			
Amanda K	10	AS	Lives with mother
Bill M	12	Autism	Lives with mother and 18 year old sister
Ethan N	16	Autism	Lives with foster parents and 2 foster brothers



### ***Positive view of family life***

The children presented a positive picture of family life. Immediate family members – and grandparents and other relatives with whom they had regular contact – were clearly important to them. Those with siblings were able to identify positives about their brothers or sisters.

*“He’s a little bit crazy, with his stupid jokes...but he’s my best friend.”* (Ian A speaking about his brother Michael)

Where their siblings also had ASD, their behaviours sometimes embarrassed or annoyed them. However there were also situations where they showed understanding and acceptance.

*“Sometimes, he does that kind of like noise thing and he flaps his hands up and down and that... It can be embarrassing.”* (Michael A speaking about Ian)

*“He tends to thud and bang a lot, and makes silly noises, and he tends to pull his hair out a lot as well. ‘Cos...it’s part of his condition.”* (Susan E speaking about her brother Benjamin)

They were generally very positive about their relationships with their parents, identifying things they did together. Andrew enjoyed playing computer games with his father, and going flying with him. They described favourite family activities, including trips to cinemas, shopping centres and to DIY stores, swimming, visiting grandparents, as well as spending time at charity shops and recycling centres.

### ***Isolation***

Howlin (1998) describes children with ASD as socially isolated and, although they identified family activities that they enjoyed, the children’s favourite activities were essentially solitary. They played with their collections of toys (Susan had 46 dolls, Sarah had 10 toy cats, all of which they had bought on eBay, Amanda had over 200 toy animals), spent hours on computers, watched DVDs and videos and played computer games. Amanda was a voracious reader, and was obsessed with Harry Potter books; she also spent time playing music alone.

Her major interaction was with her pet rabbits. Ian enjoyed the trampoline; there was a large trampoline in the back garden on which he bounced for considerable periods, regardless of the weather. Natalie enjoyed shiny objects, and engaged in self-stimulatory behaviour, flapping them, squinting at them and rocking. These solitary activities took up most of the children's free time.

*"After school (I) get changed, come down, have a cup of tea, then go on the PlayStation (till teatime). After tea, it's back on the PlayStation."* (Ethan N)

Even where children said they had friends at school, they rarely saw them outside this context. The sole exception was Susan: she regularly spent time at a short breaks residential home with children with whom she was familiar from school and with whom she shared common interests. The children's pattern of breaks was planned to facilitate this.

### ***Lack of awareness of the impact of ASD on the family***

The children seemed largely unaware of the stress and tension reported by other family members. Only Benjamin – diagnosed with semantic pragmatic disorder – identified the stresses and strains within daily life.

*"There's a lot of things I don't like about my family really...They're mainly annoying...my mum is annoying because she nags a lot, she's basically just a bit bossy...and my sister's very screamy and she sleeps mainly half the day."* (Benjamin E)

### ***Problems at school***

In contrast to their positive view of home life, but reflecting first hand accounts (Sainsbury, 2000) and research (Humphrey and Lewis, 2008), some children identified problems at school. Causes of difficulty included the school environment, teachers, and bullying from other children.

*“Every time I try and find some peace and quiet, noise always finds me. That’s the annoying thing.”* (Benjamin E)

*“There is a teacher who talks really quickly, and I find it hard to understand...She goes ‘Ba-ba-ba-ba-ba-ba-ba-ba-ba’, and I don’t know what on earth they’re talking about.”* (Amanda K)

*“There was a girl who was picking on me for quite a while. She kept calling me nasty names and making fun of me just ‘cos of my problems.”* (Michael A)

#### **6.4. Informal support**

The initial survey indicated that families had limited informal social support. This was supported by the interview data from all families. The extended family was the major – sometimes only – source of support to many families. Even so, half the families interviewed received no support at all from this source. In some cases, such support was simply unavailable: grandparents were dead, they had no relatives, or relatives lived abroad, for example in the USA or Pakistan. In others, grandparents were elderly and disabled, requiring care and support themselves; or relatives did not offer support due to their fear or inability to deal with the child’s behaviour.

*“My parents, they’re elderly, they can’t cope with him, they don’t understand.”*  
(Alison C)

The failure of extended family members to understand ASD was highlighted again and again.

*“If I’m honest, I resent my husband’s sister because she’s crap with the boys and she’s quite judgemental about them.”* (Andrea A)

*“Amanda was only diagnosed about three and a half years ago, and I think really it took about a year for my parents to accept it. They thought she was just a badly behaved child, and I wasn’t strict enough with her, because it was just me and her and she doesn’t have a male influence on her.”* (Donna K)

In some cases the support provided by the extended family was positive and extremely beneficial. Even though this might only come from a single source, this support (whether ad hoc or regular) could be crucially important.

*“If I’m doing a visit or something ...if I’m going to be out...it’s usually (my husband’s) dad baby-sits, and I’ll just go.” (Andrea A)*

*“Saturday nights is now sleepover at grandma’s, so we get Saturday night to ourselves, regardless. It’s nice to relax, for an evening, and the next morning we wake up rather than get woken up.” (Megan L)*

The survey further suggested that only limited support was provided by friends or neighbours; again, this was supported by the interviews. The pressures of caring for a child with ASD, and the impact of his/her behaviours, meant families had little time or opportunity to develop relationships with neighbours or colleagues and this compounded their feelings of isolation.

*“We’re outcasts from things. We’re sort of left out, aren’t we?” (Maggie G)*

The county had numerous support groups for parents of children with ASD. However none of the fathers had ever attended, either because they viewed them as being for mothers, because of work commitments, or simply because they disliked being in groups.

*“Nikki’s got a couple of groups that she sees, with children in a similar situation. It’s usually for a woman’s lunch, down one of the pubs or something.” (Brian D)*

Some mothers had found attending such groups useful, while others reported that attendance had actually increased their stress. Some parents were unable to attend due to child care difficulties, while others – like the fathers – disliked groups.

*“I ended up giving advice to everybody, and then when I went there and said, ‘Look I really need help with this’, no one was willing to help me. There was no one there to support me ...I’ve got my own problems, you know...I wanted help as well.” (Gwen F)*

Church was another source of informal support. Some families had a strong religious faith – and their churches were some of the few ‘mainstream’ settings that supported them and accepted their children.

*“We get more support from church than from our family.” (Marie E)*

Finally, Donna K had been told by social workers that it could take a long time to access short breaks. Thus she had arranged her own support by finding a childminder who was willing to care for her daughter.

*“Angela, who lives round the corner...I went to see her one evening, and explained the situation...She had some experience of working with children with special needs, so she said she’d give it a go. That was three, three and a half years ago, and she’s still there. She’s been a tower of support.” (Donna K)*

## **6.5. Formal support: social workers**

Social workers hold a central role in the assessment and provision of statutory support to families that have children with ASD. Whether families are eligible for services, what type and level of service should be provided, whether the family even needs ongoing social work involvement: all these matters hinge on social workers’ decisions and judgements. So what had been families’ experience of social workers, and how did they understand their role?

### **6.5.1. Uncertainty about role**

All fourteen families had experienced some social work involvement though only nine had an allocated social worker at the time of the interviews. Studies across the field of social care suggest service users often find social workers’ roles unclear (Lymbery, 2001; Manthorpe *et al.*, 2007). This lack of clarity concerning what social workers actually did was shared by many family members in this study, in particular husbands, siblings and children with ASD. This was compounded by many interviewees having never met their family’s social worker. Only two siblings had ever met the family’s social worker, with only one sixteen year old feeling that she knew what they did (she felt they helped arrange transport, provided wheelchairs and arranged for siblings to access Young Carers’ Groups). Of the seven husbands or partners, two had never met a social worker. Three more did not understand what

the social worker did regarding the family, stating that they left communication and liaison with professionals to their wife. Some suggested this was due to social workers visiting while they were at work; others were happy to leave contact to their wives.

*“I’ve probably only seen her once, and she just sat there at the school review. But... what she actually does I don’t really know.”* (Brian D)

*“With Andrea only working part-time and her hours being quite flexible, she can meet them when she needs to meet them; where if I need to meet them, it means taking time off work.”* (Peter A)

*“I think we have a social worker. (Laughs)...I should be more interested.”* (Philip I)

Of the ten children with ASD who had a social worker, six had met their social worker, but only two could recognise them from their photograph, with two others feeling they understood their role; however, this understanding was extremely limited.

*“I think he sort of comes round to see how I am, and he talks to me about things.”* (Susan E)

*“To see how things are going.”* (Ethan N)

### **6.5.2. Stigma**

The literature indicates that negative attitudes exist towards social work involvement and that stigma is associated with receiving such support (Colton *et al.*, 1997; Davidson and King, 2005). Some parents initially felt uncomfortable about seeking and receiving statutory support. They associated having a social worker with inadequacy and failure as a parent.

*“My attitude was, “Oh God!”...With social workers, you automatically think that you’re a bad mother.”* (Marie E)

*“You’re thinking they’ll be looking around, and thinking that I’m not looking after her properly, and they’re going to take her away.”* (Nikki D)

### 6.5.3. High turnover

It is acknowledged that there is a national shortage of social workers (Hill, 2007; Huxley *et al.*, 2005). Social workers experience high levels of stress and burnout (Coyle *et al.*, 2005), with many trained social workers moving into other fields (Dominelli, 2004) and with individuals working only a short time in the profession (the expected working life of a social worker is eight years for men and fifteen for women) (Curtis *et al.*, 2009). The families here reported high turnover of social workers; ten year old Natalie D's family had been allocated five different social workers (two of whom were students) while eight year old Andrew I's had been allocated four. This constant change gave rise to a variable and inconsistent service, made building relationships difficult, and created uncertainty.

*"We've had a few. Every time they turned up, 'Hi, I'm your new social worker, I'll be looking after your case'...then a month later, 'Oh, I've got a new job'. So the continuity wasn't there. You know, I'm an aircraft engineer, and when you're building an aeroplane it's best not to hand it over half way through to somebody else, 'cos they'll put it on the wrong way round! Continuity's important...and you build experience up as well." (Philip I)*

*"When Olga went, it was devastating, not just because she was brilliant but ...you realise how dependent you are upon them, and it felt like your world was falling apart. I knew I'd get another but the future person is an unknown quantity, might not be as good. So yeah, I was devastated. I think obviously for me and for obvious autistic reasons it's best to have the same people for the long term. But you can't, because of the way the world is. People move on." (Alison C)*

### 6.5.4. Variability of service

Families in all subgroups had mixed experiences of social workers, with positive and negative comments being made across the groups. Some were enthusiastic about the support they had received.

*"Fantastic, Dorothy...she just did understand, I don't know how, but she's very clever and picked up on a lot of things." (Alison C)*

The main criterion by which families judged their social worker was their effectiveness in obtaining support and services for the family. Where workers helped families to access benefits or appropriate formal support, they were viewed very positively.

*“Lucy was just absolutely fantastic; she was just so supportive. She pulled out all the stops.”* (Maggie G)

However others spoke negatively about their experiences, and felt they had received a poor service.

*“She let us down so many times on things that... she really was a waste of space.”* (Sam I)

*“She was useless...absolutely useless.”* (Nikki D)

Some social workers had shown little understanding of ASD. Some found it particularly hard to recognise the difficulties and needs of higher functioning children, while some made little effort to get to know the child with ASD or to understand the child and the family’s needs.

*“When she met him...He comes across as being normal, you see. He doesn’t look any different... he knows how to behave when visitors are here.”* (Maggie G)

*“I don’t think they’ve really got any idea what it’s like to be me living here or to be Pete living here, but then... when they visit, they visit at times when the children are at school so they don’t see it how it is... they don’t see me when I’m pissed off and sitting on the floor crying.”* (Andrea A)

Some parents further felt social workers took no account of their wider caring roles (for example regarding elderly parents and relatives, or concerning their other children’s disabilities or health needs) or acknowledged the impact of parents’ own disabilities.

There were numerous examples where families felt ill-served by social workers. Asma J is the single mother of four children (one has ASD, another has learning difficulties). Her short breaks stopped when her family link carer became pregnant; she then requested that the



service continue, provided by another family. Ten months later she found her social worker had not actioned this request and that she was not even on a waiting list for a service. Kath and Harold N fostered Ethan for another local authority. They had received no support or advice regarding his condition either from the placing authority or workers where they lived, and were not even aware that specialist teams of social workers for disabled children existed. Donna K told how child protection concerns had been voiced by school staff due to Amanda's behaviour in the period before she was diagnosed with AS. The impact of social worker involvement with the family caused Donna (whose husband had walked out on the family when Amanda was one year old) and her partner to split up, leaving her once more a single carer.

*"Because of Social Services getting involved, the strain really just got too much. So he left. So I was on my own again with her."* (Donna K)

## **6.6. Formal support: short breaks**

### **6.6.1. Factors associated with use**

Eight of the fourteen families interviewed had experience of short breaks (six as current and two as former/would-be users), while six had never used services. Factors associated with using short breaks clustered into four categories: the need for a break from caring, the child's behaviour, the family's desire to access social opportunities and the desire to expand the social opportunities accessed by the child receiving short breaks. Where families chose or sought to use short breaks, the final decision tended to lie with the child's mother. In many cases they were the only adult in the household but even in two-parent households, the decision to use short breaks centred on the mother's choice and needs.

*"You know, especially with Nikki, when she's got Natalie seven days a week...just to have a little bit of a break where she's not worried about what Natalie's doing,*

*even for a day and a night...you can actually get on with your life a little bit.”*  
(Brian D)

### ***Need for a break***

Most families who accessed or wished to access short breaks felt they “needed a break” from the pressures of caring; informal support was either insufficient to meet their needs or non-existent.

*“Any help that we can get would be really good...just to have some sort of break from it.”* (Maggie G)

### ***The child’s behaviour***

This impacted significantly on the family’s perception of their need for a break. Some children exhibited aggressive or disruptive behaviour, some needed continual attention or stimulation, while others displayed extreme distress but could not communicate why. In all these situations, the end result was that other family members felt enervated and stressed.

### ***Social opportunities for the family***

Time to address the needs of family members other than the child with ASD was frequently identified as associated with using short breaks. Parents strongly asserted that the child with ASD was but one member of the family, and that all family members had needs. In particular, they emphasised the desire for quality time with their other children.

*“I needed to spend time with my daughter, without Kieran there... because we didn’t do anything together at all.”* (Gwen F)

### ***Social and educational opportunities for the child with ASD***

Parents, siblings and children with ASD alike identified giving the child with ASD social opportunities and the opportunity to develop their skills away from home as important factors in seeking to use short breaks.

#### **6.6.2. Factors associated with non-use**

Factors associated with non-use of short breaks clustered into the same four categories that emerged in the survey: family attitude and values, concern regarding the impact of service use on the child with ASD, service shortfall and lack of information. Among families who did not wish to use services, family attitudes and values and concern regarding the child were the major factors cited for non-use; where families wished to use a service, service shortfall was the most important issue.

#### ***Family attitudes and values***

All families that did not wish to access services identified factors associated with non-use that fell within this category. These included not wanting to use such services, not considering the child's behaviours as problematic, feeling protective, being concerned about trusting people outside the family and disliking separation, which would lead them to worry about the child if he were not with them.

Donna K had created her own support network – via family and paid support – and therefore felt no need for formal services. The Ns, Ethan's foster-carers, felt strongly that using short breaks fell outside their concept of acceptable parenting.

*“I wouldn't say, ‘we fancy a weekend on our own, you know, off you go’. You don't do that to your own children, do you?” (Kath N)*

Family members' attitudes and feelings were also identified as potential factors associated with non-use, where families wanted services. Despite their wish for formal support, they were torn because they enjoyed being together, because family members would worry if the child with ASD were away and because they mistrusted formal services.

*"It's probably one of the reasons why we never went down that avenue, isn't it. The worry of how somebody else could have coped...if it went wrong." (Sandra H)*

### ***Concern about the impact upon the child***

Concerns about the impact of attending short breaks on the child was voiced both by families who did not wish to use services and some would-be service users. Concerns related to the child's inflexibility, potential confusion, and fears the child would interpret attendance as punishment. Sandra H also voiced her concerns about the potential for abuse in formal service settings.

*"Is it worth it? He goes away for two days, and you've had a nice break, but when he comes back, he's all jumbled up. It'd take you a week to get him back on track again." (Harold N)*

*"It just really worries me...about abuse and things like that...I mean, I know, like, to get in those sort of jobs they have to go through like checks and things, but...people still get through, don't they? It just worries me that, and...it worries me that people are going to be nasty to him." (Sandra H)*

### ***Service shortfall***

This was the main factor associated with non-use among would-be users. Two families had previously used services but when their link carer had stopped working for the local authority their service had not been replaced. Donna K had sought a service but was told by social workers that there was a 'huge waiting list', so did not pursue matters further. The G family

was assessed as eligible for short breaks when Sarah was in primary school. Nine years later, Sarah was a student in further education. No service had ever been provided.

*“They said, don’t worry it’ll probably take a while...It’ll take us about six months to get you a suitable match. Two years later somebody rung up, I said ‘who are you, oh yeah; I’d forgot all about that’. And we never ever got any Family Link... in the end there weren’t nobody to help us...” (Arthur G)*

### ***Lack of information***

The Ls, who were not seeking a service, cited lack of information as a factor in this; they simply did not know what services existed or whether they would be eligible to access them

*“Because of the information that I haven’t got, I don’t know.” (Simon L)*

*“(I’ve) never known whether we would be eligible...” (Megan L)*

### **6.6.3. Contact with services**

Different family members – mothers, fathers, siblings and the children with ASD themselves – had differing levels of contact with, and experience of, short breaks services. Mothers were again those who had most contact with the short breaks providers regarding planning, attending meetings and reviews and ongoing communication. Where present, fathers again had more limited dealings with the service (such as driving to take and collect the child) and a more superficial relationship with service providers. All siblings interviewed whose brothers or sisters attended short breaks had met the service providers, and had visited the service setting. The children with ASD, of course, had direct experience of attending short breaks; their views and comments related directly to their concrete experience of being away from home.

#### **6.6.4. Functions of short breaks**

Short breaks were felt to perform a number of discrete (though linked and sometimes overlapping) functions. Some related to the child with ASD, others to the rest of the family. Even families who did not wish to use short breaks identified that they could provide social and learning opportunities for children with ASD and even those families, who felt strongly that using such services went against their values, could identify situations where such services might prove beneficial.

*“If Ethan had continued the way he was going – being violent – we might in the future think, well, we could do with a weekend free of this, without worrying what Ethan’s doing.” (Kath N)*

It was further identified that functions performed by short breaks could change over time. Andrea A’s family started using this service to give the rest of the family a break from Ian’s behaviours. Over time, going to the service became an important part of Ian’s social life and routine, and it remained valuable to him even after the family’s stresses had reduced. The multiple functions performed by short breaks are outlined below.

##### ***Opportunity to relax***

The most commonly cited function was to provide other family members with opportunities to relax, free from the pressures of caring for, supervising and entertaining the child with ASD.

*“We lay in! We may not do anything, in that we won’t plan some big trip or anything, but it’s just, you can relax a lot more.” (Nikki D)*

### ***Social opportunities for the family***

Short breaks also gave family members time to engage in social activities. Initially, some parents found adjusting to spending time without the child with ASD difficult.

*“When he first went, the first night, I felt awful, I thought, Oh God, I don’t know if I’m going to like this.” (Sam I)*

However, when confident that the child was safe, they became able to take advantage of the breaks, developing their own and their other children’s social lives. Mactavish and Scheien (2004) found that, in two-parent families where there is a child with a developmental disability, recreation activities usually involve small combinations of family members. This was common in such families in this study with one parent engaging in the “normal” activity, while the other cared for the child with ASD.

*“We can’t go to the pictures as a family. If there’s a kiddie film on that we’d like to take Margaret to, it’s either me or Simon that takes Margaret while the other stays with James.” (Megan L)*

In single parent families, the situation is even more restricted.

*“We don’t really go out as a family.” (Stella M)*

Short breaks provided opportunities to engage in social activities which the child with ASD could not tolerate. They also gave siblings the chance to enjoy social experiences in the home, such as having friends round for sleepovers.

*“We would go to cinema with the girls, be out late, and have dinner at like Pizza Hut... It was really nice to not have the responsibility of Andrew around.” (Sam I)*

*“If he was away, I could have like ten girls round or something. Because he can’t cope with them, and goes too hyper... he’ll just come and jump on you all and that, and it’s just not worth trying to make it work really.” (Jane I)*

### ***Social opportunities for the child with ASD***

Short breaks were also seen as giving children with ASD opportunities to do things they could not or would not do at home. Whereas at home parents had other domestic responsibilities to undertake – cooking, ironing, washing – care staff within short breaks settings were focused on the children. Furthermore children had the opportunity to spend time with their peers within a safe, understanding environment.

*“It is something that is entirely hers. She doesn’t have to share it with mum if she doesn’t want to.” (Marie E)*

### ***Developing the child with ASD’s skills***

As well as providing social opportunities, short breaks were seen as fulfilling an educative function, as environments where children could develop their social and independent living skills. Within short breaks settings, children could not have their own way all the time and had to learn to take turns, as well as learning skills such as food preparation, laying tables, washing up and doing their washing.

*“She packs her own bag... Obviously I check it all out and whatever... but what other opportunity would she have to learn to do that?” (Marie E)*

### ***Carrying out essential activities***

Short breaks enabled families to undertake practical everyday activities – shopping, cleaning the house, decorating and doing homework – which were essential but could not be carried out (or only with difficulty) when the child was at home, as well as meeting family commitments with which the child would not cope.

*“We had a christening to go to, so we arranged for the Family Link carer to have him overnight that night, so we could go the whole day without having to worry.” (Bob F)*



### ***Attitudes towards and understanding of the function of short breaks among children with ASD***

The children with ASD had a much more limited understanding regarding the function of short breaks. Only Susan E could say why she attended short breaks.

*“Well basically, the reason why I go there is because it gives my mum a break, and plus it gives me a break from having to be around mum and Benjamin all the time.”* (Susan E)

However, to what extent this is Susan’s own understanding, and to what extent she is paraphrasing her mother is uncertain; it became clear that Marie shared a lot of information with Susan and Benjamin, and often in Benjamin and Susan’s interviews it felt as if I was hearing them speaking their mother’s words. No other child attending short breaks could identify why their family used them; sixteen year old Peter B, who had attended a residential short breaks service for ten years, asked me at the end of his interview

*“Why do I go there?”* (Peter B)

#### **6.6.5. Positive and negative factors: families**

Families who used or had used short breaks, and children who attended them, identified factors which they felt contributed positively or negatively towards the quality of the short breaks experience. These are summarised here, firstly regarding parents’ and siblings’ comments and experiences, then those of the children with ASD.

Positive and negative factors identified by parents and siblings clustered into a number of groupings: from broader organisational and family issues to the specifics of the child’s experience.

## ***Organisational factors***

### *Clarity of purpose*

Most service-users used ASD-specific services; almost all felt it was vital their children attended such services. Reasons included the use of ASD-specific approaches, such as TEACCH (Schopler *et al.*, 1995), and the focus on autism, which they considered very different from other disabilities. Where parents had used generic services, they felt these had been inappropriate, due to lack of structure within the settings and the staff/carers not understanding autism.

### *Availability*

Limited availability meant some families assessed as eligible for services could not receive them due to resource shortfall. The G family had waited nine years for a family link placement only to find that when she became eighteen Sarah was no longer eligible for this service; she would require a further assessment to ascertain if she and her family met adult services eligibility criteria. Even where families did receive short breaks, service levels were sometimes considered inadequate.

*“Resources are relatively limited, and maybe he doesn’t get as much respite as we would probably like him to have...but some respite is better than no respite.”*  
(Sam I)

### *Accessibility*

Service providers – both residential and family-based – often required children to be discharged in the morning, to clean rooms and prepare for the next child. This limited the time provided to the families, reducing the benefits of the break. Families often transported their children to and from short breaks. Due to the size and shape of the county, and the location of

services, this could necessitate a round trip of fifty miles or more each journey. This had financial implications and again ate into the family's time apart from the child.

### *Continuity*

Families highlighted the importance of continuity. Negative effects due to lack of continuity seemed particularly to impact on families using family based short breaks, where a change in the link carer's circumstances, or their unavailability, could bring the family's support to an end. Even where families successfully used such services, parents were aware that things could change suddenly.

*"Obviously it's best to have the same people for the long term. But you can't. People move on... And there's nothing you can do about it."* (Asma J)

Families using residential services, which were less dependent on individual workers, did not raise this issue.

### *Consistency with other settings*

Consistency of approach and reinforcement of the norms and routines used in school or at home were identified as positive factors. Consistency was also felt to help children feel secure, because they were better able to understand what was happening.

*"They had TEACCH, which was really good, because that's what she had at school."* (Nikki D)

### *Social educational function*

As discussed in 6.13, many parents viewed short breaks as having a social educational function, providing environments where the child could learn adaptive social skills and behaviours, tolerate new experiences and become more independent.

*“It does him good to spend time with other children. At home there’s no, ‘You can’t have (the PlayStation) for another hour, because it’s someone else’s turn.’ Also, actually spending time away from home, I think he’s much more of an independent lad.” (Andrea A)*

### *Information*

As in other studies (Cavet, 2000; Preece, 2000; Redmond and Richardson, 2003) inadequate information about what services were available was identified as problematic.

### *Communication*

Effective communication between short breaks services and families was identified as vital. Parents generally reported positive experiences. However sometimes communication problems between the family and the provider, or within the short breaks setting itself, were reported. Parental dissatisfaction more commonly related to communication with social workers, whom they felt often did not keep families informed.

### *Environmental factors*

A homely, non-institutional environment was felt to be beneficial to the children. At the same time, it was felt important that the environment was adapted to be visually clear for the children with ASD.

*“The environment is autism-specific, and TEACCH-specific...Ian goes there, and you know, it’s very clear to him.” (Andrea A)*

### *Staff factors*

Parents who felt they were receiving a positive service expressed satisfaction with short breaks staff and often developed good working relationships with them. However some

situations were identified where families had been dissatisfied with staff. These occurred where staff did not communicate effectively with families or where practice fell short of the standards expected. Staff knowledge and training and their personal attributes were identified as key factors affecting the quality of short breaks. A sound understanding of ASD and appropriate training were seen as essential by mothers, fathers and siblings alike.

*“She’s worked with him at school...and she knows all about TEACCH etc, so she’s trained... It needs to be someone that fully understands his needs.” (Nikki D)*

Parents became dissatisfied when they felt staff did not understand their children’s conditions; this led to Andrea A withdrawing Ian from family link. Problems also arose where workers were unconfident with the children, which impacted on both the level and quality of services.

*“Doreen (the family link carer), she actually caused me more stress... ‘cos she’d ring me up and say, Patrick’s doing this, he’s making noises, I think I’ll have to cut the time down. I was really upset ‘cos that’s not support. That’s making me feel that even the worker can’t help or cope with him, therefore I’m stuck with him forever.” (Alison C)*

Workers’ personalities, attributes and qualities were considered significant. Patience, a positive, tolerant attitude, friendliness, openness, good communication skills and professionalism were all identified as important.

### ***Child factors***

#### ***Individualisation***

Individualisation, and the ability to differentiate services to meet the varied needs of children across the spectrum, was identified as important.

*“They’re all individuals, you know. If you have a room full of autistic children, they can be completely different from each other.” (Brian D)*

### *Grouping of children*

In the residential service, grouping children into compatible groups – by age, interests or both – was seen as a helpful strategy making children's experiences more positive. However, high demand for services and a wide range of children led to what parents considered inappropriate groupings of children, which they viewed as impacting negatively on their children. This could cause the children significant distress.

*“There’ve been occasions when she got very, very upset a few times where another child was in. He really upsets her, really badly...She did get where, when I was taking her, she was getting really stressful, grinding her teeth all the time.”*  
(Nikki D)

### *Problems caused by the impact of child's ASD*

The child's need for sameness could make attending short breaks problematic. Natalie refused to use any toilet other than at home. Though manageable at school (she was only out of the house for a few hours) this caused significant problems when she attended short breaks, resulting in numerous urine infections. Consequently her family never had more than two nights' break at a time. Ibrahim started soiling himself when he went for overnight stays away from home, and told his mother that he was unhappy: Asma reverted to teatime and evening visits only. Jacqui felt that the constraints of group living restricted Peter's freedoms, such as being unsupervised and being able to have his meals when he wanted them. However, these families continued either to use or to seek short breaks, as they felt that their family as a whole required the help these services provided.

### *Psychological factors*

Psychological aspects of using short breaks – both positive and negative – were clearly articulated, and the positive impact of formal support was clear.

*“Short breaks are fantastic and it’s great support, psychologically...” (Gwen F)*

However, significant negative factors were also identified. Where families did not wish to use services they were concerned about the child’s happiness, feared the possibility of abuse, and worried how others would care for their child. Service-users spoke of the negative psychological impacts of using services – feelings of guilt, of being judged as not coping, of not being in control of what was happening to their child, and of missing them. These issues were mostly articulated by mothers, though some fathers and siblings also spoke of them.

Many mothers felt guilty about using short breaks, and needing support caused them to feel inadequate. These feelings sometimes reduced when they saw their child enjoying attending the service; in others, the feelings of guilt continued.

*“I felt really, really guilty. I didn’t want to tell anyone ‘cos I felt awful.” (Nikki D)*

*“I’d gone expecting not to like (the service) probably because I felt guilty and I didn’t want to like it, in a funny sort of way.” (Andrea A)*

Using short breaks was as something that could cause others – either potentially or actually – to view them as unable to cope. Some mothers had not told their wider family about the support they received.

*“They don’t even know about it. It’s another world. They know I get support, but I don’t go into it.” (Jacqui B)*

Other experienced disapproval and judgemental behaviour both from family members and the general public due to using services.

*“I suppose my mum, she doesn’t disapprove of respite for any reason other than that the family should be able to sort things out, he shouldn’t need to go for respite...So yeah, it’s a bit of an issue, but only really with my mum. It’s her issue rather than mine, ‘cos I don’t care...well, I do care...” (Andrea A)*

Further negative feelings were engendered by parents' feeling they were no longer in control of what was happening to their child. One father spoke of how he was fearful as he did not know what was happening in the short breaks setting, while Andrea, discussing her feelings when she first used short breaks, said

*"I felt so uncomfortable with him being there. He was so small, he was so tiny, and I had no control over what went on."* (Andrea A)

Where families acknowledged their need for short breaks, family members still missed the child while they were away.

*"It's difficult, because you still worry about him, because he's not with you. And it's sort of like a double-edged sword, really, 'cos you like not having him with you but, on the other hand, you don't like not having him with you."* (Sam I)

### ***Whole family perspective***

The importance of services focusing on addressing the needs of the whole family was stressed time and again by parents and siblings alike.

*"I thought it was good, 'cos it was a good opportunity for him as well as us, like... 'cos (when we're together) if we don't go out with him, that means that we can't do things and he can't do things. But if he goes (to short breaks) then he can do things that he wants and we can do things that we want here."* (Yusuf J)

### **6.6.6. Positive and negative factors: children with ASD**

Most children with ASD interviewed identified both positive and negative aspects of attending short breaks; Natalie and Patrick were observed engaging in activities they seemed to enjoy. As other research identifies (Beresford *et al.*, 2007; Mitchell and Sloper, 2002), children's perceptions are more concrete than those of their families and are firmly grounded in their experience.



### ***Environmental factors***

Children identified factors within the residential environment they liked, such as the sensory rooms, sensory garden and play equipment.

*“I like the swing. I tend to go on the swing nearly all the time.”* (Susan E)

*“The sensory room is very relaxing and pretty, ‘cos it’s got all sorts of pretty lights.”* (Peter B)

One child who slept in two different rooms at a short breaks residential home identified a clear preference for one room over another. However there were aspects of the environment that children did not like, such as the sound of traffic at night or of the radiators.

*Sometimes the radiators are a bit noisy. You know, how they make a noise sometimes....Bang bang bang!”* (Ian A)

### ***Staff factors***

Previous research (Preece, 2002) suggests some children using residential services might have limited knowledge of the staff there. In this study, Ian could name only two staff from their photographs. Others however were able to identify most of the home’s staff. Children’s key workers or link carers, and care staff who worked closely with them were most readily identified and spoken of most positively.

*“I like Cecelia...and I like Edith...And when I’m there, Edith’s always on at the weekend.”* (Susan E)

However staff who made demands upon the children and night staff, who required them to go to bed, were spoken of in negative terms.

*“I just don’t like Amy, ‘cos she’s always bossy.”* (Susan E)

### ***Child factors***

Wing (1996) identifies a continuum of social interest in ASD, from children who are aloof, through those who are socially passive to the ‘active but odd’. Children attending the residential short breaks service fell into the first two categories. Some could identify other service-users from their photographs, but social relationships seemed superficial. Two children spoke positively of other children, identifying attributes they liked about them.

*“Simon – he’s funny!”* (Ian A)

*“Peter...I get on really well with him. Sometimes we tend to get a bit silly together; we just wind each other up and have a laugh.”* (Susan E)

However no children spoke of having friends, or looking forward to being with others. Most comments about other children described behaviours that they disliked, such as screaming at the table at meal times, biting and hitting.

*“Some of the children I’m not particularly keen on.”* (Peter B)

*“I didn’t used to like Stefan all that much... he tended to pinch people.”* (Susan E)

Natalie’s only observed behaviour regarding other children was her avoidance of any interaction or contact with them. She became distressed if they persisted in attempting to engage with her or came close to her.

### ***Use of ASD-specific approaches***

Susan identified the use of visual schedules (Schopler *et al.*, 1995) as helpful.

*“Yeah, yeah... ’cos then I don’t forget what I’m supposed to do.”* (Susan E)

Other children were observed using visual schedules in their short breaks settings. Natalie used a photograph schedule to transition between activities – snack, time in the sensory room,

playing in the garden, washing her hands and teatime. She moved from activity to activity without prompting, and did not appear anxious or unhappy at any point in the afternoon.

### ***Activities available***

Children identified activities they enjoyed that were available in the short breaks settings. These activities included going out on trips – to restaurants such as McDonalds (the preferred activity of a number of children), to parks and the cinema. They also spoke positively of activities on offer within the settings. Their preferred leisure activities were often solitary: playing on the computer, PlayStation, watching TV and videos, and listening to classical music. Also popular were activities that provided sensory stimulation: the foot spa, sensory room, sensory garden, trampoline and swing. Michael, a teenager with AS, enjoyed the activities on offer at a youth club he attended. These again included computers and a PlayStation, but also interactive activities: playing pool, playing games, chatting and painting on a graffiti wall.

Children were observed undertaking activities that they appeared to enjoy; these included playing with Play-Doh, playing with bricks, playing with sand, matching cards and picture dominos, doing jigsaws and playing in the garden and sensory room. However some activities, such as drawing and doing jigsaws, or getting hair wet (which was an unpopular activity for Susan both in the short breaks setting and at home) were described in negative terms.

*“The worst thing is probably when you have to have a bath or shower. ‘Cos once I’ve had a shower, and my hair gets all wet, and because I’ve got a lot of it, it usually takes quite a long time to dry it.” (Susan E)*

### ***Psychological factors***

Many of the children accepted going to short breaks settings as part of their routines, and some identified aspects they enjoyed. However Andrew simply disliked being away from home.

*“I got very upset going to sleep at her house...’cos sleeping at her house...yes...and just...and I wanted...to stay...and I wanted...and I wanted my mummy. So I didn’t want to go to her house.” (Andrew I)*

### **6.6.7. Service shortfall and areas for development**

Finally, areas were identified where parents felt there was insufficient provision, or where there was a need for development and improvement. These are discussed below.

#### ***Availability of existing range of services***

Existing services were identified as inadequate to meet demand and need. Families who had been assessed, who met eligibility criteria, and who had been allocated services still sometimes did not receive all that which they had been identified as needing due to a shortfall in available workers. Particular problems seemed to exist regarding family based short breaks. Even after services had been agreed, families might go years without support if a suitable link was not found. Furthermore, if link carers decided to stop working for any reason, the families they supported could be left without support.

Difficulties arose when service providers were unable to deal with the child’s behaviours, or managed them inappropriately. Using services could exacerbate the child’s anxiety and the level of presenting behaviour and become counterproductive. Finally, problems occurred where demand for services was great, resulting in service levels being limited. Holiday play

schemes in particular were considered inflexible and inadequate, with some families receiving only a day or two's support over the school summer holiday.

*"I only had two days. Unfortunately, I mixed up the days, and I went to the scheme on the wrong days. My days were already past. So I wasn't able to use even those two days." (Asma J)*

Some children were supported to access local mainstream play schemes. Again difficulties were reported, as the predictability and clarity needed by children with ASD was not there.

*"They'd change things at the last minute, and this upset him. Or one day he thought he was going swimming, it said take a swimming costume because it was wet play, he gets it in his head he's going swimming; and he screamed and went mad because he didn't understand." (Sam I)*

### ***Children and young people with AS***

Services appropriate for children with AS were identified as needed by all families with such children.

*"Those that are on the fringes of the spectrum I think are often more disabled by everyone else, disabled by the environment, than a lot of those with more obvious disabilities, because they get the sympathy and facilities." (Marie E)*

A range of potential developments was suggested, including AS-specific youth groups or clubs to help develop social skills. It was felt that such groups would need to be carefully planned and managed, due to these individuals' specific difficulties. Counselling support and overnight short breaks were also identified as areas for development. The need for support to enable these children to access mainstream services was identified. Some children had previously attended mainstream youth services: their experiences had generally been poor, due to the expectations of staff and the behaviours of other children.

*"They overestimate the abilities of the Asperger child, and the underestimate the difficulties. You know, just because a child is talking back at you doesn't mean to say they've understood the question." (Andrea A)*

## **Teenagers**

Specific activities appropriate for teenagers were identified as needed by family members across all three subgroups.

*“Social things and that, there don’t seem to be many of them, does there? Like barbecues...and just... like a bit more grown up things.”* (Hannah B)

Play schemes and other activities were often too juvenile for and unappealing to older children. Speaking about George H, his sister Caroline said,

*“I think, ‘cos he’s in his room all the time, I think there should be something he can go and do with like lads, girls his age...Sports, like basketball, a little pool table, just for them to muck about with...just something for them to do. I’m definitely strong about this...that there should be places for them to just go, and stuff for them to do. Because growing up with him, all I’ve ever known him to do is sit in his room. And it’s a bit upsetting really, for someone to do that.”* (Caroline H)

Again, a sound understanding of ASD was felt important for staff, so that

*“...if he decides to flip, have a temper tantrum or whatever, they’d understand it.”* (Caroline H)

## **Babysitting**

Current and would-be service users identified the need for ‘babysitting’ services that could look after all children in the family. Services for children with ASD did not provide care for non-disabled siblings; while mainstream babysitters were unwilling to look after the child with ASD. As a result, parents often found it hard to go out together on their own.

*“I think there is a gap... ‘Cos...I don’t think it’s always necessary that your child goes away overnight, as long as you’ve got the option of you going out for the night, which isn’t always the case.”* (Maggie G)

### ***After-school clubs***

After-school clubs were identified as an area for service development, particularly by families who currently did not wish to use short breaks.

*“Something after school the odd night, do you know what I mean? Make him tired.” (Sandra H)*

### ***Support with preferred activities***

Families across all three subgroups identified the need for support to enable their children to access preferred activities, either individually or in groups.

*“There’s trampolining – he loves his trampoline...we’d consider trying to find some sort of trampolining group that would cater for his needs, rather than a general child’s trampolining group”. (Sam I)*

In some cases, parents were unable to take their children to these activities, due to their work or caring commitments, transport difficulties or their own disabilities.

*“I know there’s a trampolining club, somewhere out (name of town) way, but there’s nothing in this area. Without being able to drive, I’m stuck.” (Alison C)*

Where families lived close to county boundaries, the nearest service might be provided by a different local authority. Here again, accessing services proved difficult.

*“The nearest big town, that’s in a different county, and...it’s more complicated.” (Sam I)*

It was further felt that siting local play areas around the county, specifically for disabled children, would be helpful. As children grew older, access to preferred activities through mainstream routes became impossible. Nikki said,

*“It’s really, really hard. But it’s such a shame, ‘cos there’s so little. I mean, Natalie loved places like Berzerk and she’s too big now. It’s a shame, ‘cos as they get older, you actually find there’s less places you can go with them. Even McDonalds with play area – she’s too big for that now, so you have to avoid that, because she doesn’t understand she’s too big for that.” (Nikki D)*

### ***Support for siblings***

Non-disabled siblings identified that support services targeted at their needs would be helpful. Information about ASD, the chance to meet other siblings, and advice were identified as service gaps.

*“As a child, I should have been given a bit more information about what the future held. At the time you’re told, Peter’s autistic, you don’t know what’s going to be happening...I didn’t know he’d never read or write. So...more information would have been better. And maybe meeting people of my age, who had a sibling who was autistic...’cos at the time, I didn’t know and I still (twelve years later) don’t now know anyone that’s got a brother or sister with autism.” (Hannah B)*

### ***Schools***

Many families identified situations where difficulties at schools had gone on to cause problems at home. They felt that better support in school would make the child’s life better across settings. Problems were most commonly reported in mainstream schools.

*“I just wish there was something out there for the schools; because the schools are useless. They just don’t seem to understand the kids. They see Kieran getting on with his work and being ‘normal’...and because he’s sat there doing his lessons they just don’t realise the knock-on effect it has when he gets home. The temper tantrums. The crying. ‘I don’t want to go to school!’ ‘I hate it!’.” (Gwen F)*

*“She had terrible problems when she was first at school. It was awful; it was the worst time of my life, I think, the first two years that she was at school.” (Donna K)*

However, some parents were also dissatisfied with special schools.

*“It’s a do-gooder school. Yap yap yap we’ll do this. Yap yap yap we’ll do that...and nothing ever happened. We just felt that she was marking time till they got rid of her at sixteen.” (Arthur G)*



### ***Transition to adulthood***

Finally, parents of children in their mid- to late-teens were concerned about the transition from children's to adult services. They felt they were given little information about the transition process and post-eighteen service provision.

*"I'm expecting somebody to phone me up one day, and say I'm your social worker, you've been referred to Adults; and then they'll come around and see me, tell me all about it and everything...but I don't think there'll be anything there."*  
(Maggie G)

Much of the effort of social workers, schools and other professionals was seen as focussing on accessing further education college placements. However, as Maggie G said,

*"But... you can't do College for the rest of your life. It's only a course. I don't know how long it is – a year or two years – but you can't stay there forever, can you?"* (Maggie G)

With regard to the longer-term future, families were depressed by what they saw as the lack of support.

*"And like...the future, when you start looking at the future, there's nothing out there. You know there's not and I know there's not, and I see people who, my friends, who're...in front of me, and they say the same thing. That there's nothing out there. Once school and college and that's finished, where do you go then? You know, what is there? And there's not nothing there. You know."* (Jacqui B)

In this chapter I have presented the findings of the final of the three phases of the research. In the next I shall go on to consider each of the four original research questions in turn, discussing them in the light of these three studies.

## **Chapter 7: Answering the research questions**

*The three preceding chapters have presented and discussed the findings from the three studies undertaken within this project: the initial survey of families that have children with ASD within one local authority, the survey of social workers who supported these families, and the interviews carried out with mothers, fathers, siblings and children with ASD themselves. In this chapter I return to the four original research questions identified at the start of the project (see 2.6.) and discuss them in the light of what has been learned from these studies. I begin by discussing and summarising what has been learned of whole families' experience of living with ASD. I then move on to look at what has been learned regarding whole families' attitudes to, and experience of, short breaks. Following this, an original set of quality indicators for short breaks services for families that have children with ASD is presented, derived from whole families' perspectives. Finally I summarise the factors, both within and outside the family, which are associated with whether or not families seek formal support and an original model of service use/non-use is proposed. This model is consistent with my epistemological position, the underpinning theory and the data.*

### **7.1. What can we learn of whole families' experiences of living with ASD?**

The three preceding chapters have shed light on some or all of the research questions and of subsidiary questions derived from these. In this chapter I return to these original four questions and discuss them in the light of what has been learned within the family survey, the survey of social workers and the family interviews. The first research question concerned the experience of whole families living with ASD. Key findings related to family composition, parental employment, the child with ASD's dependence, the need for and availability of

support, differences in how families conceptualise living with ASD and that different family members experience the presence of ASD in different ways. These are discussed below.

#### **7.1.1. Family composition**

The survey data revealed a number of facts about the composition of the families. In almost a quarter of households (22%,  $n = 34$ ) there was only one adult present: mothers caring alone for their child or children made up 21% of the households ( $n = 31$ ). Eighty-four per cent of households ( $n = 126$ ) contained more than one child, and of these at least 5% ( $n = 7$ ) contained two children with ASD.

#### **7.1.2. Parental employment**

Only 10% of the households ( $n = 15$ ) contained two adults in paid employment, with 38% living on just one income. In total, twenty-nine families (19%) were unwaged. Within the 34 single-parent households, over half the adults were not in paid employment ( $n = 18$ , 53%).

#### **7.1.3. The child with ASD's dependence**

The children with ASD living within these 150 households were highly dependent, with a mean dependence of 7.4/10. Comparison with Robinson and Stalker's generic research showed the mean dependence of these children with ASD to be higher than that of children within the generic group. Indeed, the dependence level of children of non-users in this study (6.9/10) was higher than that of children in families receiving services in Robinson and Stalker's research (6.7/10, see 4.4.1). Over two-thirds of the 155 children were dependent in seven or more areas ( $n = 104$ ). Managing the child's behaviour, and getting around and out

into the community, were particularly problematic, causing problems in 87% of families (n = 136).

#### **7.1.4. The need for and availability of support**

The findings highlighted in 7.1.1 to 7.1.3 would suggest that many families that include children with ASD might be in difficult situations; attempting to juggle the care needs of the children, living on limited incomes, providing a high level of support and supervision towards the child with ASD and finding it difficult to access the community. In such circumstances, support from other sources would seem helpful; however, little informal support was available. Eleven households (7%) received none whatsoever, with a mean of only two sources of informal support available to the main carer. Support from beyond the nuclear family (spouse/partner and children) was limited. Grandparents provided support to less than 40% of households, other relatives and friends to less than 20%, and neighbours helped only seven families (5%).

A small majority (n = 89, 59%) reported that they were satisfied with the level of informal support that they received, but this varied across the three subgroups: 61% of would be users of short breaks (n = 30) were unhappy with this situation. Overall, more than 50% of families identified an immediate need for formal support in the form of short breaks, with almost two-thirds of families feeling they would need such support at some point. However only a quarter of families were actually receiving support in this form

### 7.1.5. Range of experience

It is clear that families experience living with ASD in different ways and by no means all of the families who participated in this study report living with ASD in negative terms. Where children were less dependent, families were generally positive about their situations. Forty-eight families with children dependent in six or fewer areas of dependence responded to the survey (32% of the survey sample). Only a handful of these considered their lives severely negatively affected by their child's behaviours and needs; most described their child with ASD in positive terms.

*"She is normal for a thirteen year old...if not better!"* (Parent of 13 year old girl)

*"He is mostly laid back and easy to handle."* (Parent of 14 year old boy)

However, deeper investigation of the data revealed an important point. The thirteen year old girl described as *"normal...if not better"* could not use public transport and required supervision and prompting to do anything other than watch television. The *"mostly laid back and easy to handle"* fourteen year old boy had phobias and obsessions which severely restricted his family's lives. He needed an adult in the house with him at all times and constant supervision out of the home as he had no road sense; he spent most of his time on the PlayStation. It seems some families who described their situations in such positive terms had adapted to the presence of ASD in such a way that their understanding of 'normal daily life' bore little resemblance to societal norms.

*"We can usually maintain an even pattern of behaviour if our son is allowed to do...the things that he enjoys doing."* (Parent of 10 year old boy)

Among survey respondents whose children were categorised as being highly dependent, again some families described their situation, and their child's behaviour, in mostly positive terms

(although in this case only a small minority, 10 out of 102 households, mostly with older teenagers) . They acknowledged that their families had adapted how they lived and what they did to accommodate the child with ASD, and that their lives were restricted by living with the condition.

*“(He is) calm and settled...providing there are no expectations placed on him to deal with different situations.”* (Parent of 15 year old boy)

In these families, keeping the child happy and minimising his/her stress level had become the prime consideration around which family life was constructed. I shall return to this point in discussing family coping styles. However, despite the positive appraisal of their situation by this minority, it is clear that the majority of families identified their children with ASD as being highly dependent (68% of the survey sample) and that in the majority of these cases it was acknowledged that the whole family was significantly affected by the presence of ASD.

#### **7.1.6. Difference of experience between family members**

Over two thirds of the families surveyed in this study considered the child with ASD to be highly dependent, and in the majority of these cases it was acknowledged that the whole family was significantly affected by the presence of ASD. However the findings of the interviews carried out with whole families where there were highly dependent children support the assertion that different individuals in the same family may have very different perspectives on the same situation (Banks *et al.*, 2001), for it was identified that different family members experienced and conceptualised the presence of ASD in the family unit in different ways. This is shown by the differing themes that emerged through analysis of the interview data (6.3.1-6.3.4).

The dominant themes of the mothers interviewed were those of isolation, of experiencing stigma, of acceptance of the impact of ASD upon themselves, but of concern about its impact on their other children and of concern and uncertainty about the future. In this area, this study reinforces the findings of previous research, which have identified stress, social stigmatisation and isolation as characteristic of mothers of children with ASD (Duarte *et al.*, 2005; Tomakin *et al.*, 2004; Tunali and Power, 2002). Fathers shared this concern and uncertainty about the future, but tended in general to be more withdrawn – both from day to day care of the child with ASD and from contact with professionals. They also tended to minimise the difficulties present in family life, using humour to address their situation, while at the same time viewing their own family as being particularly in need of professional support. Again, this reinforces the findings of previous studies. Gray (2002), Lehr Essex *et al.* (1999) and Quinn (1999) have all found that fathers tend to be more withdrawn than mothers, both from day to day caring tasks and from interaction with formal support systems. It has further been found that fathers may exhibit less stress than mothers (Gray, 1993; Moes *et al.*, 1992) and that they may tend to suppress their emotions (Gray, 2002).

Where the child with ASD was not the only child, themes present in the brothers' and sisters' narratives were their acceptance of living with ASD as normality, the restriction of opportunity and the stress that they experienced, along with the embarrassment they often felt. However, despite these issues, the analysis reinforces the findings of previous research (Rivers and Stoneman, 2003; Roeyers and Mycke, 1995) in stressing the closeness of the sibling bond. By way of contrast, the children with ASD themselves were generally positive in their view of family life, and unaware of the stresses and problems perceived and experienced by other family members. However – and again in common with the both the

findings of other research (Connor, 2000; Humphrey and Lewis, 2008; Kim *et al.*, 2000) and with autobiographical writings by individuals with ASD (e.g. Sainsbury, 2000) – the children reported difficulties at school, highlighting their own stresses and negative experiences and a general theme of their lived experience, at home and school, was isolation.

This reiteration of the themes of the family members' narratives shows that families have a shared but differing experience of the difficulties and stress of living with ASD in the family and that different family members experience living with ASD in different ways. Furthermore, the broad themes outlined above are not exhaustive, and even within the small number of families interviewed, the experience of some mothers, fathers and siblings differed significantly from the 'norm'. So, while the majority of fathers withdrew from the day to day care tasks, Simon L was heavily involved, and arranged his work commitments around the care of his two children. In the same way, the experience of siblings could vary even within the same family as a result of their personalities and their interaction with the child with ASD.

*"I do more (direct care of her 8 year old brother with ASD) than my sister, 'cos he'll go through these stages, and decides he really doesn't like her...and so, I have to look after him."* (Jane I)

The literature in the field of ASD has tended to consider families as if they were homogenous entities, and has further foregrounded and privileged maternal perspectives as mothers often act as spokespersons for their families. It has also been seen that social workers and professionals tend to privilege the mother's perspective, as she is generally their main point of contact with the family. This study reveals that there is a rich diversity in how mothers, fathers, children with ASD and their siblings experience family life, and how they understand and experience the presence of ASD within their family. This is an important and original finding – as far as I have been able to determine this is the first study to investigate the



experience of whole families in this way – and, thus, a significant contribution to the knowledge base.

## **7.2. What can we learn of whole families’ attitudes to and experience of short breaks?**

This study further adds to the knowledge base by addressing some limitations of the existing literature: the tendencies of research into short breaks and families that have children with ASD to focus on the needs and experience of parents, neglecting to seek the views of the children with ASD or to have a ‘family’ focus. In this study, the views and experiences of parents, their children with ASD and other siblings were gathered to enable a picture of the whole family’s attitudes and experience to be developed.

### **7.2.1. Shortfall in service availability**

A clear finding from the initial survey is that an insufficient level of short breaks is available. As is shown in 4.3.6 and 4.3.7 over 50% of families surveyed felt an immediate need for short breaks, and almost two-thirds identified that they would require short breaks at some point. However, only about a quarter of families were currently able to access this type of support. This supports other literature which has identified the shortfall in availability, and the difficulty families with ASD have in accessing short breaks and appropriate support.

### **7.2.2. Families’ stated reasons for short breaks use and non-use**

Families identified a number of reasons for using and not using short breaks. These are important factors but I argue in this chapter that they are not exhaustive; these ‘reasons’ are underpinned by further factors associated with the child, the family, as well as access to, and sources of, informal and formal support. The stated reasons given by families for using short

breaks cluster into four categories (see 6.6.1). These are the behaviours exhibited by the child with ASD, the need for a break from carrying out the caring role, the desire to provide family members with social opportunities and the desire to provide the child with ASD with social opportunities. Reasons for non-use of short-breaks (which were consistently identified in the family survey and the later interviews) also cluster into four categories (see 4.3.6. and 6.6.2): family attitudes and values, concern about the impact of using short breaks on the child, service shortfall and lack of information.

### **7.2.3. Functions of short breaks**

Although families may have had specific reasons for seeking to use short breaks, such as the need for respite from caring, or from the child's behaviours, they identified a range of further functions performed by these services. Different family members conceptualised the purpose of short breaks in different ways and the children with ASD themselves had only a limited understanding of their functions (or indeed, why they attended services). Overall, families conceptualised short breaks as performing a number of discrete, yet linked – and sometimes overlapping – functions: providing family members with opportunities to relax, providing social opportunities for both the family and the child with ASD and developing the child's skills. Even families that did not wish to use short breaks viewed such services positively, acknowledging the potential utility of such services to all family members and identifying situations where they could be helpful (see 4.3.8 and 6.6.4).

The conceptualisation of short breaks as providing opportunities to develop the child with ASD's skills is well supported by the literature in the field of ASD. Consistency of approach across different settings (home, residential and educational), to promote a 'twenty-four hour

curriculum' for individuals with ASD, has long been identified as beneficial (Van Bourgondien and Elgar, 1990). Forster, writing in 1989, argued for the importance of providing consistency of structure and programming across settings, to provide learning opportunities and to facilitate the generalisation of skills throughout the whole day. Writing specifically of services for children with ASD, Jordan and Jones (1997b) discuss the importance of collaboration across settings to deliver a twenty-four hour curriculum. Jordan and Powell (1995) give more details, arguing that

*“...there is clearly a need for parents to be involved in the education of children with autism...This need...also applies to care staff where the child is in residential schooling or some form of care provision, whether permanent or as respite. Education can neither stop nor start when the school bell rings. The nature of the learning difficulties (in autism) are such that, in effect, the home or care situation is often a more natural and meaningful context for the education to take place. It is also clear that the education will only be effective if the strategies used are consistent across environments.”* (pp145-6)

However, fulfilling a social educational role as part of a twenty-four hour curriculum is identified as a function of short breaks neither within the literature nor in national or local policy. Although this social educational role is discussed by parents in this local authority in both this and an earlier study (Preece, 2000), short breaks are not conceptualised in this way within social care legislation or literature. Thus families and social workers may well be conceptualising short breaks very differently. This issue is discussed further below, in the section discussing the interaction between families and social workers.

#### **7.2.4. Positive attitude towards ASD-specific services**

Both the survey (4.3.8) and the interviews (6.6.5) illustrate that families with experience of service-use generally felt that ASD-specific services generally met the needs of their children best. This is discussed further in the section regarding quality below. This is a clear point of

divergence between the attitudes of families and that of their social workers, who contrastingly felt that in many cases children with ASD could be successfully integrated into generic services (5.5.4). These issues are discussed further in 7.6.

### **7.3. What factors are associated with quality in short breaks services by whole families?**

I will now move on to consider the next research question concerning factors associated with quality in short breaks by families. As the literature review shows, recent government policy and initiatives have shown an increasing focus upon measurement of quality in social care support services, including short breaks. *Removing Barriers for Disabled Children* (Department of Health 1998a), the *Quality Protects* initiative (Department of Health, 1998b), the *National Service Framework* (Department of Health, Department for Education and Skills, 2004) and *Aiming High for Disabled Children* (HM Treasury/Department for Education and Skills, 2007) all identify the need for ‘quality’ short breaks for disabled children and their families. *Aiming High for Disabled Children*, the latest of these, specifically identifies the need to

“...develop best practice in building efficient, high quality short break provision based around the needs of disabled children and their families... (and) present solutions to the particular problems faced by...children with autism spectrum disorders.” (HM Treasury/Department of Education and Skills, p50)

So how is quality in such services understood, and to what extent do quality indicators in generic short breaks services relate to the needs and experience of families with children with ASD? These issues are discussed within this section of the thesis, and quality indicators specific to this group are suggested.

### **7.3.1. Generic quality indicators in short breaks**

Research has sought to identify what comprises 'quality' in short breaks and how it can be identified. In the mid-1990s, the Council for Disabled Children organised workshops for parents of disabled children to identify their perspectives regarding short breaks services. Reporting on these workshops, Russell (1995, 1996) identified key priorities. Parents wanted services that were local, available on demand, well-managed (particularly regarding short waiting lists and good pre-placement preparation) and age-appropriate. They wanted good quality child care, specialist input where necessary, information and choice and for services to be part of integrated programmes of family support.

Researchers at the Norah Fry Research Centre, University of Bristol, in conjunction with the Department of Health, were concurrently developing evaluation materials for short breaks based upon research into the impact upon disabled children of the Children Act 1989 (Minkes *et al.*, 1994; Robinson *et al.*, 1994, 1996). They suggest fourteen areas where quality can be evaluated. These are clarity of function and children served, assessment procedures, publicity and information, consultation with children, staff training and support, cultural sensitivity, inter-agency working, partnership with parents, integration with non-disabled children, location and physical environment, administration, quality of care, reviews and complaints (Robinson *et al.*, 1996).

More recently the Shared Care Network, with the Department for Education and Skills, has produced guidance on short breaks (Carlin *et al.*, 2004) to support the *National Service Framework for Children, Young People and Maternity Services* (Department of Health/Department for Education and Skills, 2004). Twelve areas are identified as impacting

upon quality across short breaks services. These are: service provision and eligibility criteria; information; staff recruitment and assessment; staff preparation and training; approval of carers (in family-based services); status and payments of carers (in family-based services); short break agreements; matching and introductions; health and safety; child protection; recording; monitoring and review. Concerning children with ASD, the need for specific training is emphasised, as is the importance of providing structure and working consistently with other settings (Carlin *et al.*, 2004).

In support of the government's *Quality Protects* initiative (Department of Health, 1998a), the Social Policy Research Unit at the University of York has undertaken research in conjunction with the Family Fund Trust and Barnardos (Mitchell and Sloper, 2002, 2003). This in part focused upon identifying quality indicators for a range of services including short breaks and was carried out with consultation groups of parents and disabled young people. Twenty-one parents were involved; they had children across a range of disabilities, including cerebral palsy, physical disability, learning disability and ASD. Twenty-seven young people (aged eleven to seventeen) across a range of physical, learning and communication difficulties were involved; none are specifically identified as having ASD. It is unclear whether some parents and children came from the same families or whether the groups were unrelated (the parents were from Yorkshire and the Midlands, while the children were from Yorkshire and the North-West). A number of factors are identified that parents and children consider as quality indicators in regard to short breaks (see Table 7.1).

**Table 7.1      Quality indicators for short breaks identified by parents and children in Mitchell and Sloper's study (2002)**

<b>Quality indicators identified by parents</b>	<b>Quality indicators identified by disabled children</b>
Meeting the child and whole family's needs	Staff understand about my disability
Listening to the child and family members	Staff know how to help and look after me
Treating the child and all family members with respect	Staff listen to me
Staff knowledge and training	Staff ask me for my ideas and take notice of what I say
Welcoming and helpful staff	I can ask the staff questions and they explain things to me
Service respects family's culture	Staff allow me to make choices
Service flexibility	Services provide me with opportunities to meet and make friends
Service reliability	I have a variety of activities to choose from
Service continuity	I have opportunities to develop my independence
Providing family members with a break	I have a break from my family
Quality of information	
Easy to travel to	
Opportunities for children to make and meet friends	
Opportunities for children to mix with the local community	
Professionals working together and communicating	

### **7.3.2. Quality and ASD**

The research and guidance summarised above has had a generic focus and it is not possible to identify the extent to which the specific issues of the parents of children with ASD and those

children with ASD who participated in the studies are reflected in these indicators. Little research has sought to identify the perspectives of children with ASD and their parents in this area. However, earlier studies that I have carried out have identified some differences between these groups and the results of the generic studies.

A survey of 18 parents whose children with ASD accessed ASD-specific residential short breaks (Preece, 2000) showed that, whereas the parents in Russell's study (1996) wanted services to be available on demand, these parents recognised the imbalance between availability of short breaks and demand, and acknowledged that services should be prioritised according to need. Parents also identified that specialist services might not be local, and that the need for such provision may preclude a wide range of choice. None spoke of needing age-appropriate services; however, it was not possible to determine whether this was due to the service grouping children into approximate age cohorts, or to the solitary nature of their children and their difficulties with group activities and experiences.

Consultation with three children attending the same service (Preece, 2002) provided insights into their experience. It was identified that consistency of approach across environments made their experience of short breaks more positive and that the children's experience was impacted by staffing levels, staff training, individual workers' personalities, skills and attributes, and by other children attending the service (particularly their behaviours and the demands they made upon staff time and attention).

Data collected in the interviews give us the opinions of related groups of family members regarding factors affecting quality in short breaks. As identified by Mitchell and Sloper



(2002) parents focused on broader organisational issues (as did older siblings), including the availability, reliability and flexibility of services, and staff skills and training, as well as identifying the importance of the emotional impact of using services. Children with ASD and their younger siblings focused more concretely on the day-to-day experience of using the service, such as staff attributes, the impact of other children and issues such as the environment, food and activities. As identified in 6.6.5 and 6.6.6., key factors, grouped into six categories, can be derived from their discourses (shown below in Table 7.2). It is noteworthy that differences exist between factors identified in generic studies and those identified here. Some may result from the area where the study took place. For example, cultural awareness/appropriateness was not identified as an issue, which may reflect the overwhelmingly white British population in this county: Studies undertaken where larger minority ethnic populations exist identify these as significant factors affecting service quality (Flynn, 2002). Other differences may relate to the characteristics of ASD and these children's particular difficulties. Whereas parents in the generic studies spoke of wanting their children to have opportunities to be with and make friends, parents here focused more upon those children with whom they did not want their children to mix, and on preventing others from causing their children distress. Families in this study emphasised the social educational aspects of short breaks, and stressed the need for consistency across settings. Where short breaks were viewed as a positive change from the norm for other children, maintaining predictability was considered a virtue in short breaks for this group.

**Table 7.2 Factors associated with quality in short breaks services by children with ASD and their families**

<b>Organisational factors</b>	<ul style="list-style-type: none"> <li>• <i>Availability</i> – appropriate services are available</li> <li>• <i>Accessibility</i> – services are sufficiently local that accessing them is not problematic</li> <li>• <i>Reliability</i> – users can trust that services will be available</li> <li>• <i>Flexibility</i> – services adapt to changing needs and fit around the family and its needs (rather than the family having to fit in with the service)</li> <li>• <i>Consistency</i> – there is consistency of approach across home, school and short breaks settings, particularly with regard to the use of ASD-appropriate approaches. Short breaks function as part of a 24-hour curriculum providing social educational opportunities</li> <li>• <i>Communication</i> – effective communication systems are in place <ul style="list-style-type: none"> <li>○ within the short breaks service</li> <li>○ between the short breaks service and the family</li> <li>○ between the short breaks service and other professionals (e.g. schools, social workers)</li> </ul> </li> <li>• <i>Information</i> – there is accessible and accurate information available</li> </ul>
<b>Environmental factors</b>	<ul style="list-style-type: none"> <li>• <i>The building and grounds</i> are ASD-friendly and are designed to enable the children to have privacy, space and to be safe</li> <li>• ASD-appropriate approaches are used to clarify the environment and make it meaningful</li> </ul>
<b>Staff factors</b>	<ul style="list-style-type: none"> <li>• <i>Knowledge and training</i> – staff are trained and knowledgeable about ASD in general, and with regard to the children using the service in particular</li> <li>• <i>Personal attributes</i> – staff are friendly, welcoming and child-friendly, and enthusiastic about working with individuals with ASD</li> </ul>
<b>Child factors</b>	<ul style="list-style-type: none"> <li>• Where children are grouped, these groupings should take account of the impact of children on each other, their preferences and their sensitivities</li> <li>• The child with ASD is not unhappy in the setting</li> <li>• Children are supported to make meaningful choices through the use of appropriate tools</li> <li>• The service is individualised to address the needs and preferences of each child (e.g. activities on offer, access to water/electricity in rooms, communication systems)</li> </ul>
<b>Psychological factors</b>	<ul style="list-style-type: none"> <li>• Staff within the service, and the service as a whole, acknowledge and understand the sometimes conflicting emotional/psychological impacts of using services</li> <li>• Systems and practices are developed to minimise feelings of guilt and stigma associated with service use</li> </ul>
<b>Whole family perspective</b>	<ul style="list-style-type: none"> <li>• The service acknowledges that it exists to meet the needs of the whole family, not just the child with ASD</li> </ul>

Comparison of the children's quality indicators in Mitchell and Sloper's study (2002) with this one also highlights the impact of ASD upon the children's responses. Where children in the generic study emphasised interaction with others, being given attention and being understood, factors identified by the children with ASD are much more concrete. Only one spoke of having fun with other children; others were typically described in neutral or negative terms. Friendship and fun with others was clearly not a priority for either parents or children. On the other hand, children spoke at greater length of more tangible factors, such as videos, DVDs and activities that they liked, the food they ate, and the building.

Factors such as respecting the family and its culture, and meeting the whole family's needs, are identified as indicators of quality throughout the literature; but in this study the importance of services acknowledging and addressing the psychological impacts of using such services were identified. While short breaks are readily conceptualised as providing instrumental support, the interviews revealed that some families also sought to find emotional support in these services. Carver *et al.* (1989) suggest that, although these support functions may co-occur in practice, they are conceptually distinct, the former being associated with problem-focused coping, and the latter with emotion-focused coping. Although explicitly articulated as an indicator of quality by only a handful of parents, most discussed the emotional turmoil that could result from using services; wanting time away from the child but missing them, feeling relieved the child was elsewhere but also guilty, feeling a loss of control. While such responses are natural and initially functional, continuing to focus on these emotions can impede individuals from moving beyond their distress (Carver *et al.* 1989; Scheier and Carver, 1977). Acknowledging, understanding and responding to families'

psychological situations – and thus helping them to take advantage of the opportunities offered by short breaks – is clearly an important factor impacting on service quality.

#### **7.4. What factors – within and outside the family – are associated with whether or not families access formal support through short breaks?**

To consider this research question I will draw on data collected in all three stages of the research. This study adds to the knowledge base in this area by suggesting that the way that factors associated with short breaks use or non-use are often conceptualised within the literature has been overly simplistic, and that a more complex and interactive model more effectively explains the phenomenon of ‘using – or not using – short breaks’.

##### **7.4.1. Hypotheses from the literature**

As discussed in Chapter 2, literature on short breaks’ use by families with children with ASD is complex and confusing. Some studies suggest short breaks are used by families with the most dependent and challenging children, whilst others argue those are the very families who find services hardest to access. The literature regarding factors associated with service use suggests that

*“...respite care tends to be used most by families who have limited support networks.”* (Randall and Parker, 1999, p125)

and that

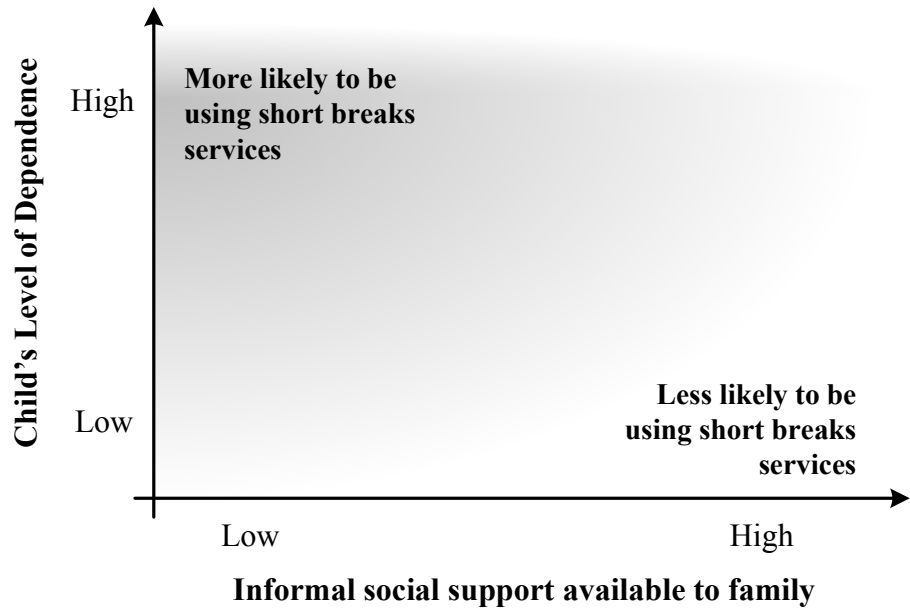
*“...in general, it is the severity of the child’s difficulties that appears to be the primary factor distinguishing between users and non-users. Thus Halpern (1985) demonstrated that users of respite care had children who were more severely retarded, more physically incapacitated and more adult dependent than those of non-users. Marc and MacDonald (1988) added severe behaviour problems to this list of severe disabilities.”* (Randall and Parker, *ibid.*)

This is supported by Chan and Sigafoos (2000) who reviewed studies on child and family characteristics of families using short breaks services. They too identified severity of the child's disabilities (including behavioural and communication difficulties) and the child's subsequent dependence as influencing the likelihood of using short breaks. Alongside these factors they identified numerous studies linking the level of informal support systems and social networks available to short breaks use (e.g. Cohen, 1982; Grant and McGrath, 1990; Salisbury, 1990; Sherman, 1988). They further suggest that families with more children tended to make greater use of short breaks. However, only one study has reported on this (Robinson and Stalker, 1993) and this was not included in the hypotheses to be tested in the survey. Subsequent analysis of my survey data found that the number of children in the household was not a significant variable between short breaks users and non-users in this study:  $\chi^2 = .95$ ,  $df = 3$ ,  $p = .9$ .

The literature suggests that a model such as Figure 7.1 below might be used to conceptualise short breaks use, and its validity was examined through testing the hypotheses in the family survey (see 4.3.9). This process identified that the difference in informal support available to users and non-users of short breaks was not significant ( $p = .7$ ). However children with autism from families who used short breaks were indeed more highly dependent than those of non-users ( $p = .05^*$ ). Further analysis of data (4.4.9) gathered from current service users and those who wished to use services found that, although the children of service users were slightly more dependent (see Table 7.3), the difference between the two groups was not statistically significant ( $\chi^2 = 2.58$ ,  $df = 2$ ,  $p = .3$ ). This supports findings reported elsewhere in the literature, which suggest that many families whose children with ASD have significant

support needs, are not accessing services (Barson, 1988; Oberheim, 1996; Sargent, 1995; Trenenan *et al.*, 1997).

**Figure 7.1** Factors associated with the use of short breaks services by families of children with ASD: model derived from the literature



**Table 7.3** Comparative levels of dependence: users and would-be users of short breaks

	Mean dependence	SD
Users of short breaks (n = 41)	8.2	1.95
Would-be users of short breaks (n = 49)	7.7	2.5

Families accessing short breaks were compared both with non-users as a whole (4.4.3), and with that subset of non-users who wished to access short breaks but who could not (4.4.9). These comparisons consistently identified further factors (in addition to the child’s dependence) which were more significantly associated with whether families used or did not use such services. These factors were the child’s age, diagnosis, school placement and whether or not the family had a social worker. This identified the need to investigate social

workers' understandings of ASD and to explore the experience and attitudes of service users, would-be service users, and families who did not want to access services.

#### **7.4.2. Range of factors**

The results of the three phases of this project suggest that factors associated with short breaks use are more complex than can be conceptualised using the two-dimensional model suggested by the literature and tested in the survey; such a model is inadequate to describe short breaks' use, and a range of factors are associated with short breaks' use or non-use. The discussion to this point has identified factors associated with the child, such as his or her diagnosis, age, and the type of school he or she attends. Factors associated with the family also have an impact: their perception of need, their attitude towards services, and their perception of the impact of service use on the child (positive or negative). External factors also play a part, such as the availability of services, eligibility criteria for services and whether or not a social worker was allocated to the family. Analysis of survey and interview data regarding the key characteristic structural components identified within the review of family systems theory (2.1.) sheds further light upon systemic factors – within the family, outside the family, and relating to the interface between the family and others –that may impact upon the family's experience and upon whether they use, seek to use or do not use short breaks. I discuss this further in the next section.

#### **7.5. Systemic factors and short breaks**

In this section these systemic factors are discussed under the four headings of family structure, family interaction, family functions and family life cycle. I begin with the microsystem of the nuclear family, before considering the family in its wider context.

### 7.5.1. Family structure

As previously stated (2.1.3.), family structure comprises the family's membership characteristics, its cultural style and its ideological style (including coping characteristics).

#### *Membership characteristics*

##### *Number of adults in household*

The mothers' reports show the heightened sense of isolation and need for support that may be experienced within single parent families (mothers were the sole adult in 91% of the 34 single parent families in this study).

*"It's hard because I don't see anybody really because...like, when I have friends with autistic children, they can't cope with the children, so you don't see anyone, and you feel isolated". (Alison C)*

Comparison of users and non-users of short breaks did not find the number of adults in the household to be significantly associated with short breaks' use (see 4.4.2): the proportion of single parent families was only slightly higher among short breaks' users (28%) than non-users (22%) (see Table 7.4).

**Table 7.4      Adults in household: users and non-users of short breaks**

	Users of short breaks (n = 39)		Non-users of short breaks (n = 111)	
One adult	11	28	24	22
Two adults	28	72	87	78
Total	39	100	111	100

Nonetheless, formal supports such as short breaks might be expected to be particularly helpful to such families, and the majority of single parent families (56%, n = 19) expressed a need for formal support through short breaks. This desire seems to be heightened when the children exhibit greater dependence: 71 % (n = 17) of single parent families with children with 7+ dependence expressed a need for short breaks, compared to 34% of two-adult households.



This heightened perception of needing formal support is statistically significant ( $\chi^2 = 9.98$ ,  $df = 1$ ,  $p = .005^{**}$ ) (see Table 7.5).

**Table 7.5 Perceived need for short breaks: single and two parent families of children with 7+ dependence**

	Single parent households with children of 7+ dependence (n = 24)		Two parent households with children with 7+ dependence (n = 76)	
	No	%	No	%
Need short breaks	17	71	26	34
Do not need short breaks	7	29	50	66
Total	24	100	76	100

#### *Socio-economic status*

Some research suggests short breaks are used particularly by families facing financial hardship (Grant and McGrath, 1990; Robinson and Stalker, 1993; Salisbury, 1990). However, Marc and McDonald (1988) found no significant differences regarding socio-economic status between users and non-users. My initial questionnaire asked respondents to indicate the occupations of adults in the household; only 2 respondents (non-users) did not. The occupations of each family's principal wage-earner were categorised using the National Statistics Socio-economic Classification (NS-SEC) (Office for National Statistics, 2001) (see Table 66). Chi-square analysis did not indicate either the principal wage-earner's job classification ( $\chi^2 = 3.5$ ,  $df = 3$ ,  $p = .5$ ) (see Table 7.6) or the number of adults in a parental role who were in employment ( $\chi^2 = 3.29$ ,  $df = 5$ ,  $p = .7$ ) (see Table 7.7) to be significant variables between users and non-users of short breaks within these families.

**Table 7.6 Socio-economic status of principal wage earners in family survey**

Class	Description	Families using short breaks (n = 39)		Families not using short breaks (n = 111)	
		No	%	No	%
1	Higher managerial	7	18	27	24
2	Lower managerial	3	8	19	17
3	Intermediate	7	18	14	13
4	Small employers	0	0	3	3
5	Lower supervisory and craft	3	8	4	4
6	Semi-routine occupations	6	15	9	8
7	Routine occupations	3	8	15	13
8	Not in employment	10	26	17	15
	Unclassified/ not known	0	0	3	3
<b>Total</b>		<b>39</b>	<b>100</b>	<b>111</b>	<b>100</b>

**Table 7.7 Adults in household in employment**

	Families using short breaks (n = 39)		Families not using short breaks (n = 111)	
	No	%	No	%
2 x full-time employment	3	78	12	11
1 x full –time employment, 1 x part-time employment	11	28	35	31
1 x full-time employment	13	33	28	25
2 x part-time employment	0	0	3	3
1 x part-time employment	3	8	13	12
No adult in employment	9	23	20	18
<b>Total</b>	<b>39</b>	<b>100</b>	<b>111</b>	<b>100</b>

*Age of parent(s)/main carer*

Grant and McGrath (1990) suggest younger parents are more likely to use short breaks services. Within this study, the ages of parents/carers were requested all but four of the 150 families provided this information. Mean age of the main carer (generally the mother, but also including father and grandmother) across the whole population was 41.0 yrs (SD = 6.7). In

families using short breaks it was 40.8 yrs (SD = 6.4); in non-users it was 41 yrs (SD = 6.8). This was not significantly associated with use or non-use ( $\chi^2 = .27$ , df = 2, p = .9).

### *Presence of other challenges*

Many families interviewed were affected by other difficulties apart from the presence of autism, and indeed many of the families using short breaks were those where families faced multiple challenges. Two families had two children on the autism spectrum; Patrick's mother was unemployed and suffered from depression; Kieran's stepfather was physically disabled, and the marital couple, as well as being unemployed, were principal carers for elderly relatives. However, additional challenges were also experienced by families in the other two groups. Sarah's younger brother had severe diabetes, which required close management. One of Ibrahim's elder brothers had learning disabilities. Bill's mother provided care for her own mother, who was mentally ill.

### *Cultural characteristics*

A family's cultural style may be influenced by racial, religious and ethnic factors, as well as the family's socioeconomic status. Almost 95% of families in this study were White European. Black families were under-represented within the research population: only two African-Caribbean and one Asian family responded. All three had accessed short breaks. One was still doing so, one no longer felt a need and the third, Ibrahim's family, were seeking a service. The small number of families of non-white origin makes attempting to develop inferences regarding the impact of ethnicity on service use futile. However, Asma identified cultural differences between the UK and her native Pakistan which led to Ibrahim's behaviours being perceived as less problematic there.

*“It’s a different world. Because...you go there and you don’t have to worry about him touching people, or approaching babies, or cuddling them, or kissing them – because that’s appreciated, that’s liked, that’s something people encourage...”*  
(Asma J)

Seligman and Darling (1997) suggest that religious parents may be deeply immersed in a faith-based support network. Three families interviewed in my study said religion was important in their lives. However, although Asma woke to pray before dawn each day, and considered it her destiny to have a son with autism, she did not suggest that her religion affected her attitude towards service use, and she still wished to access short breaks. Moreover the two families that identified their churches as major sources of social support, and environments accepting of their child’s ASD, were both users of short breaks.

*“I’ve always got the impression that Susan was accepted for what she was. She was very much part of this community. She was never excluded. She was loved and cherished...That’s been a big thing.”* (Marie E)

### ***Family ideology and coping characteristics***

Before the interviews I had been curious as to whether analysis would identify different dominant coping styles between the three subgroups. Would the narratives of families that chose not to use short breaks suggest higher use of positive reframing or denial? Might service users perhaps demonstrate higher usage of strategies such as seeking instrumental support and planning, or perhaps helplessness? However, although data supported earlier research that suggested withdrawal from dealing with the stressor might be associated with fathers, as might humour, specific coping strategies could not be associated with the desire to use services or not. A larger-scale quantitative study, using a coping-methods scale or a scale to identify families’ ideological styles, may shed light on these issues. Within this study

families within all three subgroups displayed a range of ideological styles, and all used multiple and varied coping strategies.

Carver (1997) identifies *acceptance* as accepting the stressful situation is real and has occurred. ASD is a difficult disability to ignore; it significantly impacts upon social interaction and communication, and the desire for routine and sameness and the child's restricted interests can be extremely restrictive. It is unsurprising, therefore, that all families demonstrated acceptance.

*Seeking instrumental support*, a problem-focused coping strategy whereby social support and assistance is sought, is clearly identified in families accessing or seeking short breaks. But it is also demonstrated by families who do not want services. Although the source of support may differ (a privately-arranged childminder, or the child's grandparents rather than statutory services) the strategy is the same. Similarly *planning* (thinking about how to cope with the stressor) and *active coping* (taking active steps to minimise its impact) (Carver *et al.*, 1989) are found throughout the three subgroups.

Less adaptive coping strategies were also exhibited. *Behavioural disengagement* (giving up on attempting to attain goals with which the stressor is interfering) was demonstrated in Bill M's family, who had never sought, and did not wish to access, services. Asked about typical evenings with this 12 year old, his mother's initial description did not seem unusual.

*"He has his tea more or less straight away, and watches a bit of telly, plays on his Gameboy...and has a bath...and goes to bed. Once he's there, you could drop a bomb, and that's it."* (Stella M)

However, deeper questioning identified that – as with some families that described daily life positively in the survey – Stella made significant accommodations to keep Bill happy. She cooked her own and his ‘evening meal’ in the mid-afternoon, and they ate as soon as he arrived home. From then until bedtime and beyond, his mother was with him constantly. Although he had his own bedroom, it was used only to store his clothes and toys and he slept in his mother’s bed each night. Stella was resigned and had forsaken all personal wishes and aspirations.

Interviewer: *Are there any things you find it hard to do, that you’d like to do, but can’t?*

Stella M: *No, don’t really bother me to be honest, ‘cos it’s what you get used to. So I don’t really bother.*

The accommodations to Bill’s ASD had been far-reaching and had impacted on the whole family. Bill’s father no longer lived in the family home, and had not done so since Bill was 2 years old. In Stella’s absence, Bill’s eighteen year old sister Cindy had to replicate her mother’s routine, sleeping with him in her mother’s bed.

*“I have had him on my own at night...I have to go to bed when he wants to go to bed, which I don’t like doing, obviously. He won’t sleep in my bed or in his bed and he won’t go to bed on his own if mum’s not here, so I have to go to bed in mum’s bed with him, ...it’s a bit difficult.”* (Cindy M)

Though Stella had taken Bill away on holiday, Cindy had never had a holiday and stayed with her father instead. Nonetheless, Stella considered herself “*one of the lucky ones*”.

Other negative strategies, such as withdrawal, were exhibited within families in all three subgroups. It would be inappropriate to infer that dysfunctional coping strategies are characteristic of families that are not seeking to access services; positive and negative coping strategies are used across all subgroups.

### 7.5.2. Family interaction

#### *Cohesion*

Cohesion refers to how members of subsystems within the family interact and the nature of the boundaries between these subsystems (as well as between family members and non-members (Olsen *et al.*, 1980)). Seligman and Darling (1997) conceptualise cohesion as a continuum, with enmeshment and disengagement at the poles, and well-functioning families situated in the middle. Families in each subgroup strove – often consciously and overtly – to function healthily. Marie initially sought to use short breaks to develop Susan’s sense of autonomy and had planned how she intended to increase Benjamin’s independence.

However, most families presented as enmeshed to some degree. A number of potential factors might be involved, including the impact of the impairments of ASD and the child’s dependence, the routines and ways of thinking that have become norms, as well as family members’ individual characteristics. Some families present or perceive themselves as united against the outside world.

*“We’re sort of left out, aren’t we? Which is probably what’s made our relationship so strong, and ...you know, we love each other to bits, and we love each other’s company all the time...and it’s probably ‘cos there’s nobody else, is there?” (Arthur G)*

Often parental and sibling duties were blurred, with siblings (particularly sisters) taking on caring roles. Turnbull *et al.* (2006) describe how they may be drawn into the parental subsystem, leading them to experience fewer parent-child and other sibling interactions, and causing their own needs as a child to be subordinated and overlooked. This situation is described time and again across all three subgroups and concern about the impact of living with ASD upon their other children is a major theme in the mothers’ narratives. Many

parents were acutely aware of the blurring of roles, speaking of the guilt and anxiety it caused, although others had given it less thought.

*“I think I rely on them too much. We get to situations where I say you need to be here...It can be quite difficult at times because...because there isn’t really anybody else who I’d want Andrew to be with, really, or trust him with.”* (Sam I)

*“She tries to help out as much as she can. She’s as good as gold!”* (Simon L)

Despite most families presenting as enmeshed to some degree, those that actively sought to use short breaks identified support needs as outweighing their concerns about the impact of change or of separation. However, even having identified the need for formal support, using it remained problematic. Parents spoke of guilt and uncertainty when their child was at the short breaks service, as well as concerns regarding how others viewed them.

*“People that don’t know us, I say my son goes to respite, and it’s like then you’re a mother that doesn’t cope. You’re not coping with your child so we’re going to give you a weekend away.”* (Andrea A)

### ***Adaptability***

Many single mothers spoke of their ex-husbands being unable to cope with the demands of the child with ASD. Inability to accept the child’s condition, reluctance to engage with and relate to the children, and problems sharing their wife’s time and attention were commonly reported. Some mothers felt in hindsight they felt that their husbands may themselves have had traits of autism which prevented them adapting to their changed situation.

*“My feeling is that dad was never going to make much of a go of being a dad actually... He’s got his own issues, and I think that he certainly has autistic tendencies himself, very Asperger’s.”* (Marie E)

However Andrew’s father felt that similarities he identified between himself and his son helped him understand and accept Andrew’s condition.



*“The similarity between myself and Andrew...It’s something I think about a lot. You know, you ask yourself the question, where did he get it from? Why has he got it? I don’t ... I don’t particularly feel any guilt, you know, that I’ve fathered him, and maybe it’s come down my side. We were lucky enough to have two completely normal children, and one who’s slightly wacky.” (Philip I)*

### **7.5.3. Family functions**

Having a child with ASD in the family has been shown throughout this project to impact upon family functioning across all its dimensions. It can affect family members’ ability to work, to undertake day-to-day activities, to pursue leisure activities, to socialise, and to participate in learning and education. It can restrict opportunities for intimacy and can impact on family members’ feelings of self-esteem. Family functioning was significantly affected in all families interviewed.

### **7.5.4. Family adaptation**

Differences of interpretation were apparent with regarding families’ perception and reaction to ASD. Whilst some railed against the impact of ASD on family functioning, others had ‘hyper-accommodated’, accepting and adapting to its limitations. Darling’s (1979) model of modes of adaptation (see 2.1.7) was used to plot the modes of adaptation of the families interviewed (Table 7.8). Seligman and Darling (1997) warn that this model is only approximate, and suggest that many families may not have achieved their typical mode of adaptation until the disabled child is approaching or entering adolescence. Nonetheless, I consider this a useful tool in conceptualising families within the three subgroups, understanding their interactions with professionals and considering the impact of service provision and non-provision. Family modes of adaptation are discussed and consideration is

given to those families that cannot be easily placed within this model. (Detailed outlines of the families and how they fit within Darling's typology are provided in Appendix 13).

**Table 7.8      Positioning the families using Darling's typology of modes of adaptation**

<b>Mode of adaptation</b>	<b>Users of short breaks</b>	<b>Would-be users</b>	<b>Non-wanters</b>
<i>Normalisation</i>	Natalie D's family Peter B's family	—	Amanda K's family James L' family
<i>Altruism</i>	Ian and Michael A's family Susan and Benjamin E's family	—	Ethan N's family
<i>Crusadership</i>	Kieran F's family	—	—
<i>Resignation</i>	—	George H's family Sarah G's family	Bill M's family
<i>Families that cannot be placed in this model</i>	Patrick C's family	Andrew I's family Ibrahim J's family	—

### ***Normalization***

Seligman and Darling suggest that availability of supportive resources in the community (formal or informal) is the most important determinant of normalisation in families with children with disabilities. Four families interviewed - two short breaks users and two who do not want services- could be considered to have achieved normalization. They were not unaffected by the presence of ASD and still faced significant difficulties. Nonetheless, they were able to participate in and enjoy many 'normal' experiences. With the help of formal and/or informal support, they were

*"...able to achieve a nearly normal style of life during the childhood years."*  
(Seligman and Darling, 1997, p87)

It is noteworthy that the short breaks users had received support from the ASD-specific residential short breaks service for many years. Similarly, the families that did not want services had well-established informal support packages in place, provided by grandparents and privately arranged childminders.

### *Crusadership*

Before and after diagnosis, families generally engage in a process of seekership: first seeking reasons for the child's behaviour, then appropriate school placements and support. By mid-childhood most families have ceased this process of seekership. However some families, due to limited opportunities or inappropriate services, adopt a mode of crusadership or prolonged seekership (Seligman and Darling, 1997). Families can be triggered into this mode at times of change or transition: This is what occurred with regard to the F family. Although satisfied with the short breaks support package, transition between primary and secondary education has been difficult for Kieran, and much of the family's time and energy was spent in conflict with the local education authority.

### *Altruism*

Most parents who can achieve normalization – with or without formal support – choose that mode of adaptation. Some however elect to remain active within the world of disability, altruistically working to help others achieve a more normalized lifestyle. Two mothers using short breaks could be categorised as altruists, as could one of the families not seeking services. It is noteworthy that, as before, the families using short breaks had well-established residential short breaks. The third family are foster-carers, who have elected to live and work within the field.

### ***Resignation***

Families who have adopted this mode are characterized by Seligman and Darling (1997) as doubly stigmatised, apart from 'normal' society but not integrated into alternative 'disability' support systems. Three families could be categorised as functioning within this mode. The M family had no desire to access services and were resigned to their situation. The other families both described themselves as would-be users, but their reasons for resignation were different. The Hs were initially offered short breaks but identified reasons to turn these services down. As time passed they found it became increasingly difficult to imagine using services, and rationalised reasons for not doing so. The Gs had hoped to access a service, but none was ever offered; on reaching the age of eighteen, Sarah became ineligible for support.

### ***Families that do not fit this model***

While the families above could be located – however approximately – into Darling's model of adaptation, three families could not. These were not altruistic, crusading or resigned. They all strove to achieve normalization, but had not achieved it. The Cs had recently started using short breaks, the Is and Js has previously used family-based short breaks which ceased when the worker became pregnant. It is noteworthy that these families' children are aged seven and eight. At this point in their family life cycles it may have been too early to have settled into a typical mode of adaptation. It was clear their families wished to live as normally as possible, and recognised their need for formal support to achieve this.

### ***Contribution of Darling's typology in conceptualising short breaks use***

Using Darling's typology identifies some important points with potential practical implications. Families using short breaks could in the main be conceptualised as having

achieved normalization; they could be placed within the categories *Normalization* and *Altruism*. One family that had recently begun to use services had not yet achieved this, and felt its condition to be fragile, while another was locked in conflict with the local education authority. Two mothers could be viewed as altruists, using the skills they had developed helping their own families, to help others. Among families that did not want short breaks, the Ns were clearly altruists, who had chosen to become involved in the world of disability. The others had either achieved normalisation without the need for formal support or as resigned to their situation. None of these families seeking short breaks had achieved normalisation, nor were they altruists or crusaders. The families of younger children clearly sought normalisation and needed formal support to achieve this. However the families of older teenagers had become resigned, though for different reasons. George's family had been offered services but had chosen not to pursue them, due to their fears about others caring for him and his happiness. Sarah's family waited nine years for service that never materialised, an experience which had led to them becoming inward-looking as a family and bitter towards social care professionals.

Though the number of families is too small for any meaningful generalisations or conclusions to be inferred, some important points can be drawn. Some families will achieve normalization without formal support; however, for others, short breaks will make an important contribution to their achieving this outcome. Factors inside and outside the family can lead to families becoming resigned and having poorer outcomes. Support, whether formal or informal, needs to be established and reliable for families to achieve positive outcomes. Finally, within this group of families, residential short breaks have been more reliable and successful in helping families achieve normalisation whereas family-based services (though preferred by social

workers and viewed as more ‘normal’) have been less successful in achieving desired outcomes.

#### **7.5.5. Family life cycle**

The family life cycle comprises six stages – from the new couple to the family in later life. Families studied in this project fall into three of these stages – families with younger children, families with adolescents and those at the launching stage. Data from both survey and interviews show that accessing short breaks can be more problematic for those with younger children, and also highlight families’ concerns about the inadequacy of services for young adults with ASD.

#### **7.5.6. The family in context**

##### ***The family and the extended family***

The family survey found that families that have children with ASD receive limited support from the extended family (4.3.5). Grandparents provided support in only forty per cent of families, with other family members providing support in less than a fifth. Overall, 44% of short breaks users are supported by the wider family, while 49% of non-users received support. Of families wishing to access services, 47% received some support, while 50% of those who did not wish to access services received support. As can be seen, these percentages are similar, and the differences between subgroups are insignificant.

##### ***Friends and neighbours***

Friends and neighbours provide even less support. Descriptions of family life and the children’s dependence suggest that friends and neighbours may be wary of these children and

feel deskilled when interacting with them. In total, friends and neighbours provided support to only about seventeen per cent of families. Short breaks users were more poorly supported than non-users, receiving less than half the support that they did (10% compared with 21%).

### ***The family and social workers***

Interaction with social workers was strongly associated with accessing short breaks, with 83% of children attending such services having an allocated social worker. But, as has been shown earlier (4.4.9), 60% of children in families seeking services also had social workers. So what factors relating to social workers, their perceptions of the child with ASD and the family, and the relationship between the worker and the family, might be associated with short breaks use and non-use?

### **7.6. Families and their social workers: different understandings of short breaks?**

The literature review carried out for the survey of social workers (5.2) identified a number of potential factors impacting on the relationship between social workers and families that have children with ASD. Social workers may be unconfident working with disabled children and their families, and may feel unsure communicating with such children; they may hold stereotypical beliefs about disability, which may affect their judgement; they may have an inaccurate understanding of the causes, characteristics and interventions in ASD and it is likely that different team members working with the same population will have widely divergent understandings about ASD. All of these factors will impact on how they perceive families and how services are provided.

In addition, a further set of factors will influence how social workers conceptualise support services and the values that they place upon, and consider inherent in, these services. Some of these will be mesosystemic factors, such as the staff in the team at the time, or the availability of services in that place and time. Others will be exosystemic or macrosystemic, concerning how workers and the organisation conceptualise services, disability and need. I will now move on to consider these latter factors.

#### **7.6.1. Short breaks in legislation**

A number of factors contribute to how social workers conceptualise the services that exist to support children and families and the values that they place upon, and view as inherent in, these services. Significant among these is the legislation under which services are provided, legislation which influences professional training and the ethos of the teams delivering those services. Before the Children Act 1989 (Department of Health, 1989), services for disabled children were provided under generic disability legislation, such as the Chronically Sick and Disabled Persons Act (Department of Health, 1970). The Children Act 1989 was the first to relate to all children, including those with disabilities. It imposed on local authorities the general duty of providing a range of services to all ‘children in need’ in their localities with the purpose of keeping these children safe and well. Among those children defined as ‘in need’ were all disabled children.

Key principles of the Children Act 1989 included the duty of safeguarding children, promoting the upbringing of children by their own families, considering the child’s welfare as the paramount concern and providing services in the least intrusive or ‘abnormal’ way (Department of Health 1989, 1991). These principles may impact upon social workers’



conceptualisations of disabled children, and the services provided for them, in a number of significant ways. Disabled children are grouped – as ‘children in need’ – not with the general population of children but with those at risk of impaired health or development without support. The foregrounding of the ‘paramount’ importance of the welfare of the ‘child in need’ may cause workers to neglect the needs and perspectives of parents and siblings. The imperatives of keeping children in their own families, and of providing services in the least ‘abnormal’ ways, can privilege in-home or family based services. Furthermore the positioning of short breaks as a preventive service – to keep children safe and well and promote the upbringing of children by their own families – may colour workers’ attitudes about the purpose – and potential recipients – of such services, limiting their understandings of the potential range of functions such services may provide.

Current legislation and policy continues to position short breaks as preventive services. The most recent policy initiative concerning disabled children is *Aiming High for Disabled Children: Better Support for Families* (HM Treasury/Department for Education and Skills, 2007). Outlining ‘why short breaks matter’, it states the following.

*“Families with disabled children often face particularly high levels of stress which may result in family breakdown...Disabled children are disproportionately represented within the looked after population, making up 10% of all children in care, and only around 5% of the overall population.”* (HM Treasury/Department for Education and Skills, 2007, p45)

#### **7.6.2. Perceptions regarding different models of service delivery**

Short breaks services providing support in the child’s own home tend to be viewed as “more normal” and thus more favourably than services outside the home (MacDonald and Callery, 2004). Short breaks provided in family settings are viewed more positively than residential

services. There are many reasons why professionals – in child care and disability services – may have negative attitudes towards such services. Legislation has a clear influence (see 7.6.1 above). These professionals may also have concerns about potential institutionalisation, and lack of stimulation where disabled people are grouped. Such issues were commonly reported in Britain during the 1970s and 80s (Oswin, 1973, 1984) and continue to be reported elsewhere (Morrison, 2004; Sellick, 1998). They may also have fears concerning abuse, stemming from scandals and enquiries in residential child care homes and schools (Corby *et al.*, 2001; Smith, 2008). Moreover, the impact of the social model of disability upon the philosophy of social work has been such that any services that remove disabled children from their families (such as short breaks) may be perceived as inherently negative, and as contributing to the social exclusion of these children (Cocks, 2000; Middleton, 1999).

*“One of the ways in which many disabled children experience childhood is through the provision of respite care. Within this provision there appears to be an acceptance of the process of separating a disabled child from their parents and their neighbourhood at an early age. This holds against the prevailing view that children need to be with their parents and families.”* (Cocks, 2000, p509)

Unswerving adherence to this philosophical standpoint might lead social workers to perceiving negative impacts for the child, even when this might not be the case. Withers and Bennett (2003), writing regarding a girl with profound physical and learning disabilities, describe how social workers had believed the child would experience emotional distress if separated from her parents, and had argued against residential short breaks despite the stress of caring having brought the couple’s marriage to breaking point. Developmental testing identified that the girl was insufficiently cognitively developed to experience separation and, after short breaks began, the parents’ marriage recovered and they felt more able to care for

their daughter. This can also be considered an example of social workers failing to understand the reality of profound disability on the child's experience.

### **7.6.3. Cost and availability**

Cost and availability may also impact upon providers' perceptions. Investigating the economic cost of ASD in the UK, Knapp *et al.* (2007) identify the total cost as £28 billion per year, and that much of the cost of supporting children falls on local authorities. Bebbington and Beecham (2007), analysing data from the 2001 Children in Need survey (National Statistics/Department of Health, 2002), suggest that children with ASD comprise four per cent of all children in need, and that local authority expenditure on this group may be equivalent to £100m per year. Costs will have increased significantly since the data were collected. The costs of social care support are higher for children with ASD than for other disabled children or children in need, particularly where children have additional behaviour or communication needs (Bebbington and Beecham, 2007).

Moreover, children over eleven are more likely to use more expensive residential services, while younger children were more likely to use family based services (Knapp *et al.*, 2007). This is the case within this study. Children in family-based short breaks had a mean age of 8.7 years ( $SD=2.9$ ), while the mean age of those using residential short breaks was 13.7 years ( $SD=2.6$ ). Family-based breaks cost the local authority £94 per night, while residential services cost a minimum of £220 per night. Moreover, costs may double if a child needs an elevated level of support. Providing the family of a child with significant support needs with two nights of short breaks each month in a residential setting might cost the local authority as much as £11,440 per year.

As well as being expensive, research shows that short breaks are in limited supply nationally, with demand greater than availability, and that children with ASD spend the longest time on waiting lists (Cramer and Carlin, 2008). Within this location, services were severely limited. The residential short breaks services had little spare capacity and families were held on a waiting list. The number of ASD-specific link carers available had fallen from four to two and the family-based short breaks service had a waiting list of 55 children, over half of whom were diagnosed with ASD.

#### **7.6.4. Differing perceptions of social workers and families**

Social workers may be guided – by the legislation, by their training and by the limited availability and cost of resources – into a less flexible, more restrictive understanding of short breaks than that held by families. This assertion is supported by MacDonald and Callery (2004) who suggest that social workers and parents do perceive short breaks differently, and that they attach different values to the varying forms of service provision. They show that, while parents view short breaks outside the family home as a positive opportunity to obtain relief from stress, this method of providing short breaks is that which is least preferred by social workers, who view it as an intervention most appropriate in crises.

Such a restrictive conceptualisation might prevent short breaks being provided to those who are not presenting as ‘in crisis’ but who rather view short breaks as a social educational intervention. It might lead professionals to target services at those seen as most disabled, thus limiting access for children with AS or higher-functioning autism. It may also cause social workers and families to problematize the child and to frame the family’s experience of living with him or her in negative terms, to gain access to services.

The survey of social workers revealed their inconsistent, and in many cases inaccurate, understanding of ASD and, moreover, that some had inaccurate understandings of approaches used within the county with these children, within schools, social care settings and the community. As in MacDonald and Callery's study (2004), their attitudes regarding the efficacy and appropriateness of models of service delivery differed from those of families. Over 65% of social workers considered it possible to integrate children within generic social care disability services. By contrast, only 18% of families surveyed shared this view. This is a clear point of divergence and again – as with their more restrictive conceptualisation of services – might lead to misunderstanding or conflict between professionals and families.

#### **7.6.5. The family and short breaks service providers**

As identified in 3.2, my professional role within the short breaks service precluded my investigation of the opinions of staff in this field. Nonetheless, families' accounts show the importance of the relationship between the family and the person or service providing the short break, particularly with regard to the family's trust in their ability to understand and adequately care for the child; examples were given of families forgoing services when they did not have this confidence. More generally, the ways that families conceptualise the role of short breaks, and their attitude towards formal social support and service providers' understanding of the impacts of service use, have been identified as important factors associated with service use or non-use.

#### **7.7. Towards a model for understanding short breaks use and non-use**

This project has identified both the impact of ASD upon families and the diversity of experience that was found both within families using services and those that did not. The

three studies have all contributed towards our understanding of the phenomenon of short breaks, and each has shed light upon factors associated with their use or non-use. The initial survey identified a number of broad factors associated with use or non-use of short breaks (see Table 7.9 below).

**Table 7.9 Factors identified as associated with short breaks use or non-use in the family survey**

<b>Factors associated with use</b>	<b>Factors associated with non-use</b>
Perceived benefits to parents	Family values
Perceived benefits to siblings	Service shortfall
Perceived benefits to child with ASD	Concern re impact on child
Need to undertake necessary activities	Lack of information about services
Higher dependence level of child (p = .05*)	Lower dependence level of child (p = .05*)
Child's age (11 years or over) (p = .05*)	Child's age (under-11 years) (p = .05*)
Diagnosis (ASD with learning disabilities) (p = .001***)	Diagnosis (Asperger Syndrome) (p = .001***)
School placement (special school) (p = .001***)	School placement (mainstream school) (p = .001***)
The child has a social worker (p = .001***)	The child does not have a social worker (p = .001***)

The survey of social workers revealed their inconsistent and often inaccurate understanding of the causes and characteristics of ASD, and of approaches used for individuals with the condition. It was demonstrated that the perceptions of social workers can vary dramatically, and that families may therefore receive inconsistent responses from these professionals. The

impacts of this may be wide ranging, potentially affecting whether families are viewed as in need of or even as eligible for formal support.

The family interviews provided further examples of their varied experience of social workers but reaffirmed their importance as brokers and gatekeepers of services. The interviews revealed a range of issues that families associated with quality in short breaks, as well as explicitly identifying further factors that were associated with short breaks use or non-use. These factors are summarised in Table 7.10.

**Table 7.10 Factors identified as associated with short breaks use or non-use in the family interviews**

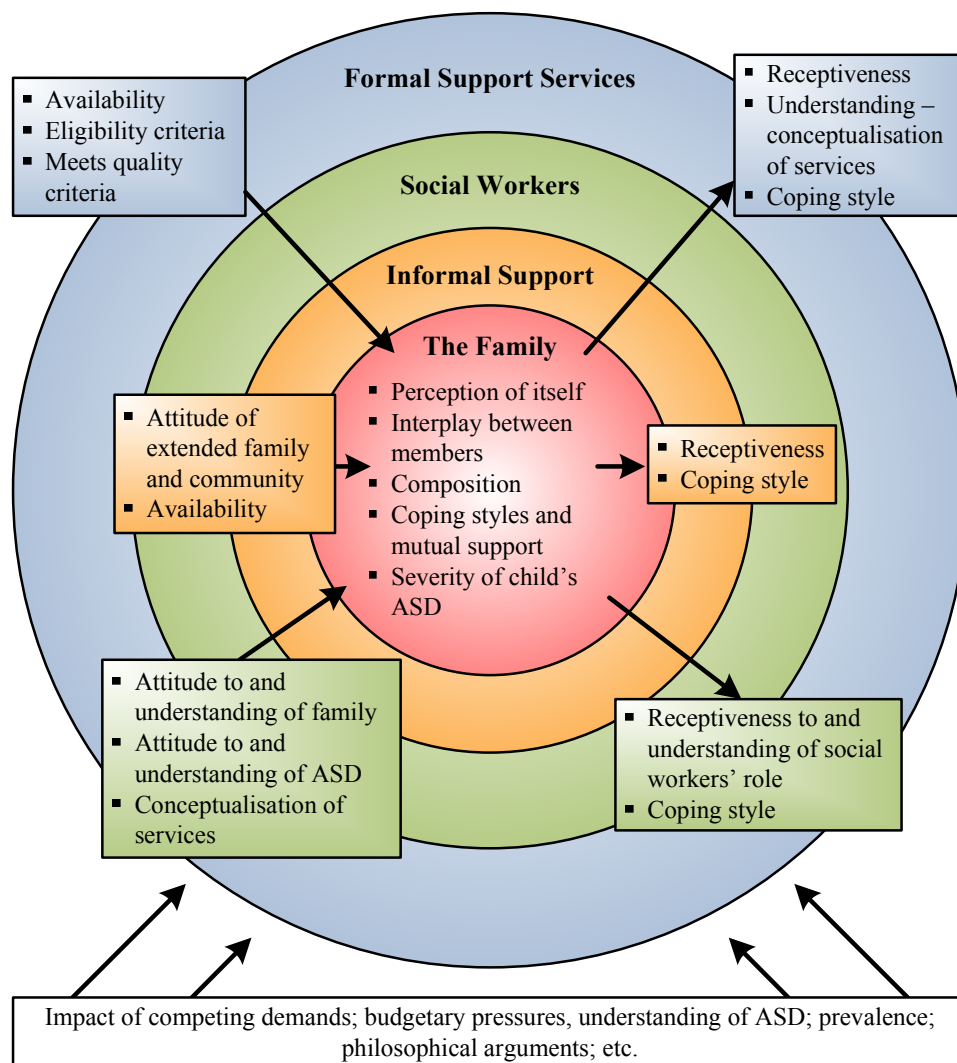
<b>Factors associated with use</b>	<b>Factors associated with non-use</b>
Impact of the child's behaviour on the family	Positive interpretation of child's behaviour
Perceived inadequacy of support from other family members/extended family/social network	Perceived adequacy of support from other family members/extended family/social network
Availability of appropriate formal support services	Service shortfall
Positive experience of social workers and care providers	Negative experience of social care professionals
Perceived benefits to parents, siblings and child	Feelings of guilt
Positive attitude towards service use	Lack of confidence in others to care for child
Family coping style – range of styles from actively seeking instrumental support to helplessness	Perceptions of stigma associated with use of formal support services
Family adaptation – range of adaptation, but seeking or achieving normalization	Family coping style – range of styles from actively seeking instrumental support to helplessness
	Family adaptation – range of adaptation, from resignation to normalization.

Consideration of this multiplicity of factors identifies the limitations of current understandings of why families use or do not use short breaks. The linear model which I derived from the literature and tested in the hypotheses has been demonstrated to be oversimplistic. Such a model cannot accommodate the wide range of factors, both internal and external to the family, which has been revealed by this project to be associated with short breaks use or non-use. It is suggested that a more interactive systemic model might more accurately represent the interplay between the family and their potential sources of formal and informal support (Figure 7.2).

This model is derived from the social ecological model within family systems theory, where the family is conceptualised as a microsystem interacting with other systems (although it must be noted that strata within this model, other than the microsystem, are not directly equivalent to the mesosystem, exosystem and macrosystem discussed in 2.1.8 (see Figure 1)). This model is consistent with a realist epistemological position, wherein the social world is identified as complex and stratified and a function of realist research is to understand the interactions and relationships between these strata (3.1). It is further consistent with the findings of the three phases of this project, and the synthesis undertaken within this chapter, and illustrates the various strata, interactions, relationships and tensions identified within the phenomenon of short breaks use.



**Figure 7.2 Factors associated with short-breaks use and non-use: a systemic model**



Within this model the phenomenon of short breaks use is situated within a societal context. At the heart of the model is the nuclear family, the target recipient of the service. As the model identifies, there are a number of internal family factors that are associated with whether the family uses or does not use such a service. These include factors related to the family's structure (including membership characteristics and socio-economic status), family interaction (between individuals and subsystems), the family's level of cohesion and adaptability, the

family's adaptation to the presence of ASD, family members' coping strategies, the family's ability to perform and negotiate family functions and its position within the family life cycle, as well as factors specifically relating to the child with ASD. These latter include his or her level of dependence, behaviours, abilities and prognosis.

Around the family are situated the potential providers of informal support – their extended family, and friends and neighbours within the community. Crucial factors in the interactive relationship between the family and this stratum include the family's coping style, its receptiveness to seeking and accepting informal support, as well as whether support is available and the attitude of extended family members, friends and neighbours to the family's situation, and their understanding of ASD.

Social workers perform a crucial function within this model, and are positioned as both the brokers of, and gatekeepers to, the family's accessing formal support services. Again there are a number of key factors which impact upon the interaction between the family and social workers. With regard to the family, these include their understanding of the social worker's role and their receptiveness to having a social worker (which again are dependent upon microsystemic factors such as their ideological and coping styles). With regard to the social workers these include their understanding of, and attitude towards, the family and their situation, their understanding of and attitude towards ASD in general and its presentation within the family member(s) with ASD in particular, and their conceptualisation of short breaks services and their purpose.

Beyond the social workers are situated the formal support services. Key factors in their interaction with the family include those factors associated with quality by the families in this study, ranging from organisational factors such as availability, accessibility and eligibility criteria through to psychological factors, understanding and acknowledging the psychological impacts of service use and having a whole family perspective. On the family's part, key factors again include the microsystemic factors already discussed as well as their conceptualisation of, and attitude towards, formal short breaks support.

Finally, all of these interactions take place within a wider societal context and are impacted upon by a wide range of cultural, political and financial factors. Societal attitudes towards disability in general and ASD in particular, (which can be shaped by how ASD and disability are portrayed in newspapers, on TV and in the cinema) have an impact. So does the political climate, which will influence the philosophical and political models underpinning service provision (for example, whether disabled children should be supported in specialist provision or included in mainstream settings, whether the state should provide services or whether parents should be enabled and supported to arrange their own support). The health of the economy, both local and national, is of importance as this will affect the availability of funding for services. Furthermore, there will always be conflicting demands for public funding. In social care services for children, events such as child deaths, or major child protection scandals, can lead to the ring-fencing of funding for child protection services, and the subsequent siphoning away of finance from other service areas.

In this chapter I have discussed the four research questions in the light of the three phases of the research I have undertaken. In the next chapter I will identify limitations within the study,

problems I faced in undertaking it and things I would have done differently. I will identify the extent to which the research questions have been answered, and the degree of confidence that can be placed on these findings, and the contribution which this thesis makes to the knowledge base. Finally I will identify potential areas for future research.

## **Chapter 8: Concluding comments**

*In this concluding chapter I identify the extent to which the research questions have been answered, and the degree of confidence that can be placed on these findings. I discuss difficulties that I encountered undertaking the study, its limitations, and aspects that I would have changed or done differently. I summarize the contribution that this thesis makes to the knowledge base, and its potential value in research and practice. Finally I will identify potential areas for future research.*

### **8.1. To what extent have the research questions been answered?**

This research was undertaken to seek to answer four specific research questions, derived from the literature and from my professional experience and previous research. These were as follows:

- what can we learn of whole families' experience of living with ASD?
- what can we learn of whole families' experience of and attitudes towards short breaks?
- what factors are associated by whole families with 'quality' within short breaks?
- what factors, both within and outside the family, are associated with whether or not families access formal support through short breaks?

The findings of the three phases of the research, reported on in Chapters 4, 5 and 6, are synthesised in Chapter 7 to address these four questions. In Tables 8.1 to 8.4, over the next four pages, I summarise the key findings

**Table 8.1      What can we learn of whole families' experiences of living with ASD?**

- More than 80% of households, 25% of which are single parent households, are home to brothers and sisters in addition to the child with ASD
- A significant number of families are unwaged – almost a fifth of the total, rising to more than half of the single parent households. In only 10% of families are two parents working on a full time basis
- Children with ASD have high dependence, with over two thirds identified by parents as dependent in 7 or more of Robinson and Stalker's 10 areas of dependence. The presence of ASD significantly affects family life and functioning. Almost three-quarters of these children require constant supervision and managing behaviour and difficulty getting out and about are issues in almost nine out of ten families
- Families are able to access only limited informal support, in the main from within the nuclear family. There is little difference between the informal support available to families that use short breaks and those that do not
- Families have a shared but differing experience of the difficulties and stress of living with ASD in the family and that different family members experience living with ASD in different ways
  - The main themes of mothers' narratives were isolation, feelings of stigma, acceptance of the impact of ASD on themselves, concern about its impact on their other children, and concern about the future
  - Fathers main themes were withdrawal, minimising difficulties, humour, uncertainty about the future and viewing their own family as in particular need of professional support
  - The main themes of siblings' narratives were the acceptance of the impact of ASD as normality, restriction of opportunities, the closeness of the sibling bond, embarrassment and stress
  - The themes emerging from consultation with the children with ASD were their generally positive view of family life, isolation, lack of awareness of the impact of ASD on the family and problems at school

**Table 8.2      What can we learn of whole families' attitudes to and experience of short breaks?**

- Over 50% of families have a current need for short breaks, and over two thirds feel they will need short breaks at some point. However only a quarter are actually accessing services
- Families that use short breaks speak positively of their benefits to parents, siblings and children with ASD. Nonetheless, using short breaks can cause family members to feel emotionally torn
- A number of shortcomings were also identified, particularly with regard to lack of appropriate services, difficulty accessing services and problems relating to information and communication
- Families seek to access short breaks because of the behaviours exhibited by the child with ASD, to get a break from carrying out the caring role, to enable the rest of the family to undertake social activities and to provide social opportunities to the child with ASD
- Families consider short breaks to perform a number of functions: providing family members with opportunities to relax, providing social opportunities for both the family and the child with ASD and developing the child's skills
- Families that used short breaks felt ASD-specific services were most appropriate. Social workers by contrast believed that in many cases children with ASD could be successfully integrated into generic disability services

**Table 8.3      What factors are associated by whole families with ‘quality’ within short breaks?**

- Parents, siblings and children with autism identify a number of factors as being associated with quality in short breaks services
- A number of factors concern the way services are organised These relate to:
  - the availability of appropriate services
  - the accessibility of service
  - the service being reliability provided – knowing the short breaks would happen
  - flexibility – services being able to adapt to families’ changing needs
  - consistency between home, school and short breaks
  - effective communication
  - accessible and accurate information
- Environmental factors associated with quality are:
  - that the building and grounds are ASD-friendly, providing safety and privacy
  - that ASD-appropriate strategies and approaches are used
- Factors relating to staff are:
  - their knowledge and training
  - their personal attributes
- Factors relating to the children using the service are:
  - grouping children appropriately, taking account of their preferences, sensitivities and impact on each other
  - that children are happy in the setting
  - that children are helped to make choices and to have some agency
  - that services are individualised
- Psychological factors are:
  - acknowledging and understanding the sometimes conflicting emotional and psychological impacts of using services
  - that systems and practices are developed to minimise feelings of guilt and stigma associated with service use
- Finally, it is vital that the service has a whole family perspective, acknowledging that it exists to meet the needs of the whole family, not just the child with ASD



**Table 8.4      What factors, both within and outside the family, are associated with whether or not families access formal support through short breaks?**

- The availability of informal social support is not a significant variable associated with use or non-use of short breaks
- Children with ASD in families that use short breaks are more dependent than children in those that do not ( $p = .05^*$ ). However, other factors are equally or more significantly associated with use or non-use.
- Factors identified as being associated with short breaks use are:
  - perceived benefits to parents, siblings and the child with ASD
  - the need to undertake necessary activities
  - child aged 11 years or over ( $p = .05^*$ )
  - child diagnosed with ASD plus learning disabilities ( $p = .001^{***}$ )
  - child attending special school ( $p = .001^{***}$ )
  - child has a social worker ( $p = .001^{***}$ )
  - impact of child's behaviour on the family
  - perceived inadequacy of informal support
  - availability of appropriate formal support
  - positive experience of and/or attitude towards formal social workers and care providers
  - family coping style and adaptation
- Factors identified as being associated with non-use are
  - family values
  - service shortfall
  - concern about the impact of service use on the child
  - child aged under-11 ( $p = .05^*$ )
  - child diagnosed with Asperger Syndrome ( $p = .001^{***}$ )
  - child in mainstream education ( $p = .001^{***}$ )
  - child does not have social worker ( $p = .001^{***}$ )
  - positive interpretation of child's behaviour
  - perceived adequacy of formal support
  - service shortfall
  - negative experience of and/or attitude towards social workers and care providers
  - family coping style and adaptation
- The way that social workers conceptualise ASD and understand families' situations can also impact on whether they use or do not use short breaks
- An interactive systemic model might be helpful in understanding the interplay between families, social workers and short breaks services

## **8.2. How much confidence can be placed on these findings?**

As Chapter 2 identifies, there is already a considerable literature investigating the experience of families living with ASD (see 2.3.1). However, most of this literature is focused on one particular perspective within the family (2.5.4); and so researchers have, for example, focused on the parental experience (Gray, 1993-2002), or on that of siblings (Gold, 1993; Kaminsky and Dewey, 2002). Studies have also often had small or non-representative samples, as is discussed in 2.5.7. The literature regarding these families' experience of short breaks is more limited and, as is shown in 2.4 and 2.5, sometimes contradictory, and the experience of children with ASD is under-researched.

Within this project, I feel I have overcome some limitations of earlier research and literature. In the first phase, the family survey, I surveyed all families that had a child with ASD registered on the local authority's register of disabled children, 70-80% of the total. The response rate of 61% gives the findings of this survey an accuracy of +/- 5% at 5% significance and the sample's representativeness has been verified (4.8.2, Table 4.2). Ninety-six per cent of social workers responded in the second phase. These high response rates give my findings strength, validity and credibility. The third phase of the research comprised semi-structured interviews carried out with fourteen families. A purposive, dimensional sampling approach was used to select the families, using robust and explicit criteria; consultations were individualised to make the process accessible to participants and other sources were used to triangulate the data. Robust design processes were used throughout: quantitative data collection tools were either designed in conjunction with 'the researched' or previously published tools were used. Qualitative tools were designed with families and made use of my professional expertise. Trialling and piloting procedures were rigorous. External rating of

samples of data and checking for inter-rater reliability was used across the whole study to validate the interpretation of qualitative data.

I therefore consider that these findings can be approached with confidence when considering the singularity under scrutiny: families that have a child with ASD within this geographical area at this time. External generalisability is not claimed, for the opinions, attitudes and experiences of families living with ASD and those who work with them are shaped by many factors, including the level and types of service provision available (for example, ASD-specific care services had been established in the county used for more than a decade). Moreover, social and demographic factors (the county is largely rural, with a low ethnic minority population) make direct comparison untenable with areas such as inner cities (even within other local authorities in England and Wales where the same legislative framework governs service provision). Acknowledging these limitations, I would suggest that the findings may – due to the rigour with which this study has been undertaken – have wider value, and that they are worthy of consideration and scrutiny by those to whom this topic is relevant.

### **8.3. Original contribution**

This thesis contributes to the knowledge base in a number of areas. It has the potential to influence future research and to impact practically upon service delivery for this population through dissemination of its findings in journal articles. Key aspects of this contribution are as follows.

### **8.3.1. Contribution towards understanding of family life in families affected by ASD**

As far as I have been able to ascertain, this is the first case study of its size dealing with this topic, and the first in which the views of whole families, including children with ASD, have been gathered from within the same families, and where the views of families who use services, who wish to use services, and those who do not want services, are investigated. It identifies significant themes which are common across mothers', fathers', siblings' and children with ASD's experiences, and highlights the range of experiences that can exist between members of the same family. At a practice level this study identifies the need for practitioners to be aware that short breaks services may be required to perform different functions and deliver different outcomes to the various members of families receiving services. These findings will be disseminated more widely; an article regarding children with ASD's experience of family life, social work support and short breaks has been published in the peer-reviewed *British Journal of Learning Disabilities* (Preece and Jordan, 2010)

### **8.3.2. Contribution towards understanding of factors associated with short breaks use and non-use**

This study adds to our previous understanding regarding factors associated with short breaks use and non-use by identifying key factors that are strongly associated with service use and non-use. It suggests that an original systemic model to describe family's interactions and relationships with sources of informal and formal support may help to conceptualise of service use or non-use. Such a model has the potential to inform both research and social care practice. An article focused upon the family survey and its findings regarding factors associated with service use and non-use was published in the peer-reviewed *Journal of Autism and Developmental Disorders* (Preece and Jordan, 2007a).

### **8.3.3. Contribution towards understanding of quality indicators in short breaks services for families of children with ASD**

The research identifies factors which are identified with quality in short breaks services by entire families using such services (mothers, fathers, siblings and children with ASD) as well as those identified by non-users. This contribution is timely given the emphasis on the development of services for children with ASD and their families under the government's *Aiming High for Disabled Children* agenda (HM Treasury/Department for Education and Skills, 2007). An article identifying and discussing these indicators has been published in the peer-reviewed journal *Practice: Social Work in Action* (Preece, 2009)

### **8.3.4. Contribution towards understanding of social workers' perceptions of ASD**

The second phase of the research, the survey of social workers with regard to their understanding of ASD, was, as far as can be ascertained, the first study to have been carried out regarding this topic. At a practice level this study has identified the need for social workers to be provided with effective training and accurate information about ASD. An article reporting on this study has been published in the peer-reviewed *British Journal of Social Work* (Preece and Jordan, 2007b).

### **8.3.5. Contribution to the knowledge base regarding methods of consulting with children with ASD**

In Appendix 10 I report how the characteristic problems of ASD impacted within the third phase of the research, and how strategies used successfully with children with ASD, such as aspects of the TEACCH approach, were adapted to develop tools and strategies to maximise the children's participation and the accuracy of the information obtained. This aspect of the research has clear practical application, across research and practice. This topic is reported on

within the paper published in the peer-reviewed *British Journal of Learning Disabilities* (Preece and Jordan, 2010).

#### **8.4. Things I would have done differently**

Like all other research, this study has limitations. Some arise from theoretical choices: deciding to collaborate with parents to design data collection tools precluded using formalised tools to measure stress and family coping. Some relate to the data-driven research design. When I undertook the first phase of the research, I did not know the shape of phases two and three; undertaking the second phase, I did not know what questions I would be asking in the third. Hindsight enabled me to identify questions I wished I had asked: questioning families in the survey about attitudes to and experience of social work support; identifying more precisely the patterns and levels of support that families received, particularly the amount of time children spent at family-based short breaks; asking social workers what they considered the purpose of short breaks. The potential value of these questions became clear either during the process of analysis or within the next stage of the study.

Other issues did not become apparent until the data synthesis process, long after the research had been undertaken, such as that it would have been helpful to have had more in-depth information about social workers' previous experience and the type of settings in which they had worked. Interviewing families where the child's dependence had been rated by the survey respondent as below-7 would have shed further light on the experience of these households and it would have been interesting to investigate whether the other family members shared the respondents' perspectives.

Further limitations arose from the research being carried out by a lone researcher, on a part-time basis, whilst also working full-time as a practitioner. This limited the amount of time available to undertake the research, which for example impacted on the number of interviews that could be undertaken; and also affected the length of time that it took to complete the project (over seven years from initial registration to submission of the thesis).

### **8.5. Challenges and key areas of learning**

As a PhD student, I was learning how to undertake research at the same time as I was doing it, which meant that certain processes took an extremely long time: from beginning to prepare the transcribed interviews for analysis using NVivo to the completion of the analysis process took thirty-two months. Methodological limitations regarding the discrete phases of the study are identified within the individual *Discussion of method* sections in Chapters 4, 5 and 6. In this section I will identify specific challenges that I encountered on my journey towards the completion of my PhD. I begin by describing some of the general difficulties I faced, before moving on to describe three areas of specific learning: working collaboratively with parents, consulting with children with ASD and undertaking research interviews.

#### **8.5.1. Problems on the way**

The description of the research project in a thesis necessarily smoothes out some of its rough edges. Blind alleys followed are glossed over. A clearer route through the data is presented than may at times have seemed the reality. There have been points at which I had to stop in order to learn new skills – such as undertaking research methods training, and obtaining and learning to use NVivo. Furthermore, in undertaking this study there have been points (particularly in its earlier stages) at which things went far from smoothly. During the process

of inputting the data from the family survey into Excel, I copied across data from a corrupted memory stick onto my computer. As a result of this I lost three weeks' worth of data and had to start again from scratch. Whilst analysing the data from this survey, I identified the discrepancy between the number of children (155) and the number of families (150). As a result of this I had to revise all of the analyses relating to families. In the course of this, I identified that I had mistyped some data into Excel: therefore, it was necessary to recheck all of the survey data to ensure their accuracy. As a result of these early setbacks I became assiduous at backing up data. This was fortunate in 2007 when my laptop computer suddenly 'died' whilst in Holland: less than an hour's work was lost.

Though I had lost little data, the need to replace my computer was not without its problems. Having bought a new laptop, I found that NVivo 2.0 could not be loaded on to it as my disk was corrupted. When I attempted to buy another copy, I found that the programme had been updated to NVivo 7 and the earlier version was no longer available for purchase. The new version differed significantly from the one with which I had become confident; I had by this time coded a large amount of the transcribed data and did not want to have to start again. Eventually I managed to source another copy of NVivo 2.0 at the university. However, for a two month period I was unable to undertake any coding.

Further problems occurred due to issues unrelated to the research. In the summer and autumn of 2004 I had a period of ill health that left me suffering from vertigo and tinnitus and feeling unwell and continually tired. Another period of ill health in early 2006 left me unable to work on the research for three months. Work demands also impacted significantly. In the latter half of 2008, the need to respond to the *Aiming High for Disabled Children* initiative coincided



with the opening of a new residential home for children with ASD, just as one of my assistant managers was away on a placement for six months. These periods of being limited in the amount of work I was able to undertake on the research were extremely frustrating, and getting back 'into' researcher mode was challenging at times.

### **8.5.2 Developing the research tools with parents**

An area of challenge arose immediately from my decision to design research tools in collaboration with parents (Preece, 2005). The decision to do so was made on ethical and methodological grounds: to ensure that the researched were involved in the production of the research. However, points of tension were recorded in my diary, in particular with regard to the development of the family survey tool. After the pre-test meeting with the parents from the neighbouring county in October 2003, I wrote in my research diary of the discomfort I felt during the meeting due to the two conflicting roles that I held. I went to the meeting as a research student, seeking support and advice in the development of my research tool. However, some parents' perceptions of me were based on my professional role as a manager of services for children with ASD and – in their eyes – an “expert”. As such they were eager to question me about this professional role, the services I managed, and to seek advice and information. I did not feel able to directly advise or support parents (particularly where they were in conflict with their local authority); however, I was openly seeking their support and advice for my study, but could not offer the same in return.

Further tension arose immediately before the pilot study questionnaires were circulated. It was agreed that the anonymous information gathered in the pilot study would be shared with Autism X-shire, so that it could be used to highlight issues in their county. This seemed an

acceptable and appropriate trade-off. However, the society's officers wished to select the families in the sample, to maximise response and to get a 'stronger' message from the information. I had to stress that this would invalidate both the information (for them) and the pilot study (for me); and a random sampling method was agreed. However the society's officers' lack of research awareness and their desire for change meant that this process became uncomfortable.

I learned a number of valuable lessons involving families in the research design. I found that differing agendas will invariably cause some degree of conflict; however, it was my responsibility as a researcher to negotiate this conflict in a way which maximised the input of the researched without compromising the integrity of the research. It became apparent that an ethical, rigorous stance might reduce willingness to collaborate or participate and that consulting and collaborating with parents in research design does not mean unquestioning acceptance of their suggestions or preferences. The final responsibility for the research tool was mine, and it was vital that the tool was fit for purpose. Finally, and crucially, I learned that some role discomfort is probably inevitable, especially for a professional who is only a part-time researcher. This discomfort must be owned and acknowledged by the researcher, to reflexively acknowledge his/her role and the situated nature of the research being undertaken (Finlay and Gough, 2003).

Overall, I believe that collaborating with parents strengthened both the research tool and the research process and I feel that this was an important contributing factor to the eventual response rate of 61% in the family survey, and also to the effectiveness and appropriateness of the interview protocol in the third phase of the study.

### **8.5.3 Consultation with children with ASD**

A significant aspect of this study was undertaking consultation with children with ASD. As I identify in Appendix 10, difficulties were encountered in all of the characteristic areas of ASD. Challenges to the consultation process arising from impairments in social interaction included classic autistic aloofness, cue-dependence, and immature and gauche behaviour. Challenges arising from impaired communication included anxiety at communicating, the need for adult support, limited and concrete understanding and use of language, idiosyncratic speech and echolalia. The children had difficulty expressing preferences and emotions regarding people; they exhibited poor personal memory and overselectivity, and a tendency to defer and acquiesce to their parents if present. Visual supports were a helpful tool to elicit information, but could potentially limit the discussion, as the children tended not to extrapolate beyond the visual cue. Triangulation was identified as vital, as sometimes the children's answers and understanding were inaccurate. A detailed analysis, both of the challenges encountered and of the methods and tools that were used to maximise the effectiveness and accuracy of the consultation process, is provided in Appendix 10.

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### **8.5.4. Conducting research interviews**

After twenty-five years as a qualified social worker, my experience and expertise has been developed in undertaking social work interviews. Kadushin (1990) typifies social work interviews as having three functions: information-gathering (finding out about the case or situation), diagnostic (assessing eligibility or the appropriate intervention) and therapeutic (as part of the intervention undertaken to effect change). By contrast, Gillham (2000) defines research interviews as being undertaken to obtain information and understanding of issues relevant to the aims and questions of a research project. This latter activity has a much clearer

focus, and in it one does not seek to develop an ongoing relationship with the interviewee. Indeed effective closure, and clarifying the limits of the relationship, is a key facet of the research interview. Undertaking research interviews meant developing a new skill set, and has been a further area of growth.

## **8.6. Areas for further research**

All research suggests further studies that could be undertaken. I conclude this thesis by outlining what seem to me to be key areas in which the findings of this study could be built upon and taken forward. These are through undertaking a similar study within a different population, through undertaking research to identify the service providers' perspective, researching the impact of short breaks on family stress, undertaking research into the coping strategies of the three subgroups identified in this study (short breaks users, those that wish to use short breaks, and those who do not want to access such services), and through testing the suggested model in other areas to see if it is robust.

### **8.6.1. Researching within a different population**

It is acknowledged that the findings of this case study are valid only for the population studied and further, that the county under scrutiny has a number of characteristics – low minority ethnic population, ASD-specific services – that may make it different from many other settings. To test whether my findings – and indeed the tools developed – might have wider value, it would be necessary to replicate this research in a different setting. This was attempted during the course of this research project. Initially, my supervisor and I met with rejection from local authorities, perhaps because they did not wish to quantify levels of unmet need. In 2007 we liaised with an inner London authority that wished to replicate the family

survey. However, the authority's social care provision was restructured, and other priorities took over. As a result, work on this project did not proceed.

#### **8.6.2. Researching the service providers' perspective**

This study focuses principally on the viewpoints of family members, with a lesser focus on social workers' perspectives. Missing from this study (due to the inappropriateness of my researching this area) is the perspective of service providers. Few studies have included this perspective (Gray, 1998; MacDonald and Callery, 2004). Further research to understand how service providers understand the role of short breaks, how they conceptualise quality, and how they perceive the needs of families, would be a helpful addition to the knowledge base.

#### **8.6.3. Researching the impact of short breaks on family stress**

The elevated stress experienced by such families is well-identified (Bebko *et al.*, 1987; Benson, 2006; Duarte *et al.*, 2005) and I hesitate to suggest further research in this area. However, the impact of short breaks upon family stress levels is under-researched (Guralnick *et al.*, 2008; Mullins *et al.*, 2002) and studies to identify outcomes of short breaks, in terms of their impact on both parental and whole family stress, would be valuable.

#### **8.6.4. Research into coping strategies of the three subgroups**

An equally considerable body of research has already been undertaken over twenty-five years regarding stress and coping in families that have children with ASD, using a wide range of methods ranging from administering psychological scales to ethnography (Abbeduto *et al.*, 2004; Bristol, 1984; Gray, 1994; Hastings *et al.*, 2005). However, my research was inconclusive with regard to whether families in the three subgroups (service users, would-be

users, and families who did not want a service) drew to any significant extent upon different coping strategies. Research focusing upon these three subgroups may shed further light upon this topic.

#### **8.6.5 Testing the model**

The model suggested in 7.7 (Fig 7.2) was developed as a result of the data analysis process, and is not necessarily generalisable to other settings or populations. Nonetheless it would be of interest to see if this model has utility or purpose for other areas of study - for example other populations, such as families of children with learning or physical disabilities. Would the model help our understanding in these areas? Might it be a useful tool for conceptualising short breaks use across different populations?

#### **8.7. Postscript**

The initial planning of this doctoral research was undertaken in February 2003. The last interview was concluded in June 2005. In the five years that have passed since the fieldwork was completed, significant changes have occurred with regard to social care services for children and families in general, and concerning support for families with disabled children – including those with ASD – in particular. It seems appropriate to conclude this thesis by identifying these changes and their impact upon the phenomena of ‘social care support’ and ‘short breaks’; and by reflecting upon the lessons that I feel this research offers to practitioners within local authorities in 2010.

### **8.7.1. Developments in social care**

When this study was carried out, the predominant models of social care support for disabled children and their families across the country were family-based and residential short breaks provided or brokered by local authority social workers. Some limited in-home short breaks (predominantly provided to very young children or those with complex health needs) were also provided in some areas. Additionally, services such as befriending schemes and holiday play schemes were also widely available, though these were often considered as separate to and different from short breaks.

In 2003 it became mandatory for local authorities to offer direct payments to parents of disabled children, in lieu of services, to enable them to make their own arrangements for their family's social care support. It was quickly identified that direct payments needed to be a true choice, rather than the only option available. Some parents preferred or needed more traditional sources of service delivery, and recruiting carers and personal assistants could be as difficult for parents as for local authority Family Link schemes (Leece *et al.*, 2003). Other families preferred the flexibility and sense of empowerment that direct payments afforded (Carlin, 2006) and by 2005 almost 2800 families across the UK were using these to fund short breaks, specialist nursery placements and personal assistants, and to carry out a range of tasks from providing personal care to enabling children to access community activities (Davey *et al.*, 2007). The number of users has continued to rise since that time. Research on the impact of direct payments remains limited, but generally positive (e.g. Stainton and Boyce, 2004).

The adoption of person-centred planning, and person-centred approaches, across adult and children's services over the past decade has also steadily increased (Sanderson, 2000; Taylor,

2007). This has led to an increase in the number of workers, in schools and community settings, whose role is to facilitate the involvement of disabled children and to promote effective consultation with them; and the importance of ensuring social workers are able to communicate with such children, and its implications for social work training and practice, has been acknowledged (Mitchell *et al.*, 2009).

The *Every Child Matters* agenda led to the restructuring and reorganisation of local authority education and children's services departments throughout the UK (Aspect, 2006). 'Social services' provision for children became integrated with other children's services, such as education and youth services, and many social workers now work alongside educational psychologists or advisory teachers within the same departments. This should and does offer opportunities for more effective working across school and community settings, and could be helpful in enabling a more holistic view to be taken of children and families' needs, and in making the 24-hour curriculum a reality for an increased number of children on the autism spectrum. However, despite considerable progress in interagency working, Lord Laming's report following the death of 'Baby P' (Laming, 2009) identified that considerable barriers and problems remain in working across disciplines, professional cultures and organisational boundaries.

The *Aiming High for Disabled Children* initiative, running from 2007-2011, was introduced to transform services for disabled children and their families (HM Treasury/Department for Education and Skills, 2007). Action is targeted within three priority areas – access and empowerment, responsive and timely services, and improving quality and capacity. Though discussion of service delivery within the short breaks implementation guidance focuses on



traditional models – overnight breaks in family based and residential services; daytime breaks through sitting or befriending services (Department for Children, Schools and Families/Department of Health, 2008) – a clear message of the initiative is that ‘short breaks’ can occur in a number of different ways, not just in their traditional forms.

*“These include day, evening, overnight and weekend activities, and can take place in the child’s own home, the home of an approved carer, a residential or community setting. Short breaks come in a variety of formats and each one can last from just a few hours to a few days, and occasionally longer, depending on the type of provision and the needs of the child and the family.”* (Department for Children, Schools and Families/Department of Health, 2008, p11)

Within the local authority in which this research was undertaken, the results of my initial survey and the subsequent family interviews were fed into the *Aiming High* consultation process; and the needs and wishes of these families has informed subsequent service developments. After-school clubs with appropriate supports, sibling groups and specific activities for children with AS have all been established with *Aiming High* funding. Further challenges remain – particularly in the light of the austerity measures being taken by the new coalition government elected in May 2010, and the promise of cuts to public spending – but it is pleasing that some areas of shortfall identified by families have been addressed.

### **8.7.2. Short breaks in context**

As this thesis argues, short breaks perform an important function in supporting families that have children with ASD. Equally clear is that such services are not a panacea for all such families’ difficulties, and that for some families they are neither an appropriate nor a desired intervention. Christie and Fidler (2001), writing about educational provision, identify the importance of a continuum of provision for a continuum of need, and this is also true regarding community and social care support. As this research identifies, a range of

appropriate short breaks needs to be available for families that have children with ASD, including daytime and overnight breaks in appropriate settings and contexts; but short breaks themselves must be located within a continuum of services to address a range of family needs and situations. These should also include, but are not limited to, effective diagnosis and post-diagnostic support and education (Whitaker, 2002; Flynn *et al.*, 2010), direct intervention and modelling of appropriate management techniques (Preece and Almond, 2008), effective collaboration to provide continuity between school and home settings (Howley *et al.*, 2001), and appropriate provision (either residential or fostering), to provide longer term accommodation for children who are unable, either temporarily or permanently, to continue living within their families (Preece, 2008).

### **8.7.3. The importance of assessment**

In a world of budgetary pressures, where demand outstrips availability, it is tempting to develop indicators or criteria that can be used to determine eligibility for services such as short breaks. However, although this research identified factors associated with short breaks use or non-use – such as the child’s age and level of dependence, their diagnosis and school placement, allocation to a social worker – these factors were mediated by the views of the social workers involved, and were also influenced by service availability, the effectiveness of information and by family attitudes and perceptions. Such variables only suggest whether families are more or less likely to access a service, and indicate nothing about individual children’s and families’ needs.

Furthermore, in March 2009, the High Court issued the ‘Islington Judgement’, its judgement in a case where the London borough’s decision not to provide support to a disabled child and

his family who did not meet its eligibility criteria for services was contested. The court ruled in the family's favour; and its judgement highlighted that eligibility criteria cannot be applied mechanistically, that decisions about service provision should always take account of the child and family's particular circumstances and needs, and that eligibility criteria should not be applied before an adequate assessment of the child and family's needs has been undertaken (Council for Disabled Children, 2009).

Assessments of children in need carried out by social workers are undertaken within the 'Framework for the Assessment of Children in Need and their Families' (Department of Health/Department for Education and Employment/The Home Office, 2000). Such assessments address three dimensions: the child's developmental needs, parenting capacity, and family and environmental factors. Marchant and Jones (2000) identify that this assessment framework is highly relevant for disabled children and their families, and argue that information from assessments can change the nature of service provision, especially where unmet need is aggregated and used to inform service planning (Marchant and Jones, 2000). It is important therefore that assessments are needs-led rather than resource-led, and that they are based on a whole family perspective, both in terms of engagement within the assessment process and in terms of the identification of appropriate service provision. However, the findings of the thesis suggest that there is still a long way to go if this is to be made a reality for all families. Moreover, the impact of limited resources and the increasing numbers of children diagnosed with ASD is such that, regardless of the quality of assessments, local authorities will struggle to have the capacity to address the demand for services.

#### **8.7.4. Underpinning principles**

Finally, how might the underpinning principles of effective social care provision for families that have children with ASD be defined? Parents and children alike in this research have confirmed the importance of consistency across educational and social care provision, so what is suggested by research within education? In 2008, Jones *et al.*, reviewing educational provision and practice for children in England with ASD, identify four key themes emerging from their research. These are that specific knowledge of the individual child is vital; that effective engagement with and support for the family is crucial; that appropriate and timely support is essential; and that knowledge regarding autism and effective strategies is needed by all. These themes are equally valid in the field in which my research was undertaken, and this thesis affirms their importance within social care support for families with children on the autism spectrum.

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**Appendix 1****Research Timeline**

<b>Date</b>	<b>Work undertaken</b>
January 2003	Registration commenced.
February 2003	Identification of topic. Commenced literature review.
July 2003	Meeting with parents from nearby local authority re design of survey of parents.
August 2003	First draft of initial survey tool. Initial coding frame.
October 2003	Parent survey – pilot study.
November 2003	Parent survey tool distributed.
December 2003- February 2004	Data inputting.
February-June 2004	Data analysis.
July 2004	Identification of need to survey social workers and undertake semi-structured interviews with families. Paper written on survey of families.
August-October 2004	Design and pilot of survey of social workers.
October-November 2004	Social worker survey tool distributed.
November 2004	Identification of potential group of families to interview. Initial contact with families.
February 2005	Family interviews – pre-testing and piloting process.
March 2005	Paper based on parent survey accepted by <i>Journal of Autism and Developmental Disorders</i>
March-June 2005	Carried out family interviews.
May 2005	MPhil to PhD transfer

Date	Work undertaken
June-August 2005	Transcription of interviews.
June 2005	Presented paper on collaborating with parents at University of Birmingham Student Research Conference. Paper subsequently published in proceedings of conference.
August-December 2005	Analysis of social work survey.
December 2005	Preparation of family interview transcripts for NVivo.
January 2006	Paper written on social worker survey.
January 2006-September 2007	Coding family interview transcripts in NVivo.
June 2006	Paper on social worker survey accepted by <i>British Journal of Social Work</i> .
July 2006	Presented paper at University of Birmingham Student Research Conference. Paper subsequently published in proceedings of conference.
February 2007	Papers on parent survey published in <i>Journal of Autism and Developmental Disorders</i> .
July 2007	Paper on social worker survey published in <i>British Journal of Social Work</i>
September 2007-September 2008	Analysis of family interviews.
April-May 2007	Preparation of poster for Autism Europe Congress. Presentation of paper at Webautism Tutor weekend, University of Birmingham
June 2007	Presentation at TEACCH UK conference, University of Northampton.
August 2007	Presentation of poster at Autism Europe Congress, Oslo.
May 2008	Preparation of papers on interviewing children with ASD and on quality indicators in short breaks.
October 2008	Emergence of alternative model of factors regarding short breaks use and non-use.

Date	Work undertaken
November 2008	Presentation of paper and workshop at conference, Pedagogic University, Krakow, Poland.
December 2008	Paper on quality indicators in short breaks accepted by <i>Practice: Social Work in Action</i>
April 2009	Commenced writing up.
July 2009	Paper on interviewing children with ASD accepted by <i>British Journal of Learning Disabilities</i> .
September 2009	Completion of first draft of thesis. Paper on quality indicators published in <i>Practice: Social Work in Action</i> .
November 2009- March 2010	Redrafting and revising.
March 2010	Paper on interviewing children with ASD published in <i>British Journal of Learning Disabilities</i> .
April 2010	Submission of PhD thesis.
June 2010	Viva
July 2010	Submission of corrected PhD thesis.

## Appendix 2

## Letter to parents of children with ASD

*NB. The original, as sent to parents, was written printed on local authority headed paper*

20 October 2003

Dear parent/carer,

### **Survey of families with children with autistic spectrum disorder in (*name of local authority*)**

I am writing to ask you to take the time to answer the enclosed questionnaire.

It is important that (*name of local authority*) Social Services seek and listen to the opinions of parents and carers about the range of short break (respite care) services that it provides. I hope that this survey will enable you to tell us your opinions and feelings about short breaks services and your wishes and needs in this area.

In order that you can feel free to be completely honest in their answers, this survey is anonymous. The circulation of the questionnaire is being managed by the disability register team. Unless you wish to be involved in further in-depth interviews, it will remain totally anonymous. It is very important that families feel able to be open as all your comments – critical, favourable or whatever – are extremely valuable.

All findings gathered will be shared with senior management in (*name of local authority*) Social Services, and will be used to inform future service developments. A copy of the findings will be circulated to all parents surveyed in the spring. In addition, this survey is part of a research project I am carrying out towards a PhD at the University of Birmingham, supervised by Dr Rita Jordan. It is intended that the survey results will be published in a journal, highlighting the support needs of families with children with autistic spectrum disorder more widely.

This form will take about 30 minutes to complete. Please answer as fully as possible. When you have completed the form, please return it to me at [*address here*] in the stamped addressed envelope provided by 14 November.

I also hope to follow up some questionnaires with more in-depth interviews. If you and your family would be willing to be involved in these interviews, please indicate this on the questionnaire. Depending on the number of responses, it may not be possible to interview all these families.

Please do take the time to complete the survey – as fully as you can – as it is important that we hear your voice. Thank you in advance.

Yours sincerely,

David Preece  
Team Manager

## Appendix 3

### QUESTIONNAIRE FOR PARENTS OF CHILDREN AND YOUNG PEOPLE WITH AUTISTIC SPECTRUM DISORDER

Please answer all questions as fully as possible. Your answers are confidential to yourself and the research worker. If you have more than one child with autistic spectrum disorder, please complete a questionnaire for each child: you can get another questionnaire from [address here].

#### Section 1: Your Family

1. Child's date of birth:.....
2. Child's sex:            Male            Female (*please delete as necessary*)
3. Child's diagnosis:.....
4. School attended:.....
5. Please can you say what your ethnic origins are by ticking the appropriate boxes below. (We need to know this information in order to find out how acceptable respite care services are to people from minority ethnic groups).

	Child's mother	Child's father
Black, Afro-Caribbean origin		
Black, African origin		
Black, Asian origin		
Black, Other (please specify)		
White, European origin		
White, Other (please specify)		

#### 6. Members of your household

Please fill in the table below, allowing one line for every person who lives in your house.

Person No.	Relationship to child	Age	Occupation	Full/part-time
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				

7. Please can you say if your child needs help in the following areas. Please tick the appropriate boxes and describe the help s/he needs.

	Yes	No	Describe help needed
Washing			
Dressing			
Toileting			
Eating and drinking (including dietary issues)			
Managing his/her behaviour			
Occupying self			
Getting around / going out and about			
Communicating			
Does s/he need constant supervision?			
Does s/he have sleep difficulties?			

8. What is your child's behaviour like most of the time? Please describe.

.....

.....

.....

.....

.....

.....

.....

.....

9. Do any of the following people help to look after your child? Please tick as many boxes as necessary.

Your partner		Neighbours	
Your other child(ren)		Friends	
The child's grandparents		Other people	
Other relatives		If other, please give details	

10. Is this a satisfactory arrangement for you? Please tick

Yes	
No	

11. Does your child stay away from home overnight without you? Please tick.

Frequently	
Sometimes	
Rarely/never	

12. If so, where does your child usually stay? (e.g. with relatives, respite care service, school trips)

.....  
 .....  
 .....

## Section 2. Short break (respite care) services

13. Do you currently have a social worker? Please tick.

Yes	
No	

14. Has anyone ever suggested that you might use 'respite care' services? Please tick.

Yes	
No	

15. If yes, what person (e.g. another parent, teacher, social worker, etc)

.....  
 .....

16. Where would you go to find out more about 'respite care' services?  
 .....  
 .....  
 .....

17. Do you feel the need for 'respite care' at the moment?

Mother		Father	
Yes		Yes	
No		No	

18. Which, if any, 'respite care' services are you using at present. Please tick as many boxes as necessary.

A residential home	
A residential (boarding) school	Weekly
	Termly
	Other
A family-based scheme	
A sitting service	
A childminder	
Domiciliary care (home help)	
Play group	
Holiday playschemes	
Sessional worker/befriending	
Other (please say what)	
None at all	

19. If you are not using any 'respite care' services, please say why not. Give as many reasons as you wish.  
 .....  
 .....  
 .....  
 .....  
 .....  
 .....  
 .....  
 .....  
 .....  
 .....



20. Which, if any, 'respite care' services have you used in the past. Please tick as many boxes as necessary.

A residential home	
A residential (boarding) school	Weekly
	Termly
	Other
A family-based scheme	
A sitting service	
A childminder	
Domiciliary care (home help)	
Play group	
Holiday playschemes	
Sessional worker/befriending	
Other (please say what)	
None at all	

21. If you have used a 'respite care' service in the past, please say why you are no longer doing so?

.....

.....

.....

.....

.....

.....

.....

### Section 3: Future Needs

22. Do you think you may need 'respite care' in the foreseeable future? Please tick.

Yes	
No	

23. If yes, how much help do you expect to need in the next 12 months? Please indicate both how often and how long you would prefer the breaks to be (e.g. one evening per fortnight, one weekend a month, etc).

.....

.....

.....

.....

24. What, if any, benefits do you think your family might gain from using 'respite care' services?

.....

.....

.....

.....

.....

#### Section 4: General Attitude to 'Respite Care'

25. Please tick the box which most closely reflects your view on each of the following statements.

	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
Using respite care services emphasises the difference between disabled children and others					
Respite care can prevent children being received into long-term care					
Parents should always be responsible for looking after their own children					
Respite care can improve a child's skills and abilities					
Respite care is only useful if it includes overnight breaks					
There is not enough information available about respite care services					
The needs of children with autistic spectrum disorder can be met within general respite services					

26. If there is anything you wish to add, please do so below.

.....

.....

.....

.....

.....

.....

.....

27. The researcher is hoping to follow up this survey by conducting a number of interviews about 'respite care' with parents of children with autistic spectrum disorders and with brothers and sisters. If you or your children would be willing to take part in this next stage of the research, please indicate below and fill in the contact details.

	Yes	No
I/we would be willing to be interviewed		
My/our child(ren) are willing to be interviewed, and I/we give consent for this		

Age of child with autistic spectrum disorder, if to be interviewed.....

Child's verbal ability.....

Number of brothers and sisters willing to be interviewed (if applicable).....

Age(s).....

Contact name.....

Address.....

.....

.....

.....

Telephone number.....

Thank you very much for taking the time to complete this questionnaire.  
Please return it in the stamped/addressed envelope provided to:

**David Preece**  
**[address here]**

## Appendix 4 Questionnaire for social workers

### Questionnaire on autistic spectrum disorder

*(Adapted from Mavropoulou & Padelidu, 2000)*

#### Demographic information

**Gender:**     a   male     b   female     *Please circle as appropriate*

**Age:**

#### Experience (in years)

- a)     social work/care with disabled children     .....
- b)     social work/care with mainstream children     .....
- c)     social work/care with disabled adults     .....
- d)     other – please specify     .....

#### Questions

**The following questions are aimed to explore workers' perceptions and attitudes towards persons with autistic spectrum disorder. The answers are not evaluated as right or wrong, and this questionnaire is anonymous.**

*Circle letters or numbers as appropriate.*

1.     Which of the following factors do you think are the main causes of autistic spectrum disorder?  
*(Rank the factors using (1) for the most significant cause and (5) for the least significant cause).*

.....Brain damage

.....Lack of mother's emotional response to the child

.....Social causes (e.g. poverty, lack of resources at home)

.....Heredity

.....Other factor (please specify):

2. The diagnosis of autistic spectrum disorder can be carried out mainly with:
  - a) neurological examination
  - b) psychiatric examination of the child's behaviour
3. Autistic spectrum disorder occurs more often in:
  - a) boys
  - b) girls
4. Autistic spectrum disorder becomes fully present in a child:
  - a) from birth to the end of the first year
  - b) from the second to the third year
  - c) from the third year onwards
5. Autistic spectrum disorder can be accompanied by learning disability.
  - a) Yes
  - b) No
6. Autistic spectrum disorder is an early form of schizophrenia.
  - a) Yes
  - b) No
7. People with autistic spectrum disorder have a reduced life span as a result of their condition.
  - a) Yes
  - b) No

8. In your opinion, what are the characteristics of a child with autistic spectrum disorder?

*(Circle as many statements as appropriate)*

1. Has hearing problems
2. Has temper tantrums
3. Does not seek the company of others
4. Does not seek physical contact with others
5. Does not play with objects
6. Has sleeping problems
7. Has problems in his/her eating routine
8. Makes clumsy movements
9. Does not make eye contact
10. Does not get attached to a person
11. Does not understand the feelings of others
12. Does not develop speech
13. Over-reacts to noise
14. Does not have self care skills
15. Has hallucinations
16. presents problems in his/her physical appearance and health
17. wants to keep his/her environment the same
18. avoids change in his/her daily routine
19. seems distant
20. does not have feelings
21. has obsessions
22. engages in stereotypical behaviour

9. Autistic spectrum disorder is a condition that can be fully cured.
- a) Yes
  - b) No
- 10a. To what extent is psychotherapy effective for the treatment of a person with autistic spectrum disorder?
- 10b. To what extent are specialised interventions and services effective for the treatment of a person with autistic spectrum disorder?
11. Do you believe that it is possible to integrate a child with autism into a generic disability service?
- a) No
  - b) Yes
  - c) If yes, describe the conditions under which this is feasible.

12. Special provision can help a child with autistic spectrum disorder to  
(Circle as many statements as appropriate)

1. read and write
2. develop emotional relationships with others
3. express his/her desires using speech
4. understand the feelings of others
5. play with other children
6. reduce his/her repetitive behaviours
7. reduce his/her tendency to self-injury
8. complete an activity independently
9. develop basic self-care skills
10. get relief from anxiety and emotional tension

13. The most appropriate service for a family with a child with autistic spectrum disorder is residential care.

- a) Yes
- b) No

Thank you very much for responding.

Please return your completed questionnaire, by **Friday November 5, 2004**,  
to:

**David Preece**  
**(address here)**



## **Appendix 5 Family interview schedules**

### **a) Parent schedule**

#### **1. What is family life like?**

##### *Prompts*

- Typical day? Weekday? W/E?
- Impact of child with ASD?
- What do you do together as a family?
- Are there any things you can't do, or find difficult?

#### **2. What informal support do you receive?**

##### *Prompts*

- Help from friends and family?
- Impact on nuclear family - what does this enable you to do?
- How does using this help make you feel?
- Has the need for such help caused any issues within your family?
- Do you use any other informal supports, e.g. support group?

#### **3. What is your experience of social worker support?**

##### *Prompts if **no social worker***

- Why not?
- Have you ever thought of seeking help from Social Services? If not, why?

##### *Prompts if **family has social worker***

- Have they been helpful? If so, how?
- Problems?
- How did they assess your needs?
- What do they understand of your needs?
- What do they understand of your child's condition?
- How do they get on with your child?

#### **4. What is your experience of respite care?**

##### *Prompts if family **don't use services***

- Have you ever thought of using respite care?
- What do you think is the purpose of short breaks?
- What would be important features/quality indicators?
- Why don't you use respite care?
- How do you think respite care would help your family?

- What would it enable you to do?
- How do you think your child would feel about going?
- How would your other children feel about X going?
- How would you feel about your child with ASD going?
- How do you think others – family, friends, and neighbours – would view your use of respite care?
- If negative, would this impact on your decision to use services?

*Prompts if **family use services***

- Why did you choose to use respite care?
- What do you think is the purpose of short breaks?
- What are important features/quality indicators?
- What is good/bad about respite care? (inc. information)
- Has using respite caused any problems? Within immediate family? Wider family? Elsewhere?
- What do you do when X is there?
- How do you feel about X going?
- How do you think X feels about going?
- How do your other children feel about X going?
- Do you think respite care has benefits for X?
- Need for ASD specific respite? Or generic?

## **5. What else would help?**

*Prompts*

- How could short-breaks be better for your family?
- Are there services that should be in place that would help you more?
- Can you think of any other supports that would make life better – for you? For your child with ASD? For the rest of the family?

## **b) Sibling schedule**

### **1. What is family life like?**

#### *Prompts*

- What's X like as a brother/sister?
- What do you do together?
- How do you get on?
- Are there any things you can't do, or find difficult, because of how X is?
- How does this make you feel?
- How do your friends feel about X? How does this make you feel?
- Do you ever help look after X? If so, what do you do?
- Have your parents talked you about X's ASD?
- Do you ever think you need to know more about his/her condition?

### **2. What's your experience of social workers?**

#### *Prompts*

- Has a social worker ever been to see you?
- If so, do you know why he/she came?
- What did he/she do?

### **3. What's your experience/understanding of respite care?**

#### *Prompts if **family use services***

- How do you feel about X going to respite care?
- Why do you think X goes there?
- What do you do while X is there?
- How do you think X feels about going?
- What do you think short breaks should be like: for the child with ASD? For your parent(s) and you)?
- Have you ever seen where X goes? What did you think of it? How could it be better?

#### *Prompts if **family does not use services***

- Have you ever heard of short breaks?
- Why might families want their children with ASD to go to short breaks?
- What would you want short breaks to be like? For X? For your parents and you?
- What would you do while X is there?
- How would you feel about X going?
- How do you think X would feel?

#### **4. What else would help?**

##### *Prompts*

- Activities?
- Things you'd like to do?

#### **c) Children with ASD schedule**

##### **1. Family life**

##### **2. Likes and dislikes**

##### **3. Respite care / professionals**

##### **4. Wishes**

##### *Outline of schedule for more able children*

#### **1. What is family life like?**

##### *Prompts*

- Important people in your life?
- What do you do together?
- Brothers/sisters – *Best thing? Worst thing? We have fun when...? He/she annoys me when...? We get on together when...?*
- What do you do on an ordinary day? Say today – when did you get up? Breakfast? How did you get to school? (other questions as necessary, e.g. best thing? Worst thing?)
- *Repeat for weekend.*

#### **2. What are your likes and dislikes / skills and interests?**

##### *Prompts*

- What are your favourite things (to do? To eat? Videos? Books?)
- Are there any things you don't like doing?
- Are there things you are good at?
- Are there any things you find hard to do?
- Are there any things you need help to do?

### **3. What is your experience of services and professionals?**

#### *Prompts*

- Have you ever met your social worker?
- Do you know why s/he comes to see you?
- What does s/he talk to you about?

#### *(for residential short breaks service)*

- Have you been to *(name of service)*?
- What happens there?
- Why do you go there?
- What is it like? What's the best thing/worst thing?
- Likes/dislikes?

### **4. Wishes?**

#### *Prompts*

- If you could have a magic wand and wish for something to happen, what would you wish?
- Are there any things you'd like to do but can't?
- Would you need help? What help?

## **Appendix 6   Family interviews: initial codebook**

### **Family structure**

- ***Membership characteristics***
  - Single parent
  - Two parents
  - Extended family
  - Income
  - Physical health
  - Mental health
- ***Cultural beliefs***
- ***Ideological style***
  - Beliefs about disability
  - Religion
  - Science
  - Fate

### **Family interaction**

- ***Subsystems***
  - Parents
  - Siblings
  - Extended family
  - Extra-familial
- ***Cohesion/adaptability***
  - Interdependence
  - Independence
  - Individual identity
  - Group identity
- ***Communication***
  - Open communication
  - Closed communication

### **Family functions**

- ***Economics***
- ***Daily care***
- ***Recreation***
- ***Socialisation***
- ***Self esteem***
- ***Affection***
- ***Educational/vocational***
- ***Spirituality***

**Family lifecycle stages**

- *New couple/marriage*
- *Child bearing and infancy*
- *Families with young school age children*
- *Families with adolescents*
- *Launching*
- *Families in later life*

**Impact of disability**

- *Positive*
- *Negative*

**Coping strategies**

- *Withdrawal*
- *Avoidance*
- *Passive appraisal*
- *Reframing*
- *Spiritual support/religious coping*
- *Informal social support*
- *Formal social support*

**Social workers****Special schools****Mainstream schools****Asperger Syndrome****Learning disabilities****Ag of child**

## **Appendix 7 Family interviews: first letter to survey respondent**

*NB. The original, as sent to parents, was written printed on local authority headed paper*

Dear.....

### **Re: Survey of families with children with autistic spectrum disorders in Northamptonshire: follow-up interviews**

Last autumn you kindly completed a questionnaire for me, and indicate that you were willing for your family to be involved in further in-depth interviews with regard to short break (respite care) services. Thank you again for your willingness to participate in this research.

I am now planning to carry out the follow-up interviews, and would very much like to involve your family in this stage of the research. I intend to carry these interviews out **between March and May** – I am very aware that the period around Christmas is a busy time!

I would like to visit to your house twice in all. The initial visit would be to

- discuss the research
- explain how the interviews would be carried out
- and answer any questions you have.

This will also give me an opportunity to discuss your child with ASD's communication skills, and discuss with you how best to interview him/her, or gauge his/her opinions about the respite care placement. This visit will probably take about an hour, and it would be helpful if everyone potentially involved in the interviews can be there.

I will carry out the interviews – which I would like to record on tape – on the second visits, which should occur within a couple of weeks of the first. I hope to be able to interview children and parents separately, to enable both parties to speak freely, and to allow any differing opinions to emerge. However if children want a parent with them while they are interviewed, that's fine. Equally, brothers and sisters can be interviewed separately, or can choose to be interviewed together.

Please complete the attached form indicating that you are still willing to participate in this research study, and return it to me in the enclosed envelope by **Friday 20 November 2004**. I will then phone you up to arrange an initial visit shortly after the New Year (*NB. I will confirm this visit to you in writing, and also send out some letters for your children, explaining the research to them, in the New Year*).

If you no longer wish to participate, please indicate this on the attached form.



If you wish to contact me to clarify anything, please contact me on *phone number* (office) or *phone number* (mobile).

Thank you in advance,

David Preece

**Agreement form**

I consent to be interviewed as a part of this research project (*can all adults in the home please sign here*)

1. ....

2. ....

My/our children are willing to be interviewed and I/we give consent for this

.....

My/our contact phone number is .....

The best time to ring us is .....

**OR**

I no longer wish to participate in this research project.....

Please return this in the envelope enclosed by **Friday 20 November** to:

**David Preece**

*Address here*

## Appendix 8 Family interviews: letter to older child with ASD

*NB. The original, as sent to parents, was written printed on local authority headed paper*

### Research with families with children with Autistic Spectrum Disorders: information for children with ASD, aged 11+

Dear *name of child here*



Hello.

My name is David Preece.

I work with children who have Autistic Spectrum Disorders in *name of local authority here*. I am also studying at Birmingham University.

I am carrying out a project talking to families where there are children with Autistic Spectrum Disorders. I hope to be talking to parents, brothers and sisters, and the children with Autistic Spectrum Disorder themselves.

I want to find out about:

- what you like to do
- your family
- any activities you enjoy or places you like going to
- any extra help or things you'd like to do

I hope that this project will help us to help other families with children with Autistic Spectrum Disorder.

Your mother has already agreed that the family will take part in this study. I will be coming to your home once or twice, to ask some questions, and record the conversation on tape.

You can ask me questions about the project at any time. My phone number is *phone number here*. I won't tell your parents what you said, unless you ask me to.

When I write the research up, all names and places will be changed, so no one reading it will know who I have talked to.

Please read the Agreement form attached to this letter. If you are happy for me to come and see you, please write your name at the bottom of the form.

If you don't want to be in the project, that's fine as well. You don't have to be - even if the rest of your family is.

Bye for now

David Preece

-----

## **RESEARCH WITH FAMILIES WITH CHILDREN WITH AUTISTIC SPECTRUM DISORDER**

### **Agreement Form**

- I have read the letter
- OR
- The letter has been read to me.
- I would like to take part in the project.
- I know I can leave the project at any time if I change my mind.

NAME.....

OR

Signed on behalf of .....(child's name)

By.....

## Appendix 9 Family interviews: letter to younger siblings

*NB. The original, as sent to parents, was written printed on local authority headed paper*

### Research with families with children with Autistic Spectrum Disorders: information for brothers and sisters aged 7-10



*Hello name of child here*

My name is David Preece.

I work with children who have Autistic Spectrum Disorders in *name of local authority here*. I am also studying at Birmingham

University.

I am carrying out a project talking to families where there are children with Autistic Spectrum Disorders. I hope to be talking to parents, brothers and sisters, and the children with Autistic Spectrum Disorder themselves.

I want to find out:

- what you do together
- how you get on together
- any help you would like to have

I hope that this project will help us to help other families.

Your mother has agreed that the family will take part in this study. I will come to your home once or twice. If you want, you can draw some pictures and record tapes.

You can ask me questions about the project at any time. My phone number is *telephone number here*. I won't tell your parents what you said, unless you ask me to.

When I write the research up, all names and places will be changed, so no one reading it will know who I have talked to.

Please read the Agreement form attached, or get someone to read it to you. If you are happy for me to come and see you, please write your name at the bottom of the form.

If you don't want to be in the project, that's fine as well. You don't have to be - even if the rest of your family is.

Bye for now

David Preece

## RESEARCH WITH FAMILIES WITH CHILDREN WITH AUTISTIC SPECTRUM DISORDER

### Agreement Form

- I have read the letter  
OR
- The letter has been read to me.
- I would like to take part in the project.
- I know I can leave the project at any time if I change my mind.

NAME.....

OR

Signed on behalf of..... (child's name)

By.....

## **Appendix 10 Ascertaining the views of children with ASD: practicalities and problems**

### **A10.1. Introduction**

Obtaining the views of disabled children, both about their experience of daily life and about the services in place to support them, is a requirement of legislation and policy both national – such as the *Children Act* (Department for Education and Skills, 2004) and *Aiming High for Disabled Children: Better Support for Families* (HM Treasury/Department for Education and Skills, 2007) and international – for example, the *Convention on the Rights of Persons with Disabilities* (United Nations, 2006). A body of literature is growing on the practicalities of gathering the views of disabled individuals. Visual communication supports such as ‘Talking Mats’ (Cameron and Murphy, 2002; Murphy and Cameron, 2008) have been developed and have been used successfully with a range of children including those with mild learning disabilities (Bell and Cameron, 2008), multi-sensory impairment (Taylor, 2007) and profound and complex learning needs (Whitehurst, 2006). The potential to attribute opinions to individuals (Brewster, 2004) has been identified, particularly with regard to those who have no speech, or whose disabilities are so profound that attempts to identify their views are highly inferential (Ware, 2004); though they are not always accurate sources of information (Reid and Green, 2002), the use of peers or familiar adults in the individual’s life as proxy informants can be helpful in such situations (Taylor, 2007; Ware, 2004).

Though this body of research is rapidly developing, only a small number of studies have focused specifically upon the experience of children and young people with ASD (Beresford and Tozer, 2003; Beresford *et al.*, 2004; Preece, 2002). This literature is supplemented by a growing number of published personal accounts (Gerland, 2003; Jackson, 2002; Sainsbury, 2000). These provide valuable insights into the lives of people with ASD, but have been

mainly written by more able individuals, whose experience and understanding may be different from that of children with ASD across the range of ability. Research into the experience of those with ASD is important as recent studies suggest its prevalence may be as high as 1% of the population (Baird *et al.*, 2006). However, while the literature on the experience of their parents is extensive, the children's own experience – both of daily life and of social care support – remains under-researched, and the literature on the practicalities of undertaking research to ascertain the views of children with ASD remains limited.

In this Appendix I discuss in depth the process and methods which were used to obtain data from the children with ASD within this study, as well as highlighting the problems and limitations encountered within this process. An article based upon this Appendix is in press for the British Journal of Learning Disabilities.

#### **A10.2. The children**

In total, ten boys and four girls with a diagnosis of an ASD aged between 7 and 18 years took part in this phase of my doctoral research (for the sake of brevity, the words 'child' and 'children' are used to refer to the children and young people participating). Details of their ages, diagnoses and their families are given in Table A10.1 below. It should be noted that the children had a wide range of abilities and impairments, and that ten attended schools for children with moderate to severe learning difficulties. The sample included two sibling pairs: a 14 year old boy with Asperger syndrome (AS) and his 12 year old brother with ASD, and a 15 year old girl with ASD and her 13 year old brother with semantic pragmatic disorder. One child came from a Pakistani family. The remaining children were white British, reflecting the



low incidence of families from minority ethnic backgrounds in this shire county. They lived in a range of locations around the county, including urban, suburban and rural settings.

### **A10.3. Issues regarding consent**

Parental consent having been given, consent from the children themselves was sought via an individualised letter explaining the research and an initial visit. The children were made aware that they did not have to participate even though other family members would be doing so. Due to the potential for acquiescence (Rodgers, 1999) I treated the child's level of engagement in the initial visit, and the opinions of their parents and siblings about their responses, as secondary indicators of consent. It is recognised that this meant that consent sometimes hinged on the interpretation of the child's behaviour or responses by other family members; however, this was a necessary decision in seeking to involve these children. Furthermore, consent was understood as being a continuous process rather than a one-off agreement (Marchant *et al.*, 1999), and it was accepted that consultation sessions would stop when the children wished or if they showed distress.

Two children (Natalie and Patrick) had no speech, could not read or write, found social interaction extremely stressful, and had limited intentional communication, largely restricted to motoric gestures or the use of pre-symbolic objects (Ockelford, 1993). Middleton (1999) and Morris (1998b) suggest that such children are both practically and ethically best included in research by 'being with them': therefore they participated through the first author observing them at home and in their short breaks settings. The observation of Patrick at home ended within ten minutes, as he was distressed to find the researcher there when he returned home

from school; by contrast, he accepted the researcher's presence in his family link placement without demur.

**TABLE A10.1      Details of Participants**

Name	Age (yrs)	Diagnosis	Details
<b>Families using short breaks</b>			
Michael A	14	Asperger Syndrome	Lives with parents (father diagnosed with AS) and 12 year old brother with ASD in small town. Attends special school.
Ian A	12	ASD	Lives with parents (father diagnosed with AS) and 14 year old brother with AS in small town. Attends special school.
Peter B	16	ASD with Severe Learning Disabilities	Lives with mother and her partner in rural village. Attends special school.
Patrick C	7	ASD	Lives with mother in suburban setting. Attends special school.
Natalie D	10	ASD	Lives with parents and 13 year old brother in rural village. Attends special school.
Benjamin E	15	Semantic pragmatic disorder	Lives with mother and 13 year old sister with ASD in county town centre. Attends mainstream school.
Susan E	13	ASD	Lives with mother and 15 year old brother with semantic pragmatic disorder in county town centre. Attends special school.
<b>Would-be users of short breaks</b>			
Sarah G	18	ASD	Lives with parents and 9 year old brother in rural village. Attends agricultural college.
George H	15	ASD	Lives with mother and 18 year old sister in suburban setting. Attends special school.
Andrew I	8	ASD	Lives with parents and 2 sisters (aged 16 and 15) in rural village. Attends special unit in mainstream school.
Ibrahim J	9	ASD	Lives with mother, 2 brothers and sister in county town centre. Attends special unit in mainstream school.
<b>Families who do not wish to use short breaks</b>			
Amanda K	10	AS	Lives with mother in large village. Attends mainstream school.
Bill M	12	Autism	Lives with mother and 18 year old sister in rural village. Attends special school.
Ethan N	16	Autism	Lives with foster parents and 2 foster brothers in suburban setting. Attends mainstream school.

#### **A10.4. Data collection**

Data were collected from the children with ASD (as it was from their parents and siblings) in three areas of investigation: their day to day experience, including their likes and dislikes; their experience of social workers and short breaks services; and finally, their wishes.

Twelve children were verbal, though many also used communication supports such as daily schedules (Mesibov *et al.*, 2005), photographs, and the Picture Exchange Communication System (Frost and Bondy, 2002). All of these children were interviewed in their own homes. Six children were interviewed alone; in the other six cases a parent was present, at either the child or parent's request.

#### ***Introductory letters***

Where parental consent had been given for the children with ASD to take part in the interviews, letters explaining the research to the children were attached. Two versions of the letter were prepared: one for children over 11 and one for younger children (see Appendix 9 for an example of a letter to an older child). The purpose of the letter was to introduce me to the children, to outline the purpose of the study and to explain about participation. Each letter was personally addressed to the child, and included a photograph of me. In order to ensure that I look how the child expected I had to ensure that the length of my hair was similar to that in the photograph, that I remained clean-shaven throughout the interview period, and that I wore the same jacket and shirt for each interview.)

Each letter explained that the child's parent(s) had already agreed to participate in the study, and that I would be visiting the home, to ask some questions and record the conversations.

They were told that they could ask me questions about the research at any time, in confidence (I gave my work telephone number) and that even though their parents were going to be interviewed, they themselves did not have to be, and they could withdraw from the research at any time. Finally I told them that when the research was written up it would be anonymised. However I could not promise the children full confidentiality, as I did not know at the time the letter was sent how the interviews were to be conducted and whether children would be interviewed in private or with their family.

The letter had a short form attached, to be signed either by the child or on their behalf, to signify that they were willing to participate in the research. This letter was collected from the family at the initial visit.

#### **A10.5. Initial visit**

The initial visits were carried out between 8 March and 21 April 2005. These visits were arranged by telephone for times convenient to the families; and children's consent letters (if children were to be interviewed) were sent out as soon as the date was arranged. One initial visit had to be rescheduled as the child with ASD was ill, and one visit began about an hour late as a parent had a doctor's appointment: apart from these, all initial visits occurred at the time and date arranged.

After clarifying issues regarding consent and willingness to participate (see above), the second part of the initial visit focused on how each specific family was to be interviewed. All of the families were willing to be recorded, and we discussed whether they would be interviewed individually or in groupings. None of the parents or siblings had any hearing

impairments or disabilities impacting on the interview process, nor were any interpreters needed. Significant discussion also took place with regard to adaptations needed to make the interview process more appropriate for the child with ASD.

Two of the families (the F and L families) were not willing for their children to be interviewed. As discussed above, two further children, Patrick C and Natalie D, were included in the consultation process by being observed. Where children with ASD were to be interviewed I discussed with the families whether communication supports – such as photographs, symbols or timetables – should be used. In four cases, the young person's parent(s) made the decision that they did not wish visual supports to be used, or that they felt their child did not need visual supports. In these cases, the parent(s)' wishes were respected, and no visual supports were used. With regard to eight of the children it was agreed that visual supports would be used. These are described more fully below.

Where children with ASD were to be interviewed, I spent some time with them during this initial meeting engaging with them in a preferred activity. This varied from child to child. With Ethan N, I looked at a book about cars; with Peter B, I played Uno sitting on the living room floor; while Amanda K introduced me to the family's pets.

Finally during the initial visit, I briefed all family members who would be interviewed about the areas of investigation, set a time for the interviews (about a week later) and left accessible outlines of the interview structure with them, to maximise their comfort and confidence and give them time to think about the topics under consideration. This was important for all family members, but particularly so for the children with ASD, where previous research has

identified that they have a poor event memory (Bowler *et al.*, 2000; Capps *et al.*, 1998; Lincoln *et al.*, 1995). Flack *et al.* (1996) identify that children with ASD

*“are likely to have difficulty saying what they did at school when asked by the parent in the evening and an equal difficulty saying what they did the evening before or even what they did just before coming to school.”* (p89)

Other problems identified in the communication of children with ASD include the phenomenon of recency – in which the person always chooses the last in any series of options: Lincoln *et al.* (1995) have shown that people with ASD demonstrate a significant recency effect. Furthermore, it has been identified that children with ASD have characteristic difficulty in understanding narratives (Bruner and Feldman, 1993) which can impact significantly upon their ability to participate in an interview about their experience, as

*“...in order to talk about past events, the child needs to understand how narratives are constructed as well as to have the personal memory to recall the event.”* (Jordan and Powell, 1995, p61)

On the other hand, children with ASD perform well in cued memory tasks (Bennetto *et al.*, 1996; Boucher and Lewis, 1989; Mottron *et al.*, 2001). It was intended that briefing the children with ASD could enable them time to think about the questions upon multiple occasions over a period of time between the first and second visits and might reduce the effect of these characteristic memory difficulties, and help improve validity.

## **A6. The interview visit**

Interviews were conducted at a second visit, about a week after the initial visit. The timescale was kept short so that the event would be relatively fresh in the child with ASD's memory. In some children were given a visual cue that the interview date was coming up by putting my photograph from the introductory letter on the child's calendar or schedule (Schopler *et al.*,

1980). It also helped some children cope with the interview process if they could see that it was preceded and followed by preferred activities. In the photograph below, Andrew I's schedule showed that he would have a drink and crisps before the interview, and that he could play with his hand-held computer game when the interview was finished (see Figure A10.1).



**Figure A10.1. Andrew I's schedule for the afternoon of his interview**

### ***The interviews***

Each interview comprised three distinct but interlinked phases (Gillham, 2000). In the initial introductory phase I reintroduced myself to the interviewee, and engaged in introductory rapport building. Many of the children with ASD were highly interested in the tape recording equipment, and enjoyed participating in the sound-checking process, even playing musical instruments and/or singing in some cases. During the main body of the interview, the interviewee gave their answers to the questions on the interview schedule that they had been

previously given. The interviews had no fixed time length – rather I allowed each interviewee to talk for as long as they wished. Interviews lasted between 15 and 40 minutes, with an average of 25 minutes. The children were offered the opportunity to draw, as this has been previously shown to be an effective tool in engaging with children with learning disabilities and eliciting their views (Marchant *et al.* 1999, 2001). However none chose to draw pictures to illustrate their feelings – though one child did present me with a drawing of a train. Two children were strongly opposed to drawing at all, and their parents told me that they did not ever draw. Finally, at the end of the process, the tape recorder was switched off, the researcher ascertained whether the child wanted a copy of the interview transcript or of the tape, and the process was concluded. In some cases the child wanted to listen back to the tape, to listen to what they had said. A cassette or transcript was sent to the each interviewee within a month. All interviewees were given the opportunity to delete responses from the record, or to provide any additional information.

### ***Photographs and visual supports***

Though drawing was not used as a tool to elicit data during the data collection process, photographs and visual supports were extensively used in interviewing the children with ASD. Four parents did not want visual supports to be used in their children's interviews, considering them unnecessary. In the other eight cases, individualised visual supports were made for each child to address their individual communication needs. These were developed in consultation with their families and where possible the children themselves, and were used extensively to support the data collection process. Powell and Jordan (1992) suggest that photographs can serve as useful '*aides-memoire*' to children with ASD. Photographs – of people, places and activities – to act as prompts were suggested in all the seven instances



where parents felt that the use of supports would be beneficial (with brothers and sisters, and the children with ASD themselves, contributing enthusiastically in the process of identifying what would be useful prompts). Individualised sets of photographs were collated for each of the children. Where photographs included the children (for example undertaking activities at short breaks) they were taken by a member of the short breaks staff to minimise intrusiveness (Watson *et al.*, 2006). For Ian A, who attended the residential short breaks service, the set of photographs comprised his bedroom at the residential home; various leisure activities on offer there (including activities that were identified as being preferences and ones he did not like); members of staff at the home; other children who stayed for short breaks at the same time as him; his school; places that he went in the community (park, cinema, fast food restaurants); and his social worker.

In total, over 100 photographs were taken to support the interviews undertaken with these seven young people. These items were used differently with different children. In some cases they were shown to the child as a prompt for discussion. Other children needed to manipulate them concretely: for example, placing photographs or schedule cards into piles to identify their attitudes. The choices available were differentiated for each child depending on their understanding. Some children had ‘I like’ and ‘I don’t like’ piles; others had a third ‘I don’t care’ pile if they were able to be more precise in describing their attitudes. Two examples of tools developed to identify preferences are shown below. Peter B identified his likes and dislikes in a manner similar to the ‘Talking Mats’ approach (Cameron and Murphy, 2002) (Figure A10.2 below), while Ian A identified his attitudes using a sorting task similar to tasks that he used in the classroom (Figure A10.3).

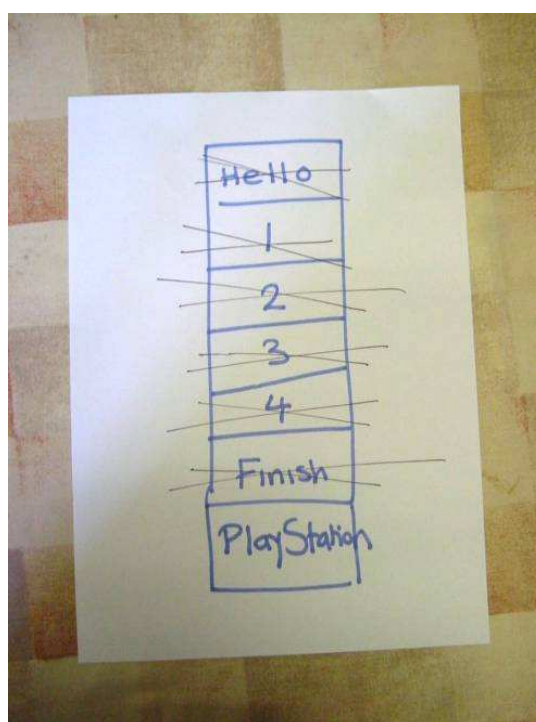


**Figure A10.2. Peter B's mat for identifying preferences.** In this case, identifying preferred staff at the residential short breaks home.



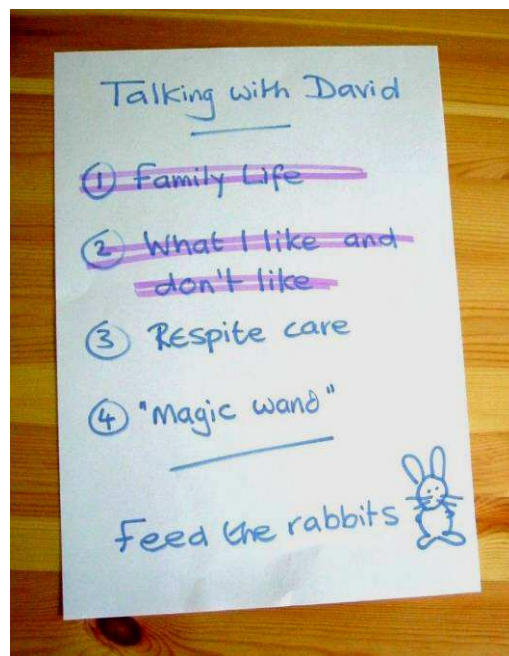
**Figure A10.3. Ian A's sorting task.** Identifying his attitudes towards activities on offer in the short breaks setting.

In addition, TEACCH schedules and ‘work systems’ (Mesibov *et al.*, 2005) were used to visually identify for young people when the interviews were taking place; the sequence of events in the process; that the process was progressing to a conclusion; and that a preferred activity would take place afterwards. Schopler *et al.* (1995) suggest that presenting this information visually can help militate against the tension that can arise in an individual with ASD if they feel that an activity seems never-ending due to their time perception difficulties. These again were individualised as needed for the young people. Andrew I’s schedule showing the sequence of events around the interview is shown above in Figure A10.1. In Michael A’s case, I wrote out a work system at the start of the interview, showing him the sequence of events: that we would say hello, that I would ask him questions in four areas, that the interview would finish, and that PlayStation would come next (see Figure A10.4).



**Figure A10.4. Michael’s work system**

PlayStation was his preferred activity and we had agreed with his mother that, at the conclusion of his interview he could go to his room to play on his PlayStation. The paper lay on the table, facing him, throughout the interview. As the interview progressed through its different phases, I drew a line through the phase that had been completed. Amanda K's work system was similar to Michael A's, but the areas under investigation were identified and she crossed them through with a felt pen of her choice. Again the interview was followed by a preferred activity, in this case feeding the rabbits (see Figure A10.5).



**Figure A10.5. Amanda K's work system**

Other children needed this information to be presented in a more concrete form: for example, in Andrew I's case, removing numbered cards from a board placed in front of the child to 'count down' to a photograph of a favourite video (which he would watch at the conclusion of the interview)

### **A10.7. Observation**

Patrick C and Natalie D were observed by the first author at home and in their short breaks settings. Contemporaneous notes were made regarding activities undertaken by the children, the children's willingness to undertake them and seeming enjoyment of them, the children's affect and their interaction with others, both adults and other children. These notes were discussed afterwards with parents and short breaks staff to check for accuracy.

### **A10.8. Triangulation**

Volkmar *et al.* (1997) have challenged research that considers data such as observation or comment in isolation; furthermore Ware (2004) and Taylor (2007) highlight the limitations of observation and proxy reports and the importance of taking account of a wide range of sources of information. In this study, the interview and observation data were supported by multiple data collection techniques – semi-structured interviews with other family members, short breaks staff and social workers; reading documentary evidence, including social work assessments, children's files and daily notes – enabling triangulation to be undertaken (Robson, 2002).

### **A10.9. Issues and problems in researching the views of children with ASD**

Access to the perspective of children with ASD is important, and it is identified within Chapter 6 that relevant and valuable data in this under-researched area were elicited. The children's positive view of family life contrasts with both that of other members of their own families in the larger study and with that of families with children with ASD in general (Koegel *et al.*, 1992; Randall and Parker, 1999). The picture emerging of their solitary evenings and difficulties at school complements what is already known from personal

accounts (Aston, 2000; Sainsbury, 2000). Their uncertainty about their social workers mirrors that of service users in other areas of social care (Lymbery, 2001) and highlights a clear need for social workers to engage more effectively with the disabled children on their caseloads and the wider family. Furthermore, whereas previous research on short breaks and children with ASD has predominantly identified areas of difficulty (Anderson, 1996; Sargent, 1995), the identification by these children of both positives and negatives suggests a more balanced range of experience, mirroring the findings of Radcliffe and Turk (2007).

However, the responses obtained to our questions about wishes highlight some of the difficulties inherent in carrying out research of this type with children with ASD. Beresford *et al.*, (2007) found, when interviewing a group of children with ASD, that most could not realistically discuss their hopes and wishes regarding the future. Beresford *et al.* (2004) further suggest that questions about wishes and aspirations may be meaningless or even threatening for children with ASD, given their concrete thinking, dislike of change, lack of personal insight and difficulties in conceptualising future events. I asked the children

*“If you could have a magic wand and wish for anything in the world, what would you wish for?”*

with a view to comparing responses with Connors and Stalker (2003), where the same question was asked. However, the question proved ineffective: Sarah replied,

*“I’d wish I could be a wizard. I’d be able to cast magic spells... changing people into frogs!”* (Sarah G)

while Michael said

*“I would...um...um...um...I would wave the magic wand and produce one thousand quid!”* (Michael A)

Even when the wording was simplified, answers revealed the difficulties children with ASD have in this area.

Interviewer: *If you could have any wish, what would you like to happen?*  
Ethan N: (silence).  
Ethan's foster-mother: *Anything, Ethan, anything you like...*  
Ethan N: *Don't know.*  
Interviewer: *Are there any things you wish you could go and do?*  
Ethan N: (shakes head).  
Interviewer: *Nothing?*  
Ethan N: (laughs). *No.*

This highlights the need to ensure that all aspects of the methods of data collection are appropriately differentiated to address the reality of the children's experience and to take account of the impairments of ASD. Such children characteristically experience difficulties in a number of areas that impact on a social communicative process such as consultation. These include problems in social interaction, in communication, in emotional understanding and in memory. At the same time I as a researcher faced problems in areas such as the use of visual supports and undue parental influence. I believe it is vital that these problems are acknowledged, as not to do so would present an unrealistic impression of the consultation process. The major issues that I and the children faced are discussed below.

#### **A10.9.1. Difficulties arising from impairments in social interaction**

Wing and Gould (1979) describe impaired interaction with both adults and peers as being characteristic of children with ASD. They suggest a continuum of social responsiveness, from 'classic' autistic aloofness through individuals who will respond to – but not initiate – social interaction, through to those who seek social interaction but are socially naïve and do not 'get it right'.

All children participating demonstrated impaired interaction. Patrick C and Natalie D were effectively non-verbal and extremely autistically aloof: their only observed initiated interactions with others comprised seeking known adults – at home and in their short breaks settings – to get their needs met: to gain access to a toy or a DVD, to get food, or to go outside, for example. Both rejected interaction from others, and Natalie D became distressed, shaking her hair and rocking, if attempts persisted. They participated in the consultation process only as the subjects of observation.

Most of the other children responded to a greater or lesser extent to social interaction, but were cue-dependent and did not initiate interaction or communication. Siegel (1996) and Bogdashina (2005) describe how children with ASD can exhibit delays in processing language. Some children seemed to take longer than usual to respond to questions. Since their parents were present during the interviews, this resulted in the adults often butting in, which further reduced the child's opportunities for interaction. Ian A seemed uncomfortable being interviewed and moved closer to his mother as the process went on.

A small number were socially active within the interview setting, but were immature, gauche and socially inappropriate. Amanda K, when asked about her skills, sat on the floor with her legs behind her head. Ibrahim J climbed onto the researcher and started scratching his head.

His mother explained:

*“When somebody has less hair...like you still have got hair, but my dad or my brother, they are completely bald, and I think he doesn't understand that people lose their hair with age and he just...something happens to his hand, and he just wants to scratch people. He does that. And when I see somebody like that, I get alerted anyway, that he might do that, because he finds it, I don't know, funny or amusing or what that he likes to do that...” (Asma J)*



### **A10.9.2. Difficulties arising from anxiety at communicating**

Groden *et al.* (1994) have shown that individuals with ASD can experience anxiety and distress at communicating; and that they can also have problems understanding the intentions of others (Flack *et al.*, 1996) only exacerbates their difficulties. Most children in this study displayed anxiety in this area. Patrick C and Natalie D engaged with others only motorically, in order to get their needs met. Ibrahim J ran out of the room during his interview; Bill M ran into the kitchen or over to his mother or sister several times. Where parents were in the room during the interview, children sometimes sought support in communicating from them.

Interviewer:	<i>What don't you like?</i>
Ian A:	<i>Well the ...glue things... and...(indecipherable)...</i>
Andrea A:	<i>Say again.</i>
Ian A:	<i>Uh...can you help me?</i>
Andrea A:	<i>OK, OK.</i>
Ian A (louder):	<i>Help me!</i>
Andrea A:	<i>Tell me again.</i>
Ian A (louder still):	<i>Please!</i>

### **A10.9.3. Difficulties regarding use of language**

Capps *et al.* (1998) identify that verbal children with ASD may have problems in conversing; Howlin (1998) and Jordan and Powell (1995) describe language problems experienced by children with ASD, including limited and very concrete language, echolalia, and idiosyncratic language use. These factors impacted on the consultation process. Many responses were limited to single words or short phrases.

Interviewer:	<i>Who's really important to you? Who do you love the most?</i>
Andrew I:	<i>Jane.</i>
Interviewer:	<i>Who's Jane?</i>
Andrew I:	<i>My sister.</i>
Interviewer:	<i>And what do you do with Jane.</i>
Andrew I :	<i>Everything.</i>

Echolalia was particularly notable in one young man's answers.

Interviewer: *What do you like doing at home?*  
Bill M: *What do you like doing at home?*  
Interviewer: *What do you like?*  
Bill M: *What do you like?*

Idiosyncratic indistinct speech was noted in three interviews, which made the interview and transcription processes problematic.

Interviewer: *What do you do with your dad?*  
Ian A: *My dad... (indecipherable)... nice presents...  
(indecipherable) ... and not get cross...*

#### **A10.9.4. Difficulties concerning preferences and emotions**

Powell and Jordan (1997) identify the problems children with ASD experience in evaluating their emotions and using them to evaluate situations. As in previous research (Preece, 2002) the children could best identify preferences with regard to concrete topics such as food.

*"Here's my list of what I don't like. Mushrooms, pickled beetroot, eggs, anything picked, gherkins or cucumber, Golden or Cinnamon Grahams, onions, radish or horseradish, lemon, mint sauce, pretzels, too much salt and swede. And the foods I like, really, really love are tortilla wraps, spaghetti carbonara – I always say calabrana – spaghetti carbonara, tortellini, pasta, raspberries, omelette – and that's weird, 'cos I hate eggs – um, sausages, chocolate, chilli, nachos, honey gammon and lasagne."* (Amanda K)

However, identifying emotions regarding people – or reasons why they liked or disliked them – was more difficult, as is shown in the two following extracts from interviews with George H and Peter B.

Interviewer: *What's the best thing about your sister?*  
George H: *Um...um...*  
Interviewer: *Is there anything you like about your sister?*  
George H: *Um...she's always fine.*  
Interviewer: *How about your mum? What's the best thing about your mum?*  
George H: *Um...um...*

Interviewer: *Is there a best thing?*  
George H: *Um...she always cleans our house.*

Interviewer: *Who's important to you? Who do you like a lot?*  
Peter B: *I think that's a hard question.*

This difficulty was also apparent when the children were asked about daily life.

Interviewer: *What do you do to have fun? Are there things you do as a family that you like?*  
George H: *I don't know.*

Interviewer: *Are there any things that you have to do that you don't like doing?*  
Michael A: *Um...sometimes at school you have to do subjects, like topics that aren't really that interesting.*  
Interviewer: *Which subjects at school don't you like?*  
Michael A: *Um...can't really think.*

#### **A10.9.5. Poor personal memory and overselectivity**

As indicated earlier, problems with personal event memory and appreciating narrative, makes it difficult for individuals with ASD to reflect on and express their experiences. Jordan and Powell (1995) refer to the 'tunnel attention' of children with ASD; Pierce *et al.* (1997) and Rosenblatt *et al.* (1995) describe this as 'overselectivity', whereby they fail to respond to, or even to notice, many components of their environment. The impact of these problems is shown in the following excerpt from the interview with Peter.

Interviewer: *What's the taxi journey (to school) like? Does that take a long time?*  
Peter B: *Yeah.*  
Interviewer: *Are you in the taxi on your own, or with anybody else?*  
Peter B: *Lots of people.*  
Interviewer: *Lots of people...do you know their names?*  
Peter B: *No.*  
Interviewer: *No... So when you're at school...Who's your teacher, at the moment?*  
Peter B: *Why don't you know this one?*

Interviewer: *Do you know your teacher's name?*  
Peter B: *No. Why don't you know it though?*

#### **A10.9.6. Issues concerning visual supports**

The use of visual media is recognised as an effective way in which to engage with children (Christensen and James, 2000); and Powell and Jordan (1992) have suggested that photographs can serve as useful tools to help children with ASD remember events. Within this study, the use of photographs was helpful in eliciting more complete answers from children.

Interviewer (shows photo of computer at short breaks residential home): ... *the computer?*  
Susan E: *Yeah, I play on the computer.*  
Interviewer: *What games do you play on the computer?*  
Susan E: *I play...sometimes I play Spider Solitaire. And sometimes I play just the ordinary Solitaire...and a game called Free Cell.*

It was also clear that some children enjoyed the process of looking at and discussing the photographs.

Peter B: *Have you got any more photos?*  
Interviewer: *No.*  
Peter B: *What am I going to have to do, then, if I want some more photos?*  
Interviewer: *I haven't got any more photos. They were just to see if they helped you remember things, or talk about things...*  
Peter B: *I can take some with my camera, if you want.*  
Interviewer: *Well, you could... Would you like more photos?*  
Peter B: *Yeah.*

The use of visual work systems – to show the passage of time, and identify that the process would be followed by a preferred activity seemed helpful: no children asked to end the interview early. Taking along examples of the visual systems children used in their short breaks settings was also helpful in enabling some children to talk about how they used them.

However the use of visual supports is inherently problematic, and consideration had to be given to the concreteness and literalness of the child's understanding. Whereas one child could look at their evening schedule – showing bath, supper and bed in pictorial format – and talk about what they did during those activities, another might interpret being given these symbols literally, and begin to undertake these activities. Furthermore, it is acknowledged that, although visual supports facilitated the communication process, they also potentially restricted discussion to the range of photographs or symbols offered to the child.

#### **A10.9.7. Parental influence on the child's answers**

Where children's parents were present during the interviews, the children showed a tendency to defer to them, particularly when visual supports were not used. In these interviews the children's responses were interrupted and influenced by the adult present.

Interviewer:	<i>What videos do you like?</i>
George H:	<i>Um...the same...</i>
Interviewer:	<i>Lord of the Rings?</i>
George H:	<i>Uh-huh...or DVD.</i>
Sandra H:	<i>What about funny ones? You like funny ones too, don't you?</i>
George H:	<i>Yeah...</i>
Interviewer:	<i>Which ones?</i>
George H:	<i>Er...</i>
Sandra H:	<i>Dodgeball...</i>
George H:	<i>Oh yes...Dodgeball...</i>

A particularly striking example of the impact of acquiescence, and the acceptance of routine, was shown by Peter B, who had been attending a residential short breaks service for ten years. At the interview's end, when asked if he had any questions for the researcher he said,

*"Why do I go there?"* (Peter B)

### **A10.9.8. Importance of triangulation**

The need for triangulation and the use of multiple data sources was highlighted several times, as the children's responses were often incomplete or inaccurate. For example, Sarah G proudly identified her ability to get ready for college independently.

Sarah G: *I have my breakfast, and get dressed, and get ready.*  
Interviewer: *Do you do all that by yourself?*  
Sarah G: *I do!*

However, triangulation with her mother identified Sarah's difficulties in this area – difficulties of which she was unaware.

Maggie G: *...and then she...I have to sort her clothes out, if she's got clean clothes...*  
Interviewer: *How much help does she need in the morning?*  
Maggie G: *When it comes to putting clean clothes on, I have to go and sort them out, 'cos she would put anything on. So I have to put suitable clothing out for her to wear...It could be the weather or it could be, well, trousers that were not suitable. Usually it's the weather...or totally mismatched colours, and things like that.*

### **A10.10. Concluding comments**

Undertaking these interviews as part of my doctoral research has added to the existing body of knowledge by giving a voice to the opinions of children with ASD with regard to family life and social care support. I fully endorse the suggestion of Beresford *et al.* (2004) that it is important to share not only the results obtained in research projects but also the problems and setbacks encountered. In this spirit I have prepared this appendix so that in this doctoral thesis I share not only what I learned from the children, but also the issues that I faced in carrying out the research, and the tools and processes that helped me complete it. The findings reported within the main thesis and this appendix are of course relevant to these children in this place

and time, and it is not suggested that generalisations should be drawn from this study. However I hope that my experience will be of use to others carrying out research in this field.

## Appendix 11: Family interviews: final codebook

### Family Structure

- ***Membership characteristics***
  - Single parent
  - Two parents
  - Extended family
  - Income
  - Physical health
  - Mental health
- ***Cultural beliefs***
- ***Ideological style***
  - Beliefs about disability
  - Religion
  - Science
  - Fate

### Family Interaction

- ***Subsystems***
  - Parents
  - Siblings
  - Extended family
  - Extra-familial
- ***Cohesion***
  - Interdependence
  - Independence
  - Individual identity
  - Group identity
  - Enmeshment
  - Disengagement
  - Bonding
- ***Adaptability***
  - Adaptability
  - Chaos
  - Rigidity
- ***Communication***
  - Open communication
  - Closed communication
  - Negotiation

### Family Functions

- ***Economics***
- ***Daily care***
- ***Recreation***
- ***Socialisation***
- ***Self esteem***
- ***Affection***
- ***Educational/vocational***
- ***Spirituality***

### Family Lifecycle Stages

- ***Life before children***
- ***Child bearing and infancy***
- ***School age***
- ***Families with adolescents***
- ***Launching***
- ***Life after children***

### Impact of disability

- ***Positive impact of disability***
- ***Negative impact of disability***
- ***Anger at child with ASD***
- ***Anger at others***
- ***Guilt***
- ***Worry about future***
- ***Isolation***



### **Coping strategies (from Brief COPE)**

- *Active coping*
- *Planning*
- *Seeking emotional support*
- *Seeking instrumental support*
- *Positive reframing*
- *Acceptance*
- *Religion*
- *Venting of emotions*
- *Denial*
- *Helplessness*
- *Withdrawal*
- *Humour*
- *Substance use*
- *Self-blame*

### **Age**

#### **Short breaks**

- *Positive aspects of short breaks*
- *Negative aspects of short breaks*
- *Quality in short breaks*
- *Reasons for use*
- *Reasons for non-use*

#### **How family sees itself**

#### **Attributions re ASD**

### **Social workers**

### **Special Schools**

### **Mainstream Schools**

### **Understanding of ASD**

### **Asperger's**

### **Professionals**

### **Service Gaps**

### **Informal Support**

### **Formal Support**

### **Learning Disabilities**

## Appendix 12

## Family interviews: matrix of siblings' responses

Family	Short breaks: positives + quality	Negatives	Attitudes re SWs	View of family	Support provided	Coping/ adjustment	Shortfall
<b>Would- be service users</b>							
Caroline H	None identified.	<p>Feels her brother would dislike being away from family.</p> <p>She would dislike separation from brother.</p> <p>Would worry about how others were treating him.</p>	Has not met SWs, does not know their role.	<p>'He's just normal to me, because I haven't got any other brothers or sisters...'</p> <p>Upset when separated from brother. 'We're just always together so we're just used to that...'. Would like her brother to live with her when older.</p> <p>'If I wanted to do something, it would always be, someone had to look after George, someone always had to be there for George, sort of thing...so we can't all go off and do our own thing. Like we all have to sort out who's having George when and stuff...so that's a bit of a drag'.</p> <p>Very close, protective family.</p>	Provides some support. Takes brother into town, shopping.	Acceptance (2)	Age-appropriate sports activities: 'it's not fair on them being shut up all the time is it, in their rooms and stuff.'
Linzi I	<p><b>Positives</b></p> <p>'It was really nice to not have the responsibility of Andrew around.'</p> <p>Opportunity to go to cinema, eat out at Pizza Hut, relax.</p> <p>Treat for Andrew</p> <p><b>Quality indicators:</b></p> <p>Understanding of autism</p>	None identified	Has not met SWs. Doesn't really know what they are/what they do.	<p>Used to parents not being as supportive of things she does (athletics) as she'd like.</p> <p>Has missed out on chance to get into county team due to caring role (sister had exam).</p> <p>Feels life is harder now than when she was younger, as has more 'on her plate' with schoolwork etc.</p> <p>'It's quite hard, like, going out places with him as well, 'cos it can be pretty... it can be embarrassing sometimes, 'cos he shouts a lot, and all that...'</p> <p>'It's a little bit hard sometimes. My friends ask me am I upset, and they don't really understand if I explain it to them, but I guess it's made me stronger inside because it's given me something hard to cope with at a young age. So more difficulties that I face later on in life will, I guess, be easier to get over...and things like that, I guess.'</p>	<p>Provides direct care to Andrew (father at work, and mother often at work too).</p> <p>Parents both feel it causes some resentment.</p> <p>Mother says she is very reliant on both daughters.</p>	<p>Acceptance (3)</p> <p>Emotional support (1)</p> <p>Positive reframing (1)</p> <p>Withdrawal (2)</p> <p>Venting emotion (1) – father said will fight brother.</p>	<p>Support for sibs:</p> <p>'Sometimes I do get very stressed out about it, and just need someone to talk to, other than my family. Because they're often how I'm feeling...so it's difficult.'</p>

Jane I	<p><b>Positives:</b> Opportunity to have friends round, get homework done, go out shopping, do cleaning, chill, go to cinema</p> <p><b>Quality Indicators:</b> Staff personality + approach</p> <p>Good introduction process</p> <p>Child with ASD enjoying service (didn't want to leave).</p>	None identified	Has met first and current SWs. Feels they are there to help, e.g. re transport, wheelchairs, arranging Young Carers for sibs.	<p>Finds life very hard, with lots of stress.</p> <p>Would like to go to university, but concerned at how she will get on in GCSEs. Feels Andrew affects her ability to work: 'If I want to sit at the table and do homework or something, if I've got to write something, he'll come and like ruin the work and start ripping it up, or just crunching it; and he'll sit there and get food all over it; and he'll have a go at me and tell me that I shouldn't be sitting at the table to do homework, I should be doing it here, or wherever... And if I want to go on the computer, and do Internet research, or go on any of the revision websites, or anything like that, normally, when I want to go on the computer, he'll just hit me till I get off there.'</p> <p>'There's been times when we've been in the supermarket and that, and he'll do something, or start screaming, or anything like that, and people'll just... you can just hear them like sniggering or whispering and that... and I basically just ignore it, and give them really dirty looks, like yeah, whatever, I don't really care, because you don't know what the real situation is...'</p>	<p>Provides direct care to Andrew (father at work, and mother often at work too). Parents both feel it causes some resentment.. Mother says she is very reliant on both daughters.</p> <p>Jane see herself as being the one who's there for Andrew when he's fallen out with mother or sister.</p> <p>Says she provides more care than Linzi, as she goes out with her boyfriend.</p>	Acceptance (3) Helplessness (1) Withdrawal (1) – father said will go off and sulk	Need more short break services available
Yusuf J	Opportunity both for child with ASD and rest of family. He can do things he wants (swimming, McDonalds) and we can do things we want (bowling, going out for pizza)	None identified	Does not know if he's met the SW, does not know what she does.	<p>Restricted in what he/family can do, due to Ibrahim's behaviours.</p> <p>Ibrahim fights with Yusuf and Layla.</p>	Does not provide care for brother	Acceptance (2)	<p>More short breaks services – as before</p> <p>Group activities</p>
Layla J	Opportunity to go for pizza/to town		Has never met SW	-	Does not provide care for brother	Acceptance (2)	None identified

Imran J	Opportunity to go out to town		Has never met SW	-	Does not provide care for brother	Acceptance (1) Withdrawal (1)	Club – sports activities
Tom G	Would appreciate time with mum and dad alone – without arguments	None identified	Said he'd met SWs, but confusing them with sessional workers.	Sister can be argumentative; and it's not nice when she is distressed/self-harms or attacks others.		Humour (1)	Club – preferred activities (computers, drawing)
<b>Current users</b>							
Carl D	'I think it's all right. She obviously enjoys it, and we get some free time, so that's OK...We can go to like a proper restaurant, where you have to wait for food and that, 'cos we can't really do that with Natalie, we have to go somewhere like fast food places...Or we can go bowling, maybe, or something like that...noisy things. Theme parks and so on.'	Concerned about 'big kids' at the respite unit – worried they might hit her.	Has never met SW. Thinks their job is 'to make sure we're taking care of her properly.'	Very positive and accepting about family situation – 'normal' sibling niggles.  'Yeah, you sometimes get people looking at her if she's making a load of noise or something...well...I'm a bit bothered by it, but I'm not, like, really defensive, I just don't mind that much.'	Does not provide care for Natalie	Acceptance (3)	None identified
Hannah B	Give parents a break – opportunity to go out.  Give sister a break – knowing she wouldn't be annoyed by Peter.	No negatives identified.	Has met SWs. Not too sure what they do. Assumes they 'organise the respite care, and just organising services available. Maybe like	'I suppose it was hard 'cos...I mean, I've moved out now, but when I was living at home it was quite hard, 'cos obviously Peter would have his tantrums, and he'd come and annoy me when my friends came round and...just ...so it was hard, more hard on mum than me probably, 'cos she was the one dealing with him all the time.'  'I don't think I missed out at all'.	No longer lives with mother and Peter. Used to help with Peter 'quite a lot. In fact at one stage, I can't remember how old I was, Peter kind of favoured me to my mum. He just...there was one stage where he wouldn't...if I	Venting of emotions (1) Active coping (1) Acceptance (2)	"As a child, I should have been given a bit more information about what the future held. At the time you're told, Peter's autistic, you

	<p>Enable Peter to interact with others of his own age and to go out, i.e. fishing, country parks, meals (I remember thinking he does more than I do).</p>		<p>talking about schools that are available, things like that really...I'm not really too sure.</p>		<p>went out of the house he'd cry.'</p> <p>'I don't think I babysat him that much, just I mean at the weekend, when mum and dad would go out, I'd look after him. But I'd still make a point of doing things with him, like taking him to the shops, or taking him...he quite liked to come with me to see my friends..'</p>		<p>don't know what's going to be happening... I didn't know he'd never read or write. So...more information would have been better. And maybe meeting people of my age, who had a sibling who was autistic...'cos at the time, I didn't know and I still (twelve years later) don't now know anyone that's got a brother or sister with autism."</p>
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Non-wanters							
Cindy M	No positives identified.	<p>Would be concerned about him being away from home (other than at his dad's).</p> <p>Thinks he would dislike being out of his routine.</p> <p>Would worry about him.</p>	Can't remember ever meeting a SW or 'any of it'.	<p>'It's a bit difficult sometimes'.</p> <p>Does not feel she missed out on opportunities when growing up due to having brother with ASD.</p> <p>Gets annoyed by brother's obsessive, repetitive and intrusive behaviours.</p> <p>Goes out a lot in evenings – stays at home more when brother is staying with his father.</p> <p>Finds it difficult – gets angry and embarrassed when others stare at her brother.</p>	<p>If mum's got to go down the shop, I'll look after him. I don't really have him on my own, like at night or anything. I have had him on my own at night on the odd occasion, but like with that he...you either have to go to bed with him...so I have to go to bed when he wants to go to bed, which I don't like doing, obviously, and I have to watch on telly what he wants to watch...so that's why I don't really have him...I don't mind having him...</p>	<p>Acceptance (3)</p> <p>Withdrawal (2)</p> <p>Venting of emotions (1)</p>	

### Appendix 13 Adaptation modes of the families interviewed

As discussed in 7.3.4, the fourteen families interviewed displayed different modes of adaptation to the presence of disability within the family. These are plotted within Darling's (1979) typology of modes of adaptation below (Table A13.1). In the main body of the text, key points only are discussed. Within this appendix, a more detailed account of each family's adaptation to living with ASD is presented.

**Table A13.1 Positioning the families using Darling's (1979) typology of modes of adaptation**

<b>Mode of adaptation</b>	<b>Users of short breaks</b>	<b>Would-be users</b>	<b>Non-wanters</b>
<i>Normalization</i>	Natalie D's family Peter B's family	–	Amanda K's family James L' family
<i>Altruism</i>	Ian and Michael A's family Susan and Benjamin E's family	–	Ethan N's family
<i>Crusadership</i>	Kieran F's family	–	–
<i>Resignation</i>	–	George H's family Sarah G's family	Bill M's family
<i>Families that cannot be placed in this model</i>	Patrick C's family	Andrew I's family Ibrahim J's family	–

#### ***Normalisation***

Four the families have achieved normalisation. These are discussed below.

##### *Natalie D's family*

Ten year old Natalie's family lived in a large cottage in a small village where they were accepted and where neighbours were friendly. Although they received no support from extended family members, Natalie's mother – who did not go to work – had a number of

friends, some of whom had children with ASD and some who did not, who provided emotional support. Though her husband provided little support during the week (due to his job working for a motor racing team) and could be away from home for weeks during Grand Prix season he shared responsibility for child care when he was able. The family was relatively affluent, and were able to enjoy holidays in the Mediterranean each year.

The family had been using residential short breaks for five years. They had had some difficulties with regard both to the service and to social work support but felt that their current social worker was “*really, really good*” and that the short breaks were working well. Regular short breaks enabled Natalie’s mother to go shopping and undertake other activities that were hard to do with Natalie, as well as allowing both parents to spend quality time with each other and with Natalie’s thirteen year old brother.

#### *Peter B’s family*

Sixteen year old Peter B lived with his mother and her partner in a modern house on a housing estate on the edges of a large village in the north of the county. He had been attending the residential short breaks service for eight years, at his mother’s request, despite his father’s reluctance. Using this service enabled his mother to spend time with her two daughters and to focus on their needs and education. At the time of the interviews one of the girls was working abroad; the other maintained close contact with her family. Peter’s mother was also able to resume her employment as a hairdresser, and to have a social life, which led to her meeting her current partner.



She too had no support from her extended family, but was supported both by the short breaks service, her daughter and her ex-husband, with whom Peter had regular overnight stays. She used to attend support groups, but these “*fizzled out*”; nonetheless she maintained contact with some parents who became friends.

These two families achieved normalisation as a result of formal support. By contrast, Amanda’s and James’ families were able to access sufficient supports informally.

#### *Amanda K’s family*

Amanda K, a nine year old with AS, lived with her mother Donna, a fingerprint expert working for a neighbouring county’s police force, in a modern semi-detached house in a small market town. Having been told by social care services that there was a “*huge waiting list*” for services, Donna sought out and employed a childminder who lived around the corner. She was well-supported by her own parents, who moved home to live nearby on the same housing estate. She had no contact with her husband for almost nine years: he left home one evening and never returned. She believed in retrospect that he may have been on the autism spectrum himself. Nonetheless she maintained a good relationship with his parents, who were also supportive with regard to Amanda. Amanda enjoyed attending her mainstream school where she was doing well, and participated in weekend musical activities as well as caring for her many pets.

#### *James L’s family*

Seven year old James’ family, nuclear and extended, had adapted their lifestyle to accommodate his ASD. James’ father Simon was a golf professional. He worked flexible

hours, enabling him to undertake child care responsibilities and allowing James' mother to work full time as an office manager. The family lived in a modern detached house in the suburbs of the county town. They were well supported by James' paternal grandparents, who moved from Germany to live on the same housing estate. They had both James and his eight year old sister for an overnight stay every weekend, offered further support during the week, and took his sister away on holiday. Megan, James' mother, had a number of friends that she met during the diagnostic process at the local Child Development Centre with whom she enjoyed socialising.

These four families achieved some level of normalization only through the availability of appropriate formal or informal social support. The social worker's initial assessment of Natalie's family – carried out in January 1999, when the family had no support – identified that the family was under great strain, isolated, and that her brother was missing out on parental time. Peter's mother was also highly stressed, and described Peter's behaviour when he was younger as "*horrendous*".

Diagnosis was a crucial catalyst towards normalization for Amanda's family. She was not diagnosed until the age of seven, and before this her violent behaviour towards others had led to her exclusion from nursery and school. Amanda was self-harming and saying that she wanted to be dead, and child protection concerns had been voiced with social services. When Amanda was diagnosed with Asperger Syndrome, and appropriate supports were put in place at school, her behaviours became explicable, and her mother was able to construct her support network.

James' family were enabled to live as normal a life as they did by the decisions made by James' father and paternal grandparents. Simon's ability to work flexibly enabled James mother Megan to return to work; but when the family completed the survey in late 2003, they identified that they had no social life as they were unable to find a childminder who would look after him. This situation only improved when James' grandparents moved back to England.

### ***Crusadership***

Before and after diagnosis, families generally engage in a process of seekership: initially seeking a reason for the child's behaviour, then seeking appropriate school placements and support. By mid-childhood most families have ceased this process of seekership. However some families, due to limited opportunities or inappropriate services, adopt a mode of crusadership, or prolonged seekership (Seligman and Darling, 1997). In some cases families can be triggered into this mode at times of change or transition. This is what occurred with regard to Kieran F's family.

### ***Kieran F's family***

Kieran F, who was eleven years old and had AS, lived with his mother, stepfather and fifteen year old sister in a small terraced house in the heart of a large village in the north of the county. Kieran's mother and stepfather, Gwen and Bob, were Born Again Christians, and church attendance was a focal activity for the family. Gwen and Bob were both unemployed, and Bob was physically disabled and used a wheelchair. They also had carer responsibilities with regard to elderly relatives. Kieran's natural father had no contact with his wife or

children: he had been imprisoned for child abuse, and Gwen felt that he may also have had AS.

Historically, this family had enjoyed a good relationship with both education and social care services. However, though the family's relationship with social care services remained positive, and they were satisfied with the short breaks they received, Kieran's family (and in particular his mother, who used to work in adult education) were embattled with her son's secondary school over what they viewed as their failure to meet his needs. Though Mrs F was satisfied with the local primary school, she did not like any of the secondary schools into which it fed, and appealed to have him go to a school outside the local area. The family was successful in this appeal, but as he was educated outside his local area due to parental choice, the local council would not transport eleven year old Kieran to and from school. Therefore Gwen and Bob had to transport him and his sister Sally to and from different schools, many miles apart.

Although she was initially impressed by Kieran's school, as time passed Gwen felt that the staff did not understand his needs and that he was being bullied there. It became increasingly difficult to get Kieran to attend school, and when he did he returned home crying and upset.

She was increasingly dissatisfied with the school and her relationship with the staff deteriorated. She felt the school were threatened by her knowledge of autism and her experience of working in education and was fighting to get them to change their practice. The school suggested that he might be educated more appropriately within a special education

setting, but she wanted him to remain in a mainstream school. She spent much of her time on the phone to, or writing letters, to senior managers in the Local Education Authority.

### ***Altruism***

Most parents who are able to achieve normalization – with or without formal support – choose that mode of adaptation. However some choose to remain active within the field of disability, altruistically working to help others achieve a more normalized lifestyle. Two single mothers using short breaks could be characterised as altruists (as could one of the families that did not wish to use services). These families are described below.

#### *Michael and Ian A's family*

Michael, a fourteen year old with AS, and his brother Ian, an eleven year old with autism, lived with their mother and father in a semi-detached house in the heart of a small market town. Their father, himself diagnosed with AS, worked as an industrial scientist. Their mother Andrea worked as an autism professional, advising families who had children with ASD. In her work, she taught parents how to use ASD-specific approaches to help manage their children's behaviour. This was a service that she herself had received when Ian was three years old, and she now used the expertise she had developed over the years of working with her own sons (now aged fourteen and eleven) to help others. She was passionate about working in the field and had undertaken training to gain qualifications in autism

Andrea was supported in her altruism by appropriate and effective formal and informal networks. Ian attended a residential short breaks service, where the same ASD-specific approaches that were used at home and school were consistently employed. Pete, the boys'

father, did all of the cooking in the family and he, or their grandfather, were there with the boys if Andrea was working in the evening. Andrea's own parents – despite disapproving of the use of formal short breaks – provided support: they had both children to stay from time to time, and would look after one child to enable both parents to engage in activities with the other.

Before formal support was in place, the family's situation was much more difficult. The social work assessment undertaken regarding the family in December 1999 identified that relationships within the nuclear family had broken down, and that the boy's father was not living in the family home. He was unable to both cope with the boys' behaviour and hold down his job. Andrea was the sole carer, and was physically and mentally exhausted. Short breaks were being sought in the hope that the support would help the family to re-engage as a family, and that Pete would return home. As a result of using short breaks, this outcome was achieved.

#### *Susan and Benjamin E's family*

Fourteen year old Susan had autism, and twelve year old brother Benjamin had a diagnosis of semantic pragmatic disorder. They lived with their mother Marie in a large Victorian terraced house in the centre of the county town. Marie, a Classics graduate, worked as the office manager for a local autism charity. She ran a helpline, as well as organising Saturday clubs and holiday activities, and a number of the other parents interviewed had had contact with her and had been helped by her.

Marie was a single parent. She received no support from her ex-husband, a legal academic whom she believed may well have had AS himself. She furthermore received no support from the extended family on either his or her family sides. She had a number of friends that she had met through her work – all of whom had children with ASD – and also received a lot of support from her church. Nonetheless, a social work assessment undertaken in May 2000 identified that both she and Benjamin were under great strain as a result of Susan's behaviour. The respite provided by the residential short breaks service was important to the family's functioning.

#### *Ethan N's family*

Ethan's family's situation was different from that of the all others interviewed in that – unlike all of them – Ethan's family had consciously and purposefully chosen to enter 'disability world'. Sixteen year old Ethan was fostered, and Harold and Kath, his foster-parents, had worked as foster parents for decades; one of their own daughters was now a foster-carer in her own right. As well as fostering Ethan, they had two other foster-children (all teenage boys) in their home. They received no support from their extended family, nor did they seek it; and they were often scathing in their criticism of social care professionals. Their desire to work as foster-carers sprang from their values –

*“...you're trying to show them that there is a better side of life than they've experienced up until coming to you.” (Kath N)*

– and these values also prevented them from considering seeking short breaks.

*“I wouldn't say, oh we fancy a weekend on our own off you go you lot. You don't do that to your own children, do you? So why should you do it with these? That's how we look at it.” (Kath N)*

However, though they did not wish to use any social support, it must be remembered that they were caring for Ethan – and his foster-brothers – by choice, and that they could cease to be

foster-parents at any time they wished. In that regard, their situation was very different from any of the other families interviewed.

### ***Resignation***

Families who have adopted this mode are characterized by Seligman and Darling (1997) as doubly stigmatised, apart from 'normal' society but also not integrated into alternative 'disability' support systems. Three families, Bill M's, George H's and Sarah G's, could be best categorised as within the resignation mode.

#### ***Bill M's family***

Ten year old Bill lived with his mother Stella and eighteen year old sister Cindy in a small terraced council house in an industrial village. Stella, who was unemployed, was separated from her husband, who lived at the other end of the village. He still provided her some support with regard to Bill, as did Cindy and an older sister who had left home but lived in a nearby town. Family life revolved around keeping Bill happy. He and his mother ate their evening meal as soon as he returned home from school (at about four o'clock), and his mother then spent the rest of each evening playing with him or supervising him. He did not sleep in his own bedroom, but with his mother in her bed. To get him to settle, she had to go to bed when he did. If for any reason she was not there, Cindy followed the same routines. The family expressed no desire to access services and were resigned to continuing to care for Bill as they had always done.

About a year after the interviews took place Stella died suddenly as a result of a brain tumour. Bill's eldest sister moved back into the family home and she and Cindy continued to look



after Bill with support from their father. The family continued to function within their established mode of adaptation, continuing to care for Bill without seeking to access formal support.

### *George H's family*

George lived with his mother, Sandra, and older sister Caroline in a small terraced house on a suburban housing estate. Sandra had categorised herself in the initial survey as wishing to access short breaks but unable to. However, in the course of her interview she described how, when a potential link family had been identified some years earlier, she chose not to pursue this service, as she was afraid that George would feel he was being punished. The family had later been offered another link: she met with the suggested family, and decided that they were unsuitable. Although the family remained 'on the list' for a link family, no other family had come forward and George was by this time fifteen years old. Sandra identified that

*"probably he needs to get out in the community for his social skills...you know he really does need to get out. But it worries me to death. Because I'm thinking, Oh my God! He's leaving his safety net." (Sandra H)*

She had become afraid of accessing services, and cited her many fears: her concerns about how George would interpret leaving home, her belief that it was too late to change his routines, her fears of possible abuse in short breaks settings, as well as being worried about how his sister would interpret this action. All of these were given as reasons for maintaining the status quo. She felt that no one outside the nuclear family could effectively manage his behaviours but her support options were limited: her own parents were dead; her ex-husband (whom she felt in retrospect may have had AS) had little contact and provided no support; she spoke to only one neighbour. The only support she received was from her sister, who

occasionally ‘babysat’ (sic) George if Sandra was working late. As a result Sandra was resigned to spending the rest of her life caring for George.

Eighteen year old Caroline, George’s only sibling, identified the negative impact of the family’s mode of adaptation upon herself.

*“I think my mum’s more protective over me because of what George’s like; and that’s stopped me from doing things... (Also) if I wanted to do something, it would always be, someone had to look after George.”* (Caroline H)

However, at the same time, she shared her mother’s perspective. She did not wish him to spend time away from home as she felt he would dislike it, because she would dislike being separated from him, and because she would worry how he was being treated. She wanted her brother to live with her when she was older

*“‘Cos I don’t like being apart from him. I don’t like it!”* (Caroline H)

Life in the family home revolved around George and keeping him happy, and George’s family, like Bill’s, was resigned to looking after him for the rest of her life.

#### *Sarah G’s family*

Eighteen year old Sarah’s family – who are would-be users of short breaks – had also become resigned to looking after her without support into adulthood. But whereas George’s family had turned down potential links, no short breaks had ever been offered to Sarah’s family. The family had applied for this service when she was nine; no match was found and no service was offered in the subsequent nine years. At the time of the interviews she was eighteen and the family was no longer eligible for support from Children’s Services. In the interview the family identified that their need for support has reduced and become less relevant as she has got older anyway.

Sarah, her younger brother (who had diabetes) and her mother and father lived in a small village in the north of the county. They received no support from their extended families, and had very limited social contacts outside the nuclear family. Though they were wealthy – Sarah’s father owned his own factory and the family lived in a large, spacious bungalow – their lifestyle was extremely restricted. They viewed themselves as ‘outcasts, very isolated’ and they had not been out socially in five years. Mr and Mrs G identified that all they had wanted by way of support was the opportunity to go out occasionally as a couple, and to have some time to do things with their son together, without having to plan everything around Sarah. However, they had given up on receiving effective support. They were pessimistic about adult services and instead had planned to ensure that they would have sufficient financial security that they could give up work to care for their daughter.

### *Families that do not fit Darling’s model*

While the families discussed above can be placed – however approximately – into Darling’s model of adaptation, three families could not be readily located within it. These families were not altruistic, crusading or resigned. They were all striving to achieve normalization, but had not yet achieved it. One of these families was using short breaks at the time of the interviews, though the service had only recently been put in place. The other two had previously used short breaks: however no services were available to them at that time.

### *Patrick C’s family*

Patrick was an only child aged seven years who lived with Alison, his mother, who was diagnosed with clinical depression. Her ex-husband lived in the USA; her only brother lived in the Canary Islands. Her parents lived two hundred miles away, and she described time

spent with them as being extremely stressful. Her old friends, from before her son was born, had *'faded away'*.

At the time of her initial assessment for services in March 2004, Alison was distressed by her son's behaviour and fearful of him. She lived in a small, affluent market town but did not drive, and getting from place to place was extremely problematic as public transport was extremely limited. She felt isolated and alienated from her neighbours and was using anti-depressants and alcohol as part of her coping strategy. However, Alison was not resigned to her situation, and felt that both she and her son needed support to *'broaden their horizons'* and live a more normal life. She therefore moved to a larger town, with better public transport, closer to her son's school. She sought formal support and had received parenting support and training from the local Autism Family Advisory Service; and at the time of the interview she had recently started receiving short breaks provided by a link carer, with whom she had developed a positive relationship.

This service was still in its early days, and Patrick had not yet begun to stay overnight away from home. Alison did not feel that she had yet achieved anything close to normalisation, and was acutely aware of both the fragility of her own mental health and her dependence on continuing professional support. She was fearful of change: she described herself as *'devastated'* when she had a change of social worker and was constantly concerned about what would happen if her short breaks could not continue.

*"It's not predictable, it can happen any time, can't it? Yeah, and it does throw us, and there's nothing you can do about it."* (Alison C)

### *Andrew I's family*

Seven year old Andrew I lived with his mother, father and two teenage sisters in a small terraced house in a market town at the southern tip of the county. This was about an hour away from the county town, where he was educated. They had received short breaks some years previously, but these had ended two years before the interviews when the short breaks carer became pregnant. They had received no services since then, though they are hoping to access short breaks again (either with a family or via a residential service) in the future.

Sam, his mother, had been disqualified from driving following a serious accident. She worked part-time at a local co-op. Her husband – who felt that he may himself have ‘traits of autism’ – was the main wage earner. He worked as a flying instructor about a hour’s drive from home, and also spent most of his weekends engaged in flying. He acknowledged that he provides only limited support, and that he was more of a ‘family man’ before Andrew’s diagnosis. Sam identified that

*“he finds it quite hard, and it’s his way of shutting off.”* (Sam I)

The family received no support from their extended family and the marital couple were extremely conscious of their dependence on their teenage daughters.

Sam had made some friends in a local disability support group that sometimes met at their home; and the girls both attend the Young Carers group. However thinking of what they missed about short breaks and what benefits they felt they would receive from accessing services again, the family consistently identified how they need these supports to achieve ‘normal’ outcomes – to enable their elder daughter to use the computer to revise for exams

without being attacked; to enable their younger daughter's friends to visit the house; to go out for a relaxed meal.

### *Ibrahim J's families*

Eight year old Ibrahim lived with his sister, two brothers and mother Asma in a Victorian terraced house in the centre of the county town. His thirteen year old brother also had a learning disability. Asma, who worked as a translator for the local authority, received little or no help or support from friends, family or neighbours. She did not see her ex-husband, and most of her extended family lived in Pakistan.

Ibrahim used to spend time with the same short breaks carer that supported Andrew I's family. As with their family, his care too ceased when the carer became pregnant, and at the time of the interviews the J family had received no service for two years. Asma, his mother, had believed that Ibrahim was on a waiting list, but had recently discovered that this was not the case. Asma identified a need for a break from caring, and for an opportunity to spend time focused on her other children.

*"I never have the opportunity – Ibrahim being here – to sit down with them, and to do anything with them...read a book...always there is this fight going on, and you have to watch him, and it is just too much. The life is too much, too stressful. We just want a little break so that I know I'm the mother of three other children as well."* (Asma J)

It was noteworthy that the children within this latter group – who do not fit the model – are aged seven and eight. At this point in the family life cycle it may have been too soon for their families to have settled into a typical mode of adaptation. It was clear that they were striving to live as normally as possible, and that they recognised a need for formal support to help

them to achieve this. However this support was either not put in place, or was insufficiently established to have met the families' needs.

At this point it was impossible to tell whether services would be put in place to meet their needs; whether they, like Sarah's family, they would find themselves moving towards resignation; or whether they would seek to achieve normalization by having the child with autism put in a residential placement outside the home (Llewellyn *et al.*, 1999). In the case of Andrew I's family, this latter course of action was effectively imposed upon the family. Following the interviews, residential short breaks were successfully established. However, Andrew was excluded from his primary school placement due to his behaviours. He was placed in another school in a different area of the county, but this placement too broke down; the seventy mile round trip in a taxi and his isolation in the school setting – he was educated separately from the other children – may have contributed to this. No in-county educational placement could be identified, and Andrew would not interact with education staff in his own home. As a result, apart from time at the short breaks setting, Andrew was at home all the time and was becoming increasingly isolated. His being at home all the time was preventing his sisters from revising for AS and A Levels. His mother was unable to work, as she needed to be at home to be with him, and this was affecting the family's finances. Consequently, at the age of nine, Andrew I moved to a 52-week per year placement at a residential school 150 miles from home.