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University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Examining the debilitating experience of form filling by parents of children with additional needs in pursuing disability support services

Calvin M Odhiambo

CARL Research Project

in collaboration with

We Care Collective

Name of student(s):	Calvin M Odhiambo
Name of community group:	We Care Collective
Name of community group liaison person:	Liz Kyte and Gillian Mullaly
Academic supervisor(s):	Fiona Dukelow and Eluska Fernandez
Name and year of course:	MA Social Sciences (Social Policy)
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Community Academic Research Links (CARL) is a community engagement initiative provided by University College Cork to support the research needs of community and voluntary groups/ Civil Society Organisations (CSOs). These groups can be grassroots groups, single-issue temporary groups, but also structured community and voluntary organisations. Research for the CSO is carried out free of financial cost by student researchers.

CARL seeks to:

- provide civil society with knowledge and skills through research and education;
- provide their services on an affordable basis;
- 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
- enhance the transferrable skills and knowledge of students, community representatives and researchers (Living Knowledge Network).

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CARL is part of an international network of Science Shops called the Living Knowledge Network – website and on Twitter @ScienceShops. CARL is also a contributor to Campus Engage, which is the Irish Universities Association engagement initiative to promote community-based research, community-based learning and volunteering amongst Higher Education students and staff.

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Abstract

Social service provision for children with additional needs is a very integral part of a community social and welfare support system. While some family care providers obtain a sense of purpose and self fulfilment from caring for loved ones, they equally admit that the process of seeking support from the institutions mandated to provide the support has been challenging and depressing.

In a move to support families raising children with additional needs, over time Ireland has established a disability support strategy comprising of financial support and services offered by different state agencies. However, the access to these services involves a bureaucratic form filling process. The forms contain questions intended to capture vital information that the relevant agencies purport to be relevant for planning and budgeting for the persons with additional needs. Family care providers are therefore expected to fill in different evaluation forms which capture different elements of either constant, progressive or episodic needs and personal demographic data.

The We Care Collective approached Community Academic Research Links (CARL) at University College Cork (UCC) to seek someone to do research and collect data on the lived experiences of parents of the forms filling process. This was informed by the fact that their members have described the process as enduring and endless, which is a practical description of a debilitating experience characterized by long waiting periods to access services. The bureaucratic process has exposed the family care providers to an administrative burden of care and has been criticized for medicalizing disability assessment while ignoring a social and human rights assessment approach. This has generated an experience of stigma and quiet violence of bureaucracy in handling the forms right from the point of access.

It is on this that this study seeks to examine the debilitating experience of form filling by parents to children with additional needs in pursuing disability support service from state agencies in Cork, Ireland.

List of abbreviations

A&E… .....Accident and Emergency
ADHD… .....Attention Deficit Hyperactivity Disorder

CARL… ..... Community Academic Research Links

CAMHS .....Child Adolescent Mental Health Services

CBR….....Community Based Research

CIB… ..... Citizen Information Board

CSO… ..... Civil Society Organization

CRPD… .....Convention of Rights for Persons with Disability

DCYA… .....Department of Children and Youth Affairs

ESRI… ..... Economic and Social Research Institute

GP….....General Practitioner

HIQA.....Health Information and Quality Authority

HSE… .....Health Service Executive

NDA ..... National Disability Authority

NPASCYPDD……National Policy on Access to Services for Children and Young people with Disability and Development Delay

SREC…..... Social Research Ethics Committee

ST… ..... Speech Therapist

OT… .....Occupational Therapist

UCC….....University College Cork

UN… ..... United Nations

UK… ..... United Kingdom

CHAPTER 1

1.1 Introduction

This thesis is a qualitative research study on the debilitating experience of form filling by parents to children with additional needs in pursuing disability support service from state agencies in Ireland. The study is a community-based research (CBR) project which is positioned within the participatory research paradigm. It has been conducted under the auspice of Community-Academic Research Links (CARL) at the University College Cork (UCC). CARL is a community engagement initiative provided by UCC to support the research needs of community and voluntary groups/Civil Society Organizations (CSOs). These groups can be grassroots groups, single-issue temporary groups, but also structured community and voluntary organizations.

The We Care Collective is a CSO made up of parents and care givers for children with additional needs based in Ireland. Their main activities include championing inclusivity, diversity and care with a membership open for family caregivers for children with additional needs, or an ally who shares their vision and aims (http://www.wecarecollective.ie). The organization began as a conversation between mothers sharing their challenging experiences with a broken system and their heartbreak and struggles without support.

The lived experience of family care givers who belong to the We Care Collective oscillates around the challenges of getting information regarding disability services, filling forms in seeking to justify the needs of their children with additional needs, long periods of waiting for services and inaccessibility/insufficiency of services and service providers. They described a feeling of helplessness, weakness, neglect, impairment among others, similar feelings of frustrations were reported by non-members of the group in the same situation.

These experiences therefore informed the description of the research topic as a debilitating experience. The concept of debilitating experiences is borrowed from an article by Macpherson et al (2021) entitled *"Debilitating landscape of care and support, envisaging alternative futures".* In this article Macpherson et al (2021) describe the debilitating landscape of care and support in England and Scotland. The article describes how the pressure of time resources and

precaritisation in the work force are creating a ‘debilitating landscape of care’ that further erodes the capabilities of the people that work in the care sector and people with learning disabilities. They emphasize the contextual and structural forms of suffering that affect those involved in providing and receiving social care. According to Macpherson et al (2021) this analysis was inspired by Berlant’s (2007 p 57) conception of ‘slow death’ as the ‘physical wearing out of the population’ as well as Puar’s (2017) description where debility is conceptualized as endemic, perhaps even normative, to disenfranchised communities.

A good example of a debilitating experience is a feeling described by Gillian and Darren Milne who are parents to children with disability. In an interview by RTE Prime time in May 2022 Gillian stated that;

> “We've basically been punished for having children with special needs. You feel almost to blame. Did we not fight hard enough? Some days you just don't want to go on. And it's not that you don't want to go on. You're just struggling to find the strength to go because, you're worn out, you think you're just worn out to the point where that's it. Then you look at the boys and you have to keep going. You have no choice…” (McMorrow, 2022)

A similar experience is shared by Elizabeth Kyte, a parent providing care for her children with disability in Cork. In a local Cork newspaper Echo interview in August 2021, she stated that;

> “In our society, mothers and the disabled are seen as a drain on a profit-driven system. It’s like we’ve been dumped in some limbo waiting room because they don’t know what to do with us and they don’t want to be confronted by the differences and the needs. It’s a quiet violence, this unnecessary, preventable slow traumatizing of families...” (Horgan, 2021).

In the same interview Kyte further explains the frustration of form filling:

> “We are overloaded with paper forms asking you to detail your worst day over and over again…. It’s the wall of bureaucracy, the delays, the form-filling, the temporary diagnoses, and the lack of any carer support that has worn us down over time. …More
>
> and more onerous paperwork and red tape is added instead of simplifying the system to ensure children get the support they need in a timely and efficient manner…”

This above description perfectly fits into the description of the concept of debilitation by Macpherson et al (2021). This therefore informed the focus of this participatory CBR study as an examination of the debilitating experience of form filling by parents of children with additional needs in pursuing disability support services from state agencies in Cork.

1.2 Statement of the problem

While many studies have been conducted on disability in Ireland, no study has adequately addressed the debilitating experience of form filling by parents to children with additional needs in pursuing disability support service from state agencies in Ireland.

Ireland adopted the Disability Act 2005 as a move to cushion the struggle of persons with disability and their care providers. With regard to children with disability, the Act stipulates that any child below 5 years with a disability is entitled to have their disability, health and education needs independently assessed without thinking about the cost or availability of the services. According to the report by the Dun Rathdown County Childcare Committee (2013) ratifications were made that came up with policies that provided for regular follow-up assessments as needs change and that parents or guardians were supposed to make applications in writing on a standard form which would be accessed from the local Health Office or online.

However, this process of making applications for assessment or support from state agencies has been debilitating since most of the parents to children with disability are already straining to provide unpaid care for their children. We Care Collective members describe the form filling process as traumatic and one that involves reliving distressing and stressful experiences citing an example of having to recount your worst day ever with your child over and again. They state that these forms are labour intensive, very lengthy, detailed, intrusive and require significant amounts of documentary evidence which needs to be collated. While these forms are significant in terms of accessing services and supports, We Care Collective members note that some of the forms rather present barriers to access the services because of the debilitating experiences parents go through in filling them. This study will therefore seek to develop a deep understanding of the lived experience of parents in their quest for disability services from state agencies for their children.

1.3 Current state of disability and care in Ireland

According to the CSO Census data of 2016, 4.54 per cent of children aged 3-5 years were recorded to have a disability in Ireland (ESRI 2021). The incidence of 3–5-year-old children with blindness/deafness and psychological/emotional disabilities was approximately 0.54 per cent and 0.59 per cent respectively in 2011 (ESRI 2021). The above statistics silently communicates the number of parents and care providers who have to sacrifice their daily careers and social life to care for persons with disability. The 2016 Census of population indicates that approximately 89,000 of the persons with disability were between 0-19; these are children under guardian or parental care (CSO 2016). The same report indicates that 195,263 persons were involved in provision of unpaid care out of which 16,926 provided the care for 24 hours a day, 7 days a week, a bracket in which many family caregivers fall into (CSO 2016).

According to Neely-Barnes and Dia (2008), children with additional needs receive most of their support from family members with most family caregivers being mothers, fathers and in other instances grandparents. Families are viewed as a critical source of support for children with disabilities. Backer et al. (2005) note that family members absorb the additional pressure of time, emotional resources, and financial/ economic resources associated with having a child with additional needs. Mothers are heavily involved in providing care. Cronin (2018) notes that caregiving role was viewed as a mother's full-time responsibility with women providing two thirds of all unpaid care hours in Ireland.

Cronin (2018) further notes that the mothers caring for children with disability describe the news that one's child has an intellectual disability to be devastating for the family, particularly in a situation where they believe that the disability is likely to significantly impact on the child's opportunities, future and life chances. There is huge adjustment needed by the whole family. For many mothers, their perception of mothering, or their previous experiences of mothering in the context of a typically developing child, offers a weak reference point (Ryan and Runswick-Cole, 2008). This indicates the kind of a mental state that parents find themselves in and it is at this point that they need full support from community and state agencies, which starts the process of seeking support by filling different forms and encountering a multitude of obstacles.

1.4 Purpose of the study

This study sought to examine the debilitating experiences of accessing, filling and follow up of forms by parents to children with additional needs in pursuing disability support services from state agencies in Cork County-Ireland. It will be a participatory CBR research where parents with lived experience discuss their experience.

1.5 Objectives

This study was led by the following objectives;

1. To explore the experience of access to the forms by the parents of children with additional needs.
2. To explore the experience of form filling with regard to content of questions/ information needed in the forms.
3. To explore the experience of form filling with regard to the structure of the forms.
4. To examine the experience of the parents with regard to the feedback from different state agencies in how their children are assessed for services.

1.6 Research questions

The study sought to answer the following questions

1. How do parents of children with additional needs experience the process of access to forms for disability support services?
2. How do parents of children with additional needs experience the process of form filling with regard to content of question/ information needed in the forms?
3. How do parents of children with additional needs experience the process of form filling with regard to the structure of the forms?
4. How do parents of children with additional needs experience of the process of form filling regard to the feedback from different state agencies on their children's eligibility for services?

CHAPTER 2. LITERARURE REVIEW

2.1 Introduction

This chapter will focus on debilitating experiences of family carers supporting their children with additional needs. It will attempt to discuss literature on the experience, emotions, perceptions, and recommendations involved in the processes of pursuing disability services from different State organizations and the use of different forms in different countries. Drawing from the literature on disability claims and welfare claims in general, it will then discuss four major concepts that describe the experience, feelings, perceptions and opinion of informal care providers as a result of interaction with forms and services from the state. The major concepts of focus include: the administrative burden of care, the violence of bureaucracy, the concept of waiting and the medicalization of disability assessment. The chapter will also highlight lessons learned and recommendations from good practice.

2.2 The administrative burden of care

Holler and Tarshish (2022) describe the concept of administrative burden as an individual's experience of the policy implementation process as onerous, with formal and informal practices that influence a persons' encounters with state programs and the cost of the programs. Holler and Benish (2022) further elaborate that such encounters turn out to be burdensome resulting in various material and adversary consequences that may lead to non-take-up of welfare rights. In their article on *"The Role of Waiting, Communication Breakdowns and Administrative Errors*" Holler and Tarshish (2022) note that the interaction between citizens and social security bureaucrats can be described as a complex event that may often elicit anxiety, confusion, and frustration. In the context of seeking state support for children with additional needs in Ireland, parents or other care givers are involved in a constant process of interacting with state agencies, either in person or online through the forms they fill.

A relevant illustration of the of the administrative burden of care is described by Holler and Tarshish's (2022) study in Israel where in one instance, a participant described the burden involved in the completion of the application process raising concern over the time involved in filling out

forms, including the formal application documents and the attachment of proof documents. According to the participants, the process was time consuming, leading to intense negative feelings of pressure and frustration, thus constituting a significant hinderance in the take-up process (Holler and Tarshish 2022). Other administrative burdens noted by participants included the impossibility of contacting officials directly, such as over the phone, when need arose; they described frustration and feelings of helplessness as a result of this unilateral communication breakdown (Holler and Tarshish 2022). With regard to new technologies, most of the participants criticized the implementation process noting that they often constituted a single, default channel which made life difficult for the technologically illiterate.

Statistics from the *State of Caring* by Family Carers Ireland (2020) indicate that at least 75% of care providers reported to have experienced difficulties accessing services for at least one of the people they care for, with subsequently 70% of care providers having missed out on support as a result of inaccessibility to the right information. The findings further indicate that out of the 70% of those who felt they missed out on support, 75% missed out due to lack of information on entitlements while 57% were not aware about the availability of the support (Family Carers Ireland, 2020). Furthermore, more than one third (37%) doubted their eligibility and entitlement to support, even though they were eligible and eventually those who could not access the support were more likely to have been in debt because of caring (34%, compared to 30% of all other care providers) (Family Carers Ireland 2020). It is very heartbreaking when parents miss out on support because they cannot get the right information or don't even know where to access the information, this indicates a lacuna in the government system and that parents would continue to suffer in silence.

According to Holler and Tarshish (2022) poor communication between the state and citizens is not only limited to the state's failure to inform citizens, but it also includes the struggles of the citizen to convey information to the state. This may occur in instances where the benefit claimants find it challenging to make an inquiry, reach welfare staff or report administrative errors (Widlak and Peeters, 2020). As a result, this kind of communication breakdown may cause not only learning and compliance costs, but also psychological costs, as a result the claimants is likely to feel frustrated and disempowered (Holler and Tarshish 2022)

Research conducted by Inclusion Ireland (2022) on processing disability services for children and young people indicated that 48% of families identified challenges with communication from the

service providers as one of their top three areas of concern noting that many families that participated in the survey regretted a lack of clarity on the plans and timeframes by service providers. According to Inclusion Ireland (2022) most of the respondents explained that they found it hard to navigate into the system and understand how it works while many other families did not receive consistent and regular information on services and appointments as expected. Some respondents felt that there was a lack of understanding and consideration from service providers about the circumstances families found themselves in and a perceived lack of flexibility in the appointments among other challenges (Inclusion Ireland 2022).

In Ireland, statistics from *State of Caring* (Family Carers Ireland 2020) indicate that parents to children under the age of 18 were more likely than other care providers to feel they missed out on support because they could not access the right advice or information (73% compared to 70% of other carers). Furthermore, 68% of parents of children with disability over 18 felt they missed out and 13% of these could not identify themselves as care providers for over eleven years. The report *State of Caring* (2020) also indicate that caring can have significant adverse impacts on the health and wellbeing of the care providers further pointing out that compared to the general population, family care providers who responded to their survey were more likely to have ill health and a longstanding disability, illness or medical.

2.3 The violence of bureaucracy

The concept of violent bureaucracy has been used a lot in contemporary social policy issues to describe the power imbalance regarding the implementation of social services. The description of the concept can be traced back to the writings of Galtung (1969) who argued that violence is impersonal and that it was produced and distributed within the power structures and institutions that govern societies. This therefore meant that violence was present in avoidable situations where the monopoly of insight and resources by a group or class excluded another.

In the UK context Tyler (2020) argued that in the wake of austerity measures, to legitimize the reforms, concerted efforts were made by politicians and the media to create an increasingly hostile socio-political environment which framed Britain's poor people as a central threat to national security. Classed and racialized groups were targeted including migrant, unemployed, disabled persons leading to emphasis on top-down processes of stigmatization in order to garner public support for welfare reform (Redman and Fletcher, 2018).

Similarly, family care providers in Ireland have been subjected to dehumanizing process in seeking support for their children with disability. This has led to different physical, mental and psychological medical conditions. For example, among the serious challenges as noted by Chadwick et al (2013) is that many families especially in Ireland report that their kin with a disability were likely to be ignored when going out into the community, sentiments shared by Oliver (1996) who noted that people with additional needs and their care providers talk about constant struggles to assert their basic rights as citizens. Furthermore, research had identified that mothers of both disabled children and adults risk being pushed to the periphery of society leading to a state of isolation, loneliness and poor health (Shearn and Todd, 2000).

As a result of the different struggles, statistics from Family Carers Ireland (2020) *State of Caring* report indicate that only 4 in 10 (38%) family care providers who responded to the survey reported being in good or very good health. Almost half (45%) of care providers had long-term illness, health problem or disability while 80% of these care providers felt that their caring responsibilities had influenced their illness or disability. These findings above make it clear that the poor health of family care givers is directly related to their day-to-day challenges in service provision. It is evidence that care providers are vulnerable to both physical, psychological and emotional burnout.

According to Inclusion Ireland (2022) regarding the personal cost associated with providing long hours of care, roughly 16% of those providing care for over 50 hours a week and 20% of sandwich care providers (care providers who have part other time employments) reported a generally bad or very bad health. Moreover, 29% noted that their quality of life in the future is likely to decline in the next twelve months. The sacrifice that comes with provision of care coupled with stigma from some community members and endless bureaucracy impacts negatively on the lives of family care providers.

As a result of the debilitating experiences in care, the National Carers Strategy (2020) reported that more than half of family care givers reported being mentally and physically "drained" by their role. Subsequently, more than half reported having a medical problem noting that the most frequent problem was back injury while over half reported a significant mental health problem, the most frequent being anxiety disorder.

2.4 The concept of waiting

The concept waiting is significant in this study because one of the major concerns of family care providers is the long period of waiting for either feedback on eligibility, results, referrals, treatment, and other services from the state agencies. During this period their lives remain in darkness filled with anxieties, uncertainties, and worries. The waiting periods may vary from weeks to years in limbo without knowing what will come out of their applications.

Cena and Dettano (2022) in their analysis on waiting as an operational element in the implementation of social policy gives four different dimensions of waiting, however; in my discussion I will focus on three which include: the practice of waiting as a relationship with time that is linked to the experiences of the past and the expectations of the future; the feelings linked with waiting, such as uncertainty, despair, endurance, fear, and mistrust; and finally waiting as involving relations in power and exchange whereby making someone wait or being made to wait is determined by the interactions and the persons position in the social structure which could as well be considered as an instance of bureaucratic violence.

With regard to waiting, Inclusion Ireland (2022) puts the situation into context in their study where the majority of parents report that their child spent exceedingly long time on a waiting list for assessment or therapy with their figures indicating that 95% had waited for a period exceeding 6 months without services, 85% reporting to have waited for more than 12 months and were still waiting. Furthermore at least 27 families reported distress on receiving service statements which indicated need for intervention scheduled for over two years after assessment. Since communication between the state agency and the parents is through the forms, it becomes very debilitating for parents to dedicate their whole life to care and blindly wait for more than 12 months to get support.

With regard to the challenges coupled with form filling, the NDA (2020) noted that parents of children with disabilities found themselves on long waiting lists of more than 3 months for children to be assessed or to receive therapy, The report termed this as unacceptable although much was to be blamed on the scarcity of current resources. It was also regrettable that there were waiting lists of up to 2 years or more in some parts of Ireland to access children's services.

Waiting as an act or process can be very debilitating in nature. For example, Cena and Dettano

(2022) explain that the time of waiting is characterized by different moments which may include being occupied with assumptions and worries as well as the devastation of abandonment and anger. They further argue that in instances where things cannot be done immediately; temporal and spatial delays were enforced thus imposing evidence of the subordination, dependence, and inferiority of those who were forced to wait. This implied the power dimension of making someone wait lies in the ability of others to control the resource of time (Schwartz, 1974). Eventually the reference point to be able to act fades off leading to dependence and subjection (Cena and Dettano 2022).

2.5 The medicalization of assessment

Waddington and Priestley (2020) highlight that disability assessments play a key role in the provision of services considering the fact that they are used to determine individuals' eligibility for public support for disability status in cash or in kind. In the case of adults with disabilities, they state that the forms are broadly used to determine who gets exemption from participation in the labour market, who has entitlement to social security payments, who is eligible to practical help at home, etc. In consideration to this, disability assessments are very essential in budgetary gatekeeping and social validation (Garsten & Jacobsson, 2013).

There are three major actors in handling the forms in the process of seeking support for the person with disability; this includes the person with the disability or their legal representative who could be the parent; a professional who could be a medical or social officer; and the state agency. The person with disability or the legally approved representative bears the responsibility

of filling the forms and explaining different challenges experienced. The professional conducts physical, psychological or social evaluation regarding the state of the disabled person, while the state agency approves, rejects or gives recommendation regarding the support.

Mabbett (2005) notes that the concepts and methods that underpin the assessments remain complex, contested and elastic to the extent that they vary among different states, welfare regimes, over time and between policies. This is attributed to the diverse social, political, and economic state of every nation. Different states also describe disability in very different terms.

Waddington and Priestley (2020) further argue that any definition of disability framing an assessment mechanism should be informed by a social-contextual rather than an individualized approach and that assessments should consider the challenges that a person encounters and their

needs. They therefore advise that it is relevant to take into consideration the principle of participation of disabled people and their organizations in assessment and policy design (Waddington and Priestley 2020). Practical examples of places where disabled people are included in the decision-making process include Belgium and Cyprus. Both countries have adopted a human rights model of assessment which was accompanied by consultation with disabled people's organizations (Waddington and Priestley 2020).

The process of disability reform frequently generates concerns about disability assessment; among other issues of concerns in the assessment have oscillated around individualization and de-contextualization in disability assessment (Waddington and Priestley 2020), a concern associated with the inappropriateness of medicalized assessment.

Inclusion Ireland (2022) attributes some of the challenges related with assessment to the confusion about the assessment of need process amongst families. It notes that while the Disability Act 2005 says the assessment of need is meant to determine whether a child has a disability as well as determining the nature and extent of disability; the Health Service Executive (HSE) clarifies that there are two distinct assessments with different waiting periods. The first one is the assessment of needs which is a short screening assessment, and the second is a diagnostic assessment. The HSE therefore advocates in view of families for whom diagnosis is important and that having waited for assessment of need they should not have to be waitlisted a second time to receive diagnosis with further waitlisting for intervention.

2.6 Lessons learned and Recommendations

Systems that include feedback from assessment forms are more responsive to citizen needs, for example a study conducted by Waddington and Priestley, (2020) found out that in the Czech Republic where while the advice of disabled people's organizations was not always followed by the authorities, their input contributed to efficiency and a partial de-medicalization of the assessment process. Yet this example from Czechia did not involve a radical or transformative effect on the disability assessment system. Nevertheless, it illustrates how the direct involvement of disabled people and their organizations, in practical ways, can help to de-medicalize assessment norms, increase dignity in the process, and assert the capacity of individuals to engage with

decisions about their lives within existing assessment mechanisms. They also point to the potential for more radical collaborative reforms. With regard to disability in children, Adele (2021) stresses the importance of social inclusion of children with disabilities to their all- round development and wellbeing noting that children with disabilities have equal access to early years provision thus adequate supports should be put in place to facilitate the access and delivery.

Van Exel et.al (2008) acknowledge that to effectively decide how best to support care-givers in their care and support role, governments and policy makers need comprehensive information on the care needs of children with disabilities; this should also include the costs of the financial, emotional and clinical burden experienced by parents. Van Exel et.al (2008) further acknowledge that parents and other informal caregivers experience a lot of economic and health challenges.

An example worth noting is in the Flanders region of Belgium where an integrated care system for young people introduced a central single point of access for disability services known as the intersectoral access portal (De Bruycker, 2018; Diels & Van Puyenbroeck, 2015). The portal allowed the integration of all the different applications for disability support from the Flemish Agency for Disabled Persons within the general youth system including mental healthcare and child and family services. This would mean that for example, a blind child who has a mental health condition would no longer has to apply for separate benefits from different service providers (Waddington and Priestley 2020). This therefore brought about disability mainstreaming, simplification of the application and assessment process (Waddington and Priestley 2020). The integration and/or centralizing disability related services cuts down on waiting times since most services are accessible within one location and state service providers can easily collaborate. A single point of access also reduces the administrative burden because inter and intra departmental networking can take place without many logistics like traveling.

According to Waddington and Priestley (2020), similar lessons can be learned from France where local departmental offices for disabled persons serve as single entry points for assessments based on socio-medical indicators. Assessment is conducted by a multidisciplinary team which identifies what is needed to compensate for the shortcomings in activity or to overcome restrictions in participation to achieve full potential and to fulfil rights and entitlements. Such a holistic assessment is believed to provide a gateway to the Disability Compensation Benefit which compensates for additional costs of living with disability (Nicolas & Ebersold, 2018)

Another case that has centralized services in order to improve efficiency and reduce duplication is Latvia. In Latvia a general disability register is used to determine eligibility for a disability identity card through e-government service portals provided by national and local government (Podzina, 2018). This facilitates the direct communication and data exchange thus reducing unnecessary bureaucratic processes between claimants and the State Medical Commission for the Assessment of Health Condition and Working Ability.

The study of experiences of family care providers and their interaction with state agencies is pegged around an equality and rights approach for family care providers of children with additional needs. According to the Dun Rathdown County Childcare Committee report (2020) the principles of equality and rights dictates that children with disabilities are entitled to similar legal, political, social and economic rights as much as those without disability. Cognizant to the fact that there may be difficulties in having those rights implemented, the Disability Act 2005 was adopted to facilitate the participation of people with disabilities in society by championing the provision of disability specific services and improving access to all necessary public services (Rathdown County Childcare Committee 2020). Rights are an essential element of disability assessment as Weddington and Priestley (2020) note that among other elements, three drivers for change to disability assessments are: budget driven, technically driven, and rights driven. Giving a human rights model of disability includes an assessment of needs, will and preferences of the individuals concerned, it further focuses on the elimination of barriers and the promotion of full and effective participation of persons with disabilities in society (Waddington and Priestley, 2020).

2.7 Conclusion

The National Disability Authority (2012) acknowledges that in Ireland, the government recognizes the benefits that come because of the health and social care sectors from the care that families and other caregivers provide to children with disabilities. While the government have tried to justify the resource allocation decisions by the state to back up the efforts of these care providers, the statistics from the Family Carers Ireland (2020) as discussed above indicate that efficacy in the service delivery has not been achieved.

High percentages of care providers feel either missed out, had trouble, or ended up being indebted because of their role in care provision as a result of the administrative burden of care. Subsequently

data from the National Carers Strategy (2020) has also highlighted that more than half of family care givers reported being mentally and physically drained.

The main question therefore is how to achieve the goal of resource allocation (which is to support the care providers and improve the lives of persons with additional needs) and support without compromising the means of achieving the goal of support. It would make no sense when the means for accessing support becomes more traumatizing and debilitating to the family care providers.

This chapter has therefore highlighted the four major concepts which include; the administrative burden of care, the violence of bureaucracy, the concept of waiting and the medicalization of assessment. It is also worth taking note that the concepts discussed are very interrelated and do not stand in isolation, for example the both the concepts of administrative burden and the violence of bureaucracy may have the element of waiting.

The chapter has also highlighted good practices like in France where assessments for disability are conducted by multidisciplinary teams which is a very wholistic approach of assessment.

CHAPTER 3. POLICY FRAMEWORK.

3.1 Introduction

The element of family care provision, its policies and implementation vary in different states and is highly informed by different social, political, economic and geo-cultural variables. In some countries care for people with disabilities is highly structured while in others it is very amorphous or even considered as a charitable work and not a right. In the Irish context, care for persons with disability has been the object of a constant fight for recognition in common with other social groups whose care needs have been ignored or problematized (Dukelow and Considine, 2017). Dukelow and Considine (2017) note The United Nations Convention on the Rights of People with Disabilities (CRPD) was the first international human rights treaty of the twenty-first century that sought to protect and enhance the rights of people with additional needs and equal rights in all areas of life. While the Convention was adopted by the UN General Assembly in 2006, different countries adopted it at different times. Ireland signing it in 2007 (Dukelow and Considine, 2017), but did not ratify it until 2018.

3.2 Policy framework for disability in Ireland

In the context of this study, Ireland has different legislations, reports and (Policies, Procedures, Protocols and Guidelines) PPPGs that ideally guide the provision of family care provision. It also has different state and non-state-based structures that are or should ideally be responsible for the implementation of the same. However, it is worth noting that the degree of compliance to the policies is still a subject of discussion and critique as well as the efficacy of the existing structures and systems put in place by the state and non-state agencies.

The HSE National Policy on Access to Services for Children and Young people with Disability and Development Delay HSE-NPASCYPDD (2021) identifies 12 main policy documents that guide the provision of additional needs to children in Ireland, these include; the Child Care Act, 1991, the Children and Family Relationship Act, 2015, the Children First: National Guidance for the Protection and Welfare of Children, 2011, the Children's Act 2001, the Disability Act, 2005, the Education for Persons with Special Needs, 2004, the Joint Working Protocol – Primary Care, Disability and Child & Adolescent Mental Health Services, HSE 2017, the National Consent Policy HSE 2014, the National Policy on Discharge and Transfer of Services for Children with

Disability and Developmental Delay, 2016, the Report of the Reference Group on Multidisciplinary Services for Children aged 5 to 18 Years (2009).

On the same breath, The National Carers Strategy (2011) highlights 5 different policy documents that addresses the needs of family care providers. These include; the National Disability Strategy (2004), the Vision for Change (2006), the National Housing Strategy for People with a Disability (2011- 2016) as well as the Children and Young People's Policy Framework (2012-2017).

The key state actors in the provision of care for children with disability are supposed to work in intersectoral collaboration between all departments. Some of the directly affected departments include; the Department of An Taoiseach DoT, the Department of Children and Youth Affairs DCYA, the Department of Education and Skills DES, the Department of Environment, the Department of Health DoH, Department of Jobs, the Enterprise and Innovation DJEI, the Department of Public Expenditure and Reform DPER, the Department of Social Protection DSP Department of Transport, Tourism and Sport DTTS, the National Employment Rights Authority NER. National Carers Strategy (2011) However there seem to be a gap in networking and collaboration among the departments.

In a move to facilitate effective service provision; the state through the Department of Justice and Equality initiated the formation of the National Disability Authority (NDA) to facilitate and coordinate issues surrounding disability and care. The NDA was established in June 2000, under the National Disability Authority Act, 1999 as an independent statutory body (NDA 2006). One of the functions of the NDA, as outlined in the National Disability Authority Act, 1999 includes supporting the achievement of good standards and quality in the provision of programs and services provided or to be provided to people with disabilities. According to Dukelow and Considine (2017) The department of Justice and Equality also initiated the National Disability Strategy which was launched in 2004 which contained a number of components which included;

the Disability Bill 2004, which became the Disability Act 2005, sectoral plans and a commitment to multi-annual investment program.

Although Ireland was the last country to ratify the CRPD convention, in 2018, it had different internal structures working towards the achievement of some of the elements contained in it. For example, in August 2005, the Minister requested that the NDA prepare and submit a draft Code of Practice that the matters referred to in sections 26, 27 and 28 of the Disability Act 2005 (NDA 2006); The code of practice under section 26, addressed the issue of public bodies requirement to ensure that their services are accessible for people with disabilities by providing integrated access to mainstream services; section 27 required the public bodies to ensure that the goods or services that they purchase were accessible, unless it would not be practicable or justifiable on cost grounds or would result in an unreasonable delay (NDA 2006)

Yet, it is worth noting that while the country has well drafted policy documents, there is still a major gap in the implementation of the policies. Challenges ranging from the lack of human resources, inadequate financial resources, unnecessary bureaucratic procedures, insufficient structures etc. still dominate the testimonies of the persons with additional needs and their care providers. A case scenario is displayed in the report on future needs for disability services which was carried out under the auspice of Working Group 1 for Transforming Lives implementation process where the research, analysis and drafting of the report were carried out jointly by the chairperson of the working group (Eithne Fitzgerald) in 2018. According to the working group 1 report (2018), the gross spending on disability services had fallen by 7% between 2009 and 2016, a time during which the population requiring services grew, this was supported by the fact that the numbers registered on the National Intellectual Disability Database grew by 8.4% over the same period. Since the government had cut funding for disability services at a time when there was an increase in the need conveys a picture of either a lack of commitment to provide the services based on need or of derailing the service provision as intended.

The report by Transforming lives (2018) further indicated that during that year the Children's therapy services were short by about 300 to 400 posts while the cost of the extra staffing would be in the region of €16-21m a year and this was exclusive of pension or other overhead costs. The report further reflected that the ratio the ratio of staff to children's service users would

require 480 additional staff immediately, and a further 100 by 2026. This is a clear indication that the shortage of staff would hinder the effective implementation of the policies. Coupled with the cut to budgets, the efficiency and efficacy on the implementation of policy and service provision would automatically face a huge challenge.

Findings from the report acknowledge significant unmet need for personal assistant services, while noting that it was hard to get solid data on how many are outside the service, and how far the hours provided to those who get it falls short of what is required.; they estimate that there is an additional €17m may be required by 2021 for personal assistant or home support, and much of that would be immediate (Transforming lives 2018). The insufficiency of personal assistant at a time when data is indicating the rise in need is a clear indication that the implementation of the policies would face major challenges.

The Transforming lives (2018) report further noted that while a number of reports had examined future demand for health service, the reports had not quantified the impact on future needs under the HSE's disability services program. A practical example was the ESRI's 2017 report Projections of Demand for Healthcare in Ireland 2015-2030 which did not cover the cost of the disability service program neither did the Irish Government Economic & Evaluation Service's report 'Budgetary Impact of Changing Demographics 2016-2026' (2016). Whereas the HSE's Planning for Health 2017 discussed some of the forecasts from the National Intellectual Disability Database NIDD, it did not provide any estimates of the cost of future additional demand for residential disability services, which is by far the most expensive element of the whole disability program (Transforming lives 2018). The fact that disability services have not been adequately addressed in these documents creates a big lacuna in the provision of the services.

A research report by Inclusion Ireland on the experience of parents caring for children with progressive disability on access to services indicated a big gap between the policy and its implementation. Out of the 1,013 families that participated in their study; 83% of respondents reported lack of services as one of their top 3 main concerns, most of them reported that the services were understaffed and underfunded and that many team positions were not filled (Inclusion Ireland 2022)

Lack of clear information also dominated as one of the main challenges that parents faced. In the study, Inclusion Ireland (2022) indicated that 48% of families cited difficulties with communication from the service as one of their main concerns citing that most of the families in the survey regretted a lack of clarity on the plans and timeframes.

> "Most of respondents found it hard to navigate into the new system and understand how it works. Many others reported no understanding around how the system works. Responses also showed that many families do not receive consistent and regular information on services and appointments. Some felt that there was a lack of understanding and consideration from services about the circumstances families found themselves in. There was a perceived lack of flexibility in the appointments being scheduled, especially for parents working and with other children with disabilities…" (Inclusion Ireland 2022)

These findings further indicate that there is a gap between the policy and actual service provision.

Finally, the respondents in the report mentioned poor quality of services as their final major concern. According to Inclusion Ireland (2022) 19% of respondents pointed out specific issues with the quality of service which included the high turnover of staff in services, the lack of experienced staff to offer the services, there was large caseloads per team which compromised sustainability to provision of quality service., Parents also mentioned that they were worried about the transition of services from primary to secondary school which had been a challenge as well as the transitioning from child to adult services (Inclusion Ireland 2022)

3.3 Conclusion

It is evident that Ireland is not short of institutions, structures, systems, and written policies to facilitate the implementation of disability support services; however there seems to be a gap in strategy and implementation. The challenges experienced in the implementation may have been as a result of lack of or limited participation of the persons directly affected thus the inefficacy of the implementation.

There seem to be a gap in networking and collaboration among the state departments and non-state department therefore there is a lack of concentration of force regarding the implementation of the disability services. .

CHAPTER 4. RESEARCH METHODOLOGY

4.1 Introduction

This chapter describes the research design and the practical implementation of the research project. It will give insights into the research design, study area, target population, sampling procedure, data collection process, ethical considerations, and data analysis. As a participatory research project under the auspices of UCC CARL, the methodology was agreed upon in a consultative meeting between the researcher and the We Care Collective under the moderation of UCC CARL project coordinator.

The selection of the methodology is informed by lessons from different scholars in the field of disability studies. First and foremost, I refer to Stanley and Wise (1983: 206), who noted that researchers interested in disability studies and research should make themselves more accountable to disabled people by opening up the study or research rationale to the widest possible scrutiny. With regard to this, I believe that the joint participation/conducting a participatory study that brings on board representatives with lived experiences in form filling through the We Care Collective, the UCC-CARL project coordinator, academic supervisors and the researcher will address fundamental features of the power relationship existing between researchers and researched.

Lessons will also be borrowed from Oliver (1992: 105) who highlights the concerns of disabled people have increasingly expressed their segregation, inequality, and poverty in terms of discrimination and oppression by noting that research has been seen as part of the problem instead of being the solution. In this light, disabled people have perceived research as a violation of their experience and furthermore as irrelevant to their needs since it fails to improve their material circumstances and quality of life. With regard to these concerns, I believe that participatory research will give the care providers/ parents an opportunity to come up with their own concerns, priorities and set the agenda for the research.

4.2 Research Design

Before this research began, different civil society organizations (CSOs) had posted requests to UCC-CARL to facilitate research with them on different topics. I identified and became interested on a topic posted by We Care Collective - a CSO, to study challenges experienced by family care providers in access to disability services from the state. We discussed it with my supervisors and

the coordinator of UCC-CARL then completed and applied to CARL for matching. A four-way online meeting was set up between me, my supervisor, the coordinator of CARL and representatives from We Care Collective to discuss the proposed topic. The team discussed and agreed on how the CSO and I might approach the research, what support the supervisor and community partner can offer, the timeline for the research and schedule for contact during the research, and the final handover date. An agreement was signed which covers these issues and also proposals to disseminate the completed research, and how the CSO will use the research.

This study therefore adopted a CBR research design. Bates and Burns (2012) describes CBR as a collaborative enterprise between academic researchers comprising of staff and students working in collaboration with community members with a goal of social action and social change for the purpose of achieving social justice.

The CBR approach in the context of this research is therefore the model infused in higher learning institutions in Ireland which Strand et al. (2003, pp.3,8) describe as "a partnership of students, faculty and community members who collaboratively engage in research with the purpose of solving a pressing community problem or effecting social change". Bates and Burns (2012) note that CSOs can be incorporated in higher education research activities through the collaborative involvement in CBR. In this case CSOs refers to organizations that are directly liked to communities and often composed of community members, these may include: voluntary and community organizations, faith-based organizations, resident groups, non-profit organizations, associations, trade unions and so on.

4.3 Research method

This study adopted qualitative research methods. This is in concurrence with O'Day et al. (2003) who acknowledge that qualitative methodologies have become very effective tools in understanding the complexities in the social context of disability research, noting that the approach has proven the power to describe and clarify the interdependence of human interaction, cultural attitudes, institutional processes, and public policies. The qualitative method is also good in exploring lived experiences. Since this study is based on the social context of disability and tries to examine experiences within an interaction between parental care providers and the state through forms, qualitative approach will be the most suitable method.

In the same spirit, qualitative research is a multimethod which involves the study of things in their natural settings, as well as attempting to make sense of and/ or interpret phenomena in terms of the meanings people bring to the phenomena (Denzin and Lincoln 1998 p 3). I believe that to conduct this study within the specific context of County Cork in collaboration with the We Care Collective, the use of qualitative method will help me make sense and interpret the debilitating experience of the parents in handling different forms.

I was involved in this research as an active learner and the persons with lived experiences on handling the forms have expertise in that field. O'Day et al. (2003) advocate that the role of a researcher in the qualitative approach should be that of an active learner who can tell the story from the participant's point of view instead of acting as an expert who knows more about the experience than those living it. O'Day et al (2003) further note that qualitative methods allow study participants to speak in their own voices rather than conform to the words and categories chosen for them by others. In this study, the participants actively selected their issues of concern, they have been fully participating in selecting the preferred method of data collection and identification of forms.

Finally, I support the notion that the systematic use of qualitative research techniques brings forth the experiences of individuals with disabilities and their care providers and reflects the issues they encounter in relation to the study topic. It further keeps the researcher focused upon the reality of the disability experience and provide effective means both for understanding participants' perceptions and for developing action strategies that will address the challenges (O'Day et al. 2003).

4.4 Selection of forms

Regarding continuous meetings and the CARL agreement, the two coordinators from the We Care Collective; the representatives and the researcher collected and mapped all forms used in Ireland for the purpose of accessing services for children with additional needs (up to the age of 18years).

The coordinator of We Care Collective and the researcher looked at these existing forms, the We Care Collective coordinators then sent WhatsApp messages to other members to identify at least 3 forms that they feel most challenging to deal with. Forms that have a combination of the characteristics were selected for the study;

- Forms which were traumatic to fill in as they involved reliving distressing and stressful experiences, ie. recounting your worst day ever with your child over and again.
- Forms which were labour intensive in that they are lengthy, detailed, intrusive and require significant amounts of documentary evidence which must be collated, including medical and diagnostic reports.

With regards to the procedure above, three forms were identified; the Application for Assessment of Needs Form, The Domiciliary Care Allowance Form, and The Assessment of Needs Complains Form. However, an open space was left for the participants to discuss any other form that they felt they had concern with.

4.5 Sampling

The study adopted a non-probability purposive sampling technique. This is because the participants intended to be interviewed are existing members of the We Care Collective. Since the members inputs and contributions have been sought throughout the process; the recruitment of the participants was carried out by the coordinators of the Collective.

Considering the fact that the Collective is still a small group, the sample size was decided to be limited to six group members. However only five group members participated in the study because the sixth member was out of the country and was not able to participate within the time frame that was allocated for data collection and analysis.

The inclusion criteria for participation were valid membership of the group since all the members were parents to children with disability who have come into contact with the different forms.

4.6 Data collection

Data was collected via semi-structured interviews conducted by the research with each of the members individually. According to Rowley (2012), interviews are normally preferred in conducting qualitative research in circumstances where the researcher is interested in gathering facts or gaining or understanding the participants/subjects' opinions, attitudes, experiences, processes, behaviors, or predictions. This study majorly focused on experiences, feelings, emotions and perceptions of the interviewees in relation to debilitating experience of form filling

by family care providers while pursuing support from the state, hence the preference for interviews. Rowley (2012) further notes that in circumstances where there is a possibility of identifying people in key positions who understand a situation, interviews are preferable because they provide more details and insights. Rowley (2012) also acknowledges that the most common and preferred type of interview is the semi-structured interview. In this study, a semi structured interview was preferred in order to explore the experience and feelings of the respondents. The interview was designed with varying numbers of questions and varying degrees of adaptation.

With regard to this study, member of the Collective that I liaised with for the research discussed appropriate date for the interview with each member willing to participate in the study. A two-week period running from 14th August 2022 to 28th August 2022 was settled upon. The researcher then met each participant and conducted a semi-structured interview with each one. The interview questions were drawn from areas of concern on the experiences of form filling.

4.7 Ethical considerations

Ethical consideration is a mandatory and important element in conducting any research, be it academic or professional social research.

The ethical consideration standards for this research were informed by the guidance provided by the UCC code of research conduct and research policies and the guidance provided by the National Disability Authority on conducting research with people with disability. The UCC- Social Research Ethics Committee approval form was used as a checklist for compliance. The conditions for qualification to conduct community research through the UCC-CARL were met.

The National Disability Authority (2009) in their article on ethical guidance for research with people with disability series 13, acknowledge the importance of research that involves people with disabilities for its role in uncovering issues requiring attention; in informing policy; in monitoring and evaluating programs and services; and finally in tracking how social and economic change affects people with disabilities.

The following ethical issues were addressed and implemented in the process of planning and conducting the actual research.

In accordance with the CARL process, a formal application was made to UCC through the supervisors, an approval was granted by supervisors and UCC-CARL project to carry out this project.

The proposal was reviewed by the supervisors to ensure that the research process would respect dignity, autonomy, equity and diversity for all persons involved. This was reflected in the language used in the proposal, the objectives, the methodology and the questions in the proposal.

The respondents were provided with appropriate and accessible information about the research. The We Care Collective representatives were part of the team that participated in the proposal development process. Vital documents like the; interview information sheet, informed consent form, interview schedules were either mailed, sent as hard copy or sent through WhatsApp to the members using the media they chose.

The participants were assured of confidentiality throughout the process. Pseudonyms codes were used instead of names.

The respondents were informed of their right to withdraw from participation at any time up to two weeks after their interview was carried out. It was also clarified that analysis of the data will start in 14 days after the interview hence it will be impossible to withdraw the information entered in the analysis

The respondents were allowed to select their preferred time for interview within a given time frame of 14 days.

The respondents selected their preferred venue for the interview. This was to accommodate both their physical and psychological needs during participation.

The respondents were informed that, with their consent, there would be an audio recording of the interview. They were also informed that data sharing, storage and deleting will be done in accordance with UCC-SREC guidelines. This included assuring respondents that transcription would be confidential. Data would also be converted into anonymous form as soon as possible.

The participants were also informed that they could access the final report through the CARL project office in UCC.

4.8 Data analysis

This study employed a combination of deductive and inductive latent thematic analysis. Deductive coding is a top-down approach where the researcher starts with a set of predetermined codes and then find excerpts that fit those codes. Inductive coding is a ground-up approach where the researcher derives the codes from the data without necessarily starting with preconceived notions of what the codes should be, the researcher simply allows the narrative or theory to emerge from the raw data itself (Saldana and Johnny, (2009).

Saldana (2009) explains that in practice, research studies often combine both deductive and inductive approaches to coding. In most instances a researcher could deductively start with a set of codes, but then inductively come up with new codes and iterate on the codes as one sifts through the data. This is what I adopted in this study.

Maguire and Delahunt (2017) notes that the goal of a thematic analysis is mainly to identify themes and patterns in the data that are important or interesting which are then used to address the research or say something about an issue. This approach involves much more than simply summarizing the data; a good thematic analysis interprets and makes sense of the data (Maguire and Delahunt, 2017). To further narrow it down; Caulfield (2022) describes the deductive thematic analysis as a deductive approach that involves coming to the data with some preconceived themes one expects to find reflected there, based on theory or existing knowledge.

In this study, based on the literature review as outlined in chapter two, the researcher generated four main themes as the major concepts of focus which included: the administrative burden of care, the concept of waiting, violent bureaucracy and the medicalization of disability assessment. Caulfield (2022) highlights a six-step process for thematic analysis which include: familiarization, coding, generating themes, reviewing themes, defining and naming themes, and writing up. Different colors were also used for inductive coding which was applied for the sub themes which had not been pre-determined and discussed in the literature review sections. Some of the sub themes coded inductively included; filling out forms, staff and system failure, referrals and complains, violence of recounting worst scenarios, violence of unnecessary delays, violence of recounting worst scenarios.

1. Familiarization with the data

The researcher took time to familiarize with the data. This included reading through all the

different transcripts to understand the flow and content.

2. Generating initial codes

In this stage the data was organized in a meaningful and systematic way. Each segment of the data that was relevant or captured something interesting about the themes or the research question was noted and highlighted. This was done by use of different colored highlighters with six different colors. Red was for administrative burden, green for the concept of waiting, pink for

Violent bureaucracy, blue for medicalization of assessment and yellow for any new interesting theme that may come up. A pen was used to write down the name of the new theme next to the yellow highlighter. A new theme of objectification was identified.

Generating themes

Initial themes had been generated at the beginning of the study. The themes were named and defined at this initial stage, however during the coding new emerging themes were sought.

3. Reviewing themes

The themes were reviewed in relation to the coded data to see if they made sense regarding the study and the data collected.

The sub themes were generated through the Inductive Latent Thematic Analysis, this is because not all sub themes were pre-determined before the study began. The study was also open for any new theme that would arise in the process of the study.

4.9 Conclusion

It is worth taking note that the above chapter on methodology was arrived at through different consultative meetings between the researcher, representatives of We Care Collective and the academic supervisors. In consideration to the fact that the study was a CBR project seeking to examine experiences of family care providers; we decided that the research should adopt a purely qualitative approach of data collection and analysis. The team settled on the use of a semi structured interview as an appropriate tool for data collection.

The representatives of the We Care Collective involved members in selecting forms that would be used as a reference in understanding their experience, in regard to this; three forms were identified, however general personal experience would be given much consideration and the members were at liberty to discuss any other form they felt was significant to the interview process.

The participants in the study were recruited by the representatives of We Care Collective representatives through a non-probability purposive sampling since participation was open for members who must be family care providers for their children with additional needs. The data analysis was through a combination of Deductive and Inductive Latent Thematic Analysis. While the main themes were identified through a Deductive LTA approach, the sub themes were open for Inductive LTA. The analysis was also open for any new theme that would arise in the course of the study.

The ethical considerations in the study were guided by the UCC-SREC guidance, The UCC-CARL guidance and the NDA guidance for research with persons with additional needs.

CHAPTER 5 FINDINGS

5.1 Introduction

This chapter will focus on the accounts of the parents over their lived experience of access to forms, filling the forms, feedback, and referral system, follow up on forms and in general any other interaction with the forms they shared. The accounts have been categorized and discussed based on the four major themes which include the administrative burden of care, the medicalization of disability assessment, the violent bureaucracy, and the experience of waiting.

For purposes of anonymity, pseudonyms participants and to any persons they mentioned in the process of the interview including the name of their children. The following names were used, Daisy, Violet, Rose, Lilly and Iris. The children and other professionals were also given pseudonyms.

5.2 Administrative burden of care

In the process of the interview, the respondents expressed different frustrations regarding their experience with filling different forms and having to repeat the same process over and over again. While every respondent described their experience in their own way, their experiences were categorized into five different elements of administrative burden, these include filling out forms, failure of staff or system, handling of complaints and referrals, documented proof and missing out on support.

5.2.1 Filling out forms

While describing her experience with filling out forms; Lilly narrates how she had to fill out the forms again and again. She further describes how she remained in the dark concerning the cancellation of her previous forms and how it hindered her application to other services

> "They cancelled our Assessment of Need form which we did not know of at the time. So, we were waiting for three years for CAMHS. Again, we had to fill out forms and give them to the teachers too after meeting the psychiatrist, OT, speech therapist and all other service providers. When I rang them up, they said my last Assessment of Need application was cancelled so I had to do the form all over again and was advised to put in a complaint form after 3 months to speed up my application."

This demonstrates how the parents, who are already involved in active full time care provision, have to do additional work of filling out forms even when it's as a result of lack of update by staff.

On the same breath Rose describes the long-term feeling of having to repeatedly fill out lengthy forms for different or same departments for years un-ending

> "In those three years, separately, I did school paperwork, just standard school paperwork, and we filled out I would say five or six different sets of forms. So, each form could have 8-10 pages over and over again…"

This felt disheartening where in an ideal situation the departments could have accessed the forms through networking and collaboration.

Daisy on the other hand describes how she went through a depressive form filling experience in order to get a place for her son in the school. She was compelled to repeat a whole process of form filling because one of the forms missed out a sentence from the psychologist as it ought to have been written. This was frustrating because the process of finding the psychologist would involve prior booking for the same service and being placed on a waiting list that may take another year while the child had to wait long to be admitted in the school. Violent bureaucracy made it impossible to simply look for the psychologist to re-do the form and include the sentence immediately.

> "They said that his psychological report is actually valid. But they couldn't accept it because it was missing a sentence. I said that it says he will be best suited to a small classroom environment. 'It's missing the exact sentence we need therefore this will not give him a place'. I asked what I was supposed to do and they said I had to get a full new psychological education assessment done."

Daisy also narrates how the process of form filling for changing banks was surprisingly awkward involving back and forth writing and posting of handwritten letters to the domiciliary care office. In the process, the office wrote a letter to the bank which never reached the bank, as a result she missed out on the payment for that month.

> "You have to write a handwritten letter to the domiciliary care office to state that you are moving banks, with your bank information, your address, and your PPS number; handwritten, no email, no phone, in 2022!.. I had to write a letter and post it in the post

office. Then they send another letter stating that my letter didn't arrive to the bank and so I had to write another letter…I had to wait for another month to get paid. So, that is the bureaucracy we have to deal with…"

5.2.2 Staff and system failure

Staff, structures, and systems form an integral part in the implementation of any policy, the burden of care is mainly viewed through the lens of interaction between policy implementers and their subject. When staff, systems and structures become inefficient the result becomes anxiety, frustrations, and confusion by the subjects.

Lilly regrettably describes her decision to trust the system as to have delayed her child's diagnosis therefore compelling her to seek services from private institutions which she had to pay for. This elicits a sense of betrayal by the state and self-blame by parents who feel they never did enough for their children.

> "Eventually we had to go private because we were failed by the system. Our child was waiting for an assessment from 2014, so when we had no diagnosis or therapies offered, we went to a private psychologist in March 2020. In the meantime, David missed out on all the early interventions and the support that he could have been given if we had gone private, at the very start…"

Rose also describes the feeling of not getting the desired services from the staff in the initial stages of caring for her child after delivery. She feels the system is overwhelmed by staff shortages therefore leaving the available staff overwhelmed thus they don't focus on the entire care of the child. Rose states that in the case of her son;

> "While he was in the neonate unit, they were focusing on just him getting bigger and stronger, being able to feed and get him home. And then once he was able to do that, I think they're just overwhelmed as a service. They thought that was their job done…"

While every parent would desire a standardized treatment for their child, a deviation from the same brings a debilitating feeling of frustration.

Violet's description of her encounter and feelings with an ineffective staff and system gives a clear experience of how debilitating it can be when a parent watches the disability of her child progress while the State agencies drag their feet in delivering the much-needed services.

> "So, they would have come out to us last November because there was a year's gap, they were restructuring as you probably know. But again, I had to challenge them that 'hello it has been a year, can we have some help please', which is not a great foot to start off. It was desperate because I had to pick up myself every day and go ring them. I just kept saying if I am really tenacious, I would get there eventually. But I think nobody should go through that…"

Violet further describes her disappointment with the fact that the State agencies that provide interrelated services do not have clear structures for networking and collaboration, this therefore leaves the care provider with the experience of having to repeat the same story, re-fill the same forms to the different organization which is unnecessary duplication, time wasting and labour intensive. Violet describes this frustration:

> "How does CAMHS link in with AST, how do these services link in with education because they are all interlinked, but you have to go to each one and each one tells you to go round to the others. I think they kind of should have an organizational process map to make it easier…"

Daisy also describes how she could not access services due to delays resulting from understaffing. It is very debilitating that after going through the entire process of filling in forms hoping that the process for support is in progress, only to realize that the entire process had come to a stop because somebody had not been employed. Daisy narrates that;

> "And I think there was a delay in March, because somebody wasn't employed. So, they upheld our complaint and said, 'Yes, this should have been done in three months, and it hasn't been yet now for 18 months.'"

Daisy further shares her experience on how a staff member was breaking the news on her child's disability soon after birth. She finds I hard to describe how confusing and painful it was.

> "I remember just talking to the midwife…small talk…just because it was just so painful, and uncomfortable. I just didn't know what else to do. And I can't believe that now. Although I know that later, I had a sort of out of body experience. And I think that's when you experience extreme…when you experience shock, you know, that can be a reaction. So, it was much more physical but, with my son, I think it was almost like a slow torture, because I kept like Googling and comparing him and thinking…"

The first contact (normally the first professional to ascertain the child has additional needs) with the parent of a child with disability is very important because it shapes the perception of the parent, creates an understanding, builds, or destroys expectations etc. Its therefore prudent that the staff conveys the message in a very socially and physically appropriate manner.

In relation to applying for an Assessment of Need and subsequent submitting a Complaint Form, Daisy also describes the debilitating process of follows:

> We only found out about how you actually get an assessment need from our public health nurse (PHN). It's a kind of baptism by fire at the inherent exclusion and ableism of the State towards children with additional needs and disabilities. The PHN visited when our daughter was born with down syndrome and was concerned that our 4-year-old son did not respond to our daughter or herself as she would expect. We had applied for an ASD assessment of need 12 months previously but the PHN suggested that we really needed to get our son assessed before he started school in six months' time and that the only way to get it done was to make a complaint as the State has an obligation under the Disability Act to provide assessments within 3 months of application. Given our situation with now potentially two disabled children, the PHN found out about the process, got the complaint forms for us, put us in touch with the complaints officer and told us to ask Marion House, the ASD service, where we were on the waiting list and to let them know, we would be making a complaint in order to speed up the assessment. It was a traumatic process feeling that even to get the most basic assessment you have to go through yet another bureaucratic hurdle.
>
> I still have the very weighty file for it and when I came across it the other day it makes me feel sad and incredibly stressed thinking of that time which should have been bonding with our youngest daughter and family but this was intruded upon by being pulled into this very stressful bureaucratic process. There was no counselling or support, it was just a very de-humanizing, paper trail of a family being left to come to terms with their children's complex needs in isolation. I also feel vindicated and empowered looking at that file as it was our first piece of advocacy or activism really, in at the deep end. We were fortunate to have the insider knowledge from the PHN because of our 'exceptional' situation of having two children with additional needs and the capacity, but time and again I find myself passing this knowledge onto new parents I meet randomly in playgrounds. Every time I have to hand down this information, I am confounded by the inbuilt ableism exclusion and failure of the system. I am also shocked to find our family isn't that exceptional, there are so many

families struggling with multiple children with additional needs, so the fact that they are even less able to advocate for themselves makes the inbuilt exclusion in the system even more ethically wrong.

5.2.3 Referral and complaint challenges

Being given referrals and follow up on complaints was another concern of the care providers. Lilly describes her long wait after a referral to Children Disability Network Teams CNDT that seemed to last ages and never bore any fruit.

> "We received 6 weeks psychological support for our child's deteriorating mental health, including self-harm. We were then told that because of our child is autistic the mental health difficulties are caused by the autism and our child was being discharged from CAMHS. So CAMHS sent a letter to CDNT to request support and interventions for our child. We waited for over a year on a waiting list. When I contacted CDNT for an update, they said our son needed an assessment from CAMHS for the voices and the visions that he experienced as they didn't feel qualified and wanted a psychiatric assessment. So, we had to contact our GP for another referral to CAMHS.

Similarly, Rose describes how she spends a lot of time making follow-ups since her child has been seen by different doctors due to high staff turnover. She describes her concern that her child's report keeps going to different doctors and she must follow up and locate it.

> "And there was a pediatrician attached to that team who asked me if I know where to go. And we met him twice. But since then, we've had no pediatrician. And because our child was in and out of hospital the last two years and there have been different doctors seeing him, his reports have kept on going to different doctors and I'm trying to locate them. I've spent hours on the phones to three different hospitals trying to find where his medical referrals have gone…"

Violet describes one of her concerns to be the fact that whenever applying for assessment, you are sent a complaint form in a pre-emptive move that your services will be delayed, and you'll launch a complaint.

> "Also, when you apply for the assessment of need at the time, when they acknowledge it, they send you a complaint form because there was a statuary obligation to have him assessed within 6 months of application which they knew, so they just send you a complaint form which is kind of desperate because you know it's going to be more than 6 months…"

Daisy also describes the debilitating process of follow up which involves continuous phone calls and walk-ins to offices.

> "And I think there was a lot of toing and froing, with the complaints officer. I'm waiting to hear like, well, they help uphold our complaint. So, you have to do all of the legwork".

5.1.4 Proof of documentation

Consistent and continuous request for documentation on proof of disability was also described as very frustrating. In circumstances where the child has a permanent and lifelong disability, parents were still compelled to provide proof of disability periodically.

5.2.5 Missing out on support

Finally, there were experiences of almost missing out on services due to different logistical challenges. Rose describes how she almost missed out on the services because she was living between the north and south side of the city.

> "The services were split between the north side of the city and the south side of the city. And we lived kind of in the middle of the border. So, I think we slipped through the cracks for a few weeks. Later, I asked, where are we on there? Did they have our name and details? Had they been contacted about us? And they said, no, they hadn't. And they said, oh, you probably slipped through the cracks, because we were neither northside or southside, we were somewhere in the middle…So, then I rang the offices in the north side. And they said, no, we don't have any records of either. It's probably because you live somewhere in the middle…"

5.3 Violence of Bureaucracy

Bureaucratic violence sets in when citizens who are recipients of welfare support experience quiet suffering due to the physical, social, and psychological burdens placed by the State institutions. It can be paraphrased as deliberate use of draconian bureaucratic procedures by those who are powerful to intimidate, frustrate, discourage, or sabotage the efforts of the powerless to access resources. It's a silent power struggle where legitimate tools and resources are tactically used by those in power to oppress the powerless by triggering the feeling of helplessness, hopelessness, or lack of worth. The experience of the participants in this study was categorized into five major areas that made them feel that violence of bureaucracy was at play due to the feelings and emotions the events elicited.

5.3.1 Quiet violence in follow up

Lilly describes how she had to go through a tedious process of follow up to access OT services. Despite having got a recommendation from the psychiatrist, she had to make several phone calls, write emails, and eventually even had to write a letter. This can be translated as reaching a point of despair where other people may give up in the pursuit of the services due to the impression that the people in power either ignore or do not offer the services or communicate otherwise efficiently. Lilly tells how her child's psychiatrist sent a letter to another department in the HSE asking for OT services for her child, but nothing happened.

> "And I had to follow up many times with letters, emails, phone calls as David didn't receive any occupational therapy which was recommended by CAMHS. Finally, CAMHS prescribed anti-psychotic medication with recommendation that CNDT provide OT and psychology support. David was then on medication without any support from the CNDT. I had to contact the CNDT to ask why we had not received any support. They replied to say that they had not received a letter from CAMHS requesting this service. So, I wrote a handwritten letter to CNDT and CAMHS to document our history of interacting with both services, including the letters from the CAMHS psychiatrist to my GP and other service providers with no follow up from CAMHS to ensure these supports were put in place. I did not receive a response or acknowledgement for my letter and I had to continuously ring

CNDT for psychology support which was provided after David was put on anti-psychotic medication."

5.3.2 Quiet violence of neglect

Lilly also describes how she experienced neglect after her son had undergone different examinations by a psychologist and psychiatrist. She was left without a report only to be informed after a whole year that the psychologist did not believe his son had ADHD.

> "We then had five speech therapy sessions and one with the OT, one with the psychiatrist, two with the psychologist. After all of that, the psychologist left CAMHS without writing a report. …[our] psychiatrist met us and told us verbally that the psychologist didn't believe that David had ADHD and they weren't giving us any support although the OT in her report recommended occupational therapy sessions…"

After all the back-and-forth movement that never bore fruit, Lilly finally lost all the hope and faith she had in the public system, in fact she had self-blame for having trusted the system which eventually failed her. She finally resorted to the private services which she had to pay for:

> "We just didn't realize that it would take that long for the government to give us the services, you know, we trusted that the government would actually do something, and they didn't… I do regret that we trusted the public system and that we didn't go private sooner. But I'm still putting my faith into the system because we're still waiting for supports…"

Violet equally shares her experience of the violence of bureaucracy when she summarizes that the entire process of pursuing support from the State agencies weakened her spirits to the point that she had to go for several counselling sessions just to move on.

> "And I knew it would get to the point where I would have just collapsed if I hadn't sorted it. I have had this said to me repeatedly by my family, "How do you do it? I don't know how you did it" because it was grueling, there was no joy. It wasn't hard compared to other people's lives, but it was really hard day in day out, in that regard and I go for counseling all the time and that is borne out of my heart in order to survive because I felt in my house if I went down, they all went down…"

Daisy also describes having experienced the violence of bureaucracy when the prescreening in her child's school was used to exclude her child because the school might have not wanted to or couldn't deal with his behavior. She also describes feeling helpless and disempowered when waiting for feedback after launching a complaint.

> "[The child] had done some prescreening with his preschool. Basically, he ended up being excluded from the creche, because they couldn't deal with his behavior, or they didn't want to. So, we had to find an alternative preschool for him who were really, really good, and could cope with the kind of toileting side of things, so yeah, you just, you're not really in any control, you're completely disempowered. You are in their hands, aren't you? Because there's not, there isn't an indication given 'we will get back to you in next days', or, you know, the only thing that you get the timeframe for is if they uphold your complaint and say yes, this child should have had an assessment of need by now and it needs to be done in three months…"

Iris expresses her devastation because care providers are taken in circles as they seek the services who are oblivious to the fact that they are already struggling with other care obligations and responsibilities. She states that.

> "We have enough to cope with, we have enough to deal with, we have enough, trying to do therapies at home…speech and language, trying to do extra homework, all extra things that he needs without these additional bullshit excuses. And that's what it is because its total bureaucracy…"

Iris equates the experience to that to seeking information from a landlord which is hard to get and may eventually get you kicked out of the house.

> "And it's just a small stupid detail and I think people don't understand, you know, if you have to go get…if you have to get information from your landlords. The last person in Ireland you want to contact when you are looking for things is a landlord. Because you're frightened, they will try to sell your house or get you kicked out…"

5.3.3 Quiet violence of delay

Unnecessary delay also seems to stand out at as a violence of bureaucracy strategy that involves delay of service provision by default or design which is likely to precipitate the negative experience emanating from the power imbalance. In an experience shared by Lilly, she describes how she waited for a long time to get the feedback from the Assessment of Needs and wait even longer for feedback from the complaint she launched. Either way, even the long wait was not a guarantee that you'll eventually get the services you waited for. She states that,

> "Once the Assessment of Need form has been done it needs to be processed within three months and they get back to you, but they don't. They didn't. So, you have to put up a complaint to ask them to come back to you. We submitted a complaint as our child was still in danger, struggling with suicidal thoughts and self-harming…"

Daisy also confirms finding the forms really demeaning. Ideally filling forms whose intention is helping should elicit a feeling of empathy and support but in contrast the forms in this case made the care providers feel demeaned thus eliciting a debilitating feeling. Daisy states that

> "I found these forms really demeaning because suddenly to get any kind of support; financial support for caring for my children I had to narrate our worst times, because I knew I wasn't going to be going back to work anytime soon. With two kids with additional needs, I needed to apply for first for Domiciliary Care. And you can't get Carers Allowance until you have got domiciliary care…"

5.3.4 Quiet violence of form filling

The violence of bureaucracy also presented itself in form of repeated form filling, the fact that the care providers have to fill the same or different forms again and again thus becoming very burdensome and debilitating. They sometimes go through a repeat process of form filling even in scenarios where the forms got lost in the hands of staff or in scenarios where the forms can be easily accessed through networking and collaboration with other stakeholders.

Lilly narrates her experience of filling out forms and questionnaires again and again.

> "When David was referred to CAMHS a second time, at the meeting with a new psychiatrist and an OT, they both said they believed David had ADHD and asked us to fill out more forms, and we filled out more questionnaires and we gave the school the questionnaires. We've done this now many times because CAMHS asked us to do this the last time. The teachers filled out forms, we filled out the co-parent forms and agency also filled out the form. After all that form filling, we were told that the initial psychiatrist wanted to halt the process and do a Dundee Protocol instead which is a screening process, and after completing yet more forms for this, eventually we were told that they didn't think David had ADHD and all his difficulties were due to his autism …"

Daisy describes her experience of filling out the forms as emotionally difficult especially taking note that some parents have more than one child with additional needs and has to go through that process for every child.

> "So, all I remember filling out forms for Luke, the assessment of need, and then the complaint. So, it's just form upon form upon form. And they want evidence to go with this. It's just emotionally difficult…"

In addition, Daisy states that the process is made more labour intensive because most of the forms require additional support documents.

> "I spent the first six months of my daughter's life filling in the Domiciliary Care Form, and then the Carers Allowance Form. It was pretty much a full-time job for these six months, caring for her and my son. I found form-filling was just really labour intensive. And required a lot of additional documentation to support your financial situation. Because I think, one, one or both are means tested…"

Iris shares her experience of how the forms were labour intensive and voluminous in terms of many pages, she also narrates the experience of a friend she helped noting that other challenges included that of the challenge with language barrier noting that it was harder for the care providers who do not understand English because the forms have not been translated into other languages.

> "I did it when my son was born, filled out assessment of need form. Oh my God! Pages

upon pages! And this lady, their family are Polish, and her English is quite good … but I think if uneducated and English isn't ones first language, I would think one would find it those forms very difficult to fill out…"

Iris also raises a concern why she has to repeatedly and periodically fill in obvious facts like the disability of the child while its very clear that the child has a life-long condition and needs support. In the process she describes the feeling as sickening which is indeed debilitating.

> "My son has Down Syndrome, my nephew is autistic, there's no cure. Why would you need to [answer]: Do they still have autism? Do they still have Down Syndrome? Do they still need medical care? Domiciliary care or any of those things, Carers Allowance, or whatever, this blows my mind how still one has to fill out those forms for a lifelong condition. When I start talking about these things… it's like every month when you are about to fill these forms you feel sick, because you're like in the next few days you have to relive the experience…"

5.3.5 Quiet violence of worst scenarios

Perhaps the 'worst scenarios' could be considered the most bitter pill when it comes to filling of forms in order to get disability related support from the State.

According to Violet, there is always a conflict of conscience between focusing on the positive progress of your child versus having to narrate the worst scenarios that every parent would wish to forget.

> "So, I remember I applied three times, and I wrote the scenarios and it's awful. But sometimes when you are writing these applications, you feel like you must put in the worst-case scenario all the time when you're writing them. So, you really want to be positive and you're trying to train your brain to be positive and look, you know, life goes on. Then, eventually you have to switch your brain into worst case scenario and you're nearly pleading…sometimes you feel almost guilty that you have to apply for it…"

Similarly Rose also expresses the disappointment in narrating the worst-case scenarios while filling the forms.

> "I was filling in a form that was 20 pages, the worst days of my kid's life; it was to write the worst day of your child's life after the diagnosis. I was just very sad, somebody [caring for someone] with a disability is entitled to have Domiciliary Care Allowance, so why should I need to fill in a form that is so laborious and undermining and doesn't ask anything positive of your child? So that was my experience of it really and if it is an entitlement, it should be a tick box, it shouldn't be a 20-page form."

Daisy describes the feeling of documenting the worst moments in the form filling as emotionally difficult and disturbing. This element literally elicits a debilitating feeling and puts care providers into conflict with their own conscience.

> "So, I think, for me, filling that in is emotionally quite difficult. Because you're trying to confront yourself; Part of me wants to put down the honest fact, like on a bad day, while part of me doesn't. This is horrific. So, it is confronting you really with the reality. The other part of you is kind of trying to protect your child and think, oh, if I put down everything that's really bad, he will get it [the allowance]."

Daisy further describes the elements as emotionally charged and soul destroying.

> "You have to, in order to get these benefits, really put down your worst day that you've had with your child, and that's very soul destroying. And they are set up really, for people with who, I'm finding, are people with physical disabilities or older people. So right, then you're putting your children in that category. So, it kind of diminishes their capability. And you're putting it down and writing really powerful about that. And to reread that yourself is very upsetting…"

Iris on the other hand puts the feeling into context by describing it as getting slapped on the face repeatedly and all you do is give the other cheek.

> "Then came the psychological assessment and that was like getting slapped in the face repeatedly for a couple of hours it was basically like a traumatic experience for any parent because literally you have to go against every parental instinct you have to present your

child at their worst state to actually get support. So, it is against everything in you to present your child at their worst. You always want to present a child at their best, like my child is good at this, is good at that you know…"

5.4 Waiting

The experience of waiting for the outcome of applying for services is an important element in examining the debilitating effects in form filling. This is because forms are completed to access services, and the completion of form filling marks a new phase of waiting for a service, feedback, referral, or outcome. Waiting also displays the power imbalance between service providers and parents. In the interview with the participants, each mother described their different experience on waiting; how it made them feel, how it shaped their perception on service provision and how it compared to their expectations.

Violet describes how she was subjected to a two-year waiting after her GP referred her to CAMHS, her waiting for assessment was further interrupted by the COVID 19 pandemic. She describes how terrible it felt to be on the waiting list and watch as her child's disability progressed. This shows how powerless a family care provider can feel when she has done all she can to get the best for their child and watches as the condition of her child worsens since her fate is on the hands of others.

> "OH My God! It was terrible, it still is. I found it terrible, like emotionally because I could see my child in pain. I was heartbroken for him. I couldn't help him. I went down every route I knew and we were still without any support. Everything we accessed for him I found, does that make sense? And that's neither here nor there, and then you hear all the services are here, but the services were like the Emperor's New Clothes, they didn't exist."

On the other hand, Daisy explains experiencing delays after application for assessment, filing a complaint and getting assurance that her case would be handled within three months. However, eighteen months down the line her case had not been handled.

> "And I think there was even a delay in March, because somebody wasn't employed. We went through all that. And they upheld our complaint and said, yes, this should have been done in three months, and it has been 18 months…"

Daisy also describes how it took more than ten days for her child to get a medical examination for Down Syndrome when she was in the hospital after delivery.

> "They took her off then to get her heart checked. And she came back, but we didn't see anyone else or a consultant. This was a Friday until the Monday and then they take a blood test to confirm Down Syndrome. So, we knew we weren't going to know for sure, for 10 days…"

Daisy also described the experience of other parents she met and had random discussions with.

> "I've met so many parents in the playground just randomly, and they told me, 'Oh, my son, I'm waiting for a diagnosis. I've waited for two years', and 'I haven't heard anything'…"

Lilly describes how she had to wait for three years on the CAMHS waiting list which hindered her from applying for any other state support and then an additional one year to access psychological assessment.

> "We were then waiting three years with no support. So, three years on the CAMHS waiting list because we were told there was no psychologist or psychiatrist in our area. In the meantime, we filled out an assessment of needs application which is in compliance with the policies in February 2015, which was cancelled without our knowledge because we were on CAMHS waiting list…"

Rose describes having left the hospital with her child who had a disability and never heard from the hospital again until she made a follow up call, even after signing the documents, she had to wait for five months to get services: "We were just sent home and we never heard from the services'.

5.5 Medicalization of disability assessment

While the nature of disability, and the associated risks and needs vary with different individuals; most assessments take a medical approach and examination. Even in instances where close relatives and care providers give verbal encounters and visible observations, care providers are still subjected to medical assessments for which they may be on a waiting list for a very long time.

An interview with Lilly illustrates how medicalization of assessment can be frustrating when you feel your child deserves more than just a medical approach:

> "David was prescribed anti-psychotic medication by a psychiatrist in CAMHS for chronic fear and anxiety due to voices and visions, without being provided with any OT or psychology interventions prior to or at the beginning of his medication treatment. As parents we felt extremely concerned that David was on anti- psychotic medication without any interventions and felt obliged to write to both CAMHS and CNDT to ensure that David was provided with OT and Psychology as a matter of urgency…"

This experience reveals a very medicalized approach to handling disability where the professionals resort to continuously give drugs at the expense of other interventions.

Rose also narrates how her interaction with a professional who knew the disadvantages of a medicalized approach helped her develop a positive attitude towards care, while the GP ignored her opinion and continued filling medical forms. Rose states that

> "The medical expert or the GP, was already filling the form, even without consulting what I knew, he believed he knew so much… I remember there was a lot of like disability things that we crossed out, every one of them and another medical practitioner told me; look here Rose I don't believe in any of that. I'll tell you what your son is able to do and not just what he is not able to do…"

Violet described her encounter of disappointment when she was pushed to take her child to A&E. While as a parent she believed in a more holistic approach to treatment that would involve social, psychological and medical, the doctors hurriedly recommended A&E. Violet states that;

> "He would kind of buildup and build up and he had nights in which he couldn't stop banging so we had just to try and contain him in his bedroom and one night I rang the out of hour doctors service and they said bring him to A&E if need be. People would say that to me in the past, but I always felt like "why would I bring my child to A&E?" as in, surely, we don't have to get to that point crisis before we go there."

Daisy narrates her experience with a medical professional who used technical medical descriptive terms that she could not understand to describe her child who had a disability:

> “And then a doctor came in and she started examining my child. And she kind, she said to me and my spouse, I think my partner was holding her, and she said, have you heard of Trisomy 21? And I said, No, I don't know what that is. And she said, well, it's often called Down Syndrome. And then she just kind of pointed out all the features of Down Syndrome that she saw in my child. And it was really like someone reading out a textbook, or maybe talking about a specimen, I was just really shocking the way she did it. And then she just left, she literally ran out the room. …my husband nearly fainted on the floor…”

Apart from the lengthy explanation loaded with medical terms, Daisy also describes how the child was taken for medical examination which the results were not even explained to her.

> “And then they just took the baby…because they will need to check her heart because obviously, heart problems are a big problem with children with Down Syndrome. So, they took her off, then to get her heart checked. And she came back, but we didn't see anyone else or a consultant…”

CHAPTER 6. DISCUSSION

This study was a community-based research project that sought to examine the debilitating experience of form filling by parents of children with additional needs in pursuing disability support services from the state. It is a narrative of lived experience of family care providers focusing on the experiences, feelings, emotions and perceptions of the interviewees in relation to the experience that the parents go through in their interactions with the forms as they pursue the services. The study topic was proposed by We Care Collective - a CSO / lobby group which was interested in exploring the challenges experienced by family care providers in the process of accessing disability services from the state.

This discussion will therefore seek to evaluate and interpret the findings which were guided by the four main concepts which include; administrative burden of care, the violence of bureaucracy, the concept of waiting and the medicalization of disability assessment in relation to the purpose of the study and the research objectives. The discussion will also reflect on addressing the research questions.

6.1 Discussion on the concept

This study was guided by four major concepts which include the administrative burden of care, the violence of bureaucracy, the concept of waiting and the medicalization of disability assessment. It is worth taking note that the concepts are interrelated and interdependent with each other and do not exist in entire isolation. A good example in a statement would be Violet who stated that;

> "I had to wait for two years for assessment because there only one psychologist who had at that time gone on annual leave."

Such a statement may be analyzed under one or both concepts of waiting and the concept of administrative burden of care.

6.1.1 The administrative burden of care

This concept revolves around an individual's experience of the policy implementation process as onerous with an assumption that the formal and informal practices influence a person's encounter with the State program and their cost. The concept of administrative burden of care has been discussed under five different elements which include; filling out forms, failure of staff or system,

handling of complaints and referrals, documented proof and missing out on support.

6.1.2 Filling out of forms

The findings from this study indicate that care providers went through depressing experiences by having to repeatedly and periodically fill the same forms for different interrelated departments. In other instances, they had to re-fill the same forms because the forms were lost due to negligence of staff. One participant had to repeat an entire process of form filling because the psychologist missed out on writing a sentence as it was supposed to be written. In other instances, the participant had to write a hand written letter in desperate attempt to plead her need. The challenges experienced arose due to several possible explanations including shortage of staff, staff negligence, poor networking and collaboration among departments.

6.1.3 Failure of staff or system

The findings of the study also revealed that care providers underwent constant pressure due to failures of either staff or the systems. Participants described having to wait for services for long periods due to shortage of staff. In other instances, the participants had to make constant follow-ups by walk-in to offices, make phone calls because there was no proper feedback on the Progress or processing of their application forms. The reason for this isn't clear but may have been due to staff shortage and negligence.

6.1.4 Handling of complaints and referral

The participants identified the referral and complaint handling process as very debilitating. The participants explained instances where they would be referred for services by professionals only to be denied the same services by the professionals they have been referred to. In other instances, the records or documentation of their children would get lost in the process of referral. The care providers also noted that in some instances it took too long for their complaints to be addressed.

6.1.5 Proof of documentation

Participants found it very frustrating when they were compelled to attach different documents as proof of disability of their children. This was debilitating because access to the same documents

required long processes that included booking for the services, waiting for feedback and sometimes having to pay for the services in private institutions. This became more disturbing in instances where parents were supposed to provide proof of the child's disability seven years down the line yet the documents had been provided after birth and it was automatic that the child had a permanent lifelong disability.

6.1.6 Missing out on support

The participants also described instances where they temporarily missed out on support for a period of time due to technical or logistical challenges. Some missed out because initial examination ruled out a particular type of disability only to be diagnosed at letter stages. Others missed out because they lived in an area where they could not access the services. Possible explanations could be poor networking and collaboration by the agencies as well as poor follow up on clients after first contact or after referral.

6.2 Violence of bureaucracy

Violence tends to exist in a bureaucratic process when the process is intended to or perceived to have an intention deliberate use of draconian procedures by those who are powerful to intimidate, frustrate, discourage, or sabotage the efforts of the powerless to access resources. It's a silent power struggle where legitimate tools and resources are tactically used by those in power to oppress the powerless by triggering the feeling of helplessness, hopelessness, or lack of worth. The experience of the participants in this study was categorized into five major areas that made them feel that violence of bureaucracy was at play due to the feelings and emotions the events elicited. The major areas include the quiet violence of follow up, the quiet violence of neglect, the quiet violence of delay, the quiet violence of form filling and the quiet violence of worst scenario.

6.2.1 The quiet violence of follow up

The participants narrated how they had to make follow-up to the point of despair or even giving up. The aspect of the quiet violence of bureaucracy stands out when the process either by default or design frustrates members to the point of giving up. Parents confessed losing trust in the system after repeated and unsuccessful follow up that made them seek some services from the private sector which came at a very high cost.

6.2.2 The quiet violence of neglect

Participants also described their frustrations in scenarios where they had a professional examination and were neglected for a whole year without a report or services. Subsequently after unsuccessful follow up, some members felt neglected by the state and had to resort to private services. In these scenarios, neglect may be viewed as deliberate attempts to frustrate care providers and push them out of the system.

6.2.3 The quiet violence of delay

This study also found that delay could have been used as a strategy to discourage the uptake of the disability services. The parents narrated scenarios where their children had to wait for long to either get appointments, referrals, examinations, results, or feedback on complaints making them perceive that delay was deliberately used to slow down services to discourage the uptake. There could be other several possible explanations for such scenarios which may include periods for processing of documents, high volume of people seeking the services and few staff who evaluate the forms.

6.2.4 The quiet violence of form filling

The violence of form filling is the most common form of violence of bureaucracy described by all the care providers. This encompasses the voluminous nature of the forms and the number of repeated times the care providers have to fill them. This is especially very burdensome to parents who have more than one child with additional needs who have to fill the forms for both children. Some parents suggested that they have become personal assistants to their children because they are always filling and filing forms for their children. The experience of having to refill forms even when they are misplaced or lost under care of staff is even more frustrating.

6.2.5 The quiet violence of recounting the worst scenarios.

This study found out that the section on recounting the worst scenario a parent has ever had with her child is the most debilitating experience in the form filling process. The parents explain the continuous battle with their conscience when they have to imagine and put down their worst scenario with their children in order to access the support from the state. While the parents try to

see everything positive about their children, the form compels them to narrate and put down the worst scenarios. The reason or justification for this is not clear.

6.3 The concept of waiting

Waiting has been discussed as elements in both administrative burden of care and violence of bureaucracy above, however in different instances waiting existed independently as a concept. This study found out that waiting for long periods became a norm in every state agency right from the start of application to the point of approval or rejection to access services.

In their experience, the family care providers noted that after applying for CAMHS you have to wait for a period between six months and two years. After applying for psychological or psychiatrist examination you have to wait for between three months to many years. After applying for OT, you have to wait for months to receive the services. After applying for special schools, you have to wait for several months and so on and so forth. The most debilitating part of the experience is that even after complaining you may end up waiting for months for your complaint to be addressed. The process and period of waiting is always full of anxieties and uncertainties, according to the parents; the period may also involve back and forth follow ups through phone calls or walk-in to offices.

Eventually the biggest blow comes to some parents who are eventually denied the services after going through all the trouble of waiting and follow up.

6.4 The concept of medicalization of assessment.

This study realized that medicalization of assessment was one of the major concerns for the parents seeking support from the state agencies. In their encounters, some parents narrated scenarios where they could barely hold on because of they were instructed to seek A&E services in scenarios where they believed that their child needed a combined approach of social, psychological, and medical interventions. Parents explained that they would wait for many months or even years to see a social worker, a psychologist, or a psychiatrist only for the condition of their children to worsen and to be told to go for A&E.

The parents also noted that some terms for professionals like audiologist or ortho-pediatrics which they come across when filling forms were very confusing. To make the matters more complicated,

the parents said that in some instances the medical professionals would only focus on the physical wellbeing of the child and discharge them without doing a comprehensive social and psychological examination. The parents narrated instances where the medical examiners would only ask medical questions and tick boxes since they knew the parents didn't understand the medical terms.

6.5 Discussion on Research objectives and questions

This study addressed the following research questions as guided by the research objectives:

1. How do parents to children with additional needs experience the process of access to forms for the disability support services?
2. How do parents to children with additional needs experience the process of form filling with regard to the content of the questions?
3. How do parents to children with additional needs experience the process of form filling regarding the structure of the forms?
4. How do parents to children with additional needs experiences the process of form filling with regards to the feedback from different state agencies?

While the answers to some of these questions came automatically as the respondents shared their experience; the researcher applied prompts and probes prompts in the process of interview to address any question that the respondent had not discussed. Most of their feelings were captured and the findings analyzed under the different concepts.

The first question sought to understand how parents to e children with additional needs experienced the process of access to forms for the disability support services.

Most of the participants did not express difficulty in accessing the forms, they accessed the forms after the first contact with the professionals who diagnosed their children with the disability. The main challenge was knowing about the forms. It was a concern of what form, then how or where to get it would come automatically. For example, some parents didn't know that there were forms that one would use to register complaints, but once they learned about the forms, they easily accessed it.

The second concern was that some forms would be accessed digitally, this would need digital

literacy, digital machines like computers and internet. The second question sought to understand how the parents to the children with additional needs experienced the process of form filling with regard to the content of the questions. Many parents expressed frustrations with the nature of questions in some forms. The parents felt devastated with the questions that expected them to recount the worst moments they experienced with their children. The parents also felt frustrated with the medical terms that were used in some forms.

The third question sought to address how the parents to the children with additional needs experienced the process of form filling with regard to the structure of the forms. The participants shared the frustrations they had with the bulky and voluminous nature of some forms. They noted that some forms had eight to ten pages and the same form had to be filled in duplicates for different state departments, this was even more involving to parents who had more than one child with additional needs.

The fourth question sought to address how the parents to children with additional needs experienced the process of form filling with regards to the feedback from different state agencies. The participants shared their concern about the long periods they had to wait for to get feedback from state agencies. They also described the process of follow up that involved walking to offices of making phone calls in order to get feedback.

CHAPTER 7. CONCLUSION

This chapter will wrap up this study by summarizing the key research findings in relation to the concepts discussed and the research aims and questions. The chapter will also highlight on the value and contribution of the study. The chapter will be also reviewing the limitations of the study and recommend opportunities for future studies and research.

This study aimed to examine the debilitating experience of form filling by parents of children with additional needs in pursuing disability support services from the state. The study adopted a qualitative research method where data was collected through interviews from five participants who shared their lived experience in pursuit of the support from the state. The data collected was organized and analyzed in four major themes which included the administrative burden of care, the violence of bureaucracy, the concept of waiting and the medicalization of assessment.

The findings of the research strongly indicated that the process of application for support from the state agencies can sometimes be very enduring, endless and frustrating; a combination of physical, emotional and psychological fatigue that can be described as debilitating. The narration of the lived experience by the care providers who participated was dominated by a tedious process of form voluminous filling which went on and on up to date. The family care providers also described a frustrating follow up process that would involve endless phone calls, back and forth walk-in to offices, endless emails that in some instances still bore no fruit. The participants described instances where their forms would get lost within the system and nobody would inform

them about it, upon discovery on follow up; they'd be compelled to re-fill the same voluminous forms and search for the support documents.

The participants further described what they felt as intentional attempts to use bureaucratic processes as a form of violence to discourage their access to the services. They described how the agencies lacked networking and collaboration which made the process of follow up so tedious and debilitating. The participants also narrated instances where they felt neglected and powerless by the state agencies to the point that they had to look for the services from the private sector which came at a high cost. All the participants felt the evaluation process that involves recounting their worst moments made them re-live painful memories of the process of caring and caused a conflict within their conscience. The participants also felt that state agencies deliberately slow down the process of service delivery to slow down the access of the services by the deserving citizen.

Apart from that the participants faulted the period of waiting for either feedback, services, referrals or address of complains. Waiting in the dark was a norm with the possible explanation of either a long waiting list or shortage of staff. The participants had waiting periods that ranged from six months to two years and above for services that they ought to have accessed either immediately or within six months. Some waited for more than two years and still ended up missing out on the support.

The family care providers also recounted episodes where they found the evaluation forms to be so medicalized that the general practitioners felt that the parents did not understand the process, hence they just filled out the forms without actively involving the parents. Some parents narrated incidences where their children who had an intellectual disability were put on medication while the social and psychological care like OT was totally neglected. The parents pointed out hard or rather confusing medical terms like ortho-pediatrics that were used in the forms. The parents could not understand or differentiate some of the professional terms while filling out the forms.

It is worth noting that the above study used a small sample of participants who were selected through a non-random process. However, the findings of this study mark a great eye opener to the people responsible for making and implementing the policies that relate to access of disability services by care provider from state agencies. The lived experience of the parents who interact with the forms as they seek state support should inform the policy makers on how to improve empowerment on what forms to use and their access; what contents to include or remove from the forms due to their emotional impacts; how to improve on networking and collaboration to reduce duplication and the tedious process of follow-up; and how to efficiently handle feedback and complaints.

This study, or rather its findings, recommend further research interactions with forms on a wider scale; preferably a national scale that would involve all stakeholders from different state agencies, care providers, persons with disability and policy makers.

The study findings would also recommend a consultative bottom-up interaction and empowerment of both the service users and service providers in order to participatorily come up with solutions that work best for all the people involved.

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APPENDIX 2

PARTICIPANT INTERVIEW INFORMATION SHEET

Examining the debilitating experience of form filling by parents to children with additional needs in pursuing disability support service from state agencies in Cork- Ireland.

BY CALVIN M. ODHIAMBO

CARL Research Project

in collaboration with

We Care Collective





Name of student(s):	CALVIN M. ODHIAMBO
Name of community group:	WE CARE COLLECTIVE
Name of community group liaison person:	GILLIAN MULLALY & LIZ KYTE
Academic supervisor(s):	ELUSKA FERNANDEZ & FIONA DUKELOW
Name and year of course:	MA SOCIAL POLICY 2022
Date completed:	

Dear Participants

Thank you for considering to participate in this research project. The purpose of this document is to explain to you what the project is about and what your participation would entail and contribute to project. This document would therefore enable you to make an informed choice in regard to your participation.

The purpose of this study is to examine the debilitating experience of form filling by parents of children with additional needs in pursuing disability support service from state agencies in Cork-Ireland. Should you choose to participate, you will be asked to take part in a one-to-one interview with the researcher. During the interview, the interviewer will take notes and the interview will be audio recorded to facilitate accurate reporting after the interview. The interview is expected to take 40-60 minutes to complete. The participant will also be able to stop the interview if they wish to do so at any point;

Participation in this study is completely voluntary. There is no obligation to participate, and should you choose to do so, you can refuse to answer specific questions, or decide to withdraw from the interview. Once the interview has been concluded, you can choose to withdraw at any time in the subsequent two weeks.

All of the information you provide will be kept confidential and anonymous, and will be available only to the researcher, the supervisors and the research team involved in review and

marking. The findings will be shared with the We Care Collective. The only exception is where information is disclosed which indicates that there is a serious risk to you or to others. Once the interview is completed, the recording will immediately be transferred to a safe UCC data storage platform and wiped from the recording device. The interview will then be transcribed by the researcher, and all identifying information will be removed. Once this is done, the recording will also be deleted and only the anonymized transcript will remain. This will be stored on a University College Cork supported cloud storage platform. The data will be stored for minimum of ten years. The information you provide may contribute to research publications and/or conference presentations.

Since the approval process has gone through an ethical review process and consultation with different stakeholders, we do not anticipate any negative outcomes from participating in this study. At the end of the interview, I will discuss with you how you found the experience and how you are feeling.

If you have any queries about this research, you can make inquiries through 121107758@umail.ucc.ie f.dukelow@ucc.ie, E.Fernandez@ucc.ie

If you agree to take part in this study, please sign the consent form overleaf.

APPENDIX 3

Participant informed consent form

PARTICIPANT INFORMED CONSENT FORM FOR PARTICIPATION IN RESEARCH ON;

Examining the debilitating experience of form filling by parents of children with additional needs in pursuing disability support service from state agencies in Cork- Ireland.

BY CALVIN M. ODHIAMBO

CARL Research Project

in collaboration with

We Care Collective

I .....agree to participate in Calvin Odhiambo's research study.

The purpose and nature of the study has been explained to me in writing.

I am participating voluntarily.

I give permission for my interview with Calvin Odhiambo to be audio recorded.

I understand that I can withdraw from the study, without repercussions, at any time, whether before it starts or while I am participating.

I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.

I understand that anonymity will be ensured in the write-up by disguising my identity.

I understand that disguised extracts from my interview (e.g. my name / location won't be used) may be quoted in presentations and publications (e.g. article, book chapter, student thesis, social media publicity of the study's findings, etc.), if I give permission below (please tick one box):

I agree to participate in this study ☐

I do not agree to participate in this study ☐

Signed: ……. Date: .....PRINT NAME: ……

APPENDIX 4

INTERVIEW SCHEDULE

Section 1 Introduction

- Climate setting beginning by introduction and re-affirming ethical standards including confidentiality
- Confirming relation to the child eg. Parent and primary family care provider

Section 2 General demographic questions

- How many children with disabilities do you have? What age(s) are they?
- How did you get to learn about the disability of your child/children and what age(s) were they at time?

  How would you describe the process you went through to understand how and where to get support from the state?

- What was your experience of the assessment processes you went through in order to access services for your child/children?
-

For this research, the We Care Collective members have selected three forms that are frequently completed by parents of children with disabilities: the Assessment of Needs form, the Domiciliary Care Allowance form and (specific name of complaints form here). How many of these forms have you had experience of completing? Section

Section 3 Experience

- What aspects of these forms did you find particularly difficult to deal with?
- How did the process of filling the forms affect you/ your daily activities including caring for your child?
- Approximately, how long did you wait for a response to your application or receive services after submitting your application?
- How would you describe the process of waiting for a response and how it affected you?
- If you had reason to make a complaint, what did you find difficult about this process and the form you had to fill in?

Section 4 Conclusion

What would you like to see change about how parents of children with disabilities have to apply for services for their children?

Do you have anything further you would like to say?