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UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

“You have to fight for everything.” An exploration of the experiences of parents accessing early intervention.

Helen Devery

CARL Research Project
in collaboration with
Togher Family Centre

CARL
COMMUNITY - ACADEMIC
RESEARCH LINKS
University College Cork, Ireland

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- promote and support public access to and influence on science and technology;
- create equitable and supportive partnerships with civil society organisations;
- enhance understanding among policymakers and education and research institutions of the research and education needs of civil society, and
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Acknowledgements

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Statement of originality

I wish to state that the work in this study is all my own. Where I have referenced the work of others, I have cited it accordingly using recognised academic conventions. I reviewed the originality report using TurnItIn prior to submission and have edited the document accordingly.

Abstract

Togher Family Centre commissioned this study to explore how to support the families whose children are referred to early intervention. In this qualitative study, I interviewed both Irish and New Irish parents to explore their experiences. Evidence suggests that positive outcomes are associated with effective social support. I therefore inquired into how well they were supported on both a practical and an emotional basis.

The main theme extracted, related to parents' frustration with the lack of structural support. The comparison between Irish and New Irish families found that although all parents utilised practical support provided by friends, family and communities, New Irish parents received less emotional support. All parents were found to be extremely resourceful and resilient and actively looked for ways to support their children.

My key recommendation is for Togher Family Centre to provide a parents' support group. I am also calling upon the Irish Government to tackle the lengthy waiting lists for early intervention services.

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Chapter outline

Chapter One introduces the topic of the study. It set out the aims and objectives and provides an overview of the theoretical framework and structural context.

Chapter Two provides a review of the literature which informed the background to the study. It covers the relevant Irish policy and reviews similar studies carried out in an international context.

Chapter Three traces the development of the study's methodology from its theoretical underpinnings through to the selection methods, interview procedure and data analysis.

Chapter Four sets out the findings of the interviews organised thematically under the headings of structural support, instrumental support, emotional support, language and personal agency

Chapter Five provides an in-depth discussion of the main themes identified in chapter four.

Chapter Six concludes the study. It revisits the original study aims in order to evaluate the significance of the findings. It considers the wider implications for consideration and provides a set of recommendations. A brief discussion of the limitations is followed by a final reflective piece on the research process.

Chapter One
Introduction and Background

1.1 Introduction

The question which prompted this research, emerged some years ago whilst I was teaching young children with autism. It gradually occurred to me that every single one of the families I had worked with had sought a private diagnosis for their child. Every single one had paid for private occupational and speech therapy and had obtained the eligibility for the home tuition I provided. I often wondered what had happened to those who couldn't afford to 'go private'. When I started to look around me, I noticed what was happening. The families who had relied on the public system *did* receive diagnoses. But they often came years too late. The children had lost out on those early years, when intervention is most effective. Their parents had often coped alone, without support.

This question in effect, provoked a powerful sense of social injustice and inspired me to pursue a career in social work. It also forms the basis for this study.

1.2 Title

"You have to fight for everything"; an exploration of the experiences of parents accessing early intervention.

1.3 Rationale

The aim of this dissertation arose out of the conversations I had with staff from Togher Family Centre. Many staff, in the course of their work, had identified children who appeared to have speech and language delays and/or autistic tendencies. They had referred the children's parents to the HSE early intervention services for diagnosis but had seen little, if no outcome. Some felt that this was an issue which primarily affected the families who were new to Ireland; other staff members disagreed, arguing that it applied to families from all ethnic backgrounds. It was agreed that the staff needed to know more about what was happening in order to plan how to support those families affected. One possible solution proposed was the founding of a parent support group.

1.4 Aims and objectives

The study therefore aimed to provide a stage for people's voices to be heard, to ensure that family support services could effectively meet the needs of the community. It aimed to explore the experiences of the families accessing early intervention, paying particular attention to those from new Irish communities. A review of the literature indicated that a study of this kind had not been performed in Ireland before. In the context of growing ethnic diversity in Ireland revealed in the Growing up in Ireland cohort study (Roder et al 2014), it became apparent that more research like this was needed, to enable service providers to meet the needs of all community members.

1.5 Context of the study:

1.5.1 Togher Family Centre

Togher Family Centre is a community based service situated in the suburbs of Cork City. It offers a broad range of universal and targeted services including three preschools, an after school resilience project (Happy Hub), a parent and toddler group, parent support and a child contact centre.

The report, 'We Shout a Little Louder' (Sheridan et al 2016) which examined the socio-economic context of parents and children attending the centre, found that its families "experience a high level of socio-economic disadvantage". Parents are more likely to be unemployed, or "working at risk of poverty" and have high levels of dependency on social welfare. Furthermore, they were found to have a reduced level of access to a wider range of support services in comparison to those in other disadvantaged areas of Cork City.

The 2015-2016 annual report (Togher Family Centre 2016) shows that thirty-four per cent of the families who use the centre are not originally from Ireland and that thirty per cent of children using the centre's services speak English as a second language. The report also documents the numbers of children with complex and additional needs. Over the four preschool groups, (comprising of one hundred and fifty-nine children) thirteen children had a diagnosed additional need, and sixteen were classed as having an undiagnosed additional need. Thirty-eight had speech and language difficulties and twenty-two were on a waiting list.

1.5.2 Disability Services

All children in Ireland are entitled to receive an 'Assessment of Need' under the Disability Act (2005). Referrals from professionals or parents are considered by the HSE Early Intervention Intake Forum who

decide which service is most appropriate. If the child receives a diagnosis of autism, they are placed on a waiting list for services including speech and language therapy, occupational therapy and psychology. Parents can alternatively choose to obtain a private diagnosis and pay for therapeutic services.

1.5.3 Social support and family centred practice

This model informs the practice of the agencies whose work underpins this study; the family centred model used by the early intervention system, and the community support model used by the Togher Family Centre.

Social support theory recognises the positive contribution that formal and informal supports offer to child development and family functioning (Dunst 2000). It takes its inspiration from Ecological Theory which conceives of an individual's well-being as influenced by a series of interconnected, nested systems. Bronfenbrenner (1979) explains;

"…parents' evaluations of their own capacity to function, as well as their view of their child, are related to external factors such as flexibility of job schedules, adequacy of child care arrangements, the presence of friends and neighbours who can help out in large and small emergencies, the quality of health and social services and neighbourhood safety."

(Bronfenbrenner 1979 p.7)

1.6 Theoretical perspective

This study recognises that effective social support must be planned around the needs of community members. The theoretical perspective of social constructivism, which places 'knowledge' within people's collective understandings and lived experiences therefore, has shaped this study. In order to align the perspective of this study with Togher Family Centre's commitment to "a future of opportunity for all" it has been infused with elements of critical theory.

1.7 Discussion of terms used

Disability: This term has been used interchangeably with 'developmental delay' and 'special needs' throughout this study. It is intentionally left open ended for inclusivity, but in this context generally refers to autism and speech and language delays.

Early Intervention: Although used widely to describe a variety of family support models, this term is used here to refer to the system of supports which help young children with developmental delays or disabilities. An early intervention team usually includes psychology, speech and language therapy, occupational therapy and social work support.

New Irish: This term was chosen to refer to those people who are not indigenous to Ireland. Togher Family Centre and I felt that it offered more inclusive, positive connotations compared to 'non-national' or 'immigrant'. It also avoids entering the debates around citizenship, as recognised by the authors of the report 'New Irish Families' (Roder et al 2014).

1.8 Conclusion

This research commissioned by Togher Family Centre is a qualitative study designed to explore the needs of a particular group of parents. Using a social constructivist approach, it will seek to understand the issues through the perspective of the parents involved. It is located within the social support theoretical framework which recognises that the well-being of families can be enhanced through the provision of family centred practice.

Chapter Two
Literature Review

2.1 Introduction

I will begin my review of the literature by providing an overview of the legislative context. I will then discuss the development of early intervention policy which uses a family centred approach. I will next review the studies which explore the experiences of families using early intervention services in the UK, New Zealand, Australia and Canada, uncovering the key debates and drawing out the theories which offer the potential for my research. I have included studies which refer to families from all backgrounds, but in the context of my research question, have chosen to focus on the dimensions of culture and ethnicity as particular themes. Finally, I will review the literature on parental agency and resilience.

2.2 Legislation, policy and procedure

The rights of children with disabilities are enshrined within the United Nations Convention of the Rights of the Child, ratified by Ireland in 1992. Although provided for under all articles, children with disabilities are specifically referred to in Article 23 (Developmental Rights for Children with Disabilities.) This has been translated into domestic policy in Ireland through the Education for Persons with Special Educational Needs Act (2004) and the Disability Act (2005). The Disability Act (2005) affords all children the statutory entitlement to an assessment of their health and educational needs and a care plan, known as an Assessment of Need. A report must be produced within six months of receipt of an application and followed by a service statement which lists the services and supports that the state provides. The Irish government has been accused of failing to meet these entitlements. In a report produced in 2017, Barnardos found that 96% of children had waited for longer than the statutory timeframe.

The provision of services to children with disabilities, which was formerly criticised for its medical, expert-led approach, (Carroll et al 2013; Foran and Sweeney 2010) has evolved in recent years. The

Bio-Psychosocial model which is the current guiding framework, provides for practice which is more family oriented. It reflects the influence of two paradigms; the social model of disability and Social Systems Theory. It recognises the importance of strengths-based, partnership models with service providers and embraces the formal and informal networks which sustain individual and family well-being (Carroll et al 2013.)

The emergence of the family oriented approach was articulated through the policy document Progressing Disability Services for Children and Young People (HSE 2013). This led to the publication of Outcomes for Children and their Families (Standards and Performance Reporting Working Group 2013) which provides a new standardised model of best practice, linking provision with service delivery outcomes. This model, currently being rolled out nationwide, recognises the family's unique expertise and uses a strengths based, collaborative approach. As studies discussed below propose however, outcome is not solely dependent on service delivery, but is strongly related to contextual factors such as the availability of community support, family cultural background, levels of parental stress and family functioning. This perhaps calls for more a nuanced perspective which could explore the family within a contextual analysis to address some of the 'whys' where provision is seen to be wanting.

2.3 Family centred practice

2.3.1 General themes

Larkin and Moore's (2005) review of studies which investigates the effectiveness of family centred practice, found that its benefits are mediated by access to social support and the presence of a supportive and well-functioning, wider family. Barriers to family involvement in services included,

"…providing services at times that were incompatible with family commitments… poor parent-practitioner communication… insufficient service provision ...and difficulties in finding childcare for siblings" (Larkin and Moore 2005, p.27).

The researchers do not expressly identify the issue of ethnicity as significant for service provision other than noting that the "racial, cultural, ethnic and socioeconomic diversity" of families could conflict with the "values, attitudes and lifestyles" of the practitioner (Larkin and Moore 2005, p.55.)

2.3.2 Family centred practice with migrant families

Ethnicity however, was found to be a statistically significant factor in the uptake and success of services according to a study by Birkin et al (2008.) In their review of early intervention in New Zealand, the authors found that poor uptake of the service was related to low levels of awareness of the programme,

alternative cultural understandings of autism and language and communication barriers. This study develops a model of successful service provision on a concept of 'clinical/cultural match' where separate thematic clusters relating to "family-influenced" factors and "programme influenced" factors converge. This approach contrasts with the conceptual frameworks used by other researchers (Welterlin and LaRue 2007; Larkin et al 2005; Khanlou at al 2015; Khanlou et al 2017; Slade 2013) who understand these themes as inter-dependent and integral to the lived experience of many families from ethnic minorities.

Welterlin and Larue (2007) explore family functioning within an ecological context, looking at how cultural beliefs and norms shape the understanding, diagnosis and treatment of autism. They call for the development of services which enable a better "contextual fit" with families from ethnic minorities, such as increasing the provision of translators and a better awareness of cultural variation in family values and beliefs. They advise that families should seek out clinicians of the same "cultural or linguistic background" and consider ending contact with practitioners who are "unable to meet the criteria for collaborative and culturally sensitive partnerships" (Welterlin and Larue 2007 p.758.)

Slade (2013), Khanlou et al (2017) and Khanlou et al (2017) however, highlight the perceptions of powerlessness experienced by many minority ethnic families. These studies locate access barriers within a wider systematic discussion of the unequal distribution of power and resources. Slade's study on behalf of the National Autistic Society, (Slade 2013) elevates the voices of families from Black, Asian and Minority Ethnic (BAME) communities in the UK. It found that people's perceptions of being excluded from mainstream culture impacted on their self-esteem and confidence. These, compounded by language barriers, reduced some parents' ability to articulate their needs in an unfamiliar service setting, furthering their experiences of powerlessness and social exclusion.

"White families meet white professionals and seem to be on personal terms. We are made to feel like outsiders." (Slade 2013, p.18)

2.4 The experiences of migrant families - using the model of social support

Studies by Khanlou et al (2015) and Khanlou et al (2017) present the perspectives of both service providers (2015) and mothers (2017) with the aim of promoting more equitable access to early intervention through the provision of improved social support. They explore the experiences of families within an intersectional analysis which includes social exclusion, economic hardship, and isolation from extended families. They place social support at the heart of their study, recognising its positive influence on the provision of optimal and timely disability services as well as reducing parental stress and

promoting family well-being. The authors utilise House's (1981) theory which categorises social support according to 'structural,' 'instrumental', 'emotional' and 'perceptive' elements. This framework offers a way of understanding support and/or barriers, according to objective, concrete factors as well as subjective experiences.

2.5 Parental agency

An analysis of the barriers to early intervention should also review the ways in which parents and carers take a proactive role in supporting their children. In research conducted by Marshall et al, (2017) parents reported the ways in which they acted as advocates, sourcing services for their children. The study found that parents needed to be "proactive, persistent and assertive" (p.190) and that they took an active role in promoting their children's development at home. Henrickson et al (2000) found that when mothers felt that their concerns were not taken seriously by physicians, they trusted their instincts and persisted until they found help for their children.

2.6 Conclusion

The literature reviewed here indicates the diversity of approaches which international researchers have taken. Whilst some authors (Larkin and Moore 2005) focus on the quality of provision with the assumption that all families benefit from a universal service, others (Slade 2014; Welterlin and LaRue 2007; Birkin et al 2008; Khanlou et al 2015 and Khanlou et al 2017) argue that that those from minority ethnic backgrounds deserve particular targeted support to ensure equal access.

The most useful studies for social work and community support, understand the dynamics of access and uptake of services within an ecological model which incorporates family, community and service provision. The reports selected agree that family based early intervention has the best outcomes when other instrumental and emotional supports are provided.

As my research is intended to inform Togher Family Centre, a model which links families with community support is essential. I therefore, used a theoretical framework similar to that used by Khanlou et al (2015) and Khanlou et al (2017.) Their social support model offers a way to categorise the findings of the research and might help to identify the social supports which Togher Family Centre could provide.

Chapter Three
Methodological Approach

3.1 Introduction

This section will trace the development of the project from the initial proposal through to the data analysis. It will show how the overall epistemological framework of social constructivism, aligned with the participatory ethics of community based research informed the nature of the study. It will conclude with a discussion of the limitations of a study of this type and the ethical challenges which it presented.

3.2 Study aims

The aim of the research was to explore the experiences of parents who have young children with disabilities, investigating the perceived barriers to and/or satisfaction with the system of early intervention. The established research suggests that all families share some challenges accessing and engaging with services, but that families from new immigrant communities experience a further degree of difficulty. I therefore intended to explore the experiences of both Irish and New Irish families in order to identify whether this divergence is reflected in the experiences of the Togher community.

My objectives were to explore;

- The experiences of families living in the Togher area who engage with early intervention.
- Whether all families have similar experiences or whether they diverge according to Irish or New Irish identity.
- Whether some families have managed to overcome any perceived barriers and if so, how.
- What recommendations parents have for community support.

3.3 Theoretical perspective

My theoretical perspective was informed by the commission I was given via University College Cork's Community-Academic Research Link process (CARL). Togher Family Centre, having conducted their own quantitative studies, had called for further qualitative research to "explain the whys" relating to the nature of disadvantage in the local community and to analyse the specific needs of families and children. This dictated the epistemological framework that I would use; a perspective which understands that our knowledge of the world which informs our everyday experiences, is negotiated through our individual perspectives and shared assumptions. Known as social constructivism, this approach has been defined as the perception that knowledge is "created by the interactions of individuals within society" (Schwandt 2003). I have chosen a version of constructivism which distances it from the stricter interpretations which embrace relativism. A reliance on relativism would imply that all realities are equally valid, thus denying the researcher an ethical standpoint from which to make recommendations and call for social change (Andrews 2012). I have employed a social constructivist framework therefore, which interprets a particular phenomenon though individual experience, but have interwoven this with the threads of critical theory.

3.4 Methodology

The CARL initiative, as with other community based research programmes, is based on a participatory approach. Situated in the ideological stance of social change, it emphasises the processes of public engagement and reciprocity (Bates and Burns 2012; Durham Community Research Team 2011). It entails the use of a qualitative type methodology which calls for the exploration of everyday experience in order to solve problems or effect social change (Strand et al 2003). This corresponds with the central characteristics of qualitative research, identified by Creswell as;

"…addressing the meanings individuals or groups ascribe to a social or human problem," using "an emerging…approach to enquiry," to enable an analysis which "includes the voices of participants" and acts as "a call for change." (Creswell 2013, p. 44)

Using individual interviews enabled me to develop a closer relationship with participants and create a space in which they could discuss their experiences and emotions at a level beyond that of 'everyday' conversation. It allowed me to collect data which was rich and in-depth, enabling a "complex detailed understanding of the issue." (Creswell 2013, p.48)

3.5 Method

3.5.1 Introduction

Following an initial process in which the topic of research was broadly negotiated, a contract between myself, my supervisor and the community partner was agreed (as part of the CARL process). It covered the research timeline, supports, resources and the handover date. It was agreed that the study findings would be communicated directly to the participants during September 2018 and that the results would be disseminated to other community members by Togher Family Centre, possibly in the form of an infographic leaflet. As agreed under the terms of the CARL agreement the research would also be published online (at www.carl.ie) and would remain freely available.

The initial research question which focussed on the experiences of New Irish parents was later refined following conversations with the centre's staff. They relayed anecdotal evidence that the parents who were experiencing challenges accessing early intervention came from Irish as well as New Irish backgrounds. With this in mind, the centre manager and I decided that a comparative study would be more appropriate to signpost the direction for future resources.

I explored the topic in some depth through conducting a review of the literature which investigated the barriers to early intervention. I included studies which referred to the experiences of immigrants, focussing on those which referred to social support.

3.5.2 Interview questions

My interview questions were designed to be open ended, allowing the participants to guide the agenda. I used the questions to guide the conversation however, by using the thematic framework of social support as proposed by Khanlou et al (2017.) This framework categorises social support under three separate dimensions;

- **Structural support**. This refers to parents' engagement with disability services including communication with staff and ability to 'navigate' the system.
- **Instrumental support.** This refers to the tangible, practical methods of support; both formal (community agencies) and informal (friends and family).
- **Emotional support.** This describes support at the personal level, most likely to be provided by close family members.

I decided at an early stage that I wanted the interviews to reflect the ideology of participatory research. I wanted to prevent the study from becoming a deficit-based piece, constructing parents as 'vulnerable' or simply as 'subjects.' I instead, aimed to position the respondents as 'agents,' allowing them to

demonstrate their own ability to problem solve. I included some questions therefore, which asked participants about their successes, and encouraged them to share their advice for the benefit of other parents. This information would of course, also help in formulating my recommendations.

The question guide was next refined and approved by the Togher Family Centre manager. Significantly, questions that initially referred to 'barriers' were expanded to allow the participants to define whether their experiences were positive or negative. These changes removed a large degree of researcher bias and allowed me to gather richer and more meaningful data. The interviews began with a number of closed questions to elicit demographic data relating to the child's age and disability, the participants' country of origin, their confidence with English and their current use of Togher Family Centre services. The answers were later incorporated with the results to create a meaningful evidence base for the development of future services. During the interviews, I ensured that I explained the rationale for these questions. I had to be clear for example, that I needed to ask for their country of origin as I was conducting a comparative study. The discussion phase was initiated by asking respondents to talk about their children. I felt that this would help to create a rapport and alleviate any initial anxiety. I also wanted to ensure that the child remained at the heart of the process.

3.5.3 Sampling and Recruitment

Through consultation with UCC tutors and Togher Family Centre staff, seven or eight interviews were judged to be sufficient for this relatively small scale study. This number would limit the time taken for transcription but would yield sufficient amounts of data. The participants were identified by staff from the three pre-schools under the Togher Family Centre umbrella; Cur le Cheile, Tus an Bothar and Togher Family Centre pre-school. Three participants were Irish and four identified as New Irish, all having some level of contact with the early intervention system. In addition, the participants were identified according to their perceived emotional ability to engage in the process, based on the understanding that many parents going through the diagnostic process might be emotionally vulnerable. The interview questions were piloted with a member of staff whose child had a diagnosed disability. Interviews were kept to approximately half an hour each in order to keep the amount of data at a manageable level for analysis.

3.5.4 Data collection and analysis

I recorded the interviews on a Dictaphone and transcribed them shortly afterwards. I analysed the data firstly by coding segments of speech according to their content. I then placed each segment into a category according to the dimensions of *structural, instrumental* and *emotional support* as well as

coping methods and *advice*. I next analysed the content in each category in order to form what Creswell (2013) refers to as "the essence" of the interviews. These higher order meanings were generated by reading across all of the transcripts and also within the 'Irish' and 'New Irish' groups. The themes were then double checked by referring back to the original transcripts.

3.6 Ethical issues and challenges

3.6.1 Ethical Considerations

Ethical approval was sought through UCC's Social Research Ethics Committee (SREC). Approval was contingent on my ability to ensure informed consent, privacy and anonymity, data protection and security and safeguarding issues. To ensure informed consent, I distributed a flyer to the preschool staff which gave basic information on the study including the right to anonymity. I then phoned each participant to answer any questions they had and gave them a more detailed information sheet at the interview. I asked them to sign a consent form which allowed them to withdraw from the study up to two weeks afterwards, and gave them the option not to allow me to use direct quotations in my write up. The contact details of two support organisations were provided in the information sheet to address the needs of any parents who may have felt distressed following the interview.

As some of the participants were identified by staff as having English as an additional language, the forms were; i) translated into Polish and ii) written in plain, jargon free-English (see appendix for flyer, information sheet and all forms.) A translation service was offered to three participants, identified by staff as having lower competence in English. Two of those people declined the offer and one accepted, so a Polish translator was engaged. I ensured that the Polish participant was happy to use the translator available. I briefed the translator beforehand and asked her to sign a confidentiality form.

3.6.2 Ethical Challenges

Difficulties relating to communication arguably posed the biggest challenge to the ethical validity of the study. In all four interviews with the New Irish participants, there was some degree of difficulty for both the interviewer and interviewee in communicating and fully understanding each other's contributions. The participants' levels of English varied but all interviews involved some degree of ambiguity where I, as the interviewer had to seek clarification. Whether my interpretations were precise or not remains unknown.

The interview which involved the use of a translator also posed significant challenges. Some elements of the participant's contributions appeared to have been left out by the translator, perhaps to make the

answers more concise. This inevitably impacted on the inherent 'meaning' available for analysis and was to an extent, difficult to identify and eliminate. A further limitation to the ethical soundness related to the fact that the translator was a member of staff. This inevitably had some bearing on the respondent's ability to answer my questions, specifically relating to a difference of opinion which had emerged between herself and the pre-school team.

3.6.3 Other Challenges and Limitations

Glesne and Peshkin (1992) argue that "generalizability holds little meaning for qualitative researchers". I am however cognisant that the premise of the research (making recommendations for a community service) depended on a certain degree of generalizability. Having to base my recommendations on the experiences of only seven parents would inevitably limit the study's usefulness.

Another limitation relates to the extent to which this sample could be taken to represent the group identified by the research question. A review of the literature suggests that barriers to early intervention have the greatest impact on the wellbeing of children and parents from the most marginalised and isolated families. It is questionable whether the sample reflected this; these families were in fact relatively engaged in the community (attending community services) and showed relatively high levels of confidence and motivation, evident in their willingness to voluntarily engage in the interview process.

3.7 Reflexivity

Before exploring the findings of my study, I should provide an acknowledgement of my own part in the process of study design and analysis. My review of the literature had focussed on a range of international studies which found that immigrant families experienced additional challenges accessing early intervention. It is possible that I structured my data analysis process and conducted my interviews in such a way that I indeed, found those additional challenges (i.e. I found what I was looking for). My professional experience and personal beliefs regarding the shortcomings of the early intervention system may also have motivated me to look harder for findings which confirmed these views, perhaps unintentionally disregarding the accounts which contradicted them.

The people I interviewed came from a variety of different backgrounds and may have perceived my role as an outsider, or a representative of 'the system'. They might have perceived me as having more power to effect change than I actually hold and were perhaps more motivated to share their challenges rather than their successes. These considerations would contribute to the argument that the process of interviewing as is never a neutral activity, but is rather an active process in which each party's desires, feelings and biases are used to construct a "mutually created story." (Fontana and Frey 2005 p.696)

With this in mind, I endeavoured to reduce the degree of bias, ensuring that my results were cross checked and that each theme was representative of the majority of the respondents' experiences.

3.8 Conclusion

This study used a quantitative approach which employed a theoretical framework based on both social constructivism and critical theory. Commissioned as a piece of community based research, it was informed by the principles of participation and social action. The study was carried out in accordance with the ethical standards prescribed by UCC's SREC committee and was conducted with the active participation of Togher Family Centre. The main ethical challenges I encountered were related to language barriers.

Chapter Four
Findings

4.1 Introduction

This chapter will begin with an overview of the results, followed by a detailed exposition of the findings organised under the headings of structural support, instrumental support, emotional support, language and communication and coping methods. The participants' comments have been anonymised by using 'P' followed by their interview number.

4.2 Overview

Seven people were interviewed for this study; three were from Ireland, two were from Poland, one from Sudan and one from India. Their experiences related to seven children. At the time of the study, two children were three, three were four, one was seven and one was twelve. The reasons given for their referral were Autism (five children), speech delay and Down's syndrome. The parents' languages were given as English, Polish, Arabic, Hindi and Marwari. When asked about their confidence with spoken and written English, all Irish respondents reported that they were generally confident, one using friends to help fill in forms. Two New Irish people expressed a moderate level of confidence understanding and speaking English, the other two found it challenging. Three of the four identified filling in forms as difficult. They all used the services of the Togher Family Centre preschools, one also used the Happy Hub after school service.

Although the findings here are listed under separate headings, there is considerable overlap and interaction between them. Practical supports for example, sometimes also offered a degree of emotional support. I decided to use the additional heading of 'language and communication' to account for some important additional barriers which emerged from my analysis.

Overwhelmingly, the dominant theme was 'waiting'. Parents from both groups spoke of their frustration waiting to receive a diagnosis and therapeutic services and felt that that this had taken a heavy emotional toll on their families. Most were able to tap into practical support from friends or family in the meantime. All parents reported being emotionally impacted by caring for a child with a developmental

disability and sourcing the appropriate therapeutic services. They all however, demonstrated high levels of agency in advocating for their children and actively sought out support and information using their own resources.

There was a high degree of similarity between the experiences of Irish and New Irish parents. New Irish parents' experiences however, diverged from the Irish group in two crucial ways. Firstly, they tended to report feeling more isolated, lacking the emotional support of family. Secondly, they tended to experience difficulties with understanding and speaking English. This presented as a problem for communicating effectively with professionals. It also tended to complicate the diagnosis process where developmental delays in communication were confused with delays in learning English as a second or additional language.

4.3 Findings

4.3.1 Structural Support

Most of the participants reported waiting for considerable amounts of time for assessments, and for follow-on therapeutic services.

"I was on that waiting list a year and a half before I even sat down with them." (P2)

Their experiences of waiting were marked by anxiety and extreme frustration. Some parents expressed incredulity; the system which they had been told was based on rapid intervention, was unavailable at the precise time it was needed.

"for me it's ridiculous you know, because this is early intervention team ...and the name of that is, you know…not true!" (P1)

One father described how his son had to wait for the HSE service which provides orthopaedic insoles. By the time his child had waited to be assessed, and had waited for the insoles to be made and delivered, he had completely grown out of them. Another parent reported being told at her child's initial screening that she should go home to start complaining straight away. Some were unaware of the resources they were eligible for, many stating that they had no idea who to approach or where to go to. One parent had been told to expect her son's behaviour to become harder to manage in puberty, but had not been provided with any information on how to access support or advice.

"There was no, what do you do next, who do you see, who do you take them to when that happens. That doesn't exist."(P2)

The anxiety of waiting seemed to be exacerbated by the perceived lack of transparency in how the system operates. One mother resorted to ringing every week for an update.

"still I don't get answer, nothing, we still waiting." (P1)

Another only realised that she had been forgotten about after being told she'd *"slipped through a hole." (P1)*

4.3.2 Instrumental support

Parents reported seeking practical help from a variety of sources. They capitalised on the skills and knowledge of their friends and families in sourcing advice and support for their child's disability. One parent for example, enlisted the help of a friend who was a teacher, to give her child one-to-one support every week. Another parent sought the medical advice of his sister who practices as a GP in Sudan. Some families (from both groups) were entirely reliant on informal care arrangements for their childcare needs, especially those who worked long hours. Whilst the Irish parents in the study were able to rely on their families for this type of help (with the added benefits of the emotional support they offered), New Irish families had to depend upon friends who were less likely to offer support on a personal level.

Many respondents however, particularly those from the New Irish group, felt that they had to be careful not to 'over-burden' their friends or family. One New Irish parent commented that,

"everybody is busy, his family… or he is working". (P5)

Another expressed similar sentiments, *"…people they have her own life". (P1)*

Most participants used the internet for information and practical advice relating to their child's disability. Two parents named discussion forums on Facebook as valuable resources. One described how he found out through an online parents' forum about a type of underwear designed to prevent children from smearing. He described his relief on discovering this "simple practical solution" saying that,

"a lot of the time there's simple answer of information, to say where they go, who to talk to or what is your experiences". (P6)

He emphasised the usefulness of sharing the knowledge and experiences which only parents could provide.

"a lot of the time it's the parents who come up with the solution because they are the ones suffering from it. And they have to come up with something and so, if I wasn't in one of those groups, I wouldn't have known it. There's a massive sea of information out there." (P6)

A mother in the study told me about a support group which she had helped to form following a post diagnostic meeting.

"three of us kept in touch straight after that cos we felt no one would help us out here, we'd all do it cos there's no one." (P2)

She told me how the group had shared information and tips. They made sure that whoever was available would attend local courses and feed the information back to the group.

The support and advice given by Togher Family Centre staff from all three preschools was identified by the majority of parents as instrumental in identifying their child's disability and seeking a diagnosis. Two also mentioned the Happy Talk group sessions provided by the centre as a valuable resource. One parent had attended the English language lessons at the local primary school and another had used the services of NASC to apply for social welfare.

4.3.3 Emotional support

Most Parents described how alone they felt caring for a child with a disability. Some spoke of not being able to sleep for worry and of feeling unable to cope. The realisation that their child had a disability was for many, extremely upsetting.

"I all the time cried because my life was you know, crash." (P1)

Many felt frustrated and worn down by having to wait for so long for services. One parent described her reaction on receiving a call from a therapist, looking to reschedule a long awaited appointment.

"I started crying in the middle of the shop and I said 'you can't do this to me no more, you know I'm over two years waiting now.'" (P2)

Many worried about what the future would bring.

"you know I'm like, will he ever talk." (P7)

The majority of respondents felt that their child's disability had put additional pressures on their relationships with other family members. Two participants revealed how the financial pressure of both parents having to work had impacted on the amount of emotional support they were able to offer each other. One parent described how she and her husband only saw each other during car journeys to and from work. She described how this had affected her marriage, comparing her relationship with her husband as *"only friends or people living together" (P1).* This further impacted on her ability to be emotionally resilient in coping with the demands of parenting a child with disabilities.

All of the Irish respondents cited their families as sources of emotional support. Many felt however, that they had to 'manage' some family members' emotions. One parent described how she had to put on a brave face to avoid upsetting her older children who were studying for theirs exams. Another described how upset and frustrated she had felt when her in-laws refused to believe their grandchild had a disability. The same parent described her own mother's reaction on hearing about her grandson's diagnosis of autism.

"she was heartbroken… they just felt like they had failed him." (P2)

The New Irish parents were less able to identify sources of emotional support, having left their own support networks behind in their home countries. Many felt alone, having no one to talk to about their worries.

"*it's difficult when you be too far from your family for something like that." (P5)*

One New Irish parent described feeling "emotionally overwhelmed" when he and his wife first arrived into the country. They struggled to navigate an unfamiliar health system in order to find services for their son. They had both felt socially isolated, the only emotional support at that time coming from their social worker.

"there's no family here and we had limited friends at the time and you don't talk to everybody about your today things, what goes on in your mind." (P6)

Another father described how he felt responsible for his whole family's emotional needs. As his wife spoke little English, he had to deal with the preschool and clinical staff single-handedly. This responsibility had left him feeling very alone.

"sometimes I feel nobody feel my emotions…what I need or what I talk about." (P5)

Another parent talked about her conflicted feelings, wanting to be close to her family in Poland but choosing to remain in Ireland for the sake of her son.

"I wish back to Poland because that is my country …but I think, and this is my opinion, that Ireland is more opened for children disabilities." (P1)

4.3.4 Language and communication

Although the participants weren't specifically asked about language, three of the four new Irish parents identified their lack of English as a factor that had caused difficulties with their child's diagnosis. One parent found that it prevented him from understanding the professionals involved in his son's care. He also found that he was unable to communicate his concerns to them.

"I feel he cannot feel what I am feeling, you get my point? Because I am worried…he not feel I am serious". (P5)

Language was also identified as a complicating factor in identifying and assessing some children's developmental delays. One parent remembered how his daughter was initially referred for a speech and language assessment only to find that her speech improved in the meantime. As this delay was attributed to the fact that the family spoke three languages at home, it meant that he and his wife were slower to contact the GP when their youngest child appeared to have a similar speech delay. It only became apparent later on however, that his was not a *language* issue but a *communication* disorder.

Another parent described how her daughter's preschool teachers had identified what they had perceived to be a developmental delay after observing her child's unusual behaviour.

"in the view of the teacher it was like the child was jumping on the table, hiding somewhere, no understanding comments, don't speak, use own language." (P4)

However, after an appointment with a psychologist in Poland, and a further visit to the Irish psychologist with a translator, it was detected that the child's communication and behaviour difficulties were simply a result of a delay in picking up English. This therefore, was the reverse of the situation described above.

4.3.5 Coping methods

All of the respondents displayed a powerful sense of personal agency, identifying their resilience and ability to fight for resources as strengths. Many felt compelled to write a succession of letters and emails and make repeated phone calls, sometimes every week. They all spoke of having to "demand" or "fight" for resources. Having no formal supports, they had felt forced to rely on their own reserves. When I asked at the end of the interviews whether they had any advice for other parents, all of the participants responded by warning parents not to accept being told to wait. They should instead, actively advocate for their child's needs.

"It's all on your own shoulders you know …it's up to you like." (P2)

One parent described her intense frustration, when her concerns about her son weren't acknowledged. She remembered watching her child repeatedly lining up his toy cars on the floor, experiencing the gut instinct of knowing there was something wrong. She recommended that other parents should follow through on their instincts if they feel that something isn't right, not to hold back but to get help. Another knew from her work in special needs that something was wrong. She reported having to fight for a second opinion.

"I knew in my heart and soul that wasn't average." (P7)

She described feeling that the only way to get taken seriously was to *"kick up a fuss"*. She advised other parents to *"just keep fighting and don't back down." (P7)*

Another described reading through all of the relevant legislation to be sure that her child qualified for early intervention. She advised other parents to persist in seeking help but also to use their own resources.

"because the more people you talk to, the more courses you go on, it makes your life easier and nobody else will do it for you." (P2)

Two of the Polish participants used their own resources to pay for a private diagnosis, one travelling to Poland for a second opinion. Many other New Irish parents talked about the challenges of navigating an unfamiliar system, often in a new language. One father urged others in his position to avoid *"taking a step back,"* to push themselves forward in the hope that in time, their confidence would improve and things would get easier (P5). Another New Irish parent described how he and his wife had decided to move to Ireland specifically to access better services for his son. He described his realisation on their arrival that it wouldn't be easy.

"the services obviously, I was thinking would be massively, completely different world, but there is always struggle, you have to look for things, to fight." (P6)

The same parent described how he had initially felt powerless knowing his child was on a waiting list but not knowing for how long. He described how he was able to google a name he found on a letter to get an email address. He was able then to bypass the gatekeeping system to find out exactly where his child was on the waiting list.

One Irish parent gave a powerful description of what it was like having to manage without HSE services and supports.

"sometimes I think I'm a house mum, I'm this, I'm that, I'm an occupational therapist, I'm a speech and language therapist, there's nothing I couldn't leave go because I'm not…you have to do it yourself." (P2)

A few of the respondents welcomed the idea of starting a parents' support group. This, they felt would be of benefit to the many others in the community, particularly those whose children had recently been referred to early intervention. Group members would be able to learn from the experiences of others and could share practical advice. They might also be able to provide emotional support by sharing their concerns, as well as providing hope for the future.

4.4 Summary of key findings

- Overwhelmingly, the most common experience related to waiting for assessments and services.
- Parents from both groups relied on practical help from friends and families.
- All parents found parenting a child with disabilities to be emotionally demanding.
- Irish parents were more likely to receive emotional support due to the close proximity of their extended families.
- All families displayed a range of proactive, positive strategies which focussed on advocating for their child's needs and used practical ways to aid their child's development at home.
- Difficulty with English proved to be a barrier to effective communication with service staff. Some parents found it affected their ability to understand and be understood. It also seemed to be a complicating factor in the diagnostic process.

Chapter Five
Discussion

5.1 Introduction

The findings of this study are analysed here under four main themes; the lack of services, the necessity of social support, parents' resilience and language issues.

5.2 Discussion

Every single parent in this study was forced to wait an inordinately long time for their child's assessments and therapeutic services[1]. Parents reported feeling exasperated and frustrated, not only with having to wait but also having no indication when their child's turn would come. This echoes the experiences of parents in international studies (Khanlou et al 2017; Marshall et al 2017; Hendrickson et al 2000). The lack of transparency appears to impact on parents' levels of stress and is experienced as profoundly disempowering. Parents in this and other similar studies describe the futility of having to wait for a service which is proven to be most effective when a child is young (Marshall et al 2017; Hendrickson et al 2000; Barnardos 2017; Khanlou et al 2017).

The benefits of practical support from formal and informal sources are well documented. Parents such as those in this study who lack support networks, experience higher levels of depression and stress (Khanlou et al 2015; Khanlou et al 2017; Larkin and Moore 2005) and are at a greater risk of social isolation. This particularly affects immigrant parents who lose their support networks after leaving their home countries. This lack of support compounds the difficulties many parents face when they and their children have to leave the house. When parents take the 'easier' option to remain at home, it further isolates them. Some families' ability to engage with their communities are also impacted if they lack

[1] The waiting times reported by the parents in this study are as indicative of those experienced by others in the region, according to the findings presented by Barnardos in 2017. This study used HSE statistics to show that children from the Cork area, and South Lee in particular were among those on the longest waiting lists in the country. Barnardos found that among children waiting for an assessment of need, 96% had waited for longer than the statutory timeframe, 67% waiting over a year and 20% waiting over two years. The same children waited for an average of twelve to eighteen months for the recommended follow-on intervention services.

confidence in speaking English. Participants in this study reported that this made it more difficult for them and their spouses to meet new friends and avail of community support.

The associations between social and emotional support are well recognised in the literature. Khanlou et al (2015) and Khanlou et al (2017) for example, conceive as social support as a systems of interactions between formal and informal systems and identify a strong link between social support and well-being. The findings of my study point to a clear distinction between the sources of instrumental support and emotional support. Although Irish and New Irish parents availed of both friends and family for help with practical matters such as childcare, emotional support was only gained from the interactions with extended family members, in particular the participants' own parents. This had important implications for New Irish families. Although they had developed their own social networks, they often found that they were unable to use friends or community contacts for emotional support. Although many remained in contact with their families over the phone or the internet, their physical absence left parents feeling lonely and isolated.

Furthermore, the experiences of Irish participants showed that despite the supportive presence that families offered, they were at times, not able to offer the understanding and empathy that parents needed. It appears that in the final analysis, caring for a child with a disability is an emotionally isolating experience regardless of the presence of friends or family.

In contrast to the work of Khanlou et al (2015) and Khanlou et al (2017), this study incorporated a perspective which recognised the high levels of personal agency demonstrated by parents. Although all respondents in this study felt frustrated and disempowered by the system, they appeared to have combatted their perceptions of powerlessness by making full use of their own personal resources. Parents used a variety of strategies to challenge the system and address their children's developmental needs. They relied on their own instincts as well as their own knowledge and expectations of typical development, to assess whether their children needed to be seen by specialists (Marshall et al 2017; Henrickson et al 2000). When they found that they were either not listened to, or placed on lengthy waiting lists, they persisted in their attempts to seek help.

Language difficulties have been found to impact on some parents' levels of engagement with early intervention service staff (Marshall et al 2017; Khanlou et al 2015; Welterlin and Larue (2007). However, this study unexpectedly found that language issues also feature as complicating factors in the diagnostic process. The complexities of the interconnections between language acquisition and developmental communication delays cannot be discussed here. However it could be argued that a more effective translation service could have eliminated some of the difficulties encountered.

5.3 Conclusion

The results point to three main themes; the lack of services, the necessity of social support and the power of self-reliance. It is evident that in a reiteration of the study recently performed by Barnardos[2] (2017), the main barrier to early intervention is a lack of resources in the system itself. This has had serious impacts on the well-being of families concerned about their children's developmental needs. In the meantime, parents have been forced to fall back on their own resources, simultaneously trying to provide for their children's needs whilst challenging the system for the provision of professional help. I would argue that their ability to do this is contingent on their reserves of resilience and emotional well-being which in turn, are nurtured through the emotional support that comes from close family members. New Irish families appear to lack this kind of support as their families and close friends often live abroad. The absence of this support, often coupled with difficulties with English can have adverse consequences for their well-being and places them at a greater risk of social isolation.

[2] "The majority of parents in our survey perceived that the primary reason for the delay in their child getting an initial assessment or treatment is because of the ongoing underfunding by the Government in Ireland's public health system" (Barnardos 2017).

Chapter Six:
Conclusion and Recommendations

6.1 Introduction

In this final chapter, I will review my findings according to the original aims and objectives of the study. After giving a brief outline of the study's limitations, I will present my key findings and recommendations. I will conclude with a reflection on my personal learning during the process.

6.2 Study limitations

From the outset, I became aware of the importance of establishing a value framework for the study. I had initially planned to use grounded theory. I felt this approach would allow my interviewees to guide me towards the issues of significance which would be in keeping with the democratic and emancipatory principles of community research. However, more pragmatic considerations led me to decide to conduct a phenomenological study instead. This enabled me to make use of a pre-established theoretical framework, keeping the data easier to categorise and at a more manageable size. Nonetheless, I feel that I was able to maintain a degree of flexibility by using an interview style which allowed the participants to take the lead.

Due to the breadth of its design, this study perhaps lacked the space to delve further into many of the issues it raised. I had imagined that I would be able to discuss of the quality of interactions between parents and professionals which is identified as an issue in the supporting literature. However, the diversity of responses and the scale of the study limited my ability to give this enough space. Interestingly, and revealingly, some respondents expressed a reluctance to comment; they felt so relieved to be finally getting a service that they lacked the energy and willingness to complain.

6.3 General conclusions

In order to be able to support families going through the early intervention services process, Togher Family Centre staff asked whether there were any barriers that needed to be overcome. The literature reviewed suggested that the barriers to engagement relate to a lack of family focussed provision, cultural

differences, and social exclusion. Whilst not wishing to discount these explanations, this study has found that the main barrier to early intervention in Ireland is quite simply a lack of resources. In their pursuit of their children's statutory rights, parents are therefore, forced to "**fight for everything**."

6.4 Recommendations

6.4.1 Practice; Parents' Support Group

As evidenced by my findings, it is critical that parents caring for children with disabilities are well supported. Their need for support is even greater during the time they spend waiting to receive HSE services. I believe that the implementation of a parents' support group by Togher Family Centre would go some way towards meeting that need. Groups are an effective way of building community connections and perceptions of belonging. They offer the opportunities for shared experiences and foster mutual support, resilience and empowerment (Masten 2001). A support group would offer an environment for sharing practical ideas and could provide a setting where parents could meet and connect socially. A useful programme that this group might consider is the 'Being Well' programme facilitated by The Brothers of Charity. This programme takes a holistic approach, building carers' awareness of attending to their own needs through stress management, relaxation, healthy eating and physical exercise. (Brothers of Charity 2012).

Research could be conducted with the parents' group to determine which supports they feel their children might benefit from. Togher Family Centre could extend its 'Happy Talk' programme for example, or develop a 'social skills' session.

6.4.2 Policy

The chronic under-resourcing in the early intervention sector has resulted in long waiting lists for resources. This denies children their statutory entitlement to the services which are crucial to their development. It also has a corrosive impact on their families, elevating the risk of poor mental health and social isolation. The public/private divide which has resulted has led to a situation where those who are already affected by economic disadvantage and social isolation are further disadvantaged.

It is essential therefore that the long delays in the public health system are addressed as a matter of priority. The rollout of the Programme; 'Progressing Disability Services for Children and Young People,' designed to make disability services consistent and equitable, must be accelerated to address the regional disparity which currently places children in Cork at a much greater disadvantage than the rest of Ireland (Barnardos 2017).

6.4.3 Additional Recommendations

The findings of this study show the value of the support that preschool staff are able to offer parents. These relationships should be capitalised on to ensure that families are linked in to services such as support groups and English language classes.

The issues raised here relating to understanding and speaking English, suggest that there may be barriers to effective communication within the early intervention services. Whilst many parents may have some understanding of the functional, everyday vocabulary, they may not feel able to communicate more abstract ideas or discuss their emotional concerns. This indicates the need for a greater awareness of communication barriers amongst staff and a wider availability of translation services within HSE services.

6.6 Reflection

Conducting this piece of research has proved to be a highly engaging and stimulating exercise. Over the past nine or ten months, I have made use of the skills and learning which I have acquired during the MSW programme. By drawing together the themes from areas such as 'community work', 'child and family welfare', 'group work', and 'social exclusion,' I have achieved a much deeper knowledge of the issues in social work practice. I have also found that I have grown in confidence in my ability to engage with people, using person centred and strengths based approaches. Although the research I had conducted helped to guide my interviews, I ultimately found that the evidence pointed to quite different conclusions. I learnt the valuable lesson therefore, that I should be cautious in making assumptions about people's needs, motivations and behaviours. Learning to *really* listen to other people has meant acknowledging my own preconceptions, and then endeavouring to put these aside.

I had not initially considered conducting a piece of CARL research, imagining that it would result in extra work. During a lecture however, in which the ethos of community research was discussed, I realised that this would provide the opportunity to address the issues which had inspired me to train as a social worker. I would not simply be reading about equality, justice and diversity and how others had worked to promote positive social change, but could actively contribute to it through my work. In some ways, my initial thoughts proved to be correct in that it certainly involved a lot of work! However, what I hadn't been prepared for was the huge sense of satisfaction and achievement I felt on completion of the project.

Although much of my learning came from reading about the theory and developing my practical skills, the true value came from the opportunity to think about the wider issues relating to social work and society. Whereas I had initially focussed on the value of social work at the individual level, I had

underestimated the impact of wider social policy on individuals and families. I have achieved a better understanding of the principles of practice which highlight the duties of social workers to engage in advocacy and critical debate (IASW). This will I hope, make me a better social worker. I would also like to return to return to research in the future, to contribute in a different way to better practice.

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Appendix 1

INFORMATION SHEET (1)



What is the Study? As part of my Social Work Masters course at University College Cork, I will be carrying out a research study with the Togher Family Centre. We want to find out about the experiences of parents whose children use early intervention services. I will be comparing the experiences of parents who were born in Ireland with parents who are new to Ireland.

What will the study involve? I will interview you for about half an hour, asking about your experiences. At the beginning I would like to ask a few questions about your child, where you are from and what your level of English is. In the main part of the interview I will ask about seven questions. I will record your answers on a Dictaphone.

Why have you been asked to take part? You have been asked because the staff member who knows you feels that you might have the experiences that would help me with this research.

Will your participation in the study be kept confidential? Yes. I will make sure that whoever reads this will not know who you are.

Please let the staff member know if you are interested. If you are, I would be happy to meet you in January to answer any questions you might have. Thank you.

Appendix 2

INFORMATION SHEET (2)

UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

What is the Study? As part of my Social Work Masters course at University College Cork, I will be carrying out a research study with the Togher Family Centre. We want to find out about the experiences of parents whose children use early intervention services. I will be comparing the experiences of parents who were born in Ireland with parents who are new to Ireland.

What will the study involve? I would like to talk to you for about half an hour. At the beginning I would like to ask a few questions about your child, where you are from and what your level of English is. In the main part of the interview I will ask about seven questions. I will record your answers on a Dictaphone.

Why have you been asked to take part? You have been asked because the staff member who knows you, feels that you might have the experience that would help me with this research.

Will your involvement in the study be kept anonymous? Yes. I will make sure that whoever reads this will not know who you are. If I use something you've said in my research, I'll make sure there won't be any clues to show who said it.

What will happen to the information which you give? Your information will only be seen by me and my supervisor. I will keep the Dictaphone in a locked drawer and will encrypt the

information on my laptop. After the project is finished, it will be kept for at least ten years and will then be destroyed.

What will happen to the results? The results will be presented in the thesis. They will be seen by my supervisor, a second marker and the external examiner. The thesis may be read by future students on the course. Parts of the study might be published by The Togher Family Centre. I will be giving a presentation based on the study to UCC students and staff.

What are the possible disadvantages of taking part? I don't think that you will be badly affected by doing the interview. It is possible that talking about your experience might be upsetting.

What if there is a problem? After we have finished, I will talk to you how you felt during the interview it and how you are feeling now. If you do feel upset, you could speak a member of the Togher Family Centre, call Shine Ireland on 021 4377052 (for autism) or the Special Needs Parents Association on 087 7741917.

What if I change my mind? If you don't want to take part, you can leave the study at any time up to 2 weeks after your interview.

Who has checked this study? Approval must be given by the Social Research Ethics Committee of UCC before studies like this can take place.

Any more questions? If you need any more information, you can contact me: Helen Devery on 08568381250, email: 113137522@umail.ucc.ie. Phone 086 8381250 or email my supervisor, Pearl Doyle at: pearl.doyle@gmail.com

If you agree to take part in the study, please sign the consent form attached

Appendix 3

CONSENT FORM

University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

I……agree to take part in Helen Devery's research study.

The reasons for the study and how it will be done has been explained to me in writing.

I am participating voluntarily (nobody is making me do it).

I will allow for my interview with Helen Devery to be audio-recorded.

I understand that I can change my mind and leave the study at any time, before it starts or while I am being interviewed. I can also say that I don't want my interview to be used in the study up to two weeks after the interview.

I understand that I can say if I don't want the recording of the interview to be used, for up to two weeks after the interview. If this happens, the information will be destroyed.

I understand that my name won't be used in the write-up. Anything that might give a clue about who I am will be changed.

I understand that if I tick the first box below, my own words from the interview can be used in the thesis and other publications. (Please tick one box)

I **agree** to my own words from the interview being used. ☐

I **do not agree** to my own words from the interview being used. ☐

Signed: …… Date: ……..

PRINT NAME: ……

Appendix 4

INTERVIEW QUESTIONS

DEMOGRAPHIC FORM

1. How old is ……. (*child's name*)?
2. What is his/her special need?
3. Where are you from?
4. How long have you been in Ireland?
5. What languages do you speak?
6. How confident do you feel when you're speaking English?
7. How well can you understand other people who speak English?
8. How confident do you feel when you're writing in English?
9. How well would you say you can read English?
10. Which Togher Family Centre services have you used?

INTERVIEW QUESTIONS

1) I'd love to hear a bit about your son ….*name*….. /daughter…..*name*…….
   What's s/he like?

2) Can you tell me about how ….*name*…….came to be diagnosed?
   (Prompts: how long did it take, who did you speak to?)

3) What did you think about the diagnosis?

4) What help did she/he get after this?
   (Prompts: e.g. occupational therapy, speech and language therapy, psychological assessment...)

5) What were your thoughts on these services?
   (Prompts: In what way were they useful/relevant?
   How well could the staff understand you and what you were concerned about?
   How well could you understand them?
   How did you get on with the paperwork?
   What was it like getting to the appointments?
   How much of a difference did they make to you and (child's name)?

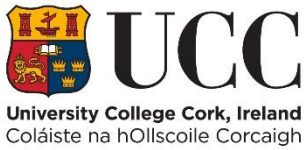
6) What practical help did you get at this time?

(Prompts: childcare, transport, help with child's behaviour, money
If none, what would have been useful?)

7) What was is like for you emotionally?
   (Prompts: How did you feel at the start?
   What was it like for you going through it?
   How do you feel now?
   Who understand what you were going through?)

8) What would you say to someone else going through this?

Appendix 5



CARL Research (Helen Devery): Interpreter Confidentiality Agreement

I _____ *(name)*

wish to confirm that I have read the terms and conditions of

_____ *(agency name)*

and that I will abide by the agreement.

I will respect and treat as confidential any personal information or observations regarding the children and/or their families, acquired in the course of the interview process for the CARL research project.

Signed_____

Name (printed) _____

Date _____

Togher Family Centre Limited
6 Maglin Grove, Deanrock Estate, Togher, Cork Ireland

To whom it may concern,

Togher Family Centre has given Helen Devery permission to carry out her research in this centre.

If you require any further information please contact me on 02143316766.

Kind Regards

Emma O'Callaghan Mullins

Management Team