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The Parent Connection:

The Power of Peer Support for Parents of Children with Complex Needs

ENABLE IRELAND FINAL REPORT

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About this project

A joint initiative between primary investigators, Dr. Lhara Mullins and Dr. Devon Goodwin, at the University of Galway and Enable Ireland. This project was supported by the JBDB Fund at Community Foundation Ireland and The TK Maxx and Homesense Foundation.

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Table of Contents

List of Tables

List of Figures

Foreword

We are delighted to present to you this report on 'The Parent Connection: The Power of Peer Support for Parents of Children with Complex Needs', a joint initiative between primary investigators at the University of Galway and Enable Ireland. This report will describe how our pilot project was initially established, developed, delivered and evaluated and will present the research findings and subsequent recommendations.

The idea for this project stemmed from our own lived experiences as parents of children with complex needs and disabilities, in addition to our motivation as academics to explore and discover. We recognised the unique emotional and social support needs of parents like us, which we found often came informally via interactions with other parents who brought similar lived experience. Due to the demands of parenting and caregiving for a child with complex needs however, some parents lack the time and resources to make these connections with their peers and can feel alone in their parenting journey. We wanted to create something which would address this distinctive need for peer support, by parents, with parents and for parents, of children with complex needs and disabilities.

The Parent Peer Support Pilot Project has been a journey of co-creation, connection and community. As primary investigators, we are immensely proud of what this project has accomplished and are grateful to the inspiring parents and staff who made this happen.

This report will outline the key actions undertaken within the Parent Peer Support Pilot Project and will present the research methodology employed to evaluate its impact. The key findings from the data analysis will be presented and the discussion chapter will examine these findings, in the context of addressing the research aim and objectives.

Finally, recommendations will be made based on the evaluation of this pilot project, to inform future similar parent peer support initiatives.

1. Executive Summary 'The Parent Connection: The Power of Peer Support for Parents of Children with Complex Needs'

Project Title: The Parent Peer Support Pilot Project

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Overview

Researchers at the University of Galway in partnership with Enable Ireland, aimed to measure the impact of a peer support intervention, for parents of children with complex needs and disabilities. Peer to peer support is an informal type of support which aims to meet emotional, social contact and practical needs. Experienced parents of children with complex needs were provided with support parent training and subsequently provided peer support to their parent match, over a 12-week period in 2024. Enable Ireland staff members provided supervision sessions to support parents, at monthly intervals.

The Participants

Twenty parents took part in this study: ten parents providing peer support and ten parents receiving peer support. Ten Enable Ireland staff members participated and provided supervision sessions to support parents. Participants were based in five Enable Ireland

Community Disability Network Teams: Galway City West, South East Cork City, West Central Cork City, South Cork City, and North Tipperary.

The Research

This mixed method study used both qualitative and quantitative methods to examine the impact of peer support for parents providing support, receiving support and staff involved in the project. Questionnaires and focus groups were used to collect data from parent participants both before and after the peer support intervention. Interviews were conducted with staff members.

The Results

Peer support can lead to meaningful improvements in parental efficacy and perceptions of current supports. Results propose that support parents wish to share their lived experiences to instil a sense of hope, connection and community, for parents starting their journey. Findings indicate that the impact of peer support can create a ripple effect, presenting learning opportunities for staff and more profound insights into the reality of life for parents and families. Results highlight the growing support needs of parents of autistic children.

Recommendations

Parent peer support could be rolled out more broadly and complement existing formal service provision, providing meaningful emotional and practical support for parents of children with complex needs. Parents should be fundamental within the planning and

delivery of future parent peer support initiatives. Further research is necessary to determine the unique support needs of parents of children.

2. Background and Context

2.1 Introduction

The Parent Peer Support Pilot Project aimed to examine the impact of a peer support programme for parents of children with complex disability. This pilot project was undertaken via a partnership between researchers at the University of Galway (both parents of children with complex disabilities), and Enable Ireland, a national disability service provider who support 13,000 children and adults in 14 counties.

The Parent Peer Support Pilot Project is based on an ecological understanding of child development, which recognises the context within which the child develops and its impact on their wellbeing and development. The Bowen ecological theory of family systems, proposes that family members are intrinsically connected and influence one another's wellbeing and anxiety (Bowen, 1978). Consequently, influencing the wellbeing of one family member, can positively impact the wellbeing of others.

Consistent with this evidence, recent guidance for CDNTs (2023, p.2) acknowledges that "the child's family and those who are with them every day are the most important people in their lives" and affirms that "family centred practice is a fundamental principle of the Children's Disability Network Team (CDNT) model of service". This project aims to evaluate the feasibility and impact of peer support, for parents of children with complex needs and disabilities and staff involved in service provision.

2.2 What are Children's Disability Network Teams?

Children's Disability Network Teams (CDNTs) "provide specialised support and services for children who have a disability and complex health needs. A CDNT supports a child's development, wellbeing and participation in family and community life" (HSE, n.d.). CDNT's are comprised of practitioners such as: Occupational Therapists, Psychologists, Physiotherapists, Social Workers, Speech and Language Therapists, Dieticians, Family Support Workers, Nurses, Social Care Workers, Behaviour Specialists, and Therapy Assistants.

Enable Ireland is a large non-profit organisation that "provides services to over 13,000 children and adults with disabilities and their families from over 40 locations in 14 counties" including 20 CDNTs (Enable Ireland, 2023). Their mission is "to be an innovative leader, providing quality services, positive life experiences and advocating for an inclusive society, which empowers people with disabilities" (Enable Ireland, n.d.).

The interest and investment of Enable Ireland in this project, which explores the benefit of a potential new model to support children and their families, is evidence of their commitment to being an innovative leader in children's disability services.

2.3 Current Challenges within Children's Disability Services in Ireland

The current challenges concerning resources and services for children with complex needs and disabilities in Ireland, along with their families, is an ongoing issue of public concern. The roll out of the Progressing Disability Services for Children and Young People Programme (PDS Programme) in 2021, aimed to streamline and centralise services for children with complex needs, by reconfiguring the teams which had been providing

diagnosis-based supports (e.g. physical disability, intellectual disability etc.), to teams providing supports based on the needs of children in a particular geographical area, regardless of diagnosis. This reconfiguration saw staff members working within HSE, Brothers of Charity and Enable Ireland children's disability services, redeployed to newly amalgamated multidisciplinary and sometimes multi-agency CDNTs. Unfortunately, this reconfiguration has resulted in delays and disruption to accessing services, for some children with complex needs and their families (Families Unite for Services and Support-FUSS, 2023). FUSS (2023) report that staff on CDNTs are faced with insurmountable workloads in the wake of the introduction of the PDS Programme and interact less frequently with children and families. Staff recruitment and retention have been identified as an ongoing challenge within CDNTs throughout the country (FUSS, 2023).

2.4 What is the Purpose of a Pilot Project?

A pilot project, or pilot research study, aims to explore the feasibility of an approach to practice or research (National Centre for Complimentary and Integrative Health, NIH, 2024). Piloting is about trialling or testing to gauge if an initiative has the desired impact, what the benefits and challenges are, and what should be modified or implemented, should a similar project be delivered (Leon, Davies & Kreamer, 2011). In essence, a pilot study is used to determine what works, what doesn't and why, in terms of feasibility (NIH, 2024). This pilot project aimed to create, plan, deliver and evaluate, the impact (if any), of parent peer support for parents of children living with complex needs and disabilities in Ireland.

2.5 What is Peer Support?

Peer support, most succinctly, “describes the process of giving and receiving support between two people who share similar life experiences” (Meltzer et al. 2021, p.579). At its most basic, it involves two parties with a shared lived experience. In some cases, both parties may have the same level of experience (a ‘level playing field’), and in others one party may have substantially more lived experience than the other (more of a ‘mentorship’ role).

Peer support has been found to “offer hope” in the face of challenging life circumstances, and to “provide emotional and practical support, and empower recipients to navigate towards finding the resources and tools required to enhance their well-being" (Hunt & Byrne, 2019, p.8). Likewise, “engagement in parent peer support programmes can improve family quality of life and may have multifaceted benefits at the interpersonal, intra-individual self-change, and sociopolitical levels” (Dew et al., 2019, p.344). The work of McCrossin et al. (2022, p.1) also “revealed complex aspects of the emotional processes of peer support that have not previously been described”, finding that “the peers [supported and supporting] combined self-reflection and emotional expression in order to simultaneously provide empathy and bridge communication between a parent and service providers”.

Just as important, however, is the recent appreciation in research that these are not “separate and discrete benefits” (Meltzer et al. 2021, p.579); rather, the positive outcomes of peer support are “interconnected and mutually reinforcing” (ibid.). While Meltzer et al. (ibid.) identify a very long list of the benefits of peer support, including

“exchange of information, benefiting from experience and problem solving; motivation/encouragement and self-confidence/personal development; social interaction and friendship; understanding, perspective and belonging/community; working together for change; and resilience and well-being", they also propose a framework to understand these benefits in an interconnected manner, helping us to see the cumulative and sometimes exponential nature of these benefits.

2.6 The Needs of Parents of Children with Complex Needs

One without personal experience may wonder, however, what need peer support for parents of children with complex disability is trying to address? While it has long been established that children with complex needs require additional supports above and beyond those of typically developing children, it is only more recently that evidence has also recognised that “parents and family caregivers of children with complex needs... often experience lower levels of psychological, emotional, and social well-being, compared to parents and family caregivers of typically developing children” (Arman, 2022, p.1320; Sartore et al. 2021). McConkey et al. (2023) reiterate such ideas and add that caregivers face increased social isolation and less opportunities for social engagement, particularly if they live rurally. While Bhopti et al. (2020) report that the caregiving role for parents of a child living with disability not only impacts caregiver health and wellbeing, but also overall family quality of life.

While it has been, and should be, highlighted that many parents also report positive experiences of parenting a child with complex needs (Greer, 2006), even this research does not deny the reality of the challenge (ibid.); families of children with complex needs

“experience a high level of pressure to meet children's needs while maintaining family functioning” (Sartore et al, 2021, p. 1).

When asked to describe their experience, parents routinely emphasise feeling unsupported (Douglas, 2016; Milsoevic, 2022), having challenges navigating health and educational supports for their child (Hock, 2022), and perhaps most importantly, experiencing extremely challenging and uncomfortable emotions like “grief, loss, guilt and burden” (Klein, 2019, p.2). Importantly, because these experiences are marginalised, meaning they do not parallel the experiences of most parents (parents of typically developing children), parents also report “having difficulty speaking with family and friends about what they experience because it is perceived as different to what “normal” parents experience” (Gudka et al., 2023, p.1).

Klein et al. (2019; building on Swain et al., 2014) highlight how this process of marginalisation can happen gradually and cumulatively, as parents are “excluded from full participation in all aspects of civic life, including family, work, and leisure” (Klein et al., 2019, p.2). What is interesting in Klein et al’s work, however, is that they also highlight an often neglected moral and emotional dimension; the experience of feeling judged as a bad parent, blamed for not being able to ‘fix’ their child or their behaviour, or scrutinised. Ryan (2010, p.869; drawing on Cloke & Jones, 2005) dubs this an experience of “soft criminality”. Klein (2019) suggests the remedy is not traditional professional-led interventions like psychotherapy or parenting workshops, but rather peer support. Klein et al. (ibid., p.1) advocate that there is something in the normalising effect of shared lived experience that can help shift parents “from individualised positions of burden, isolation

and social exclusion to confident, positive, active connectedness, by means of an affective and effective relational process [that they call] 'solidarity-as-care'".

This concept of 'solidarity-as-care', or a need for some type of solidarity or shared experience, resonates in much of the work on parental experiences of parenting children with complex needs. Rafferty and Beck (2020) suggest that this can be looked at through a lens of "critical-enacted social support" (Goldsmith, 2004, in ibid., p.1389), which offers "value, meaning, and reliability beyond that of a medical professional" (ibid.). Sparks (2023, p.141) suggests simply that "these parents and other caregivers have unique needs that are understood best by others who face the same challenges."

This is not to deemphasise the importance of professionally delivered support services, such as counselling, psychotherapy, social care support, and parenting workshops, but rather to highlight an important and very real gap in our understanding of how best to holistically support these parents and families. As participants in Gudka et al's (2007, p.1) study expressed, it is most likely that peer support has a unique role to play in "a flexible range of service components which provide holistic support", addressing needs that cannot be met only with professional-led services.

2.7 Rationale for Supporting Parents within a Children's Disability Service; Paradigm Shift

This mounting evidence concerning the needs and experiences of parents of children with complex disability is extremely important given the paradigm shift that has occurred in social services (Devaney et al., 2011; 2021) and is occurring in disability services over the last two decades. Specifically, the focus in disability services has moved from

exclusively focusing on and assisting the child with disability to the recognition that the child develops within the context of the family system, and that optimal developmental outcomes are more likely when the unique needs of all members of the family unit are appreciated and addressed (Rivard et al. 2022; McConkey et al. 2023). Although there were some voices leading this paradigm shift internationally as early as the 1980s (Turnball & Turnball, 2002), in Ireland it is only more recently that scholarship has placed a more valued emphasis on the experience of and importance of the well-being of the whole family, of the child with complex needs (HSE, 2023; Greer et al. 2006; McConkey et al. 2023).

2.8 Models of Peer Support; Positioning the Piloted Model

As the needs and resources of all communities differ, the model of peer support proposed and developed in different contexts will likewise differ. The research in this domain reflects this diversity in terms of the models that have been piloted, trialled, and/or evaluated. While many of the core mechanisms at play are the same, it is worthwhile to also attend to some of the differences, broadening our understanding of what peer support is, and can look like.

The current pilot study utilised a modified version of the Parent-to-Parent (P2P) USA model of peer support for parents of children with disabilities, developed by parents for parents in the 1970s (Dodds & Walch, 2022). P2P is a parent run organisation and is comprised of a network across 40 states in the USA ; they create 14,000 parent matches annually (P2P USA, 2024). P2P USA maintains an extensive directory of parents who volunteer to assist other families, and programmes “provide matches between trained

supporting parents and parents who request assistance" (P2P USA, 2024). Training is provided to the volunteer parents, and they are matched to parents requesting help with challenges similar to those that the volunteer has experienced (Singer et al., 1999). Details on how we adapted the current programme from the base P2P USA model will be discussed within the methodology section.

The P2P USA programme, described above, and the model piloted in the current study, are relatively non-prescriptive, equipping parents with communication, interpersonal, and child-protection skills, but not involving any set curriculum or information transfer goal. Many peer support programmes appear to follow similar guiding principles, relying on the nature of the organic relationship based on shared lived experience as the agent of change (Dodds et al., 2024).

The Community Families Programme in Ireland (formerly Community Mothers), for example, was established in Ireland in the 1980s, and is a home visiting volunteer led initiative, aimed at promoting the health and wellbeing of mothers and children (from 0 – 3 years) (Brocklesby, 2022). While not specifically for parents of children with complex needs, it is also a relatively non-prescriptive peer support programme that "provides information, support and builds friendships and connectivity in local communities" (Community Families, n.d.). It has been found to promote self-care and wellbeing for recipients, in addition to reducing isolation (Brocklesby, 2022).

Other peer support programmes reported in the literature, however, have followed a more structured model. Hock et al. (2022, p.2091), for example, reports on a pilot of a "brief, peer-delivered, home-visiting program for parents" of autistic children. The logistical

structure of the programme was very similar to that of our adapted P2P USA programme; the content, however, differed because there was an explicit curriculum/set material to be delivered to the parent receiving support. This curriculum material was a programme to develop skills in co-parenting called Autism Parent Navigators (APN). The findings of this study report statistically significant improvements in pre and post intervention data relating to caregiver strain, quality of life, and family empowerment (Hock et al. 2022).

Moody et al. (2019) also report on a more structured model of peer support that they call a "parent mentorship" programme for parents of autistic children. They evaluated this 6-month programme via a randomised control trial, comparing outcomes of a group receiving the peer support intervention, to those of a waitlisted group. The structure and delivery of parent mentorship within this study was also more instructional and educational, rather than just supportive, and aimed to "teach parents how to navigate systems of care in ways that are most meaningful for their family (based on family-centred action planning), while creating ongoing support through parent-to-parent mentorship" (ibid., p.425). Results found marginal, though statistically non-significant improvements on measures of family function and quality of life, and significant increases in service utilisation, particularly in the form of out-of-school activities. Qualitative findings suggested that peer mentorship can help parents to feel less isolated and offer reassurance (Moody et al. 2019).

Likewise, Martin et al. (2019) developed a structured, curriculum-based peer support programme for parents of children with developmental difficulties. The HOPE programme focused on "self-management skills, including goal setting and expressing gratitude" (p.980). Supporting parents were provided with training and ongoing support

to deliver the 6-week intervention at weekly intervals. In total, 108 parents participated in at least three of the six sessions and findings indicate that depression and anxiety levels of parents receiving the peer support intervention reduced significantly, within pre and post-test analysis (Martin et al. 2019).

Mills et al. (2020) conceptualised their peer supporting parents as "peer counsellors", and their structured, curriculum-based programme had dual aims; "to provide parents with a forum to share their experiences and develop a sense of shared identity as caregivers of autistic individuals; and second, to provide parents with the knowledge and skills to support their own psychological well-being". Sixty-three parents received support within this 6-week project, and results found improvements in stress levels, quality of life and a reduction in family distress (ibid.). Interestingly, Mills et al. (ibid.) also discuss the importance of cultural sensitivity and responsiveness in peer support, noting that cultural stigmas around disability and the availability/lack of professional support services in the parent's first language, can greatly impact outcomes. In their view, peer supporters who "come from the same culture and share similar experiences" (ibid., p.334) as receiving parents, can help culturally diverse families overcome barriers to support.

Jamison et al. (2017) also investigated peer support in an ethnically and culturally diverse minority sample, matching the cultural backgrounds of the supporting and recipient parents. They used a model called Family Peer Advocates (FPAs) which "has been utilised across service delivery systems to provide family-to-family support, facilitate engagement, and increase access to care" (p.1314). Through a randomised control trial with four supporting parents (FPAs) and 39 recipient parents, they found significantly

increased knowledge of Autism and reduced levels of stress. Interestingly, FPA training was based on the Parent Empowerment Program (PEP), the elements of which seem to parallel the P2P USA training in the current project quite closely, and FPAs also received supervision from a licensed social worker, paralleling one of the adaptations made in the current pilot (Jamison et al. 2017).

Are the more structured, curriculum-based programmes parent peer support then, or something different? While they all have much in common, and many of the benefits are similar, the models presented by Hock et al. (2022), Moody et al. (2019), Martin et al. (2014), and Mills et al. (2020) may arguably be better described as a 'peer model of service delivery' (Jamison, 2017, p.1315.). Jamison's (2017) model, while also identified by Jamison as a 'peer-to-peer model of service delivery', on closer reading appears to be based almost exclusively on peer support. Without access to the details of the training packages and the curriculums, it may be quite impossible to untangle which programmes are which, but sensitivity to the fact that there are differences in the models of these programmes is key. While there may not be a hard and fast line between 'peer support' and 'peer service delivery', arguably the presence or absence of a set curriculum or set package of information to be conveyed, is important to the distinction.

One other distinction in models of peer support is 1-1 versus group settings. While the models above, like the current pilot, rely on a structure of 1-1 meetings, other studies have investigated the impact of group-based peer support for parents of children with complex disabilities. Distinctions within group settings also occur; some groups are parent-led (Kingsnorth et al., 2011), some are parent-led but co-facilitated by in-training professionals (Batchelor et al., 2021), others are facilitated by a professional

(Hammarberg, 2014; Mills, 2021; Prest, 2022; Wakimizu, 2022), and some seem to blur lines with paraprofessionals who are also parents of children with complex disability 'leading' the group (Klein et al. 2022). Facilitated peer support groups include the MyTime programmes, of which there are over 260 in Australia (Wynter, 2015).

Knowing there is such great diversity in form, goals, and content of the various models reflected in the research on peer support for parents of children with complex disability, it is important to define the currently piloted model as a 1-1 model, as opposed to group, as parent-led, as opposed to professionally facilitated, and as explicit-curriculum free, as opposed to those aligning more closely to a 'parent service delivery' model.

3. Methodology

3.1 Aim and Objectives of the Current Study

The aim of this pilot study was to evaluate the impact of a parent peer support programme for parents of children with complex needs and disabilities in Ireland.

Focusing on three participant groups, the pilot study key objectives were to:

- Evaluate the impact (if any) of being a recipient of peer support, for parents of children with complex needs and disabilities (Group 1).
- Explore the motivation to participate and the impact of participation (if any) for support parents (Group 2).
- Ascertain the views and experiences of participating staff members, concerning the impact (if any) of peer support (Group 3).

3.2 Study Design

This study utilised a mixed-methods approach to evaluate the impact of a parent peer support programme for parents of children with complex needs and staff members, using both quantitative and qualitative data collection and analysis methods.

3.3 Participants

Three distinct participant groups were included in the study as outlined in table 3.1:

Table 3.1: Participant Groups

Group Number	Group Name	Description
1	Recipient Parents	Parents of children with complex needs receiving peer support

2	Support Parents	Parents of children with complex needs providing peer support
3	Enable Ireland Staff Members	*Staff members providing formal supervision to support parents

*Note: Funding for this research project ensured that CDNT staff member participation did not reduce the availability of clinical time to the teams involved.

Sampling

Groups 1 and 2 (Recipient and Support Parents)

A purposive sampling strategy was adopted for this project, as it was a pilot of a peer support initiative undertaken within a specific organisation. Purposive sampling is the recruitment of participants based on specific knowledge or insights they have (Cresswell & Plano Clark, 2011).

In this case, the population of interest were parents with experience of parenting a child with complex needs, and there were parents of 12,994 children meeting this criterion assigned to the 20 CDNTs led by Enable Ireland in 2023. This pilot project recruited participants from a subset of this pool; parents assigned to five Enable Ireland CDNTs – Galway City West, South East Cork City, West Central Cork City, South Cork City and (upon expansion) North Tipperary. Enable Ireland acted as gate keepers and extended the invitation to participate, to families assigned to participating CDNTs.

The original sample target size was 40 parents, 20 within each group (support parents and recipient parents), culminating in 20 matches. This target sample size was determined based on the Principal Investigator's (PIs) capacity to oversee the project, provide training

to participants, and co-ordinate the delivery of the peer support pilot. The target sample size was not achieved, however, as there was limited response to the recruitment emails. In an effort to enhance recruitment efforts, an additional study site (Tipperary) was added. Despite these measures, the total number of parents recruited to participate was twenty-one (ten support parents and eleven recipient parents). One participant (recipient parent) discontinued their participation prior to meeting with their parent match, resulting in a final sample size of ten parent matches (twenty parents in total). This sample was deemed sufficient for the aim and objectives of this pilot to be achieved.

Group 3 (Enable Ireland Staff Members)

All staff working on the Enable Ireland Galway and Cork teams were eligible to participate in the project. Staff were emailed with information about the project and the invitation to participate. An online information session for staff members was provided, in response to an initial low uptake of participants. The target sample size for Group 3 (Enable Ireland staff members) was ten, with each participant originally intended to provide supervision to two participants from Group 2. While thirteen staff members were recruited and trained, ten subsequently participated due to the lower than anticipated number of support parents recruited. Also due to lower than expected recruitment in the parent groups, each staff member was ultimately assigned one participant (rather than the intended two) to provide formal supervision to.

Inclusion Criteria

- Group 1: parents of children in receipt of services or on the waiting list for services, within participating Enable Ireland CDNTs.

- Group 2: parents of children in receipt of services or on the waiting list for services within participating Enable Ireland CDNTs *and* who are at least *five years post their child's diagnosis.

*This inclusion criterion was amended and reduced to two years post their child's diagnosis, to reflect the extensive caregiving experiences which occur while awaiting assessments.

- Group 3: Enable Ireland staff members employed within participating Enable Ireland CDNTs.

Exclusion Criteria

- Parents of children not in receipt of/on a waiting list for services from participating Enable Ireland CDNTs.
- Support parents with less than two years of parenting experience/experience post diagnosis.
- Enable Ireland staff members not employed at participating Enable Ireland CDNTs.

Recruitment

PI's recruited participants for Groups 1 and 2 (parents) via email and postal invitations, in the small number of cases where no email contact information was available. Enable Ireland acted as gatekeepers within the recruitment phase of the pilot and disseminated the recruitment information and invitation to participate, to all families receiving their services and on the waiting list for services. Enable Ireland also acted as gatekeepers in recruiting staff members (Group 3) via email dissemination of information about the study and invitation to participate.

Table 3.2 below presents the final sample recruited within each group. to participate in the Parent Peer Support Pilot Project:

Table 3.2: Sample Size by Group

Group	Role	Sample Size
1	Receiving Support	10
2	Providing Support	10
3	Providing Supervision	10

Screening forms for parent participants (Group 1 and 2) at recruitment asked about the nature of their child's complex needs, so that peer matches could be made based on unique parental caregiving experience and support need (where possible). Table 3.3 below presents participant attributes in terms of parenting and caregiving experience, based on their child's diagnoses or unique needs.

Table 3.3: Participant attributes (Groups 1 and 2) in terms of child's diagnosis or unique needs

Child Unique Need/Disability	No. Of Recipient Parents	No. Of Support Parents
Down Syndrome	1	1
Autism	9	5
Intellectual Disability		2
Cerebral Palsy		2

3.4 Data Collection

Quantitative Questionnaire - Recipient Parents (Group 1)

Recipient parents participated via online survey, in the form of a customised pre-intervention and post-intervention questionnaire. The questionnaire collected self-report data measured on a 5-point Likert scale, in 5 main categories.

The over-all goal of the questionnaire was to measure improvements in parental well-being, which is a complex construct. As there is limited research on peer support for parents of children with complex needs, there was no pre-existing scale or survey instrument for this purpose.

To design the questionnaire, therefore, research was undertaken on component factors that contribute to overall well-being in the specific population of parents of children with complex needs, and five categories were decided upon from this research. These categories are resilience, parental support, parental self-efficacy, perceived parental stress, and overall well-being.

A search was undertaken for pre-existing scales developed to measure these five categories of experience, and these scales were then assessed for suitability and adapted for purpose by the primary researchers and the research assistant over several meetings.

The scales used for development of the questionnaire are presented in table 3.4 below:

Table 3.4: Scales used in development of the Questionnaire

Resilience	The CD-RISC 10 Connor Davidson Resilience Scale. Five items were taken verbatim, and two items specific to the population of parents of children with complex needs were added (Connor & Davidson, 2003).
Parental Support	Multidimensional scale of perceived parental support (MPSS) (Zimet, G., 1988). Seven items were adapted for the specific population of parents of children with complex needs.
Parental Self-Efficacy	Self-efficacy items from the Parenting Sense of Competence Scale (PCOS) (Johnston & Mash 1989; Gibaud-Wallston & Wandersman, 1978). Three items were taken verbatim, and three were adapted to the population.
Perceived Parental Stress	The Parental Stress Scale by Judy Berry and Warren Jones (1995). Five items were taken verbatim, and three items were adapted to the population.

Overall Well-being	The items on the well-being scale were developed by the researchers of the current pilot study, informed by the existing evidence base and literature review.

The questionnaire employed a Likert Scale for rating responses (strongly agree to strongly disagree), facilitating participants to indicate the degree to which they agreed with various statements.

Five qualitative questions were also included at the end of the questionnaire, providing recipient parents an opportunity to add their expectations for and thoughts on participating, in the Parent Peer Support Pilot Project. The pre-and post-program questionnaire was administered electronically via email, housed on Microsoft forms, and took approximately eighteen minutes to complete. See **Appendices A and B** respectively for pre-pilot and post-pilot questionnaires.

Focus Groups - Support Parents (Group 2)

Support parents participated in semi-structured pre- and post-programme focus groups to discuss their motivations, experiences and impact of participation with the study's research team. The focus groups took place online via Microsoft Teams at a time convenient to all participants and each focus group lasted approximately ninety minutes. See **Appendices C and D** respectively, for pre-pilot and post-pilot focus group guides.

Individual Interviews - Enable Ireland Staff Members (Group 3)

Enable Ireland staff members took part in a structured individual post-programme interview, with the researcher online via Microsoft Teams. Interviews took place at a time convenient to the participating Enable Ireland staff. This was to ascertain their views and experiences of being involved in the Parent Peer Support Pilot Project. On average these interviews took approximately 35 minutes. See **Appendix E** for interview guide.

3.5 Data Analysis

Quantitative Data

The quantitative data was managed and analysed via Microsoft Excel, which facilitated data entry, organisation and data analysis. Data was analysed at both the category (resilience, parental support, parental self-efficacy, perceived parental stress, well-being) level and individual questionnaire item level for the group overall. All data was tested for normalcy, and as the assumption was met, repeated-measures t-tests were used to look for significant changes. Data was also analysed at the category level for individuals, to facilitate insights in the interpretation of the group level data.

In light of participant qualitative feedback post-programme, Fisher's test of independence was also run to see if there was a significant effect of meeting modality (virtual vs. in person) on overall mean individual survey outcome (negative or positive change).

Qualitative Data

The qualitative data from the pre-and post-focus groups and individual interviews, were audio-recorded via Microsoft Teams and transcribed verbatim. The audio recordings were deleted once transcribed. Additional notes and annotations to indicate vocal inflexions and utterances further noted, to capture non-verbal communication.

The data was analysed using Braun and Clarke's reflexive thematic analysis (Braun and Clarke, 2022), a six-phase process which includes data familiarisation, coding and theme generation and development, followed by refinement and reporting.

First, the transcripts were comprehensively analysed by the researcher using a semantic, inductive approach as defined by Braun and Clarke (2022). Once the researcher was familiar with the data, a range of codes were identified. Microsoft Excel was used to organise the data as the sample size was not large enough to necessitate specialised qualitative software. The study team then discussed the identified codes, grouped them into similar codes and then searched for themes. These themes were then taken back to the transcripts for more focused coding. These agreed-upon themes were refined, defined and named, each given a written description until the emergent themes were crystallised and illustrative quotes were selected for each.

Inter-Coder Reliability

To ensure the reliability and validity of the thematic analysis, inter-coder reliability was established. Initially researchers independently coded selected questions in the transcripts using Braun and Clarke's six-step thematic analysis. After this independent coding, the researchers met to compare codes, discuss discrepancies, and refine their

coding framework. This collaborative process helped to ensure consistent application of codes across all transcripts, contributing to the credibility of the identified themes.

3.6 Confidentiality/Anonymity

Recipient Parents (Group 1):

Each participant was assigned a numerical identifier to maintain confidentiality yet enable the linking of data during pre-and post- programme questionnaires.

Support Parents (Group 2):

Pseudonyms were assigned for use in focus group discussions to ensure anonymity. A key linking identifiers/pseudonyms to participants, was securely stored by the University of Galway, accessible only to the principal investigators.

Enable Ireland Staff Members (Group 3):

Enable Ireland staff members were assigned a numerical identifier, to anonymise their interview data.

3.7 Participant Engagement

Recipient Parents (Group 1):

Recipient parents completed electronic questionnaires pre- and post-programme via Microsoft Forms and participated in six fortnightly visits with their support parent. Each meeting lasted approximately 1 to 1.5 hours in duration and occurred either at their home, an alternative meeting space or remotely.

Support Parents (Group 2):

Support parents attended two online training sessions of approximately 2 hours in duration, completed Garda Vetting and Children First training. Support parents further participated in six fortnightly visits with their parent match (1-1.5 hours each), attended monthly supervision sessions, and took part in two focus groups.

Enable Ireland Staff Members (Group 3):

Enable Ireland staff members received a day of in-person training, provided monthly supervision sessions to support parents (three sessions; 1 hour in duration), and participated in a post-pilot structured individual interview with researcher (30-60 minutes in duration).

3.8 Ethical Approval

Ethical approval was obtained from both Enable Ireland (reference: RA90) and the University of Galway Ethics Committees (reference: 2023.02.023). An ethical amendment was subsequently sought in response to recruitment challenges, to facilitate the inclusion of an additional study site. A Data Protection Impact Assessment was completed in respect of this study.

Informed consent was acquired from all study participants and participants were provided with detailed information about the purpose, risks and benefits of participation. Participants were informed of the voluntary nature of their participation, and their right to withdraw from the study at any point without consequences. It was also made clear that

participation or non-participation in the project would in no way – positively or negatively – impact on service provision from Enable Ireland.

3.9 Positionality and Reflexivity

As parents of children with complex disabilities, and academic researchers working within the fields of social care and education, both principal investigators occupied a unique positionality in relation to the project. This positionality required continued self-reflection throughout, and both principal investigators supported and encouraged each other in this process. In relation to the development of the training materials, this proved a strength, as many of the Group 2 (supporting) parents remarked in the focus groups on the uniqueness and benefit of the project being led by parents with a shared positionality. Both PIs were able to share their own experiences with participants during the training, which encouraged within the Group 2 parents a position and attitude of reflection, vulnerability, and authenticity, which are important elements in the peer support process. This sharing and reflection represented a fundamental component of the P2P model adapted for the current project.

In relation to the data analysis, the positionality of a parent of children with complex disability proved both a challenge and a strength, but it was essential to continually ensure that the analysis reflected the data, and not the experience of the researchers. Data collection and analysis was primarily undertaken by the researcher employed. Double coding, reviewing and reanalysis of findings were undertaken by both PIs and the researcher independently, in a cyclical fashion and subsequently, triangulation of the

data occurred. This process enabled rigour and enhanced reliability within the eventual generation of final themes.

4. Project Implementation

4.1 Programme Overview

The Parent Peer Support Pilot Project was designed to provide parents of children with complex needs (Recipient Parents, Group 1) with emotional, informational and social support. Support parents (Group 2) were classified as a parent with a child who received their child's diagnosis at least five years prior, who had navigated similar challenges and were trained to offer support meetings every two weeks. This requirement was later reduced to two years since their child's diagnosis, in an effort to address recruitment challenges and acknowledge the extensive lived experience of parents who may have experienced waiting lists for assessment and diagnosis of their child. The programme was designed by the project's Principal Investigators (PI's) based at University Galway and was implemented in collaboration with Enable Ireland.

Using philanthropic funding allocated to the Parent Peer Support Pilot Project, Enable Ireland purchased a membership alliance package from Parent to Parent (P2P) USA. This package included training provision to PIs and steering committee chair, training resources and access to advertising and recruitment materials. Initial and ongoing access to support, guidance and advice from P2P was further provided.

The Parent Peer Support Pilot Project implemented some changes to the standard P2P programme which were deemed necessary, to promote safety and reduce potential risks to participants. These changes are outlined in table 4.1 below:

Table 4.1: Change Implemented to Reduce Risk

Change Implemented	Rationale
Inclusion of Formal Supervision	This element of support was implemented to promote the self-care and wellbeing of supporting parents and provide a space for them to raise any concerns or questions they had while providing peer support.
Children First Training	Undertaking Children's First online certified training was implemented for support parents, to promote child safety and clarify the support parent role, should a child protection or welfare concern arise.
Support Parent Garda Vetting	Support parents were required to undertake Garda Vetting to demonstrate their good character. This requirement was included in an effort to reduce risks and promote the safety and wellbeing of recipient parents and their families.

The programme followed a structured yet flexible format to adapt to the unique needs of each parent match. The design of the programme centred around four core elements – training, matching, the parent peer support sessions, and formal supervision of the parent peer supporters.

Training Overview

Training for Support Parents (Group 2)

Prior to the programme commencement, the support parents undertook support parent training online, delivered by PIs over two evenings. The training provided an overview and rationale for the project and clarity around the role and expectations of the support parent. Based on the established training materials within the P2P licensing agreement, support parent training included the topics of active listening, boundaries in peer support and the FARM method of facilitating supportive conversations (Feelings; Ask Questions; Resources; Make a Plan). Support parent training further explored how to respond to a parent in crisis and information on the formal supervision by Enable Ireland staff. All support parents received a resource handbook on parent peer support, including support materials and resources they could share with their recipient parent. Additionally, the support parents completed Children First Training and were Garda Vetted to ensure they were adequately prepared for their roles.

Importantly, the Group 2 parents were also invited to feed their own insights and ideas into the training and the programme, and modifications were made based on this input. One significant modification based on Group 2 feedback was the inclusion within the resource handbook of a contract/statement of understanding, defining the role of the parent peer supporter that must be signed at the initial session. This inclusion provided better role definition and clarity for both parents within the parent match.

Training for Enable Ireland Staff Members (Group 3)

Enable Ireland staff members undertook one day of training in person, or 2 hours online (for those who could not attend in-person). This training was developed and delivered by the PIs, one of whom has a significant background lecturing on formal supervision.

The content of the training covered the background/history of the current pilot programme, information on peer support abroad (P2P USA) and in Ireland, as well as training in formal supervision and role definition. There was time provided for staff to work through case study examples of scenarios that may arise, and how they would be responded to in practice. Staff members also received a resource handbook and were invited to contribute their own resource ideas to the handbook.

Finally, although training was not provided to Group 1 parents, as recipients of peer support, Group 1 parents were provided with a condensed version of the resource handbook (provided to Groups 2 and 3).

Matching

Recipient parents were matched with a support parent based on their child's diagnosis, specific needs, age, and location, in so far as possible.

Parent Peer Support Sessions

The peer support sessions comprised of six bi-weekly face-to-face or remote support sessions over three months, each lasting 1 to 1.5 hours. Parent matches who met in person were given the option of meeting at the recipient parent's home, at a neutral location (i.e. a coffee shop or park) or were able to book space at their local Enable

Ireland offices. Parent matches who met remotely could meet via telephone or videoconferencing.

There was no set curriculum to be followed, and parents were encouraged and trained to actively listen, to ask questions to encourage their matches to share and to share experiences from their own journey, which they felt were relevant and appropriate.

Formal Supervision of Supporter Parents

The support parents received formal supervision provided by an Enable Ireland staff member, approximately once a month. The first reason for the inclusion of supervision was to promote safety and oversight of the programme, as this pilot is the first of its kind for this population in the Irish context.

Formal supervision was also included, however, to gain insights from Enable Ireland staff on the challenges, benefits of, and feasibility of a parent peer support programme in the context of children's disability services. This encouraged awareness of and support for the parent peer support pilot programme within the organisation and facilitated the concerns and hopes of frontline staff that are supporting families, to also be reflected in the findings.

Supervision Role Description

The supervision role centred around building a relationship with the support parent through meetings. The practitioner listens to them as they share their experience of being a supporting parent. A crucial part of the role is to facilitate the parent's self-reflection,

achieved by using open-ended questions that encourage the parent to reflect on their interactions, often by structured listening, where they actively listen and guide the supporting parents through a process of self-reflection without being directive. This listening is purposeful, intended to help the parents process their experiences and challenges while offering subtle prompts that allow them to reflect on their interactions with the families they are supporting.

Additionally, the role involves creating a space of safety, where the parent feels comfortable enough to share concerns or express anything that is concerning them or upsetting them. The supervisors ensure that the parent understands they don't have to carry the burden on their own, emphasising the importance of emotional support and preventing feelings of isolation.

5. Results

This chapter will present both quantitative and qualitative results, based on the comprehensive data analysis undertaken in respect of each of the 3 groups of participants; recipient parents, supporting parents, and Enable Ireland staff.

5.1 Group 1 Results: Recipient Parents

Recipient parents completed questionnaires both pre and post intervention (before and after they met with their parent match and received support). Results for Group 1 will be presented in two parts: quantitative (based on scaling questions and comparison pre and post intervention) and qualitative (based on open ended questions pre and post intervention).

Quantitative Results: Recipient Parents

Group level changes

A Shapiro-Wilk Test for Normality for all pre and post data sets in all categories showed normality of data, and repeated measures t-tests were performed to test for statistically significant improvements in the parental self-report data at both category (resilience, parental supports, parental self-efficacy, perceived parental stress, and overall well-being) and individual questionnaire item level. All results at category level are reported, while only statistically significant item-level results that add insight into the changes at category level are included.

Overall, there were statistically significant ($p<0.05$) gains on the scales of parental supports and parental self-efficacy (medium to large effect sizes), notable but non-significant gains in resilience and over-all well-being (small effects sizes), and a reduction (but non-significant and of no effect size) on the scale of perceived parental stress. Table 5.1 below presents the statistical significance and effect size of the changes observed in each category/scale based on pre and post pilot data for Group 1:

Table 5.1: Statistical Significance and Effect Size Changes Group 1

Scale	Test of Significance	Cohen's d (effect size)
Perceived Resilience	*t = 1.017, p=0.17*	d = 0.32, (small effect size)
Parental Supports	*t =2.1380, p=0.03**	d = 0.67, (medium to large effect size)
Perceived Parental Self-Efficacy	*t = 2.4227, p = 0.019**	d = 0.76, (medium to large effect size)
Well-Being	*t = 0.45, p = 0.33*	d = 0.14, (small effect size)
Stress Levels	*t = -0.13, p = 0.45*	d = -0.041, (no effect size)

Figure 5(a) below illustrates the group level changes identified based on pre and post data analysis on each of the 5 scales used:

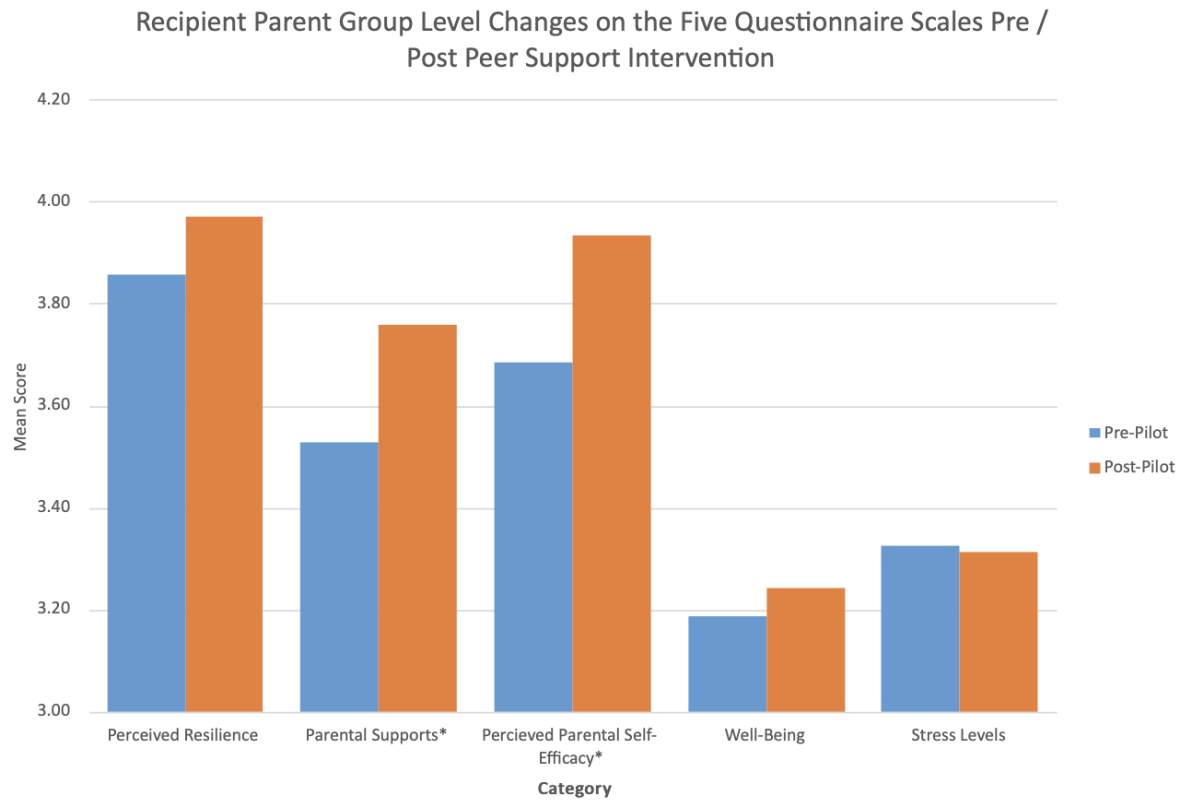

Figure 5 (a): Recipient parent group level changes

Perceived Resilience:

Table 5.2: Items on the Parental Perceived Resilience Scale

I feel I have accepted my child's diagnosis
I feel I have emotionally processed my child's diagnosis
I am able to adapt when changes occur
I can deal with whatever comes my way
Under pressure, I stay focused and think clearly
I think of myself as a strong person when dealing with life's challenges and difficulties
I am able to handle unpleasant or painful feelings like sadness, fear, and anger

There was a notable improvement in overall scores on the perceived resilience scale, demonstrating a slight improvement in the parent's ability to cope and be resilient in parenting a child with additional needs.

The effect was not statistically significant (p=0.17), but a test of Cohen's d (0.32) does indicate a small positive effect size. While the effect size is small, this can be partially attributed to a small sample size. [The Shapiro-Wilk Test for Normality showed normality of data both pre (p=0.536) and post (p = 0.31)]

Parental Supports

Table 5.3: Items on the Parental Support Scale

I have people I can to talk to about my child's complex needs
I am aware of supports available to me to help my child and family and how to access these
I have people to talk to who understand how I feel
I feel lonely in my parenting
I feel supported by my family in raising my child.
I feel supported by a significant person in raising my child
I feel confident that if I reach out, support is available.

One of the largest gains was in perceptions of participant's parental supports. This positive effect was statistically significant (p = 0.03), and a test of Cohen's d (0.67) reflects a medium to large effect size. This suggests that the peer support project led to meaningful improvement in parent's perceptions of their current support system after the programme. [The Shapiro-Wilk Test for Normality showed normality of data both pre (p=0.269) and post (p = 0.655)]

Notably, the item with the largest overall increase on this scale was "I have people to talk to who understand how I feel" (Cohen's d = 0.86), which is indicative of a large effect size. This was followed closely by significant increases and medium to large effect sizes for the items "I have people I can talk to about my child's complex needs" (p = 0.02, d = 0.77) and "I feel confident that if I reach out, support is available" (p = 0.02, d = 0.77).

Parental Self-Efficacy for Parenting a Child with Complex Needs

Table 5.4: Items on the Parental Self-Efficacy Scale

I meet by own personal expectations for expertise in caring for my child.
I understand my child's disability and how this impacts them
I know how to help and support my child to reach their full potential
I feel confident when communicating my child's needs to other people (teachers, doctors, therapists etc)
I know how to help my child when they are distressed
I honestly believe I have all the skills necessary to be a good parent to my child

The largest gain was in perceptions of parental self-efficacy for parenting a child with complex needs. This positive effect was also statistically significant ($p = 0.019$), and a test of Cohen's d (0.76) reflects a medium to large effect size. This suggests that the peer support project had a moderate to strong positive effect on how parents perceived their ability to manage the complexities of parenting a child with additional needs. [The Shapiro-Wilk Test for Normality showed normality of data both pre ($p=0.359$) and post ($p = 0.094$)].

Notably, the largest increase for an item on this scale, and indeed the largest gain on the survey, was on the item "I know how to help and support my child to reach their full potential" ($p = 0.003$). Cohen's d (1.16) indicates this is a very large effect size. This is a surprising finding; that a parent peer support programme for parents of children with complex needs could be a very important element in helping and supporting children to reach their full potential.

Well-being

Table 5.5: Items on the Parental Well-Being Scale

My mental health is negatively affected by parenting a child with complex needs
My sleep is impacted due to my child's needs
I am satisfied with my social life
I take time for self-care regularly
My mood is low regularly
I feel I have things to look forward to
Overall, I feel well

There was a notable improvement in over-all scores on the well-being scale. The effect was not statistically significant (p=0.33), but a test of Cohen's d (0.14) does indicate a small positive effect size. While the effect size is small, it demonstrates a slight improvement in the parent's overall well-being.

Notably, some items in this scale, such as sleep and mental health, are affected by complex factors that may be beyond the scope of peer support to significantly impact in a pilot of only 12 weeks. [The Shapiro-Wilk Test for Normality showed normality of data both pre (p=0.603) and post (p = 0.195)].

Stress Levels

Table 5.6: Items on the Parental Stress Scale

I feel hopeful about my child's future
I feel I cope well with the demands of parenting
I am happy in my role as a parent
Caring for my child sometimes takes more time and energy than I have to give
I sometimes worry whether I am doing enough for my child
I enjoy spending time with my child
I feel my choice and control are restricted due to my parenting responsibilities
I feel overwhelmed by the responsibility of being a parent

There was a very small but not notable decrease in scores of the perceived stress levels scale. The effect was not statistically significant (p=0.45), and a test of Cohen's d (-0.041)

indicates no effect size. This means that there is no meaningful decrease or increase in perceived stress levels.

On an item level, there are two interesting points to note within this category. The first is that there was a significant gain on the item "I feel I cope well with the demands of parenting" (p=0.007), which showed a large effect size (Cohen's d = 0.95). [The Shapiro-Wilk Test for Normality showed normality of data both pre (p=0.923) and post (p = 0.875)].

The second is that this was likely off-set by the only large single-item decrease in the study: "I feel my choice and control are restricted due to my parenting responsibilities". Significance tests were not appropriate, as it was a one-tailed test, the finding merits mention due to its uniqueness (all other findings across survey items were positive or neutral). As will be elaborated on in the discussion, we feel the demands of being asked to carve out a 1 to 1.5 hour meeting every two weeks to receive peer support, likely brought into light for the recipient parents just how limited they are in their ability to access time to care for themselves, and this was reflected on this item.

Individual Participant Level Changes

While reporting on the individual participant level is not appropriate overall in this analysis, there is one observation from the individual level data that does merit mention. This is the contrast between the parents who met their support parent in person, vs. those who met their support person online or via telephone (virtually).

Sparked by feedback in the qualitative data, the Fisher test of independence was run to see if there was a significant effect of meeting modality (virtual vs. in person) on overall mean individual survey outcome (degree and direction of change). Fisher's exact test

statistic value was found to be 0.0333, which is significant at $p < .05$. This important finding indicates that meeting in person rather than virtually has a significant impact on the positive outcomes for parents receiving support.

Qualitative Results: Recipient Parents

From the four open-ended questions included at the end of the questionnaire, both pre and post intervention, four important themes emerged. These themes are presented in table 5.7 below:

Table 5.7: Themes Group 1 Qualitative Results

Theme 1	Finding Your Tribe: Feeling Seen, Heard, and Understood
Theme 2	Tools for Tomorrow: The Practical Side of Peer Support
Theme 3	The Juggling of Parent Caregivers (Carving out Time/Guilt)
Theme 4	The Magic is in the Match: Finding the "Right Fit"

Each theme is an over-arching description that pulls together participant experiences in a meaningful way but is also composed of essential elements that were coded in the development of the themes. Each theme will be described, and then the essential elements that compose the theme will be detailed, with supporting quotes from participants.

Recipient Parent Theme 1 - Finding Your Tribe: Feeling Seen, Heard, and Understood

The theme "Finding Your Tribe: Feeling Seen, Heard, and Understood" brings together deeply emotional experiences of recipient parent participants; both the pre-programme longing for connection and support (peer-intervention) and the post-programme

reflection on the value of peer support in having met some of those needs and desires. The coding under this theme strongly emphasised the importance and value of shared experiences; both those shared experiences that are difficult, overwhelming, and isolating, and those that are joyful, such as forming friendships, feeling supported and reassured, and finding calm and connection.

From the outset, parents were seeking emotional support and connection with their parent match, hoping for someone who truly understood the challenges of raising a child with complex needs. Pre-programme, parents expressed a strong desire to feel seen, heard and understood. Post-programme feedback confirmed that this need was met, with many parents describing how sharing their stories, frustrations and triumphs created connection with their support parent. Some of the recipient parents reported forming friendships, receiving emotional validation, and having a space to express vulnerability without judgment were key to relieving feelings of isolation and fostering a sense of community.

Table 5.8: Examples Quotes Recipient Parent Theme 1

Pre-Programme Quotes:	Post-Programme Quotes:
"[I'm looking for] support on things that may help in the road ahead."	*"[It was so valuable] to chat once a week to someone in the same if not worse situation than I am in! We totally understood how difficult it can be to have a child with extra needs that none of our friends had experience with so didn't understand!"*
"I want to feel seen and heard, I want to laugh with someone who truly gets it."	*"[It made a difference] having someone to talk to who understands and is empathetic."*

Table 5.9: Essential Elements Recipient Parent Theme 1

Recipient Parent Theme 1: "Finding Your Tribe: Feeling Seen, Heard, and Understood"	
Pre-Programme Essential Elements	Post-Programme Essential Elements
Reassurance and Validation	Shared Experiences
Building Connections	Friendship and Social Connection
Emotional Relief	Humour and Positive Interaction

Pre-Study Essential Elements of "Finding Your Tribe: Feeling Seen, Heard, and Understood"

Reassurance and Validation

In the pre-study responses, parents expressed wanting emotional support and reassurance from peers who understand the unique challenges of raising children with additional needs. They expressed the need for connection, validation, and the comfort of knowing others share their experiences. Many parents wanted to express their feelings openly, without the fear of being judged, seeking understanding and encouragement. Feelings of isolation and being overwhelmed were common among parents and the hope of the peer support programme was to alleviate these negative feelings by connecting with others who genuinely "*get it*". They also reported a sense of gratitude and excitement when given the chance to be part of this parent peer support programme.

For example, one parent stated, *"I want to feel seen and heard, I want to laugh with someone who truly gets it*". Another expressed that "*it will be nice to validate those feelings with someone in a similar position*".

Building Connections

Building connections within a space of authenticity, where parents feel they can show up as they are, was also highly valued. Even anticipating being able to connect with others who do not need an explanation was deemed beneficial, as captured in the pre-study quote from a parent that "*I feel the benefits already. Feeling like I can show up just as I am*".

Some parents also focused on looking to build support and kinship networks, including a parent who stated "*[I'm looking for] support on things that may help in the road ahead*", and another who said, "*I hope that I might also benefit from a feeling of kinship and understanding*".

Emotional Relief

Before the programme, parents also expressed that through peer support they hoped to reduce the sense of being overwhelmed and isolated. Their sense of isolation was very prominent, and they were seeking mutual support from others who understand their journey. They expressed this as an emotional need, and they went into the programme hoping for emotional relief. This was captured in numerous statements such as "*I need to feel more connected and less isolated*", and "*it can be reassuring to know we're not alone*".

Post-study Essential Elements of “Finding Your Tribe: Feeling Seen, Heard, and Understood”

Shared Experiences

In the post-study responses, many recipient parents expressed that the emotional relief and connection they had hoped for had indeed been actualised. They spoke of a sense of relief in having connected with others who were also raising children with complex needs and emphasised that a shared understanding with their peer supporter had fostered a sense of belonging that was often missing in their usual social circles.

This sense of belonging was deep reaching for many participants. The act of sharing their stories, venting frustrations, and celebrating small victories with someone who "*gets it*" helped to reduce feelings of isolation. It allowed parents to express their emotions without fear of judgment, providing them with a sense of resonance and like-mindedness. This is captured in the words of one parent who reflected on the value of being able "*to chat once a week to someone in the same if not worse situation than I am in! We totally understood how difficult it can be to have a child with extra needs that none of our friends had experience with so didn’t understand!*".

A common sentiment was that what made the parent peer support programme valuable to them was "*having someone to talk to who understands and is empathetic*", and one parent felt that *"[Through the programme, I gained] a window into another parent's life*".

Friendship and Social Connection

Post-programme, many parents also reported forming valuable friendships, feeling understood, and finding someone they could speak to openly about their struggles. Many

parents reported that they had gained a friend they could turn to during difficult times, providing both emotional support and companionship.

This element speaks to the potential long-term support benefits of a parent peer support programme, which are unique in that no other form of professional support can potentially offer this. One parent stated of her match that "*we have become good friends. I feel I have gained a good and supportive friend*", and another that they had "*gained a good friend I can speak to openly about my child*". Importantly, parents saw this as a potential resource for problem-solving and moments of future crisis or need, as reflected in the words of one parent that they now have "*a friend I know I could call on if needed*".

Humour and Positive Interaction

The third essential element in “Finding Your Tribe: Feeling Seen, Heard, and Understood” from the post-programme data, was humour and positive interaction. Parents highlighted the importance of humour as a means of breaking the ice and creating a more relaxed environment. For many parents, this was a way to build friendships and find a sense of normalcy amidst the difficulties of raising a child with complex needs. The laughter in their interactions created safe space where they could share stories and feel uplifted.

This demonstrates that humour wasn't just an added benefit, but a vital aspect that contributed to the overall success and impact of the interaction in the peer support experience. This focus on humour and laughter has not previously been reflected in the research on peer support, but evident in statements such as "*lots of laughs were had which is always a win*!" and "*we have lovely chats and great laughs*".

Recipient Parent Theme 2 - Tools for Tomorrow: The Practical Side of Peer Support

"Tools for Tomorrow: the Practical Side of Peer Support" is a theme that brings together recipient parents' desires for and experience of gaining practical knowledge that is relevant to the unique journey of raising a child with complex needs, from someone who is on a similar journey. Like wanting directions up a mountain from someone who has walked it and who knows the intricacies of the path; someone who understands the potential challenges without needing to be told about them, who knows what supplies or resources might be needed for those challenges, and who knows the secrets of where best to find them.

Parents highlighted this need for practical advice on parenting children with specific challenges, such as Autism and Dyspraxia. They sought guidance from those who have similar experiences with their children and wanted to learn more about community resources, services, and future planning for their children. Importantly, recipient parents also wanted to gain a deeper understanding of their child's perspective and to understand their child in a deeper way; this desire for understanding was highlighted by parents in conjunction with a hope of enhancing their ability to support their child's development effectively.

Parents reflected that peer support had provided valuable knowledge and resources, which were now helping them navigate the challenges of parenting a child with complex needs. These practical benefits included knowledge exchange, strategies, and signposting new resources. This tangible support had also enhanced their confidence in navigating their children's needs and offered hope for the future.

Table 5.10: Example Quotes Recipient Parent Theme 2

Pre-Programme Quotes:	Post-Programme Quotes:
"[I'm hoping for] really, the full range, especially coping strategies for oppositional behaviour."	*"[I] came to know about a couple of support systems available for my child, especially when transitioning to secondary school."*
"I hope to gain a better understanding of the services available for my child."	*"[My match provided] information on some (voluntary) supports I hadn't been aware of."*
	"[I gained] confidence in continuing to do us! I doubted myself at times, but speaking to someone in a similar position made me realise no one knows our kids like we do."

Table 5.11: Essential Elements Recipient Parent Theme 2

Recipient Parent Theme 2: "Tools for Tomorrow: The Practical Side of Peer Support"	
Pre-Programme Essential Elements	Post-Programme Essential Elements
Parenting Advice	Practical Advice and Resource Sharing
Community and Professional Supports	Gaining Confidence
Understanding my Child's Perspective	Future Perspective
Future Planning	

Pre-Programme Essential Elements

Parenting Advice

In the pre-programme questionnaires, recipient parents expressed a desire for advice tailored to their unique situations, wanting to learn from others who have navigated similar challenges. This advice included strategies for managing behavioural issues, emotional dysregulation, and other day-to-day difficulties.

Some parents sought general advice, for example one parent wanted to "*get some good advice regarding parenting a child with ASD & Dyspraxia*", and another wanted to "*learn from others' experiences*". Others, however, also had more specific advice desires, most commonly in relation to behaviours that challenge. One parent was seeking "*really, the full range [of advice], [but] especially coping strategies for oppositional behaviour*", and another expressed that "*dealing with a child who has high emotional regulation concerns can be challenging. I am hoping to get help regarding this*".

Community and Professional Supports

Pre-programme, recipient parents communicated their need to learn more about available services and supports. Some of these parents were on waitlists for CDNT services, and some of them had very little access to support resources of any kind for their child or themselves. They wanted to gain insights from others who had successfully accessed community and other resources, understand how disability services operate, and to learn how to advocate effectively for their child's needs.

While some of them focused on current supports, such as the parent who said "*I hope to gain a better understanding of the services available for my child*", others were also looking forward to the future, including the parent who said "*I'd love to learn more about what opportunities and supports there are for teens going forward*" and the parent who wanted to "*understand the future pathway better for my [child]*".

Understanding My Child's Perspective

Recipient parents also expressed hope that peer support from parents of similar children would help them gain a deeper understanding of their child's perspective. They expressed

wanting to see the world through their child's eyes to provide more effective support. This included wanting advice on how to cope with challenging situations, and an awareness that other parents may have insights on how to interpret and respond to the unique needs of children with complex disability.

One parent stated that they sought "*greater insight into how [my child] sees the world and how to help him deal with it more effectively*", and another said they wanted to "*get insight and maybe some new ideas on how to handle situations with our daughter. Learn from other's experiences*". This beautiful and generous sentiment is expressed well by the parent who stated simply "*I am hoping that I will be able to understand my son's needs better*".

Future Planning

Parenting a child with complex disability inevitably means helping that child forge a unique path through life, that may look different to the path of a typically developing child. A future focus was important to recipient parents, because many expressed concerns about future pathways for their children, hoping to gain knowledge that will ease anxiety and support future long-term planning. As one parent said, in relation to future planning, "*I am hoping that I will be able to understand my son's needs better and be in a better position to help him*".

Post-Programme Essential Elements:

Practical Advice and Resource Sharing

Post-programme data from recipient parents reflected that many of their hopes and desires for “Tools for Tomorrow” had been realised. Parents said they had gained practical advice, including information about support systems, parenting strategies, and voluntary services, especially during transitions. One parent said they "*came to know about a couple of support systems available for my child, especially when transitioning to secondary school*". This valuable information was new to them, and they had not been exposed to or able to access it previously.

As one parent said, they gained “*information on some (voluntary) supports I hadn't been aware of*", and another found out about community-based activities appropriate for their child; specifically, that "*the local SEN youth club had a junior section*". These resources and supports are not of need or interest to most of the people in the recipient parent’s usual social circles (i.e.. family, friends without children with complex needs), and professionals are likewise often unaware of broader community supports and informal networks, so peer support from a parent who was also seeking the same supports in the community was viewed as extremely valuable.

Gaining Confidence

Another element of the theme “Tools for Tomorrow: The Practical Side of Peer Support” was “*gaining confidence*”. Engaging with other parents who faced similar challenges, “*someone to talk to who understands and is empathetic*", helped them recognise their strengths and validate their own approaches to parenting, which, in turn, boosted their

confidence in their abilities. As one parent said, they gained "*confidence in continuing to do us! I doubted myself at times, but speaking to someone in a similar position made me realise no one knows our kids like we do*".

Future Perspective

For many parents, interacting with other parents, especially those with older children, offered a glimpse into the potential path of their own child's development. This exchange of experiences provided hope and a sense of direction. Seeing how other parents had managed certain stages helped alleviate some of the anxiety and uncertainty they felt about their child's future. As one parent said, "*my children are younger [than my supporting parent's children], so [it gave me] some hope that it may get easier in the future",* and another phrased this as having gained *"a sense of perspective*."

Recipient Parent Theme 3 - The Juggling of Parent Caregivers (Carving out Time/Guilt)

The theme "The Juggling of Parent Caregivers (Carving out Time/Guilt)" highlights the challenges parents' face, in relation to time constraints and emotional struggles brought up by these time constraints. Parents highlighted a sense of tension and stress due to the challenge of finding a balance between their child's needs and their own, especially while trying to prioritise self-care. They understand the importance of balancing their children's needs with their own well-being but struggle to do so.

Post-programme, parents still spoke of significant challenges in managing their time, balancing the demands of caregiving, and handling unforeseen personal events that impacted their time to participate in the project. Overall, this theme was influenced by

various external factors, including time constraints, family responsibilities, and personal life challenges. Addressing these barriers explicitly with their support parent and ensuring flexibility in participation, was crucial for a more supportive experience.

Table 5.12: Essential Elements Recipient Parent Theme 3

Recipient Parent Theme 3: The Juggling of Parent Caregivers (Carving out Time/Guilt)	
Pre-Programme Essential Elements	Post-Programme Essential Elements
Time Management	Time Management
Emotional Challenges and Growth	Family and Care Responsibilities
	Personal Life Events

Pre-Programme Essential Elements

Time Management

Before the programme, recipient parents expressed their struggles with balancing their time between caring for their children, managing other family responsibilities, and attending to their own self-care needs. Finding time to participate in this parent peer support programme was a key concern. Parents spoke of worrying about "*finding the time to participate and feeling guilt at being away from my family during the meetings*", as well as wondering "*how to get more hours in the day*".

Emotional Challenges and Growth

On the pre-programme questionnaire, recipient parents expressed concern about opening up to their supporting parent on personal matters and spoke about how being vulnerable in front of strangers can be daunting. For example, one parent said, "*I can get*

quite emotional about personal struggles, so that may be uncomfortable for a stranger". This was balanced, however, by participants also anticipating personal growth and emotional relief by sharing their experiences in a supportive environment. In the words of another parent, "*I feel I will be a better parent and a more grounded me*" after the parent peer support programme.

Post-programme essential elements:

Time Management

Post-programme, rather than finding their worries about time management had been alleviated, parents said that they still faced significant challenges in managing their time, balancing the demands of caregiving and busy family schedules, and handling unforeseen personal events that impacted their time to participate in the project.

For some, this had led to feelings of guilt about taking up their peer supporter's time and they worried that they had not being able to commit fully. Overall, this element was influenced by various external factors, including time constraints, family responsibilities, and personal life challenges. Positively, some recipient parents were able to address these logistical barriers explicitly with their support parent, and found the supporting parent to be flexible, which allowed for success in the programme despite setbacks.

Parents said they had had difficulty "*finding the time to commit to the planned meetings*", that "*sometimes [they] found it hard to find the time for the telephone calls and also felt guilty that I was taking up too much of [the supporting parent's] time*", and others simply struggled with "*finding time to meet*".

This can be considered alongside the quantitative survey finding that a large negative change was seen on the item "*I feel my choice and control are restricted due to my parenting responsibilities*". Together, these indicate a very significant finding of the study: that even a supportive opportunity like a parent peer support programme needs to be designed and considered within the context of the significant caring demands of parents of children with complex disability.

Family and Care Responsibilities

Related to the more general element of time management were specific concerns about finding childcare or leaving others in charge of their child, while they took the time for meeting their parent match, particularly for parents with younger children. For example, an evening meeting left one participant's spouse/partner handling dinner, bath, and bedtime routines alone, increasing stress and creating a sense of guilt for not being present for those tasks. In their own words, it was difficult "*finding the time to participate and feeling guilty that this left my partner under pressure while I was away - we could only meet in the evenings and with two small children, dinners, baths, and bedtime are really a two-person job at the moment*".

This highlights the need for flexible support structures that can adapt to the dynamic family life, and highlights that childcare concerns are a very real concern, if not a barrier for parents seeking and wanting peer support, or any other supports. As one parent said, the most difficult aspect of the programme was "*finding care in order for me to take the time out to meet*", so any future parent peer support programme should take this into consideration in design.

Personal Life Events:

During the 12-week parent peer support programme, several recipient parents also faced unforeseen personal events, such as bereavements, health issues, or changes in family routines. These events not only made engagement more challenging but also underpinned the importance of flexibility within the peer support model. For one participant "*it wasn't easy to finalise all the meetings as my Dad passed away, and my daughter had to go to hospital in Dublin, but we managed to complete it, and my peer support parent was very understanding*". For another parent, they reflected that "*I think the timing is probably a confounding variable for me - we had an extremely difficult summer, and my son became very dysregulated with the change in routine from school*".

Recipient Parent Theme 4 - The Magic is in the Match: Finding the "Right Fit"

The fourth theme for the recipient parents, also present as a theme for the supporting parents, was "The Magic is in the Match: Finding the "Right Fit"". This theme represents participant reflections about the success of peer support, relying heavily on the compatibility of the matches. While some parents experienced a very high level of match compatibility and connection, others felt that differing circumstances, geographical distance, and mismatches in experiences limited the supports' effectiveness.

This theme, named after a catchphrase used in the P2P USA training - "the magic is in the match" - confirms that what is relevant in the experience of parent peer support programmes in other contexts, is also relevant to parents in the Irish context.

Table 5.13: Essential Elements Recipient Parent Theme 4

Recipient Parent Theme 4: The Magic is in the Match: Finding the "Right Fit"	
Pre-Programme Essential Elements	Post-Programme Essential Elements
Finding the "Right Fit"	Shared Understanding and Compatibility
	Preference for Local Matches

Pre-Programme Essential Elements

Finding the 'Right Fit'

Pre-programme, many recipient participants stressed the importance of connecting with others who have shared experiences and values. They felt that a 'good fit' in peer support relationships is crucial for effective mutual support. One parent said that "*I think it might be hard to find the right person. To find a 'good fit' with a parent whose child has the same level of support needs*", indicating apprehension about whether someone else would really understand the complexities and intensity of their circumstance, while another recipient parent worried about a potential "*mismatch with parents and having differing values*".

Post-programme essential elements

Shared Understanding and Compatibility

Post-programme data for recipient parents reflected that those who felt that they had been well matched with parents with experiences quite similar to their own, reported a more positive support experience. This reflects variability within the population of parents of children with complex disabilities; there are many varying diagnoses, many levels of support needs, many cultural and family backgrounds, differing educational

levels and personalities, differing religions, differing gender identities, differing social classes etc.

For those parents who felt there had been mismatches in personal circumstances, child age gaps, types or levels of needs of the child, or parenting experiences, they also felt this had sometimes limited the relevance of the support. One parent reflected that "*our [my peer supporter's and my] circumstances are very different, so I didn't get what I was really looking for from the meetups*".

Even those parents who had had good matches, however, emphasised the importance of match. In the words of a well-matched recipient parent, "*I think the success of peer support also relies heavily on personal relationships - I did 'click' with my peer support partner, which meant I opened up to her, but this might not be the case for everyone*".

Some parents reflected that an important component of matching is also a consideration of ensuring the supporting parent is at a more advanced stage in their journey; while efforts were also taken to ensure this (supporting parents were several years post diagnosis or service commencement), it may have been that, due to waitlists and diagnosis delays, some recipient parents had actually been parenting their child with complex needs for many years, albeit without a diagnosis or access to services. In the words of a parent *"It was helpful but would be more helpful if there was a greater difference between the level of experience of the two participants*".

Researchers were aware of the importance of strong matching and arranged matches with similar profiles to the maximum extent possible. However the small sample size within this pilot, meant that matching on multiple variables was not always possible. The

strength and salience of this finding in the experience of participants, however, underscores the importance of putting significant effort and value on the matching process of a parent peer support programme.

Preference for Local Matches

Relatedly, an important post-programme reflection of recipient parents was on a 'Preference for Local Matches". Geographic proximity was highlighted as a very important factor in a peer support programme, with many (though not all) expressing a preference for in-person meetings as opposed to remote ones.

In relation to proximity, one parent said that "*the main challenge is we live in different counties, so had to do video calls... if we lived in the same county, we could have met for coffee, which would've been a lot better!*" This sentiment was echoed by another parent who said that *"It would be much better, if possible, people could be matched that live in the same county*". Another parent said that "*I would have liked the project to be one-on-one parenting help rather than online and more locally*".

5.2 Group 2 Results: Supporting Parents

Qualitative Results: Supporting Parents

From the two focus groups held with supporting parents, both pre- and post-intervention, five important themes emerged and are presented in table 5.14 below:

Table 5.14: Themes Group 2 Qualitative Results

Theme 1	*"To be the Hope We Once Needed"*
Theme 2	From Fear to Fulfilment: Finding Strength in Connection
Theme 3	From Parent to Peer Supporter; Confidence Through Training
Theme 4	The Magic is in the Match
Theme 5	Impact of Supervision on Experience

Again, each theme is an over-arching description amalgamates together participant experiences in a meaningful way but is also composed of essential elements that were coded in the development of the themes. Each theme will be described, and then the essential elements that compose the theme will be detailed, with supporting quotes from participants.

Supporting Parent Theme 1 - "To be the Hope We Once Needed"

The theme "*To be the Hope We Once Needed*" signifies support parents' wish to share their lived experience and to offer someone else in a similar position a supportive space. The essence of this theme relates to support parents' reflections on their own personal journey of becoming a parent to a child with complex needs, and what they needed at particularly challenging times.

This theme represents the value participants place on creating a sense of community and was communicated via terms and phrases which depict imagery of travelling "*the same journey*" and being "*in the same boat*". "*To be the Hope We Once Needed*" also encompasses the unique emotional challenges and responsibilities associated with the supporting parent role, such as balancing the emotional investment and desire to give back with the reality of one's own responsibilities.

Table 5.15: Example Quotes Supporting Parent Theme 1

Pre-Programme Quotes:	Post-Programme Quotes:
"I feel I've some lived experience to share."	*"It was good to be, actually be able to chat to somebody and know that they know... you know?"*
"Well I would hope to give them some hope."	

Table 5.16: Essential Elements Supporting Parent Theme 1

Supporting Parent Theme 1: "To be the Hope We Once Needed"	
Pre-Programme Essential Elements	Post-Programme Essential Elements
Creating a Collaborative Community.	Positive Connections and Emotional Support.
Shared Lived Experiences.	Sense of Community.
Instilling Hope.	Balancing Emotional Investment and Responsibilities.
Providing a Safe Space.	

Essential Elements Pre-Pilot:

Creating a collaborative community

Supporting parents reflected on the sense of inclusion and collaboration when discussing their participation in the Parent Peer Support Pilot Project up to this point, particularly in the context of the training they received. They felt the training sessions had been a safe and supportive environment within which they could share their stories, fostering trust and reducing feelings of isolation.

Moreover, they valued that the training facilitated a sense of co-creating the project - reflected in statements like *"[what was valuable] was the collaborate piece*" and "*It just*

felt like we're a part of the project. You know it just felt like the training was almost like co-created. It felt like we were part of it".

Parents valued that the training drew heavily on the sharing of experiences and stories, including those of the trainers, and this fed directly into the sense of a collaborative community. As another parent said, "*because it felt... yeah, like a community. I thought that the training was a good balance of us being able to share some of our own lived experience*".

This community, or intentionally cultivated space of sharing lived experience, held significant emotional impact for supporting parents; they felt it was a space created by parents, with parents, and for parents of children with disabilities. One parent said, "*we're all part of this whole group together, which is really good", while another said, "it's good that we're all like... kind of like on the same boat*".

Shared Lived Experiences

A significant motivator for supporting parents was the desire to help others in similar situations. Parents wanted to share insights from their own journeys, offering reassurance that feelings and situations can change over time. They emphasised the importance of learning from each other's experiences and gaining confidence and courage to navigate the complexities of raising a child with complex needs. One parent said "*I know every child, every situation, isn't the same. But if it's the journey that we travelled that we .. we could pass on... maybe our experiences*", while another wanted to give a newer parent reassurance "*that they're not alone*".

Another parent reflected on how they experienced periods of difficulty in earlier years of raising their child, but have increased well-being currently and see their own growth as a source of value to others; "*I'm much better now compared to when it happened at the start... I feel I've some lived experience to share*". Others identified specific needs that they know, through lived experience, are essential on the journey, such as the parent who wanted "*the chance to be that 'one good listener'* for someone, coming "*from a place of lived experience*", or the parent who identified specific areas of expertise they had developed, saying "*I feel I have a lot of experience with regard to services, schools, behaviours, sensory issues, etc*".

Interestingly, for some supporting parents, the peer support pilot resonated with something they had longed for in the past, as captured in the words "*I used to think 'God there really should be something where you could go and speak to another parent or you know somebody who was in the same situation as you or whatever'* ...and um... and then *when this came, I was like okay I better try and be part of this*".

Instilling Hope

The support parents also explicitly discussed a strong wish to instil hope and positivity in the recipient parents. They wanted to show that life with children who have additional needs, despite challenges, can still be very much fulfilling. The drive to provide hope came from their own experience of needing encouragement during difficult times. For example, one parent said, "*I hope they achieve a sense of hopefulness for the future... that they will feel that I was nodding knowingly not just supportively*", while another wanted to pass on "*just the hope and self-belief that they have got this*".

Providing a Safe Space

Supporting parents emphasised the importance of creating a non-judgmental environment where parents can freely share their concerns and emotions. This safe space was described by participants as somewhere recipient parents could be "*totally honest*" and "*say whatever they want*".

This is important as it was a salient element for almost all supporting parents, indicating a deep awareness of the importance of this safe space to express and work through things that may not be safe to express in any other environment. For example, one parent desired that their match could "*be totally honest with how they're feeling and get... get all that emotional baggage out for that time that they're with me*". Another said *"[my match] can say exactly what they want and maybe express their worst fears or you know..."*.

Supporting parents expressed an understanding of the value of having one's feelings heard and validated, as evident in the words "*probably I would love if the person felt um... heard. You know, so that they could say whatever they wanted to say. And not as alone*". They also realised, however, that this vulnerability to share in a safe space can take time, as another parent wanted to give their match "*permission to take it slowly, and to feel, own, overcome and learn from all the raw and unexpected emotions*".

Essential Elements Post-Pilot

Positive Connections and Emotional Support

After the parent peer support programme, support parents reflected on how they had formed meaningful relationships that provided emotional support, with some matches leading to friendships. Most supporting parents described their meetings as "*just really,*

really natural. I really looked forward to the actual meetings" or as "*just like going to meet one of my girlfriends*".

The shared challenges and similar experiences between the parent matches created a sense of camaraderie. Most support parents expressed enjoying the company of their match parent, as captured in statements such as "*we really had a lot in common, and we got on really well*" and "*it was nice to have shared experiences*".

For some (but not all) matches, the Parent Peer Support Pilot Project created lasting connections that will continue post-programme, captured in quotes such as "*I've definitely made a really good friend out of this*", "*we're good mates now, and we will continue that*", and "*it was lovely to be there to support her, and we have built a strong friendship*".

Sense of Community

As anticipated pre-programme, a palpable sense of community and understanding was articulated post-programme by support parents, in their reflections of their time spent with their parent match. The following quotes represent participants' expressions of how meaningful it felt to foster shared experiences with another parent, when you "*know that they know... You know"?*

This sense of community was highly valued and meaningful, with participants saying, *"I found it - just the sense of community, you know, like it was for me, the experience was very meaningful, and it felt just right*". This building of community came easily from the

points of connection between the matches, as captured in the quote, "*it was just easy to be there for somebody with a similar lived experience.*"

Balancing Emotional Investment and Responsibilities

While experiences were overwhelmingly positive, there were challenges reported. One of these was the intense emotional impact of reflecting on their own parenting journey and having it "*bring up stuff*" for them.

As one parent said, *"I actually got very emotional at the beginning of, I think after my first meet up with her, because I went back to like we ended up doing our birth stories and stuff like that. And for me, I got a post-natal diagnosis from my son, and she had had a prenatal. I did go through quite an emotional, you know, week or so, just kind of, umm, I think I just went back to that stage and kind of felt very sorry and sympathetic for myself*".

For some, the responsibility of their role as a support parent felt excessive at times and resulted in fatigue. One parent said, "*Two hours of listening… and because it is emotional and it is bringing up stuff for me as well, you know, I think [that was] the challenge*".

For others, the challenge was in struggling with the weight of responsibility they felt, particularly within their first meetings with their parent match. This sense of pressure and responsibility is captured in the words "*because I kind of had put so much responsibility on myself to listen. You know, I was asking all the right questions. You know, I just kind of felt like I went in with almost too much responsibility, and I came away absolutely exhauste*d".

Others found the balancing of the emotional investment was in not trying to force the recipient parent to feel a certain way or to rush their process. One parent said "*I found I*

had to stop myself being too positive… I needed to make sure that I was listening to her and keeping it where she was", while another reflected that "*I really do need to concentrate and, you know, make them feel that it's about the support we're giving them*".

Supporting Parent Theme 2 - From Fear to Fulfilment: Finding Strength in Connection

The theme "From Fear to Fulfilment: Finding Strength in Connection" represents the journey and emotional growth experienced by supporting parents in their own parental journey; past challenges, acknowledging how far they have come, and continued growth through the parent peer support programme.

When introduced to the project, parents felt an immediate connection, finding it to be a *"fabulous idea"* that resonated with their own experiences. Many of the parents resonated with the project, recognising it as something they wish they'd had, filling a gap they had identified during their own parenting journey, and viewed it as an opportunity to reflect on their own progress.

What is also captured here, and perhaps was unanticipated, was the emotional and personal growth that supporting parents experienced throughout the peer support process.

Table 5.17: Example Quotes Supporting Parent Theme 2

Pre-Programme Quotes:	Post-Programme Quotes:
"You know you do move forward. Some forward moves may take years. But there are little movements. You know, forward all the time."	*"It made me more resilient as I reflected on my own past."*
"I'm not as afraid as I used to be."	*"It reframed a lot of things for me....it paints them in a more positive light."*

Table 5.18: Essential Elements Supporting Parent Theme 2

Supporting Parent Theme 2: "From Fear to Fulfilment: Finding Strength in Connection"	
Pre-Programme Essential Elements	Post-Programme Essential Elements
Lived Experience of Emotional Growth	Reflections on Personal Growth
Recognising Past Need	Satisfaction in Giving Back
	Strength, Resilience and Growth through Supporting Others

Essential Elements Pre-Pilot

Lived Experience of Emotional Growth

Pre-programme, supporting parents reflected on their personal progress and emotional acceptance, recognising the journey from initial fear to a new sense of normalcy. They express how navigating their journeys has led to self-growth and fulfilment, and now they hope to use their experience to support others. One parent said, "*It's been going on for about 4 years... So about 4 years in and I'm not as afraid as I used to be*", while another reflected that "*Like now, it's totally normal that my [child] is the way [they are] and I'm really proud of [them]... and I love [them]*".

The sense of time for this growth to take place was acknowledged and captured in the quote "*You know you do move forward. Some forward moves may take years. But there are little movements. You know, forward all the time*".

Recognising Past Need

Importantly, many parents reflected on past needs that they had in their own journey, also tying into the previous theme of "*to be the hope we once needed*". This element represents support parents' recognition of the importance of peer support, and their readiness to offer the empathy and guidance they had longed for in their early parenting stages.

One parent reflected, "*I would have loved if it was available when I started my journey with my [children]*", while other parents pondered "*Why wasn't this already there for us at the start of our journey?*" and said that it "*made a huge difference to us as a family and the journey we were on, so I was keen to reciprocate*".

Essential Elements Post-Pilot

Reflections on Personal Growth

Interestingly, supporting parents reflected on the personal growth they had experienced stemming from their participation in the project. Participation had prompted them to reflect on their past emotional experiences and to consider them as something potentially useful to another, facilitating continued reflection and personal growth.

Some participants found that revisiting past experiences helped them reframe those memories. For instance, one participant shared how "*it reframed a lot of things for me….it*

paints them in a more positive light", while another said, "*It brought back things to me….and it was good*", highlighting the programme's role in personal development.

The process of reflecting on how far they had come allowed participants to appreciate their growth and resilience, as captured by the quote, "*It encouraged me to reflect on my own journey and where I am now*".

Satisfaction from Giving Back

Post-programme, supporting parents reported feeling fulfilled and said they appreciated the opportunity to make a positive impact on their recipient parent's life. One parent said, "*It was great to pass it on to someone else….to help someone*", while another said they had derived "*a real sense of achievement from doing it*", and a third reflected that "*it was really nice to feel like I made a difference in someone else's life*".

Strength, Resilience and Growth through Supporting Others

The reflective nature of the programme, particularly through supervision, empowered support parents in their own growth and in developing *emotional resilience.* One parent said*, "I* learned a lot from my match, and it helped me grow", another said, "*The supervision helped me process my feelings and become stronger*", and yet another, "*It made me more resilient as I reflected on my own past*".

Support Parent Theme 3 - From Parent to Peer Supporter; Confidence through Training

Theme 3 represents the impact of training on the support parent role. It presents participants' thoughts and experiences on what worked well and what could be changed

to enhance training for future iterations of a parent peer support project. Overall, participants felt competent and prepared for their role supporting their match parent, attributing their readiness to the thorough and professional nature of the training. This theme further represents parents' appreciation for the clarity of information, preventing participants from feeling too overwhelmed. The resources which were provided during the training were described as valuable tools for ongoing support.

Table 5.19: Example Quotes Supporting Parent Theme 3

Pre-Programme Quotes:	Post-Programme Quotes:
"I feel prepared from the training certainly and from the sessions as well."	*"It gave me the confidence I needed."*

Table 5.20: Essential Elements Supporting Parent Theme 3

Support Parent Theme 3: "From Parent to Peer Supporter; Confidence through training"	
Pre-Programme Essential Elements	Post-Programme Essential Elements
Preparedness	Assurance through training
Reassurance in Resources	Community Connection
Clarity in Roles and Boundaries	Effective Use of Practical Tools
	Authenticity in Training

Essential Elements Pre-Pilot

Preparedness

Participants expressed feeling equipped and ready for future tasks due to the thoroughness and clarity of the training provided. When asked about the training and if

they felt prepared, one parent said, "*I personally feel competent going forward*", and another said, "*I feel… yeah, prepared and ready*".

This is important feedback for continuing parent peer support programmes for this cohort of parents, as another said, "*It was really good, just very.. very concise and covered all angles I think*", and another, "*I feel prepared from the training certainly and from the sessions as well*".

Reassurance in Resources

Resources provided during training, including those co-created with the supporting parent group, gave a sense of security to support parents in their role. The importance of clear protocols and resources are captured in the quotes, "*I do feel reassured. Like I feel… to trust the process. You know there is protocols, there is training, and we have lived experience you know?*", and "*I found the training very in-depth and the handouts/resource pack will guide me as I progress through my meetings with parents*".

Clarity on Roles and Boundaries

Pre-programme, an essential element of training and preparation was creating clarity regarding their role as a support parent; what the role was, but just as importantly, what it wasn't. The significance of this clarity on roles and boundaries is captured in the quote, "*Now in fairness, we have done a lot of training sessions and all of that to know how much of a boundary we need to set and everything*".

Another parent reflected, "*I feel it was good training and it answered a lot of my questions with regard to boundaries, I feel prepared to listen and allow this person to just talk*". This

clarity also gave a sense of safety and confidence to parents: *"I'm just really glad with the training that it is very… I know now that I can't do that. So, I feel very safe for myself in that*."

Importantly, although the training was comprehensive, it wasn't prescriptive, and care was taken in providing a manageable amount of information, which was important to one parent who said, "*I thought it was very clear what our role is. And [the training was] not too overwhelming. And not too much information where you're kind of going 'ooh!' you know? It wasn't too overwhelming; it wasn't too much*".

Essential Elements Post Pilot

Assurance Through Training

Post-programme, reflecting on their training, supporting parents generally reported they had felt well-prepared for their roles and praised the comprehensiveness of the training they received. These reflections on their training at the post-pilot stage illustrate the impact of this on the confidence and readiness of support parents to meet their matches. Such assurance is evident within the following participant quotes: *"It gave me reassurance going into the match… I did find it very helpful*" and "*It gave me the confidence I needed*".

Community Connection

The training sessions not only equipped participants with knowledge but also fostered a sense of community and mutual support. The collective and collaborative nature of the training experience worked to create a sense of belonging and shared purpose. As one parent said of the training, "*I felt energised…coming away feeling, oh, wow, I'm part of something big here*", and another "*It was nice that we met in a group as well…to see the faces behind the project, and also the people within it*".

This is important information for considering future models of training for parent peer support programmes; especially for a programme with rolling enrolment, creating training cohorts would potentially be advisable.

Effective Use of Practical Tools

Post programme, support parents expressed appreciation for the practical aspects of the training, such as visual aids and structured documentation, which helped solidify their understanding and provide ongoing support. These tools were crucial in helping participants feel equipped to handle their roles effectively, as evident in the following statements: *"[It was helpful] having that kind of - the visual printout, you know, again, that you could kind of go back on it*".

Importantly, the co-created contract defining roles, as suggested by parents in the training, proved to be a very valuable addition to the pilot model. When asked what was valuable about training, one parent mentioned, "*The kind of document that we both signed…it did start to state what we should and shouldn't be doing*".

Authenticity in Training

Participants valued the authenticity of the training experience and appreciated that the trainers also had lived experience of raising children with complex needs. This authenticity added depth, made the training feel more relevant and helped participants connect more deeply with the training material. As one parent said, "*There was just an authenticity to this [pilot programme] … it didn't feel like just a piece of research, or just a piece of work*". This is important to consider for future programmes, as the positionality of the trainers as parents of children with complex needs was brought up many times

throughout the data as a valuable agent in creating cohesion and a collaborative community.

Support Parent Theme 4 - The Magic is in the Match

The theme "The Magic is in the Match" was relevant not only to the recipient parents but also to the supporting parents. This theme represents the strong preference for peer support matches to be tailored based on the compatibility of both parental characteristics and their children's unique needs.

Participants expressed that matching based on similar diagnoses lead to more relatable experiences and deeper connections. This theme also represents experiences regarding the meeting format and the challenges of parent peer support matches where parents are from different counties and therefore met online, rather than in-person. Notably, this theme was apparent only within the post-pilot data, after support parents had completed their match meetings and supervision sessions.

Table 5.21: Example Quotes Supporting Parent Theme 4

Pre-Programme Quotes:	Post-Programme Quotes:
n/a	*"Matching based on diagnosis could help create more relatable experiences."*
	"It was difficult to build the same connection through a screen."

Table 5.22: Essential Elements Supporting Parent Theme 4

Theme: "The Magic is in the Match"	
Pre-Programme Essential Elements	Post-Programme Essential Elements
n/a	Proximity and In-Person Meetings
	Matching based on Child's Diagnosis
	Proposals for Customisable Matching
	Enhanced Training for Diverse Matches

Essential Elements Post-Pilot

Proximity and In-Person Meetings

Post programme, supporting parents emphasised the importance of geographic proximity in the matching process and the capacity to meet in person. The home of the recipient parent, coffee shops, and meeting outdoors for a walk were the primary meeting places of matches based in the same county. Many felt that being able to meet their match in person significantly enhanced the effectiveness of the interaction. As one parent said, "*We met for coffee and one or two walks. It was primarily face to face. So it was wonderful, absolutely wonderful", and another, of walking with their match*, "*It felt it kind of gave us a different energy*". Privacy was also valued, captured by the quote, "*We met, actually in her house, and it was lovely, because it was very private and easy to talk*".

Matches who met online, rather than in person, were viewed as less beneficial, highlighting the need to consider location in future iterations of the project. One parent who met virtually said, *"It was hard because it was, it was online or it was over the telephone and was no... I felt that I might have been of more help if I was in person*". Another who met virtually said, "*Bringing the cup of coffee to the computer just didn't feel, you know, it kind of just didn't feel kind of natural*".

Matching Based on their Child's Diagnosis

While again, every effort was made to make good matches, due to the cohort size, matching on all dimensions wasn't always possible. One dimension that was emphasised as important by some supporting parents post-programme was the feeling

that their match would have been more beneficial if it had been based on the similarity of the children's diagnoses.

This is evident within the following quotes from support parents who were matched with a parent whose child had a different diagnosis to their own (which occurred in three out of ten matches). One said, "*I suppose our circumstances were very different. The diagnoses are different, and the stage at which they were received were very different, too. I think it would have been a different and probably a deeper experience for both of us if I had had a parent with the same diagnosis*", and another that, "*It would have been better if the match had similar experiences*".

In keeping with this, parents who had been matched with parents of a child with a similar diagnosis to their own child, spoke to the importance of this. One parent said, "*I do feel personally it was good to be matched with somebody with a similar diagnosis*".

Support parents acknowledged the challenges within the matching process in this study, expressing that ideal matches were difficult to achieve due to the varying needs and the limited number of participants. Such acknowledgements were communicated via quotes such as, "*You're kind of at the mercy of who signs up*", and "*It's hard to find the perfect match given how diverse everybody's needs are*", and "*Sometimes it's just not possible to match perfectly, and that's okay*".

This reflects that parents do express flexibility and understanding around match variability, but the preference for strong matching across multiple child and parent dimensions is also clearly expressed.

Proposals for Customisable Matching

Some support parents suggested that a more customisable approach could improve compatibility and lead to deeper connections. Such an approach, it was suggested, could take into account the child's diagnosis, parental preferences (i.e.. location, preferred modality of meeting, cultural background, language) and could potentially improve the matching process and enhance participant satisfaction. Parents had innovative ideas here, such as, "*If there was a way like a dating app to express preferences for a match… that might be good*", or "*a system where you choose based on your preferences"* might improve compatibility. One parent said, "*It would be great to have more control over who you're matched with*", and future iterations of a peer support project would be advised to consider such suggestions regarding match compatibility.

Enhancing Training for Diverse Matches

Match compatibility/diversity was a very strong concern and theme for parents, and supporting parents also made suggestions for improving the training provided to support parents in relation to diversity within matches. As some diversity in matching is inevitable, this is an important consideration to improve training going forward.

Parents suggested including more scenario-based work during training, thinking through potential situations where they might be matched with someone with a different experience or different diagnosis, as illustrated in this quote, "*Maybe if there was just a little extra focus on…imagine you're paired with someone, and they don't have the same diagnosis. A discussion around…how do you think that's going to be challenging* ".

Supporting Parent Theme 5 - Impact of Supervision on Experience

Post-programme, supporting parents reflected on the supervision provided by Enable Ireland staff members during the Parent Peer Support Pilot Project. The supervision was generally well-received, with participants describing their experiences as supportive and beneficial.

The theme of "Impact of Supervision on Experience" captures the overwhelmingly positive sentiment and sincere appreciation of support parents for the dedicated time their supervisors provided. This theme further represents participants' perspectives on the mode of supervision, in addition to some varying reflection on the necessity, or lack thereof, for this as an essential element of the programme.

Table 5.23: Example Quotes Supporting Parent Theme 5

Post-Programme Quotes:
"I got an awful lot out of it. I just felt, you know, they really were listening."

Table 5.24: Essential Elements Supporting Parent Theme 5

Supporting Parent Theme 5: "Impact of Supervision on Experience"	
Pre-Programme Essential Elements	Post-Programme Essential Elements
n/a	Supervision Viewed as Very Beneficial
	Challenges with Remote Interactions
	Necessity of Supervision

Essential Elements Post-Pilot

Supervision viewed as Very Beneficial

Some participants felt that supervision was a highly beneficial and supportive aspect of the programme. They valued the dedicated time and support provided, viewing it as a

significant positive element of their peer support experience and feeling seen; as one parent put it, "*I thought it was a privilege…it was amazing to have that hour*".

The emotional support which supervision offered was identified as particularly significant by support parents, as evident in the quote, *"[The supervisor] was brilliant, and [they were], you know, really supportive and kind of enthusiastic and positive*".

Parent responses also hint at the type of role that supervisors also played, largely in terms of emotional support and facilitating reflection. One parent said, "*I don't know [if] maybe she has heard [what it's like for parents] before, but she's, she saw me, you know, I got really emotional with her about, you know, the start of my journey with my son*", and another that "*I found [the supervisor] very good, because at the start I was kind of, because that emotional piece, I suppose*".

Challenges with Remote Interactions

The mode of supervision, particularly whether it was online or in person, significantly influenced participants' experiences. While some appreciated the convenience of online meetings, especially when balancing other commitments, others found them less effective compared to face-to-face interactions.

The two sides of this situation are both captured in the quote, "[*Meeting online] wasn't as comfortable, but…I probably would have found it really difficult to make time to physically go somewhere*".

Necessity of Supervision

Despite the general positivity towards the supervision process, some participants debated the necessity of supervision, particularly if they did not encounter significant

challenges. One participant indicated that while appreciated, supervision might not have been essential for everyone. In their view, *"[Supervision] was nice, but I don't know, I wouldn't say for me, it was really necessary*".

Support parents' own professional experiences may also impact this, as suggested in the words of another parent, "*I suppose I had a lot of the information already, so I didn't need any help or advice or anything like that*". Another said of supervision, *"I think it was very useful, but I wouldn't see it as necessary as I don't think it's 100% like a necessary element*".

These views, balanced against a majority of support parents who did view supervision as essential, suggest that perhaps flexibility in the requirement for supervision for supporting parents may be prudent in future parent peer support programmes.

5.3 Group 3 Results: Enable Ireland Staff Members

Data from Enable Ireland staff members was collected through individual 1-1 semi-structured interviews. Staff members were asked about their backgrounds and their motivations to participate. Although many had been involved in other programmes aimed at supporting parent needs within disability services, most had not been involved in a parent peer support project previously. Despite this, from their professional experience, they viewed peer support as not only a very promising approach to improving family-centred practices, but also a way to recognise the potential of parents and the value of their lived experience. Interestingly, in the post-programme interviews, staff reflected not only on how the parents had supported each other, but on how much had

been learned by the Enable Ireland staff members from this experience of meeting with and viewing parents in a new light.

Qualitative Results: Enable Ireland Staff Members

The data from the interviews with the Enable Ireland Staff members who had provided formal supervision to the supporting parents was coded into two main themes.

Table 5.25: Themes from Enable Ireland Staff Qualitative Results

Theme 1	"This Could Really Bridge the Gap"
Theme 2	The Ripple Effect: Another Layer of Co-Creation
*Enable Ireland Staff feedback on training and thoughts on scaling the project / going forward are also included	

Enable Ireland Staff Theme 1 - This could really bridge the Gap

The theme "This could really bridge the gap" is named after a code developed within the data analysis, based on a direct quote from a staff member's interview. This accurately encapsulates the thoughts and experiences of staff members concerning their acknowledgement of current service limitations in children's disability services, apprehension about parent expectations, and views that parental peer support could help attend to the needs of families in their services. It also encapsulates staff insights on a deeper level, in relation to seeing the potential in parents to share their knowledge and lived experience and viewing peer support as a mechanism of harnessing this.

The data in this theme reflects staff awareness regarding the effect of these resourcing shortages on families and speaks to their genuine care and concern, which fuels their wish to engage in innovative ways to support and empower families.

Table 5.26: Essential Elements Enable Ireland Staff Theme 1

Enable Ireland Staff Theme 1 - This Could Really Bridge the Gap
Essential Elements
Apprehension about parent expectations.
"This could really bridge the gap."
Seeing the potential in people.

Apprehension about Parent Expectations

The first element in this theme was apprehension about parent expectations. Several staff members expressed pre-programme anxiety about potentially facing dissatisfaction from parents in light of the current service limitations, particularly from those parents who might feel that their child was not receiving sufficient intervention from Enable Ireland. As one staff member said, "*I think as well one of my worries might have been, you know, the worry around, you know, this is a parent in our service, we'd say, whose child probably isn't receiving an awful amount of therapy or intervention....I was a little bit apprehensive about would that come up maybe in the context of the sessions and how would I deal with that*".

Another staff member reflected on the emotional impact for staff working in such an under-resourced service, reflecting that, "*I think it's just a bit of, maybe a feeling of guilt in that, I suppose, like I feel for parents that I wish things were better*".

"This Could Really Bridge the Gap"

The second essential element of this theme is, "This could really bridge the gap", reflecting an Enable Ireland staff member's recognition of the emotional and practical benefits of this form of support, seeing it as necessary in supporting parents of children with additional needs navigate their challenges. The staff members' recognition of the gaps in the services, such as waiting times and staff shortages, highlights the necessity for alternative support systems such as parent peer support programmes.

Staff did not view the peer model as a replacement for professional services but as an opportunity to reduce parental stress and enhance empowerment through lived experiences with peers. Staff members also highlighted that peer support provides insight from the lived experience of parenting a child with complex needs that a lot of clinicians can't replicate.

Another staff member reflected that they are aware of the need for more respite and support for parents, saying, "*I'm concerned that there's not a lot of focus on respite and support, and this project offers a way to fill some of those gaps*".

Seeing Potential in People

A third interesting element of the theme, "This could really bridge the gap", represents staff members' insights into the potential benefits of harnessing and providing an avenue for parents to use the knowledge and skills they have through lived experience, to contribute to supporting others. As one staff member who had experience in training people into helping professional roles reflected, "*I suppose it's about seeing the potential in people*".

Another staff member recognised that, "*A lot of [parents] are super stressed and super kind of…I think fighting for services and battling, you know, in general and every day, is probably taking a lot of energy out of them. Whereas I feel like [the parent peer support programme, and the supervision of supporting parents] would be kind of giving them some energy and filling the cup, as they say.*"

Enable Ireland Staff Theme 2 - The Ripple Effect (the learning goes all ways)

The theme "The ripple effect" (the learning goes all ways), encapsulates staff insights and experiences about what they saw as multiple levels and directions of learning, which resulted from the Parent Peer Support Pilot Project. Theme 2 encompasses reflections on their own professional growth and development through the process, which they experienced positively, as well as the positive emotional impact they perceived on the parents they were supervising. It also includes insights they gained into parental resilience, and thoughts about the impact of this on adapting services to meet parent needs.

Table 5.27: Essential Elements Enable Ireland Staff Theme 2

Enable Ireland Staff Theme 2: The Ripple Effect (the learning goes all ways)
Post-Programme Essential Elements
Professional Development and Growth for Staff
Positive Supervision Experience
Positive Emotional Impact for Parents
Layers of Understanding Parental Resilience
Adapting Services to Meet Parent Needs

Professional Development and Growth for Staff

The staff members reported how the programme enhanced their own professional competencies, particularly building on their supervisory skills. While building on these skills, the staff members had an opportunity to reflect and expressed how the programme offered an opportunity for growth. Many staff expressed how what they had learned through the process of supervising support parents would enhance empathy in future contexts for them.

Some staff reflected on how it can be difficult to gain the type of perspective into parents' lives that they had through the supervision process. For example, one participant said, *"Like, if you were a young therapist, maybe even not having any children yourself, certainly not having any children with disabilities, there are some things you would just never know [unless you had an opportunity like this]*".

Another staff member reflected on how this experience had changed her own professional practice, stating, "*I took a bit more time and I'm trying to do this going forward to actually really, like, listen and ask how parents were doing*". This was echoed by another who shared that *"[this experience] made me realise that I often go straight into focusing on the child, so I think it's changed my practice a little bit*".

Positive Supervision Experience

This element of "The ripple effect" captures the sense of enjoyment and positive emotions experienced by the staff during supervision. It aligns with quotes like, "*I really enjoyed it*", and "*it was very positive, to be honest*". Another staff member said, "*I enjoyed*

speaking with the [supporting] parent and I suppose you get a little bit of a buzz off how they're getting on as well", while yet another shared, "*Ah yeah, I really enjoyed it. And I found her to be a breath of fresh air*".

The positive tone of the experience for the Enable Ireland staff reflects on the positive nature and meaningful impact of the programme and suggests such a programme could be a positive addition to the overall climate of a children's disability service.

Positive Emotional Impact for Parents

Alongside their own professional growth and development, the staff members also observed the growth and empowerment of the supporting parents that they supervised, describing how the act of supporting others had several positive outcomes for both recipient and supporting parents. Staff reflected on several aspects of emotional impact and growth that they had witnessed. For example, one staff member said that "*seeing [my supporting parent] realise what she could offer and how she could help was really rewarding… You could see it made her feel good*". Another stated, "*It was great to see her development and confidence grow*".

Other benefits mentioned included how staff perceived that the parent peer support programme had reduced feelings of isolation, helped participants form strong social bonds, and facilitated the sharing of advice and resources.

Layers of Understanding Parental Resilience

This theme reflects the staff's increased awareness of the resilience, resourcefulness, and strength of parents raising children with complex needs. This impact is captured in the words of one participant: "*It just really reminded me of the resilience and strength of*

parents and how resourceful they are and how amazing they are". Another reflected that this way of interacting with parents had allowed them to understand new and important aspects of what life for families of children with complex needs entails, saying, "*You think in 'xx' years that I would understand that quite well. But then actually this was different. This is like another layer of understanding*".

Other staff also reflected that they hadn't previously had the opportunity to learn about parents' lives in such an intimate way, saying, "*I think for me, a massive learning about what it's like to be a parent of a child with additional needs*".

Adapting Services to Meet Parent Needs

This element focuses on reflections about how services could be improved and better aligned with the needs of parents. It builds on what staff reflected on learning about parents, from parents, that they hadn't previously had the opportunity to learn. Staff mentioned that the experience had prompted them to wonder "*how our service should be changing and adapting more to meet the needs of parents*". Another shared that *"[the peer support supervision experience] made me think about including parents, like asking parents to come in and share their journey or share their learnings*".

Another staff member also identified the uniqueness of what she saw happening in the parent peer support programme, as something valuable and different to other professional supports, saying, *"I could see how if she was able to share that [her experience] with other parents and her service, how beneficial it would be compared to a therapist*".

Feedback on Training / Thoughts on Scaling/Going Forward:

Enable Ireland Staff members were overwhelmingly positive about the peer support pilot, and also keen to share thoughts on how to improve the training they received, and their thoughts on how such a parent peer support programme model might be scaled up or made sustainable going forward. These have been summarised into seven main points.

5.4 Enable Ireland Staff Member Recommendations

Table 5.28 below presents an overview of the key recommendations of staff members (Group 3) regarding future iterations of parent peer support.

Table 5.28: Enable Ireland Staff (Group 3) Recommendations

1	Optimise training for supervisors.
2	Implement rolling recruitment and a tailored matching system.
3	Employ a dedicated coordinator on staff at Enable Ireland.
4	Integrate the programme into the suite of services.
5	Empower parents as active contributors.
6	Include a feedback system.
7	Ensure long-term sustainability.

1. Optimise Training for Supervisors

Participants generally felt that the training provided clear guidance on their own roles and responsibilities. However, there was a recurring uncertainty about the training that supporting parents received, which sometimes led to challenges during supervision. This theme points to the need for better communication about the supporting parents' preparation, to ensure supervisors are fully informed.

Some staff members also expressed a desire for more structured guidance and practical tools to use during supervision sessions. The lack of a clear framework made some participants feel less confident, particularly when faced with unexpected challenges or silences during sessions. This theme suggests that providing more detailed session templates or question prompts may be valuable.

As there was a delay between training and the programme commencing (due to delays in recruitment and associated ethical compliance), staff also mentioned the importance of training being timely.

2. Implement Rolling Recruitment and Tailor Matching System

Staff felt it would be beneficial for a parent peer support programme to have rolling and continuous recruitment, rather than the cohort approach that was used in the current project (which was due to the limitations of the research process). Staff felt that this would enable the use of parent testimonials to engage more parents.

This recommendation should be balanced against the finding that support parents felt a great sense of collaborative community from the group/cohort-based training sessions.

3. Employ a Dedicated Co-ordinator

Staff felt that a future iteration of a parent peer support programme would need to have a staff member who manages training, supervision, and the match process. Staff members placed emphasis on dedicated coordination of the programme, expressing the view that it would need strong leadership and continuous recruitment efforts to sustain its momentum.

4. Integrate the Programme within Suite of Services

Enable Ireland Staff would like to see a parent peer support programme embedded within the larger suite of services, so that they could recommend it as an option for parents of the children with whom they work.

5. Empower Parents as Active Contributors

Staff mentioned that if the parent peer support programme were rolled out on a larger scale, they would recommend offering structured opportunities for parents to co-create aspects of the programme and opportunities for parents to share their experiences with peer support.

6. Include a Feedback System

Staff also recommended that if a parent peer support programme were to be rolled out on a larger scale, they would ensure it included a system where parents can provide feedback, insights on areas of improvement needed, or on what's working well.

7. Ensure Long-term Sustainability

While staff expressed how they believe a parent peer support programme should or could be rolled out nationwide, they also acknowledged that this requires care and sustainable scaling, to ensure the programme maintains quality as it scales. That is, while staff recognised the potential of national expansion of a parent peer support programme, they also warned against doing this too quickly.

Staff recommended that any expansion have an expansion strategy plan. They mentioned that a parent peer support programme would need to be scaled carefully, building slowly and ensuring a robust and well-functioning structure and protocols. In the words of one staff member, "*Obviously there [is] potential for growth. But I suppose if you start small you can identify any kind of teething problems early on*".

6. Discussion

The discussion will present key findings which represent the overall results on the impact and feasibility of peer support. While the results chapter presented both quantitative and qualitative results and demonstrated the positive impact for all three groups, on a group-by-group basis, this chapter will discuss nine key findings based on the total data set. Each key finding will be discussed in the context of how this addresses the research aim and objectives. The relevance of these findings will be considered in the context of the existing evidence base, and core recommendations based on this discussion, will be presented throughout.

The aim of this pilot study was to evaluate the impact of a peer support intervention, for parents of children with complex needs and disabilities in Ireland. Key objectives aimed to evaluate this impact regarding three specific groups of participants:

- Parents of children with complex needs and disabilities receiving peer support (recipient parents/Group 1).
- Parents of children with complex needs and disabilities providing peer support (support parents/Group 2).
- Enable Ireland staff members providing supervision sessions to support parents (staff members/Group 3).

The discussion will centre on the following nine key findings derived from the analysis:

Table 6.1: Key Findings for Discussion

Key findings for discussion	
1	It isn't just recipient parents who benefit from peer support.
2	The "Magic" really is in the match.
3	Peer Support benefits parents, but also has a significant effect on helping parents know how to support their child to reach their full potential.
4	The pilot project training was appropriate, but additional training for diverse matches should be added.
5	The positionality of trainers/coordinators as parents of children with complex needs enhances cohesion, engagement, and collaborative community building.
6	Caring duties do not go away when parents take time for themselves, and should be addressed in the design of parent peer support programmes.
7	Flexibility within peer support project design and timelines is required; In-person is better than online when possible and appropriate.
8	Supervision is essential for some supporting parents, but should be flexible or optional.
9	The needs of parents of children with Autism were strongly represented.

Key Finding 1: It isn't just recipient parents who benefit from peer support

While it was hypothesised that recipient parents would benefit from peer support, the results were surprising in that they showed significant benefits across all three participant groups: recipient parents, support parents, and staff supervisors.

Impact on Recipient Parents

The impact of peer support for recipient parents was notable in terms of improvements in parental efficacy and perceived parental supports. The data demonstrated that peer support in the context of this project positively impacted recipient parents' perceptions of supports available to them and in terms of their knowledge about how to help their child with complex needs.

Impact on Support Parents

Support parents were positively impacted by peer support in terms of their personal growth and development, facilitated through training, participation in a collaborative community, reflection in supervision sessions, and a sense of providing something of value to others, which they themselves would have needed in the past. Support parents were also positively impacted in terms of the connections and friendships they forged with their parent match and in the context of the community and collective action their participation facilitated.

Impact on Staff

Staff members were positively impacted through their engagement in providing supervision to support parents and the opportunities for reflection and new learning that this unique space presented. Staff reported professional satisfaction with the supervision sessions, which provided them a unique opportunity to meet parental support needs and, in essence, "*fill their cup*". Findings suggest staff genuinely enjoyed supporting parents on their peer support journey and witnessing the personal growth and development of parents as they progressed through supervision sessions.

Staff were also positively impacted by their involvement, in terms of taking an active role in laying the foundations for alternative methods of parent support. The FUSS report (2023) identified extremely high rates of stress and burnout among clinicians employed within CDNTs within the context of staffing issues, reconfiguration of teams, and changes in service delivery models. This pilot project, however, presented a completely new dynamic for interaction between staff and parents, culminating in a space of new

appreciation for and insight into one another's roles. Although this project aimed to meet the support needs of parents of children with complex needs and disabilities, we realise the needs of staff members were indirectly addressed, with staff reporting a sense of agency and hope.

Interestingly, staff members also reported developing an enhanced and richer awareness of the challenges faced by families of children with disabilities than they had had previously. The 1-1 supervision element of this project facilitated these deeper layers of understanding and insight concerning parent needs and reality, culminating in opportunities for positive feedback, and staff reported a renewed appreciation for parents' resilience and lived experiences. It is unlikely that this depth of understanding would be achieved via any other training or education mechanism. While it may be tempting for future programme models to assign one staff member to the role of coordinating and overseeing parental peer support, opportunities for involvement by a broader range of staff should also be kept in mind as valuable.

Within the previous research undertaken, while Jamison et al. (2007) did involve social workers in their parent peer support programme to supervise their Family Peer Advocates (FPAs/supporting parents), no study to date that the PIs are aware of has examined the impacts on those providing formal supervision to parent peer supporters. These findings are novel in their addition to the literature on peer support.

Key Finding 2: The "Magic" Really is in the Match

Match compatibility mattered! A clear preference for matches based on the child's unique needs (including diagnosis) and parenting experiences/characteristics was one of the most salient findings for both recipients and supporting parents.

Although caring for a child with complex needs brings some commonality in terms of experiences regardless of child diagnoses, such as stress, isolation, and challenges in navigating systems, parent peer support was more impactful and meaningful when matches also had the shared experiences of a particular diagnosis or set of needs.

This should perhaps be unsurprising when considered within the context of Goldsmith's (2004) explanations for when and how receiving "enactments of social support" will be evaluated as helpful and relationally satisfying. Goldsmith writes that not all enactments of social support are received equally, and in fact some acts of support can even be considered insulting or insufficient (ibid.); a greater similarity of shared lived experiences, is one of many things that enhances the likelihood of successful social support (ibid). Goldsmith (2004) emphasises the significance of these shared lived experiences in considering why peer support is sometimes more effective, when compared to family or professional support. Indeed, meeting other parents for support who have walked in their shoes and are in the same boat was the key motivating factor for participation for parents in this study.

Future iterations of parent peer support for parents of complex needs and disabilities, therefore, should aim to tailor matches based on shared experiences in terms of the

child's needs/diagnosis and the capacity geographically to meet in person (if they so wish). Although the current pilot did not consider it, larger scale parent peer support programmes may potentially even consider cultural and linguistic factors in matching, as suggested by Dodds et al. (2018) and Jamison et al. (2017), or gender, as suggested by Batchelor et al. (2021) who looked at an all-male peer support group. While in almost every sphere of modern life we seem to herald the merits of diversity, perhaps peer support is one small domain that has a different agenda - the more commonalities that parents can be matched on in peer support, perhaps the better.

More research refining the characteristics of strong matching should be undertaken, as the strength and salience of this finding in the experience of participants underscores the importance of putting significant effort and value on the matching process of a parent peer support programme.

Key Finding 3: Peer Support benefits parents but also has a significant effect on helping parents know how to support their child to reach their full potential

Notably, the largest increase for a singular item/question on the survey, was on the item "I know how to help and support my child to reach their full potential" ($p = 0.003$; Cohen's $d = 1.16$ / very large effect size). This is a surprising finding; that a parent peer support programme for parents of children with complex needs could be a very important element in helping and supporting children to reach their full potential.

This finding must be taken in the context of the United Nations Convention on the Rights of the Child (UNCRC; 1989). Article 6 of the UNCRC states that state parties shall ensure

to the maximum extent possible the survival and development of the child; that is, governments, and government agencies, must ensure – to the maximum extent possible – that children reach their full potential. This brief twelve-week parent peer support programme for parents of children with complex needs, has significantly increased parents' perception that they "know how to help their child reach their full potential". This is strong evidence of the rationale for future funding and support for similar and expanded programmes.

Key Finding 4: The pilot programme training was appropriate, but additional training for diverse matches should be added

The data analysis provided valuable information on the appropriateness of the training provided and how this could be changed or improved, for future iterations of this project. Parents found the training valuable and the resources appropriate to guide them as they progressed through the support-giving journey. Support parents particularly valued the lived experience of both PIs (who delivered the training) and the authenticity this added to their positive and collaborative experience of the support parent training.

Parents who were matched with parents with different parenting experiences, or children with differing needs or diagnoses, however, recommended additional and more tailored training. Specifically, they suggested training to further prepare supporting parents for a match which was perhaps less compatible. Future training, therefore, should further incorporate role play scenarios to enable support parents to practice their support-giving role within diverse scenarios.

Training for Enable Ireland staff members (Group 3) was further deemed appropriate and well received, in particular the open format for asking questions. Most staff members felt well prepared for providing supervision, based on the training they received, and they appreciated the opportunity for interacting in-person with other clinicians. Some staff members suggested that the gap between the training session and when they started providing supervision was too long (due to recruitment challenges), and a refresher session would have been helpful. Recommendations were also made for more structured templates and processes for facilitating supervision for support parents, such as specific questions or supervision templates.

Key Finding 5: The positionality of trainers/coordinators as parents of children with complex needs enhances cohesion, engagement, and collaborative community building

The positionality of the PIs within this pilot project, emerged as significant in terms of its impact on training provision and communication with participants. Participants expressed that the shared experiences of PIs created a climate of authenticity and a real and genuine sense of knowing. As parents of children with complex needs and disabilities themselves, both PIs were participative in their approach to this research and in their commitment to creating a space of support for other parents. These values were mirrored by support parents and a sense of co-creation and community began to emerge within the interactions between support parents and PIs. This collective action to create this supportive space and be “the hope they once needed” culminated in a truly unique shared sense of commitment to achieving the pilot project's aim and objectives.

Key Finding 6: Caring duties do not go away when parents take time for themselves, and should be addressed in the design of parent peer support programmes

The only large decrease seen on an item in this survey was on the item/question “I feel my choice and control are restricted due to my parenting responsibilities”. Significance tests were not appropriate, nor was a test of effect size, but the PIs feel that this finding merits mention due to its uniqueness (all other findings across survey items were positive or neutral).

In reflecting upon this item – that respondents reported they felt more strongly that their choice and control were restricted due to parenting - we realised that even the request for these parents to take six-to-nine hours for themselves, over a three-month period, to receive support, had potentially brought to the forefront just how restricted they are, in a logistical manner, due to their caring responsibilities.

This highlights the need for flexible support structures that can adapt to the dynamic family life, and highlights that childcare concerns are a very real concern, if not a barrier, for parents seeking and wanting peer support, or any other supports. As one parent said, the most difficult aspect of the programme was "*finding care in order for me to take the time out to meet*".

It is important, therefore, to concurrently address the ever-present childcare and/or caring demands that parents are under, in any programme designed for parents of children with complex needs. A programme encouraging parents of children with complex needs to attend to their own self-care, or to “take time for themselves”, must take into consideration this very real challenge at the design stage.

Key Finding 7: Flexibility in programme design, delivery and timelines is required. In person is better than online when possible and appropriate

During the course of the twelve-week parent peer support programme, several participating parents faced unforeseen personal events, such as bereavements, health issues, or changes in family routines. These events not only made engagement more challenging but also underpinned the importance of flexibility within the peer support model.

Unfortunately, some recipient parents expressed negative emotions, such as guilt, due to needing flexibility in arranging meetings. Positively, however, some recipient parents were able to address these logistical barriers explicitly with their support parent and found the support parent to be flexible.

This highlights a potential area for improvement in programme design and training; anticipating scheduling challenges for both recipient and support parents, and providing clear guidelines and reassurance in this domain, could reduce stress and negative emotional impacts when such situations inevitably occur.

While having the option to meet either in-person or by distance (online or telephone) can enhance programme flexibility, it is also important to balance this against the finding that the impact of peer support was influenced by the mode of contact that match meetings adopted. Specifically, recipient parents reported greater positive changes when match meetings occurred in person, and supporting parents also expressed greater satisfaction with in-person meetings.

While scholars like Wakimazu et al. (2022) have found that more curriculum-based and facilitated online peer support in group settings can be effective, for a 1-1 unstructured model of peer support, our results suggest in-person meeting is preferrable, if possible and appropriate (keeping in mind that for a small number of parents distance meetings may allow some engagement rather than none).

Key Finding 8: Supervision is essential for some supporting parents, but should be flexible or optional

The impact of supervision on the experiences of peer support was largely positive, with most support parents benefiting from this opportunity to reflect and offload. Yet supervision was deemed unnecessary for a smaller number of support parents and consequently, did not impact greatly their experiences of participating in the Parent Peer Support Pilot Project.

While the supervision element of the programme is relatively unique, and the benefits supported in the findings, future programmes may want to consider making some or all supervision sessions optional, based on supporting parent preferences, availability, and experience.

Key Finding 9: The needs of parents of autistic children were strongly represented in the sample

An indirect yet notable finding which warrants discussion, is the support needs of parents of autistic children. Parents of autistic children were overwhelmingly represented within our recipient parent group, with nine out of ten recipient parents reporting autism as their child's diagnosis. Although our sample size is small, this study suggests a particular need

for support identified by parents of autistic children. This is relevant in terms of the national and international increase in autism diagnoses within the last ten years (Department of Health, 2018; Centre for Disease Control, 2024; Zeidan et al. 2022) and further reflects the evolving and unique support needs of caregivers of autistic children.

7. Summary of Recommendations

- Expand/roll out of peer support on a larger scale within CDNTs.
- Recruitment of both a dedicated staff member and a parent with lived experience, or, alternatively, a staff member with lived experience, to lead the coordination of peer support initiatives within existing services and communities.
- Match compatibility should be prioritised, even if this means rolling recruitment and waiting for a compatible match.
- Match parents based on capacity to meet in person, as opposed to online/intercounty.
- A twelve-week matching programme seems an appropriate length of time for formal matches, as positive gains were seen in this length of time. Many parents continued friendships with their matches informally after this period.
- Support parents should be matched with only one recipient parent at a time, due to the evidence of the impact of the time commitment on parents of children with complex needs. Support parents could remain on a database for future matching, if the programme continued to be rewarding for them.
- Training provision should also include materials specific to match incompatibility/supporting a parent with different parenting experiences/child needs.
- Supervision for support parents should be based on the individual's need for support.

- Further research is needed to identify the extent and nature of needs specific to autistic children and their families and subsequently develop parental and family support initiatives to address such needs.

8. Study Challenges and Limitations

While this study provides robust evidence for the potential of peer support to benefit not only recipient parents but also supporting parents and professionals on a Children's Disability Network Team, it is not without limitations.

Most significant of the limitations was the sample size of recipient and supporting parents that we were able to recruit. Despite extensive efforts to extend the sampling area from Galway and Cork to include North Tipperary, there was very little take-up on recruitment efforts.

Further notable within the context of sample size as a limitation, is the retention and drop-out rate of participants within this study. A drop-out rate of 10% occurred, which accounts for one support parent discontinuing their participation after meeting with their parent match on two occasions. In addition, another support parent was unable to participate in the post-pilot focus group, which means that the post-pilot data for Group 2 is based on the experiences and perspectives of eight out of ten support parents. Such limitations are reflective of the overall findings of this study concerning the competing demands and responsibilities of parents of children with complex needs and disabilities (Key Findings 6 and 7).

Further relating to recruitment challenges and the small sample size obtained, matching based on availability, rather than compatibility, could further be viewed as a limitation within the current study. Due to the low uptake of participants, three matches were created where parents had different parenting experiences/children with dissimilar diagnoses.

9. Conclusion

The Parent Peer Support Pilot Project was a joint initiative between researchers at the University of Galway and Enable Ireland. The aim of this study was to evaluate the impact of peer support for parents of children with complex needs and disabilities in Ireland. This report provided a detailed account of the research methods and project activities undertaken within the Parent Peer Support Pilot Project (2022-2024). The results presented highlight the positive and meaningful impact of peer support for both parents of children with complex needs and disabilities and staff members. Findings propose that participants view peer support as a beneficial and unique mechanism of informal support provision for parents of children with complex needs.

Overview of Report

An exploration of existing literature regarding peer support was presented, which highlighted the potential benefits of this unique type of informal support. This review of the evidence base outlined a broad spectrum of approaches and mechanisms for delivery of peer support, from educational, to home visiting, peer mentoring, advocacy and group-based models.

The methodology chapter outlined the processes and mechanisms undertaken to plan, collect and analyse both quantitative and qualitative data, via a mixed methods approach and ethical considerations were further presented. This report provided a detailed account of the project activities undertaken, including recruitment, training, matching of parents, delivery of peer support, and supervision sessions.

The results chapter presented the key findings from this study in the context of the research and objectives, based on each group/data set. Finally, the discussion chapter presented the overall findings of this research project and explored the relevance of each in the context of the existing evidence base. Subsequently, recommendations regarding feasibility and practicalities for future iterations of parent peer support initiatives were outlined.

Impact

Results suggest that peer support presents a unique mechanism for informal emotional and practical support for parents of complex needs and disabilities, via the harnessing of lived experience. Recipient parents were positively impacted by receiving peer support and reported small to medium positive changes in parental resilience and perceived parental supports. Findings presented further noted a more significant positive impact in terms of parental self-efficacy and the recipient parent's perceptions on how they cope with their child's unique complex needs and disabilities. Recipient parents were further impacted by peer support in terms of social and emotional connections, feeling reassurance and gaining insights into practical ways they could help their child. This

report outlined the impact of peer support for recipient parents in terms of how this was influenced by the compatibility of matches and mode of contact.

Findings were presented regarding the positive impact of peer support for support parents, in terms of fulfilment in providing the hope they themselves once needed, and through the personal growth and development the peer support journey presented. This report outlined the motivation of support parents to actively engage in creating a safe space for other parents, based on their unique lived experiences and emotional growth as a parent and peer supporter. The findings asserted that support parents were impacted via the emotional growth and development presented within peer support training, supervision, and support provision. The authenticity of the support parent training and the lived experience of the PIs was further described as significant in impacting support parents in their engagement and satisfaction. Similar to results for Group 1 (recipient parents), support parents reported more positively impactful experiences when they were matched based on compatibility, rather than availability.

Results were presented regarding the impact of peer support for staff members (Group 3), which identified developing greater insights into the needs of families of children with complex needs and disabilities and that peer support could really bridge a gap in terms of the need for informal support provision. Staff members reported experiencing professional growth and development as a result of their participation and genuinely enjoying the unique opportunity to engage with parents within supervision sessions. Staff members also emphasised their perspective that a parent peer support programme has the potential to "bridge the gap" between the reality of family support needs and the resources currently available in CDNT services nationwide.

Feasibility and Recommendations

This report has illustrated the feasibility of a peer support initiative delivered within the medley of existing children's disability services and has described the resources, changes, and improvements which could enhance future iterations of a similar project. Although the small sample size within this project is a notable limitation, valuable insights, experiences, and perspectives were gathered and key recommendations around the practicalities of creating and delivering a peer support programme were identified.

Recommendations include: rolling recruitment of parents, more tailored match compatibility, matches meeting in-person as opposed to online, and the employment of both a dedicated staff member and parent with lived experience (or alternatively a staff member with lived experience) to lead the roll out of future peer support initiatives. Recommendations outlined in this report further include the need for more specific training to include role plays and how best to support a parent match when the recipient and supporting parent's children have a differing diagnosis or needs. The report further identified that supervision is a useful, but perhaps not an essential, component of parent peer support, and should be considered based on the individual support needs of each supporting parent.

Finally, this pilot project report identified the over-representation of parents of autistic children in our sample, as presenting with support needs (nine out of ten recipient parents). This unexpected finding highlights the potential unmet need of this group and

prompts a recommendation for more in-depth research to identify the unique needs of parents and families of autistic children. Such research could subsequently inform more autism and neurodiversity specific parental supports, initiatives and funding streams.

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12. Appendices

Appendix A: Pre-Pilot Questionnaire

Appendix B: Post-Pilot Questionnaire

Appendix C: Pre-Focus Group Guide

Appendix D: Post-Focus Group Guide

Appendix E: Interview Guide for Enable Ireland Staff

Appendix F: Primary Investigator Biographies

12.1 Appendix A Pre-Pilot Questionnaire

Pre-Intervention Questionnaire Recipient Parents

Please answer the questions below relating specifically to your child with complex needs. For questions 1-35, rate your answers from 1: strongly disagree, to 5, strongly agree. For questions 36-41, please provide as much information as possible in the box provided.

SD= Strongly Disagree; D= Disagree; NA = Not applicable or Can't decide; A= Agree; SA= Strongly Agree

No.	RESILIANCE	SD	D	NA	A	SA
1	I feel I have accepted my child's diagnosis					
2	I feel I have emotionally processed my child's diagnosis					
3	I am able to adapt when changes occur.					
4	I can deal with whatever comes my way.					
5	Under pressure, I stay focused and think clearly.					
6	I think of myself as a strong person when dealing with life's challenges and difficulties.					
7	I am able to handle unpleasant or painful feelings like sadness, fear, and anger.					
	SUPPORT	**SD**	**D**	**NA**	**A**	**SA**
8	I have people I can to talk to about my child's complex needs					

9	I am aware of supports available to me to help my child and family and how to access these					
10	I have people to talk to who understand how I feel					
11	I feel lonely in my parenting					
12	I feel supported by my family in raising my child.					
13	I feel supported by a significant person in raising my child					
14	I feel confident that if I reach out, support is available.					
	SELF EFFICACY	**SD**	**D**	**NA**	**A**	**SA**
15	I meet by own personal expectations for expertise in caring for my child.					
16	I understand my child's disability and how this impacts them					
17	I know how to help and support my child to reach their full potential					
18	I feel confident when communicating my child's needs to other people (teachers, doctors, therapists etc)					
19	I know how to help my child when they are distressed					
20	I honestly believe I have all the skills necessary to be a good parent to my child					
	WELLBEING	**SD**	**D**	**NA**	**A**	**SA**
21	My mental health is negatively affected by parenting a child with complex needs					
22	My sleep is impacted due to my child's needs					
23	I take time for self-care regularly					
24	My mood is low regularly					
25	I feel stressed regularly					
26	I feel I have things to look forward to					
27	Overall, I feel well					
	PARENTAL STRESS	**SD**	**D**	**NA**	**A**	**SA**
28	I feel hopeful about my child's future					
29	I feel I cope well with the demands of parenting					
30	I am happy in my role as a parent					
31	Caring for my child(ren) sometimes takes more time and energy than I have to give.					
32	I sometimes worry whether I am doing enough for my child(ren).					

33	I enjoy spending time with my child(ren).					
34	I feel my choice and control are restricted due to my parenting responsibilities					
35	I feel overwhelmed by the responsibility of being a parent.					

36. Can you explain why you have decided to participate in the Parent Peer Support Pilot Project?

_____
_____

37. What do you hope to gain from participating in this project?

_____
_____

38. What do you think the challenges of participating in this project might be for you?

_____
_____

39. What do you think the benefits of participating in this project might be for you?

_____
_____

40. What part of your parenting do you most wish to get support regarding, from participating in this project ?

_____
_____

41. Is there any other information you would like to share regarding your participation in this project?

_____
_____

12.2 Appendix B Post-pilot Questionnaire

Post-Intervention Questionnaire Recipient Parents

Please answer the questions below relating specifically to your child with complex needs. For questions 1-35, rate your answers from 1: strongly disagree, to 5, strongly agree. For questions 36-41, please provide as much information as possible in the box provided.

SD= Strongly Disagree; D= Disagree; NA = Not applicable or Can't decide; A= Agree; SA= Strongly Agree

No.	RESILIANCE	SD	D	NA	A	SA
1	I feel I have accepted my child's diagnosis					
2	I feel I have emotionally processed my child's diagnosis					
3	I am able to adapt when changes occur.					
4	I can deal with whatever comes my way.					
5	Under pressure, I stay focused and think clearly.					
6	I think of myself as a strong person when dealing with life's challenges and difficulties.					
7	I am able to handle unpleasant or painful feelings like sadness, fear, and anger.					
	SUPPORT	**SD**	**D**	**NA**	**A**	**SA**
8	I have people I can to talk to about my child's complex needs					
9	I am aware of supports available to me to help my child and family and how to access these					
10	I have people to talk to who understand how I feel					
11	I feel lonely in my parenting					
12	I feel supported by my family in raising my child.					
13	I feel supported by a significant person in raising my child					
14	I feel confident that if I reach out, support is available.					
	SELF EFFICACY	**SD**	**D**	**NA**	**A**	**SA**
15	I meet by own personal expectations for expertise in caring for my child.					
16	I understand my child's disability and how this impacts them					

17	I know how to help and support my child to reach their full potential					
18	I feel confident when communicating my child's needs to other people (teachers, doctors, therapists etc)					
19	I know how to help my child when they are distressed					
20	I honestly believe I have all the skills necessary to be a good parent to my child					
	WELLBEING	**SD**	**D**	**NA**	**A**	**SA**
21	My mental health is negatively affected by parenting a child with complex needs					
22	My sleep is impacted due to my child's needs					
23	I take time for self-care regularly					
24	My mood is low regularly					
25	I feel stressed regularly					
26	I feel I have things to look forward to					
27	Overall, I feel well					
	PARENTAL STRESS	**SD**	**D**	**NA**	**A**	**SA**
28	I feel hopeful about my child's future					
29	I feel I cope well with the demands of parenting					
30	I am happy in my role as a parent					
31	Caring for my child(ren) sometimes takes more time and energy than I have to give.					
32	I sometimes worry whether I am doing enough for my child(ren).					
33	I enjoy spending time with my child(ren).					
34	I feel my choice and control are restricted due to my parenting responsibilities					
35	I feel overwhelmed by the responsibility of being a parent.					

36. How would you describe your overall experiences of participating in the Parent Peer Support Pilot Project?

_____

_____

37. What did you gain, if anything, from participating in this project?

_____
_____

38. What were the challenges with participating in this project for you?

_____
_____

39. What were the key benefits of participating in this project for you?

_____
_____

40. What part of your parenting do you feel you got the most support regarding, from participating in this project?

_____
_____

41. Is there any other information you would like to share regarding your participation in this project?

_____
_____

12.3 Appendix C Pre-Focus Group Guide

Focus Group Protocol Pre-Pilot

Study objectives (relevant to this instrument): -

Exploring the motivation to participate and the impact of participation (if any) for support parents.

Key terms:

Motivation –drive, motivation, interest, reason, purpose

Impact – Current and future status of something.

Population of interest – Support parents

Focus group protocol

1. Greetings and welcome
2. Information regarding Lhara/Devon presence and purpose
3. FGD culture
    a. Avoid interrupting a speaker.
    b. This is not a test by any means. We would like to learn your thoughts and perspectives about this project. There is no right or wrong answer.
    c. Openly but respectfully communicate agreement and disagreement.
    d. Confidentiality – all information shared in the group will remain within the group.
    e. Audio recording and anonymisation.
    f. No set order for answering questions, start if you feel like you are ready and if you have something to share.
    g. Time keeping: We have a total of 6 questions, about 10 minutes for each question - therefore, we might not be able to take responses from all participants for every question. You can choose to skip 1 or 2 questions if you do not have anything new to add.
4. Start discussion.

	Question and follow up	Rationale
1	Could you tell me about your first thoughts when you heard about this parent peer support project?	This question will give a sense of their current perceived status of wellbeing particularly with respect to parenting a child with disability.
2	Why did you decide to participate in this project?	This question provides insight on the following:

	Could we begin with discussing about what motivated you to participate in this project? – use as prompt if needed • Follow up with: Could you tell us a bit more about the part of the project which drew your attention?	• Struggles faced as a parent of children with complex needs (without such peer support) • Aspects of the project such as training, skill development, networking, providing support, helping others, sharing personal knowledge – that the parents are interested in
3	What do you hope the parents you support will achieve by the end of this project?	This question provides insight into: • Why the support parent feels it will add value to recipient parent's life. • How they envision change for the recipient parents.
4	What do you hope to accomplish for yourself, from participating in this project?	This question will provide insight into: • Key takeaways or expected takeaways from this project • This can be compared to actual takeaways at FGD 2
5	What are your feelings on parent peer support now, before commencing meeting with your parent match?	This question provides • Insight into concerns and apprehensions • Points that can be followed up on in the post-pilot focus group – were the concerns actualised, mediated, addressed, or did they turn out to be unfounded. This can contribute to research and future training materials This question provides insight into: • Views – positive, negative, apprehensive (about peer support) Why the support parent feels it will add value to their own/recipient parent's life
6	What are your thoughts about the support parent training you have received? • Follow up: How prepared do you feel before you begin support? • If you could add something to the training, what would that be?	This question provides • Feedback on training sessions • Preparedness of support parents
7	Are there any other thoughts or comments about your participation in this project you would like to share?	Provides opportunity to share anything that is not addressed by the moderator.

12.4 Appendix D Post-Focus Group Guide

Moderator's Guide - Parent Peer Support Pilot Project
Post-Pilot Focus Group with Supporting Parents (Group 2)

Section	Blurb
Welcome & Introduction (5 Minutes)	Welcome, we are so glad everyone was able to reunite this evening following the completion of the peer support meetings. My name is Niamh, and I am the research assistant on this project and Lhara and Devon the principal investigators of this study are also here this evening. The purpose of tonight's focus group is to gather insights and feedback on your experience of the peer support pilot project. We look forward to learning more about your experiences through this group discussion. There is no right or wrong answer, and we invite you to share your perspectives on this project. Before we get started let's go over some housekeeping and guidelines for a respectful discussion and a safe space to share. We ask if everyone can openly but respectfully contribute and communicate their insights and experiences. Please speak up so everyone can hear, but also be mindful when another participant is speaking, to wait for them to finish before sharing your thoughts. While we will be on a pseudonym name basis, rest assured that your real name will not be attached in any report we create. All your responses will be kept confidential, and the audio recordings will be deleted once the data is transcribed. Lhara and Devon will be here for technical support only and will leave their cameras and mics off unless they are needed. Once the focus group discussion ends (in 1 hour), I will leave and Lhara and Devon will chat with you all. **Obtain verbal consent for recording.** Let's begin!

Focus	Flow - Questions
Opening – Experience 5 minutes	As you know, the aim of this study was really to examine the experience of and the impact of a parent peer support programme for parents of children with complex needs and disability. We will look at many aspects of this

	today. I thought it would be nice to start off just asking *what this experience was like for you*?
Impact 5 minutes	Okay great, thanks. And if you could summarise the impact of this programme on you, in just a sentence or two – *what has the main impact of this programme been for you?* - <u>Try to prompt each participant to respond to this.</u> What do you think the *impact of this project has been for your parent match*?
Benefits 10 minutes	Great stuff. Sometimes it's nice to try to summarise things – we'd also like to gather a sense of the benefits that support parents may experience while participating. So, during the 12 weeks of meeting, what *benefits if any did **you** experience*? (Prompts if necessary: and what about on a more personal level / broader level / psychologically/ emotionally / socially - in terms of community / in terms of your own parenting/confidence/skills development?) And *do you think these benefits will last long-term*, or are there any other benefits that may have a lasting impact?
Mode of contact 5 minutes	Thanks so much. I just want to segway a bit before we speak about challenges, because I know that some pairs met in person, and some online or via telephone, and that may have influenced the experience. *So, can you just say what mode of contact you and your parent match had, and how you think that impacted the experience*?
Challenges 10 minutes	Okay, and moving on to challenges – *were there any challenges that arose during the project that you think we should know about*?
Training Feedback 5 minutes	What are *your thoughts on the training you received* before beginning your role? What are *your thoughts on the resources* made available to you (resource handbook, slides, videos etc.)? Prompt: Did *you feel prepared going into your role* based on the training you received?

	Is there anything which should be added or changed to the training or resources based on your experience?
Supervision Feedback 5 minutes	Then you all had a staff member of Enable Ireland as your supervisor, what are your *thoughts on the supervision* you received throughout the project? How *necessary do you feel the supervision* was for you? -Extra time only/bonus question: did you meet your supervisor in person or online and how did this impact your supervision experience?
Improvement 5 minutes	Let's say, this project is to be run again, are there any improvements or changes would you suggest? Would you participate in a similar project if it was run again?
Additional Comments 5 minutes	Are there any other thoughts or comments about your participation in this project you would like to share?
If Time: Project description	We have just five minutes left, so if you could describe this project to someone who didn't know anything about it, what would you say?

12.5 Appendix E: Interview Guide for Group 3 (Enable Ireland Staff)

Moderator's Guide - Parent Peer Support Pilot Project

Individual Interviews - CDNT Staff Members (Group 3)

Section 1: Welcome & Introduction (3 Minutes)

- Thank the CDNT Staff Member for their time
- Introduce myself and the purpose of the interview

My name is Niamh, and I am the research assistant on this project and the purpose of this interview is to gather insights and feedback on your experience of the peer support pilot project and learn more about your experiences through this discussion. There is no right, or wrong answer and we invite you to share your perspectives on this project.

All your responses will be kept confidential, and the audio recordings will be deleted once the data is transcribed.

Obtain verbal consent for recording.

Section 2: Background (2 Minutes)

Question
Firstly, can we take two minutes, can you briefly describe your professional role with Enable Ireland?
How long have you been working in this role?

Section 3: Initial Impressions & Expectations (5 Minutes)

Question
Can you tell me about your initial motivation to participate in the parent peer support pilot project? Had you ever heard of parent peer support project?
What apprehensions or concerns did you have prior to participating?

Section 4: Training and Preparation (8 Minutes)

Question	**Sub-Question/Prompt**
How well did the training you received prepare you for supervising the supporting parents?	How did this training influence your approach to supporting parents?
What are your thoughts on the resources you received for supervising the supporting parents?	Can you describe or why there a particular an instance where these resources helped you support parents more effectively?
Can you tell me a little about the ongoing support you received (throughout the peer support project)?	What improvements, if any, would you make to the ongoing support you received?
What improvements, if any, would you suggest to the training or resources provided?	

Section 5: Role (10 Minutes)

Question
How would you explain your role in supervising the supporting parents, to someone unfamiliar with the project?
Can you describe **your** experience supervising support parent?
Were there any challenges that the support parents faced, and how did you help them to address these?
What aspects of supervision, if any, did you find challenging, can you elaborate on them?
What aspects of supervision did you find most rewarding, can you elaborate on this?

Section 6: Impact and Effectiveness (8 Minutes)

Question	**Sub-Question/Prompt**
What are your thoughts on how well-prepared the parent you supervised were in supporting their parent match?	Can you share examples where their preparedness significantly impacted their support for the match parent?

What do you perceive as the primary impact of this project on **first the supporting parents** and **secondly the recipient parents**?	

Section 7: Benefits and Drawbacks (5 Minutes)

Question	**Sub-Question/Prompt**
Can you describe any challenges **you faced** while participating in the project? **E.g. Training, time, supervision**	Did you seek any support or guidance while facing these challenges? Were there any lessons you learned from overcoming these challenges?
Can you describe any benefits **you gained** from participating in this project?	In what ways, if any, have these benefits contributed to your professional development? How will the experience from this project impact your future practice, if at all?

Section 8: Future Directions (10 minutes)

Question	**Sub-Question/Prompt**
What recommendations would you make for future iterations of this project?	
In the future, if the parent peer support programme were to be scaled up and implemented across Enable Ireland locations, what would this look like for you and your team?	What do you foresee the role of Enable Irelands staff members, to be in part of this roll out? **Please elaborate**
In relation to the P2P project: What do you think the impact a larger rollout would be for Enable Ireland? Prompt: Do you perceive any benefit adding PSP to the suite of services for your CDNT team overall?	
In relation to the P2P project:	

What do you think the impact of a larger rollout would be for Enable Ireland families?	

Section 9: Closing (2 minutes)

Question
Are there any other thoughts, comments or feedback you would like to share about your experiences participating in this project?
Thank the staff member for their valuable time and insights. Inform the CDNT Staff Member of the projects following steps, how the data will be used and when they can expect to hear the study results.

12.6 Appendix F Primary Investigator's Biographies

Dr. Lhara Mullins

Dr. Lhara Mullins is a lecturer in health promotion at the University of Galway and the programme director of the BA (Hons) Social Care. Lhara is a prolific lifelong learner and completed an undergraduate degree in Social Care (2010), a Masters in Social work (2012) and a PhD in health promotion (2023). Lhara is a passionate and active advocate locally and nationally for all things autism and neurodiversity related and has authored two books to date on this topic. Lhara has extensive experience in community care and in leading equality, diversity and inclusion initiatives. Lhara's lived experience caring for 3 autistic children and as a neurodivergent person herself, fuels her motivation to explore the unique and evolving needs of children and families living with disabilities.

Dr Devon Goodwin

Dr. Devon Goodwin is a lecturer in educational sociology and inclusive education, in the School of Education at the University of Galway and the programme director of the BA Children's Studies. Her initial degree in Psychology (BA Hons, 2003) led to a career working in residential support services for children with diverse needs, including autism. In 2013 she qualified as a primary school teacher, and worked in both mainstream and special education settings, before completing her PhD. in the sociology of education (2020). Devon is a long-serving board member of the Galway Autism Partnership, and a passionate advocate for critically informed disability pedagogy. Her lived experience as a parent of neurodivergent children and as a neurodivergent person have given her great

passion and depth of understanding for the importance of research on how society can help every child reach their full potential.

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