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Parents' experiences of compassion and adjustment in the context of their child's neurodevelopmental condition.

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Submitted in partial fulfilment of the requirements for the degree of

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Chapter 1: Systematic Review

Parental Resolution of a Child's Intellectual Disability Diagnosis: A Systematic Review

Prepared in accordance with the author requirements for Advances in Neurodevelopmental Disorders

Author Guidelines

Abstract

This review aimed to provide a critical synthesis of the current literature base exploring parents' acceptance of their child's Intellectual Disability (ID) diagnosis. Two research questions were addressed: (Research question 1 [RQ1]) How do parents experience the journey towards resolution or acceptance of their child's ID diagnosis? (Research question 2 [RQ2]) What factors facilitate or hinder parental resolution or acceptance? A systematic search of research published since 2010 was conducted on 4 June 2026. Studies were screened in two phases: (1) by title and abstract and (2) by full text. Seventeen studies were included in the review. Quality appraisal was used to assess methodological quality and organise studies for thematic synthesis. Four analytical themes were generated: (1) Emotional rupture and recurrent grief and (2) Making sense of the diagnosis, both address the nature of the parental journey (RQ1); (3) Rebuilding the parental role relates to both RQ1 and RQ2; and (4) Support and barriers around the family identified facilitating and hindering factors (RQ2). Parental resolution of their child's diagnosis was not a fixed endpoint, rather an ongoing process shaped by emotional, relational and service contexts. The findings from this review highlight a need for ongoing clear and compassionate professional support, peer support, culturally sensitive practice and coordinated future-care planning to aid parental resolution.

Keywords: Parental resolution, diagnosis acceptance, parental adjustment, Intellectual disability

Introduction

An Intellectual Disability (ID), formerly known as a Learning Disability (LD) is a neurodevelopmental condition characterised by deficits in general mental abilities that affect how an individual functions in conceptual, social and daily-life areas, with onset in late infancy or early childhood (DSM-5; APA, 2013). An ID is a lifelong diagnosis that can have significant positive and negative impacts on the individual and family (Beighton & Wills, 2019). Receiving a formal diagnosis can be a powerful tool to help reduce parents' uncertainty and self-blame (Williams et al., 2022) and access appropriate supports tailored to their child's needs (Dikow et al., 2019). Further positive implications include improved family closeness, personal growth, and joy (Beighton & Wills, 2019). However, these positive outcomes should not overshadow the emotional journey of undergoing an assessment and the lifelong challenges of raising a child with additional needs. Mencap family survey (n.d.) highlighted the challenge parents face when coming to terms with the fact that their child's future and their parenting journey will differ from how they imagined. Although parents shared that they experience fear and sadness, there were often positive feelings like relief and reassurance after receiving their child's diagnosis.

Literature on parents' process of accepting their child's neurodevelopmental diagnosis reveals a complex interplay of emotions, perceptions and coping mechanisms. This process of adapting and accepting their new reality is often referred to in the literature as "resolution of diagnosis". Originally derived from attachment theory, the construct of resolution explains how parents adjust and accommodate their internal representations and expectations to meet their new reality of parenting a child with additional needs (Marvin & Pianta, 1996). Resolution is powerful because with this understanding and acceptance of the challenges associated with their child's diagnosis, they are better able to meet their child's individual needs. This ultimately facilitates a stronger child-parent relationship and has positive impacts on both parent and child wellbeing (Barak-Levy & Atzba-Poria, 2015).

Theoretical frameworks such as attachment theory (Bowlby, 1969), social identity theory (Turner et al. 1979) and self-schema theory (Markus, 1977) are relevant to understanding parental acceptance of their child's ID Diagnosis. Attachment theory posits that early relational experiences shape internal working models including parents' expectations of themselves, their child and the caregiving relationship. The construct of resolution is theoretically grounded in but distinct from attachment theory. Resolution relates to the specific cognitive and emotional processes parents engage in to reorganise their internal representations and expectations following their child's diagnosis (Marvin & Pianta, 1996). As such, resolution is a dynamic response to the diagnostic event rather than the quality and organisation of relational bonds. Findings from Barak-Levy and Atzba-Poria (2013) suggest that parents who achieve resolution are able to integrate the diagnosis into a revised but coherent understanding of their child and their parenting role. Social identity theory offers a complementary

perspective by proposing that individuals derive a significant part of their sense of self from the groups to which they belong (Markus, 1977). Parents' experience of their child's ID diagnosis may disrupt their social identity through stigma (Gray, 2002) and through a perceived mismatch between their anticipated parenting identity and the reality of raising a child with additional needs. Similarly, Self-schema theory suggests that the cognitive frameworks an individual holds about themselves guide how they process and understand their experiences (Turner et al., 1979). For example, parents who hold rigid self-schemas around what 'good parenting' or a 'typical child' looks like may make it more difficult to accept their child's diagnosis. These frameworks suggest that parental acceptance of an ID diagnosis goes beyond emotional adjustment and involves the reorganisation of relational expectations, parenting identity and self-perception.

An Italian study by Di Renzo et al. (2020) looked at 50 parents' ability to respond to their child's (aged 24-58 months) signals and adjust to their needs during play interactions. Their findings suggest that parents who displayed higher acceptance and insight of their child's autism were more attuned to their child's needs during play interactions when compared to parents with lower acceptance. Feniger-Schaal and Oppenheim (2013) found similar results showing increased maternal sensitivity in mothers with a greater acceptance of their child's ID.

Previous systematic reviews have focused on the parental experience of caring for a child with ID (Beighton & Wills, 2019; Marsh et al., 2020), parental quality of life (Barratt et al., 2025) and understanding experience of stigma for ID (Ali et al., 2012). One review to date has looked at the factors associated with parental resolution of a child's autism diagnosis (Naicker et al., 2022). Naicker et al. (2022) synthesised 14 studies (N=592) published between 2017 and 2022 and was limited by the small number of eligible studies. There is a gap in previous systematic reviews examining parental acceptance and resolution across ID and related diagnoses. Existing reviews have either focused exclusively on autism, or looked at broader caregiving experiences, stigma, stress or quality of life rather than factors that facilitate or hinder parents' ongoing resolution of their child's ID diagnosis. Therefore, it remains unclear how parents experience the process of resolution or acceptance following their child's ID diagnosis, and which factors shape this process.

This review will contribute distinctively by synthesizing recent evidence for parents of children with ID and related diagnoses. The review was limited to studies published from 2010 onwards. This reflects the contemporary changes in language and conceptualisation of ID in the DSM-V and the associated policy shifts toward community based care. These changes occurred gradually rather than representing a distinct shift. This systematic review addressed two research questions: (1) How do parents experience the journey towards resolution or acceptance of their child's ID diagnosis? (2) What factors facilitate or hinder parental resolution or acceptance of their child's ID diagnosis?

Methods

Registration

The protocol for this systematic review was registered with the International Prospective Register of Systematic Reviews (Prospero; CRD420251239298) on 24 November 2025 and reported in line with PRISMA guidelines (Appendix 1.1). The Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ; Tong et al., 2012) was used to ensure transparency of reporting (Appendix 1.2).

Search strategy

Data sources

A systematic search was conducted on 4 June 2026. The following databases were searched: EBSCOhost CINAHL, PsycINFO (OVID), Medline (OVID), Web of Science (Core Collection) and Scopus. These databases cover healthcare, psychology, and interdisciplinary and emerging research which allows for the identification of comprehensive research in parental resolution.

Each database was searched individually to reduce the likelihood of papers being missed due to conflicts with database index terms. Reference lists from included studies, related systematic reviews and meta-analyses were hand searched for additional papers.

Search terms

The search terms were formulated using the SPIDER framework. The strategy was developed with support from a specialist Health and Well-Being Sciences Librarian from the University of Glasgow. Boolean logic was used to improve the sensitivity and specificity of the search. A preliminary search showed that relevant studies used varied language (e.g., acceptance, resolution, adjustment, coping and coming to terms with the diagnosis). The following concepts were searched:

- Parents, caregivers and families
- ID, LD and related diagnoses
- Diagnosis, acceptance, resolution and coping

The full search strategy is provided in Appendix 1.3.

<u>Inclusion criteria</u>

- Qualitative, Quantitative and Mixed-Method empirical research that explored acceptance of ID diagnosis
- Participants are parents or carers of a child with a diagnosed ID (e.g., LD, Down Syndrome (DS), etc.)
- The child's primary diagnosis is ID, LD, DS, Global Developmental Delay (GDD), or any ICD-11/DSM-5 equivalent

- Studies including a mixed-disability sample will be included only where findings for ID are separately reported or 50% of the sample have a primary ID diagnosis
- Studies that explore parental resolution, acceptance, adjustment or coming to terms with the child's diagnosis
- Studies using the term "acceptance" will be included only where acceptance refers to accepting the child's diagnosis, disability or the implications of the condition
- Conducted in any setting
- Published after 1 January 2010 (reflecting the contemporary shift in diagnostic language and conceptualisation of ID, seen in the shift from 'mental retardation' in DSM-IV to 'intellectual disability' in the DSM-V)
- Published in English or with English translations available
- Published in a peer-reviewed empirical journal

Exclusion criteria

- Studies not focused on parents or primary caregivers
- Studies focused only on professionals, siblings, teachers, service providers or the ID individual's experience
- Studies that exclusively focus on diagnostic process, diagnostic disclosure, service access or parents' immediate reactions (within the first month) following the diagnosis being given
- Studies published before January 2010
- Not published in English without available translation
- Not published in a non-empirical peer-reviewed journal (e.g., book chapters, commentaries, literature reviews, systematic reviews, grey literature, conference abstracts and dissertations).

Review Process

Study Screening

The Principal Investigator completed database searches and the citations were imported into Covidence software. Covidence identified duplication in studies which were manually checked by the PI. The de-duplicated search results were screened by title and abstract, in line with the inclusion and exclusion criteria. Where it was unclear if an article should be included, the full article was identified for full text screening.

Full texts were retrieved for the studies identified meeting inclusion criteria during Phase 1. Full text articles were uploaded onto Covidence and read in detail to ensure relevance; irrelevant papers were excluded. In line with PRISMA standards, researchers reported reason for full texts being excluded. To ensure for reliability of screening, 10% of articles were independently screened by a second reviewer (FH) at each phase and any conflicting opinions were discussed to reach consensus.

Data extraction

A standardised extraction database/tool was developed and applied to texts included at phase 2 (full text screening). Information was extracted from included papers by hand and recorded on an uploaded extraction form on Covidence.

Data extracted included:

- Study characteristics: study title, authors, year of publication, country of study, research design, data collection method and data analysis.
- Study sample: sample size, sampling method, population, age range of parents, age range of child, child's diagnosis, setting, ethnicity.
- Study findings: key quantitative or qualitative findings, themes and sub-themes, limitations.

The accuracy of data extraction was verified by a second reviewer (FH) for four of the included studies (20%). Disagreements were discussed until consensus was reached.

Quality appraisal

As recommended by the ENTREQ guidelines, each study was appraised for methodological quality and risk of bias using the Mixed-Method Appraisal Tool (MMAT; Hong et al., 2018; Appendix 1.4). This tool was used to ensure methodological rigour and reliability of the findings. The MMAT checklist assessed the quality of research design, recruitment, data collection, analyses, reflexivity, ethical considerations and value of research. To ensure reliability, a second reviewer (FH) independently appraised four studies of varying quality ratings. Quality appraisal results were used to group studies based on quality, which informed interpretation of synthesis without excluding studies.

Data synthesis

This systematic review used the thematic synthesis (TS) approach developed by Thomas and Harden (2008) to synthesise the available research relating to parental attitudes towards their child's ID diagnosis. As the research in this area is currently limited, TS allowed for an overview of the current research landscape by integrating themes across the different qualitative, quantitative and mixed-methods studies. The results of the quality appraisal were used to guide TS; the "results" or "findings" sections of high-quality studies were line-by-line coded using language that stayed close to the original text. The free codes were extracted into a word document, with codes capturing similar meaning transformed into one code. Initial codes from high-quality studies were used as a code bank for medium-quality studies. Where relevant to the review aim, new codes were added to the code list. Relevant quantitative statistical findings were converted into narrative finding statements and then mapped into the synthesis. Code frequencies as they appear across studies and used in theme

construction can be found in Appendix 1.5. Similar codes were grouped together to form broader descriptive themes and subthemes, and an initial thematic map (Appendix 1.6) was developed to explore the relationship between themes.

Researcher reflexivity

The researcher is a white female, neurodiverse Trainee Clinical Psychologist with clinical experience working in ID and Neurodevelopmental Child and Family services. The researcher's personal and professional experience of supporting children with ID and families motivated this review. However, the researcher is aware they hold pre-existing assumptions about what family's acceptance of a diagnosis looks like clinically and this may have influenced their interpretation of findings. As this review synthesised existing literature, the researcher aimed to remain close to primary authors' interpretation and participants' quoted accounts. Screening, coding and theme development were discussed with supervisors and an independent reviewer to challenge assumptions and support the trustworthiness of the synthesis.

Results

Data screening

Initial database searches identified 4,243 articles, 2,236 remained after deduplication and screened by title and abstract. Furthermore, 2,115 studies were excluded and 121 articles were included for full text screening. An independent reviewer (FH) screened 10% of retrieved articles with a 92% interrater agreement; discrepancies were discussed and resolved. Of the total, 105 full texts did not meet the inclusion criteria and were excluded. Hand-searching of 696 citations identified nine studies for further screening. Eight were excluded following abstract screening and one study progressed to full-text screening and was included. Seventeen studies were included in the quality appraisal and data synthesis. Figure 1.1 outlines the screening process in a PRISMA (2020) diagram.

Study characteristics

Summaries of the study characteristics can be found in Table 1.1. The accuracy of extraction from four papers was checked by FH with interrater agreement of 100%. Studies were published between 2012 and 2025 and conducted in the USA (n=5), Israel (n=4), Australia (n=2), UK (n=1), Spain (n=1), Indonesia (n=1), Kuwait (n=1), Sweden (n=1) and Japan (n=1).

The total number of participants across studies was 1,152 (784 mothers, 366 fathers and 2 sisters). All participants were between the ages of 25-83 years. The primary child diagnosis was DS (n=8), ID (n=8) and mixed-ID diagnoses (n=1). Ethnicity was not reported for 56% of participants.

Study design included qualitative (n=10), quantitative (n=4) and mixed-methods (n=3). Data was collected through semi-structured interviews (n=9), questionnaires, online surveys (n=4) and focus groups (n=1). Qualitative methods of analysis were thematic analysis (TA; n=4), grounded theory (GT; n=3) content analysis (n=3), Interpretative Phenomenological Analysis (IPA; n=2) and qualitative comparative analysis (n=1). Quantitative and mixed-methods studies statistical analysis included: descriptive statistics (n=7), categorical Reaction to Diagnosis (RDI semi-structured interview; n=4), group comparison tests (n=4), correlational analysis (n=3), chi-square analysis (n=1), regression (n=1) and cluster analysis (n=1).

Quality appraisal

Of the included studies, 16/17 (94%) were rated either high or moderate methodological quality using the MMAT, and one was rated lower quality (Table 1.2). The MMAT does not provide an overall numerical score. MMAT ratings were considered across the relevant criteria and used to inform the interpretation of findings. It is unlikely that removing low-quality studies would alter the four core themes. This is due to initial coding being based on high-quality studies with medium-quality studies contributing to the existing code bank. Rather it would likely reduce the depth of specific subthemes.

Interrater agreement following co-rating was initially 95% (38/40). Disagreements centred on adequate detail regarding the clarity of aims. After discussion between raters, there was 100% agreement.

All studies included a clear statement of the research aims and most studies demonstrated generally appropriate study designs and findings that were supported by the data. However, some were rated 'can't tell' due to a lack of information as detailed below.

Qualitative studies such as Brown (2013), Boström & Broberg (2014), AlShatti et al. (2021), Fernández-Ávalos et al. (2021), Ridding and Williams (2019) and Pillay et al. (2012) were rated as having higher methodological quality, with theme consistently being supported by participant quotations to create rich accounts. Brown's (2013) use of purposive sampling, semi-structured interviews, line-by-line coding and constant comparison made it particularly strong. Reflexivity was a common limitation in the qualitative studies; in all but one study (Gotay, 2025), authors failed to consider their role or assumptions. Mixed-methods studies demonstrated higher methodological quality where qualitative findings were clearly integrated with and used to contextualises quantitative patterns (Barak-Levy & Paryente, 2023). Bentley et al. (2015) and Nelson Goff et al. (2016) were limited by self-selected samples and thinner qualitative data from open-ended surveys. Several studies provided limited detail with regard to recruitment and analytic procedures (Korkow-Moradi et al., 2017; Takataya et al., 2016), sampling representativeness and non-response bias (Barak-Levy & Atzaba-Poria, 2013, 2015) and questionnaire validity (Wahyuni et al., 2024).

Figure 1.1

PRISMA flow diagram

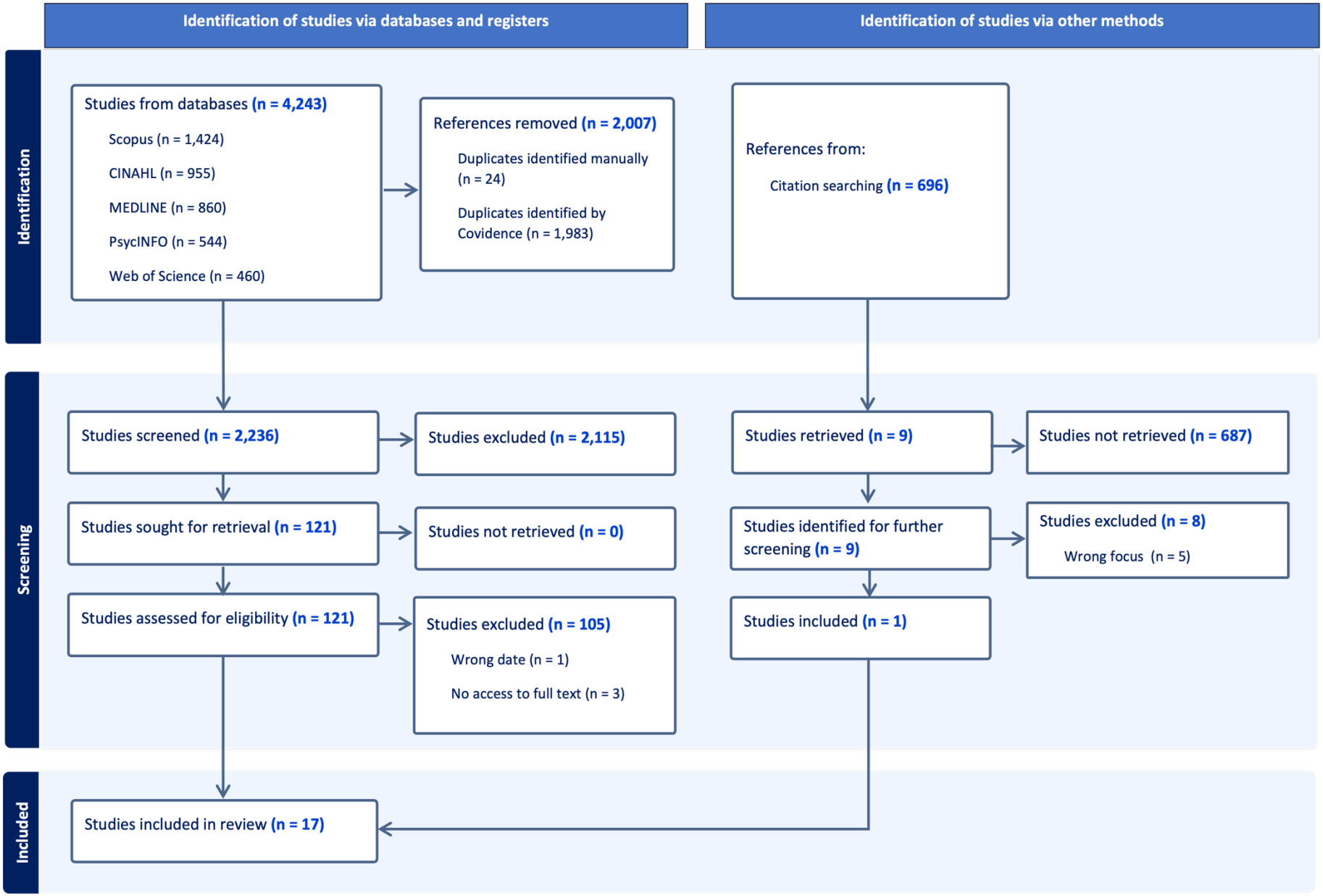


Table 1.1

Study characteristics

Author(s), Year & Place	Sample Characteristics	Design & Methodology	Qualitative Findings Themes & Subthemes / Quantitative Relevant Findings
AlShatti et al. (2021) Kuwait	21 caregivers (19 mothers, 2 sisters). Parent Age = 28-57 Child Diagnosis = DS Child Age = 5-32 years Ethnicity = NR Purposive sampling	Qualitative Semi-structured interviews TA	Caregivers' struggle after diagnosis of DS Impact on the caregiver is huge Educational and social participation by persons with DS is challenging Perceptions of and satisfaction with inadequate services and facilities
Barak-Levy and Atzaba-Poria (2013) Israel	136 parents (71 mothers and 65 fathers) Parent age = Mothers 25-49 (M=37.51, SD=6.27), Fathers 27-57, (M=40.25, SD=6.47) Child diagnosis = GDD Child age = 4-7 yrs (M=5.53, SD=0.73) 62% boys. Ethnicity = NR Purposive Sampling	Quantitative Cross-sectional RDI Demographic Questionnaire Semi-structured interviews coded as resolved/unresolved and subcategorised into emotional, action and cognitive coping styles	Most parents were unresolved with the diagnosis (59% of mothers and 60% of fathers). Mothers tended to express a more emotional coping style ($p \leq .05$) while fathers tended to use a more cognitive/neutralising style ($p \leq .05$). Later diagnosis, lower education and lower SES were generally linked to poorer resolution, with significant associations for fathers for later diagnosis ($p \leq .01$), lower education ($p \leq .05$), and lower SES ($p \leq .05$). The uncertainty/milder appearance of DD may prolong hope that the child will "catch up", complicating resolution.
Barak-Levy and Atzaba-Poria (2015) Israel	136 parents (71 mothers and 65 fathers) Parent age = Mothers 25-49 (M=37.51, SD=6.27), Fathers 27-57, (M=40.25, SD=6.47) Child diagnosis = Mild ID Child age = 4-7 yrs (M=5.53, SD=.73) 62% boys. Ethnicity = NR	Quantitative Cross-sectional RDI Demographic Questionnaire Dyadic Adjustment Scale for marital adjustment, Social Support Questionnaire 6, CHAOS scale for household chaos, Parenting Stress Index, Emotional Availability Scales for parent-child interaction	Family risk was associated with higher parental stress for both parents ($p < .01$). Unresolved parental resolution was most impactful in families with high family risk and was linked to less positive mother-child interaction ($p < .05$). No significant results were found for the father-child interaction. Resolved mothers in low-risk family contexts reported the lowest stress levels ($p < .05$). Unresolved fathers in high-risk family contexts reported highest stress, although this interaction did not reach statistical significance ($p < .10$).

	Purposive Sampling		
Barak-Levy and Paryente (2023) Israel	62 parents (42 mothers and 20 fathers) each from a different family. Parent age = 28-54 (M=37.1, SD=5.05) Child diagnosis = ID or ASD/ID Child age = 4-15 yrs (M=4.5) Ethnicity = NR Purposive Sampling	Mixed-methods Combining categorical RDI classification with qualitative content analysis of semi-structured interviews. Content analysis	59.7% of parents were classified as resolved (55% mothers, 68.2% fathers) and 40.3% as unresolved. Qualitative themes detailed below: Emotions, - Guilt - Shame - Emotional breakdown Thoughts - Preoccupation with surrounding stigma - Troubled about the child's future Actions - Concealment - Search for help - Effort to reject the diagnosis
Bentley et al. (2015) USA	50 fathers Parent age = 30-65 (M=49) Child diagnosis = DS Child age = 2m-25yrs (M=7.2yrs) Ethnicity = 86% white Convenience sampling	Mixed-methods Open-ended online survey Directed content analysis Herth Hope Index (HHI); Couples Satisfaction Index (CSI-4); Satisfaction With Life Scale (SWLS); Family Crisis Oriented Personal Scales (F-COPES).	Three father coping profiles were identified: Mastering (n=13) Connecting (n=23) Thriving (n=14) Quantitative findings showed significant cluster differences in hope, couple satisfaction, life satisfaction and coping. Fathers in the 'Thriving' cluster reported highest coping scores compared to fathers in 'Connecting' and 'Mastering'.
Bingham et al. (2012) USA	Six mothers Parent age = 24-38 Child diagnosis = DS, Rubinstein, Taybi syndrome, carbohydrate deficient glycoprotein syndrome, hydrocephalus or GDD Child age = 10-34 months	Qualitative Demographic questionnaire Repeated semi-structured interviews, observational field notes, and a second round of interviews using modified 'Ways of Coping' questionnaire prompts. TA	Mothers' suspicions and diagnostic experiences Palliative coping responses: - denial - questioning why - wishful thinking Problem-solving strategies: - seeking professional support - seeking information

	Ethnicity = 100% Caucasian		- seeking social support - reframing - seeking spiritual support
Boström and Broberg (2014) Sweden	Seven fathers Parent age = 25-43 Child diagnosis = ID/DD Child age = 5m-5yrs Ethnicity = NR Convenience sampling	Qualitative Longitudinal IPA Demographic Questionnaire Semi-structured interviews at three time points: within 6 m of diagnosis, 1 yr later and 5 yrs later	An interrupted path - no longer taking things for granted Being a good father Dealing with the unexpected: - Vulnerable openness - Contained openness - Avoiding the unexpected
Brown (2013) Australia	Six mothers Parent age = 44-58 Child diagnosis = ID Child age = 16-24 yrs Ethnicity = NR Purposive sampling	Qualitative Semi-structured interviews TA	Initial diagnosis – expectation and realisation The solemnity – double mourning The personal – reaction and response Pivotal point – crisis and coping Milestones – lost and found The future – challenge and change Meaning making – identity and agency
Feniger-Schaal and Oppenheim (2013) Israel	40 mothers Parent age = NR Child diagnosis = ID Child age = 2.5-5.5 yrs (M=47.25m, SD=12.4m) Ethnicity = NR Purposive sampling	Quantitative Cross-sectional RDI RDI, Emotional Availability Scales, Mullen Scales of Early Learning, Vineland Adaptive Behaviour Scales, Social Communication Questionnaire	27.5% of mother were classified as resolved; 72.5% were unresolved. Mothers classified as resolved showed greater maternal sensitivity in free play ($p = .05$) and social play ($p = .04$) compared to unresolved mothers, with a significant overall effect of resolution, $F(3,34) = 4.99$, $p = .006$. Findings suggest that resolution diagnosis may support more sensitive caregiving where the ID is more ambiguous.
Fernández-Ávalos et al. (2021) Spain	16 parents (11 mothers, 5 fathers) Parent age = 53-83 Child diagnosis = ID	Qualitative Semi-structured Interviews GT	Reception of the diagnosis Emotional bonds with the child Experience of loss and feelings in response to diagnosis Recurrent grief

	Child age = 18-40 yrs Ethnicity = NR Purposive sampling		Coping strategies to face loss and grief Differences as a function of the time of diagnosis and the ID severity Generated theory
Gotay (2025) USA	Six mothers Parent age = 41-75 Child diagnosis = DS Child age = 22-54 yrs Ethnicity = 5 Caucasian, 1 African American Purposive sampling	Qualitative Demographic form Semi-structured interviews IPA	Why us? - Condemning judgment - God-chosen mother of child gift - Purposeful personhood Future-oriented conflictions: - fear of loss and death - faith in God's plan - planning and self-reliance
Korkow-Moradi et al. (2017) USA	Five mothers Parent age = NR Child diagnosis = DS Child age = 3-52 yrs Ethnicity = 4 Caucasian, 1 Latina Convenience sampling	Qualitative National Survey Semi-structured interviews GT	Initial reactions Barriers - Professional bias - Not-knowing Buffers - Partner influences - Becoming an advocate - Sibling relationships - Family support Acquiring a new perspective - Learning - Growth - Benefits of the child - Encouraging advice
Nelson et al. (2016) USA	445 parents (86.5% mothers) Parent age = 41.91 (SD=9.66) Child diagnosis = DS Child age = 4 age groups (5, 5-11, 12-18, 18+ yrs) Ethnicity = 90.7% White	Mixed-methods Cross-sectional mixed-method survey National online survey including quantitative scales and qualitative open-ended response	Quantitative findings showed significant differences in coping across the life stage, with higher coping in middle childhood and adolescence compared to early childhood or adulthood. Acceptance was a key theme across all life stages and was more common among parents of adult children. 48% of parents with adult children identified acceptance as central to their attitude toward the diagnosis. Qualitative themes included: - Having a positive attitude

	Convenience sampling	Qualitative comparative analysis F-COPES; Herth Hope Index; Satisfaction With Life Scale; Revised Dyadic Adjustment Scale; Couples Satisfaction Index	- Child's developmental level - Acceptance of the diagnosis - Spiritual coping - Society's view of their child - Being blessed - Personal growth (of parent) - Fear of future - Resources
Pillay et al. (2012) Australia	Eight mothers Parent age = NR Child diagnosis = DS Child age = 7-12 yrs Ethnicity = NR Purposive sampling	Qualitative Demographic questionnaire form Semi-structured interviews TA	The journey begins: birth, diagnosis and acceptance Raising a child with DS Significant stressors - Children's behavioural problems - Health conditions - Society's misconceptions - Finding a work-life balance - Financial stress - Schooling - What does the future hold? Sources of support - Personal spirituality - Hope - Prayer - Personal coping styles - Inspirational resources - DS - Support from organised religion Outcomes of being a mother to a child with DS.
Riddling and Williams (2019) UK	15 Fathers Parent age = 26-52 Child diagnosis = DS Child age = 8m-8yrs (mean=4.3yrs) Ethnicity = NR	Qualitative Demographic Questionnaire Semi-structured interview GT	Accommodating the child - Age of child - Negative emotions and stress - The challenges of DS - Presence of co-morbidities - Challenge of comparing - Challenges to accessing support - Involvement at birth

	Purposive sampling		- Employment - Adaptation - Information searching - Family set-up - Accessing support Adapting parental/spousal role - Age of child - Challenges of negative emotions and stress - Challenges to relationships - Challenges of gender role - Positivity - Renegotiation of relationships - Gender role - Employment Adapting society - The challenges of negative experiences - Societal acceptance
Takataya, Yamazaki and Mizuno (2016) Japan	Nine fathers Parent age = 30s-50s Child diagnosis = DS Child age = 11yrs (Mean) Ethnicity = NR Convenience sampling	Qualitative Focus group interviews and individual interviews Content analysis	Crisis of life Emotional turmoil - Shocked by the condition - Child's life Attitudes toward the disability - Image of disability - Unusual experience - Disability and its relation to fathers - Bracing for disability - Meaning of child's existence - Ignorance about DS Parental responsibility - Parental responsibility - Raising a child - Division of parental role - Life itself is severe Realisation of fatherhood - Emotional attachment to my child

			- Feeling like a father - Growth as a person Difference of feelings between mother and father - Difference of feelings between mother and father - Mutual supportive relationship between husband and wive Contact with people - Professional advice - Effects on siblings - Family involvement - Relationship with people around family - Existence of parent association
Wahyuni et al. (2024) Indonesia	184 parents (114 mothers, 70 fathers) Parent age = 25-55 Child diagnosis = ID Child age = NR Ethnicity = NR	Quantitative Cross-sectional survey	Parental role ($p < .001$) and self-esteem ($p = .001$) were significantly associated with parental acceptance of child's ID diagnosis. 'Good' parental role was reported by 42.9% of parents and 36.5% reported having 'good' self-esteem. However, the direction of these associations was not entirely clear from the results and finding should be interpreted cautiously.

Table 1.2

MMAT Ratings

	MMAT Questions																
Included studies	S1	S2	Q1.1	Q1.2	Q1.3	Q1.4	Q1.5	Q3/4.1	Q3/4.2	Q3/4.3	Q3/4.4	Q3/4.5	Q5.1	Q5.2	Q5.3	Q5.4	Q5.5
*AlShatti et al. (2021)																	
Barak-Levy & Atzaba-Poria (2013)																	
*Barak-Levy & Atzaba-Poria (2015)																	
*Barak-Levy & Paryente (2023)																	
Bentley et al. (2015)																	
Bingham, Correa & Huber (2012)																	
Boström & Broberg (2014)																	
Brown (2013)																	
Feniger-Schaal & Oppenheim (2013)																	
Fernández-Ávalos et al. (2021)																	
Gotay (2025)																	
Korkow-Moradi, Kim & Springer (2017)																	
Nelson et al. 2016																	
Pillay et al. (2012)																	
*Riddling & Williams (2019)																	
Takataya, Yamazaki & Mizuno (2016)																	
Wahyuni et al. (2024)																	

Green=Yes; Red=No; Amber=Can't tell

S1 and S2 are MMAT screening questions. Q1-Q5 refer to the relevant MMAT category for each study.

Header shading: white = high quality; light grey = moderate quality; dark grey = low quality

*= Study has been co-rated

Thematic synthesis

Four descriptive themes and eight subthemes were developed: *Emotional rupture and recurrent grief; Making sense of the diagnosis; Rebuilding the parental role; and Support and barriers around the family.* The first two themes of *Emotional rupture and recurrent grief* and *Making sense of the diagnosis* primarily addressed RQ1 by describing the nature of parents' journey towards resolution or acceptance. The *Rebuilding the parental role* theme addressed both research questions; it captures the ongoing adjustment process (RQ1) and the internal and relational factors that facilitate it (RQ2). RQ2 is addressed by the final theme, *Support and barriers around the family,* which identified the external contextual factors that facilitate or hinder parental resolution. Across the synthesis, acceptance was viewed as an ongoing process shaped by emotional responses, meaning-making, parental identity, supports and concerns about the future rather than a fixed endpoint. Figure 1.2 presents a thematic diagram of the findings. Quantitative and mixed-methods findings were integrated into the synthesis by converting relevant statistical findings into narrative statements. Rather than being presented separately, quantitative findings were used to strengthen and qualify the qualitative themes. Primary data is presented within quotation marks and secondary data in italics.

Emotional rupture and recurrent grief

Receiving their child's diagnosis was described through emotional responses and disrupted parental expectations of their child, family life and future. Emotional distress was one of the most frequent patterns across the synthesis.

Shock and loss

Across 12 studies, parents described experiencing shock, fear, sadness, anger, guilt, shame and denial following their child's diagnosis being given. Shock/overwhelm and fear/anxiety were among the most frequent emotional codes, appearing in eight studies. Diagnosis was often experienced as an emotional rupture in parental expectations of their child and parenthood, with one parent describing: "Whole level of shock, and then numbness" ('Boni', Bingham et al., 2012: p.378) and feeling that their "World was in ruins… trapped in a profoundly intense storm of emotions" (Barak-Levy & Paryente, 2023: p.7). These qualitative accounts convey receiving their child's diagnosis as emotionally destabilising and disorienting, thus leaving little room for immediate acceptance.

Emotional rupture was closely tied to parents' experiences of loss. As one mother explained, "With any child, you have an expectation when someone's born… you've lost those expectations, particularly with the intellectual disability" ('Margaret', Brown 2013: p.117). Other parents described "Dreadful grief. Extreme distress…" ('Betty', Pillay et al., 2012: p.1503) for the child they had imagined and "Loss of everything, loss of the child, loss of the relationship…" ('103 Father', Fernández-Ávalos et al., 2021: p.716) to the life they had expected. Parents' feelings of loss reflect the painful adjustment to their changed reality rather than rejection of their child. Brown (2013)

referred to this loss as a *double mourning:* parents experience grief for their imagined child and their altered future as a carer. Emotional rupture and loss act as early barriers to parents' integrating the diagnosis with their expectations and complicate parents' resolution.

Quantitative findings support parents' experience of ongoing emotional difficulties. Barak-Levy and Atzaba-Poria (2013) found that 59% of mothers and 60% of fathers of children with GDD were unresolved. Similarly, Feniger-Schaal and Oppenheim (2013) found that 72.5% of mothers of children were classified as unresolved. These findings support the qualitative theme of emotional rupture remaining present after the initial period following diagnosis.

Recurrent, non-linear grief

Resolution was a non-linear adjustment, with parents' grief resurfacing across the parenting journey. *Recurring grief* (Fernández-Ávalos et al., 2021) was the reactivation of parents' sense of loss and emotions with similar intensity to that experienced in the beginning. "Hitting a barrier through every age change" ('Frances', Brown, 2013: p.119) with parents describing grief being reactivated by comparison to other children or peers, developmental milestones, being stuck in the past and concerns about their child's future (Fernández-Ávalos et al., 2021).

This pattern was also evident among parents of older children and adults. Parents of adult children with ID described sadness and loss long after the diagnosis, with one parent sharing: "You never completely accept it. It's there, you have your sadness… The sadness that he could have been normal" ('109 Father', Fernández-Ávalos et al., 2021: p.717). Other studies supported this interpretation of adjustment over time. Riddling and Williams (2019) conceptualised fathers' adjustment as a *fluid trajectory*, whereas Nelson Goff et al. (2016) found that parents' coping differed across child life-stage groups. Similarly, Boström and Broberg (2014) described fathers' experiences of their child's diagnosis as an *interrupted path – no longer taking things for granted* followed by *being a good father.* Fathers' subsequent adjustment moved between more *vulnerable* and more *contained* forms of openness rather than following one trajectory towards resolution (Boström & Broberg, 2014).

Across these studies, acceptance and grief were described as coexisting rather than mutually exclusive. Recurrent grief is an *adaptive, dynamic and circular process* shaped by *personal* and *societal factors* (Brown, 2013).

Making sense of the diagnosis

This theme captures the meaning that parents attempt to make to understand and reframe their child's diagnosis. Meaning-making was described through searching for reasons, seeking information, drawing on spirituality or hope, and gradually seeing the child beyond their diagnosis.

Searching for understanding

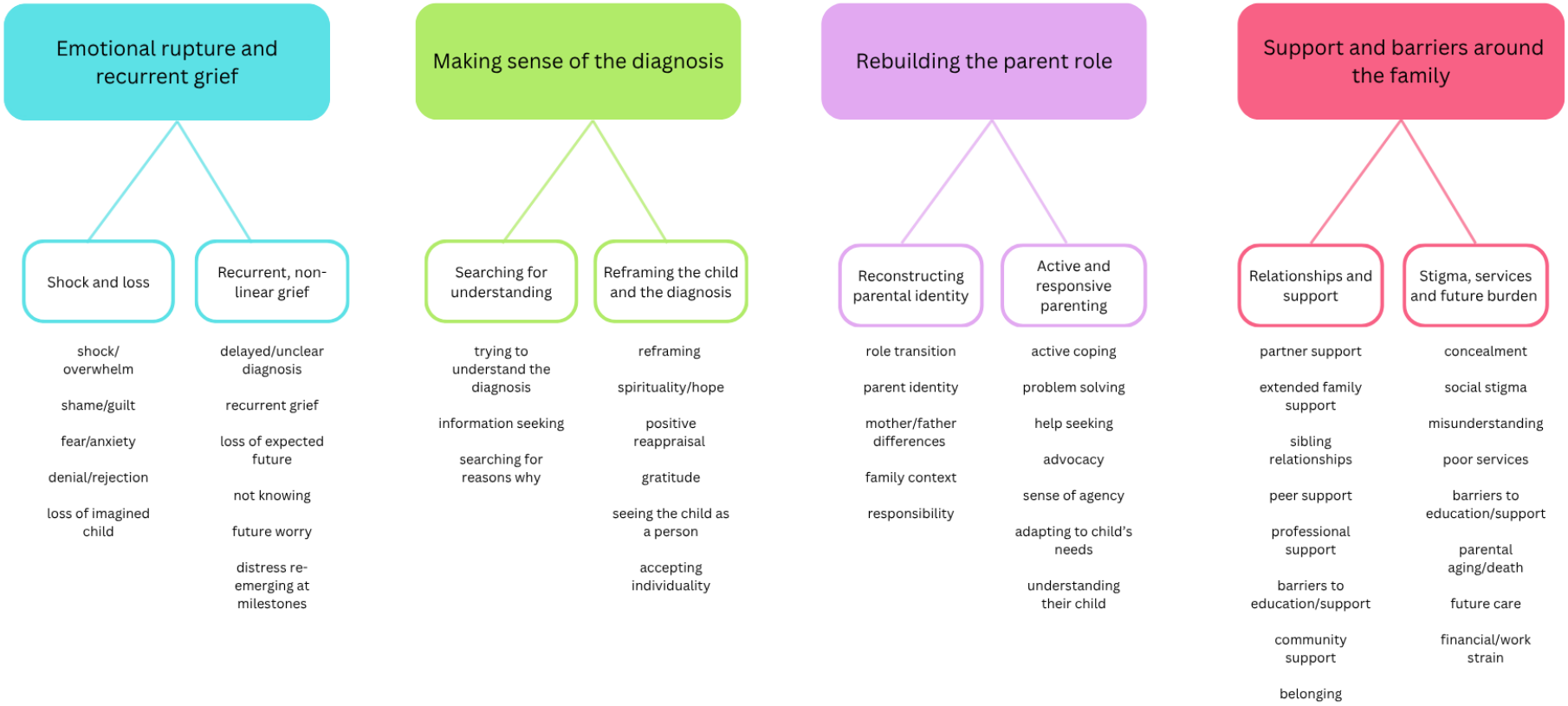
A common theme across the synthesis was parents searching for explanations following diagnosis. This included practical information seeking, looking for medical/genetic explanations, questioning why the diagnosis had happened and trying to understand what the diagnosis means for their child's future. Bingham et al. (2012) identified mothers as using *palliative coping* (e.g., denial, questioning, wishful thinking) and *problem-solving* (e.g., seeking information, professional support, social support, reframing and spiritual support) strategies. 'Suni' described uncertainty as difficult: "We're still searching to find out 'why.'… Not knowing is hard" (Bingham et al., 2012: p.379). Korkow-Moradi et al. (2017) also identified *not knowing* as part of mothers' adjustment following diagnosis, alongside their emotional response. Similarly, parents in Pillay et al. (2012: p.1503) asked, "Why me?" and "What have I done wrong? What did we do to deserve this disabled child?" This highlights how searching for understanding can extend beyond practical information, seeking to include emotional, spiritual and self-blaming questions.

For some parents, searching for understanding involved questioning or resisting the diagnosis. Barak-Levy and Paryente (2023) found that many parents spoke of their *hopes to reject the diagnosis* by seeking another opinion or hoping that improvement over time would invalidate the diagnosis: "Maybe if I make an effort and go for another opinion with another doctor, they will tell me it was a mistake..." ('Meir', p.10).

Quantitative findings also suggest that uncertainty can hinder parental resolution, with later diagnosis being associated with poorer resolution (Barak-Levy & Atzaba-Poria, 2013). The authors suggested that less clear presentations of GDD may prolong parents' hopes that the child will "catch-up" and thus make it harder to integrate the diagnosis. Across both quantitative and qualitative studies, searching for understanding included both attempts to gain information and attempts to make sense of uncertainty, blame, prognosis and the child's future needs.

Figure 1.2

Thematic Diagram of Parental Resolution of a Child's ID Diagnosis



Rebuilding the parent role

Across studies, adjustment involved reconstructing parental identity and becoming more responsive to their child's needs. Parents described adjustment as a practical and relational process that went beyond changing how they understood the diagnosis.

Reconstructing parental identity

Parents experienced changes in how they viewed their role as parents following their child's diagnosis. This reconstruction of maternal identity was reflected in mothers' accounts of acquiring a *new perspective* and experiencing personal *growth* (Korkow-Moradi et al., 2017). On the other hand, Brown (2013) described changes in mothers' *identity* and *agency* as their children aged and their support needs increased; one mother stated, "'I wouldn't wish it on anybody, but I think it has made me a different person… I have got an inner strength through this" ('Margaret', p. 119). Quantitative findings also linked parental role and self-perception with acceptance. Wahyuni et al. (2024) found an association between parental self-esteem and role with parental acceptance, although the direction of these relationships was not fully clear from the reporting.

Takataya et al. (2016) found that Japanese fathers moved from *emotional turmoil* towards a *realisation of fatherhood,* with fathers sharing everyday care and responsibility helping them *feel like a father* to their child with DS over time. Similarly, Ridding and Williams (2019) traced a fluid trajectory of UK fathers' adjustment through *accommodating the child* to *adapting the parental role*. Further, fathers categorised as *thriving,* described meaning and purpose as central to their personal growth (Bentley et al., 2015). These studies present a gradual reworking of maternal and paternal identity through responsibility, care, meaning and adapting to their circumstances over time.

Active and responsive parenting

Parents' emotional adjustment was described through deliberate changes to coping strategies. Bingham et al. (2012) identified maternal uses of *problem-solving strategies* including seeking support, professional support, social support, reframing and spiritual support that coexist with palliative emotional responses (e.g., denial). In the early period following diagnosis, advocacy for the child and knowledge about the diagnosis acted as a buffer to the emotional barriers of *not-knowing* (Korkow-Moradi et al., 2017). Likewise, AlShatti et al. (2021) found that caregivers' initial struggle to accept the diagnosis prompted active searching for information, services and support groups.

Parental responsiveness to their child was also related to their acceptance of their child's diagnosis. Quantitative findings indicate that resolved mothers display higher maternal sensitivity (Feniger-Schaal & Oppenheim, 2013) and that parental resolution is associated with adaptive parent-child

interaction (Barak-Levy & Atzaba-Poria, 2013). Barak-Levy and Atzaba-Poria (2015) found that mothers tended towards emotional coping styles while fathers leaned towards cognitive or neutralising styles. This was also reflected in qualitative accounts, in which adapting care was linked to becoming more responsive to the child's needs. Ridding and Williams (2019) found that fathers who appeared open could still be privately avoidant. Fathers described affection and responsibility developing through caregiving, whereas *information-searching* and *accessing support* aided fathers' adjustment (Ridding & Williams, 2019).

Support and barriers around the family

This theme captures the wider relational, social and service context around parents. Supportive relationships and professional guidance helped facilitate parents' resolution, while stigma, poor communication, limited services and future-care concerns were described as barriers that make adjustment harder.

Relationships and support

Parents described support from partners, extended family, peers and professionals as vital in helping manage the emotional and practical demands of their child's diagnosis. Family or partner support appeared across 11 studies and was the most frequently coded facilitator in the synthesis. Korkow-Moradi et al. (2017) identified partner influence, *family support and becoming an advocate* as buffers in mothers' adjustment following their child's DS diagnosis. Ridding and Williams (2019) found that a supportive partner relationship allowed fathers to more comfortably renegotiate gender roles within the household.

Bingham et al. (2012) identified *professional support, information seeking, parent groups and social support* as coping strategies used by mothers after their child's diagnosis. Practical support was reflected in parents' use of therapies, services, education resources and support groups. Support groups were described as a source of "comfort" (Brown, 2013) and as providing a space to feel understood and a pathway through an uncertain future (Pillay et al., 2012). Mothers spoke of shared experience as a helpful facilitator for realising they were not alone: "Talking to other mothers that I've met along the way has… really, really helped" ('Jane', Pillay et al., 2012: p.1508) and "I gain strength from other moms" (Bingham et al., 2012: p.339). Ridding and Williams (2019) found that fathers' adjustment was facilitated through *accessing support* and *information* as part of *accommodating the child* and *adapting their parenting role.*

Across these studies, support did not remove the difficulty of their child's diagnosis; rather it offered reassurance, reduced isolation and helped parents feel less alone in making sense of their child's needs. Bingham et al. (2012) recommend that professionals provide clear and sympathetic

communication, opportunities for parents to ask questions, realistic hope, written information and signposting to community supports.

Stigma, services and future burden

Conversely, stigma, misunderstanding, inadequate services and fears about the future were linked to poorer resolution. Brown (2013) shared mothers' descriptions of judgement, verbal abuse, public humiliation and loss of friendships as triggers for recurrent grief. Similarly, Barak-Levy and Paryente (2023) identified fear of stigma, concealment of the diagnosis and attempts to reject the diagnosis as barriers to resolution. Stigma can come from both informal relationships and wider social systems; Gotay (2025) described mothers' experience of judgement from religious, medical and public contexts. Further, AlShatti et al. (2021) reported that parents perceived social participation and education as challenging due to stigma and inadequate services.

Professionals and services can act as a barrier to resolution, with parents describing poor communication, limited emotional support (Pillay et al., 2012), lack of clear information or opportunities to ask questions (Bingham et al., 2012), challenges with accessing health education and social services (AlShatti et al., 2021). Parent accounts in Pillay et al. (2012) highlight how receiving a diagnosis without considerate professional support can be distressing, with one mother stating, "I was told by the paediatrician… by myself, so that was probably the most traumatic thing that's ever happened to me" ('Hannah', p.1503).

Future concerns were particularly evident in studies involving older children or adults with ID. Transitions into adult disability, health and employment services were linked with increased frequency and intensity of grief (Brown, 2013). Fernández-Ávalos et al. (2021) found that most parents had *partially accepted the diagnosis and the feeling of loss,* and noted that the process was easier when *the child had a milder ID.* They related this to parents perceiving their child as having greater chances of independence and future progress, whereas parents of children with more severe ID continued to describe vulnerability and concerns about their child's future care. Quantitative and mixed-methods findings also highlight the role of future concerns and contextual stressors. Nelson Goff et al. (2016) found that parents' coping differed across child-life stage groups; parents with adult children described ongoing caring responsibilities, fewer resources and concern about the future. This pattern supports qualitative findings of reactivation of grief across transitions and milestones. Further, Barak-Levy and Atzaba-Poria (2013) found that lower education and socioeconomic status were linked with poorer resolution. This suggests that practical and social disadvantage may make adjustment more difficult.

Discussion

Overview of findings

This review aimed to critically synthesise qualitative, quantitative and mixed-methods research to address two research questions: how parents experience the journey towards acceptance (RQ1); and what factors facilitate or hinder this process (RQ2). Four themes were generated from the synthesis of 17 studies. The themes of emotional rupture and recurrent grief and making sense of the diagnosis were identified as central to the parental journey of acceptance (RQ1). In relation to the second research question, the theme of support and barriers around the family addressed identified the relational, professional and structural factors that shape parents' resolution. The third theme of rebuilding the parental role speaks to both research questions. This theme captured the active adjustment process through which parents reconstruct their identity and become more responsive to their child, this process is both descriptive of the journey (RQ1) and in itself a facilitating factor (RQ2). Together, these findings suggest that resolution is an ongoing, non-linear process, shaped by parents' internal adjustment and supports around them.

Two findings were particularly evident. First, grief was not confined to the period surrounding the diagnosis rather it resurfaced around developmental milestones, comparisons with peers, concerns about future care and transitions. This finding challenges the simple progression from unresolved to resolved. Second, several apparent barriers to resolution were external to the parent rather than reflecting an individual psychological process.

Relevance to existing literature

The findings of this review highlight that grief and acceptance frequently coexist, with many parents' describing resolution as something revisited across their child's life. This aligns with the theoretical construct of resolution first derived from attachment theory (Marvin & Pianta, 1996) with qualitative data highlighting the reorganisation of parents 'internal representation of their child's disability and expectations of parenthood. Boss's (2007) concept of ambiguous loss helps to explain this pattern. Ambiguous loss describes the distress that arises when a loss lacks a clear endpoint or social script through which grief can be processed. Unlike bereavement, Boss attempts to explain the loss experienced when someone remains physically present, but is experienced as psychologically changed. Parental grief following an ID diagnosis maps onto this; the anticipated child is lost while parents continue to care for the child who is present. Bentley et al. (2015) used the theory of ambiguous loss to describe fathers grieving the expected child while parenting the child they had. Further, Brown's (2013) "double mourning" captures the related process of parents simultaneously mourning the anticipated child and grieving future losses yet to come. This lens helps to explain why grief resurfaces across the child's life course rather than resolving towards a fixed endpoint. These

findings extend the construct of resolution by suggesting that acceptance is an ongoing process of involving the reorganisation of expectations as circumstances change. Ambiguous loss complements the resolution model by helping to explain why grief can recur despite acceptance and may represent a more accessible framework for families to access (Boss, 2007).

Parents' understanding of the diagnosis and their emotional acceptance of it are two related but distinct processes. Following diagnosis, parents attempt to understand their child's diagnosis but also what this means for their family and future through information seeking, questioning 'why' the diagnosis had occurred, drawing on faith or spirituality and gradually revising expectations of the child and parenthood. These findings overlap with Naicker et al.'s (2022) synthesis of parental resolution of autism, which identified parents' knowledge, beliefs, culture and faith as important factors in reframing the diagnosis and developing resolution. However, the current findings extend this by suggesting that meaning-making is not limited to the period immediately following diagnosis but is instead revisited as parents renegotiate their identity and role in response to new information or milestones. This is consistent with Marvin and Pianta's (1996) resolution model, which emphasises the reorganisation of parents' expectations and internal representations of their child following diagnosis (Gray, 2002). Meaning-making is also linked to changes in parental identity and role. The social identity and self-schema frameworks introduced in this review help to explain how parents' adjustment involves reorganisation in their self-schemas and how they fit into society. These cognitive and self-identity adjustments go beyond an emotional reaction to their child's diagnosis and may support the ongoing journey of acceptance. The findings are also consistent with the attachment-informed basis of resolution, as parents described reorganising expectations of their child and parental role. Further evidence suggests that greater resolution was associated with more sensitive parent-child interactions; however, it is important to note that attachment processes were not directly examined in the included studies. Parents described greater advocacy, responsibility and responsiveness to their child. Further, parental resolution was also linked to greater sensitivity and attunement in the parent-child relationship (Di Renzo et al., 2020).

Parents' ability to rebuild their role and emotionally accept their child's diagnosis is shaped by the supports available to them and the barriers they face. Family and peer support consistently reduced isolation and helped parents make sense of their child's needs, consistent with prior research on parent-to-parent support (Shilling et al., 2013). Conversely, stigma, judgement and social exclusion hindered acceptance by reactivating grief (Ali et al., 2012; Gray, 2002), whereas poor services and limited information as reported across several of the included studies, prolonged uncertainty rather than resolving it. Parents' concerns about adulthood and future care echoes the findings of Heller and Caldwell (2006) who suggest that inadequate future-planning can create burden. These challenges

suggest that “non-resolution” may sometimes reflect parents’ ongoing structural uncertainty rather than their inability to accept their child.

A critical question arising from this synthesis is whether the findings are unique to ID or reflect a more common parental response to childhood disability or illness. Several processes identified in this review appear to transcend diagnoses, including grief, uncertainty, changing expectations and meaning-making (Clark-Whitney et al., 2026; Thompson & Smith, 2025; Naicker et al 2022). However, given the diagnostic ambiguity of ID diagnoses, resolution may be more challenging as parents may continue to hope their child will ‘catch up’. Further, the lifelong and pervasive nature of ID creates ongoing uncertainty about the child’s development and future care, which features more heavily in the ID literature than in other diagnostic contexts. Stigma and limited societal understanding of ID may also influence how parents make sense of and disclose their child’s diagnosis.

Strengths and limitations

This review offers the first synthesis focused specifically on parental resolution of a child’s ID diagnosis. In contrast to Naicker et al. (2022), which has an autism-specific focus, this review draws together qualitative, quantitative and mixed-methods, and ID diagnoses across childhood and adulthood. The broader inclusion of ID diagnoses (e.g., mild ID, DS, GDD, etc.) is both a strength and a weakness of this review. It allows for the identification of common patterns and captures shared processes across diagnoses; however, it also introduces heterogeneity as the conditions differ in presentation, prognosis and support needs, thus limiting generalisation to any one group.

Included studies were conducted across a range of countries and reflected varied religious and cultural settings. However, ethnicity was inconsistently reported, making cultural transferability difficult to assess. Despite including fathers, mothers still outnumbered them (784 vs 336), with only six studies including both parents. There was considerable variation in how acceptance or resolution was defined and measured across studies. Conceptual variations reduced comparability and could have oversimplified the fluctuating nature of parental adjustment.

The 2010 cut-off was selected to prioritise the contemporary shift in diagnostic language and conceptualisation of ID in the DSM-V. Although the cut-off was selected deliberately it remains a limitation of this study as relevant earlier studies (including foundational research on parental resolution) were excluded. Additionally, due to available resources, the review was limited to English-language, peer-reviewed studies, which may have further limited findings. As such, the findings of this synthesis should therefore be interpreted a contemporary evidence base rather than an exhaustive historical account of parental resolution of ID.

Implications for practice, policy and future research

Parental resolution appears to be shaped by structural and psychological factors, as such the responsibility should not fall solely on parents. Governments and services have a duty of care to address environmental barriers, such as poor communication, service access and future-care uncertainty. At a practice level, the non-linear, recurrent nature of parental grief highlights the importance of professional engagement with parents across the child's life course. Service should provide clear and compassionate communication, signposting to peer support groups, and culturally and spiritually sensitive support for parents' meaning making. Further, these findings highlight the importance of professionals supporting parents through transitions and engaging fathers alongside mothers.

At a policy level, the findings support investment in a coordinated, multi-agency approach to parental support. In Scotland the Getting it Right for Every Child (GIRFEC) framework provides a policy mechanism through which child and family services are expected to consider the wellbeing of the whole family unit (Scottish Government, 2012). The current findings highlight that parental wellbeing is inseparable from child outcomes with parental resolution of their child's diagnosis being associated with greater parental sensitivity (Feniger-Schaal & Oppenheim, 2013) and more adaptive parent-child relationships (Barak-Levy & Atzaba-Poria, 2015). As such, GIRFEC's wellbeing framework should be applied to parental wellbeing in the context of disability by embedding support for parents into the child's care plan. Coordinated future-care planning across health, education and social care services could help reduce the burden of uncertainty that this review identified as a driver of sustained non-resolution.

Given that this review combined related diagnoses, future reviews should compare resolution across a broader range of neurodevelopmental diagnoses so that diagnosis-specific patterns could be identified. Further, future research would be strengthened by greater ethnic diversity and more consistent measurement of resolution.

Conclusions

Parental resolution of their child's ID diagnosis is best understood as a dynamic and recurring process rather than a fixed outcome. Resolution is shaped by parents' grief, meaning-making, identity change and the social and structural context surrounding the family. Grief and acceptance can coexist with distress re-emerging throughout their child's life course. It is important to bear in mind that parents' "non-resolution" may reflect poor access to support or services, stigma and uncertainty about future care rather than an inability to accept their child. The findings highlight a need for compassionate, culturally responsive and continued support for these families.

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Chapter 2: Major Research Project

A qualitative exploration of the lived experiences of parents participating in a compassionate mind training group for children with neurodevelopmental disorders: How does the intervention influence parents' self-perceptions and attitudes towards their child's condition?

Prepared in accordance with the author requirements for Advances in Neurodevelopmental Disorders

Author Guidelines

Plain Language Summary

Background: Raising a child with a neurodevelopmental disorder (NDD) can bring about challenges that impact parents' well-being, mental health and overall quality of life. These parents experience increased stressors related to their child's behaviour, caregiving demands, stigma and financial pressures. Parental well-being plays a vital role in their child's development. Self-compassion has-been identified as a protective factor against stress and depression in parents of children with neurodevelopmental conditions. Compassionate Mind Training (CMT) groups aim to help parents build self-compassion and manage the difficult feelings. There is little known about parents' experiencing of attending a CMT group, or how it affects the way they relate to their child.

Aims: This study aimed to explore the parents' experiences of attending a CMT group in the context of having a child with an NDD (e.g., ASD, ADHD, ID/LD).

Research questions: (1) What are parents' experiences of attending a CMT group for parents of children with an NDD? (2) How do parents make sense of the impact of the group on how they see themselves and their relationship with their child?

Methods: Participants were parents of children with a suspected NDD who had attended a CMT group in NHS Ayrshire and Arran. Four participants took part in virtual individual interviews. Interview were recorded, transcribed and analysed using Interpretive Phenomenological Analysis (IPA). IPA is an approach that explores how people make sense of important experiences.

Findings: Three main themes were generated from the interviews. These captured parents' experiences of the group being a safe and non-judgemental space. Parents talked about developing a kinder and more compassionate relationship with themselves. The shift in parents' self-compassion also seemed to help them respond to their child with more patience and curiosity. Parents reported that these changes following the group have strengthened their relationship with their child.

Conclusions: Parents found the CMT group to be a valuable experience. Attending the CMT group appeared to help parents build greater self-compassion and feel less alone in their experiences. The study amplifies the voices of this vulnerable group and highlight the significance of integrating self-compassion into interventions for parents of children with NDD.

Abstract

Raising a child with a neurodevelopmental disorder (NDD) can bring about challenges that impact parents' well-being, mental health and overall quality of life. These parents experience increased stressors related to their child's behaviour, caregiving demands, stigma and financial pressures. Parental well-being plays a vital role in their child's development. Self-compassion has been identified as a protective factor against stress and depression in parents of children with neurodevelopmental conditions. This study aimed to explore the individual experiences of parents of children with an NDD who participated in a Compassionate Mind Training (CMT) Parent Group, as well as any influence the intervention has on their self-perceptions and their relationship with their child. Interpretive Phenomenological Analysis (IPA) was used to qualitatively explore these parents' experiences. IPA's suitability for idiographic, meaning-focused analysis of small samples made it the most appropriate analytical approach given the study's aims and recruitment context. Four parents of children with a suspected NDD engaged in semi-structured interviews. Data was transcribed and analysed using IPA's seven-stage methodological approach. Three main themes were generated from the interview data: 1) The group as a safe and containing space; 2) developing a compassionate parental identity; and 3) compassion as a tool for repairing the parent-child relationship. CMT appeared to operate by shifting parents' internal orientation from threat-based self-criticism towards compassionate self-relating and more attuned parenting. The findings of this study should be interpreted within the idiographic scope of IPA. The implications of this study highlight a need for parenting support that extends beyond behaviour management and psychoeducation to address parents' emotional needs.

Keywords: Compassionate Mind Training, Neurodevelopmental conditions, parent group, self-compassion

Introduction

Parenting a child with a neurodevelopmental disorder (NDD) such as Autism Spectrum Disorder (ASD), Attention Deficit Hyperactive Disorder (ADHD), Intellectual Disability (ID), or Foetal Alcohol Spectrum Disorder (FASD) is complex and has unique challenges that can lead to poor parental mental health and well-being. These challenges include managing their child's behavioural difficulties, facing increased stigma, and dealing with higher caregiver and financial demands (Ngo et al., 2012; Parish et al., 2008; Scherer et al., 2019; Woodman et al., 2015). A systematic review by Scherer et al. (2019) found that parents of children with an intellectual or developmental disability were more likely to have depression and anxiety symptoms compared to parents of children without a disability. Parental well-being is associated with the children's socioemotional, cognitive, neurobiological and health outcomes (Frosch et al., 2021). Thus, we must find ways to bolster parental well-being and reduce levels of stress and depression.

Parent training (PT) programs are well-established interventions for NDD youth referred to Child and Family Services. PT interventions have a primary focus on psychoeducation which provide parents with helpful information about their child's condition as well as parenting strategies adapted to their child's NDD. A systematic review by Deb et al. (2020) investigated the effectiveness of different PT interventions for parents of autistic children. The systematic review yielded small to moderate effect sizes for the effectiveness of PT on reducing child behaviour and parental stress. Deb et al. (2020) suggests that traditional PT interventions with heavy reliance on psychoeducation and behavioural strategies do not sufficiently address the underlying emotional and psychological challenges faced by parents. As such, these parents are not equipped with coping strategies to manage the increased stress, anxiety and emotional burnout they are more susceptible to experience as parents of an NDD child.

A systematic review by Merriman et al. (2020) found that psychological interventions, including Mindfulness-Based Stress-Reduction (MBSR) programs and Acceptance and Commitment Therapy (ACT), can significantly reduce stress and improve well-being among parents of children with an NDD. Three previous intervention studies have included self-compassion as an outcome measure after incorporating content on compassion into MBSR programs for parents of individuals with ASD, ADHD and ID (Bazzano et al., 2015; Benn et al., 2012; Jones et al., 2018). The authors of these studies theorised that self-compassion might help explain improvements in parents' mental health.

Self-compassion is defined as the ability to respond to personal distress with care and balanced awareness and is commonly measured using Neff's Self-Compassion Scale (Neff, 2003). A study by Robinson et al. (2018) found that self-compassionate parents of children with an ID tend to experience lower levels of stress and depression, even after accounting for other known stressors like economic difficulties and high parent burden. Self-compassion has also been shown to improve emotional resilience and quality of life for parents of children with ASD and acts as a predictor for

overall parental well-being independent of the severity of their child's difficulties in social interaction, communication and stereotyped behaviours (Wong et al., 2016). Furthermore, self-compassion is considered a protective factor against psychological distress caused by affiliate stigma (Wong et al., 2016). Given the potential benefits of self-compassion on mental health outcomes, integrating this aspect into group interventions for parents of children with developmental disabilities could be advantageous.

Compassion-focused therapy (CFT) builds on traditional cognitive behavioural therapy; it was developed to tackle shame and self-criticism while increasing self-compassion (Gilbert, 2010). CFT's theoretical basis is the three systems model, which posits that emotion regulation is governed by three interacting systems: a threat, drive and soothing systems. CFT proposes that psychological distress often reflects an overactive threat and an underdeveloped soothing system. The threat system is a fast-acting system that detects and responds to danger. The drive system motivates goal-directed behaviour and achievement. By contrast, the soothing system is associated with feelings of safeness and contentment; it is activated through experiences of warmth, connection and companionate relating. CFT proposes that psychological distress frequently arises from an imbalance across these three systems, where the threat system is overactivated and the soothing system is underdeveloped.

CFT also articulates three 'flows' of compassion. Each flow represents a direction through which compassion can be promoted: compassion towards others, receiving compassion from others and self-compassion. These three flows are considered interdependent and difficulty in one flow often reflects difficulties in others. One of the key components of CFT is Compassionate Mind Training (CMT), which uses mindfulness, cognitive restructuring and compassionate imagery techniques to strengthen the soothing system, bolster self-compassion and influence emotion regulation (Gilbert, 2010; Gilbert & Irons, 2005). Research indicates that CMT effectively reduces self-criticism, increases self-compassion and improves mental health outcomes (Bratt et al., 2019; Gilbert & Procter, 2006; Kirby et al., 2023). CMT provides a promising approach for addressing the psychological needs of parents of children with developmental disabilities.

Even with the growing interest in compassion-focused interventions for parental well-being, there remains a notable gap in understanding the lived experiences of parents of children with NDD who participate in such interventions. Existing studies have shown short-term improvements in mental health outcomes, such as reduced stress, anxiety and depression, following compassionate interventions (Bratt et al., 2019; Kirby et al., 2023). Despite these promising preliminary findings, there needs to be more research on whether improvements in self-compassion translate into long-term benefits for parents' mental health and well-being. Further, all these intervention studies have utilised a quantitative research design and overlook any possible qualitative insights which may capture the more nuanced and subjective experiences of participants. This qualitative study aims to address this

gap by exploring the deeper, more nuanced impacts of a CMT parent group on parents' self-perceptions, stigma and attitudes toward their child's neurodevelopmental condition.

Aims and Research Questions

This study uses a qualitative design to investigate parents of children who were understood as having an NDD (i.e., ASD, ADHD, ID, FASD; a formal diagnosis was not required) individual subjective experiences of a CMT group within the context of their child's NDD. It aims to explore their experiences of attending the CMT intervention. It also aims to explore how these parents make sense of their experiences of having a child with a neurodevelopmental condition and the impacts it has on their self-perceptions and attitudes towards their child's condition. This study aims to provide insights into parental experiences of compassion-focused interventions for this vulnerable population.

Methods

Ethics

The study has received a favourable ethical opinion and has been reviewed and approved by the London - City & East Research Ethics Committee (REC reference: 25/PR/0693; Appendix 2.3). Management approval was granted NHS AA Research and Development (Reference: 2025AA033; Appendix 2.4).

Design

As little is known about parental experience of engaging in the CMT Group in the context of their child with a NDD, this study adopts a qualitative approach using Interpretive Phenomenological Analysis (Smith et al., 2022) semi-structured individual interviews. IPA is underpinned by theoretical principles of phenomenology, hermeneutics and an ideographic approach. It focuses on exploring how individuals make sense of their experiences and offers an interpretation of these experiences in a manner that remains true to their narratives instead of relying on pre-existing categories or hypotheses (Smith & Osborn, 2015). IPA was selected because over other qualitative methods (e.g., Reflexive Thematic Analysis) because of its prioritised person-centred and idiographic meaning-making, specifically how individual parents understood and experienced changes associated with attending the CMT. Its case-by-case approach allowed attention to nuance of the differences in how individual parents incorporated compassion into their understanding of themselves and their child.

IPA is concerned with understanding how people make sense of important experiences in their lives. It recognises that participants are already interpreting their own experiences and that the researcher then makes sense of those interpretations. This process is known as double hermeneutics. In practice, this meant that the analytical process involved two levels of interpretation. At the first level,

participants were making sense of their experience of attending the CMT and interpreting their own emotional responses and changes they had noticed in themselves and in their relationship with their children. At the second level, the PI interpreted those participant interpretations and drew on theoretical knowledge of CFT, IPA methodology and clinical experience in this population. For example, Noah described using compassionate imagery when distressed and shifted linguistically from 'I' towards 'we' when describing their internal dialogue. Noah was making sense of their own emotional experience, while the PI interpreted this change in language as potentially reflecting the self-compassionate flow and activation of her soothing system. This interpretation was a layer of meaning that Noah did not explicitly articulate but which the researcher brought through their theoretical framework. The double hermeneutic process was made transparent through the researcher's reflective journal (Appendix 2.11) and explored in supervision.

Rather than trying to make broad claims about the wider population, IPA focuses closely on individual experiences. It aims to develop a rich, detailed understanding of how people experience a particular situation. Because of this, IPA studies regularly involve small and homogenous sample sizes to allow for an in-depth analysis of each individual's experience. Smith et al. (2009) suggest that a sample size of three to six participants is suitable for a doctoral IPA project.

Group intervention design

The CMT Parent Group was delivered by the Neurodevelopmental Empowerment and Strategy Team (NHS AA) in partnership with the Community Paediatric Psychology Service (NHS AA). The group ran as a half-day workshop followed by a six-week group. The group was available to families of children with a diagnosed NDD or who were understood as having an NDD; no formal diagnosis was required.

The CMT Group materials were adapted for the NHS Ayrshire and Arran Community Paediatric Psychology Service from the eight-week Balanced Minds CMT course (Irons & Heriot-Maitland, 2021), which is based on the work of Prof Paul Gilbert. A brief overview of the group content is provided in appendix 2.6.

Recruitment

CMT Group attendance did not automatically enrol families in the research project. Purposive sampling was used to recruit participants. The services facilitating the group sent the research flyer and information to all group participants. Research participation invitations were distributed to three different blocks of CMT groups: Autumn 2024, Spring 2025 and Autumn 2025. Interested participants contacted the Principal Investigator (PI) via email to opt-in. The PI had no prior contact with participants.

The participant information sheet and the consent form were digitally sent to the individual along with a Microsoft Teams invite for the arranged interview. Participants were asked to complete the consent form and email a copy prior to the interview. The consent form was reviewed at the start of the interview to verify participants' understanding.

Six participants expressed interest and provided consent to be contacted by the PI for further information. One withdrew interest, and one participant had only attended the workshop rather than the 6-week course. Four parents participated in the semi-structured interviews. Study participants were offered a £50 'Love2Shop' voucher in recognition of their time.

Research procedure

Consenting participants completed a demographic questionnaire (Appendix 2.7) prior to attending the scheduled interviews. Interviews were conducted virtually using Microsoft Teams. Participants attended from home and the PI confirmed that no other individuals were present. Consent was reviewed at the start of the virtual interview. Interviews lasted between 36 and 54 minutes and were audio recorded using the PI's NHS mobile device. No repeat interviews were carried out. Interview recordings were stored securely on a OneDrive account within the NHS and deleted after transcription was completed. Interviews were transcribed verbatim using the transcription tool on Microsoft Word; transcripts were checked and reviewed by the PI for accuracy. Transcripts were anonymised prior to analysis and identifiable information was stored separately. Due to time constraints, transcripts were not returned to participants for comment.

A preliminary semi-structured interview guide was developed by the PI following initial reading of literature regarding CMT training for parents. The schedule was further developed in supervision with the PI's field supervisor (CMT Group facilitator) and research supervisors. The final guide was run past experts with lived experience to ensure the questions were accessible and relevant to the participant population. Due to limited resources, the interview schedule was not pilot tested. The interview guide was divided into three categories: questions related to their experience of the CMT, exploration of their self-image as a parent of a child with a disability and views of their child's neurodevelopmental disorder (Appendix 2.8)

Data analysis

The interviews were analysed using IPA seven-stage methodological approach (Smith et al., 2022). Smith et al. (2022) defined the seven stages as: 1) Immersing in the data by reading and re-reading the transcripts; 2) Exploratory noting; 3) Constructing experiential statements; 4) Searching for connections across experiential statements; 5) Naming the personal experiential themes (PETs) and consolidating and organising into a table; 6) Continuing the individual analysis of the other cases; 7)

Working with PETs to develop group experiential themes (GETs) across cases. This method ensured a detailed and interpretative exploration of participants' lived experiences.

The PI was the sole data coder. Themes were developed inductively without a predetermined coding framework. The PI kept a reflective diary noting thoughts, biases and emotional responses that emerged during the interviews or analyses and reflected on how these influenced the interpretation of data (Appendix 2.9). Supervision was utilised to ensure reflexivity and maintain methodological rigour. It also provided a space to reflect on and manage the emotional impact of engaging closely with parents' accounts of self-criticism and distress. Supervision played an important role in processing the emotional impact of the data and reflecting on how personal responses may have influenced interpretive decisions.

Reflexivity

I am a white, female, neurodiverse Trainee Clinical Psychologist who has completed multiple specialist child placements with a focus on neurodevelopmental conditions in NHS AA. As a neurodiverse clinician with my own personal and professional experiences, I have developed a heightened awareness of challenges tied to neurodiversity. However, as I am not a parent, I also sit as an outsider to participant experiences. I had no existing relationship with participants, however, I recognise the power dynamic of me being a professional and asking them about their vulnerable experiences. My clinical knowledge of NDD assessments and interventions may have shaped how I interpreted participants' narratives. It was therefore important that I remained conscious of participants' experience leading the research rather than my own assumptions about what a meaningful outcome should look like. Given my emotional investment in this population, I was aware of the challenges in separating my clinical role from being a researcher. Throughout the research process I kept a reflective journal (Appendix 2.11) to increase my awareness of how my assumptions, thoughts and feelings influenced data collection and analysis. During analysis I ensured coding stayed close to participants' words rather than imposing my own interpretations.

Results

Four parents participated in the study. All parents were White British/Scottish, had two or more children and spoke English at home. Three participants were single parents. All had completed further education and two had postgraduate degrees. The mean age of their child with the suspected NDD was 11.75 years. Relevant characteristics are provided in Table 2.1. Pseudonyms have been used to protect their confidentiality.

Table 2.1

Participant Characteristics

Parent Name	Parent Age	Child Age & Gender	Suspected NDD	Household Structure	Previous service involvement
Alex	45-54	10 (Boy)	Autism (on waitlist for assessment)	Single parent	SLT, LIAM, Educational Support, private psychology assessment
Noah	35-44	7 (Boy)	ADHD	Two parent household	NEST, Paediatric service for incontinence
Kit	25-34	12 (Girl)	Autism/ADHD (on waitlist for assessment)	Single parent	CAMHS, Social Work, Educational Support, Police
Charlie	45-54	18 (Boy)	Autism	Single parent	Educational Support

From the interviews with the four parents who attended the CMT Group in the context of their child with neurodevelopmental differences, three Group Experiential Themes (GETs) and ten sub-themes were identified.

Table 2.2

Group Experiential Themes and Sub-Themes

Group Experiential Themes (GETS)	Sub-themes
The group as a safe and validating space	Feeling safe, accepted and emotionally held
	Shared parental experience reducing isolation
Compassion as a tool for relating differently to self	Parenting under the pressures of exhaustion and judgement
	The "bad parent" narrative: living under the weight of self-criticism and shame
	Developing a more compassionate and accepting relationship with self
	Self-care reframed as necessary and relational
Compassion as a tool for understanding and connecting with their child	Understanding behaviour through a compassionate, ND-informed lens
	Growing awareness of emotional and behavioural patterns
	Emotion regulation as relational and co-created
	Compassion-enabled reconnection in the child-parent relationship

The group as a safe and validating space

This GET highlights participants' experience of the CMT group environment as a psychologically safe and relational space. In CFT terms, the group appeared to function as an activator of the soothing system by providing a warm, accepting and non-judgemental environment. Further this theme highlights how experiencing compassion from others (one of the three flows of compassion) can serve as a foundation for developing self-compassion. This GET encompasses two sub-themes: the group as emotionally containing and the relief of shared parental experience on reducing isolation.

Feeling safe, accepted and emotionally held

All four participants described the group environment as containing and psychologically safe. They used words such as 'safe' and 'non-judgemental', which conveyed their sense of being genuinely accepted in the group. For Alex, the group occurred concurrently with their marital separation. For them, the group provided essential containment that extended beyond parenting difficulties.

> *"It was a real bit of a lifesaver to get into a place that was very calming and very soothing."* Alex

The word 'lifesaver' conveys how the group emotionally sustained Alex during difficult personal circumstances. For them, the group was more than a parenting intervention; it represented the convergence of parental stress, personal crisis and relational support.

Charlie used structural rather than emotional terms to communicate the safety they felt in the group.

> *"Very kind and non-judgemental. You also felt very easy, you didn't feel under any pressure. Speak if you want to speak, don't, if you don't."* Charlie

Words like 'non-judgemental', 'easy' and 'didn't feel under any pressure' highlight Charlie feeling safe. They described safety as freedom of choice and reduced pressure rather than warmth or emotional intimacy. This differs from the other participants and highlights that the group felt safe for a wide range of reasons. For Alex, the group offered emotional containment, whereas for Charlie, the group felt safe because pressure was removed.

Alex reflected on what specifically made the group feel containing. They located the feeling of safety in the relational aspect rather than the intervention content focus.

> *"I think being able to share things and be heard and be kind of understood and accepted … I think that actually really makes a big difference."* Alex

For them, safety was not about receiving information or strategies but about feeling safe and heard. Alex emphasises the relational mechanism through which the group produced its effect. They returned to this theme throughout their interview, which highlights the significance of relational safety.

Shared parental experience reduced feelings of isolation

All the participants described their experience of sharing parenting difficulties in terms that surpassed exchanging information. They related shared parenting experiences to normalising struggles and countering societal narratives around parenting challenges and personal inadequacy. Hearing other parents' experiences reduced feelings of isolation for all participants.

> *"It was nice to obviously realise that it was all the parents in the same situation as me, sometimes it feels as if you're like quite alone."* Kit

Kit talks about shared experience as if it should have been self-evident, yet the emotional weight and word choice of 'obviously' make it clear that it was anything but. Further, 'quite alone' feels like an

understatement considering Kit's experience of parenting in isolation, particularly given their daughter's school non-attendance and limited access to supports.

> *"It was a nice wee way to be part of something, with people that you kind of got to know, but didn't know at the time. So, it was alright to be in that environment."* Charlie

This captures the group's relational aspect and the paradox of instant belonging with people they had just met. '*It was all right to be in that environment'* is Charlie's quiet way of conveying a significant emotional experience.

> *"As much as you don't wish anyone has any bad experiences, that was helpful (other people opening up as well)."* Noah

Noah communicates relief in hearing others' parenting struggles. The group normalised difficult experiences and gathered parents who understood each other. This understanding disrupted isolation in a way that more content-focused elements of the intervention did not.

Compassion as a tool for relating differently to self

The second GET describes how each participant moved from a dominant threat-system orientation, characterised by self-criticism and catastrophising, to a more soothing system grounded in their relationship with themselves. This theme captures the process of developing the self-to-self flow of compassion in which they learn to respond to their own distress with the care and understanding one might extend to a friend or loved one. This shift was not a complete transformation but rather the development of a competing compassionate voice alongside the pre-existing self-critical one. This GET comprises four sub-themes: parenting under pressure; the weight of pre-existing self-criticism and shame; developing a more compassionate internal identity; and reframing self-care as necessary and relational.

Parenting under pressure of exhaustion and judgement

All participants discussed levels of difficulties that came from raising a child with neurodevelopmental differences. However, Kit's story stood out due to the complexity and worsening of their situation. Throughout the interview, Kit described themself as living in a constant state of stress rather than moments.

> *"I'm in survival mode quite a lot just now. So, it's trying to get myself out of the survival mode so that then I can be the best person for everybody else."* Kit

‘Trying to get myself out’ frames recovery as an ongoing goal rather than something they have achieved. ‘Best person for everybody else’ highlights their goal for recovery from their own depletion so that they can better support their children.

Alex describes a similar pattern of suppression followed by dysregulation:

> *“I think I would kind of push through things and then to a point where um if I was really stressed or really tired and then I would start shouting and I would really lose patience.”* Alex

Here, ‘push through’ conveys exhaustion being endured rather than being addressed compassionately. All participants communicated previously parenting from depletion and now recognising that this heightens parental emotional dysregulation, which then negatively impacts their child and the parent-child relationship.

Further, the societal context within which all participants are parenting likely relates to their internalised self-criticism:

> *“When you have children who are neurodiverse. Then it's easy to think that it's because you're a bad parent when it's not … There’s lots of people who are just sceptical, even questioning if neurodiversity is a thing or don't really get … or will just put it down to bad parenting.”* Noah

> *“It's kind of been a fight over the last couple of years to get involved with services and there was quite a lot of judgement … I think if other people's more positive towards me, I can be more positive as well.”* Kit

Noah described people who minimise neurodivergence and interpret behaviour as bad parenting. This perceived societal stigma meant parents could internalise their child’s difficulties as their own personal failures. Noah is moving away from societal pressures and separating their identity from their child's presentation, while Kit’s self-perception remains tied to support and judgments. Their parental identity remains vulnerable to external conditions in a way that Alex, Noah and Charlie’s have become less so.

The “bad parent” narrative: Living under the weight of self-criticism and shame

All four participants described varying degrees of self-criticism. For Alex, this self-critical orientation manifested most vividly through catastrophising:

> "*If he's like this now, then he won't be a very good partner or husband or like, I don't know, whatever, in the future, and then he won't be in a relationship for very long, and then he won't be happy … and then that puts a whole load of weight back on me again."* Alex

This quote suggests Alex re-entering a catastrophising spiral in real time. The metaphor of 'weight' makes self-blame cognitive, emotional and physical. Their child's future relationships appear to rest on their parenting 'right' now. This reflects the internalised responsibility they feel.

Noah described a self-critical pattern that was both intense and habitual:

> "*Just falling into my usual thing of feeling absolutely awful and just really beating myself up about it."* Noah

'Beating myself up' is physical and violent, while 'my usual thing' signals habituation. This was not an exceptional response to failure, but an automatic pattern activated by difficulty.

Charlie's account demonstrated a previous all-or-nothing self-evaluation that left minimal room for adequacy or contextual explanations:

> *Before the group, I'd say I was much more on edge. I was much less understanding of me. I was really battling and struggling with change and everything. And it was all things that I couldn't change… and every decision would have been wrong… Everything I'd done was wrong and it was just a really, really bad situation."* Charlie

Developing a more compassionate and accepting relationship with self

Following the group, all four participants described movement towards a more compassionate self-identity. This new identity did not eradicate self-criticism, rather it served as an alternative and competing lens. Noah called it 'another voice' that could challenge the dominant self-critical one.

> *"I remember like lying on my bed and then I was trying to think about this compassionate polar bear ... trying to be like, right, we're feeling really bad, but this is like, yeah, it's a really hard situation. And, so I think, yeah, that's a difference and less likely to go into sort of like shame spiral."* Noah

First, Noah specifically names a compassionate exercise that they genuinely use. Second, the pronoun shift from 'I" to "we" is evidence of their externalising and soothing their distressed self from a compassionate position. This is a CFT mechanism of holding one's own suffering with the warmth one would extend to another and communicates the reduction in shame over time.

Similarly, both Kit and Charlie communicated a shift in pronouns from "I" to "you" when thinking about self through a more compassionate lens. Letter writing was powerful for developing self-compassion and helping to separate events from their perception of themselves as parents.

> *"I've never done that before and I found it very powerful. So, I gave myself some like leeway ... you know, you need to relax, you need to take your foot off the gas."* Charlie

Charlie gives themself permission and recognition that parenting is difficult. They hold themself to a high standard and compassion is a mechanism for releasing that pressure. They recognise that compassion is less about reframing failure and more about humanising difficulties and giving themself permission to ease.

> *"For me to handle that situation in that way is massive. Because usually I would be shouting, you're gaffer's this... It's just not nice … Whereas when you can actually sit down and open your doors and make it feel safe for your kid to communicate with you, it's so much better."* Charlie

Charlie's parental identity is being reconstructed through changes in the quality of their presence rather than absence of difficulty. 'Open your doors' is a metaphor for emotional availability, as such their new parental identity is tied to their emotional availability and presence. Charlie saying it is 'massive' communicates the pride they have in themself. This pride acts as self-compassionate recognition of their progress.

Alex's parental identity reconstruction was organised around a shift in authority:

> *"I do feel more confident in parenting … It's helping that I'm not being swayed so much by his father's views or having to do whatever someone else is telling me ... You can kind of listen to your own intuition more."* Alex

Alex is becoming more confident in their own intuition and moving away from external influences. They are developing conviction in their approach without getting outside reassurance. Their parental identity is becoming more self-authorising rather than relying on others.

Self-care reframed as necessary and relational

Interwoven with self-compassion was a shift in participants' understanding of their own wellbeing. All four participants began with a sense that self-focus was selfish but came to see self-care as foundational to effective parenting.

> *"I always kind of felt that that was a little bit selfish to focus on me first. It was always like, no, I have to give whatever to the kids, and even if I don't have anything, I still just have to give it."* Alex

Alex spoke of parenting from an empty tank. They saw self-sacrifice as a moral obligation and their own lack of capacity as an invalid reason to stop giving. This belief was what the course helped reframe. Alex's account of their cognitive shift captures cognitive and behavioural change that is imperfect and ongoing:

> *"I think the biggest takeaway is maybe the shift in mindset to look at, how I am … but still, even as I say, it sounds a bit selfish, but like it's how I am, so that I can parent from a place which is calmer and more loving and more connected.*" Alex

Alex has intellectually taken on board the new idea of self-care as part of good parenting, however, the old moral convictions persist alongside the new. This is evidenced by their reflection of, 'Even as I say it, it sounds a bit selfish' which shows the old and new beliefs coexisting.

Noah described the cognitive manoeuvre needed to accept self-care as essential:

> *"It's really hard just to prioritise something for yourself, but telling yourself that this is for your children, even though it's a focus on you. I feel like that helped me."* Noah

Counterintuitively, self-care only became accessible when they removed the focus from themself and put it in the context of supporting their children. This speaks to the entrenched idea of parenting and self-sacrifice as evidenced by the indirect route to justifying self-care.

Compassion as a tool for understanding and connecting with their child

The third GET captures the relational extension of compassionate self-relating. Here, participants described changes in how they understood and responded to their children's behaviour and distress. This theme reflects the third flow of compassion, the development of compassion towards others. It also reflects the co-regulatory effects of the parent activating their soothing system thus influencing their children's feelings of safety and emotion regulation. These positive changes in their relationships with their children were characterised by small moments of connection and understood as signs of relational repair.

Understanding behaviour through a compassionate, neurodevelopmental-informed lens

All four participants described a shift in understanding their child's behaviour. This cognitive reframing involved recognising that misbehaviour was not intentional, rather their child communicating a need for emotional attunement. The best example of this reframe was by Alex:

> *"I can recognise that, yeah, that's a sign that [child] is struggling and not like a sign that I'm, you know, a bad parent or like doing everything wrong."* Alex

Alex previously viewed their child's difficult behaviours as evidence of parenting failure. This quote shows a shift to seeing behaviour as a communication of their son's struggle. The phrase 'not like a sign that I'm a bad parent' names and displaces the old belief.

> *"Realising that's really what they need when they're having this hard time … they just need that compassion, that we might think whatever they're having a really hard time about is silly or whatever, but it's not to them and that they just need [compassion]..."* Noah

Noah communicates recognition that children's behaviour speaks to the child having a hard time rather than intending to be bad. It also highlights, that as adults, how easy it can be to assume that something is trivial, when in fact it is important to their child.

Charlie communicated the shift through the phrase: *"be curious, not furious".* The brevity and rhythm of the statement make it easy to remember and access under pressure. It effectively highlights curiosity as a compassionate alternative to negative reactivity and punishment that can damage the parent-child relationship.

Growing awareness of emotional and behavioural patterns

Charlie articulated the primacy of awareness most clearly; they positioned it as essential.

> *"Unless you can actually manage to be aware, the self-reflection in yourself, and be aware of your emotions and be aware of your own well-being. It's going to be a challenge because life throws up challenges and even more so when you've got a child that's neurodivergent."* Charlie

The repetition of 'be aware' frames awareness as a prerequisite for action. Charlie grounded this in body cues such as feeling tense, sweating or shouting, treating these as early warning signs rather than failure.

Noah developed their own personal warning system for communicating emotional overload:

> *"I always refer to it as being like on the edge, I'll say to them, like I'm feeling a bit on the edge now, like don't ask anything of me."* Noah

Noah's self-awareness of their emotional states allows them to self-regulate while also signalling their needs to their children. This is evidence of them making relational and self-regulatory changes.

Alex identified that the most significant benefit of self-regulation practice is preventative:

> *"I think maybe having those compassion tools means that I'm less at a point where I'm like burnt out or tired or irritable already before even going into an interaction."* Alex

'Before even going into an interaction' highlights how awareness and regulation is more than crisis management, rather it locates the change upstream of the parenting moment. They recognise that compassion increases their emotional capacity, which then leads to nicer interactions and less need for repair.

> *"When you are thinking rational, I think you can kind of switch over and think of what you're going to do beforehand and what you're going to say, and I think that plays a massive role in how the behaviours are."* Kit

Kit recognises that their capacity for reflection depends on them first being regulated enough to reach it. This awareness is important; however, it is also constrained by their baseline of chronically being in survival-mode.

Emotion regulation as relational and co-created

All four participants came to understand emotion regulation as occurring between people rather than within them.

> *"I think they're maybe not getting to such an intense level as they were before … How I'm responding to him has changed as well, which has allowed him to kind of come out of those angry outbursts."* Alex

Alex positions their own regulation as actively shaping their son's dysregulation. They are modelling calm which is creating a calm space for their son through their own responses. Their calmness acts as co-regulation, which is a relational mechanism.

Charlie described the relational benefits of regulation through the conflict-guilt-repair cycle they were previously trapped in:

> *"Because you're eliminating the big explosions. You're eliminating the battles and then you're feeling guilty after it. It kind of minimises the knock-on effect."* Charlie

The guilt cycle itself is relational; it damages the relationship and complicates future interactions. Charlie acknowledges that regulation serves the relationship by improving individual moments and breaking the guilt cycle. Regulation acts as protection to the relationship from cumulative harm.

Noah spoke of a dual function in their regulatory practice:

> *"Doing some breathing exercises then that helps me respond better to them because I'm taking the time out rather than just trying to respond straight away ... I'm like modelling it to them as well."* Noah

Modelling is not the purpose of Noah's practice but a valued additional by-product. Their children appear to take in their regulatory practice even when they resist direct engagement. Noah described receiving compassion from their children, *"My daughter said to me, 'it's okay, you're just having a hard time' ... Getting that compassion back from them. It's so lovely because it's not something that I ever had when I was growing up and it's nice that they must be picking up on some ... So that's, yeah, quite special."* Their daughter's words echo the compassionate inner voice the group aims to cultivate. The fact that their child, through observing Noah, could offer this to them is evidence of the group's relational impact. Further, 'not something I ever had when I was growing up' adds an intergenerational dimension where compassion was absent from Noah's own childhood but is now a pillar in their parenting of their children. As such the group effects may extend to these participants' children without any direct child work.

Compassion-enabled reconnection in the child-parent relationship

Most participants described positive changes in their relationships with their children as their key takeaway from the group. These were characterised by small moments of connection which are understood as signs of relational repair.

> *"I've noticed that. A bit more kind of freedom, I guess, in him expressing slightly less angry moments ... it's been like me versus him type of feeling, like, rather than us trying to, um, connect. And I feel like there's less of that."* Alex

Alex describes a shift from 'me versus him' towards connection. Their repeated use of 'freedom' suggests affection is less conditional and more available, while still acknowledging that change is partial.

Kit was most tentative in describing relational shifts:

> *"I can get some more compliments than I've had before. Maybe opening up a bit more about certain things."* Kit

For Kit, whose situation involves police intervention and being in a chronic state of survival mode, even small shifts represent hard-won gains for positive connections. It makes sense that they are tentative as it reflects an accurate awareness of how precarious positive change is in their circumstances.

> *"There is a difference in our relationship and maybe [him] wanting to see me, wanting to spend more time with me because the battles are just … the battles are ending."* Charlie

Charlie describes small but meaningful changes in their relationship with their son, linking their son's wish to spend more time with them to less conflict. They described relational repair through small, deliberate acts: "*I always do wee check-ins with him every day. Like, I'll send a text message … 'Well done' or 'I'm so proud of you' or 'I'm looking forward to seeing you'. Just all these wee acts, are kind of like saying I'm here."* These acts are counterintuitive to their cultural script, *"Wee things we don't say when we are Scottish".* Charlie takes pride in the effort they have put into repairing the relationship and building trust with their son and the impact this has on their son's behaviour. The mechanism of change is relational: trust was rebuilt through regulation, consistency and changed presence.

Discussion

This study explored parents' experiences of attending a CMT group in the context of their NDD child and how this shaped their self-perceptions and understanding of their child's NDD. Three themes emerged: 1) the group as a safe and validating space; 2) compassion as a tool for relating differently to self; and 3) compassion as a tool for understanding and connecting with their child. These themes suggest that participants experienced changes in how they related to themselves. Participants associated changes in their self-compassion with changes in their parenting and relationships with their child. CMT operates by shifting parents' relationships with themselves, which positively benefits their parenting capacity and relationships with their children.

The aetiology of parental stress in the context of NDD is multifaceted, encompassing child behavioural challenges, comorbid diagnoses and mental-health difficulties, parental coping style, external support systems, financial strain and societal stigma (Craig et al., 2016). Curley et al. (2023) identified cognitive appraisals as a key maintenance process of parental stress for parents of autistic children. Parents who perceive their child's behaviours as intentional or controllable experiences increased stress, while short-term coping strategies (e.g., avoidance and denial) offer only temporary relief. However, parents with cognitive flexibility and self-compassion are likely more resilient and better equipped to handle stressors.

Notably, participants in this study did not report any substantial changes in how they conceptually view their child's NDD. However, participants described a change in how they interpreted their

child's behaviours. Rather than a diagnostic reframing, participants' causal attribution changed. All of the participants described a more compassionate and curious understanding of their child's behaviours and their own emotional reactions. Enav et al. (2022) found that a brief mentalisation-based intervention improved parents' capacity for reflective cognitive appraisal, which reduced parental stress and supported more attuned caregiving. The current findings suggest that CMT may achieve a similar reappraisal shift through a compassion-focused route. Rather than simply teaching parents to think differently about NDDs, participants described a softening of the self-critical and threat-based lens through which parents interpreted both their child's behaviour and their own parenting.

This maps onto the three systems model underpinning CFT (Gilbert, 2010). Participants' pre-group account of catastrophising, shame, the 'bad parent' narrative and parenting from a state of chronic exhaustion are consistent with a threat system dominance. The demands of parenting a child with NDD may be understood within the three systems model as contributing to heightened threat responding. Whereas participants' descriptions of self-care as selfish and difficulties with emotion regulation may reflect limited access to the soothing system during periods of distress. Participants' report of letter-writing and compassionate imagery can be understood within CFT as attempts to develop greater access to their soothing system. Self-criticism remained present alongside the newer compassionate voice. All participants saw this as an ongoing process rather than a complete shift. This is consistent with CFT's view that the threat system is rebalanced rather than eliminated (Gilbert, 2010). Developing a stronger soothing system through CMT may be particularly important as it offers parents a way to respond to heightened stress with greater calm and compassion.

Further, the three GETs can be interpreted in relation to the three flows of compassion described by Gilbert and Irons (2005). The first GET, *The group as a safe and validating space*, reflects the development of receiving compassion from others. Participants described the group environment as warm and accepting, which may support the development of the soothing system by fostering safeness and emotional containment. The second GET, *Compassion as a tool for relating differently to self*, reflects cultivating self-compassion. Here, participants described 'another voice' capable of responding to distress with kindness rather than criticism. The final GET, *Compassion as a tool for understanding and connecting with their child,* is consistent with compassion towards others. Participants described becoming more attuned and less reactive in their responses to their children. However, the three system model may have limits in accounting for high levels of adversity. Despite actively engaging with the CMT content, Kit described remaining in 'survival mode'. Their ongoing difficulties may have made it harder to access feelings of safeness and soothing. Kit's account highlights the importance of considering wider life circumstances when interpreting experiences through the three systems model.

Parental stress and child behaviour exist in a bidirectional relationship, with higher levels of parenting distress being associated with increased internalising and externalising behaviours of autistic children (Zaidman-Zait et al., 2014). Eshraghi et al. (2022) propose a 'spillover hypothesis' in which parental stress alters child behaviour both directly, via parenting behaviour, and indirectly, via strain on the parent-child relationship. The present study offers phenomenological accounts that are consistent with this proposed relationship. All participants described a prior pattern in which their own dysregulation heightened their child's distress and behaviours. Following the group, most of the participants reported reduced conflict in the parent-child relationship and lower levels of challenging behaviour. Participants described their own increased regulation alongside calmer interactions with their child. Alex noted that changes in how they responded to their son had 'allowed him to come out of his angry outbursts faster'; Charlie described the 'knock-on effect' of eliminating 'the big explosions' and the guilt cycle that followed. This pattern is consistent with the wider literature on parental emotional scaffolding and co-regulation. Parents' capacity to remain sensitive to their child's emotional state and to repair after conflict is associated with lower child physiological stress and fewer externalising behaviours in autistic children (Ting & Weiss, 2017). This links directly to the third GET, *compassion as a tool for understanding and connecting with their child*. Participants' accounts suggest a possible relational pathway through which CMT may be experienced as helpful. The findings suggest that the CMT mechanism of change may be relational, interrupting the bidirectional stress cycle between parent and child and thereby supporting more positive interactions. These accounts raise the possibility of indirect benefits for children by changing how parents respond during stressful interactions.

The CMT group benefits extended beyond the compassion-focused course content. The group functioned as a source of community for a parenting population that is more vulnerable to feeling isolated. Current research suggests that parent groups build peer support networks around shared experiences, which help reduce isolation and normalise distress for parents of children with complex needs (Roughan et al., 2019; Sartore et al., 2021). The present findings affirm that group functioning runs deeper than pure learning alone. Participants particularly valued being met with acceptance rather than judgement within the CMT group. This ties in with Neff's (2003) conceptualisation of self-compassion as comprising self-kindness, common humanity and mindful awareness. For all participants, the group appeared to function as a safe space where they could be vulnerable without any anticipated judgement. This is consistent with Gilbert's (2010) compassion-focused model, which suggests that experiencing warmth and acceptance from others can activate the soothing system, making self-compassion easier to access.

It is important to consider whether these relational benefits are best explained by CMT specific mechanisms or by the established effects of peer support (Sartore et al., 2021). Participants described

using named CFT techniques (e.g., compassionate imagery, letter writing and compassionate self-talk) in daily life; this suggests at least some internalisation of CFT principles. All four participants described a cognitive shift from self-criticism to self-compassion. This cognitive shift is more consistent with the intended focus of CFT on developing self-compassion. However, the qualitative design does not allow the contribution of CFT content to be separated from the effects of generic social support. Further, participants described responding to their children with greater curiosity and compassion. This is consistent with the three flows model. These participant accounts are consistent with the intended mechanisms of CFT and suggest that participants were applying CMT content beyond the group. However, social support was also a meaningful part of the group experience and may have contributed to these outcomes.

Further, the group as a tool extended beyond the group's formal life. Participants from the most recent cohort created a WhatsApp group to maintain contact. All four expressed a desire for ongoing contact beyond the six-week structure (e.g., a refresher course, drop-in sessions or informal peer support). This is unsurprising, given that self-compassion was described as an effortful and ongoing process.

Strengths and limitations

This study's in-depth interviews generated rich, idiographic accounts of how parents experienced and made sense of attending the CMT group. The data offer novel findings within this population relating participants' experiences of parental self-criticism, threat-based appraisals of child behaviour and the bidirectional repair of the parent-child relationship. These qualitative findings extend our current understanding beyond outcomes typically measured by symptom-focused or psychoeducational parent training.

A significant limitation of this study was small sample size. Despite repeated recruitment emails from services, increased participant-voucher funding and the PI attending a current group to explain the study, only four participants completed the research interview. IPA was selected as it is well suited to small, purposively sampled groups and supports detailed, idiographic analysis of individual experiences (Smith et al., 2009). However, due to the idiographic nature of IPA, the findings should not be considered representative of a wider population of parents of children with NDD. Difficulties with recruitment reflect the challenges of conducting research with this vulnerable and under-researched population. Caregiver demands and limited time are both a barrier to participation (MacNeil et al., 2025) and a core finding in this study. Parents also self-selected to participate in the CMT group and research study, as such findings may not reflect the perspectives of parents who did not find the group of value.

The study sample lacks diversity, as all participants were White British or Scottish, educated and spoke English as their first language. While consistent with the ethnicity profile of Ayrshire and Arran, it limits the transferability of findings. This is important because access to neurodevelopmental supports is influenced by wider social and structural factors. These findings should therefore be read as a rich account of these parents' experiences rather than a representative account of the wider population of parents of children with NDD.

It is important to note that none of the participants' children held a formal NDD diagnosis at the time of interview (two of the four were awaiting assessments). In NHS Ayrshire and Arran, where this study took place, referrals for NDD assessment alone are no longer accepted unless the young person also meets Child and Family Services criteria of moderate to severe mental health difficulties. Those referrals that are accepted experience long wait times, often several years. This reflects recent changes in service provision across several Scottish health boards. If a formal diagnosis were a prerequisite for accessing support or participating in research, there is a high risk of excluding families who may need it most. While parental and self-identification do not replace a formal assessment, they reflect families' current observations and challenges. As such, services like NEST, which provide support without a formal diagnosis are increasingly important to support this vulnerable population. Including parents of children without a formal NDD diagnosis is both a strength and a limitation of this research. It speaks to the study's relevance and reflects the population such interventions aim to serve. However, it must be noted that these parents' experiences may differ from families whose children are formally diagnosed.

Clinical and policy implications

The findings from this study carry implications for how parenting support can be implemented. The findings suggest value in parenting support that extends beyond behaviour management and psychoeducation to consider parents' emotional experiences. While these interventions are important, they do not sufficiently address parents' emotional burden. The current findings suggest that parents and young people may benefit from interventions that explicitly address parental stress, self-criticism, emotional regulation and compassion. One way to do this would be to embed compassion-focussed support within existing parent interventions. This may help bolster engagement and offer support to families who are currently unable to access a formal diagnosis. Notably, several participants reflected that the groups' compassion-focused content would benefit any parent. This suggests the threat-based self-criticism this intervention addresses may be a broader feature of parenting.

In stretched Child and Family Services, group-based interventions may be a cost-effective way to support several families simultaneously (Roughan et al., 2019). However, parents who may benefit most from such groups may also find it hardest to attend. The study highlights parents' challenge of

prioritising their own well-being. This suggests that services need to think carefully about how parent well-being groups are framed.

Future research

Future research should aim to longitudinally explore the impact of compassion-focused materials in individuals that this study failed to reach. For example, those from minority groups or families of children with ID. Longitudinal research would help establish if gains described by participants are sustained over time and whether follow-up contact improves durability. Looking at different diagnostic groups could help explore more nuanced differences between and within experiences of parents of children with different conditions. Given the proposed bidirectional relationship between parental and child well-being, incorporating child-report or measures of relational repair would help corroborate parents' accounts. Further, future research could explore the specific mechanisms of action underpinning CMT group interventions for this population.

Conclusion

Parents who attended this CMT group in the context of their NDD child experienced it as a safe and validating space that they associated with reduced their isolation and greater compassion towards themselves. Participants related this compassionate shift with greater connection and perceived relational repair with their child. Rather than reporting significant changes in how they conceptualised their child's NDD, participants described changes in how they appraised and responded to their child's behaviour. Participants described improved understanding and curiosity around their child's behaviour as communication. Given the bidirectional relationship between parental and child well-being, compassion-focused parent support may represent a meaningful and indirect route to improving outcomes for NDD children and their families.

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Appendices

Appendix 1.1: PRISMA Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	p.8
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	p.9
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	p.10-11
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	p.11
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	p.12
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	p.11
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Appendix 1.3
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	p.13
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	p.13
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	p.13-14
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	p.13
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	p.13, 27
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	n/a
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	p.13
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	p.14
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	p.13, 27
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Figure 1.2 Appendix 1.5, 1.6

Section and Topic	Item #	Checklist item	Location where item is reported
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	n/a
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	n/a
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	n/a
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	n/a
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	p.14-15 Figure 1.1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	p.14-15 Figure 1.1
Study characteristics	17	Cite each included study and present its characteristics.	p.15 Table 1.1
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	p.27 Table 1.2
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimates and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Table 1.1
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	p.26-37
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	n/a
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	n/a
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	n/a
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	n/a
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	n/a
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	p.37
	23b	Discuss any limitations of the evidence included in the review.	p.38-39
	23c	Discuss any limitations of the review processes used.	p.38-39
	23d	Discuss implications of the results for practice, policy, and future research.	p.39
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	p.11
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	p.11
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	n/a

Section and Topic	Item #	Checklist item	Location where item is reported
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	n/a
Competing interests	26	Declare any competing interests of review authors.	n/a
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	n/a

Appendix 1.2: ENTREQ guidelines

Item	Guide and description	Reported on page
Aim	State the research question the synthesis addresses	p.9, 11
Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis and describe the rationale for choice of methodology (e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).	p.14
Approach to searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until theoretical saturation is achieved).	p.11
Inclusion criteria	Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type).	p.12
Data sources	Describe the information sources used (e.g. electronic databases (MEDLINE, EMBASE, CINAHL, psychINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar), hand searching, reference lists) and when the searches were conducted; provide the rationale for using the data sources.	p.11
Electronic search strategy	Describe the literature search (e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research and search limits).	Appendix 1.3
Study screening methods	Describe the process of study screening and sifting (e.g. title, abstract and full text review, number of independent reviewers who screened studies)	p.13
Study characteristics	Present the characteristics of the included studies (e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).	p.15
Study selection results	Identify the number of studies screened and provide reasons for study exclusion (e.g. for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications the research question and/or contribution to theory development).	p.14-15, table 1.1
Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).	p.13

Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).	p.13
Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	p.13, 26
Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	p.26, table 1.2
Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? (e.g. all text under the headings “results /conclusions” were extracted electronically and entered into a computer software).	p.13, table 1.1
Software	State the computer software used, if any.	n/a
Number of reviewers	Identify who was involved in coding and analysis.	p.13-14
Coding	Describe the process for coding of data (e.g. line by line coding to search for concepts).	p.14
Study comparison	Describe how were comparisons made within and across studies (e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).	p.14
Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	p.14
Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations or the author’s interpretation	p.30-37
Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).	p.30-37

Appendix 1.3: Search history (Conducted 4 June 2026)

OVID: PsycINFO

1	exp Parents/ or exp Mothers/ or exp Fathers/ or exp Caregivers/	141796
2	(parent* or mother* or father* or caregiver* or carer* or famil*).ti,ab.	633202
3	1 or 2	637724
4	exp Intellectual Development Disorder/ or exp Learning Disabilities/ or exp Developmental Disabilities/	49023
5	((intellectual* or learning* or developmental* or mental* or cognit*) adj2 (disab* or impair* or retard* or defici* or handicap* or disorder* or difficulty* or subnormal*)).tw.	200392
6	((((down* adj3 syndrome*) or fragile X or fraxe or fraxa or prader) adj3 willi*) or (williams adj3 syndrome*) or feotal alcohol* or fetal alcohol*or microcephal* or global developmental delay or GDD or (low adj1 IQ)).mp. or (borderline adj1 IQ).tw. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	2919
7	4 or 5 or 6	213465
8	(diagnos* adj3 (adjust* or adapt* or accept* or resolut* or reaction* or response* or cop*)).ti,ab.	4080
9	((parent* or mother* or father*) adj3 (adjust* or adapt* or accept* or resolut* or cop*)).ti,ab.	11044
10	("parental resolution" or "maternal resolution").ti,ab.	31
11	8 or 9 or 10	14979
12	3 and 7 and 11	786
13	limit 12 to english language	725
14	limit 13 to yr="2010 -Current"	544

OVID: Medline

1	exp Parents/ or exp Mothers/ or exp Fathers/ or exp Caregivers/	222695
2	(parent* or mother* or father* or caregiver* or carer* or famil*).ti,ab.	2235038
3	1 or 2	2263367

4	exp Intellectual Disabilities/ or exp Learning Disabilities/ or exp Developmental Disabilities/	156200
5	((intellectual* or learning* or developmental* or mental* or cognit*) adj2 (disab* or impair* or retard* or defici* or handicap* or disorder* or difficulty* or subnormal*)).tw.	366632
6	((down* adj3 syndrome*) or fragile X or fraxe or fraxa or (prader adj3 willi*) or (williams adj3 syndrome*) or (fetal or feotal alcohol*) or microcephal* or global developmental delay or GDD or (low adj1 IQ) or (borderline adj1 IQ)).tw.	353275
7	4 or 5 or 6	770519
8	(diagnos* adj3 (adjust* or adapt* or accept* or resolut* or reaction* or response* or cop*)).ti,ab.	31580
9	((parent* or mother* or father*) adj3 (adjust* or adapt* or accept* or resolut* or cop*)).ti,ab.	14527
10	("parental resolution" or "maternal resolution").ti,ab.	20
11	8 or 9 or 10	45915
12	3 and 7 and 11	1354
13	limit 12 to english language	1286
14	limit 13 to yr="2010 -Current"	860

EBSCOhost CINAHL

S1	TI (parent* OR mother* OR father* OR caregiver* OR carer* OR famil*) OR AB (parent* OR mother* OR father* OR caregiver* OR carer* OR famil*)	(620,584)
S2	TI ((intellectual* OR learning* OR developmental* OR mental* OR cognit*) N2 (disab* OR impair* OR retard* OR defici* OR handicap* OR disorder* OR difficulty* OR subnormal*)) OR AB ((intellectual* OR learning* OR developmental* OR mental* OR cognit*) N2 (disab* OR impair* OR retard* OR defici* OR handicap* OR disorder* OR difficulty* OR subnormal*))	(123,524)
S3	TI ("down syndrome" OR "fragile x" OR "prader willi" OR "williams syndrome" OR "fetal alcohol" OR microcephal* OR "global developmental delay" OR GDD OR "low IQ" OR "borderline IQ") OR AB ("down syndrome" OR "fragile x" OR "prader willi" OR "williams syndrome" OR "fetal alcohol" OR microcephal* OR "global developmental delay" OR GDD OR "low IQ" OR "borderline IQ")	(12,820)
S4	S2 OR S3	(133,846)

S5	TI (diagnos* N3 (adjust* OR adapt* OR accept* OR resolut* OR reaction* OR response* OR cop*)) OR AB (diagnos* N3 (adjust* OR adapt* OR accept* OR resolut* OR reaction* OR response* OR cop*))	(11,490)
S6	TI ((parent* OR mother* OR father*) N3 (adjust* OR adapt* OR accept* OR resolut* OR cop*)) OR AB ((parent* OR mother* OR father*) N3 (adjust* OR adapt* OR accept* OR resolut* OR cop*))	(10,156)
S7	TI ("parental resolution" OR "maternal resolution") OR AB ("parental resolution" OR "maternal resolution")	(12)
S8	S5 OR S6 OR S7	(21,444)
S9	S1 AND S4 AND S8	(618)
S10	S1 AND S4 AND S8	(618)
S11	S1 AND S4 AND S8	(460)

Scopous

TITLE-ABS-KEY((parent* OR mother* OR father* OR caregiver* OR carer* OR famil*) AND (((intellectual* OR learning* OR developmental* OR mental* OR cognit*) W/2 (disab* OR impair* OR retard* OR defici* OR handicap* OR disorder* OR difficulty* OR subnormal*)) OR ("down syndrome" OR "fragile x" OR "prader willi" OR "williams syndrome" OR "fetal alcohol" OR microcephal* OR "global developmental delay" OR GDD OR "low IQ" OR "borderline IQ")) AND ((diagnos* W/3 (adjust* OR adapt* OR accept* OR resolut* OR reaction* OR response* OR cop*)) OR ((parent* OR mother* OR father*) W/3 (adjust* OR adapt* OR accept* OR resolut* OR cop*)) OR ("parental resolution" OR "maternal resolution"))) AND PUBYEAR > 2009 AND PUBYEAR < 2026 AND LIMIT-TO(LANGUAGE, "English")	1424

Web of Science (Core Collection)

1	TS=((parent* OR mother* OR father* OR caregiver* OR carer* OR famil*))	3,679,762
2	TS=(((intellectual* OR learning* OR developmental* OR mental* OR cognit*) NEAR/1 (disab* OR impair* OR retard* OR defici* OR handicap* OR disorder* OR difficulty* OR subnormal*))	584,459
3	TS=(diagnos* NEAR/2 (adjust* OR adapt* OR accept* OR resolut* OR reaction* OR response* OR cop*))	38,020
4	TS=((parent* OR mother* OR father*) NEAR/2 (adjust* OR adapt* OR accept* OR resolut* OR cop*))	19,972
5	TS=("parental resolution" OR "maternal resolution")	31
6	#3 OR #4 OR #5	57,787
7	#1 AND #2 AND #6 AND LA=(English) AND PY=(2010-2026)	955

Appendix 1.4: Mixed-Methods Appraisal Tool

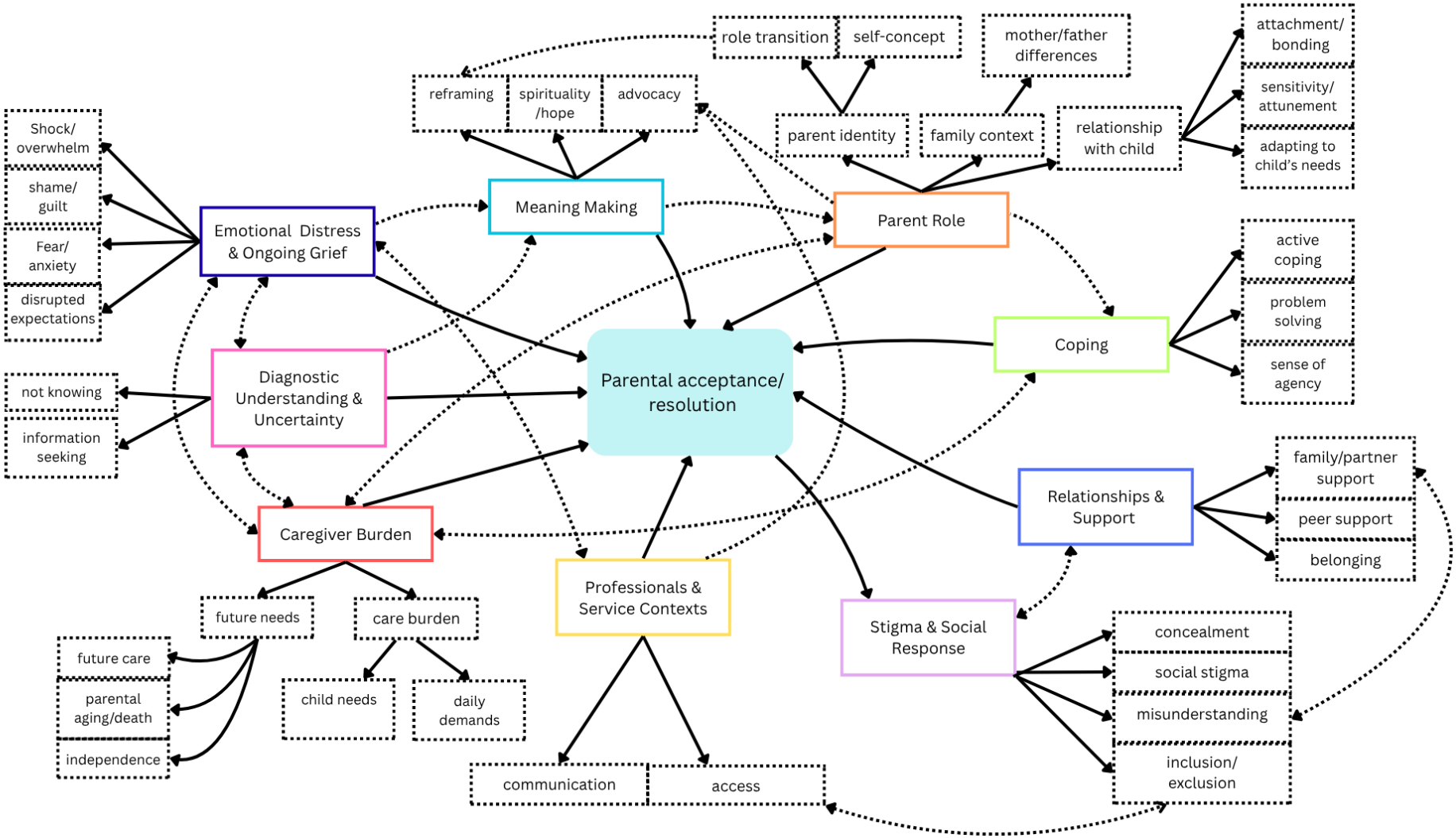
Mixed-Method Appraisal Tool PDF

Appendix 1.5: Code frequencies

Code	Study Author/date																
	AlShatti et al. (2021)	Barak-Levy & Atzaba-Poria (2013)	Barak-Levy & Atzaba-Poria (2015)	Barak-Levy & Parvente (2023)	Bentley et al. (2015)	Bingham, Correa & Huber (2012)	Boström & Broberg (2014)	Brown (2013)	Feniger-Schaal & Oppenheim (2013)	Fernández-Ávalos et al. (2021)	Gotay (2025)	Korkow-Moradi, Kim & Springer (2017)	Nelson et al. 2016	Pillay et al. (2012)	Riddling & Williams (2019)	Takataya, Yamazaki & Mizuno (2016)	Wahyuni et al. (2024)
Initial shock/overwhelm	✓			✓			✓	✓		✓		✓		✓		✓	
Fear/anxiety	✓			✓						✓	✓	✓		✓	✓	✓	
Sadness/anger								✓		✓						✓	
Guilt/self-blame				✓							✓						
Shame				✓							✓						
Denial/rejection	✓			✓		✓				✓							
Loss of imagined child					✓		✓	✓		✓				✓	✓		
Recurrent or ongoing grief					✓			✓		✓			✓				
Non-linear adjustment					✓	✓	✓	✓		✓			✓	✓	✓		
Emotional breakdown				✓													
Delayed diagnosis	✓	✓															
Diagnostic ambiguity		✓					✓		✓								
Not knowing	✓	✓					✓									✓	
Information-seeking	✓					✓						✓			✓		
Searching for why/reasons		✓		✓		✓				✓	✓					✓	
Reframing/positive reappraisal	✓				✓	✓		✓		✓	✓	✓	✓	✓			
Spirituality/religious coping/hope	✓					✓					✓		✓	✓			
Gratitude						✓					✓	✓	✓	✓		✓	
Child as person					✓			✓			✓					✓	
Understanding child needs	✓							✓	✓			✓					
Role transition/ parent identity					✓		✓	✓			✓		✓	✓	✓	✓	✓
Responsibility	✓						✓	✓							✓	✓	✓
Advocacy								✓				✓			✓		
Active coping/ problem solving			✓	✓	✓	✓		✓		✓			✓	✓	✓		
Help seeking	✓			✓	✓	✓		✓		✓			✓	✓			
Future planning				✓							✓						
Mother/father coping differences		✓	✓		✓		✓								✓	✓	

Code	Study Author/date																
	AlShatti et al. (2021)	Barak-Levy & Atzaba-Poria (2013)	Barak-Levy & Atzaba-Poria (2015)	Barak-Levy & Parvente (2023)	Bentley et al. (2015)	Bingham, Correa & Huber (2012)	Boström & Broberg (2014)	Brown (2013)	Feniger-Schaal & Oppenheim (2013)	Fernández-Ávalos et al. (2021)	Gotay (2025)	Korkow-Moradi, Kim & Springer (2017)	Nelson et al. 2016	Pillay et al. (2012)	Riddling & Williams (2019)	Takataya, Yamazaki & Mizuno (2016)	Wahyuni et al. (2024)
Bonding/attachment							✓					✓			✓	✓	
Sensitivity/attunement			✓						✓								
Adapting to child's needs			✓				✓	✓	✓							✓	
Family/partner support	✓		✓		✓	✓	✓	✓		✓	✓	✓		✓		✓	
sibling/extended family support							✓	✓				✓				✓	
Peer support	✓				✓	✓		✓								✓	
Community support	✓									✓	✓		✓				
Stigma/social judgement	✓			✓				✓			✓		✓	✓	✓		
Concealing diagnosis				✓													
Misunderstanding	✓			✓				✓					✓	✓	✓		
Inclusion/exclusion								✓							✓		
Diagnosis delivery/professional communication	✓							✓									
Professional support	✓			✓		✓	✓	✓				✓				✓	
Service access (e.g., barriers, waitlists)	✓							✓							✓		
Education barriers or supports	✓													✓			
Caregiving burden/daily demands	✓					✓	✓	✓		✓		✓	✓	✓	✓		
Child medical needs	✓											✓		✓			
Behavioural challenges								✓	✓						✓		
Financial/work strain								✓						✓	✓		
Future care	✓			✓			✓	✓		✓	✓		✓	✓			
Family risk		✓	✓														
Parental stress			✓		✓	✓				✓					✓		
Resolved/unresolved variation		✓	✓	✓	✓				✓				✓				✓

Appendix 1.6: Initial thematic map



Appendix 2.1: CORE-Q

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	49
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	49
Occupation	3	What was their occupation at the time of the study?	49
Gender	4	Was the researcher male or female?	49
Experience and training	5	What experience or training did the researcher have?	49
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	48
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	48
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	49
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	47, 49
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	48
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	48
Sample size	12	How many participants were in the study?	48
Non-participation	13	How many people refused to participate or dropped out? Reasons?	48
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	48-49
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	48-49
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	49-50
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	49
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	49
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	49
Field notes	20	Were field notes made during and/or after the inter view or focus group?	49
Duration	21	What was the duration of the inter views or focus group?	49
Data saturation	22	Was data saturation discussed?	n/a
Transcripts returned	23	Were transcripts returned to participants for comment and/or	49

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	49
Description of the coding tree	25	Did authors provide a description of the coding tree?	n/a
Derivation of themes	26	Were themes identified in advance or derived from the data?	49
Software	27	What software, if applicable, was used to manage the data?	n/a
Participant checking	28	Did participants provide feedback on the findings?	n/a
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	51-60
Data and findings consistent	30	Was there consistency between the data presented and the findings?	50-60
Clarity of major themes	31	Were major themes clearly presented in the findings?	50-60
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	50-60

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Appendix 2.2: Final approved MRP proposal

https://osf.io/k7q6v/files/cv9br

Appendix 2.3: Ethical approval letter

Ethical approval letter removed due to confidentiality issues.

Appendix 2.4: Management approval letter

Management approval letter removed due to confidentiality issues.

Appendix 2.5: Data analysis plan

https://osf.io/k7q6v/files/783yr

Appendix 2.6: Parenthood with Neurodivergent Children- the course

Parenthood with Neurodivergent Children: The Course

Compassionate Mind Training

Compassionate Mind Training (CMT) is a core element of Compassion Focused Therapy (CFT), and it can be thought of as the foundation of psychoeducation and skills training that are requirements for CFT to be successful. CMT involves psychoeducation about mind-body interaction (based on evolutionary psychology theory) and the three systems model of emotion regulation. It also involves understanding the psychological definition of compassion, and that there are three flows of compassion (self to other; other to self; and self to self) and that these flows of compassion can become blocked. The skills training aspect of CMT incorporates mindful awareness, breathwork, and compassion-focused imagery.

CMT is derived from the work of Professor Paul Gilbert. Clinical Psychologists Dr. Chris Irons and Dr. Charlie Heriot-Maitland developed a 8-session CMT programme for adults in the general population, which was found to result in significant increases in self-compassion, self-reassurance, positive emotions and wellbeing, alongside significant reductions in self-criticism, attachment anxiety, and psychological distress; these changes were maintained at three-month follow-up (Irons and Maitland, 2021).

CMT facilitator training & accreditation

A clinician within the Community Paediatric Psychology Service completed the following training and group supervision to become an accredited CMT Facilitator of the Irons and Maitland 8-week CMT programme. All training and supervision was delivered by Balanced Minds Ltd and funded by NHS Ayrshire and Arran Psychological Services:

- Two day Introduction to Compassion Focused Therapy Skills Workshop;
- Three day Advanced Clinical Skills in Compassion Focused Therapy;
- 8-session CMT programme;
- Five-day Compassionate Mind Facilitator Training course;
- 8 x 90-minute group supervision sessions.

Iterations of compassion-focused parent-level group interventions

Four iterations of the compassion-focused parent-level group interventions were delivered by clinicians from the Community Paediatric Psychology Service between October 2023 and December 2025. All groups were facilitated by the lead clinician (trained via Balanced Minds) and a supporting clinician. Feedback from programme participants was sought following each iteration and their views, along with facilitators' reflections and input from other stakeholders.

Parenthood with Neurodivergent Children: The Workshop and The Course

The fourth iteration of the compassion-focused parent-level group intervention was delivered in two parts, The Workshop and The Course. The Workshop last for three hours and can be treated as a standalone intervention or as a prerequisite to The Course, which comprises six sessions (each lasting two hours). The format and the session content is shown in Figure 1.

The Workshop – content

- Context-setting, including psychoeducation regarding parental burnout, and validation of the reasons parents and caregivers of children with additional needs/developmental differences are at greater risk of parental burnout.
- Psychoeducation regarding the "Tricky Brain" concept and three systems/circles model of emotion regulation, drawn from Compassion Focused Therapy and Compassionate Mind Training literature.
- An Introduction to coping skills, including breathwork, mindfulness, and self-compassion exercises.

The Course – content by session

Each session is structured to last for two hours, with a 20 minute break in the middle. As well as psychoeducation content and experimental practices, there is time for questions and reflective discussion as a group.

Session 1

- A recap of the "Tricky Brain" concept and three systems/circles model of emotion regulation, drawn from Compassion Focused Therapy and Compassionate Mind Training literature.
- Mindful awareness psychoeducation and skills training.
- Breathwork skills training.

Session 2

- Psychoeducation regarding the concept of compassion.
- Rationale for the value of compassion in "parenthood plus".
- Mindful awareness psychoeducation and skills training.
- Breathwork skills training.

Session 3

- Psychoeducation regarding:
    - The concept of "Multiple Selves";
    - The flow of compassion to the self (self-compassion);
    - Fears, blocks, and resistances within the flow of self-compassion.
- Introduction of self-compassion practices.
- Continuation of mindfulness and breathwork practices.

Session 4

- Psychoeducation regarding:
  - The Inner Critic;
  - Self-criticism in the context of parenthood plus.
- Introduction of compassion for the Inner Critic practices.
- Continuation of mindfulness, breathwork, and self-compassion practices.

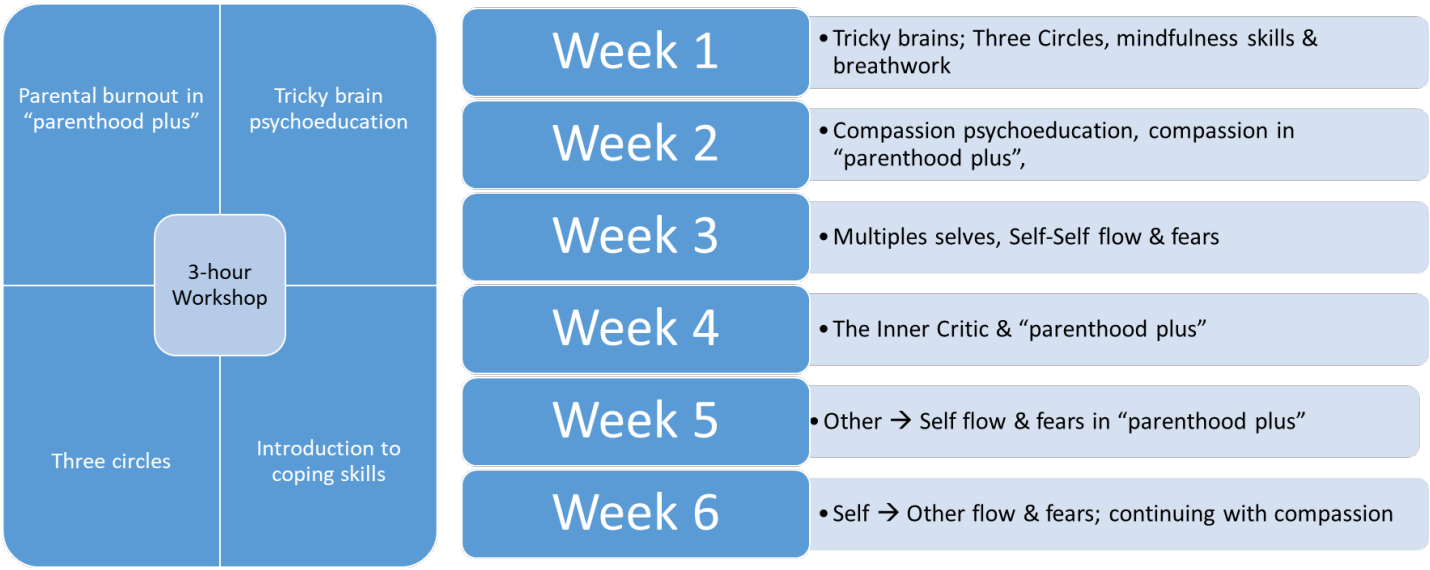
Session 5

- Psychoeducation regarding:
  - Other to Self-flow of compassion;
  - Fears, blocks, and resistances within the Other to Self-flow of compassion.
- Introduction of practices to support noticing and accepting compassion from others.
- Continuation of mindfulness, breathwork, self-compassion, and compassion for the Inner Critic practices.

Session 6

- Psychoeducation regarding:
  - Self to Other flow of compassion.
  - Fears, blocks, and resistances within the Self to Other flow of compassion.
- Continuation and review of all experiential practices.
- Future planning for how to take all skills and reflections from the course forward.

Figure 1. Format of PNC: The Workshop and PNC: The Course



Appendix 2.7: Demographic Questionnaire

https://osf.io/bdzf5

Appendix 2.8: Interview schedule

https://osf.io/k7q6v/files/yb9gx

Appendix 2.9: Detailed record of data analysis

https://osf.io/k7q6v/files/kdzhy

Appendix 2.10: Study documentation

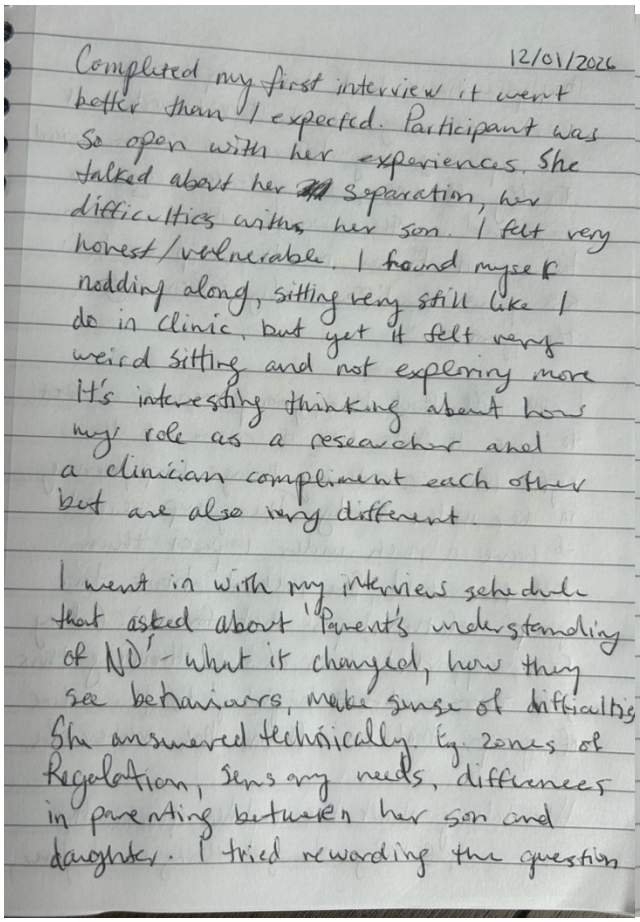
Participant consent form: https://osf.io/k7q6v/files/jzhbc

Privacy notice: https://osf.io/k7q6v/files/6zwx8

Participant information sheet: https://osf.io/k7q6v/files/b5zr8

Recruitment flyer: https://osf.io/k7q6v/files/wrstk

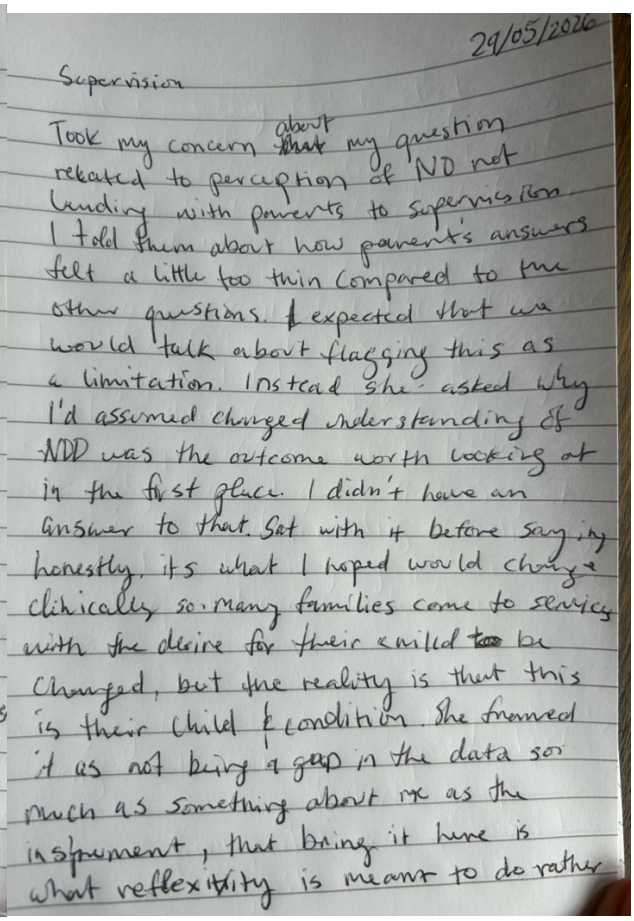
Appendix 2.11: Excerpts from reflective journal



12/01/2026

Completed my first interview it went better than I expected. Participant was so open with her experiences. She talked about her separation, her difficulties with her son. I felt very honest/vulnerable. I found myself nodding along, sitting very still like I do in clinic, but yet it felt very weird sitting and not exploring more. It's interesting thinking about how my role as a researcher and a clinician compliment each other but are also very different.

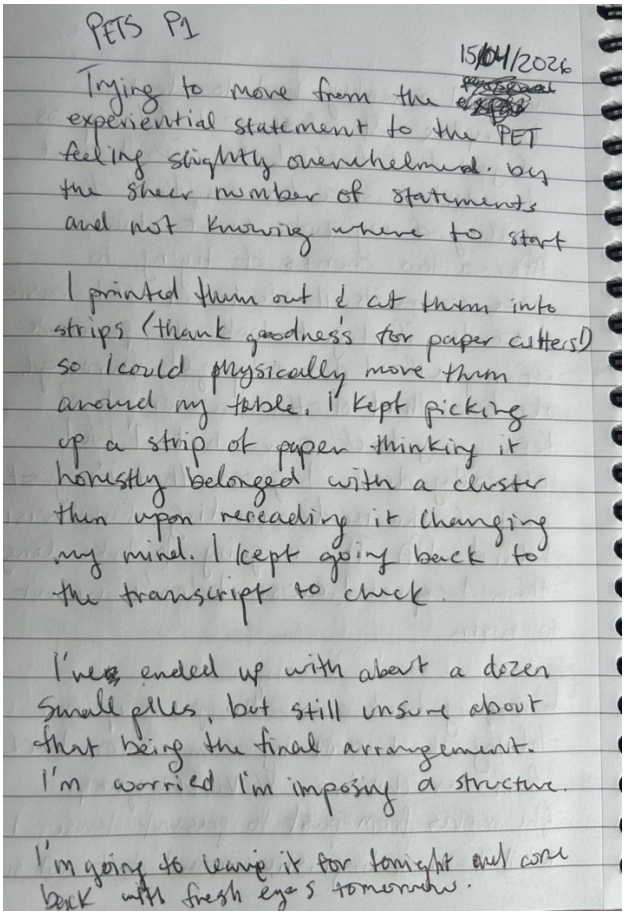
I went in with my interview schedule that asked about 'Parent's understanding of ND' - what it changed, how they see behaviours, make sense of difficulties. She answered technically. Eg. zones of Regulation, sensory needs, differences in parenting between her son and daughter. I tried rewording the question



29/05/2026

Supervision

Took my concern about my question related to perception of ND not landing with parents to supervision. I told them about how parent's answers felt a little too thin compared to the other questions. I expected that we would talk about flagging this as a limitation. Instead she asked why I'd assumed changed understanding of NDD was the outcome worth looking at in the first place. I didn't have an answer to that. Sat with it before saying honestly, it's what I hoped would change clinically so many families come to services with the desire for their child to be changed, but the reality is that this is their child & condition. She framed it as not being a gap in the data so much as something about me as the instrument, that being in here is what reflexivity is meant to do rather



PETS P1

15/04/2026

Trying to move from the experiential statement to the PET feeling slightly overwhelmed by the sheer number of statements and not knowing where to start

I printed them out & cut them into strips (thank goodness for paper cutters!) so I could physically move them around my table. I kept picking up a strip of paper thinking it honestly belonged with a cluster then upon rereading it changing my mind. I kept going back to the transcript to check.

I've ended up with about a dozen small piles, but still unsure about that being the final arrangement. I'm worried I'm imposing a structure.

I'm going to leave it for tonight and come back with fresh eyes tomorrow.

Analysis of transcript 07/03/2026

Started exploratory noting on P2's transcript. I opted to type my notes because it takes away pressures of getting it right or not having enough room. Fran gave me a template for Zuber she used which is really helpful. Honestly it took me a few minutes before I actually wrote anything. I really wasn't sure what I was doing. The book I'm using talks about the different types of comments which made sense until I actually had to start. Descriptive felt safest so I did a pass of just that first. I also found that I needed to take breaks, that the quality of my notes went down. After a few chunks of trying to make comments it started to get easier. I wonder if I just took the pressure off myself. I did only get through about a third of the transcript. I kept going back over what I had already done. I guess that is just part of the read/rereading familiarising behind IPA. This is going to take longer than I expected cause I don't want to rush.

Was going back over this participant talking about receiving compassion back from her children [redacted] she moves from past to present tense. I noted it as a linguistic comment but not sure

Appendix 2.12: Data availability statement

Study data is not publicly available due to ethical and privacy considerations. It can be accessed upon reasonable request subject to appropriate institutional approvals.