Father Engagement with Disability Services: The Perceptions and Experiences of Fathers and Psychologists

By

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Abstract

Background and Aims: This study sought to explore father engagement with disability services in Ireland by capturing the perceptions and experiences of fathers of children with an intellectual disability or developmental delay (ID/DD), and psychologists working in disability services. Disability services often consider the mothers' perspective to be representative of both parents, which can leave fathers of children with an ID/DD feeling disengaged in their relationship with disability services (Curtiss et al., 2021; Docherty & Dimond, 2018). This contradicts the ideologies underpinning family-centred practice, which is a core principle of Ireland's national programme of disability service reconfiguration known as 'Progressing Disability Services for Children and Young People in Ireland'.

Sample: Fathers were recruited from disability services, special schools, and social media parent groups through voluntary response sampling. Psychologists were recruited from disability services through purposeful sampling.

Method: A mixed-methods, sequential explanatory design was adopted. A newly developed questionnaire on father engagement with services (FEWS-Q) was completed by fathers (n = 77), followed by semi-structured interviews with fathers (n = 9) and with psychologists (n = 8). Internal reliability analysis and descriptive statistics were used to analyse the quantitative data, while thematic analysis was used to analyse the qualitative data accrued. The bioecological model of human development (BMHD) and family systems theory were applied as theoretical frameworks to explore this multifactorial phenomenon

Results: Survey and interview results highlighted feelings of exclusion from services from fathers, which were corroborated by psychologists. Fathers and psychologists described factors across all five systems of the BMHD that affect father engagement with disability services, and this was used as a framework to structure and explore the themes that were generated. Positive discrimination towards fathers, services offering father groups, and the establishment of an early relationship between fathers and services may help to improve engagement.

Conclusions: The findings of this study support previous research findings that fathers feel disengaged and unsupported by services which has implications for service delivery within the family-centred practice model and for intervention efficacy. The internal reliability and construct validity of the FEWS-Q is promising and this instrument merits further exploration with a larger sample size to determine its robustness.

Declaration

I hereby declare that this thesis is entirely my own work and has not been submitted for any other awards at this or at any other academic establishment. Where use has been made of the work of other people, it has been fully acknowledged and referenced.

Name: Ronan Cunningham

Signed:

Ronan Cunningham

Date: April 28th, 2022

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Ba mhaith liom buíochas ó chroí a ghabháil le gach uile duine agaibh. Ar scáth a chéile a mhaireann na daoine.

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List of Abbreviations

BMHD – The Bio-ecological Model of Human Development

FST – Family Systems Theory

FCP – Family-centred Practice

DS – Disability Services

PDS – Progressing Disability Services for Children and Young People

CDNT – Child Disability Network Team

CAMHS – Child and Adolescent Mental Health Services

ID – Intellectual Disability

DD – Developmental Delay

ASD – Autism Spectrum Disorder

Chapter 1: Introduction

"There should be positive discrimination, programmes, supports programmes on social media just dedicated to dads to give them the boost to say it's OK to be a dad of a child with complex needs, it's OK to be upset and it's OK to cry and be miserable and feel like your life is over. There needs to be spaces created for dads to process this, and to learn that it's OK."

(Quote from Mark, a father participant in this study)

1.0 Chapter Introduction

This chapter will introduce the rationale for exploring father engagement with disability services. Some key terms associated with this study will be outlined, and the theoretical frameworks adopted to conceptualise this issue will be defined. Finally, an overview of the structure of this thesis will be delineated at the end of this chapter.

1.1 Thesis Rationale

The following empirical findings and policy developments formed the rationale for this thesis. Fathers of children with disabilities are a challenging population for disability services (DS) and healthcare providers to engage (Carpenter & Towers, 2008; Flippin & Crais, 2011; McConkey, 1994). They often feel undervalued, alienated, excluded and overlooked in many facets of their child's life (Carpenter & Towers, 2008; King et al., 2007; MacDonald & Hastings, 2010) including in a service delivery relationship (Flippin & Crais, 2011; Giallo et al., 2015; Marsh et al., 2020). Mothers are regarded as the primary parent and caregiver by disability services which can see fathers becoming disengaged with services (Docherty & Dimond, 2018; Laxman et al., 2015; Ly & Goldberg, 2014). When fathers do engage with DS, there are a number of benefits associated with this for the child (Quinn, 1999) and for the family system (Laxman et al., 2015; Simmerman et al., 2001).

DS in Ireland are currently undergoing significant change with the implementation of Progressing Disabilities Services for Children and Young People (PDS) nationwide (Health Service Executive, 2020a). PDS policy emphasises the importance of adopting a family centred practice (FCP) approach to service delivery (Health Service Executive, 2020b; McCarthy & Guerin, 2021). In many families, the father forms an integral part of the family system, and maximising the potential of the family system is a key element of FCP (Espe-Sherwindt, 2008).

In light of the empirically-established challenges and benefits associated with father engagement with DS, coupled with the changing policy landscape in Irish DS, this study sought to explore father engagement with DS by gaining the perceptions and experiences of fathers and psychologists on this phenomenon.

1.2 Key Terms

1.2.1 Fathers. The term 'fathers' in the present study encompasses a male who fulfils a caregiving role[1] to a child with an intellectual disability or developmental delay (ID/DD). This includes biological fathers, stepfathers or partners to mothers of children with an ID/DD (Maxwell et al., 2012).

1.2.2 Psychologists. In this study, the term 'psychologists' encompasses Educational, Clinical or Counselling psychologists working in DS. Alterations to eligibility requirements in psychology recruitment means that these three divisions are all eligible to work in DS in Ireland (Health Service Executive, 2016). Exploring the role of psychologists in promoting FCP and engaging fathers in the disability service context is a central tenet of this study.

1.2.3 Engagement. There is considerable variability and a lack of consistency in the use of the term 'engagement' in the context of parental engagement with services (Fletcher & StGeorge, 2010). In this study, the term 'engagement' is used to describe the investment, commitment, involvement and expectations of fathers of children with an ID/DD in their relationship and interactions with DS (Fletcher & StGeorge, 2010; King et al., 2020).

1.3 Theoretical Frameworks

The theoretical frameworks adopted in a research study have a significant impact on the approach taken by the researcher, as well as on the research design adopted (Mertens, 2014). Two theoretical frameworks were used to guide this research process and to structure and contextualise the data accrued as part of this process.

1.3.1 Primary Theoretical Framework. The primary theoretical framework adopted was the Bio-Ecological Model of Human Development (BMHD) (Bronfenbrenner & Morris, 2006). The phenomenon of interest in the present study is located at the frontier of the family system and the healthcare system, both of which are influenced by wider social systems. Therefore, it was necessary to adopt an ecological perspective to facilitate an exploration of this phenomenon, and to locate the issue of father engagement with DS within a wider social

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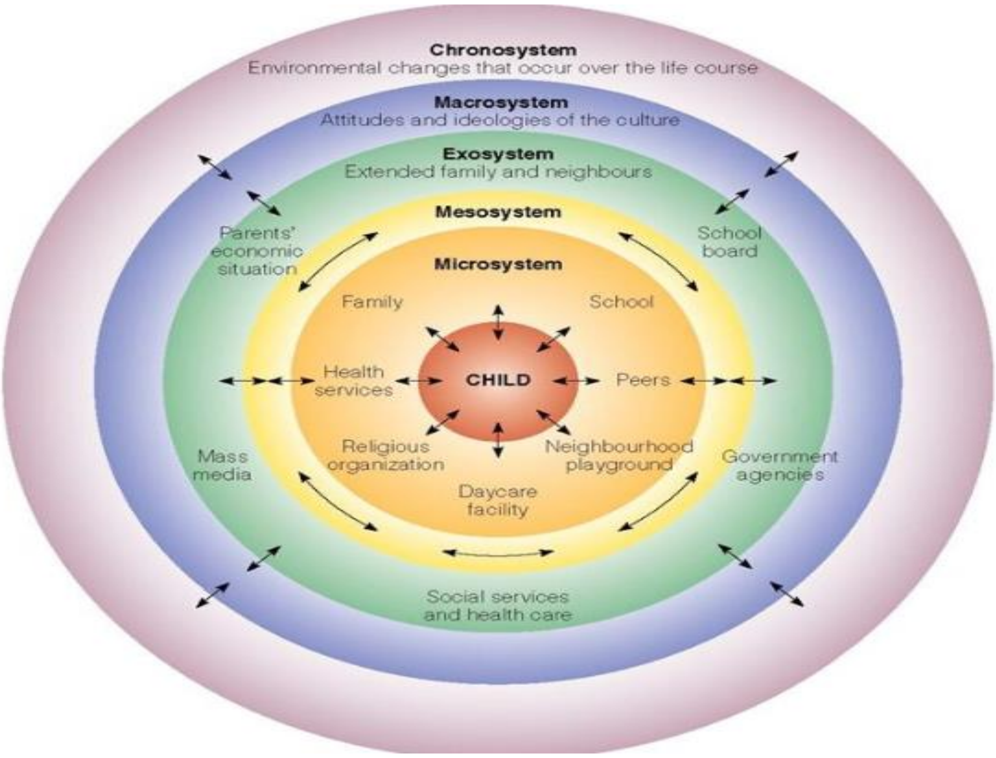
[1] It should be noted that fathers in previous literature, as well as those who volunteered their participation in this study, were one half of a heteronormative parenting relationship, where the father identified as male and the mother identified as female. Therefore, the language used in this chapter and subsequent ones will work from this binary.

context. This theory describes five layered systems in which the child and their family are embedded (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006). Children and families interact with these various systems, and can influence them as well as being influenced by them (Bronfenbrenner & Morris, 2006). A detailed description of the BMHD and its relevance in the context of this study can be found in chapter two.

1.3.2 Secondary Theoretical Framework. The secondary theoretical framework adopted in this study was Family Systems Theory (FST) (Bowen, 1974). This theory asserts that a family is a group of interconnected individuals operating within a social system, and that each member of this system is impacted by other members within the family system (Bowen, 1974). In this study, FST allowed for the conceptualisation of the role of the father within the family system and facilitated an exploration of how this role might impact engagement with DS. A detailed overview of FST and its relevance to the present study can be found in chapter two.

Figure 1: *The BMHD (Bronfenbrenner & Morris, 2006)*



1.4 Design, Methodology and Analysis

The study adopted a mixed-methods, sequential explanatory design framed within a pragmatic research paradigm. An online survey was completed by fathers of children with an

ID/DD and follow up interviews were conducted with a random sample of participants from the survey. Interviews were then conducted with psychologists working in DS, who were recruited through purposeful sampling. An analysis of internal reliability and content validity was undertaken with the newly designed father engagement with services questionnaire (FEWS-Q). Descriptive statistics were used to report the findings of this questionnaire. Thematic analysis was used to analyse the interviews conducted with fathers and psychologists.

1.5 Thesis Structure

Chapter one of this thesis has provided an introduction to the research area and a rationale for undertaking this research project. Chapter two expands on some of the key terms, concepts and theories that have been introduced in chapter one, before culminating in a systematic review of the research literature on father engagement with healthcare services and father involvement with their children. The findings of this review are then synthesised, generating three research questions that are explored in chapter three, the empirical paper. In chapter four, a critical review of the research process is undertaken which explores the strengths and limitations of the research, ethical considerations, implications for practice, policy, training and future research. The unique contribution made by this research project is then outlined in the form of an impact statement.

Chapter 2: Literature Review

2.0 Chapter Introduction

This chapter presents an analysis of the research literature on father involvement with their children and father engagement with services. While findings from research involving fathers of children with an intellectual disability or developmental delay (ID/DD) are considered most relevant to this review, findings from research involving fathers of children from other disability groups, as well as fathers of children with typically developing children will also be considered, where applicable. The aim of this chapter is to contextualise the present research study by bringing together key findings in this research area and synthesising these findings systematically. A context and rationale will firstly be provided in which the theoretical frameworks being adopted and concepts being investigated in this review will be outlined. Following this, the systematic review approach adopted will be described, the process of appraisal of the studies included in the review will be illustrated, and the findings of this review will be discussed.

2.1 Context and Rationale

This section will begin with a definition of some of the key terms and concepts associated with the present study. This will be done to situate the specific problem area within the contemporary research literature and current policy landscape. This review seeks to explore the significance of the involvement and engagement of fathers of children with an ID/DD in their children's lives and with DS. It is important to define some of these key concepts to provide a platform from which the rest of this review can be understood and contextualised.

2.2 Theoretical Context

To understand father engagement with DS, and indeed father involvement in the lives of children with ID/DD, it is apt to first locate this phenomenon within a wider theoretical framework based on the broader social context in which fathers and their children live. The Bio-ecological Model of Human Development (BMHD) (Bronfenbrenner & Morris, 2006) and Family Systems Theory (FST) (Bowen, 1974) have been chosen to conceptualise the experiences of fathers in this broader social context.

2.2.1 The Bio-ecological Model of Human Development

In the case of children with ID/DD and other developmental disabilities, the context of father involvement will be mediated by factors such as the characteristics of the child's presentation, the impact that the diagnosis has on the family, the father's marital relationship, the broader policy context that impacts service provision, and their own beliefs about disability that have developed throughout the course of their lives (da Silva et al., 2016). The BMHD is a useful theoretical lens to observe father involvement and engagement because it sees development as a multidimensional phenomenon and a process that is influenced by a myriad of interrelated factors (da Silva et al., 2016). This theory looks at the bi-directional interactions that occur between the individual, the family and wider society (Rogers et al., 2009). The BMHD asserts behaviour is influenced by five separate but interacting domains, spanning from proximal contexts (e.g. individual traits, beliefs and couple relationships) to broad cultural contexts (e.g. nationality) (Rogers et al., 2009).

The *microsystem* is the first layer of this system, and refers to the individual's immediate environment and context, for example their home, school and neighbourhood (Cabrera et al., 2014). Within the family microsystem lies the parent-child system. Parent-child development is a reciprocal and dynamic process that is in perpetual evolution which impacts all of the actors who are part of this process (Cabrera et al., 2014). This layer of the BMHD is pertinent to the present study because it includes the relationships between parents and their children. The next layer of the BMHD is the *mesosystem*, which encompasses the relationship between the family system and other microsystems in which the members of the family spend time (Rogers et al., 2009). This includes relationships with schools and other organisations, including DS. The BMHD asserts that relationships between these various microsystems within the mesosystem can impact on child development. For example, the relationship between parent and teacher can impact a child's experiences of school (Cabrera et al., 2014). By this logic, it can be posited that the relationship between parents and services will have an impact on the child's, and the family's, experiences with services.

The next layer of the BMHD is the *exosystem*, which conceptualises the relationship between microsystems and systems in which the individual may not be directly involved, for example, the workplace of a parent (Rogers et al., 2009). These interconnected social systems impact parent behaviour, which impacts family relationships (Cabrera et al., 2014). In the context of the present study, a demanding work schedule may decrease the time that a father has at home with children, which impacts the parent-child microsystem. Furthermore, if a father cannot attend appointments due to work demands, this may impact the microsystemic relationship between that father and the school or the service where the appointment is being held. The *Macrosystem* is related to the evolving political, cultural, economic and geographic conditions in which families are situated (Cabrera et al., 2014). This system encompasses broader factors that may not have a tangible or direct influence on the individual, but that affect them nonetheless (Bronfenbrenner, 1986). In the present study, the macrosystem impacts in terms of policy underpinning and influencing the provision of services, and societal beliefs or stigma around the role of the father and disability generally.

The final layer of the BMHD is the *chronosystem* which reflects environmental events and transitions throughout the lifespan (Cabrera et al., 2014). This accounts for changes that occur over time, for example changing relationships, changes in perspectives and changes in service provision. Given that ID is a lifelong and pervasive developmental disability, the chronosystem accounts for how time is a factor in understanding and dealing with such a diagnosis (da Silva et al., 2016). In the context of the present study, it may be challenging for a father to initially comprehend the ID diagnosis and the necessary services for their child, but, with time, this understanding and interaction may become more stable.

2.2.2 Family Systems Theory

Family Systems Theory (FST) asserts that a family is a group of interconnected individuals operating within a social system, and that each individual is significantly impacted by other members within the system (Rouse, 2012). The model relates strongly to the BMHD. Within the microsystem are the immediate relationships that an individual experiences in their lives, including their familial relationship. FST asserts that within the family system are subsystems, which are interdependent (Roper et al., 2014). These include parental relationships, sibling relationships and parent-child relationships and each family member has varying roles within each subsystem (Roper et al., 2014). These subsystems are best understood by viewing the family as a whole, rather than in individual parts (Roper et al., 2014). FST conceptualises children's existence within a wider context, taking into account the interconnection of the ecological layers of family, community and society (Wright et al., 2010). The family system affects and is affected by the environment in which it finds itself, and adapts when necessary to maintain balance and homeostasis (Mandak et al., 2017; Minuchin, 1985).

Fathers form an integral part of the family support system (Flippin & Crais, 2011) and provide a long-term support role for children with disabilities throughout the life course

(Emerson et al., 2012). Fathers' relationships with their children have implications for the family subsystems within the family system, and the wider context of family interactions with the community and society, including with DS (Mandak et al., 2017). FST posits that families empowerment is a pivotal aspect of maximising the potential of each family member in a clinical relationship, which underpins family-centred practice, a concept that will be further explored later in this chapter. Minuchin (1985) discussed the co-parenting system and how this can impact father involvement with their children. Fathers construct their parenting role within the co-parenting relationship, meaning that the characteristics of the co-parenting relationship can significantly impact father involvement (Pancsofar et al., 2019). In many co-parenting relationships, mothers may be considered the main point of contact or the decision-maker in their child's future, which can mean that fathers assume a support rather than a central role (Pancsofar et al., 2019). This can impact subsystems within the family, and processes of adaptation within the family system (Roper et al., 2014).

2.3 Overview of Intellectual Disability and Developmental Delay

Intellectual disability (ID) and developmental delay (DD) are genetically and phenotypically heterogenous disorders (Vasudevan & Suri, 2017). They can occur in isolation or in combination with other congenital disorders, neurological features and behavioural difficulties (Srour & Shevell, 2014; Vasudevan & Suri, 2017). DD, also known as global developmental delay, is a diagnosis reserved for children under five who have failed to meet developmental milestones, and benchmarks in intellectual functioning (American Psychiatric Association, 2013; Srour & Shevell, 2014). There are three widely applied classification systems used by health professionals when diagnosing ID. These are the International Classification of Diseases (ICD-11) (World Health Organisation, 2019) the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013) and the American Association on Intellectual and Developmental Disabilities publication: Intellectual Disability: Definition, Classification and Systems of Supports (AAIDD-12) (Schalock et al., 2021). Across these classification systems, ID is defined as a set of neurodevelopmental disorders that begin in childhood and are characterised by limitations in both intellectual functioning and adaptive behaviour as expressed by deficits in social, conceptual and practical skills (American Psychiatric Association, 2013; Schalock et al., 2021; World Health Organisation, 2019). ID can be congenital or acquired, and can occur at prenatal (e.g. chromosomal disorders), perinatal (e.g.

anoxia at birth), or postnatal (e.g. brain injury, seizure disorders) stages (Bélanger & Caron, 2018; Srour & Shevell, 2014). For those with a mild or moderate ID, a specific underlying aetiology is less likely to be recognised than in those with a severe or profound ID (Patel et al., 2018). Please see Appendix N for further detail on risk factors associated with the development of ID.

2.3.2 Classification Systems

Clinicians must adhere to a rigorous assessment process in the identification of ID which is outlined by the parameters set in the three classification systems used to define ID. Functional deficits must be measured by trained psychologists using reliable and standardised psychometric instruments (Carr et al., 2016). A standard score of 70 or below in the realms of adaptive and intellectual functioning are indicative of an ID (Srour & Shevell, 2014). In the DSM-5 and the ICD-11, ID is categorised into four ranges based on standardised scores of intelligence quotient (IQ) level on assessments of cognitive functioning (Carr et al., 2016; World Health Organisation, 2019). These ID ranges are outlined in Table 1 below. While these classification systems are clear cut and can help in the provision of services and funding, best practice denotes that ID and DD should be conceptualised using a biopsychosocial lens rather than relying solely on a static measurement of IQ or adaptive functioning (Kranzler et al., 2020; Petasis, 2019; Vasudevan & Suri, 2017). This is reflected in the International Classification of Functioning, Disability and Health model of intellectual disability (World Health Organisation, 2019) which takes personal, contextual and environmental factors into account when defining ID (Carr et al., 2016).

Table 1: *ID Classifications (WHO, 2019)*

Range of ID	Standardised Score (IQ Level)
Mild intellectual disability	50-55 to 70
Moderate intellectual disability	35-40 to 50-55
Severe intellectual disability	20-25 to 35-40
Profound intellectual disability	Below 20-25

2.3.3 Prevalence

In the western world, it is estimated that roughly 1-3% of the population have an ID (Lee et al., 2020). The estimated incidence of DD is similar to ID, in that 1-3% of children aged 5 years or younger are thought to have a DD (Vasudevan & Suri, 2017). In Ireland, the

National Intellectual Disability Database (NIDD) and the Central Statistics Office (CSO) collect data on the prevalence rates of ID in the country. Based on the most recent NIDD figures, which were published in 2017, the prevalence of ID in Ireland is 5.96 per 1,000 people (Hourigan et al., 2018). There is a much higher incidence rate among males in Ireland, which reflects international trends. 59.1% of the ID population in Ireland are male, while 40.9% are female (Hourigan et al., 2018). According to the NIDD report, 32% of people with an ID in Ireland are in the mild range, 42% are in the moderate range, 14% are in the severe range, 3% are in the profound range and 9% are unverified (Hourigan et al., 2018). 35% of the ID population in Ireland are aged 0-19 years.

2.4 Disability Services in Ireland

Disability services (DS) offer specialist interventions and supports for children with disabilities and their families. Services comprise health and social care professionals, and cater for children with disabilities and complex needs aged 0-18 years (Health Service Executive, 2020b). To understand the composition of Irish DS in the present day, it is necessary to explore their historical development to see how this has influenced current thinking and practice.

The state achieved political autonomy in the early 1920s and with this came the responsibility of supporting vulnerable groups within Irish society (Linehan et al., 2014). However, it lacked the resources to fulfil this obligation, resulting in religious orders providing many health, educational and social services (Sweeney, 2010). Within the remit of religious orders was the need to provide services for people with an ID (Linehan et al., 2014). While these services were initially adult-oriented, the establishment of special schools for children with an ID on the same campus as adult services saw the inception of DS for children (Linehan et al., 2014; Sweeney, 2010).

By the 1950s, the rate of expansion of specific services for people with an ID overwhelmed the capacity of these religious orders, which saw the development of a strand of voluntary services known as ‘parent and friend associations’ (McCormack, 2004; Ryan, 1999). These organisations quickly grew in number, meaning that DS in Ireland developed in a largely uncoordinated and unsystematic manner. For over half a century, the majority of services for people with an ID in Ireland were provided by independent voluntary bodies who receive funding from the state (Carroll et al., 2013; Inclusion Ireland, 2012). These services unquestionably provided innovative interventions and were pivotal in dismantling large institutions for people with an ID (Linehan et al., 2014). However, because of their uncoordinated development, they were delivered with varying philosophies underpinning their practice and a dearth of general uniformity in their approach to supporting families of children with disabilities (Carroll et al., 2013).

2.4.1 Progressing Disability Services

'Progressing Disability Services for Children and Young People' (PDS) is a reformative programme established to address the ad hoc development of Irish DS, and to create a more equitable and standardised form of service delivery for children with disabilities (Health Service Executive, 2020a, 2020b; MacLachlan, 2019). The process of coordinating the implementation of this programme began in 2010 and is ongoing. The HSE has outlined twelve core principles of PDS to influence and inform the delivery of services (Carroll et al., 2013). These principles can be seen in table 2 below. PDS requires resources from HSE services and voluntary bodies to be pooled in the formation of Children's Disability Network Teams (CDNTs). CDNTs are newly-established interdisciplinary teams that provide services for children with disabilities and complex needs (Health Service Executive, 2020b). Once reconfiguration has been achieved nationwide, the intention is that all CDNTs will work to the same model of service delivery which should bring uniformity and equity to the provision of DS in Ireland (Health Service Executive, 2020b; MacLachlan, 2019).

Table 2: *Principles of PDS*

12 Core Principles of PDS:		
1. Accessibility	2. Accountability	3. Bio-psychosocial model
4. Clinical governance and evidence-based practice	5. Cultural competence	6. Early detection and referral
7. Equity of access	8. Evaluation of outcomes	9. Family-centred practice
10. Inclusion	11. Interdisciplinary Team Working	12. Staff are valued and respected

2.4.2 Family-Centred Practice

A central tenet of PDS is that a family-centred practice (FCP) approach to service delivery is adopted (McCarthy & Guerin, 2021; National Disability Authority, 2015). While there has been evidence of FCP in DS in Ireland since at least the 1980s (Carroll et al., 2013), services have formally subscribed to the FCP model for over a decade. This PDS principle has influenced service provision even prior to full national reconfiguration (Health Service Executive, 2020b). FCP is established as best practice in paediatric service delivery in Ireland and internationally (McCarthy & Guerin, 2021). FCP is pertinent to the present study as it is positioned as part of the family systems paradigm (Dempsey & Keen, 2008). The underlying philosophy of FCP is that family support is vital in the lives of children with additional needs, and as such, families should be empowered to engage in decision making with them (Raghavendra et al., 2007). FCP is a partnership approach to healthcare, underpinned by the premise that the wellbeing and needs of a child are best met within the family system guided by consultation and collaboration with external professionals (Neff et al., 2003). This model of practice asserts that the care-delivery process and collaboration between family and service is as important in achieving successful child and family outcomes as direct assessment and intervention work (Espe-Sherwindt, 2008; McCarthy & Guerin, 2021).

For FCP to be implemented with fidelity, there should be a sharing of unbiased and complete information by practitioners, and parental involvement should be meaningful, individualised, flexible, coordinated and responsive (Wright et al., 2010). Parents' feelings of self-confidence and the quality of the family-team partnership is what defines effective delivery of family-centred practice (Rouse, 2012). There is evidence to suggest that while FCP has a strong conceptual basis, the operationalisation of FCP in practice and its true efficacy in service delivery requires further empirical support (McCarthy & Guerin, 2021). Much of the literature describes FCP as a unidirectional practice when in reality, the relationships within an FCP approach need to be conceptualised ecologically (McCarthy & Guerin, 2021; Shields, 2015). The mutual and interactive process of the therapeutic relationship between child, family and service must be considered at the micro level, while the wider, systemic variables that influence the implementation of FCP must also be considered to truly understand this practice (McCarthy & Guerin, 2021). The present research seeks to add to this evidence base with a particular emphasis on the inclusion of fathers within the FCP model of service delivery. To deliver services in line with the principles and ideologies set out in PDS, it is vital to meaningfully engaging fathers in the service-delivery relationship, as a central part of the family system.

2.5 Father's Role: An Evolving Concept

Previous literature indicates that fathers of children with disabilities often feel undervalued, alienated, excluded and overlooked in many facets of their child's life (Carpenter & Towers, 2008; King et al., 2007; MacDonald & Hastings, 2010) including in a service delivery relationship (Flippin & Crais, 2011; Giallo et al., 2015; Marsh et al., 2020). Previous research suggests that fathers are often cast in a secondary role with a presumption that the mother of the child is the primary caregiver (Boyd et al., 2019; Molloy & Pierro, 2020). This can result in fathers being left on the periphery in many areas of child care, which may affect engagement with services for their child (Flippin & Crais, 2011; Ly & Goldberg, 2014).

In recent years, notable social changes have seen the role of mothers and fathers evolving (Marsh et al., 2020). The role of the father developed significantly during the twentieth century, moving from a disciplinarian and breadwinner model to a more multidimensional role, involving other elements, such as nurturing and support to accompany traditional expectations (Boyd et al., 2019). In a recent study on father involvement with social services, Molloy and Pierro (2020) propounded that a more contemporary father figure has emerged from shifts in expectations of what fathering means. According to Molloy and Pierro (2020) "as the societal norm of what it means to father is changing toward a new understanding of fathering, men's identity and involvement with their children is shifting" (p. 2). While this may be the case, evidence would still suggest that fathers are considerably less involved in many facets of the lives of children than mothers (Marsh et al., 2020). This includes involvement in therapeutic support and care, and is true even when both parents are in full-time employment (MacDonald & Hastings, 2010; Roach et al., 1999).

2.5.1 Father Involvement

There is a developing literature base regarding the contribution that fathers can make to the behavioural, cognitive and social development of their children (McBride et al., 2017). Research in the context of neurotypical children has found that increased father involvement is beneficial in terms of reducing behavioural problems in infants (Frosch et al., 2001) and teenagers (Carlson, 2006). Furthermore, increased father involvement has been correlated with enhanced language acquisition and cognitive development in the early years (Roggman et al., 2007).

The research base pertaining to father involvement with children with disabilities is somewhat less developed, but findings point towards similar benefits for this population. For example, in systematic reviews regarding father involvement in the presence of disability, Flippin and Crais (2011) and Quinn (1999) found that it can promote increased childhood competence and social skills. Moreover, father involvement has also been linked with increased cognitive skills in children with disabilities (Ricci & Hodapp, 2003). Simmerman et al. (2001) highlight that father involvement can positively impact on the wider family system, with mothers of children with ID reporting less stress when satisfied with their partner's involvement and contribution to childcare. Crowe and Florez (2006) found that in families of children with disabilities, father involvement is even more important because of the increased time required to meet the child's care needs. In general, children with an ID have complex, lifelong needs and they are reliant on support from their family members, particularly their parents, across the entire lifespan (Giallo et al., 2015; Olsson & Hwang, 2001). Parents of children with an ID face many challenges and difficult decisions, and are at greater risk of developing poor mental health than parents of typically developing children (Giallo et al., 2015; Olsson & Hwang, 2001). Davis et al. (2017), asserts that access to appropriate services and the development of a strong clinical relationship is crucial for maximising parental quality of life. This suggests that engaging and involving fathers with DS could have significant benefits for the entire family system. In support of this assertion, Laxman et al. (2015) discovered that effective father engagement with DS promotes positive family outcomes, including enhanced role definition for fathers and reduced depressive symptoms in mothers.

2.5.2 Father Engagement with Disability services

It is consistently reported in the research literature that fathers are a difficult population to engage in clinical relationships (Carpenter & Towers, 2008; McConkey, 1994). Fathers are seen as less willing to engage with the clinical relationship and the process of service delivery than mothers (Carpenter & Towers, 2008). This has seen services focusing on mothers, who are often regarded as more engaged and knowledgeable than fathers (Carpenter & Towers, 2008; Huang et al., 2012; McBride et al., 2017). Constraints regarding employment, social support and parental relationship status can also play a part in hindering father engagement with services (Fox et al., 2015). According to Molloy and Pierro (2020), services make efforts to deliver 'father-friendly' programmes with the aim of engaging fathers, but there is a lack of understanding of what 'father-friendly' actually means. Thus, such programmes can be based on assumptions of gender norms and societal norms of the role of the father (Panter-Brick et al., 2014). This can be harmful and limiting to the role identity of fathers (Fox et al., 2015) and undermine the emotional needs of fathers. Failing to involve fathers - as a key member of the family system - undermines the ideologies that are set out in the FCP model of service delivery (McCarthy & Guerin, 2021). Engaging fathers with DS could help children with ID/DD to reach their potential, while empowering fathers in the service delivery relationship could help to develop parental self-efficacy (Fox et al., 2015; Laxman et al., 2015).

2.5.3 Psychologists in Disability Services

Engaging families with DS is part of the role of practitioners working on multidisciplinary teams within services. Services are embodied by these clinicians who interact with families during appointments and consultations. Moreover, the practices adopted by these clinicians can help to promote or hinder FCP in services (Weglarz-Ward et al., 2019). Within Irish DS, CDNTs are comprised of practitioners from various disciplines including speech and language therapists, occupational therapists, physiotherapists, social workers and psychologists. It is beyond the scope of the present study to gain the perspectives of professionals from each of these disciplines. Therefore, the perspective of psychologists was selected as the most pertinent perspective to procure within the present study.

Psychologists are important members of disability service teams who serve many functions within these teams (Beard & Barter, 2016). A key aspect of the psychologist's role is to provide family support and to engage families in an assessment and intervention process. They are the diagnosticians on clinical multi-disciplinary teams who have a particular expertise in the area of child development (Carr, 2015). Moreover, they play a particularly important role in fostering FCP within a service because they are often linked in with a family early in their voyage with DS, helping to establish the relationship between service and family (Brothers of Charity, 2013; Gaskin, 2015). Psychologists working in DS help families to understand and come to terms with their child's disability, and offer practical support and advice to families to promote positive, alternative understandings of disability (Gaskin, 2015). Furthermore, by adopting a biopsychosocial lens, psychologists endeavour to understand the family system which should, in theory, help to promote FCP in DS (Smith & Nicassio, 1995; Woods, 2019). While the experiences of psychologists are sought within the present research, this review will enquire into the views and experiences of practitioners working in DS to gain a broad understanding of previous research in this area, which will inform the research process.

2.6 Rationale for this Review

The evidence presented in this section suggests the need for a deeper understanding of the role fathers can play in the lives of children with ID. The BMHD (Bronfenbrenner & Morris, 2006) asserts there are many variables in wider society that can impact the involvement of fathers with their children, while FST (Bowen, 1974) asserts that maximising father involvement is necessary to fulfil the potential of the family system. In terms of service delivery, family-centred practice has its roots in FST and this approach to service delivery is regarded as international best practice (Health Service Executive, 2020a). While the family-centred service delivery model includes the father theoretically, the actual extent of father involvement in practice remains unclear and in need of further exploration (Fox et al., 2015). Furthermore, while interest in the fathers' perspective is growing, research on families of children with disabilities has largely focused on the views of mothers, taking this perspective as representative of both parents (Boyd et al., 2019).

With all of this in mind, the aim of the present systematic review is to critically appraise the available international research literature on father involvement and engagement with their children with ID or DD. This review places a particular emphasis on research that has been accrued from the perspective of fathers and from the perspective of professionals working in DS.

The Current Review

2.7 Review Questions:

- What are the processes and outcomes associated with father engagement with services for their children with an ID/DD?
- What are the factors and experiences that influence father involvement in interventions and programmes for their children with an ID/DD?

2.8 Search Strategy

A literature search was conducted in August 2020, and replicated in January 2022 to capture the most contemporary research for this review. The databases selected for this search process were identified based on some other notable systematic reviews compiled on the experiences of fathers of children with an ID (Bogossian et al., 2019; Burcher et al., 2021; Marsh et al., 2020). The following databases were systematically searched:

- Academic Search Complete
- APA PsycINFO, Education Source
- ERIC
- CINAHL complete
- Medline

To facilitate a detailed search for relevant literature to be included in this review, the ‘multifield’ search function was used. The search terms adopted were as follows: (“Father Involvement or Father Engagement”) and (“Disability or Intellectual Disability or Developmental Disability or Developmental Delay or Mental Retardation) and (“Children or Adolescents or Youth or Child or Teenager”) and (“Service or Programs or Interventions or Resources”). Multiple terms were used in each search field in an endeavour to capture as much relevant literature as possible that could then be screened against the inclusion and exclusion criteria which is outlined in table 3.

Table 3: *Literature Search Inclusion and Exclusion Criteria*

Criteria	Inclusion	Exclusion	Rationale
1. Publication Type	The study has been published in a peer-reviewed journal	The study has not been published in a peer-reviewed journal	The study should be of a certain academic standard
2. Publication date	The study has been published in the previous 20 years	The study has not been published in the previous 20 years	The publication date of the study should be recent in order to provide contemporary findings
3. Language	The study has been published in the English language.	The study has not been published in the English language	It is preferable that the study has been published in English for readability and understanding of the articles
4. Study Type	The study must use original, primary data	The study uses secondary data (e.g. a review study or a study using secondary analysis)	The systematic review requires studies that have gathered primary data.
5. Participants	The study must include the perspective of fathers of children with ID/DD, or service providers working with fathers of children with ID/DD	The study does not include the perspective of fathers of children with ID/DD, or service providers working with fathers of children with ID/DD	The review question is concerned with appraising the perspective of fathers of children with ID or the perspective of service providers working in services for children with ID
6. Measure / Results	The study must assess father involvement either qualitatively, quantitatively or through mixed-methods	The study does not assess father involvement either qualitatively, quantitatively or through mixed-methods	The review question is concerned with father involvement

2.9 Search Results

The initial search found 125 articles for review. Following the removal of duplicate articles, 72 texts remained for title screening. The title of each article was read and they were assessed in terms of relevance to the review questions and the inclusion and exclusion criteria that was set out. Following the process of title screening, a further 34 texts were removed as prospective possibilities for this review. This left 38 articles for abstract screening. This process involved the screening of the abstracts of the remaining articles while applying the inclusion and exclusion criteria outlined in Table 3 to each article. Twenty two articles were excluded following abstract review, leaving 16 studies for full text review. Of these remaining articles, 11 met the inclusion criteria for the present review. The search process is illustrated in the PRISMA flow chart in figure 2 (Liberati et al., 2009). The 11 articles included in this review are listed in Table 4. These articles are mapped out and summarised below, as recommended by Gough et al. (2017), in table 5.

Figure 2: *Systematic Review Search Process PRISMA Flowchart*

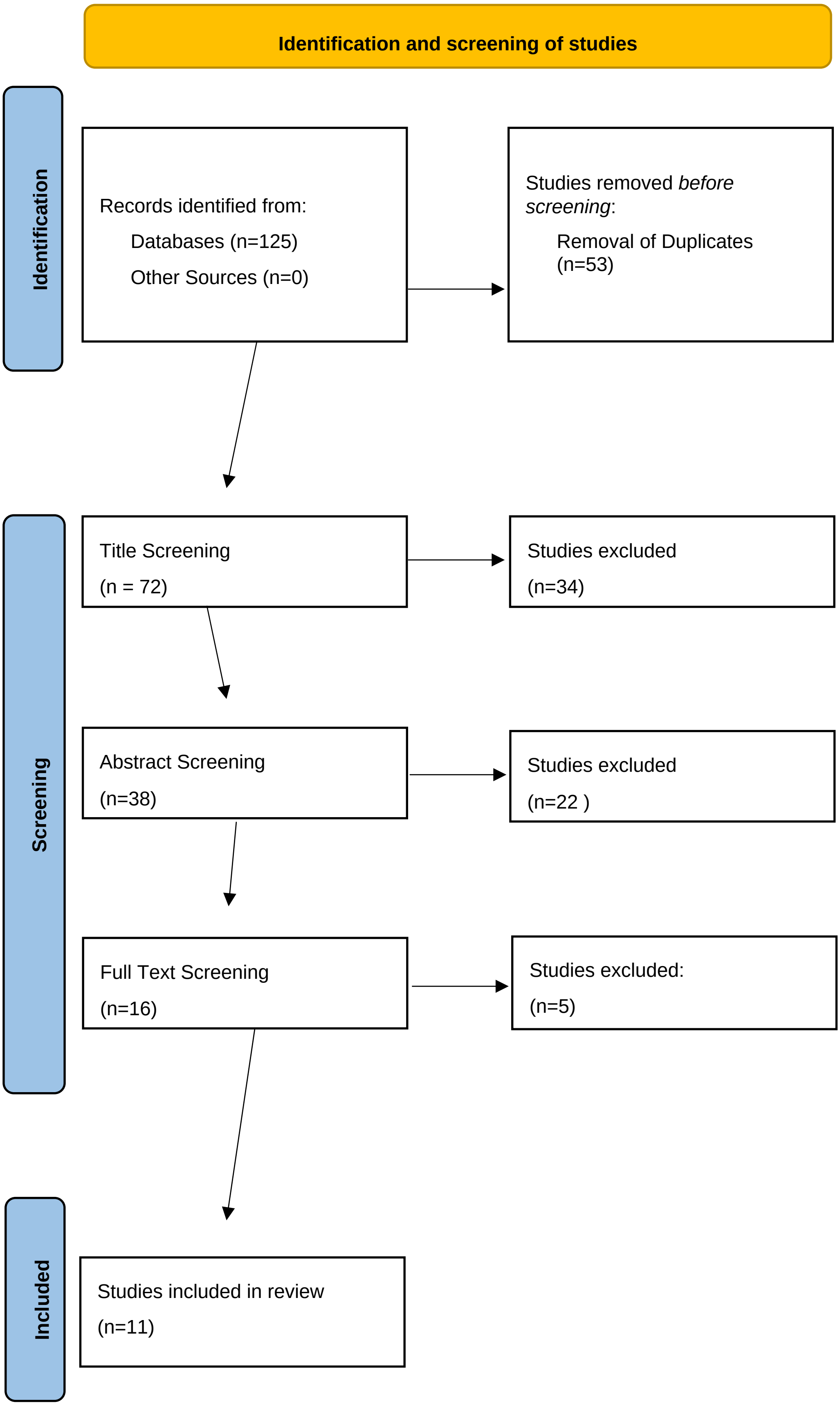


Table 4: Summary of Studies Included in Systematic Review

Study Citation
1. Bagner, D. M. (2013). Father's role in parent training for children with developmental delay. *Journal of Family Psychology, 27*(4), 650-657.
2. Curtiss, S. L., McBride, B. A., Uchima, K., Laxman, D. J., Santos, R. M., Weglarz-Ward, J., & Kern, J. (2021). Understanding provider attitudes regarding father involvement in early intervention. *Topics in Early Childhood Special Education, 41*(2), 147-159
3. Docherty, F., & Dimond, R. (2018). “Yeah that made a big difference!”: The importance of the relationship between health professionals and fathers who have a child with down syndrome. *Journal of Genetic Counselling, 27*(3), 665-674.
4. Fox, G. L., Nordquist, V. M., Billen, R. M., & Savoca, E. F. (2015). Father involvement and early intervention: Effects of empowerment and father role identity. *Family Relations*, *64*(4), 461-475.
5. Huang, Y. P., Chen, S. L., & Tsai, S. W. (2012). Father’s experiences of involvement in the daily care of their child with developmental disability in a Chinese context. *Journal of Clinical Nursing, 21*(21-22), 3287-3296.
6. May, F. S., Mclean, L. A., Anderson, A., Hudson, A., Cameron, C., & Matthews, J. (2013). Father participation with mothers in the signposts program: An initial investigation. *Journal of Intellectual & Developmental Disability, 38*(1), 39-47.
7. McBride, B. A., Curtiss, S. J., Uchima, K., Laxman, D. J., Santos, R. M., Weglarz-Ward, J., Dyer, W. Jeans, L.M. & Kern, J. (2017). Father involvement in early intervention: exploring the gap between service providers’ perceptions and practices. *Journal of Early Intervention*, *39*(2), 71-87.
8. MacDonald, E. E., & Hastings, R. P. (2010). Mindful parenting and care involvement of fathers of children with intellectual disabilities. *Journal of Child and Family Studies*, *19*(2), 236-240.
9. Oryono, A., Iraguha, B., Musabende, A., Habimana, E., Nshimyiryo, A., Beck, K., Habinshuti, P., Wilson, K., Itangishaka, C., & Kirk, C. M. (2021). Father involvement in the care of children born small and sick in rwanda: Association with children's nutrition and development. *Child : Care, Health & Development, 47*(4), 451-464.
10. Sheldon, J. P., Oliver, M., & Yashar, B. M. (2020). Rewards and challenges of parenting a child with Down syndrome: a qualitative study of fathers’ perceptions. *Disability and Rehabilitation,* 1-12.
11. Simmerman, S., Blacher, J., & Baker, B. L. (2001). Fathers’ and mothers’ perceptions of father involvement in families with young children with a disability. *Journal of Intellectual and Developmental Disability*, *26*(4), 325-338.

Table 5: *Mapping/summary of included studies*

Study	Location	Participants	Data Collection Method	Design	Outcomes
Bagner (2013)	United States	44 families of children with a DD and externalising behaviour	Survey following parent training	Quantitative	Single-mother families were significantly more likely to drop out of the intervention than two parent families. Externalising behaviour was lessened with father involvement in this programme.
Curtiss et al. (2021)	United States	511 EI service providers' perspectives on father involvement and engagement	Open ended Survey	Qualitative	Providers reported that increased father involvement and engagement with the service was positive. Providers identified barriers to father involvement e.g. systemic and cultural factors. Some providers believed it was not their responsibility to engage fathers.
Docherty & Dimond (2017)	United Kingdom	7 fathers of children with Down Syndrome	Interviews	Qualitative	Negative experiences with services for these fathers resulted from feeling excluded, receiving negative information about their child's condition and a perceived lack of support. Positive experiences with services came from being made to feel like an equal parent, being given clear information.

Fox et al. (2015)	United States	Fathers of 141 children with Developmental Delay	Father Role Salience Scale Reflected Appraisals of Fathering Father Role Satisfaction Scale	Quantitative (Correlation)	Higher levels of father empowerment and father role identity consistently predicted higher levels of father involvement.
Huang et al. (2012)	China	Fathers of 16 children with Developmental Delay	Interview	Qualitative	Father Involvement was impacted by the hope that clinicians gave them in terms of their child having a reasonable quality of life, the perceived quality of services being provided to their children and maximising family function.
May et al. (2013)	Australia	134 fathers and mothers who participated in the signposts program (compared with 483 mothers who participated without fathers)	Pre and post intervention (Signposts Program)	Quantitative	While all participants experienced positive results from participating in the signposts program, mothers who participated alongside fathers showed a higher benefit than mothers who participated alone.
McBride et al. (2017)	United States	511 Early Intervention clinicians	Open ended Survey	Mixed-methods	Father Involvement can have a positive impact on service outcomes, however services identified

					barriers that limited their ability to successfully engage fathers.
MacDonald & Hastings (2010)	Ireland	105 fathers of children with ID	Parental Involvement in childcare measure	Quantitative (Correlation)	Father involvement in parenting tasks and child socialisation related to higher levels of reported mindfulness
Oryono et al. (2020)	Rwanda	Fathers and mothers of 226 children born pre-term, with developmental delays and at risk of developing ID.	Interviews Ages and Stages Questionnaire	Mixed-methods	Father involvement in childcare was mediated by household size and the extent to which the mother was involved. Father engagement was significantly and positively associated with the child’s overall development.
Sheldon et al. (2020)	United States	175 fathers of children with DS	Open-ended Survey Questionnaire	Qualitative	Father-child bond found to be strong, barriers to involvement include system and institutional problems and negative attitudes of other people.
Simmerman et al. (2001)	United States	60 families of children with severe ID	Father help and satisfaction scale Perceived burden of care scale	Quantitative (Correlation)	Father involvement and help highest in areas of playing, nurturing, discipline and deciding on services

2.10 Critical Appraisal

Following the identification of the studies to be included in this review, it was necessary to evaluate and appraise them in terms of their methodological quality and relevance to the review question. Gough's (2007) weight of evidence (WoE) framework was used to critically appraise the selected studies. This is a widely used critical appraisal tool that outlines that studies should be assessed based on their methodological quality (WoE A), their methodological relevance (WoE B) and the relevance of the study to the review questions (WoE C) (Gough, 2007). An overall weighting of these three scores was then attained based on the overall relevance of the studies in answering the review question (WoE D).

WoE A is a method for assessing the quality of execution of the studies selected for review (Gough, 2007). This is not a review specific critique, but rather a critique of the overall methodological quality of the study. In the present review, studies adopted quantitative, qualitative, mixed-methods and correlational approaches to research. It was necessary to use quality indicators tailored for each of these research approaches in ascertaining a WoE A score. An adapted version of a checklist for critically analysing correlational and causal comparative studies developed by Mertens (2014) was used as a means of appraisal for the correlational studies included in this review. The adapted version of this form used in the current review assesses the methodological quality of studies across 6 judgment areas. 'The Critical Review Form for Qualitative Studies' (Letts et al., 2007) was used to appraise the qualitative studies. The most relevant sections of this form in terms of methodological quality are: Study design, Sampling, Data Collection and Procedural Rigour. In the present review, qualitative WoE A scores were attained from an accumulative score of these sections. The Mixed-Methods Appraisal Tool (Hong et al., 2018) was utilised to assess the mixed method studies included in this review. Finally, the Quality Assessment Tool for Quantitative Studies (Thomas et al., 2004) was used as a means of attaining a WoE A score for the quantitative studies. Further details on WoE A scores, as well as examples of the use of these appraisal tools, can be found in Appendix 1.

WoE B is concerned with the appropriateness of the evidence gathered in the studies in answering the review question (Gough, 2007). The present review question was concerned with gathering the perspectives and experiences of participants. This was taken into account in the conceptualisation of the criteria for WoE B. All of the studies consulted in this review used either interview or survey methods for data collection, and these are two appropriate methods of data collection for incorporating the perspectives and experiences of the participants (Mertens, 2014). Therefore, for the WoE B scoring, it was decided that these methods of data collection should be appraised. Data saturation in interview approaches (Mertens, 2014) and high response rate (70%+) in survey studies are considered to be a high standard of research practice (Mertens, 2014). Using the aforementioned guiding principles, studies that showed evidence of data saturation in interviews and higher response rates in surveys were afforded higher WoE B scoring

Weight of evidence C relates to the relevance of the study and its findings to the review (Gough, 2007). In the present review, WoE C criteria was set based on the sample population in question in these studies. Gough (2007) notes that it is important that the sample being scrutinised is from an appropriate context to answer the review question. Some studies included in this review used the views of fathers combined with mothers on father involvement, while others featured fathers of children with other disabilities aside from ID or DD. Furthermore, studies that incorporated the views of practitioners working in services were relevant to the present review question. WoE C scores were afforded on the basis of studies that showed evidence of investigating the most relevant samples to the research question, i.e. studies that exclusively investigated the views of fathers or practitioners working in DS, and studies that focused exclusively on ID or DD were afforded a higher WoE C score.

Finally, WoE D scores were obtained by calculating the average sum of the scores across WoE A, WoE B, and WoE C. A detailed account of WoE criteria and scoring is provided in the appendices. These sections outline specific quality indicators used to provide the WoE scores, and the scores of each WoE section is also tabulated in the appendices. A summary of the WoE scores for each article is provided in Table 6.

Table 6: *Summary of WoE scores for each study*

Study Citation	Research Methodology	WoE A score	WoE B Score	WoE C Score	WoE D Score
Bagner (2013)	Quantitative	2	3	1	2
Curtiss et al. (2021)	Qualitative	3	3	2	2.66
Docherty & Dimond (2017)	Qualitative	3	2	2	2.33
Fox et al. (2015)	Quantitative (Correlation)	3	2	2	2.33
Huang et al. (2012)	Qualitative	3	3	2	2.66
MacDonald & Hastings (2010)	Quantitative (Correlation)	3	2	2	2.66
May et al. (2013)	Quantitative	1	3	1	1.66
McBride et al. (2017)	Mixed-methods	3	3	2	2.66
Oryono et al. (2020)	Mixed-methods	2	3	1	2
Sheldon et al. (2020)	Qualitative	2	2	2	2.33
Simmerman et al. (2001)	Quantitative (Correlation)	3	3	1	2.33

2.11 Study Characteristics and Participant Demographics

The studies included in this review reflect international findings on father involvement with their child with ID or DD and engagement with services for their children. Six of the studies were carried out in the United States (Bagner, 2013; Curtiss et al., 2021; Fox et al., 2015; McBride et al., 2017; Sheldon et al., 2020; Simmerman et al., 2001), one study was carried out in the United Kingdom (Docherty & Dimond, 2018), one study was carried out in China (Huang et al., 2012), one study was carried out in Australia (May et al., 2013), one study was carried out in Rwanda (Oryono et al., 2021) and one study was carried out in Ireland (MacDonald & Hastings, 2010). The number of participants in these studies ranged from 7 fathers (Docherty & Dimond, 2018) to 511 practitioners (McBride et al., 2017) and the collated sample of the studies in this review included 1359 fathers and practitioners across the 11 studies.

In terms of participant demographics, there was some variability across the studies included in this review. According to Gough (2007), it is important that the sample being scrutinised is from an appropriate context to answer the review question. The review question sought to explore the factors that influence father involvement with their children with ID and father engagement with DS. The aim of this review process was to appraise the perceptions of fathers and of practitioners working in DS on this question. Therefore, studies that exclusively investigated the views of fathers and practitioners working in DS, and studies that focused exclusively on ID or DD would have been considered the optimal population demographic to be incorporated in this review. However, studies that did not entirely meet this standard were also considered relevant to the present review. For example, some of the included studies used the views of fathers and mothers on father involvement, and others featured fathers of children with other disabilities aside from ID or DD (although, it was necessary that ID or DD were featured in the study to meet the inclusion criteria outlined in Table 3). Furthermore, only two studies incorporated the views of DS (Curtiss et al., 2021; McBride et al., 2017), but did not state the roles of the practitioners that were surveyed on father engagement. In the process of critically appraising these papers, this was taken into account and higher WoE C scores were afforded to studies that showed evidence of investigating the most relevant populations to the research questions.

2.12 Research Design

The eleven studies included in this review analysed father involvement across a variety of ecological and social contexts. These studies focused on different variables and conditions within ecological microsystems and mesosystems that were considered pertinent in potentially impacting the extent of father involvement with their child with ID or DD (Bronfenbrenner & Morris, 2006). The studies used an array of data collection methods and research approaches in examining the phenomenon of interest.

Three of the studies in this review used a correlational approach in examining father involvement with their child with ID or DD (Fox et al., 2015; MacDonald & Hastings, 2010; Simmerman et al., 2001). These studies used various survey instruments to measure father involvement (see Table 7), and looked at relationships between father involvement and other variables. For example, Fox et al. (2015) examined how empowerment and father identity would impact father involvement. MacDonald and Hastings (2010) looked at the relationship between having a mindful parenting approach and father involvement. Simmerman et al. (2001) examined how maternal satisfaction and stress was related to father involvement with their child with ID.

Four of the studies in this review used a qualitative design in examining father engagement with their child and with services. Huang et al. (2012) adopted a phenomenological approach to understanding father involvement in the everyday lives of their children with a DD. This study used interviews to gain an in-depth perspective on father involvement, utilising thematic analysis to summarise arising themes related to father involvement. Participants in this study were fathers of children with a developmental delay attending an early intervention disability service in Taiwan. Docherty and Dimond (2018) interviewed fathers of children with Down Syndrome on their experiences with health professionals, using an interpretative phenomenological analysis to understand these lived experiences. Sheldon et al. (2020) also utilised a qualitative approach endeavouring to elucidate the perceptions of fathers on the rewards and challenges associated with parenting a child with Down Syndrome. This study used an open-ended survey approach, and responses were analysed through inductive content analysis. Curtiss et al. (2021) also used an open-ended survey approach to qualitative data collection.

Two studies in this review adopted a mixed-methods approach in looking at father engagement with their child and their child's DS. McBride et al. (2017) engaged the views of professionals working in DS with regard to father involvement with their children with ID and father engagement with services. This study used an online survey of professionals working in Early Intervention (EI) services which incorporated a measure of father involvement in EI and open-ended survey questions regarding perceived barriers to engagement. Oryono et al. (2021) combined an open-ended, qualitative survey with a measure of child development to ascertain the impact of father involvement in children with a DD. This survey was completed by fathers and mothers of children born prematurely who had been identified with a DD.

Finally, the remaining two studies in this review used quantitative methods to explore father engagement with services. Bagner (2013) measured the impact of father involvement in a Parent Child Interaction Therapy intervention training programme. The findings of the father-involved group (i.e. fathers and mothers completing intervention training) were compared with findings from a single mother group (Bagner, 2013). May et al. (2013) adopted a similar approach in their research. A group of mothers and fathers who participated in the signposts programme, which is a programme specifically designed for parents of children with an ID, were compared with a group of mothers who participated on this programme on their own. Pre and post intervention data was gathered from both of these groups.

2.13 Data Collection Methods and Findings

All of the studies in the present review sought to acquire participant perceptions and experiences on father engagement and involvement with their child and with their child's services. These perceptions and experiences were captured through survey and interview approaches. According to Mertens (2014) surveys are an effective method for understanding social dynamics and the participant perspective within a large population sample. Qualitative interviews are a useful approach in gaining in-depth knowledge of a topic and in allowing the perspectives of the participants to emerge (Barker et al., 2015). With this in mind, it was important to appraise the quality of such approaches. The criteria set out in WoE B (Appendix 2) looked to achieve this by assessing whether the surveys utilised had achieved a high response rate, and whether the qualitative interviews undertaken had reached a point of data saturation. Seven of the studies included in this review achieved this criteria by reporting response rates and data saturation (Bagner, 2013; Curtiss et al., 2021; Huang et al., 2012; May et al., 2013; McBride et al., 2017; Oryono et al., 2021; Simmerman et al., 2001) while four studies either failed to report saturation or response rate, or showed lower response rates (Docherty & Dimond, 2018; Fox et al., 2015; MacDonald & Hastings, 2010; Sheldon et al., 2020) and this was reflected in their WoE B scores.

In the present review, a variety of measures were employed to examine different elements of father involvement and engagement. Table 7 summarises these instruments and highlights details of reliability and validity that were shared in these studies. Some studies looked at the direct involvement of fathers, others used parental satisfaction as the unit of measurement, while others focused on the perceived role salience of fathers in the context of disability. A cohort of studies adopted a different approach to looking at the benefits of father involvement by measuring child outcomes, using pre and post measures following interventions that fathers were involved in.

Paternal involvement with their children was a focus of some of these studies. For example, MacDonald & Hastings (2010) used the *Parental Involvement in Childcare Measure* to assess the extent of father involvement in everyday childcare tasks. This measure considered fathers' perceived involvement in daily activities with their children with an ID, such as dressing, feeding and putting the child to bed. This measure found that fathers who did not work outside of the home and who had younger children with ID were more involved in daily care tasks. Fathers were also more likely to be involved in socialisation-related parenting tasks when their child was male and their partner worked outside of the home (MacDonald & Hastings, 2010). Simmerman et al. (2001) measured the amount of help that fathers provided and their parental satisfaction, as well as fathers' and mothers' perceived burden of care in the context of having a child with an ID. The *Father Help and Satisfaction Scale* was used in this study, which measures the satisfaction of both parents regarding father parental contributions. It was found that fathers contributed with specific tasks e.g. playing and nurturing, but were less involved in other tasks e.g. teaching/therapy and attending service appointments. The *Perceived Burden of Care Scale* found that mothers who were satisfied with fathers' involvement and child caring reported lower caretaker burden, while mothers who were less satisfied with the contribution of fathers in the family system perceived their burden of care to be greater. Similar results were reported by May et al. (2013), who used the *Parenting Hassles Scale* to measure the daily stresses experienced by families of children with a disability following a parenting intervention. Families with involved fathers reported lower levels of daily stresses than single mother families (May et al., 2013).

Fox et al. (2015) looked at father empowerment and how this related to father involvement and engagement with early intervention services in the context of having a child with a disability. Feeling empowered through collaboration with services rather than having a paternalistic relationship with services was found to predict father involvement in this study (Fox et al., 2015). This study also measured father role salience and satisfaction. These two variables were found to be highly correlated with each other, and had a modest correlation with father engagement. It concluded that the strongest predictor of father involvement and engagement with early intervention services was the empowerment of fathers in the service relationship (Fox et al., 2015).

Three of the studies in this review were concerned with measuring child outcomes following father involvement in an intervention programme. These studies lend weight to the previously discussed benefits of father involvement, including reduced maternal stress and positives in terms of child development. Oryono et al. (2021) found that fathers are more likely to be involved with their children if mothers are supportive of the fathers role and that children’s development was positively impacted by father involvement in this cohort of children with a DD, as measured by the *Ages and Stages Questionnaire.* May et al. (2013) lend weight to this assertion, as measured by the *Developmental Behaviour Checklist.* Bagner (2013) used the *Child Behaviour Checklist* to rate externalising behaviours among children with a DD. This measure was completed with families prior to a Parent-Child Interaction Therapy intervention, and father-present families were compared with absent father families. This study reported that externalising behaviours were more significantly reduced in father-present families than absent father families following the intervention training. Once again, this finding shows the importance of father engagement, and the benefits of father involvement. May et al. (2013) used two different measures to assess child behaviour and development before and after an intervention using the Signposts program. These were *The Developmental Behaviour Checklist* and the *Difficult Behaviour Assessment Form.* While mothers generally reported improved scores on these subscales following the completion of the Signposts programme, the effect size was greater among mothers who participated in this programme alongside a father.

It is noteworthy that, while these studies all looked at father involvement and engagement, they did so using indirect measures. No direct measure of father engagement was applied in any of these studies. Rather than directly trying to explore father engagement levels, these studies looked at factors that might influence father engagement, or conducted pre and post measures of the benefits of father engagement. Furthermore, many of the measures and questionnaires administered in these studies were general parental questionnaires, or adapted versions of questionnaires that were originally designed to be completed by mothers.

Table 7: *Measures Employed in Reviewed Studies*

Survey Instrument and study in which survey was used	**Measures:**	**Reliability**	**Validity**
Ages and Stages Questionnaire (Oryono et al., 2021)	Child development outcomes	Not reported	Not reported
Family Care Indicator (Oryono et al., 2021)	Mothers and fathers' level of involvement and availability with their children	Not reported	Not reported
Child Behaviour Checklist (Bagner, 2013)	Problem and externalising behaviours in children	High	High
Father Role Salience Scale (Fox et al., 2015)	Salience of the father role to a man's identity	High	Not reported
Family Empowerment Scale (Fox et al., 2015)	Family Empowerment in the context of having a child with a disability	High	Not reported
Father Role Satisfaction Scale (Fox et al., 2015)	Satisfaction with being a father	Satisfactory	Satisfactory
Parental Involvement in childcare measure (MacDonald & Hastings, 2010)	Parental involvement in childcare	Not reported	Not reported
Father help and satisfaction scale (Simmerman et al., 2001)	Father participation in the childcare of a child with a disability	High	High
Perceived burden of care scale (Simmerman et al., 2001)	The subjective burden of care giving	Not reported	Not reported

The Parenting Sense of Competence Scale (May et al., 2013)	Perceived parent efficacy and satisfaction	High	Not reported
The Depression, Anxiety and Stress scale (May et al., 2013)	Perceived parent depression, stress, anxiety	High	Not reported
The Parenting Hassles Scale (May et al., 2013)	Daily stresses experienced by families of children with a disability	High	Not reported
The Developmental Behaviour Checklist (May et al., 2013)	Assesses problem behaviours in children with a disability	High	Not reported
The Difficult Behaviour Assessment Form (May et al., 2013)	Assesses child aggression and obedience	Not reported	Not reported

2.14 Synthesis of Findings

The findings of this review exhibit the importance of father involvement and engagement in the lives of children with an ID/DD. These studies have elucidated that the involvement of the father has many benefits regarding the child's development, and the therapeutic relationship between service and family. However, there have also been findings suggesting that involving and engaging fathers is challenging, identifying barriers and hurdles that make it difficult for services to engage fathers, and for fathers to engage with services. Finally, some of these studies have offered findings on ways to try to maximise father involvement and engagement with services. In this section, the main findings from these studies will be synthesised under three broad categories:

1. The Benefits of Father Involvement
2. Challenges and Barriers
3. Fostering Involvement

2.14.1 The Benefits of Father Involvement

Many of these studies have highlighted the unique benefits arising from father involvement with their children and engagement with services. In an open-ended survey of 511 clinicians working in an early intervention service, Curtiss et al. (2021) sought to understand provider attitudes towards father involvement and engagement with services. This study revealed that clinicians noted many benefits regarding the involvement of fathers with their children and with services. Four studies in this review noted the significance of father involvement relating to the impact and efficacy of interventions (Bagner, 2013; Curtiss et al., 2021; May et al., 2013; Oryono et al., 2021).

Curtiss et al. (2021) found that fathers' involvement is important because it establishes more active stakeholders in the family-service mesosystemic relationship, which is ultimately beneficial for child outcomes. More information can be picked up and applied when both parents are present at service appointments as opposed to just one parent being present (Curtiss et al., 2021). Practitioners surveyed in this study attested that when fathers are involved, children achieve desired milestones quicker, and there is a greater carryover of recommendations and programmes from the service to the home environment compared to when just one parent is involved (Curtiss et al., 2021). The findings of May et al. (2013) lend weight to this assertion. This study found that while all parents who participated in the Signposts programme experienced benefits from this training, these were more significant in families where both parents partook in the training. Father engagement resulted in reduced stress for mothers, improved confidence and perceived efficacy as a parent and even reductions in the reporting of child externalising behaviours (May et al., 2013).

Bagner (2013) found significant benefits from father involvement in a Parent-Child Interaction therapy intervention for parents of children with DD and externalising behaviours. In this study, there was a comparison made between involved father families and absent father families. In families where the father engaged with this intervention, there was a greater reduction in reported externalising behaviours and children from the involved father families displayed a greater treatment response in general (Bagner, 2013). Furthermore, this study reported that families with an involved father were nine times more likely to complete the intervention programme than in single-parent families (Bagner, 2013). This was due to the spousal support offered when two parents engaged with the intervention, and the fact that at least one parent was likely able to attend the scheduled intervention sessions (Bagner, 2013). Oryono et al. (2021) reported that father involvement in daily programmes and early learning activities with children with a DD was associated with increased development in these children. This study reported that father involvement in early childhood is pivotal for children who are born with medical vulnerabilities, and that programme interventions need to encourage opportunities for fathers to engage with children to optimise development in children with a DD and other vulnerabilities (Oryono et al., 2021).

The benefits of father involvement in terms of the completion and successful implementation of interventions and programmes is clear from the findings of this review. An interesting observation associated with these findings is that father involvement appears to be beneficial for two distinct reasons that reflect relationships within the microsystem and the mesosystem. Firstly, having a second parent present means that communication is enhanced and that families are more likely to translate the information provided by services to the home environment. Secondly father involvement is useful for intervention completion and implementation because fathers appear to have a unique influence and role to play. The father being involved brings more balance to an intervention programme. Curtiss et al. (2021) asserted that children show increased attention and engagement when the father is involved. Findings suggest that fathers have a unique role in this regard because children enjoy gaining attention from their father, while fathers can also have more realistic expectations for children and have a different role from mothers in terms of discipline (Curtiss et al., 2021). Parents can work together and develop a shared understanding of their child’s needs (Curtiss et al., 2021). Moreover, the father being involved allows clinicians working in services to gain an enhanced insight into the family system by gaining both parents’ perspectives (Curtiss et al., 2021). This facilitates the creation of tailored and individualised family service plan goals.

Curtiss et al. (2021) discussed how increased father involvement benefits the entire family system. According to the participants in this study, engagement from fathers results in mothers feeling more supported. When the stress and burden of having a child with complex needs and negotiating services is equally shared it brings parental parity, which can result in strengthened marital relationships (Curtiss et al., 2021). Simmerman et al. (2001) also found that father involvement can positively impact the wider family system, with mothers of children with ID reporting that they experience less stress when they are satisfied with their partners involvement and contribution to childcare. McBride et al. (2017) highlighted the importance of an equitable division of labour in relationships of parents of children with disabilities to maximise the family system. Interestingly, Huang et al. (2012) and Oryono et al. (2021) found that father involvement was strongly related to being supported and encouraged by their spouse to involve themselves in the service delivery relationship. This suggests a cyclical relationship between father and mother involvement, indicating the importance of this microsystem in terms of the relationship with services in the mesosystem. The more included and encouraged fathers feel, the more likely they are to be involved and engaged, which in turn benefits the family system by reducing maternal stress and burden, and strengthening the marital relationship. Simmerman et al. (2001) noted that to understand father engagement, the dyadic marital relationship has to be considered. It was observed in this study that mothers who value fathers acting in a caregiving role reported less anger, depression and anxiety when the father played an active role, but that mothers who did not value the father acting in a caregiving role experienced elevated emotional problems with increased father involvement and participation. This highlights the importance of the microsystemic relationships within each family system, and how these impact wider, mesosystemic relationships with services (Bronfenbrenner & Morris, 2006).

2.14.2 Challenges and Barriers

While many benefits associated with father involvement and engagement were deduced from the findings of these studies, the challenges and barriers associated with the successful involvement and engagement of fathers also emerged strongly as a theme. These challenges will be considered from the perspectives of fathers and of services to facilitate a balanced understanding of these barriers.

Services' Perspective. McBride et al. (2017) discussed father engagement from the perspective of practitioners working in early intervention DS, and found that, while service providers viewed fathers as having a positive influence on child development, they saw them as challenging to engage. This study showed that service providers viewed fathers as more disengaged and less interested than mothers, generally (McBride et al., 2017). This study noted that the division of labour is an ongoing issue in terms of father engagement with services because more often than not, the father is at work while the mother is the primary caregiver. It was found that fathers often cite work commitments as the reason why they cannot attend service meetings or therapy sessions (McBride et al., 2017). McBride et al. (2017) also found that beliefs of service providers can impact father engagement, as some professionals working in services may believe that fathers lack parental efficacy. Curtiss et al. (2021) found that service providers expressed uncertainty over how to increase father engagement and that many practitioners did not view this as part of their role. A lack of access to fathers means that they cannot engage fathers meaningfully, and some service providers attested that it was not in their power or their remit to try to engage fathers more (Curtiss et al., 2021). It was noted in this study that service providers believed the impetus for father engagement needed to come from fathers and families rather than from services. Of note in the findings of these studies is a disconnect between the attitudes of services toward the benefits of father involvement, and the engagement of fathers by services. It would appear that services recognise the importance and value of the involvement and engagement of fathers, but may not see it as their role to engage fathers.

Fathers' Perspective. From the perspective of fathers of children with an ID/DD, there are interesting findings regarding barriers or challenges they face in engaging with services. Fathers highlighted a culture of bias toward mothers within services which stifled their involvement (Docherty & Dimond, 2018). Fathers can feel like an inconvenience at appointments, and can feel excluded, even when they attend appointments, as the comments and questions of the practitioner are generally directed to the mother (Docherty & Dimond, 2018). Fathers of children with DS highlighted the importance of clear and direct communication with them, as well as inclusive practice from services (Docherty & Dimond, 2018). Docherty and Dimond (2018) expressed in their findings how fathers are often made to feel as though they do not belong at appointments when they attend, and that the appointments are for mothers. In light of this, it is interesting to consider that Simmerman et al. (2001) found that two-thirds of the mothers and fathers surveyed in their study rated fathers as helpful and involved in terms of deciding on services for their child and in child-rearing activities. However, only one-third of respondents reported that fathers were helpful and involved in attending appointments and driving the child to appointments (Simmerman et al., 2001). This suggests that fathers may feel alienated or unwelcome at service appointments, which may result in disengagement. Father participants in the study by Huang et al. (2012) also emphasised how being overlooked and experiencing feelings of powerlessness and uncertainty diminished the likelihood of forming a positive relationship with a service.

One of the main barriers to full engagement and involvement among fathers appears to be the amount of time they feel they can devote to their child (Sheldon et al., 2020). Previous research has described how raising a child with a disability requires increased time devotion to meet the child's needs (Boyd et al., 2019). Fox et al. (2015) mentioned how inflexible work schedules limit fathers' capacity to fulfil their parenting roles. This finding elucidates how the exosystem can impact child development, because work commitments can hinder father engagement with services. MacDonald and Hastings (2010) found that fathers who did not work outside of the home were more likely to be involved in daily care tasks and carried out more child-related parenting tasks. Fox et al. (2015) noted that financial strain has a significant negative effect on father engagement because fathers often see it as their role to provide financially for the family. The financial pressure of caring for a child with an ID was also highlighted as a theme by Sheldon et al. (2020). This was linked to emotional strain, as fathers felt pressure to provide financially for their child with an ID, who would need support for the rest of their lives. McBride et al. (2017) discussed how traditional gender roles continued to impact father involvement with services. According to professionals working in early intervention services, fathers view their role in light of social expectations where they are perceived as providers rather than caregivers (McBride et al., 2017).

Another factor that stifled father involvement with their child was a perceived sense of parenting inadequacy, with fathers reporting frustration with the level of need of their child, and having to negotiate their own stereotypes and prejudices around disability (Sheldon et al., 2020). Once again, this saw fathers focusing on the traditional gender role of provider due to a lack of perceived competence in their ability to perform the necessary caring role when a child has an ID (Sheldon et al., 2020). Fathers also noted that mothers had a specific way of interacting and caring for their child, and that their spouse could not compromise and acknowledge that fathers may have a different approach to parenting to mothers (Sheldon et al., 2020). Finally, fathers noted the challenge of keeping up with systems and paperwork and the constant battle involved with attaining the requisite level of support to meet their child's needs (Sheldon et al., 2020).

2.14.3 Fostering Involvement and Engagement

The findings of the studies included in this systematic review indicate involving and engaging fathers can be challenging for many reasons. However, some suggestions have been provided on how best to involve and engage fathers of children with an ID/DD with services.

Fox et al. (2015) found that empowerment predicted father engagement with services. According to this study, fathers who become empowered by their involvement in family-centred services develop greater confidence in their parenting ability and self-efficacy. Empowerment, which is an intentional outcome of FCP (McCarthy & Guerin, 2021), can shape the nature of father engagement and increase the level of father involvement which highlights the importance of services adopting an FCP approach (Fox et al., 2015). Father participants in the study by Docherty & Dimond (2018) highlighted the importance of their interactions with services, and how such interactions can work to make them feel empowered. By communicating clearly with fathers and involving them meaningfully in the service delivery relationship, fathers become empowered and more inclined to continue to engage with services (Docherty & Dimond, 2018; Fox et al., 2015). Fox et al. (2015) found that role salience and role satisfaction are important predictors of fathering behaviour. Assisting fathers to develop positive interpretations of their roles appears to be a key factor in enhancing father engagement and involvement with services. When fathers have a high level of role salience and satisfaction, they become more responsive to the expectations of others (Fox et al., 2015). This has implications for how services should interact with fathers, highlighting that enhancing a father’s sense of salience, responding positively to engaged parenting, and normalising expectations for father involvement in a range of activities with children may enhance father engagement with services (Fox et al., 2015). In fact, empowerment and enhanced role salience can even negate other issues that may have been stifling engagement, for example financial pressures experienced by fathers (Fox et al., 2015).

Services emphasising that both parents are equally important is a recommendation provided by Curtiss et al. (2021) with regard to enhancing father engagement. Building partnerships with fathers by requesting their opinions and exploring their experiences can help them to feel valued and empowered in the service delivery relationship, which aligns with the FCP model (Curtiss et al., 2021). It is also recommended to offer clinicians continuous professional development opportunities to learn how best to involve fathers in services for their children (Curtiss et al., 2021). Taking practical steps to overcome some practical barriers was also propounded as a potential solution to facilitate father engagement with services. For example, completing consultations on the phone to suit fathers and offering flexible working hours so that fathers can attend appointments (Curtiss et al., 2021). Furthermore, progressing policy initiatives like offering stipends for fathers so that they can take time off work to attend appointments was recommended by early intervention clinicians (Curtiss et al., 2021). The mother has a role to play in engaging fathers, according to many of these studies. Huang et al. (2012) and Oryono et al. (2021) mentioned that father engagement with services is enhanced when they feel encouraged and supported by their partner. Curtiss et al. (2021) emphasised that the mother should be used as a middleman between fathers and services to encourage fathers to engage and participate.

A factor that was implicated in fathers failing to engage with services is that fathers often adopt a long-term view, expressing concerns about their child's future (MacDonald & Hastings, 2010; Sheldon et al., 2020). Fathers worry about what might happen to their child after they have died, and how their child will support themselves financially in the future (Sheldon et al., 2020). This appears to reflect traditional gender roles, where the father is responsible for providing financially for their child (Fox et al., 2015; McBride et al., 2017). Due to such concerns, fathers tend to look at the bigger picture which can mean they are not as engaged and involved in the day-to-day tasks, leaving the mother to engage with such tasks (Pelchat et al., 2003; Sheldon et al., 2020; Simmerman et al., 2001). This is intriguing to consider in light of the finding that fathers who assume a mindful parenting role display consistently higher rates of father involvement in care and support (MacDonald & Hastings, 2010). Mindful parenting is defined as being present and aware in everyday interactions with children. According to MacDonald & Hastings (2010), fathers who adopt a more present-centred outlook are more involved with their children with an ID. This was exemplified by fathers who worked at home being more involved in daily care tasks and child-related parenting practices (MacDonald & Hastings, 2010). The findings of this study showed promise for the use of mindfulness-based interventions with fathers of children with an ID. By helping fathers to focus on the present rather than being constantly worried about the future, fathers should become more engaged and involved with their children with ID (MacDonald & Hastings, 2010).

2.15 Discussion

The current systematic review sought to identify, evaluate and synthesise the available empirical research on the involvement and engagement of fathers of children with ID or DD in their children's lives and with DS. Findings from this review suggest that many interacting factors within the wider social and familial ecology influence father involvement with their children, and engagement with DS. This review identified that service providers regard fathers as difficult to engage and reach for numerous reasons. This finding is well supported in the previous research literature in this area of interest (McConkey, 1994; Quinn, 1999). The findings of this review suggest that there is a need for further investigation into the factors that influence the engagement of fathers with DS. There were some uncertainties and inconsistencies in these findings, which serves as a reminder that father engagement is not a one-dimensional phenomenon, but is part of a wider ecological system and is influenced at every level of this system (Cabrera et al., 2014).

Many of the studies in this review did not engage the views of fathers exclusively, with some incorporating the views of mothers as well as fathers to describe father engagement. This presents a challenge in understanding fathers' subjective experiences and perceptions authentically because father responses may have been influenced by the other participants in these studies. Fathers' experiences in parenting a child with a disability are unique and differ from mothers' experiences (Boyd et al., 2019; Huang et al., 2012). With this in mind, the investigation of these experiences from the fathers' perspective in isolation is necessary. Furthermore, of the eleven studies included in this review, only two engaged the views of service providers (Curtiss et al., 2021; McBride et al., 2017) and it is important to explore the views of such professionals in greater detail on the issue of father engagement.

The goal of many of these studies was not to inquire about father engagement directly, but to see how this relates to other variables. As a result, the studies in this review looked at the involvement of fathers in the lives of children with disabilities across a range of contexts. This meant that the findings of this review are difficult to generalise to fathers of children with an ID/DD, and indicates that research in this area is underdeveloped. This finding is also reflected in a recent literature review by Boyd et al. (2019), who noted that findings in the area of father experiences and perceptions are under-researched, and that the bulk of research in this area has been around stress and coping. Furthermore, many of the studies included in this review looked at disability quite generally rather than focusing on an explicit form of disability, for example ID. Once again, this means that findings in this area are quite broad and that there is a need for understanding engagement with regard to specific forms of disability.

In addition to the highlighted methodological concerns, there were some contextual concerns associated with this literature review. The review focused on international literature in order to attain a picture of the global situation of father engagement with DS. However, demographic characteristics and cultural factors were not accounted for which could call the generalisability of the findings of this review into the Irish context into question. Services for people with disabilities operate with different approaches from country to country, and many of the findings in this review occurred in different contexts. It would appear that there is a need to broach the perceptions of fathers and services within the same context in order to extend understanding on the involvement and engagement of fathers of children with ID or DD in their children's lives and with DS. Based on this review of the literature, no such approach has been taken within an Irish context.

As the number of children with ID increases globally (Marsh et al., 2020) and with the complex needs of this population, it is important to ensure that the families of these children are well supported. To achieve this, maximising the family system by engaging every stakeholder through an FCP approach is necessary (McCarthy & Guerin, 2021). While FCP incorporates fathers on a theoretical level, this review suggests that the actual extent to which fathers experience inclusion in this model is unclear. At present, DS in an Irish context are undergoing reconfiguration as PDS is in the process of being implemented nationwide. This is a restructuring that is strongly underpinned by the FCP model of service delivery (Health Service Executive, 2020b). With this in mind, gaining a deeper understanding of this issue has never been more pertinent as services look to evolve and develop. Understanding father engagement with Irish DS could work to enhance family function and establish necessary support structures for families of children with ID.

2.16 The current study and overall aim of the research

In summary, from the above review a number of gaps in the empirical literature have been identified in relation to father engagement with DS and their experiences of having a child with an ID/DD. There is a dearth of research exploring father engagement with DS in the Irish context, there is a need to enquire further into the implementation of the FCP approach in Irish DS given that this is a core principle of PDS, there is a lack of a direct measure of father perceptions of and engagement with DS, and the specific role of psychologists working in DS in the engagement of fathers of children with an ID/DD also requires further empirical exploration.

With the findings of this review in mind, the aim of the current research is to explore the perceptions and experiences of fathers of children with an ID/DD and psychologists regarding father engagement with Irish DS. Specifically, this research aims to answer the following research questions:

- How do fathers of children with an ID/DD perceive their engagement with disability services?

- What are the experiences of fathers of children with an ID/DD with disability services?
- What are the experiences of psychologists working in disability services of the engagement of fathers of children with an ID/DD with disability services?

Chapter 3: Empirical Paper

Methodology

3.1 Chapter Introduction

This chapter will describe the background and rationale for the methodology employed in the present research study. The study adopted a mixed-methods, sequential explanatory design framed within a pragmatic research paradigm. An online survey was completed by fathers of children with an ID/DD and follow up interviews were conducted with a random sample of participants from the survey. Interviews were then conducted with psychologists working in DS, who were recruited through purposeful sampling. Details of this research process will be outlined in this chapter which includes information regarding survey design, participant recruitment, quantitative and qualitative data analysis approaches, ensuring rigour and ethical considerations.

3.2 Aims of the Study

This study sought to capture the perceptions and experiences of fathers of children with an ID/DD on their engagement with DS. The aim of the research was to identify how father engagement with DS can be improved in the future given that services in Ireland are at a time of considerable reconfiguration with the implementation of PDS. To compliment the perspective of fathers, the experiences of psychologists working in DS were also sought on the issue of father engagement with the services. It was hoped that this added dimension would provide more balanced findings and would carry more weight in terms of influencing future policy and practice in this area.

3.2.1 Research Questions

Following a systematic review of the research literature, the following research questions were generated:

1. How do fathers of children with an ID/DD perceive their engagement with disability services?
2. What are the experiences of fathers of children with an ID/DD with disability services?
3. What are the experiences of Psychologists working in disability services of the engagement of fathers of children with an ID/DD with disability services?

3.3 Research Paradigm

In research, a paradigm refers to the philosophical assumptions that define the worldview of the researcher and inform the actions taken during research (Denzen & Lincoln, 2005; Edmonds & Kennedy, 2016). A paradigm provides the researcher with a method of understanding and navigating the complexities of the real world during the research process and informs the interpretation of data amassed during this process (Kaushik & Walsh, 2019; Teddlie & Yu, 2007).

The pragmatic paradigm was adopted in the present study. This worldview is associated with trying to find solutions to problems by using the most felicitous research methods available (Creswell, 2010; Edmonds & Kennedy, 2016). Pragmatic inquiry focuses on the creation of knowledge so that action can be taken toward solving the research problem (Cohen et al., 2017). The present investigation focused on understanding the issue of father engagement with DS and locating practical solutions to this issue. Considering this, the pragmatic approach is well aligned with the current research aims (Creswell & Creswell, 2017; Edmonds & Kennedy, 2016).

3.4 Research Design

A research design is the procedure which guides the collection, analysis, interpretation and dissemination of data in a research study (Creswell & Clark, 2017). In the present study, a mixed-methods, sequential explanatory research design was adopted. This approach allowed the researcher to gather data through quantitative and qualitative methods to gain a thorough understanding of the phenomenon being studied (Creswell & Clark, 2017; Doyle et al., 2016; Edmonds & Kennedy, 2016).

3.4.1 Mixed-Methods Design

There are strengths and limitations associated with both qualitative and quantitative research methods (Cohen et al., 2017; Teddlie & Yu, 2007). In the present study, both approaches were combined. This was completed in line with the pragmatic paradigm as all necessary means were adopted in answering the research questions posed (Creswell, 2010; Creswell & Creswell, 2017). In this study, both quantitative and qualitative research questions were investigated which meant a mixed-methods approach was necessary (Creswell, 2019; Edmonds & Kennedy, 2016; Teddlie & Yu, 2007). Doyle et al. (2016) developed a checklist of rationales for using mixed-methods research which was utilised in the present study. The rationales used for conducting mixed-methods research in the present study are outlined in Table 8.

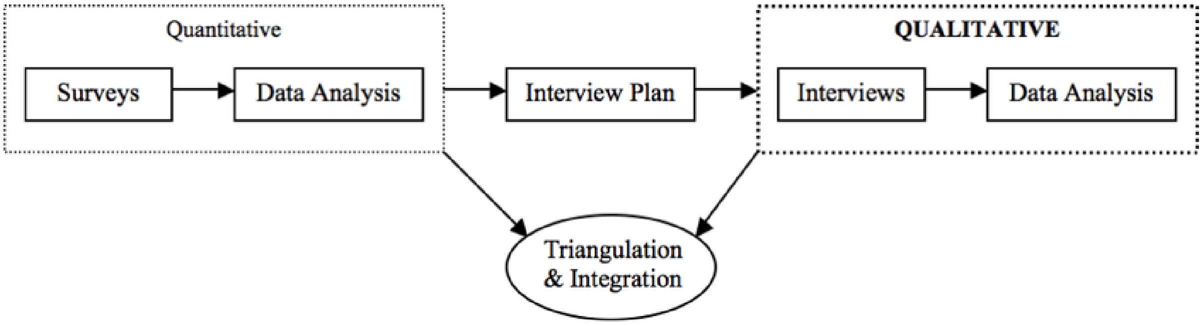
Table 8: *Rationales for mixed-methods research, adapted from Doyle et al. (2016).*

Rationale	Explanation
Triangulation	Quantitative and qualitative methods are used so that findings can be mutually corroborated
Off-setting weaknesses	Ensuring that the weaknesses of each individual approach are minimised and accounted for by the other approach
Completeness	Provides a more complete picture of the phenomenon being studied
Expansion	The first phase of research has findings that need to be expanded upon
Illustration	Qualitative data are used to add to quantitative findings, or to illustrate these findings further

3.4.2 Sequential Explanatory Design

The present research consists of a broad quantitative phase followed by a smaller-scale qualitative phase to further explain the quantitative findings. This approach to mixed-methods research is termed a ‘sequential explanatory design’ (Doyle et al., 2016; Edmonds & Kennedy, 2016). This research project brought together positivist and constructivist worldviews by departing from a deductive, realistic philosophical approach through surveys and complementing this with an inductive, interpretative approach through interviews. As Bryman (2006) asserts, qualitative data puts “meat on the bones” (p. 107) of the dry quantitative data collected. The ‘Follow-Up Explanatory Model’ of mixing data was adopted in this study, which allows a researcher to utilise interview data to explain and expand on survey data that has been collected (Creswell & Clark, 2017).

Figure 3: *Sequential Explanatory Design*



3.5 Quantitative Data Collection

3.5.1 Questionnaire Design

There was no previous existing questionnaire investigating father engagement with DS. It was therefore necessary to design a questionnaire that could be used to collect data in the quantitative phase of this research. Questionnaire and scale development are critical to understanding previously unexplored phenomena in health, social and behavioural research (Boateng et al., 2018). A web-based questionnaire was created which was completed by fathers of children with an ID/DD. This questionnaire was called the Father Engagement With Services Questionnaire (FEWS-Q). Web-based questionnaires are appealing for researchers because they allow a for a wider geographical spread of participants to partake in a research project (Gosling & Johnson, 2010), they facilitate convenient data storage and analysis and are easier to disseminate than paper and pencil surveys (Dillman, 2011; Roberts & Allen, 2015). The present study also took place in the context of the COVID-19 pandemic. Online surveys were the safest way to collect data given that social contact was not necessary with this approach.

The design of the FEWS-Q took place over two stages. The first stage involved the drafting of questionnaire items based on a systematic review of the research literature (Patten, 2016). FST and the BMHD were also used as a framework for subscale and questionnaire item development. Certain themes emerged from the literature and these were used to create four subscales of this questionnaire: Emotional Impact, Caring Role, Service Role and Social Role. The goal of the Emotional Impact subscale is to examine the emotional experience of having a child with an ID/DD. The Caring Role subscale examines the role of the father in caring for their child with an ID/DD. The Service Role subscale is concerned with the role services can play in engaging and supporting fathers of children with an ID/DD. The Social

Role subscale looks at the social role of the father from the father's perspective, and the role of wider social norms in influencing father engagement with services. A short summary of what each subscale examines, as well as the theoretical framework underpinning each subscale can be found in Appendix 6. As well as these four subscales, a short demographic survey was developed as part of the FEWS-Q. This demographic information was used to describe the participants in the present study, and allowed for an exploration of whether father demographics influenced engagement with services.

The second stage of the development of the FEWS-Q involved piloting through an iterative design process with a convenience sample of fathers, psychologists and a researcher experienced in survey design. Questionnaire piloting is recommended to examine the clarity and usability of a questionnaire, as well as the operationalisation of the constructs and the composition of the questions asked (Aiyelaagbe et al., 2017; Patten, 2016). Piloting was important in the present study because the FEWS-Q was newly designed without being normed or standardised.

An iterative design process allows for multiple perspectives to be considered and evaluated in the design of a new survey (Esposito, 2004). The questionnaire was sent to psychologists currently working in DS (N=5) and fathers of children with an ID/DD (N=4). Having experts in an area review your questionnaire items can help to shed light on any amendments that may be necessary (Patten, 2016; Riordain et al., 2011). In the present study, text-based qualitative feedback was sought from the questionnaire reviewers on each questionnaire item. This feedback was explored and clarified with the reviewers, and then utilised to make amendments to the questionnaire items. The amended questionnaire was then sent to an experienced researcher (N=1) who provided further feedback on questionnaire items, structure, and design. Further amendments were made, and the questionnaire was then ready to be posted online. The final version of the FEWS-Q consisted of 37 closed questions in a 5-point Likert scale format. Likert scales are commonly used in social sciences to examine people's experiences and attitudes (Józsa & Morgan, 2017). A 5-point Likert scale format was chosen ahead of a 7-point Likert scale because this approach has been shown to enhance response rate and reduce participant confusion and frustration when completing a questionnaire (Babakus & Mangold, 1992; Hutchinson, 2021). To maximise response rates, the length of the FEWS-Q was kept to a minimum and there was consideration given to the layout to encourage participation and completion (Dillman, 2011).

Participants also had the option of providing qualitative information at the end of each section of the FEWS-Q. A text box was provided for participants to expand on the questionnaire items (Cohen et al., 2017; Creswell & Creswell, 2017). This open-ended qualitative data was used to elucidate the closed questions in the Likert scale.

3.5.2 Participant Recruitment

Following the design of the FEWS-Q, it was necessary to recruit fathers who met the inclusion criteria. The inclusion and exclusion criteria for father participants are outlined in Table 9. An email was compiled to inform certain organisations and personnel about this research project and in this email, they were asked to share the information sheet and consent form (Appendices 11 & 12) with prospective participants. The main channels through which fathers were recruited were DS, special schools, social media parent groups and various disability organisation websites. The study adopted a voluntary response sampling method given that the sample comprised participants who voluntarily elected to partake in the research (Creswell & Clark, 2017).

Specifically, four DS and three special schools agreed to share the study information with fathers of children with an ID/DD. Flyers were created to advertise the study (See Appendix 8) and these were distributed through DS and special schools. The services and special schools also sent a PDF version of the flyer to parents who consented to be contacted by email. In total, 300 physical flyers were printed and distributed, with many more being shared by email.

A social media page was set up on Instagram, Facebook and Twitter called “Father Engagement with Disability Services Study” with information about the study included as well as a link and QR code which led to the online survey. The social media page was used to network with charitable organisations and private parent groups of children with an ID/DD on these three social media platforms. Numerous ID/DD organisations and parent groups were contacted on social media as these to share information about the study (see appendix 14 for full list of organisations). Many of these organisations requested that the researcher fill out a research checklist to ensure that this research would be relevant and of benefit to people with an ID/DD. Following a review of the completed research checklists by these organisations, information about the study was shared with their members on their websites and social media platforms. These groups were carefully selected by the researcher to ensure that prospective participants would meet the inclusion criteria of the study, as outlined in

Table 9. The FEWS-Q was left open to participants to complete for three months, between July and September 2021. The questionnaire was closed once relevant online and social media groups had been exhausted and questionnaire completions ceased.

Table 9: *Inclusion and Exclusion Criteria (Fathers)*

Inclusion Criteria:	**Exclusion Criteria:**
• Must have a child with a diagnosis of ID/DD (comorbid diagnoses are allowed e.g. ID + ASD). • Must be over 18 years of age • Their child must be aged 19 years or younger. • Their child must be currently availing of Early intervention or School aged disability services.	• Father does not have a child with a diagnosis of ID/DD • The father is under 18 years of age • Their child is over 19 years of age, ineligible even if the child has an ID/DD • Their child is not availing of Early intervention or School aged disability services.

3.5.3 Sampling

It was necessary to estimate sample size of participants that would be required for statistical significance in the analysis of the FEWS-Q. In achieving this, it was imperative to gain an accurate figure of the number of fathers of children with an ID/DD in Ireland so that the requisite number for a representative sample could be obtained. There are no statistics collected on the amount of fathers of children with an ID/DD in Ireland, meaning that estimations of the number of fathers of children with ID/DD were based on statistics gathered on the number children with an ID/DD living in Ireland. According to the Central Statistics Office, this number is 10,032 (Central Statistics Office, 2016). Using the Qualtrics sample size calculator, this figure was inputted with a confidence level of 95% and the margin of error of 10%. This accounted for any fathers who may not be involved with their children or who may be deceased. This calculation provided a desired sample size of 96.

In total, 77 fathers completed the FEWS-Q survey which is less than the desired sample size. While this is noted as a limitation of the present study, significant efforts were made to contact fathers through online platforms, special schools and DS. See Appendix 14 for a full list of organisations that were contacted to share the study. This lack of engagement from fathers may be an implication in itself that fathers do not see it as their role to complete service-related work.

3.6 Qualitative Data Collection

3.6.1 Semi-Structured Interviews

Following the quantitative phase of this research, the qualitative phase commenced in line with the sequential explanatory design (Doyle et al., 2016). The first element of the qualitative phase was semi-structured interviews with fathers of children with an ID/DD. The goal of these interviews was to explore the survey data collected in more detail to answer the research questions and achieve the research objective.

Semi-structured interviews provide a flexible framework to guide the exploration of participant thoughts, beliefs and experiences about a particular phenomenon (Dearnley, 2005; Pathak & Intratat, 2012). There are limitations to using semi-structured interviewing that should be noted. They can be a highly time-consuming data collection method that may be inconvenient for interviewees and open to researcher bias (Cohen et al., 2018). However, interviews can allow for a profound exploration with participants which can result in meaning emerging from the data (Cohen et al., 2018). They allow participants the freedom to decide what they believe should be discussed and how much of an explanation they should provide (Pathak & Intratat, 2012). It was important that the issue of father engagement with DS was explored in-depth so that themes could emerge to offer an understanding and interpretation of this phenomenon (Cohen et al., 2018; Dearnley, 2005). Therefore, semi-structured interviewing fitted well with the present research design.

Kvale (1996), identified two distinct approaches to interviewing. The first is termed the ‘miner approach’ and sees the interviewer trying to mine the information out of the interviewee. The second is termed the ‘traveller approach’ and sees knowledge and information as a journey of co-construction throughout the interview (Kvale, 1996). The traveller approach was adopted in the present study so that knowledge could be constructed intersubjectively. In line with this approach, it was necessary to design a flexible interview schedule to inform these semi-structured interviews. The interview schedule should keep the interviewer on topic by guiding the conversation without providing a rigid structure that could stifle the natural flow of conversation (Cohen et al., 2018; Pathak & Intratat, 2012). The research literature was consulted for best practice in designing an interview schedule. Robson & McCartan (2016) offer a guiding structure for an interview schedule, which includes a warm up section, a main body, a cool off section and a closing section. This structure was adopted in the present study. The main body of the interview was broken into four subsections which looked at experiences with services, perceptions of services, family system and bio-ecological system. These subsections reflected the research questions and the guiding psychological theories that were used to frame father engagement with DS. Patten (2016) provides an overview of the types of questions that can be asked in a research interview including questions on experience and behaviour, values and opinions, knowledge, feeling and demographic questions. Elements of all these questions were used in the present semi-structured interviews. For the full interview schedules, see Appendix 10 & 11.

Following the father interviews, psychologists working in DS were interviewed. Semi-structured interviews were used which were guided by an interview schedule. The sections of the psychologist interviews mirrored those used in the father interviews as the goal was to gain the services' perspective on this issue. Since this was a sequential explanatory research design, findings from the father interviews were used to inform questions posed to psychologists during this stage of qualitative data collection.

Interviews with fathers and psychologists were completed online via video call on the zoom platform. This research took place during the COVID-19 pandemic, as government guidelines dictated interviews could not take place in-person. Zoom allows for recording of interviews, with participants' consent. This was useful for subsequent transcribing of interviews.

3.6.2 Participant Recruitment

Fathers who completed the FEWS-Q were asked if they could be contacted for follow-up interviews. This was optional and 21 fathers who were happy to be interviewed provided their email addresses at the end of the survey. Random sampling then occurred from this group of fathers. Each father was assigned a different number which were put into an online random generator to provide the researcher with a set of random numbers. The fathers who matched these numbers were then contacted for interview. Two fathers were contacted at a time and this process was repeated until data saturation was achieved. In total, fourteen fathers were contacted, nine were interviewed and five did not respond to the interview invitation. Data saturation refers to the point at which no new information, codes or themes emerge from the interview data being analysed (Braun & Clarke, 2021).

Psychologists were recruited through DS for interview. This recruitment was achieved through purposeful sampling. This is a sampling technique that is widely used in mixed-methods and purely qualitative research to identify and select individuals or groups of people who are expertly knowledgeable or notably experienced with a phenomenon of interest (Creswell & Clark, 2017; Palinkas et al., 2015). As well as expertise, this sampling method takes availability, willingness to partake in research and ability to communicate experiences and opinions into account (Bernard, 2017). This sampling method has limitations, for example, bias in selection may influence the generalisability of the findings. Nonetheless, this was seen as a relevant sampling technique for the psychologist interviewees given that their expertise and experience was sought on the phenomenon of interest.

Table 10: *Inclusion and Exclusion Criteria (Psychologists)*

Inclusion Criteria:	**Exclusion Criteria:**
• Must be working in a disability service in Ireland • Must be over 18 years of age • Must be an accredited Educational, Clinical or Counselling psychologist • Must provide informed consent to participate in this research project	• Psychologist is not working in a disability service in Ireland • Is under 18 years of age • Is not an accredited Educational, Clinical or Counselling psychologist • Has not provided informed consent to participate in this research project

3.7 Data Analysis

3.7.1 Quantitative Analysis

In the present study, the quantitative data gathered through the FEWS-Q was analysed using the Statistical Package for Social Sciences (SPSS v28: IBM). Descriptive statistics was used as the primary procedure of data analysis of the FEWS-Q data. An individual item analysis using descriptive statistics was adopted to understand and describe the data from the FEWS-Q by grouping responses together. This offered insight into the overall feelings of fathers on the areas explored and informed question development for the interview phase of the research. Given that the FEWS-Q is a newly developed questionnaire, it was necessary to analyse the four subscales of the 37-item FEWS-Q for internal reliability and content validity. The Cronbach’s Alpha coefficient for each subscale was computed. To investigate these results further, an exploratory factor analysis was undertaken. Suitability for factor analysis was explored using a Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy and Bartlett's test of sphericity. Each item of the FEWS-Q was subjected to principal component analysis (PCA), and a further Cronbach's Alpha coefficient for the newly arranged subscales following PCA was computed, which showed promising results. The findings of this analysis are located in the results section.

3.7.2 Qualitative Analysis

In qualitative research, there is no universally accepted method of data analysis (Robson & McCartan, 2016). Qualitative data analysis should be in-depth, dynamic and recursive, becoming more intensive as the study develops and themes begin to emerge (Braun & Clarke, 2006; Merriam & Tisdell, 2015). In the present study, the raw qualitative data that was gathered through the questionnaires and semi-structured interviews was transcribed, coded, and analysed for themes and subthemes. This approach is termed thematic analysis and is widely used as a method of qualitative data analysis (Clarke & Braun, 2014; Merriam & Tisdell, 2015). Thematic analysis is a flexible approach to finding themes that can describe a data set, and can be used with many different types of data sets and theoretical frameworks (Clarke & Braun, 2013). This fits well with the pragmatic approach that was adopted in the present study. Thematic analysis allows the researcher to understand their data by building a thick description and detailed picture of what is occurring within a particular situation or phenomenon (Braun & Clarke, 2006; Clarke & Braun, 2014; Merriam & Tisdell, 2015). In the present study, this phenomenon was father engagement with DS.

In the past, thematic analysis was criticised for lacking clear steps or guidelines that could be followed. However, Braun & Clarke (2006) have outlined a six-step approach to thematic analysis which was adopted in the present study. Like thematic analysis itself, these guidelines are flexible and the researcher may move backward and forward between these steps if this is necessary when analysing the data (Braun & Clarke, 2006). In the present study, the codes and themes were determined inductively rather than deductively (See Appendix 15 for examples of code creation). This means that they emerged from the data rather than being pre-determined or predicted based on previous research (Terry et al., 2017).

The first step of this thematic analysis involved familiarisation with the data. By transcribing the data verbatim, a certain level of familiarity was achieved with each interview transcript. To add to this familiarity, each transcript was read and re-read prior to identifying codes or themes within the data. The goal was simply to become familiar with the raw qualitative data that had been collected. It was then necessary to analyse and reduce the data into comprehensible and groupable sets. Initially, each interview transcript was analysed for codes. These broad codes captured the semantic and conceptual reading of the data (Braun & Clarke, 2006). To reduce researcher bias, a sample of the interview transcripts were coded by an independent coder who was also a doctoral student on the DECPsy programme (Braun & Clarke, 2006). Differences in codes were discussed with the independent coder, and amendments were made where necessary (Braun & Clarke, 2006).

The third phase involved searching for themes within this coded data. Braun & Clarke (2006) note that this is an active process of theme construction by the researcher followed by the collation of the coded data to a relevant theme. This involved grouping codes together that were related and generating more specific themes and subthemes from these broad codes (See Appendix 16). The next stage involved a review of the themes generated. This was a reflective process of scrutinising whether the themes told the story of the data. It also involved a mapping of the relationships between different themes and subthemes. The fifth phase of thematic analysis involved naming and defining each theme, and the final phase of analysis involved the write up of each theme to tell the story of the data accrued and situating this in the context of previous research literature in the area (Braun & Clarke, 2006). In writing up the findings, the BMHD was used as a structuring framework. As such, the themes generated were mapped onto each of the five nested systems within the BMHD to facilitate the situating of these themes within a wider social context.

3.8 Rigour

Various criteria are used to assess the rigour of a research study. Lincoln & Guba (1985a) propounded a framework for analysing the rigour of a study under the headings of: Credibility, Dependability, Confirmability and Transferability. While this framework is often used for appraising purely qualitative research, it has also been used to appraise mixed-methods studies as well (Creswell, 2010; Teddlie & Yu, 2007). Please see table 11 for the application of this framework to the present study.

Table 11: *Rigour in the Present Study*

Element of Rigour	Description of application
Credibility	Credibility refers to the value and authenticity of the findings produced in a study. To ensure credibility, the researcher must ensure that the research was carried out in a cohesive and replicable manner (Houghton et al., 2013). According to Creswell (2017), credibility is related to validity which is a quantitative term. Credibility should be assessed in both the quantitative and qualitative research methods used in a mixed-methods project (Creswell & Creswell, 2017). In the present study, steps were taken to ensure the credibility and validity of the study. In the quantitative phase of the research, the validity of the survey was ensured by having it reviewed by outside experts and amending it according to their feedback (Patten, 2016). Best practice guides to questionnaire design were also followed in the construction of this questionnaire (Boateng et al., 2018). The internal reliability and validity of the survey was also tested by conducting a Cronbach's Alpha test on each subscale, and a PCA on each individual survey item using SPSS. In the qualitative interviews, steps were also taken to ensure the credibility of the study. A member check was completed after each interview with every research participant. This involves summarising the key points of the interview to them and ensuring that this accurately reflects their views (Houghton et al., 2013). Furthermore, participants were reminded that they were not obliged to participate in the study and could withdraw from the study at any point. As well as this, confidentiality and anonymity were stressed to each participant at the outset of each interview. This enhanced credibility because it ensured that participants were willing and comfortable to partake in the present research (Houghton et al., 2013).
Confirmability	Confirmability is related to the degree that the findings in a research project can be confirmed by other researchers (Lincoln & Guba, 1985a). Confirmability means that findings are not completely subjective or figments of the imagination of the researcher, but are drawn from the data analysis carried out (Miles & Huberman, 1994). In the present study, a thorough description of the data obtained and the analysis of this data enhanced confirmability. Consulting the research literature base in the design of the questionnaire and interview schedules were important steps toward to enhance the confirmability of this study. It should be noted, however, that given that these were designed by the researcher, it is possible that some unconscious and unintended investigator biases may have influenced the design of these data collection tools. During this research process, it was important that the researcher remained reflective on their position and on their values to try and quell any internal biases or preconceptions that may have influenced the data analysis. The use of a reflective journal was adopted in this endeavour, as well as a thorough understanding and description of the research paradigm adopted (Clarke & Braun, 2013; Merriam & Tisdell, 2015).

	This ensured that the findings were reflective of the ideas and experiences of the participants rather than any preferences or ideals held by the researcher (Shenton, 2004).
Dependability	Dependability refers to the consistency and stability of the data collected. This term can be compared to reliability in a quantitative study (Creswell & Creswell, 2017). According to Koch (1994), even if the reader does not share the same interpretation of the data as the researcher, the method by which they arrived at this conclusion should be clearly discernible to the reader. The use of triangulation of data is an important step to ensure dependability (Merriam & Tisdell, 2015). This was adopted in the present study by using multiple methods of data collection including questionnaires collecting quantitative and qualitative data and interviews with fathers of children with ID and psychologists working in disability services. This approach lends itself to the validity of the research findings and the generalizability of the findings.
T**ransferability**	Transferability refers to the extent that the findings of a research project can be transferred to other contexts or settings (Lincoln & Guba, 1985a). With qualitative research, transferability is dependent on the provision of rich and thick descriptions of the data generated (Houghton et al., 2013). Themes were described in detail, and quotations from raw data were also used to provide the reader with a representative and thorough description of the findings. Moreover, detailed descriptions of the data collection methods and tools were provided to enhance the transferability of the findings of this project (Houghton et al., 2013). Quantitative transferability was ensured by assessing the internal and external validity of the data.

3.9 Ethical Considerations

Ethics in research is concerned with not only the outcome of research, but the entire process of how the research is conducted (Clarke & Braun, 2013). Prior to commencing data collection, this study received ethical approval from the Mary Immaculate College Research Ethics Committee (See Appendix 18) as well as ethical approval from three DS. It was necessary to consider issues such as informed consent, maintaining anonymity of participants, storing of non-anonymised data, ensuring voluntary participation, and avoiding researcher bias in the design of this study. Steps taken to account for the aforementioned ethical issues were reviewed by the various ethics committees and permission to conduct research was granted. It was then important to adhere to the steps outlined in the ethics applications. Written information sheets and consent forms (See Appendix 12 & 13) were provided to all participants, as well as an oral description of the project to those who took part in the interviews. Measures were also taken to ensure the anonymity and confidentiality of the participants (e.g. the use of pseudonyms, collecting minimal non-anonymised data).

This research also took place during the COVID-19 global pandemic, and it was important to ensure steps were taken to protect participants. In this endeavour, all data collection took place online to eliminate social contact so that participants were not in danger of catching the virus by participating in this research project. All data that was gathered in this project was stored in line with the MIC data retention policy and schedule.

Results

4.0 Results Introduction

This chapter will present the results accrued in this research process. The three research questions below will be addressed in turn by presenting the findings of each phase of this research process. Firstly, the results from the quantitative phase of this research will be outlined in answering the first research question. The demographic data collected from participants will be tabulated, followed by a presentation of the responses collected from each subscale of the FEWS-Q. Qualitative data collected on the FEWS-Q will also be exhibited. Findings from an internal reliability analysis of the FEWS-Q will then be delineated, including an exploration of item-scale correlation and a principal component analysis. Secondly, the qualitative findings from the interviews with fathers will be described in answering the second research question. Finally, the qualitative findings from the interviews with psychologists will be described in answering the third research question. Emergent themes and subthemes will be outlined and structures using the five nested systems of the BMHD (Bronfenbrenner & Morris, 2006) as a framework.

Research Questions:

- How do fathers of children with an ID/DD perceive their engagement with disability services?
- What are the experiences of fathers of children with an ID/DD with disability services?
- What are the experiences of Psychologists working in disability services of the engagement of fathers of children with an ID/DD with disability services?

4.1 Participant Demographics

In total, 77 fathers completed the FEWS-Q online survey. Demographic information was gathered from them, which is summarised in table 12 below. As well as demographic information about themselves, demographic information was also gathered from fathers regarding the characteristics of their child with an ID/DD.

Table 12: *Father and Child Demographics*

Variable	Survey Results	Variable	Survey Results
Age of fathers		**Age of children**	
Age range	32-74 years	Age range	0-19 years
Mean age	46.89	Mean age	10.13
Standard Deviation	8.51	Standard Deviation	4.87
Marital Status	**N (%)**	**Age when ID/DD was identified**	**N (%)**
Married	67 (87%)	0 (prenatal diagnosis/ first year of life)	38 (49%)
Separated/Divorced	5 (6%)	1	6 (8%)
Cohabiting	2 (3%)	2	10 (13%)
Other	3 (4%)	3	7 (9%)
		4	3 (4%)
		5	8 (10%)
		6	2 (3%)
		7	3 (4%)
Employment Status	**N (%)**	**ID range**	**N (%)**
Employed	56 (73%)	Mild-Moderate	57 (74%)
Self-employed	13 (16%)	Severe-Profound	9 (12%)
Stay at home dad	4 (5%)	Developmental Delay (unspecified range)	11 (14%)
Retired	3 (4%)		
Unable to work	1 (1%)		

Country of origin	**N (%)**	**Diagnosis**	**N (%)**
Ireland	70 (91%)	Down Syndrome	20 (26%)
England	3 (4%)	Intellectual Disability (Unspecified)	17 (22%)
Other	4 (5%)	ID and Autism Spectrum Disorder	14 (18%)
		Developmental Delay	11 (14%)
		Other	15 (20%)
Language spoken at home	**N (%)**	**Gender of children**	**N (%)**
English	74 (97%)	Male	53 (68%)
Other	3 (3%)	Female	25 (32%)
Highest level of education	**N (%)**	**Education Setting**	**N (%)**
Undergraduate degree	29 (38%)	A special school	34 (45%)
Masters degree	23 (30%)	A special class in a mainstream school	13 (17%)
Further education qualification	14 (18%)	Currently out of school/ availing of a home tutor	11 (15%)
Secondary school completed	7 (9%)	A mainstream class in a mainstream school	11 (15%)
Primary school completed	3 (4%)	A mainstream preschool	5 (7%)
Doctorate qualification	1 (1%)	A special preschool	1 (1%)
Area of Ireland lived in	**N (%)**		
Leinster	57 (74%)		
Munster	15 (20%)		
Connaught	5 (6%)		

Number of children in family	**N (%)**
One child	9 (11%)
Two children	29 (38%)
Three children	33 (43%)
Four children	5 (6%)
Five or more children	1 (1%)

4.2 Survey Results

The first research question in this study, which related to fathers' perceptions of their engagement with DS, was addressed by gathering data from fathers using the FEWS-Q. The quantitative results from each subscale of this survey will be outlined in this section using an individual item analysis through descriptive statistics. Furthermore, qualitative data gathered through this survey will also be presented to further elucidate the quantitative findings.

4.2.1 Emotional Impact Subscale

4.2.1.1 Quantitative Data. The emotional impact subscale consists of nine items and explores the perceived emotional experience of being a father to a child with an ID/DD. The scale also explores fathers' perceived social and familial support in parenting a child with an ID/DD. Table 13 outlined the responses to each item of this subscale.

4.2.1.2 Qualitative Data. To add to the quantitative findings accrued in the emotional impact subscale, fathers were also given the option to expand on their answers qualitatively through a text-box entry at the end of each subscale of the FEWS-Q. 14 fathers provided qualitative feedback on the emotional impact of parenting a child with an ID/DD. Fathers noted the emotional impact of their child's diagnosis as being significant, with one father writing: *"It's an extraordinary experience at first when you are told of your child's disability, but you have to learn to accept it quite quickly for what it is."*

The emotional impact of having a lack of support from friends and family was also highlighted, with one father stating: *"Having a child with an intellectual disability means friends hide because they don't know what to say and family try but always say the wrong stuff."* Other fathers noted that having a child with an ID is a positive experience, with one father saying: *"My life is all the better having him in it and getting through the struggles together."*

Finally, some fathers noted a lack of support has impacted their wellbeing because they cannot show their true feelings. One father wrote: *"fathers feelings aren't taken into account as it's primarily seen as the mother's concern and dad is just expected to work and get on with it. The sadness for the difficulty my child will experience is perceived to be only felt by mums."* Another father simply stated: *"As a dad, it's hard to show how you're really feeling."*

Table 13: *Emotional Impact Subscale Item Responses*

Questionnaire Item	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1. In general, having a child with an intellectual disability has been a positive experience as a father	31 (40%)	13 (17%)	14 (18%)	9 (12%)	10 (13%)
2. Since my child was born, I have experienced higher levels of stress and anxiety	46 (60%)	23 (30%)	5 (6%)	2 (3%)	1 (1%)
3. I often feel isolated as a father of a child with an intellectual disability	32 (42%)	23 (30%)	7 (9%)	7 (9%)	7 (9%)
4. My social life has been negatively impacted since my child was born	33 (43%)	16 (21%)	15 (19%)	9 (12%)	4 (5%)
5. My family offers me emotional support as a father of a child with an intellectual disability	28 (36%)	16 (21%)	11 (14%)	13 (17%)	9 (12%)

6. My friends/peers offer me emotional support as a father of a child with an intellectual disability	22 (29%)	17 (22%)	16 (21%)	12 (16%)	10 (13%)
7. I worry about my child’s future regularly	59 (77%)	14 (18%)	4 (5%)	0 (0%)	0 (0%)
8. It was a difficult time for me when my child was diagnosed with an intellectual disability	54 (70%)	14 (18%)	6(8%)	2 (3%)	1 (1%)
9. Having a child with an intellectual disability has a positive impact on family life	22 (29%)	14 (18%)	16 (21%)	12 (16%)	13 (17%)

4.2.2 Caring Role Subscale

4.2.2.1 Quantitative Data. The caring role subscale examines the father's perception of their role in caring for their child with an ID/DD. This subscale consists of six items. Table 14 outlines the responses to each item of this subscale.

4.2.2.2 Qualitative Data. Fourteen fathers also provided qualitative feedback on their perception of their caring role. Fathers noted that work commitments can impact upon their caring role: *"I am too busy with work or tired after work. My wife brings my son to appointments and works with him. It's not really my thing, I leave it to her."* Another father mentioned: "*Service appointments and programmes take place when I am in work so I'm never at them, I used up all my parental leave at the start."*

Other fathers described how even when they attended sessions, they felt overlooked with two fathers stating: *"I felt my presence wasn't acknowledged or cared about"* and *"communication with fathers is where the system breaks down."*

Table 14: *Caring Role Subscale Item Responses*

Questionnaire Item	**Strongly Agree**	**Agree**	**Neither Agree nor Disagree**	**Disagree**	**Strongly Disagree**
10. I have a loving bond with my child.	69 (91%)	4 (5%)	3 (4%)	0 (0%)	0 (0%)
11. My spouse is my child’s primary caregiver.	25 (33%)	15 (20%)	16 (21%)	12 (16%)	7 (9%)
12. The care for my child is equally shared between parents.	26 (43%)	16 (21%)	9 (12%)	20 (26%)	5 (7%)
13. The care that I provide is valuable and important to my child.	57 (75%)	15 (20%)	4 (5%)	0 (0%)	0 (0%)
14. I am involved in carrying out the programmes/interventions that my child’s disability team recommends for them.	22 (29%)	22 (29%)	17 (22%)	8 (11%)	7 (9%)
15. I feel that I am very involved in the life of my child.	50 (66%)	20 (26%)	2 (3%)	4 (5%)	0 (0%)

4.2.3 Service Role Subscale

4.2.3.1 Quantitative Findings The service role subscale consists of 13 items and it explores fathers' perceptions of the role that services can play in engaging and supporting them. Table 15 outlines the responses to each item of this subscale.

4.2.3.2 Qualitative Findings Eighteen fathers provided qualitative feedback on their perceptions of the role of services in supporting and engaging them. Fathers' perception was they fulfil an *"Invisible role"* in the eyes of services, with one claiming: *"The few times I met therapists with my wife I was largely ignored. Questions I would well know the answer to were ever only put to my wife."* Another stated: *"A dad's view will be dismissed by services for the mother's view."*

Fathers noted services contact their spouse and rarely, if ever, contact them. One wrote: *"I rarely communicate with my child's disability team. They usually communicate with my wife and I get information through her"* while another added: *"I have only met with anyone in a disability service once, at the time of my child's diagnosis. I have never been contacted directly by them since, they always contact my wife."* One father highlighted that contact was initially made by the disability team with his wife when she was on maternity leave, and this channel of communication has simply developed from there: *"Contact with this team was initially made when my wife was in the maternity hospital and all contact seems to just go through her as a result."*

Fathers were critical of services generally, particularly regarding the lack of appointments and opportunities for them or their spouse to engage with services. One father claimed: *"access to services is the biggest problem facing parents of children with disabilities"* and *"with the complex needs our son has, it's 18 hours a day, 24/7. I don't have time to watch a movie or go on a course. People in services have no idea of what it's like."*

Table 15: *Service Role Subscale Item Responses*

Questionnaire Item	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
16. My child's disability/clinical service team have always emphasised the importance of my involvement	5 (7%)	17 (22%)	11 (14%)	19 (25%)	24 (32%)
17. My child's disability/clinical service team make every effort to keep me informed and involved.	4 (5%)	20 (26%)	13 (17%)	15 (20%)	24 (32%)
18. My engagement with disability services is good.	2 (3%)	17 (22%)	17 (22%)	13 (17%)	27 (35%)
19. Fathers should receive personal support/counselling from their child's disability services.	37 (49%)	15 (20%)	14 (19%)	7 (9%)	2 (3%)
20. My views and concerns about my	7 (9%)	24 (32%)	20 (26%)	11 (14%)	14 (18%)

child are valued by my child’s disability team.					
21. Services need to be more flexible in terms of their opening times and days of work.	53 (70%)	12 (16%)	11 (14%)	0 (0%)	0 (0%)
22. I would attend courses on supporting my child if they were made available to me.	41 (54%)	19 (25%)	12 (16%)	3 (4%)	1 (1%)
23. I meet with my child’s disability team often (at least 3 times per year).	10 (13%)	9 (12%)	9 (12%)	12 (16%)	35 (47%)
24. The service that my child attends communicates with me as a father directly.	6 (8%)	13 (17%)	11 (15%)	16 (21%)	29 (39%)
25. It is difficult for me to attend all of my child’s appointments.	39 (52%)	22 (29%)	2 (3%)	8 (11%)	4 (5%)

26. The services for children with an intellectual disability are good at including fathers.	2 (3%)	20 (26%)	13 (17%)	16 (21%)	25 (33%)
27. My child’s service has always acknowledged my role as caregiver.	10 (13%)	15 (20%)	26 (34%)	13 (17%)	12 (16%)
28. My views and wishes are always taken on board by my child’s disability team members.	11 (15%)	17 (23%)	25 (33%)	9 (12%)	13 (17%)

4.2.4 Social Role Subscale

4.2.4.1 Quantitative Findings. The social role subscale consists of 9 items and examines the social role of the father from his perspective, and the role of wider social norms in influencing father engagement with DS. Table 16 outlines the responses to each item of this subscale.

4.2.4.2 Qualitative Findings. Ten fathers expanded on their answers on the social role subscale with qualitative data. One noted that the mother automatically adopts the role as primary caregiver due to maternity leave when the child is born, but that both parents become equally involved if she returns to work: *"As the onus is on mother's to have extended leave after the birth, they would be viewed as the primary care givers at that point but once they return to work that would no longer be the case."*

Another father sated mothers were still the primary caregiver while fathers generally fulfil a different role: "*Mothers are still the main carers for children. I think this is the view of the constitution & the vast populace. In general as a father, it is socially acceptable to focus on your own career etc and be an absent parent."*

Other fathers asserted that these roles should be shared, claiming every family situation is different. One father described how he had given up work, while his wife continued working: "*I had to give up my aspirations of being a full time professional and turned down two good positions"* while another emphasised: "*Every family's situation is unique. In some families the mother's job is better paid so the mother continues to work and dad might become the full-time carer."*

Table 16: *Social Role Subscale Item Responses*

Questionnaire Item	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
29. As parents we have discussed how we divide our attendance at meetings and appointments.	31 (41%)	27 (36%)	11 (14%)	3 (4%)	4 (5%)
30. It is the main role of the child's mother/primary caregiver to carry out programmes and go to clinic appointments.	16 (21%)	10 (13%)	19 (25%)	22 (29%)	9 (12%)
31. Mothers are still the main carers for children.	21 (28%)	16 (21%)	16 (21%)	12 (16%)	11 (15%)
32. Society today has a very positive attitude to children who have an intellectual disability or developmental delay	4 (5%)	11 (14%)	12 (16%)	18 (24%)	31 (41%)

33. It is the fathers role to provide financially for their children.	12 (66%)	21 (28%)	29 (38%)	11 (14%)	3 (4%)
34. Children with an intellectual disability or developmental delay have the same opportunities as other children.	0 (0%)	3 (4%)	3 (4%)	16 (21%)	54 (71%)
35. Fathers are involved in their children’s care in the early years.	32 (42%)	27 (36%)	11 (14%)	4 (5%)	2 (3%)
36. Fathers are involved in key decisions for their children (e.g. school selection).	36 (47%)	31 (41%)	9 (12%)	0 (0%)	0 (0%)
37. The role of fathers in general has changed in recent years.	26 (34%)	27 (36%)	23 (30%)	0 (0%)	0 (0%)

4.2.4 FEWS-Q Analysis

The four subscales of the 37-item FEWS-Q were analysed for internal reliability. The Cronbach's Alpha coefficient for the *Emotional Impact* subscale, which had 9 items, was 0.77. The Cronbach's Alpha coefficient for the *Caring Role* subscale, which had 6 items, was 0.63. The Cronbach's Alpha coefficient for the *Services Role* subscale, which had 13 items, was 0.90. The Cronbach's Alpha coefficient for the *Social Role* subscale, which had 9 items, was 0.50. 31 of the 37 items on the FEWS-Q showed a strong corrected item-scale correlation ($r > 0.3$). While these findings were promising, it was apparent that there were some issues with the FEWS-Q, notably with the *Caring Role* and *Social Role* subscales as their Cronbach's Alpha coefficient was below 0.7. Furthermore, 6 of the 37 items on this questionnaire showed poor item-scale correlation ($r < 0.3$). To investigate this further, an exploratory factor analysis was undertaken in the form of a principal component analysis.

Each item of the FEWS-Q was subjected to principal component analysis. Suitability for factor analysis was explored using a Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy and Bartlett's test of sphericity. The KMO value was 0.635 and Bartlett's test of sphericity was significant, which deemed the FEWS-Q moderately suitable for principal component analysis. A KMO value above 0.5 renders the sample adequate for factor analysis (Hadi et al., 2016). Principal component analysis revealed the presence of ten components with eigenvalues exceeding 1. A parallel analysis for mean eigenvalues revealed that there were four significant components, while an inspection of the scree plot lent weight to this finding as there was a notable break after the fourth component. Since the data was found to be orthogonal, a varimax rotation was performed using four components. Each component showed a high number of loadings, with just one instance of cross loading. These four components explained a total of 50.8% of the variance (22.2%, 13.9%, 8.7%, 6.0% respectively), which supported the assertion that there are four main factors evident on the FEWS-Q. Further inspection of these factors allowed them to be identified based on the items that were loaded onto each factor. These factors were similar to the original four subscales of the FEWS-Q and can be identified as *Father-Service Relationship, Emotional Impact, Role of the father, and Stress and Support from services.* The principal component analysis suggested the deletion of six items (29, 37, 13, 7, 25, 33) due to poor item scale correlation. This left 31 items across these four factors. The analysis also suggested the rearranging of items to form new subscales based on the items that loaded onto each factor (see table 17 for factor loadings for each new subscale).

A further Cronbach's Alpha test was run on these four factors, or new subscales, to assess their internal reliability. The Cronbach's Alpha coefficient for the *Service Relationship* factor, which now had 12 items, was 0.88. The Cronbach's Alpha coefficient for the *Emotional Impact* factor, which now had 8 items, was 0.82. The Cronbach's Alpha coefficient for the *Role of the father* factor, which now had 7 items, was 0.77. The Cronbach's Alpha coefficient for the *Stress/support from services* factor, which had 4 items, was 0.61. While the Cronbach's Alpha for the *Stress/support from services* factor remained below 0.7, the removal of any items did not improve this score.

The findings of this factor analysis have implications for the future use of the FEWS-Q. The rearranged subscales and omitted items following factor analysis resulted in a more stable and reliable measure (as per their Cronbach's Alpha coefficient scores). These new subscales were based on the items that loaded onto each of these factors following a varimax rotation. Having said this, the participant numbers for a factor analysis are relatively small, as it is a rule of thumb to have 10-15 participants for each item on a questionnaire (Hadi et al., 2016). With this in mind, these results should be interpreted with caution, and further analysis is necessary with a larger sample size.

Table 17: *Questionnaire Item Factor Loadings Following Principal Component Analysis*

	Component			
Questionnaire Item	**1 (Service Relationship Factor)**	**2 (Emotional Impact Factor)**	**3 (Role of the Father Factor)**	**4 (Stress/Support from Services Factor)**
The services for children with an intellectual disability are good at including fathers.	.921			
My child's disability/clinical service team make every effort to keep me informed and involved.	.904			
My engagement with disability services is good.	.868			
My views and wishes are always taken on board by my child's disability team members.	.855			
My views and concerns about my child are valued by my child's disability team.	.839			
The service that my child attends communicates with me as a father directly.	.812			
I meet with my child's disability team often (at least 3 times per year).	.786			
My child's service has always acknowledged my role as caregiver.	.774			

My child’s disability/clinical service team have always emphasised the importance of my involvement.	.747	
Society today has a very positive attitude to children who have an intellectual disability or developmental delay.	.627	
Services need to be more flexible in terms of their opening times and days of work	.451	
I often feel isolated as a father of a child with an intellectual disability	.419	
It is difficult for me to attend all of my child’s appointments**.**		
I worry about my child’s future regularly		
In general, having a child with an intellectual disability has been a positive experience as a father.		.808
Having a child with an intellectual disability has a positive impact on family life.		.794
My family offers me emotional support as a father of a child with an intellectual disability.		.740
My friends/peers offer me emotional support as a father of a child with an intellectual disability.		.724

Fathers are involved in their children's care in the early years.	.623	
Fathers are involved in key decisions for their children (e.g. school selection).	.577	
My social life has been negatively impacted since my child was born	.532	
I have a loving bond with my child.	.471	
The care that I provide is valuable and important to my child		
My spouse is my child's primary caregiver.		.868
It is the main role of the child's mother/primary caregiver to carry out programmes and go to clinic appointments**.**		.776
Mothers are still the main carers for children**.**		.671
The care for my child is equally shared between parents		.578
I feel that I am very involved in the life of my child		.573
It is the fathers role to provide financially for their children**.**		

Children with an intellectual disability or developmental delay have the same opportunities as other children**.**	.401	
I am involved in carrying out the programmes/interventions that my child’s disability team recommends for them	.469	
The role of fathers in general has changed in recent years.		
It was a difficult time for me when my child was diagnosed with an intellectual disability		.664
I would attend courses on supporting my child if they were made available to me**.**		.649
Fathers should receive personal support/counselling from their child’s disability services**.**		.506
Since my child was born, I have experienced higher levels of stress and anxiety		.490
As parents we have discussed how we divide our attendance at meetings and appointments.		

4.3 Father Interview Results

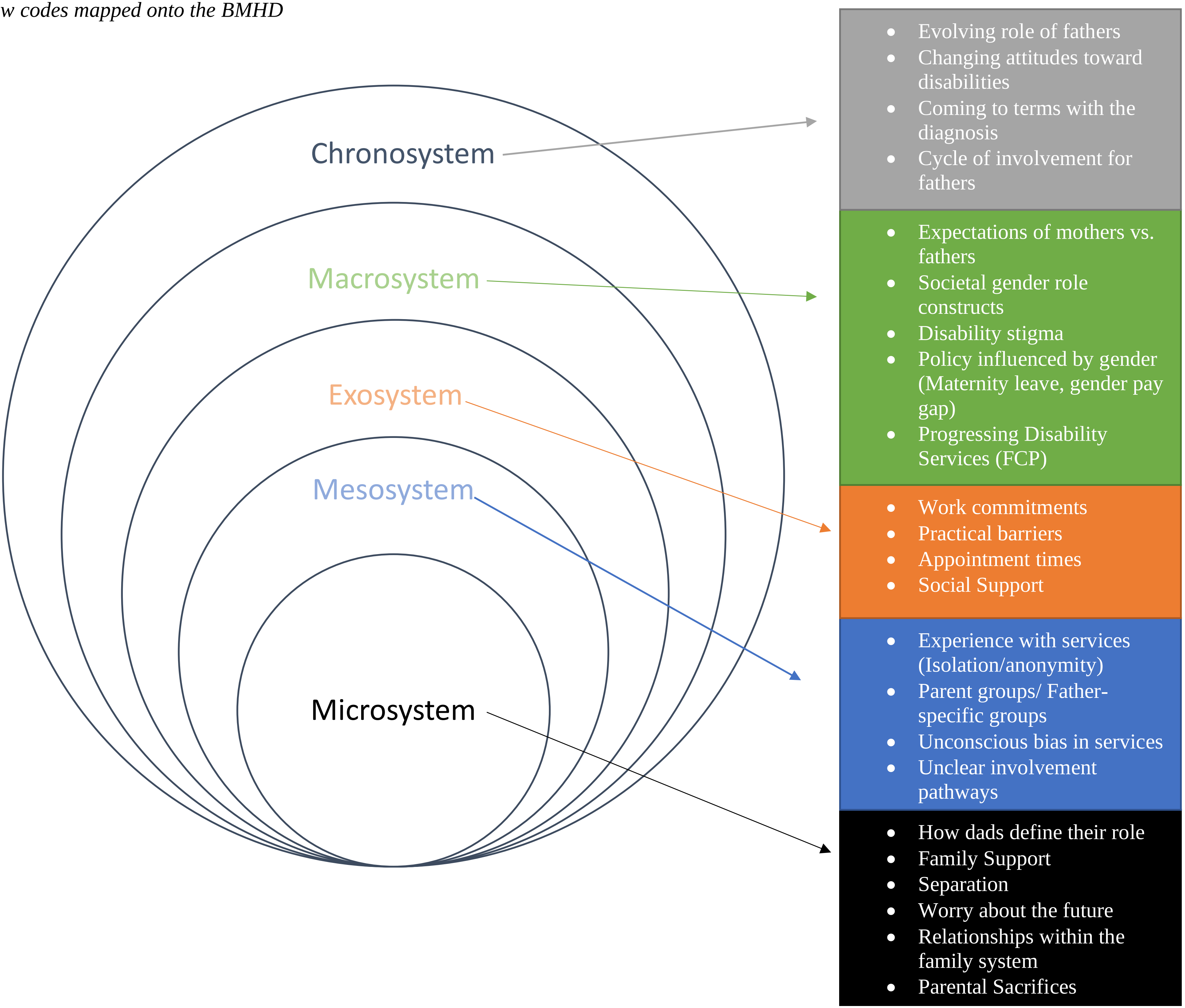
The second research question in this study was addressed by interviewing fathers of children with an ID/DD about their experiences on their engagement with DS. In total, nine fathers were randomly selected from the survey sample and interviewed. The demographic characteristics of each of the interviewees are summarised in table 18. Results from these interviews are presented in terms of themes and subthemes, arising from a thematic analysis (Braun & Clarke, 2006). The themes and subthemes are mapped onto each nested system of the BMHD, which has been used as a framework to structure these results (Bronfenbrenner & Morris, 2006). Additional quotes from interviewees relating to each theme and subtheme can be found in Appendix 19.

Prior to developing themes and subthemes, the interview codes were firstly mapped onto the BMHD, which can be seen in figure 4.

Table 18: *Father interviewee characteristics*

Father Pseudonym	Age	Age of child	Range of ID/DD	Marital Status
"Derek"	74	16	Severe-Profound	Married
"James"	47	9	Severe-Profound	Married
"Ryan"	39	1	Developmental Delay	Married
"Phil"	42	16	Mild-Moderate	Divorced/ Separated
"Michael"	46	9	Mild-Moderate	Married
"Brendan"	44	8	Mild-Moderate	Married
"John"	50	19	Mild-Moderate	Divorced/ Separated
"Isaac"	38	3	Developmental Delay	Married
"Mark"	48	7	Severe-Profound	Married

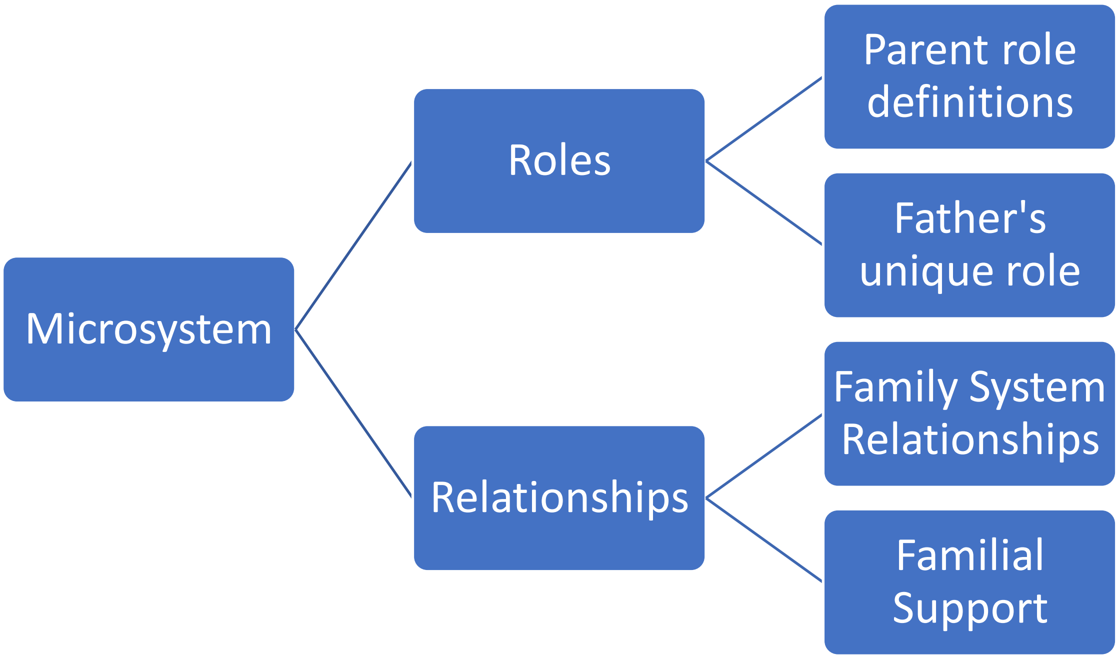
Figure 4: *Father interview codes mapped onto the BMHD*



4.3.1 The Microsystem

From the interview codes, two main themes were generated that were located within the microsystem. These themes were entitled “Roles” and “Relationships”. Within these themes were further subthemes, which are discussed below. A visual representation of the themes and subthemes within the microsystem can be seen in figure 5.

Figure 5: *Microsystem themes and subthemes (Father Interviews)*



4.3.1.1 Theme 1: Roles. The first theme discussed within the microsystem is “Roles”. Fathers highlighted a number of roles that they fulfilled as a parent and discussed how these roles have impacted their engagement with DS. Fathers also noted the different roles within their families, including parent role definitions when parenting a child with an ID/DD and complex needs.

4.3.1.1.1 Subtheme: Parent Role Definitions. The interviewees attested that parent role definitions can influence how each parent engages with their child and the services their child accesses. All nine of the interviewees discussed how their parent roles were impacted by having a child with an ID/DD. In seven of the nine interviews, fathers considered mothers to be their child’s primary caregiver, while they fulfilled a role of provider for their children and supporter for their spouse. However, all fathers claimed to play an important role in caregiving, even if they did not internalise this as their main role definition. This finding parallels with the survey results accrued. According to Mark, there is no denying that children have a different relationship with their mother compared to their father:

"There is no denying that there is a different relationship between child and mother and child and father, it's just reality and that's fine, but that's not to say fathers can't have a meaningful input and involvement."

A factor that appears to solidify the parent role definitions that were apparent across the interviews, is the need for one parent to cease working due to the complex demands of parenting a child with an ID/DD. James discussed how before their child's birth, he shared equal responsibility in terms of providing financially for the family with his wife, but this has now changed in light of their circumstances. His wife has had to give up work, which has resulted in the financial burden of supporting the family resting upon his shoulders:

"I am the provider, yes. For a while it was 50/50, but my wife had to give up work a few years ago and then there was a very clear dividing of roles."

Brendan shared a similar experience, which is exemplified in the quotes in Appendix 19. In fact, six of the nine interviewees shared similar experiences of their wife having to sacrifice her working career to become the full-time carer for their child.

4.3.1.1.2 Subtheme: Father's Unique Role. It was apparent from the interviews that fathers play a unique role within the family system in supporting their child with an ID/DD. While mothers appeared to fulfil the primary caregiver role, fathers found alternative ways to support their child. In eight of the nine interviews, fathers described themselves as advocates trying to help their child to access services, while supporting their spouse through this advocacy process. They discussed how trying to ascertain the necessary services for their children is an important and relentless role. Derek, father to a 16-year-old boy, who has been fulfilling a parent role as an advocate for many years, eloquently described the impact that battling for services has had on his family system:

"If you hold a glass of water out from your body for a minute, there is no problem. For an hour, it starts to become a problem, do it for three hours or longer and your arm falls off. There is such a lack of support."

Fathers also considered part of their role to include planning for their child's long-term future, particularly the three fathers of teenage children interviewed. These fathers worried about how their child will navigate inevitable life transitions. Phil, whose son is 16 years old, said:

"His future, and what he's going to do when he's older and when we aren't here anymore is the number one thing that would keep me up at night time."

4.3.1.2 Theme 2: Relationships. The second theme that was generated from the interviews and that mapped onto the microsystem was termed "Relationships". Fathers discussed how relationships within their immediate family system and the emotional support that family members provided for them was crucial in coming to terms with their child's disability. This relates to a theme located in the chronosystem, which describes how fathers appear to take longer to come to terms with a disability diagnosis and to establish their role, which will be discussed later in this section.

4.3.1.1.1 Subtheme: Family System Relationships. Five of the interviewees discussed how having a child with complex needs has impacted relationships within their family system, including their relationship with their spouse, and with their other children. Positive and negative impacts were highlighted by fathers. Brendan described the relationships within his family system, saying:

"If we compare my daughter with her peers, she has had to put up with a lot. For me and my wife, it has changed things, there is no comparison."

Both of the separated parents who were interviewed noted that the needs of their child was a factor in their separation from their spouse, claiming that the relentless battle to access services, and their unbalanced relationship with services, was a stressor that impacted their family system relationships. John, who has separated from his wife in recent years, described how this affected his family system:

"He needs a lot of extra care and there are little frustrations within the family. It's a primarily positive experience but it's not anything I would wish on anyone. It's a huge effort and impacts the family hugely."

4.3.1.1.1 Subtheme: Familial Support. Five interviewees discussed how having a support network within their family system was important for them in helping to manage their child's care and to have time to engage with external services. Michael noted that his family were fortunate to receive support from their wider family system:

"Our families are very supportive. We get more from my wife's parents because they live so close. We try not to burden them too much, but it is difficult to manage on our own."

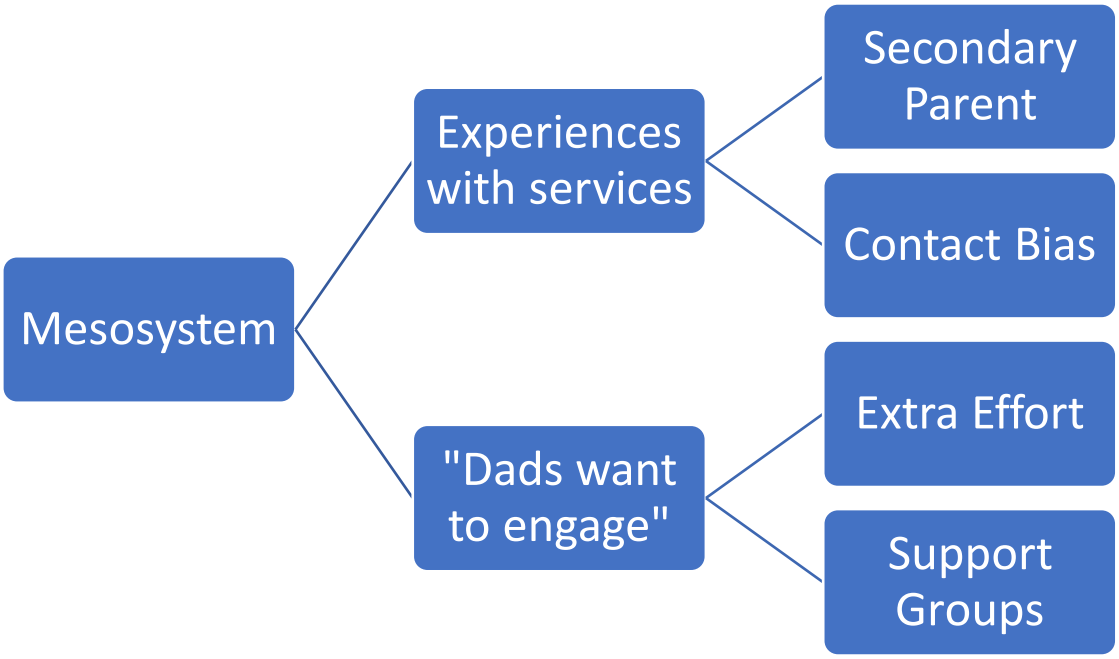
The other four fathers described how their families were not so fortunate, and how they would have liked to have had more family support. Cited reasons for a lack of support included geographical location, and disengagement from wider family when their child was born. Mark believed a lack of support from the wider family system affected his attendance at disability service appointments:

"Without that support, the level of frustration and burnout is pretty high. In terms of appointments, it always had to be one or other of us who attended because one of us had to mind the other kids."

4.3.2 The Mesosystem

The mesosystem captures the relationships between the family system and other systems in which the family spends time, including DS. Two main themes that emerged within the mesosystem were: "Experience with services" and "Dads want to engage."

Figure 6: *Mesosystem Themes and Subthemes (Father Interviews)*



4.3.2.1 Theme 3: Experiences with Services. Within these interviews, fathers discussed the experiences with DS. Two subthemes were generated within this theme, entitled: “Secondary Parent” and “Contact Bias.”

4.3.2.1.1 Subtheme: Secondary Parent. Seven of the fathers interviewed reported feeling viewed as the less important parent in the family-service relationship. Isaac reported this, stating:

“There’s definitely a pecking order and dads are number two. I definitely feel less important.”

Derek described how he felt services view fathers:

“Dads are treated benignly but for the real stuff, they go to the mother.”

Other fathers used words like *“aloof”* (Mark) and *“clueless or invisible”* (James) to describe how they thought services perceived fathers. The interviewees felt that services generally saw the mother as the expert, which often was the case, but it was felt there was a little recognition for the important role fathers can play in the family-service partnership.

4.3.2.1.2 Subtheme: Contact Bias. Based on their experiences, seven fathers claimed there was a bias toward contacting mothers, thus hindering their ability to engage with services. Some believed that this was a naturally occurring unconscious bias. John stated:

“There’s one point of contact and it’s always the mam and that was challenging. My experience is that this is not sexist, it’s habit.”

Others believed mothers are the favoured contact within services and fathers were overlooked even when they wanted to be contacted. Isaac was baffled at being actively overlooked by services:

“My son’s mum is the contact even though both of our contact details are down but it’s always mum who is called.”

4.3.2.2 Theme 4: “Dads want to engage”. The second theme that emerged within the mesosystem is that fathers want to engage with DS. This theme was divided into two subthemes, “Extra Effort” and “Support groups.”

4.3.2.2.1 Subtheme: Extra Effort. The interviewed fathers attested that gaining recognition from services required a concerted effort on their part. This parallels with the advocacy role that many fathers appear to adopt in an attempt to be meaningfully involved. Mark made the point that:

"In terms of the first point of contact for disability services, unless you make it explicitly known that you're actively involved and interested, they will always automatically contact the mother."

Passive fathers can be overlooked by services according to participants, and there was a consensus that many fathers can be overly passive or disinterested, which can lead to all fathers suffering as a result of this attitude. Brendan, for example, described how he tried to engage with services, but felt overlooked by them simply because of his understanding nature.

"I definitely think that dads have a lack of engagement. That their job doesn't include engaging with disability services."

4.3.2.2.2 Subtheme: Support Groups. Eight of the nine fathers interviewed underscored the need for emotional support for fathers of children with an ID/DD, expressing interest in attending father-specific support groups if they were organised by DS. In fact, several highlighted how such groups are a necessity for promoting wellbeing among fathers. Interviewees mentioned attending parent groups and being members of support groups on social media, but many of these, as Ryan described are:

"Mum's groups with a few dads in them."

Brendan discussed the benefit of services facilitating meetings with fathers who share similar experiences and process their child's disability, because men are less likely to use informal opportunities to talk than women:

"even if there isn't an organised thing for women, they will meet and talk. It would be nice to meet some men in the same position as me to offload and share things. It would be great if services could offer that."

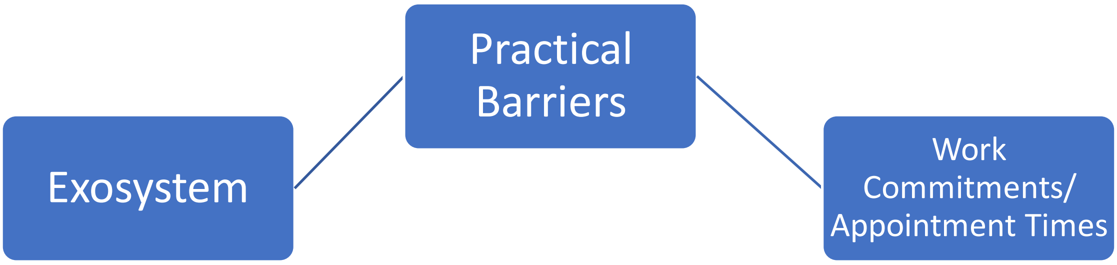
Other fathers mentioned their positive experience of such groups in the past. Michael said he attended a new parents' conference organised by Down Syndrome Ireland when his daughter was born, saying:

"Everyone had a different story to tell and it was really beneficial. They put dads together and mums together, people were crying as it was the first time they had spoken about it in public."

4.3.3 The Exosystem

The exosystem encompasses formal and informal social structures that impact relationships within the microsystem and the mesosystem (Bronfenbrenner & Morris, 2006). One theme was generated from the interviews that is located within the exosystem, called 'Practical Barriers', and within this theme lies the subtheme of 'Work Commitments/Appointment Times.'

Figure 7: *Exosystem Themes and Subthemes(Father Interviews)*



4.3.3.1 Theme 5: Practical Barriers. Practical barriers, such as appointment times and busy work schedules, were emphasised as factors that stifle fathers' engagement with DS.

4.3.3.1.1 Subtheme: Work Commitments/Appointment Times. Six out of the nine fathers interviewed mentioned their work as impacting engagement with DS. The three who did not see this as an issue were either self-employed or work remotely and have flexible work schedules. According to Phil:

"I attended meetings only when I could because I was the one working at the time and, therefore, I couldn't always be there for these appointments. But I attended when I could while my wife attended all of them."

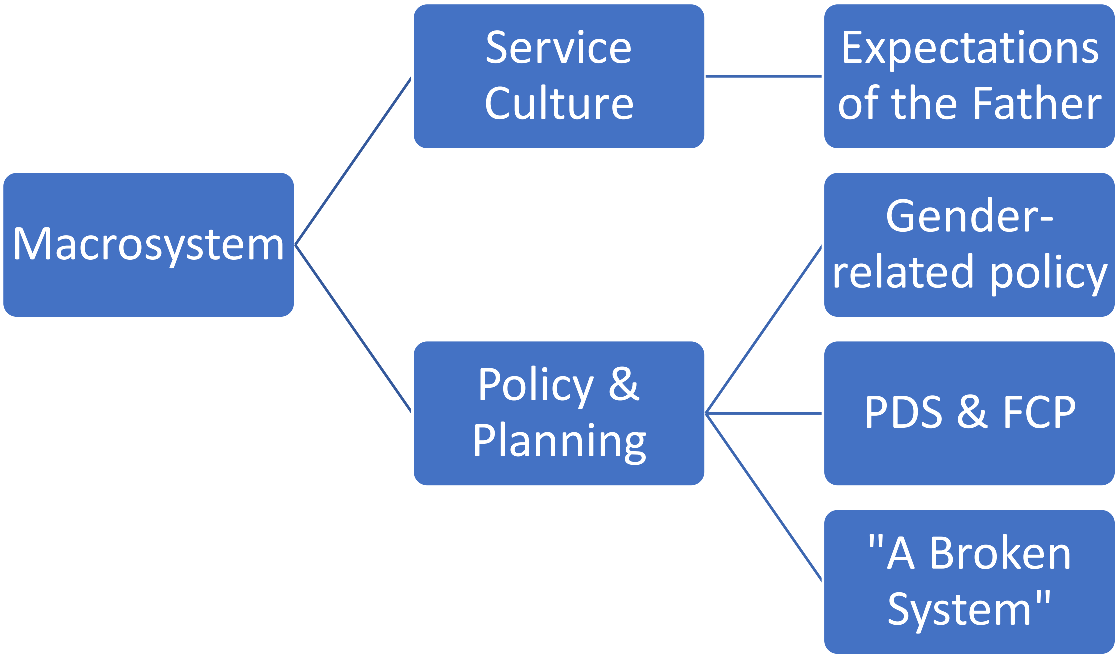
The fathers interviewed would like to attend more appointments, but their work schedules prevent that from happening. James discussed issues with 9am-5pm appointment times and how services can be quite inflexible:

"You don't get therapy appointments on a Saturday or Sunday, it's all 9-5 based."

4.3.4 The Macrosystem

The macrosystem encompasses the evolving cultural and political conditions that influence and are influenced by the other systems within the BMHD. This includes policy that underpins and influences DS, and societal beliefs about the role of the father and disability in general.

Figure 8: *Macrosystem Themes and Subthemes (Father Interviews)*



4.3.4.1 Theme 6: Service Culture. During the interviews, fathers discussed how certain societal attitudes and beliefs towards gender and disability have influenced their experiences of parenting a child with an ID/DD and their engagement with DS. Within this theme, a subtheme was generated: ‘Expectations of the Father.’

4.3.4.1.1 Subtheme: Expectations of the father. The construct of gender was discussed by all of the interviewees. It was noted by four fathers that there can sometimes be different expectations of people based on their gender which can influence engagement with DS. In many ways, this subtheme relates strongly to the subtheme of ‘role definitions’ within the microsystem, but this subtheme looks at the expected roles of parents with a wider, social lens.

Fathers identified expectations placed on them as different to those placed on mothers of children with an ID/DD. Since mothers are typically considered to be the primary caregiver, there is a pressure and expectation on mothers to always be present and available, whereas the father's presence or engagement is seen by services as a bonus. Some fathers said they would only be contacted by services for 'bigger' meetings or appointments, or when there were challenging behaviours exhibited from their child. Regarding service appointments, Phil responded:

"My ex-partner would go to them all and only if there was a really big issue would I go."

Five fathers noted that to be routinely involved, they needed to assert themselves and make a concerted effort, but the expectation from services is that they will not be involved to the same extent as the mother. This relates to the subtheme of 'extra effort' in the mesosystem. According to Mark:

"you do kind of have to work around it and let them know that you are involved and you are interested."

4.3.4.1 Theme 7: Policy and Planning. It was clear from the interviews with fathers that policy influencing DS, and policies that are gender-based, have had an impact on their engagement with services. Within this theme, three subthemes arose: 'Gender-related policy', 'PDS & FCP', and "A Broken System".

4.3.4.1.1 Subtheme: Gender-related policy. Throughout the interviews, three fathers drew attention to gender-related policies and cultures that have influenced how they engage with DS. Two of the most prominent examples were maternity leave and the gender pay gap. Fathers mentioned how mothers become the main point of contact during maternity leave, when it makes sense for them to attend appointments. However, that places the father on the periphery from the beginning, while the mother's position as the primary contact and perceived primary caregiver is solidified. According to Isaac:

"As the partner who doesn't breastfeed, it makes sense for the mother to be on leave. However, this means that things might tend to fall to her to look after services ....I've often been intrigued by the Scandinavian model, where each parent gets the same amount of time off to spend with kids."

The gender pay gap was also highlighted as a reason that, when the child's needs are complex and one parent needs to cease working to become the full-time carer, it tends to be the mother. This puts her full-time job as the child's carer and thus she attends all of the appointments with DS. Speaking about wider policy and culture that influences engagement with services, Michael noted:

"The gender pay gap is a big thing. Women earn less than men which is ridiculous but it is still there."

Conversely, in Mark's family, where the mother earns more money, he has decided to work reduced hours and to fulfil more of a caring role to facilitate her career progression:

"The nature of my wife's role means that she's progressing through the managerial levels in the pharmaceutical industry. I decided to hold off and stay where I was because the hours and days are flexible. It means that I am often more of a carer during the week than my wife."

4.3.4.1.2 Subtheme: PDS & FCP. Given that DS are at a time of significant reconfiguration at present, it is unsurprising that the topic of PDS and FCP was mentioned regularly. Fathers showed mixed feelings towards the change in services, with some hoping that services will improve as a result, while others, particularly those with children in the severe-profound range, worried that this reconfiguration would result in a lack of expertise in care. The FCP model was also discussed, with some fathers displaying hesitancy around its implementation, and others supporting the theoretical basis of this approach to service delivery. Brendan, whose son is in the mild-moderate range, displayed an open-mind to the implementation of PDS:

"We are hoping this new thing, Progressing Disability Services, will bring a positive influence to services."

Derek, whose son is in the severe-profound range and has complex needs, is worried the uniformity of care that is a central caveat of PDS means his son will be treated the same as other children who have less significant needs, stating:

"There is nothing so unequal as the equal treatment of unequals."

Mark was sceptical about the FCP approach, worrying that it would place further burden on parents:

"The model of service delivery will be this kind of transformational shift from professionalised intervention therapies to the family-centred approach. Reading between the lines, the families and the parents become the therapists.."

4.3.4.1.3 Subtheme: A Broken System. All fathers expressed frustration at the system of service delivery, citing it as negatively impacting their experiences with DS. It was common across interviews for fathers to acknowledge the positive work being carried out by practitioners who unfortunately were stuck in a system not fit for purpose. According to Derek:

"On the one hand within this dysfunctional system, you have some great people, angels if you like. But they are caught up in a system that is not working."

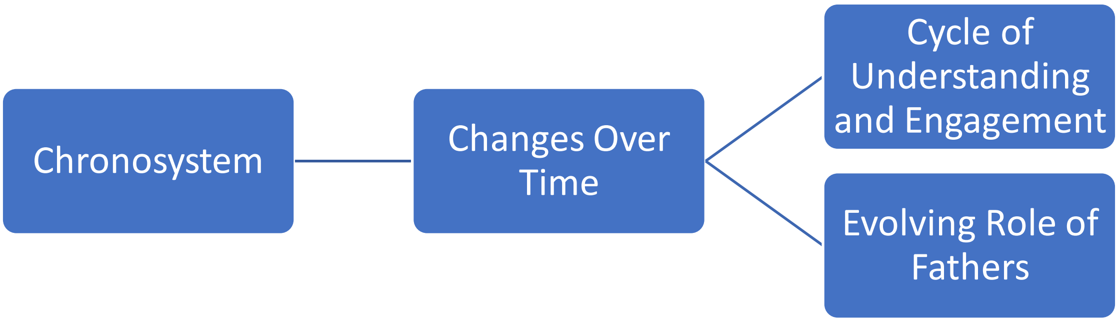
Brendan commented:

"No one has a problem with the individuals; it's the 'big brother' thing. It's always 'we don't have resources', well why don't you have resources?"

4.3.5 The Chronosystem

The chronosystem describes transitions and environmental events, as well as changes in perspective that occur over time. The theme and subthemes generated within the chronosystem are visually represented in figure 9 below.

Figure 9: *Chronosystem Themes and Subthemes (Father Interviews)*



4.3.5.1 Theme 8: Changes Over Time. Within the chronosystem, one theme was generated: 'Changes Over Time.' Within this theme, two subthemes emerged: 'Cycle of Understanding Engagement' and 'Evolving Role of Fathers.'

4.3.5.1.1 Subtheme: Cycle of Understanding and Engagement. Seven out of nine fathers interviewed mentioned the difficulty coming to terms with their child's disability after their diagnosis and how this impacted on their engagement with DS. Ryan, whose child is only a year old, is still coming to terms with his diagnosis and commented:

"I suppose this is the first time I have ever spoken about it. I'm holding back a bit of emotion now, you know. Maybe down the road I will talk to someone about it. His birth happened so quick, the diagnosis and everything. A lot went on."

Fathers emphasised that emotional support in the early days would have been helpful in processing and coming to terms with the diagnosis. Speaking about the potential of counselling sessions being offered shortly after diagnosis, Isaac stated:

"I would say that they might be very beneficial. It's a struggle to get your mind around in the early days."

In terms of this initial shock influencing engagement with DS and involvement with their children, James shared a compelling view:

"From what I have seen, most dads bury their head for the first couple of years and try to ignore what is happening and either work or do something else as it's usually the mum who is the full time caregiver…Then, as they get more used to the situation and a routine forms, they might start to get more involved."

4.3.5.1.2 Subtheme: Evolving Role of Fathers. Interviewees were asked if they felt the role of the father has changed in recent times from their experiences. All expressed the view that in terms of parenting, fathers are expected to fulfil more of a caring role than traditionally was the father's remit. Moreover, they stressed a desire to fulfil this role. According to Phil:

"I think more is expected of fathers, I think fathers want to give more."

Interestingly, Ryan thinks that the attitudes toward the role of the father in services is *"still a bit behind"* the changing role of fathers in society in that they see parent roles to be very clearly defined. Mark propounded that services need to over-compensate to overcome this traditional view of parenthood to help fathers to become more engaged:

"We (fathers) just need opportunities for us to become involved. The HSE could do a lot more to encourage this, like positive discrimination methods to include dads and make sure they're involved. That would only be a short-term thing because that becomes self-fulfilling. When one generation of dads improves their interactions with services, the kids following them will learn from that."

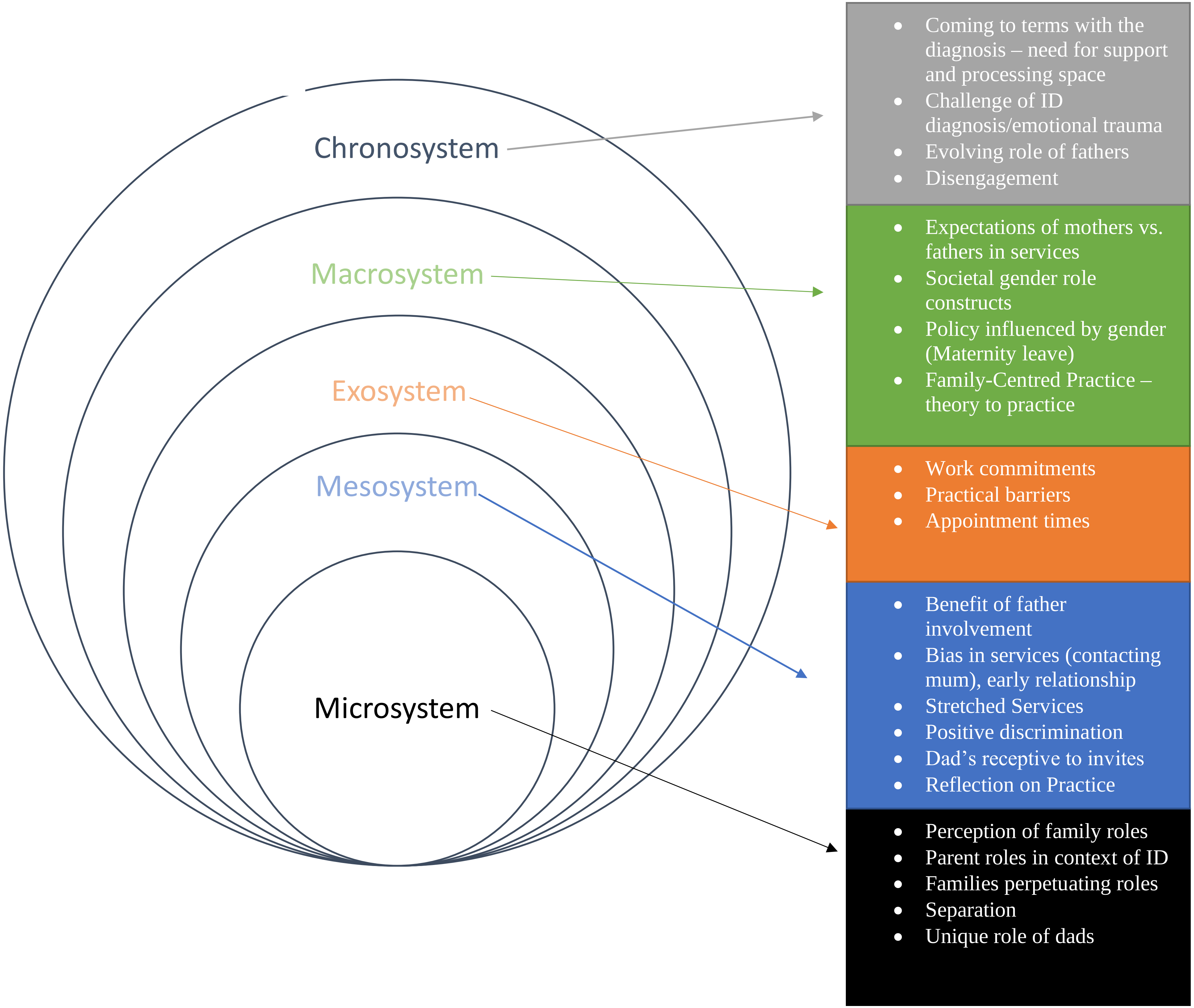
4.4 Psychologist Interview Results

The third research question in this study was addressed by interviewing psychologists working in DS about their experiences on the engagement of fathers of children with an ID/DD with DS. In total, eight psychologists were purposefully sampled for interview. The demographic characteristics of each of the interviewees are summarised in table 19. Results from these interviews are presented in terms of themes and subthemes, arising from a thematic analysis (Braun & Clarke, 2006). The themes and subthemes are mapped onto each nested system of the BMHD, which has been used as a framework to structure these results (Bronfenbrenner & Morris, 2006). Additional quotations to supplement the data presented in this section can be found in Appendix 20. Prior to developing themes and subthemes, the interview codes were firstly mapped onto the BMHD, which can be seen in figure 10.

Table 19: *Psychologist Interviewee Characteristics*

Psychologist Pseudonym	Disability Service Experience	Type of Psychologist
“Ruth”	2 Years	Educational
“Audrey”	13 Years	Educational
“Sarah”	5 Years	Educational
“Emily”	2 Years	Clinical
“Thomas”	7 Years	Educational
“Michelle”	2 Years	Clinical
“Matthew”	6 Years	Clinical
“Stella”	13 Years	Educational

Figure 10: *Psychologist interview codes mapped onto the BMHD*



- Coming to terms with the diagnosis – need for support and processing space
- Challenge of ID diagnosis/emotional trauma
- Evolving role of fathers
- Disengagement

- Expectations of mothers vs. fathers in services
- Societal gender role constructs
- Policy influenced by gender (Maternity leave)
- Family-Centred Practice – theory to practice

- Work commitments
- Practical barriers
- Appointment times

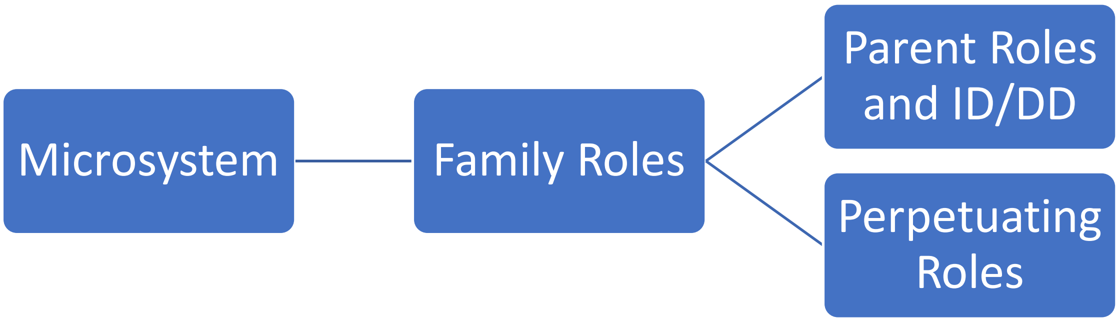
- Benefit of father involvement
- Bias in services (contacting mum), early relationship
- Stretched Services
- Positive discrimination
- Dad’s receptive to invites
- Reflection on Practice

- Perception of family roles
- Parent roles in context of ID
- Families perpetuating roles
- Separation
- Unique role of dads

4.4.2 The Microsystem

Psychologists were asked about their experiences of the parent roles that develop within the microsystem during the interviews. Within this domain, the theme of family roles was generated from the discussions with the psychologists. This theme was divided into two subthemes: 'Parent Roles and ID/DD' and 'Perpetuating Roles'.

Figure 11: *Microsystem Themes and Subthemes (Psychologist Interviews)*



4.4.2.1 Theme one: Family Roles. The psychologist interviewees discussed their experience of parent roles in the context of ID/DD and how this may influence father engagement with DS. Psychologists also drew attention to factors that could be perpetuating these roles.

4.4.2.1.1 Subtheme: Parent Roles and ID/DD. Six of the eight psychologist interviewees discussed how parent roles can become more deeply ingrained when parenting a child with complex needs. This can result in more traditional roles being adopted, whereby the mum is the caregiver while the father is the provider. Speaking of working with parents of children with an ID/DD, Ruth mentioned:

"I can see in some families it (having a child with an ID) would have polarised their roles"

Stella offered insight into why these roles may become so ingrained in families of children with complex needs. Since the mother often must stop working to support her child, she internalises the role of carer as her full-time job, defining herself in these terms. This involves taking on more responsibility with service appointments similar tasks as part of her role within the family system. According to Stella:

"I think it's about identity, core beliefs, my value as a person will be impacted by my success as a mother. The dad's value as a person will be impacted by their success in their job."

Michelle offered a prospective further explanation for the entrenchment of these roles, suggesting that there may be pressure on mothers to fulfil a caring role and to overcompensate for the turbulent early years that many children with complex needs face:

"I see some mothers that I work with trying ultra-hard to repair that time that they felt they didn't have with the child early on. I wonder is there more pressure on mothers to feel that they've made up for that difficult start."

4.4.2.1.2 Subtheme: Perpetuating Roles. Five of the eight psychologists noted that while the presence of disability and complex needs may be the catalyst for promoting traditional parent roles, there are also a number of factors that play a part in perpetuating and solidifying these roles within the family microsystem. Service practices, internalisation of roles, care allowances and parental separation can push mothers towards the caring role and fathers toward the provider, or disengaged parenting role. On service practices perpetuating gender roles within the family system, Audrey noted:

"We feed into that narrative as a service by contacting moms first and not making a concerted effort to phone dads."

Audrey expanded that mothers can unconsciously exclude fathers because of how parent roles tend to develop in families of children with a disability:

"Moms construct the role of the dads in the lives of those with disability…some would almost dismiss the dad. The mom needs to be the main person in this."

Ruth made the point that certain care allowances can further cement these parenting roles within the family system:

"The way it is set up in Ireland with the domiciliary care allowance, it nearly lends itself to that arrangement (of mother being the carer). So, you nearly have to work especially hard not to fall into those patterns."

Parental separation was also a factor noted by psychologists that can leave the father isolated and anonymous in a clinical relationship because it is generally the mum whose caring role becomes even stronger in this context. Emily noted that:

"When parents are separated, it is almost exclusively dealing with the mother and separated dads can feel almost totally alienated."

4.4.3 The Mesosystem

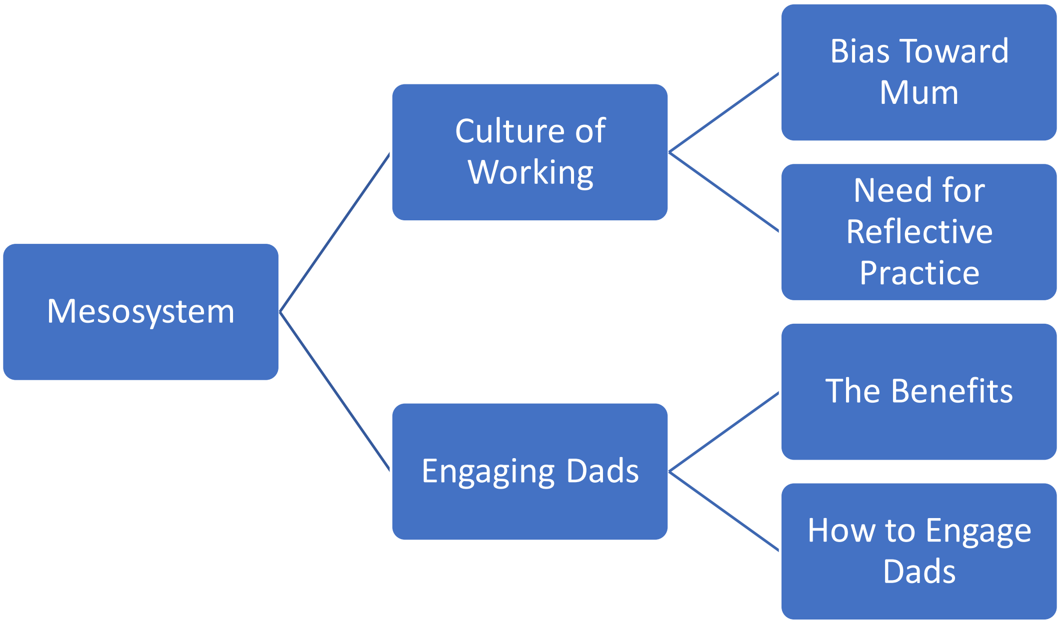
The mesosystem captures the relationship between DS and the family microsystem. A visual representation of the themes and subthemes in the mesosystem from the psychologists' perspective can be seen in figure 12.

4.4.3.1 Theme Two: Culture of Working. Psychologists shared their views on how the culture of working within services can influence service relationships with the family microsystem of children with an ID/DD, and how this can affect father engagement with services.

4.4.3.1.1 Bias Toward Mum. Every psychologist interviewee mentioned feeling that a bias existed in DS towards contacting mothers over fathers. This reflects attitudes towards parent roles within the microsystem, whereby the mother is conceptualised as the primary caregiver. According to Michelle:

"Even if dad's number is there and I can't get mam, I will keep trying her for a few days."

Figure 12: *Mesosystem Themes and Subthemes (Psychologist Interviews)*



Similarly, Thomas made the point that in his practice, it is automatic to ring the mother, barring an explicit exception where the father was known to be the primary contact:

"Clinicians, therapists and myself would automatically pick up the file and ring the mum. It was maybe one or two families where you would know dad was the point of contact."

Some psychologists offered insight into how this culture of working has developed within DS, pointing to the fact that services are very busy and stretched which can mean working in the most efficient and automatic way possible. According to Matthew:

"Contacting mum is probably an implicit bias that we carry rather than asking who else is there and how should they be involved in this intervention. Clinicians are extremely busy. Sometimes you feel lucky just to have an appointment with anybody in the family."

4.4.3.1.2 Subtheme: Need for Reflective Practice. Psychologists noted that reflection is needed to challenge these biases and preconceptions that are implicit within services. According to Emily:

"Sometimes the assumption is that dad wouldn't know and mum is best informed. I'm guilty of this and have to challenge myself."

It was also noted by psychologists that, although reflection is needed on who to contact, some of the responsibility also lies with the family, or whoever has filled out the contact form. According to Sarah:

"I'm not conscious if I perceive them differently. It comes back to who is the primary contact and you look up the child's primary carer, if dad is there, you'd ring him. It seems the primary contact is generally the mum and that comes from forms sent out to the family, and the choice lies with them."

4.4.3.2 Theme 3: Engaging Dads. Psychologists also discussed how engaging fathers can be a major benefit to the formulation process and mentioned engagement approaches that had been successful for them in the past.

4.4.3.2.1 Subtheme: The Benefits. Five of the eight interviewees mentioned that involving the father can enhance the relationship between services and families and can even aid with case formulation and intervention selection. Audrey spoke about this:

"Involving the dad aids your understanding of the family system which strengthens your formulation and therefore whatever interventions you recommend."

Thomas argued that by not gaining both parents’ perspectives, we are not only missing out on learning about the whole family system, but we are also putting undue pressure on the mother:

“I really dislike doing an assessment if the dad isn’t involved, feeding back to mum who then has to feed back to dad. We’re putting huge pressure on mums to be that communicator and carry everything for the children in two-parent families.”

4.4.3.2.2 Subtheme: How to Engage Dads. The psychologist interviewees discussed some methods that they have used, or would like to use, to engage fathers. Psychologists expressed that positive discrimination, such as explicitly inviting fathers to appointments, may be necessary to improve father engagement with DS. On the need for positive discrimination, Michelle noted:

“The way to remedy this situation is an explicit acknowledgement and reaching out with positive discrimination towards dads.”

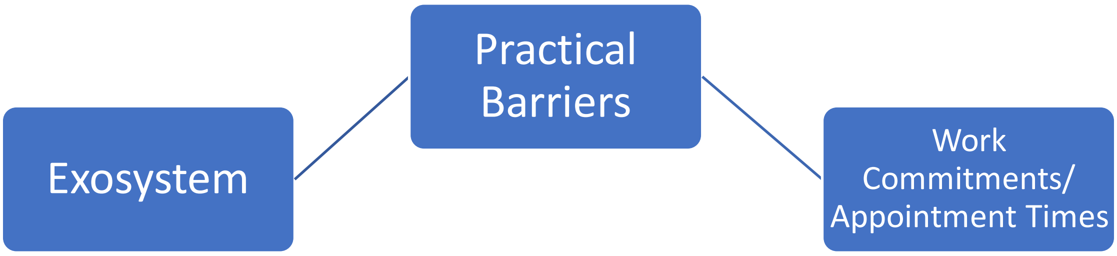
Interestingly, Emily noted that whenever she has made the effort to include and invite fathers, they have responded positively. She thinks that clinicians should challenge themselves to explicitly invite both parents to appointments. As noted by the fathers in their interviews, often an early relationship can be established with mothers which can make it harder for fathers to become involved. Psychologists noted that establishing an early relationship with the father could alleviate this issue and see fathers feeling more involved, resulting in increased engagement. Three of the eight psychologists interviewed referred to a model of intake used in CAMHS stipulating both parents must attend the first session. According to Thomas:

“CAMHS would send out their appointment letters, saying, ‘Both parents have to attend this’. I think we generally tend to be very accommodating to families but it’s something that we should do, especially at intake and assessment to make both the mum and dad, if available, feel like part of the process.”

4.4.4 The Exosystem

The psychologists who took part in the interviews noted some barriers within the exosystem that can hinder father engagement with DS. Some points paralleled with the views of fathers, while additional barriers were also identified. A visual representation of the themes and subthemes within the exosystem can be seen in figure 13.

Figure 13: *Exosystem Themes and Subthemes (Psychologist Interviews)*



4.4.4.1 Theme 4: Practical Barriers. A number of practical barriers were highlighted by psychologists that, from their experience, can stifle the engagement of fathers of children with an ID/DD with DS. Two subthemes emerged within this theme: 'Work Commitments/Appointment Times' and 'Other Barriers'.

4.4.4.1.1 Subtheme: Work Commitments/Appointment Times. In line with the father participants, work commitments influencing engaging with DS was flagged by seven of the eight psychologists interviewed. When discussing why fathers may not be as proactive as mothers in attending service appointments, work commitments were cited by seven participants as hindering father engagement. However, according to Michelle, even when mothers are working, they find a way to attend.

"But even with mums that are working, we don't run into that as much. I don't know if they have more flexibility or they feel more able to say in work that they have an appointment concerning a child."

Matthew offered a different perspective on work as a practical barrier that impacts engagement, saying that it can be used as a convenient excuse by some fathers who struggle to comprehend their situation:

"It's probably a convenience for some dads to stay in work instead of being at these appointments. By attending they are confronted by their child's disability and this may be unbearable."

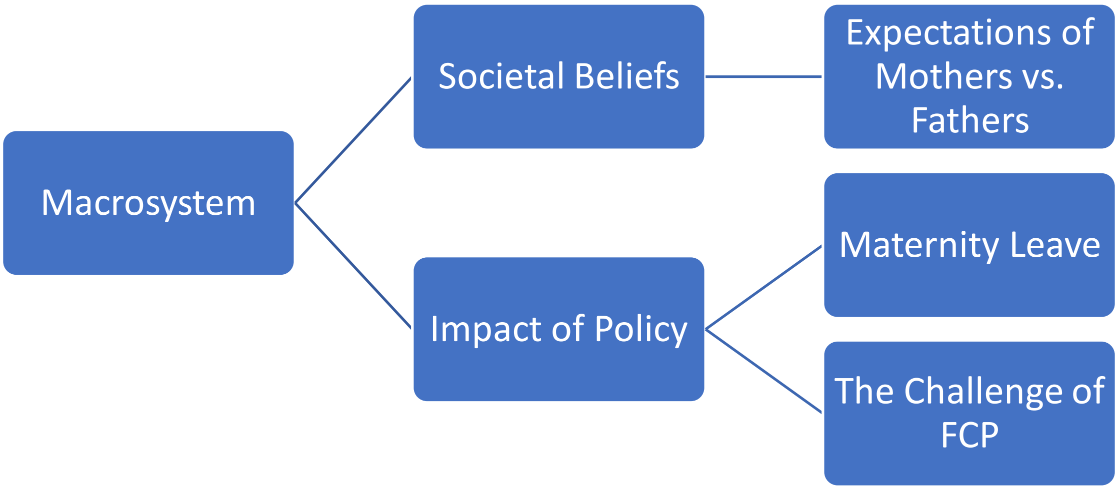
4.4.5 The Macrosystem

Psychologists discussed how policy, societal beliefs and other factors within the macrosystem can influence father engagement with DS. A visual representation of the themes and subthemes generated within the macrosystem from the psychologist interviews can be seen in figure 14.

4.4.5.1 Theme 5: Societal Beliefs. Some societal beliefs about gender roles, and parent roles were raised as factors that can influence father engagement with services by psychologists. Within this theme is the subtheme of 'Expectations of Mothers vs. Fathers.'

4.4.5.1.1. Subtheme: Expectations of Mothers vs. Fathers. From the psychologist interviews, it was apparent that they saw father engagement with services as a wider societal issue as well as a familial issue within the microsystem, a service issue within the mesosystem and a practical issue within the exosystem. Six of the eight interviewees discussed how society has very different expectations for mothers compared to fathers and how this has seeped into the culture within services and within family systems.

Figure 14: *Macrosystem Themes and Subthemes (Psychologist Interviews)*



According to Ruth: *"we are only a couple of decades beyond a time when women weren't allowed to work after marriage. That's within our parents' lifetimes and, if they raised us, we're obviously going to be slightly biased."*

Matthew spoke about how these societal expectations of the mother has influenced service culture, and described how he views services as covertly and implicitly patriarchal:

"My view was that services at their core are deeply patriarchal. We take the woman and tell her what to do. We place a lot of emphasis on gender-based social constructs on what mums should do, they should always be available. They should sacrifice themselves, their careers, their lives, everything."

4.4.5.2 Theme 6: Impact of Policy. An emergent theme from the psychologist interviews was how policy that influences DS as well as wider social policy can influence father engagement with DS. Within these theme there are two subthemes: 'Gender-related Policy' and 'The Challenge of FCP'.

4.4.5.2.1 Subtheme: Maternity Leave. As was noted by the father interviewees, the psychologists expressed how policy related to gender can impact upon father engagement with DS from a wider, social perspective. This includes maternity leave, which was also raised by some of the fathers interviewed. Michelle noted:

"I think there are lots of social forces against dads. Even thinking about maternity leave against paternity leave, mums being available for consultation against the dads. It goes beyond disability services but they are parts of the structure that doesn't facilitate father engagement."

Due to maternity leave, the channels of communication are opened with mum, which means a relationship is established between the family and the service that does not involve the father. According to Stella:

"If you're getting people in early intervention, you know mam's on maternity leave and it sets up the channels of communication. It sets up that she's the person who does the visits and I think that they can become the expert on clinic visits. It's nearly hard to bring dad in then."

4.4.5.2.2 Subtheme: The Challenge of FCP. Six psychologist interviewees also mentioned the challenge of delivering a family-centred practice. According to Emily, the theory of FCP sounds very appealing, but it is difficult to move this model of service provision from philosophy to reality:

"I think the service is on board with the theory of it (FCP) but the operation hasn't followed through yet and I hope it will. We need to make small changes like involving dads."

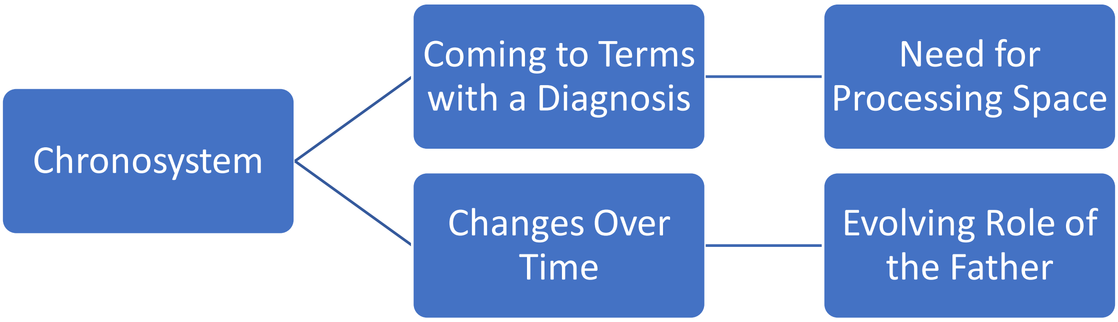
Audrey also shared her views on FCP, discussing how it is important to remain reflective within this process and to communicate with families on what they need. Ruth asserted that, due to the complexities of the reconfiguration of services under PDS, FCP is not even on the agenda yet. Services are simply trying to find an efficient way of working together in their new disability network teams:

"This current service(I'm working in) is so far away from even working together cohesively that the consideration (of implementing FCP) is not even on the radar."

4.4.6 The Chronosystem

In terms of how the chronosystem might influence father engagement with DS, the psychologists attested that coming to terms with a diagnosis the evolving role of the father are influential factors. A visual representation of the themes and subthemes within the chronosystem can be seen in figure 15.

Figure 15: *Chronosystem Themes and Subthemes (Psychologist Interviews)*



4.4.6.1 Theme 7: Coming to terms with a Diagnosis. As fathers had mentioned in their interviews, the psychologists noted that from their experience, fathers had taken longer to come to terms with the emotional trauma of a diagnosis of ID/DD than their spouse. Within this theme, two subthemes emerged: 'Need for Processing Space' and 'Evolving Role of the Father.'

4.4.6.1.1 Subtheme: Need for Processing Space. In their interviews, fathers recounted the challenge of coming to terms with their child's diagnosis. This was echoed by psychologists who noted that fathers do not have the same opportunity to process the emotional trauma of a diagnosis as mothers do, since mothers usually attend service appointments and parent training run by services. According to Matthew:

"The mums expertise and thoughtfulness grows as she has more exposure to clinicians and their way of thinking and their way of figuring things out. There is a risk that not only are mums expected to go but because they're going they become more expert."

Thomas described father-specific groups he has run and how to provide them with the space to process their child's disability:

"It's just a place where they can come and speak about some of the difficulties they're encountering and just rage at times, or sympathise with each other about things and that space is important for them. This is a massive therapy piece for dads. It's like the first step on the grieving process."

Audrey made the point that post-diagnostic counselling for families in general would be beneficial, but is particularly pertinent for fathers who do not get that processing space with professionals, due to lack of engagement:

"One of our psychologists did post-diagnostic counselling and you got five sessions. That, I feel, would really benefit families if it was normalised."

4.4.6.1.2 Subtheme: Evolving Role of the Father. As fathers had noted previously, the psychologists all made the point that the father's role is changing and evolving to become more of a carer role and to become more involved. However, psychologists also noted that there is still a long way to go before parenting roles are equal, as the mother is still overwhelmingly seen as the primary carer. According to the psychologists, we are in a time of change both what is expected of fathers, and in the desire and willingness that fathers are demonstrating to be more involved in the care of their children. According to Stella:

"There's unarguably much more involvement and expectation that dad's will be involved with their kids, have a relationship with their kids and be involved in the caregiving. It hasn't changed enough, it's nowhere near equal."

Discussion

5.1 Discussion Introduction

In this section, the findings of the current study will be examined within the context of previous research literature in the area of interest. This study captured multiple perspectives and sought to answer three overarching research questions which were:

- How do fathers of children with an ID/DD perceive their engagement with disability services?
- What are the experiences of fathers of children with an ID/DD with disability services?
- What are the experiences of Psychologists working in disability services of the engagement of fathers of children with an ID/DD with disability services?

As the primary theoretical framework adopted in this study, the BMHD (Bronfenbrenner & Morris, 2006) offers an applicable and comprehensive perspective from which to interpret and understand the complex findings that were generated through this mixed-methods design. As the secondary theoretical framework utilised, FST (Bowen, 1974) has aided an understanding of the role of the father within the family system, and is particularly useful in conceptualising the microsystemic relationships that impact father engagement with DS. The perceptions and experiences of fathers and psychologists that were captured in this research process exemplify that father engagement with DS is a multifactorial phenomenon that encompasses issues at the family systems level, the service level, and the societal level. Hence, the findings of the present study will be examined across these three levels through a juxtaposition with findings from previous research literature in this discussion section.

5.2 The Family Systems Level (FST)

The Quantitative and qualitative data gathered in this study highlighted the impact that family system dynamics can play in father engagement with DS. While results from the Caring Role subscale of the FEWS-Q point to fathers feeling that they fulfil an important caring role for their child and that their parenting contributions are valuable, expansion on this data through interviews elucidated that the majority of fathers conceptualise their role within the family system as that of secondary carer but primary provider. This was echoed by psychologists, who testified that in the families they worked with, the mother is customarily the primary caregiver within the family system. Psychologists also described how, from their experience, traditional gender roles are prominent in families of children with an ID/DD. A factor that appears to solidify this is the need for one parent to take on the full-time caring role due to the complex needs of the child. There are other variables, for example the gender pay gap and maternity leave, that influence this and will be discussed later in this chapter.

Some findings from this study in terms of parental roles within the family system are supported in previous research findings. For example, Fox et al. (2015) found that financial strain in the presence of disability can solidify parent roles because fathers adopt the role of financial provider. In the present research, it was also noted that fathers often take a more long-term approach toward caring for their child with an ID/DD. Fathers worry about what might happen to their child after they have passed away, and who will support them financially. This finding is also described in previous research (Sheldon et al., 2020). Due to such concerns, fathers tend to look at the bigger picture which can mean that they are not as engaged and involved in the day-to-day tasks, such as attending appointments (Sheldon et al., 2020; Simmerman et al., 2001). McBride et al. (2017) discussed how traditional gender roles continued to impact father involvement with services, which was reiterated by the psychologists interviewed in this study.

Other findings related to parental role definition from this study are novel in nature and have not been documented in previous research. For example, psychologists purported that the internalisation of the caring role on the mother’s side can influence father engagement with DS. Psychologists noted that the mother’s perceived identity and core beliefs can be entrenched within this caring role, while the father’s is related to the providing role which can further polarise these roles within the family system. Oftentimes, children with an ID/DD can have a turbulent start to life and parents miss out on vital attachment opportunities if children are hospitalised, for example. One psychologist noted that, due to the internalisation of the caring role, mothers can endeavour to make up for this lost time through over-compensation. This can result in mothers being dismissive of fathers who try to assert themselves in the caring role, because the mother relies on her performance in this role for personal validation. This finding is interesting to consider in light of previous research findings, which claim that father engagement with services is enhanced when they feel empowered (Fox et al., 2015), encouraged, and supported by their partner to engage with services (Curtiss et al., 2021; Huang et al., 2012; Oryono et al., 2021). Simmerman et al.

(2001) noted that mothers who value fathers acting in a caregiving role reported less anger, depression and anxiety when the father was involved and played an active role, but that mothers who did not value the father acting in a caregiving role experienced elevated emotional problems with increased father involvement.

Another key finding from this study is that fathers find it challenging to come to terms with their child's ID or DD diagnosis and it can take time for them to process this, which can have an influence on their engagement with DS. On the Emotional Impact subscale of the FEWS-Q, fathers reported that it was a difficult time for them when their child received their diagnosis and that their levels of stress and anxiety had increased since their child's diagnosis. To lend weight to this, fathers in the interviews spoke about the challenging early years of the diagnosis and how many of them disengaged and turned to the traditional role of the provider within the family system.

It is compelling to move beyond FST and to interpret these findings with the wider lens of the BMHD. This finding is particularly pertinent to the chronosystem, which encompasses life transitions and changes in attitudes over time, but also has significant implications for the microsystem and the mesosystem. Within the microsystem, this disengagement when coming to terms with their child's diagnosis means that the role of primary carer is generally adopted by their spouse, placing significant pressure upon them. This, in turn, impacts the mesosystemic relationship between family and disability service, because the mother becomes the primary contact and service attendee. Previous research has highlighted how fathers and mothers interpret their child's disability differently (Pelchat et al., 2003) and how fathers can find a diagnosis of a disability to be arduous and traumatic (Cheuk & Lashewicz, 2016; May, 1996). Fathers can experience a perceived sense of parenting inadequacy and feelings of frustration with the level of need of their child, while having to try and negotiate their own stereotypes and prejudices around disability (Sheldon et al., 2020). As such, the present research findings appear to amplify the findings of previous research in this area, while extending them to suggest a cycle of involvement from fathers in the lives of children with an ID/DD. Findings from the present study suggest that, with time, fathers become more comfortable with their child's disability and become more engaged as the child becomes older. This engagement may take alternative forms, which exemplifies the unique contribution fathers can make. This contribution can include the adoption of a strong advocacy role for their child, which many fathers in this study proudly attested to.

5.3 The Service Level

The present research findings also implicate issues at the service level as influential regarding father engagement with DS. This was clear from the data gathered in answering all three of the research questions. Results from the Service Role subscale of the FEWS-Q showed that fathers felt that their engagement with services was poor, that they did not feel that services had made efforts to keep them informed and involved and that services do not communicate with them directly. These results are indicative of fathers feeling overlooked by services, which is a well-established finding in previous research (Carpenter & Towers, 2008; Flippin & Crais, 2011; Giallo et al., 2015; King et al., 2007). This data was expanded upon during interviews with fathers, who highlighted that they felt like a secondary parent in the eyes of services and that their opinions and contributions were either not sought, or regarded as secondary to the mother’s views.

The results of the present research strongly indicate that there is a tendency in services to contact the mother first, with some participants, including psychologists, going as far as to describe this as a bias. The majority of fathers in this study did not view this tendency as a sexist act, but rather as a culture of working that is deeply embedded within services. This bias is a significant contributing factor to fathers’ feelings of isolation and invisibility in their relationships with services. Previous research supports these findings, which has found that the culture of bias toward mothers in services can stifle father engagement with services (Curtiss et al., 2021; McBride et al., 2017) and that even when fathers do attend appointments, they can feel excluded or like an inconvenience whose views are overlooked in favour of the views of their spouse (Docherty & Dimond, 2018; Huang et al., 2012). An interesting finding in the present study is that fathers felt that they had to over-compensate or make a concerted effort to engage effectively with services. Some fathers described how they would intentionally contact services and make it explicitly known that they want to be a point of contact and take an active caring role for their child. Even so, these fathers said that the bias toward contacting the mother often persisted, and even when fathers had attended appointments and made it known that they wished to be the main point of contact, services continued to revert to the common practice of contacting the mother.

This finding is fascinating to consider from the psychologists’ perspective, who openly stated that DS need to make more of an effort to include fathers. Psychologists highlighted a need to reflect upon the culture of bias that exists within services to achieve the ideologies set out in FCP. Psychologists noted that when they have engaged in inclusive practices with fathers, fathers have generally been receptive to this. This finding parallels with the work of Fox et al. (2015) who found that empowerment was an important predictor of engagement with services. Docherty and Dimond (2018) highlighted how something as simple as having positive interactions with services can enhance fathers feelings of empowerment. Empowerment of the child's family is an intentional outcome of the FCP approach (McCarthy & Guerin, 2021) which suggests that services need to work to empower fathers as well as mothers to satisfy one of the core competencies of PDS. Positive discrimination toward fathers was highlighted as a possible mechanism for achieving this, with the suggestion that services needed to be explicit in inviting fathers to appointments and events and emphasising the importance of their involvement. Psychologists in this study also expressed the benefits of including and empowering fathers as part of the clinical relationship and formulation process. It was propounded that fathers offer a unique perspective, and that gaining the perspective of the father as well as the mother provides a more holistic representation of the family system, which can aid in the selection and implementation of assessment and intervention approaches. This finding reiterates that engaging the entire family system should be seen as best practice within DS.

On the FEWS-Q survey, fathers overwhelmingly reported that they would like to attend father-specific groups if DS offered them and that they would be in favour of receiving support and counselling from services. This is a compelling and novel finding in the present study, which implies the need for DS to fulfil a more inclusive and supportive role to fathers. In the interviews, fathers mentioned that they had attended some parent groups through DS, or that they were part of some online communities for parents, but that these were mother-dominant with fathers feeling in the minority. Furthermore, the previous research finding that mothers and fathers interpret a diagnosis of a disability differently (Pelchat et al., 2003; Pelchat et al., 2009; Saloviita et al., 2003) suggests that an umbrella parent group may fail to meet the specific needs of these distinct groups. Psychologists that were interviewed highlighted a lack of processing space for fathers in dealing with their child's diagnosis, which has implications for the aforementioned challenges within the chronosystem of coming to terms with their child's disability. Psychologists also noted that the expectation that mothers should attend appointments means they are allowed a space to process their child's difficulties and to become expert on their needs. This can further entrench the role definitions within the family system and create a cycle of alienation for fathers.

A psychologist who had previously organised groups exclusively for fathers divulged that these groups provided fathers with a processing space, and allowed them to share and feel supported. Previous research has pointed to the fact that father groups can be helpful in terms of peer support and empathy from other fathers who are in a similar position (Carpenter & Towers, 2008; King et al., 2007). The findings of the present research suggest that such support is sorely needed by fathers, who corroborated that while friends and family try to be helpful and sympathetic, they simply do not understand the position of families of children with an ID/DD. With these findings in mind, this research points to the need for father-specific support groups within DS. Making these groups father-specific and engaging in positive discrimination appears necessary to ensure that fathers attend. Ultimately, this will help fathers process the emotional trauma of having a child with an ID/DD.

5.4 The Societal Level

While factors at the familial and the service level undoubtedly influence father engagement with DS, the findings accrued as part of this research process also point to wider societal factors that influence this phenomenon. The exosystemic issue of inflexible work schedules clashing with service appointments was a barrier identified by fathers and psychologists during all three phases of data collection within this study. On the FEWS-Q survey, fathers noted that services should be more flexible in terms of their opening hours and appointment times, while fathers who were interviewed spoke about how their work schedule did not lend itself to attending service appointments since these are held during the day. This issue relates to wider political and cultural issues within the macrosystem, some of which were raised by fathers and psychologists during the interviews. The gender pay gap was raised as a practical reason that contributed to the polarising of parent roles within the microsystem. In general, there was a trend that one parent needed to make the sacrifice of becoming a full-time carer, which meant putting their career on hold. The parent who earns the most money is most likely to remain in work for obvious financial reasons. The father fulfilled this role in the main, due in part to the gender pay gap. One father interviewed purported to earn less than his wife, who worked more hours than him and continued to progress her career while he remained working part-time and fulfilling more of a carer role. This is interesting to note because this outlier within the sample offers tentative evidence to suggest that the parent who ceases working is decided upon for financial and practical reasons, rather than being a gender-based decision or a decision based on preconceived parenting roles.

While research on the gender pay gap in families of children with disabilities appears to be scarce, previous research on this phenomenon in general offers some context with which to interpret the results accrued in the present research. Research from the United States suggests that a ‘motherhood penalty’ exists, meaning that mothers are less likely to be offered promotions and are more likely to be offered lower wages than women without children (Kricheli-Katz, 2012). Furthermore, a ‘fatherhood bonus’ has also been observed, meaning that many fathers actually receive higher wages and better work-related opportunities after they have had a child (Glauber, 2008; Killewald, 2013; Miller & Vagins, 2018). With such findings in mind, it is hardly surprising that fathers are more likely to remain in employment following the birth of a child with complex and often expensive needs, while the mother would then naturally assume the role of full-time carer.

Delving deeper into policy that influences father engagement with DS, maternity leave was highlighted in the interviews with fathers and psychologists as a factor. Both participant groups described how the channels of communication with a service are opened when the child is an infant, when the mother is the parent who is available because she is on maternity leave. This means that mothers become the main point of contact and from the beginning, fathers are absent. This sets a self-fulfilling prophecy in motion whereby the mother becomes more expert on the child’s needs because she attends more appointments and becomes engaged with services, meaning that the father takes a back seat and the mother continues to become more expert, further solidifying the aforementioned traditional gender roles that emerge within the microsystem. This is supported by previous research that suggests that increased paternity leave for fathers is associated with higher levels of father involvement and engagement with their child’s care in the early years. This finding has been consistent across different countries and settings, suggesting that fathers who take longer parental leave are more attuned to a caring and present fathering role (Johansson, 2011) and are more engaged with caretaking and developmental tasks (Petts & Knoester, 2018; Wray, 2020). These findings have strong implications when interpreted in the context of the present research, which suggests that a barrier to father engagement with DS includes the establishment of an early relationship between services and the mother due to maternity leave availability, which embeds traditional parent roles deeper within the family system. Furthermore, extended parental leave would allow fathers to spend more time with their children in the early days and to be more engaged with caring tasks. This may help fathers to process their child’s disability more effectively, while being available to attend appointments would offer fathers a further processing space.

Finally, it emerged in the interviews with fathers and psychologists that there are different societal expectations of fathers and mothers which can impact upon engagement patterns with DS. There is an expectation on mothers to always be available to attend appointments, while this level of availability is not expected of fathers. It can be inferred from the findings of this study that fathers attendance is seen as a bonus, while mothers attendance is seen as imperative. Psychologists noted that this gender-based social construct places great pressure on mothers, who are socially defined by their perceived ability to perform their caring role.

5.5 Conclusion

The present research findings exemplify the complex nature of the phenomenon under investigation. By viewing and interpreting the issue of father engagement with DS through a broad, ecological lens, it was possible to begin to map some of the familial, service-related and societal factors that influence this multidimensional phenomenon. These findings have significant implications for clinical practice within DS, for the generation and development of policy relating to FCP in DS, and for future research in the area of father engagement with services. Furthermore, there are methodological considerations stemming from this research that must be acknowledged and considered when interpreting these findings. These will be outlined in the following chapter, where a critical reflection will take place on the research process and findings.

Chapter Four: Critical Review

6.0 Critical Review Introduction

In this chapter, a critical reflection will take place following the completion of this research project. The pragmatic research paradigm adopted in the present study will be examined in terms of ontology, epistemology, axiology and methodology. The researcher will reflect on the methodological approach adopted and will reflect on some of the key strengths and limitations associated with this project. A reflection will also be documented on some unexpected ethical dilemmas that arose throughout this research process. These will be discussed in terms of their implications for the research, and how they were handled by the researcher. The unique contribution that this research has made to the field of knowledge on father engagement with services will be outlined, as well as the implications of this research for clinical practice, policy development and future research in the area.

6.1 Reflections on the Research Paradigm

A paradigm provides the researcher with a method of understanding and navigating the complexities of the real world during the research process, and informs the interpretation of data amassed during this process (Kaushik & Walsh, 2019; Teddlie & Yu, 2007). The pragmatic paradigm was adopted in the present study. Pragmatic inquiry focuses on the creation of knowledge so that action can be taken toward solving the research problem (Cohen et al., 2017). In fact, the word ‘pragmatic’ was originally derived from the Greek word ‘pragma’ which means to take action (Pansiri, 2005). The present investigation was focused on understanding the issue of father engagement with DS and locating practical solutions to this issue. Considering this, the flexible and action-oriented nature of the pragmatic approach was considered to align well with the goals of the present study (Creswell & Creswell, 2017; Edmonds & Kennedy, 2016). The pragmatic paradigm also complimented the mixed-methods methodology adopted in the present study (Teddlie & Yu, 2007). By integrating quantitative and qualitative research findings, the researcher was able to draw upon post-positivist and constructivist worldviews, locating the findings broadly within these diametrically opposed positions. According to Lincoln and Guba (1985b), a paradigm is comprised of key elements including ontology, epistemology, axiology and methodology. These key elements will be examined in terms of their relation to the pragmatic paradigm adopted in the present study.

Ontology is concerned with the nature of reality, and various ontological positions reflect various conceptions of reality (Cohen et al., 2018). A pragmatic approach to reality allowed the researcher to accept that there are numerous ways of viewing the world, and that each of these has advantages and disadvantages (Cohen et al., 2017). By engaging with pragmatism, the researcher was not forced to select between singular or multiple realities, but could accept the existence of a single real world which all individuals experience and interpret uniquely (Mertens, 2014). In terms of the present research, this approach to reality facilitated the exploration of father engagement with DS through the perceptions and experiences of the fathers and psychologists who took part in the study.

Epistemology refers to the assumptions that are made about the nature of knowledge, how knowledge is acquired, constructed, and communicated (Cohen et al., 2018). Adopting a purely positivist or constructivist epistemology was not deemed appropriate in the present study, given the need for a broad exploration of fathers' perceptions of their engagement with DS in the quantitative phase, followed by a more in-depth exploration of fathers' and psychologists' experiences in the qualitative phase. Moreover, other epistemologies, such as critical realism, were deemed inappropriate to the present study, given that this study sought to acquire the perceptions and experiences of the participants on a phenomenon of interest. Therefore, the pragmatic epistemology adopted in the present study allowed the researcher to adopt the most practical and felicitous methods of answering the research questions (Mertens, 2014). This research project brought together positivist and constructivist worldviews by departing from a deductive, realistic philosophical approach through surveys and complementing this with an inductive, interpretative approach through interviews. This was achieved in line with the sequential explanatory approach to mixed-methods research (Creswell & Clark, 2017).

Axiology is concerned with values in research (Cohen et al., 2018). In pragmatism the ethical basis for conducting research relates to gaining increased knowledge and information in a particular area with the view of achieving a particular goal (Mertens, 2014). Considering the present research sought to understand the issue of father engagement with DS and locate practical solutions to this issue, it is clear that a pragmatic axiology is pertinent. Finally, in terms of methodology, a central tenet of pragmatism is that the researcher should not be restricted by a single method of research, but should adopt the methods most suitable and effective in addressing the research questions posed (Creswell & Creswell, 2017). In the present study, both quantitative and qualitative methods were considered essential in addressing the research questions.

6.2.1 Reflection on the Theoretical Frameworks adopted

A theoretical framework should provide a structure from which to conceptualise a phenomenon of interest (Tudge et al., 2009). From the outset of this research project, it was apparent that the phenomenon of interest was a complex, systemic one. A review of previous research in this area highlighted its multifactorial nature, and the findings of the present study lend weight to this. Locating theoretical frameworks that could be used to structure the many elements of this phenomenon was imperative. In this regard, pragmatic thinking was employed to find theories that were best placed to understand father engagement with DS and address the research questions.

Systemic theories were explored and FST (Bowen, 1974) was firstly employed as a theoretical framework to understand father engagement with DS. This theory asserts that a family is a group of interconnected individuals operating within a social system (Bowen, 1974). FST was useful in conceptualising the impact of the systems and subsystems within the family system on father engagement with DS. However, it was clear that this phenomenon spanned a significantly broader ecological system that was not accounted for within FST. It was therefore necessary to locate a primary theoretical framework that could be used to conceptualise father engagement with DS on a broader level. The primary theoretical framework adopted was the BMHD (Bronfenbrenner & Morris, 2006). This framework was complemented by FST, which was used as a secondary framework to conceptualise and understand father engagement with DS. FST relates strongly to the microsystem in the BMHD which, as the results accrued suggest, is the fundamental system from which wider ecological systems develop.

The BMHD views development as a complex and multifaceted system of relationships spanning various nested systems (Bronfenbrenner & Morris, 2006; Tudge et al., 2016). The BMHD allowed for the array of factors that affect father engagement with DS to be structured and understood within logical nested systems ranging from the immediate family environment to wider social, cultural and environmental factors. The use of this theoretical framework helped to explain connections between various elements of this phenomenon, allowing insight which led to the formulation of new ideas and connections regarding this phenomenon (Tudge et al., 2009). Furthermore, utilising the BMHD as a framework for mapping the themes and subthemes that were generated through inductive thematic analysis ensured that the complex findings of this study were comprehensively reported across each nested system. The adoption of this theoretical framework can therefore be seen as a notable strength of this study.

6.2 Strengths and Limitations of the Current Research

There are certain strengths and limitations associated with all forms of research and it is important to reflect on these to continue to progress research standards in the area of interest (Ioannidis, 2007). In this section, some of the key strengths and limitations in terms of the research design, data collection and sample used in this study will be delineated and addressed.

6.2.1 Research Design

Adopting a mixed-methods approach to research should not result in two methodologies that are insufficiently applied, but should result in quantitative and qualitative methodologies that are completed rigorously and that complement one another (Creswell & Creswell, 2017; Teddlie & Yu, 2007). In line with this assertion, the present research endeavoured to implement a rigorous approach in both the quantitative and qualitative elements of this project.

In the early stages of research planning, the researcher envisioned this project as a qualitative one in which the experiences of a small group of fathers and psychologists would be sought on father engagement with DS. However, with some inquiry, it became apparent that research in this area was limited, and that no study within the Irish context had explored father engagement with DS. This highlighted a need for the collection of quantitative findings that could be generalised to a wider population, as well as qualitative data to further explore and enrich the quantitative findings. A methodological strength of the current study is that information was triangulated to better understand the phenomenon under investigation. The sequential explanatory design allowed for the effective integration of data in this study, as areas for further exploration from the quantitative phase were addressed in the qualitative phase. Hong et al. (2018) highlight effective integration as a key criteria for methodological quality in mixed-methods research.

There are also limitations that should be considered regarding the research design adopted in the present study. Critics of a mixed-methods approach often cite an ‘incompatibility thesis’, which states that quantitative and qualitative methods cannot be mixed in a single study due to their fundamental ontological and epistemological differences (Doyle et al., 2009). The pragmatic approach has also been criticised for placing such importance on the research questions, allowing them to dictate the research process rather than the method or underlying paradigm (Doyle et al., 2009). While gaining data from multiple perspectives through quantitative and qualitative means was a strength of the present study, this also meant that the amount of information shared from each population needed to be limited to fit within the assigned parameters and structure of this research project.

Some practical limitations associated with this research design must also be noted. Undertaking quantitative and qualitative research approaches is a time-consuming process. Collecting and analysing large amounts of quantitative and qualitative data with limited resources was a challenging aspect of this research process. Nonetheless, the adoption of a mixed-methods, sequential explanatory design was necessary to understand a previously under-explored phenomenon and is arguably one of the major strengths associated with this study. The sequential explanatory design unquestionably allowed for the collection of a more complete picture of the phenomenon being investigated (Creswell & Clark, 2017).

6.2.1 Data Collection and Sample

The design of the FEWS-Q is a methodological strength of the present study. Preliminary Principal Component Analysis and Cronbach’s Alpha tests of internal reliability display promising results for this questionnaire. It showed satisfactory to good internal reliability, and four main factors loaded onto the questionnaire which accounted for 31 of the 37 items. While this questionnaire requires some further examination with a larger sample size, there is tentative evidence to suggest that the FEWS-Q is a promising measure that can be used to explore father engagement with services. Previously, there was no measure available that is specific to father engagement in relation to a population with disabilities, this can be the prototype for development into a robust measure and could be utilised by services to monitor their therapeutic response to fathers.

It is also a limitation that the survey used as part of this study was not standardised or normed. While internal reliability and construct validity is promising, the relatively small sample size means that these results must be interpreted with caution. Furthermore, it was beyond the scope of the present research to develop a parallel questionnaire for psychologists to complete, which meant that this population could only take part in the qualitative element of the present study.

The sample of fathers recruited in the present study (N=77) was relatively small in scale which means that the generalisability of these findings can be called into question. Furthermore, the representativeness of this sample of the overall population of fathers of children with an ID/DD must be scrutinised. Ireland is an increasingly diverse society, yet the sample of fathers who participated in this study were native English speaking Caucasian men with high levels of employment and education, and low rates of separation. The use of voluntary response sampling through the online survey meant that the participants who volunteered were likely to have strong opinions on the topic under investigation and were also willing and motivated to spend time completing the survey (Murairwa, 2015). Furthermore, given that this was an online survey, respondents needed to have access to an electronic device and required a certain level of electronic literacy to complete the survey. The overall sample that completed the FEWS-Q was 77, while sample size estimation for statistical significance showed that the required number was 96. Despite significant efforts from the researcher to recruit more fathers through contacting social media groups, special schools and DS, the sample of participants fell short of the desired amount and this must be noted as a limitation of the present study.

The sampling approach used to recruit psychologist participants must also be acknowledged as a limitation of the present study. Non-probabilistic, purposeful sampling was used which means that the findings from this population of psychologists may not be representative of the entire population (Etikan et al., 2016). Furthermore, the psychologists recruited were from a small number of services in Ireland, and therefore, the experiences of the psychologists that were captured may not be representative of other DS around the country. The majority of psychologists who took part in this study were Educational Psychologists (EPs) (N=5) and female (N=6). Further balance in terms of gender and psychological discipline to capture the views of more clinical and counselling psychologists on this issue would have offered more representative findings.

CDNTs are generally multidisciplinary in nature. It was beyond the limited scope of this research to gain the perspectives of other clinicians working in services, it must be acknowledged that using the views of psychologists only as a representation of the views of DS is a limitation.

6.2.3 Additional Strengths and Limitations

This is the first study of its kind in an Irish context. The findings of the present research contribute to the current international literature on father engagement with services and offer findings that can help to improve the experience and engagement of fathers of children with an ID/DD with DS in Ireland. This research shows that there are issues and barriers in existence regarding the engagement of fathers with services, and that there is a need to address such issues to achieve the ideologies set out in the FCP model of service delivery. The findings of this research are timely because DS in Ireland are currently undergoing exponential change with the implementation of PDS in many services nationwide. The findings of the present research offer an opportunity for services to reflect on previous shortcomings and misgivings, and to try and engage in reflective, best-practice approaches going forward in line with the core objectives of PDS. The current research is unique within the Irish context and should be viewed as a useful resource for services to inform inclusive, family-centred practice moving forward.

This research process offered fathers a space to process their child's disability and to discuss their needs. This was highlighted as something that has been sorely lacking for fathers, and some fathers who participated in this study attested that the research interviews were the first time that they had verbalised some of their feelings and emotions about having a child with complex needs, and trying to get them the services that they require. This exemplifies the need for emotional support for fathers of children with an ID/DD to process their child's disability. As the research findings suggested, DS should offer such supports to fathers through father groups and post-diagnostic counselling. This approach would have positive implications for fathers and for the wider family system.

Furthermore, the interviews also offered the psychologist participants a space to reflect on their own practice, and how inclusive they have been in their practice. Many psychologists highlighted how busy their schedule is, and how this can impede upon their ability to take time to reflect. Psychologists noted that engaging in the interviews offered allowed them to reflect, and that this would have a positive impact on their inclusive practice going forward.

The issue of researcher positionality and reflexivity must be noted as a potential limitation in the present study. This may have impacted upon the responses that were provided in this research process. At times during the interviews, fathers appeared to associate the researcher with DS which may have impacted upon the information that they were willing to share. To overcome this issue, it was necessary for the researcher to reiterate his impartiality continuously during the interviews and to remind fathers that he was not associated with any particular disability service.

6.3 Ethical Dilemmas

Despite receiving ethical approval from the Mary Immaculate Research Ethics Committee (MIREC) prior to the commencement of this research process, some unexpected ethical dilemmas arose during this research process that the researcher had to overcome (Bryman, 2006). These ethical issues undoubtedly merit discussion and consideration.

Firstly, given that purposeful sampling was utilised in the recruitment of psychologist research participants, it transpired that some of the psychologist interviewees were previously known to the researcher through various placements that have been completed as part of the DECPsy professional training programme. As such, it was necessary to ensure that good ethical practice was adhered to in the recruitment of these participants, and that certain ethical parameters were emphasised in order to ensure that informed consent was attained from these participants (PSI, 2019). In achieving this, the prospective interviewees were advised that participation in this research project was entirely voluntary and that they could refuse to partake, or withdraw from the research at any time without the necessity of providing a reason for this (BPS, 2009). Participants were also advised at the outset of each interview that they were free to abstain from any question that they were not comfortable answering without having to explain this, and they were advised once again that they were free to withdraw from the research at any point (BPS, 2009).

A further ethical dilemma that arose during this research process was dealing with the emotive nature of the topic under discussion during the father interviews. Many fathers confided that this interview was the first opportunity they had to verbalise their feelings and experiences regarding their child’s diagnosis of a disability, and on their experiences with DS which were often negative experiences. It was necessary to have procedures in place to support fathers if they became overly distressed or upset during the interview process. In such an eventuality, it was decided that the interview should be discontinued and fathers would be referred to support services, such as the HSE national counselling service and Samaritans (BPS, 2009; PSI, 2019). While such plans were not required, it was important to have them in place. Previous research has also highlighted that participants distress in partaking in a research project can be lessened if they feel as though they are making a valuable and worthwhile contribution to an area of study that they consider important (Decker et al., 2011). As such, the important contribution that fathers would make was emphasised on the participant information sheet, and fathers were reminded of this at the outset of each interview.

The issue of transference from participants was another unanticipated ethical challenge that was encountered in the present research study. Due to the emotional and passionate conversations that occurred during the interviews, it was difficult for the researcher not to become motivated to advocate for the research participants and to maintain neutrality in the conversation. Prior to each interview, the researcher took time to reflect on their positionality and to ensure that emotional transference between researcher and participants did not impede their ability to remain impartial (BPS, 2009). While it was important to be sympathetic and to listen actively and attentively to participants, it was crucial to limit biases and preconceptions and to remain neutral in order to gather accurate information without unduly influencing the conversation.

6.4 Implications for Practice

The findings and conclusions drawn from this study aim to inform practice within DS to ensure that services can uphold the highest standards of inclusion to meet the needs of individual families. There are a number of practice implications arising from the findings of this study which will be delineated and discussed in this section.

The findings of this study highlight that services should focus on providing continuous professional development opportunities for staff with regard to the FCP approach. This should include recommendations from international best practice on how to implement this approach within DS. Services should also evaluate the FCP approaches that are being undertaken to understand the effectiveness and feasibility of this approach to service delivery within each service. When further developed through empirical testing, the FEWS-Q could be used by services to self-monitor their inclusion and engagement of fathers within the FCP approach.

This research project indicates that it is imperative that services offer flexible appointment times that suit both parents to attend. A major stumbling block to father engagement in this study was that appointments are held during the day. This also places undue pressure on mothers, who, even when they are working full-time, are expected to attend service appointments. A solution to this issue may be services incorporating shift working into their practice, giving the option of weekend appointments, or offering practitioners time in lieu to facilitate more flexible and inclusive appointment times.

Services must also engage in inclusive practices which involve contacting any family member who wishes to be involved in the service-delivery relationship. A bias toward contacting mothers was highlighted by fathers in this study and corroborated by psychologists. It should be standard practice in services to make contact with any parent or guardian of a child and to offer them the opportunity to become involved in the service-delivery relationship. This is particularly true in the case of separated parents, and services should facilitate the inclusion of both parents in such an instance, even if this requires that two separate appointments are held. Psychologists in this study highlighted the potential for DS to adopt the CAMHS approach at intake, whereby it is mandatory for both parents to attend the first meeting. This will allow for a relationship to be established with both parents at the outset, and will mean that one parent is not placed at a disadvantage or excluded. On a practical level, services must ensure that contact details of both parents are captured at intake so that both parents can be contacted.

An important implication of this study is that services must offer emotional support for fathers of children with an ID/DD, particularly in the form of post-diagnostic counselling, as a matter of course. This study has provided strong evidence that fathers' emotional response to the news that their child has a disability is a profound one. Fathers can become isolated following a diagnosis, whereas mothers who attend appointments in services are offered a space to process their child's disability. There was also a consensus among participants in this study that mothers are better at seeking emotional support from friends and family, which seems to stem from the influence of gender norms. There is a lack of acknowledgement of the trauma associated with a diagnosis of a disability for fathers, and parents in general, and this needs to be addressed within services.

Psycho-education on their child's disability provided by services is also warranted. Fathers in this study spoke about their difficulty in fully comprehending their child's disability in the early days. Given their extensive training and knowledge on child development, EPs may be the best-placed practitioners to provide such psycho-education and training to parents of children with an ID/DD within DS.

The findings gathered also show that services should immediately engage in positive discrimination toward fathers to ensure their participation and engagement with services. One way of achieving this would be to offer father-specific parenting groups that meet the unique needs of this parent population. The accounts provided by fathers and psychologists suggest that such groups will help fathers with processing and coming to terms with their child’s disability. Fathers in this study attested that peer support from other fathers in a similar situation would be invaluable to them. Interestingly, fathers attested they would not like to be pressured to attend emotional support groups and speak about their feelings and experiences. Instead, services could frame groups as ‘coffee mornings’ or ‘father get-togethers’ with no requirement to discuss their child’s disability and their feelings or experiences. Participants noted they would be more likely to engage with such a format than an explicit emotional support group. By engaging with peer support, such discussions would happen organically, according to the fathers in this study. To extend this, mother-specific groups should also be offered which cater to the needs of this distinct parent population.

Finally, services need to offer practitioners opportunities to engage in reflective practice through mandatory peer supervision which should be scheduled at regular intervals, evaluated and reviewed. It is imperative that practitioners working within services remain cognisant and reflective of their implementation of the FCP approach, and in their inclusion of fathers in the service-delivery relationship.

6.5 Implications for Policy and Training

The current research findings also have implications for policy at the psychologist training level, the service level and at the wider social level. Some of the key implications for policy arising from the findings of this research are outlined here.

The professional training of all psychological disciplines eligible to work in DS (educational, clinical, counselling) must emphasise the importance of engaging the entire family system in a service-delivery relationship. These training courses need to provide trainees with an in-depth understanding of the FCP approach to service delivery from a theoretical and practical point of view. This is particularly important to include on professional training programmes for EPs, given that the role of the EP has evolved in recent years rendering newly qualified EPs as eligible to work across a range of services. This study has further highlighted the need to translate the ideologies of the FCP approach to practice.

Policy should be developed to embed an inclusive practice within DS and to ensure that a family-centred approach is truly being offered. This might include the dissemination of contact sheets that emphasise the necessity for both parents contact details to be included, if applicable. This policy should also foster accountability in practice to counteract the culture of bias toward contacting mothers within services. This might include the necessity for clinicians to document which parent has been contacted, and whether attempts have been made to contact both parents. Parents should not be framed as ‘primary and secondary’, but rather should be recognised for the unique contributions that they can both provide. Moreover, services should acquire feedback from parents on the inclusivity of the service at regular intervals. It should be stipulated that feedback from both parents should be attained in order to offer a holistic perspective on their service experience.

Services should engage in audits to ensure that an FCP approach is being offered by their service. This might include a review of the practice across disciplines within a multidisciplinary team to enquire whether both parents, and indeed other family members have been contacted and given the opportunity to be included in the service-delivery relationship. Such audits should occur regularly to ensure that clinicians remain reflective and accountable with regard to this issue. The findings of a short audit might be discussed at monthly team meetings within services, for example, and this should be enshrined within service policies so that this issue remains a contemporary one within services.

Policy should be developed within services, and shared with psychologists and other practitioners, to emphasise the importance of gaining multiple perspectives within the family system in order to foster a comprehensive formulation that will inform assessment and intervention work. Acquiring multiple perspectives should not be seen as an ideological best practice, but should be framed as a necessity as part of everyday casework.

Ireland should follow the example of other countries (e.g. Sweden, Canada, Germany) with regard to the issue of extended paternity leave for fathers. Given that the father’s role is evolving and moving toward a more caring role, fathers should be given the opportunity to fulfil this role from the outset of their child’s life. This is particularly important with regard to fathers of children with an ID/DD and other complex needs, who may need additional time to process and comprehend the needs of their child. Providing fathers with an opportunity to attend early appointments within a disability service will allow them to feel part of this process from the beginning, while simultaneously reducing the burden upon the mother who is expected to attend appointments as the primary carer.

6.6 Implications for Future Research

This research also has implications for future research. Some of the key implications arising from the present study for future research will be delineated in this section.

Further validation of the FEWS-Q questionnaire (in its new format following a Principal Component Analysis) is an important research implication of the present study. Results of this analysis, as well as internal reliability analysis using Cronbach's Alpha, were promising for this newly-designed questionnaire. However, these results must be interpreted with caution given that the sample size was not adequate to draw any definite conclusions from on a statistical level. The reliability of the FEWS-Q merits further investigation with a larger sample of fathers. If found to be internally reliable with a larger sample, this measure could be utilised as a psychometric measure by other researchers to explore father engagement with services in other healthcare and educational settings, and indeed in other countries or geographical locations.

Exploring father engagement with services in other healthcare and educational settings is a recommendation for future research in this area. This study offers a snapshot of engagement with DS in Ireland, but gaining further information on practices of inclusion across the National Educational Psychological Service, Schools, Primary Care services, CAMHS and even within private practices could offer a more comprehensive insight into why father engagement can be an issue with services in general.

Taking a multidisciplinary approach to future research which engages practitioners from multiple disciplines, e.g. Speech and Language Therapists, Physiotherapists, Occupational Therapists, Social Workers etc. is recommended for future research to gain a more comprehensive understanding of this issue.

The present research focused on a specific population of disability service attendees, namely children with an ID/DD. While this provided an in-depth look at the needs and experiences of this particular population of fathers, it would be compelling for future research to look at the needs of fathers of children with other forms of disability, complex needs or mental health issues.

While the present research acquired the perspective of fathers and psychologists on this issue, it is recommended that more of a collaborative approach to research may be useful in future to try and arrive at some mutually generated solutions on this issue. One such approach for involving key stakeholders in a collaborative manner has been coined as

Experience-based co-design (EBCD) (Bate & Robert, 2006). This is a process of collaboration that is focused on gaining the perspectives of important stakeholders in a clinical relationship with the ultimate goal of improving engagement and experiences with services (Mulvale et al., 2016). This research approach was developed from participatory action research, learning theory, and narrative-based approaches to change. EBCD has been primarily used in healthcare settings such as hospitals, but there has been a distinct lack of utilisation of this collaborative research approach in the realm of mental health and DS (Chisholm et al., 2018). This approach comprises individual interviews with parents and clinicians where experiences and feelings are captured, followed by focus groups with parents and staff to discuss these findings and produce collaborative improvements (Gustavsson, 2014).

6.7 Unique Contribution of this Research

This research has made a unique and distinct contribution to the knowledge base in a number of ways which are outlined below.

The design of the FEWS-Q is a unique contribution made by the present research study. While this instrument requires further validation through empirical research, there is noteworthy potential based on an analysis of internal reliability and construct validity that this questionnaire could be used to reliably explore father engagement with DS. This could be done for research purposes, or as previously noted, the FEWS-Q could be used by services to self-monitor their inclusion and engagement of fathers within the FCP approach.

This study has uniquely brought together parent and service perspectives in discussing the issue of father engagement with DS. Such an approach to research has not been previously undertaken. Previously, studies generally focused on gaining a single perspective (either that of parent or service) on this issue. Furthermore, within the Irish context, there has been a paucity of research that has captured the voices of fathers of children with an ID/DD and the present research project worked to address this issue. This previously under-represented population were empowered in the present research to share their perspective on their perceptions and experiences of engaging with DS, resulting in compelling and powerful evidence that services need to change their approach to service-delivery to include fathers meaningfully in this process.

This study has also exemplified that FCP is an aspirational model of service delivery at present within Irish DS rather than being a realistic one. Psychologists attested that while services subscribe to this model, the extent to which it is being implemented within DS is questionable. This was further evidenced by the finding that many fathers have rarely, if ever, been contacted by their child's disability service, and have never been offered any parental support by DS.

The findings of this study have pinpointed some notable gaps within the Irish health service. There is a concerning discrepancy with regard to the engagement of mothers versus fathers with DS. This study has framed this issue within a wider ecological context and has offered explanations and solutions for this discrepancy. The findings of this study have noted many barriers that have hindered fathers engagement with DS. Moreover, the findings of the present research elucidate that parental role expectations have placed mothers under significant pressure to engage with DS. This study found a further discrepancy between the fathers' perceptions of their changing role and the widely held view among psychologists that parental roles within families of children with an ID/DD are more traditional and polarised. Reflection is needed within services on this viewpoint, as it may be contributing to the in-built bias toward automatically contacting mothers and seeing them as representative of both parents.

These research findings have provided fathers of vulnerable children with an outlet to voice their frustrations at the shortcomings within DS. This research has highlighted the glaring need for emotional support for fathers of children with complex needs. Findings from this study suggest that fathers find it difficult to process a child's diagnosis and that they experience emotional trauma at the time of diagnosis, similar to mothers. The study has exemplified how fathers wish to engage with peer-to-peer support in DS, and wish to receive emotional support and counselling from services. There is a need to move beyond simple acknowledgement and toward positive action to support wellbeing and address the emotional trauma that fathers, and indeed the entire family system, experience at the time of diagnosis. It is noteworthy that the interviews conducted in this study offered many fathers a first opportunity to verbalise their feelings about their child's diagnosis and complex needs. This is a significant and alarming finding associated with the present study.

7.0 Impact Statement

The findings of the current research have made a unique contribution to the understanding of a previously grossly under-researched issue, and have implications at the empirical, practical, policy and training level. This is the first study that has documented the perspectives of services and of fathers in exploring father engagement with disability services. The adoption of the BMHD and FCP as theoretical frameworks allowed for the conceptualisation of this issue within a wider social ecology with findings revealing factors at the familial, service and societal level influencing father engagement with disability services. Moreover, this research was undertaken against a backdrop of exponential change in disability services in Ireland with the national implementation of PDS. As a consequence, this research is significant in its contribution and timely in its dissemination.

The strongest impact of this research is its contribution to practice within disability services. The study findings suggest that while the FCP model of service delivery is widely supported on a theoretical level, its translation from philosophy to reality is an ongoing challenge, despite it being regarded as international best practice (Health Service Executive, 2020b; McCarthy & Guerin, 2021). While there are many factors that impact upon father engagement with services, practice at the service level can exacerbate this issue. There is an urgent need for a more inclusive, reflective and accountable practice within disability services. Recommendations toward achieving this are outlined in this study. The need for post-diagnostic emotional support for fathers, and positive discrimination to engage fathers with services are fundamental changes that must be implemented.

At the policy and training level, this research posits various implications. The professional training of psychologists must emphasise the importance of engaging the entire family system in a service-delivery relationship. This research advocates for the necessity of gaining multiple perspectives within the family system to foster a comprehensive formulation. Policy should be developed to embed an inclusive practice within disability services, to ensure that a family-centred approach is truly being offered, and to enshrine accountability in practice to counteract the culture of bias toward contacting mothers within services. Parents should not be framed as ‘primary and secondary’, but should be recognised for the unique contributions that they can make. At the macro level, it is recommended that Ireland’s policy on paternity leave is revised to allow fathers to fulfil a caring role from the beginning, and to reduce the social pressures and expectations on mothers to be available to fulfil the primary carer role.

This study should act as a platform for further research into father engagement with services. The promising internal reliability and content validity of the FEWS-Q merits further validation. This instrument could be used in future empirical research on father engagement and could be applied by services to monitor their practice on father engagement. Future research should adopt a collaborative, problem-solving approach to exploring father engagement with services, for example, the use of an Experience-Based-Co-Design approach may be considered (Bate & Robert, 2006).

The primary goal of this study, in line with the pragmatic paradigm, was to explore father engagement with disability services, to locate barriers and to generate solutions. Findings will be disseminated through publication, and by presentation at the individual service level, as well as at larger conferences pertaining to the FCP model of service delivery. Findings will be shared with CDNT managers and practitioners, the HSE National Disability Services Quality Improvement Team, and many other organisations that helped to facilitate this research process (See Appendix 14) who have recognised father engagement as an ongoing and contemporary issue within disability services.

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Appendices

Appendix 1: Weight of Evidence A Quality Criteria and Scoring

WOE A assesses the general quality of the methodology and design of a study (Gough, 2007). In assessing the WOE A for the studies used in this review, published and widely implemented coding protocols were utilised to ensure that a robust and reliable methodological critique was carried out. An adapted version of a checklist for critically analysing correlational and causal comparative studies developed by Mertens (2014) was used as a means of appraisal for the correlational studies included in this review. The adapted version of this form used in the current review assesses the methodological quality of studies across 6 judgment areas. ‘The Critical Review Form for Qualitative Studies’ (Letts et al., 2007) was used as a means of appraisal for the qualitative studies included in this review. The most relevant sections of this form in terms of methodological quality are: Study design, Sampling, Data Collection and Procedural Rigour. In the present review, WoE A scores for the qualitative studies included were attained from an accumulative score of these sections. The Mixed Methods Appraisal Tool (Hong et al., 2018) was utilised to assess the one mixed method study included in this review. The table below outlines how scores from these instruments were converted to WoE A ratings (i.e. 3 (High), 2 (Medium), 1 (Low). An example of the use of each of these coding protocols is included as part of this appendix and can be found below.

WoE A Score Conversion Criteria

WoE A Score	Criteria	Rationale
3 (High)	Average score of 0.67-1 across areas judged	Scores on the Mertens (2014) form are based on 6 judgment areas (i.e. scores range from 0-6)
2 (Medium)	Average score of 0.34-0.66 across areas judged	Scores on the Letts et al. (2007) appraisal form are based on 4 judgment areas (i.e. scores range from 0-4). Scores on the Mixed

		Methods Appraisal Tool are based on 5 judgment areas (i.e. scores range from 0-5)
1 (Low)	Average score of 0-0.33 across areas judged	These criteria converts these scores to WoE A Scores (i.e. 1-3).

Overall WoE A Scores

Study	**High (3)**	**Medium (2)**	**Low (1)**
Bagner (2013)		✓	
Curtiss et al. (2021)	✓		
Docherty & Dimond (2017)	✓		
Fox et al. (2015)	✓		
Huang et al. (2012)	✓		
MacDonald &Hastings (2010)	✓		
May et al. (2013)			✓
McBride et al. (2017)	✓		
Oryono et al. (2020)		✓	
Sheldon et al. (2020)		✓	
Simmerman et al. (2001)	✓		

Quality indicators for correlational research

(Adapted from Mertens, 2014, p. 181)

Full Article Reference: MacDonald, E. E., & Hastings, R. P. (2010). Mindful parenting and care involvement of fathers of children with intellectual disabilities. Journal of Child and Family Studies, 19(2), 236-240.

Did the authors address group similarities and differences?

Y ✓

N

N/A

Unknown/unable to code

Authors operationally defined who belonged in each group

Y ✓

N

N/A

Unknown/unable to code

Did the authors address the issue of homogeneity?

Y ✓

N

N/A

Unknown/unable to code

Did the authors take measures to avoid post hoc fallacy?

Y

N ✓

N/A

Unknown/unable to code

Was subgroup analysis conducted after the initial groups were defined?

Y

N ✓

N/A

Unknown/unable to code

If a predictive relationship was studied, was the predictor variable used to select participants?

Y

N

N/A

Unknown/unable to code

If a third variable could cause both the independent (predictor) and dependent (criterion) variable, did the authors control for this?

Y ✓

N

N/A

Unknown/unable to code

Average WoE A across areas of judgment:

Total quality rating score of 5 across 6 judgment areas.

Overall rating of evidence:

3 (High) ✓

2 (Medium)

1 (Low)

0

Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018)

Full Article Reference: McBride, B. A., Curtiss, S. J., Uchima, K., Laxman, D. J., Santos, R. M., Weglarz-Ward, J., Dyer, W. Jeans, L.M. & Kern, J. (2017). Father involvement in early intervention: exploring the gap between service providers' perceptions and practices. Journal of Early Intervention, 39(2), 71-87.

5.1 Is there an adequate rationale for using a mixed methods design to address the research question?

Y ✓

N

Can't Tell

5.2 Are the different components of the study effectively integrated to answer the research question?

Y ✓

N

Can't Tell

5.3 Are the outputs of the integration of qualitative and quantitative components adequately interpreted?

Y

N ✓

Can't Tell

5.4 Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?

Y ✓

N

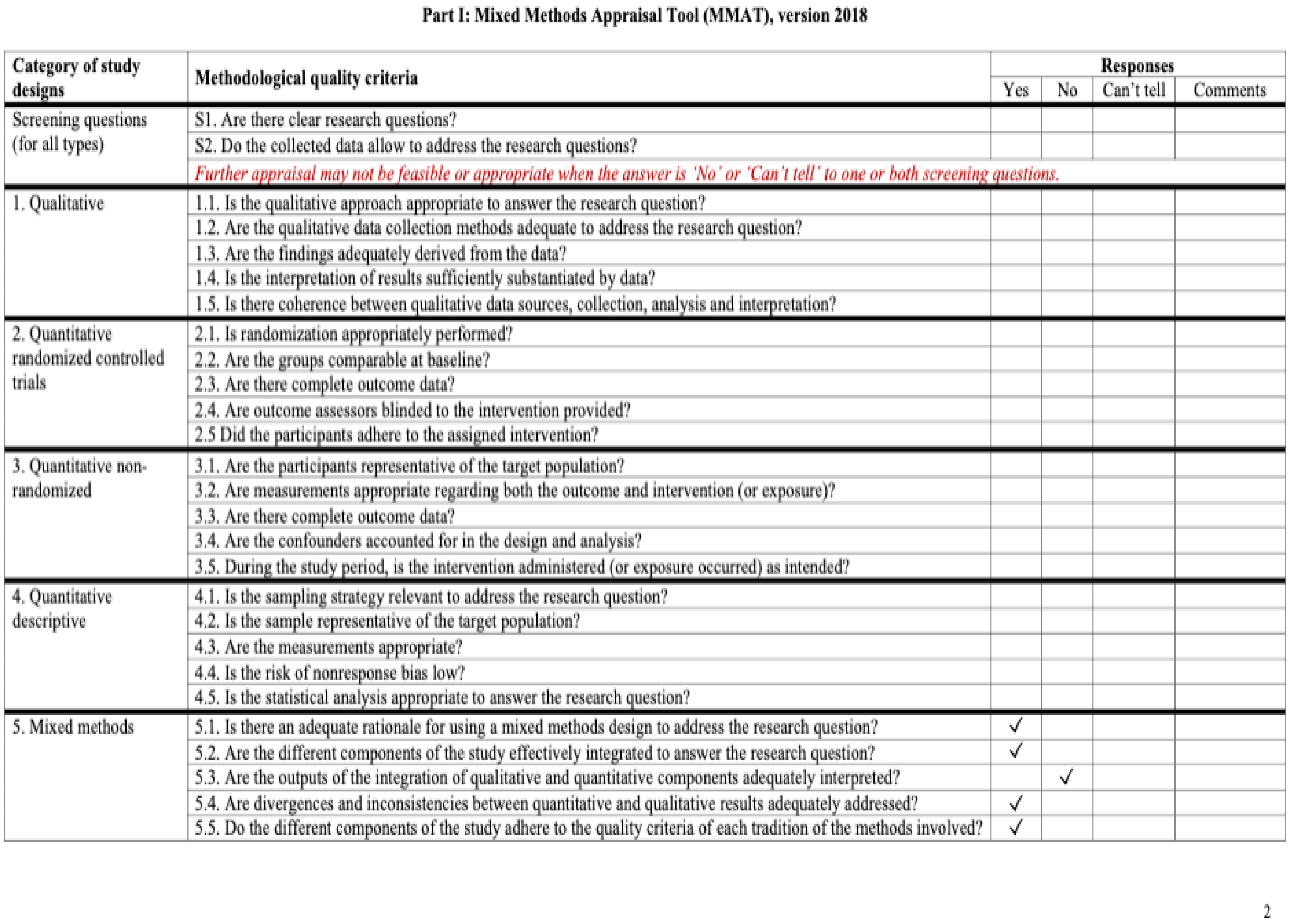
Can't Tell

5.5 Do the different components of the study adhere to the quality criteria of each tradition of the methods used?

Y ✓

N

Can’t Tell



Part I: Mixed Methods Appraisal Tool (MMAT), version 2018

Category of study designs	Methodological quality criteria	Responses			
		Yes	No	Can’t tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?				
	S2. Do the collected data allow to address the research questions?				
	Further appraisal may not be feasible or appropriate when the answer is ‘No’ or ‘Can’t tell’ to one or both screening questions.				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?				
	1.2. Are the qualitative data collection methods adequate to address the research question?				
	1.3. Are the findings adequately derived from the data?				
	1.4. Is the interpretation of results sufficiently substantiated by data?				
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?				
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?				
	2.2. Are the groups comparable at baseline?				
	2.3. Are there complete outcome data?				
	2.4. Are outcome assessors blinded to the intervention provided?				
	2.5 Did the participants adhere to the assigned intervention?				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?				
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?				
	3.3. Are there complete outcome data?				
	3.4. Are the confounders accounted for in the design and analysis?				
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?				
	4.2. Is the sample representative of the target population?				
	4.3. Are the measurements appropriate?				
	4.4. Is the risk of nonresponse bias low?				
	4.5. Is the statistical analysis appropriate to answer the research question?				
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?	✓			
	5.2. Are the different components of the study effectively integrated to answer the research question?	✓			
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?		✓		
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	✓			
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	✓			

Average WoE A across areas of judgment:

Total quality rating score of 4 across 5 judgment areas.

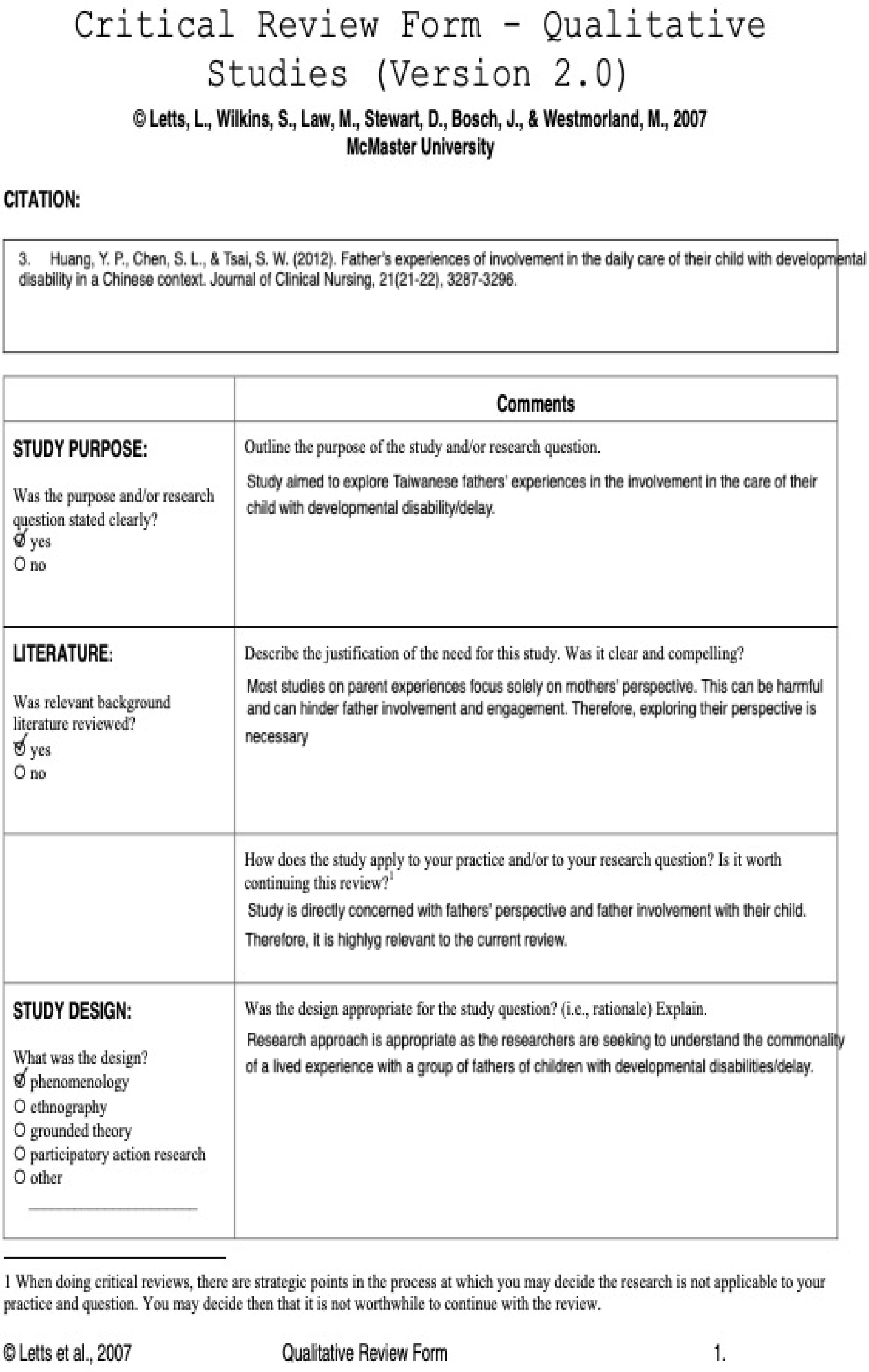
Overall rating of evidence:

3 (High) ✓

2 (Medium)

1 (Low)

0



Critical Review Form - Qualitative Studies (Version 2.0)

© Letts, L., Wilkins, S., Law, M., Stewart, D., Bosch, J., & Westmorland, M., 2007
McMaster University

CITATION:

3. Huang, Y. P., Chen, S. L., & Tsai, S. W. (2012). Father's experiences of involvement in the daily care of their child with developmental disability in a Chinese context. Journal of Clinical Nursing, 21(21-22), 3287-3296.

	Comments
STUDY PURPOSE: Was the purpose and/or research question stated clearly? ☑ yes ○ no	Outline the purpose of the study and/or research question. Study aimed to explore Taiwanese fathers' experiences in the involvement in the care of their child with developmental disability/delay.
LITERATURE: Was relevant background literature reviewed? ☑ yes ○ no	Describe the justification of the need for this study. Was it clear and compelling? Most studies on parent experiences focus solely on mothers' perspective. This can be harmful and can hinder father involvement and engagement. Therefore, exploring their perspective is necessary
	How does the study apply to your practice and/or to your research question? Is it worth continuing this review?[1] Study is directly concerned with fathers' perspective and father involvement with their child. Therefore, it is highlyg relevant to the current review.
STUDY DESIGN: What was the design? ☑ phenomenology ○ ethnography ○ grounded theory ○ participatory action research ○ other ________________	Was the design appropriate for the study question? (i.e., rationale) Explain. Research approach is appropriate as the researchers are seeking to understand the commonality of a lived experience with a group of fathers of children with developmental disabilities/delay.

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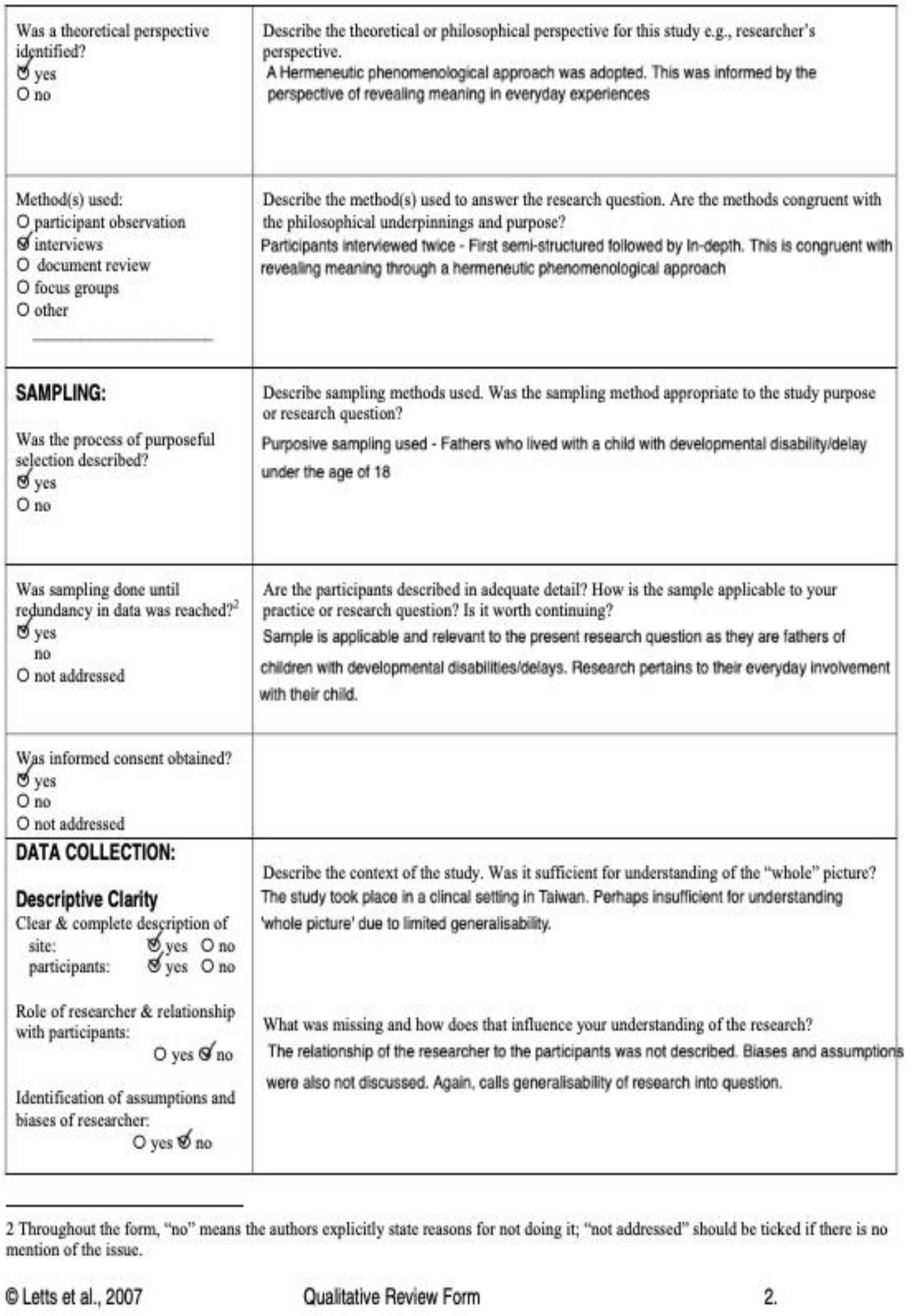
[1] When doing critical reviews, there are strategic points in the process at which you may decide the research is not applicable to your practice and question. You may decide then that it is not worthwhile to continue with the review.



Was a theoretical perspective identified? ☑ yes ○ no	Describe the theoretical or philosophical perspective for this study e.g., researcher's perspective. A Hermeneutic phenomenological approach was adopted. This was informed by the perspective of revealing meaning in everyday experiences
Method(s) used: ○ participant observation ☑ interviews ○ document review ○ focus groups ○ other	Describe the method(s) used to answer the research question. Are the methods congruent with the philosophical underpinnings and purpose? Participants interviewed twice - First semi-structured followed by In-depth. This is congruent with revealing meaning through a hermeneutic phenomenological approach
SAMPLING: Was the process of purposeful selection described? ☑ yes ○ no	Describe sampling methods used. Was the sampling method appropriate to the study purpose or research question? Purposive sampling used - Fathers who lived with a child with developmental disability/delay under the age of 18
Was sampling done until redundancy in data was reached?[2] ☑ yes no ○ not addressed	Are the participants described in adequate detail? How is the sample applicable to your practice or research question? Is it worth continuing? Sample is applicable and relevant to the present research question as they are fathers of children with developmental disabilities/delays. Research pertains to their everyday involvement with their child.
Was informed consent obtained? ☑ yes ○ no ○ not addressed	
DATA COLLECTION: **Descriptive Clarity** Clear & complete description of site: ☑ yes ○ no participants: ☑ yes ○ no Role of researcher & relationship with participants: ○ yes ☑ no Identification of assumptions and biases of researcher: ○ yes ☑ no	Describe the context of the study. Was it sufficient for understanding of the "whole" picture? The study took place in a clincal setting in Taiwan. Perhaps insufficient for understanding 'whole picture' due to limited generalisability. What was missing and how does that influence your understanding of the research? The relationship of the researcher to the participants was not described. Biases and assumptions were also not discussed. Again, calls generalisability of research into question.

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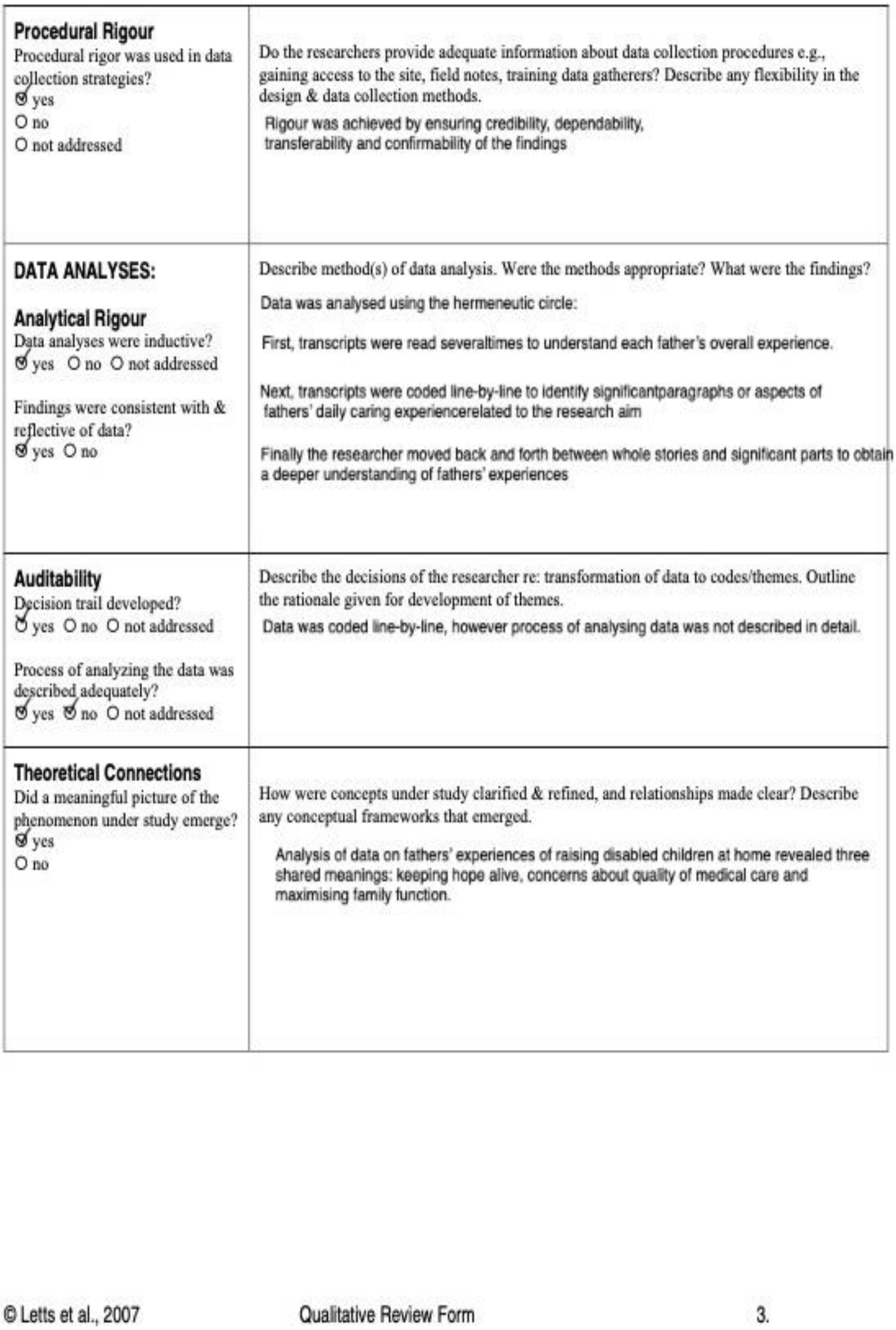
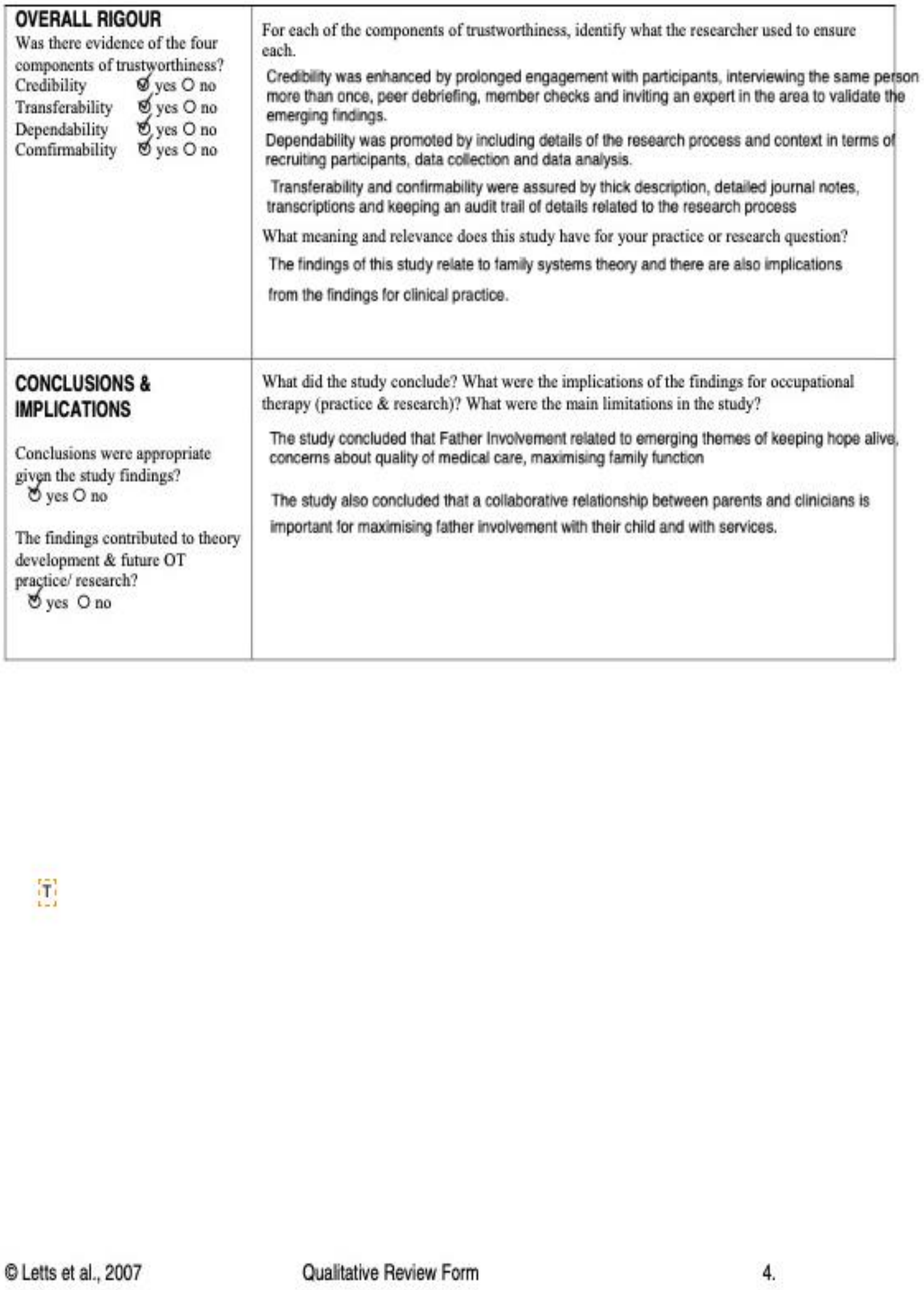
2 Throughout the form, "no" means the authors explicitly state reasons for not doing it; "not addressed" should be ticked if there is no mention of the issue.

© Letts et al., 2007 Qualitative Review Form 2.



Procedural Rigour Procedural rigor was used in data collection strategies? ☑ yes ○ no ○ not addressed	Do the researchers provide adequate information about data collection procedures e.g., gaining access to the site, field notes, training data gatherers? Describe any flexibility in the design & data collection methods. Rigour was achieved by ensuring credibility, dependability, transferability and confirmability of the findings
DATA ANALYSES: **Analytical Rigour** Data analyses were inductive? ☑ yes ○ no ○ not addressed Findings were consistent with & reflective of data? ☑ yes ○ no	Describe method(s) of data analysis. Were the methods appropriate? What were the findings? Data was analysed using the hermeneutic circle: First, transcripts were read severaltimes to understand each father's overall experience. Next, transcripts were coded line-by-line to identify significantparagraphs or aspects of fathers' daily caring experiencerelated to the research aim Finally the researcher moved back and forth between whole stories and significant parts to obtain a deeper understanding of fathers' experiences
Auditability Decision trail developed? ☑ yes ○ no ○ not addressed Process of analyzing the data was described adequately? ☑ yes ☑ no ○ not addressed	Describe the decisions of the researcher re: transformation of data to codes/themes. Outline the rationale given for development of themes. Data was coded line-by-line, however process of analysing data was not described in detail.
Theoretical Connections Did a meaningful picture of the phenomenon under study emerge? ☑ yes ○ no	How were concepts under study clarified & refined, and relationships made clear? Describe any conceptual frameworks that emerged. Analysis of data on fathers' experiences of raising disabled children at home revealed three shared meanings: keeping hope alive, concerns about quality of medical care and maximising family function.

© Letts et al., 2007 Qualitative Review Form 3.



OVERALL RIGOUR Was there evidence of the four components of trustworthiness? Credibility ☑ yes ○ no Transferability ☑ yes ○ no Dependability ☑ yes ○ no Comfirmability ☑ yes ○ no	For each of the components of trustworthiness, identify what the researcher used to ensure each. Credibility was enhanced by prolonged engagement with participants, interviewing the same person more than once, peer debriefing, member checks and inviting an expert in the area to validate the emerging findings. Dependability was promoted by including details of the research process and context in terms of recruiting participants, data collection and data analysis. Transferability and confirmability were assured by thick description, detailed journal notes, transcriptions and keeping an audit trail of details related to the research process What meaning and relevance does this study have for your practice or research question? The findings of this study relate to family systems theory and there are also implications from the findings for clinical practice.
CONCLUSIONS & IMPLICATIONS Conclusions were appropriate given the study findings? ☑ yes ○ no The findings contributed to theory development & future OT practice/ research? ☑ yes ○ no	What did the study conclude? What were the implications of the findings for occupational therapy (practice & research)? What were the main limitations in the study? The study concluded that Father Involvement related to emerging themes of keeping hope alive, concerns about quality of medical care, maximising family function The study also concluded that a collaborative relationship between parents and clinicians is important for maximising father involvement with their child and with services.

© Letts et al., 2007 Qualitative Review Form 4.

Average WoE A across areas of judgment:

Total quality rating score of 3 across 4 judgment areas.

Overall rating of evidence:

3 (High) ✓

2 (Medium)

1 (Low)

0

Appendix 2: Weight of Evidence B Criteria and Scoring

Weight of Evidence B is concerned with the appropriateness of the evidence gathered in the studies in answering the review question (Gough, 2007). The present review question was concerned with gathering the perspectives and experiences of participants. This was taken into account in the conceptualisation of the criteria for WoE B. All of the studies consulted in this review used either interview or survey methods for data collection, and these are two appropriate methods of data collection for incorporating the perspectives and experiences of the participants (Mertens, 2014). Therefore, for the WoE B scoring, it was decided that these methods of data collection should be appraised. Data saturation in interview approaches (Mertens, 2014) and high response rate (70%+) in survey studies are considered to be a high standard of research practice (Mertens, 2014). According to Guest, Bunce and Johnson (2006) for saturation to occur in qualitative interviews, there needs to be at least 12 interviews conducted. Using the aforementioned guiding principles, studies that showed evidence of data saturation in interviews and high response rate in surveys were afforded higher WoE B scoring. WoE B criteria and scores for each study are summarised in the table below.

WoE B Criteria and Rationale

WoE B Score	Criteria
3 (High)	Survey response rate is above 70% or there is evidence of data saturation (12 interviews) depending on the research approach adopted.
2 (Medium)	Survey response rate is below 70%, or data saturation is not indicated.
1 (Low)	Survey response rate and number of interview participants is either unclear, unsatisfactory or not reported.

Overall WoE B Scores

Study	**High (3)**	**Medium (2)**	**Low (1)**
Bagner (2013)	✓		
Curtiss et al. (2021)	✓		
Docherty & Dimond (2017)		✓	
Fox et al. (2015)		✓	
Huang et al. (2012)	✓		
MacDonald &Hastings (2010)		✓	
May et al. (2013)	✓		
McBride et al. (2017)	✓		
Oryono et al. (2020)	✓		
Sheldon et al. (2020)		✓	
Simmerman et al. (2001)	✓		

Appendix 3: Weight of Evidence C Criteria and Scoring

Weight of evidence C relates to the relevance of the study and its findings to the review (Gough, 2007). In the present review, WoE C criteria was set based on the sample population in question in these studies, because Gough (2007) notes that it is important that the sample being scrutinised is from an appropriate context to answer the review question. Some of the studies included in this review used the views of fathers combined with mothers on father involvement, and others also featured the fathers of children with other disabilities aside from ID or DD. Furthermore, studies that incorporated the views of EPs would be seen as more relevant to the present review question. WoE C scores were afforded on the basis of studies that showed evidence of investigating the most relevant samples to the research question, i.e. studies that exclusively investigated the views of fathers or EPs working in disability services, and studies that focused exclusively on ID or DD were afforded a higher WoE C score. WoE C criteria and rationale as well as scoring for each study is set out in the tables below.

WoE C Criteria and Rationale

WoE C Score	Criteria
3 (High)	The study uses information from a sample of fathers of children with an ID/DD AND clinicians. This sample is highly relevant to the review question, thus findings are also considered highly relevant to the review question.
2 (Medium)	The study uses information from a sample of fathers of children with an ID/DD OR clinicians. Findings are considered less relevant to the review because the sample draws upon a single population and therefore findings are not as specific to the review.

1 (Low)	The views of fathers or clinicians working in disability services are considered only as part of the findings and the emphasis of the research paper is on other populations (e.g. mother's perceptions of fathers) or ID/DD are considered but other forms of disability are more prominent. This sample is less relevant to the review and therefore findings are also considered less relevant.

Overall WoE C Scores

Study	**High (3)**	**Medium (2)**	**Low (1)**
Bagner (2013)			✓
Curtiss et al. (2021)		✓	
Docherty & Dimond (2017)		✓	
Fox et al. (2015)		✓	
Huang et al. (2012)		✓	
MacDonald &Hastings (2010)		✓	
May et al. (2013)			✓
McBride et al. (2017)		✓	
Oryono et al. (2020)			✓
Sheldon et al. (2020)		✓	
Simmerman et al. (2001)			✓

Appendix 4: Weight of Evidence D Criteria and Scoring

Weight of evidence D scores comprise a combination of the scores obtained in the three sets of judgments in WoE A, WoE B and WoE C (Gough, 2007). In order to categorise these scores, a commonly used scoring system was employed in the current review. This system is summarised in the table below. The overall WoE D scores for each paper in this review are also tabulated below.

WoE D Criteria and Rationale

WoE D Score	Overall average WoE Score
3 (High)	2.4 – 3
2 (Medium)	1.7 - 2.3
1 (Low)	1 – 1.6

Study Citation	**Research Methodology**	**WoE A score**	**WoE B Score**	**WoE C Score**	**WoE D Score**
Bagner (2013)	Quantitative	2	3	1	2
Curtiss et al. (2021)	Qualitative	3	3	2	2.66
Docherty & Dimond (2017)	Qualitative	3	2	2	2.33
Fox et al. (2015)	Quantitative (Correlation)	3	2	2	2.33
Huang et al. (2012)	Qualitative	3	3	2	2.66
MacDonald & Hastings (2010)	Quantitative (Correlation)	3	2	2	2.66
May et al. (2013)	Quantitative	1	3	1	1.66
McBride et al. (2017)	Mixed methods	3	3	2	2.66
Oryono et al. (2020)	Mixed methods	2	3	1	2

Sheldon et al. (2020)	Qualitative	2	2	2	2.33
Simmerman et al. (2001)	Quantitative (Correlation)	3	3	1	2.33

Appendix 5: Questionnaires consulted in design of the FEWS-Q

Survey Instrument and study in which survey was used	**Measures:**	**Reliability**	**Validity**
Ages and Stages Questionnaire (Oryono et al., 2021)	Child development outcomes	Not reported	Not reported
Family Care Indicator (Oryono et al., 2021)	Mothers and fathers' level of involvement and availability with their children	Not reported	Not reported
Child Behaviour Checklist (Bagner, 2013)	Problem and externalising behaviours in children	High	High
Father Role Salience Scale (Fox et al., 2015)	Salience of the father role to a man's identity	High	Not reported
Family Empowerment Scale (Fox et al., 2015)	Family Empowerment in the context of having a child with a disability	High	Not reported
Father Role Satisfaction Scale (Fox et al., 2015)	Satisfaction with being a father	Satisfactory	Satisfactory
Parental Involvement in childcare measure (MacDonald & Hastings, 2010)	Parental involvement in childcare	Not reported	Not reported
Father help and satisfaction scale (Simmerman et al., 2001)	Father participation in the childcare of a child with a disability	High	High
Perceived burden of care scale (Simmerman et al., 2001)	The subjective burden of care giving	Not reported	Not reported

The Parenting Sense of Competence Scale (May et al., 2013)	Perceived parent efficacy and satisfaction	High	Not reported
The Depression, Anxiety and Stress scale (May et al., 2013)	Perceived parent depression, stress, anxiety	High	Not reported
The Parenting Hassles Scale (May et al., 2013)	Daily stresses experienced by families of children with a disability	High	Not reported
The Developmental Behaviour Checklist (May et al., 2013)	Assesses problem behaviours in children with a disability	High	Not reported
The Difficult Behaviour Assessment Form (May et al., 2013)	Assesses child aggression and obedience	Not reported	Not reported

Appendix 6: FEWS-Q Subscales, Descriptions and Framing Theory

Subscale	Description	Framing Theory
Emotional Impact	The goal of the Emotional Impact subscale is to examine the perceived emotional impact of having a child with an ID/DD. This subscale asks fathers whether their stress levels have increased since having a child with an ID/DD, whether they feel emotionally supported by family and friends, and whether having a child with an ID/DD has had a positive impact on their lives.	**BMHD, FST** This subscale looks at relationships within the family system, specifically within the microsystem, and how this might impact upon service engagement. This subscale encompasses both theoretical frameworks used in this study.
Caring Role	The Caring role subscale examines the role of the father in caring for their child with an ID/DD. This subscale asks fathers whether they perceive their spouse to be the primary caregiver of their child, whether care for the child is equally shared between parents, whether the care they provide for their child is valuable and important and whether fathers have a role in carrying out programmes and interventions recommended by services.	**FST** This subscale looks at the perceived caring role of the father within the family system and how this might influence father engagement with services.

Service Role	The Service Role subscale is concerned with the fathers' perceptions on the role services can play in engaging and supporting them. This subscale asks whether disability service teams have emphasised the importance of the father and made efforts to include fathers, whether fathers' views are taken on board by services, whether services offer fathers counselling or training, how regularly fathers meet with disability service teams, whether services are flexible and accommodating to ensure fathers can attend appointments and whether services make efforts to keep fathers informed and involved. This subscale	**BMHD** This subscale looks at the relationship between father and disability services, which is a mesosystemic relationship that is influenced by the wider exosystem, macrosystem and chronosystem (Bronfenbrenner & Morris, 2006).
Social Role	The Social Role subscale looks at the social role of the father from the father's perspective, and the role of wider social norms in influencing father engagement with services. This subscale enquires whether it is the fathers role to provide financially for their children, if	**BMHD** This subscale is concerned with how wider social and gender norms within the mesosystem, exosystem and macrosystem might influence father

	it is the mother’s role to attend service appointments and carry out programmes, whether children with an ID/DD have the same opportunities as other children, whether fathers are involved in key decisions for their children, and fathers’ perceptions of the attitude of society toward children with an ID/DD.	engagement with services.

Appendix 7: Original FEWS-Q Items

Statement	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
In general, having a child with an intellectual disability has been a positive experience as a father *Emotional impact*					
Since my child was born, I have experienced higher levels of stress and anxiety *Emotional impact*					
I often feel isolated as a father of a child with an intellectual disability *Emotional impact*					
My social life has been negatively impacted since my child was born *Emotional impact*					
My family offers me emotional support as a father of a child with an intellectual disability					

Emotional impact					
My friends/peers offer me emotional support as a father of a child with an intellectual disability *Emotional impact*					
I worry about my child’s future regularly *Emotional impact*					
It was a difficult time for me when my child was diagnosed with an intellectual disability *Emotional impact*					
Having a child with an intellectual disability has a positive impact on family life *Emotional Impact*					
I have a loving bond with my child *Caring Role*					
My child’s mother is his/her primary caregiver *Caring Role*					

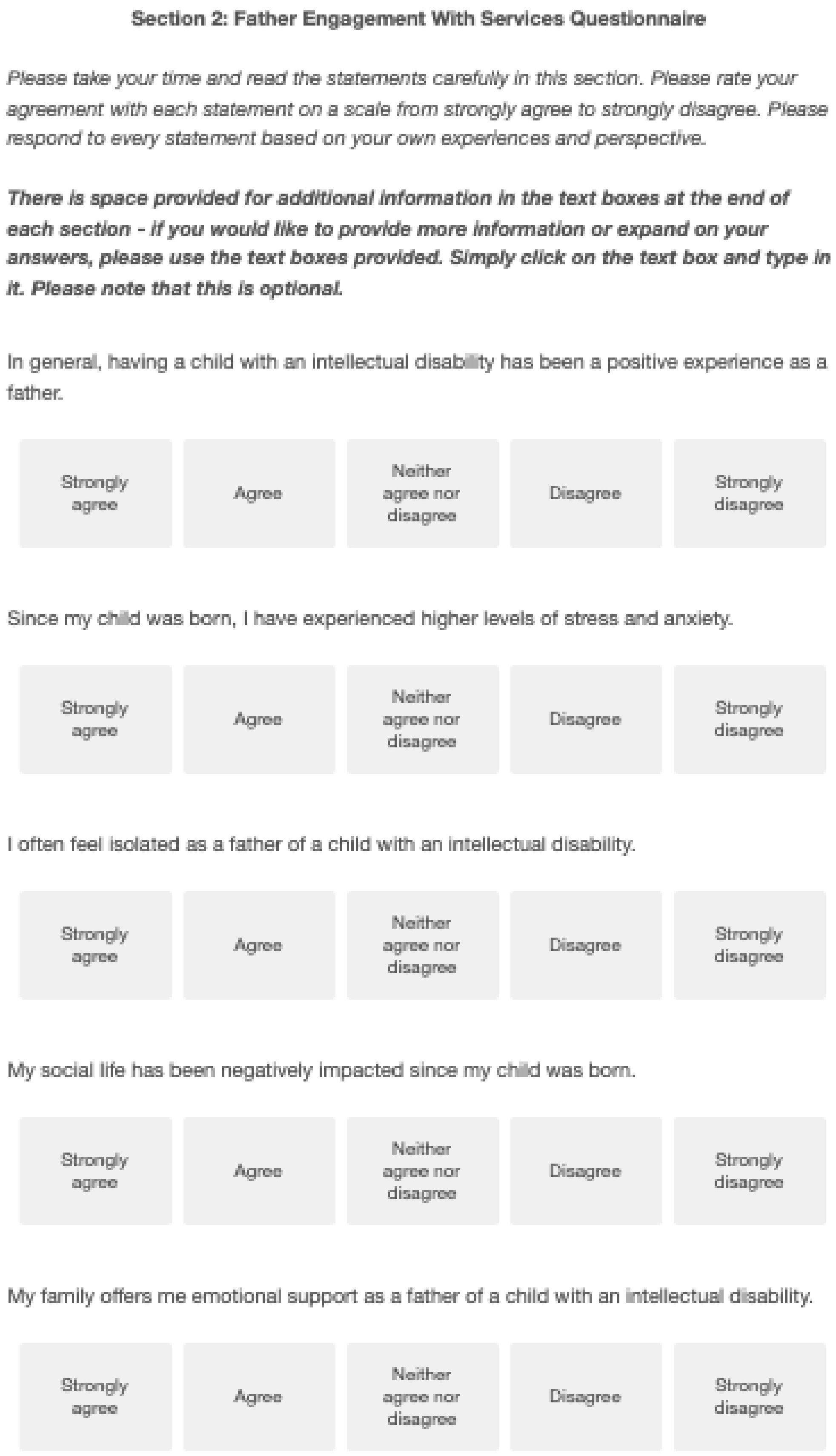
The care for my child is equally shared between parents *Caring Role*					
The care that I provide is valuable and important to my child *Caring Role*					
I am involved in carrying out the programmes/interventions that my child's disability team recommends for them *Caring Role*					
I feel that I am very involved in the life of my child *Caring Role*					
My child's disability/clinical service team have always emphasised the importance of my involvement *Service Role*					
My child's disability/clinical service team make every effort to keep me informed and involved					

Service Role					
My engagement with disability services is good *Service Role*					
Fathers should receive personal support/counselling from their child’s disability services *Service Role*					
My views and concerns about my child are valued by my child’s disability team *Service Role*					
Services need to be more flexible in terms of their opening times and days of work *Service Role*					
I would attend courses on supporting my child if they were made available to me *Service Role*					
I meet with my child’s disability					

team often (at least 3 times per year) *Service Role*					
The service that my child attends communicates with me as a father directly *Service Role*					
It is easy for me to attend all of my child’s appointments *Service Role*					
The services for children with an intellectual disability are good at including fathers *Service Role*					
My child’s service has always acknowledged my role as caregiver *Service Role*					
My views and wishes are always taken on board by my child’s disability team members *Service Role*					

As parents we have discussed how we divide our attendance at meetings and appointments *Social Role*					
It is the main role of the child's mother/primary caregiver to carry out programmes and go to clinic appointments *Social Role*					
Mothers are still the main carers for children *Social Role*					
Society today has a very positive attitude to children with disabilities *Social Role*					
It is the fathers role to provide financially for their children *Social Role*					
Children with an intellectual disability have the same opportunities as other children					

Social Role					
Fathers are involved in their children’s care in the early years *Social Role*					
Fathers are involved in key decisions for their children (e.g. school selection) *Social Role*					
The role of fathers in general has changed in recent years *Social Role*					



Section 2: Father Engagement With Services Questionnaire

Please take your time and read the statements carefully in this section. Please rate your agreement with each statement on a scale from strongly agree to strongly disagree. Please respond to every statement based on your own experiences and perspective.

There is space provided for additional information in the text boxes at the end of each section - if you would like to provide more information or expand on your answers, please use the text boxes provided. Simply click on the text box and type in it. Please note that this is optional.

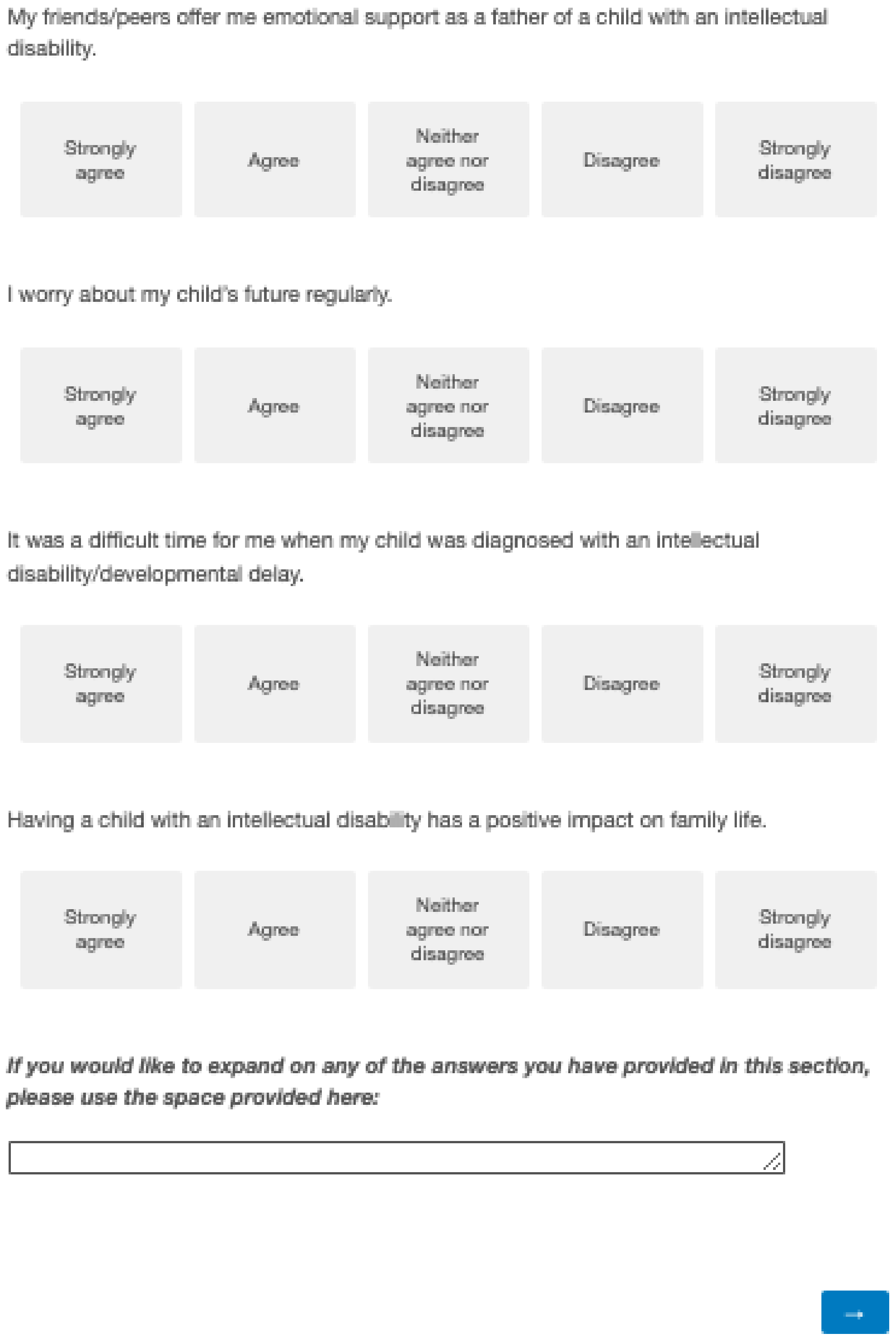
In general, having a child with an intellectual disability has been a positive experience as a father.

Since my child was born, I have experienced higher levels of stress and anxiety.

I often feel isolated as a father of a child with an intellectual disability.

My social life has been negatively impacted since my child was born.

My family offers me emotional support as a father of a child with an intellectual disability.



My friends/peers offer me emotional support as a father of a child with an intellectual disability.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

I worry about my child's future regularly.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

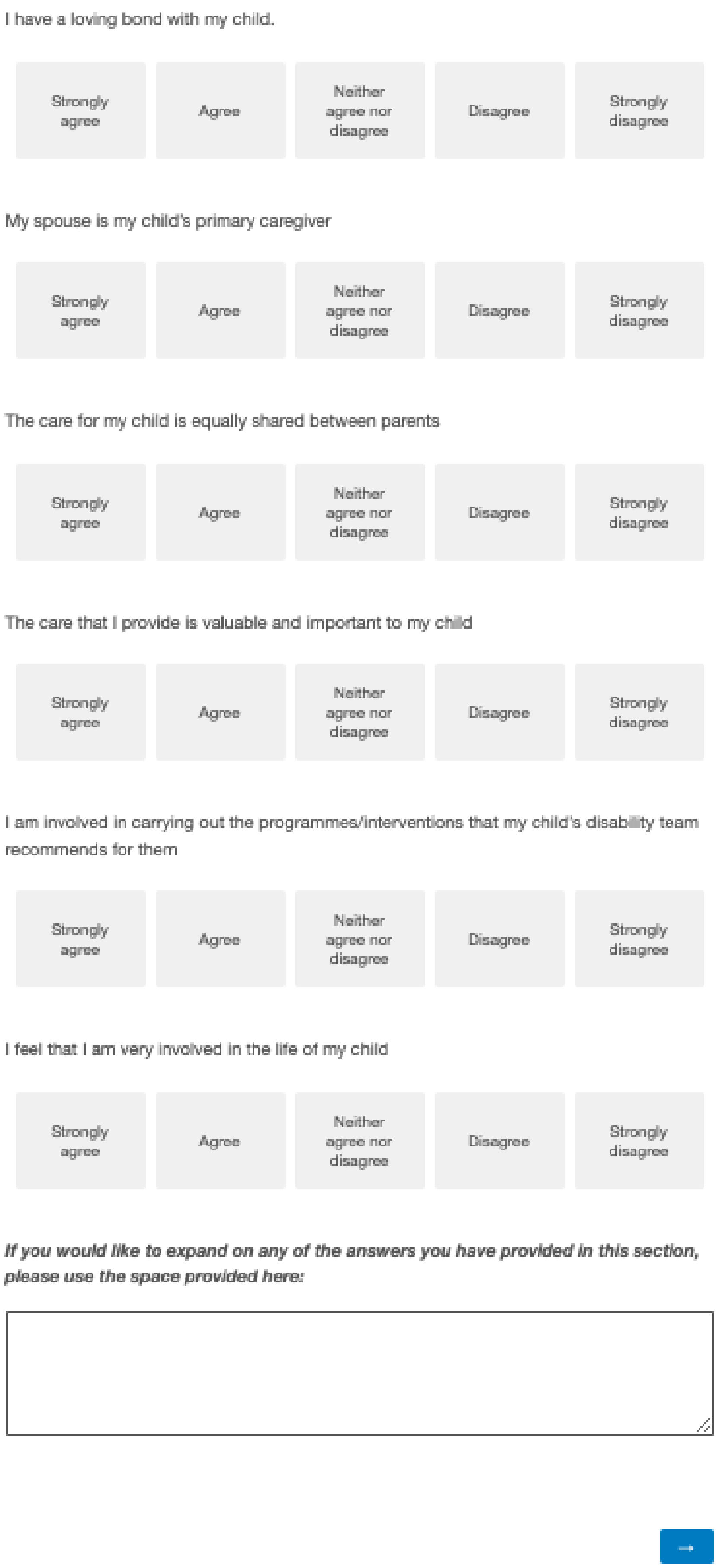
It was a difficult time for me when my child was diagnosed with an intellectual disability/developmental delay.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

Having a child with an intellectual disability has a positive impact on family life.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

If you would like to expand on any of the answers you have provided in this section, please use the space provided here:



I have a loving bond with my child.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

My spouse is my child's primary caregiver

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

The care for my child is equally shared between parents

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

The care that I provide is valuable and important to my child

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

I am involved in carrying out the programmes/interventions that my child's disability team recommends for them

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

I feel that I am very involved in the life of my child

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

If you would like to expand on any of the answers you have provided in this section, please use the space provided here:

The service that my child attends communicates with me as a father directly.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

It is difficult for me to attend all of my child's appointments.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

The services for children with an intellectual disability are good at including fathers.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

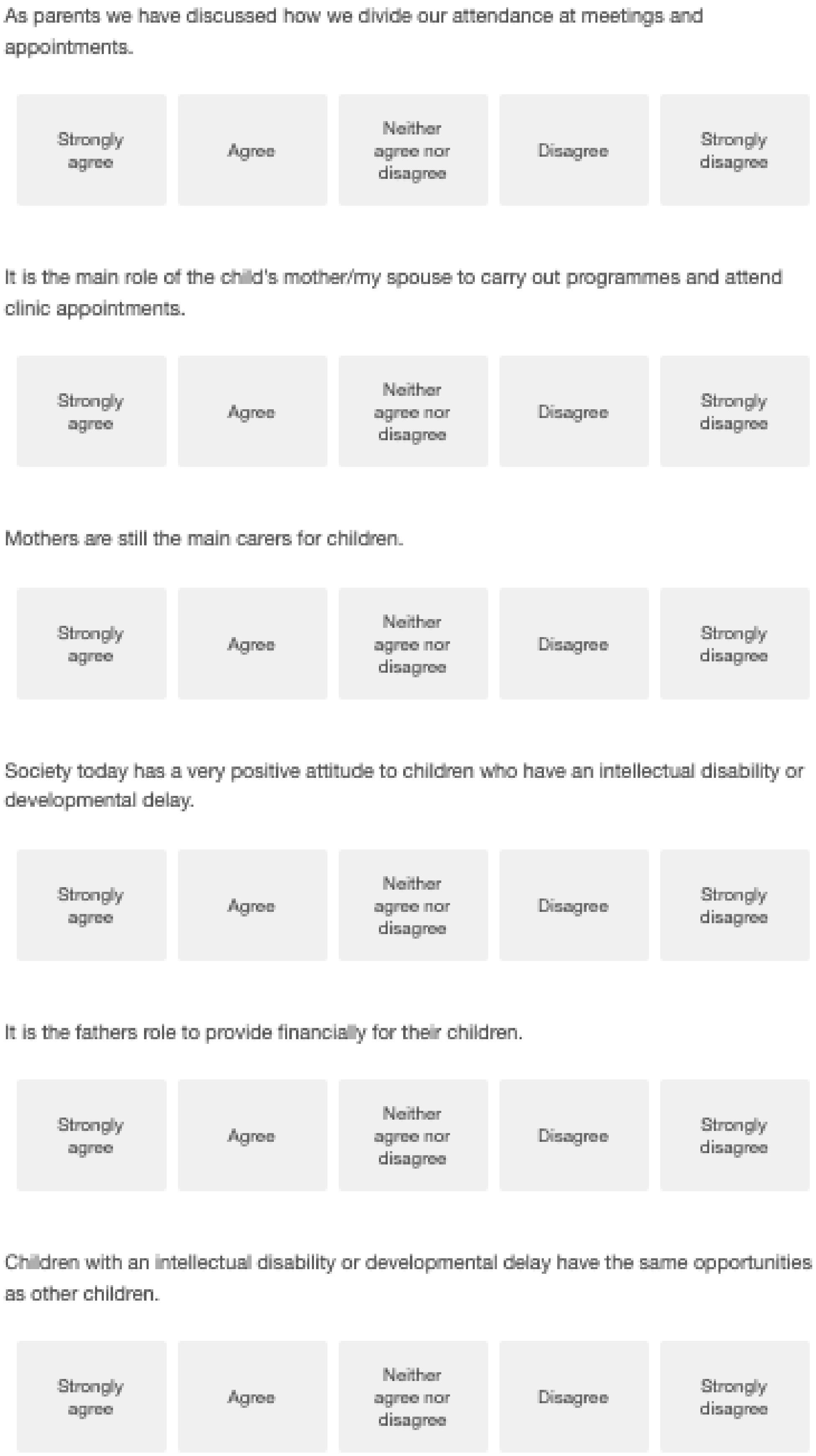
My child's service has always acknowledged my role as caregiver.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

My views and wishes are always taken on board by my child's disability team members.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

If you would like to expand on any of the answers you have provided in this section, please use the space provided here:



As parents we have discussed how we divide our attendance at meetings and appointments.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

It is the main role of the child's mother/my spouse to carry out programmes and attend clinic appointments.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

Mothers are still the main carers for children.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

Society today has a very positive attitude to children who have an intellectual disability or developmental delay.

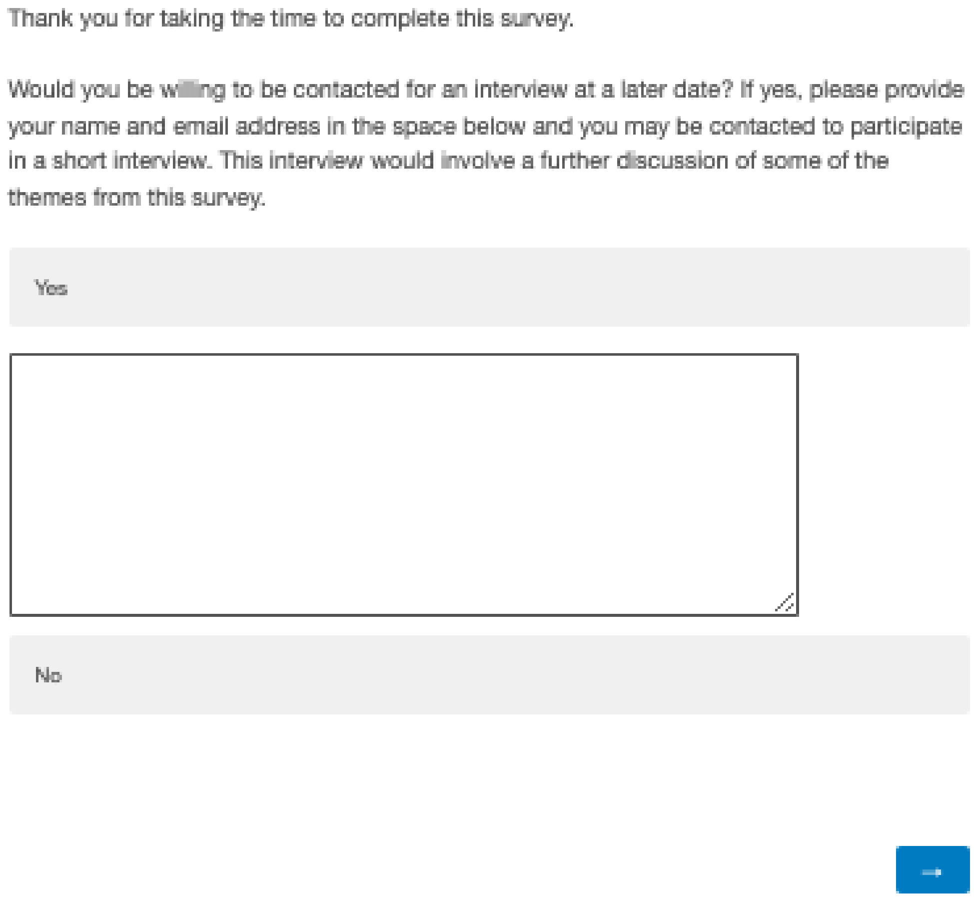
Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

It is the fathers role to provide financially for their children.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree

Children with an intellectual disability or developmental delay have the same opportunities as other children.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree



Thank you for taking the time to complete this survey.

Would you be willing to be contacted for an interview at a later date? If yes, please provide your name and email address in the space below and you may be contacted to participate in a short interview. This interview would involve a further discussion of some of the themes from this survey.

Yes

No

Appendix 8: Research Flyer

Fathers and Disability Services study

Participants needed to help improve father's engagement and experience with disability services in an Irish context.

Research suggests fathers feel **undervalued** and **disengaged** with services. However, in reality, **little is known** about the factors that influence father engagement with disability services.

This is what this study **seeks to understand**. If you are eligible to participate **your insight would be invaluable** to our study.

- **What's involved?**
  An **online survey available at the URL** or **QR code below**
  https://micquality.qualtrics.com/jfe/form/SV_2gDycITbllaRZFc
- **Are you eligible?**
  You must be over 18 and the father of a child with an Intellectual Disability or Developmental Delay who is aged between 0-19.

To apply or for further information, contact:

Ronan Cunningham (Principal Researcher)
19280262@micstudent.mic.ul.ie | +353831696937

Dr. Margaret Farrelly (Research Supervisor)
Margaret.farrelly@mic.ul.ie

Appendix 9: Child ID Categories in the Present Study

Type of ID/DD	**No. of participants**
Down Syndrome	20
Intellectual Disability (Unspecified)	16
ID and Autism Spectrum Disorder	14
Developmental Delay	11
Angelman Syndrome	2
Williams Syndrome	1
Congenital CMV	1
Rett Syndrome	1
Ring 18	1
Charge Syndrome	1
Mowat Wilson Syndrome	1
Williams Syndrome	1
Prader Willi Syndrome	1
Tuberous Sclerosis Complex	1
KCNA2	1
XQ28 Duplication Syndrome	1
ID and Multiple Sulfatase Deficiency	1
Cri Du Chat Syndrome	1

Appendix 10: Interview schedule (fathers)

Interview Protocol

Individual Interview Schedule

OPENING

Hi, (insert name) how are you doing today? Thank you for attending the interview, how's your day going?

I'm really happy that you are available to help me with my study. Have you read and understood everything on the consent form? I would be happy to go through anything that you are not sure about at this time or answer any questions that you might have?

[Make sure they are comfortable before explaining purpose of interview.]

(Purpose of interview) –

If you're happy you understand, I'll begin by briefly explaining the purpose of this interview. This interview is about exploring some of your perceptions and experiences on your engagement with disability services. As a dad of a child with additional needs, your perspective and insights into this topic are really valuable.

Remember that all of your information is extremely helpful and that there are no wrong answers to these questions.

I'd like to remind you at this time that your identity will be protected and that your name will not be used in the interview. You also have the right to stop the interview at any time, if you so wish.

(Time line) -

The interview should not take too long, maybe about 30 – 45 minutes.

Remember that you can stop me to ask questions at any time and if you want to stop the interview or skip any questions at any time there is no problem at all with that. If you're happy that you understand everything, I'd like to begin the interview now if that's ok with you.

Preamble

Can I just confirm your details and your child's details before we get into the interview questions?

- Age of father/child
- School setting
- Nature of ID (mild, mod, severe, profound)

Note taking.

<u>Section 1 – Experiences with services</u>

1. Can you tell me about your experiences with disability services?

- **Prompts:** From the beginning (when child was an infant), did/do you feel supported by the service?

2. Do you meet with or have contact with your child’s disability service team regularly?

- **Prompts:** How regularly? Has this changed over time? (i.e. since child has become older?)

3. In your experience, have disability services made an effort to include you, as a father, meaningfully?

- **Prompts:** Can you tell me more about this? Do they contact you directly? Can you give an example? Do they emphasise the importance of father involvement?

4. From your experience, are services flexible and/or accommodating in terms of meetings, appointments etc.? (Related to EST)

- **Prompts:** Can you tell me a bit more about that? Opening times, times of appointments etc.

5. Have you ever attended/been offered parenting courses/counselling sessions/any father-specific training by services?

- **Prompts:** If so, can you tell me about this? Do you feel that speaking to other fathers of children with ID would be beneficial to you? Can you expand on this point?

Section 2 – Perceptions of services

1. Do you feel that disability services have been helpful and supportive to you and your child/family over the years?

- **Prompts:** Do you feel that you could do with more help/support from services?

2. In your experience, are services balanced in their contact with fathers and mothers?

- **Prompts:** Why do you think this is/isn't?

3. How do you think services view fathers?

- **Prompts:** Caring, absent, careless, less involved than mothers, primary/secondary parent etc.

4. Overall, how would you describe your relationship/engagement with disability services?

- **Prompts:** Positive/negative? Non-existent?

Section 3 – Family System (caring role/emotional impact)

1. How do you see your family role as a father of a child with an ID/DD?

- **Prompts:** Do you see yourself as the provider (financially)/ the carer / the one who has to be strong etc. Do you feel under pressure to fulfil a certain role as a father? Do you think that the mother is the primary caregiver?

2. Does your perceived family role have an impact on your engagement with services?

- **Prompts:** For example, is it seen as the mother's role to attend appointments etc. or is it the father's role to select services and advocate for their child?

3. Do you feel that family support is important when you have a child with additional needs?

- **Prompts:** Do you feel supported by your immediate/wider family? Does this help with stress/anxiety?

4. Do you think that having a child with an ID has had an impact on your other relationships within your family?

- **Prompts:** i.e. your relationship with your spouse, with your other children. Could be positive or negative.

Section 4 – Bio-ecological Model (social role)

1. Do you think that having a child with an ID has changed how you and your family are perceived socially? Does this influence your social engagement/participation?

- **Prompts:** e.g. by peers, by people in the wider community. Is this seen as a positive or a negative in general?

2. Do you think that your interactions with services, professionals are unique as a father of a child with ID?

- **Prompts:** Are they different from a mother's interactions, for example. Do services treat you differently?

3. Do you feel socially supported (by friends, services, specialists) as a father of a child with an ID?

- **Prompts:** Or do you feel isolated?

4. Do you think that the role of the father has changed in recent years?

- **Prompts:** If so, does society recognise this change?

To finish, if you could summarise briefly, what do you think the biggest barriers to father engagement with disability services are?

CLOSING

- It has been a pleasure getting to know more about you and some of the experiences that you have had and the information that you have shared with me has been really helpful. I thank you again for taking the time to take part in this interview and helping me with my study.
- Is there anything else you think would be helpful for me to know before we finish this interview?
- Have you got any questions or issues that you would like to discuss with me?

OK, thanks again. If you find that you have any questions at a later date, please feel free to contact me at any time via phone or email. My contact details are provided on the information sheet that you received before this interview. If you would like another copy of, I'd be happy to give you one now.

Appendix 11: Interview Schedule (Psychologists)

OPENING

Hi, (insert name) how are you doing today? Thank you for attending the interview, how's your day going?

I'm really happy that you are available to help me with my study. Have you read and understood everything on the consent form? I would be happy to go through anything that you are not sure about at this time or answer any questions that you might have?

[Make sure they are comfortable before explaining purpose of interview.]

(Purpose of interview) –

If you're happy you understand, I'll begin by briefly explaining the purpose of this interview. This interview is about exploring some your experiences of father engagement with disability services. As a psychologist working in a disability service, your perspective and insights into this topic are really valuable.

Remember that all of your information is extremely helpful and that there are no wrong answers to these questions.

I'd like to remind you at this time that your identity will be protected and that your name will not be used in the interview. You also have the right to stop the interview at any time, if you so wish.

(Time line) -

The interview should not take too long, maybe about 30 – 45 minutes.

Remember that you can stop me to ask questions at any time and if you want to stop the interview or skip any questions at any time there is no problem at all with that. If you're happy that you understand everything, I'd like to begin the interview now if that's ok with you.

Any questions?

- **Consent**
- **Freedom to Withdraw – do not have to answer any questions**
- **Recording**

- **Note Taking**

- Type of Psychologist (Educational/clinical/counselling)

- EI/SA

- Number of years working in disability services:

Section 1 – Experiences with fathers

1. As a psychologist working in a disability service, could you begin by telling me about your experiences of father engagement with disability services?

- **Prompts:** How regularly you meet dads vs. mums. Would both parents often attend appointments? Have you noticed any pattern?

2. Do you feel your service emphasises the importance of father involvement at intake? Would both parents be present from the start?

- **Prompts:** Would both parents be present if diagnosis given?

3. Do you feel your service in general tries to gain both parents perspectives? (even if separated)

- **Prompts:** Is there an emphasis on contacting both parents? Is including fathers something that is discussed? Flexible appointments/meetings during the week?

4. Does your service offer any parenting courses, training or counselling?

- **Prompts:** Is it advertised that such courses are for fathers as well as mothers? Benefit of peer to peer support.

Section 2 – Perceptions of fathers in practice

1. Do you feel that fathers can be resistant/less willing to attend appointments than mothers?

- **Prompts:** Have you faced resistance from fathers in the past? Can you tell me about this?

2. From your experience, do you think that services perceive fathers differently to mothers?

- **Prompts:** e.g. maybe not the primary contact, less present than mothers.

3. Do you feel as comfortable working/communicating with fathers as you do with mothers?

- **Prompts:** Could you tell me a bit more about this?

4. Do you obtain data from both parents when exploring developmental history etc.? Does father involvement add to the efficacy of intervention, etc?

- **Prompts:** Are fathers involved in this process generally?

Section 3 – Family Role (caring role)

1. From your experience, how do parenting roles differ between mothers and fathers?

- **Prompts:** Mother carer, father provider, other. Do you think fathers are under pressure to fulfil a certain role?

2. Do you think there are familial barriers to father engagement with services?

- **Prompts:** i.e. if father is working, provider, secondary caregiver.

3. Do you feel that your service offers a family-centred approach to practice?

- **Prompts:** Do you offer services to the entire family or just the child who is linked in with the service?

Section 4 – Bio-ecological Model (social role)

1. Do you feel that there are societal barriers to father engagement with disability services? (e.g. gender roles)

- **Prompts:** If so, can you tell me a bit about this?

2. Do you feel that there are practical barriers to father engagement with disability services?

- **Prompts:** e.g. appointment time and work conflicts, separation**?**

3. Do you feel that the role of fathers has changed in recent years?

- **Prompts:** Is this something you've noticed in your practice i.e. fathers wanting to be more involved.

To finish, if you could summarise briefly, what do you think the biggest barriers to father engagement with disability services are?

CLOSING

- ➢ It has been a pleasure getting to know more about you and some of the experiences that you have had and the information that you have shared with me has been really helpful. I thank you again for taking the time to take part in this interview and helping me with my study.
- ➢ Is there anything else you think would be helpful for me to know before we finish this interview?
- ➢ Have you got any questions or issues that you would like to discuss with me?

OK, thanks again. If you find that you have any questions at a later date, please feel free to contact me at any time via phone or email. My contact details are provided on the information sheet that you received before this interview. If you would like another copy of, I’d be happy to give you one now.

Appendix 12: Information Sheets

Participant Information Sheet (Fathers)

You are being asked to take part in a research study. Please take time to read the following information so that you understand why the research is being done and what it involves. Ask us if there is anything that is not clear or if you would like more information.

TITLE OF THE STUDY:

Father engagement with disability services: the perceptions and experiences of fathers and psychologists

INVITATION

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Feel free to ask any questions if anything you read is not clear or you would like more information. Take time to decide whether or not you would like to take part in this study.

WHO I AM AND WHAT IS THE STUDY ABOUT?

My name is Ronan Cunningham and I am a doctorate student in Mary Immaculate College, Limerick. I am studying to become an Educational and Child Psychologist. I am conducting this research in order to complete a dissertation as part of the requirements for the Doctorate in Educational and Child Psychology.

This study is designed to investigate the perceptions and experiences of fathers of children with an intellectual disability and Psychologists on father engagement with disability services in Ireland.

WHAT WILL TAKING PART INVOLVE?

Taking part in this research project will involve filling out an online survey. The survey will ask if you would be open to taking part in an interview at a later date and if you consent, this research may also involve participating in a semi-structured interview.

The online survey will gather some basic information about you and your child and will also gather some information about your engagement with disability services (i.e. how involved you feel with your child's disability service). This should take no longer than 15 minutes to complete.

If you are contacted for interview at a later date, you will be asked some questions to look a bit more at your engagement with disability services. This interview may be completed in person or online, and should take no longer than 90 minutes to complete.

WHY HAVE YOU BEEN INVITED TO TAKE PART?

You have been invited to take part in this research project because you are the father of a child with an intellectual disability/developmental delay who attends a disability service. Therefore, you have valuable experiences and insight to offer about the services that you and your child receive. Any information that you can share on this topic is considered helpful and the insight that can be gained from the views of fathers like yourself are invaluable in this kind of project.

DO YOU HAVE TO TAKE PART?

No, there is no obligation to take part in this study. You have been contacted because you may have valuable insights to share on the topic of interest, but participation in this project is completely voluntary. You have the right to refuse participation. At any time if you decide that you no longer wish to participate, you can withdraw from the study without any consequences.

WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF TAKING PART?

If you decide to participate in this study, you will be providing valuable knowledge and insight about your experiences of engaging with disability services as a father of a child with an intellectual disability. You are in a unique position to have insight on this matter, which is why you have been contacted to partake in this study.

Research in the past has shown that fathers of children with intellectual disabilities are not as involved as mothers in the clinical relationship with disability services. This could be explained by many different factors and this study seeks to explore the relationship between fathers and disability services to gain a deeper understanding of this relationship. There has been a lack of research conducted exploring this relationship and gaining your perspective in this project could be very helpful in getting a better understanding of this interaction. There are no wrong answers – any information provided will be considered valuable and useful to the project. Please note that there will be no monetary reward of any kind for participating in this study.

While there are no obvious risks associated with participating in this study, at any time if you no longer wish to participate, you can withdraw from the study without any consequences. Your participation is completely voluntary.

WILL TAKING PART BE CONFIDENTIAL?

Yes, your anonymity will be protected if you decide to participate in this project. The survey information collected will be completely anonymized. If you are selected to take part in the interview phase of research, a pseudonym (different name) will be used to refer to you and the views that you express in the interview process. Your real name will not be used at any point in the writing up of this research.

It should be noted however that there may be some situations when it might be necessary to break anonymity. For example, if I feel strongly that there is a genuine risk of harm to you or another individual based on what you say I am obliged to share this information with the appropriate authorities. I will make sure to raise this issue with you first, however.

HOW WILL INFORMATION YOU PROVIDE BE RECORDED, STORED AND PROTECTED?

Non-anonymised (distinguishable) data will be collected in this study in the form of audio recordings and signed consent forms. This means that you can be recognised by the content of this data. Procedures are in place for the storage of this data. Any audio/electronic records that are generated will be stored on an encrypted USB key that only I will be able to access. Any physical non-anonymised data generated will be stored in a locked personal filing cabinet. If at any time you wish to access this data, you can simply contact me (contact details included below) and I will facilitate this. You are entitled to do this under the Freedom of Information Act (2014).

WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?

The results of the study will be used for academic purposes in the submission of my dissertation. Depending on the significance of the results of the study, my dissertation may be put forward for publication in an academic journal and/or presented at a conference.

WHO SHOULD YOU CONTACT FOR FURTHER INFORMATION?

Please feel free to contact me at any time before, during or after participation. I can be reached be email at 19280262@micstudent.mic.ul.ie or by phone at 0831696937. You can also contact my research supervisor Dr. Margaret Farrelly by email at Margaret.farrelly@mic.ul.ie.

Participant Information Sheet (Psychologists)

TITLE OF THE STUDY:

Father engagement with disability services: the perceptions and experiences of fathers and psychologists

WHO I AM AND WHAT THE STUDY IS ABOUT?

My name is Ronan Cunningham and I am a doctorate student in Mary Immaculate College, Limerick. I am studying to become an Educational and Child Psychologist. I am conducting this research to complete a dissertation as part of the requirements for the Doctorate in Educational and Child Psychology.

This study is designed to investigate the experiences of fathers of children with an intellectual disability and Psychologists on father engagement with disability services in Ireland.

WHAT WILL TAKING PART INVOLVE?

Taking part in this research project will involve completing an interview. In the interview, you will be asked some questions about father engagement with disability services from your professional perspective. This interview will be completed online via zoom, and should take no longer than 30-60 minutes to complete.

WHY HAVE YOU BEEN INVITED TO TAKE PART?

You have been invited to take part in this research project because you are a Psychologist working in a disability service who works closely with families on a day-to-day basis. Therefore, you have valuable experiences and insight to offer about your professional experiences of father engagement with disability services. Any information that you can share on this topic is considered helpful and the insight that can be gained from the views of Psychologists like yourself are invaluable in this kind of project.

DO YOU HAVE TO TAKE PART?

No, there is no obligation to take part in this study. You have been contacted because you may have valuable insights to share on the topic of interest, but participation in this project is completely voluntary. You have the right to refuse participation. At any time if you decide that you no longer wish to participate, you can withdraw from the study without any consequences.

WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF TAKING PART?

If you decide to participate in this study, you will be providing valuable knowledge and insight about your experiences of engaging with disability services as a Psychologist working in a disability service. You are in a unique position to have insight on this matter, which is why you have been contacted to partake in this study.

Research in the past has shown that fathers of children with an ID/DD are not as involved as mothers in the clinical relationship with disability services. This could be explained by many different factors and this study seeks to explore some of these potential factors. There has been a lack of research conducted exploring this relationship and gaining your perspective in this project could be very helpful in getting a better understanding of this interaction.

While there are no obvious risks associated with participating in this study, at any time if you no longer wish to participate, you can withdraw from the study without any consequences. Your participation is completely voluntary.

WILL TAKING PART BE CONFIDENTIAL?

Yes, your anonymity will be protected if you decide to participate in this project. The survey information collected will be completely anonymized. If you are selected to take part in the interview phase of research, a pseudonym (different name) will be used to refer to you and the views that you express in the interview process. Your real name will not be used at any point in the writing up of this research.

It should be noted however that there may be some situations when it might be necessary to break anonymity. For example, if I feel strongly that there is a genuine risk of harm to you or another individual based on what you say I am obliged to share this information with the appropriate authorities. I will make sure to raise this issue with you first, however.

HOW WILL INFORMATION YOU PROVIDE BE RECORDED, STORED AND PROTECTED?

Non-anonymised (distinguishable) data will be collected in this study in the form of audio recordings and signed consent forms. This means that you can be recognised by the content of this data. Procedures are in place for the storage of this data. Any audio/electronic records that are generated will be stored on an encrypted USB key that only I will be able to access. Any physical non-anonymised data generated will be stored in a locked personal filing cabinet. If at any time you wish to access this data, you can simply contact me (contact details included below) and I will facilitate this. You are entitled to do this under the Freedom of Information Act (2014).

WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?

The results of the study will be used for academic purposes in the submission of my dissertation. Depending on the significance of the results of the study, my dissertation may be put forward for publication in an academic journal and/or presented at a conference.

WHO SHOULD YOU CONTACT FOR FURTHER INFORMATION?

Please feel free to contact me at any time before, during or after participation. I can be reached be email at 19280262@micstudent.mic.ul.ie or by phone at 0831696937. You can also contact my research supervisor Dr. Margaret Farrelly by email at Margaret.farrelly@mic.ul.ie.

Appendix 13: Consent Forms

PARTICIPANT CONSENT FORM

Father Engagement with Disability Services: The perceptions and experiences of fathers and psychologists.

Please take time to read the following information carefully.

Please read the statement on the left, and tick the box on the right if you agree and understand this statement

Consent to take part in a research project

- I... voluntarily agree to participate in this research study.

I understand that even if I agree to participate now, I can withdraw at any time or refuse to answer any question with no repercussions of any kind.	
I understand that I can withdraw permission to use data from my interview after the interview, in which case the material will be deleted.	
I have had the purpose and nature of the study explained to me in writing and I have had the opportunity to ask questions about the study.	
I understand that participation involves the completion of a 30-60 minute interview with the researcher (via zoom)	
I understand that I will not benefit directly from participating in this research.	
I agree to my interview being audio-recorded. If I do not want my interview to be audio recorded, I will mention this to the researcher who will then take notes during the interview	
I understand that all information provided for this study will be treated confidentially and all data anonymized.	
I understand that disguised extracts from my interview may be quoted in a research dissertation, and potentially in published papers and at academic conferences.	
I understand that if I inform the researcher that they or someone else is at risk of harm they may have to report this to the relevant authorities - this will be discussed with me first but may be required to report with or without my permission.	

I understand that signed consent forms and original audio recordings will be retained. Any audio/electronic records that are generated will be stored on an encrypted USB that only the researcher and the research supervisor will have access to. Physical consent forms will be stored in a locked personal filing cabinet. In line with the MIC Data Retention Policy, anonymised data may be retained indefinitely as required by the researcher.	
I understand that a transcript of my interview in which all identifying information has been removed will be retained for at least two years following the interview.	
I understand that under freedom of information legislation I am entitled to access the information that I have provided at any time while it is in storage as specified above.	
I understand that I am free to contact any of the people involved in the research to seek further clarification and information.	

Contact details

Ronan Cunningham, Researcher

Email: 19280262@micstudent.mic.ul.ie

Phone: 0831696937

Dr. Margaret Farrelly, Research Supervisor

Email: Margaret.farrelly@mic.ul.ie.

Signature of research participant

…………………………………………

Signature of researcher Date

………………………………………..

Appendix 14: Intellectual Disability Organisations Contacted

Organisations Contacted	Channel of Contact
Inclusion Ireland	Contacted through their website
Down syndrome Ireland (Plus 10 regional branches)	Contacted through their website
Enable Ireland	Social Media (Facebook/Twitter/Instagram)
Irish Fragile X Society	Social Media (Facebook/Twitter/Instagram)
Profound Ireland	Social Media (Facebook/Twitter/Instagram)
RARE Ireland Family support Network	Social Media (Facebook/Twitter/Instagram)
Rare Diseases Ireland	Social Media (Facebook/Twitter/Instagram)
Áirc Midlands	Social Media (Facebook/Twitter/Instagram)
Rett Syndrome Association of Ireland	Social Media (Facebook/Twitter/Instagram)
National Institute of Intellectual Disability	Social Media (Facebook/Twitter/Instagram)
Disability.ie	Social Media (Facebook/Twitter/Instagram)
National Institute of Intellectual Disability	Social Media (Facebook/Twitter/Instagram)
National Advocacy Service of Ireland	Social Media (Facebook/Twitter/Instagram)
Lakers: Meeting Special Needs	Social Media (Facebook/Twitter/Instagram)
Frontline Ireland	Social Media (Facebook/Twitter/Instagram)
PSI Intellectual Disability SIG	Social Media (Facebook/Twitter/Instagram)
Bluestack Special Needs Foundation	Social Media (Facebook/Twitter/Instagram)
Blossom Ireland	Social Media (Facebook/Twitter/Instagram)
Special Needs Parents Ireland Network	Social Media (Facebook/Twitter/Instagram)
Bluebird Care Ireland	Social Media (Facebook/Twitter/Instagram)
Disability Louth	Social Media (Facebook/Twitter/Instagram)
Special Heroes Ireland	Social Media (Facebook/Twitter/Instagram)

KARE, Promoting inclusion of people with intellectual disabilities	Social Media (Facebook/Twitter/Instagram)
Avista	Social Media (Facebook/Twitter/Instagram)
Spina Bifida Hydrocephalus Ireland	Social Media (Facebook/Twitter/Instagram)
The Children's Clinic, Ireland	Social Media (Facebook/Twitter/Instagram)
Angelman Syndrome Ireland	Social Media (Facebook/Twitter/Instagram)
Cheeverstown House	Social Media (Facebook/Twitter/Instagram)
AHEAD Ireland	Social Media (Facebook/Twitter/Instagram)
Muiriosa Foundation	Social Media (Facebook/Twitter/Instagram)
Western Care Association	Social Media (Facebook/Twitter/Instagram)
Labour Disability – Ireland	Social Media (Facebook/Twitter/Instagram)
Raredisease.ie	Social Media (Facebook/Twitter/Instagram)
Oakridge children's services	Social Media (Facebook/Twitter/Instagram)
Lamh Sign	Social Media (Facebook/Twitter/Instagram)
Disability Action Coalition	Social Media (Facebook/Twitter/Instagram)
Disability Federation of Ireland	Social Media (Facebook/Twitter/Instagram)
Ability West	Social Media (Facebook/Twitter/Instagram)
DCAWarriors	Social Media (Facebook/Twitter/Instagram)
Sensational Kids Ireland	Social Media (Facebook/Twitter/Instagram)
LEAP Ireland	Social Media (Facebook/Twitter/Instagram)
WALK	Social Media (Facebook/Twitter/Instagram)
National Disability Services Quality Improvement	Social Media (Facebook/Twitter/Instagram)
National Institute of Intellectual Disabilities Studies	Social Media (Facebook/Twitter/Instagram)
22Q11 Ireland	Social Media (Facebook/Twitter/Instagram)

Appendix 15: Example of Initial Code Creation from Interviews

Data	Initial Codes
<u>Example 1 – Father</u> Interviewer (I): In your experience with services, have you found that they have made an effort to include you meaningfully?	
Participant (P): Our child’s mum is the contact and I believe that both of our contact details are down but it’s always mum who is called. I believe we get a circular letter that is addressed to both of us and that’s probably the only case of us being equal. I’ve been called before, when they couldn’t get in contact with mum, but I believe in that conversation, they were phoning me looking for mum. That’s one of the main reasons why I signed up for your survey. Even for online forums or groups; the main whatsapp group we’re part of is mostly addressed as “Hey Ladies” which made me check whether I was the only dad in the group. Out of 45 participants, I think I’m the only male.	*Unconscious bias in services* *How dads define their role* *Experiences with services (Isolation/Anonymity)* *Father-specific groups*
I: So why do you think services contact the mum first?	
P: I think that’s the traditional thing of mum being the person that looks after the children. You know, mum used to stay at home and mind the kids and there’s always been that kind of view. Coupled with the fact that it’s maternity leave to mind the baby. I will say, as the partner in the relationship who doesn’t breastfeed, it does make sense for the mother to be on leave. For my own upbringing, it wasn’t like that, it was equal for my parents. They both worked and my mother actually worked longer hours than my dad. In modern circumstances, once mummy goes back to work it does changes, unless she has another child, as is the case with us. In that circumstance, things might tend to fall to her to look after services or to have more time - to theoretically have more time - to be chasing up services.	*Expectations of mothers vs. fathers* *Maternity leave* *Societal gender role constructs*

	Unconscious bias in services
<u>Example 2 – Psychologist</u>	
I: Could you tell me about your experiences of father engagement with services. How fathers engage with services, if it differs from mothers.	
P: When I first heard about this research, I was thinking, it's really nice to be involved in research, and that's an easy enough investment, an interview for an hour. I also thought that it might be good for me to think about this for an hour because I think that we … I suppose I can only talk for myself, but I do see this in other people, that there is a bias towards contacting mothers. And if there's two contacts, unless you are told otherwise, you'd contact the mother. So, actually, I think that is a big obstacle in that there is a societal assumption that it is the mother who you contact. Then, you've set up the relationship with the mother, or the communication channel with the mother.	*Reflection on Practice* *Bias in services* *Societal gender role constructs* *Early Relationship (with mum)*
I've always worked with, up until now, with people quite significant disabilities and often one of the care givers will have, well won't be working, or one of the care givers will be part-time and you'll know which of the times that they're available. I think that is usually the mother. There was a piece of research done by someone, a trainee, I think probably about ten years on fathers' experiences of disability. One of the things that I think I remember from that research is, and obviously this is qualitative, one of the themes coming up was the idea if, if I'm going to be … I'm going to be a really good parent to this, I'm going to go back to core beliefs with this. (For) the women, that is that I will be a good parent and I will be at home, and I will invest. And for a father that theme is, I will provide.	*Parental Sacrifice* *Expectations of mothers vs. fathers in services* *Parent roles in context of ID* *Families perpetuating roles* *Societal gender role constructs*

Appendix 16: Examples of Final Codes, Subtheme, Theme Creation

Father quotes	Codes	Subthemes	Theme
"I'm the breadwinner who pays the bills but very involved come half six or seven" (Brendan)	How dads define their role	Parent Role Definitions Father's Unique Role	Roles (Microsystem)
"I am the provider, yes. For a while it was 50/50, but my wife had to give up work a few years ago and then there was a very clear dividing of roles." (James)	Parental sacrifices How dads define their role		
"There is no denying that there is a different relationship between child and mother and child and father, it's just reality and that's fine, but that's not to say fathers can't have a meaningful input and involvement." (Mark)	Relationships within the family system		
"I am carer, provider, dad, entertainer." (Isaac)	How dads define their role		
"His future, and what he's going to do when he's older and when we aren't here anymore is the	Worry about the future (unique role)		

number one thing that would keep me up at night time." (Phil)			

Father quotes	**Codes**	**Subthemes**	**Theme**
"There's one point of contact and it's always the mam and that was challenging. My experience is that this is not sexist, it's habit." (John)	Experience with services (isolation/anonymity) Unconscious bias in services	Secondary Parent Contact Bias	Experiences with services (Mesosystem)
"Dads are treated benignly but for the real stuff, they go to the mother." (Derek)	Experience with services (isolation/anonymity)		
"There's definitely a pecking order and dads are number two. I definitely feel less important." (Isaac)	Unconscious bias in services		
"My wife became the main point of contact because she is a teacher." (Michael)	Experience with services (isolation/anonymity) Unclear involvement pathways		
"My ex-wife would go to all of the service appointments, and	Experience with services (isolation/anonymity)		

only if there was a big issue would I go" (Phil)	Unconscious bias in services		

Psychologist quotes	Codes	Subthemes	Theme
"Involving the dad aids your understanding of the family system which strengthens your formulation and therefore whatever interventions you recommend." (Audrey)	Benefit of father involvement	The Benefits How to Engage Dads	Engaging dads (Mesosystem)
"Often, dads are better at meeting the child where they're at. They haven't really thought about it, over-analysed it. It's just a matter of what she likes. It doesn't impact my value as a person how well I play with this kid and how well this kid plays with me. I can just play with her where she is." (Stella)	Benefit of father involvement		
"It's not that he (the father) doesn't want to be involved, it's that he feels excluded and unwanted in terms of his interaction with	Bias in services Reflection on practice		

services. The way to remedy this situation is an explicit acknowledgement and reaching out with positive discrimination towards dads.” (Michelle)	Positive Discrimination
“Every time I have invited a dad to attend, they have wanted to attend – there has always been a genuine reason if they couldn’t attend. If you ring a family and specify that you want both to attend, the dads generally will come. That is almost challenging yourself to send the invite because the soft option is just to contact mum.” (Emily)	Dad’s receptive to invites Positive Discrimination
“CAMHS would send out their appointment letters, saying, ‘Both parents have to attend this’. In disability services, that’s not something we would do. I think we generally tend to be very accommodating to families but it’s something that we should do, especially at intake and assessment to make	Reflection on practice Benefit of father involvement

both the mum and dad, if available, feel like part of the process.” (Thomas)			

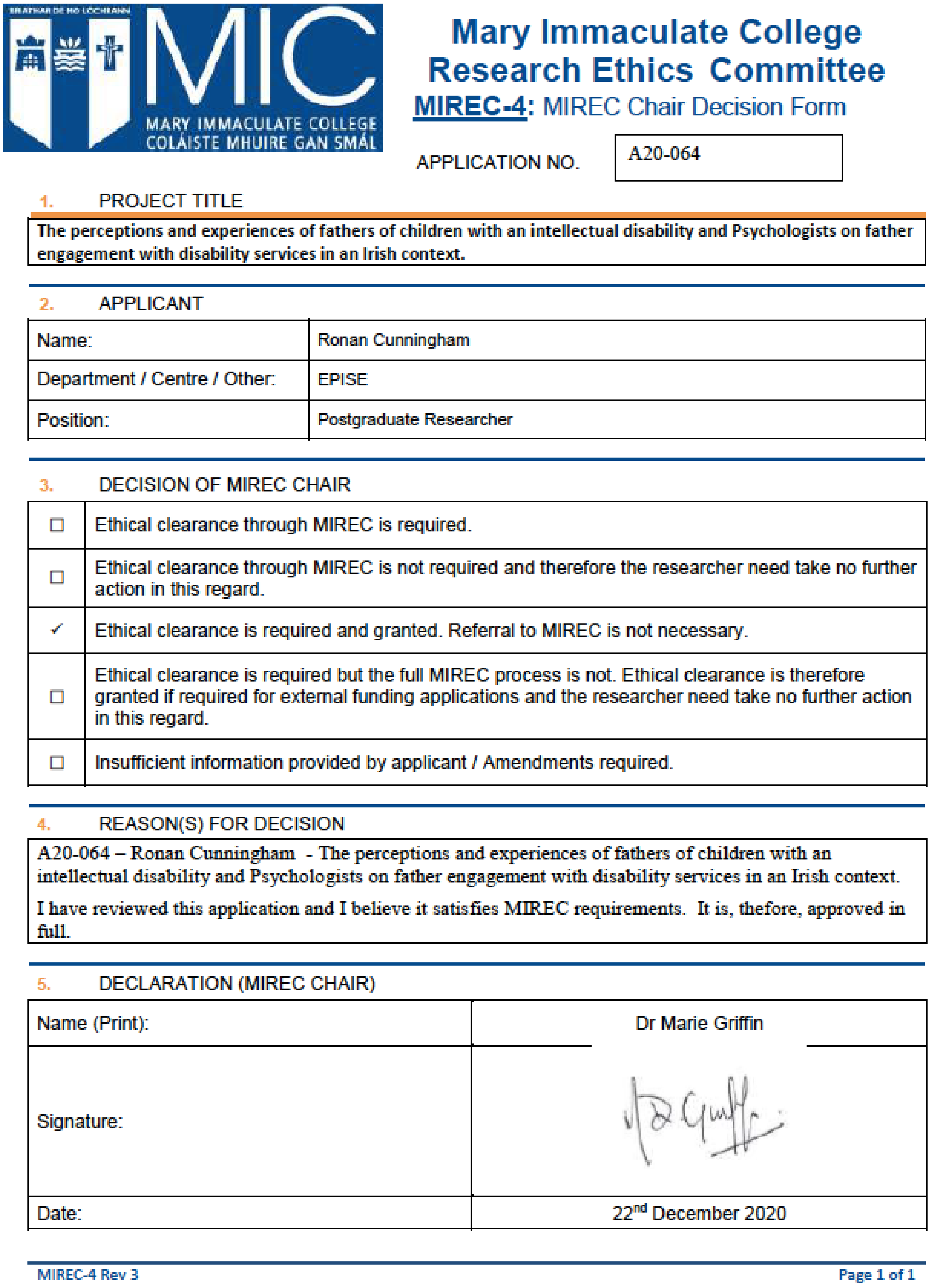
Psychologist quotes	Codes	Subthemes	Theme
“The mums expertise and thoughtfulness grows as she has more exposure to clinicians and their way of thinking and their way of figuring things out. There is a risk that not only are mums expected to go but because they’re going they become more expert.” (Matthew)	Need for support and processing space Coming to terms with a diagnosis	Need for Processing Space	Coming to terms with a diagnosis (Chronosystem)
“It’s just a place where they can come and speak about some of the difficulties they’re encountering and just rage at times, or sympathise with each other about things and that space is important for them. This is a massive therapy piece for dads. It’s like the first step on the grieving process.” (Thomas)	Need for support and processing space Coming to terms with a diagnosis Challenge of ID/ emotional trauma		

"One of our psychologists did post-diagnostic counselling and you got five sessions. That, I feel, would really benefit families if it was normalised. While that isn't there for either parent, there is some processing space for mums to explore the emotional issues around having a child with a disability, but if dads have very little time to explore that with clinicians, then that (processing space) is just not there for them." (Audrey)	Need for support and processing space Coming to terms with a diagnosis Challenge of ID/ emotional trauma

Appendix 17: Risk factors for ID - Adapted from Carr et al. (2016)

Timing	Biomedical	Social	Behavioural	Educational
Prenatal	Chromosomal Disorders Single-gene disorders Syndromes Metabolic disorders Cerebral dysgenesis Maternal illness Parental age	Poverty Maternal malnutrition Domestic violence Lack of access to prenatal care	Parental drug use Parental alcohol use Parental smoking Prenatal immaturity	Parental cognitive disability without supports Lack of preparation for parenthood
Perinatal	Prematurity Birth injury Neonatal disorders	Lack of access to birth care	Parental rejection of caretaking Parental abandonment of child	Lack of medical referral for intervention services at discharge
Postnatal	Traumatic brain injury Malnutrition Meningoencephalitis Seizure disorders Degenerative disorders	Impaired child-caregiver interaction Lack of adequate stimulation Family poverty Chronic illness in the family Institutionalisation	Child abuse and neglect Domestic violence Inadequate safety measures Social deprivation Difficult child behaviours	Impaired parenting Delayed diagnosis Inadequate early intervention services Inadequate special educational services Inadequate family support

Appendix 18: Ethical Approval from MIREC



Mary Immaculate College Research Ethics Committee

MIREC-4: MIREC Chair Decision Form

APPLICATION NO. A20-064

1. PROJECT TITLE

The perceptions and experiences of fathers of children with an intellectual disability and Psychologists on father engagement with disability services in an Irish context.

2. APPLICANT

Name:	Ronan Cunningham
Department / Centre / Other:	EPISE
Position:	Postgraduate Researcher

3. DECISION OF MIREC CHAIR

☐	Ethical clearance through MIREC is required.
☐	Ethical clearance through MIREC is not required and therefore the researcher need take no further action in this regard.
✓	Ethical clearance is required and granted. Referral to MIREC is not necessary.
☐	Ethical clearance is required but the full MIREC process is not. Ethical clearance is therefore granted if required for external funding applications and the researcher need take no further action in this regard.
☐	Insufficient information provided by applicant / Amendments required.

4. REASON(S) FOR DECISION

A20-064 – Ronan Cunningham - The perceptions and experiences of fathers of children with an intellectual disability and Psychologists on father engagement with disability services in an Irish context.

I have reviewed this application and I believe it satisfies MIREC requirements. It is, thefore, approved in full.

5. DECLARATION (MIREC CHAIR)

Name (Print):	Dr Marie Griffin
Signature:	
Date:	22nd December 2020

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Appendix 19: Additional Quotations from Father Interviewees

Microsystem Quotes

Domain	Theme/Subtheme	Participant	Quote
Microsystem	Roles/Parent Role Definitions	Mark	*"The mother is perceived as the primary caregiver and when you see how children interact within the family dynamic, that is reasonable. There is no denying that there is a different relationship between child and mother and child and father, it's just reality and that's fine, but that's not to say fathers can't have a meaningful input and involvement."*
Microsystem	Roles/Parent Role Definitions	Brendan	*"I am definitely not the primary carer. I'm the breadwinner who pays the bills but become very involved come half six or seven. I put our son to bed, feed him, I'm very hands on."* *"My wife qualified as a carer and got benefits for two years so she was at home as his carer. Then other medical things happened and there was no way she could return to work. Her job is, which is terrible to say, our boy's carer."*
Microsystem	Roles/Parent Role Definitions	James	*"I am the provider, yes. For a while it was 50/50, but my wife had to give up work a few years ago and then there was a very clear dividing of roles."*
Microsystem	Roles/Father's Unique Role	John	*"We were pushy and constantly asked 'why not?' I used everything in my power. I even wrote to my local TDs explaining my situation."*

Microsystem	Roles/Father's Unique Role	Ryan	*"You have to push for it. There was a bit of a delay when my son was born and we were under the impression that services would come to us. No. You have to push for everything. They're only proactive when you push them to be."*
Microsystem	Roles/Father's Unique Role	Derek	*"If you hold a glass of water out from your body for a minute, there is no problem. For an hour, it starts to become a problem, do it for three hours or longer and your arm falls off. There is such a lack of support."*
Microsystem	Roles/Father's Unique Role	Phil	*"My biggest worry is what happens when he isn't in school anymore? I know there are services, but what do you do for an adult? His future, and what he's going to do when he's older and when we aren't here anymore is the number one thing that would keep me up at night time."*
Microsystem	Relationships /Family System Relationships	Brendan	*"My other daughter was only two when my son (with an ID) came along and we have only known that since. If we compare my daughter with her peers, she has had to put up with a lot. For me and my wife, it has changed things, there is no comparison. I have no idea what it would be like to be normal parents going out on a Saturday night."*
Microsystem	Relationships /Family System Relationships	John	*"Everyone is very kind with my son and he's the eldest so his brother and sister are younger and make allowances but he needs a lot of extra care and there are little frustrations within the family. It's a primarily positive experience but it's not anything I would wish on anyone. It's a huge effort and impacts the family hugely."*

Microsystem	Relationships /Familial Support	Michael	*"We are lucky that our families are very supportive. We get more from my wife's parents because they live so close. We try not to burden them too much, but it is difficult to manage on our own at times."*
Microsystem	Relationships /Familial Support	Mark	*"Without that support, the level of frustration and burnout is pretty high. In terms of appointments, it always had to be one or other of us who attended because one of us had to mind the other kids. Usually, it was mum who attended because she is the one who is going to be working with our child and implementing techniques and recommendations learned from services."*

Mesosystem Quotes

Domain	**Theme/Subtheme**	**Participant**	**Quote**
Mesosystem	Experiences with services /Secondary Parent	Isaac	*"There's definitely a pecking order and dads are number two. I definitely feel less important."*
Mesosystem	Experiences with services /Secondary Parent	Derek	*"Dads are treated benignly but for the real stuff, they go to the mother."*
Mesosystem	Experiences with services /Contact Bias	Isaac	*"My son's mum is the contact even though both of our contact details are down but it's always mum who is called. I believe we get a circular letter that is addressed to both of us and that is probably the only case of us being equal. I've been called before, when they couldn't get in*

			contact with mum, and I believe in that conversation, they were phoning me looking for mum.”
Mesosystem	Experiences with services /Secondary Parent	Mark	*“You’re not the first point of contact, whether it’s schools or services. I would be second in line for most things. I have managed to change that a little bit by proactively making the call back. You do kind of have to work around it and let them know you are involved and interested.”*
Mesosystem	Experiences with services /Secondary Parent	John	*“There’s one point of contact and it’s always the mam and that was challenging. My experience is that this is not sexist, it’s habit.”*
Mesosystem	Dads want to engage /Extra Effort	Mark	*“Dads are much more involved than they used to be, but definitely in terms of the first point of contact for disability services, unless you make it explicitly known that you’re actively involved and interested, they will always automatically contact the mother.”*
Mesosystem	Dads want to engage /Extra Effort	Brendan	*“I’m not a shouter or a giver outer. I get palmed off the same as others”* (when describing his efforts to engage with services).
Mesosystem	Dads want to engage /Extra Effort	John	*“I definitely think that dads have a lack of engagement. That their job doesn’t include engaging with disability services.”* (on interested fathers suffering due to the attitudes of passive fathers)
Mesosystem	Dads want to engage /Support Groups	Mark	*“There should be positive discrimination, programmes, supports programmes on social media just dedicated to dads to give them the boost to say it’s OK to be a dad of a child with complex needs, it’s OK to be upset and it’s OK to cry and be miserable and feel like your life is over.*

			There needs to be spaces created for dads to process this, and to learn that it's OK."
Mesosystem	Dads want to engage /Support Groups	Isaac	*"The main WhatsApp group we're part of is mostly addressed with 'Hey Ladies!', which made me check to see whether I was the only dad in the group, Out of 45 participants, I think I'm the only male."*
Mesosystem	Dads want to engage /Support Groups	Brendan	*"Men are men. We don't chat about these things, but even if there isn't an organised thing for women, they will meet and talk. It would be nice to meet some men in the same position as me to offload and share things. It would be great if services could offer that."*
Mesosystem	Dads want to engage /Support Groups	Michael	*"Everyone had a different story to tell and it was really beneficial. They put dads together and mums together, people were crying as it was the first time they had spoken about it in public. That was really good, a 'clear the head' session which put me in the right frame of mind going forward."*
Mesosystem	Dads want to engage /Support Groups	James	*"It was specifically for dads. They tended to be less coffee and chat, more practical. A first aid course, then a coffee and chat afterwards, about the first aid course. Financial supports for disabilities. Very practical. It was brilliant. I found the men who had older children were very supportive of those who had just had a diagnosis or come into the system."*

Exosystem Quotes

Domain	**Theme/Subtheme**	**Participant**	**Quote**
Exosystem	Practical Barriers/ Work commitments, appointment times	Phil	*“I attended meetings only when I could because I was the one working at the time and, therefore, I couldn’t always be there for these appointments. But I attended when I could while my wife attended all of them.”*
Exosystem	Practical Barriers/ Work commitments, appointment times	James	*“The HSE and other services work 9-5 so you don’t have a choice. You don’t get therapy appointments on a Saturday or Sunday, it’s all 9-5 based….If anything was available out of hours that’d be great but we could sort every medical waiting list in Ireland if people worked shifts.”*
Exosystem	Practical Barriers/ Work commitments, appointment times	Isaac	*“Her schedule is very rigid and she would have a lot more meetings etc. In that regard, it would make sense for me to go to appointments because I can work evenings or weekends, if necessary.”*
Exosystem	Practical Barriers/ Work commitments, appointment times	Michael	*“My wife became the main point of contact because she is a teacher and works more flexible hours.”*

Macrosystem Quotes

Domain	Theme/Subtheme	Participant	Quote
Macrosystem	Service Culture/ Expectations of the father	Phil	*"My ex-partner would go to them all and only if there was a really big issue would I go."*
Macrosystem	Service Culture/ Expectations of the father	Derek	*"I would be a mine of misinformation in comparison to her."*
Macrosystem	Service Culture/ Expectations of the father	James	*"Some dads are very involved – it spans from 0 to 100%.. It's very wide and they all seem to differ but it's unusual they'd be overly involved, as they tend to have big gaps in their understanding and knowledge of what's going on."*
Macrosystem	Service Culture/ Expectations of the father	Mark	*"I would be second in line for most things. I have managed to change that a little bit by proactively making the call back, but you do kind of have to work around it and let them know that you are involved and you are interested."*
Macrosystem	Policy and Planning/ Gender-related policy	Isaac	*"As the partner who doesn't breastfeed, it makes sense for the mother to be on leave. However, this means that things might tend to fall to her to look after services or to have more time – to theoretically have more time – to chase up services….I've often been intrigued by the Scandinavian model, where each parent get the same amount of time off to spend with kids."*
Macrosystem	Policy and Planning/ Gender-related policy	Michael	*"The gender pay gap is a big thing. Women earn less than men which is ridiculous but it is still there. That will change and they will have to bring in legislation to say that can't happen anymore."*

Macrosystem	Policy and Planning/ Gender-related policy	Mark	*“The nature of my wife’s role means that she’s progressing through the managerial levels in the pharmaceutical industry. I decided to hold off and stay where I was because the hours and days are flexible. It means that I am often more of a carer during the week than my wife. I still do my 30-hour per week job but decided not pursue further promotions or opportunities.”*
Macrosystem	Policy and Planning/PDS & FCP	James	*“I’ve heard that (FCP) mentioned in PDS and we’re one of the last to the table in PDS and we haven’t noticed anything family or parent centric. I don’t believe the parents get any support for themselves – it is all centred around the kid.”*
Macrosystem	Policy and Planning/PDS & FCP	Brendan	*“We are hoping this new thing, Progressing Disability Services, will bring a positive influence to services. We’re not fully convinced but we’ve had a meeting with our key worker and I suppose yeah, we will start the fight now with that person.”*
Macrosystem	Policy and Planning/PDS & FCP	Derek	*“There is nothing so unequal as the equal treatment of unequals.”*
Macrosystem	Policy and Planning/PDS & FCP	Mark	*“The model of service delivery will be this kind of transformational shift from professionalised intervention therapies to the family-centred approach. Reading between the lines on that one, the families and the parents become the therapists. Families are so over-burdened, there’s just no hope.”*

Macrosystem	Policy and Planning/ A Broken System	Derek	*“On the one hand within this dysfunctional system, you have some great people, angels if you like. But they are caught up in a system that is not working.”*
Macrosystem	Policy and Planning/ A Broken System	Brendan	*“No one has a problem with the individuals; it’s the ‘big brother’ thing. It’s always ‘we don’t have resources’, well why don’t you have resources?”*

Chronosystem Quotes

Domain	**Theme/Subtheme**	**Participant**	**Quote**
Chronosystem	Changes Over Time/ Cycle of Understanding and Engagement	Ryan	*“I suppose this is the first time I have ever spoken about it. I’m holding back a bit of emotion now, you know. Obviously there’s people to talk to. Maybe down the road I will talk to someone about it. His birth happened so quick, the diagnosis and everything. A lot went on.”*
Chronosystem	Changes Over Time/ Cycle of Understanding and Engagement	Michael	*“The initial shock was very upsetting. I didn’t know what was ahead., I phoned my brother in the UK and we talked it through and it was great. I remember that night driving home from the hospital saying that my life has changed.”*
Chronosystem	Changes Over Time/ Cycle of Understanding and Engagement	Isaac	*“I would say that they might be very beneficial. It’s a struggle to get your mind around in the early days.”*

Chronosystem	Changes Over Time/ Cycle of Understanding and Engagement	James	*"From what I have seen, most dads bury their head for the first couple of years and try to ignore what is happening and either work or do something else as it's usually the mum who is the full time care giver….The dad works and leaves them to it and doesn't get overly involved. Then, as they get more used to the situation and a routine forms, they might start to get more involved."*
Chronosystem	Changes Over Time/ Evolving Role of Fathers	Derek	*"In my lifetime, there was a cultural change because both parents are working now. It is no longer a farmer in the field and the mother in the kitchen."*
Chronosystem	Changes Over Time/ Evolving Role of Fathers	Mark	*"We (fathers) just need opportunities for us to become involved. The HSE could do a lot more to encourage this, like positive discrimination methods to include dads and make sure they're involved. That would only be a short-term thing because that becomes self-fulfilling. When one generation of dads improves their interactions with services, the kids following them will learn from that."*

Appendix 20: Additional Quotations from Psychologist Interviewees

Microsystem Quotes

Domain	Theme/Subtheme	Participant	Quote
Microsystem	Family Roles/Parent Roles and ID/DD	Ruth	*"I can see in some families it (having a child with an ID) would have polarised their roles"*
Microsystem	Family Roles/Parent Roles and ID/DD	Audrey	*"There can be really traditional roles (in these families) and I can only think of one dad who has given up his job to care for his child with an intellectual disability whereas there would be lots of mums who have done this."*
Microsystem	Family Roles/Parent Roles and ID/DD	Stella	*"I think it's about identity, core beliefs, my value as a person will be impacted by my success as a mother. The dad's value as a person will be impacted by their success in their job. There's a reason that the mothers will be more anxious about behaviours. Really frustratingly and contradictingly, dad being more relaxed about it probably means he's dealing with everything much better and, actually, his input is what's needed."*
Microsystem	Family Roles/Parent Roles and ID/DD	Michelle	*"A lot of the children we're working with have had difficult early starts – long-term hospitalisations as infants. I definitely think this impacts the attachment style that develops later on and I see some mothers that I work with trying ultra-hard to repair that time that they felt they didn't have with the child early on. I wonder is there more pressure on mothers to feel that they've made up for that difficult start."*

Microsystem	Family Roles/Perpetuating Roles	Audrey	*“Mom’s job is the child and they take sole responsibility for that and again, I don’t know how much we feed into that narrative as a service by contacting moms first and not making a concerted effort to phone dads or making the arrangement for home visits when dads are there.”* *“Moms construct the role of the dads in the lives of those with disability…some would almost dismiss the dad. On a home visit I attended, dad came into the room and was almost shoo-d out of the room. No, don’t phone him, phone me. The mom needs to be the main person in this. We don’t explore this enough, whether it is a co-dependent relationship or whether mom feels they have to take responsibility and be the sole carer and pushes the father out.”*
Microsystem	Family Roles/Perpetuating Roles	Ruth	*“The way it is set up in Ireland with the domiciliary care allowance, it nearly lends itself to that arrangement (of mother being the carer). So, you nearly have to work especially hard not to fall into those patterns.”*
Microsystem	Family Roles/Perpetuating Roles	Matthew	*“Family breakdown is a big thing in disability and the stress and strains of disability. Then you end up with single parent families. I’ve only ever had one single parent family that was the dad. All the rest are single parent families that are the mum.”*
Microsystem	Family Roles/Perpetuating Roles	Emily	*“When parents are separated, it is almost exclusively dealing with the mother and separated dads can feel almost totally alienated.”*

Mesosystem Quotes

Domain	Theme/Subtheme	Participant	Quote
Mesosystem	Culture of Working/Bias Toward Mum	Michelle	*"Even if dad's number is there and I can't get mam, I will keep trying her for a few days. And even if mam doesn't answer, I will keep trying to get to speak to mam before ringing dad."*
Mesosystem	Culture of Working/Bias Toward Mum	Thomas	*"Clinicians, therapists and myself would automatically pick up the file and ring the mum. That was just the way it was. It was maybe one or two families where you would know dad was the point of contact for various reasons, but the vast majority of cases, it was just an automatic thing to ring mum."*
Mesosystem	Culture of Working/Bias Toward Mum	Stella	*"There's an acknowledgement that we need to do more about this, but just efficiency and busyness, that attitude of just get it done is there. That communication channel (with mum) is just easier."*
Mesosystem	Culture of Working/Need for Reflective Practice	Emily	*"Sometimes the assumption is that dad wouldn't know and mum is best informed. I'm guilty of this and have to challenge myself. Social workers are particularly good at this and, while we are psychologists, we have to be reminded despite knowing all the theory and how things work, we have to avoid falling into the pitfall of doing all the parent work through mum."*
Mesosystem	Engaging Dads/ The Benefits	Audrey	*"Involving the dad aids your understanding of the family system which strengthens your formulation and therefore whatever interventions you recommend, the outcomes will*

			be better. The other thing I notice with dads is they may have a different perspective and this enriches the whole process."
Mesosystem	Engaging Dads/ The Benefits	Stella	*"Often, dads are better at meeting the child where they're at. They haven't really thought about it, over-analysed it. It's just a matter of what she likes. It doesn't impact my value as a person how well I play with this kid and how well this kid plays with me. I can just play with her where she is."*
Mesosystem	Engaging Dads/ The Benefits	Thomas	*"We know from the whole psychosocial model of the importance of the whole family unit, so I really dislike doing an assessment if the dad isn't involved, feeding back to mum who then has to feed back to dad. We're putting huge pressure on mums to be that communicator and carry everything for the children in two-parent families."*
Mesosystem	Engaging Dads/ How to Engage Dads	Ruth	*"We're not exactly helping matters; maybe the engagement isn't there to begin with but maybe we could be doing a bit more to bring it along."*
Mesosystem	Engaging Dads/ How to Engage Dads	Michelle	*"It's not that he (the father) doesn't want to be involved, it's that he feels excluded and unwanted in terms of his interaction with services. The way to remedy this situation is an explicit acknowledgement and reaching out with positive discrimination towards dads."*
Mesosystem	Engaging Dads/ How to Engage Dads	Emily	*"Every time I have invited a dad to attend, they have wanted to attend – there has always been a genuine reason if they couldn't attend. If you ring a family and specify that you want both to attend, the dads generally will come. That*

			is almost challenging yourself to send the invite because the soft option is just to contact mum."
Mesosystem	Engaging Dads/ How to Engage Dads	Thomas	*"CAMHS would send out their appointment letters, saying, 'Both parents have to attend this'. In disability services, that's not something we would do. I think we generally tend to be very accommodating to families but it's something that we should do, especially at intake and assessment to make both the mum and dad, if available, feel like part of the process."* *"We need to be harsh saying your appointment will happen when both of you can come to it. Not accepting anything else unless there was a hugely valuable excuse. So from the moment of intake that's needed to get das involved."*
Mesosystem	Engaging Dads/ How to Engage Dads	Matthew	*"We can't call on mum all the time, Would it be possible for you to attend every fourth session so that we're ensuring that everyone's ideas are being heard, valued and shared?"*

Exosystem Quotes

Domain	**Theme/Subtheme**	**Participant**	**Quote**

Exosystem	Practical Barriers/ Work Commitments, Appointment Times	Sarah	*"Our services operate Monday-Friday 9-5pm which makes it harder for them to engage if they are working."*
Exosystem	Practical Barriers/ Work Commitments, Appointment Times	Michelle	*"Some dads go to great lengths to let you know their schedule in advance so we can arrange the meeting to suit. But that (working hours) is definitely a barrier. But even with mums that are working, we don't run into that as much. I don't know if they have more flexibility or they feel more able to say in work that they have an appointment concerning a child."*
Exosystem	Practical Barriers/ Work Commitments, Appointment Times	Matthew	*"It's probably a convenience for some dads to stay in work instead of being at these appointments. By attending they are confronted by their child's disability and this may be unbearable. The question isn't often asked 'why isn't dad attending?' Is it because of the time, his work is so busy, is it because of some other psychological factor that he unconsciously cannot bear the pain of thinking about the child's disability or the blame for why they're disabled."*

Macrosystem Quotes

Domain	**Theme/Subtheme**	**Participant**	**Quote**
Macrosystem	Societal Beliefs/ Expectations of Mothers vs. Fathers	Ruth	*"When you boil it down to traditional roles within the family, we are only a couple of decades beyond a time when women weren't allowed to work after marriage. That's within our parents' lifetimes and, if they raised us, we're obviously going to be slightly biased and you'd like*

			to think that the next generation will be slightly less biased."
Macrosystem	Societal Beliefs/ Expectations of Mothers vs. Fathers	Matthew	*"My view was that services at their core are deeply patriarchal. We take the woman and tell her what to do. We place a lot of emphasis on gender-based social constructs on what mums should do, they should always be available. They should sacrifice themselves, their careers, their lives, everything. I don't think the same demands are made for dads. Maybe the more modern construction of a father is different, but the traditional one that we are more likely to draw on is that dad is the worker, the breadwinner, rather than the carer."*
Macrosystem	Impact of Policy/ Maternity Leave	Michelle	*"I think there are lots of social forces against dads. Even thinking about maternity leave against paternity leave, mums being available for consultation against the dads. It goes beyond disability services but they are parts of the structure that doesn't facilitate father engagement and doesn't promote it in a real way."*
Macrosystem	Impact of Policy/ Maternity Leave	Stella	*"If you're getting people in early intervention, you know mam's on maternity leave and it sets up the channels of communication. It sets up that she's the person who does the visits and I think that they can become the expert on clinic visits. It's nearly hard to bring dad in then."*
Macrosystem	Impact of Policy/The Challenge of FCP	Emily	*"I think the service is on board with the theory of it (FCP) but the operation hasn't followed through yet and I hope it will. We need to make small changes like involving dads and make sure we aren't overburdening families. The*

			service has a lot further to go. That's the broader health service and not just this service."
Macrosystem	Impact of Policy/The Challenge of FCP	Audrey	*"I think we aspire to FCP but I don't know if we check in to see with families because what we think is individualised FCP might not be what meets the needs of that family."*
Macrosystem	Impact of Policy/The Challenge of FCP	Ruth	*"I was on placement in a service that had reconfigured 10 years ago as part of a pilot project and the difference in service efficiency in implementing FCP was huge. This current service is so far away from even working together cohesively that the consideration (of implementing FCP) is not even on the radar."*

Chronosystem Quotes

Domain	**Theme/Subtheme**	**Participant**	**Quote**
Chronosystem	Coming to Terms with a Diagnosis/ Need for Processing Space	Matthew	*"The mums expertise and thoughtfulness grows as she has more exposure to clinicians and their way of thinking and their way of figuring things out. There is a risk that not only are mums expected to go but because they're going they become more expert."*
Chronosystem	Coming to Terms with a Diagnosis/ Need for Processing Space	Thomas	*"It's just a place where they can come and speak about some of the difficulties they're encountering and just rage at times, or sympathise with each other about things and that space is important for them. This is a massive therapy piece for dads. It's like the first step on the grieving process."*

Chronosystem	Coming to Terms with a Diagnosis/ Need for Processing Space	Audrey	*"One of our psychologists did post-*diagnostic counselling *and you got five sessions. That, I feel, would really benefit families if it was normalised. While that isn't there for either parent, there is some processing space for mums to explore the emotional issues around having a child with a disability, but if dads have very little time to explore that with clinicians, then that (processing space) is just not there for them."*
Chronosystem	Coming to Terms with a Diagnosis/ Evolving Role of the Father	Stella	*"There's unarguably much more involvement and expectation that dad's will be involved with their kids, have a relationship with their kids and be involved in the caregiving. It hasn't changed enough, it's nowhere near equal. I think that paid paternity leave is the only solution."*
Chronosystem	Coming to Terms with a Diagnosis/ Evolving Role of the Father	Emily	*"This research has shown me that the role of the father is not as progressive as we would like to think it is."*