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Exploring Visions of Inclusion:
Women's Disability Activism in Georgia

CEERES Master's Thesis

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Acronyms and Abbreviation

CRPD – Convention on the Rights of Persons with Disabilities
CSOs – Civil society organisations
DAOs – Disability advocacy organisations
DPOs – Disabled people's organisations
NGOs – Nongovernmental organisations
SOPs – Disability Service provider organisations

Abstract

This thesis aims to investigate the intersection of gender and disability rights activism in The Republic of Georgia by focusing on the narration and gendered experience of women disability activists. Since the ratification of the CRPD, disability in Georgia has been studied by looking at the discrepancy between disability policies and disabled people's lives, pointing out the poor policy implementations, lack of human rights-based services and negative attitudes towards people with disabilities. These studies have not or only to a limited extent grasped grassroot activism around disability in Georgia. I used in-depth semi-structured interviews with 12 women disability rights activists, researchers, and professionals to investigate the gender implications of disability advocacy. Disability advocacy in Georgia is a feminized sphere, mainly due to mothers of children with disabilities being the strongest voice among disability NGOs. Gendered expectations of women as traditional "carers" of society have not only pushed women into civil society activism and disability service provision, but also made it difficult to disentangle disability rights struggles from the notion of care. Disabled women activists, however, have been marginalized within disability activism in Georgia, experiencing a dual discrimination as women and disabled. Nevertheless, disabled women activists have begun to form a social group consciousness, pointing out their own oppression form both paternalistic and patriarchal practices that prevail within disability rights activism and organisations.

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1. Introduction

Disability issues have increasingly been looked at through a social justice lens, recognizing that disability is not an individual medical problem, but a problem caused by social oppression. This approach emphasizes societal, cultural, economic, and political structures which discriminate against people with disabilities and thereby violate their human rights. Women disability activists in Georgia have increasingly taken up this paradigm shift in framing their claims. In doing so, they put themselves in line with the global disability rights movement which has been promoting a social model of disability. The social model approach identifies the social construction of disability by distinguishing impairment (the arguably biological condition) from disability (society's response to impairment).

Women-led disability rights activism and advocacy in Georgia has proven that women's activism has the power to achieve social and political change. Despite all the difficulties and the consensus among all respondents that not enough has yet been done to achieve inclusion as understood by the UN Convention on the Rights of Persons with Disabilities (CRPD), many interview respondents working in the field of disability either as professionals or activists positively assess the achievements of disability advocacy over the past two decades. And yet, the disability rights movement is only beginning to foment. Currently, it seems that its future depends on whether women activists will be able to find allies in the government, advance their cause in society and academia, and unite the currently scattered disability organisations under the human rights approach.

This dissertation aims to study the intersection of gender and disability activism in Georgia. In other words, we will look at the broader intersection of women's agency and the struggle for social justice transformation from a disability perspective. To address this topic, the following set of research questions was used: (1) How do women narrate their activism in the field of disability rights? (2) What role does gender play in disability activism? And, (3) what are the implications of women's disability activism in society and for the affected people?

Intersectionality helps to explore "locations of oppression and marginalization" where they are not obvious at first sight (Sarah Woodin, 2014:88). Looking at more than just one social category (e.g., disability and gender) can uncover experiences of marginalized groups and individuals. It can also disclose the way how different oppressive systems reinforce each other and create a new system of oppression. As Goodley put it, "[i]ntersectionality is not simply about bringing together these markers but to consider how each supports or unsettles

the constitution of one another. Intersectionality seeks to explore convergence and divergence of multiple markers" (Goodley, 2013:636).

It has been noted that disability affects women, especially in transitioning countries (Shakespeare, 2005; Mete 2008). Disabled women are more stigmatized and excluded than disabled men (Makharadze, 2020). Simultaneously, on-disabled women are more affected by the socio-economic implications of disability than non-disabled men, if one of their family members happens to have an impairment (Philpott, 1995; Phillips 2009, 2011; Mete, 2008). In the Georgian context the amount of grassroots disability initiatives and NGOs led by non-disabled women is remarkable, (especially when compared to the number led by non-disabled men). These women activists are often mothers of children or adults with disabilities and have established active networks in civil society. At the same time, disabled women activists face gender-based discrimination within the disability movement which affects their access to resources and their influence within disability organisations. Yet there is little empirical knowledge about how these women activists, both non-disabled and disabled, organize themselves, what their visions of inclusion are, and what the gender specific implications are for the society, the affected people, and the political reality that mothers represent the strongest voice in grassroot disability rights activism in Georgia.

I use the women's dominated civil society sector in Georgia as a framework to understand the gendered dimension of disability activism. Using qualitative interview data with women disability activists in Georgia, this inductive study contributes to the growing body of empirical works around disability in Georgia, taking women's self-organisation and grassroots perspectives into account.

People with disabilities were described as one of the most vulnerable groups in Georgia (Public Defender, 2019), because state disability services are limited and access to resources of predominantly patriarchal and hierarchical informal networks is difficult for people with disabilities. However, networks mainly cultivated by women have expanded and professionalised around disabled families and individuals over the past two decades. Women have founded service provider organisations and disability advocacy organisations alongside with information centres, support groups, etc. aiming to improve the everyday life of disabled children, adults, and their carers (mostly mothers). Simultaneously, in recent years, women with disabilities have been forming their own group consciousness out of which a few disabled women's organisations have emerged. In Georgia, these initiatives are minimally if at all supported by governmental funds (except for service provider organisations) and often rely on unpaid work of women and mothers. Their main goals are to promote social and professional

inclusion, independent living, accessible environment, and better medical treatment for people with disabilities – objectives that are in line with the rights set out in the CRPD.

Since the ratification of the CRPD in 2014, the Georgian Public Defender (2015, 2016, 2017, 2019) and human rights organisations (UN Women Georgia 2022, UNICEF, 2016) have increasingly published reports on the human rights situation for people with disabilities. The reports shed light on the discrepancy between the rights on paper and the lived reality of people with disabilities, often finding that the state fails to provide the necessary services and to protect the rights. Such human rights reports on disability are important, as they examine access to health care, public spaces, independent housing, education, and employment, focusing on the government's responsibility to provide these rights. Other research by the disability centre of the Tbilisi State University has taken new approaches to focus on people with disabilities' needs and used gender as a factor to understand the dual discrimination of women with disabilities (Tamar Makhaladze, 2020). These approaches alone, however, do not capture a holistic image of disabled people's and their allies' experiences. Disability activism and organizations in Georgia have so far represented a gap in the English-language literature.

In this dissertation, I begin with laying out the existing literature on women's activism in the civil society sector of post-communist countries, highlighting the challenges women have faced in transitioning societies and their responses through NGO work. Second, I provide an overview on the evolution and interaction of disability studies and disability rights movements that is important for conceptualizing disability. I then provide a short introduction into feminist disability scholars' critique of the category of care that is important for understanding disabled activists' debates around interdependence. Next, I aim to describe how disability is responded to in the Georgian context while providing an overview of desk research, reports, and empirical data conducted in this study. Last, I present the analysis of the interviews conducted with 12 women disability activists and experts in the field. The analysis focuses on the narration of women's activism, their visions of inclusion, and gender-specific challenges of their work.

2. Women and civil society in Georgia

Understanding the gendered aspects of transition after the fall of the communist regime, the economic and social challenges for women, their ascribed gender roles in society, and women's responses to this through civil society activism is an important prerequisite for understanding the narratives of women disability rights activists who speak in this research.

The concept of civil society has been theorized by a wide range of scholars with regards to the specific implications in post-socialist countries (Alyiev, 2017; Bernhard 2020; Howard, 2002; Phillips 2005). Civil society in the Western world has been described as an independent sector located between the state and the free market (Cohen and Arato, 1992). From this standpoint, civil society is expected to keep the state in check and strengthen democratization. Under communism, an independent sector from the state did not exist as the state party controlled every sphere of public life. Phillips (2005:498), however, argues that this might have led to the emergence of the "ultimate" or "proto" civil society located in the private sphere through Soviet-era networks of relatives, acquaintances, and kinship providing families and individuals with goods, services, and information that were not provided by and out of reach of the state. Alyiev (2017; 2015) however, argues that the legacies of these Soviet networks are in fact not necessarily "civil", but rather hindering the consolidation of a democratic state and the establishment of strong state institutions. Nowadays, the practice of informal networks that is widely spread among the entire Caucasian region are undermining civil society development as they hinder people "to engage in collective action or to join NGOs because informal networks provide all the social capital that they may need" (Aliyev, 2015:204). The informal networks themselves, however, have a strong top-down dynamic resulting in unequal distribution of resources and the embracing of patriarchal structures, clientelism and corruption (ibid., p. 206).

Nevertheless, many of the informants to the present study stressed that personal informal networks (such as good relationships with doctors, professionals, other parents of children with disabilities, and personal connections abroad) were crucial for establishing their own interest groups and organizations that later became part of today's NGO sector in Georgia. Alyiev's study on the use of informality in Georgian NGOs has shown that, on top of that, informal networks are crucial tools for securing grants, accessing resources, and obtaining influence in decision making bodies (2015b).

Tocqueville (2002) argued that the state power represents the majority, whereas the minority is left with the civil society sector, a vital space where united citizens put forward their claims to the public and the political sphere. Others have questioned this assumption (Doyle, 2018; Phillips, 2005). In accordance with Phillips, I use a cautious approach to civil society theory to understand the multi-layered environment in which disability rights activism in Georgia is embedded:

> "Detailed studies of civil society institutions […] have questioned the romanticism of the 'grassroots,' exposed the less than altruistic motives of many NGO activists, critiqued donors' practices, questioned the clear-cut distinction between public and private spheres that much civil society theory assumes, and disputed the assumption that civil society necessarily constitutes a non-state sphere" (Phillips, 2005:499).

Civil society is indeed not an entirely independent and democracy promoting space. Conditions attached to funding, co-option by the state, low social capital, and associational participation in post-communist societies are issues that were also raised among disability rights activists in Georgia interviewed in the present study. Jessica Doyle (2018) raises the relevant concern that civil society organizations might not always serve the interests of the citizens, but rather be used as a henchman of the state. Therefore, she argues, further "micro-level" studies are needed in the field of civil society activism.

After Georgian independence in 1991, Western politicians, international organizations, and scholars saw the budling of a vibrant civil society sector as essential for a successful transition to liberal democracy. A lot of Western funds, expertise, and expectations have therefore been invested in Georgian civil society building, especially in NGOs, at the expense of other groups and institutions. The euphoria that resulted in a veritable civil society transplant (or export) often overlooked the local conditions in which organisations and activists were or are working in Georgia. Local obstacles to building a flourishing, democratic civil society in Georgia are, as mentioned above, informal networks, practices of patronage, political apathy, and public distrust towards formal organisations (Howard, 2002; Alyiev, 2017). Even though the concept of civil society is not congruent with NGOs, international donors have favored NGOs as they have been perceived as the "connective tissue of democratic political culture" (Jane Wedel, c.f. Ishkanian, 2004:263).

In 2011, Transparency International estimated that there were 10,000 NGOs working in Georgia (cited in Ritvo et al., 2013:13). It is difficult to say how many of them are functional, however, it is believed that many registered NGOs are inactive or perceived as disconnected from society (Ritvo et al., 2013). Many people in Georgia (19% according to a survey by Ritvo et al., 2013) believe that the NGO sector exists for a self-serving purpose and uses grants to enrich and employ the NGO workers and their families but have no societal impact beyond the people directly involved. Many do not know what NGOs do and cannot distinguish them from governmental institutions. This mismatch of NGOs and their target group is also enhanced by the NGOs orientation for and adaptation to international donors which disconnects them from the local needs (Ritvo et al., 2013). A Georgian disability activist interviewed for this study summed it up as follows:

> "Generally speaking, the work of NGOs is quite misunderstood in Georgian society. There are a lot of misconceptions or myths around NGO's and social activism in general. And of course, more so about the women with disabilities. A lot of it actually, comes from pro-Russian propaganda directly. There are a lot of myths that all this civil society make a lot of money. Which maybe there are a few

larger organisations that do have good salaries, but most of us do not make good money. And especially not stable money." (Elene, disabled activist and researcher)[1].

In conclusion, NGOs in Georgia face major challenges such as state co-option, importance of informal networks in their operation, difficulties to fit international donor's profiles, and disconnection with their local target group. These are challenges that prevent civil activism from voicing people's claims and need from the grassroots.

Gendered transition and feminized civil society activism

The "gendered nature of post-Soviet transition" (Ishkanian, 2004:263) has become a field of academic interest and attention has been given to civil society as an increasingly feminized sphere in several post-Communist countries (Phillips, 2005; Ishkanian, 2005; Andrea Berg, 2005; Racippi and O'Sullivan See, 1995). Scholars researching civil society organizations in transitioning post-Soviet states have found that women have been disproportionally active in the third sector. In 2010, women made up 58% of NGO staff in the Georgian capital and 63% in rural regions (Chkheidze, 2010). However, this active position of women in one of the public spheres is less an expression of successful emancipation, but rather of exclusion from other public spheres such as politics and entrepreneurship (Natsvlishvili, 2015).

"'Feminization' of the NGO sector" in the South Caucasus and beyond has been seen as a women's strategy to weather the gendered challenges of the transition (Ishkanian, 2004). After independence was achieved with the help of women, gender roles excluded women from political ruling elites and parties, limiting their participation in building the new state.

> "While there has been a decline in women's representation at the formal (national and local) government levels and in political parties, there is an unprecedented increase in women's participation in NGOs […]. By choosing NGOs, women reaffirm the ascribed gender roles and gender- based divisions of labor and avoid the criticisms that they would face if they entered political parties or government, but are still able to work in and through the public sector to achieve their personal and community objectives" (Ishkanian, 2005:173).

This quote emphasizes the intersection of gender and civil society activism. Prevailing gender roles, as I will explain in the following section, have affected women's public functions and resources. Furthermore, international donors play a remarkable role in developing the civil society sector in transitioning countries and they have given preference to funding women's organizations and initiatives. Women learned how to fit international donor's profiles and win grants through "gender issues" (Ishkanian, 2004:266). Women's high levels of education and

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[1] To guarantee anonymity, all respondents are referred to by pseudonyms.

language skills have helped them to attract foreign donors. They were seen as popular beneficiaries as their work seemed to be more "cost-effective" due to lower salaries and readiness to do unpaid work (Buvinic et al., 1996:13, cited in Ishkanian, 2005:176).

Women have traditionally been responsible for social issues (such as disability, childcare, health, food provision) that became even more pronounced during the transition period when state support drastically decreased. "Georgia's Orthodox church and culture reinforce traditions that family members, especially women, are the main providers when relatives need help" (Ritvo, 2013:14). It is these gendered functions of women in combination with women having experience in social professions that has made it easier for them to raise socially relevant issues (Chkheidze, 2010). The engagement in collective action and civil society organisations has helped women to deal with these responsibilities. This created an opportunity for women to establish their work in the form of civil society activism to deal with a state system that was not able to care for its citizens.

By looking at personal transformation of women in the civil society sector in post-Soviet Ukraine, Phillips put forward a bold thesis: "perhaps the state and international foundations are 'empowering' civic activists in order to shift responsibility for social welfare into the non-state sector" (2005:506). As this study will argue, this assumption seems to be valid for the Georgian context too. In Georgia, the state has no strategy for developing human rights-based disability services and relies entirely on NGOs and family care (Piérart et al., 2020).

To sum up, during the transition period, women have been experiencing a harsh pushback into the private sphere (Racippi and O'Sullivan See, 1995). NGO work "has allowed women to remain active in public life" (Ishkanian, 2004:283). As put by Ishakinan, the "category of women was and continues to be an ideological site for political, religious, and economic projects" (2004:162). By looking at female responses to local socioeconomic challenges (for example through activism and NGOs), we can observe women's contributions to change and development in an increasingly global post-Soviet Georgian society.

Women's role and resources

Waterston's (eds., 2017) anthology on "Gender in Georgia" represents the first English-language publication dedicated entirely to this topic and make clear that "[g]ender equality is one of the most disputed issues in contemporary Georgia" (Sumbadze, 2017:172). Patriarchal gender roles persist in Georgia, especially in the rural areas. They are rooted in so-called

national traditions (but actually nationalism) and religion, both of which enjoy a high standing in society, and determine women's role and place in Georgian society.

Patriarchy is "a system of social structures, and practices in which men dominate, oppress and exploit women" (Walby, 1989:214). This order determines who has power and access to resources and who is deprived of it by maintaining gender roles. Furthermore, "stepping out of expected gender norms and roles" can be met with repression (Abrahamyan et al., 2018) which is one reason why people remain in those roles. Patriarchy also comes with gendered division of labour. This does not mean that women have less work or functions within the family or society, but their functions are devalued by the system (Philpott, 1995). For instance, care work (traditionally seen as women's task) represents a great effort in many cases but is not valued by society.

Being incorporated into the work force of the socialist economy, Soviet-Georgian women started to receive higher education, which, however, did not free them from carrying the sole responsibility for the household and family. These Soviet approach towards women (the so-called double burden) largely persists until today in Georgia. The shallow nature of gender equality became obvious in the 80s when women's quota was abolished in the local Soviets (Ishkanian, 2005). During the transition to market economy, women experienced higher unemployment and were disproportionally represented in low paying jobs. To this day, women are also more likely to do unpaid work, and face disadvantages in the job market despite high qualifications (Chkheidze, 2010). Women have been suffering disproportionally from the shrinking welfare state. In addition, they were burdened with the responsibility to provide food and goods for the family in an environment where food and most goods were simply not available (Ishkanian, 2005).

Costanza Curro (2012) has argued that within Georgian national identity "womanhood and motherhood are regarded as two inseparable categories" (2012:117). In other words, women are "valuable" only if they comply with their ascribed roles as mothers which implies socially constructed attributes like modesty, submissiveness, pragmatism, purity, self-sacrificing, and being the "guardians of tradition" (Nogaideli, 2012; Rekhviashvili, 2010:7). It is difficult for women to break through the limitations these national gender roles put on them, because first women have internalized these roles and participate in reproducing national/patriarchal ideologies (Yuval-Davis 1998; Rekhviashvili, 2010) and second, people who do not meet these norms are treated as "enemies" of the people (Curro, 2012).

Ishkarian described how women NGO workers in the South Caucasus have used this traditionalist/nationalist discourse to justify their activism in civil society. They have expanded

their roles as mothers from the familial level to the social level, where they teach their children new democratic values. Therefore, "NGOs are the *natural path* for women's activism in the post-Soviet period" (2004:269, italics in the original). As I will discuss further down, mothers interviewed in this study also narrated their activism as having its source in motherhood and therefore being a "natural" development.

Even though Georgian women are increasingly responsible for contributing to the household budget and have taken up roles traditionally held by men (like becoming the main breadwinner), their social status has remained secondary (Chkheidze, 2010). Sometimes, the blurring of gendered functions are consequences of social progress, but more often of economic compulsion (Sumbadze, 2017; Corso, 2014).

Ultimately, traditional gender practices restrict women's resources including time, power, finances, and empowerment necessary to bring forward their own interests in society. On the other hand, as described above, many women have found ways to keep active in the public through civil society activism and the NGO sector, without stepping out of prescribed gender roles.

Many women activists who informed this research do not necessarily describe themselves as feminists or even consider gender to be an important factor within disability activism. In practice, some of the women interviewed have little interaction with feminist theories. But also, some women did hold feminist stances and saw gender as a horizontal category intersecting with all areas of life, including and especially disability. Like Abrahamyan et al. in their feminist analysis of peacebuilding organizations in the South Caucasus, I "do not rely on women identifying themselves as feminist in order to measure how well gender norms and patriarchal values are challenged within different organizations and groups" (2018:50).

3. Disability Studies and disability rights movements: Bringing forward the social model

The past four decades, have seen increasing academic interest in disability issues. The growing recognition of disability studies as an interdisciplinary academic field has led to fruitful intersections with other disciplines within the social sciences. It is not without the effort of the international disability rights movement that disability studies was able to take an independent

path and generate ideas and concepts that are relevant beyond academia. The disabled people's movement was important for and is still close to the field of disability studies in the UK and North America (Watson & Vehmos, 2020). "Like every social movement, the Disability Rights Movement needed critical analysis of the social problems it was addressing" (Šumskienė and Gevorginaniene 2021). The contribution of disabled scholars and their allies to the field was therefore crucial to advance disability studies and create a "metaphoric ramp" interconnecting academia with the disability community (Longmore, 1995, cf. Šumskienė and Gevorginaniene 2021).

It is only towards the last turn of the century, however, that disability has been addressed outside of medical issues (Shakespeare, 2005). Until the 1980s, disability was largely understood as "an individual medical problem or a 'personal tragedy'" (Barnes, 2020:14). Consequently, the medical model, representing "deficit understandings of disability", has been the underlying message of many policies and societal responses to disability, and might still prevail within societies, academia, and policy makers in Western and Eastern Europe (Barnes, 2020:15). The medical model has been the reason (and justification) for economic and social exclusion of people perceived as disabled. It is only with the introduction of the social model (Mike Oliver 1983) that scholars and activists contributed to a deeper understanding of disability as a social construct created and entertained through social and physical barriers. The social model distinguishes between impairment (biological dimension) and disability (social dimension). The UK based disability rights organisation Union of the Physically Impaired Against Segregation defined disability within the social model as follows:

> "Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from society. Disabled people are therefore an oppressed group. It follows from this analysis that having low incomes, for example, is only one aspect of our oppression. It is a consequence of our isolation and segregation in every area of social life, such as education, work, mobility, housing etc." (UPIAS 1976: 4, cf. Barnes, 2020:16).

This approach allowed for shifting disability into the sphere of social justice, focusing on the structural discrimination by society rather than the person's impairment. It became the principal tool for disability advocacy and policy and was positively received within the disability movement and beyond. Following this, a wave of euphoria saw the end of disability coming. Vic Finkelstein (1988) described in a fictive utopian story a barrier-free village, where, in absence of a disabling environment, disability disappeared (c.f. Watson & Vehmos, 2020).

The social model thinking makes sense because it allows us to see the similarities to other socially oppressed groups based on gender, race, ethnicity, social class, etc. At the same time, this model emphasises the anti-essentialist approach to disclose the "social construction

of human differences" (Goethals et al., 2015:85). Disability, as this research claims, is the result of a disabling environment. As this research focuses on grassroots disability rights activism, my very interest in disability lies in its social dimension. In other words, grasping disability/ability dichotomy as a social construction that discriminates against an oppressed group (in this case people with disabilities), urges disability activism not to focus on "services" or "charity", but to implement disability rights (Goodley, 2013). Victoria Shmidt (2014) has conceptualised this approach as disclosing "activism and self-organization among disabled people" rather than pursuing paternalistic practices.

There is both feminist and postmodern critique of the social model, mainly criticizing the artificial separation of disability and impairment and the marginalisation of the latter (Bê, 2020:424-425). I see the social model not as opposed to postmodern feminist critique, but much more as compatible and adaptable (as does Bill Hughes, 2014). I agree with Barnes, against criticism from within the disability studies, that the disability/impairment dualism does not rule out that impairment itself is not a purely biological but also a cultural phenomenon and an open category. "The meaning and experience of impairment, disability and disablism morph over time, not simply because of the developments in 'scientific thinking' around the body and mind, but often because of changes in social policy, government guidelines and legislation" (Goodley, 2011:9). Nor does the social model in my understanding neglect that surgery as well as physical and cognitive limitations can be real elements of disabled people's life (Shakespeare, 2005).

Despite this, the social model has managed to weather significant internal crises and has prevailed, among others, as a dominant model, especially for the disability rights movement. To this day, new and traditional models and approaches within disability studies have co-existed and enriched one another (Watson & Vehmas 2020).

Globalizing disability rights and studies?

The adoption of the CRPD by the UN in 2006 represents a major achievement and a paradigm shift in the international disability rights movement. The convention introduced the legal basis for a human rights-based approach towards disability, rejecting all forms of paternalistic treatments of disabled persons. People with disability are (at least theoretically) granted full protection of their human rights, including their rights to self-determination, independent living, and full social, political, and economic inclusion. This international treaty has been viewed as a breakthrough by the international disability rights movement.

For disability rights activism in the West, "the importance of social models of disability cannot be overstated. From a disability human rights perspective, these models share a significant approach to overcoming prejudice and discrimination: the view that disability is based on a social, structural, and contextual understanding" (Sabatello, 2013:17). NGOs played and still play a significant role in advancing a human-rights framework in democracies, advocating for self-determination and independent living which represent key demands of the disabled people's movement (as visible in their slogan "Nothing About Us Without Us!") (Holland 2008, Sabatello, 2013).

Disability studies remain a Western-centric field. Nevertheless, the interest in disability experience outside western contexts is growing rapidly. Rasell's and Iarskaia-Smirnova's anthology *Disability in Eastern Europe and the former Soviet Union* (2014) is therefore even more enriching for the field. Disability research in the former Soviet Union started to take root with work done by Kate Thomson (2006) and Elena Iarskaia-Smirnova (1999, 2001). Key themes were "perspectives of disabled people and their families, particularly in relation to the use of state services and attempts to overcome discriminatory professional and social attitudes" (Rasell and Iarskaia-Smirnova 2014:10). Using intersectionality, they addressed gendered dimensions of disability, especially in relation to caregiving and sexuality (ibid.). Other authors (some of whom are also represented in this anthology) have made valuable English-language contributions to the understanding of disability networks and (self-)organisation in the post-communist space, such as Sarah Philips (2009, 2011, 2014), Victoria Shmidt (2011), Svetlana Borodina (2021).

In Georgia, disability studies remain a rather marginal field, although, there is growing interest among local universities. Since 2015, Tbilisi State University (TSU), maintains a Disability Research Centre (DRC) that carries out evidence-based research on disability on a regular basis. In the past few years, several Bachelor's and Master's theses have been written by students of the Department of Social Work at TSU which have shed light on different facets of disability. It is quite characteristic of post-socialist disability research to not be considered its own academic discipline but to be located within Social Work studies (Philips, 2014). Furthermore, Tamar Makharadze, head of the DRC has regularly published reports and research in the field, mainly in the Georgian language. In 2020, she conducted a participatory study available in English, using gender as a parameter to look at disabled women's yet unmet needs in rural areas of Georgia in the context of the Covid-19 pandemic (Makharadze, 2020). Despite the limited English-language information, disability studies in Georgia are growing and the

increasing interest of local and foreign disability researchers and professionals might lead to a fruitful collaboration in the future.

The emergence of disability movements in the Soviet and post-Soviet context

Under Soviet rule, disability was treated as an individual medical problem or human "deficit" and hidden from society. Sarah Phillips in her article about Soviet Disability History recalls the story of a Soviet apparatchik, who, during the Olympic games in Moscow in 1980, was asked whether the Soviet Union would send a team to the Paralympic games in Great Britain the same year. His reply to the Western journalist was apparently: "There are no Invalids in the USSR!" (Fefelov, 1986 c.f. Phillips, 2009). This answer, however absurd it may be, reflects the state-socialist disability policies of total exclusion. People with disabilities posed a threat to the Soviet self-image of an "abled", "uniform", and "healthy" nation that left little room for human diversity (Phillips, 2011: 62).

From the 60s onwards, closed institutions "(*doma-internaty*)" were the state authorities' solution for disability. Mykola Swarnyk, a Ukrainian disability activist and head of the Lviv commission on accessibility stated: "We all had rights on paper, but the [Soviet] state, where everyone was happy and was joyfully building communism, did not foresee special needs. Therefore, for these [disabled] children they built *internaty* outside of towns, which many considered a perfectly normal, rational way to deal with the problem of disability" (2005, cf. Phillips 2011:65).

Internaty were run under the medical model and located outside of urban centres which fortified the social exclusion of the residents. Parents who would have preferred an alternative solution, such as community-based living, were socially and materially pressured to send their children to institutions, as access to medical care, social support, and resources outside of institutions were restricted. Such practices prevented professional and private networks of support to form around disabled people and their families (Shmidt, 2011), which made them, up to date, dependent on institutions and enforces disabled people's vulnerable position in society today.

For the building of a disability movement, these institutions played an ambivalent role. On the one hand, the similar experiences and problems that people with disabilities shared under these inhuman circumstances "allowed a disability rights consciousness to foment" (Phillips, 2011: 68). On the other hand, the state's power over these institutions was omnipotent so that

these networks of activists were easily controlled and disrupted (ibid.). Individual activists were treated as dissidents which drastically limited their range. In addition, the Soviet system ranked persons with disabilities according to their "usefulness" for the labour market. People who were seen as "useless" due to their inability to work within the given context were denied social services, whereas people who were integrated into the labour market received minimal support. Phillips calls this approach to disability a "functional model" (2011). This approach fostered competition between different groups of disabled people and suppressed the emergence of a collective disability consciousness which largely hindered disability rights activism from taking root in Soviet-Georgia. Instead, disability groups (such as wheelchair users, the blind, or the deaf) organised themselves independently of each other to improve their lives based on their own specific needs, but without criticizing Soviet practices towards disability as such (Borodina, 2021). After the collapse of the Soviet Union, the successor states inherited these organisations and their fragmentation. The present study found that the legacy of "divide and rule" still has an impact on Georgian disability rights activism today. As I will discuss in the following sections, a unified human rights movement based on disability pride and identity, if it exists, is still in its infancy in Georgia.

In the increasingly free civil society, activists and organisations in post-socialist countries have started taking up the claims that their western counterparts raised two decades earlier. While the West had experienced different stages of the disability movement (gradual development so to say), post-socialist disability activism introduced these subjects more precipitously. "[D]iverse disability initiatives rapidly emerged, developed, expanded, and in many cases these periods and types overlapped with each other" (Šumskienė and Gevorginaniene, 2021).

Bearing the post-communist legacy of low social trust and minimal civic activism in the region, disability advocacy faces major challenges such as "lack of cohesion or shared identity" (Holland, 2008:552). Holland has found that disability activism in the post-socialist Central Europe focuses more on "consensus-based approach" than using "conflict models" (2008). This means that civil society organizations tend to emphasize disability service provision over disability rights implementation. In this way, they avoid challenging current state practices which might not be in the interest of people with disabilities. This, alongside with the large discrepancy between disability policies and actual practices that occur due to poor monitoring and implementation methods are problems that Georgian disability activism also faces today (based on respondents' opinions). As I will discuss further down, Georgian disability activism consists to a large extent of small and medium-scale NGOs, of which many are disability service

provider organisations (SPOs). According to interviewees, these SPOs tend to be consensus-based, which is in contradiction with others, for example advocacy organisations without service provision.

As discussed above, disabled researchers and others were crucial in allying the academic field of disability studies with the movement in the West from the 70s/80s onwards (like Mark Oliver, Vic Finkelstein, and others). In post-socialist contexts, however, academia was slow in joining the civil activists' forces in introducing a new disability paradigm. Academic research had suffered from limited academic freedom under communist ideology. Their discourses were therefore less radical. They were, "for instance, still focused on the treatment of specific disabilities of pupils instead of analyzing the right to inclusive education" (Šumskienė and Gevorginaniene 2021). Furthermore, the academic discourse "lacks holistic approaches" in the "spirit of the CRPD", and is therefore lagging "behind the civil society organizations which are the first to promote the human rights perspective" (Šumskienė and Gevorginaniene 2021). This dynamic is, however, starting to change in Georgia with scholars using new ontological and epistemological approaches to disability, providing evidence-based research focusing on structural and societal problems. The problem remains the low institutionalization of disability studies in the region and the dependence on individual researchers to push the topic forward (Šumskienė and Gevorginaniene 2021). Whereas there is some English-language literature about the emergence of disability organisations in post-Soviet Russia, Ukraine, Belarus, and the former Eastern bloc countries, fairly little is known about Georgia and the South Caucasus.

There is no doubt that the application of the medical model of disability, institutionalization, and stigmatization in academia and society have caused human rights deprivation for people with disabilities in post-communist states including Georgia (Holland, 2008; Rasell and Iraskia- Smirnova, 2014). The aim of this dissertation, however, should not be to decry such 'backward' practices (as Holland notes, such an approach would be nothing but hypocritical) but to understand local challenges, resources, and views on disability and inclusion by women disability rights activists. Such an approach might improve our understanding of gendered civil activism in Georgia and shed light on where and how international cooperation can successfully support disability rights movements in the region. Women disability rights activists in Georgia are increasingly putting forward claims for political and social change in a challenging setting constrained by scarce resources, a limited welfare system, and patriarchal structures. Their achievements, struggles, and visions of the future remain largely unknown to English-language literature.

Feminist Disability studies and the critique of the "care"-category

Feminist disability studies can serve as a theoretical roadmap to capture gendered disability rights activism in Georgia. Feminist disability scholars have placed disability as another socio-cultural category alongside race, ethnicity, gender, and sexuality (Bê, 2020). Their work is aimed at challenging power hierarchies by uncovering "how society artificially constructs notions of normalcy" (Bê, 2020:422). This has helped poststructuralists to view disability as the constructed "other" and deconstruct the social power dynamics that keep these categories in place.

In a patriarchal and ableist environment, women and disabled persons are seen as the other, representing an opposing pole to the "normal", abled men. The "norm" is an implicit category whereas the "other" is articulated as such (Goodley, 2011). In order to secure the privileged position of the implicit norm, the other is excluded from resources and self-representation. Poststructuralism can break the power of this system by pointing out that it is rooted in social values rather than "nature or rationality" (Goodley, 2011:105). Or, as Garland-Thomson put it:

> "Many parallels exist between the social meanings attributed to female bodies and those assigned to disabled bodies. Both the female and the disabled body are cast as deviant and inferior; both are excluded from full participation in public as well as economic life; both are defined in opposition to a norm that is assumed to possess natural physical superiority" (1997:19 c.f. Bê, 2020:431).

This thinking proves that feminist disability studies is an interdisciplinary platform where concepts and ideas come together that do not necessarily have anything to do with disability in the first place. So, feminist disability writers have contributed to both, feminism and disability studies while questioning ableism.

A poststructuralist feminist lens helps in dismantling how disabled people are discriminated against within a neoliberal system, where discourses of normalcy (who is included and who is excluded?) are dominated by patriarchal (and capitalist) values. In this sense, I use an intersectional framework of female agency and disability to approach the struggle for social justice for people with disabilities in Georgia. Drawing on Nancy Fraser's theory, Phillips (2014:166) has described social justice as a "triad of redistribution in the economic sphere, recognition in the socio-cultural sphere, and representation in the political sphere".

Furthermore, feminist disability scholars have opposed the prejudicial conclusion that disability automatically requires care; an assumption that has uncritically been taken up by some non-disabled feminists. Mainstream feminists had overlooked and wronged disabled

people by accepting the idea of disability as a "burden" that non-disabled women must carry as the traditional "carers in society" (Thomas 2007, c.f. Bê, 2020). The notion of care as it has been discussed in relation to disability undermined disabled people's human rights. Janice McLaughlin (2020:484) notes:

> "In addition, via the significance of charitable organisations in 'caring' for disabled people, care is sometimes framed as an act of charity. Disability writers have pointed out that the language of charity is inappropriate; in particular, how it acts to disallow the sense that the disabled person has a right to query the care they receive (Hughes 1999; Lindemann 2003). Charitable caring for Hughes 'mobilised the emotions invested in the tragic and the pitiful' (2002: 577), while Kittay suggests that care is understood not as a right but instead is provided 'out of a gratuitous kindness, a kindness they have no right to demand' (2002: 271)".

Taking note of this justified criticism, how can we critically, constructively, and holistically look at care? Feminist disability writers have contributed to this dilemma by sharpening our "understandings of dependency, independence and interdependence" (Bê, 2020). McLaughlin examines the "meanings associated with care" and highlights "the value of recognising the interdependencies which lie at the heart of all family life for challenging the social and institutional marginalisation of disabled people" (2020:478).

Thus, the notion of in/dependence needs to be fundamentally questioned. First, obviously it seems like non-disabled people are more "able" to live without support since they are living in a world that has been tailored to them. Second, we must question whether non-disabled adults really live independently in their communities or whether we simply do not perceive their dependency because it disappears against the background of normalcy? The notion of interdependence is therefore crucial for describing how every human being is embedded in a society from which they benefit and to which they contribute. Therefore, we shall keep in mind that "[c]are is a problematic category in disability debates" (McLaughlin, 2020:484) that serves to disempower people with disabilities. "Finally, the recognition that we all are born dependent and we all need care is the foundation of a social and moral obligation: we should all receive the care we need. Social justice then flows from a two-fold condition: equality of access to care and society's support of caregivers" (Winance, 2016:106). This dissertation draws on disabled feminists' work to look at disability rights advocacy by disabled and non-disabled women, as well as mothers of children with disabilities in Georgia from a critical perspective.

It remains, of course, a major challenge to bring together these universal human rights perspectives on people with disabilities on the one hand, and the everyday real-life experiences and obstacles of many people and families with disabilities in Georgia on the other hand. Theories of interdependence that might come with fundamental structural change can seem far-fetched for people who struggle with existential problems in Georgia. The difficult balancing

act will be to overcome the emphasis on care, without neglecting the extra costs and effort that disability can cause to families (in our case read mothers and women) in certain cases (McLaughlin, 2020). However, we must be carefully looking at where we locate the "burden"; Is the impairment or is the disabling environment (like "battles [with] social services and health care providers" ibid.) the source of the problem?

To sum up, this study holds an anti-essentialist view on disability and gender. According to Goethals et al. "[t]he anti-essentialist perspective, that disability studies endorses in various manifestations, is important for what it teaches us about disability, and the social construction of human differences generally" (2015:85). Both categories are social constructs that are embedded and reproduced in cultural and social norms, and eventually result in structures of oppression. Such constructed dichotomies (disabled/non-disabled person, abnormal/normal body, women/men) have been perceived as "fixed" and used to exclude or oppress people. The anti-essentialist perspective can move beyond these categories and simultaneously look at the way how these categories limit the possibilities and participation of certain groups of people (for example people perceived as women or/and disabled).

4. Methodology

In terms of methodology, considering the local settings for understanding activism around disability in Georgia remains crucial. This includes historical, cultural, and political factors around disability (Rusell and Iarskaia-Smirnova, 2014). Further, this dissertation must acknowledge inside and outside perceptions and attitudes towards people with disabilities and local disability experiences that are specific for the socio-cultural context of present-day Georgia and often consist of disability being limited to a medical issue combined with stigmas and prejudices. Demands for a self-determined and independent life may seem alienating in a context where basic material needs of many people are not met (Goodley, 2011). Yet, people with disabilities and their networks have often adapted individual local strategies to deal with their situation according to the socio-political and economic realities (Rusell and Iarskaia-Smirnova, 2014).

This research uses an interpretivist approach to study women's disability rights activism in Georgia. It uses an inductive strategy to capture women's narratives around their experience as disability activists. This methodology was useful to approach the issues surrounding these women without limiting the findings to pre-defined categories. This allows for a deeper

understanding of what disability *means* for these persons in the given context, which networks and resources exist, and how they influence or shape the meaning and perception of being disabled in Georgia. In addition, this research aims to reveal gender implications of disability activism, which requires an intersectional approach, looking at how narrations of gender and disability activism correlate. The research questions that guided this study were defined as follows: (1) How do women narrate their activism in the field of disability rights? (2) What role does gender play in disability activism? And based on the second question, (3) what are the implications of female disability activism in society and for the affected people?

The research questions are framed in a way that they can capture the individual experiences of women activists, their visions of inclusion, and the challenges they face as women and as disability activists. Inspired by Goethals et al. and in line with an interpretivist methodology, this study acknowledges the importance of reflexivity "for conducting critical and intersectional disability studies research" (2015:76). A reflexive approach urges the researcher to reflect on their own standpoint. In my case, for instance, a "western" student's experience, informed by mainly anglophone secondary literature and concepts around disability and feminism, does not necessarily correspond to the lived reality "on site". As a result, "stories of lived experience of both the subject and the researcher are co-constructed and negotiated between the people involved as a means of capturing complex, multi-layered and nuanced understandings" (ibid, p. 83). I believe that such subjectivity does not "falsify" the "trueness" of the results but brings academia closer to real life and contributes to a mindful dialogue between different cultural contexts.

Analytical framework: The CRPD and the Human Rights based approach

The shift towards a human rights-based approach is the international disability rights movement's big achievement and has led to the creation of the CRPD that, since 2006, has been signed by 182 state parties. The government of Georgia has signed and ratified the CRPD and the optional documents in 2014 and 2020, respectively. The activists and NGOs who participated in this study base their demands on the Convention. The CRPD serves as an analytical and legal basis for disability rights activism worldwide, including Georgia, and is therefore very present in this dissertation. Therefore, some basic concepts and understandings such as "human rights approach" and "inclusion" of the Convention will be outlined in this section.

The human-rights approach to disability is rooted in the social model but goes one step further by formulating "a governing policy framework" that considers adjustments to guarantee that "persons with disabilities can exercise all their human rights" equally with others (Harpur, 2010). Key principles of the CRPD and the human-rights approach are respect for disability as part of human diversity, protection of dignity and autonomy, gender equality, and non-discrimination.

Disability policy is not tied to social policy, but an issue that intersects with all policy fields. In this sense, the Convention does not create any new, particular human rights for disabled people, but for the first time, human rights were formulated from the perspective of disabled people and noted in relation to their living conditions (Bruns, 2013).

Social inclusion is a key theme of the CRPD. The focus of inclusion is not on the adaptation of the individual to a prevailing "norm", but on the breaking of this very norm. In this sense, inclusion is a concept based on the equal value and equal rights of all members in society and makes sure that each individual person can fully participate in all social processes (ibid.). Further, it is crucial to include persons with disabilities in all implementation processes of the Convention:

> "In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations" (CRPD, article 4(3)).

The CRPD represents an unprecedented applicable tool for disability rights activists worldwide. It is, furthermore, marked by the active participation of civil society. 120 member states and over 450 NGOs worldwide were involved. Furthermore, people with disabilities contributed significantly as representatives of NGOs, government delegations or the United Nations. The participation of disabled people in the drafting process has given the CRPD a high degree of legitimacy (Bruns, 2013).

However, the Convention's success will depend on whether and to what extent it is possible to sensitise society to the issues. The CRPD aims to change society as a whole and concerns general areas such as gender equality and the development of democratic processes. These goals should be achieved with strong involvement from civil society. Disability activists and organisations in Georgia have been working on the basis of the CRPD and were able to force change while invoking the CRPD in court. There are, however, major difficulties when it comes to bringing the principles of the CRPD closer to the general population and the government.

Conceptualization: Georgian disability activism and disability organisations

While disability organizations play a "stabilizing function" within the disability rights movement, "they *are not* the movement itself" (Waldschmidt et al., 2015). In fact, it would be premature to speak of a unified disability rights movement in Georgia. Informants to this study have described disability activism in Georgia as "fragmented and competing" and divided in "several parts and pieces" with no common strategies and little potential to achieve mass mobilization around a common cause or even exert political pressure as a united force. Some disability organizations lack internal democracy, reinforce patriarchal hierarchies, or let the political elite play them off against other disability groups for their own organisational interests.

Disability rights activism is a broad term that describes a network of NGOs, activists, and groups and their effort to improve the life of people with disabilities by various means, using different, sometimes contradictory approaches. This study will use a similar categorization to Waldschmidt et al. (2015:113) to distinguish the existing organisations working in the field of disability in Georgia. First, disabled people's organisations (DPO's) are membership-based organisations that aim to ensure disabled people's self-representation in society and politics. Second, disability advocacy organisations (DAO's) are organisations that advocate on behalf of people with disabilities and are almost exclusively led by women. And last, Service Provider Organisations (SPOs) are organisations that spend government money on disability services which they provide. In Georgia, these organisations are mainly founded by non-disabled mothers.

To do justice to the CRPD's principles of self-representation of people with disabilities (and to the analytical framework of this study), the distinction between organizations *of* and organizations *for* people with disabilities are crucial (Waldschmidt et al., 2015; Barnes, 2010). DAOs and SPOs interests can overlap with disabled people's interests, but do not necessarily do so in every case. Instead, those organisations have their own agenda as service providers or parents' groups for instance. In the Georgian context I identified three major problems related to these categories. (1) SPOs do not always present themselves as such. (2) Disabled people's organizations are described to be dominated by men and patriarchal structure, and (3) disability advocacy organisations that are run by women (mainly mothers of disabled children or adults) are often not clearly distinguished from disabled people's organisations, meaning that they are treated as *being* the voices of people with disabilities, while they are in fact only speaking *on behalf* of them.

The disability rights movement in the West has been studied through the lens of a new social movement paradigm based on the movement's "focus on autonomy, empowerment and transformation of consciousness as well as civil rights and internationalism" (Waldschmidt et al., 2015:111-112) rather than material claims. Other scholars such as Marie Sépulchre (2020) have looked at disability activism through the lens of citizenship struggle. People with disabilities have in many countries been granted equal rights on the legal level but continue to face structural inequality that hinders the full exertion of these rights. Increasingly, Georgian disability activists too, have been working on cultural and political recognition as well as reducing structural discrimination that impede people with disability from enjoying their legally recognized rights. In Georgia, however, where basic material needs of many vulnerable groups are not met, claims related to economic well-being still matter within disability rights activism. Both approaches are relevant to disability activism in Georgia today.

As mentioned above, disability organisations in post-communist countries have thend to be more "consensus" oriented than "conflict" oriented, meaning that they compromise human rights approaches for service provision (Holland, 2008). In Georgia, especially SPOs (but not only) prefer a consensus model to disability development which causes conflicting interests with other groups and organisations.

Waldschmidt et al. (2015) emphasize that social activism and collective action is always restricted by outside factors surrounding the group or movement such as state structures, democratic culture, and the extent of the welfare system. This dissertation will outline key features of the Georgian context, but a detailed analysis is beyond its scope. For example, we have touched upon the CRPD as a human rights framework that organizations and individuals use to frame their claims. However, we cannot elaborate Georgian disability policies thoroughly, thus, the focus of this study lays on women activists' resources, motivations, and challenges.

Having this focus in mind, it is important to state that non-disabled women, mostly mothers of children with disability, are at the forefront of disability activism and disability service provision in Georgia. SPOs and DAOs are mostly initiated and led by mothers or less frequently by non-disabled professional women. Disabled women activists and NGO workers, however, are largely underrepresented and silenced through different structural factors within DPOs and disability activism in general. It remains an enormous challenge for the movement and the state authorities to clear away structural discriminatory and paternalistic practice towards women with disabilities that hinder them from actively engaging in disability advocacy, gaining control over their lives and over disability services (UNDP, 2021).

Data collection and analysis

Using qualitative research methods, I conducted twelve in-depth semi-structured interviews with women disability activists in Tbilisi. This method proves to be best for addressing inductive research questions and for "exploring understandings, perceptions and constructions of things that participants have some kind of personal stake in" (Sage, 2019:2 c.f. Braun and Clarke, 2013). For the twelve interviews, women engaged in disability advocacy organisations, in disabled people's organisations, and in service provider organisations, as well as women working in academia were chosen. In many cases, the women interviewed had double or triple roles, underlying that the used categories are merely points of reference helping to disentangle the field but they do not always have clear dividing lines. (For example, one participant was a mother of a child with a disability, working in academia and engaged in disability advocacy through an NGO. Another participant was a woman with a disability engaged in a DPO and doing research.) The participants' first-hand experience in working in the field of disability activism in Georgia is crucial for this research. All participants are based in Georgia and working in or around Tbilisi. The interviews were conducted via the online video-communication tool zoom and audio recorded. Each interview lasted 60 to 120 minutes and took place in English, German or Russian.

Prior to the interviews, background knowledge was acquired through intensive desk research as well as during correspondence with disability/human rights experts and workers in the field of disability in Georgia. A flexible questionnaire was used as an interview guide that covered general questions, leaving enough space for the interviewees to influence the course of the discussion. This was particularly important as the interpretivist research design pursues an inductive approach that is sensitive to the different realities, concepts, and ideas of the participants that cannot be determined beforehand (Della Porta and Keating 2008). The questions in the interview guide were designed to capture common practices as well as personal experiences.

The qualitative data was transcribed and processed using thematic analysis which started once half of the interviews were conducted. Early data analysis did inform and improve the interview guide during the data collection process and incorporate unexpected topics (Braun and Clarke, 2013). The Russian and German language transcriptions were analysed in the original language and some parts were translated (by me) to be quoted in this dissertation. Such multilingual research bears some particular challenges for researchers. The different languages in which interviews are conducted can affect the meaning conveyed because certain languages

can have specific connotations to different words (and it also defers among different speakers). Each language has its own culture that affects the way people communicate. Especially when conducting thematic analysis, these differences must be considered.

Selection and recruitment of participants

As in many regions of the world, the rural and provincial areas of Georgia are especially challenging when it comes to including people with disabilities and providing human rights-based services. This is due to a lack of infrastructure, lower financial means, and rigid social norms. Due to the Covid-19 pandemic, however, research in rural areas appears more difficult as data collection can only be done remotely and requires a good internet connection as well as technological skills and equipment on the side of interview participants. Therefore, the geographical scope of the research focussed on participants in the capital city of Tbilisi and its proximity. Also, civil society initiatives and organisations are usually initiated and based in the capital or in other urban centres.

Most women I interviewed are engaged in disability activism through some kind of disability NGO. Some of these NGOs do not have any funding, others are funded by international donors. However, even those struggle with financial problems. A smaller number of respondents were professionals working in state institutions or service provider organisations, or both. Half of the respondents were mothers of children with disabilities active in parents' organisations. Many women take part in different activities or organisations related to disability at the same time. The other half were either non-disabled professionals, researchers, lawyers or disabled women activists. A common pattern of the participants was their high education and their successful career in governmental institutions, academia, or the private sector previously or simultaneously to their activism. They all speak at least one foreign language and many of them have connections abroad. The high status and competence of women working in the civil society sector in post-soviet countries has already been described by Berg (2004) and Ishkanian (2004, 2005) likewise.

The recruitment of participants was initially informed by the project *Meet – Train – Encourage* (MTE, http://www.mte-georgia.ch). MTE is a private initiative aiming to connect and support different local individuals, activists and organisations working with people with disabilities and their families in Georgia. I used their partners and network to find suitable informants. In a second step, the "snowball method" was used to find further participants. The

key criterion was that respondents identify as women and as disability activists or members of a disability network (e.g. members of a disability organization or parents' group, professional, etc.). There were no further selection criteria for the recruitment of the participants such as age or type of organisation.

Limitations

The hereafter presented results cannot claim to be representative. Nor can the findings be generalised for Georgia as the group of participants is too small to make general assumptions that exceed the very limited context of where the study was conducted. The goal of the study was to examine and contextualize narratives of women activists. The fact that the results of this study represent only a small piece of the big picture is beyond question. However, it can contribute to a broader net of research in this field and generate new questions and indications. Then, it must be noted that any study about disability in Georgia faces problems with official statistics, data, and information. Due to a lack of sufficient definition and illumination of disability-related issues, it is hard to find a solid ground to work on. In the past 10 years, studies on disability have been conducted by members and students of the Disability Research Centre at the Tbilisi State University, but they are mostly only available in Georgian.

Insufficient knowledge of the Georgian language in my case is another obstacle I had to face with this project. This must be considered for both the empirical fieldwork (conducting interviews, discussions with experts, etc.), as well as for conceptual and theoretical work. It also limited the sampling of respondents.

The interview questions were designed in a way that they were non-intrusive and left it up to the respondents to reveal as much information as they wanted. With this, I aimed to assure that respondents were able to speak freely and openly. This is important considering that topics around disability and gender issues can be very sensitive in Georgia (Makharadze, 2020).

Most of my respondents were non-disabled mothers of children or adults with disabilities and non-disabled women who advocate on behalf of people with disabilities through their respective NGOs. I acknowledge that this ratio is reproducing a problematic power structure as disabled women's activism tends to be silenced and restricted by non-disabled women's and disabled men's voices. This problem should be given attention throughout this dissertation. On the other hand, non-disabled mother's and women's activism contributes to a large extent to the field of disability in Georgia. It is therefore a legitimate starting point for

understanding gendered disability rights activism and women's visions of inclusion in Georgia. I believe that in order to expand the knowledge on disability topics, more diverse studies are necessary meaning that people with disabilities must be included in the research process rather than remaining the object of the research.

5. Empirical findings

Responding to disability in Georgia

Measuring disability in Georgia poses big challenges as little reliable data is accessible (Makharadze, 2020). Lack of reliable data on disability is a common obstacle that is not unique to Georgia but occurs in most countries and makes it difficult to capture the real scope of disability issues, blurs the need for action, and weakens political advocacy. It is for this reason that the CRPD urges state parties to develop data collection strategies. There are, however, problems that are particular to Georgia such as systematic underreporting of cases caused by the municipalities' passivity regarding the registration of people with disabilities. People with disabilities, especially in rural areas, have little access to information about social support or private services and face physical and social barriers to access state institutions which deprive them from receiving support (IDFI, 2017; WorldVision, 2014). In 2017, the number of registered people with disabilities receiving social support in Georgia corresponded to 3,5 % of the country's total population (IDFI, 2017), which is significantly less than the world's average of 15% disabled people suggested by the World Bank (2022) and casts doubt on whether all people entitled to disability services in Georgia are covered.

As mentioned above, legislative steps have been taken to improve disability rights in Georgia not least under the pressure of civil society and international organisations. However, people with disabilities in Georgia have not yet seen an implementation of full equal rights, and in many cases, *de facto* Soviet-era practices such as long-term institutionalisation and stigmatisation are prevailing (UNDP, 2021). In 2009, Georgia introduced inclusive education, of which the scope and the quality is very low. This, combined with neoliberal reforms of the social safety net and large-scale privatization of former state services creates the shaky foundation on which disability is experienced today. "[W]hen social problems become individualized, as often happens with neoliberalization, the effects for already marginalized persons can be devastating." (Phillips, 2011:6).

Despite the commitment to deinstitutionalization, the process is progressing slowly. Large institutions for children and adults still exist in Georgia especially for people with psycho-social disabilities. Besides the state, the Georgian Orthodox Church also runs orphanages, including for children with disabilities, where child abuse has been. There are abuses in state institutions, too, that are run under the medical model and use Soviet practices such as disciplinary measures (PHR, 2020, 2021, 2021b). In cases where deinstitutionalization is happening, big institutions are replaced with small groups, but the institutional approach prevails and there is no real state commitment to introduce community-based living. For example, a children's home for children with disabilities in Tbilisi, which is currently in the process of deinstitutionalization, will be closed. However, the children are placed in smaller settings and groups, but still in a closed institution. Such developments of "trans-instituionalization" are representative for post-socialist states (Sumskiene and Gevorgianiene, 2021). "[L]arge institutions are broken down into smaller units - group living houses, but instead of services oriented to the protection of the rights of people with disabilities, only the size of the institution changes" (ibid.). This shows that CRPD demands such as community-based living, reasonable accommodation, and equal opportunities, are seen as theoretical concepts, but they are not implemented with sufficient political will or competence.

Disability rights activists and organisations are a crucial force in the transition to a human rights approach. Nevertheless, we cannot lump all organisations together. As mentioned above, we can identify three main categories of organisations that differ in terms of their interests and strategies: (1) Disabled people's ogranisations (DPOs) are membership-based organisations. They often advocate for their group specific need (such as for example the Blind union advocates for the needs of people with visual impairments). However, as interviewees reported, traditional DPOs lacked internal democracy, they were often dominated by disabled men and excluded disabled women, and sometimes failed to address disability from a human rights perspective. Some of these organisations were described to be consensus-oriented and on good terms with the government. There are other examples of DPOs founded by women. These organisations unite around the struggle for social justice for all people with disabilities rather than focusing on "types" of impairment and their needs. Thus, like most western DPOs, they focus on human rights and are more conflict oriented. However, these initiatives are still marginalized. Second, (2) Disability advocacy organisations (DAOs) are in most cases founded by mothers of children with disabilities (with a few fathers on board – Fathers' initiatives exist too but are the exception to the rule). Furthermore, young, usually female professionals in the field of disability have started successful initiatives and NGOs; A good example is the NGO

Partnership for Human Rights. DAOs range from somewhat to very conflict oriented and represent, at this point, the driving force that is pushing for a human rights approach in Georgia. Third, (3) Service provider organisations (SPOs) have, in general, stable funding from the state. Even if the allocated money is not enough to guarantee high quality services or even enough spots for all people that need the service (many people with disabilities are on waiting lists), the organisations receive some funding for the service provision. SPOs were described as consensus-oriented by respondents in this study. We can observe that the boundaries between the different types of organisations are not very rigid. Advocacy organisations founded by parents may also provide services and SPOs may present themselves as advocacy organisations to attract foreign funds. DPOs may collaborate with parents and include non-disabled people. In this sense, these categories are only a simplified categorization, but are helpful to grasp the different actors in the field.

Desk research and interviews have shown that new disability organisations such as the Association for People in Need of Special Care (APNSC) were founded as early as 1989 with the financial help of foreign donors and agencies. The Association of Disabled Women and Mothers of Disabled Children (DEA) was founded in 1998 in Zugdidi under the initiative of Oxfam GB and NL. In 2006, on the initiative of an association of parents of children with down syndrome in Tbilisi, the first early intervention program in Georgia was founded with funds from the George Soros Open Society Foundation. Hand in Hand, an NGO focusing on community-based housing was established in 2010. The Georgian Down Syndrome Association was founded in 2017 by parents and an adult with Down Syndrome. These are only a few selected examples of the civil society initiatives that existed and exist in Georgia and are well established today.

Informants reported that many services (such as community-based living groups, day care centres, early intervention centres) are founded and run by mothers, however, they do not necessarily present themselves that way. Usually, parents' organisations come up with initiatives in service provision and found a SPO with the funding of international organisations. After a certain time, they convince the state to finance them. Since the ratification of the convention, international organisations expect the government to fund services (as it is required by the CRPD), therefore, SPOs are more dependent on state funds.

> "The amount of funds each [service provider] organization gets from the state is not enough. The salaries are very low. For example, we cannot give some kind of minimal salary to our employees. We struggle with finding some materials and finding some toys and so on. There are very few funds that can support organisations in purchasing toys and materials they need. It's a struggle, on the one hand. On the other hand, the state supports such organisations, there are state funded programs, it

gives us a real feeling of stability. You don't have to think that next year you won't have the basics" (Nutsa, NGO-Founder and researcher, non-disabled mother).

During a visit to the regions, I was told that the salary of an employee in a state funded day care centre in the region of Kakheti was 70 GEL per month (23 USD). Another informant who worked in a state funded early intervention program in the capital confirmed: "What you earn there is almost like volunteering. So, if you work there, you have no interest in money". According to the participants, the government has no strategy for building adequate and accessible service provision in the country but relies entirely on CSOs for initiating disability programs and services.

> "Actually, everything that is happening in the government, is initiated by the grassroots (by grassroots organizations). It rarely happens that it comes top down. In this particular field, everything happens bottom-up. The parents, mainly parents, or some kinds of organizations initiate some activities, or some projects, and then they convince the state to fund these activities" (Nutsa, NGO-Founder, non-disabled mother).

The government in Georgia is weak at identifying needs of persons with disabilities. The funding is always too low to guarantee quality services and control mechanisms are weak or non-existent. The government allocates money for certain services, but due to a shortage of SPOs, part of the money is being returned back to the budget because there is no place where it can be spent. The UNDP report (2021) criticised the fact that the government has not been able to build a monitoring and implementation council, which would be the very minimum for any successful government initiative in this field. The government's passive attitude puts a lot of pressure on the NGOs which are expected to initiate the much-needed disability programs:

> "they [the government] always keep telling us: "okay, if you want us to do something, then propose a plan". Which means that we should bring them essentially an already prepared program. They want us to tell the relevance (which you know, we would do), but then they also want us to count the budgetary implications, the expenses where this money should come from in the budget. Then we should also provide them with an overview of international practice, how is it done in other countries. And essentially they want us to write them ready programs, already. And this really requires a lot of organizational capacity. And a lot of technical knowledge, expertise, which we may not have. And if we are not doing this, then they are saying that we are not being constructive.
> But even if the NGOs do all this with some donor funding support, even then it does not mean that the government will take it fully into account. They will still make a lot of cuts to what has originally been proposed. So, this is a huge issue" (Elene, NGO-Founder, disabled activist).

The activists are under-resourced to live up to these expectations. It comes down to a lot of volunteer work from which, it can be argued, researchers, the government, and international donors and NGOs benefit more than people with disabilities:

> "When we are invited to contribute to different focus groups, to research,… we always do it because we believe that this is important and this is how we can make an impact. But at same time, this is also a bit exploitative, because we dedicate our time, let's say for free, and we are told that this is

for us, that we will benefit. But in the end, we never know: will we benefit to this action plan, if our comments are not taken into consideration anyways, maybe in 10 years… maybe yes maybe not…” (Nana, disabled activist).

Women activists feel like they are compensating for the state's ignorance and incompetence to care for its citizens. Phillips has found similar results in Ukraine, where NGO leaders were saying that they were "carrying out the work of the state" (2005:500) when providing basic support for economically disadvantaged families. Keeping this in mind, I agree with Phillips that transitioning states including Georgia have been placing the responsibility for the wellbeing of citizens on the civil society sector instead of coming up with their own strategies. This puts a lot of pressure on the NGOs, as activists repeatedly explained. In this sense, activists are not just responsible for pushing for more rights and access but are also burdened with developing strategies and creating services – tasks that are otherwise allocated to state institutions. Most women activists took it for granted that women are taking up this task as "carer of society".

Today, the central government runs large long-term institutions and finances small group institutions and a variety of different programs such as early intervention, day centres, rehabilitation, community 24 hours services, house care, and personal assistance. All of these programs and services are provided by civil society organisations (SPOs). They are, however, in shortage and do not cover all geographic areas. Municipalities run large scale institutions and day centres and finance civil society-initiated programs such as house care and different therapies.

Under the influence of the medical model that sees disability primarily as a "care" problem, disability has become a women's issue. Phillips (2011:58) has described the role of women in the family (mainly mothers) who started to take care of so-called "invalids" (mostly veterans) after the Soviet state limited social services in the 60s. In Georgia, the whole system still relies on these patterns. In practice, this is a system that prevails not only in Georgia, but in most parts of the world (Pattison, 2021).

When a family member happens to have a disability, it often leads to additional economic distress. Because social services are not sufficiently available, not all medical needs are covered by the state insurance, accessibility is not guaranteed, and structural discrimination prevents full social and economic participation, so disabled people or their families must find additional resources (such as care, personal assistance, assistive devices, money for medical treatment, lifelong financial support) to compensate. Victoria Shmidt (2014) found that families without strong informal networks in Georgia have little choice but to send their disabled children to institutional care. Because of an inadequate health care system, people with disability rely on kinship relations to get basic medical care (WorldVision, 2014). The material

needs of families lead to more institutionalization. Lack of support networks (including schools, parents, state services, NGOs,) increase this tendency (Shmidt, 2014). Women have traditionally been seen as responsible for compensating the lack of inclusion and accessibility through care, a system reinforced through patriarchal and ableist values.

As mentioned previously, caregiving is considered a women's responsibility in Georgia, and even more so when a child has a disability (according to all respondents). Myths, such as that it is the woman's genes that are to be blamed for the child's disability, or religious arguments, such as the child's disability is a punishment for the mother's sins were commonly mentioned and condemned by mothers and other activists in this study and point to a highly problematic view of disability as a deficient deviation from the "normal" in Georgian society. Simultaneously, it also points to women's secondary position in Georgian society and religion as they are to be "blamed". It is also common for fathers to leave their families after the birth of a child with a disability. Fathers leaving mothers with disabled children has been observed in other highly patriarchal and economically weak societies as well: "The burden of shame, guilt, embarrassment, ridicule, and financial worries is borne almost exclusively by the mothers of disabled children as the primary caregivers" (Philpott, 1995:88-89). Furthermore, expectations of women as full-time caregivers shows that they are seen as more dispensable breadwinners (Phillips, 2009). These gendered expectations, I argue, have in the long run pushed non-disabled women as carers into disability rights activism in Georgia.

Becoming active: Women's Grassroot Initiatives

Retrospectively, the vast majority of women described their path to disability rights activism as a "natural" progression of their life course. Many were previously active in social professions, such as psychologists, nurses, teachers, or doctors, and mention that their experience in those fields facilitated their entry into disability activism. Furthermore, their experience made them aware of the urgent need for societal change to achieve improvement in people with disabilities' lives. In other words, activists gradually moved from the micro (individual) to the macro (societal) level when starting their activism.

> "I worked in the setting of a clinic and hospitals and neurological therapeutic center. And then I had a feeling that I was not protecting my clients outside of the therapeutic setting. And the results we had from the therapies were simply lost, because the society didn't want to accept it [disability or people with disabilities]. So, I moved to the human rights protection field because I understood that individual goals and individual achievements were not stable if I didn't take care of the environment" (Natia, NGO-Founder, non-disabled activist).

This quote is representative of the experience of many activists interviewed in this study. Women regularly reported that their work cannot be sustainable if the "structures" (that is - ableism) remain the same. Changing the disabling environment around people with disabilities and their families is often the motivation for civil activism. All women in this study recognized that disability is a problem that must be solved by adapting the environment rather than fixing the person. However, the implementation of this concept remains difficult. Women's grassroots disability activism is impeded by many factors such as little political influence, limited visibility in society, and the lack of a unified movement.

For the mothers of disabled children who took part in the study, the birth of their child represented a turning point in their life that, because of lack of support and opportunities for their children and themselves forced them to become active. In the absence of an enabling environment, mothers compensate for the gap that exists in education, physical environment, health care, etc.

> "As I got my child with down syndrome, I started to learn about it. By that time I had some friends abroad, some in USA some in GB, some in Germany. And they were sending me some kind of books or literature. I was reading a lot and finding out that there were lots of possibilities to support my child and children in general with down syndrome. And I learned by that time that the possibilities [in Georgia] were not as much as they should have been. I got connected with another parent. Her child was born two months later. We met accidentally at our pediatrician's office. And we decided that we should do something, at least some awareness raising activities together. And so, we have founded a parents' organisation. And professionals were also included, because some professionals like our pediatrician and some psychologists were my good friends. So to say, it was some kind of social support because I was acquainted to them. And so we founded this organization" (Nutsa, NGO-Founder and researcher, non-disabled mother).

A common pattern in the narration of these women is the importance of personal networks with other mothers for access to information and support. The mothers in this study all had their children in the mid to late 2000s. A time when, they say, policy makers were just beginning to address issues of inclusion. Practically no inclusive services and very limited information for parents and professionals was available in the country at the time their children were born. Most of the mothers relied on friends and acquaintances in Western Europe and the US who were crucial for accessing up to date information, books, and studies about early intervention.

The forming of these networks can be described as spontaneous actions based on personal needs that only later become professionalized and formalized by the founding of, for instance, an NGO or a parents' association. In this sense, NGOs are also a form of mutual support for the members. This is a phenomenon that has also been described by Berg (2004) in the case of Uzbek women and Phillips (2005, 2009) in the case of post-Soviet Ukraine. With the lack of governmental support and civil initiatives, women have to build their own structures

of support. In the Georgian disability field, they do so by forming parents' (but actually mothers') support groups that gradually expand their target from helping their group members to helping other people in similar situations around them. These informal networks of support have helped mothers to form a political consciousness around their issues that helped them to professionalise and increase their activity on societal level. "Social and political activity requires a critical mass of individuals who recognize that the discrimination or oppression they are experiencing is a systematic or political problem, not a personal one, and that the rectification of the injustice they experience is possible" (Popkova, 2004:174). Private networks of mothers have helped such "critical mass" to take shape.

Mothers working in DAOs have emphasised the importance of parents' organisations for new mothers of children with disabilities. The lack of professional information and support for new parents is immense. The information and support that mother-founded NGOs provide to other parents is the only help available in the country, as they say.

Scholars have noted that the responsibility of care means limiting opportunities for women compared to men (Boylan, 1991; Philpott 1995), however, through activism and collective action, they have been able to empower themselves and turn the responsibility of care into a professionalized sphere (founding service provider organisations, doing research, raising awareness, helping other parents with information and support through their organisations).

> "We have several women in our organization with three or more children, and I also have two children, and we are supporting each other a lot! We are driving each other from one place to another, not all of us have a car. So, during Covid-19 we had to support each other with a very strong caring system. Informal, but still a system, right? So, I am not sure if men could be part of this. Because we know how to support a breast-feeding mother who is our accountant. We cannot seek for another accountant, you know, even if she cannot come to work for many, many months, we will still fit into her routine and try to help her" (Khatia, NGO-worker, non-disabled researcher).

As this quote points out, civil society organisations primarily build informal support networks for women who are engaged in them. In most cases these are purely female networks where information, solidarity, and mutual help is provided by likeminded people. Like women activists in Phillips' study (2005) of Ukrainian women NGO leaders, my informants recognized the social dimension of their personal struggles and responded through social, collective action. Interestingly, many women were reluctant to the idea of winning men over to the cause and getting them involved. It seems that personal networks are gendered and when they transform into more professionalised and institutionalised CSOs for instance, they remain a relatively gender-specific sphere. As the statement above shows, this activist is not sure whether men could work in their NGO because they, by default, cannot be part of women's informal support network.

Furthermore, CSOs are platforms for women to become active on the societal level and to bring forward their issues to the public. As women are expected to take care of disabled family members it is usually they who stop their current profession to take on this task. Therefore, mothers of children and adults with disabilities have their own material and emotional needs which they can meet through collectivizing their efforts with other mothers. As primary caregivers, mothers need help too. However, unpaid advocacy work puts an additional burden on women who, in certain families, are the main breadwinner and caregiver at the same time.

> "First, I kept my job at the Ministry and when I had free time, I worked for our NGO. But three years ago, I stopped [working in the Ministry]. Now I work here [in the NGO] full-time. Because it was too much, working from 9am to 6pm and afterwards being active in the NGO. And at home I had to be an active mother, too. I could do that for a while, but then it became overwhelming" (Tamar, NGO-worker, non-disabled mother).

Unpaid work is an important part of disability advocacy. Usually, women do not see this work as a salary job. In many cases, they had one or two other jobs besides the NGO work. Certain women activists see the lack of or minimal income as one of the reasons why men are less interested to work in this field. "Men don't see a perspective in advocacy work. We work without money. Men don't want to work without salaries, that's not interesting for them" (Maia, NGO-Founder, non-disabled mother).

The salaries in SPOs are incredibly low and work in DPOs or DAOs is often unpaid. According to the interview data, most women who are active are mothers of children with disabilities. They are seen as having a "natural motivation" to improve the life for their children. "The Mothers have a personal motivation. They don't give up. They fight harder than people without emotional involvement" (Tamar, NGO-worker, non-disabled mother). Participants said that loyalty to the organization they work in and personal involvement were key for the success of NGOs. A mother described her motivation like that:

> "If I look back at my life, it has never been difficult for me to do all of that [activism]. It was easy for me because even before, I always had a job where I was helping others. And this desire to help other people became even stronger, because my son has the same needs. And I think that the engine that keeps us going is strongest if we're doing this on a voluntary basis. But it also leads to demotivation if you're doing this for years without any success. So, depending on that, you don't need financial compensation, but at least recognition. I think as long as there is still so much to do, as long as our children don't have all the development and educational opportunities that others have, we will always be strong and become even stronger" (Maia, NGO-founder, non-disabled mother).

Many mother activists see their work as a meaningful and "fulfilling" task. They employed a narrative framing their role as mothers as the essential core of their activism. In other words, they use the idea of mothers' "natural" calling to care for their children to make sense of women's engagement in disability rights activism and service provision. From this perspective,

it seems less surprising that women are willing to work in this field without financial remuneration, whereas men are not. These gendered aspects of disability rights activism will be given more detailed attention in the following sections.

Even if mother activists think that not enough has been improved yet and that the process is slow (or more precisely slowed down by the government and the lack of unity within the movement), they are mainly confident that things will continue to improve. Phillips has described women's social justice activism as "personally empowering and transformative" but whether this "meaningful personal transformation" translates "into political empowerment" depends "on the structural forces and hegemonic discourses that shape and constrain personal and collective agency" (2005:493-495).

To sum up, women's experience in social professions in combination with their personal networks have helped them to establish CSOs around disability issues. While engaging in collective action, mothers have found a way to remain active in the public sphere and weather their personal struggles as primary caregivers, a development that has been described by many mothers as personally empowering and meaningful.

Representation versus Self-representation: Mothers of Children with Disabilities and Women with Disabilities

In the tradition of a paternalistic view on people with disabilities, policies and services (as well as research) were introduced "for" rather than with or by people with disabilities. This continues to be a global problem. It is self-evident that policies developed without a say of those who are affected, cannot be effective or they even run the risk of being discriminatory against those who they are supposed to protect. According to the CRPD, state parties commit to ensure and promote the work and participation of DPOs in all political spheres. While this requirement is far from being met even in advanced democracies, the first step is to ensure that disabled people and DPOs are included in political processes that target disability policies and services.

The demand for self-representation is strong among disabled women activists interviewed in this study. These activists refer to the CRPD and the human-rights model when they claim that people with disabilities (including women with disabilities) should be able to self-represent their interests in disability councils and working groups at government level. As they say, within Georgian disability activism, the distinction between representation (speaking on behalf of people with disabilities) and self-representation (people with disabilities speaking

for themselves) is blurred. This also concerns, for instance, parents' organisations and SPOs that claim to speak on behalf of disabled persons but might not always represent their interests. Disabled activists in this study criticized the circumstance that clear distinctions are not being made.

> "I would say, generally, the issue of definition is a problem. When they say, "people with disabilities participated in some kind of decision making", who do we mean? Do we mean, as I mentioned, these state sponsored GONGOs[2] [reference to SPOs]? Do we mean parents? Or adults with disabilities? Because that's a different interest group, you know, *parents*. Parents always say: "we are also people with disabilities" but this is not quite the case. They have their own needs as parents because they are often discriminated by association. They are often deprived of possibilities of self-development of going to work or whatsoever. But these are *different* issues" (Elene, NGO-founder, disabled activist).

Mothers of children or adults with disabilities in many cases take on roles of bridging the gap between the needs of their children and the inadequate environment. This requires, as mentioned above, additional economic resources such as time and money. Mothers are, compared to fathers, also more affected by stigmatization if they have a child with disability which shows the intersection of patriarchy and ableism. We have discussed above, how the responsibility for helping disabled family members is, in many cases, placed entirely upon women. Such factors can provoke precarious situations for non-disabled mothers and women. It is therefore important that mothers' organisations are active in defending their interests. As Philpott noted, primary caregivers need help too. However, it appears crucial that government institutions and international donors note the difference between disability organisations speaking on behalf of people with disabilities and organisations in which disabled people represent themselves. According to the CRPD, the latter should be prioritized in government consultation and decision-making processes. A human rights lawyer regretted in an interview that this approach is not commonplace. As an example, she mentioned a meeting for the forming of a coordination council (required by Article 33, CRPD – but after 3 years still not established), where the government invited non-disabled people in the room and provided zoom links for disabled people.

Disabled women emphasized that the participation of disabled people is not only crucial from a perspective of cultural recognition that manifests itself in self-representation, but also noted that parents are not necessarily representing their children's interests but their own interests as caregivers.

> "And often I would say they [the interests of parents] even come to be contrary and at odds with the interests of people with disabilities. Because people with disabilities, you know, want more

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[2] Government-organised Nongovernment Organisations, meaning organisations that represent themselves as independent civil society organisations but are funded by the state and therefore less critical of the latter.

independence, want more control over their life, less dependency on their families. And parents with children with disabilities would actually lobby for things that would actually tie them more to their children. For example, they lobby a lot for parents' compensations. So that they would be caregivers - official personal assistance of their children. Which is different you know, personal assistance is different from family care" (Elene, NGO-Founder, disabled activist).

This activist argues for more self-determination in the tradition of feminist disability scholars. Persons with disabilities, and especially women with disabilities, must get more control over disability services to gain more independence. Using the concept of interdependence, disabled activists do not deny that they need services (or care). On the contrary, adequate services are a prerequisite for an independent living. However, disabled people lose autonomy, if disability policies and services remain in the hands of non-disabled people. Or to put it in Myriam Winance's words: "All autonomous subjects have also at some point been and still are dependent subjects […]. In this vision, it is therefore not a matter of opposing 'autonomy' and 'dependency' but of showing how care relationships and dependency underlie autonomy" (2016:105).

In Georgian disability activism, however, the category of *women with disabilities* seems to be blurred with *mothers of children with disabilities*. A disabled activist told me that during a meeting with high level politicians that was officially supposed to be a meeting with disabled women, three quarters were actually non-disabled mothers. The women with disabilities who were in the minority did not feel like they could bring forward their points and questions. "We [women with disabilities] were really talked over. But in official documents it said: *Politician X met with women with disabilities*. But where is our impact? Where is our role as agents of change? Or, you know, as people who hold their own lives?".

Coming from the angle of feminist disability studies, it seems important to carefully disentangle the struggle of mothers and their need for support, empowerment, and social recognition on the one hand, and disabled women's demand for more control and autonomy on the other hand. This is crucial as not to fall into the old pattern of equating disability with a need for care, and a need of care with dependency. It is the government's and national and international donors' responsibility, I argue, to empower people with disabilities, especially women with disabilities, and their representative organisations, so that they can help shape disability policies and policy implementations.

"In theory the government says: 'Yes, we do switch to the human rights-based approach, and yes, disability is about social barriers and not about somebody's health condition.' But that is not how people with disabilities are perceived in practice. If people with disabilities are stuck in their homes, then nobody is going to believe this. People will say: 'Well, that's written somewhere in the law, but…' They won't believe us if you still see that so many people are begging. People with disabilities are simply begging" (Nana, disabled activist).

This statement refers to the discrepancy between legislative change and the actual improvement for disabled people's life. Like with other oppressed groups, concepts of equality can only be implemented while the image and the position of power of people with disabilities improves. Therefore, disabled women activists demand more agency through, for example, disability councils on the state and municipal level.

Georgia, however, does not have a unified database of DPOs or NGOs that work on disability issues. Therefore, "it is difficult to ensure the involvement of all interested organisations in decision-making processes and to ensure equal participation and determine whether the views of DPOs are prioritized" (UNDP, 2021:41). According to the same report, working groups that have been created to ensure people with disabilities' participation are composed of service provider organisations and DAOs and lack the direct involvement of people with disabilities (especially women). In addition, activists consider state institutions and the government not to be sensitised enough to understand what participation and democratic process regarding the CRPD really means. This is the case because

> "they [the government] are not hiring persons who are committed in disability rights. They are hiring people who are loyal to the government with some knowledge in human rights. This 'some human rights knowledge' is not enough for such sensitive issues, not to exclude persons with disabilities from a meeting *on* persons with disabilities. They are not choosing employees based on professional merit, but loyalty based" (Natia, NGO-founder, non-disabled activist).

It is important for the movement that non-disabled people stand in solidarity with disability rights. However, for the successful implementation of a human-rights approach, it is essential that people with disabilities can represent themselves in key positions and that their places are not filled by parent organisations or other non-member-based NGOs. However, this also means that gender-specific barriers must be broken down so that women with disabilities can represent their own interests at the social and political level.

In conclusion, disabled women activists claim that control over disability services and policies should be located among DPOs and disabled individuals, including women. It is also international donors' and the government's responsibility to assure visibility, resources and agency needed to membership-based organisations. Distinguishing disabled people's rights from the notion of care and dependency remains very difficult, and this might be a product of but also a reason for low involvement of disabled people and their organisations in decision making processes. The most important factors impeding progress are the government's attitude and the lack of data covering membership-based organisations.

Framing Women's Visions of Inclusion

Women in this study described the full implementation of the CRPD as the ultimate objective they are working towards. For many of them, inclusion will be achieved once the category of disability disappears. This reflects the social model of disability which sees disability as the product of a disabling environment that is only accessible to individuals who conform to the norm (those who are seen as non-disabled). As we will see in the excerpts below, the social model is broadly accepted by women disability activists in Georgia.

> "If all people accept/embrace disability as normal, the rest will change automatically. If all people are aware of human diversity, then people with disabilities will be mainstreamed and everything like education, the labor market, the physical environment and so on, will be built in an inclusive way. As soon as we internalize that, everything will be fine. And so, disability will disappear. There will be no more 'extra groups'" (Tinatin, non-disabled professional).

> "I want us to live in a society with very different people, but all have the same value and position. Everyone is equally recognized and treated equally. Our [organisation's] goal is that people are not frightened when they meet a child or adult with disability in the street, that they do not stare or ask stupid questions. But that living with a disability is simply a lifestyle among others" (Maia, NGO-founder, non-disabled mother).

Disability as a "lifestyle" refers to disability being a socio-cultural category that changes over time. In this sense, many activists, especially mothers, see the need to change people's mindset and attitude as a priority (or prerequisite) to achieving inclusion. It is therefore not surprising that many of their organisations are involved in raising awareness. Activists emphasized how difficult it is to change society's attitude towards disability, but their hope lies in the new generation which, according to them, is different from the "old one" and able to understand human rights values. Mothers' DAOs' strategies can vary from somewhat to very conflict-oriented. However, informants have reported that these organisations usually become more consensus-oriented, once they start providing disability services.

A smaller group of activists (including disabled women and human rights lawyers), however, take a more radical approach. Inclusion needs to be "forced" on society through legal mechanisms and policies. People's attitude towards disabled people will then automatically change as soon as people with disabilities are present and represented in all spheres of public life. The argument for this approach lies in the thinking that people with disabilities cannot wait for society to go through the required development to finally be able to enjoy their rights. Therefore, the most important domains are deinstitutionalization and independent living, cultural recognition, and political and economic participation. Some activists stated that the only way to achieve these goals in Georgia was through litigation. A non-disabled human rights lawyer stated: "In Georgia, if you don't have power behind your words, people will not follow

or believe you, or just simply do the right thing. But the court's ruling should be enforced by the law enforcement and by the police. So, of course, this power is more convincing, than the right cause itself".

Such litigation-based, conflict-oriented models of disability development are met with reluctance or resistance by the authorities. The government prefers to spend money on disability services rather than human rights and social justice development. For instance, disability activists and their organisations have been fighting in vain to introduce employment quotas. Activists suspect that the government is not ready to make systematic changes as they are afraid of business elites. This shows the difficult ground on which disability activists act in Georgia.

Conflict-oriented activists and organisations have trouble gaining the solidarity of the broad public. On the one hand, this may be due to a general political apathy that is common to all post-Soviet countries; on the other hand, it also has to do with the issue of disability itself, which, according to prevailing Soviet thinking, is not considered a socially relevant problem but an individual one. In this sense, disability is thought of in the framework of "pity" and "charity", but not of rights. Activists also see the low social development in the country as one of the biggest problems for any kind of human rights-based approach. An activist argued that human rights for people with disabilities are difficult to mainstream in Georgia, because even on a political level, the values of the CRPD are not understood.

> "The funny thing is that our government ratified the UNCRPD without even understanding what was behind it. They knew it was a Convention, a good Convention that would make them look good on the international stage. But they didn't realize how strong of a mechanism this is"

And further:

> "[T]he way these values were introduced were like "oh, these are good values because they are in the Convention". It means that people cannot really identify their ownership of these values. I think that a lot of international organisations that are also providing human rights education do not really consider this post-Soviet mentality that "oh, these Western societies are bringing some causes, we have to follow them". But human rights are not about we "have to". This is why in Georgian society there is a huge issue with understanding human rights. For example, what is freedom? What is freedom of expression? They find it really hard to understand because it doesn't directly lead to everyday needs of, you know, food, and clothing and housing. And there is a disconnection" (Natia, NGO-founder, non-disabled activist).

It seems obvious that "imported" values and rights have a small impact on people's life if politicians and CSOs fail to credibly integrate them into the national context. At the core of most respondents' visions lies a call for radical social justice transformation based on universal human rights and concepts of equality. However, there is a great discrepancy between grassroots activists on the one hand, and policy makers and boarder society on the other hand. All interviewed women struggle to advance their visions of inclusion in an environment where

democratic values have only been introduced recently and social inequality remains one of the biggest issues.

Disabled women activists' visions of inclusion explicitly target both gender and disability issues. In this sense, they have a different epistemological take on disability rights as they consider gender to be a horizontal category crossing all areas of disability. In this sense, they break up the disability bubble and seek allies in, for example, non-disabled women's organizations.

> "[T]here was one organization that started to train mothers or pregnant women for positive parenting. And one of our disabled women activists asked if they are prepared to include women with disabilities and they were like… they didn't... you know, they couldn't imagine that women with disabilities could become mothers and have children, too" (Elene, NGO-Founder, disabled activist)

This approach is difficult as there is a lack of consciousness regarding disability issues outside of the disability bubble. Disabled women activists are struggling with mainstreaming their cause among non-disabled women's organisations. Disabled women are more marginalized as a social group and less politically or socially active because of structural barriers and discrimination. Many experts and reports have pointed out the dual vulnerability of women and girls with disabilities in Georgia (Makharadze, 2020; PHR, 2021; UN Women, 2021). Even if this issue is particularly exigent in Georgia, discrimination of women with disabilities remains a global problem. International feminist disability studies have increasingly criticized that disabled women have been overlooked by both feminists and disability rights activists at the same time. As one interview participant put it: "[I]n the women's rights movement, women with disabilities are also very much underrepresented. So, it's both. Somebody once said: In disability communities we are women and in women's rights communities we are invalids. You know, invalid people" (Elene, NGO-Founder, disabled activist and researcher).

Acknowledging the twofold exclusion of women with disabilities, a few DPO's founded by disabled women in Georgia have made it their mission to empower disabled women's positions in both the women's rights movement and the disability rights movement respectively (see e.g., Association of Disabled Women and Mothers of Disabled Children "DEA" and the Platform for New Opportunities). However, these organisations face considerable challenges such as funding, limited reach and rigid stereotypes about gender and disability.

> "For a long time, gender and disability were not considered together. People thought that these two things were completely separate aspects. And in Georgia in 2009 they created a good legislation for people with disabilities, however, in this legislation the differences between women and men with disabilities were not pointed out. Because the people could not see why there would be a difference. Not only in society, but also the women with disabilities did not see themselves as a distinguished interest group from men with disabilities. At the same time, international organization could also not see this issue. Only in 2014 the UN women created a draft of the strategy (plan) where they also

highlighted that there is an inequality between women [without disabilities] and women with disabilities. So, they created a strategy to give opportunity to women with disabilities and to enable them to participate in all activities, internationally or locally" (Irina, NGO-Founder, disabled activist).

Such intersectional initiatives are rare in Georgia, but crucial. They aim to uncover the particular barriers disabled women face vis-à-vis a patriarchal ableist environment. For instance, are women with disabilities experiencing a *double* oppression or is their oppression of a different *quality*? (Sarah Woodin, 2014). This level of analysis is important to consider, thinking that intersectionality does not mean to just add two or several categories on top of each other, but to look at the different quality their intersection may produce, and the reciprocate effect they engender. Therefore, as a respondent noted, gender should be considered as an intersectional topic underlying all disability laws and activities. "There is also the problem that there is no separate statistic showing data on women with disabilities. The data shows women as a whole, but not a subgroup of women with disabilities." She continues:

> "Our organization is unique, because it is not in a closed circle, meaning that we try to work with organisations that have a completely different profile form us. For example with ogranisations that have a political, economic, or social profile. Because we want the whole society to see that our cause – the needs of women with disabilities – is really important. And therefore, our target group are not only people with disabilities, but also the local and central government, all women, youngsters, media, NGOs. This strategy is really important for social inclusion and integration. Because we want women with disabilities to be representing themselves, that they stand for themselves" (Irina, NGO-Founder, disabled activist).

To conclude, like western disability rights movements, activists in this study employ the social model as their vision of inclusion. Mothers and disabled activists both use, as I argue, a conflict-oriented approach, as they focus on cultural recognition and human rights rather than material needs. Even though material needs and disability services are claims that are raised by all activists, the important distinction to consensus-oriented models is that they are framed in a human rights rather than "charity language". In addition, disabled women activists emphasise gender as a marker of exclusion within disability activism. Their consciousness as a distinct social group is only beginning to be shaped with the help of a few still marginal organisations and individual activists.

Consensus or Conflict oriented? Co-option, Monopolization, and inter-NGO Competition

Like any social movement, disability activism in Georgia interacts with the social and political environment (Waldschmidt et al., 2015). This environment can promote or hinder activism from

flourishing. Critical civil society research has noted that not every civil society organization or group operates independently from the government and performs its assigned "task" to keep the state in check. Governments can use CSOs to promote government strategies while manipulating civil society consent (Doyle, 2018). Such co-option practices do not necessarily need to be part of a larger government strategy but can appear because of financial dependency.

The respondents have almost commonly raised the issue of state co-option of SPOs and monopolization within the field of disability activism as one of the biggest impediments to creating a strong, unified disability rights movement in Georgia. SPOs receive funding from the state, but they also seek funding from international donors for monitoring CRPD implementation. Activists see two major issues with this practice. First, these SPOs have much more resources based on their proximity to the state budget which allows them to dominate the field over others, for instance over advocacy organisations. "They have resources, they can mobilize people, parents, children, because they have beneficiaries", as a respondent said. Organisations that do not provide services with government funds have a smaller visibility which allows SPOs to monopolize the field. Second, due to the double role of SPOs, there is a threat that these organisations might promote state narratives rather than keeping government practices in check.

> "So, service providers that are spending government money are self-identifying as advocacy groups, but in fact, they are only implementing government services which are almost always in shortage. Not of good quality. So, when the people are angry at the government, those disability organisations are in the middle, kind of buffering the government from the pressure. And that's why there is no movement" (Nana, disabled activist).

This critical view of SPOs is widespread among activists. One activist, for instance, called these SPOs "GONGOs" (Governmental-organized non-governmental organisations), implying that they are not independent and their function within disability activism should be questioned. Another activist said that SPOs main interest lay in being in a good relationship with the government. "Then you are in power" (Natia, NGO-Founder, non-disabled activist). Because the majority of the respondents to this study were not service providers but members of DAOs and DPOs, they were very critical of SPOs and perceive them as hindering the movement from taking on a stronger human-rights approach.

Furthermore, women activists and professionals have reported that the government uses government friendly SPOs to pit different interest groups against each other or to "buy" consensus from civil society. For instance, if partially government funded organisations are used as watch dogs and are consulted for policy recommendations, it is obvious that the results will not benefit the concerned people. Most respondents assumed, that SPOs use a consensus-

oriented approach because they are dependent on the state budget. Conflict-oriented organisations feel undermined by consensus-model SPOs. However, it is often representatives of SPOs who participate in disability councils rather than people with disabilities themselves (UNDP, 2021). This casts doubt on the seriousness with which the views of people with disabilities are considered by the government. Many see the double role of SPOs as impeding the building of a united front of disability organizations vis-à-vis the government.

> "So, if we think about, what hinders the movement? First, this ambiguous situation 'who is who?' really hinders the movement, because it gives the opportunity to the few larger organisations that receive both, state and international funding, to monopolize the field. Then we have a few more or less independent organizations and activists, but because they don't provide services, they have very little and unstable funding from donors. Only for research or for reports. And that's why they cannot attract supporters, attract beneficiaries, and reach out to more people with disabilities. They don't have these resources. Their voice always remains somewhere in the background" (Elene, NGO-Founder, disabled activist).

This statement shows that state funded SPOs are perceived as a threat for smaller non-governmental organisations, as they are seen as loyal to the government rather than to the cause of the disability rights movement. Many disability organisations do not provide services and are therefore in a financially more vulnerable situation, as their funds rely entirely on international donors and are not stable. Such organisations are mainly DAOs and DPOs. These organisations do advocacy work for free. Finances are one of the biggest issues within disability activism, especially for awareness raising organisations that do not provide services

Activists see international donors as responsible for contributing to this financial imbalance between SPOs and disability organisations that do not provide services:

> "I mean, this never happens in any other movement. If you take, for example, US based donors, they look very thoroughly into whom are they funding. And they would not fund organisations that are associated with political parties, especially with the government party. But in the disability movement this happens, you know, that organisations that are very friendly with the government are still being funded as watchdogs" (Khatia, NGO-worker, non-disabled researcher).

This statement points to a lack of knowledge or consciousness of the local disability rights landscape by international donors. Women working in small advocacy organisations (both membership-based and mothers' organisations) have repeatedly reported the difficulties to fit international donors' agendas and attract funds for activities, among other things because they compete with much larger government funded organisations. This in turn links back to the overall problem of civil society development in Georgia. First, as respondents stated, corporate social responsibility is very low in Georgia, meaning that little local private funding is available, and NGOs are dependent on government and international funds. Second, international donors, as noted above, seem to ignore local challenges such as corruption, lack of understanding of democratic values, and government co-option or pressure on civil society organisations. As

many scholars rightly criticised, civil society organisations, especially in transitioning countries, are not entirely independent from the state or the market (Phillips, 2005; Alyiev, 2017; Doyle, 2018) which can, as in this case, hinder a strong social movement.

In addition, according to respondents, the Georgian government appears to be hostile towards conflict-oriented NGOs and individuals using different strategies to silence those voices. A human rights lawyer explained how SPOs are played off against other organisations: "For example, if I ask someone [from a SPO] to come as a witness to the court hearing to say that the government must improve something, they will be dismissed. The government fires them and they cannot provide services anymore. Sometimes, they are even prohibited to contact us because we are perceived as problem makers" (Natia, NGO-Founder, non-disabled activist). Likewise, a woman activist working in a state institution mentioned that regarding disability and human rights protection, state institutions do not welcome critical voices. She explained:

> "No one wants to have employees who speak up. That is our problem. In a month, I will probably be unemployed because of the restructuring of the institution (deinstitutionalization). My colleague and I have always worked honestly, we love our work, and we work accordingly. And the structure where we work, they know us. And we sometimes said something [about the bad circumstances], not often tho'. I told you, for instance, what we saw happening in this institution in S. We reported these incidents sometimes. That's why they may see us as a problem. Now they are closing this institution, but they could offer us another job, they lack professionals. But they don't do that because they don't want to have people who speak up. It was like that under communism, and now it's like that again" (Tinatin, non-disabled professional).

It is noteworthy that between 2008 and 2010 "[d]espite adoption of a national Disability Action Plan in 2010 to promote inclusion of persons with disabilities in society", the institution mentioned in the quote above (together with a few other long-term institutions) was renovated and expanded with the help of US government money and funds form UNICEF (DRI, 2013). It should be obvious at this point that such international investments are misplaced and at odds with disability activists' efforts.

Besides competition within the funding system, disunity and different interests of organisations hinder a strong movement. One respondent stated: "There is no unified [disability rights] movement in Georgia. There are several parts and pieces. But it's not unified, by no means". Many activists regret that some disability organisations, mainly SPOs and traditional DPOs put their interests as an organisation above a common goal, namely to implement a human-rights approach of disability development. A respondent said that her organization came to realize that the different disability organisations must collaborate closer together if they want to have a stronger impact. Therefore, they have just started a platform aiming to enhance collaboration between different organisations. However, this seems to be a difficult task for organisations that are used to advocating for their own disability group-specific cause.

> "It is a painful process until everyone understands that there is no winner or loser. It is really painful. Because people are used to looking out for their own interests. And that can't always work. So, there are different opinions, there are different needs within the disability topic. People who are blind, who are deaf, who have Down syndrome, or cerebral palsy have different problems - and also different interests. But we should somehow come together in a row, then we'll be strong" (Maia, NGO-Founder, non-disabled mother).

As a Soviet legacy, successor states including Georgia have inherited fragmented and therefore disempowered disability organisations (Philips, 2009). As mentioned above, the impact of disability activism depends on how successfully different disability organisations and activists will gather around a common human rights-based approach, creating ties and solidarity beyond individual groups and material needs.

To sum up, the research data suggests that the disability rights movement in Georgia suffers from similar weaknesses as other post-communist societies in Europe (see Holland, 2008). Above all, this includes the non-confrontational attitude towards government disability policies by influential SPOs within the field. Consensus-based SPOs have an easier time existing within disability activism as they receive state funding and are, according to some disability activists, favoured by the government and the society. This results in a disequilibrium in resources and power which creates an even tougher situation for those working solely on disability rights advocacy. Then, the fragmentation of disability organisations and their inability to gather around the goal to shift the paradigm of disability development toward a human-rights based approach weakens the movement significantly.

Gender Conflict: Challenging and Reproducing Gender Roles

The gender ratio in disability organisations points towards a reinforcement of traditional gender roles within disability activism. A study by the Open Society Foundation in 2016 found that DPOs are mainly headed by men and allow only little input from women with disabilities (UNDP, 2021:40). According to their findings, only 0-20% of members in membership-based organisations advocating for disability rights are women. The underrepresentation of disabled women within membership-based organisations was a topic that was frequently raised by interview participants.

> "So, within the disability field in Georgia, if you count the head, simply the head count, you will see that boys and men with disabilities will get bigger resources. Girls and women with disabilities are kept silent. Often, on social media as well. And nobody dares to take a side for these women because that'd mean to criticize men with disabilities" (Natia, NGO-Founder, non-disabled activist).

Women activists stress that traditional DPOs are not just gender blind, but women activists feel actively silenced and excluded, and their issues are not considered: "If you look into traditional organisations that have existed since Soviet times, they were more or less founded and led by people with disabilities, these organizations are very patriarchal, very gender blind I would say. Not even blind, but sexist in a way, where women are in a more subordinate position" (Elene, NGO-Founder, disabled activist, and researcher). Topics that concern women with disabilities such as sexual and reproductive health and education are usually dismissed by these organisations or they even position themselves against those rights.

In most municipalities where disability councils exist, women with disabilities are not represented (UNDP, 2021). Instead, it is men with disabilities, mothers, or service provider representatives. Disabled women activists point out that their issues cannot be represented by mothers' organisations or SPOs. Neither can they accept that men-dominated membership-based organizations are speaking on their behalf. Clear distinction of different social groups within the field of disability is crucial for sustainable social justice transformation.

When it comes to non-member-based organizations, however, women (mainly mothers) are much more active than men. Some mothers did not question why men are less involved and are seeing it as "normal" that the field is dominated by mothers and women professionals: "So, the reason is nature and nurture – I don't know. Why women? It's cultural. Why are mainly mothers taking care of children? Women take care of children, this is happening everywhere and here too" (Nutsa, NGO-Founder, non-disabled mother). This statement reflects two links that were discussed at the beginning of this dissertation. First, womanhood is strongly connected to motherhood, and motherhood is framed in the notion of care and a set of other responsibilities. Second, this understanding of gendered expectation and disability points to a prevailing view of disability as a problem of "care" rather than a problem of rights. Reducing people with disabilities to objects of care, as is discussed above, contradicts the very essence of the CRPD and many disabled people's claims for more autonomy. However, while framing disability as a "female" responsibility of care, women can become active in the public sphere without rootedly challenging gender norms that are assigned to them. Similar results were found by Ishkanian in her study of Armenian women NGO workers who attached their social activism to notions of motherhood (2004).

> "Because with us it was always very traditional, the mothers were with their children, walking, feeding, dressing. And in recent years, all that has changed. And society has accepted that fathers should take care of the children more, like mothers. But with the issue of disability, it is even more difficult. The topic of disability is seen even more as a women's issue in society, I think" (Tamar, NGO-worker, non-disabled mother).

However, attitudes towards men's and women's roles within the field of disability are very heterogenous. Mothers have an ambivalent take on conceptualizing disability as a natural female issue of care. Whereas some see it as "normal" or "a matter of course" that predominantly women take up the task of advocating for their children, others are very critical of it. Two mothers working in a parent's organisation were telling me about their NGO-internal discussions around the low involvement of their husbands.

> "A few days ago, we talked about actively involving our fathers [meaning husbands]. Some of them are already active, but never as active as we women are. And it is a very visible trend in Georgia. When any problems arise, it is mainly women how try to solve them. It is completely different however, when it is about keeping privileged positions or advantages – in this case, men are very active [laughs]" (Ana, NGO-worker, non-disabled mother).

These women connected men's low involvement to their gendered social privileges to care only about themselves, whereas women bear responsibilities to care for so-called vulnerable groups (e.g. elderly or disabled). Having identified such discriminating gender roles, these mothers openly question the push back of disability issues into the private sphere: "I think the society is responsible [for children with disabilities]. The government is responsible. I think everyone has some kind of responsibility". This statement does not necessarily challenge traditional female roles as carer but expresses a desire to resettle the issue form the private to the societal level.

Compared to mothers, the disabled women activists interviewed address the gender conflict more openly and pursue more feminist goals. They are seeking self-representation as women within disability discourses and recognition as disabled people within the women's movement. Because they are discriminated as women *and* as people with disabilities, for them it is unavoidable to tackle these issues simultaneously.

> "It's disadvantage on three levels: If we look at the big picture of gender gap of course men are more privileged because they don't 'worry' about their children with disabilities, because the women worry more. At least it seems this way. If we look at the level of disability, again, men are more vocal because of the patriarchal structure, men are usually more vocal. And on the level of women with and without disabilities, women without disabilities are more visible because they have an advantage, they don't have a disability themselves" (Elene, NGO-founder, disabled activist).

For disabled women activists power structures underpinned by patriarchy and ableism put two layers of discrimination impeding their agency within disability activism. Fist as women with disability they experience more stigmatization, and their voices are silenced vis-à-vis disabled men. Second, as we have already discussed, they are overtalked by non-disabled women who have more social capital for raising their claims.

The struggle for social justice transformation through civil society activism is seen as a sphere where non-disabled women can exercise more power independently from men. Disability is a sphere where mothers have the say in a public sphere and have already developed

their own strategies without men. Asking an interviewee why she thinks non-disabled men are not active compared women in disability rights advocacy, she replied:

> "When I think about it thoroughly, it's really because of us [women]. We also prefer to organise everything on our own. We wish that we had also men among us. But at the same time, we don't do much for this to happen. And arguing with men because they have a different opinion is also uncomfortable for us. And so, there are also excuses on our side, such as 'I'd rather do it myself because you don't do it the way it should be anyway'" (Maia, NGO-founder, non-disabled mother).

Women can improve their positions in society through social justice struggle and establish their own networks and influence in the civil society sector. Women have, to a certain extent, gotten used to taking a dominant position in disability activism, while they are also aware of the responsibility and difficulties they are carrying while men do not.

> "Because from our side, this dominance is also activated in various areas or tasks. It is also activated in us because we think: "I have more to say here" or "I can do better there". So somehow it is logical that we as women are so active now and achieve all of this. But on the other hand, we didn't want to fight alone, or to feel abandoned in the struggle" (Ana, NGO-worker, non-disabled mother).

On the other hand, mother activists described their men counterparts as weak and useless when it comes to solving societal issues. These gender expectations have an impact on how work and power are distributed within society and limit women's activities to "female" topics. At the same time, men have the privilege not to "care". Men's lack of responsibility regarding disability was described by some as an essential male trait: "Very often, when a child with disability is born, the fathers leave the family. Why? They are afraid. They cannot take on the responsibility. And they are weak." (Tamar, NGO-worker, non-disabled mother). This narrative of men as weak and irresponsible runs across the spectrum of all respondents: "Many men, when they see children or adults with disabilities, they say 'oh, I can't do that'. They have tears in their eyes. Women are stronger. And they have motherly feelings. And whatever the case, men have tunnel visions, women have a holistic view" (Tinatin, non-disabled professional). Many of the respondents did not challenge the assumption that men and women are essentially different and have different strengths and therefore roles, but still challenged male privileges.

A bit more than half of the respondents think that disability activism could benefit from more non-disabled men's or fathers' involvement. Others see men's involvement as a potential threat, because more men also means that the dominant position of women would be endangered, and women could be pushed back. This fear is rooted in assumptions of "typical" male behaviour as bossy, undemocratic, corrupt and clientelist, as this statement shows:

> "Even within activism, they [men] act like bosses, you see. It's really tiresome. We are so tired. We are really tired of having so many bosses around. So, women are more honest. We don't have to hide that we have a lot of issues. All of us have a lot of issues. With children, with health care, with social protection. […] as I mentioned, men are not discussing with us. They go and seek some

connections. Making deals, making negotiations. Isolating women from the negotiations. Hiding things" (Maryam, non-disabled activist).

While women are perceived as democratic beings, able to perform collective action and solidarity, men are seen as a threat for disability rights activism as they use corrupt and exclusionary methods. This fear also points to the attitude of women activists that sustainable social change can only be achieved through democratic processes and open negotiations that involve the entire society and do not favour certain groups over others. The same concerns were expressed regarding disabled men and men dominated DPOs:

> "[D]isabled men, in Georgia, I cannot generalize, but there is a pattern, that disabled men are in a very good relationship with the government. Not only with the government but also with the shadow government – Oligarchs – so, if we have some kind of public platform to discuss some disability related issues, they are solving things behind the scenes. And then they approach us: 'everything has been solved already, it's in vain that you're gathering and discussing. Nobody needs your discussion'. Everybody knows that this is a pattern. Some of them are in the parliament other are their allies. So yeah, disabled men have a lot of good connections with non-disabled men who are in power" (Natia, NGO-Founder, non-disabled activist).

Men dominated DPOs are not perceived as allies by many disability rights activists interviewed. On the contrary, these organisations are described as embracing informality, which, as Aliyev (2015, 2017) points out, is so widespread in Georgia and the South Caucasus. The problem with this is that informality leads to uncivil practices and use of patronage and corruption that undermines democratic processes and excludes people, here women with disabilities, from decision making processes. Furthermore, traditional DPOs are narrated as using their privileges (being men and not women with disabilities) to keep women in subordinate positions.

> "Women with disabilities are involved [in DPOs] in more technical ways. Usually, they are expected to do all the writing, whereas men are expected to meet the government and voicing their concerns with high level officials. […] There is no research about it, but only from watching men and women, I would say that women with disabilities probably do much more work. As I said, women are usually those who write, do all the research, and men are the ones that talk at larger events or talk to government officials privately" (Elene, NGO-founder, disabled activist).

We have discussed that power structures in Georgia are very patriarchal and rigid. Looking at women's representation in decision making positions, in government or parliament, they are largely underrepresented. Coming from this perspective, some activists have framed disability rights activism as a part of a broader social justice struggle that includes gender equality but also other dimensions that are important for Georgia such as ethnic and religious minorities, the poor, etc. Activists have seen women as putting much effort and unpaid work into grassroots activism, whereas the top-down responses are dominated by men in powerful positions. An activist sees the implications of this system the following way:

> "Well, that's why our policies are lame. Our policies do not reflect (or respond to) reality. I mean, we [women] are pushing from the bottom up. But they [men] are too powerful. But you know, if we

become better professionals, we'll be able to change that. I believe in litigation. Really! I think that currently, women lawyers are the best in disability rights, women's rights, and children's rights. Men judges try to silence us sometimes. But they cannot overwrite the fact that we are better educated, and we put a lot of effort into it. I think one day it will have some results. Maybe not today. But, you know, I think it's a process. It's the very beginning for us. It has been only 30 years since we became independent. I cannot expect to be like the UK or the US in terms of disability rights. But I think we are doing some good things, because for the last two years, we have had a lot of achievements. […] And if we keep this work going, after several years, things will change" (Natia, NGO-founder, non-disabled activist).

The fight for disability rights in Georgia is narrated here as a wholesome social justice transformation that includes challenging patriarchal hierarchies. While advocating for underprivileged groups, women can increase their own position in society over the long run, even if for the moment their impact might be limited. This activist argued further that women are better advocates because they themselves experience social injustice:

"I think more women should be involved, to be honest. I don't know… Men activists do things differently. In Georgia at least, they want to be seen as powerful persons, who are in charge and who are well educated, etc. But women… For example, I started mentoring several women with disabilities and they started to write blog posts about first-hand experience in reproductive and sexual health. And no one else can do this, if you don't have the experience of being harassed at the gynecologist, right?! So, I like the way women are putting the issues. "It concerns me, I have experienced it. You cannot say that I am lying because I myself are the proof". On the other hand, men are usually coming from a position of power, right?! They're like: "it should be done like this". So, it really depends, but for me it's really effective to have women's voices" (Maryam, non-disabled activist).

This study has highlighted how disability tends to be framed as a "feminized" problem. Some activists, however, see a disadvantage that mainly women are advocating for disability rights. This way, they argue, the cause is less supported in broad society. This points towards the construction of women and disability as the 'other' compared to the dominant 'one' (able bodied men). The 'other' represents a group whose interests have no space in the hegemonic social discourse.

"When men are more active, society is more tolerant towards the issue. When society sees that fathers are also involved [in disability rights activism], society perceives it differently. Because it is so genetically anchored that the mother always takes care of the child. It's a connection between mother and child that lasts the whole life that is taken for granted. […] And if you saw the fathers on TV or radio talking about the subject, with competence and also joy, that would be like a wave. It would be a role model for other fathers. In Georgia it is like that, we still have a lot to do. Society, at the moment, only ever sees the mothers speaking in public. But if they saw the fathers who are active, they would perceive it very differently. Then, their attention would awake" (Tamar, NGO-worker, non-disabled mother).

The statement above regrets the lack of male role models for fathers. However, it also shows the activist's assumption that men's voices are more heard in society (at least with regards to disability advocacy). Other activists shared this view, explaining that a certain negative attitude towards the claims of mothers and women would decrease, if men were standing with them. In

this sense, if men were involved, the struggle for rights would be broader supported in society and would therefore probably be more effective.

> "Unfortunately, sometimes we can see negative reaction from the society when they see female activism. For instance, there is a very popular quote: "Does this woman not have a patron?" like, you know, someone who keeps this female [sic] in check. But these kinds of reactions are gradually fading away. Because people see that women are equal to men. And women prove this by their ability, by their experience" (Irina, NGO-Founder, disabled activist).

Disabled activists, too, have seen backlash towards women's civil activism, and more so in cases where disabled women speak up. In a strongly patriarchal society, women demanding rights and services can be met with aversion and contempt. Women's disability rights activism attacks prevailing power structures and thereby threaten the privileges not only of men but also of non-disabled people in general. As this activist revealed, there seems to be a misconception of disability advocacy in Georgian society:

> "And as I say, when some positive change happens, it's never attributed to me or women activists, it's attributed to donors or to the government. And we are always seen as provocateurs, intrigants, who are always finding some negative in everything. We are not super popular. We are either pitied, by those who don't know what we do. But by those who know what we do, they undermine us on purpose because…"
> *Interviewer: Because you are disturbing somehow?*
> "Yeah, yeah exactly" (Elene, NGO-Founder, disabled activist).

The societal responses to disability activism are dependent on the claims and the way these claims are framed. Demands for autonomy, full legal capacity, personhood, etc. seems to be difficult to understand for the broader Georgian society that has been used to framing disabled people as dependent on care and charity. And even more so if these demands are raised by disabled women.

On the other hand, some women refuse to see gender as a factor impeding women's agency. One activist stressed that men and women have equal opportunities, while framing the strength of female agency as inherent to motherhood: "I think in this century women are being heard. I cannot say that the government perceives us differently just because there is no man working here." And further: "Men have their own inner energy, which is different from ours, they have a strength that perhaps women do not have. But mothers and women can do a lot for their children, overcome a lot of mountains. I don't know if men could do that" (Tamar, NGO-worker, non-disabled mother). Mothers are seen as the more effective drive for social justice transformation as they have a personal (if not to say "natural") motivation to do so.

Overall, I have argued that mothers are the largest and strongest group within disability rights activism because of women's care roles and the prevailing perception of disability being a problem of care. This has pushed more non-disabled women than men into disability rights

activism. The framing of disability as a "feminized" sphere, as I argued, has also made it more difficult to disentangle disability issues from care as a form of charity. The 'charity' or 'pity' approach towards disability prevails in people's minds to this day. Thus, claims for equal rights are sometimes hardly received in broader society.

Whereas some women see advantages in more involvement of their husbands, such as for example broader acceptance of their claims in society, they also fear men's domination if they entered the field. Men, including disabled men, are not necessarily seen as allies to the women's driven disability rights activism in Georgia. On the contrary, men's ascribed qualities such as being corrupt or bypassing women are seen as a threat to social justice transformation.

6. Conclusion

This research aimed to discover gender implications within disability rights activism in Georgia. By looking into how women activists organize themselves, how they narrate their activism, and what gender expectations and gaps they face, this study has found several intersections of gender and disability in Georgia.

Non-disabled Women play a remarkable role in Georgian disability activism. Most disability initiatives stem from mothers of children with disabilities and their organisations. The fact that mothers and not fathers are giving up paid work to take up responsibility for their children with disabilities points to the dominance of traditional gender roles in Georgia. Women are still excluded from traditionally male dominated spheres such as politics and entrepreneurship. While civil activism, including disability advocacy has been a way for those women to remain active in the public space, it is also an expression of gender-specific challenges. Georgian women have endured a lack of state support for themselves and their children through self-organisation and collective action. It makes sense to think more about Phillip's thesis, suggesting that the state shifts the responsibility to care for its citizens from state institutions to the civil society sector, using gendered expectations of women (2005). Women in transitioning societies have found the civil society sector to be a place where they can gain the upper hand and through which they can find ways to weather difficulties of the post-Soviet transition (Ishkanian, 2004, 2005; Berg, 2004).

The fact that disability activism is a feminised sphere does not automatically empower disabled women. Disabled women activists feel disadvantaged compared to non-disabled

mothers who have more social capital to bring forward their claims to the public. Disabled women activists were found to be overlooked by state institutions and donors. They have significantly less resources than non-disabled mothers or disabled men and yet, they consider themselves a distinct interest group that must not be represented by others but aims for self-representation. The current situation within the field of disability activism points towards disability being trapped in patriarchal hierarchies and approached with paternalistic mindsets. As I have argued, with mothers representing the strongest force in disability advocacy, it might be difficult to win over the society to the idea that disability is not an issue of care or charity, but a human rights issue. Even though mothers' organisations use the CRPD as their basis and do explicitly use a human rights-based approach towards disability, the narrative of their activism often contains a traditional view of motherhood and care.

The disability rights movement in Georgia might benefit from overcoming this stage and bringing forward the claims of people with disabilities by disabled women and men themselves. It seems like one of the most important topics within gendered disability activisms in Georgia is the implicit alienation of non-disabled mothers and disabled women. Do mothers consider disabled women's perspective on care and interdependence in their activist work? Is it possible to overcome the exclusion of disabled women as "the cared for" opposed to the non-disabled women as "carers" (Morris, 1993)? These are questions that might determine the development of the Georgian disability rights movement.

Disabled people's, including disabled women's, participation is an important prerequisite for the development of sustainable and fair disability rights. Like many political practices in post-communist countries, participation of DPOs and individual people with disabilities in local disability councils and beyond is easily turned into something resembling a role play. When the government claims that people with disabilities participated in a particular decision-making process, it usually means that it was actually SPOs or mothers of people with disabilities who joined the round table. This is an issue that was raised by all activists who were not themselves active in parent's organizations or SPOs.

The gender conflict within disability activism was mentioned more explicitly by disabled activists and non-disabled activists who were not mothers of children with disabilities. Disabled men silencing women with disabilities in their organisations discloses how patriarchal structures are being reinforced within disability activism and especially in traditional DPOs. Women reported that it is difficult to bring forward democratic values and human rights claims because men dominated DPOs and SPOs tended to represent interests tied to the needs based on their impairment rather than shifting to a human rights-based approach that addresses all

people with disabilities. Furthermore, men are suspected of seeking patronage relationships with politicians and thereby hinder a disability movement to become a civic network of solidarity and shared resources. Instead, informality as described by Aliyev (2015) is a practice that hinders democratic development within disability activism.

Further research is needed to understand the gender dimension of disability activism across Georgia. Especially looking into disabled women's initiatives will shed light on how civil society activism shapes the consciousness of a new emerging social group. Furthermore, researching interdependency of disabled families in Georgia using a feminist disability studies approach is crucial to understand the gendered challenges of mothers today. Looking further into the reciprocity of responsibility of care and women's activism can produce valuable knowledge of women's agency in transitioning countries.

As many other oppressed groups around the globe, women with disabilities and their supporters in Georgia have found a language to frame their claims for inclusion in the notion of civil rights, human rights, and social justice. This development should be viewed in a global context, where disability movements have challenged social, political, and economic exclusion. To keep disability studies alive, scholars across the world must do justice to these achievements and keep contributing to comprehensive and practical conceptualisations of changing disability experiences. Thus, more local based research in the Caucasus region must be encouraged that includes people with disabilities. This will help to conduct real life-relevant studies that are adapted to local conditions and represent true added value.

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