Understanding Carers' Experiences: A Qualitative Exploration and Meta-ethnography Exploring Experiences of Caring for Individuals with Intellectual Disability

By

Eleanor Drew

A thesis submitted to the University of Birmingham for the degree of

DOCTOR OF CLINICAL PSYCHOLOGY

Department of Clinical Psychology

School of Psychology

The University of Birmingham

May 2025

Thesis Overview

This thesis has been submitted by Eleanor Drew in completion for the degree of Doctor of Clinical Psychology (ClinPsyD) at the University of Birmingham. The thesis contains three chapters.

Chapter one is a meta-ethnography exploring the experience of support groups for family caregivers of individuals with intellectual disability. The meta-ethnography approach allowed the author to synthesise qualitative research obtained through a systematic literature search. This synthesis revealed three overarching themes related to the benefit of shared experiences, changes experienced by the carers and the group processes. The review highlights the importance of prioritising support groups in this population and provides recommendations for ensuring their effectiveness.

Chapter two is an empirical research paper using Interpretative Phenomenological Analysis (IPA) to explore paid carers lived experience of providing support to individuals with intellectual and/or developmental disability and harmful sexual behaviour. Six paid carers were interviewed and analysis of transcripts revealed three superordinate themes. The carers spoke of how they have developed to manage the emotional demands of the role, how this can be impacted by people around them, positively and negatively, and the importance of collaborative and client-centred care. Clinical implications are discussed including strategies that may serve to improve carer wellbeing and in turn, client care.

The final chapter of this thesis includes two press release papers aiming to clearly communicate key findings from the previous chapters.

Acknowledgements

I would firstly like to thank all of the participants that took time out of their busy lives to participate in this research study. Thank you for providing such honest accounts of your experiences, I hope this paper accurately describes them.

I would also like to express my deep gratitude to my thesis supervisor Dr John Rose. Thank you for being a consistent, supportive and reassuring supervisor throughout the highs and lows of qualitative research! Thank you to the DClinPsy course team, and in particular Dr Gary Law and Dr Andy Fox, for your invaluable support and guidance.

Thank you to the team of researchers on the HaSB-IDD clinical trial. In particular Dr Lisa Richardson and Dr Glynis Murphy, thank you for your continued support and determination during the turbulent data collection process and for always being available for any queries or support needed. I would also like to express my thanks to Viv Cooper and each member of the Challenging Behaviour Foundation carers group who gave up their time to consult in the development of this research project. Having your input reminded me why this research is so important and kept me motivated.

To the 2022 cohort and the lifelong friends I have made on the course. I am so grateful to have been on this journey with you.

Lastly I would like to thank my family. Mum, Dad, Harriet and my partner Ewan – none of this would have been possible without your unwavering support over the years. You are my team of personal cheerleaders, believing I could do it even when I didn't. Thank you.

Contents

Chapter One – A Meta-ethnography Exploring the Experience of Support Groups for Family Caregivers of Individuals with Intellectual Disability (ID) 1

Abstract 1

1.1 Introduction 3

Impact of Providing Care 4

Needs of Family Carers of ID 5

Support Groups 7

Aims 8

1.2 Methodology 8

Meta-ethnography 8

Systematic Literature Search 11

Data Analysis and Synthesis 34

1.3 Results 39

1.4 Discussion 50

References 60

Chapter Two - A Qualitative Exploration of Paid Carers Experience of Caring for Individuals with Intellectual and/or Developmental Disability and Harmful Sexual Behaviour 72

Abstract 72

2.1 Introduction 74

Defining Key Concepts 74

Caring for Individuals with IDD and HSB 75

Research Rationale and Aims 77

2.2 Methodology 79

Context 79

Design 79

Data Collection 86

Data Analysis 88

Reflexivity 95

2.3 Results 96

Theme 1: The Balance of Drive and Burden 97

Theme 2: Relational and Social Shaping of Care 102

Theme 3: Working Together to Put Clients Unique Needs First 108

2.4 Discussion 113

Results Overview 113

Findings in Context 115

Clinical Implications 118

Future Research 120

Strengths and Limitations 121

Conclusion 122

References 124

Chapter 3 – Press Releases 135

3.1 Meta-ethnography Press Release 135

3.2 Empirical Press Release 138

Appendices – Chapter one 141

Appendix 1A - NICE (2012) Quality Appraisal Checklist 141

Appendix 1B - Data Extraction Spreadsheet – Study Characteristics 148

Appendix 1C - Data Extraction Spreadsheet Themes and Subthemes 149

Appendix 1D - Grouped Themes and Subthemes Across Papers 150

Appendix 1E - Linking Key Concepts From Papers 153

Appendix 1F - Using Third Order Constructs to Develop Concepts 154

Appendix 1G - Emerging Themes Across Papers 155

Appendix 1H - Exert of Extraction Grid Displaying Overarching Themes Including First and Second Order Constructs 156

Appendix 1J - 3 Main Themes and Subthemes Identified 158

Appendix 1K - Reflective Log 159

Appendices – Chapter two 161

Appendix 2A - Ethical Approval 161

Appendix 2B - Participant Eligibility Criteria From HaSB-IDD Trial Protocol 162

Appendix 2C - Participant Information Sheet 163

Appendix 2D - Participant Consent Form 170

Appendix 2E - Semi-structured Interview Schedule 173

Appendix 2F - Carers Support Information 178

Appendix 2G - Extract of Initial Codes and Experiential Statements on a Transcript 179

Appendix 2H - Screenshots Displaying Process of Grouping PETS 180

Appendix 2I - Screenshots Demonstrating Process of Developing GETs 183

List of Illustrations

1. **Meta-ethnography: A Meta-ethnography Exploring the Experience of Support Groups for Family Caregivers of Individuals with Intellectual Disability (ID)**

Figure 1: PRISMA Flowchart Displaying Screening Strategy

Figure 2: Quality Appraisal for all 12 Papers

Figure 3: Thematic Map

Figure 4: Extract from Line of Argument Synthesis of Theme 1 – Shared Experiences

2. **Empirical Research Paper: A Qualitative Exploration of Paid Carers Experience of Caring for Individuals with Intellectual Disability and Harmful Sexual Behaviour**

Figure 1 – Themes and Subthemes Emerged From the Data

List of Tables

1. **Meta-ethnography: A Meta-ethnography Exploring the Experience of Support Groups for Family Caregivers of Individuals with Intellectual Disability (ID)**

Table 1: Seven Steps for Conducting Meta-ethnography Outlined by Sattar et al. (2021)

Table 2: Keywords and Search Terms in Systematic Search

Table 3: Inclusion and Exclusion Criteria for Systematic Search

Table 4: Allocated Number and Study Details for Each of the Included Papers

Table 5: Key Themes Across the Papers

2. **Empirical Research Paper: A Qualitative Exploration of Paid Carers Experience of Caring for Individuals with Intellectual Disability and Harmful Sexual Behaviour**

Table 1: Participant Eligibility Criteria

Table 2: Participant Demographics

Table 3: Individual Stages of IPA as outlined by Smith et al. (2022)

Table 4: Overview of Group Experiential Themes and Subthemes with Participants Contributing to Each

Chapter One – A Meta-ethnography Exploring the Experience of Support Groups for Family Caregivers of Individuals with Intellectual Disability (ID)

Abstract

Intro and Aims

Family carers of individuals with intellectual disabilities (ID) face different challenges compared to paid carers, often experiencing increased stress related to their role. Research highlights their unmet needs, including lack of social support, stigma and financial strain. Evidence suggests that social support interventions can be protective for family carers, enhancing coping skills and their sense of control. This meta-ethnography aimed to explore how support groups are experienced by family carers, focusing on helpful and meaningful aspects, to inform future interventions.

Method and Results

Using a meta-ethnography method a systematic search was conducted of five databases. Seven qualitative studies were identified and appraised using a quality appraisal checklist. Through line of argument synthesis, three overarching themes and eight subthemes were identified: shared experiences, changes observed through group attendance and experiences of group process. Carers gained a sense of understanding through shared experience with others, as well as personal growth, increased confidence and a shift towards supporting others. Helpful aspects included a clear structure, while challenges emerged when group content was too generic.

Discussion and Implications

Findings highlight that support groups are important and should be prioritised by services. They benefit carers emotionally, socially and psychologically. Clinically, services should prioritise designing groups that are well structured, accessible and relevant to the individuals attending them. Furthermore, carers emerged as empowered advocates, indicating the need to include them in service design and research. A dedicated staff member to liaise with carers may help foster this collaboration.

1.1 Introduction

Intellectual Disability (ID), also commonly termed Learning Disability (LD) in the UK, is a developmental difference characterised by impairment in intellectual and adaptive functioning, both arising before adulthood (British Psychological Society [BPS], 2015). Marrus and Hall (2017) highlight that suspicion of ID can arise in childhood but a diagnosis is often not made until a child is at least five years old. Children under the age of five years old are instead diagnosed with Global Developmental Delay (GDD), when a delay is observed in two or more domains. Additionally, children with a mild ID may not be diagnosed until school age, when the academic setting highlights cognitive difficulties.The term family carer refers to an individual who provides unpaid care to a family member who requires it (NHS England, n.d.). This role is distinguishable from a paid carer who may support the individual with ID as their profession and are paid for their work. Family caregiving for individuals with ID is common, and in 2017 living with family was the most common living situation for adults with ID receiving long-term support (Public Health England, 2020).

Individual and societal factors have likely contributed to these rising numbers, with reduced institutionalisation resulting in family care being the key support for the ageing population (Brennan et al., 2020). The term family caregiver can include different relations. Although research focuses primarily on parent carers, family carers can include siblings and other relatives (Totsika et al., 2017). As an individual with ID ages (Coyle et al., 2014) or family circumstances change (e.g. parents age or pass away) siblings are required to take on caring roles (Brennan et al., 2020; McCarron et al., 2014). Given individuals with ID's increasing life expectancy, the term 'parents' also refers to those with adult children with ID. Being a family caregiver can be a complicated and enduring role, and it can be difficult to separate the caring role from their relationship with the individual (NHS England, n.d.) which

is true for any family relation, not just parents. The author therefore hoped to explore the experiences of family caregivers as a broad concept incorporating any family relation who has been providing care for a significant period of time.

Impact of Providing Care

Family carers of individuals with ID can experience increased stress and carer burden (Griffith & Hastings, 2014; Moriwaki et al., 2022; Thompson et al., 2014). Research suggests mothers, fathers, siblings and grandparents are all impacted by increased family burden through caring for individuals with ID and mental disorders (Irazábal et al., 2012). This impact includes increased levels of psychological distress among parents (Masulani-Mwale et al., 2018), such as anxiety and depression (Megreya et al., 2020). It has been demonstrated that one factor related to this burden is social isolation, particularly around difficulties they can face in public or social settings (Thompson et al., 2014) and negative attitudes from members of the public (Ali et al., 2012). Family caregivers can feel isolated from others due to their child's behaviours and having difficulty finding others in a similar situation to themselves (Chakraborti et al., 2021; Mitter et al., 2019). Similarly, Masulani-Mwale et al. (2018) observed the rate of psychological stress in parent carers of children with ID in Malawi and found that a lack of psychological support was one of the factors that predicted distress.

Whilst multiple studies indicate the negative impact of caring for an individual with ID, there is also research highlighting the positive impact this role can have. Taunt and Hastings (2002) demonstrated that parents of a child with ID also identify a positive impact on themselves and their families in relation to enhanced learning and perspective on life. This was supported by Bunga et al. (2020), who highlighted that parents caring for a child with ID observe positive impacts on themselves including increased tolerance, patience and empathy, allowing them to provide effective care for their children. It is suggested that to find positive

meaning from their caring role, parents draw on a number of coping strategies (Beighton & Wills, 2019) and providing a space to build these strategies in others could enhance overall wellbeing in family carers.

In order to enhance wellbeing it is important that coping strategies within family carers are understood. Research suggests that family carers of individuals with ID demonstrate alternative coping styles compared to parents of children without an ID, and less frequently utilise emotional support (Bawalsah, 2016; Bujnowska et al., 2021; Halstead et al., 2018; Vernhet et al., 2019). The study by Bujnowska et al. (2021) found that carers of people with ID were less likely to seek emotional support from others as a means to cope. Based on this, it is helpful to understand what specific social support needs family caregivers of individuals with ID have, and whether these needs can be met through support groups.

Needs of Family Carers of ID

There is clear evidence that family caregivers of individuals with ID experience significant psychological stress and require support from professionals, making it important to understand their needs and what type of support will be most effective. A number of studies have sought to explore the needs of family caregivers. Chien and Lee (2013) explored the needs of parents of children with ID in Hong Kong, and highlighted four key challenges faced by this group; needing more information for caregiving, health concerns, limited psychosocial support and stigma faced by seeking help. Similarly, Resch et al. (2010) identified barriers that parents faced when caring for a child, and found four key themes; information and service accessibility, finances, inclusion and family support. They identified a mismatch between the needs of the carers and the provision of services, specifically that family support, financial and educational needs were not being met by local services. The importance of understanding the specific needs of carers was highlighted, demonstrating the necessity for further research within this area. Griffith and Hastings (2014) explored the

experiences of caring for a family member with ID including the experiences of mothers, fathers, siblings and grandparents. Themes that emerged from the data included; altered identity, crisis management and feelings about the future. Support services were most effective when delivered by highly trained staff members and when this was not present, support services could increase levels of stress for carers. Halstead et al. (2018) demonstrated that social support is a protective factor for mothers of children with ID and highlighted the need for interventions to focus on building social support. They also found that coping ability had a positive impact on wellbeing in mothers, therefore interventions should focus on developing coping skills.

Kleefman et al. (2015) further highlighted the importance of building support in parents of children with mild ID after they found that as many as one in seven parents required support due to stress as a result of their child's psychosocial problem. They stated that formal support was most needed, aiming to provide parenting skills to reduce problems. Jandrić and Kurtović (2021) also suggested the need for formal interventions and stated that these should focus on providing information about ID, realigning families expectations of their child and the support they can provide to enhance a sense of control and parental satisfaction.

Understanding family caregivers' experience of support groups may provide insight into whether they want to access more support from others, and if so, why? Although social support has been found to be a protective factor for maternal well-being of children with ID (Halstead et al., 2018), it is frequently lacking for this group of carers (Felizardo et al., 2016; Resch et al., 2010; Whitney, 2023). Felizardo et al. (2016) studied parents in Portugal who had a child with a disability, including ID. They found differences in the level of stress experienced and the availability of social support, with family caregivers receiving the lowest levels of social support. They concluded by recommending that interventions should focus on

developing support networks, and provide support and resources targeted at families' specific needs.

Support Groups

It is clear from the literature that family carers of individuals with ID face many personal and organisational challenges, with research highlighting the importance of effective support to maintain their wellbeing. This necessary support can range from formal, evidence-based training programmes to peer-led emotional support groups (NHS England, 2015). Support groups can be defined as individuals with similar experiences meeting to provide support and companionship in professional-led, family-led or psychoeducation based groups (Worrall et al., 2018). Evidence has suggested that such groups can allow members to gain hope, learn coping strategies and overcome isolation and stigma (Chien & Norman, 2009; Worrall et al., 2018). For family carers of individuals with ID, support groups can positively impact social interaction and emotional/informational support (Wei et al., 2012). They have also been demonstrated to play an important part in strengthening relationships and building resilience within family caregivers (Chakraborti et al., 2021). An important factor in the effectiveness of such groups is participants feeling understood and being able to share information with others (Jackson et al., 2018), as well as perceived sameness with other group members (Chakraborti et al., 2021). Heiman (2002) interviewed parent carers of children with disabilities (including ID) and concluded that social support and resources were necessary interventions for this population, with parents highlighting the numerous benefits of support groups. Earlier research has indicated building relationships, social learning and a change in perspective as key factors relevant in the effectiveness of support groups (Kurtz & Powell, 1987).

Whilst the research indicates that support groups may be effective, further research is needed to understand which therapeutic components of support are beneficial for family

carers (Chien & Norman, 2009), demonstrating a clear need to increase research in this area. Understanding family carers' experiences of such groups can provide further insight into how groups function effectively, and suggest content to include to enhance support (Chakraborti et al., 2021).

Aims

The aim of this meta-ethnography is to explore how support groups are experienced by family carers of individuals with an ID. It is hoped that quality appraising and synthesising qualitative research papers on this topic will allow for a thorough exploration and identification of any patterns that arise. Specifically, the review aims to look at patterns relating to how support groups are received by participants, whether they are deemed helpful, and what aspects of the group are meaningful and effective. It is hoped this may help inform future interventions for family carers.

1.2 Methodology

Meta-ethnography

Meta-ethnography is a qualitative synthesis method commonly used in healthcare research to integrate relevant literature about a specific topic (Sattar et al., 2021). The process seeks to explore existing interpretations of qualitative data from individual studies and synthesise them (Noblit, 2018). This approach allows for the synthesis of qualitative studies to deepen understanding and generate new, higher-order interpretations of a particular phenomenon (Luong et al., 2023; Sattar et al., 2021). It is particularly useful for informing health services and exploring human experiences, such as participation in a support group (France et al., 2014). Meta-ethnography was considered to be the most appropriate methodology to meet the current research question, as it seeks to explore how support groups are experienced by family carers of individuals with ID.

Meta-ethnography goes beyond reporting findings and combining them, it uses participant data and original author interpretations from individual studies, to provide new understandings across the studies (Cahill et al., 2018; Campbell et al., 2012). This was an important factor in the current review which aimed to understand how support groups were experienced and what aspects of them were meaningful. The inductive and interpretive nature of meta-ethnography is appropriate for this aim because it focuses on the what and how of human experience to uncover meaning and inform effective interventions (Luong et al., 2023).

Meta-ethnography is distinct from other qualitative synthesis approaches, such as grounded theory, as it allows for conceptual richness and includes studies with varying methodologies (Sattar et al., 2021; Soundy & Heneghan,, 2022). Unlike thematic and narrative synthesis, it develops new interpretations (France et al., 2014), allowing expansion of insight and meaningful contributions to clinical practice (Cahill et al., 2018). This was essential for the current study, which sought to understand how and why support groups were meaningful for family carers.

To conduct a meta-ethnography, a researcher considers the context within which a study was conducted and generates higher order themes and conclusions across the literature. Clear guidance is important, and it follows a structured, seven-phase process originally outlined by Noblit and Hare (1988), and later clarified by Sattar et al. (2021). These steps are shown in table 1 below.

Table 1

Seven Steps for Conducting a Meta-ethnography Outlined by Sattar et al. (2021)

Stage	Description

1) Getting started	Find an area of interest and consider if meta-ethnography is appropriate.
2) Deciding what is relevant	Defining the focus of the review, selecting studies from a search criteria, and developing an inclusion and exclusion criteria. Conduct a quality appraisal of the included studies to understand credibility of each paper.
3) Reading the studies	Reading and becoming familiar with the identified studies. Begin to extract raw data to inform first and second order constructs. Understanding study characteristics and providing context to the data.
4) Determining how studies are related	Considering the relationship between studies, understanding and explaining this. Identifying overarching concepts across papers by reviewing and analysing themes within them.
5) Translating the studies into one another	Comparing concepts from each included paper. Referring back to the context of each to determine the relationship between them, exploring similarities and differences between concepts.

6) Synthesising the translations	Compiling the findings from the papers and determining if the synthesis is Reciprocal, Refutational or Line of Argument.
7) Expressing the synthesis	Providing a summary of findings from the synthesis and reflecting on the process whilst providing recommendations and conclusions.

As outlined in stage one, this meta-ethnography began with developing an area of interest and exploring research already available in this area. The author had a keen interest in the experiences of caring for people with ID, and has clinical experience of facilitating support groups for caregivers of individuals with severe and enduring mental health difficulties. Additionally, during a Patient and Public Involvement (PPI) meeting with a carer group, the importance of this research was highlighted to the author, by individuals with lived experience of caring for a family member with ID. In discussion with their academic supervisor, it was agreed that the current meta-ethnography should focus on family carers experience of support groups.

Systematic Literature Search

Once the topic of interest had been refined, a systematic literature search was conducted to identify all relevant literature in the field. This phase involved identifying any existing reviews on this topic to ensure a meta-ethnography was necessary. A scoping review focusing on the implications of peer support networks for families of individuals with neurodevelopmental and intellectual disabilities (NDID) was identified at this stage (Chakraborti et al., 2021). This research highlighted the need for further systematic reviews, including quality appraisal of included studies. The author discussed this review with their

supervisor, and it was decided to use the existing scoping review to inform the current review but ultimately this meta-ethnography would focus on carers of ID specifically, rather than carers of a wide range of NDIDs. The current review was then registered with the international systematic review register, PROSPERO, to prevent duplication of work.

Search Strategy

The search strategy was systematic to ensure that all relevant literature was captured. The aim here was to be exhaustive but not biased. The database search terms are displayed in table 2 below.

Table 2

Keywords and Search Terms in Systematic Search

Keyword	Search terms
Learning Disability / Intellectual Disability	Intellectual disab* OR Learning disab* OR develop* disab*
Carer	Carer* OR parent* OR caregiv* OR famil*
Support group	Support OR "mutual support" OR "support group" OR intervention* OR group

Firstly, the research question was separated into three key terms that captured the essence of the question. Alternative descriptors for the keywords were then considered and included in the search terms. Published reviews exploring similar topics were reviewed to

identify relevant key words and language used within the field. It was important that the key words captured the specific population of interest.

Truncation was used to ensure plurals and different spellings were captured in the search results i.e. disab* to capture disability or disabilities. Boolean operators (AND/OR) were used to combine search terms, ensuring multiple terms were present in the articles and they had one or both of the key terms. Filters and limiters were then applied, limiting papers to English Language, Full Text papers, Open Access, Article, Dissertation/Thesis and Human participants. Peer reviewed articles were not specified, although this would imply methodological robustness, the author intended to quality appraise all selected articles and did not want to exclude any at this point. No date range was specified during the searches. Therefore, results from the databases' creation - 07/01/2025 were shown. Five electronic databases, publishing studies related to healthcare, were searched using the above strategy. These were: Proquest, Scopus, CINAHL, PsycINFO and Web of Science.

Inclusion and Exclusion Criteria

An inclusion and exclusion criteria were developed in discussion with the author's supervisor to ensure that all papers selected to be included in the review were relevant to the question. These criteria are displayed below in table 3.

Table 3

Inclusion and Exclusion Criteria for Systematic Search

Inclusion	Exclusion	Rationale
Adult family carers (over the	Paid carers, child carers (under the age	Aiming to provide an alternative view to the author's empirical research paper focusing on

age of 18), any family relation. This includes siblings who may not be registered as the primary carer for an individual but do contribute to an individual's care and support network.	of 18 with a caring responsibility).	paid carers. It is understood that family members make up a large proportion of care support for individuals with ID (Linden et al., 2024; Riches et al., 2023), and therefore it felt important to include their voices. Research suggests that siblings are often required to take on caring roles as family circumstances change (Brennan et al., 2020; McCarron et al., 2014), therefore it was felt important to understand these experiences.
Carer described as caring for an individual with ID, of any age. For young children a diagnosis of global developmental delay (GDD) is included as this	Carers of individuals with a physical disability only. Caring for an individual with Autism Spectrum Disorder (ASD) or neurodevelopmental disability only.	The author wanted to focus on experiences of caring for individuals with ID, so carers of clients with ASD or a neurodevelopmental disability, without ID, were excluded. Children diagnosed with Global Developmental Delay (GDD) are also included in this review. As stated in the introduction of this review, individuals presenting with delays in two or more domains, before five years old, are often diagnosed with GDD. It is hoped that by

is indicative of a delay in developmental milestones (Mencap, n.d.) and ID is often not diagnosed until 5 years old.		including caregivers of young children with GDD this will ensure the review captures a spectrum of developmental difficulties that can be associated with an ID diagnosis. It is hoped that this will provide a more comprehensive understanding of experiences and caregiver support needs.
At least half (50%) of the participants in the sample of the paper under consideration were identified as caring for someone with an ID/LD/GDD.	Papers where less than half of the sample are caring for individuals with ID/GDD.	In order to meet the aims of the research question and ensure that the experiences of caring for ID/LD/GDD were specifically explored in this review.
Groups where the focus was on support for	Groups focused on supporting carers and the individual with ID i.e., multiple	Whilst it is acknowledged in the literature that multiple family member support groups exist, in which the person being cared for also attends, (Worrall et al., 2018). These were excluded in the

family carers only.	family member support groups.	current review as the aim was to focus on family carers experiences only.
Groups where the focus was on family members to receive support, including mutual / peer support. Groups facilitated by professionals, peer-led, or by individuals with lived experiences.	Training programmes / skills based programmes	For the purpose of the current review, a broad yet evidence based definition of support groups is used. This reflects the diversity of group formats described in the literature, explored further in the paragraph below this table. Focusing on groups in which the main aim is to provide social support will give a rich understanding of experience and meaning gained from the group, rather than skills obtained. Groups facilitated by professionals were included, if the aim was to facilitate conversations among carers.
Support delivered in a group attended by two carers, or more. Groups running for any	Support delivered as 1:1	An important consideration in the current review was the diversity of support groups. As noted by Jackson et al. (2018) support groups can vary in their frequency and duration, with meetings occurring weekly, monthly and bimonthly. Based on the evidence that frequency and duration can vary considerably, this was not set as an exclusion

length of time / frequency.		criteria. In the current review the emphasis was on understanding family carers' experiences of a support group, and it was felt that they could have this insight after attending only one session or multiple. Additionally, the author was concerned that limiting the inclusion criteria by number of sessions attended could have led to a bias in the findings. It is possible that by applying such a criteria, the synthesis would only include studies where people hadn't dropped out of groups, possibly because they were more satisfied with the support group.
Online/offline groups including social media	None	Both online and face-to-face groups were included as it was felt important to explore the impact of the online community/support, given the worldwide changes that occurred during the COVID-19 pandemic. Additionally, evidence suggests that support groups can be facilitated through face to face or online platforms. As highlighted by Worrall et al. (2018), the internet can be considered a helpful alternative for providing support.

Qualitative papers / mixed method papers	Quantitative papers, literature reviews, protocols and descriptive only qualitative papers. Quantitative data from mixed methods not included in meta-ethnography.	Hoping to gain an in-depth understanding of individuals' experiences. Mixed method designs were considered if there was a thorough analysis of the qualitative data obtained.
Any country of origin	Non-English language paper	The aim was to gain an understanding of carers' experiences and it was felt that including groups from different countries and cultures would aid in this understanding. Non-English language papers were excluded due to limited translation resources.
Studies conducted in the last 10 years	Studies older than 10 years old	Only studies published within the past 10 years were included. This was outlined to ensure the most current research and methodologies were captured in the search. This helps to ensure the review reflects the latest empirical findings that are relevant to current clinical practice.

Family Carer Definition. For the purpose of this review, family carers were considered as anyone who looks after (unpaid) a family member who needs support due to

illness or disability (NHS England, n.d.). Definitions of a carer are not always explicitly described within the literature and therefore the current review will include papers where a family relation has some involvement in caring for the individual with ID. This is to ensure the review is comprehensive.

Intellectual Disability Definition. Within this review, presence of ID is determined by terminology used in the included papers. Unfortunately, due to poor reporting standards it is not possible to use IQ data to determine presence of ID, as this information is not always included in the papers. Therefore, caregivers will need to be reported as caring for an individual labelled as having an Intellectual Disability, Learning Disability or Global Developmental Delay.

International Literature. The decision was made to include international literature in this review to widen the accessibility of the findings and draw from a broader evidence base. The author acknowledges that healthcare for people with ID can vary across countries, with services being shaped by organisational contexts. However, it felt important not to limit inclusion to UK and western papers only, as doing so could risk making the research Eurocentric. As highlighted by Breuer et al. (2024), understanding and sharing practices across countries can create mutual understanding and promote best practice policies to reduce inequalities. Their paper explored the organisation of healthcare services for people with ID across 13 countries and found that similar challenges were faced (Breuer et al., 2024). There is additional evidence to suggest that pressures felt by families of a child with ID/DD can have commonalities across cultural contexts (Heer et al., 2015). Based on this, the current review aims to interpret international findings whilst paying careful attention to cultural and systemic differences that may exist. The author hopes to recognise these difficulties, alongside the value of including the perspectives, to develop inclusive conclusions.

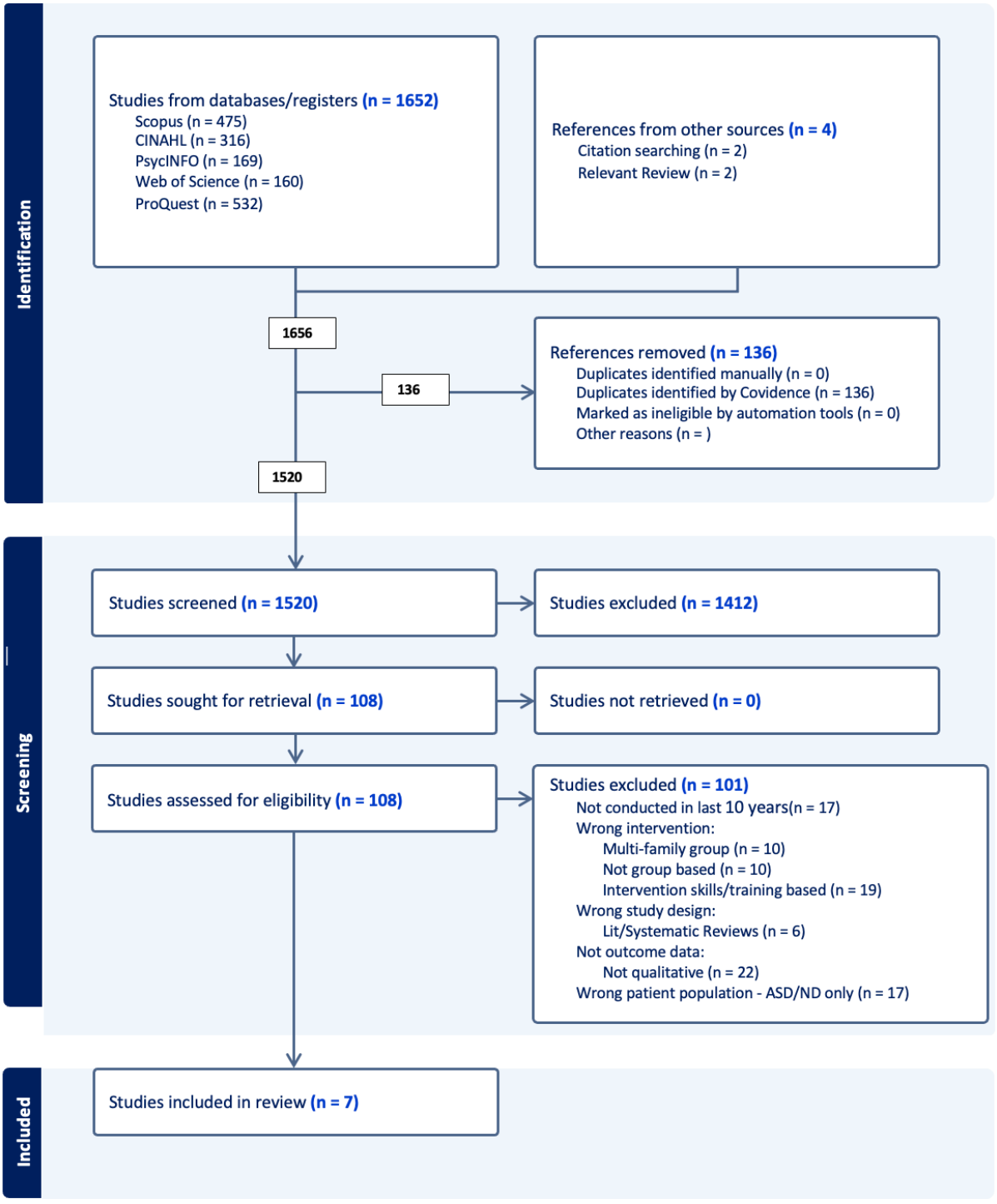
Support Group Definition. Support groups can be understood as settings in which individuals with a shared experience come together to provide, and receive, emotional and social support. According to Nichols and Jenkinson (1991, as cited in Wei et al., 2012), support groups are a type of mutual support that involves a group of individuals, and a leader, coming together to share a common need. These groups can be peer-led or facilitated by healthcare professionals. Worrall et al. (2018) similarly described support groups as a place for individuals with similar experiences to provide emotional support, share coping strategies and build trust. Based on these definitions the inclusion criteria for a support group in the current review was set to include groups where family carers were provided with the opportunity to share their lived experiences, mutual or peer support was provided, they were peer or facilitator led and online or in-person formats.

Systematic Screening Process

All references retrieved during the search were exported to Covidence where they were screened against the inclusion and exclusion criteria. This screening strategy is displayed below in figure 1, the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) flow chart.

Figure 1

PISMA Flowchart Displaying Screening Strategy.



Searches were conducted in August 2024 and January 2025. These yielded a total of 1652 results obtained from the initial search of databases and four from other sources. Two further papers were identified through citation searching and two from a historical review (Chakraborti et al., 2021). After removing duplicates, 1520 papers were screened at title and abstract level. This identified 108 relevant papers that were sought for retrieval. These papers

were screened against the inclusion and exclusion criteria outlined in table 3, and 101 papers were excluded. A measure of inter-rater reliability was introduced at this stage. A second rater blind rated just over 10% of these 108 papers (12 in total) and agreed with the exclusion decisions reached by the first rater on all of the 12 studies rated. Reasons for these exclusions can be seen in the PRISMA chart in Figure 1. These reasons included papers that were more than 10 years old, papers that studied the carers of individuals with ASD or DD only and papers in which the intervention aimed to teach skills or strategies rather than provide social support to family carers. This screening process resulted in seven papers being included in the current review.

Quality Appraisal

When reviewing literature, it is important to systematically assess the quality of included studies. This allows authors to determine how reliable the findings are before drawing broader conclusions about a research topic. Quality appraisal involves identifying the type of study, selecting a relevant checklist, comparing study methodology to the criteria, and summarising the results (Tod et al., 2022). Critical appraisal of qualitative research is made challenging by the lack of generic reporting standards and diversity in qualitative methodology (Clarke, 2022), and therefore a number of checklists are available. The aim of critical appraisal in this review was to explore the methodological standard within the papers and use this to evaluate bias and inform conclusions about findings within this field of research.

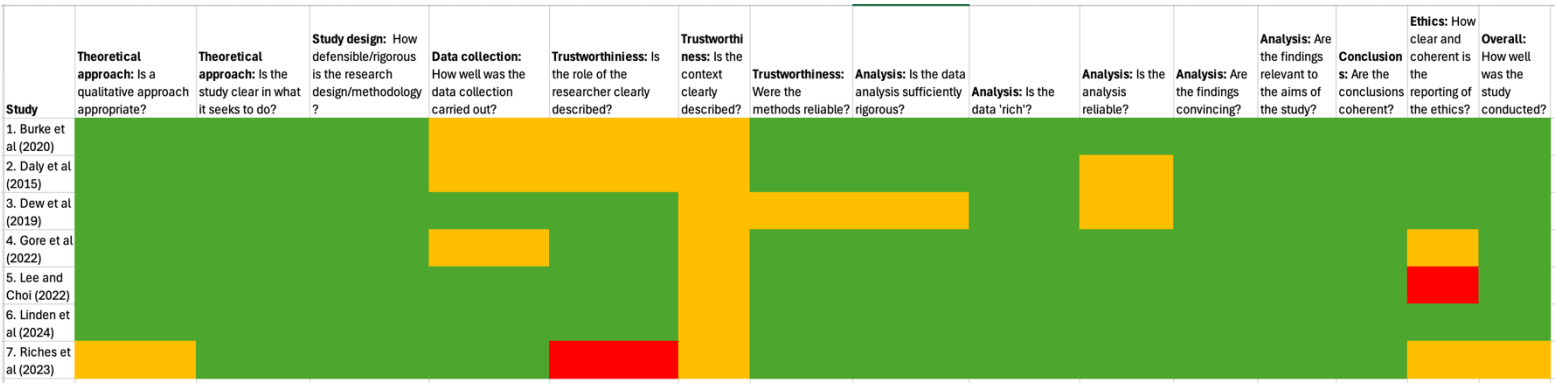
For the current review, the National Institute for Health and Care Excellence (NICE) Quality Appraisal Checklist (National Institute for Health and Care Excellence [NICE], 2012) was selected. This contains 14 questions assessing the validity and trustworthiness of studies, as well as method specific questions such as appropriateness of the qualitative approach and how rich the data is. The specific questions can be found in Appendix 1A. The author felt this

was a helpful tool to explore individual performance of studies, whilst reflecting on wider trends within the literature such as whether papers consistently fell down in one methodological area (Tod et al., 2022).

All included papers were read and scored against the checklist, using a RAG rating. Green indicated the criteria was met, amber indicated it was unclear and red indicated the study had not met the criteria outlined in the checklist. The results of the rating are shown in Figure 2. The RAG rating allowed the author to identify quality trends across the papers, without ruling papers out with arbitrary scores and labels (Tod et al., 2022). To ensure reliability of ratings the papers were read and scored against the checklist by two raters. The first rater scored all seven papers, then two were blind rated by the second rater. The two ratings were compared to determine if similar critiques were identified. This revealed the same overall rating that both papers were generally of good quality, however their reporting of ethics and clarity of the researcher role were unclear. The presence of a second rater is recommended to reduce impact of bias within the scoring (Higgins et al., 2011).

Figure 2.

Quality Appraisal for all seven papers



The findings indicate that the papers were generally of a good standard and met most of the quality criteria. However, methodological weaknesses were identified in two areas: trustworthiness and ethics. One paper (Riches et al., 2023) failed to clearly describe the role

of the researcher and was therefore rated as not meeting trustworthiness criteria. Similarly, a further three papers did not demonstrate clear reporting of ethics (Gore et al., 2022; Lee & Choi, 2023; Riches et al., 2023). All papers were given an amber rating for clarity of context as poor reporting standards limited the detail of individual characteristics described in the papers i.e., IQ scores. The author and the blind rater did not mark the papers as failing to describe context because some demographic information was included i.e., age, location and condition. The decision was made to include all seven studies in the current review as the papers that failed to meet a criteria only failed in one area and were generally of an acceptable standard in all other areas.

Participant Characteristics

The included papers were organised into alphabetical order and given a number from one to seven. Assigned numbers and important characteristics for each paper are displayed in Table 4.

Table 4

Allocated Number and Study Details for Each of the Included Paper

Author	Year	Focus/Aims	Context of Support	Location	Sample Size	Sample Context	% caring for ID/LD/GDD	Methodology	Analysis
1. Burke et al.	2020	Examine outcomes of a support program for siblings of individuals with IDD.	A psychoeducational group for siblings focusing on peer support, education and information. Support group ran for 15 hours across two days delivered by adult siblings of individuals with ID.	USA	21	Adult siblings of individuals with IDD. Average age 36, ranging from 21 to 67. Most female (71.4%) and most highly educated. 85% white.	76.2% ID	Questionnaires with open and closed ended questions	Thematic Analysis

2. Daly et al.	2015	Evaluate family support groups for individuals with ID. Included parents, grandparents and siblings.	Four support programmes for all family members, two parent led and two professional led. Mixture of evening and mid-week sessions for one year prior to interviews.	Ireland	21 interviews conducted from a total of 38 participants who responded to surveys	18 mothers, one sister and two fathers took part in interviews. 53% had a family member with ID, others had physical disability or autism.	52% ID	Open ended survey questions	Thematic Analysis
3. Dew et al.	2019	Mothers experience of participatin	Peer support programme co-designed by parents for family members	Australia	13	All mothers of children with ID from preschool age to young	100% ID	Semi-structured interviews	Thematic Analysis

		g in parent peer support programmes. Processes contributing to effectiveness of the programme.	of individuals with ID. Group provided access to training, social network, mentoring and social activities.			adult. Most in metropolitan area, most employed. Aged between 32-54.			
4. Gore et al.	2022	Explore family carers experiences of attending a support	Co-produced support group for families with a child with ID. Eight 2.5 hour sessions co-	UK	35	Majority were female (32), most participants White British or White Irish (33). Mostly birth/grandparents	60% of England sample GDD	Semi-structured interviews and focus groups	Thematic Analysis

group blending exercises, group discussions and information giving, outcomes of this and the processes that operated within the group.	facilitated with family caregiver focusing on providing information, group discussion and practical exercises.	(94%), one foster parent and one adult sibling. Mean age was 36.9 in NI and 38.8 in England. Children had variety of learning, physical and communication needs.

5. Lee and Choi	2023	Examine feasibility of parent support group sessions. Focus on how they perceive the meaning and role of the group and the feasibility	24 week support group for parents or caregivers of children with ID aged between 17-21. Aiming to encourage mutual support through small group activities and discussions.	South Korea	29	Family carers of individuals with an ID and enrolled in a special school. Age ranges from 28 to 58. Mothers (96.6%), one sister.	79% ID	Individual interviews and focus groups	Thematic Analysis

		of the programme.							
6. Linden et al.	2024	Exploring acceptability of a new online support programme for family carers of individuals with Profound Intellectual and	A 14 module co-designed online support programme for family carers. Covering topics including mental wellbeing, family relationships and accessing support.	UK and Ireland	70 survey respondents, 10 interviewed	All family carers – 47 female and 23 male of which 36 were mothers, 17 fathers, one grandparent and 11 other family relations including siblings. Mean age 40 years, 24-65. Of the ten in interviews seven	100% profound and multiple ID	Semi-structured interviews	Thematic Analysis

		Multiple Disabilities.				were female, nine were parents and one was a sibling.				
7. Riches et al.	2023	A caregiver support service was evaluated for coping and resilience, impact of strategies for support and satisfaction	Carer support service led by a not for profit organisation for families of individuals with ID. Aimed to increase caregiver capacity, provide resources and support family needs.	Singapore	36 interviews (328 in full study)	Caregivers - parents, siblings, aunties or grandparents of individuals with ID. 50% were fathers, 36% mothers and 14% siblings. Age ranges from 31 to 70 years. Five different ethnic	100% ID	Interviews and focus groups – open ended questions	Content Analysis	

	with services.	backgrounds - Chinese, Malay, Indian, Filipino and Sri Lankan.

All papers included in the review were published within the last 10 years. With the most recent paper being published in 2024 (Linden et al., 2024) and the oldest paper published in 2015 (Daly et al., 2015). There was a broad geographical spread of papers, focussed on the developed world. There were a total of 165 participants that provided qualitative data across the seven papers. The smallest sample size was 13 participants and the largest was 35. From the demographic information available, at least 127 of these participants were female and 32 male. This does not include papers where participants were described as 'siblings' and gender was unspecified (Riches et al., 2023). All family carers were either a parent, grandparent, sibling or foster parent. The known ages of participants ranged from 21 to 70 years old.

Broadly, the papers aimed to explore the experience of support groups, either peer, self-help or mutual support, from the perspective of family carers of individuals with ID. It is important to note that while the focus was on family carers of ID, some papers included a mix of ID and other disabilities. For these papers they were included if more than 50% of the sample were described as caring for individuals with ID/LD/GDD. As stated above in the inclusion criteria, where it is clearly described in the paper that data relates to a carer of an individual without an intellectual or developmental disability, this data has not been used in the analysis. For example, in the paper by Burke et al. (2020), the condition of the individual being cared for was given as context for the quotes and where this related to an individual with Cerebral Palsy or Down Syndrome, this was not included in the synthesis. Furthermore, the paper by Gore et al. (2022) coded the data to indicate whether the participant was from the Northern Ireland (NI) sample or the England sample. In the NI sample only 32% of participants cared for an individual with GDD and therefore this data was not included in the synthesis. In some instances the author was limited by the level of detail provided in the individual papers, and therefore it was not always possible to exclude all of these quotes.

The methodology for the studies is also displayed in the demographics table above (table 4). A mixture of open-ended questionnaires, semi-structured interviews and focus groups were used to collect the qualitative data within the papers. With regards to analysis, Thematic Analysis was the most common, utilised in six of the seven papers.

Data Extraction

As per Sattar et al. (2021) step three in the meta-ethnography process relates to reading the studies, becoming familiar with the data, and extracting raw data to inform first and second order constructs. The author became familiar with the content of the papers and then extracted key information, including demographics, into a standardised data extraction spreadsheet using Excel (Appendix 1B). This included study characteristics, methodology and key findings. Once the author was familiar with the studies, verbatim data from each of the individual studies was extracted, along with themes and subthemes from each paper (Appendix 1C). Across the seven papers there were 58 themes and subthemes presented. These themes were supported by direct participant quotes (first order constructs), and verbatim interpretations from the authors (second order constructs). On the data extraction spreadsheet, colour codes were used to identify first order constructs (red) and second order constructs (green). Including both first and second order constructs ensured the context of the data was maintained during analysis and synthesis. During this extraction the author made comments on the data which formed third order constructs, these were displayed in a separate column on the data extraction spreadsheet.

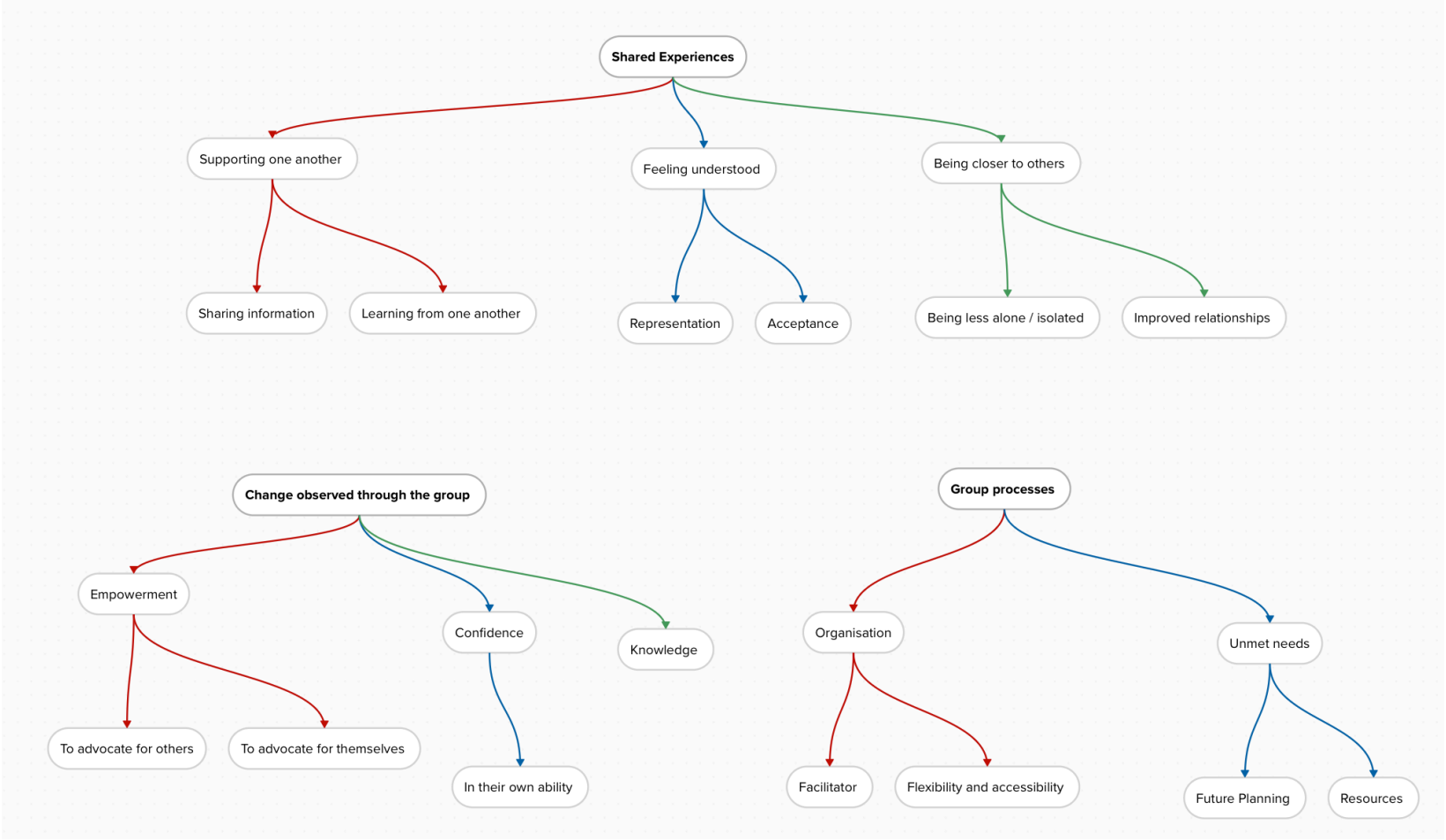
Data Analysis and Synthesis

Data analysis and synthesis began by following Sattar et al. (2021) step four and five of conducting a meta-ethnography. This involved considering the relationship between studies by reviewing all themes and sub-themes from the papers and identifying similar

concepts across the papers. A concept relates to an idea that developed through the comparison of different instances and the need to explain, rather than just describe the data (Sattar et al., 2021). After reading the key themes and the verbatim data, the themes were grouped together and coded based on similarity, and links were made by colour coding similar patterns and findings (Appendix 1D). In papers with a mixed sample (ID/LDD/GDD and other disabilities), where carers of individuals with ID/LDD/GDD had not contributed to a theme this was not included in the analysis. The author then made notes about possible connections and drew together the similar themes colour coded and highlighted, identifying new concepts emerging across the papers (Appendix 1E). First and second order constructs from the data extraction grid were then reviewed, along with the context of studies, to help develop these emerging concepts and ensure they were faithful to the data. At this stage, the author's third order constructs were reviewed to further develop the concepts (Appendix 1F). Initially, five main concepts and 13 subthemes were identified (Appendix 1G). Once a relationship between the themes in the papers had been identified, the author made note of the emerging concepts, this formed the basis of the translations (Sattar et al., 2021). The author then followed phase five (Sattar et al., 2021) and created an extraction grid with the overarching themes, including first and second order constructs (Appendix 1H). These emerging concepts were then revised again after re-reviewing the first and second order constructs within each subtheme (Appendix 1I). This resulted in three main concepts and eight sub-themes (Appendix 1J). Figure 3 below displays a thematic map of the emerging concepts and sub-themes.

Figure 3.

Thematic Map of Emerging Concepts and Sub-Themes



The next stage followed step six, synthesising the translations (Sattar et al., 2021). At this stage the author considered whether the synthesis was reciprocal, refutational or line of argument. The author began by narratively summarising the first and second order constructs for key themes in paper one. This was then compared to the constructs from paper two, and then so on for each of the seven studies. Once all papers had been compared, a synthesis of interpretations was created. Based on the similarities within the concepts across the papers, it was felt that a line of argument synthesis was appropriate, in which a storyline of the themes is produced to understand the concepts beyond each individual study. An example of this line of argument synthesis for Theme 1 (Shared experiences) is shown below in Figure 4.

Figure 4

Extract from Line of Argument Synthesis of Theme 1 – Shared Experiences

Line of argument synthesis

Theme 1: Shared Experiences
Papers: 1, 2, 3, 4, 5, 6, 7

Findings from paper one indicated that participants felt the value in being able to share information with others, as well as learning from others. This was particularly beneficial when they connected with others in a similar situation to their own, creating opportunities for bonding and understanding. It was important to group members that they felt represented by individuals in the group. This allowed them to feel less alone, developing awareness that others were in the same situation and that they had people to turn to for support. Similarly, in paper two participants highlighted being able to make connections with others in the same situation. This created a strong sense of belonging and mutual support. This resulted in improved family relationships and communication at home. In paper three participants emphasised the value of sharing information and learning from others. They felt that matching with peers in the dame situation to theirs was beneficial. They also described the benefits of a closed group creating a safe and non-judgemental space. This made it easier for them to share their own experiences, allowing them to build relationships with others and feel less isolated. Paper four further highlighted the benefit of sharing information with others and the value of giving and receiving information. Where similar experiences were shared participants felt understood and accepted. This reduced feelings of isolation. Paper five highlighted the benefit of group participation in reducing isolation through an increased sense of bonding and connecting with others. This paper highlighted the importance of feeling their own situation was represented in the group, allowing people to form stronger connections. Representation was also a key theme in paper six. Participants appreciated feeling understood, which occurred through shared experience and characteristics. Information provided in the group felt more helpful when it came from people who appeared similar. Reducing social isolation through connecting with others was a further theme in this paper. Finally, paper seven included the importance of bonding and sharing experiences to help people feel less alone. Being able to receive support from others with a shared experience was a notable benefit of group attendance.

Reflexivity

In line with a social constructivist theoretical framework, the author acknowledged the influence their perspective could have on the interpretation of the data. Therefore, throughout the analysis the author kept a reflective log as recommended by Soundy and Heneghan (2022). During the extraction and analysis phases, the reflective log allowed the author to critically consider alternative interpretations of the data and ensured transparency in

the decision making process. When beginning to synthesise emerging concepts, the author documented their reasons for arriving at each overarching theme. This reflexive process provided a clear outline of how translations developed over time (Soundy & Heneghan, 2022). An extract of this reflective log is included in appendix 1K.

1.3 Results

Below is a summary of the meta-ethnography results. Synthesising the papers resulted in three key themes identified. First, family caregivers who attended support groups reported the benefits of sharing experiences with others in the same situation. They also spoke about the change they experienced through attending the support group and reflected upon how they experienced the group processes. These key themes as well as the sub-themes can be seen in Table 5 below. The number of occurrences of the theme across the seven papers was also noted, along with which papers they occurred in.

Table 5

Key Themes Across the Papers

Key Themes	Occurrences	Paper
Benefits of Shared Experience - Supporting one another - Feeling understood - Being closer to others	7	1, 2, 3, 4, 5, 6, 7

Changes observed through group attendance - Empowerment - Increased confidence - Knowledge	7	1, 2, 3, 4, 6, 7
Group Processes - Organisation - Unmet needs	5	2, 3, 5, 6, 7

Theme 1 - Shared Experiences

Across all the papers, group members reflected on the value of being with others who shared the experience of caring for a family member with Intellectual Disabilities (ID). These shared experiences were described as particularly powerful and lead to benefits grouped under three subthemes: Supporting One Another, Feeling Understood and Being Closer to Others.

Subtheme 1 – Supporting One Another

Across the papers participants valued mutual support from other group members, citing the main meaning of the group as *"empathising"* and "*offering psychological sympathy*" (Lee & Choi, 2023 p. 1183). They consistently described the positive feeling of being able to share their learning and information with others. As one participant explained, they could *"Act as a conduit to share the resources, information and support"* (Burke et al., 2020 p. 87). This mutual support took place both online (Dew et al., 2019) and during face-to-face group meetings (Gore et al., 2022). Participants also noticed the benefit of being able

to share resources and advice with people outside the group, in their wider support networks (Linden et al., 2024). Importantly, most participants viewed sharing information with others as mutually beneficial, they were grateful to receive the advice and being able to give it to others "*The family bonding activities do provide us a platform to contact with other caregivers – share our parent-child experiences with each other*." (Riches et al., 2023 p. 123).

The opportunity to learn from one another was particularly valued when peers had relevant lived experience, *"The older participants provided a wealth of knowledge but more importantly, inspiration for us younger participants"* (Burke et al., 2020 p. 87). Learning also came through reflection from others, with one participant describing how their peers challenged their perspective.

> *I just found it really interesting seeing how people looked at things and how I needed to broaden my perspective on things. They caught me out and questioned me a couple of times with some of the ways that I looked at things and I thought that was really good. It helped me learn. I really liked all the opportunities for training.* (Dew et al., 2019 p. 352).

Supporting one another appeared to move beyond exchanging practical tips and resulted in carers feeling competent and valued.

Subtheme 2 – Feeling Understood

A key benefit of shared experience was the sense of being understood. Unlike interactions with friends, caregivers felt comfortable sharing with their peers, *"I have friends who can only pity me. But with fellow caregivers, we really feel we know our problems together."* (Riches et al., 2023 p. 123). Representation appears to be critical to this sense of

understanding*, "I was also pleased to hear regional voices. Accents that I could recognise as being my own. People I could identify with"* (Linden et al., 2024 p. 10). Whether it was regional accents or a male voice, representation allowed participants to feel valued and recognised (Linden et al., 2024). Peer matching based on caregiving circumstance was utilised in some groups and appeared to further enhance this sense of recognition (Dew et al., 2019). This shared understanding created feelings of acceptance for participants. Representation and acceptance appeared closely intertwined, feeling represented by others in the group created a safe, non-judgemental space where carers could share openly, *"I can't say these things to my mum or my friends because they would be worried about me"* (Gore et al., 2022 p. 893. This non-judgmental stance of groups was repeatedly emphasised, particularly when facilitators had lived experience themselves. This mutual understanding appeared to allow participants to speak openly, without fear of reaction (Gore et al., 2022). Family carers recalled situations when they experienced discrimination from families who didn't understand. However, the groups became a space where they could share frustration and challenges, trusting that others would understand.

> *Most of the time when you post in [parent peer support program Facebook group] people will offer suggestions and stuff like that, but they understand more that you've probably already tried everything. You don't get judged at all. I think when you've got a child that's challenging, one of the biggest barriers you have to reaching out is being judged.* (Dew et al., 2019 p. 351)

Subtheme 3 – Being Closer to Others

A final subtheme that emerged as a benefit of shared experiences was the sense of closeness developed with peers, which reduced feelings of isolation. For some this included

feeling less alone in their role as a carer and an improvement in their family relationships, *"I know that I have a group of people I can turn to"* (Burke et al., 2020 p. 86). The groups provided a space for carers to build connections with one another. By connecting with other people with shared experiences carers felt they were not alone and experienced encouragement from those in a similar position to them (Lee & Choi, 2023).

> *Well I found a huge benefit was meeting other parents... whilst I know that's not, you know, possibly the initial objective of having a workshop or a meeting I think that's definitely a secondary benefit and turns out to be hugely beneficial because ... you start talking to other people and you get a sense of kind of 'I'm not on my own here', you know, and you can actually make contact with people.* (Daly et al., 2015 p. 45)

These connections sometimes developed into friendships, something which further alleviated isolation, *"I don't have many friends, but I feel like they're my friends. I know we're all [in] an organisation but we are all friends because we all support each other"* (Dew et al., 2019 p. 353).

The development of these relationships appeared to further increase the sense of closeness to others.

> *I don't feel like I'm in this on my own. I don't feel so isolated and so removed from the rest of society. I stopped going out. I stopped seeing people. I don't feel like that anymore because they [peer support program] give me that boost.* (Dew et al., 2019 p. 349)

This reduction in isolation often translated into wider benefits, such as increased resilience, willingness to seek support and greater optimism about managing future challenges (Riches et al., 2023). Some participants reported that group support gave them a motivation to re-engage socially (Dew et al., 2019) and feel more hopeful about their role

(Daly et al., 2015). Others stated that group attendance provided relief from everyday pressures and social isolation, as well as allowing time to be spent with other family carers (Dew et al., 2019; Lee & Choi, 2023). In some cases, family relationships and communication within the home also improved through joint attendance at the support group, *"So by him [husband] attending the meetings with me, he was included in the thought process and in the vision going forward and he really took to it"* (Daly et al., 2015 p. 45).

In summary, the experience of attending a support group with individuals in a similar situation to their own allowed group members to develop connections with others and feel that they were understood. Because of this, carers perceived the group to be a safe and non-judgemental space where they could openly share concerns, as well as give and receive support.

Theme 2 – Changes observed through group attendance

The second overarching theme from the synthesis was the changes in confidence, knowledge and empowerment family carers experienced through attending the support groups. Together these factors enhanced carers' ability to support themselves and their family members.

Subtheme 1 – Confidence

Family carers' confidence in their own ability was one element that appeared to change through attending the groups. Carers reported gaining confidence and new ways of thinking, often adopting a strengths-based perspective in how they view themselves and their family member.

> *Actually, we've reviewed everything she's doing with a view to the sort of positive things that are happening in her life and about the building of friendships, the building of her social side and ... we've been supporting that.* (Daly et al., 2015 p. 44).

Furthermore, participants described how group support increased their self-confidence and esteem, which led to a stronger sense of identity and belief in their own abilities. For example, participants explained how being encouraged to speak at events, despite initial reluctance, changed how they viewed themselves.

> *We'd go to talks and they'd [program staff] ask me to talk and I'm not a very good public speaker ...I didn't like it at the time, but when I done it, I was like, wow, I can do that. I've done that. I'll still never be a public speaker, but it's made me feel more than just a mum as well. It's given me something for myself.* (Dew et al., 2019 p. 352)

This change also shaped carers' self-perception as parents, *"It's helped me understand that I'm actually a good mum. It's given me that confidence you know?"* (Gore et al., 2022 p. 894). It appears that this altered perception allowed participants to feel more confident in their ability to care for their family member.

> *When you used to think, oh my god, you are in melt down, thinking I'm doing an awful job and I have then days when I think I wish I could help them more, I wish I could do more for my children. But this has helped me get that, that confidence. I am really doing a good job.* (Gore et al., 2022 p. 894).

Subtheme 2 – Knowledge

Participants often described leaving the groups with more knowledge than they arrived with, as noted by one participant, *"I did not know that there are so many resources out there"* (Lee & Choi, 2023 p. 1183). An increase in knowledge was consistently reported across papers and linked to feelings of capability, *"The more knowledge you have the more you can do with it"* (Daly et al., 2015 p. 42). For some, this involved learning new coping strategies and ways of responding to challenging behaviours (Gore et al., 2022).

> *I just put the breakfast in his mouth but now, where now, I actually decide to say 'let's put one sock on and you do the other sock.' So I have started doing that so that's really helpful..* (Gore et al., 2022 p. 895).

Learning was often described as most effective when it was active and facilitated through group discussions *"Listening to lectures or guest speaker sessions is a passive way of learning. But it becomes a more active way of learning when we share the learning with each other based on the books and resources"* (Lee & Choi, 2023 p. 1184). Participants also valued practical information and guidance about caring for their family member, *"Talks on leaving a financial means to take care of person with disability etc. have helped a lot*" (Riches et al., 2023 p. 123). Some explicitly identified knowledge gaps they hoped to address in future workshops, *"I feel that I have still a lot of skills I do not know about ... how to teach my daughter and would like to attend more workshops in this aspect"* (Riches et al., 2023 p. 124). This included knowledge about caring for their family member in the future (Linden et al., 2024). When relevant information was not available, participants reported feeling disempowered and uncertain about how to support their family members (Riches et al., 2023).

Subtheme 3 – Empowerment

As well as experiencing changes in confidence and knowledge levels, carers reported feeling more empowered to advocate for themselves and their relatives. This included family members beginning to recognise themselves as a resource (Burke et al., 2020), and the need for self-care, *"Right now, what you need is to look after yourself"* (Dew et al., 2019 p. 349). Across the papers participants acknowledged the power they had to make these changes, *"In order to give [child's name] independence and go from being a guardian to a supporter, I*

started thinking about "How should I change, and how should I create my environments?" (Lee & Choi, 2023 p. 1183). For some the need to advocate for their own wellbeing was still motivated by how able they were to care for their family member.

> *What the session taught me is two things, one is I have to look after myself, coz who is going to look after [name of child], it isn't about just me soldiering on I actually have to look after myself coz I have got somebody else to look after as well and for your own mental wellbeing you've got to.* (Gore et al., 2022 p. 894).

Advocacy extended beyond the personal, to social and political spheres, with participants motivated to strive for collective action, *"With the power of the individual, Dream Road may not be sustained. But with the power of the group, we could solve problems and change the system"* (Lee & Choi, 2023 p. 1183). For some carers this action was directed towards communities.

> *"She [the trainer] also discussed what inclusion was. . . which I think is very important. . . where children have a right, especially in a pre-school setting, to be able to be involved and to play alongside a non-disabled child" (Daly et al., 2015 p. 42).*

Whereas others described feeling empowered to speak directly to professionals, *"[I hope to] connect with more legislators to get the needs of our siblings to become a higher priority"* (Burke et al., 2020 p. 87). Importantly, empowerment was not only experienced individually, but also collectively. By joining with others, carers described feeling able to push for systemic change and hoped to share this motivation with others (Burke et al., 2020).

In summary, group attendance led to carers observing changes in themselves in multiple aspects. The support groups led a development in carers' confidence and their ability to acknowledge their own capabilities. This appeared to be facilitated by learning in the group impacting their perceived level of knowledge. As a result of attending the groups carers

described feeling a sense of empowerment to advocate for themselves, and others. The motivation of which appeared to be to provide better care for their family members.

Theme 3 – Group Processes

The final concept to emerge from the synthesis related to the way groups were structured and delivered, as well as unmet needs identified by participants.

Subtheme 1 – Organisation

Participants valued a clearly defined agenda for the group, outlining the purpose and reasons for being there (Lee & Choi, 2023). Across papers, the information and resources provided during the support group were valued (Riches et al., 2023), particularly when these were easy to access across different platforms, *"I like the fact that they make things that you can revisit, the videos and the training and the resources and things"* (Dew et al., 2019 p. 352). The ability to access information in their own time was highlighted in other papers and appeared to ease some of the pressures and demands faced by carers, *"you could go to whatever was relevant to you at that particular time"* (Linden et al., 2024 p. 8). It was important that the accessible information was comprehensive, *"To me it was very well thought out. As I say, the topics covered, I think. . . the siblings who are carers will relate to some people. So they tried to cover all angles"* (Linden et al., 2024 p. 8).

Small group sizes were particularly valued, as they enabled meaningful conversations. However, it was also acknowledged that some people would want to take more of a listening role rather than sharing their own experiences. In this case practical tips were beneficial, "*Practical tips are very much helpful, because some people don't want to ask others … they don't want to share their feelings, thoughts, to others. So yeah, tips, some practical tips are also helpful."* (Linden et al., 2024 p. 8). Flexibility was also important in session delivery, as some carers needed to attend sessions outside of working hours*, "Besides, it would be better*

if the workshops are conducted at night and on weekends as most caregivers are not free on weekdays" (Riches et al., 2023 p. 126).

The relevance and authenticity of facilitation mattered and paid coordinators were also seen as essential for ensuring continuity and support.

> *She's doing all that background work that's so important, like ensuring that everyone does stay connected ... sometimes the families that need the most help don't ask for it. So, she's the one who's there to make sure – 'You haven't checked in. Is everything okay?* (Dew et al., 2019 p. 350)

Subtheme 2 – Unmet needs

In addition to the benefits of the group, participants identified unmet needs and commented on how the groups could be improved. Several participants wanted structured follow-up points after the group ended to support maintenance of connections made in the group, *"Maybe to meet up once a year ... You made a lot of friends during these courses and it is one way to keep in contact"* (Daly et al., 2015 p. 46). Similarly, it was suggested that having an action plan for the end of the group would have been beneficial (Lee & Choi, 2023).

Critiques were also offered about information provided during sessions, which at times felt too generic and lacking detail (Linden et al., 2024). As well as how information was provided, with participants believing they could have benefitted from clearer boundaries within the group and additional training for supporting one another, *"Some really strong guidelines and boundaries on what actually that [being a family partner] is and how that looks. Then the training should be about staying within those boundaries as well"* (Dew et al., 2019 p. 354).

Group members offered recommendations for group improvements, and this included altering when the groups were delivered to participants (Linden et al., 2024; Riches et al., 2023), and language used to define the group. Finally, while relational needs such as belonging and acceptance were met through the groups, practical needs including respite care and practical resources remained unmet. Family carers identified needing support to relieve some of the everyday pressures of caring, as well as emotional support through the support groups, "*We (as the mother and father) need to have respite, for a week or two, from having to take care of our son … his half-day at (organisation's) workshop is a great help."* (Riches et al., 2023 p. 125).

In summary, when discussing experiences, participants reflected on the group process. They described valuing groups that were accessible, flexible and provided relevant information. The role of a facilitator was valued, with this being most powerful when the facilitator had lived experience. Participants also shared reflections on how groups could be improved to meet their unmet needs, acknowledging the ongoing pressures faced by family members.

1.4 Discussion

This meta-ethnography aimed to explore how support groups are experienced by family carers of individuals with ID, specifically focusing on helpful and meaningful aspects of the group. Results of this meta-ethnography highlighted three key themes that emerged from the data. The benefit of a shared experience with others in their position was identified, as well as the different changes that occurred for the carers through attending the groups. The third theme was how the carers experienced the group process and any unmet needs they had.

Across all papers, the family caregivers reported that they benefitted from the shared experience element of the group, similar to the findings from Chakraborti et al. (2021).

Namely, the benefit of being in a space with other family carers who understand the experiences they have had. Previous research has highlighted the importance of information being provided in these groups (Riches et al., 2023) and the current synthesis highlights how particularly beneficial this is when information comes from individuals who have the same lived experience. The effectiveness of perceived sameness has previously been identified (Chakraborti et al., 2021), and in the current review it emerged that feeling represented allowed participants to feel understood by their peers, and therefore were more able to openly share in the group. By being open with the group, the participants felt valued and accepted, which was further enhanced by seeing their personal characteristics represented in group information. Feeling valued has previously been highlighted as a need for family caregivers (Chadwick et al., 2013), therefore the confirmation of this in the current review is important to consider in future service developments.

Participants also described the dual aspect of support in the group, as family caregivers became motivated towards providing support and advice for others (Gore et al., 2022), rather than primarily seeking support for themselves. This may reflect a move from egoism, focusing on alleviating their own distress, to empathic concern, where the wellbeing of others and ways of helping them became their focus. According to Batson's empathy-altruism hypothesis (Batson et al., 1987, 2015), this move suggests that carers began to experience empathy for others, which motivated their altruistic behaviour to support others, independent of the need to reduce their own distress. This effect may have been enhanced by caring for family members that are facing similar challenges. Furthermore, this finding may indicate an increased sense of wellbeing for these carers, which has been linked to helping others (Oarga et al., 2015), particularly when the motivation behind this helping is intrinsic (Weinstein & Ryan, 2010).

A key factor that allowed openness in the group was the non-judgmental stance taken by individuals with shared experience. Unfortunately, carers of individuals with ID often face discrimination and stigma from the general public (Mitter et al., 2019), and it was important that these groups provided a space where this was not present and carers felt supported to develop a more positive identity. The final element to emerge from the benefits of shared experiences was a developed sense of closeness to other people through attending support groups. Primarily, family caregivers felt that being supported by others in a similar situation to their own, and being able to support them, created a sense of connection to others. Participants reported developing connections with other family members which often changed from a peer relationship to friendships. They highlighted that having these connections reduced the isolation they felt. This is an important finding given previous research has highlighted the increased rate of isolation experienced by carers (Thompson et al., 2014). As participants no longer felt that they were alone with their difficulties they also felt more able to seek support from others. This provides a helpful insight into the effect of support groups, as family caregivers have previously been less likely to seek emotional support from others (Bujnowska et al., 2021). This sense of closeness also translated to family relationships, with participants reporting that joint attendance in the group improved communication and relationships in the family home.

The second key concept to emerge from the synthesis was participants experiencing a sense of change through group attendance. Different aspects were changed, including their confidence, level of knowledge and sense of empowerment. Personal changes were described by the participants, many felt that through gaining information and resources in the group, they developed their own skills and agency. Assertiveness, competence and self-efficacy all improved as a result. This demonstrates how support group attendance can be linked to an increase in their self-efficacy, namely the belief in their ability to implement changes

(Bandura, 1977) with some describing this as a change in their sense of self (Gore et al., 2022). As group members' knowledge and beliefs about themselves changed, this led to a change in how they view others, namely their family members with ID. Participants reported feeling more positive about their family members abilities, and felt they were better able to cope with behaviours they previously found challenging. The benefit of receiving practical knowledge from the groups was also highlighted across papers, with participants reflecting on how disempowered they were when they felt unequipped to support their family member with ID.

Linked in with this change, group members described a change in their style of thinking, whereby they became more motivated and empowered to advocate for their family members, and for themselves. It appeared that attending the group changed how participants viewed themselves and their ability to create change. They began to think about collective social and political action that could be taken. Collective action describes the phenomena in which an individual from a group works to improve the conditions for the group (Wright, 2010), in the current review this relates to family caregivers beginning to consider improving the experience of others in their situation. This often happens through the formation of a collective identity (Wright, 2010), in the current case this was likely through spending time with individuals with shared experiences. According to Social Identity Theory (Tajfel & Turner, 1979), this can be driven by developing a shared identity with the group, fostered by connecting with others with similar experiences to their own. Identifying with others in the group can impact self-efficacy, which is further increased if the group has shared demographic characteristics with the individual (Guan & So, 2016).

The final concept to emerge from the synthesis related to how the group process was experienced by participants. This included organisation of the groups and any needs that remained unmet. Broadly, participants found having an agenda and clear, accessible

information was beneficial for the functioning of the group. Across papers the participants highlighted the time pressures they face. They noted that adapting group timing and flexibility to access information in their own time eased this pressure. The role of a coordinator (preferably with lived experience) was an additional factor greatly valued by participants. Unmet needs across the papers related to information provided within the group being too generic and no follow-up support after groups ended. The synthesis revealed that when information provided is too generic or impersonal, it can be received negatively by group members. As highlighted in the first theme, the participants greatly valued the connections they made through meeting with others with shared experiences. It was reported that support to maintain these connections after the groups ended would be highly valued by participants.

These results appear to indicate that support from others empowers and provides confidence which then enables individuals to value their knowledge to support themselves and others. This is done within a framework where certain characteristics can amplify this impact, such as a clear agenda and facilitators with lived experience.

Clinical and Research Implications

The current review demonstrates how support groups can be positively received by family carers of individuals with ID. It is vital that these results are used to develop current service provisions, as previous research has highlighted a failing in service provisions to meet carers needs (Resch et al., 2010). One important recommendation is increasing the availability of social interactions for family carers. Previous research highlighted this (Felizardo et al., 2016), and the current findings further support this recommendation, as family caregivers report feeling less isolated and alone after attending support groups. Facilitating spaces in which family carers can socialise with individuals with shared experience could also serve to reduce some of the stigma this group of individuals experience (Mitter et al., 2019). The

results further support the rationale for implementing support groups in services as empowering carers may lead to less professional support being required, if they felt more knowledgeable and confident in their own capabilities. If a service was considering implementing a group in which family carers could seek support from one another, these findings provide useful insight. They highlight structure, accessibility and relevance as important elements for effective group functioning. This includes; clear organisation, a specific agenda and flexible group delivery that considers the time constraints family caregivers experience.

The current review suggests that family caregivers experience an increased sense of value and acceptance through spending time with others in similar positions. This is a significant finding, as previous research has indicated that carers consistently feel undervalued and not listened to (Chadwick et al., 2013). The current findings highlight the need for ID services to prioritise implementing a space for carers to share their experiences, in turn prioritising their emotional well-being, which we now understand can be improved through support groups. Furthermore, through attendance at support groups, family carers experienced an increase in agency and self-efficacy, promoting identity growth. This resulted in carers emerging as empowered advocates, motivated towards collective action. Future support groups should strive to continue increasing self-efficacy in carers, as it may reduce carers stress (van Wingerden et al., 2018) and increase their satisfaction with the caring role (Shrestha et al., 2021). The importance of this is highlighted by research indicating the benefit of effective carer interventions for improving the outcomes of individuals with ID (Bunga et al., 2020).

Amongst the many support group benefits highlighted in the results section of this report, an increase in altruism was demonstrated which would benefit from further exploration. Previous research has demonstrated that altruism is linked to an increased capacity for empathy towards others and can result in improved mental wellbeing for individuals (Irani,

2018). It would therefore be interesting to understand if support groups that aim to foster empathy towards others are effective at improving mental wellbeing of carers. A further interesting topic for future research could be the link between increased carer confidence and a wish to share experiences.

Finally, future researchers should prioritise including carers voices when conducting research and developing services. Given the evidence that carers are motivated to become involved in collective action (Lee & Choi, 2023), including carers in service development and research could provide such opportunities. This recommendation echoes suggestions made by individuals exploring the experiences of family carers of individuals with ID in Singapore (Ee et al., 2022). Having a named member of staff responsible for liaising with carers and facilitating communication with staff would be an important step towards inclusion, as research suggests communication between staff and carers can be a barrier to carers involvement in service design (Walker & Dewar, 2001). Additionally, it may be beneficial to forge links with carer organisations to focus on developing support groups in combination with family carers. Involvement in service design is especially important given the change in an individuals' needs over time and the strong knowledge, expertise and advocacy family carers can bring (Bradley, 2015).

Evaluating the Review

A strength of the current review is the diversity of the included studies. The selection criteria allowed for papers from different countries, increasing the generalisability of the findings. This included international literature from South Korea and Singapore, which can be considered developed countries, with service provision for individuals with ID. However, it is acknowledged that cultural views on intellectual disability may vary across the included countries, and systemic differences in how services and supports are structured may also shape the experiences of relatives supporting people with Intellectual Disabilities. Therefore,

the results must be interpreted with this in mind. Furthermore, papers including participants with various relationships to the person with ID/LD/GDD (parent, grandparent and sibling) were included, offering a unique perspective as previous research has focused predominantly on mothers, limiting the generalisability of findings to other relations (Shoesmith, 2024). Similarly, this review sought to include multiple types of support groups, linked by the aim of providing social support to family carers of individuals with ID. This review was further strengthened by the design in which interpretations made during the synthesis were reviewed with the researcher and their supervisor, as well as in peer researcher workshops, adding to the reliability of the synthesis. Finally, the key themes in the synthesis were all found in the vast majority of papers, suggesting that they are robust in construction.

The meta-ethnography methodology means that the current review may be limited by the flaws, and reporting standards, of the individual studies included. For example, the quality appraisal checklist highlighted that some studies within this review were limited by their reporting of ethical considerations (Gore et al., 2022; Lee & Choi, 2023;). The decision was made to include these papers to ensure the review was as comprehensive as possible, and whilst it can be considered a limitation, due to being published research, it is likely journals would have confirmed ethical conformity. Similarly, the quality appraisal checklist revealed the nature of the relationship with the researcher was unclear in some of the papers (Burke et al., 2020; Daly et al., 2015; Riches et al., 2023), which could have led to a bias in the results of the paper and in turn a bias in the conclusions of the current review. The review sought to understand the experience of support groups for family carers of individuals with ID. However, due to limited research in this area and poor reporting of demographic data across papers, some papers included in this review had a sample consisting of family carers of individuals with ID and Developmental Disabilities (DD). Where a paper included a mix of diagnoses, a minimum of 50% of the sample had to be caring for an individual with an

ID/LD/GDD. Where reporting standards would allow, only data from the carer supporting an individual with ID was included in the review. Despite the authors efforts to minimise the impact of these mixed samples, it is important to consider this when interpreting the findings of this review, and acknowledge the potential impact on the ability of the synthesis to specifically answer the research question posed.

It is also important to note findings from the papers may have been presented favourably, as some participants were current members of their support group and therefore may have wanted to portray the group in a positive light. Additionally, they were self-selected participants as they had elected to attend the group. Researcher bias may also have influenced which papers were included in this review, given the researchers were interested in understanding the helpful and effective aspects of support groups. However, it is hoped that the systematic search strategy employed by the researcher counteracted this bias in the selection process (Higgins et al., 2024). Reflecting on the search strategy, the author acknowledges that obtaining papers from citation searching may have identified older papers (Hiebl, 2023), however the author felt it was important that the review was as comprehensive as possible and therefore chose to include such papers. The number of included papers was below the average (Soundy & Heneghan, 2022), and therefore may have limited the generalisation of interpretations, however it did allow the author to gain sufficient familiarity with individual papers (Campbell et al., 2012).

Conclusions

The current paper used a meta-ethnography approach to offer new insights into the experiences of family caregivers of individuals with ID who attend support groups. A systematic search revealed seven relevant, qualitative papers exploring this topic, from which three key concepts emerged. The synthesis confirmed the emotional and relational value of attending support groups and spending time with other family carers with shared experiences.

It also highlighted how group participation fostered shifts in identity and perception among family caregivers, leading participants to feel a greater sense of confidence and thus motivation to achieve wider systemic changes. The sense of understanding gained within the group allowed them to feel supported and less alone. The final theme related to factors of group functioning that members found beneficial and what was missing from groups.

Taken together, these findings suggest that groups are not just a space for emotional release, but can serve to impact personal transformation in carers. There is a clear need for services to prioritise carefully structured and well-facilitated groups that respond to the needs of carers. Organisations would benefit from drawing on these insights to develop effective support groups for family caregivers.

References

Ali, A., Hassiotis, A., Strydom, A., & King, M. (2012). Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in Developmental Disabilities, 33*(6), 2122-2140. https://doi.org/10.1016/j.ridd.2012.06.013

Bandura, A. (1977). Self-efficacy: toward a unifying theory of behavioral change. *Psychological Review, 84*(2), 191-215. https://doi.org/10.1037/0033-295X.84.2.191

Batson, C. D., Fultz, J., & Schoenrade, P. A. (1987). Distress and empathy: Two qualitatively distinct vicarious emotions with different motivational consequences. *Journal of Personality, 55*(1), 19-39. https://doi.org/10.1111/j.1467-6494.1987.tb00426.x

Batson, C. D., Lishner, D. A., & Stocks, E. L. (2015). The empathy-altruism hypothesis. In Schroeder, D. A., & Graziano, W. G. (Eds.). *The Oxford handbook of prosocial behavior* (pp 259-281). Oxford Academic. https://doi.org/10.1093/oxfordhb/9780195399813.013.023

Bawalsah, J. A. (2016). Stress and coping strategies in parents of children with physical, mental, and hearing disabilities in Jordan. *International Journal of Education, 8*(1), 1-22. http://dx.doi.org/10.5296/ije.v8i1.8811

Beighton, C., & Wills, J. (2019). How parents describe the positive aspects of parenting their child who has intellectual disabilities: A systematic review and narrative synthesis. *Journal of Applied Research in Intellectual Disabilities, 32*(5), 1255-1279. https://doi.org/10.1111/jar.12617

Bradley, E. (2015). Carers and co-production: enabling expertise through experience? *Mental Health Review Journal, 20*(4), 232-241. https://doi.org/10.1108/MHRJ-05-2014-0016

Brennan, D., McCausland, D., O'Donovan, M. A., Eustace-Cook, J., McCallion, P., & McCarron, M. (2020). Approaches to and outcomes of future planning for family carers of adults with an intellectual disability*: A systematic review. Journal of Applied Research in Intellectual Disabilities, 33*(6), 1221-1233. https://doi.org/10.1111/jar.12742

Breuer, M. E., Pelle, T., Leusink, G. L., Linehan, C., & Naaldenberg, J. (2024). Synthesis: International perspectives on healthcare for people with intellectual and developmental disabilities. Journal of Policy and Practice in Intellectual Disabilities, 21(2), e12500. DOI: 10.1111/jppi.12500

British Psychological Society. (2015). Guidance on the assessment and diagnosis of intellectual disabilities in adulthood. Leicester: British Psychological Society.

Bujnowska, A. M., Rodríguez, C., García, T., Areces, D., & Marsh, N. V. (2021). Coping with stress in parents of children with developmental disabilities. *International Journal of Clinical and Health Psychology, 21*(3), 1-9. https://doi.org/10.1016/j.ijchp.2021.10025

Bunga, D., Manchala, H. G., Ravindranath, N., & Shankar, U. (2020). Children with intellectual disability, impact on caregivers: A cross-sectional study. *Indian Journal of Social Psychiatry, 36*(2), 151-156. DOI: 10.4103/ijsp.ijsp_81_19

Burke, M. M., Lee, C. E., Carlson, S. R., & Arnold, C. K. (2020). Exploring the preliminary outcomes of a sibling leadership program for adult siblings of individuals with intellectual and developmental disabilities. *International Journal of Developmental Disabilities, 66*(1), 82-89. https://doi.org/10.1080/20473869.2018.1519632

Cahill, M., Robinson, K., Pettigrew, J., Galvin, R., & Stanley, M. (2018). Qualitative synthesis: a guide to conducting a meta-ethnography. British journal of occupational therapy, 81(3), 129-137. DOI: 10.1177/0308022617745016

Campbell, R., Pound, P., Morgan, M., Daker-White, G., Britten, N., Pill, R., Yardley, L., Pope, C., & Donovan, J. (2012). Evaluating meta ethnography: systematic analysis and synthesis of qualitative research. *Health Technology Assessment 15*(43), 1-180 https://doi.org/10.3310/hta15430

Chadwick, D. D., Mannan, H., Garcia Iriarte, E., McConkey, R., O'Brien, P., Finlay, F., Lawlor, A., & Harrington, G. (2013). Family voices: life for family carers of people with intellectual disabilities in Ireland. *Journal of Applied Research in Intellectual Disabilities, 26(*2), 119-132. https://doi.org/10.1111/jar.12003

Chakraborti, M., Gitimoghaddam, M., McKellin, W. H., Miller, A. R., & Collet, J. P. (2021). Understanding the implications of peer support for families of children with neurodevelopmental and intellectual disabilities: A scoping review. *Frontiers in Public Health, 9*. https://doi.org/10.3389/fpubh.2021.719640

Chien, W. T., & Lee, I. Y. (2013). An exploratory study of parents' perceived educational needs for parenting a child with learning disabilities. *Asian Nursing Research, 7*(1), 16-25. https://doi.org/10.1016/j.anr.2013.01.003

Chien, W. T., & Norman, I. (2009). The effectiveness and active ingredients of mutual support groups for family caregivers of people with psychotic disorders: a literature review. *International Journal of Nursing Studies, 46*(12), 1604-1623. https://doi.org/10.1016/j.ijnurstu.2009.04.003

Clarke, V. (2022). Navigating the messy swamp of qualitative research: Are generic reporting standards the answer? *Qualitative Research in Psychology, 19*(4), 1004-1012. https://doi.org/10.1080/14780887.2021.1995555

Coyle, C. E., Kramer, J., & Mutchler, J. E. (2014). Aging together: Sibling carers of adults with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 11*(4), 302-312. https://doi.org/10.1111/jppi.12094

Daly, L., Sharek, D., DeVries, J., Griffiths, C., Sheerin, F., McBennett, P., & Higgins, A. (2015). The impact of four family support programmes for people with a disability in Ireland. *Journal of Intellectual Disabilities, 19*(1), 34-50. https://doi.org/10.1177/1744629514564584

Dew, A., Collings, S., Dowse, L., Meltzer, A., & Smith, L. (2019). 'I don't feel like I'm in this on my own': Peer support for mothers of children with intellectual disability and challenging behaviour. *Journal of Intellectual Disabilities,* 23(3), 344-358. https://doi.org/10.1177/1744629519843012

Ee, J., Lim, J. M., Kroese, B. S., & Rose, J. (2022). Family carers' experiences of providing care for their adult relative with intellectual disabilities and mental health problems in Singapore. Research in Developmental Disabilities, 126, 104241. https://doi.org/10.1016/j.ridd.2022.104241

France, E. F., Ring, N., Thomas, R., Noyes, J., Maxwell, M., & Jepson, R. (2014). A methodological systematic review of what's wrong with meta-ethnography reporting. BMC medical research methodology, 14(1), 119. http://www.biomedcentral.com/1471-2288/14/119

Felizardo, S., Ribeiro, E., & Amante, M. J. (2016). Parental adjustment to disability, stress indicators and the influence of social support. *Procedia-Social and Behavioral Sciences, 217*, 830-837. https://doi.org/10.1016/j.sbspro.2016.02.157

Gore, N., Bradshaw, J., Hastings, R., Sweeney, J., & Austin, D. (2022). Early positive approaches to support (E-PAtS): Qualitative experiences of a new support programme for family caregivers of young children with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities, 35*(3), 889-899. https://doi.org/10.1111/jar.12993

Griffith, G. M., & Hastings, R. P. (2014). 'He's hard work, but he's worth it'. The experience of caregivers of individuals with intellectual disabilities and challenging behaviour: A meta-synthesis of qualitative research. *Journal of Applied Research in Intellectual Disabilities, 27*(5), 401-419. https://doi.org/10.1111/jar.12073

Guan, M., & So, J. (2016). Influence of social identity on self-efficacy beliefs through perceived social support: A social identity theory perspective. *Communication Studies, 67*(5), 588-604. https://doi.org/10.1080/10510974.2016.1239645

Halstead, E. J., Griffith, G. M., & Hastings, R. P. (2018). Social support, coping, and positive perceptions as potential protective factors for the well-being of mothers of children with intellectual and developmental disabilities. *International Journal of Developmental Disabilities, 64*(4-5), 288-296. https://doi.org/10.1080/20473869.2017.1329192

Heer, K., Rose, J., Larkin, M., & Singhal, N. (2015). The experiences of mothers caring for a child with developmental disabilities: a cross cultural perspective. International Journal of Human Rights in Healthcare, 8(4), 218-232. https://doi.org/10.1108/IJHRH-06-2014-0011

Heiman, T. (2002). Parents of children with disabilities: Resilience, coping, and future expectations. *Journal of Developmental and Physical Disabilities, 14*(2), 159-171. https://doi.org/10.1023/A:1015219514621

Hiebl, M. R. (2023). Sample selection in systematic literature reviews of management research. *Organizational Research Methods, 26*(2), 229-261. https://doi.org/10.1177/1094428120986851

Higgins, J. P., Altman, D. G., Gøtzsche, P. C., Jüni, P., Moher, D., Oxman, A. D., Savovic, J., Schulz, J. A., Weeks, L., & Sterne, J. A. (2011). The Cochrane Collaboration's tool for assessing risk of bias in randomised trials. *BMJ*, 343, 1-9. https://doi.org/10.1136/bmj.d5928

Higgins, J. P. T., Thomas, J., Chandler, J., Cumpston, M., Li, T., Page, M. J., & Welch, V. A. (Eds.). (2024). Cochrane handbook for systematic reviews of interventions (Version 6.5). Cochrane. https://training.cochrane.org/handbook/current

Irani, A. S. (2018). Positive altruism: Helping that benefits both the recipient and giver [Unpublished master's project]. University of Pennsylvania. https://repository.upenn.edu/handle/20.500.14332/38791

Irazábal, M., Marsà, F., García, M., Gutiérrez-Recacha, P., Martorell, A., Salvador-Carulla, L., & Ochoa, S. (2012). Family burden related to clinical and functional variables of people with intellectual disability with and without a mental disorder. *Research in Developmental Disabilities, 33*(3), 796-803. https://doi.org/10.1016/j.ridd.2011.12.002

Jackson, J. B., Steward, S. R., Roper, S. O., & Muruthi, B. A. (2018). Support group value and design for parents of children with severe or profound intellectual and

developmental disabilities. *Journal of Autism and Developmental Disorders, 48*, 4207-4221. https://doi.org/10.1007/s10803-018-3665-z

Jandrić, S., & Kurtović, A. (2021). Parenting sense of competence in parents of children with and without intellectual disability. Europe's Journal of Psychology, 17(2), 75. doi: 10.5964/ejop.3771

Kleefman, M., Reijneveld, S. A., & Jansen, D. E. M. C. (2015). Prevalence and determinants of need for formal parenting support among parents raising a child with a borderline to mild intellectual disability. *Journal of Intellectual and Developmental Disability, 40*(1), 49-56. https://doi.org/10.3109/13668250.2014.956659

Kurtz, L. F., & Powell, T. J. (1987). Three approaches to understanding self-help groups. *Social Work With Groups, 10*(3), 69-80. https://doi.org/10.1300/J009v10n03_06

Lee, C. E., & Choi, M. (2023). Feasibility of school-based parent support groups for transition-aged youth with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 36*(5), 1179-1187. https://doi.org/10.1111/jar.13142

Linden, M., Truesdale, M., Leonard, R. A., Brown, M., Marsh, L., Todd, S., Hughes, N., & Forbes, T. (2024). Acceptability testing of the Carers-ID intervention to support the mental health of family carers of people with profound and multiple intellectual disabilities. *PLOS ONE, 19*(10). https://doi.org/10.1371/journal.pone.0313081

Luong, V., Bearman, M., & MacLeod, A. (2023). Understanding meta-ethnography in health professions education research. Journal of Graduate Medical Education, 15(1), 40-45.

Marrus, N., & Hall, L. (2017). Intellectual disability and language disorder. Child and Adolescent Psychiatric Clinics, 26(3), 539-554. doi:10.1016/j.chc.2017.03.001.

Masulani-Mwale, C., Kauye, F., Gladstone, M., & Mathanga, D. (2018). Prevalence of psychological distress among parents of children with intellectual disabilities in Malawi. *BMC Psychiatry, 18*, 1-7. https://doi.org/10.1186/s12888-018-1731-x

McCarron, M., McCallion, P., Carroll, R., Burke, E., Cleary, E., McCausland, D., McGlinchy, E., O'Donovan, M., Mulryan, N., & Shivers, C. (2014). Advancing years, Different challenges: Wave 2 IDS-TILDA: findings on the ageing of people with an intellectual disability: an intellectual disability supplement to the Irish Longitudinal Study on Ageing. Trinity College Dublin, School of Nursing and Midwifery. http://hdl.handle.net/10147/333034

Megreya, A. M., Al-Attiyah, A. A., Moustafa, A. A., & Hassanein, E. E. (2020). Cognitive emotion regulation strategies, anxiety, and depression in mothers of children with or without neurodevelopmental disorders. *Research in Autism Spectrum Disorders, 76*. https://doi.org/10.1016/j.rasd.2020.101600

Mitter, N., Ali, A., & Scior, K. (2019). Stigma experienced by families of individuals with intellectual disabilities and autism: A systematic review. *Research in Developmental Disabilities, 89*, 10-21. https://doi.org/10.1016/j.ridd.2019.03.001

Moriwaki, M., Yuasa, H., Kakehashi, M., Suzuki, H., & Kobayashi, Y. (2022). Impact of social support for mothers as caregivers of cerebral palsy children in Japan. *Journal of Pediatric Nursing, 63*, 64-71. https://doi.org/10.1016/j.pedn.2021.10.010

National Institute for Health and Care Excellence. (2012). Appendix H: Quality appraisal checklist – qualitative studies. In Developing NICE guidelines: The manual (PMG4). https://www.nice.org.uk/process/pmg4/chapter/appendix-h-quality-appraisal-checklist-qualitative-studies

NHS England. (n.d.). Who is considered a carer? NHS Eng land. Retrieved 14th April 2025, from https://www.england.nhs.uk/commissioning/comm-carers/carers/

NHS England. (2015). Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition: Service model for commissioners of health and social care services. https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-serv-model-oct15.pdf

Noblit, G. W. (2018). Meta-ethnography: Adaptation and return. In L. Urrieta Jr. & G. W. Noblit (Eds.), Cultural constructions of identity: Meta-ethnography and theory (pp. 34–50). Oxford University Press. https://doi.org/10.1093/oso/9780190676087.003.0002

Noblit, G. W., & Hare, D. R. (1988). *Meta-Ethnography: Synthesising Qualitative Studies.* Qualitative Research Methods (Vol 11). Sage Publications.

Oarga, C., Stavrova, O., & Fetchenhauer, D. (2015). When and why is helping others good for well-being? The role of belief in reciprocity and conformity to society's expectations. *European Journal of Social Psychology, 45*(2), 242-254. https://doi.org/10.1002/ejsp.2092

Public Health England. (2020). Chapter 5: Adult social care. GOV.UK. https://www.gov.uk/government/publications/people-with-learning-disabilities-in-england/chapter-5-adult-social-care

Resch, J. A., Mireles, G., Benz, M. R., Grenwelge, C., Peterson, R., & Zhang, D. (2010). Giving parents a voice: A qualitative study of the challenges experienced by parents of children with disabilities. *Rehabilitation Psychology, 55*(2), 139-150. https://doi.org/10.1037/a0019473

Riches, V. C., O'Brien, P., Manokara, V., & Mueller, A. (2023). A study of caregiver support services: Perspectives of family caregivers of persons with intellectual disabilities in Singapore. *Journal of Policy and Practice in Intellectual Disabilities, 20*(1), 117-131. https://doi.org/10.1111/jppi.12441

Sattar, R., Lawton, R., Panagioti, M., & Johnson, J. (2021). Meta-ethnography in healthcare research: A guide to using a meta-ethnographic approach for literature synthesis. *BMC Health Services Research, 21*(50), 1-13. https://doi.org/10.1186/s12913-020-06049-w

Shoesmith, G. (2024). *Evaluating the feasibility, acceptability and effectiveness of acceptance and commitment therapy for family carers of adults with intellectual disabilities* [Doctoral dissertation]. University of Essex. http://repository.essex.ac.uk/id/eprint/39167

Shrestha, S., Alharbi, R. J. M., While, C., Ellis, J., Rahman, M. A., & Wells, Y. (2021). Self-efficacy of direct care workers providing care to older people in residential aged care settings: a scoping review protocol. *Systematic Reviews, 10*(105), 1-5. https://doi.org/10.1186/s13643-021-01655-z

Soundy, A., & Heneghan, N. R. (2022). Meta-ethnography. *International Review of Sport and Exercise Psychology, 15*(1), 266-286. https://doi.org/10.1080/1750984X.2021.1966822

Tajfel, H., & Turner, J. C. (1979). An integrative theory of intergroup conflict. In M.J., Hatch & M. Schultz. (Eds.). (2004). *Organisational identity: A reader.* Oxford University Press. https://books.google.co.uk/books?id=BgBREAAAQBAJ&pg=PA33

Taunt, H. M., & Hastings, R. P. (2002). Positive impact of children with developmental disabilities on their families: A preliminary study. *Education and Training in Mental*

Retardation and Developmental Disabilities, 37(4), 410-420. http://www.jstor.org/stable/23880074

Thompson, R., Kerr, M., Glynn, M., & Linehan, C. (2014). Caring for a family member with intellectual disability and epilepsy: Practical, social and emotional perspectives. *Seizure, 23*(10), 856-863. https://doi.org/10.1016/j.seizure.2014.07.005

Tod, D., Booth, A., & Smith, B. (2022). Critical appraisal. *International Review of Sport and Exercise Psychology, 15*(1), 52-72. https://doi.org/10.1080/1750984X.2021.1952471

Totsika, V., Hastings, R. P., & Vagenas, D. (2017). Informal caregivers of people with an intellectual disability in England: health, quality of life and impact of caring. *Health & Social Care in the Community, 25*(3), 951-961. https://doi.org/10.1111/hsc.12393

van Wingerden, E., Sterkenburg, P. S., & Wouda, M. (2018). Improving empathy and self-efficacy in caregivers of persons with intellectual disabilities, using m-learning (HiSense APP-ID): Study protocol for a randomized controlled trial. *Trials, 19*, 1-8. https://doi.org/10.1186/s13063-018-2772-7

Vernhet, C., Dellapiazza, F., Blanc, N., Cousson-Gélie, F., Miot, S., Roeyers, H., & Baghdadli, A. (2019). Coping strategies of parents of children with autism spectrum disorder: A systematic review. *European Child & Adolescent Psychiatry, 28,* 747-758. https://doi.org/10.1007/s00787-018-1183-3

Walker, E., & Dewar, B. J. (2001). How do we facilitate carers' involvement in decision making?. *Journal of Advanced Nursing, 34*(3), 329-337. https://doi.org/10.1046/j.1365-2648.2001.01762.x

Wei, Y. S., Chu, H., Chen, C. H., Hsueh, Y. J., Chang, Y. S., Chang, L. I., & Chou, K. R. (2012). Support groups for caregivers of intellectually disabled family members:

Effects on physical–psychological health and social support. *Journal of Clinical Nursing, 21*(11-12), 1666-1677. https://doi.org/10.1111/j.1365-2702.2011.04006.x

Weinstein, N., & Ryan, R. M. (2010). When helping helps: autonomous motivation for prosocial behavior and its influence on well-being for the helper and recipient. *Journal of Personality and Social Psychology, 98*(2), 222. https://doi.org/10.1037/a0016984

Whitney, R. V. (2023). In their own words: Mothers narrate the lived experience of raising children with developmental disorders who engage in socially disruptive conduct. *Journal of Autism and Developmental Disorders, 53*(8), 3272-3279. https://doi.org/10.1007/s10803-022-05578-z

Worrall, H., Schweizer, R., Marks, E., Yuan, L., Lloyd, C., & Ramjan, R. (2018). The effectiveness of support groups: A literature review. *Mental Health and Social Inclusion, 22*(2), 85-93. https://doi.org/10.1108/MHSI-12-2017-0055

Wright, S. C. (2010). Collective action and social change. In J. F. Dovidio, M. Hewstone, P. Glick, & V. M. Esses (Eds.), *The SAGE handbook of prejudice, stereotyping and discrimination* (pp. 575–590). SAGE Publications. https://sk.sagepub.com/hnbk/edvol/hdbk_prejudicestereotypediscrim/chpt/collective-action-social-change:contentReference[oaicite:5]{index=5}

Chapter Two - A Qualitative Exploration of Paid Carers' Experience of Caring for Individuals with Intellectual and/or Developmental Disability and Harmful Sexual Behaviour

Abstract

Introduction

Paid carers supporting individuals with IDD and HSB face complex challenges including limited organisational support, stigma, and emotional strain, all challenges which can affect the carers wellbeing and quality of care for the client. Despite growing awareness, research on paid carers remains limited. The current study aims to explore carers' lived experiences of caring for an individual with and IDD and HSB, with the goal of informing tailored support.

Method

Six paid carers were interviewed regarding their experience of providing care to an individual with IDD and HSB. Semi-structured interviews were conducted online and analysed using Interpretative Phenomenological Analysis.

Results

Three superordinate themes were identified through the analysis: 'The balance of drive and burden, 'Relational and social shaping of care' and 'Working together to put clients unique needs first'. Findings illustrated that carers found the role emotionally demanding and relied on personal values, coping strategies and support from others to cope. Carers stressed the impact of other people on the role, the benefits of receiving support from others and the

difficulties of public stigma. The importance of person-centred care, specifically client collaboration and carer responsiveness, were also emphasised.

Discussion and Clinical Implications

This study highlights the emotional demands and negative public perception faced by paid carers of individuals with IDD and HSB, and how they cope with these. Key clinical implications include enhancing professional recognition, strengthening organisational support and promoting emotional processing. These strategies may improve quality of care for clients and staff retention.

2.1 Introduction

Defining Key Concepts

Intellectual disability (ID) is defined by significant impairments in intellectual and social functioning arising in childhood (before age 18) (British Psychological Society [BPS], 2015). This is commonly diagnosed using standardised assessments of general intelligence and social functioning, whilst considering additional clinical factors that could impact assessment, such as physical and mental health conditions (BPS, 2000). In some areas, particularly within forensic populations, a broader group of individuals is often considered, defined as Intellectual and/or Developmental Disabilities (IDD). This term includes individuals with a higher IQ cut off, considered in the context of their difficulties and other developmental disabilities (McCarthy et al., 2023). IDD is now also included in the DSM-5, replacing the historical term 'Mental Retardation' (APA, 2013). Research studies exploring ID and offending often include individuals in the Borderline ID range which includes IQ scores of 70 to 85 (Nixon et al., 2017). The IDD definition includes individuals with ID who may also have a diagnosis of a neurodevelopmental condition such as Autism Spectrum Disorder (ASD) (Chester, 2018). The definition was first proposed in 2011 defined as including a group of conditions characterised by impaired cognitive functions and limited adaptive behaviour (Salvador-Carulla et al., 2011). While terminology has varied historically, Intellectual Disability and Intellectual and Developmental Disability are now the commonly used terms (APA, 2013; Cluley, 2017) and will be used throughout this research paper.

Harmful sexual behaviour (HSB) encompasses a variety of behaviours but in the current thesis refers to "sexually aggressive, sexually abusive or offensive, or inappropriate sexual behaviours that victimise others" (Rich, 2011). Estimating the prevalence of HSB among individuals with IDD is challenging due to inconsistent definitions of IDD (Holland et

al., 2002) and the over-representation of this group in the criminal justice system (Lindsay, 2002). However, there is evidence to suggest that individuals with IDD may be at an increased risk of sexual offending (Nixon et al., 2017). Given the implications for the safety and welfare of individuals with IDD, the treatment and management of HSB is an important area of research, particularly how caregivers respond to this behaviour (Svae et al., 2022).

Caring for Individuals with IDD and HSB

Support needs of individuals with IDD can vary depending on the severity of their disability, with some requiring supervised living (Boat & Wu, 2015) and others requiring fulltime support in all areas of life (Mencap, n.d.). This care is typically provided by family caregivers or professional paid carers (National Institute for Health and Care Excellence [NICE], 2013). Family carers are described as anyone caring for a family member, who are often juggling this responsibility with other life commitments (NHS England, n.d.), whereas paid carers are employed to work directly with individuals with IDD, supporting them in their daily activities (NHS England, 2015). Due to the legal complexities of HSB, individuals portraying this behaviour may be more likely to receive supervision from professional carers, therefore this group is the focus of the current study.

Paid carers play a key role in supporting individuals with IDD and HSB, particularly in managing risk and influencing treatment outcomes (Svae et al., 2022). However many carers report feeling ill-equipped and lacking confidence (Saxe & Flanagan, 2016). The importance of this caring relationship is also demonstrated by the potential beneficial outcomes, including client behavioural change when carer empathy is increased (Sandhu et al., 2012). It is crucial that experiences of caring for this group of individuals is understood to ensure effective care is provided and carers have capacity for empathy and engagement.

Paid carers supporting individuals with IDD and HSB can face a number of emotional and practical challenges, with a major challenge being the lack of organisational support. Carers have reported experiencing burnout linked to low reciprocity for their efforts from the organisation (Thomas & Rose, 2010). This can contribute to staff feeling vulnerable to compassion fatigue (Rose & Walker, 2018). Research by Cope (2018) and Storey et al. (2011) highlight feelings of emotional isolation among carers, often feeling that they have limited opportunities to share their feelings at work, devaluing their emotional experiences. This led to carers feeling the need to suppress their emotions using distraction techniques (Storey et al., 2011). This is in line with previous research that highlighted the importance of organisations recognising the potential stress that support workers face (Windley & Chapman, 2010).

A second challenge for paid carers is stigma from the general public, who may display negative and poorly informed perspectives of the work. Stigma from others can be defined in three parts: stereotypes, prejudice and discrimination (Corrigan & Watson, 2002). Different definitions have emerged in the literature (Colic, 2023), but relevant to the current research is Affiliate Stigma, referring to the internalisation of negative public attitudes through association with a stigmatised group (Mak & Cheung, 2008). Affiliate stigma has been well documented in family carers, whereby individuals become aware of negative evaluations, feel the negative emotions associated with this, and thus engage in behaviours to manage it (Mitter, 2017). As a result of this, carers may find their job more difficult. Whilst some carers try to change community attitudes (Rose & Walker, 2018), others are pushed towards social withdrawal (Mitter et al., 2018) and experience a diminished professional identity. Lack of social support has been evidenced to increase the effect of stigma and may be increased in paid carers (Tekola et al., 2020), if they are not feeling supported by their organisation.

Negative societal views can also impact the relationship between carers and clients, potentially compromising quality of care (Esmail et al., 2010).

Thirdly, the impact of this role on carer wellbeing can be significant. The nature of the role can lead to increased stress (Raczka, 2005), burnout (Mills & Rose, 2011), and in some cases vicarious trauma (Rose & Walker, 2018). Exposure to distressing information, as well as contextual factors such as length of experience and setting of care, can worsen this impact (Rose & Walker, 2018). Paid carers have been shown to employ different strategies to protect against the emotional impact of this work, often choosing to defend against it rather than acknowledge the emotional challenge (Sandhu et al., 2012). While formal supervision can be effective for support staff (Rose & Walker, 2018), other staff have indicated they prefer informal peer supervision to manage this impact (Sandhu et al., 2012), suggesting the need for flexible, carer-led and multiple support strategies.

Research Rationale and Aims

Despite growing awareness of the challenges faced by this staff group, research focusing on the experiences of paid carers remains limited and requires further exploration (Rose & Walker, 2018). While NICE guidelines highlight the importance of providing training and emotional support to carers (NICE, 2015), there is no specific guidance for carers working with HSB. Furthermore, most existing studies focus on experiences of challenging behaviour (CB), rather than HSB, or on the experience of family carers. Through research into caring for individuals with challenging behaviour, several insights into organisational and personal challenges have emerged. Organisational challenges relating to a lack of training and supervision are known to impact paid carers and their relationship with individuals (Robinson et al., 2023), as well as personal challenges which include burnout, vicarious trauma and compassion fatigue (Rose & Walker, 2018). However, HSB presents distinct challenges, including moral conflict and increased responsibility (Cope, 2018). It

remains unclear whether support strategies developed for managing CB will transfer to staff working with HSB, or if tailored support strategies are required.

Similarly, existing research exploring the negative impact of community attitudes (Ali et al., 2012) has focused on family members, overlooking the potentially varying needs among professional paid carers. Exploring how paid carers experience community attitudes could allow organisations to tailor interventions to provide more effective support. Evidence suggests if an organisation can provide appropriate support for staff, it can lead to safer and more effective care for individuals with IDD (Rose & Walker, 2018). Additionally, effective support for carers may serve to enhance retention and recruitment, a major difficulty in the intellectual disability sector (Murray et al., 2022).

Aims

Based on the existing literature and identified gaps in knowledge, the present study aims to understand the lived experiences of paid carers supporting individuals with Intellectual and Developmental Disabilities (IDD) and Harmful Sexual Behaviour (HSB). It is hoped that gaining a deeper understanding of how carers perceive and navigate the challenges associated with their role, including societal attitudes and community acceptance, will contribute to a broader understanding of this area. Additionally, the research aims to consider the emotional dimensions of the caregiving role, with a view to potentially informing and tailoring future support strategies for this group of carers.

2.2 Methodology

Context

This study was nested under a national Randomised Control Trial (RCT), the HaSB-IDD trial, studying the effectiveness of a Cognitive Behavioural Therapy (CBT) intervention for individuals with IDD and HSB, including carers' perspectives. The current research study sampled carers that were recruited to the RCT who were not involved in the specific treatment intervention. These carers had volunteered through their organisations to provide additional information about their client who was taking part in the treatment as usual arm of the trial. Although the current study is distinct from the main trial, ethical approval and recruitment were linked to the broader RCT as it was seen as providing complimentary knowledge.

Design

Ethical Approval

Ethical approval for this study was obtained through the HaSB-IDD trial and granted by the NHS Health Research Authority (HRA) (Appendix 2A). The study was also registered with the University of Birmingham Research Ethics Committee. Approval from this and the NHS ensured the study adhered to ethical guidelines and considered any ethical issues such as confidentiality, risk, informed consent and potential safeguarding.

The clinical trial included healthcare sites across the United Kingdom and therefore individual Letters of Access were obtained from all NHS sites research and development departments, allowing the researcher to speak with carers working within their trust.

Recruitment

Paid carers of individuals with a diagnosis of IDD who also display HSB were identified as the group of interest in this study. A purposive, opportunity sampling method was used, and participants were recruited from the ongoing HaSB-IDD clinical trial. Recruiting through the trial gave the author access to homogenous participants with the particular experience being studied (Smith et al., 2022). The RCT contained a pre-identified sample of carers who were supporting individuals within the trial, both in the intervention and control arm. Participants for the current study were recruited through the control arm of the RCT and asked to participate in the current study. Whilst the trial had recruited family and paid carers, the author only approached paid carers for the current study to ensure the sample was relatively homogeneous (Smith et al., 2022).

The inclusion and exclusion criteria (Table 1) were developed using the RCT study protocol (Appendix 2B), providing a sampling frame for the current study. Ensuring all participants met these strict criteria ensured homogeneity within the sample, an important feature of small samples in IPA studies (Smith et al., 2022).

Table 1

Participant Eligibility Criteria

Inclusion Criteria	Exclusion Criteria
Paid carers	Family members, informal, unpaid carers
Caring for someone over 18 years old, with IDD and HSB. For the purpose of the current research this includes individuals with an IQ below 80 and adaptive behaviour deficits. Impairments in adaptive	Carers of individuals without a diagnosis of IDD, no HSB displayed, challenging behaviour not including HSB, diagnosis of autism without mild or borderline ID.

functioning were determined using the Adaptive Behaviour Assessment System (ABAS-III) (Harrison & Oakland, 2015). On this assessment scores below 80 indicate significantly below average adaptive functioning and therefore an impairment (Harris & Oakland, 2015). The author acknowledges that an IQ below 80 is above the clinical cut off for ID (typically IQ<70) and provides a rationale for this below. The RCT protocol also states that clinical judgement will be utilised if an individual scores over 80 but would still meet the DSM IV criteria for IDD, described below.	
HSB defined as illegal sexual behaviour against a person who was not consenting. Not necessarily reported to or prosecuted by the police. Occurred within the last 5 years.	
Caring for individuals in community or inpatient healthcare settings (low-medium secure).	Caring for men in prison, probation or high secure services.
Client not currently participating in the active arm of the clinical trial.	Participation in active arm for HASB-IDD RCT.

Whilst the clinical cut off for a diagnosis of ID is often cited as IQ below 70 (BPS, 2015), individuals with an IQ below 80 were included in this study to reflect the move towards a more clinically meaningful definition of IDD and capture the full extent of an individual's impairment. The BPS (2012) have recognised that using a cut off can be an arbitrary figure that may not always represent an individual's level of functioning. Similarly, Boat and Wu (2015) highlight the DSM-5 diagnostic framework's choice to remove the numeric IQ threshold when defining ID, recognising that it should be assessed by impairments in social and adaptive functioning, rather than a fixed IQ score. Furthermore, McCarthy et al. (2023) highlight that individuals with IQ scores between 70-75 can display limited intellectual functioning and it is therefore important to take IQ scores in consideration with the context of an individual's presentation and difficulties. This supports the decision to include individuals over the traditional cut off but presenting with functional impairments. The decision to use the definition of Intellectual and Developmental Disorders (IDD) also allows inclusion of individuals with ID who also have autism spectrum disorder, as outlined in the RCT protocol.

As this research focuses on individuals who also display Harmful Sexual Behaviour it was important to align with other research being conducted in the field. Smith (2016), Williams (2014) and Wakeling (2018) all note that within the UK prison system an IQ<80 is commonly used to determine access to adapted interventions. This is due to understanding that individuals within this range often require similar support to those diagnosed with ID (IQ <70). It is hoped that taking this approach within the current research will be inclusive of individuals who are likely to experience clinically meaningful cognitive and functional impairment. Within the RCT protocol it is noted that a man would still be considered for inclusion in the study if they had an IQ score above 80, if they demonstrated

cognitive and functional impairments that were indicative of ID. In this case clinical judgement was used to determine eligibility for inclusion, based on whether or not the individual would be accessing Intellectual Disability services. These cases were reviewed on an individual basis by the trial manager and chief investigator to ensure these men were not prejudiced from taking part in the trial.

The process for recruitment started with identifying suitable participants from the HaSB-IDD trial, specifically caring for participants in the control arm (not receiving active CBT treatment). It is important to note recruitment presented some challenges. Among the four trial sites contacted there were a possible 14 participants and only six of these consented to be interviewed.

Once identified, principal investigators at the local trial sites were contacted to confirm participation, whilst simultaneously contacting the local research and development lead to obtain a Letter of Access for the NHS trust delivering the trial. Participants were provided with information sheets (Appendix 2C), detailing the purpose of the study and what would be asked of them if they participated. If the participants verbally agreed to be interviewed, they were asked to complete a study consent form (Appendix 2D) by liaising with the local research lead. This was available to be completed electronically, but physical copies were also available through the principal investigator. Participants read, checked and signed the form to confirm they understood their rights to participate and withdraw from the study. Once this was confirmed, a time for the interview to take place was scheduled, and an invitation link was sent to the participant. Participants had time between arranging and attending the interview to consider their involvement.

Participants

The research was conducted across the United Kingdom. Six participants were recruited and interviewed. This was deemed an acceptable sample size for the qualitative methodology based on guidance suggesting 6-10 participants is appropriate for professional doctorate research projects (Smith et al., 2022). Participants were aged between 21-29 and >60 years old, comprised of three females and three males. Of the six participants, four identified as White British, one White Scottish and one Black African. They were living in four different regions of the UK, details not included to protect anonymity. The participants varied in their length of time spent in the role from two years to 27 years (mean length of experience = 13 years). The context of role and length of service was considered important information to ground the analysis and contextualise the interviews (Smith et al., 2022).

The names and details of the participants were changed to protect their anonymity and details of local NHS trusts were withheld to protect locations of participants. Pseudonyms and details of participant roles are shown in Table 2.

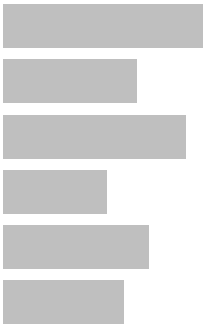
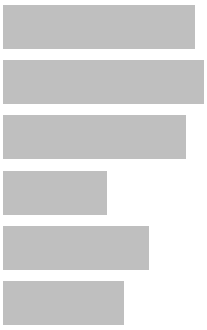
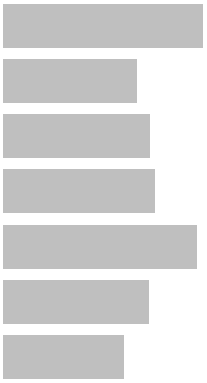
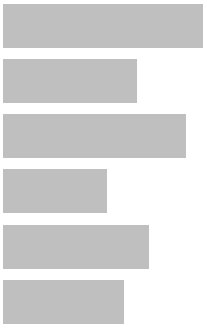
Details are also provided about the individuals being reported on by the carers. This group of carers was selected because they offer access to a particular phenomenon, individuals who are paid to care for people with IDD and HSB. They are considered a relatively homogenous sample, as all participants were considered suitable candidates for the intervention. Specifically, each carer supported an individual identified as having an intellectual and/or developmental disability (as outlined in the main RCT protocol shown in Appendix 2B) and a history of harmful sexual behaviour. Assessment scores used to confirm the presence of ID/IDD are presented in Table 2, along with the type of sexual offence committed. It is important to note that although one male was above the cut off for ID (FSIQ 82), the trial managers used clinical judgement to determine their suitability for inclusion in the intervention. To protect confidentiality, offence details are limited to whether the offences were contact or non-contact in nature.

While some differences exist between the people carers worked with (residence and variation in assessment scores) these individuals were all expected to be able to engage within a group setting and could be considered homogenous. While there were differences in the employer and specific role of staff, they were selected for interview as they were considered to be the best individual to report on the potential impact of any therapeutic intervention on the person they cared for. This level of variability was considered appropriate for the aims of the study, as it allows for convergence and divergence within the analysis (Smith et al., 2022). These contextual differences are included in the results section of this report, where they are used to deepen the interpretative analysis.

Table 2

Participant Demographics

Participant Code	Gender	Age	Ethnicity	Job role	Caring Experience	Employer	Who they are caring for:
Gemma	Female	30-39	White British	Therapy Technician	2 years	NHS, residential	
George	Male	50-59	Black African	Community carer	17 years	Private, community	

Jenny	Female	30-39	White British	Deputy Manager	>19 years	Third sector, community	
Liz	Female	50-59	White Scottish	Senior Care Support Worker	27 years	Public sector, community	
Simon	Male	21-29	White British	Registered Manager	11 years	Private, residential	
Alan	Male	>60	White British	Clinical Support Worker	3 years	NHS, community	

Data Collection

On the day of the interview both researcher and participant accessed a Microsoft Teams link to join the interview. At this stage, informed consent was confirmed and they were reminded of the use of their data and information rights, along with details of ethical approval

obtained. Ethical considerations were made throughout the data collection procedure, with participants also reminded of their right to withdraw prior to the interview starting.

A semi-structured interview schedule (Appendix 2E) was used during interviews to guide the questions. This was a key part of the IPA methodology as the flexible nature of the guide ensured that participants had a say in what was covered during the interview (Smith et al., 2022). The interviews were held on an online platform allowing sharing of the information sheets and consent form. This process increased the accessibility of research participation (Boardman et al., 2024). Each interview was audio recorded using an encrypted dictaphone. It is important to mention the video meeting was not visually recorded, only audio to protect participants anonymity (Boardman et al., 2024).

A key consideration of facilitating online interviews was ensuring rapport was built and individuals felt comfortable with proceeding. All participants were offered the choice to have their camera on or off and all chose to have their camera on. Giving participants this choice helped to balance power dynamics between the participant and the researcher (Boardman et al., 2024). Following the interview, a check out was held to provide emotional containment for the participant. This included monitoring the participant's mood and checking if additional support was required. At this stage, participants were offered a post-interview debrief sheet which thanked them for their participation and detailed support information available to them. In line with guidance on conducting sensitive interviews (Dempsey et al., 2016), this included contact details for numerous organisations available to provide additional support to carers of individuals with IDD (Appendix 2F).

Interviews were conducted between May 2024 and January 2025 and all lasted between one hour and one hour and 15 minutes, suggested by Adams (2015) to be an appropriate length to minimise fatigue. Once interviews were complete, the audio recordings

were transcribed verbatim by the researcher. These transcripts were then anonymised by removing names and locations and stored on a secure research database for analysis.

Data Analysis

Rationale for IPA

Verbatim transcripts of the interviews were analysed using Interpretative Phenomenological Analysis (IPA) outlined by Smith et al. (2022). IPA is a qualitative research methodology informed by concepts such as; phenomenology (the study of experiences), hermeneutics (theory of interpretation) and idiography (the particular) (Smith et al., 2022). Hermeneutics recognises that researchers understand participant experiences based on how the participants makes sense of them, and then the researcher interprets this account (Smith et al., 2022). Because the current research was directed towards the lived experiences of paid carers supporting individuals with IDD and HSB, it was felt that IPA was an appropriate methodology.

The aim of the current study was to explore the experiences of paid carers caring for individuals with IDD and HSB. IPA was chosen as a suitable qualitative methodology to meet this aim because of its focus on exploring individual experiences (Alase, 2017) and how they make sense of these experiences (Smith et al., 2022). The emphasis of this study was on the experience of caring itself, rather than on understanding how participants interpreted the process of the intervention. The aim was to develop a more global understanding of the relationship between the carer and the person they supported and the personal impact this has on the carer. The study sought to capture the carers' personal experiences of caring for someone who displays HSB, a deeply complex relationship that requires interpreting the unique dynamic between two individuals.

IPA is interpretative, rather than led by theory, so it allows the researcher to understand each participant's account individually before making broader claims about the group (Smith & Osbourne, 2015). It provides space for participants to provide a full account of their experience, with the interviewer probing further with prompts if necessary. This is particularly valuable when exploring sensitive and emotionally charged topics (Smith & Osbourne, 2015), such as HSB. The method allows participants to articulate their own experiences and acknowledges the role of the researcher in making sense of the participants' accounts (Smith et al., 2022), describing the process of double hermeneutics. IPA is well suited for studying socially complex experiences and requires a reflective stance from the researcher to ensure they are aware of and minimise any pre-conceptions (Tuffour, 2017).

IPA commonly utilises a semi-structured interview methodology which allows flexibility, open-mindedness and ability to capture the nuanced nature of lived experiences (Smith et al., 2022). Compared to other qualitative methodology approaches, IPA focuses on analysing rich individual data from participants, involving a more thorough analysis of each participant's transcript (BPS, 2011). This is unlike Reflexive Thematic Analysis (RTA), which focuses on identifying broader themes across a dataset (Smith et al., 2022). Whilst Grounded Theory (GT) seeks to develop theoretical explanations and often requires large data sets, IPA remains focused on understanding lived experiences at the individual level (Pietkiewicz & Smith, 2014). As these individuals were in the control group of the study and had not experienced the intervention, it was particularly important to gain an in-depth understanding of their caring relationship and experiences, making IPA the most appropriate method to address the research question.

The steps followed in the IPA procedure are outlined in Table 3. The individual transcripts were reviewed and initial codes generated highlighting conceptual, descriptive and linguistic notes (Appendix 2G). From these initial notes, experiential themes were drawn out

and these were then studied and grouped to develop Personal Experiential Themes (PETs) for each participant (Appendix 2H). Detailed analysis was completed for each individual transcript, understanding the particular meaning and sense-making of their experience, before moving on to the next, following the idiographic theory of IPA (Smith et al., 2022). Once all transcripts had PETs generated, these were analysed and grouped together to develop Group Experiential Themes (GETs), across all participants (Appendix 2I), identifying similarities and differences across the cases (Smith et al., 2022).

Table 3

Individual Stages of IPA as Outlined by Smith et al. (2022).

Stage	Process within the stage
1. Reading and re-reading	Taking the time to read a transcript fully, ensuring the participant and their experience is at the forefront of analysis. The researcher noted initial observations, including the chronological sequence of what was discussed.
2. Exploratory noting	Developing familiarity with the transcript and noting initial thoughts and comments on the data. Focusing on commenting on what matters to the participant and why. This involves three types of comments – conceptual, descriptive and linguistic. Speculative interpretations can be included

	at this point by asking questions about the data (Smith et al., 2022). The purpose of this stage is ensuring everything is documented and linked to the data – coming from what the participant has said, rather than external influences (such as the researchers' opinions). The author completed this stage of analysis by using the comment function on MS Word to highlight and add comments to specific parts of the text. Question marks were used to indicate more speculative interpretations. An extract of this initial coding is shown in Appendix 2G.
3. Experiential Statements (ES)	Attempting to reduce the volume of notes whilst maintaining complexity, ESs relate to participant experiences drawn from specific points in the transcript. This involves working to produce a summary of what the participant has said in a specific part of the transcript, bringing in the author's analysis of what was said, known as double hermeneutics.

	The author noted experiential themes by printing the transcripts with initial codes and manually writing experiential themes that emerged at specific points of the transcript. ESs were written on left margins whilst exploratory notes were in the right hand margins. An extract of Experiential Statements on a transcript is seen in Appendix 2G.
4. Personal Experiential Themes (PETs) grouped and organised in a table	Attempting to draw together ESs to highlight important parts of participants' account involves separating all individual ESs and moving them around to break up their original ordering in the transcript. The aim is to explore numerous connections between ESs. This is a gradual process of mapping connections between ESs. Once PETs have been grouped, they are named and organised into a table with subclusters. The author completed this stage by entering all ESs into an MS Excel spreadsheet allowing them to be viewed at the same time. Each ES was listed with the page and line number in which it appeared on the

	transcript for ease of reference later in the analysis. The individual statements were then colour coded to indicate possible similarities between them. Once colour coded, the colours were drawn together to be reviewed as a group and PETs were named. This process remained flexible, and the author was able to change colours and move statements between groups at the naming stage. Screenshots displaying the process of grouping PETs are seen in Appendix 2H.
5. Repeating steps 1-4 for each transcript	The above process was then completed for the next transcript, and so on. Steps 1-4 were completed in their entirety for each transcript before moving on. The author allowed for a day in between transcript analysis to ensure that each case could be treated individually.
6. Developing Group Experiential Themes (GETs) across cases	The final stage of the process is to identify similarities and differences across the PETs. Identifying any shared experiences, not group norms. At this stage it is helpful to lay out all PETs and review together at a higher

order level. This process remains dynamic, and groupings can be moved at any time. Referring to initial noting and ESs from individual transcripts can be necessary at this stage. Once similarities and differences are identified, PETs are grouped based on these and drawn together in a GETs table, identifying how the participants understand and reflect on shared experiences.

To complete this step, the researcher colour coded PETs, identifying which participant they were from. These were then reviewed and drawn into different groups depending on similarities and differences between them. The author was able to continuously review the groups and move PETs around, before identifying themes and subthemes that accurately depict the data. An extract of the process of developing GETs is displayed in Appendix 2I.

This analysis resulted in three Group Experiential Themes and six subthemes being identified across the participants, providing understanding of the meaning they make of their experiences caring for individuals with IDD and HSB.

Reflexivity

Due to the nuanced and subjective nature of qualitative research, an important component is reflexivity (Olmos-Vega et al., 2023), which can be defined as the researcher's evaluation of themselves and their impact on the findings (Shaw, 2010). Reflexivity should be an ongoing and embedded process in the research, acknowledging the understanding and context the researcher is bringing to the analysis (Barrett et al., 2020). This is an important aspect of qualitative research as both researcher and participants are humans interacting with the world (Shaw, 2010) and therefore can have an impact on analytic interpretations of the data. Within IPA, double hermeneutics means that much of the analysis is based on the interpretations the author has made about participants' sense-making (Eatough & Smith, 2017). The author therefore took time to reflect on their professional experience (Braund et al., 2024) of working within an adult community learning disability service and how this had been a motivating factor in studying this phenomenon. Thus, understanding that the researcher and their experiences can impact the interpretation of the data.

Following guidance from Levitt et al. (2021), the author employed techniques throughout the study process to ensure interpretations were grounded in the data and that they remained open to alternative perspectives. Research supervision was attended regularly throughout the analysis stage where emerging concepts were discussed. Similarly, the author attended joint workshops during data analysis in which PETs were peer reviewed and collaborative conversations were held about identifying similarities and differences between participants. A reflective diary was kept by the researcher to document when interpretations emerged and any preconceptions they held. Initial thoughts during each analytic stage were documented separately and referred to when generating the PETs. These notes were reviewed after the PETS were grouped, allowing the researcher to maintain an open mind.

Once initial group experiential themes had been drawn from the data, the author attended a carers group meeting to share the preliminary findings. This participatory method, as recommended by Levitt et al. (2021), provided an opportunity for the experts by experience to share their thoughts on the themes and enhanced the author's ability to reflect on the development of the experiential themes. This ensured they were grounded in the data, while also allowing the researcher to explore alternative perspectives (Barrett et al., 2020). This provided an opportunity to understand if the themes fit with the carers own experience and what this could mean for future developments. The author had hoped to complete this reflexive process with the participants from the study, however logistics meant this was not possible in the required time frame.

2.3 Results

Three key themes emerged from the analysis of the data: 'The balance of drive and burden, 'Relational and social shaping of care' and 'Working together to put clients unique needs first'. Each theme had two subthemes, displayed in Table 4, which will be discussed in further detail, including quotes supporting the development of each theme.

Table 4

Overview of Group Experiential Themes and Subthemes with Participants Contributing to Each.

Group Experiential Theme	Subtheme	Contributing Participant

1. The balance of drive and burden	1.1 Motivation	Gemma, Jenny, Liz, Simon and Alan
	1.2 Carrying the emotional weight and personal strategies	Gemma, George, Jenny, Liz, Simon and Alan
2. Relational and social shaping of care	2.1 The role of relational support	Gemma, George, Jenny, Liz, Simon and Alan
	2.2 How perceptions and assumptions can shape care	Gemma, George, Liz, Simon and Alan
3. Working together to put clients unique needs first	3.1 Complex care requires collaboration	George, Liz, Simon and Alan
	3.2 Tailoring care to the client	Gemma, Jenny, Liz, Simon and Alan

Theme 1: The Balance of Drive and Burden

Theme 1 describes what is required from carers to be able to do the role of caring for people with IDD and HSB. This includes the personal values and principles that the carers hold, as well as strategies they develop that allow them to endure the complex demands of the job. They describe how accepting what can't be changed and understanding the limits of their role were central to this adaptation. Additionally, carers describe their reasons for choosing this work and the motivation that keeps them in the role.

Subtheme 1.1: Motivation

Because of the challenges of the job, carers must be intrinsically motivated to do the role and many describe this as central to their practice. Participants who care for individuals with both contact and non-contact harmful sexual behaviour reported noticing positive changes in the individuals they work with, being able to educate others and feeling appreciated in their role as intrinsically motivating factors. They all described being able to recognise the personal values that are met by doing the role.

For some participants, being able to improve the lives of the people they work with was a key motivation for doing the job, "*So it's just like giving people more independence to try new things and to move on with their lives and to be positive and bring positivity to their lives" (George)*. Providing this sense of independence for clients may be even more pertinent for client's who have faced restrictions due to their risk behaviours. Participants felt this was something they were able to do when working directly with their clients, as well as by advocating for them with other people.

> *Just shows me exactly why I have to do my job and advocate for people with a learning disability you know it just goes to show that's what we do for a reason and we need to keep doing that and banging that drum about learning disabilities for people to know (Jenny).*

For others it was the relationship they had built with their clients that allowed them to tolerate the emotional challenges of the role. Building a strong relationship allowed carers to take enjoyment from the work and the activities they had done together, particularly when these were experiences the client had not had before, "*I have taken him on weekends*

away…tours away for the weekend, which is a positive he really enjoyed that. That's something that he's not done since being in foster care as a child" (Simon). In Simon's case enjoyment appears to come from providing opportunities which could be seen as healing for the client, who had not experience such events since childhood. One carer described being able to notice the positive attributes in their clients which helped navigate difficulties in the role.

> *It's enjoyable but it's also challenging, there is never a dull moment, you don't have a chance to get bored. But on the whole it's enjoyable, he gives a lot back, he's got a lovely personality, and he's a lot of fun (Liz).*

The language used in this description by Liz, could be seen to humanise her client and demonstrates her ability to see the person beyond the offence. It is interesting to consider whether the nature of the non-contact sexual behaviour helps or hinders this ability. The carers also described the motivation gained from observing changes within their client, from the impact of their work. These changes felt even more valuable when their work was noticed and appreciated by other people, *"Yeah some people will say, 'oh you are doing a wonderful job' and they appreciate it, they appreciate what we do" (George).* For both cases, this recognition came from individuals who also worked with the client but were external to the client/carer relationship.

> *They say they apparently didn't think he would make a success, they all thought he would be back in hospital now. So they are really, really pleased to see*

how well he is doing and they also report back…she can see a huge change in him (Liz).

Despite the complexity of the work, all the carers remained clear on their reasons for doing the role. The depth of the carers' motivation appears closely linked to the context of their client's lives and their presentation of harmful sexual behaviour. Reference is made to specific challenges, including the limits on client independence and the negative perception of others, overcoming both acts as a source of motivation for the carers. This clarity allowed them to tolerate the challenges and focus on developing skills to overcome these. Reminding themselves of their achievements in the role and having these recognised by others further confirmed why they do the job.

Subtheme 1.2: Carrying the emotional weight and personal strategies

All participants described experiencing the job as emotionally heavy at times, *"And he's quite draining because he will go on and on and on at you and he doesn't talk to you he talks at you" (Jenny)*, and that it had been necessary to develop personal skills to manage this. This reflects the personal impact of working with an individual who has IDD and subsequently impaired cognitive and social functioning. Carers described being overwhelmed by the communication from the client and the knowledge they were expected to hold in their mind to be able to support them, "*Yeah I think it's more emotionally and mentally draining sometimes because of all that thought process that has to go into it" (Gemma).* As carers are supporting individuals with HSB as well as IDD they have competing demands to provide emotional support and manage risk. One participant described how this weight felt like it fell

primarily on them, which could be enhanced by their community role and the scope for lone working within this.

> *At times it was taxing at times, quite overwhelming some days you know. Trying to think, I wouldn't say it was stressful I would say it was more, a lot of the onus on me, a lot a lot (Alan).*

One way carers had developed to manage these demands was being clear on what the remits of their role were. Some described developing tolerance to accept what they cannot change, "*This is how he chooses to live, we have to accept that (Jenny)".* This description refers to the acceptance of client's living standards and represents the carers professional strategy to protect their client's relationship, rather than developing passivity to behaviours. Whilst others described recognising their limits and choosing to go above and beyond this for the good of their client. In some cases, this required them to do something that their organisation would not have suggested.

> *You go out, you go over, above and beyond, to do things that you're not really supposed to do, but the positives far outweigh the negatives, do you know what I mean? If that means he's in a good mood, that means he's stable, that means he's not offending, I'll do it (Alan).*

When talking about the impact of the client's harmful sexual behaviour on their role as carers, participants described needing to detach themselves from the emotional impact of this, "*At the end of the day you have to detach the crime from the person" (Jenny)*. This

detachment was described in the context of separating work from home, and the individual from their behaviour. Given the nature of the HSB carers were witnessing, both contact and non-contact, this reflects a protective mechanism for the carer. All participants described this as a necessary skill, and some felt better able to do it than others, which may have been influenced by their varying years of experience in the profession.

> *I'm quite good at switching off from a situation and not thinking of it. I'm here as a professional; I'm not here to make friends and take loads of stress home I try to just switch off and works at work, homes at home (Simon).*

Acknowledging the challenges of their role and being able to implement strategies to protect themselves is described as vital for being able to provide care for individuals with IDD and HSB. In relation to managing the strain of the role, the strategies implemented were directed by the carer rather than their organisation. Thus, indicating that across public and private sector organisations the carer bares the weight of protecting their own emotional well-being.

Theme 2: Relational and Social Shaping of Care

This theme builds on the emotional challenges of the role explored in Theme 1 and highlights the added complexity that the work doesn't occur in isolation. Carers are required to negotiate the tension between working directly with the client, as well as navigating the impact of other people. All participants highlighted that their work can be heavily influenced by people outside the client/carer relationship, as demonstrated in these two subthemes.

Subtheme 2.1: The role of relational support

Carers described that their job role was heavily influenced through receiving necessary support from other people, namely other professionals. Carers discussed needing to be open to this support and accept when they may need to turn to others to look after themselves, in order to care for the client. An important point raised was that support isn't always related to professional difficulties, that personal life can have an impact on their ability to perform the role. Being able to raise these concerns in supervision was something the carers found helpful. The workplace setting is an important context when considering this, as organisations can be responsible for creating a culture in which these discussions are enabled, as described below by Alan who works in the community.

> *Because there might be something going on in the background, you might have issues going on at home that you're not telling anybody about. So, in supervision, as much as you talk about some patients stressing you out, but you can also say, 'well actually I've got this going on as well' (Alan).*

Participants found this support from management most helpful when it was readily available, something especially important for carers who support the client on an individual basis in the community. "*If there is ever anything you feel like you want to talk about that you can always ring the shift leader or the manager. There is always someone to talk to" (George)*. They described feeling well supported in their role when they could speak to someone freely, at a time that suited them, indicating that support from colleagues outside of protected supervision is also beneficial for carers.

My manager is quite good as well. She's like, obviously, we have supervision, but she's always there if you want to go and have a little chat or talk something through if you feel uncomfortable about something so we're lucky like that (Gemma).

Importantly, it was highlighted by a number of participants that support was equally beneficial when it was from peers, rather than management, *"I've got the support of the team. We just work well together, I think we can all cope with any challenges [the client] brings because we're quite tight" (Liz).* This reflects peer empathy based upon shared client experiences. It was noted that support from their peers felt unconscious and automatic, particularly if the carers had experienced a particular challenge. Participants described overcoming challenges together when they received support from their peers.

Yeah, I have like supervision, which is a big help, but also the team that I work in, we're very good at like kind of like… without even realising that we're doing it, we kind of debrief in the office. It's like, oh you know something we talk about it, and I think that helps a lot (Gemma).

As well as being able to share and offload challenges of the role, carers reported that support from others allowed them to problem solve and develop a new perspective on their client, "*then we will discuss and come up with a solution" (George).* This describes a process within which collaboration with colleagues led to a shift in perspective, which may be vital in the risk management of a client with HSB. Similarly, participants described the benefit of receiving training from others and working jointly with different professionals to provide

effective care for the client. This collaboration was viewed as broadly positive and enhanced the effectiveness of their care.

> *You would have a clinical psychologist, and you would have staff nurse and the person's social worker would come into the service, and they would give us all training on that individual… it was really beneficial and to my way of thinking and thinking outside of the box (Simon).*

> *I've had quite a lot of good communication with her [the Occupational Therapist], so we've had quite a lot of going back and forward. She's come in with a few ideas and wanted to have a conversation about whether they're suitable or not, so that has been good (Liz).*

It is demonstrated that all participants have experienced beneficial input from other professionals whilst providing care to their client. This support came from either receiving direct support from colleagues, or collaboratively working with others to enhance the care provided to clients. Opportunities for collaborative working with others is more readily available in some settings, such as MDT working in inpatient settings, however this was an experience described by participants across the different contexts.

Subtheme 2.2: How perceptions and assumptions can shape care

The carers' role is also influenced by individuals outside the caring profession, namely the general public during supervised leave and community outings. Carers commonly noted that members of the general public made broadly negative assumptions about their clients and the work the carers were doing in supporting individuals with IDD and HSB,

often based on minimal understanding, "'*Ooh bad, horrible, paedophiles', and there is no understanding of what might have led them to that and what challenges they have faced in life. I would say there is none" (Liz).* Liz's consideration of the public narrative appears to capture the binary view of individuals as either good or bad. However, her reference to understanding contributing factors demonstrates that this can be morally ambiguous and her role in caring for someone with IDD and HSB causes her to acknowledge this. It was further emphasised that the general public failed to acknowledge the presence of IDD in their client and the impact this may have had on offending behaviour.

> *The community normally doesn't have that kind of understanding opinion, do they? They normally think sex offender is a sex offender regardless if they've got LD, regardless if they've got needs, you know. They just see the sex offender label, don't they? They're not particularly bothered about people who struggle or people who don't have the capacity to know what is right or wrong (Alan).*

This demonstrates the legal considerations that Alan encounters within his role working with individuals with HSB, and the importance of considering capacity and culpability. Participants felt that communities were unable to see past the offending behaviour of the client which led to them stigmatising them, "*There is still that stigma from society, I think there always will be" (Jenny).* Carers felt that this stigma surrounding offending behaviour led the public to make assumptions about their clients. There were occasions in which this negative perception had a direct impact on the carer's job role. In one case the carer was required to limit their contact with the client based on the adverse actions from the general public. It was the impact of the general public that forced the carer to balance their

own safety with the needs of the client, demonstrating the complex navigations that need to take place in community teams where there is less physical and procedural security.

> *So, when that happened because of the vigilantes… we had to reduce, we had to look at the risk, reduce our contact, and when we saw him we had to be in twos and most of the time we saw him at the hospital, to be honest (Alan).*

However, there had been occasions in which the lack of awareness of the client's difficulties had led to surprisingly positive interactions with the general public, "*They get along very well. I think potentially, if there was an awareness that they had sexualised background that could potentially change perceptions, but at the minute I think everyone's alright" (Simon).* This reflects the complex decision making carers face around transparency and protection. When the general public were unaware of the client's offending histories they interacted positively with them, in these cases the reduced understanding was viewed as a protective factor.

> *In fact usually quite the opposite. When we go for the walk, people often with their dogs kind of say hello and 'do you wanna stroke the dog' and that sort of stuff… but I think it would be different if they knew what their offences were (Gemma).*

The shared experience among participants was that other people can influence their job role, positively and negatively. Attitudes of the general public are often worsened by the stigma attached to offending behaviours and it is protective for client's offending histories to remain private. All carers benefitted from having the support of other professionals and

working collaboratively, which was an important factor in balancing the challenging influence of others negative perception.

Theme 3: Working Together to Put Clients Unique Needs First

The final theme to emerge from the data was the commitment of carers to put the client's needs before their own. In order to do this, the carers needed to have a strong understanding of what the client wanted from the caring relationship, and they relied on their clients to openly communicate this to carers.

Subtheme 3.1: Complex care requires collaboration

Participants describe the experience of caring for an individual with IDD and HSB as not being possible without the client's collaboration. As these individuals present complex needs and risk histories collaboration is a necessity for safety and relational care. Carers were required to build strong relationships with their clients, and these had to be built on understanding and listening to the client, especially vital given the possible communication difficulties individuals with IDD can present. However, ultimately, the strength of this relationship was determined by how much the client was willing to share with the carer.

> *It takes time for him to talk to you. You know, the more he knows the staff, the more he opens up and he talks, but when you start working with him, he is a bit laid back he doesn't mind, but once he gets to know, you he can talk to you (George).*

This experience was echoed by Simon, who stated that his understanding of the client deepened as they revealed more about themselves. It was this deepened understanding that allowed Simon to feel able to manage the risks presented, a reminder of the dual role held by

carers in this context, between emotional support and risk management. Importantly, it was understanding the client as a person that allowed Simon to assess the risks presented, viewing the two as interconnected.

> *With managing his risk, I think it's more about knowing him. Now, because I know him quite well, I know that what his potential risks are and the way he does things. I'm quite able to understand him as a person, so part of risk management is just knowing him really (Simon).*

Whilst a strong understanding of the client strengthens the relationship and allows the carer to work effectively with the client, many felt their role was limited by what the client was willing to do, "*I stopped offering because I know he won't engage with them. He just doesn't, he's more like a social person" (Alan).* For example, Alan described having to change the offer of support and how he worked with the client because they continuously chose not to engage and focused more on what they enjoyed doing. This demonstrates how the carer is able to adapt to the client's choices when working with them in a community setting. Although the scope for flexibility in a community setting also led to challenges enforcing attendance, as described by Alan.

> *The main one was missing appointments, he was notorious for it. I mean because when he missed [the appointments] that meant I was having to move my appointments round, to make sure he was at the next one the following week (Alan).*

In contrast to this, Simon described his work being impacted by the external restrictions placed on the client due to the HSB and found this to be a motivating factor for the client to engage. Rather than being motivated by what they enjoy doing, Simon's client was influenced by external systems of control that commonly impact clients in forensic settings and motivated by avoiding potential consequences. Regardless of the motivation, it was ultimately the client's decision to engage in the work or not.

> *He understands it slightly. He knows that it means he has to be staffed, he knows it means that if he goes back to hospital, then the chances of him getting out again would be slim to none. So, I think that is a massive factor in him cooperating a little bit more with the conditions (Simon).*

Finally, carers shared their experiences of having to advocate for themselves within the role and needing to gain permission from the client to be allowed to have space, once their needs had been met. This appeared particularly relevant for staff working in community settings who are required to provide 1:1 care.

> *I would just say to him, 'I need a break; I'm going to the sleepover room for 30 minutes'. He likes to know exactly what time you're going to be back, and then he'll watch the telly or something. I'll say 'when we come back we'll do that' and he'll give me, he's got a lot better at giving me half an hour if I need it. He never used to, so we didn't ever get a break (Liz).*

The experience from all carers can be seen to demonstrate that cooperation and collaboration with the client, whatever it is motivated by, is an important factor for effective working with the client. This is also understood within the context of external restrictions commonly placed on clients who display HSB, and the importance of risk management within relationships. The analysis also indicates how the carers would prioritise the client's needs over their own.

Subtheme 3.2: Tailoring care to the client

Carers described prioritising the client by being responsive and adaptive in their approach, including communication style and delivery of care. Carers highlighted that they were required to have a clear understanding of what worked for their client, which have developed through long-term placements and a number of years working with the client.

> *He needs to talk things through; he likes to talk things through constantly. I think that he just needs you to sit and listen to him even. You don't even need to say, don't need to say much, just need to sit near him and listen (Liz).*

Two carers described that the way they would respond to the client was dependent on how the client was communicating with them, they were led by the client's presentation, demonstrating the need to engage clinical judgement. Carers were required to make a decision of what was going to be most beneficial in the moment, which for both was taking a firm stance and creating boundaries, "*I'm very firm but fair with him, I have clear boundaries with him" (Jenny),* an important skill when working with individuals who display HSB. They also described how the response to the client was tailored by what background information

they had, demonstrating how current behaviours are interpreted within the context of historical information.

> *He'll also push me further because he's always trying to see, I think it's because of the life he's had; he's always had to fight for anything, so he's always...even two years in he's still trying to see what he can get…but sometimes you have to be really firm with him (Liz).*

Similarly, carers described having to tailor the level of support and response to the client based on the needs being displayed and the legal context imposed on the client due to the HSB, "*We adapt the way we support him with his changing needs. So I'd say over the 7 years he's lived here…I suppose it goes hand in hand with whatever conditions the MoJ decides to impose upon him" (Simon)*. This included considering what was important for maintaining the therapeutic relationship and respect for the client, again demonstrating the continuous need to balance relationships and risk management.

> *Certain patients can push boundaries and think 'Oh well I'm outside and I can do what I want' kind of thing. So, in light of that then, because we're very much about protecting their dignity, so where you might challenge that if we were in our therapeutic area, when you're out in the public you don't really want to do that… you kind of don't wanna make a big scene in the public (Gemma).*

Across all participants, it appeared evident that the client was at the forefront of decisions being made, whether it was deciding which activities to offer them or how to

respond appropriately in different situations. Each participants experience of delivering care was centred around what the client needed in that moment, with the carers' needs being considered afterwards. These decisions were often also happening within the context of organisational and legal structures that require prioritisation of risk management, particularly in community settings where public safety is also of vital importance.

2.4 Discussion

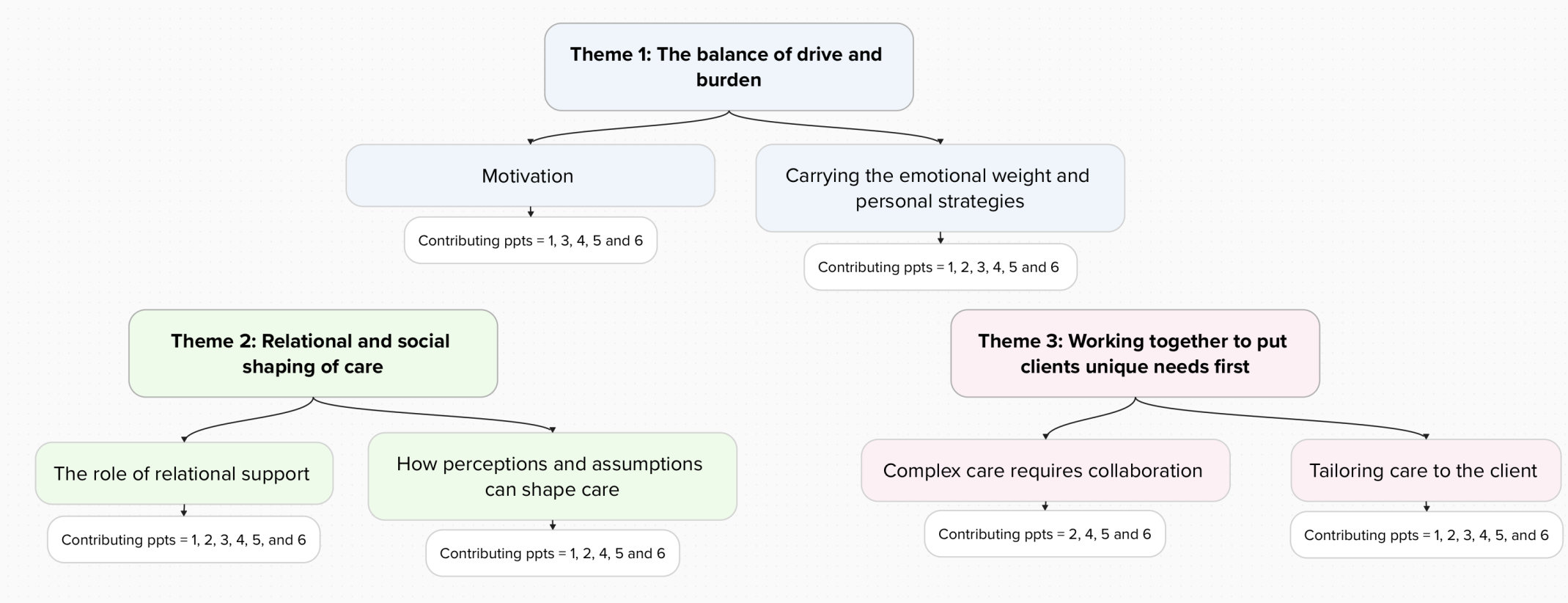
Results Overview

This study aimed to explore paid carers' experiences of supporting individuals with Intellectual and/or Developmental Disabilities (IDD) who also present Harmful Sexual Behaviour (HSB), focusing on their experiences of facing challenges and how this impacted their wellbeing. Using Interpretative Phenomenological Analysis (IPA) of six semi-structured interviews, three superordinate themes were identified: 'The balance of drive and burden', 'Relational and social shaping of care' and 'Working together to put clients unique needs first', these are displayed in figure 1.

Carers described the role as emotionally demanding, requiring them to develop coping strategies to maintain their wellbeing. A key strategy was connecting with the values and motivation that brought them to the role. They also expressed the impact of others, including colleagues, professionals and the general public, on their job role. The benefits of supervision and peer support emerged as crucial to the role, whilst negative societal perceptions added to their stress. Finally, carers highlighted the centrality of the client in their work, emphasising the importance of collaboration and responsiveness to individual needs to deliver effective care.

Figure 1

Themes and Subthemes Emerged From the Data



Findings in Context

'The balance of drive and burden' demonstrates the personal development carers undergo to manage the emotional weight of the job. Carers described the need to set clear boundaries on what they were prepared to do, to meet the needs of the client and to emotionally detach from their work. This aligns with previous research by Cope (2018) who note the common experience of emotional detachment in carers. In Cope's study, detachment related to a lack of emotional outlet for staff, similar to the findings by Storey et al. (2011), but in the current study, this was seen as a tool to maintain professionalism. In both cases, excessive detachment can risk reducing empathy in carers (Lee & Kiemle, 2015) and therefore highlights the importance of supervision and emotional support for this staff group to provide effective care for clients. This is an important finding and reveals an experience unique to paid carers, as family caregivers are likely unable to use this strategy of compartmentalising (Perera & Standen, 2014).

The second important facilitator for doing the job was motivation. Carers described a deep commitment to improving the lives of individuals they support, which was reinforced by their work being appreciated by others. This supports the findings from Stevens et al. (2021) that staff need to feel they are improving the lives of individuals they work with. Understanding what motivates carers to do the role is important because support work is often underappreciated and underpaid (Hastings, 2010), both of which have been linked to burnout in healthcare professionals (Renger et al., 2020). There is a case to be made for formalising the role through clearer ethical guidelines and professional standards, enhancing this recognition from others and enabling people to take greater pride in their work. There is also evidence to suggest that stricter training requirements and higher pay may lead to improved retention (Murray et al., 2022). This is important to consider in the UK, where

turnover in the adult social care learning disabilities workforce was over 29% in 2018 (Skills for Care, 2018), and can have detrimental effects on quality of care due to the loss of competence and experience (Svae et al., 2022).

The ‘relational and social shaping of care’ theme indicates how external factors can shape a carers’ experience. Relational support from colleagues is described as vital for carer wellbeing, echoing previous findings that peer support is an important coping mechanism (Rose & Walker, 2018). Participants emphasised that this support needs to be frequent and accessible, consistent with Haines and Brown (2018) findings that a consistent presence is required for effective joint working in healthcare professionals. Peer support was seen as automatic from colleagues and equally effective for promoting wellbeing as supervision from management, matching findings from Sandhu et al. (2012) that informal peer support was preferred. Thus, suggesting that organisations should actively create spaces for peer connection and informal debriefs. Participants also strongly valued the availability of training and felt this had supported effectiveness in the role, similar to the findings from Windley and Chapman (2010). Supervision was reportedly a helpful space for participants to process the emotional challenges of the role, supporting findings by Sandhu et al. (2012). This was most effective when it was readily available to carers and the agenda allowed them to speak freely about personal and professional issues impacting their work. The need to tailor clinical supervision to the individual carer’s needs has been previously evidenced by Malin (2000). This was supported by Mothersole (2000), who demonstrated the importance of clinical supervision when working with forensic clients and acknowledged that at times this would include discussing personal issues.

Conversely, participants reported feeling negatively impacted by the general public’s misunderstanding and stigma surrounding their work. Current participants described how stigma from the community created barriers to care delivery, supporting findings by Rose and

Walker (2018) that negative societal attitudes can increase the difficulty of the caring role. This supports the need for greater public awareness and societal narratives that recognise the value of carers' contributions. Furthermore, it highlights the need for organisations to provide training to staff in addressing this stigma and understanding the impact of this on individuals with IDD (Pelleboer-Gunnink et al., 2021).

It is also important to recognise that carers' experiences are shaped by the wider context in which they work. For example, supporting an individual in the community can provide greater opportunities for rehabilitation and community integration but may also present higher levels of risk. All of which can influence the relationship and how staff interact with the client. Organisational and staff factors, such as inpatient or community services, also have an impact. Inpatient settings may offer greater access to supervision, stricter routines and a controlled environment, whereas community settings may involve greater autonomy, but less support. These contextual differences are important to recognise because they can influence paid carers' ability to build trust and maintain therapeutic relationships with clients with IDD and HSB.

The final theme, 'Working together to put clients unique needs first' reflected the carers' prioritisation of the client's needs above their own. This required highly individualised care, strong communication and collaborative relationships. Participants stressed the importance of tailoring support to what clients want and are willing to engage in, consistent with Svae et al. (2022) who found that effective care is difficult if clients are unwilling to engage or accept it. These findings are consistent with theories of offending described by Keeling et al. (2009) which propose that difficulties with social and affective functioning can contribute to offending in people with IDD, emphasising the importance of emotionally attuned and personalised care from carers. These findings reinforce the need to professionalise the role, to acknowledge the complex skill set required for the job, and to

provide carers with skills they need to build trust and collaboration with clients. Ultimately, carers described putting the client at the heart of their work by aligning support with the client's individual goals and preferences. This finding matches with literature promoting person-centred care, and emphasising the importance of client choice and relational trust (Fleming et al., 2019).

Clinical Implications

Given the lack of existing research in this area, the current findings offer valuable insights into how support for paid carers can be improved. Key recommendations include professional recognition and training, and organisational support for wellbeing and emotional processing.

Professional Recognition

First, formal recognition of carers as a professional group could positively impact both external perceptions of the carers' role and their own sense of value. This recognition could foster a stronger professional identity for carers, particularly when paired with structured training programmes, enhancing carers current strengths and capabilities. One participant noted the historical value of such training but highlighted that it is no longer available due to funding. In the last 15 years, the number of learning disability (LD) nurses in the NHS has reduced by 43% in the UK (Royal College of Nursing [RCN], 2023), suggesting the need to reinvigorate this, and similar training, for staff working in this demanding area. Evidence suggests the benefits of a web-based training programme, shown to improve communication amongst carers and facilitate client expression (Truong et al., 2021); however organisational commitment to this training would be essential.

Furthermore, training focused on enhancing theoretical understanding of harmful sexual behaviour could better equip carers to manage complex client needs (Keeling et al.,

2009). Co-delivered training with experts by experience may also help to combat public stigma and empower individuals with IDD (Pelleboer-Gunnink et al., 2021). Certification of training can enhance carers' confidence and esteem, particularly when it formally recognises previous experience (Sandberg & Kubiak, 2013). Similarly, the importance of professional titles for 'unqualified' staff members cannot be overlooked, as job titles significantly influence professional identity (Hall et al., 2024). Thus, establishing formal qualifications and job titles could promote the professionalisation of the caring role, leading carers to feel valued and have their work recognised.

Organisational Support

Secondly, organisations play a key role in supporting carers' hard work and recognising contributions. Appreciation emerged as a key motivator in the current study. It is important that organisations align with carers' values, support their motivations, and provide emotional outlets. Organisations could enhance this sense of value by adopting a strengths-based approach that values adaptive working styles and personalised care, serving to enhance the wellbeing of carers. This includes seeking to enhance opportunities for carer contributions to be recognised through relationship-building initiatives (Hamilton et al., 2024) or financial incentives (Stevens et al., 2021; Stillman et al., 2024). Stillman et al. (2024) found that feeling valued was important in reducing healthcare workers' intent to leave their job and one theme that enhanced value was being supported financially. Higher pay could therefore lead to greater job satisfaction and lower attrition, reducing the already high turnover rate in this staff group.

Emotional Processing

Finally, while some emotional detachment from the role can be an effective coping strategy for carers, excessive distancing can hinder client care. Evidence suggests that secure

attachments with carers are vital for the emotional wellbeing of individuals with IDD (van Wingerden et al., 2018). Therefore, it is crucial that carers have access to safe and effective spaces to process their own emotional experiences and remain empathic to clients, such as reflective practice and supervision (Rose & Walker, 2018).

The current study echoed the importance of peer support and supervision in managing the emotional demands of the work. These findings align with guidance from Skills for Care (2020) and the Care Quality Commission (2013), both of which emphasise the importance of effective supervision for any member of staff working with individuals with IDD. Organisations should therefore prioritise emotional support for staff members, helping carers to maintain empathy for clients, while setting healthy boundaries between their work and personal lives (Rose & Walker, 2018). These mechanisms of support may also support carers to process and limit the noise of external influences such as stigma from the community.

Future Research

Future research needs to consider how recruitment to similar studies in the future can be enhanced. In the current study, there were challenges recruiting carers to interview, which may have been impacted by the stigma associated with being a carer (Mitter, 2017). It is important that future researchers reflect on their own role in the recruitment process to enhance recruitment of stigmatised groups, specifically being clear on why the research is important, what motivates the researcher, and why now is the right time (Stevenson et al., 2018). Ensuring accessibility is another important factor in supporting recruitment (Boardman et al., 2024). The author felt that online interviews increased accessibility and would recommend this method in the future.

Regarding topics for future research, further exploration of the impact of affiliate stigma on research contributions would provide helpful insight. Furthermore, there was a lack

of family support discussed by paid carers in the interviews. This apparent limited family involvement warrants further exploration. Finally, future research should consider working with experts by experience when conducting research, the carer consultation group in the present study made helpful and important recommendations about how recruitment could have been adapted to meet the needs of carers and attract more participants.

Strengths and Limitations

A strength of this study is the diversity of participants. Male and female carers from various UK locations and employment sectors can be seen to enhance the representativeness of the findings, providing a clearer understanding of the experience of caring for this group across different settings. The decision was made to include carers of individuals who did not meet the traditional IQ cut-off of <70 for ID, but were clinically judged to present with meaningful cognitive and functional impairments. This decision reflects the authors recognition that arbitrary thresholds for diagnosis may exclude individuals with lived experiences and who may be accessing IDD services. However, the author acknowledges that this broader inclusion criteria may limit the ability to compare these results directly to a population based on the traditional cut off and did introduce greater variability into the sample. Additionally, the homogeneity of the sample (all paid carers) aligns with IPA methodology. However, this focus limits the generalisability and transferability of findings to family carers, who are likely to have different coping strategies. To address this, feedback was sought from a family carers' expert group, who commented on the appropriateness of study materials as well as reviewing preliminary findings of the study. In doing this, they identified similarities between the key themes and their own experiences, particularly in relation to collaboration and shared decision-making. However, they also identified a major difference in relation to emotional involvement and episodes of care provided. Whilst paid

carers might face pressures to discharge clients, which can lead to disjointed care, being a family carer is often a role for life.

The study was conducted within a larger clinical trial, which aided recruitment of participants but also presented challenges. Limited direct access to participants may have impacted recruitment and engagement. Furthermore, logistical constraints tied to the clinical trial occasionally complicated ethical procedures and timelines of the research. Finally, while the six-person sample allowed for in-depth analysis of the individual participant experience, it restricts the breadth of conclusions that can be drawn about carers' experiences more generally. Although the use of IPA in this study was suitable to explore the lived experiences of this small sample, it may also limit the generalisability of the findings. The results of this study reflect the authors interpretations of a small group of participants, which is an important consideration when reflecting on the implications for clinical practice. There is also a risk of selection bias, that the six individuals who consented to the interview may have done so because they were satisfied with the support received and had more positive relationships with the local research lead. This could further limit the generalisability of the findings, as less satisfied carers may be underrepresented.

Conclusion

This study provides valuable insight into the lived experiences of paid carers supporting individuals with IDD and HSB. Specifically highlighted are the emotional demands of the role, the influence of wider social and professional networks and the importance of placing the client at the centre of care. These findings stress the importance of greater recognition for the carers' work, both through professionalisation and organisational support. This may serve to enhance carers' motivation and wellbeing, both of which are crucial for being able to do the role. By addressing recognition from others, enhancing

professional identity through training and certification, organisations may be able to improve staff retention, and the quality of care provided to this client group.

References

Adams, W. C. (2015). Conducting semi-structured interviews. In K. E. Newcomer, H. P. Hatry & J. S. Wholey (Eds). *Handbook of Practical Program Evaluation (pp.* 492-505). https://doi.org/10.1002/9781119171386.ch19

Alase, A. (2017). The interpretative phenomenological analysis (IPA): A guide to a good qualitative research approach. *International Journal of Education and Literacy Studies, 5*(2), 9-19. https://doi.org/10.7575/aiac.ijels.v.5n.2p.9

Ali, A., Hassiotis, A., Strydom, A., & King, M. (2012). Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in Developmental Disabilities, 33*(6), 2122-2140. https://doi.org/10.1016/j.ridd.2012.06.013

Barrett, A., Kajamaa, A., & Johnston, J. (2020). How to… be reflexive when conducting qualitative research. *The Clinical Teacher, 17*(1), 9-12. https://doi.org/10.1111/tct.13133

Boardman, F. K., Roberts, J., Clark, C. C. A., Onuegbu, C., Harris, B., Seers, K., Staniszewska, S., Aktas, P., & Griffiths, F. (2024). *Qualitative remote data collection guidance.* University of Warwick Press. https://doi.org/10.31273/9781911675174

Boat, T. F., & Wu, J. T. (2015). Clinical characteristics of intellectual disabilities. In T.F. Boat & J.T. Wu (Eds). *Mental disorders and disabilities among low-income children.* National Academies Press (US) (pp. 169-178). https://www.ncbi.nlm.nih.gov/books/NBK332877/

Braund, H., Turnnidge, J., Cofie, N., Kuforiji, O., Greco, S., Hastings-Truelove, A., Hill, S., & Dalgarno, N. (2024). Six ways to get a grip on developing reflexivity statements. *Canadian Medical Education Journal, 15*(5), 146-149. https://doi.org/10.36834/cmej.78824

British Psychological Society. (2000). Learning disability: Definitions and contexts. Leicester: British Psychological Society.

British Psychological Society. (2015). Guidance on the assessment and diagnosis of intellectual disabilities in adulthood. Leicester: British Psychological Society.

Care Quality Commission. (2013). Supporting information and guidance: Supporting effective clinical supervision. https://work-learn-live-blmk.co.uk/wp-content/uploads/2018/04/CQC-Supporting-information-and-guidance.pdf

Cluley, V. (2017). From "Learning disability to intellectual disability"—Perceptions of the increasing use of the term "intellectual disability" in learning disability policy, research and practice. *British Journal of Learning Disabilities, 46(*1), 24-32. https://doi.org/10.1111/bld.12209

Čolić, M. (2023). Clarification of stigma concepts in research with families of individuals with neurodevelopmental disabilities. *International Journal of Developmental Disabilities, 69*(4), 621-627. https://doi.org/10.1080/20473869.2021.1989978

Cope, K. J. (2018). *The experiences of female care staff supporting men with intellectual disabilities with sexualised challenging behaviour: An Interpretative Phenomenological Analysis* [Unpublished doctoral dissertation]. University of Leicester. https://leicester.figshare.com/account/articles/10245404

Corrigan, P. W., & Watson, A. C. (2002). Understanding the impact of stigma on people with mental illness. *World psychiatry, 1*(1), 16.

Dempsey, L., Dowling, M., Larkin, P., & Murphy, K. (2016). Sensitive interviewing in qualitative research. *Research in Nursing & Health, 39*(6), 480-490. https://doi.org/10.1002/nur.21743

Eatough, V., & Smith, J. A. (2017). Interpretative phenomenological analysis. In C. Willig & W. Stainton-Rogers (Eds.). *The Sage Handbook of Qualitative Research in Psychology* (pp. 193-209). Sage Publications. https://eprints.bbk.ac.uk/id/eprint/16386/

Esmail, S., Dary, K., Walter, A., & Knupp, H. (2010). Attitudes and perceptions towards disability and sexuality. *Disability and Rehabilitation, 32*(14), 1148-1155. https://doi.org/10.3109/09638280903419277

Fleming, P., McGilloway, S., Hernon, M., Furlong, M., O'Doherty, S., Keogh, F., & Stainton, T. (2019). Individualized funding interventions to improve health and social care outcomes for people with a disability: a mixed-methods systematic review. *Campbell Systematic Reviews, 15*(1-2). https://doi.org/10.4073/csr.2019.3

Haines, D., & Brown, A. (2018). Health professionals working effectively with support workers to enhance the quality of support for adults with intellectual disabilities: A meta-ethnography. *Journal of Applied Research in Intellectual Disabilities, 31*(2), 200-212. https://doi.org/10.1111/jar.12343

Hall, A. J., Goodwin, V. A., Allchurch, L., Capon, L., Farrell, V., Olufunmilayo, O., & Griffin, R. (2024). Feeling valued at work: a qualitative exploration of allied health profession support workers. *BMC Health Services Research, 24*(1), 1511. https://doi.org/10.1186/s12913-024-11879-z

Hamilton, M., Bainbridge, H., Baird, M., Zettna, N., Hofstatter, L., Judd-Lam, S., & O'Loughlin, K. (2024). The importance of recognition: predictors and outcomes of

carer recognition among working carers of ageing relatives. *Community, Work & Family,* 1-26. https://doi.org/10.1080/13668803.2024.2413874

Harrison, P. L., & Oakland, T. (2015). Adaptive behavior assessment system (ABAS-3): Manual. Pearson Clinical Assessment.

Hastings, R. P. (2010). Support staff working in intellectual disability services: The importance of relationships and positive experiences. *Journal of Intellectual and Developmental Disability, 35(*3), 207-210. https://doi.org/10.3109/13668250.2010.492710

Holland, T., Clare, I. C. H., & Mukhopadhyay, T. (2002). Prevalence of 'criminal offending' by men and women with intellectual disability and the characteristics of 'offenders': implications for research and service development. *Journal of Intellectual Disability Research, 46,* 6-20.

https://doi.org/10.1046/j.1365-2788.2002.00001.x

Keeling, J. A., Rose, J. L., & Beech, A. R. (2009). Sexual offending theories and offenders with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 22(5), 468-476. https://doi.org/10.1111/j.1468-3148.2009.00493.x

Lee, A., & Kiemle, G. (2015). 'It's One of the Hardest Jobs in the World': The experience and understanding of qualified nurses who work with individuals diagnosed with both learning disability and personality disorder. *Journal of Applied Research in Intellectual Disabilities, 28*(3), 238-248. https://doi.org/10.1111/jar.12125

Levitt, H. M., Morrill, Z., Collins, K. M., & Rizo, J. L. (2021). The methodological integrity of critical qualitative research: Principles to support design and research review. *Journal of Counselling Psychology, 68*(3), 357. https://doi.org/10.1037/cou0000523

Lindsay, W. R. (2002). Research and literature on sex offenders with intellectual and developmental disabilities. *Journal of Intellectual Disability Research, 46*(1), 74- 85. DOI: 10.1046/j.1365-2788.2002.00006.x

Mak, W. W., & Cheung, R. Y. (2008). Affiliate stigma among caregivers of people with intellectual disability or mental illness. *Journal of Applied Research in Intellectual Disabilities, 21*(6), 532-545. https://doi.org/10.1111/j.1468-3148.2008.00426.x

Malin, N. A. (2000). Evaluating clinical supervision in community homes and teams serving adults with learning disabilities. *Journal of Advanced Nursing, 31*(3), 548-557. https://doi.org/10.1046/j.1365-2648.2000.01309.x

McCarthy, J., Chaplin, E., Harvey, D., Tate-Marshall, K., Ali, S., & Forrester, A. (2023). Recognising & responding to defendants with intellectual disability in court settings. *Forensic Science International: Mind and Law*, *4*, 1-5. https://doi.org/10.1016/j.fsiml.2023.100116

Mencap. (n.d.). What is a Learning Disability? Mencap. Retrieved 14th April 2025, from https://www.mencap.org.uk/learning-disability-explained/what-learning-disability

Mills, S., & Rose, J. (2011). The relationship between challenging behaviour, burnout and cognitive variables in staff working with people who have intellectual disabilities. *Journal of Intellectual Disability Research, 55*(9), 844–857. https://doi.org/10.1111/j.1365-2788.2011.01438.x

Mitter, N. (2017). *Stigma experienced by the families of individuals with intellectual disabilities.* [Unpublished doctoral dissertation]. University College London. https://discovery.ucl.ac.uk/id/eprint/10028135

Mitter, N., Ali, A., & Scior, K. (2018). Stigma experienced by family members of people with intellectual and developmental disabilities: multidimensional construct. *BJPsych Open, 4*(5), 332-338. https://doi.org/10.1192/bjo.2018.39

Mothersole, G. (2000). Clinical supervision and forensic work. *Journal of Sexual Aggression, 5*(1), 45-58. https://doi.org/10.1080/13552600008413295

Murray, G. C., McKenzie, K., Metcalfe, D., Whelan, K., & Murray, A. L. (2022). Exploring the relative importance of factors that influence the job retention of social care staff working in intellectual disability services. *British Journal of Learning Disabilities, 50*(1), 13-18. https://doi.org/10.1111/bld.12365

National Institute for Health and Care Excellence. (2013). Challenging behaviour and learning disabilities: Final scope [NICE guideline NG11]. https://www.nice.org.uk/guidance/ng11/documents/challenging-behaviour-and-learning-disability-final-scope3

National Institute for Health and Care Excellence. (2015). Challenging behaviour and learning disabilities: Prevention and interventions for people with learning disabilities whose behaviour challenges [NICE Guideline NG11]. https://www.nice.org.uk/guidance/ng11/chapter/Recommendations#support-and-interventions-for-family-members-or-carers

NHS England. (n.d.). Who is considered a carer? NHS England. Retrieved 14th April 2025, from https://www.england.nhs.uk/commissioning/comm-carers/carers/

NHS England. (2015). Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition: Service model for commissioners of health and social care services. https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf

Nixon, M., Thomas, S. D., Daffern, M., & Ogloff, J. R. (2017). Estimating the risk of crime and victimisation in people with intellectual disability: a data-linkage study. *Social Psychiatry and Psychiatric Epidemiology, 52,* 617-626. https://doi.org/10.1007/s00127-017-1371-3

Olmos-Vega, F. M., Stalmeijer, R. E., Varpio, L., & Kahlke, R. (2023). A practical guide to reflexivity in qualitative research: AMEE Guide No. 149. *Medical Teacher, 45*(3), 241-251. https://doi.org/10.1080/0142159X.2022.2057287

Pelleboer-Gunnink, H. A., Van Oorsouw, W. M., van Weeghel, J., & Embregts, P. J. (2021). Stigma research in the field of intellectual disabilities: A scoping review on the perspective of care providers. *International Journal of Developmental Disabilities, 67*(3), 168-187. https://doi.org/10.1080/20473869.2019.1616990

Perera, B. D., & Standen, P. J. (2014). Exploring coping strategies of carers looking after people with intellectual disabilities and dementia. *Advances in Mental Health and Intellectual Disabilities, 8*(5), 292-301. https://doi.org/10.1108/AMHID-05-2013-0034

Raczka, R. (2005). A focus group enquiry into stress experienced by staff working with people with challenging behaviours. *Journal of Intellectual Disabilities, 9*(2), 167-177. https://doi.org/10.1177/1744629505054271

Renger, D., Miché, M., & Casini, A. (2020). Professional recognition at work: The protective role of esteem, respect, and care for burnout among employees. *Journal of Occupational and Environmental Medicine, 62(*3), 202-209. DOI: 10.1097/JOM.0000000000001782

Rich, P. (2011). *Understanding, assessing, and rehabilitating juvenile sexual offenders* (2nd ed.). John Wiley & Sons.

Robinson, S., Fisher, K. R., Graham, A., Ikäheimo, H., Johnson, K., & Rozengarten, T. (2023). Recasting 'harm' in support: Misrecognition between people with intellectual disability and paid workers. *Disability & Society, 38*(9), 1667-1688. https://doi.org/10.1080/09687599.2022.2029357

Rose, J., & Walker, A. L. (2018). Understanding Staff to Provide Effective Support and Development. In W.R. Linsday & J.L Taylor (Eds.), *The Wiley Handbook on Offenders with Intellectual and Developmental Disabilities: Research, Training, and Practice,* (421-435).

Royal College of Nursing. (2023). Learning disability nurse deserts developing across England. https://www.rcn.org.uk/news-and-events/Press-Releases/learning-disability-nurse-deserts-developing-across-england

Sandberg, F., & Kubiak, C. (2013). Recognition of prior learning, self-realisation and identity within Axel Honneth's theory of recognition. *Studies in Continuing Education, 35*(3), 351-365. https://doi.org/10.1080/0158037X.2013.768230

Sandhu, D. K., Rose, J., Rostill-Brookes, H. J., & Thrift, S. (2012). 'It's intense, to an extent': a qualitative study of the emotional challenges faced by staff working on a treatment programme for intellectually disabled sex offenders. *Journal of Applied Research in Intellectual Disabilities, 25*(4), 308-318. https://doi.org/10.1111/j.1468-3148.2011.00667.x

Saxe, A., & Flanagan, T. (2016). Unprepared: An appeal for sex education training for support workers of adults with developmental disabilities. *Sexuality and Disability, 34*, 443-454. https://doi.org/10.1007/s11195-016-9449-5

Shaw, R. (2010). Embedding reflexivity within experiential qualitative psychology. Qualitative Research in Psychology, 7(3), 233-243. https://doi.org/10.1080/14780880802699092

Skills for Care. (2018). The adult social care workforce supporting people with learning disabilities and/or autism. https://www.skillsforcare.org.uk/resources/documents/Developing-your-workforce/Care-topics/Learning-disability/The-workforce-supporting-people-with-learning-disabilities-andor-autism.pdf

Skills for Care. (2020). Effective supervision: A practical guide for adult social care managers and supervisors. https://www.skillsforcare.org.uk/resources/documents/Support-for-leaders-and-managers/Managing-people/Supervision/Effective-supervision-guide.pdf

Smith, J. A., Larkin, M., & Flowers, P. (2022). *Interpretative phenomenological analysis: Theory, method and research*.(2nd ed.). Sage Publications.

Stevens, M., Moriarty, J. O., Manthorpe, J., Harris, J., Hussein, S., & Cornes, M. (2021). What encourages care workers to continue working in intellectual disability services in England? Interview findings. *Journal of Intellectual Disabilities, 25*(1), 13-30. https://doi.org/10.1177/17446295198546

Stevenson, J., Keogh, P., Smith, J., & West, E. (2018). Reaching the right people: reflexive practice to support effective recruitment, participation, and engagement in research with communities affected by stigma. *International Journal of Qualitative Methods, 17*(1). https://doi.org/10.1177/1609406918819376

Stillman, M., Sullivan, E. E., Prasad, K., Sinsky, C., Deubel, J., Jin, J. O., Brown, R., Nankivil, N., & Linzer, M. (2024). Understanding what leaders can do to facilitate

healthcare workers' feeling valued: improving our knowledge of the strongest burnout mitigator. *BMJ Leader, 8*(4). doi:10.1136/leader-2023-000921

Storey, J., Collis, M. A., & Clegg, J. (2011). A psychodynamic interpretation of staff accounts of working with people who have learning disabilities and complex needs. *British Journal of Learning Disabilities, 40*(3), 229-235. https://doi.org/10.1111/j.1468-3156.2011.00697.x

Svae, G. B., Hassel, B., & Søndenaa, E. (2022). People with intellectual disabilities and harmful sexual behaviour: Professionals' views on the barriers to prevent harm. *Journal of Applied Research in Intellectual Disabilities, 36*(1), 176-185. https://doi.org/10.1111/jar.13048

Tekola, B., Kinfe, M., Girma, F., Hanlon, C., & Hoekstra, R. A. (2020). Perceptions and experiences of stigma among parents of children with developmental disorders in Ethiopia: A qualitative study. *Social Science & Medicine, 256.* https://doi.org/10.1016/j.socscimed.2020.113034

Thomas, C., & Rose, J. (2010). The relationship between reciprocity and the emotional and behavioural responses of staff. *Journal of Applied Research in Intellectual Disabilities, 23*(2), 167-178. https://doi.org/10.1111/j.1468-3148.2009.00524.x

Truong, A., Alverbratt, C., Ekström-Bergström, A., & Antonsson, H. (2021). Caring for persons with intellectual disabilities and challenging behavior: staff experiences with a web-based training program. *Frontiers in Psychiatry, 12.* https://doi.org/10.3389/fpsyt.2021.580923

van Wingerden, E., Sterkenburg, P. S., & Wouda, M. (2018). Improving empathy and self-efficacy in caregivers of persons with intellectual disabilities, using m-learning

(HiSense APP-ID): Study protocol for a randomized controlled trial. *Trials, 19*(400), 1-8. https://doi.org/10.1186/s13063-018-2772-7

Windley, D., & Chapman, M. (2010). Support workers within learning/intellectual disability services perception of their role, training and support needs. *British Journal of Learning Disabilities, 38*(4), 310-318. https://doi.org/10.1111/j.1468-3156.2010.00610.x

Chapter 3 – Press Releases

3.1 Meta-ethnography Press Release

How do we care for the carers? Review highlights the power of peer support for families of individuals with intellectual disabilities

Researchers at the University of Birmingham have highlighted the critical role of peer support groups in supporting family caregivers of individuals with intellectual disabilities (ID). As family carers are increasingly becoming the primary source of support as institutional care declines, these findings offer strong evidence that support groups should be prioritised by ID services.

Family carers, whether parents, grandparents, siblings or foster carers, often take on the responsibility of providing lifelong care for individuals with intellectual disabilities. In doing this role they can experience increased stress, financial hardship, social isolation and stigma from members of the general public. Recognising that social support may be a protective factor for this group of individuals, researchers set out to examine how peer support groups can impact family carers.

The review involved a systematic literature search of five databases and subsequent meta-synthesis of seven high quality qualitative studies published over the last 10 years. Together, the studies represented the voices of 165 family carers from across the world, each of whom had participated in some form of peer, self-help or mutual support group. The synthesis methodology allowed the researcher to integrate the findings across the papers to uncover three key themes; benefits of shared experiences, changes observed through group attendance and group processes.

Carers consistently described the validation and understanding they felt when surrounded by others who shared their experiences. The participants experienced a sense of belonging fostered by sharing their stories which reduced feelings of isolation and allowed carers to feel heard. This emotional connection was a key factor in their ongoing engagement and many cited the importance of the non-judgmental stance taken by other carers.

Beyond emotional support, attending the groups led to personal growth. Carers reported feeling more capable and confident, not just in their caregiving roles but also in their ability to support others. A number of participants described gaining a sense of empowerment, suggesting a shift from seeking help themselves to providing emotional support to others. This mirrors the empathy-altruism theory, whereby individuals are able to move past their own experiences of distress and empathise with others, feeling motivated to support them. Similarly, carers described a shift in perspective from spending time with others, and many felt empowered to advocate for wider systemic changes.

Importantly, the group experience mattered. Carers valued sessions that were well structured and tailored to their needs. Practical suggestions arising from the research include ensuring that group content is relevant and accessible as participants described challenges when information provided was too generic.

The implications of these findings are significant. With institutional care for individuals with ID reducing, families are increasingly being relied on to support family members with ID. This review highlights robust evidence that peer support groups can reduce the sense of isolation, support carer wellbeing and foster a sense of agency and empowerment. These appear to be key benefits that will impact families, individuals and organisations.

Researchers responsible for this review strongly encourage organisations and policy makers to prioritise the development and funding of structured and accessible support groups as standard care for families of people with ID. Furthermore, involving carers in the design and evaluation of these services will be vital. Within the review it was highlighted that many participants expressed a desire to contribute to improving services. Organisations can support this through greater inclusion in research and service planning.

Lead researcher Eleanor Drew from the University of Birmingham made the following comment, *"It is crucial that we recognise and invest in family carers, not just as supporters, but as individuals with expertise and valuable insight. We need to acknowledge that these individuals have emotional needs of their own, and it is important that services work with carers to build compassionate and effective systems of care"*.

For further information please contact:

Email: pressoffice@contacts.bham.ac.uk

Phone: +44 (0)121 414 2772

3.2 Empirical Press Release

New research reveals emotional demands among paid carers supporting individuals with intellectual disabilities and/or developmental disabilities and harmful sexual behaviour.

New research from the University of Birmingham has revealed how paid carers face unique challenges in their role caring for individuals with intellectual and/or developmental disabilities (IDD) and harmful sexual behaviour (HSB). They are frequently required to adapt and develop skills to provide effective care. The study highlights an urgent need to provide effective support and training for this group of carers, whilst challenging the stigma that continues to surround the role and the population they care for.

The research team interviewed six paid carers from different areas in the UK to explore their lived experiences. It is important to note that although multiple carers were approached to be involved in the research, only a few consented to participate, demonstrating possible barriers in engaging this group in research. Lead researcher Eleanor Drew commented, *"This is such an important area of research and it is a real concern that carers may feel unable to share their experiences. We need to understand why that is, and make space for a wider range of voices in future research"*.

Findings from the study revealed that the role is emotionally demanding and frequently misunderstood. Carers reported facing stigma from the general public, which contributed to the difficult nature of the role. To cope, many drew on their personal values and connected with their sense of purpose, focusing on the motivation that brought them to the role. The emotional toll of the role also required carers to develop strategies to protect themselves, which for many entailed detaching work from home life. Whilst this was an effective strategy to enhance their wellbeing, it potentially risked diminishing their empathy and could affect the quality of care provided to clients.

Support from peers and managers emerged as a vital protective factor for the carers. When this support was accessible and felt genuine, carers found it very beneficial. Carers also highlighted the importance of being able to speak freely with colleagues and managers, in both supervision and reflective practice. The study calls for attention to the need for safe, structured opportunities within organisations, for carers to connect with others and process their experiences. Negative perceptions from the general public were related to misunderstanding and lack of awareness surrounding harmful sexual behaviour. This may serve to contribute to a diminished sense of professional identity, in turn impacting how the carer views themselves and increases stress.

Despite these challenges, a common theme across all interviews was the deep commitment carers felt toward their clients and the work they do. Participants consistently emphasised the need to keep clients at the centre of their work, tailoring support to individual needs and fostering collaboration. This client-centred approach required adaptability and skill from the carers, which should be recognised by organisations.

The researchers argue that more needs to be done to support the development of a professional identity for carers. Initiatives such as certified training, clear job titles and formal recognition from organisations could improve retention of staff and the quality of care provided to clients. Recognition from others was cited as an important factor in carers' internal motivation and their commitment to the role.

Ultimately, the study concludes that investing in the wellbeing and professional growth of carers is not only necessary for their role, but critical in ensuring high quality care for individuals with intellectual disability and harmful sexual behaviour. Lead researcher Eleanor Drew concluded by saying, *"Creating safe spaces for emotional processing, peer support and genuine recognition are vital in helping carers remain motivated and valued in their role"*.

For further information please contact:

Email: pressoffice@contacts.bham.ac.uk

Phone: +44 (0)121 414 2772

Appendices – Chapter one

Appendix 1A - NICE (2012) Quality Appraisal Checklist

Study identification: Include author, title, reference, year of publication		
Guidance topic:	**Key research question/aim:**	
Checklist completed by:		
Theoretical approach		
1. Is a qualitative approach appropriate? For example: • Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings? • Could a quantitative approach better have addressed the research question?	Appropriate Inappropriate Not sure	Comments:
2. Is the study clear in what it seeks to do? For example: • Is the purpose of the study discussed – aims/objectives/ research question/s?	Clear Unclear Mixed	Comments:

• Is there adequate/appropriate reference to the literature? • Are underpinning values/assumptions/theory discussed?		
Study design		
3. How defensible/rigorous is the research design/ methodology? For example: - Is the design appropriate to the research question? - Is a rationale given for using a qualitative approach? - Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used? - Is the selection of cases/sampling strategy theoretically justified?	Defensible Indefensible Not sure	Comments:
Data collection		

4. How well was the data collection carried out? For example: • Are the data collection methods clearly described? • Were the appropriate data collected to address the research question? • Was the data collection and record keeping systematic?	Appropriately Inappropriately Not sure/ inadequately reported	Comments:
Trustworthiness		
5. Is the role of the researcher clearly described? For example: • Has the relationship between the researcher and the participants been adequately considered? • Does the paper describe how the research was explained and presented to the participants?	Clearly described Unclear Not described	Comments:
6. Is the context clearly described? For example: • Are the characteristics of the participants and settings clearly defined? • Were observations made in a sufficient variety of circumstances	Clear Unclear Not sure	Comments:

• Was context bias considered		
7. Were the methods reliable? For example: • Was data collected by more than 1 method? • Is there justification for triangulation, or for not triangulating? • Do the methods investigate what they claim to?	Reliable Unreliable Not sure	Comments:
Analysis		
8. Is the data analysis sufficiently rigorous? For example: • Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results? • How systematic is the analysis, is the procedure reliable/ dependable? • Is it clear how the themes and concepts were derived from the data?	Rigorous Not rigorous Not sure/not reported	Comments:

9. Is the data 'rich'? For example: • How well are the contexts of the data described? • Has the diversity of perspective and content been explored? • How well has the detail and depth been demonstrated? • Are responses compared and contrasted across groups/ sites?	Rich Poor Not sure/not reported	Comments:
10. Is the analysis reliable? For example: • Did more than 1 researcher theme and code transcripts/ data? • If so, how were differences resolved? • Did participants feed back on the transcripts/data if possible and relevant? • Were negative/discrepant results addressed or ignored?	Reliable Unreliable Not sure/not reported	Comments:

11. Are the findings convincing? For example: • Are the findings clearly presented? • Are the findings internally coherent? • Are extracts from the original data included? • Are the data appropriately referenced? • Is the reporting clear and coherent?	Convincing Not convincing Not sure	Comments:
12. Are the findings relevant to the aims of the study?	Relevant Irrelevant Partially relevant	Comments:
13. Conclusions For example: • How clear are the links between data, interpretation and conclusions? • Are the conclusions plausible and coherent? • Have alternative explanations been explored and discounted? • Does this enhance understanding of the research topic? • Are the implications of the	Adequate Inadequate Not sure	Comments:

research clearly defined? **Is there adequate discussion of any limitations encountered?**		
Ethics		
14. How clear and coherent is the reporting of ethics? For example: • Have ethical issues been taken into consideration? • Are they adequately discussed e.g. do they address consent and anonymity? • Have the consequences of the research been considered i.e. raising expectations, changing behaviour? • Was the study approved by an ethics committee?	Appropriate Inappropriate Not sure/not reported	Comments:
Overall assessment		
As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)	++ + –	Comments:

Appendix 1B - Data Extraction Spreadsheet – Study Characteristics

Author	Year	Focus/Rationale	Location	Sample Size	Sample Context	Methodology	Data Collection	Themes/Categories	Main findings	Limitations	Relevancy to my review
1. Burke et al	2020	Examine outcomes of a support program for siblings of those with IDD.	USA	21	Adult siblings of individuals with IDD. Average age 36, ranging from 21 to 67. Most female (71.4%) and most highly educated. 85% white.	Thematic Analysis	Questionnaires with open and closed ended questions	2 main themes with further subthemes. Sibling perspectives regarding systemic change, expectations for the program.	Greater empowerment reported, they wanted to become more connected. Felt solidarity with other siblings and learned new resources. They wanted to impact systemic change.	No control group, small sample and mostly white. Included those who were already connected to services, possible bias. May not be generalisable. USA only.	Yes - looks at experiences of family caregivers accessing support group, qualitative, quotes included.
2. Daly et al	2015	Evaluate family support groups for individuals with LD. Included parents, grandparents and siblings.	Ireland	21 interviews conducted from a total of 38 who responded to surveys.	18 mothers, 1 sister and 2 fathers took part in interviews. 53% had a family member with ID, others had physical disability or autism.	Thematic Analysis	Open ended survey questions	3 key themes; a locus for stimulating connection and belonging, making a difference within the family, changed mindset: a new way of thinking and being	Knowledge and skills increased, improved understanding, new strategies, increase in skills, development of support. A shift in attitude towards the person, increase in confidence,	Participants chose to take part, potential bias towards people who had positive experiences. 1 group underrepresented in the responses, unsure why.	Yes - looks at experiences of family caregivers accessing support group, qualitative, quotes included.
3. Dew et al	2019	Mothers experience of participating in parent peer support programmes. Processes parents identified as contributing to effectiveness of the programme to support them.	Australia	13	Mothers of children with ID from preschool age to young adult. Most in metropolitan area, most employed. Aged between 32-54.	Thematic Analysis	Semi-structured interviews with participants for them to describe experiences in a private and personal setting.	Impact on family life and community participation, role of paid coordinator, diversity of engagement strategies (social events, facebook, training), partner matching.	Combination of strategies used in the group was key aspect of support and many percieved it to be well-functioning. Paid coordinator relieved pressure on parents, felt able to dip in and out of engagement due to different strategies employed. Participation in training had benefits. Matching partners was a key aspect. Numerous difficulties explored.	Generalisability - 1 parent group in 1 area of Australia. Only 13/41 took part. May represent more engaged families and positive experiences. Reflects demands on the families. All participants were mothers - views of other family members not represented.	Explored experience of parent support groups and included peer support among other support strategies.
4. Gore et al	2022	Explore family carers experiences of attending a support group blending exercises, group discussions and information giving, outcomes of this and the processes that operated within the group.	UK	35	Majority were female (96% in NI and 80% in England), most White British or White Irish (96% NI and 90% England). Mostly birth/grand parents (94%), 1 foster parent and 1 adult sibling. Mean age was 36.9 in NI and 38.8 in England. Children had variety of learning,physical and communication needs.	Thematic Analysis	Semi-structured interviews or focus groups, depending on their preference. Explored experiences of the group and their attendance.	Main themes - Our group, evolving emotions and positive approaches. Subthemes - social and emotional experiences, learning and outcomes.	Increased confidence, greater realisation about need for self-care, finding new ways to support wellbeing, need for coping strategies to be included was reported. Sense of belonging, non-judgement and shared experience is important in establishing a supportive group.	Qual only method, didn't gather info on other interventions attended. Sefl-reported data has bias towards recall and social desirability. Longer outcomes were not assessed - interviews 2 months after completion.	Explores impact of a support group but isn't peer led - one theme talked about experience of being in the group with other carers, feeling normal. Good detail.
5. Lee and Choi	2022	Deliver parent support group sessions and examine feasibility. Focus on how they percieve the meaning and role of the groups and how they percieve the feasibility of the programme.	South Korea	29	Parents of individuals with a ID and enrolled in a special school, parents had attended support group. Age range from 28 to 58. Most mothers (96.6%), 1 was the sister of individual with LD.	Thematic Analysis	5 focus groups and 7 individual interviews.	The meaning of school based parent support groups and ways to develop sustainable school-based parent support groups.	Emphathising with other parents, exchanging info, engaging in collective action, clearly defined purpose and roles, small group meet ups, school based initiatives, identifying actionable plans, collaboration amongst parents and professionals.	Generalisability - was based on one school in South Korea. Qualitative data only made it hard to quantify feasibility, only focused on impact on parents.	Focused on support groups for parents, includes quotes.
6. Linden et al	2024	Exploring acceptability of a new online support programme for carers of PMID. Included mothers, fathers and a one sibling carer.	UK and Ireland	70 responded to survey and 10 took part in interviews.	Most female (67%), mostly mothers (56%), fathers (24%) and grandparent (4%). Mean age 40 years, 24-65. Of the 10 in interviews 7 were female, 9 were parents and 1 was sibling.	Thematic Analysis	Semi-structured interviews to build on findings from surveys	6 themes; time is precious, the breadth and depth of the modules, it was someones experience it was meaningful, wont work for everyone, representation people I could identify with, specific suggestions for future changes.	The programme neesd to be accesible, understandable and easy to use because carers time is valuable. It was accepbale when relevant and meaningful. Possibly it is more hlepful for carers at the early stages of their journey.	Less participation from individuals in Ireland so more representative of those in UK. Possible more experienced carers were recruited due to the methods.	Yes - looks at experiences of family caregivers accessing support group, qualitative, quotes included.
7. Riches et al	2023	Caregiver support service was evaluated for caregiver coping and resilience, impact of strategies for support and satisfaction with services.	Singapore	36 interviewed (328 in full study).	Caregivers - parents, siblings, aunties or grandparents of indviduals with LD. 50% were fathers, 36% mothers and 14% siblings. Age range from 31 to 70 years. 5 different ethnic backgrounds - Chinese, Malay, Indian, Filipino and Sri Lankan.	Qual data analysis using MAXQDA? First content analysis, then coding and themes triangulated.	Interviews - open ended Qs about goals, frequency of service, satisfaction, opinions of the impact and challenges. Also conducted focus groups with staff.	Coping and resilience, bonding networking and social connections (helpful to gain mutual support), knowledge and skills development, future planning and financial concerns, additional unmet needs, need to engage additional carers.	Group contributed to coping and resilience, reduced stress and loneliness and stronger family relationships. Participants valued the mutual support and being able to contribute meaningfully to one another. Peer support is promising area and warrants further research.	Qual data is part of a quant/qual study so not overly detailed. Some measures were not adapted for language, not validated in Asian context. Some concern over understanding of interview questions and not everyone had an interpreter. Interviews based on a convenience sample.	Include but note in write up that data is quite limited because of mixed methods.

Appendix 1C - Data Extraction Spreadsheet Themes and Subthemes

Study	Category/Concept 1	1 -3rd Order	Category/Concept 2	2 -3rd Order	Category/Concept 3
1. Burke et al (2020)	**Sibling expectations for the sibling ambassadors program** Expectations prior to the sibling ambassadors program. Siblings had specific expectations including; developing connection, becoming empowered, improving services and receiving information and resources. **Developing a sibling connection and becoming empowered** Overwhelmingly, participants anticipated establishing connections with other siblings as a result of the program (n¼10). For example, a 34-year-old sister intended to **'Connect and build a network.'** A 23-year-old brother of an individual with ASD expected to **'[Learn] how to help my sibling live a normal and healthy life.'** Relatedly, participants wanted to learn to empower other adult siblings of individuals with IDD. A 25-year-old sister of an individual with cerebral palsy anticipated learning to **'Empower others with family members with disabilities to be advocates.'** For many participants, the desire to connect with other siblings and become empowered were interconnected (n¼6). For example, a 41-year-old African American sister hoped to **'Learn the stories and experiences of others, which will help promote and motivate [her] experience and story with [her] sibling, ultimately helping others.'** **Improving services** Concerning formal supports and services, two siblings expressed an interest in improving services. For example, a 31-year-old brother of an individual with cerebral palsy expected to learn how to **'Enhance services.'** Additionally, a 34-year-old sister wanted to learn **'To connect with agencies and nonprofits to help improve services.'** A 23-year old brother of an individual with ASD, hoped to **'Build a stronger community for the disabled and their siblings.'** Similarly, a 34-year-old sibling desired to learn ways of **'[Building] more accessible, welcoming, inclusive networks, families, and communities.'** **Receiving information and resources** A 34-year-old sister hoped to learn about 'Outreach opportunities and services,' while another 35-year-old sister hoped to **'Network for information and resources.'** The desire to gain information, resources, and strategies was an interest of all siblings, regardless of age. A 22-year-old sister of an individual with ASD stated, **'I am hoping to gain some knowledge regarding advocacy due to my age.'** A 67-year-old sister of an individual with ASD expressed an interest in learning about **'The system of support for older siblings and adults with disabilities.'**	Participants hoped to develop connections, gain empowerment, improve services and receive information. People hoped to gain information to empower themselves and others in their situations. Wanting to learn from others. They were motivated to help others by improving services for individuals, families and communities. Hoping to gain information on different things.	**Completion of expectations after the sibling ambassadors program** Sibling solidarity Participants gained a sense of solidarity. Some participants reported feeling they were **'not alone'** after completing the program. A 23-year-old brother learned **'There are more people like [him] than [he] had previously known about.'** Similarly, a 35-year-old sister stated, **'I know that I have a group of people I can turn to.'** Finally, another sister indicated that **'The gains of joining together with my fellow sibs are limitless.'** Notably, solidarity was also mentioned in the summative evaluation. For example, siblings frequently reported that **'Listening to the many stories from other siblings'** was helpful. Two siblings specifically reported on the importance of developing solidarity with siblings across the lifespan. For example, a sibling wrote: **'…being able to meet with both siblings my age and older. Along side the other 20-something siblings, we were able to start our action plan and also bond over many shared experiences… the older participants provided a wealth of knowledge but more importantly, inspiration for us younger participants.** Empowerment Siblings gained a sense of empowerment as a result of participating in the leadership and support program. A 34-year-old sister of an individual with ASD stated, **'I learned how to work as a group to promote our mission efficiently.'** Siblings did not want empowerment just for themselves. Rather, as a result of the program, participants recognized the importance of sharing their empowerment with others siblings of adults with IDD. A 34-year-old sister of an individual with Down syndrome noted the need **'To connect and spread the word.'** A 55-year-old sister indicated that she **'Learned how to advocate more effectively for [her] sibling and with him'** as a result of the program. Resources Siblings left the leadership and support program with an improved knowledge of initiatives and resources. Multiple siblings reported learning about initiatives occurring at both the state and national levels. Siblings reported leaving with **'A myriad of resources'** and **'Ideas from other sibs.'** With the passage of time, participants began to recognize themselves as a resource. A 49-year-old sister of an individual with ID stated that she can **"Act as a conduit to share the resources, information, and support."** **'All resources and info obtained 1 outstanding.'** However, some siblings reported wanting more resources. For example, siblings reported wanting resources related to: the/own geographic regions; siblings of color; facilitated support; accessibility; sibling stress and mental health; and the adult service delivery system.	After completing the group participants gained solidarity with other people in their situation. Hearing similar stories was helpful. Sharing experiences with those in the same situation but demographically different was helpful. They were more empowered both for themself and their siblings. Theme of wanting to share what they had learned. Resources were gained and recognised themselves as a resource. More resources were wanted.	**Siblings perspectives regarding systemic change** Services and agencies They hoped to create systemic change within systems, including wanting more services for individuals with IDD. They also wanted easier access t resources and education. **'Residential and Day programs' opportunities.'** **'Services would be easier access to waivers to allow siblings to get better services for themselves or [their] siblings.'** **'There needs to be a resource that pulls everything together and creates a "Systems Guide for Dummies" type book or power-point. [A] step by step g what everyone needs to know about entering and navigating the system'** **'[I would like to] utilize local agencies to get information readily available.'** Policies and Legislation Siblings hoped to improve policies and legislation. Siblings reported that improving policies and legislation will have a great impact on individuals **'[Impacting] policies are number one because changing the policies to reflect more of an inclusionary tone will lift many weights and allow the cha treated just as anyone else.'** **'[I hope to] connect with more legislators to get the needs of our siblings to become a higher priority.'** Community and culture Siblings reported hoping to make systemic changes with respect to the community and culture. **'The culture has to change. Services, policies and agencies are just a small piece. Slowly, one person at time, we can make a huge difference.'** **'I am hoping to make it easier to have those with disabilities be a part of the community, not just 'in' the community.'**
2. Daly et al (2015)	**Changed mindset - A newway of thinking** This theme demonstrates the impact of the initiatives on participants' knowledge, skills, confidence and attitudes and explores how participants adopted new ways of thinking and being. Participants described a number of areas where their knowledge and skills increased, including improvement in understanding the actions of their family member with a disability, development of strategies for supporting and living with their family member, increase in problem-solving skill within the family, development of circles of support, enhanced understanding of concepts, such as personal funding, home share, respite care and disability service financing and an improved knowledge of the legal framework related to disability, **I suppose information is power really. … (Project C FM 1)** **The more knowledge you have the more you can do with it. … (Project D FM 3)** Participants described shifting their focus from the way in which their children with disability would survive in society to thinking about how their children could thrive and live a meaningful life. They described acquiring a new belief that their child as a citizen was entitled to have a full and meaningful life, not something that could be given or taken away by society. **She [the trainer] also discussed what inclusion was … which I think is very important … where children have a right, especially in a pre-school setting, to be able to be involved and to play alongside a non-disabled child … and these rights are there and parents are very slow to take them up. They feel that their child should fit into a certain set-up rather than society working around the child and she really emphasized that, do you know? Which I felt was brilliant. (Project A FM 1).** With this shift in attitude, participants demonstrated movement into a more strengths-based mindset, focusing on their child's strengths and abilities rather than solely challenges they might have due to the presence of disability. Participants also described an increase in their self-confidence to advocate for the rights and entitlements of their family member. This increased confidence was related to their enhanced knowledge and skills base, particularly in relation to understanding the legal basis for their requests; the best strategies for managing interactions with service providers; and an enhanced determination to advocate for their family member. **I am going to be the best advocate for [my daughter] … it [the initiative] has given me the tools for change … to change me, which is ultimately going to have an impact on helping [my daughter] to get to where she needs to be because I … don't have to pussyfoot around anybody. I can say, 'These are my daughter's needs. Now, how are we going to meet them?' (Project D FM 4)**	Knowledged and skills increased - their info about their family members and ability to support them. This increased their confidence to support their child. Information increased sense of power and agency. Change in the way they thought about their child - knowing their rights and what they deserve. Shifting to strengths based mindset. Change towards advocating for their child, given tools to do this, understanding their needs.	Enrichment of the quality of life of the person living with a disability Participants referred to how their enhanced awareness of the right of, and possibilities for, the family member to achieve self-determination, have their voice heard and represented, and experience a meaningful fulfilled life translated into concrete advancements. Increased community involvement, employment, engagement with hobbies and interests, independent living and socializing were some of the linked outcomes identified by a number of participants. Participants spoke of being more visible within their communities, for example, some spoke of arranging social situations in which the family member with a disability could experience enhanced integration in everyday social settings. The data also demonstrated how participants worked to ensure that the family member's plans incorporated their likes and abilities, meaning that the plan was a realistic person-led plan. **Actually, we've reviewed everything she's doing with a view to the sort of positive things that are happening in her life and about the building of friendships, the building of her social side and … we've been supporting that. (Project D FM 1)** Participants also referred to having the confidence to step back and to support the family member's freedom and participation in new endeavours and activities. **'We had to treat her as an individual … she's much more of an individual now, whereas before she had to go with the flow which didn't work for her because she has her own way of thinking and she's just an individual with learning disability. … (Project C FM 6)** Change in family dynamics, relationships and understanding With reference to the wider family, participants reported that the learning from the initiatives led to changes in family dynamics and relationships. Enhanced family communication and understanding was highlighted as central to positive family outcomes **He [husband] … had a completely different view of [names son] because as far as he was concerned [names son] … He couldn't achieve or he couldn't go forward or he couldn't, he was limited … Whereas I always hoped there might be more of a possibility, and this [initiative] gave a framework to it. So by him [husband] attending the meetings with me, he was included in the thought process and in the vision going forward and he really took to it. (Project C FM 1)** Some participants outlined examples of greater family communication and cohesiveness as a consequence. For example, one participant described facilitating discussions within the family on issues such as future planning. Others reported family members pulling together, working as a team and taking a more active role in their family member's life.	Their understanding led to family members having a more fulfilled life. They began to integrate more into community. Making sure to incorporate family members likes and interests. Focusing moving to quality of life. Change in confidence levels - more confident to support family member. Family dynamics changed - improved - by attending the group, shared understanding and connection about working together for the family member.	**A locus for stimulating connection and belonging** Participation in the family-focused initiatives also provided a locus for participants to make connections with others in similar circumstances. This identity, mutual support and, in some cases, catharsis. For participants who attended initiatives that were delivered over a longer duration (weeks) bonds and connections incrementally over the course of the initiatives. Likewise, those who participated in shorter initiatives, for instance, overw Findings of connection and belonging were of two forms. Firstly, the initiatives provided a locus wherein participants could engage with others in t with **'like-minded people' (Project D FM 3).** Connecting with others offered the additional benefit of having access to a real-world knowledge base from those in similar circumstances or those Participants referred to the credibility, value and sustaining impact of the gains obtained from these connections as inestimable. The findings furth connection and a sense of belonging led to important emotional benefits, such as opportunities to share feelings that those without disability in th reduction in feeling alone and an increase, or in some cases new found, sense of hope for the future and its possibilities. **Well I found a huge benefit was meeting other parents … whilst I know that's not, you know, possibly the initial objective of having a workshop or a n secondary benefit and turns out to be hugely beneficial because … you start talking to other people and you get a sense of kind of 'I'm not on my own make contact with people and you can, if you want, you can meet them from a support point of view or you can meet them from a knowledge based p** Findings related to the second aspect of this theme demonstrated that some participants established networks with other participants that extend initiatives – **'And then the other huge reward was the friendships' (Project A FM 6).** The data also suggested that for some participants, this expanded beyond the context of those encountered in the initiatives to include more comm development of a greater connection with, and perceived support from, family and friends. Where circles of support (themes 1 and 2) were present, perceived that these would be an important contributor to the realization of the vision for the person with a disability and a way in which to source mo means of continuity into the future. However, where such supports were not in place participants expressed a wish for structured follow-up and/or f support. **Follow-up half-day sessions monthly for a few months in order to support families. (Project D Survey)** In addition, where the forming of networks with other initiative participants had not become established, catch up days with the opportunity to link t were suggested: **Maybe to meet up once a year … You made a lot of friends during these courses and it is one way to keep in contact. (Project C Survey)**
3. Dew et al (2019)	**Engagement with the programme -** The program provided opportunities within the interpersonal and intra-individual self-change domains through the family member training or capacity building activities that provided people with information to inform their decision-making, opportunities to engage in training and advocacy which increased their self-esteem and confidence and social support which increased their connectedness and resilience. It addressed the sociopolitical domains by building the capacity of external supports through the creation of more equal relationships between family members and service providers and by offering an adjunct to the professional behaviours support on offer through the state disability service. As indicated by the concerns expressed by some participants about the process and support offered to peer support partners, this is one aspect of the program that seemingly required additional resourcing. Adequate support, via the paid coordinator role, could enhance the capacity of the program to attend to the complex task of matching and troubleshooting when matches prove unsuitable for either party. **I don't feel like I'm in this on my own. I don't feel so isolated and so removed from the rest of society. I stopped going out. I stopped seeing people. I don't feel like that anymore because they [peer support program] give me that boost to go, 'Just go and have a wine with your girlfriend. Right now, what you need is to look after yourself' Ppt 1.** **Not standing as one family but standing as a community, a belonging' Ppt 5.** The common experience underpinning mothers' engagement with the parent peer support program was that their son or daughter with intellectual disability had challenging behaviour that impacted on family life and community participation. All participants spoke about the positive difference that joining the parent peer support program which was specific to families with a son or daughter with intellectual disability and challenging behaviour made in their lives, with more than one participant referring to it as 'a lifeline'.	1st order quotes indicate common experience was feeling a sense of belonging to a community and feeling less isolated.	**Role of paid coordinator -** The paid coordinator was identified as a pivotal contact point for families and relieved the pressure on already stretched parents to ensure the ongoing viability of the program. Participants were clear that the paid coordinator role was essential to the running of the program. **She's doing all that background work that's so important, like ensuring that everyone does stay connected …sometimes the families that need the most help don't ask for it. So, she's the one who's there to make sure – 'You haven't checked in. Is everything okay?' Ppt 12.** **In the beginning, it was said …there should be no funding and it should just carry on with the parents. We [parents] all have enough passion for it …but we're all in different places, our children are all different ages …and we don't have that time and energy and commitment to be able to ring everyone up and do [the coordinator's] role. Ppt 10.** **So, it's that sort of advisory role, and she really pulls us all together. When we have breaks away, [she's] the one who coordinates it. It's less pressure for us, because we know we just have to turn up. Whereas she's the person who's organising the accommodation, tying to get the funding, making sure everyone's going to be there on time. Ppt 12.** Participants identified the importance of the coordinator role being a paid position rather than relying on parents to sustain the program. A number of participants reiterated that the coordinator role kept parents united as a group, The importance of the paid coordinator role was also reported as integral to the success of the other two themes	Having a paid coordinator was helpful and took the pressure off parents needing to organise things. They found it helpful having someone to check in on them. This felt essential to the running of the group and keeping the group united.	Additionally, the multi-modal engagement strategies on offer to parents meant they could dip in and out of engagement as the pressures of their far mediums. Some mothers in our study engaged mainly via Facebook, others preferred the face-to-face social activities and training opportunities, and some e use of Facebook as a platform to connect families was critical particularly for those living in non-metropolitan areas or who otherwise lacked proxi **There was a little boat trip …I think all those things are really good, because you're taken away from your situation, and you have maybe half a day, or don't get out a lot. I tend to have only one or two friends that I go and visit. So, having this extra thing where somebody actually invites you to go out so Ppt 7.** **I guess just chatting to other people who have learnt how to try and look after themselves, so they don't go under is good. That's what I learnt'. Ppt 9.** **I really like the Facebook page. It's really good. Families share examples and things they come across on there'. Ppt 2.** **[Another support group's] Facebook group is ridiculously huge, and they have families whose children might have a very, very mild disability which, whatwe're dealing with. You'd post in there thinking it's a safe space, but people would still be judgmental, or they would say, 'You should be doing of the time when you post in [parent peer support program Facebook group] people will offer suggestions and stuff like that, but they understand me everything. You don't get judged at all. I think when you've got a child that's challenging, one of the biggest barriers you have to reaching out is being I've been able to link into the Facebook site. Because it's a closed site you can share what's going on and then you get the support from the other pa in the metro area or close by, it's like, 'I'm coming for coffee now'. I don't have that. Ppt 1.** **I use the Facebook page a lot. I'm probably on there at least once a day. If I see anything that I think is valuable or just whatever I think would be of in motivational messages …to focus on the good stuff. Sometimes if [my child] is awake in the middle of the night because he doesn't sleep very well stuff while I'm on there, while I'm awake. There's a lot of mums that are awake at that time to be honest. Ppt 12.** **I'm not a Facebook person. I do get alerts and stuff. Not being a social media person full stop, I just ignore it. So, [another parent] will say 'Did you k would say 'No, I don't have time'. Ppt 7.** **I went to a challenging behaviour workshop and there was a speaker there that was talking about what she did to help build relationships between mentor person. That's when I joined [the program]'. Ppt 9.** **I mean I'd love to do a lot more training with the …challenging behaviours stuff. Just on that one information night the light bulb went on. I started to wo gets to that point where he's having a complete meltdown. I'd love to have much more training. Ppt 1.** **They were really good …at making me look at things from a different perspective. I just found it really interesting seeing how people looked at things perspective on things. They caught me out and questioned me a couple of times with some of the ways that I looked at things and I thought that was**

Note. This is a screenshot of the extraction sheet, indicating a sample of the extracted data.

Appendix 1D - Grouped Themes and Subthemes Across Papers

Key theme	Paper
Siblings expectations for the program Expectations prior to the program Developing a connection and becoming empowered Improving services Receiving information and resources	Burke et al 1
Completion of expectations after the program Sibling solidarity Empowerment Resources	Burke et al 1
Siblings perspectives regarding systemic change Services and agencies Policies and legislation Community and culture	Burke et al 1
Changing mindset - a new way of thinking	Daly et al 2
Making a difference within the family Enrichment of the quality of life of family member Change in family dynamics, relationship and understanding	Daly et al 2
A locus for stimulating connection and belonging	Daly et al 2
Engagement with the programme	Dew et al 3
Role of paid coordinator	Dew et al 3
Diversity of engagement strategies	Dew et al 3
Partner matching	Dew et al

	3
Our group Feeling normal Saying the unstable	Gore et al 4
Evolving emotions Doing a good job Caring for myself to care for others	Gore et al 4
Positive approaches Opening another window Over the moon	Gore et al 4
The meaning of school based parent support groups Emphathising with others Exchanging information and resources Engaging in collective action	Lee and Choi 5
Ways to develop sustainable groups Clearly defined purposes, roles and rules . Small group meet-ups School based initiatives Identifying actionable plans Collaboration among parents, professionals and the school system	Lee and Choi 5
Time is precious	Linden et al 6
The breadth and depth of module content	Linden et al 6
If it was somebody's experience, it was meaningful	Linden et al 6
Won't work for everyone	Linden et al 6
Representation: People I could identify with	Linden et al 6

Module suggestions	Linden et al 6
Coping and resilience of carers	Riches et al 7
Bonding, networking and social connections	Riches et al 7
Knowledge and skills development	Riches et al 7
Future planning and financial concerns	Riches et al 7
Additional unmet needs	Riches et al 7
Flexible service delivery	Riches et al 7

Appendix 1E - Linking Key Concepts From Papers

Step 2: Grouping initial thoughts / themes

Initial thought / theme	Theme in paper	Occurrences	Papers
A change/gain in participants - - More knowledge lead to more confidence. - More motivated?? - Better communication with others - Improved knowledge.	Siblings perspectives regarding systemic change (1) Changing mindset - a new way of thinking (2) Change in family dynamics, relationship and understanding (2) Evolving emotions Doing a good job (4) Caring for myself to care for others (4) Coping and resilience of carers (7)	5 (of 7)	1, 2, 3, 4, 5
Running of the group - Content that was helpful ./ unhelpful, - Format that was more beneficial than others.	Role of paid coordinator (3) Ways to develop sustainable groups (5) Clearly defined purposes, roles and rules (5) Small group meet-ups (5) Identifying actionable plans (5) Time is precious (6) The breadth and depth of module content (6) Module suggestions (6) Future planning and financial concern (7) Flexible service delivery (7)	4 (of 7)	3, 5, 6, 7,
Acceptance / belonging / not being judged - Feeling that from others in the same situ as themselves. - Feeling understood - Meaningful hearing other peoples stories.	Developing a connection and becoming empowered (1) A locus for stimulating connection and belonging (2) Engagement with the programme (3) Diversity of engagement strategies (3) Out group (4) Feeling normal (4) Saying the unsayable (4) Empathising with others (5) If it was somebody's experience, it was meaningful (6) Representation: People I could identify with (6) Bonding (7)	7	1, 2, 3, 4, 5, 6, 7,
Power /empowerment - Able to improve things for others - Being able to share and receive information - Able to speak up for what they still need (needs not met)	Expectations prior to the program Improving services (1) Receiving information and resources (1) Empowerment (1) Resources (1) Service and agencies (1) Policies and legislation (1) Community and culture (1) Enrichment of the quality of life of family member (2) Positive approaches (4) Opening another window (4) Over the moon (4) Exchanging information and resources (5) Engaging in collective action (5) Won't work for everyone (6) Knowledge and skills development (7) Additional unmet needs (7)	6	1, 2, 4, 5, 6, 7,
Relationship and connection important - Being able to support others	Sibling solidarity (1) Partner matching (3) The meaning of school based parent support groups (5) School based initiatives (5) Collaboration among parents, professionals and the school system (5)	3	1, 3, 5,

Appendix 1F - Using Third Order Constructs to Develop Concepts

Study	Category 1 - 3rd Order	Codes	Category 2 - 3rd Order	Codes	Category 3 - 3rd order constructs	Codes	construct	Codes	construct
1. Burke et al (2020)	Participants hoped to develop connections, gain empowerment, improve services and receive information. People hoped to gain information to empower themselves and others in their situations. Wanting to learn from others. They were motivated to help others by improving services for individuals, families and communities. Hoping to gain information on different things.	Connection Empowerment Information Help others	After completing the group participants gained solidarity with other people in their situation. Hearing similar stories was helpful. Sharing experiences with those in the same situation but demographically different was helpful. They were more empowered both for themself and their siblings. Theme of wanting to share what they had learned. Resources were gained and recognised themselves as a resource. More resources were wanted.	Shared understanding - Others in same situation Empowerment Helping others - share learning Resources	They highlighted the want for systemic change, increasing opportunities for their siblings, have a guide, getting information more readily available. People wanted to improve policies for their siblings. Wanting to change community so siblings can be a part of the community.	Helping others - their siblings Change - want systemic change, community change Information			
2. Daly et al (2015)	Knowledged and skills increased - their info about their family members and ability to support them. This increased their confidence to support their child. Information increased sense of power and agency. Change in the way they thought about their child - knowing their rights and what they deserve. Shifting to strengths based mindset. Change towards advocating for their child, given tools to do this, understanding their needs.	Knowledge/Information Helping others - family members Power and agency Change - how they viewed child, their abilities	Their understanding led to family members having a more fulfilled life. They began to integrate more into community. Making sure to incorporate family members likes and interests. Focusing moving to quality of life. Change in confidence levels - more confident to support family member. Family dynamics changed - improved - by attending the group, shared understanding and connection about working together for the family member.	Change - to family members lives, their activities Integrate into community Confidence gew Shared understanding - between family members	They were able to connect with others which built sense of belonging and support. They could connect with those in similar situations to themselves. They felt gains from these connections including emotional benefits by sharing feelings. Not feeling alone. In some cases it developed to friendships. They also connected more with their family and support networks. Recommendations to build and maintain this connection was highlighted.	Connection - belonging, with family members Gained emotional benefits, not alone Others in same situation			
3. Dew et al (2019)	1st order quotes indicate common experience was feeling a sense of belonging to a community and feeling less isolated.	Belonging Less alone	Having a paid coordinator was helpful and took the pressure off parents needing to organise things. They found it helpful having someone to check in on them. This felt essential to the running of the group and keeping the group united.	Paid coorindator kept group running, united	Not being judged. Being invited to things. Sharing resources - experience of sharing with others. Giving and receiving information. Not being an online person. Wanting to have more training and the training they did have being helpful. Realising own abilities - being more than just a mum - developing sense of identity.	Non-judgemental Helping others - sharing resources and information Wanting more training Understanding own abilities Sense of identity as a mum	Building a relationship with their matched partner was best part. Getting to know them well. Relationship is most important thing. Personality can be a mismatch in the partner matching. Needed more training in how to be a partner - boundaries.	Building connection with partners, getting to know them	

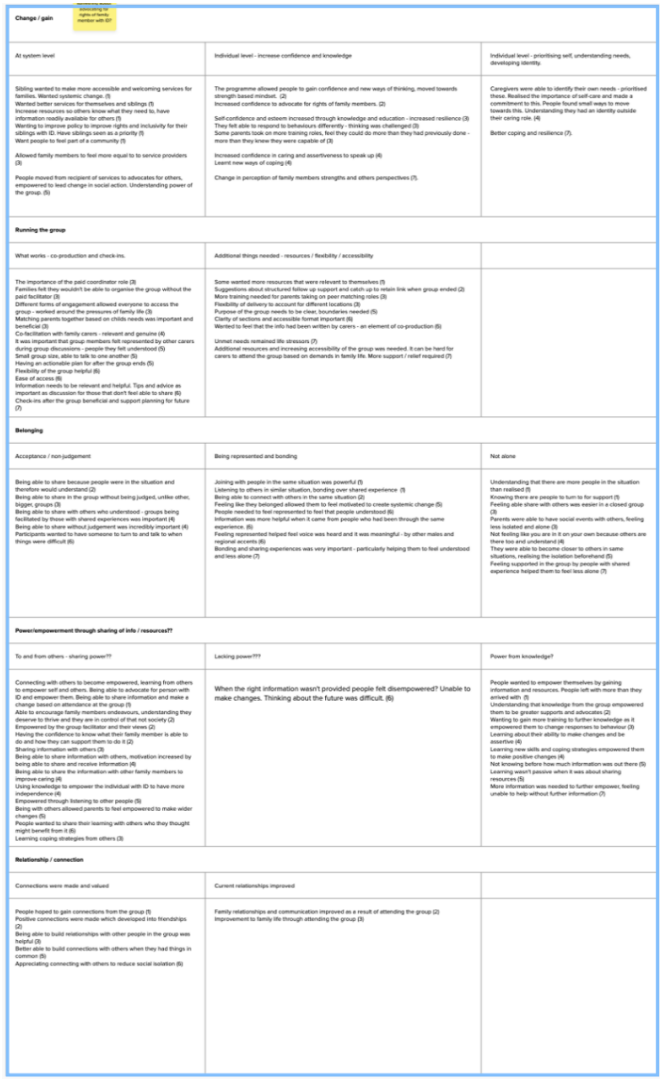
Appendix 1G - Emerging Themes Across Papers

Initial thought / theme	Occurrences	Papers
Change / gain - To systems - For individuals - Increased confidence and knowledge - Prioritising themselves / gaining an identity - understanding their needs -	6	1, 2, 3, 4, 5, 7,
Running of the group - what works - what additional things were needed	6	2, 3, 4, 5, 6, 7
Belonging / Acceptance / Non-judgement - Feeling represented	7	1, 2, 3, 4, 5, 6, 7
Power / empowerment - to others - from others - power comes from knowledge? - When they felt lacking power? Could empowerment be a subtheme under gains?	7	1, 2, 3, 4, 5, 6, 7
Relationship / connection - connections made and valued (hard when it didn't work) - improvements to standing relationships (family) based on group attendance.	6	1, 2, 3, 4, 5, 6, 7

Appendix 1H - Exert of Extraction Grid Displaying Overarching Themes Including First and Second Order Constructs

Overarching theme	1. Burke 1st and 2nd	2. Daly 1st and 2nd	3. Dew 1st and 2nd	4. Gore 1st and 2nd	5. Lee and Choi 1st and 2nd
Change/gain - To systems - For individuals - Increased confidence and knowledge - Prioritising themselves / gaining an identity - understanding their needs	Similarly, a 34-year-old sibling desired to learn ways of '[Building] more accessible, welcoming, inclusive networks, families, and communities.' They hoped to create systemic change within systems, including wanting more services for individuals with IDD. They also wanted easier access to services but would need information, resources and education. 'Residential and Day program/ opportunities.' 'Services would be easier access to waivers to allow siblings to get better services for themselves or [their] siblings.' 'There needs to be a resource that pulls everything together and creates a "SystemsGuide for Dummies" type book or power-point. [A] step by step guide and detailed glossary that explains what everyone needs to know about entering and navigating the system' '[I would like to] utilize local agencies to get information readily available.' Siblings hoped to improve policies and legislation. Siblings reported that improving policies and legislation will have a great impact on individuals with IDD and their families. '[Impacting] policies are number one because changing the policies to reflect more of an inclusionary tone will lift many weights and allow the change needed for individuals to live and be treated just as anyone else.' '[I hope to] connect with more legislators to get the needs of our siblings to become a higher priority.' Siblings reported hoping to make systemic changes with respect to the community and culture. 'I am hoping to make it easier to have those with disabilities be a part of the community, not just 'in' the community.' (3)	This theme demonstrates the impact of the initiatives on participants' knowledge, skills, confidence and attitudes and explores how participants adopted new ways of thinking and being. Participants described a number of areas where their knowledge and skills increased, including improvement in understanding the actions of their family member with a disability, development of strategies for supporting and living with their family member, increase in problem-solving skill within the family, development of circles of support, enhanced understanding of concepts, such as personal funding, home share, respite care and disability service financing and an improved knowledge of the legal framework related to disability. We had to treat her as an individual …she's much more of an individual now, whereas before she had to go with the flow which didn't work for her because she has her own way of thinking and she's just an individual with learning disability. … (Project CFM6) With this shift in attitude, participants demonstrated movement into a more strengths-based mindset, focusing on their child's strengths and abilities rather than solely challenges they might have due to the presence of disability. Actually, we've reviewed everything she's doing with a view to the sort of positive things that are happening in her life and about the building of friendships, the building of her social side and … we've been supporting that. (Project DFM 1) (2) Participants also described an increase in their self-confidence to advocate for the rights and entitlements of their family member. (1)	The program provided opportunities within the interpersonal and intra-individual self-change domains through the family member training or capacity building activities that provided people with information to inform their decision-making, opportunities to engage in training and advocacy which increased their self-esteem and confidence and social support which increased their connectedness and resilience. We'd go to talks and they'd [programstaff] ask me to talk and I'm not a very good public speaker …I didn't like it at the time, but when I done it, I was like, wow, I can do that. I've done that. I'll still never be a public speaker, but it's made me feel more than just a mum as well. It's given me something for myself. Ppt10. It addressed the socio-political domains by building the capacity of external supports through the creation of more equal relationships between family members and service providers and by offering an adjunct to the professional behaviour support on offer through the state disability service. Many mothers viewed the training hosted or provided by the programas helping them to respond to their son or daughter's challenging behaviour differently. participant 3 felt the training had challenged her thinking Reflecting the family-leadership principles underpinning the program, some participants had developed skills and taken on training roles. They were really good …at making me look at things from a different perspective. I just found it really interesting seeing how people looked at things and how I needed to broaden my perspective on things. They caught me out and questioned me a couple of times with some of the ways that I looked at things and I thought that was really good. It helped me learn. I really liked all the opportunities for training. Ppt3.	Firstly, families reported increased confidence both in terms of caregiving and assertiveness to seek and secure service supports. The second major theme centralised on emotional experiences, concerning how caregivers gained confidence, established supports they needed, and prioritised personal wellbeing within the context of raising a child with additional needs. Participants also described gaining greater realisation of the need for self-care and a commitment towards this as part of E-PAIS sessions, reflecting concepts of resilience building. This included reports from participants who, following sessions, had found small but meaningful new ways to support personal wellbeing, with resulting positive changes to mood and self-perception. It's helped me understand that I'm actually a good mum. It's given me that confidence you know? When you used to think, oh my god, you are in melt down, thinking I'm doing an awful job and I have then days when I think I wish I could help them more, I wish I could do more for my children. But this has helped me get that, that confidence. I am really doing a good job. (PC3 L2) What the session taught me is two things, one is I have to look after myself, coz who is going to look after [name of child], it isn't about just me soldiering on I actually have to look after myself coz I have got somebody else to look after as well and for your own mental wellbeing you've got to (PC2 L2) I feel like I've got no help, no support with my children at all. It's just me and my children at all times…I think I need some kind of stress release, something to make me feel good about myself…I am just trying to find away. (PC1 L2). So I went for a night out with my niece and the whole night I didn't think about you know going back, and you know, waking up early with kids, you know about owt like that. I just thought, I am having a really good time (FG L2). Not just [name of child's] mum or the person with the kid who constantly cries so I felt like me. It was really good (FG L2) Participants reported having not prioritised their wellbeing in the past but recognising, increasingly, the need to look after themselves having attended E-PAIS. Participants described how session activities and discussions helped them realise how little they did for themselves, explore beliefs that underpinned this, and come to see self-care as a further essential act. Participants recognised the need to make changes to support their own well being amidst the challenges and complexities of their life and caregiving demands. Participants also frequently described ways they had started to carve out small opportunities to rest, socialise and relax in ways that connected to their needs, interests and circumstances	Participants reported changes in socio-political, interpersonal, and intra-individual domains. By being active advocates (versus service recipients), they felt empowered among the disability community and within themselves, which finally led to collective social and political action. 'In order to give OO independence and go from being a guardian to a supporter, I started thinking about "How should I change, and how should I create my environments?"' Mrs Kim.
Running of the group - what works - what additional things were needed	However, some siblings reported wanting more resources. For example, siblings reported wanting resources related to: their own geographic regions; siblings of color; facilitated support; accessibility; sibling stress and mental health; and the adult service delivery system.	However, where such supports were not in place participants expressed a wish for structured follow-up and/or facilitator support to implement circles of support. Follow-up half-day sessions monthly for a few months in order to support families. (Project DSurvey) In addition, where the forming of networks with other initiative participants had not become established, catch up days with the opportunity to link back in with fellow initiative participants were suggested: Maybe to meet up once a year … You made a lot of friends during these courses and it is one way to keep in contact. (Project CSurvey)	As indicated by the concerns expressed by some participants about the process and support offered to peer support partners, this is one aspect of the program that seemingly required additional resourcing. Adequate support, via the paid coordinator role, could enhance the capacity of the program to attend to the complex task of matching and troubleshooting when matches prove unsuitable for either party. The paid coordinator was identified as a pivotal contact point for families and relieved the pressure on already stretched parents to ensure the ongoing viability of the program. Participants were clear that the paid coordinator role was essential to the running of the program. She's doing all that background work that's so important, like ensuring that everyone does stay connected …sometimes the families that need the most help don't ask for it. So, she's the one who's there to make sure – 'You haven't checked in. Is everything okay?' Ppt12. In the beginning, it was said …there should be no funding and it should just carry on with the parents. We [parents] all have enough passion for it …but we're all in different places, our children are all different ages …and we don't have that time and energy and commitment to be able to ring everyone up and do [the coordinator's] role. Ppt10. So, it's that sort of advisory role, and she really pulls us all together. When we have breaks away, [she's] the one who coordinates it. It's less pressure for us, because we know we just have to turn up. Whereas she's the person who's organising the accommodation, trying to get the funding, making sure everyone's going to be there on time. Ppt12. Participants identified the importance of the coordinator role being a paid position rather than relying on parents to sustain the program. A number of participants reiterated that the coordinator role kept parents united as a group, The importance of the paid coordinator role was also reported as integral to the success of the other two themes. Additionally, the multi-modal engagement strategies on offer to parents meant they could dip in and out of engagement as the pressures of their family life allowed and using a variety of mediums. I'm not a Facebook person. I do get alerts and stuff. Not being a social media person full stop, I just ignore it. So, [another parent] will say 'Did you know, blah, blah blah was happening?' I would say 'No, I don't have time'. Ppt7. 'I like the fact that they make things that you can revisit, the videos and the training and the resources and things'. Ppt4 Finally, the matching of mothers to partners who were also parents with a son or daughter with intellectual disability and challenging behaviour was a fundamental aspect of the program from its inception. Participants in our study identified a lack of training and ongoing support for this partner role, particularly important given the intensity of their	The strengths of co-facilitation were highlighted throughout interviews. Family-carer facilitators were viewed as having high expertise and unique insights regarding what works in practice, with sessions consequently seen as relevant and genuine: Mothers' observations about the difficulties in making matches were related to the limited number of available families spread over large geographic distances, personality differences and the existing stresses on parents making a commitment to their family partner difficult. Face-to-face, in-person meetings were thought by many to be ideal, although some parent partners, particularly those living further away from each other, connected via telephone or Facebook.	Unlike previous programmes, the unique challenge of this parent support group was getting active participation from parents. Although parents benefitted by listening to didactic instruction sessions across topics, parents reported potential conflicts during the discussion as they may not understand different characteristics of other children with disabilities. 'I had doubts before the meeting whether this activity could be continued. Because mothers are used to participating in parent education and lectures, but they are not used to being a leader'. Mrs Park. In addition to self-empowerment, the purpose of the meeting should be clearly stated and all members should agree upon that. I think it is important to keep reminding the mothers of why they get together and their own motives' Ms Jin. 'I think six members would be a good number of parents to work as a small group, so we can talk and practice democratically with each other'. Ms Han. To run meaningful parent support groups, group leaders and members should clearly define the purpose of the meeting, members'
Belonging / Acceptance / Non-judgement	Participants gained a sense of solidarity . Some participants reported feeling they were 'not alone' after completing the program. A 23-year-old brother learned 'There are more people like [him] than [he] had previously known about.' Similarly, a 35-year-old sister stated, 'I know that I have a group of people I can turn to.' Finally, another sister indicated that 'The gains of joining together with my fellow sibs are limitless.' Notably, solidarity was also mentioned in the summative evaluation. For example, siblings frequently reported that 'Listening to the many stories from other siblings' was helpful. Two siblings specifically reported on the importance of developing solidarity with siblings across the lifespan. For example, a sibling wrote: … "being able to meet with both siblings my age and older. Alongside the other 20-something siblings, we were able to start our action plan and also bond over many shared experiences… the older participants provided a wealth of	Participation in the family-focused initiatives also provided a locus for participants to make connections with others in similar circumstances. This led to a sense of belonging, shared identity, mutual support and, in some cases, catharsis. For participants who attended initiatives that were delivered over a longer duration (weeks), they generally referred to building bonds and connections incrementally over the course of the initiatives. Likewise, those who participated in shorter initiatives, for instance, over weekends, reported similar experiences. Findings of connection and belonging were of two forms. Firstly, the initiatives provided a locus where in participants could engage with others in the context of a shared frame of reference with 'likeminded people' (Project DFM 3). (2) Connecting with others offered the additional benefit of having access to a real-world knowledge base from those in similar circumstances or those further along in their journey. Participants referred to the credibility, value and sustaining impact of the gains obtained from these connections as inestimable. The findings further suggested that experiencing connection and a sense of belonging led to important emotional benefits, such as opportunities to share feelings that those without disability in their lives might not understand, a reduction in feeling alone and an increase, or in some cases new found, sense of hope for the future and its possibilities. 'Well I found a huge benefit was meeting other parents… whilst I know that's not, you know, possibly the initial objective of having a workshop or a meeting I think that's definitely a secondary benefit and turns out to be hugely beneficial because … you start talking to other people and you get a sense of kind of 'I'm not on my own here', you know, and you can actually make contact with people and you can, if you want, you can meet them from a support point of view or you can meet them from a knowledge based point of	[Another support group's] Facebook group is ridiculously huge, and they have families whose children might have a very, very mild disability which, not to minimise it but it's nothing like what we're dealing with. You'd post in there thinking it's a safe space, but people would still be judgmental, or they would say, 'You should be doing this, or you should be doing that'. Most of the time when you post in [parent peer support program Facebook group] people will offer suggestions and stuff like that, but they understand more that you've probably already tried everything. You don't get judged at all. I think when you've got a child that's challenging, one of the biggest barriers you have to reaching out is being judged. Ppt8. I've been able to link into the Facebook site. Because it's a closed site you can share what's going on and then you get the support from the other parents. Some of those parents are living in the metro area or close by, it's like, 'I'm coming for coffee now'. I don't have that. Ppt1. We like to try and use the strength-based approach, not 'I tell you'. I can share with you my experiences, but just talking through what's working and what's not working, she's bringing out her own answers, using that strength-based approach. Ppt10. They described the benefits of these events as providing opportunities to engage in everyday activities without the need to apologise or feel judged for their son or daughter's behaviour. Social events were viewed as a break from the everyday pressures of family and caring responsibilities as described by participant 7: There was a little boat trip …I think all those things are really good, because you're taken away from your situation, and you have maybe half a day, or a few hours away from your troubles'… I don't get out a lot. I tend to have only one or two friends that I go and visit. So, having this extra thing where somebody actually invites you to go out somewhere is quite a novelty for me, really. Ppt7. I don't feel like I'm in this on my own. I don't feel so isolated and so removed from the rest of society. I stopped going out. I stopped seeing people. I don't feel like that anymore because they [peer support program] give me that boost to go, 'Just go and have a wine with your girlfriend. Right now, what you need is to look after yourself.' Ppt1. These events also provided a chance to have less formal social interactions with other parents and alleviated the social	In particular, theme one highlighted how a sense of belonging, non-judgement and shared experience appeared critical to helping establish a socially and emotionally supportive group context. Both peer-to-peer discussions and the sensitivity and insight of facilitators with lived experience was central to supporting positive working relationships, and fostering key dimensions of partnership working. Participants felt able to speak openly and discuss intimate areas of concern. These experiences resonated with reports from families who have accessed other specialist programmes and systems of peer-support. That's what I like about the whole thing, as everyone was in the same position (FG L2). I can't say these things to my mum or my friends because they would be worried about me (PC1 L2). Social dynamics, a safe group and processes of engagement and co-creation were reported as a foundation for learning and emotional support. The value of spending time with other family carers was emphasised, with reference to how infrequent opportunities to do this had been in the past. Being with other carers of children with Intellectual and Developmental Disabilities in particular was seen as critical. Sharing experiences helped participants feel secure and express themselves openly. Participants described being able to say how they really felt during sessions and reflected on the importance of talking to people with lived experience who 'just get it,' without worrying about their reactions: Participants described how their self-perceptions of caregiving expertise evolved throughout sessions. Being able to speak openly in a supportive group, and share experiences without judgement seemed to confirm to participants they were doing the right things and to feel	By sharing similar experiences with each other, they could empathise with each other and feel comfortable with other group members. In addition, participants felt a greater sense of belonging, which was tied to collective action to address systemic issues. Such collective action as a parent group could be associated with a force for future systemic change. The current study highlighted the importance of acting on goals together in addition to planning. Simply allocating resources or information does not guarantee parents' empowerment. First, parent support groups have become a place to empathise and share fears and difficulties with respect to youth transitioning into adulthood. Parent support groups have become a place to empathise and share fears and difficulties with respect to youth transitioning into adulthood. Parents' roles and burdens are inevitably increased due to difficulties in finding resources as their children with disabilities age.

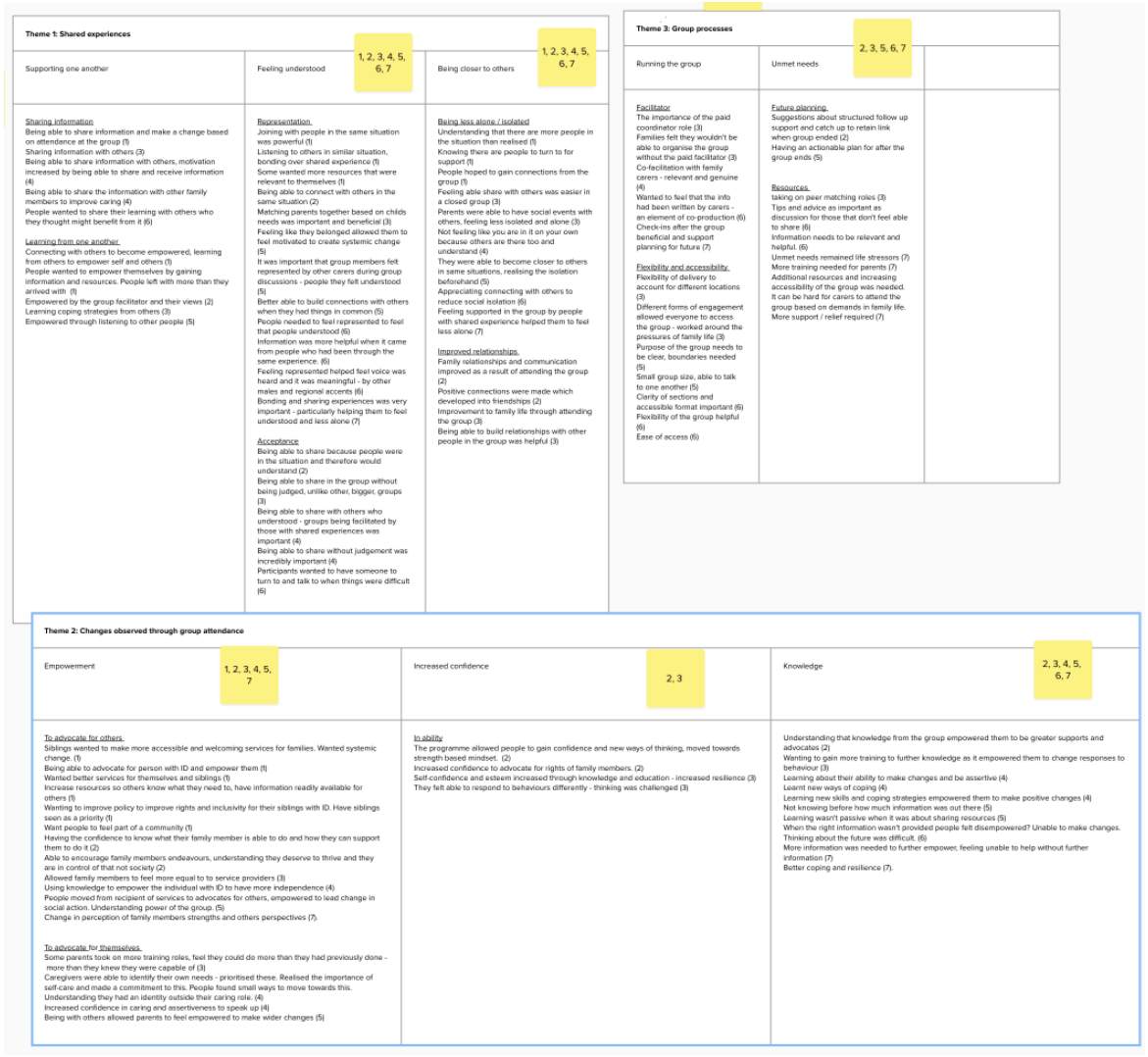
Appendix 1I - Revising Emerging Themes With First and Second Order Constructs



Change / gain		
At system level	Individual level - increase confidence and knowledge	Individual level - prioritising self; understanding needs, developing identity.
Sibling wanted to make more accessible and welcoming services for families. Wanted systemic change. (1) Wanted better services for themselves and siblings (1) Increase resources so others know what they need to, have information readily available for others (1) Wanting to improve policy to improve rights and inclusivity for their siblings with ID. Have siblings seen as a priority (1) Want people to feel part of a community (1) Allowed family members to feel more equal to to service providers (3) People moved from recipient of services to advocates for others, empowered to lead change in social action. Understanding power of the group. (5)	The programme allowed people to gain confidence and new ways of thinking, moved towards strength based mindset. (2) Increased confidence to advocate for rights of family members. (2) Self-confidence and esteem increased through knowledge and education - increased resilience (3) They felt able to respond to behaviours differently - thinking was challenged (3) Some parents took on more training roles, feel they could do more than they had previously done - more than they knew they were capable of (3) Increased confidence in caring and assertiveness to speak up (4) Learnt new ways of coping (4) Change in perception of family members strengths and others perspectives (7).	Caregivers were able to identify their own needs - prioritised these. Realised the importance of self-care and made a commitment to this. People found small ways to move towards this. Understanding they had an identity outside their caring role. (4) Better coping and resilience (7).
Running the group		
What works - co-production and check-ins.	Additional things needed - resources / flexibility / accessibility	
The importance of the paid coordinator role (3) Families felt they wouldn't be able to organise the group without the paid facilitator (3) Different forms of engagement allowed everyone to access the group - worked around the pressures of family life (3) Matching parents together based on childs needs was important and beneficial (3) Co-facilitation with family carers - relevant and genuine (4) It was important that group members felt represented by other carers during group discussions - people they felt understood (5) Small group size, able to talk to one another (5) Having an actionable plan for after the group ends (5) Flexibility of the group helpful (6) Ease of access (6) Information needs to be relevant and helpful. Tips and advice as important as discussion for those that don't feel able to share (6) Check-ins after the group beneficial and support planning for future (7)	Some wanted more resources that were relevant to themselves (1) Suggestions about structured follow up support and catch up to retain link when group ended (2) More training needed for parents taking on peer matching roles (3) Flexibility of delivery to account for different locations (3) Purpose of the group needs to be clear, boundaries needed (5) Clarity of sections and accessible format important (6) Wanted to feel that the info had been written by carers - an element of co-production (6) Unmet needs remained life stressors (7) Additional resources and increasing accessibility of the group was needed. It can be hard for carers to attend the group based on demands in family life. More support / relief required (7)	
Belonging		
Acceptance / non-judgement	Being represented and bonding	Not alone
Being able to share because people were in the situation and therefore would understand (2) Being able to share in the group without being judged, unlike other, bigger, groups (3) Being able to share with others who understood - groups being facilitated by those with shared experiences was important (4) Being able to share without judgement was incredibly important (4) Participants wanted to have someone to turn to and talk to when things were difficult (6)	Joining with people in the same situation was powerful (1) Listening to others in similar situation, bonding over shared experience (1) Being able to connect with others in the same situation (2) Feeling like they belonged allowed them to feel motivated to create systemic change (5) People needed to feel represented to feel that people understood (6) Information was more helpful when it came from people who had been through the same experience. (6) Feeling represented helped feel voice was heard and it was meaningful - by other males and regional accents (6) Bonding and sharing experiences was very important - particularly helping them to feel understood and less alone (7)	Understanding that there are more people in the situation than realised (1) Knowing there are people to turn to for support (1) Feeling able share with others was easier in a closed group (3) Parents were able to have social events with others, feeling less isolated and alone (3) Not feeling like you are in it on your own because others are there too and understand (4) They were able to become closer to others in same situations, realising the isolation beforehand (5) Feeling supported in the group by people with shared experience helped them to feel less alone (7)
Power/empowerment through sharing of info / resources?		
To and from others - sharing power??	Lacking power???	Power from knowledge?
Connecting with others to become empowered, learning from others to empower self and others. Being able to advocate for person with ID and empower them. Being able to share information and make a change based on attendance at the group (1) Able to encourage family members endeavours, understanding they deserve to thrive and they are in control of that not society (2) Empowered by the group facilitator and their views (2) Having the confidence to know what their family member is able to do and how they can support them to do it (2) Sharing information with others (3) Being able to share information with others, motivation increased by being able to share and receive information (4) Being able to share the information with other family members to improve caring (4) Using knowledge to empower the individual with ID to have more independence (4) Empowered through listening to other people (5) Being with others allowed parents to feel empowered to make wider changes (5) People wanted to share their learning with others who they thought might benefit from it (6) Learning coping strategies from others (3)	When the right information wasn't provided people felt disempowered? Unable to make changes. Thinking about the future was difficult. (6)	People wanted to empower themselves by gaining information and resources. People left with more than they arrived with (1) Understanding that knowledge from the group empowered them to be greater supports and advocates (2) Wanting to gain more training to further knowledge as it empowered them to change responses to behaviour (3) Learning about their ability to make changes and be assertive (4) Learning new skills and coping strategies empowered them to make positive changes (4) Not knowing before how much information was out there (5) Learning wasn't passive when it was about sharing resources (5) More information was needed to further empower, feeling unable to help without further information (7)
Relationship / connection		
Connections were made and valued	Current relationships improved	
People hoped to gain connections from the group (1) Positive connections were made which developed into friendships (2) Being able to build relationships with other people in the group was helpful (3) Better able to build connections with others when they had things in common (5) Appreciating connecting with others to reduce social isolation (6)	Family relationships and communication improved as a result of attending the group (2) Improvement to family life through attending the group (3)	

Change / gain		
Empowered to make changes	Individual level - increase confidence and knowledge	Improvements in relationships - current and new
For others Sibling wanted to make more accessible and welcoming services for families. Wanted systemic change. (1) Being able to advocate for person with ID and empower them (1) Wanted better services for themselves and siblings (1) Increase resources so others know what they need to, have information readily available for others (1) Wanting to improve policy to improve rights and inclusivity for their siblings with ID. Have siblings seen as a priority (1) Want people to feel part of a community (1) Allowed family members to feel more equal to to service providers (3) People moved from recipient of services to advocates for others, empowered to lead change in social action. Understanding power of the group. (5) Able to encourage family members endeavours, understanding they deserve to thrive and they are in control of that not society (2) Using knowledge to empower the individual with ID to have more independence (4) For themselves Caregivers were able to identify their own needs - prioritised these. Realised the importance of self-care and made a commitment to this. People found small ways to move towards this. Understanding they had an identity outside their caring role. (4) Better coping and resilience (7). Learnt new ways of coping (4) Being with others allowed parents to feel empowered to make wider changes (5)	The programme allowed people to gain confidence and new ways of thinking, moved towards strength based mindset. (2) Increased confidence to advocate for rights of family members. (2) Self-confidence and esteem increased through knowledge and education - increased resilience (3) They felt able to respond to behaviours differently - thinking was challenged (3) Some parents took on more training roles, feel they could do more than they had previously done - more than they knew they were capable of (3) Increased confidence in caring and assertiveness to speak up (4) Change in perception of family members strengths and others perspectives (7). Having the confidence to know what their family member is able to do and how they can support them to do it (2)	Family relationships and communication improved as a result of attending the group (2) Improvement to family life through attending the group (3) Positive connections were made which developed into friendships (2) Being able to build relationships with other people in the group was helpful (3)
Running the group		
Flexibility and Accessibility of the group	Unmet needs	Role of the facilitator
Flexibility of delivery to account for different locations (3) Purpose of the group needs to be clear, boundaries needed (5) Clarity of sections and accessible format important (6) Flexibility of the group helpful (6) Ease of access (6) Different forms of engagement allowed everyone to access the group - worked around the pressures of family life (3) Small group size, able to talk to one another (5)	Unmet needs remained life stressors (7) Suggestions about structured follow up support and catch up to retain link when group ended (2) More training needed for parents taking on peer matching roles (3) Additional resources and increasing accessibility of the group was needed. It can be hard for carers to attend the group based on demands in family life. More support / relief required (7) Tips and advice as important as discussion for those that don't feel able to share (6) Having an actionable plan for after the group ends (5) Information needs to be relevant and helpful. (6)	The importance of the paid coordinator role (3) Families felt they wouldn't be able to organise the group without the paid facilitator (3) Co-facilitation with family carers - relevant and genuine (4) Wanted to feel that the info had been written by carers - an element of co-production (6) Check-ins after the group beneficial and support planning for future (7)
Connecting with others		
Acceptance / non-judgement	Being represented	Being less alone / isolated
Being able to share because people were in the situation and therefore would understand (2) Being able to share in the group without being judged, unlike other, bigger, groups (3) Being able to share with others who understood - groups being facilitated by those with shared experiences was important (4) Being able to share without judgement was incredibly important (4) Participants wanted to have someone to turn to and talk to when things were difficult (6)	Joining with people in the same situation was powerful (1) Listening to others in similar situation, bonding over shared experience (1) Being able to connect with others in the same situation (2) Feeling like they belonged allowed them to feel motivated to create systemic change (5) People needed to feel represented to feel that people understood (6) Information was more helpful when it came from people who had been through the same experience. (6) Feeling represented helped feel voice was heard and it was meaningful - by other males and regional accents (6) Bonding and sharing experiences was very important - particularly helping them to feel understood and less alone (7) Some wanted more resources that were relevant to themselves (1) It was important that group members felt represented by other carers during group discussions - people they felt understood (5) Matching parents together based on childs needs was important and beneficial (3) Better able to build connections with others when they had things in common (5)	Understanding that there are more people in the situation than realised (1) Knowing there are people to turn to for support (1) Feeling able share with others was easier in a closed group (3) Parents were able to have social events with others, feeling less isolated and alone (3) Not feeling like you are in it on your own because others are there too and understand (4) They were able to become closer to others in same situations, realising the isolation beforehand (5) Feeling supported in the group by people with shared experience helped them to feel less alone (7) People hoped to gain connections from the group (1) Appreciating connecting with others to reduce social isolation (6)
Benefits of sharing information and resources		
Sharing with others	Power is knowledge	Learning from others
Being able to share information and make a change based on attendance at the group (1) Sharing information with others (3) Being able to share information with others, motivation increased by being able to share and receive information (4) Being able to share the information with other family members to improve caring (4) People wanted to share their learning with others who they thought might benefit from it (6)	Understanding that knowledge from the group empowered them to be greater supports and advocates (2) Wanting to gain more training to further knowledge as it empowered them to change responses to behaviour (3) Learning about their ability to make changes and be assertive (4) Learning new skills and coping strategies empowered them to make positive changes (4) Not knowing before how much information was out there (5) Learning wasn't passive when it was about sharing resources (5) More information was needed to further empower, feeling unable to help without further information (7) When the right information wasn't provided people felt disempowered? Unable to make changes. Thinking about the future was difficult. (6)	Connecting with others to become empowered, learning from others to empower self and others (1) Empowered by the group facilitator and their views (2) Empowered through listening to other people (5) Learning coping strategies from others (3) People wanted to empower themselves by gaining information and resources. People left with more than they arrived with (1)

Appendix 1J - 3 Main Themes and Subthemes Identified



Theme 1: Shared experiences

1, 2, 3, 4, 5, 6, 7

1, 2, 3, 4, 5, 6, 7

Supporting one another	Feeling understood	Being closer to others
Sharing information Being able to share information and make a change based on attendance at the group (1) Sharing information with others (3) Being able to share information with others, motivation increased by being able to share and receive information (4) Being able to share the information with other family members to improve caring (4) People wanted to share their learning with others who they thought might benefit from it (6) Learning from one another Connecting with others to become empowered, learning from others to empower self and others (1) People wanted to empower themselves by gaining information and resources. People left with more than they arrived with (1) Empowered by the group facilitator and their views (2) Learning coping strategies from others (3) Empowered through listening to other people (5)	Representation Joining with people in the same situation was powerful (1) Listening to others in similar situation, bonding over shared experience (1) Some wanted more resources that were relevant to themselves (1) Being able to connect with others in the same situation (2) Matching parents together based on childs needs was important and beneficial (3) Feeling like they belonged allowed them to feel motivated to create systemic change (5) It was important that group members felt represented by other carers during group discussions - people they felt understood (5) Better able to build connections with others when they had things in common (5) People needed to feel represented to feel that people understood (6) Information was more helpful when it came from people who had been through the same experience. (6) Feeling represented helped feel voice was heard and it was meaningful - by other males and regional accents (6) Bonding and sharing experiences was very important - particularly helping them to feel understood and less alone (7) Acceptance Being able to share because people were in the situation and therefore would understand (2) Being able to share in the group without being judged, unlike other, bigger, groups (3) Being able to share with others who understood - groups being facilitated by those with shared experiences was important (4) Being able to share without judgement was incredibly important (4) Participants wanted to have someone to turn to and talk to when things were difficult (6)	Being less alone / isolated Understanding that there are more people in the situation than realised (1) Knowing there are people to turn to for support (1) People hoped to gain connections from the group (1) Feeling able share with others was easier in a closed group (3) Parents were able to have social events with others, feeling less isolated and alone (3) Not feeling like you are in it on your own because others are there too and understand (4) They were able to become closer to others in same situations, realising the isolation beforehand (5) Appreciating connecting with others to reduce social isolation (6) Feeling supported in the group by people with shared experience helped them to feel less alone (7) Improved relationships Family relationships and communication improved as a result of attending the group (2) Positive connections were made which developed into friendships (2) Improvement to family life through attending the group (3) Being able to build relationships with other people in the group was helpful (3)

Theme 3: Group processes

2, 3, 5, 6, 7

Running the group	Unmet needs	
Facilitator The importance of the paid coordinator role (3) Families felt they wouldn't be able to organise the group without the paid facilitator (3) Co-facilitation with family carers - relevant and genuine (4) Wanted to feel that the info had been written by carers - an element of co-production (6) Check-ins after the group beneficial and support planning for future (7) Flexibility and accessibility Flexibility of delivery to account for different locations (3) Different forms of engagement allowed everyone to access the group - worked around the pressures of family life (3) Purpose of the group needs to be clear, boundaries needed (5) Small group size, able to talk to one another (5) Clarity of sections and accessible format important (6) Flexibility of the group helpful (6) Ease of access (6)	Future planning Suggestions about structured follow up support and catch up to retain link when group ended (2) Having an actionable plan for after the group ends (5) Resources taking on peer matching roles (3) Tips and advice as important as discussion for those that don't feel able to share (6) Information needs to be relevant and helpful. (6) Unmet needs remained life stressors (7) More training needed for parents (7) Additional resources and increasing accessibility of the group was needed. It can be hard for carers to attend the group based on demands in family life. More support / relief required (7)	

Theme 2: Changes observed through group attendance

1, 2, 3, 4, 5, 7

2, 3

2, 3, 4, 5, 6, 7

Empowerment	Increased confidence	Knowledge
To advocate for others Siblings wanted to make more accessible and welcoming services for families. Wanted systemic change. (1) Being able to advocate for person with ID and empower them (1) Wanted better services for themselves and siblings (1) Increase resources so others know what they need to, have information readily available for others (1) Wanting to improve policy to improve rights and inclusivity for their siblings with ID. Have siblings seen as a priority (1) Want people to feel part of a community (1) Having the confidence to know what their family member is able to do and how they can support them to do it (2) Able to encourage family members endeavours, understanding they deserve to thrive and they are in control of that not society (2) Allowed family members to feel more equal to to service providers (3) Using knowledge to empower the individual with ID to have more independence (4) People moved from recipient of services to advocates for others, empowered to lead change in social action. Understanding power of the group. (5) Change in perception of family members strengths and others perspectives (7). To advocate for themselves Some parents took on more training roles, feel they could do more than they had previously done - more than they knew they were capable of (3) Caregivers were able to identify their own needs - prioritised these. Realised the importance of self-care and made a commitment to this. People found small ways to move towards this. Understanding they had an identity outside their caring role. (4) Increased confidence in caring and assertiveness to speak up (4) Being with others allowed parents to feel empowered to make wider changes (5)	In ability The programme allowed people to gain confidence and new ways of thinking, moved towards strength based mindset. (2) Increased confidence to advocate for rights of family members. (2) Self-confidence and esteem increased through knowledge and education - increased resilience (3) They felt able to respond to behaviours differently - thinking was challenged (3)	Understanding that knowledge from the group empowered them to be greater supports and advocates (2) Wanting to gain more training to further knowledge as it empowered them to change responses to behaviour (3) Learning about their ability to make changes and be assertive (4) Learnt new ways of coping (4) Learning new skills and coping strategies empowered them to make positive changes (4) Not knowing before how much information was out there (5) Learning wasn't passive when it was about sharing resources (5) When the right information wasn't provided people felt disempowered? Unable to make changes. Thinking about the future was difficult. (6) More information was needed to further empower, feeling unable to help without further information (7) Better coping and resilience (7).

Appendix 1K - Reflective Log

Beginning to develop themes and subthemes based on 2nd order constructs across the papers. Key themes are beginning to emerge but questions are coming up within each of them that is altering my interpretations.

Theme 1 – change/gain

- Important point coming up about advocating for rights of family member with ID?

- Separating confidence and knowledge? They gained knowledge but also confidence led to a development in self-identity.

- Personal identity growth?

- Include subthemes of confidence, relationships and knowledge?

Theme 2 – Running the group

- Needing to know what will happen after the group ends and have a plan for this?

- Things that were beneficial and things that were difficult

- Able to speak up and report the needs they had that were still unmet

Theme 3 – Belonging

- Being represented allowed for sharing as they knew they wouldn't judge, because they had also lived it

- Key factor is being understood and this is most powerful through shared experiences

- Is shared experience a theme and belonging a subtheme?

- Important to include connections made – relieved loneliness

Theme 4 – Empowerment?

- Does this overlap with gains in the group?

- Carers were empowered to be more confident carers / advocates

- Power from information is a key factor?

- Can this move into a gain?

Appendices – Chapter two

Appendix 2A - Ethical Approval

Health Research Authority

East Midlands - Nottingham 2 Research Ethics Committee
Equinox House
City Link
Nottingham
NG2 4LA

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

04 January 2022

Prof G.H. Murphy
Prof of Clinical Psychology & Disability
University of Kent
Tizard Centre
University of Kent
Cornwallis NE, Giles Lane
CT2 7NS

Dear Prof Murphy

Study title:	**RCT of group CBT for men with intellectual and/or developmental disabilities and harmful sexual behaviour: the HaSB-IDD trial**
REC reference:	**21/EM/0270**
IRAS project ID:	**291027**

Thank you for your letter of 20 December 2021, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and Lead reviewer.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation

Appendix 2B - Participant Eligibility Criteria From HaSB-IDD Trial Protocol

Participants

Eligibility Criteria

Men (18 years of age and over) with IDD, including an IQ below 80 and adaptive behaviour deficits (as assessed since the age of 18), who have shown harmful sexual behavior in the last 5 years, irrespective of any conviction, will be invited to join the study, from the 4 areas of England and Wales (North, Midlands, East Anglia, South East). Any potential participants with an IQ above 80 need to be discussed with the CI/TMG on a case-by-case basis.

Intellectual disabilities (ID) is defined internationally as an IQ below 70 and significant deficits in adaptive behaviour. It used to be referred to as 'mental handicap' but more recently has been sometimes referred to in the UK as (pervasive) 'learning disabilities'. It is important to note that this is not the same as specific learning disabilities, e.g. dyslexia, where IQ is in the normal range. Many people with ID also have autism spectrum disorders and the term 'intellectual and/or developmental disabilities (IDD)' is widely used, to cover both. People with IDD in the UK receive services from Community Learning Disability Teams. These are provided for those with autism and intellectual disabilities, often including those with borderline disabilities (who have IQs 70-79), if they also have autism.

The men recruited for the trial will not necessarily have been convicted or even charged for sexual crimes, given the arbitrariness of police involvement for men with IDD, but there will need to be very good evidence from carers and case notes of harmful sexual behaviour. HSB will be defined as sexual behaviour in which the other person was not consenting (or was unable to consent), and the sexual behaviour would be defined as illegal (whether or not the police had been involved). Most men presenting for treatment in clinical services for this kind of behavior have a history of more than one incident. Incidents may not have been reported by the victim (who may be someone with more severe intellectual disabilities and may have very poor or no verbal communication skills). The incidents also may not have been reported to the police by professionals or someone in the community, because they realise the person has intellectual disabilities and they may think that they are not suitable to be dealt with by the Criminal Justice System.

It is anticipated that some men may be in low or medium secure health services, while some may be legally unrestricted, living in the community. Groups may include some or all of these categories (as was the case in SOTSEC-ID, 2010 and in Heaton and Murphy, 2013). It is likely that all men will also have family carers or paid carers who will be invited to take part in the research (see below for details). Men in prisons, on probation (with a sex offender treatment order) and in high secure services will be excluded. If men are imprisoned during the treatment trial (ie during the six months of treatment) they will discontinue in the treatment group but be included in the intention to treat analysis.

Men with autism will not be excluded as long as they also have mild or borderline ID. Though they may find group treatment difficult, the evidence is that many were included in previous group CBT research (e.g. SOTSEC-ID, 2010; Heaton & Murphy, 2013) and the men themselves have said they found the treatment helpful (Melvin, Langdon & Murphy, 2019).

Some men engage in sexually harmful behaviour but have severe intellectual disabilities and extremely limited communication skills, and so would not be able to participate in CBT. Experience suggests that this is fewer than 20% of the total cohort of men with IDD and HSB, though there is no hard evidence to back this figure up. Experience has also shown that these men, with more severe intellectual disabilities, and very poor verbal skills, are unable to benefit from CBT once their verbal comprehension falls too low, so they will be excluded.

Carers: Most men will be living with family carers (typically parents) or with paid carers in residential homes or secure services. Occasionally men will be living in a flat alone but they will be receiving support from visiting paid carers. One carer (family member or paid carer) will be recruited for each man recruited. Their role will be to provide a historical and prospective record of the man's harmful sexual behaviour and of his resource use for the health economics data.

Appendix 2C - Participant Information Sheet

Carer Interview Information Sheet

The HASB-IDD trial:

Randomised Control Trial (RCT) of group Cognitive Behaviour Therapy (CBT) for men with intellectual and/or developmental disabilities and harmful sexual behaviour

Carer Interview Information Sheet – Version 1.1 12th July 2024

This study is funded by the National Institute for Health and Care Research (NIHR) Health Technology Assessment programme (NIHR HTA Project 128550).

FUNDED BY

NIHR | National Institute for Health and Care Research

Introduction

This leaflet provides information about a research study that is titled "RCT of group CBT for men with intellectual and/or developmental disabilities and harmful sexual behaviour" or HaSB-IDD, for short.

Who we are

We are a group of researchers from the University of Kent, University of Birmingham, University of Warwick, University of Noththumbria and Norwich Clinical Trials Unit at the University of East Anglia. Together we run a type of research study called a

What is the purpose of this research?

‘Clinical Trial’. In order to make sure our work is useful for men with a learning diability, their carers and therapists we also asked the Challenging Behaviour Foundation to work with us to design this research. We are also working with NHS Trusts, charities and private clinics to help us do this research.

This research is evaluating the effectiveness of a talking treatment called SOTSEC-ID for men with learning disabilities and/or autism who have harmful sexual behaviour. For this part of the research we would like to ask you to take part in an interview to better understand your experience of supporting men with learning disabilities and harmful sexual behaviour and any treatments or support they may receive.

What are we asking you to do?

To take part in an interview. This will last up to 1-hour and will be with a psychologist in training from the University of Birmingham (who is working on the research) or a member of the research team. They will ask you questions about your experiences supporting the man in your care, to help us improve the treatment further. We want to know about your experience of supporting the man in your care, what you believe the community perception is of this client group, what therapeutic activities the man in your care engages in and what support is available to yourself and the man in your care. If the man you support has received the SOTSEC-ID therapy we would like to get your views on how you think the treatment has helped or not helped the man in your care. We will also ask your thoughts about any challenges you or the man you care for encountered, and how they were dealt with.

We can do the interview online if that suits you. We will ask if we can record the interview for our records. If we meet online and you do not want your video recorded, please just turn your camera off. With your camera off, we will only be recording your voice.

Consent

If you are happy to take part in an interview we will ask you to complete a consent form.

The decision about whether you decide to take part in an interview is yours to make. Saying no will not affect your employment if you are a paid carer. If you agree to take part now, you can change your mind in the future and you do not have to give us a reason.

You would only be asked to take part in an interview at one point in time. If the man

How long do I have to be involved?

is taking part in the SOTSEC-ID therapy this will be after the man you care for completes the

What will you do with my data?

treatment.

In this part of the research study we will use information from you and other carers to understand about experiences of the talking treatment. The researcher who comes to do your interview, in person or on-line, may be a psychologist in training from University of Birmingham, they are helping with the research.

We will also need information from you such as your name, sex, ethnicity, age group, and professional background (for paid carers) and telephone number. Only the research team will know your name or contact details, and only if they really need it for their role in the study. Everyone involved in this study will keep your data safe and secure.

If we do the interviews online, using video conferencing, we may need your email address to send a meeting link.

Pseudonymisation of data-

Your data will be stored using a code. Doing this is called pseudonymisation and we will do this as quickly as possible after collecting data from you. We will transcribe the interview, and all direct and indirect identifiers will be removed during transcription and replaced with a participant number or deleted. The key to identification will be stored separately and securely to the research data to safeguard your identity. This means that the key telling us which number matches which person will be stored separately from the data.

We may publish the findings in a peer review journal, place them on the internet or talk about them at conferences. When the study is complete, we will write a report that we will share with the organisation paying for this research which is the National Institute for Health and Care Research. We will make sure no-one can work out who you are from the reports we write. We may use anonymised quotes from any interview with you in these reports and journal articles, we will make sure that neither you or the man you support can be identified from the quotes.

At the end of the study we will save some of the data in case we need to check it or for future research. All data will be destroyed after 5 years.

The sponsor of this study is The University of Kent. They are also the data controller.

Your information rights

As a data controller we need to follow the law when we collect your data. Under the law we are allowed to collect your data for the research as a 'task carried out in the public interest'. Any special category data being collected is processed under the lawful basis 'research purposes in the public interest'.

To safeguard your rights, we will use a minimum of personally identifiable information and keep the data secure. This means that we will only collect the data we need to help us successfully complete this research study. Members of the research team will have access to this data. We will store a copy of your data on secure university and NHS servers. This includes your consent form. This form will contain your name, address, and phone number and will be stored separately from the research data.

You have rights relating to your information, these include:

- You can ask us to see a copy of the information we have about you
- If you think the information we have on you is wrong, you can ask us to correct it but because we need to make sure we can do our research, we may not be able to make changes
- If you think we do not need any of the information we have on you, you may ask us to delete it but because we need to make sure we can do our research, we may not be able to delete your data

Our privacy notice for research participants is available online here:

https://media.www.kent.ac.uk/se/40432/ResearchParticipantUniversityLevelPrivacyNotice.pdf

You can also find out more information about how your information is used here: www.hra.nhs.uk/information-about-patients/ .

You can also contact the research team, and their details are found towards the end of this leaflet.

If you decide to withdraw from the study in the future, we would like to keep the data that we have already collected. However, you can ask us not to do this.

Disclosure

We have a duty to keep your information secure and confidential. However, we are required to disclose information which suggests that someone may be at risk of harm. The reason for this is to work towards safeguarding and protecting others.

We may share such information with the local authority in your area or other statutory services who are meant to provide help. We will tell you if we need to do this.

Who is paying for the study?

What will happen to the results of this study?

This study is funded by the National Institute for Health and Care Research.
We will send you a summary of the results of the research. We will publish the findings in a journal, may place them on the internet or talk about them at conferences. You will not be identifiable. When the study is complete, we will write a report that we will share with the organisation paying for this research which is the National Institute for Health and Care Research.

Once we have finished the study, we will keep some of the data so we can check the results. We will write a report, but no one will be able to work out from our report that *you* took part.

Regulatory Authorities

The data we collect about you e.g. the interview transcript, consent forms and databases with your name and contact details may be looked at by regulatory authorities.

This may happen because these organisations will need to monitor the conduct of the study and this may involve auditing to make sure that the study is being run in such a way as to make sure it complies with relevant policies and the law. They will check to make sure the researchers are following the rules.

Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the East Midlands Research Ethics Committee. It has received approval from the Health Research Authority and Health Care Research Wales (IRAS ID 291027).

Complaints

If you would like to make a complaint, please speak to a member of the research team in the first instance (see below). However, if you do not want to speak to a member of the research team, there are other people who will help you with your complaint.

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed.

If you would like to speak to someone who is not part of the research team, please address your complaint to the Patient Advice and Liaison Service:

Patient Advice and Liaison Service (PALS)

Tel: (insert local number)

If you are unhappy with how we have used your information, you can complain to the Information Commissioner (an organisation set up to ensure personal information is used correctly). Their website is: https://ico.org.uk/make-a-complaint/
You can also call their helpline on 0303 123 1113.

You can also talk to our Data Protection team at the University of Kent if you are worried about how we are using your data. Their email is dataprotection@kent.ac.uk

If you would like to speak to a member of the study team, you can contact the Chief Investigator who oversees the research.

Professor Glynis Murphy, Chief Investigator
Email:
Tizard Centre, Cornwallis North East, University of Kent, Canterbury, Kent, CT2 7N

Thank you for taking the time to read this Carer Information Leaflet

Appendix 2D - Participant Consent Form

CARER INTERVIEW CONSENT FORM

(Version 1.1 – 12.07.24)

Title of the project: Cluster RCT of group CBT for men with intellectual and/or developmental disabilities and harmful sexual behaviour: the HaSB-IDD trial

Carer Participant Identification Number:	**Please initial in the box**

I confirm that I have read the Carer Interview Information Sheet (Version 1.1) for the above study. I have had the opportunity to consider the information, speak to the research team, ask questions, and have had these answered satisfactorily.	☐
I understand the purpose of the project and what my involvement would be.	☐
I understand that participating in the project is voluntary and I can withdraw in the future without giving a reason.	☐
I have been able to access the Privacy notice for research participants and my information rights. I understand this and agree to the research team processing my data in the ways described.	☐
I understand that data collected during the study will be confidential, unless someone is at risk of harm.	☐
I understand the information collected may be looked at by individuals from regulatory authorities or the NHS as part of an audit to check that the researchers are complying with any associated policies or the law.	☐

I understand that the information collected about me will be used to support the research and anonymised data may be shared with other researchers. I understand that the researchers are responsible for my data. ☐

I understand that if I later withdraw from the study, the researchers will keep the data that they have already collected. No further data will be collected. ☐

I understand that if I am invited to an interview, the discussion will be recorded, and I agree to this. This may include my video if we do the interview online. ☐

I am aware that some anonymised quotes from my interview may be used in reports about the study. I agree to this. ☐

I agree to take part in this study. ☐

Your details:

Print your name:

Signature:

Date:

Address:

Tel:	

To be completed by the person explaining the study:

Name of person who explained the study:	
Signature:	
Date:	

Appendix 2E - Semi-structured Interview Schedule

Carers Interview Schedule – Amendment v2

Arranging the Interview

This might be face to face or online, but the principles remain the same:

- If face to face, interviews to be conducted at therapy base, residential or other service base. If online to be conducted via web-based video e.g., zoom/MS teams
- Ensure a room is available
- Ensure privacy
- Carers to be interviewed on their own
    - If online - prior to interview check the carer knows how to join the meeting, has teams/ Zoom downloaded etc. It may be helpful to contact people beforehand to check if they have any questions / need any help.

Preparation for Interview

- Remind participants about the aim of the interview (exploring experiences of the men, the therapists and the carers)
- Review informed consent form that has been completed at start of the study, check consent
- Ask participants to bring any materials they may like to discuss
- Book audio recorder (or record online)
- Confirm agreement for recording

Introductions

Hi my name is *[say name]* and as you know I want to ask you about your experience caring for [client's name] and any challenges you might have faced.

Are you still happy to take part? *[CHECK CONSENT]*

If yes:

That's great. I'm really interested in what you think. Don't worry about speaking your mind. What you have to say is really important because you are the expert here!

I won't keep you for too long today. I'd like to talk with you for about forty-five minutes to an hour. We can stop any time you would like to.

[EXPLAIN RIGHT TO WITHDRAW]

I'm going to use this *[show recording device/explain online recording]* to record what we are saying. This will help me to remember everything you say to me today. When we have finished our meeting today, I will listen to the recording and type it up on my computer. When I type what you have said, I won't use anyone's name, so nobody will know who said what.

This makes it easier to be honest without worrying about hurting anyone's feelings. I won't tell anyone what you have said.

[After settling in, getting agreement for recording, switching recorder on and checking it is working]

I will be asking you about your experience of caring for [name - check how they refer to this person e.g., client/patient], the impact of this and any challenges you have faced in supporting them. I will also be asking about your experience of how the community accepts your client and any therapeutic engagement you might support them with.

I appreciate that that you may not be able to answer all of the questions but any help that you can give would be much appreciated. You can choose what you tell me and you can decide not to answer questions. We can stop at any time, just tell me.

Topic Guide

Part 1: Fact Finding

1. ***Participant Information***
   - 1.1. What gender do you identify with? (Female/Male/Other - specify)
   - 1.2. How would you describe your ethnicity? (Asian or Asian British, Black, Black British, Caribbean or African, Mixed or Multiple Ethnic Groups, White, Other Ethnic Group)
   - 1.3. Which category includes your age? (17 or younger/18-20/21-29/30-39/40-49/50-59/60 or older)
   - 1.4. Information about employment.
   - 1.5. Can you describe your professional background? What is your role in caring for [name]? How long have you worked in a care setting?
   - 1.6. Can you tell me where your client usually lives? Is this alone or with others?

     Prompt:

     - What is their experience of living there? What do they like or dislike about it?
     - How long has [name] lived there How long do individuals usually reside in these settings?

2. ***Relationship to the client***
   - 2.1. Can you tell me about your relationship with [name]?

     Prompt:

     - How long have you worked with/cared for this individual?

- How long have you known them?
- How much contact do you typically have with them? How long do you spend with them?

Part 2: Experiences

3. ***Experience of supporting client***
   3.1. How would you describe your experience of supporting [name]?
   3.2. What are some positive experiences/impact you have had when supporting [name]?
   3.3. What are some of the challenges, if any, you have faced whilst supporting [name]? Prompt – if unclear specify and try to refocus on HSB.
   3.4. Have you noticed any impact on yourself since supporting this client? Prompt - General wellbeing? Burnout? Stress? Do you think this might be related to your work with this individual?
   3.5. How do you look after yourself whilst supporting your client? Prompt - Do you find this easy to do?
   3.6. Do you receive any supervision? Prompt – do you find this helpful?
   3.7. Are there any other ways your organisation supports your wellbeing? Prompt – Team meetings? Debriefs?
   3.8. How do you think you've helped your clients from reoffending?
   3.9. What do you view as your role in managing your clients risk?
   3.10. Do you feel like you are meeting your clients needs? Prompt - If not, why not?
   3.11. How much do you support your client towards their future goals? Prompt - Do you know what they want to do in the future/where they want to live/if they want to work? What sort of help would they required to do this?

4. ***Perception of others/community acceptance***
   4.1. What do you think the community perception is of this client group?
   4.2. Have you ever noticed any changes in the community in response to your client?
   4.3. Are you aware of how others perceive the work you do in supporting this client?
   4.4. Have you or your client ever been treated differently because of their behaviour? Prompt – HSB specifically.
   4.5. How has this differential treatment affected your client? How has it affected you? Prompt – have you ever felt isolated in the community?
   4.6. If differential treatment – how does this make you feel? Prompt – how does it make you feel about your job?
   4.7. How do you describe your work to others and how do they react? Prompt – do you talk about working with offenders or just people with disabilities?

5. ***Exploration of therapeutic engagement***
   5.1. Is your client involved in any treatment programme? E.g., psychological/medication/occupational therapy/SOTSEC-ID
   5.2. How does this fit with how you support [name]? Prompt - Do you ever support them with this work?

5.3. Do you feel involved in this work/aware of what they are doing?
5.4. Have you ever felt isolated from what work they are completing with other members of staff?
5.5. Does your client receive any input from psychology/psychiatry/OT/Social worker/nursing etc? If yes: What do they do? Prompt - Does this appear to be helpful? How so?
5.6. What types of activities are available to your client? Prompt - Is there anything they particularly enjoy about these activities?
5.7. Are staff present during these activities? Prompt - Do you think your client is happy that staff are present?
5.8. What are some of the things your client is good at doing? Prompt - Is your client able to do things without staff support?

6. ***Access to support***

6.1. How does your client manage when they have difficulties? Prompt – who do they seek help from when they have difficulties?
6.2. How does [name] get on with staff? Prompt – do they talk to staff? Are they able to talk about thoughts/feelings with staff?
6.3. What is your clients relationship like with family? Prompt – Are they in contact with their family? If yes: Do you feel this helps or hinders their progress? Prompt - Do they have any friends or family visit? If yes: What impact do you think these visits have? Does this have any impact on your role supporting [name]?
6.4. How do you/the service work with family/friends to support clients needs?
6.5. Have you noticed any differences in your client related to the way in which you and others in the support team/service support them?

7. **Finishing the interview**

7.1. Is there anything else you would like to say?
7.2. Is there anything I have forgotten to ask you?

Thank you for speaking to me today, it is a great help.

Now I will go away and look at the things you have said, as well as the things that other carers have said. We will use the information to find out what people who care for individuals with harmful sexual behaviour experience.

We will write a report and tell you about what we found; if you would like to know.

Would you like a copy of the report?

[CHECK FOR DISTRESS]

Are you feeling okay?

If “no” - Would you like to speak to someone, such as your manager, occupational health (depending on who they are).

Thanks again for your help with this project.

Appendix 2F - Carers Support Information

Carers Support Information

Thank you again for taking part in an interview as part of the HASB-IDD trial. As stated at the end of your interview please find below some useful links for additional support, should you require it.

Challenging Behaviour Foundation

They offer information about challenging behaviour to anyone who provides support to a child, young person or adult with a severe learning disability. They can also signpost you to other specialist organisations and sources of information.

You can call the Family Support Service on 0300 666 0126

Or email them at support@thecbf.org.uk

https://www.challengingbehaviour.org.uk/

Mencap

Phone or email the Learning Disability Helpline, which is their advice and support service, for guidance and information about what support they can offer.

Call on 0808 808 1111

Email on helpline@mencap.org.uk

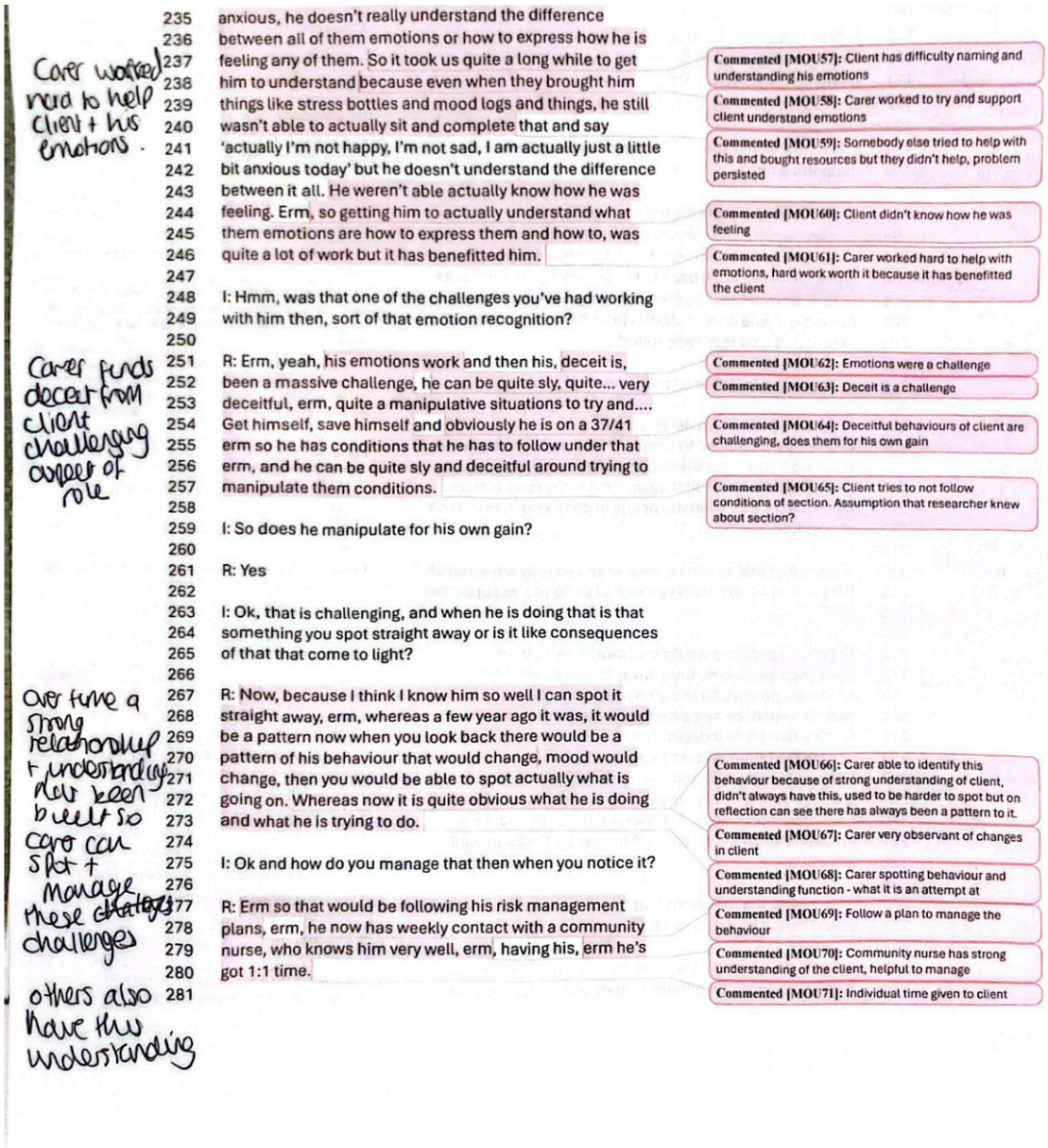
https://www.mencap.org.uk/

National Autistic Society

Get expert advice on a wide range of issues affecting autistic people and their families. In-depth advice and guidance pages on the major challenges autistic people and their families face, including behaviour, education and health issues.

https://www.autism.org.uk/

Appendix 2G - Extract of Initial Codes and Experiential Statements on a Transcript



Appendix 2H - Screenshots Displaying Process of Grouping PETS

Figure H1

Colour coding experiential statements

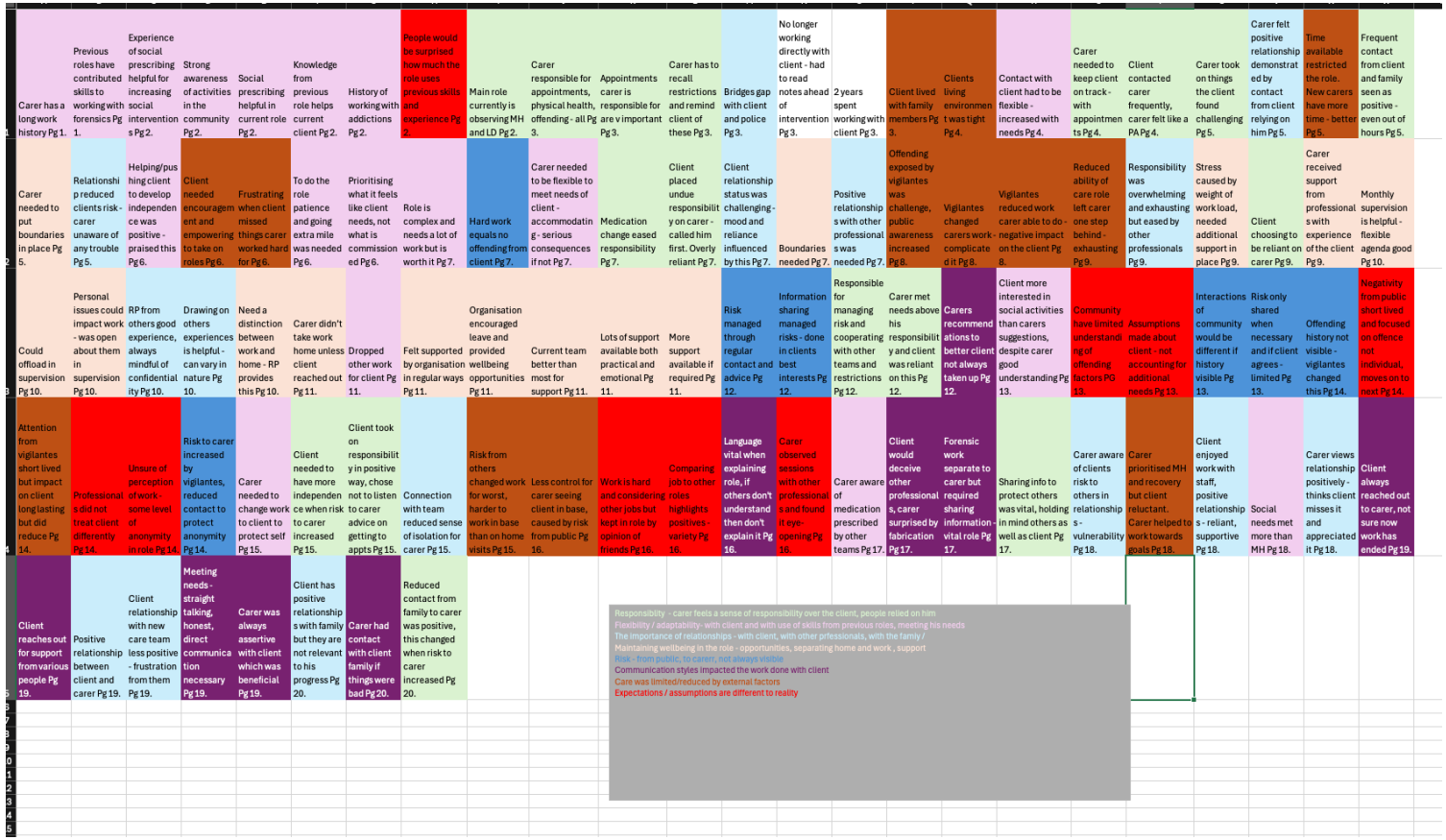
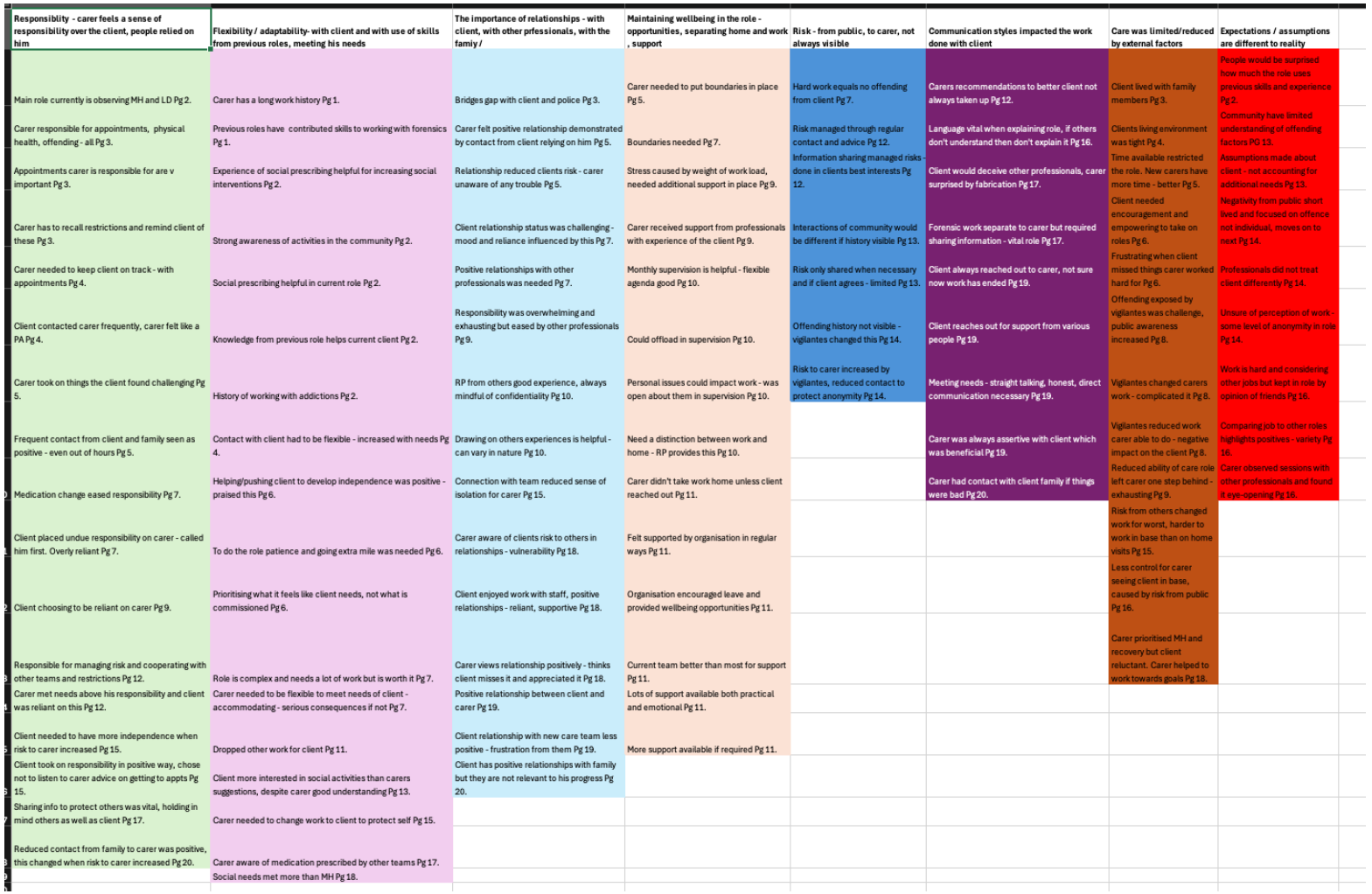


Figure H2

Grouping Experiential Statements into PETS



Responsiblity - carer feels a sense of responsibility over the client, people relied on him	Flexibility / adaptability- with client and with use of skills from previous roles, meeting his needs	The importance of relationships - with client, with other prfessionals, with the famiy /	Maintaining wellbeing in the role - opportunities, separating home and work , support	Risk - from public, to carer, not always visible	Communication styles impacted the work done with client	Care was limited/reduced by external factors	Expectations / assumptions are different to reality
Main role currently is observing MH and LD Pg 2.	Carer has a long work history Pg 1.	Bridges gap with client and police Pg 3.	Carer needed to put boundaries in place Pg 5.	Hard work equals no offending from client Pg 7.	Carers recommendations to better client not always taken up Pg 12.	Client lived with family members Pg 3.	People would be surprised how much the role uses previous skills and experience Pg 2.
Carer responsible for appointments, physical health, offending - all Pg 3.	Previous roles have contributed skills to working with forensics Pg 1.	Carer felt positive relationship demonstrated by contact from client relying on him Pg 5.	Boundaries needed Pg 7.	Risk managed through regular contact and advice Pg 12.	Language vital when explaining role, if others don't understand then don't explain it Pg 16.	Clients living environment was tight Pg 4.	Community have limited understanding of offending factors PG 13.
Appointments carer is responsible for are v important Pg 3.	Experience of social prescribing helpful for increasing social interventions Pg 2.	Relationship reduced clients risk - carer unaware of any trouble Pg 5.	Stress caused by weight of work load, needed additional support in place Pg 9.	Information sharing managed risks - done in clients best interests Pg 12.	Client would deceive other professionals, carer surprised by fabrication Pg 17.	Time available restricted the role. New carers have more time - better Pg 5.	Assumptions made about client - not accounting for additional needs Pg 13.
Carer has to recall restrictions and remind client of these Pg 3.	Strong awareness of activities in the community Pg 2.	Client relationship status was challenging - mood and reliance influenced by this Pg 7.	Carer received support from professionals with experience of the client Pg 9.	Interactions of community would be different if history visible Pg 13.	Forensic work separate to carer but required sharing information - vital role Pg 17.	Client needed encouragement and empowering to take on roles Pg 6.	Negativity from public short lived and focused on offence not individual, moves on to next Pg 14.
Carer needed to keep client on track - with appointments Pg 4.	Social prescribing helpful in current role Pg 2.	Positive relationships with other professionals was needed Pg 7.	Monthly supervision is helpful - flexible agenda good Pg 10.	Risk only shared when necessary and if client agrees - limited Pg 13.	Client always reached out to carer, not sure now work has ended Pg 19.	Frustrating when client missed things carer worked hard for Pg 6.	Professionals did not treat client differently Pg 14.
Client contacted carer frequently, carer felt like a PA Pg 4.	Knowledge from previous role helps current client Pg 2.	Responsibility was overwhelming and exhausting but eased by other professionals Pg 9.	Could offload in supervision Pg 10.	Offending history not visible - vigilantes changed this Pg 14.	Client reaches out for support from various people Pg 19.	Offending exposed by vigilantes was challenge, public awareness increased Pg 8.	Unsure of perception of work - some level of anonymity in role Pg 14.
Carer took on things the client found challenging Pg 5.	History of working with addictions Pg 2.	RP from others good experience, always mindful of confidentiality Pg 10.	Personal issues could impact work - was open about them in supervision Pg 10.	Risk to carer increased by vigilantes, reduced contact to protect anonymity Pg 14.	Meeting needs - straight talking, honest, direct communication necessary Pg 19.	Vigilantes changed carers work - complicated it Pg 8.	Work is hard and considering other jobs but kept in role by opinion of friends Pg 16.
Frequent contact from client and family seen as positive - even out of hours Pg 5.	Contact with client had to be flexible - increased with needs Pg 4.	Drawing on others experiences is helpful - can vary in nature Pg 10.	Need a distinction between work and home - RP provides this Pg 10.		Carer was always assertive with client which was beneficial Pg 19.	Vigilantes reduced work carer able to do - negative impact on the client Pg 8.	Comparing job to other roles highlights positives - variety Pg 16.
Medication change eased responsibility Pg 7.	Helping/pushing client to develop independence was positive - praised this Pg 6.	Connection with team reduced sense of isolation for carer Pg 15.	Carer didn't take work home unless client reached out Pg 11.		Carer had contact with client family if things were bad Pg 20.	Reduced ability of care role left carer one step behind - exhausting Pg 9.	Carer observed sessions with other professionals and found it eye-opening Pg 16.
Client placed undue responsibility on carer - called him first. Overly reliant Pg 7.	To do the role patience and going extra mile was needed Pg 6.	Carer aware of clients risk to others in relationships - vulnerability Pg 18.	Felt supported by organisation in regular ways Pg 11.			Risk from others changed work for worst, harder to work in base than on home visits Pg 15.	
Client choosing to be reliant on carer Pg 9.	Prioritising what it feels like client needs, not what is commissioned Pg 6.	Client enjoyed work with staff, positive relationships - reliant, supportive Pg 18.	Organisation encouraged leave and provided wellbeing opportunities Pg 11.			Less control for carer seeing client in base, caused by risk from public Pg 16.	
Responsible for managing risk and cooperating with other teams and restrictions Pg 12.	Role is complex and needs a lot of work but is worth it Pg 7.	Carer views relationship positively - thinks client misses it and appreciated it Pg 18.	Current team better than most for support Pg 11.			Carer prioritised MH and recovery but client reluctant. Carer helped to work towards goals Pg 18.	
Carer met needs above his responsibility and client was reliant on this Pg 12.	Carer needed to be flexible to meet needs of client - accommodating - serious consequences if not Pg 7.	Positive relationship between client and carer Pg 19.	Lots of support available both practical and emotional Pg 11.				
Client needed to have more independence when risk to carer increased Pg 15.	Dropped other work for client Pg 11.	Client relationship with new care team less positive - frustration from them Pg 19.	More support available if required Pg 11.				
Client took on responsibility in positive way, chose not to listen to carer advice on getting to appts Pg 15.	Client more interested in social activities than carers suggestions, despite carer good understanding Pg 13.	Client has positive relationships with family but they are not relevant to his progress Pg 20.					
Sharing info to protect others was vital, holding in mind others as well as client Pg 17.	Carer needed to change work to client to protect self Pg 15.						
Reduced contact from family to carer was positive, this changed when risk to carer increased Pg 20.	Carer aware of medication prescribed by other teams Pg 17.						
	Social needs met more than MH Pg 18.						

Figure H3

Reviewing and Developing PETs

Carers approach to the role is heavily influenced by client													
being led by the client's needs and wants	Carer felt that suggestions to client were never accepted or acted on - client chose not to engage in meaningul activity pg 18 line 812.	Client would always reach out to others for support, open to asking for help Pg 19 line 844.	Carer and client had built a positive relationship which isn't seen with all professionals pg 19 line 861.	Best engagement from client is when it is directed by his interests pg 19 line 870.	Clients actions meant carer needed to be flexible and responsive to meet needs of client - held in mind consequences of not Pg 7 line 296.	Carer always prioritsed the needs of the client and would always be responsive Pg 11 line 478.	Carers recommendations only go so far client has to be interested and motivated to engage pg 12 line 557.	Carer stopped trying because client follows his own interests rather than carers suggestions Pg 13 line 570.	Client would not listen to advice from carer and make own decisions pg 15 line 668.	Contact with client had to be flexible - increased with needs of the client Pg 4 line 165.	being heavily relied on by client	Carer feels client was happy to rely on him to meet his needs that were outside the remit of his role - social pg 18 line 828.	Carer felt responsible for ensuring client's attendance at important meetings Pg 3 line 95.
What is needed for the role to be considered positive - what is required for the carer, how success is measured, flexibility													
what the carer needs to be able to do the role	Carer feels that the role allows him to use all his skills and experiences Pg 2 line 85.	Knowledge from previous role helps current client Pg 2 line 65.	Carer understands the impact of social isolation and offers activities in the community Pg 2 line 48.	Carer is able to draw on previous work expereince in the current role Pg 1 line 37.	Carer felt appreciated by the client for the work they did together Pg 18 line 837.	Carer able to forget about the support provided when stopped working with the client Pg 3 line 117.	Time available to the carer restricted the work he could do in the role, needed to be longerr Pg 5 line 204.	Having support accessible and available is important to carer Pg 11 line 495.	There is a difference between practical and emotional support and both are important for the role pg 11 line 506.	Carer is satisfied with variety of avenues for support including being encouraged to take leave pg 11 line 487.	Carer has had to balance meeting needs of client with risk to themselves hich required change in work style pg 15 line 657.	what makes the carer successful at their role	Success is determined by meeting the client's need not by organisational outcomes or measures pg 6 line 275.
This work is heavily influenced by others- being open to support and advice from others, other people making assumptions													
important to be open to support and advice from others	Connection with team reduces sense of isolation for carer Pg 15.	It was helpful for carer to receive support from professionals with experience of the client Pg 9 line 416.	Positive relationships with other professionals needed and supports carer in his role Pg 7 line 320.	Everyone in the team brings their own experiences and they are all valuable Pg 10 line 455.	Being able to bounce ideas of other people with different experiences helps to work with client Pg 10 line 448.	Risk is managed through direct work with client and information sharing with MDT - dual aspect pg 12 line 519	Monthly supervision is helpful - carer appreciates a flexible agenda and a space to offload Pg 10 line 430.	other peoples will make assumptions	Community have a lack of understanding of client and make assumptions based on observable factors Pg 13 line 584.	Belief community don't have capacity to care or empathise with clients Pg 13 line 593.	Assumptions by public are based entirely on what they can see and infromation is limited to protect client so no negative treatment pg 13 line 600	Although client can be judged he is one of many so attention and impact is short lived pg 14 line 616.	Assumption risk to carer would be iincreased by vigilante so reduced contact to protect anonymity Pg 14 line 646.
Unexpected requirements- going above and beyond what is expected, the work weighing heavy on the carer													
going above and beyond what is expected in the role	Carer was only person supporting client so took on lots of different roles Pg 2 line 91.	Carer is aware that the realities of the role aren't what it is supposed to be but this is required to meet needs for the client which is the priority. Pg 6 266.	Carer is driven by meeting client's needs and will do more than expected to do this Pg 7 line 284.	Carer aware and allowed client to take advantage and rely on them outside bounds of the role pg 12 line 453.	the work weighs heavy on the carer	Carer feeling mentally tired by the work at time - not able to do the job he wanted to do Pg 9 line 377.	Responsibility can be overwhelming and exhausting, felt heavy, but eased by other professionals Pg 9 386.	Struggling to feel in control of the workload was stressful and heavy for carer, acknowledged needed extra support Pg 9 line 399.	Carer needs a space to mentally offload and leave the weight of work at work to maintain wellbeing Pg 10 line 463.	Managing risk requires holding lots of factors in mind and ensuring client is following Pg 12 line 531.	Understanding that personal circumstances can add to the weight of work load Pg 10 line 442.		

Carers approach to the role is heavily influenced by client													
being led by the client's needs and wants	Carer holds in mind restrictions when the client doesn't Pg 3 line 107.	Carer held in mind responsibility for things when client didn't Pg 4 line 173.	Carer understands what client struggles with and would take on responsibility for these tasks Pg 5 line 189.	Carer is happy to take on the responsibility as it shows a positive relationship that client asks for help Pg 5 line 196.	Client placed undue responsibility on carer - called him first and was overly reliant Pg 7 line 308.	Client would reach out to carer when able to resolve difficulties himself Pg 7 line 314.	Carer questioned level of support given - client is more capable than he acts and if pushed can develop som independence pg 15 line 665.	Frequent contact from client and his family is viewed positively and a sign of a good relationship - client relied on carer Pg 5 line 215.	attempting to empower the client	Carer aims to pass responsibility to client and uses positive reinforcement to do this Pg 6 line 236.	Without encouragement and empowering client is happy to not take on responsibility, despite carer seeing capability Pg 6 line 247.	Carer needed to be direct, assertive and firm with client to engage positively with him pg 19 line 874.	
What is needed for the role to be considered positive - what is required for the carer, how success is measured, flexibility													
what the carer needs to be able to do the role	Carer doesn't let frustration and setbacks stop them from meeting client's needs Pg 6 line 254.	Carer is proud that client hasn't displayed any risky behaviours since working together Pg 5 line 231.	Carer is kept in the job by the positive acknowledgement he gets from other people pg 16 line 715.	Carer views limited contact from family to carer as a sign of positive progress for client pg 20 line 907.									
This work is heavily influenced by others- being open to support and advice from others, other people making assumptions													
important to be open to support and advice from others	Language is important when explaining role, if others don't understand then carer doesn't try to explain it Pg 16 line 732.	Carer would not expect negative treatment from professionals - rise above these perceptions pg 14 line 633.	People can influence the care being provided	Client engages with family on a superficial level and didn't impact his care pg 20 line 891.	There was always risk information to share and it was carers responsibility to do this Pg 17 line 773.	Carer acknowledged vulnerability of client and was required to maintain the safety of the client and other people he interacted with pg 17 line 787	Client acted differently with other professionals - less trustworthy to others than to the carer Pg 17 line 761.	Other professionals work with client has been more short-term pg 16 line 744.	Offending being exposed by vigilantes and public awareness increasing was a challenge for carer Pg 8 line 337.	Vigilantes posed a serious risk to others and changed carers work, making it harder Pg 8 line 347.	Vigilantes reduced carers ability to complete his job effectively - had a negative impact on the client Pg 8 line 363.	Carer has awareness of other professionals involved in client's care but views these as external if not part of his team Pg 17 line 752.	Carer acknowledges role changed as risk from others increased, more limited in how he could meet needs Pg 15 line 692.
Unexpected requirements- going above and beyond what is expected, the work weighing heavy on the carer													
going above and beyond what is expected in the role													

Appendix 2I - Screenshots Demonstrating Process of Developing GETs

Figure I1

Beginning to Group Individual PETs

Figure I2

Developing Group Experiential Themes and Subthemes

Figure 13

Organising Emerging Themes and Subthemes