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Confident championing: A grounded theory of parental adjustment following a child's diagnosis of developmental disability

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Accessible summary

- This paper is about how parents adjust to parenting their child who has a developmental disability.
- We spoke to parents about their experiences and developed a theory to help explain how parents adjust when their child has a developmental challenge.
- As well as describing the stress, that parents experience, this theory also captures the fulfilment and sense of purpose that parents experience as they parent their child.
- This research is important because it helps explain what happens for parents after their child's diagnosis and provides suggestions on how services can improve to help families.

Abstract: This paper describes a study exploring the parental response to the diagnosis of their child's developmental disability. A classic grounded theory methodology was used to analyse data comprising 19 interviews and 11 memoirs written by parents. The theory explains how parents adjust to champion their child, who has been identified as having a developmental challenge. At the heart of becoming a champion is a psychological process in which parents refine their perspectives on disability awareness, their aspirations and parenting capacity as they develop their championing skills. Refining perspectives and championing are influenced by two factors: the nature of the child's challenges and service factors. The theory of Confident Championing offers a multivariant model that explains the dynamic nature of the adjustment process, capturing both the stress and the fulfilment and sense of purpose that parents experience.

KEYWORDS
developmental disability, early intervention, family-centred practice, grounded theory, neurodevelopmental disorder, parental adjustment

1 | INTRODUCTION

One of the most challenging situations facing any parent is learning that their child has a developmental disability. This study describes the development of a grounded theory, which explains how, following such a diagnosis, parents adjust their perspectives to become champions for their children.

Research has identified several factors which affect parental well-being and adjustment following their child's diagnosis. Research has established the importance of social supports (Hall et al., 2012;

Heiman, 2002; Peer & Hillman, 2014) and adaptive coping strategies (Glenn et al., 2009; Woodman & Hauser-Cram, 2013). Coping strategies refer to efforts aimed at managing stress. Two types of coping strategies have been identified. Problem-focused coping refers to efforts to alter the source of stress, and emotional focused coping refers to efforts to manage one's emotional response to stress (Judge, 1998). The importance of developing an understanding of the condition has also been highlighted (Heiman, 2002), while Kuhaneck et al. (2010) demonstrated that, armed with this knowledge, parents can begin to contest societal restraints imposed due to labels of disability.

While somewhat inconclusive research indicates that, in some situations at least, child factors can determine levels of parental stress, these factors include the child's developmental progress (Glenn et al., 2009; Pillay et al., 2012), medical status (Pillay et al., 2012), care needs (Glenn et al., 2009; Pillay et al., 2012; Woodman & Hauser-Cram, 2013) and presence of behavioural problems (Pozo et al., 2014; Seymour et al., 2013; Woodman & Hauser-Cram, 2013). Factors that mediate their effects have been found to be coping strategies (Blucker et al., 2011), parental fatigue (Seymour et al., 2013), psychological acceptance (MacDonald et al., 2010) and positive outlook (Vermaes et al., 2008).

Several theoretical models have been proposed to explain the adjustment process. A bereavement model such as the dual process model which theorises two processes in the bereavement experience, a loss orientated and a restoration orientated process, has been proposed (Sheehan & Guerin, 2018). Post Traumatic Growth Theory proposes that following a major life crisis, there is potential for growth. Strecker, Hazelwood and Shakespeare-Finch (2014) found high levels of post-traumatic growth and distress and suggest that services, while addressing parental distress, should also be mindful of the potential for parents to experience positive growth following their child's diagnosis. The Resiliency Model of Family Stress and Adjustment is a conceptual framework which offers an explanation as to how families adjust to adversity (McCubbin & McCubbin, 1996). Hall et al. (2012) successfully used this model to conceptualise the lived experiences of parenting a child with developmental disability.

Research has demonstrated a relationship between effective service and parental adjustment (Bruder, 2000; Carpenter & Campbell, 2008; Dunst & Bruder, 2002; Guralnick, 2016; Guralnick & Bruder, 2016). Services are moving from an expert professional led practice model to a family-centred practice model (Dunst, 2002), which recognises the central role that families play in influencing their child's outcomes. The strength-based focus adopted in a family-centred practice model assumes that interventions should focus on building on strengths, rather than focusing on children's deficits, to achieve better outcomes as evidenced by Raab, Dunst and Hamby (2016). Research indicates that services which adopt a family-centred practice approach achieve better outcomes for families including parental adjustment (Bruder, 2010; García-Grau, et al., 2019; Trivette et al., 2010; Raab, Dunst, and Hamby, 2016).

This research sought to explore the parental experience following the identification of their child's developmental disability. Within a classic grounded theory approach, the researcher does not develop a prior set of research questions, rather the researcher seeks to approach the research area with a broader question that facilitates the participants to speak about their experiences. Therefore, the aim of the research was to generate a grounded theory which explains the behaviour and experiences of parents following their child's diagnosis.

1.1 | Terminology

In describing this research, the term that will be used to describe a child's condition is developmental challenge. The rationale for using this term is twofold: in interviews, parents rarely used the word "disability" and this research highlights the negative impact of deficit-based language on parental well-being. The term developmental challenge was adopted, to describe individual children's conditions, as while it acknowledges the presence of a difficulty, it is not described as a deficit. While developmental challenge refers to individual children's conditions, it does not replace the broader term disability.

2 | METHOD

2.1 | Approach

The research methodology employed in this project was that of classic grounded theory (CGT). Glaser (1998) described how "Grounded Theory is the systematic generation of theory from data acquired by a rigorous research method" (p.3). Holton and Walsh (2017) explain that grounded theory results are presented as a theory which accounts for the relationships between the concepts developed from data. In exploring which grounded theory methodology to apply in this research, a review of grounded theory methodologies was undertaken which is described elsewhere (O'Connor, Carpenter, & Coughlan, 2018). Figure 1 provides an overview of classic grounded theory methodology.

2.2 | Data collection

Prior to data collection, ethical approval was granted to this project by the Research Ethics Committee of the Mid-Western Health Services Executive based in University Hospital Limerick, Ireland, Reference 055/16 and from the University of Limerick's ethics committee. Two types of data were collected in this study. The first consisted of field notes developed from interviews with participants, and the second comprised field notes developed from published memoirs.

2.3 | Participants

A total of 15 family members were recruited: 14 mothers and 1 father representing 21 children accessing 4 early intervention services

FIGURE 1 Overview of the classic grounded theory research process
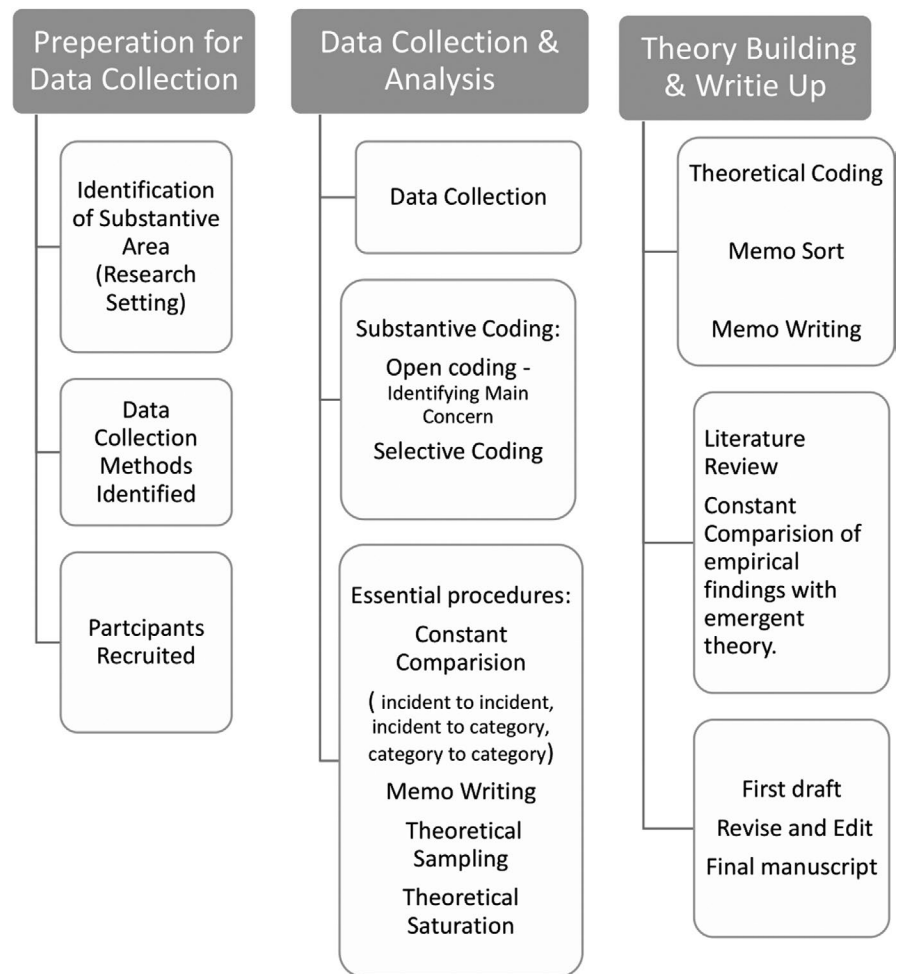
in the West of Ireland. Five of these parents had more than one child accessing early intervention services: 4 had two children and 1 had 3. Inclusion criteria included that participants were fluent in English, and their child was a client of an early intervention service.

Nineteen interviews were conducted, 11 parents were interviewed once, and 4 were interviewed twice. In a grounded theory study, it is not unusual and is often helpful to re-interview participants as part of the theoretical sampling process. Such interviews can add depth to emerging conceptual ideas as they help in probing around these emergent concepts (Holton & Walsh, 2017, p.67).

The children in this study were aged 2.5–5 years of age, and the families had been clients of EI services for between 6 months and 3 years. These children's challenges included autistic spectrum disorder (12 children), developmental delay (6 children), complex medical conditions (4 children), intellectual disability (2 children), cerebral palsy (2 children), Down syndrome (1 child) and unspecified developmental delay (4 children). Field notes were developed from each audiotaped interview.

2.4 | Secondary data

Secondary data was a set of field notes developed from 11 published memoirs written by 6 mothers and 5 fathers describing their early

experiences of parenting a child who had a developmental challenge. The inclusion criteria for these published works stipulated that they were published in the last 10 years were available in English and electronically as Kindle editions.

Table 1 provides additional information on these memoirs.[1]

2.5 | Procedure

2.5.1 | Interviews

In keeping with classic grounded theory conventions, initial interviews were open-ended, a "grand tour" question which was open enough to offer participants the space to share experiences was asked: "Can you tell me about your experiences after (child) was referred to early intervention?". This proved to be an excellent question as it resulted in "spill," a situation where the question acts as a "trigger that starts the person talking naturally and exhaustively about what concerns or interests him or her" (Holton & Walsh, 2017, p.68).

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[1]When quoting from interviews, the convention of P1, P2 etc. will be employed to indicate Participant 1, 2 etc. When quoting from memoirs, they will be referenced as per APA guidelines with an indication that this is a quotation from a parent author.

TABLE 1 Published memoirs: an overview

Author and Title	Description
Askins, S. (2015) Laugh Or You'll Cry: My Life As A Mum With MS And A Son With Autism	A mother's account of parenting a child with an ASD
Bell, K. (2010) He's Still the Same, Just Different	A mother's account of parenting a child with an ASD
B's Dad (2013). Life With An Autistic Son	A father's account of parenting a child with an ASD
Chang-Lim, E. (2017) A Mother's Heart: Memoir Of A Special Needs Parent	A mother's account of parenting a child with an ASD
Daugherty, P. (2015) Uncomplicated Life, An: A Father's Memoir Of His Exceptional Daughter	A father's account of parenting a child who has Down syndrome
Hammond, V. (2015). Whenever I Fall	A mother's account of parenting a child with complex medical and developmental challenges
Inglis, L. & Shepard, D. (2012) Happiness In His Eyes - A Story Of Love And Challenge	A mother's account of parenting a child with an ASD, developmental delay, challenging behaviours and who developed epilepsy
Melville-Ross, J. (2016). Two For Joy: The True Story Of One Family's Journey To Happiness with Severely Disabled Twins	A father's account of parenting twins who have CP and complex medical and developmental needs
Stevens C. and Stevens N. (2011) A Real Boy: How Autism Shattered Our Lives And Made A Family From The Pieces	A father's account of parenting a child with an ASD and general developmental delay
Williams, J. (2016) My Son's Not Rainman: One Man, One Autistic Boy, A Million Adventures	A father's account of parenting a child with a diagnosis of ASD and subsequent diagnosis of CP
Wright, R. (2015) The skies I'm Under	A mother's account of parenting a child with complex medical and developmental needs

2.5.2 | Memos

Memos fulfilled numerous functions in this study. Memos were used to reflect on what was emerging in the data and the interpretation of it by the researcher and helped develop each category outlining its properties and dimensions. Memos negated the need to commit ideas, evolving perspectives and concepts to memory as ideas were stored safely until needed. Memos were also used more conceptually to reflect on categories and how they related to each other. They were also useful as a system of "thinking out" problems. For instance, they acted to support the researcher as she struggled at times with the emotional effect of witnessing parental distress. The value of extensive memoing was realised during the theoretical sorting stage, which relies on the quality and quantity of memos.

2.5.3 | Data analysis

Data analysis consisted of two stages: substantive and theoretical coding. Substantive coding describes the first of two phases of coding: open and selective coding. Open coding commenced as soon as data were collected, and the data are fractured into codes which begin the process of identifying patterns in the data. Using the constant comparison procedure, all codes are compared to consolidate and amalgamate them into categories with conceptually broader titles. For instance, all indicators in field notes related to the code of "learning how to work with the child" were collated and compared with each other to develop the properties of this code, emerging as a category titled "upskilling." This category was then compared with

the category of "disability awareness" to consider overlaps and differences, and eventually, the category of "upskilling" became a subcategory of the broader category, "disability awareness." During open coding, the main concern of participants and how they resolve this concern (core category) are also identified. In this research, it was clear that parents were concerned with doing their best for their child by becoming their champion and the category of refining perspectives emerged as the way in which parents resolve this core concern.

Following open coding, selective coding is undertaken to fully develop each of the emerging categories related to the main concern (becoming their child's champion) and core category (refining perspectives). In this phase, theoretical sampling is used to identify the gaps in categories and develop interview questions for subsequent interviews. This enables the emerging categories to be fully described. For instance, gaps in the category "developing awareness" were identified in the analysis. To further develop this category, additional interview questions were included in subsequent interviews and asked as appropriate. An example of a question that was developed to support theoretical sampling for this category was "Has your view of disability changed – how and why?"

Field notes from the published memories were analysed concurrently with the field notes from interviews, both of which providing a rich source of data for analysis. As categories emerged the field notes were continually analysed to support the development of these emerging categories.

Theoretical saturation describes the situation whereby each category is fully described. Once theoretical saturation is achieved, data analysis can move on to the final phase, which is theoretical coding. During theoretical coding, the focus is on integrating categories into a theory and integrating that theory within the broader

literature. In this phase, the researcher explores and clarifies the relationships between the emergent categories, thereby building a theory to explain the patterns identified in the data. This is achieved through sorting the memo bank. After several theoretical sorts, the theory of "Confident Championing" emerged which provides a parsimonious explanation of the complex and fluid relationships between categories, which explains the parental adjustment process.

Once the theoretical sort was nearing, completion attention turned to integrating the emergent theory within the existing empirical and theoretical literature. This established the unique contribution of this research to the area, provided insights to explain existing inconsistency in research finding, suggested practice and policy implications and identified new avenues for research.

3 | RESULTS

3.1 | Theory of confident championing

The result of data analysis is the Theory of Confident Championing which described how parents adjust to become champions for their child with developmental challenge. At the heart of becoming a champion is a psychological process, refining perspectives. This process explains how parents refine perspectives in three areas: disability awareness, aspirations and their parenting capacity. Through this process, parents adjust to and evolve in their championing role. The refining perspectives process and championing are influenced by two factors: the nature of the child's challenge and service characteristics. Figure 2 provides an overview of the theory.

3.2 | Refining perspectives

This process is at the heart of the adjustment that occurs for parents, supporting them as they become champions for their child. At each stage, parents refine their perspectives on disability, aspirations and parenting capacity. There are three stages in the process: clarifying, customising and integrating. Table 2 outlines the three stages of this process.

3.2.1 | Disability awareness

During the clarifying stage, parents begin the process of developing an understanding of their child's developmental challenge with a focus on its implications, for their future. Williams (2016) described how "even the very notion of disability was still new to me and I suppose it terrified the life out of me" (L.1878).[2] There are many questions at this stage, and its duration will vary dependent on how

quickly information is available and processed. Moving on to the customising stage, parents focus shifts from identifying the developmental challenge to developing an awareness of their child's unique experience of the world. As they see the world from their child's perspective, they come to appreciate the particular challenges their child faces. Finally, during the integrating stage, parents acknowledge the presence of the developmental challenge and focus on moving forward. One mother explained, "once you get your head ready for this and get going with work you will be fine." (P 12). Parents' more nuanced perspective of disability can lead to a recognition that many of the child's challenges as due to societal restrictions rather the developmental challenge itself.

3.2.2 | Aspirations

Refining perspectives on their aspirations for their future begins by parents identifying the threats to their existing dreams and hopes. One father explains that "As we tore up the road map of our lives and set out on a less certain pathway, I found my priorities, beliefs and aspirations start to change" (B's Dad, 2013, L. 4,431). Once threats to aspirations have been identified, existing aspirations are adapted, and new ones developed. These act as guides, facilitating a changing focus from what the child cannot do to what they may achieve, resulting in a greater sense of purpose and hope. Finally, parents reconcile their old with their new aspirations, for themselves and their family. One mother describes how her son's: "future would quite possibly be different from what we had imagined for him, there was no reason to believe that it wouldn't be loving and fulfilling and happy" (Chang-Lim, 2017, L. 140). These reconciled aspirations support well-being as they facilitate a clear focus and sense of purpose.

3.2.3 | Parenting capacity

Initially, the process of building parenting capacity is achieved by persevering through the emotional turmoil following the diagnosis and in identifying what is needed to successfully parent this child. As they become more skilled, parents understanding of the importance of their role is further supported by the development of protective strategies. These enable parents to deal with everyday triggers that cause emotional distress. Refined perspectives on disability and aspirations support parent's evolving confidence in their own ability to champion their child. As one father elaborated, "there was a realization that I had far more control on the outcome of all this than I'd thought up to that point." (Williams, 2016, L. 2344). This refined perspective on their capacity enables parents to become confident in their role as champions for their child.

The process of refining perspectives progresses over time. As parents refine perspectives in one area, it influences their perspective on others; for instance as parents learn more about their child's developmental challenge, this will influence how they begin to create

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[2]At times locations rather than page numbers are listed when accessing material electronically on Kindle devices. When this is the case, locations (L.) will be used when quoting from memories accessed electronically on a Kindle device. At others times, page numbers are available, when available page numbers will be used.
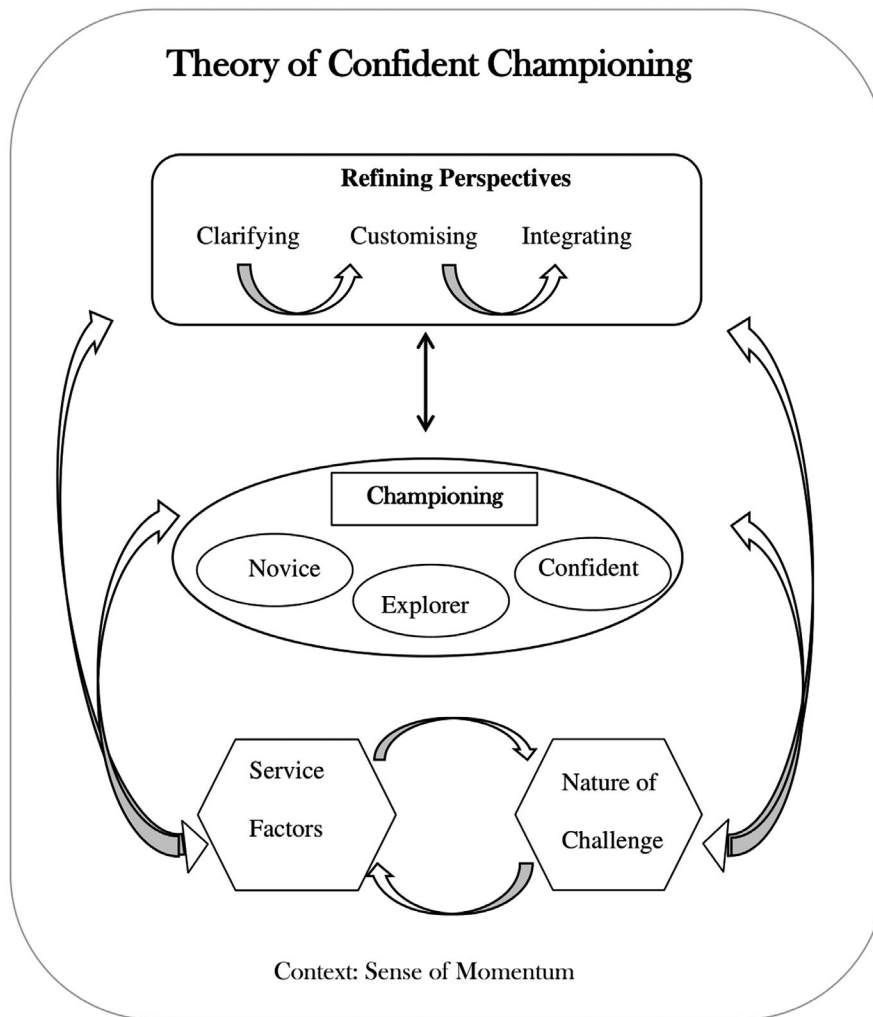
TABLE 2 Refining perspectives process

	Disability awareness	**Aspirations**	**Parenting capacity**
Stage 1: Clarifying	Clarifying nature of challenge	Deconstructing aspirations	Understanding parenting role
Stage 2: Customising	Taking Child's perspective	Constructing aspirations	Building parenting capacity
Stage 3: Integrating	Meaning of disability	Reconciling aspirations	Acknowledging parenting role

new aspirations for their child and family. While the typical progression is forward moving, this process is a fluid one which may not be always be linear. Parents can move back to previous stages and may become "stuck" in the process. Time spend in the different stages varied. Parents' unique journey though these stages are explained by the interactions between the refining perspectives process, service characteristics, challenge factors and the behavioural response of championing.

3.3 | Championing

Progressing in tandem with the psychological process of refining perspectives is a behavioural response of championing. Three types of champion were identified: Novice, Explorer and Confident Champions. Champions are working on the two broad tasks of creating pathways and sustaining their well-being. Table 3 provides an overview of how champions manage their tasks.

3.3.1 | Creating pathways

For typically developing children, there are familiar pathways in terms of what to expect as children develop but these pathways are more complex and less clear for children who have a developmental challenge. Being able to create an image of a potential pathway reduces uncertainty, provides focus for championing and supports parental well-being.

TABLE 3 The champions and their tasks

Task: Creating pathways		
Novice champion	Explorer champion	Confident champion
Accessing services	Navigating services	Active collaboration
Developing advocating	Informed advocating	Advocating
Accessing information	Upskilling	Accessing skills
Task: Sustaining wellbeing		
Novice champion	Explorer champion	Confident champion
Accessing relationships	Extending relationships	Accessing networks
Persevering	Developing resilience	Sustaining focus
Organising	Organizing daily life	Sustaining routines

The tasks for the Novice Champion are navigating unfamiliar services, developing advocacy skills and accessing information. One mother described how initially "the special needs world was so strange" (P4). The Novice Champion may feel uncertain advocating within unfamiliar early intervention services. They are also attempting to identify and access sources of information. As Explorer Champions parents continue to develop knowledge of services, refine their advocacy skills and upskill to meet the challenge. Increased familiarity with services makes navigating and advocating less daunting. One mother described: "Knowledge also refines how you advocate, it makes you become clearer on what the child needs and because of familiarity with service you can make reasonable, achievable requests" (P3). The Explorer Champion is also developing a toolkit of specialist skills, which takes time and patience, as one mother explained; "It's amazing if you don't give up, but it can be easy to give up" (P12). As Confident Champions, parents are ready to step into a coordinating role, confident in their ability to collaborate with services to access the best outcome for their child. One parent described: "because of my understanding of the condition and strategies I can now take the plan and work out how to implement it at home" (P3).

3.3.2 | Sustaining well-being

As Novice Champions, to support their well-being parents are accessing positive relationships, managing emotional reactions to the diagnosis and organising daily schedules. Parents access support from their existing informal relationships. Emotional reactions to the diagnosis can vary. One parent described how "The words smash into my face like a fist" (Melville-Ross, 2016, L. 1523), while another described how: "We were fine with the diagnosis... We just rolled on" (P15). Parents manage the challenge of the dual demands of processing the diagnosis, while attending to everyday practical demands, one parent commented that despite her distress "the dishes still needed washing" (P5). As Explorer Champions, parents continue to sustain well-being by extending their network of supports, building their resilience and creating sustainable everyday routines. Explorer Champions move beyond their close network to develop a series of relationships. The Explorer Champion also continues to develop new routines. One parent described becoming "super organized" (P3). As parents

move into the Confident Champion role, they continue to access their extended supportive network, sustain their focus and embed sustainable routines into their daily life. The circle of support that they have developed consists of a variety of relationships, both formal and informal. They have cultivated a focus on immediate goals and recognise and celebrate their child's successes, maintaining a high level of motivation and hope. Being organised and having a clear vision allows better integration of the child's needs into daily routines.

One parent captured the challenge in sustaining well-being: "It's a life magnified: the lows are much lower than you could probably imagine, and they are long and sustained. But the highs, wow, the highs, they make it all worthwhile" (Melville-Ross, 2016, L. 3126).

3.4 | Influencing factors

While refining perspectives and the evolution of championing influence each other, these are also influenced by two main factors external to them: challenge factors and service factors.

3.4.1 | Nature of the developmental challenge

Data analysis revealed three challenge factors which affect parents' well-being and adjustment: clarity of the diagnosis, additional challenges and the child's rate of progress.

4.1.1 | Diagnostic clarity
When a diagnosis is clear, it is easier to source information and gain an understanding of the diagnosis. When the condition is less clear-cut, it can lead to a more complex process which may undermine the process of refining perspectives.

4.1.2 | Additional challenges
The emergence of new behaviours that challenge, medical conditions and comorbid developmental challenges poses a major threat to parents as they progress through the refining perspectives process and championing their child. These additional challenges may require physical and emotional resources and organisational skills and can be overwhelming.

4.1.3 | Rate of progress

The child's progress can either positively or negatively affect both the refining perspectives process and the champion's behaviour. Lack of progress or regression in development will threaten parents' ability to maintain well-being. One mother described: "It wasn't just the exhaustion causing my tears, it was the immense frustration at doing all I humanly could with no beneficial effect" (Inglis & Shepard, 2012, L. 1783).

3.4.2 | Service factors

Three key characteristics of services were discovered which influence refining perspectives process and championing: service provision, therapist's competencies and quality of information and training provided.

4.2.1 | Service provision

Effective service provision supports parents as they go through this process of change and adjustment. Quick and easy access to services supports the champion to begin their work with their specialist early intervention team. When access to service is delayed, it can severe distress. One mother explained "I'm on anxiety tablets because it just feels like too much, if had more support it wouldn't be as bad" (P7).

4.2.2 | Competent therapists

Analysis of data indicated that a competent therapist will combine a mix of positive personal characteristics and expert technical skills as illustrated in the following quote: "She just understood the situation ... and she also had the experience and we were so glad" (P3).

4.2.3 | Quality of information

Clear, accessible individualised information that helps parents understand their child's challenges and their implication for their future supports parents as they refine their perspectives.

4 | SUMMARY OF THEORY

This multivariant theory of Confident Championing captures the dynamic nature of parental adjustment following the diagnosis of their child's developmental challenge. All parents do not progress through the refining perspectives stages and evolution of their championing roles at the same pace, and parents may become stuck in a stage, regress back to a previous stage or may take longer to progress in their adjustment process. In addition, the adjustment process is further influenced by two interrelated factors: service factors and nature of the challenge. These factors may support parents to adjust and achieve a sense of well-being and purpose, whereas in other circumstances these factors may have a negative effect on parental adjustment. This dynamic theory predicts the relationships between and within each of its components and can account for the variation in how parents adjust to this situation.

5 | DISCUSSION

The theory of confident championing provides a new theoretical framework which conceptualises parental adjustment following the diagnosis of their child's developmental challenge. It conceptualises this adjustment as a fluid dynamic process which is influenced by a number of factors. Empirical support for the main hypotheses underpinning the theory of Confident Championing can be found in the empirical literature. There is evidence to suggest that an underlying psychological process, through which parents explore and modify their beliefs and attitudes about the challenge, their futures and their parenting capacity, is taking place (Brown, 2016; Sun et al., 2016; Whittingham, 2014). The impact of positive changes in these areas has been found to be associated with increased well-being and adjustment and thereby supports the behavioural response of the champion (Glenn et al., 2009).

The concept of championing also finds support in the empirical literature. Within this theory, championing involves navigating services, advocating, upskilling, accessing supportive relationships, building emotional resilience and establishing sustainable routines. There is a significant body of evidence that highlights the importance of advocacy in enabling families to navigate systems (Burke et al., 2018; Heer et al., 2015). The importance of knowledge and skills has also been established (Batool & Khurshid, 2015). Research findings support the positive role of supportive relationships in providing both emotional and practical support to the parents in parenting a child with developmental challenge (Benson, 2016; Dunst & Trivette, 2009; Peer & Hillman, 2014). The benefit of coping skills has also been established in the empirical literature, and much evidence is available to distinguish between the various types of coping strategies and their impacts on well-being and adjustment (Dukmak, 2009; Hastings et al., 2005). Finally, the concept of establishing and maintaining sustainable family routines has been supported within the literature (Guralnick, 2017; Mas et al., 2016).

Research has also demonstrated the relationship between an effective, integrated service and parental adjustment (Bourke-Taylor et al., 2019; Carpenter & Campbell, 2008; Guralnick, 2016; Sukkar, et al., 2016). Research has established the importance of each of the three factors described in the theory: service provision (Edelstein et al., 2017; Loukisas & Papoudi, 2016; Moodie-Dyer et al., 2014; Tait et al., 2016), staff competencies (Bruder, 2010; Francois et al., 2015) and quality of information and training (Moodie-Dyer et al., 2014; Wilkins et al., 2010).

The theory of Confident Championing highlights the influence that factors associated with the developmental challenge have on refining perspectives and championing. Research results are mixed in this area with some indicating significant impact of challenge factors (Palancı, 2018; Rivard et al., 2014) and others suggesting that

these factors are not as significant as alternative factors (Aaron Resch et al., 2012). These findings suggest that the pathways of influence are complex. This theory posits that an additional factor which may account for these inconsistent findings is the mediating effect of the process of refining perspectives and the response of championing.

In considering the contribution of the theory of Confident Championing, this theory is consistent with current approaches which are strength-based and highlight the role of parent–professional collaboration. The theory of Confident Championing also explains the impact that a variety of factors, related to the child's challenge and service provision, has on the process of parental adjustment.

5.1 | Theoretical, clinical and policy implications

The theory of Confident Championing offers much to advance theoretical knowledge and clinical practice. While many prior studies have emphasised one of the four components of this theory (psychological process, championing behaviours, service and challenge factors), this classic grounded theory provides a unique conceptualisation that captures the dynamic nature of the interactions between these components and a novel explanation for the process of parental adjustment.

The theory also provides compelling support for the advancement of a strength-based paradigm as promoted by current service models. It offers a rationale for and an understanding of the power of parent–clinician collaboration, based on mutual respect and trust.

This research provides a unique contribution to clinical practice at the levels of individual clinician, service and system of services. Clinicians have access to a positive, compassionate framework which can help them better understand and support the families they work with. For instance, materials could be developed for clinicians to explore with parents what stage they are at and how best to tailor services to meet their current needs. Currently, the lead author is working with colleagues to develop a parent- or peer-facilitated programme for parents which is based on the Theory of Confident Championing. At the service level, the core message within this research is to maintain momentum in the movement towards a strength-based service.

5.2 | Limitations

There are several limitations in this research. It should be noted that this theory was developed based on data from participant's experiences and its broader application to describe all parent's experiences has not yet been tested. Participants were recruited from one area in Ireland. However, additional data from a variety of memoirs were used representing a broader international experience. Analysis of the data indicated a universal adjustment experience. An additional limitation of this study is the exclusion of non-English-speaking

participants. Given the evidence that ethnicity and race are related to inequities in access to services, it may be that the experience described in this research does not capture the experience of adjustment for parents who are not part of the dominant culture (Bobb, 2019; Greenwood et al., 2015; Yingling et al., 2019). A further limitation is the fact that all participants were actively engaged or seeking to engage with early intervention service. It may be that parents who do not seek to engage with services experience an alternative adjustment experience which was not captured in this research project.

5.3 | Future research

Many other potential avenues of research emerged during this research. Further exploration of the professional experience would provide insight into the factors which affect the interactions and communications between professional and families. Research is required to establish the unique contribution of each of the service and developmental challenge factors highlighted in this research. Addition research avenues include research exploring the effect of physical exhaustion on the adjustment process, the effects of refined perspectives on the ability to recognise and celebrate progress, the impact of bureaucratic demands, the impacts of the developmental challenge on parental and sibling relationships and gender differences in parental adjustment. Future research could focus an older children to establish if the adjustment process is similar or different for parents of children who are diagnosed later in childhood.

6 | CONCLUSION

The theory of Confident Championing offers a new comprehensive multivariant theory which explains a complex and continually resolving process of parental adjustment. The theory is based on the experience and perspectives of parents of young children with developmental challenge and gives a voice to their concerns and challenges. It is accessible to lay and professional audiences and highlights the importance of meeting the challenge of truly adopting a strength-based approach. Moreover, it captures the sense of fulfilment and purpose that many parents experience as they parent their young child and challenges clinicians to support parents to focus on achieving this for the families they work with. In the words of one father and champion:

> This situation gives us a purpose in our lives that reaches far beyond anything we've had to deal with before. It's all about love: a love that drives you onwards, whatever the odds, to win for your child
>
> (Melville-Ross, 2016, L. 3126)

CONFLICTS OF INTEREST
The authors have no potential conflicts of interest to disclose.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy concerns.

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