Mothers of Children with Disabilities in Slovakia: Forms of Advocacy to Ensure Better Education for Their Children

Abstract

Mothers of children with disabilities have always played an important role in their child's education. This paper examines mothers' lived experiences related to their advocacy efforts within the Slovak context. By placing mothers' perspectives at the centre of this research, mothers were given the much-needed safe platform to share their own, often silenced, stories of how they fought to ensure quality education for their children. Qualitative data were collected from nine mothers, using semi-structured online interviews. The six-stage thematic analysis, proposed by Braun and Clarke (2006), was then employed to analyse the gathered data by grouping codes into five main themes. Situating findings within the feminist and disability body of knowledge in particular, this paper explains that mothers of children with disabilities tend to be not only blamed, but also pressured to supplement the failing welfare system by providing nonstop care for their children. When mothers decided to address the shortcomings of the Slovak education system, they had to invest a lot of personal resources to be effective. Unsurprisingly, those with cultural capital have been more actively advocating and likely to be successful in their efforts. However, regardless of their socioeconomic background, all mothers adjusted their personal and professional lives to support their children. This paper concludes by drawing attention to the pressuring need to rethink the position of mothers of children with disabilities by giving them freedom and the necessary support to choose the definition of motherhood they wish to identify with by themselves.

Acknowledgements

First, I would like to thank my participants. I understand that it must have been difficult for them to share their very personal lived experiences of being mothers of and advocates for their children with disabilities. Therefore, I very much appreciate that they were willing to find the time to share their stories with me and had trust in me to represent their voice in this dissertation accurately. I hope I managed to do justice to this unique and powerful data which I had the privilege to present in this work.

I have also received enormous support from my supervisor, Professor Nidhi Singal. Thank you, Nidhi, for guiding me through the whole dissertation process. Your feedback and insights have helped me to become a more critical and reflective scholar, who understands how important it is to explore their positionality and embrace it in everything they do.

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1. Introduction

1.1 Personal Motivation

It was a beginning of another year of a summer programme for children with disabilities. One single mother and I developed a tradition that at the beginning of every day we had a brief chat about her child and life in general. During one of these discussions, she told me "You know, Ms Karin, every day I have to make a choice between going out there to beg for money for the necessities and demand adequate support for my son, and actually spending quality time with him. How does one make such a choice?".

This story was a starting point of my reflection on the different roles she and other mothers must hold to ensure that their child(ren) with disabilities have the support, especially in relation to education, which they need and have the legal right to. The quote above also represents a distressing reality of many mothers of children with disabilities in Slovakia - they are often expected to take on many different roles to support their child with disabilities, ending up feeling completely emotionally and physically distressed and overwhelmed.

As the director of a non-profit organising summer programmes for children with disabilities, I had similar intimate, honest interactions with many other mothers. Therefore, the idea of a research project which could address the role of parents – and in particular mothers - and different forms of their advocacy has emerged as a theme of my dissertation gradually, but naturally. In other words, this study is to me, not only a fascinating academic endeavour, but also a deeply personal exploration of the lived experiences of these mothers. I understand this dissertation as yet another part of my personal life-long mission of fighting for children with disabilities and their families to be included and adequately supported in society.

1.2 Slovak Educational Context: An Overview

In Slovakia, kindergartens are generally reserved for 3–6-year-old children and they are the first interaction a child has with a formal education institution[1]. The mandatory education, however, starts with the primary school which lasts nine years. Although the mandatory education lasts 10 years (nine years of primary school + an additional year of secondary school), almost all students decide to attend secondary schools for four additional years. For all these three educational levels, there are schools for children with disabilities, typically referred to as special schools[2].

Slovakia has a largely segregated education as 47.32 % of all students with an official diagnosis are educated in special educational settings (European Agency for Special Needs and Inclusive Education, 2020). Therefore, even after 30 years from the Salamanca Statement (United Nations, 1994) and almost 10 years from the Convention on the Rights of Persons with Disabilities ratification (United Nations, 2006), Slovak children and young people with disabilities are still segregated and discriminated against on the basis of their disability. More specifically, children with intellectual impairment are taught a restricted curriculum and can receive only the ISCED 1 qualification (equivalent to just the first 4 out of 9 years of primary school) which prevents them from going to grammar or vocational high schools after the completion of special primary school. Not even those with intellectual impairment educated in mainstream primary schools can attend many vocational and grammar schools because they still receive the same certificate as their peers in special schools (ISCED 1) upon graduation from their mainstream primary school. Therefore, their only option is then to attend practical schools with programmes, named as for example ‘Practical Woman’, which

[1] Some children might attend nurseries which are for toddlers (0-3 years), although they are not frequently used since mothers can take a three year long maternity leave.
[2] Primary and secondary public education is free, even for children with disabilities. Kindergartens request some tuition, but it is quite minimal.

leave them unprepared to succeed in society and the labour market (Bella, 2021). Unfortunately, children with disabilities face enormous obstacles even at the start of primary education as they are denied access to a lot of mainstream schools simply on the basis of their disability. Hence, children with disabilities in Slovakia are educated in a system with severe structural barriers, insufficient resources and specialised personnel as well as unprepared teachers to cater for the needs of all children (Hapalová, 2019).

1.3 Research Rationale and Aims

However, even in the context of Slovakia where children with disabilities are discriminated against in the education system on so many different levels, mothers of these children often find different ways to fight for their child's education. Some of them have actively tried to de-stigmatise disability and challenge the perception of disability online on social media (see for example Kovacič Hanzelová, 2019). Others have initiated legal battles, and a few of them set a positive precedent for other children with disabilities in Slovak society by winning their own cases (see for example Bella, 2021; Nadácia Pontis, 2014). There are also some mothers who have co-founded non-profit organisations such as Platforma rodín detí so zdravotným znevýhodnením (Platform of Families with Children with Disabilities)[3] or Downov Syndróm (Down's Syndrome)[4] to collectively advocate for better education on the national level.

Given there is evidence that mothers are the ones who tend to take on the main caring role in Slovakia (Dančíková, 2020), this dissertation focuses on their experience. It is not to assume that this is the case in every family or that fathers or other family members are not engaged in any advocacy at all. This paper simply reflects on the persistent trend of mothers being the main caretakers in society and aims to address it by through further investigation. More

[3] For more information about the organisation, please refer to their website: https://www.platformarodin.sk/.
[4] For more information about the organisation, please refer to their website: https://downovsyndrom.sk/v16/node/35/.

specifically, this dissertation aims to better understand and analyse the mothers' lived experiences of advocating for their child with disability, with a special focus on their child's educational trajectory. I hope that by placing the perspectives and advocacy of mothers at the centre of my dissertation, I can also give them the necessary platform to share their own story of how they have fought to ensure quality education for their children in a safe and transparent environment.

1.4 Research Overview

This dissertation is organised as follows: Chapter 2 includes a literature review with the aim to conceptualise key terms in this study such as motherhood, disability and advocacy, situating it in the context of mothers of children with disabilities, specifically. Chapter 3 discusses the methodology, including the research design, methods, sample and ethical considerations. Chapter 4 presents the findings organised in 5 main themes: the societal expectation of their role, mothers' perception of valuable education for their children, different avenues of mothers' advocacy, factors influencing their advocacy, and the impact of advocacy in their life. Chapter 5 critically analyses those findings in line with the wider literature. The dissertation concludes with Chapter 6 which focuses on implications for parents, practitioners, policymakers or other stakeholders involved in education sector in Slovakia.

2. Literature review

The aim of the literature review is to conceptualise key terms in this study: motherhood, with a special attention given to mothers of children with disabilities; construct(s) of disability; and mothers' advocacy and its different forms. More specifically, this chapter first situates the concept of motherhood within the critical feminist theoretical framework and then focuses specifically on the experience of being a mother of children with disabilities, looking not only at how society defines her roles, but also how they themselves understand them. This then directly leads to the next section which looks at the construct(s) of disability and clearly defines how this term is conceptualised in this study. The other main part of this literature review focuses on mothers' advocacy. This subsection specifically analyses mothers' lived experiences related to their advocacy, closely looking at diverse range of ways how they choose to fight for their children.

2.1 Motherhood

2.1.1 Experience and Institution of Motherhood

The study of motherhood has always had an ambivalent relationship with the feminist scholarship (Takševa, 2018). While some less recent feminist scholars used to argue for complete rejection of motherhood due to its inherent women's oppression (Allen, 1984), hooks (2000) explains that some of the more recent scholars are at the opposite end of the range, romanticising motherhood by blindly accepting its sexist stereotypes. When trying to navigate the complex idea of motherhood, Adrienne Rich's seminal work (1976) makes an important distinction between the institution of motherhood and experience of mothering, which might be particularly helpful. The former, motherhood as institution, can be understood as a patriarchal means of control introduced by male counterparts (Jiao, 2019). Therefore, motherhood as the institution can be also perceived as a mechanism to ensure that

the patriarchal structures in society prevail and women remain oppressed in various areas of lives, including employment, or political engagement. On the other hand, the latter term refers to personal experience of mothering which might not be necessarily oppressive and can be even potentially a source of empowerment (Green, 2004).

However, this framework should not serve to create a problematic dichotomy between the oppressive social structures (institution) and mothers' agency to have a positive experience of mothering. Rich herself (1976, p. 252) critically emphasises that 'any woman who believes that the institution of motherhood has nothing to do with her is closing her eyes to crucial aspects of her situation'. In other words, she explains that there is always the interaction of the two, institution and experience, which constantly influence each other. Therefore, this dissertation moves away from such inaccurate dichotomies and sees motherhood as a rather complex, diverse and layered work of raising children. Building on Rich's contribution, Green (2015) looks closer at the institution of motherhood and explains how it sophistically creates dominant discourse about what it should mean to be a mother. More specially, while she claims that women have the opportunity to choose how they want to navigate themselves within the space of motherhood, it is still important to be aware that they continue to be part of society, which to a great extent (consciously and unconsciously) imposes a set of regulations which dictate what the standard of motherhood should be.

Therefore, understanding of the evolvement of the contemporary conceptualisation of the notion of ideal motherhood in the patriarchal societies can be particularly helpful when aspiring to comprehend the impact of the institution of motherhood on the female experience of becoming mothers. By 1950s, ideal motherhood was defined as a complete self-denial and repudiation. That era can be, therefore, also understood as a complete self-renunciation, since mothers were expected to sacrifice even their own physical and mental wellbeing (Ehrenreich & English, 2005). While the post-war period and then the rest of the 20st century have

brought a lot of improvement in the perception of mothers as well as their position in society, it would be false to assume that mothers did not have to face similar harmful expectations. Around 2000, Hays (1996, p. 15) coined the term 'intensive mothering, […] child centred, expert guided, emotionally absorbing, labour intensive, and financially expensive' work to further illustrate that these societal expectations towards mothers still require them to be completely dedicated to their children at the expense of other areas of their lives. Douglas and Michaels (2004) similarly argue that this contemporary set of ideals construct unreachable standards of what is expected from a mother. Unfortunately, as a result, these unrealistic, unattainable standards then not only undermine women, but also restrict their ability to ever achieve success in their personal or professional areas of life.

2.1.2 Critical Intersectional Approach to Motherhood

However, while conceptualising both the institution and experience of motherhood, it is important to be critical and take an intersectional stance to be able to fully capture the diverse lived realities of mothering. As Mack (2018) emphasises, traditional white liberal feminist ideas are to some extent complicit in erasing the lived experiences of mothers who do not fit into the image of the white middle-class mother. Therefore, to be able to get the nuanced image of women's experience, the feminist scholarship must first and foremost acknowledge the intersectional nature of the experience of motherhood – based on the specific women identity markers, for example, class or race. More specifically, as Smith (2013) explains by building on Marxist's notion of social reproduction (Marx, 1967), the patriarchal notion of family and motherhood plays a central role in labour reproduction and economic marginalisation of women. The exploitation of women's domestic (unpaid) labour can then serve as a driving mechanism behind the social class reproduction. Moreover, the traditional notion of the nuclear middle-class family structure tends to silence, for example, experiences of single mothers, often from lower socioeconomic backgrounds, and marginalise their roles

due to their inability to reach the status of the ideal mother due to the lack of their financial and social capital to provide standard middle-class opportunities for their child(ren). Unfortunately, as a consequence of these middle-class stereotypes, many single mothers who decide to access the state support are named welfare schemers and are even blamed to have children only because they want to receive more state benefits (Kawash, 2011).

However, when Edin and Kafelas (2005) interviewed single women with limited prospects in deprived areas of Philadelphia and New Jersey, they learnt that these women decided to have children for entirely different reasons – they saw it as an opportunity to experience joy, but also achievement in their communities where being a mother carries a higher perceived level of maturity and respect. Similarly, some black feminist scholars, aligned with the Green's argument about the possibility of motherhood as an empowering experience, critically add that dominant discourses of the golden standard of motherhood often silence non-white motherhood narratives, especially of those who view motherhood as a possible alternative (Mock, 2018). Black feminist scholar Patricia H. Collins (2009) specifically writes that even though the white ideal of motherhood might disregard the role and status of black mothers, these mothers are often involved in resistive and empowering practices which play an important role in the thriving of black families. Therefore, black feminist scholarship is critical about the exclusion of not only black mothers' experience of motherhood, but also the whole body of Afrocentric knowledge which positions the notion of motherhood as a possible alternative. Hence, it is crucial not to automatically confine the experience of mothering into an exclusively negative and oppressive narrative, acknowledging that in some circumstances it might also have an empowering effect. Moreover, this subsection shows that since the interaction of different identity markers have a significant influence on the lived experiences and agency of mothers, it is important to thus situate any lived experience in these different social and economic structures to get a nuanced understanding of their lives.

2.1.3 Social Perception of Mothers of Children with Disabilities

Mothers of children with disabilities have historically experienced a particularly high degree of public scrutiny. It can be best illustrated on the narrative about mothers of children with autism spectrum disorder (ASD) and on how their role has been continuously developed in mainstream society in the last century. As Lappé (2017) explains, in the 1950s and 1970s mothers of children with ASD were even explicitly perceived as the main cause of their child's autism. American psychologist Bettelheim (1967), in particular, popularised the idea of 'refrigerator mothers' – the hypothesis which argued that bad parenting and lack of affectation caused autism (Nadesan, 2005). As a result of these dominant discourses, mothers of children with ASD or other disabilities have been substantially blamed for their child's disability (Blum, 2007; Madi et al., 2019; Scavarda, 2024).

Sousa (2011), looking at the American context specifically, further explains that even though the discourse has mostly stopped blaming mothers for causing the disability over time, the perception of mothers has moved to another problematic understanding of their roles as warrior-heroes emphasising the limitless responsibilities of mothers to care for their children. Therefore, even though there has been an improvement of social perception of mothers of children with disabilities, there is still an expectation from mothers to 'devote limitless time, energy, and resources to their children's development' (Sousa, 2011, p. 220). In other words, these mothers tend to still face unattainable expectations about how they should behave, which consequently place them at the margins of society alongside with their children. As a result of the care-taking demands and lack of adequate service for children with disabilities such as childcare, many of these mothers remain excluded from the labour market and society (Runswick-Cole & Goodley, 2018). Even if they decide to reach the ideal and often even substitute the role of the state, societal expectations often set these women up to make them feel that no matter what they do, it is not sufficient or good enough (Boshoff et al., 2016).

Moreover, mothers of children with disabilities have occupied to some extent a problematic position even within the disability community, especially in the last decades. As Ryan & Runswick-Cole (2008) explained, mothers' involvement has raised important concerns about the role of non-disabled people within disability studies and how their involvement might be complicit in moving the voice of people with disabilities to the margin of the disability movement.

Unfortunately, no such research looking at the social perception of mothers of children with disabilities have been found in the Slovak or even the central European context, therefore, it was only possible to provide an overview with a particular emphasis on the larger geographical region of Europe where Slovakia is situated, which is believed to provide at least some understanding of the necessary concepts for this dissertation.

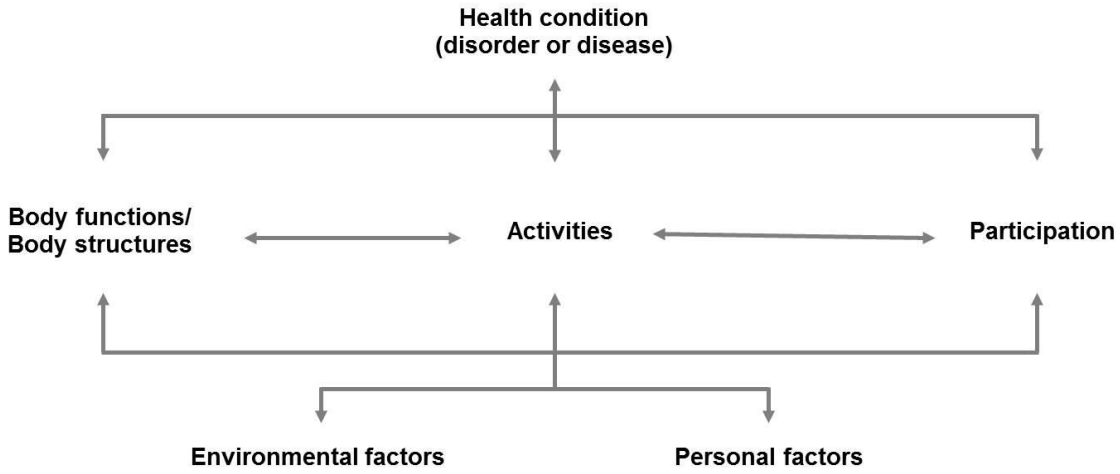
2.2 The Construct(s) of Disability

Before going into the conceptualisation of the key term in this literature review, advocacy, it is important to first look at the construct(s) of disability and how its different definitions also influence the understanding of what should be changed to improve living conditions of children with disabilities. Similarly to motherhood, the concept of disability cannot be understood only through a biological (medical) lens. The medical model explains that disability should be constructed as a problem of the individual's mind or body (Landsman, 2005). Therefore, this model has a tendency to focus on the individual and specific treatments for them. Since the medical expertise is an integral part of the model, there is also an emphasis on the creation of very specific diagnostic labels which are then believed to be helpful in accessing appropriate support for people with disabilities. Therefore, the responsibility lies on the individuals with disabilities (and often also their parents) to find ways to adjust their being and doing to fit into the structures of current societies. However,

the social model of disability rejects the premise of the medical model which burdens the individual and argues that it is not the body which has the disabling impact, but the structure and nature of society. Feminist disability scholar, Garland-Thomson (2002, p. 5), explicitly describes disability as a 'culturally fabricated narrative of the body'. In other words, she and other critical disability scholars explain that society is designed and structured to serve 'able-bodied' individuals which consequently stigmatises, marginalises and segregates certain groups of people who do not fit into its socio-culturally created standards.

Being aware of the limitations of both dominant discourses about disability, this dissertation rather builds on a bio-psycho-social multidimensional model of disability introduced by the International Classification of Functioning, Disability and Health (2002) which argues that it is the combination of biological, social and also psychological factors which constructs any disability. As illustrated in the figure, it is not only the physical impairment (such as blindness) which determines the activities which one can/cannot do (reading) and their participation in society (election or employment), because there are also environment factors (accessibility of specific support mechanisms such as presence of Braille, design of physical buildings) and personal factors (age, gender, socioeconomic status) which determine how one experiences a certain condition. However, even when using this framework, it is important to also acknowledge that disability is an umbrella term which encompasses a lot of different conditions (World Health Organisation & World Bank, 2011); therefore, the nature of the interactions of the individual factors and the lived experiences of individuals with a disability will differ as well.

Figure 2.2 The International Classification of Functioning, Disability and Health Framework (World Health Organisation, 2002)



2.3 Mothers' Advocacy

Boshoff et al. (2019) describe that generally speaking the concept of advocacy in the context of parents of children with disabilities has been largely defined within the social justice framework to ensure that their children with disabilities have the support they need. However, it is important to emphasise that the scope, aim, nature and their overall lived experience related to their advocacy work have differed based on their particular circumstances. Therefore, in this section, I will first look at how the term evolved historically, then I will analyse how the nature of the advocacy work depends on the definition of the disability itself, and lastly, I will critically review the lived experiences of mothers of a child with disabilities in particular as well as the personal factors which might influence their advocacy work and its effectiveness.

2.3.1 Its Historical Development

In the first half of the 20th century, mothers' and parental advocacy had a very individual nature. As Walmsley et al. (2017) further explain, during that period families of children with

disabilities were largely stigmatised, and thus they were also very isolated and did not know about each other. Moreover, the institutionalisation of these children meant that parental advocacy was very restricted as parents had very little knowledge of their children's living conditions. Therefore, among other reasons, these high levels of stigmatisation and institutionalisation have been also considered as one of the potential explanations why it was possible to execute around 270,000 people with disabilities during the Nazi regime in Europe throughout World War II (Evans, 2004).

Fortunately, the post-war period has been a turning point in the positive development of not only educational provision for these children, but also parental advocacy (Singal, 2020; Walmsley et al., 2017). However, literature from England and the United States (Brigham et al., 2000; Castles, 2004; Rolph 2002) explains that a life with disability was still portrayed exclusively within the deficit perspective, as a burden deserving both sympathy and support. Therefore, in the second half of the 20th century children with disabilities were still largely perceived as a great misfortune, and parents of these children were advised to put them away (Rolph et al., 2005).

However, since the 1980s and 1990s it has started to be gradually accepted that individuals with disabilities should receive support from the state (Roulstone, 2015) to have ordinary life with their families in the communities they normally lived in (Johnson et al., 2010). Therefore, during that period the focus of the advocacy activities has become to achieve the equal citizenship rights for these people. Additionally, since people with disabilities have been continuously integrated within their communities, destigmatisation has been partially improved as well. As a result, families of children with disabilities started to know each other and could also start collective local efforts to improve or even initiate services for their children (Walmsley et al., 2017). From the beginning of the 21st century, also with the rise of the de-barrierisation efforts, the goal, especially in the area of education, has been to

challenge the social norms and barriers to fully include children with disabilities into the mainstream educational track (Qvortrup & Qvortrup, 2017). Hence, in the last 2-3 decades, in particular, there were some advocacy efforts which have also had some elements of activism or resistance to disrupt and challenge the broader social structures to create a social change. Moreover, with the emergence of social media and globalisation, the advocacy has been able to evolve from the local community initiatives to large-scale global campaigns with even cross-national scope.

2.3.2 Forms of Mothers' Advocacy

Advocacy is a daily reality for many families with children with disabilities. More specifically, since mothers of children with disabilities are the people who often have to hold the position of mediators facilitating the interactions between their children and society, advocacy is to some extent inevitable in current ableist society and usually the commitment for their whole life (Read, 2000). Therefore, advocacy starts at the birth/diagnosis and then continues through different stages and areas of life (Wright & Taylor, 2014). To further understand the nature of mothers' advocacy, it might be useful to refer to the dominant disability discourses (medical and social model) and further analyse how these models influence what the specific advocacy objectives and techniques can look like in reality. Since this literature review has already conceptualised and compared the medical and social model of disability, the aim of this section will not be to repeat this information, but rather build on already shared arguments.

As explained in the earlier section, the medical model largely focuses on the official diagnosis and then consequently the right treatment for the individuals to mitigate or cure the disability. It is, therefore, mainly the medical diagnosis, not the particular needs of a child which determines the available services for people with disabilities (Haegele & Hodge,

2016). Moreover, in this model medical professionals represent a role of gatekeepers who ultimately decide what kind of services and benefits people with disabilities and their family can receive (Humpage, 2007). Since the extent and nature of the support from the state is determined on the basis of the diagnostic label, mothers are aware that in order to receive support for their children they need to go through this, often difficult, process. Advocacy in this context tends to then have an individual local character, as mothers actively engage with the educational, social, medical institutions to maximise all the available support and treatments for their children in their specific circumstances. Based on their study in the United States, Wright and Taylor (2014, p. 597) describe that to maximise these effort in education, specifically, mothers engage with three main advocacy techniques: '(a) educating, building rapport, and meeting with teachers and principals; b) becoming familiar with special education law; and c) collaborating with professionals outside the school and/or bringing advocates and supporters to individualised education plan (IEP) meetings' as their goal is to ensure that children receive the best education they can in their specific contexts.

Even though advocacy following the social model of disability might not be always in complete contradiction to the advocacy typical for the medical model, it still tends to have a quite distinct set of objectives and thus also tends to employ different advocacy activities. More specifically, as the premise of the social model is to draw attention to the social barriers and structures being responsible for the disability creation, the goal of advocacy in this context is to focus on challenging and dismantling social ableist norms (Good et al., 2017). Therefore, in this case the advocacy often has elements of or even turns to activism completely as its objective is closely linked to achieving wider social-cultural changes. It often even has the nature of a collective movement campaigning for a specific reform.

While this literature review acknowledges that specific forms of advocacy tend to be inspired by these two dominant disability discourses, it is important to also emphasise that it is often

impossible to draw clean lines between different objectives behind the advocacy. Parents regularly employ different advocacy strategies inspired by both models to maximise the best support for their children in their particular circumstances. Moreover, since this essay builds on the bio-psycho-social model of disability, it acknowledges that it is important to address all dimensions of disability in advocacy activities. Thus, it is not possible to put a normative value to any forms of advocacy without knowledge of people's specific impairment and wider environmental factors which determine how the disability is demonstrated in real life.

2.3.3 Factors Influencing Mothers' Advocacy

Similarly to the conceptualisation of motherhood, when aiming to understand mothers' advocacy in its full complexity, it is important to take the intersectional approach by looking at how mothers' identity empowers or constrains their ability to effectively advocate for their child's education. Due to the complex, and always evolving legislation and unclear structure of available services, mothers (or other caretakers in general) often find it difficult to navigate themselves within the system and do not fully know what is actually available for their children and families. Therefore, to be able to effectively perform their advocacy activities, Ewles et al. (2014) emphasise that mothers are required to acquire complex knowledge about the service eligibility and delivery as well as legislative nuances. In addition to that, there are also time and financial challenges which mothers have identified as some of the main barriers in their advocacy efforts (Rossetti et al., 2021, Wright & Taylor, 2014).

Since mothers have to rely heavily on their financial and cultural capital to support their children, those coming from affluent, well-educated backgrounds might be in a better position to do so. In Callaghan and Sylvester's study (2021, p. 135), families with children with disabilities explicitly described that they felt 'blessed' to have the knowledge, skills and resources to fight for their children. On the other hand, families from lower socio-economic

backgrounds tend to be less successful in accessing support for their children (Sperry et al., 1999), as they do not have such flexibility to adjust their work schedule to attend meetings scheduled at school (Harry et al., 1995; Lareau & Shumar, 1996; Linan-Thompson & Jean, 1997). Moreover, due to the specialised language, it might be often difficult for them to advocate for their children, especially for those who are not that well familiar with the language of instruction, as it might not be their mother tongue (Lalvani, 2012; Smith-Young et al., 2020). To conclude, the main factors which have been discussed in this subsection are following: level of cultural capital (familiarity with the system and professional jargon, specifically), financial resources as well as job flexibility, which tend to have a particularly disadvantageous impact on mothers from lower socio-economic backgrounds who usually do not have these resources at their disposal.

However, regardless of their backgrounds, having and advocating for children with disabilities has a significant impact on the lives of mothers and their families, considering both financial and social aspects (Begum & Mamin, 2019), which can also lead to family breakdown (Bonis, 2016) or further social isolation as a result of being perceived as those difficult ones (Blum, 2007). These various barriers and the stress associated with them can even impact their wellbeing and health (Bonis, 2016). However, at the same time it is important to acknowledge that families describe this process as an empowering experience which finally gives at least some kind of hope (Altiere & Von Kluge, 2009; Luong et al., 2009). Furthermore, Aboriginal and Torres Strait Islander mothers of children with ASD in Lilley et al. (2023, p. 584) describe that while their journey can be at times difficult, it is also rewarding, ‘providing knowledge that has led to transformations in understanding of self and others’. Therefore, it important not to fall automatically into a deficit narrative to be able to capture the whole complexity of mothers’ experience which can also have some positively transformative elements.

Unfortunately, even though in grey literature there is a rich body of knowledge about different avenues of mothers' advocacy in Slovakia as illustrated in chapter 1.3., there is a very limited body of academic literature regarding the lived experiences of mothers of children with disability related to advocacy within the geographical context of central Europe or Slovakia, specifically. While Di Giulio et al. (2014) conducted research on families of children with disabilities in the context of some Central European countries, including Poland, Austria and Hungary, and Šmidová and Žuffa (2018) as well as Šmidová et al. (2019) in the Slovak context, their focus was on the impact of raising a child with disabilities in general.

2.4 Research Questions

In line with the gap in literature on mothers' lived experience of advocating for their children with disabilities in the Slovak context, this study aims to provide space for mothers even from this geographical location to share their stories specific to the context of the education system in Slovakia.

2.4.1 Main Research Question

What are the lived experiences of mothers of children with disabilities in ensuring education for their children?

2.4.2 Subquestions

1. How do they perceive their role in ensuring education for their child(ren)?
2. What forms of advocacy have they employed to achieve the kind of education they value?

3. Research Methodology

3.1 Theoretical Stance

Considering the focus of this dissertation, I decided to methodologically take a feminist approach for a number of reasons. Firstly, feminist research 'has been at the forefront of challenging the silencing of women's voices in society and research' (Burns & Walker, 2005, p. 66); therefore, it offers a helpful theoretical lens to incorporate into my study which focuses on the stigmatised mothers of children with disabilities in the Slovakian context. Moreover, the feminist methodological standpoint closely aligns with the argument already explored in the literature review that in society the nature of experiences is hierarchical and unjust (Skeggs, 1994). By encouraging to explore the diversity of voices of women or other marginalised groups, this stance enables researchers to capture the full complexity of human experience influenced by social hierarchies and various forms of oppression (Brown et al., 2013). Therefore, the main strength of this approach is that the lived experiences are not presented decontextualised but are rather situated within a particular social location of individuals such as gender, disability, ethnicity or class, all having an influence on their life.

In addition to the intersectionality as one of the main tenets of the feminist methodologies, situated knowledge in regard to the researcher is also considered as the other crucial principle of this approach. Since the feminist approach invites researchers to engage in a critical self-reflection in regard to their own positionality and how it might influence not only the data analysis, but also the whole research design (Saeidzadeh, 2023), they also have space to critically reflect on their own values, beliefs or preconceptions related to their research topic (Wilson, 2023). By contemplating my roles in this dissertation and the knowledge construction process, I have been then able to add to the reflexivity and consequently even greater transparency of my work.

3.2 Research Design

This study used a qualitative survey as its research design. More specifically, since the research question focuses on the lived experiences of mothers, their perceptions of their role and in education and/or society, it was crucial to choose a research design which could allow the participants, in this study context mothers of children with disabilities in particular, to actively construct their own meaning about the social situations they have been engaged in (Cohen et al., 2018). In other words, I made this research design choice for its ability to give my participants the platform to authentically share their own story of raising and advocating for their child with disabilities. Even though the limitation of qualitative research design is that it is not possible to generalise the data to a wider population, it is important to emphasise that it is not even its purpose. Its value lies in its strength to capture the depth and complexity of one's (interpreted) lived experiences (Lichtman, 2023).

3.3 Method

Aligned with the chosen feminist theoretical stance and qualitative research design, I employed interviews for their appropriateness in exploring ones' reality and their interpretation of it (Check & Schutt, 2017; Creswell & Creswell, 2017). I identified semi-structured interviews as the most suitable data collection method because they could give me a useful framework to ensure some level of the research replicability with pre-defined interview themes and sample questions and at the same time a space to promptly react to anything interesting which occurred in the interviews (Creswell & Creswell, 2017; Wengraf, 2001) by probing or asking further questions (Smith, 1995).

Interviews were conducted online and recorded on Microsoft Teams. The online space was determined as the most confidential and convenient environment for already busy mothers since it gave them freedom to decide when and where they wanted to participate if they chose

so. Reflecting on Keen et al. (2022)'s findings on the limitations of online interviews, particularly the necessity of acquiring an appropriate software and possibility that participants might feel distressed being filmed, I made sure that that participants were informed why recording was important, but I also gave them a choice to turn off their camera if that was more comfortable. None of them chose this option and had their camera on. Mothers got the invitation email with the link a couple of days beforehand, so they had enough time to prepare for the interview technically. None of them reported any technical problems with logging in, as they had already used Microsoft Teams in their job or had been required to learn how to use it (or similar software) during the COVID era when everything including their child's education was moved online. Moreover, since my participants preferred to have their camera on, I could take almost the full advantage of visual cues such as different facial gestures (Sullivan, 2012). Interviews were conducted in Slovakia since it was the participants' mother tongue and the language which they were most comfortable to speak in[5].

The interview was divided into 7 main themes, namely (1) mother's background, (2) child's diagnosis, (3) child's educational journey, (4) mothers' response – examples of advocacy, (5) perception of their role of mothers, (6) their satisfaction with the current nature of their role, (7) vision for better education for their children. Considering the sensitive nature of the interview, I started with broad questions (for example, 'Can you tell me about the educational journey of your child?') to allow flexibility for participants to tell their personal stories and then follow-up with probing questions if necessary to allow participants to take some level of ownership over the interview. Please see the detailed interview schedule in appendices.

[5] Since I come from Slovakia and am a native speaker, it was not a problem for me to conduct interviews in Slovak.

3.4 Recruitment of Participants

The participants in this study were recruited through purposeful sampling for a number of reasons. Since this dissertation looked at different ways how mothers had actively sought quality education provision in Slovakia, I decided to engage with formal and informal communities of mothers where I have had access to and observed various instances of advocacy either in person or online in past. That led me to identify three communities where these parents were concentrated: Platforma rodín detí so zdravotným znevýhodnením (Platform of Families with Children with Disabilities), UpDown Syndrome, and Belasý Kolibrík (Blue Hummingbird)[6]. All three organisations are primarily situated in the capital city Bratislava, although Platform of Families with Children with Disabilities is an organisation with a nationwide portfolio.

Since I worked as the CEO in Blue Hummingbird for six years, I first directly contacted parents in this community due to ease of access. I sent them email with the main objectives of this study along with the information sheet and consent form. All information were translated to Slovak[7] to ensure mutual understanding regardless of their English-language proficiency. It was also explained that the interview itself would be in Slovak, so they would not have to be afraid that there would be any language barrier. I also sent them one additional email after the first week to remind them of this research opportunity. Simultaneously, I asked mothers with connections to the other two organisations to share this research opportunity by forwarding the invitation email to any potential participants along with the detailed information sheet and consent form. The sample was limited to mothers whose children were still formally educated, seeking to avoid any recollection biases. In the email and information sheet, it was explained that while this study focused on different forms of advocacy, it was repeatedly

[6] Some parents are active in more than one community.
[7] Since I am proficient in both Slovak and English, I was the one who translated all the documents to Slovak.

emphasised that that can happen on many different levels to encourage mothers to share their diverse experiences. It was therefore explained that this study aimed to look for both macro and micro, often less publicly visible forms of advocacy, since both forms can be impactful in different ways.

3.5 Sample

For this study, I managed to recruit nine mothers; however, I believe it is important to acknowledge that I have personally known eight out of nine of them for a couple of years. Seven out of nine regularly signed their children to summer programmes which my organisation used to organise annually. Therefore, I know not only them, but also their children and in some cases even the whole families. I realise that this could have both positively as well as negatively impacted my study. On one hand, I believe that our relationship helped ensure a safe environment where mothers could share their deeply personal and sometimes even painful lived experiences. At the same time, I would like to believe that the close relationship did not create the impression of obligation to participate. To ensure that, in every written as well as verbal interactions with potential participants, I always emphasised that if they decided not to participate or withdraw at any time, there will be no repercussions. Only half of them decided to take part in study at the end, which might also signalise that the mothers, who were contacted, felt comfortable to reject the invitation if they did not want to participate. Some of these issues are discussed in more detail in the 'Ethical Consideration' section.

All the participants except for two live in the capital city, Bratislava. The other two are situated in a small town in western Slovakia and a rural area in northern Slovakia. These women have achieved a high level of education, as the vast majority of them have completed university. As for their marital status, almost all mothers have raised their children with their

husband (or partners). Only one mother mentioned that she had to raise the child as a single mother. My research participants have raised children with different disabilities[8] and of various age groups (14-23 years old). More specifically, their children have been diagnosed with disabilities such as Down's syndrome, attention deficit hyperactivity disorder (ADHD), organic personality disorder, autism spectrum disorder (ASD), left hemiparesis, semantic pragmatic disorder, etc. All these conditions tend to impact their cognitive[9] and social functionings to at least some extent, in many cases also their physical abilities. Six children have been educated within the special education track of the system while the rest (three individuals) have been educated in mainstream schools, including one young man who is currently finishing university. Therefore, even though there was little variation in the mothers' socioeconomic backgrounds, the unique nature of their children's disability resulted in diverse testimonies. For more specifics about the research participants (and their children), please refer to the table on the following page.

[8] All children have been diagnosed with a disability from the birth/early age.
[9] Seven children in study have been diagnosed with intellectual impairment (usually as a consequence of their main disability such as Down's Syndrome).

Table 3.5 Further information about the research participants

Mother	**Level of Education**	**Child's**	**(Disclosed) Diagnosis**	**Types of Educational Institutions they have attended**
Olivia	University	Milan (M 19)	mild intellectual disability & semantic pragmatic disorder	special kindergarten, then moved to another one, special primary school, practical high school
Charlotte	University	Elen (F 15)	Down's syndrome	mainstream kindergarten and primary school
Sophia	University	Kate (F 13)	intellectual disability and left hemiparesis	nursery, mainstream kindergarten later moved to special kindergarten, special primary school
Camila	high school	Jack (M 15)	ASD	mainstream kindergarten later changed to special one, special primary school
Grace	University	George (M 23)	Down's syndrome, heart problems	special kindergarten, special primary school, social centre for young people with disabilities
Elena	university	John (M 25)	organic personality disorder and ADHD	religious primary school, grammar school, two level of university
Natalie	University	Emma (F 14)	Down's syndrome, heart problems	preparatory year at special kindergarten, special primary school (changed classes) and moved to another special primary school (again changed classes)
Caroline	high School	Simon (M 15)	intellectual disability (with signs of ASD and ADHD)	mainstream kindergarten later changed to several private (mainstream kindergartens), special primary school later changed to another special school in the city
Gabriella	University	Max (M 13)	ADHD	mainstream kindergarten later changed to kindergarten with special class, preparatory class, mainstream primary school

3.6 Ethical Considerations

This study complies with BERA ethical guidelines (2018) and gained the ethical approval from the Faculty of Education, University of Cambridge. Before the interviews, participants were given the information sheet and asked to sign the consent sheet that they agreed to take part in this dissertation (see Appendix 1&2). They received the forms translated to their mother tongue (Slovak) several days before to the interview to allow them to consider the implications of their participation and ask any clarifying questions. All contacted mothers were informed that their involvement in this study was voluntary, and that they could withdraw at any stage of the dissertation. The participants' anonymity was ensured by changing their names, names of their children, schools or other identifiers which could directly associate them with their responses. However, it was also acknowledged that even after this process in some cases it was not possible to ensure complete anonymity since some mothers' experiences might have been so specific and publicly known that their identity could be recognised even after the anonymisation.

Unfortunately, just before the start of my data collection, a tragedy, during which one mother with her child with a disability decided to end their lives and jump under the train, happened in Slovakia. This story was widely publicised on the national TV channels and caused a great level of sadness in the community of parents of children with disabilities, especially mothers, as this incident brought out their own painful memories when they themselves felt alone and helpless in their fight for better life for their children. Therefore, I postponed the data collection to allow my participants and also myself some time to emotionally deal with this tragedy.

As for the interviews themselves, I was well aware of the sensitive nature of the personal, often painful accounts which participants were going to share with me. Therefore, at the

beginning of each interview, I always shared the brief overview of topics we would touch, so they knew what to expect. Before any particularly sensitive question related to their lived experiences, I additionally emphasised that they would not have to answer any question they considered too personal. Moreover, I was also prepared to signpost my participants to available support if anything during the interview triggered negative association that could not easily be mitigated by a break or moving onto another question.

Lastly, being inspired by the feminist scholarship, I took the idea of reciprocity in this dissertation very seriously. Since one mother specifically asked about the option to receive research findings (translated to the Slovakian language) which she and her other colleagues in the Platform of Families with Children with Disabilities could use in their advocacy work, I understood it as a unique opportunity to disseminate my findings in a way which could benefit the community I am committed to serve. All mothers were informed, agreed and supported this intention.

3.7 Data Analysis

I used the thematic qualitative analysis approach proposed by Braun and Clarke (2006), consisting of six concrete steps. Firstly, I conducted a verbatim transcription of all nine interviews after which I repeatedly read the whole transcript. The first reading was mainly focused on ensuring the accuracy and checking for errors in the transcription. The purpose of the second reading was to familiarise myself with the data and observe any potential patterns. Since my analysis was driven by specific research questions, in Phase Two I decided to employ the theoretical thematic analysis, which meant that I coded those sections of transcripts which were relevant or/and offered anything interesting related to the research questions. I performed the coding manually by using highlighters to indicate potential patterns and writing notes on the printed transcript. To keep track of the codes, at this stage I

also created a codebook with all the identified codes. In Phase Three, I grouped together all the excerpts associated with a particular code. Then, I sorted the codes by creating initial themes. As advised by Clarke and Braun (2006, p. 90), I did not abandon any codes which did not fit into the initial themes, but rather created a theme named ‘miscellaneous’ in case my themes would be rearranged in later stages. Phase Four consisted of looking back at the data and reviewing the initial themes to ensure the themes were distinct and had enough evidence to back them up. In the next stage, I created names for my themes, with the aim to capture their essence most accurately. Lastly, based on these themes, I produced the report, providing a logical, yet interesting account of the story which my data was telling. Therefore, in this last phase, I also included vivid extracts which could particularly well demonstrate the essence of my arguments.

4. Findings

This section is divided into five main themes which emerged in the analysis process. The first section about societal expectations from mothers of children with disabilities, provides an important overview of the social context in which the study participants must daily operate. Then, my findings start focusing on education specifically and look at mothers' own desires for their child's education. The third section describes the specific forms of advocacy which mothers of children with disabilities have chosen to ensure better education for their children. Later, I also analyse which factors have influenced their advocacy and its effectiveness. Last but not least, I finish this chapter with the description of how advocacy impacts not only their wellbeing, but also their personal and professional life.

4.1 Social Expectations from Mothers of Children with Disabilities

4.1.1 Social Burden

From the collected data, it is clear that mothers of children with disabilities often have to face unreasonable and attainable expectations to fulfil their role of a 'good' mother which not only influence their wellbeing, but also quality of life. As Sophia explains, it is socially expected that '[she] will devote everything to her (Sofia's daughter), that [she] will cut [her] life and then it will be just her and her (Sofia's daughter)'. In other words, there is simply a perception that mothers should devote their (personal and professional) lives fully to their child. Natalie was even asked by a professional at her daughter's school 'to start [her] own home-schooling class for Emma (her daughter) and ideally a couple of other children, as that would be best for Emma's education'. Olivia concludes that it is socially believed that it should be the responsibility of mothers of children with disabilities to 'cover everything the state is not able to do'. In other words, participants in my study shared a strong belief they are

expected to supplement the role of the state in ensuring that all its citizens, including children with disabilities, have their human rights actualised.

This comes from a common social perception that families of children with disabilities are being an unfair burden to society they live in. Grace shared that she was explicitly 'met with the view that [she] and [her child] represent a burden to the state budget'. Aligned with that, Natalia also explains that she feels 'it is expected from [her] to eliminate any requests so [she] and [her] daughter would cost the state as little as possible'. As a result of this dominant discourse in society, some mothers like Natalie deeply internalise this view and then have an urge to apologise to everybody around them. She explains that 'during the first 3, definitely 2 months after the birth of [her] daughter, [she] felt the need to apologise to everybody that [she] allowed for [her] child to even be born'. This shows that many mothers of children with disabilities have to live with the reality that the society, they are a part of, thinks that they and their children represent too much of a financial burden to even matter to the government. When referring to the state of society and the role of mothers of children with disabilities in Slovakia, Natalie concludes, 'our society wants me to be invisible with my existence since other mothers and I should not bother society with our demands. However, even mothers, who 'decide to continue their career and, for example, employ two assistants for their children, are still judged for their decision to have their own life', adds another mother, Camila. As Grace summarises, 'what is expected of us is sometimes too much – take all these extra roles and still manage our families'.

4.1.2 Push for Normalcy

In addition, children with disabilities and their families are also expected to fit into pre-defined notions of normalcy, putting normative value on what all children should look like and how they should behave. Since some disabilities are associated with distinct visual

features, Sophia specifically describes that she has been ‘met with the view that these children destroy the image of society’. Other mothers also shared that families of children with visible signs of a disability might face even higher degree of stigmatisation and isolation since in their case it is clear that they do not fit into the able-bodied norms.

However, also mothers of children with non-visible disabilities are also expected to ensure that their children do not stand out. Gabriella, a mother of a child with ADHD, explains that society expects from her to ‘tidy up [her] child so he does not stand out from the predefined line’. She further adds, ‘Max’s (her child’s) grandparents think that I hide my child behind his diagnosis. Max has never slept at their grandparents’ house because his grandpa once even said that Max should come for a re-education visit. He believes in a traditional way of bringing up children, with belts, […] I will not let my children get hurt’. Unfortunately, even some educational institutions have shared similar views and considered sending social services to Gabriella’s place and wanted to send Max to re-education centre without any adequate reason. At the end, the school personnel themselves realised they could not do so since he was not a delinquent. Max’s example illustrates an alarming reality that some mothers of children with disabilities are still blamed for their child’s diagnosis. Gabriella concludes, ‘some neighbours think I am disgusting that I cannot raise my child well, […] one of them even sent police to us because Max by accident made a small scratch in our lift’.

This example, therefore, shows that such societal expectations and beliefs can also be translated into specific behaviour with the aim to explicitly punish these parents for their child’s disability, something which they do not have control over. Unfortunately, this finding was also generally supported by mothers of children with non-visible disabilities. Reflecting also on the tragic incident which happened a couple of weeks before the interviews, Camila sadly concludes, ‘maybe what mothers of children with disabilities really need is to see our

society not making hurtful assumptions about them and their children, but finally asking them about what they really need'.

4.2 Mothers' Own Idea of Quality Education for Their Children

4.2.1 Academic Objectives

When asked about their vision of quality education for their children, mothers in my study agreed that a good education should support their children in achieving a certain level of independence and self-sufficiency. They do not necessary view full inclusion in education as the right path to focus on. Although three mothers had children in mainstream schooling and expressed the desire for full inclusion, the majority did not think that it was possible in current circumstances. Being aware of the severe deficits of the current education system (and society), they explained that the Slovak education system is not prepared for full inclusion. More specifically, they identified lack of financial and human resources as the main obstacles. All of them strongly emphasised the need for more assistants who could individually work with their child. Elena further explained that 'it is important to ensure the availability of assistants for also highschoolers, who do not currently have access to them'. Other mothers also mentioned that it is necessary to get more SEND teachers, psychologists and other special personnel to the system since as Elena explains, 'sometimes there is 1 psychologist for 700 children'. In addition to the insufficient amount of financial and human resources, five mothers also talked about structural problems such as the poorly thought-out structure of support mechanisms (including diagnostics as well as psychological and logopaedist interventions), forcing mothers to place their children in the special education track.

Since specialised personnel is mainly concentrated in special schools where children are also educated in smaller classes, Olivia understands why it was recommended enrolling her child

in one such school. As teachers are the ones who directly interact with children in the education system the most, it is first and foremost crucial that they are adequately trained to be able to support all children in their learning. While all mothers agreed that teachers in special schools are much better prepared to work with children with disabilities, Caroline critically explains that 'nowadays when there is a shortage of qualified teachers, many teachers who come to special schools has only had experience in mainstream schools, and thus they do not know how to work well with children with disabilities'. Sophia also adds that teachers in schools 'should have better opportunities for professional development similar to other professions where it is normal to consistently expand one's knowledge'. For example, Elena specifies that being a mother of a child with disabilities as well as a teacher she is particularly missing didactic (practical) resources on how to teach specific subjects. Unfortunately, there is also another problem which are the attitudes of some teachers. Grace provided her personal example when she found an innovative way to teach maths to children with special needs and then invited teachers for such training, but they were not interested to even learn about this innovative practice.

Therefore, being aware of these structural, organisational, and financial limits of education system in Slovakia, many mothers might think that special schools are the right place for their children, although Natalie critically adds that some of these problems could be solved with a more effective budget distribution. Nevertheless, generally speaking, most mothers in my study have taken the pragmatic approach and placed their child in special school as they did not believe that full inclusion in current situation would ensure better education for their children.

4.2.2 Non-academic Objectives

Natalie, a strong advocate for inclusive education, however, challenges the academic purpose of education and argues that it should not only be about the performance and particular knowledge, but also about social skills and exposure to diverse groups of children. She specifies that 'there is a high level of segregation and isolation of children with disabilities in education system and society […] since there is a particular perception that they would not bring any benefit for their peer educated in mainstream schools, […] our society has never heard anything about the benefits of peer learning'. Charlotte, who has placed her daughter in a mainstream school in their town, further adds that she has done so because she simply wanted for her daughter to be educated in her natural environment with children she was raised with.

While most mothers would appreciate some level of inclusion in subjects like PE, art, music, they are still worried that placing their children in the mainstream schools would have negative impact on their wellbeing. Grace and Camila, for example, expressed worries about bullying. Both of them have a very sensitive child who has problems with asserting their opinion, and thus they realise that their child's personal characteristics might make them an easy target in school, especially when considering that bullying is a very frequent problem in the Slovak education system in general. However, Grace raises another interesting point related to safety by emphasising that even in special education there might be a problem with violence. To illustrate her point, she explained that in her son's classes there was a boy whose disability was characterised by frequent behaviour problems which scared her son to the extent to which he stopped talking for some period of time. Despite this experience, she and most other mothers believe that special schools can still ensure a higher level of safety and social belonging for their children. Therefore, taking into consideration both academic and non-academic factors, my study participants are convinced that inclusion might be an

overestimated concept without any particular benefits for their child in the Slovak educational context.

4.2.3 Importance of Cross-Sectoral Cooperation

In relation to quality education for their children, my participants emphasised the importance of the symbiosis of education with social services, healthcare and employment market considering the specific, and often complex needs of their children. Since a lot of children with disabilities may also have physical impairments which may require frequent physiotherapy sessions or regular doctor appointments, mothers of these children in my study emphasised the need for better healthcare services since their children's physical health also indirectly influences their ability to actively participate in the education process and have quality life after school. Similarly, some mothers also explained how important it is to strengthen the social support services provided by the state. Olivia explains that she recently talked with a single mother who lived off only minimal state financial support and was desperate about her life situation. It illustrates that without adequate social support some mothers of children with disabilities have to also think daily about how they can survive the next day, week or month, and they do not have resources nor the capacity to support their child in their development.

In addition to that, the most pressing problem which mothers identified has been the inability of the current education system to prepare these children for the labour market. More specifically, participants in this study particularly mentioned that vocational education does not properly consider the needs of the market and the potential of their children as it offers very limited, often irrelevant knowledge, skills, or experience to succeed. The other related problem is the unpreparedness of the labour market itself to include young people with disabilities. Though there are a couple of supportive companies which employ a number of

young people with disabilities, there are just a few tens of young people who have got this opportunity. Therefore, since there are almost no opportunities created for these people to be included in and contribute back to society, it also creates this unfortunate vicious circle of (nonsensical) dependency of people with disabilities on the system which could be avoided. Hence, there is an interesting paradox - society perceives people with disabilities as a burden, yet it does not support them to be independent.

4.3 Different Avenues of Mothers' Advocacy

Considering the limitations of the Slovak education system and the whole society, participants in my study often have to find different, creative ways to advocate for their children (sometimes even others) to ensure they are able to receive better education and life. From the collected data, these advocacy efforts happen on three levels: classroom, school, and wider community level.

4.3.1 Classroom Level Approach

At least half of the participants explained that what truly matters in education is the teachers of their children as they are with them the most. Therefore, mothers in this study consider a good parent-teacher partnership as an important element of quality education. Charlotte and Elena clarify that there have been many instances when they had to advocate for more effective communication as it had been incredibly difficult to support their children in learning after school without it. As Sophia honestly adds, 'many children with disabilities might not remember everything from the day, do not have notes or cannot replicate what has happened in the class, therefore it is crucial to be able to easily contact the classroom teacher to ask them about any missing information.

However, as some of them emphasised, it has not been easy to achieve that level of cooperation with teachers. Grace has already mentioned that her advocacy efforts to

incorporate more innovative learning methods in maths were simply not acknowledged by the teachers, which then urged her to 'play their (her son's teacher's) game, because it had just confused him to learn it differently at home'. Regarding effective communication, Elena and Charlotte shared that continuous reassurance of teachers that they as parents are there to also help them to make their work easier has proven particularly helpful. Unfortunately, that was not effective in all situations. In such circumstances, Charlotte decided to invite an external professional, SEND teacher, to her daughter's (mainstream) school, so they could validate her points and support her in her advocacy activity for her child. This strategy has proven to be effective also in Olivia's and Elena's case.

4.3.2 School Level Approach

Unfortunately, a lot of mothers were also forced to engage in advocacy even on the school level, for example, when the school management in their respective schools wanted to place their children in different classes to further segregate them. For example, when the mainstream school wanted to create a special class just to segregate Charlotte's daughter from her peers, Charlotte had to continuously advocate for inclusion, though as she admitted 'it was hell to always fight with the school management to the extent to which no one can really imagine'. Similarly, Gabriella also experienced a very unpleasant parent-teacher meeting just to hear in front of other parents that her child with ADHD misbehaves and should be simply expelled[10]. Knowing the complex law and all her child's rights, she succeeded in her efforts to preserve her child's enrolment at that school; however, Natalie and Caroline had to move their children to a new school at least once to accommodate their learning needs adequately. Moreover, it is important to realise that in Gabriella's case, or even when Camilla successfully advocated for better adjustments during COVID-19, these

[10] Child's pedopsychiatrist was horrified to hear that. Luckily, child's classroom teacher was changed, and child's behavior has been improved. He has even recently received an official praise for his good behaviour from the headteacher.

mothers have still needed to often bear the long-term negative consequences of their advocacy as they were frequently slandered or purposefully ignored in their child's school as the punishment for fighting for their children.

4.3.3 Wider Community Approach

A small group of four mothers have been also active in collective advocacy work. Years ago, Grace decided to co-found a non-profit organisation for families of children with Down's syndrome. This organisation does not only serve as a place of support in their everyday struggles, but also as an inclusive community which runs an experiential theatre and organises summer camps where children can go without their parents. Therefore, it allows young people with disabilities to experience not only exciting extra-curricular activities, but also independence.

Furthermore, Olivia (and to a smaller extent also Natalie and Charlotte) are employed in a large national platform for families of children with disabilities which advocates for systemic change in education, healthcare, and social services. The portfolio of their initiatives is amazing and since they 'as a collective have a bigger power; [they] are now even invited to participate in various working groups at the Ministry of Education', Olivia explains. However, to be more effective in her advocacy during the working group meetings, Olivia had to learn about the importance of bringing other partners who can support her demands such as the Association of Teachers or the Ombudsman for People with Disabilities who can make her voice heard even more. During our interview, she strongly emphasised the strength of the collective advocacy by explaining how much she wants 'the quality education for children with disabilities not to be a question of money or luck, but simply common standards for all'. Therefore, when she took her son to write an external test to be able to finally receive the ISCED 2 certificate (for what she successfully advocated for), she 'felt a great level of

satisfaction as [she] could witness many young people finally having the chance to receive this certificate even if they attended special schools'[11].

4.4 Factors Influencing Mothers' Advocacy

Unfortunately, mothers admitted that in the current deeply flawed system in Slovakia, it is the economic, social and cultural capital which often enables them to start and be successful in their advocacy work.

More specifically, Elena and Caroline explain that even the process of them learning appropriate information about their sons' diagnosis and different available interventions required a huge amount of personal financial resources. Moreover, Grace, Natalie and Sophie also add that since they have been forced to supplement the state to secure quality support for their children, they had to invest a considerable amount of their family finances to able to access private practices. For example, since Natalie's daughter who could greatly benefit from speech therapy, lost access to a speech therapist at school, Natalie mentioned that she was then forced to cover private sessions which cost 74€ per hour to support her daughter in her further development. Elena also adds that some parents in special cases cannot even afford the psychological diagnostics which can go up to 200€ in private practice.

Sophie and Grace have also benefitted from strong social networks which allowed them to access the needed information more easily at the early stages, after learning about their children's diagnosis, setting the necessary foundations for their further development. In relation to the educational journey in particular, mothers' social connections could even help their children with the admission to particular institutions, as it was in Olivia's son's case, or with successful progression to further levels of education in Gabriella's and Charlotte's cases.

[11] As explained in chapter 1.2, children with intellectual impairment educated in special as well as mainstream primary schools can only receive ISCED 1 certificate (equivalent to the first 4 years of mainstream primary school). However, this external test now enables them to get the ISCED 2 certificate if they pass a certain score threshold.

A degree in education as the important form of cultural capital has also proven to be particularly helpful in effective advocacy. Elena, Charlotte, Gabriella and Natalie, being experienced trained teacher, not only clearly understand the reality of the Slovak education system, but also know their children's rights and how these rights can be actualised. In particular, the first 3 of the mentioned mothers were very vocal about how their complex pedagogical and educational legal knowledge have made prepared to fight for their children in their individual cases. From the gathered data, it also seems that thanks to their profession these mothers also knew how to more effectively communicate with their colleagues in their child's schools. They tended to be the one who used the language of being partners who are there to help not only their children, but also the teachers.

In achieving a systemic change, Olivia on the other hand could draw from her legal education background. She specifically explained that a couple of years ago when becoming more and more aware of the profound legal disparities in the Slovak education system, especially in relation to children with disabilities, she started to collect different legal material with the intention to gradually build a legal case which would support improvement for these children. Moreover, she has been able to use this unique experience and knowledge when she now participates as a representative of the advocacy organisation at different national forums. In other words, since her background allows her to more easily navigate the legal language in the context of children with disabilities, she can more efficiently advocate for reforms in the system to improve it.

4.5 Impact on Professional and Personal Life

When asked about how having and supporting their child influenced their lives, while emphasising that raising a child with disabilities has had a positive impact on their life, they also acknowledged that their professional and social life had to be largely adjusted as well.

More specifically, Elena and Grace started working after taking a long break of as much as five years and they still had to adjust their working hours so they could support their child. For example, Elena explains that she could only accept positions with flexible working hours which do not require her to work for 8 hours daily. However, it has not been a possibility for all. Mothers like Olivia, who used to be a single mother when her son was younger, used to be forced to take very precarious positions to provide for their family. She explains, 'being a single mother at that time, I also had to take on and stay in a job where my employer knew I really needed this job, and thus he frequently sent my salary late or even every other month'. Even though, Sophia continued working full-time directly after giving the birth, she still counts with the fact that she might have to stop working soon since there are no institutions for adults with disabilities which could adequately support her child in her further development.

Furthermore, mothers also often feel a great level of isolation following the birth/diagnosis of their child with disabilities. Sometimes, it might be even situational, as it was in Grace's case, when she and her husband had to be fully focused on and be mindful of their son's health, recovery and then long-term physical limitations. Unfortunately, Camila and Elene shared that they have lost some of their friends simply because they spread false rumours about their children and them, claiming that they are not 'good enough' mothers. In Natalie's and Gabriella's case, even their own family made them feel like they were all alone in their efforts and judged them for not being able to 'properly' raise their child. Therefore, in general there still seems to be a trend that mothers are being scrutinised by their community and the society regardless of what they do. Moreover, it was acknowledged by most of my participants that without great support from her husbands and family, it would have been more complicated for them. However, they explained that the complication is not the fact that they have a child with disabilities – Camila even specifically explained that having his son

has transformed her and her family life for better – but the structure and standards of our ableist society.

5. Discussion

The findings from this study will provide important insights into the mothers' lived experiences of advocacy for their children with disabilities on different levels in the Slovak education system. To situate these findings within the larger body of literature, this discussion will particularly draw from the feminist and disability body of knowledge. First, I will explain how a cultural narrative of neoliberalism with its emphasis on independence and economic productivity, pressures mothers to supplement the shortcomings of the state's welfare system. Considering the social and educational barriers in society, I argue that these mothers then understand it is their role to fight for resources and support for their children with disabilities. To do so, they perform small as well as big acts of resistance, however, as it will be critically analysed, cultural capital seems to be a significantly empowering factor, which might advantage certain groups of mothers.

5.1 Mothers within the Cultural Narrative of Neoliberalism

The overarching finding across all interviews was that in Slovak society children with disabilities are perceived be a burden to the government since they strain the whole system of a large amount of financial and human resources. Tabatabai (2020) describes that currently in the world with its neoliberal emphasis on self-sufficiency, the ultimate goal of good parenting is understood as raising independent economic producers. However, many children with disabilities (due to both medical as well as social factors) might never be able to become as economically productive as their able-bodied peers and might even end up requiring intensified support as they grow. In this context, mothers of children with disabilities are expected to step up and take on the responsibility to fully supplement whatever the system fails to provide. This social inclination to pass its responsibility to mothers was nicely illustrated by Natalie's example in chapter 4.1.1, when she described that she was

recommended by a professional to start a home-schooling for her child and also other children with disabilities. These unreasonable expectations are further reinforced by the structural challenges in the Slovak education system and society, including lack of financial and human resources, inadequate teacher education, discriminatory legal framework (Hapalová, 2019) and lack of cross-sectoral communication between health, social and education departments critically illustrated in chapter 4.2.1.

In the context of England, Thomas (2021) explains that those mothers, who claim the support within this anti-welfare austerity environment, become an easy target of shameful and blameful configurations, similar to other marginalised groups in society who do so (Scambler, 2020; Shildrick, 2018; Tyler, 2020). Furthermore, many of them also feel undermined and stigmatised by the very institutions which should serve them and their children (Thomas, 2021). Additionally, it is important to emphasise that neoliberal restructuring alongside the budget cuts tends to leave even middle-class mothers now struggling. Participants in my study, the middle-class mothers, specified that even though they understand that they are in a privileged position compared to mothers from lower socio-economic backgrounds, they admit it is difficult even for them to financially support their children in their development when the state fails to do so. Mothers conclude by saying that current policies create a vicious cycle: although society values independence and economic productivity, it does not provide young people with disabilities with adequate opportunities to find employment which they and their families really wish for.

5.2 Intensive Mothering - Mothers of Children with Disabilities

As a consequence of previously described social and cultural narratives, mothers of children with disabilities tend to engage in intensive mothering practices, which ‘are often too much to handle’, as most mothers in this study explicitly shared in their interviews. As Sousa (2011)

adds, this cultural narrative currently requires mothers to take the role of warrior-hero being relentlessly there for their children. This social expectation of being the saviours in any (even impossible) circumstances has been also prevalent in other studies (see for example, Blum, 2007; Douglas, 2014; Singh, 2004), which likewise conclude that mothers of children with disabilities can be currently perceived as the imaginary cure for their children that does not exist.

However, as Gabriellia emphasised on the example of her son with ADHD, it is not possible to reach these unattainable standards of good motherhood, which has led to questioning of her parenting style and ability in general. Therefore, it seems that the perceptions related to invisible disabilities tend to create particularly difficult situations since children diagnosed with them do not appear any different from their peers, thus people in their community might wrongly interpret child's disruptive behaviour as their deliberate choice (Courcy & des Rivières (2017). In this study, testimonies of those mothers (Gabriella, Elena, Caroline) whose children have invisible disabilities collectively supported this finding and further illustrated that as a result of this they have often become more isolated and in two instances even blamed for their inability to 'properly raise' their children. While one mother (Sophia) of a child with invisible disabilities did not share the same experience, she explained that it is due to the calm and gentle nature of her daughter's personality. Therefore, it might not be accurate to use the visible/invisible disability dichotomy, as not only each disability has its own symptoms but also each individual with a disability has their own personality. In this specific circumstance, it seems that by invisible disabilities previously mentioned studies meant specific disabilities, such as ASD or ADHD, which tend to be most closely associated with impulsive, sometimes disruptive behaviour; however, even then it is important not to generalise any disability and rather focus on the particular symptoms.

5.3 Advocacy – Small and Big Acts of Resistance

Mothers in this study demonstrate that even in this unwelcoming and stigmatising environment, they actively engage in different practices to fight for their children. In the context of New Zealand, Blum (2007, p. 205) describes mothers of children with disabilities as 'vigilantes' in a fight for support for their children as they challenge the pre-defined notions about the 'ideal' mothers. Mothers in my study similarly decided to move from the narrative of them as saviours who silently accept the responsibility to compensate for anything the state does not provide. They predominantly focused on micro-level initiatives (classroom and school level initiatives) compared to the large-scale system campaigns. Similar to Ryan & Runswick-Cole (2008) as well as Wright and Taylor's findings (2014), in most cases their effort was temporary as it aimed to initiate a specific change in their individual case after which they withdrew or focused on something else.

In regard to the effectiveness of mothers' initiatives, this study showed slightly opposing findings since micro- as well as macro-level initiatives proved to be both effective and ineffective in achieving the change, depending on the specific cases. However, aligned to Parish & Whisnant (2006)'s conclusion, advocacy at the macro-level has been more effective in challenging the status quo and enacting structural changes which positively impact the lives of mothers and their children on a larger scale. Mothers who were members of parental organisations focusing on rather large-scale policy initiatives believed that they were in the better position to reform welfare and educational laws and thus enact institutional changes for all (Oh, 2023). Law et al. (2002) found out that the effectiveness of collective action in particular might be also associated with the enhanced collective sense of power and legitimacy as a result of mothers' participation in these organisations. However, in this study, although mothers who engaged in one specific organisation, Platform for Families of Children with Disabilities, shared the same experience, Camila and Elena described that they

had to leave a parental organisation since they became a subject of judgemental and supportive reactions there. Therefore, considering these unclear results, it would be beneficial to further investigate how the nature, structure and the dynamics in these organisations impact the effectiveness of their collective action, aiming to challenging the institutional status quo in particular. However, at the same time, it is important to also understand both small and big acts of resistance as continuum of actions influencing and building on each other. Unfortunately, it was out of the scope of this study to investigate the larger impact of mothers' individual advocacy behind their immediate circumstances, therefore, it is difficult to make any conclusion about the multiplier impact at this point.

5.4 Cultural Capital of 'Effective' Advocates

With regard to the advocacy effectiveness, this research highlights that there are certain individual characteristics which enable mothers to be more effective in advocating for their children. In particular, mothers in my study explained that their cultural capital had an empowering effect on mothers' ability to initiate a positive change. Similar to the study conducted by Taylor et al. (2019) in the U.S. context, mothers relied heavily on their professional and educational backgrounds. More specifically, those having professional background in education and law described that they were better equipped to advocate for their children in educational settings. Aligned with the findings in the U.S. context (Trainor, 2010), mothers with high cultural capital had a better perception of the implicit norms when communicating with teachers and other school senior management. Charlotte, Elena, Natalie, all of whom have a background in education, emphasised that they tremendously benefited from their professional experience and could effectively communicate with their child's teachers. The importance of effective communication was also highlighted in Stoner and Angell (2006), where mothers with these qualities were more successful in bringing out the positive change for their children. The four mothers in my study explained that when

approaching their children's teachers, it was particularly helpful to emphasise that they are there to help not only their children, but also their children's teachers – they wanted to be their partners; however, they acknowledged it was not effective in all cases. Therefore, it would be worth investigating what exactly makes the communication with educational professionals effective.

Furthermore, mothers with high cultural capital also knew how to navigate the system better. Yosso (2005, p. 80) named this resource as navigational capital – 'skills of maneuvering through social institutions', which mothers in this study directly associated with the in-depth understanding of educational laws and processes. Similar to other country contexts (Dinnesen & Kroeger, 2018, Mandic et al., 2010, Trainor, 2010), official legal documents in Slovakia are quite inaccessible for most parents since they tend to be written in a specific, hardly accessible language. As it was shown in the studies in the U.S. (Rossetti et al., 2021) and South Korea (Oh, 2023), mothers who do not have this specific capital have to undergo additional preparation to learn the professional language characterised to specific institutions to be able to build effective advocacy strategies. Mothers in my study, predominantly from middle-class background, repeatedly emphasised that they understand that they are in a privileged position since the others from lower socio-economic backgrounds face even bigger obstacles. Unfortunately, this finding does not come as a surprise since various studies have already analysed in detail how parents from, for example, linguistically diverse backgrounds have a very limited access and resources to engage in their child's education (Harry et al., 2005).

Moreover, aligned with Rossetti's study conducted in the U.S. context (2021), mothers in my study clearly acknowledge that the amount of knowledge and skills which they have to master for their advocacy work is excessive, making them even adjust their professional life to become the 'disability experts'. More specifically, all except Sophia who had an enormous

support from her employer, had to suppress their professional ambitions to be able to support their children. Some had to quit their jobs, others deliberately opted for exclusively part-time jobs or looked for job opportunities in their children's schools. Similar to findings in my study, Lutz et al. (2012) and Smith-Young et al. (2020) explain that advocating for their children has also required mothers in the context of the United States, to have a lot of flexibility since appointments in schools were often scheduled at short notice and/or inconvenient times, which was incompatible with many professions. As a result, mothers of children with disabilities tend to be forced to make enormous, unreasonable professional and personal sacrifices to completely devote themselves to their children, especially when they decide to actively fight for better support for them, their families, and children with disabilities in general.

6. Conclusion and Further Recommendations

This study has shown that disability in Slovakia is perceived purely in deficit terms, as a condition creating a burden for society. In the current neoliberal society, mothers are the individuals who are often not only blamed for their child's behaviour and limitations, but also expected to take full responsibility for raising and educating their children. Furthermore, they are simply expected to be satisfied with status quo and not to request any additional help from the state. Even though all children in my study did have access to education (though usually special schools), these places are often not adequately prepared to provide for students with diverse needs, even if the place is a special school. Having experienced discriminatory practices at their child's school, mothers in my study decided to improve the conditions for their children by advocating on micro and/or macro-level. Since most of them had a background in education or law, they had the needed cultural capital, enabling them to not only navigate the complex institutional process and systems smoothly and confidently, but also communicate effectively with the professionals in different settings.

Since achieving proficiency in professional language has been identified as challenging, yet at the same time critically important for the success of mothers' advocacy efforts, it is important to think about the ways how to empower even mothers who come from lower socio-economic to be able to access information related their child's rights and available services. Therefore, there should be a bigger emphasis on making information related their child's rights and available services accessible for mothers from all backgrounds. It is not to assert that all mothers should be engaged in the advocacy; however, they should have a choice to be involved if they decide to do so. However, those responsible for disability and education legislation and policy implementation should not burden the mothers completely and require them to alter their personal and professional life to fight for their children (and other children with disabilities). To conclude, mothers should not be put into the position of

the imaginary, often unattainable position of superheroes compensating for the role of a failing welfare system but should instead be given the opportunity and support to choose the definition of motherhood they wish to identify with by themselves.

7. References

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