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Disability Discomfort in Development

Unveiling Ableism and Disablism within Swedish Development Cooperation

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ABSTRACT

Persons with disabilities have long been overlooked and forgotten in the context of international development cooperation with less than five percent of official development aid targeting disability-related issues. Too often development agencies and organizations claim to have limited expertise related to disability, lack funds to support disability issues and pivot the responsibility of upholding the rights of persons with disabilities to someone else. Ableism, favoring those without disabilities, and disablism, viewing persons with disabilities as inferior lie at the heart of the development problem of excluding the disability community in international cooperation.

Through 12 semi-structured interviews, this study examines why disability inclusion in Swedish development cooperation is limited today. The study finds that within Swedish development cooperation disability is not seen as a priority, existing power structures limit disability-inclusive development practices and many individuals working in the sector remain uncomfortable working on disability issues. The study concludes by noting that current Swedish development practices unintentionally favor those without disabilities and continue to overlook disability-related issues. Moving forward development actors and disability rights advocates are encouraged to fight forward and not back to ensure development is inclusive of every 'body,' not just those without disabilities.

Key Words: Persons with Disabilities, International Development Cooperation, Sweden, Government Agencies, Non-profit Organizations, Organizations of Persons with Disabilities, Ableism, and Disablism

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ABBREVIATIONS

CRPD – Convention of the Rights of Persons with Disabilities

CSO – Civil Society Organization

DPO – Disabled Persons' Organization

EBA – The Expert Group for Aid Studies

EDF – European Disability Forum

IEO – The Independent Evaluation Office

IM – Individuell Människohjälp

LGBTQIA+ – Lesbian, Gay, Bisexual, Transgender, Intersex, Queer/Questioning & Asexual

MFA – Ministry for Foreign Affairs

NGO – Non-profit Organization

ODA – Official Development Assistance

OECD – Organization for Economic Co-operation and Development

OPD – Organizations of Persons with Disabilities

PWDs – Persons with Disabilities

SDG – Sustainable Development Goal

SIDA – Swedish International Development Cooperation Agency

SPO – Strategic Partner Organization

SRHR – Sexual and Reproductive Health and Rights

UN – United Nations

UNFPA – United Nations Population Fund

WHO – World Health Organization

TABLE OF CONTENTS

INTRODUCTION

According to a recent report by the World Health Organization (WHO), persons with disabilities[1] (PWDs) now represent 16 percent of the world's population (WHO, 2022). Additionally, it is estimated that 80 percent of PWDs live in the global South, and many PWDs across the global North and South alike live in poverty (WHO & World Bank, 2011; Grech, 2016). The linkages between disability and poverty are widely agreed upon (Grech, 2016; Banks et al., 2017). Social inequalities experienced by PWDs, including a lack of access to education, healthcare, and employment can result in poverty, but poverty can also lead to disability (WHO & World Bank, 2011; Grech, 2016). For example, if a person is poor and cannot afford to buy food, they may become malnourished, which could then lead to a Vitamin A deficiency. A lack of Vitamin A may result in blindness, highlighting that poverty can also lead to disability (WHO, 2009).

Although strides to ensure equity to PWDs have been made over the last few decades, including the passage of the United Nations (UN) Convention of the Rights of Persons with Disabilities (CRPD), PWDs continue to be marginalized. The UN (2018: 1) reports that the main barriers to improve the livelihoods of PWDs "entail discrimination and stigma on the grounds of disability; lack of accessibility to physical and virtual environments; lack of access to assistive technology, essential services and rehabilitation." Stein and Stein (2014: 1233) also note that "inaccessible environments, cultural attitudes…as well as additional costs resulting from disability, each contribute to the elevated worldwide poverty rate among individuals with disabilities."

In practice, these various barriers come in different forms and often lead to disability discrimination. For instance, an employer does not want to hire a person purely because the person has a disability believing the person cannot do the job in comparison to a person who is not disabled resulting in limited employment opportunities for this person, which could then potentially lead to poverty. On the other hand, a school refuses to install a ramp to the

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[1] It is important to highlight that there are disagreements within the disability community on whether to use person-first language or identity-first language when discussing PWDs (see Okundaye, 2021). This study will primarily use person-first language (i.e., PWDs), however, some authors quoted in this study use identify-first language (i.e., disabled persons).

entrance of the building preventing access to students who use wheelchairs, ultimately stopping certain students from receiving an education in their community. Although perhaps over-simplified examples, both occur across the globe today exemplifying the presence of ableism and disablism in society. Both concepts, ableism and disablism, refer to disability discrimination, the former denotes discrimination against PWDs in favor of persons without disabilities, and the latter refers to discrimination against PWDs believing they are less than those without disabilities (Campbell, 2009). The employer prefers a person without a disability to do the job (ableism), while the school discriminates against some students with disabilities believing they are unfit to attend school (disablism).

Unfortunately, PWDs often remain overlooked from initiatives aimed at targeting those most marginalized in society, such as international development cooperation. Efforts by various development cooperation actors, such as UN agencies, government agencies, and non-profit organizations (NGOs) whose goals often aim to reduce poverty, protect human rights, and increase access to services like healthcare, forget PWDs (Grech, 2016; Niewohner et al., 2020). In fact, research over the past two decades has highlighted that PWDs have largely been excluded from such efforts (see Yeo & Moore, 2003; Wehbi et al., 2009; Niewohner et al., 2020). Amponsah-Bediako (2013: 131) explains that "overlooking the development needs of people with disabilities or disinvesting in programs that directly benefit them can be one of the most dramatic forms of exclusion people with disabilities can face."

For example, Official Development Assistance (ODA) funding targeting disability-related projects remains low worldwide (Walton, 2020). Grech (2016) noted that in 2010 less than five percent of ODA funding targeted disability projects and programs. Meanwhile, between 2014-2018 less than two percent of aid projects targeted PWDs (Walton, 2020). According to Walton (2020), the international aid between these four years that targeted disability in some way equaled less than US $1 per PWDs in the global South (Walton, 2020).

Grech (2016: 4) suggests that the lack of resources, such as international aid targeting disability, reflects the exclusion of PWDs from the international development discourse and notes in *Disability in the Global South: The Critical Handbook:*

In the midst of much enthusiasm, critical issues and questions are frequently cast outside the realm of research, theoretical questioning and reflexive practice. These include, among others, questions around development itself and its willingness and capability to include disabled people in earnest and on their own terms; whether it is willing to change its (disabling) practices and whether including disabled people in development is necessarily 'good' or beneficial to them.

Grech (2016) proclaims that more research exploring and analyzing the extent to which disability is included and perceived in development is necessary, which is what this study seeks to explore as will be further discussed below.

Problem

Since the turn of the 21st century, research, although scarce, has highlighted the lack of inclusion of PWDs in international development (Yeo & Moore, 2003; Wehbi et al., 2009; Niewohner et al., 2020). According to Niewohner et al. (2020) despite PWDs having the right to be included in development-related efforts, they only continue to be left behind. As such, the specific development problem that will be explored in this study is the exclusion of PWDs in international development cooperation.

Although studying the problem globally is necessary, this study opts to take a closer look at one country, often applauded for its international development work, Sweden (Mitchell et al., 2021). This research will use Swedish development cooperation as a case study, given Sweden is one of the largest development donor countries in proportion to its economy size and is recognized by some as one of the 'more' disability-inclusive donors (OECD, 2022; Walton, 2020). Sweden's government agency for development, the Swedish International Development Cooperation Agency (Sida), is also known to prioritize reducing poverty within its partner countries (Sida, 2019).

Although Sweden is ranked as one of the more disability-inclusive donors it is important to highlight that in 2021, Swedish ODA funding targeting disability was less than one percent of its total ODA for that same year (OECD, 2022: Walton, 2020). In 2021 and 2023, the Swedish disability rights movement's umbrella organization for international development work,

MyRight, published debate articles criticizing Sida's lack of ODA funding towards PWDs and disability issues (Hansén, 2021; Munkhammar, 2023).

Purpose & Aim

Given the current exclusion of PWDs in development, the purpose of this qualitative case study is three-fold. Using interviews as the main methodology of this study, the research first seeks to explore how Swedish development actors currently address PWDs and disability issues. Second, to understand what might lead to disability exclusion within Swedish development cooperation. Third, to provide Swedish development actors with insights into the current landscape of attitudes surrounding the exclusion of PWDs in international development.

This study is significant, because it will highlight possible explanations as to why disability inclusion within Swedish development cooperation remains limited. As disability has been given little attention within the context of development on the global stage, it is only fair to assume that many development actors might not even be aware of their current exclusionary practices. This research offers a guide to understand the extent disability is currently included and where it needs to go if Sweden aspires to move towards Agenda 2030 and the Sustainable Development Goals (SDGs).

Niewohner et al. (2020: 1175) noted in *Disability and Society* that "excluding persons with disabilities means that every development actor will fail to reach their development goals of reducing poverty among the most marginalized." Further, this research can serve as a starting point for Swedish development actors to better address PWDs and disability issues in their efforts to ensure disability-inclusive development, which means all aspects-related to international development are inclusive and accessible to PWDs in the years ahead (UN, 2016).

Research Questions

To better understand potential reasons why PWDs and disability issues tend to be overlooked within Swedish development cooperation, this study thematically analyzes data collected from

12 interviews that explore the exclusion of PWDs in Swedish development with various development experts including those who focus on disability issues. As such, this research aspires to answer the following two research questions:

Research Question 1: Why might greater inclusion of persons with disabilities and disability issues in Swedish development cooperation programs and projects be difficult to achieve?

Research Question 2: Why might only a small percentage of Swedish ODA funding target persons with disabilities and disability issues?

Recognizing this is a very complex and broad topic, I want to offer some points of clarification as to the narrow scope of this study and highlight areas this study will not focus on before presenting the findings. For example, the Swedish Ministry for Foreign Affairs (MFA), serves as an important stakeholder in Swedish development cooperation (see Meeks, 2020). However, this study will only focus on the role of Sida, its partners, and the Swedish disability rights community.

Although the research will offer contextual background on strategies published by the Swedish MFA, this study does not engage with elected officials nor their staff. However, it is important to recognize the significance this office holds within Swedish development cooperation and further research on the Ministry's role, responsibilities, and perceptions of disability inclusion in development is warranted (Meeks, 2020).

Research Outline

To answer the two research questions, this study will first offer additional background on the problem, highlighting current trends of disability exclusion in development along with the current state of disability inclusion within Swedish development cooperation. Second, this study will explore existing literature, which highlights how past academics have approached studying how PWDs and disability issues are addressed in international development and how the various perceptions of disability have been explained, such as the medical and social model of disability.

Next, the study will introduce the theoretical framework that has shaped this study including the concepts of ableism and disablism, as discussed above. Following a discussion on ableism and disablism, the methodological approach of this study will be presented, which will explore the use of various exploratory qualitative methods used in this research such as several interviews with individuals from various Swedish development agencies, NGOs, and Organizations of Persons with Disabilities (OPDs).[2]

Following a discussion of the research methods applied in this research, the study will introduce and analyze the results through the lenses of ableism and disablism, unveiling the tendencies of Swedish development actors to favor persons without disabilities along with unintentional practices of viewing PWDs as inferior. The findings and analysis will be followed by a brief discussion and conclusion exploring areas of improvement to encourage greater inclusion of PWDs in Swedish development cooperation moving forward.

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[2] Also referred to as Disabled Persons' Organization (DPOs).

BACKGROUND

Ten years ago, Coe (2012: 407) highlighted that PWDs and disability issues were rarely included in development and humanitarian work despite development agencies and NGOs proclaiming that they all seek to reduce poverty and oppression by stating that:

> Disabled people are often the most excluded in any population and subject to the deepest poverty of any community group. Agencies that state that their mission is to include the poorest and most marginalized in their work, yet who do not intentionally seek to include disabled children and adults within this, are neglecting their agenda.

Several years later, Niewohner et al. (2020) found that PWDs and disability issues continue to be excluded from international development and noted that the gap between PWDs and persons without disabilities underscores the failure of the development community to be fully inclusive. Below I further explore the legal frameworks behind including disability in development and the concept of 'leave no one behind,' followed by an explanation of what disability-inclusive development really entails. Finally, I discuss the current state of disability inclusion of the Swedish development sector today.

Legal Frameworks: Leave No One Behind & Nothing About Us without Us

Over the years, progress has been made to promote, protect, and enforce the rights of PWDs across the globe, largely thanks to PWDs themselves and the disability rights movement (Grech, 2016). For example, the CRPD, which was introduced in 2006 and later signed and ratified by over 180 countries, including Sweden, was the first international treaty to officially recognize the rights of PWDs (Niewohner et al., 2020; UN, 2022). Further, Article 32 of the CRPD (2006) also states that international development programs must be inclusive and accessible to PWDs (Niewohner et al., 2020).

The 2030 Agenda for Sustainable Development and its 17 SDGs, also endorsed by Sweden, address and highlight PWDs by explicitly mentioning PWDs in Goal 4 (education), Goal 8 (decent work and economic growth), Goal 10 (reduced inequalities) Goal 11 (sustainable cities and communities), and Goal 17 (partnerships for the goals) (UN, 2018). For instance, SDG Goal

4 seeks to "eliminate gender disparities in education and ensure equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities, indigenous peoples and children in vulnerable situations" (UN, 2015: 17). Additionally, it is important to note that the SDGs were a major milestone for the disability community given the previous development framework, the Millennium Development Goals failed to mention disability entirely while the SDGs mentioned disability 11 times (Ghai, 2009).

Furthermore, one of the main universal values of Agenda 2030 is to 'Leave No One Behind' (UN, 2018; Niewohner et al., 2020). According to the Independent Evaluation Office (IEO) (2022: xii) of the United Nations Development Programme, this principle refers to "the political commitment of all United Nations Member States to eradicate poverty, discrimination and exclusion, and to reduce the inequalities that undermine the potential of individuals and humanity as a *whole*" (emphasis added).

As previously noted, the disability rights movement played an important role in ensuring the rights of PWDs were included and represented on the international stage, as is evident by the creation of CRPD and disability representation in Agenda 2030. A common slogan used by the disability rights movement over the years, 'Nothing About Us, Without Us,' was a driving force (Grech, 2016). Charlton (1998: 3) explains that the "slogan's power derives from its location of the source of many types of (disability) oppression and its simultaneous opposition to such oppression in the context of control and voice." Today, the slogan remains prominent and most OPDs express the need to directly include PWDs and demand PWDs are represented in every sector of society, including international cooperation (United Nations Population Fund, 2018).

Disability-Inclusive Development

Disability rights advocates, development related OPDs, and several development institutions such as the UN and World Bank, have all called for the international development agenda to be fully inclusive and accessible to PWDs since the 1980's (Stein & Stein, 2014). The UN (2016: 2) explains that disability-inclusive development "requires that *all persons* (emphasis added) be afforded equal access to education, health care services, work and employment, and social

protection." According to Stein and Stein (2014: 1259), to achieve disability-inclusive development organizations must embrace the following five elements:

1. Participation
2. Mainstreaming via a Twin-Track Approach
3. Accountability
4. Rights-based Development
5. Cultural Change

Stein and Stein (2014: 1260) to achieve successful participation, PWDs must be seen "as agents of change and enabled to participate fully in the development process, from planning and implementation, to monitoring." Development agencies and NGOs can follow the ten steps outlined in Appendix 1 to ensure disability participation within development cooperation.

Disability should also be included in all "thematic issues across all sectors of development schemes through mainstreaming and twin-tracking." (Stein & Stein 2014: 1263). Mainstreaming disability refers to including and incorporating disability in all areas across every development project and program while twin-tracking refers to including disability in all thematic areas, along with having programs that target and primarily focusses on PWDs and disability issues.

Stein and Stein (2014: 1266) explain that "accountability for implementing development and humanitarian schemes is crucial for achieving" disability-inclusive development. A lack of accountability by development agents can often lead to neglect. As such binding guidance and strategies are necessary to ensure development actors are accountable for ensuring and protecting the rights of PWDs.

A rights-based approach to development prioritizes duty and obligation over need and charity (Stein & Stein, 2014). The main principles of a rights-based approach also include participation, accountability, transparency, and non-discrimination (Stein & Stein, 2014). Under this approach duty-bearers, such as development actors, are responsible for empowering rights-

holders, like PWDs. However, for a rights-based approach to be disability-inclusive it is necessary for duty-bearers to view PWDs as subjects rather than objects needing to be 'fixed' or 'cured' (Stein & Stein, 2014). Stein and Stein (2014: 1271) suggest that international development actors "are positioned as duty bearers with a responsibility for ensuring that development and the process by which it is achieved promote, respect, and fulfill those rights" of PWDs.

Lastly, Stein and Stein (2014) explain that disability needs to be a part of development actors' daily activities and suggest that OPDs need to raise the awareness of development actors like those raising awareness for gender, children, and environment advocates. Stein and Stein (2014: 1277) conclude their framework on achieving inclusive development by stating that "disability rights advocates need to strategically craft their ideas in language that is theoretically and methodologically accessible to economists."

Swedish Development Cooperation & Disability

Over the last few years, the Swedish disability rights movement has criticized Sida for its lack of disability inclusion, because in 2020 less than 0.4 percent of Swedish ODA funding targeted disability and only 20 percent of ODA funding included some type of disability mainstreaming that same year (Hansén, 2021; Munkhammar, 2023). This aligns with the criticism of scholars on the global stage related to the lack of disability inclusion in international development (see Yeo & Moore, 2003; Wehbi et al., 2009; Niewohner et al., 2020). Further, Sida has stated throughout the years that they and their partners should improve their efforts on disability (see Dahlström et al., 2009; Sida, 2018; Weibahr, 2021).

Sida is tasked by the Swedish government to help organize the distribution of Swedish ODA funding (EBA, 2018). According to Sida's website the agency strives "to reduce poverty and oppression around the world in cooperation with organizations, government agencies and the private sector we invest in sustainable development for all people" (Sida, 2023).   Along with reducing poverty and oppression, some of Sida's main thematic issues of concern include human rights and democracy, climate and the environment, and gender equity (Sida, 2023). Sida funds both international development NGOs and Swedish civil society organizations (CSOs) working on development.

Sida currently has 17 Swedish-based strategic partner organizations (SPOs) who they collaborate with to strengthen civil society in their partner countries (Sida, 2022a). Current SPOs include the Swedish Red Cross, Forum Civ[3], and Civil Rights Defenders (see Appendix 2 for full list). Niewohner et al. (2020: 1172) explain, NGOs like these "are on the frontline of development in many of the world's communities, they are the in-country service deliverers that official foreign aid agencies often use to reach the communities they want to serve." None of Sida's current SPOs explicitly represent the disability community as the Swedish disability rights movement's umbrella OPD working on development, MyRight[4], is not currently a SPO.

Sida and its SPOs remain vocal in using the rights-based approach in their efforts (see Sida, 2022b). However, a few years ago the CRPD Committee called for the integration of a disability rights-based perspective in Sweden's post-2015 development framework (UN, 2014). Yet, on paper Sida (2015: 2) has stated that "promoting and increasing respect for the human rights of boys, girls, men and women with disabilities is a Swedish priority."

Following an initial review of Sida and its 17 SPOs 2021 annual reports, only five reports (Sida and four SPOs) refer to disability mainstreaming efforts and six reports (Sida and five[5] SPOs) refer to projects targeting PWDs (see Appendix 3 & 4). When compared to other marginalized groups, such as women, children, and refugees, disability is mentioned less. For example, in Sida's 2021 Annual Report, disability[6] was mentioned 33 times, while women were mentioned 239 times (Sida, 2022c). Other mentions include children (130), refugees (59), girls (75), and LGBTIQA+ persons (9) (Sida, 2022c).

Additionally, Forum Civ (2022) discusses in their 2021 Annual Report what issues their members prioritize and most reported that they focus on issues such as women's empowerment (60), environmental and climate justice (36), social and economic justice (38), peacebuilding (24), the rights of indigenous peoples and minorities (19), and sexual and

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[3] Forum Civ is a Swedish CSO that supports civil society in over 70 countries (Forum Civ, 2022).
[4] MyRight is a member of Forum Civ.
[5] Two out of the five SPOs who mentioned targeting disability, also referred to disability mainstreaming efforts indicating the same SPOs discuss targeting and mainstreaming disability.
[6] Sida's 2021 Annual Report is in Swedish, therefore the various 'disability'-related terms in Swedish were used as search criteria including 'funktionsrätt,' 'funktionsnedsättning,' 'funktionshinder' and 'funktionsvariationer'.

reproductive rights (19). Meanwhile, only 12 of their members reported some work-related to the rights of PWDs (Forum Civ, 2022).

Furthermore, only a handful of publications have examined how PWDs are addressed by Sida and Swedish development NGOs. Back in 2006, Sida released a position paper on children and adults with disabilities citing that PWDs are often some of the poorest people living in the global South (Sida, 2006). The paper explained the need to continue the analysis, dialogue, training, and financial support on disability-related issues (Sida, 2006).

In 2009, Sida adopted a work plan to integrate the rights of PWDs in their efforts (Dahlström et al., 2009). In 2013, a report evaluating Sida's work plan found that integrating disability was not seen as a priority by Sida employees and that there was a lack of awareness from staff on the plan and its implementation (Ribohn, 2013). The 2013 evaluation also noted that "the lack of competence among Sida's personnel presents a major challenge as it probably undermines the results of the work and decision processes" (Ribohn, 2013: 9).

In 2017, the Swedish government published new goals and directions for the country's disability policy (Meeks, 2020). The government also offered a plan for achieving these goals, but Sweden currently has no official disability strategy or action plan (Meeks, 2020). The 2017 goals do, however, state that "Sweden for many years has been the leader in the efforts to strengthen the rights of persons with disabilities globally" (Ministry of Health and Social Affairs, 2017: 32). The 2017 goals make no further reference to Sweden's development efforts (Ministry of Health and Social Affairs, 2017; Meeks, 2020).

Sida's most recent report evaluating their disability efforts in 2018 found that Sida staff continue to lack knowledge on disability-related issues and the need to mainstream disability with other perspectives and issues remains necessary (Sida, 2018; Weibar, 2021). Lastly in 2020, the European Disability Forum (EDF) released a brief that broadly mapped the inclusion of PWDs within Swedish international development and humanitarian aid (Meeks, 2020). Meeks (2020) found that Sida does not explicitly encourage its staff to work on disability issues. This aligns with what was written in the evaluation of Sida's disability rights efforts a

few years earlier as "many attribute the work done to a few committed employees and local initiatives" (Ribohn, 2013: 8).

Further, most of Sweden's development cooperation thematic, regional, and bilateral strategies, make no reference to PWDs or disability, while at the same time highlighting other commonly marginalized groups (see Appendix 5, 6 & 7). For instance, in Sida's *Strategy for Sexual and Reproductive Health and Rights (SRHR) in Africa*, PWDs are not mentioned, while women, young people, and LGBTIQA+ persons are when referencing groups that "often lack access to legitimate SRHR initiatives" (MFA, 2022a: 5). Yet, according to the UN (2018) PWDs are often the most excluded from having their sexual rights protected.

Additionally, Sweden's national *Strategy for Humanitarian Aid through International Development for the years 2021-2025*, makes no reference to disability either, although explicitly mentions women, children, and refugees in the context of groups at greater risk of being exposed to disasters and emergencies (MFA, 2020a). PWDs are also often at greater risk of being exposed to emergencies than other groups (UN, 2018).

None of the regional strategies mention disability or PWDs, but in fairness many of the reginal strategies do not mention any other group either (see Appendix 6). These strategies explore human rights more broadly. However, the *Strategy for Sweden's Regional Development Cooperation with Latin America 2021–2025*, does refer to women, girls, and LGBTIQA+ persons, but makes no reference to disability (MFA, 2021a).

Out of Sida's 18 bilateral strategies accessible on their website, eight of the country strategies do not mention disability at all, while eight strategies include 'disability' when highlighting the rights-based approach (see Appendix 7). Two out of the 18 strategies, Russia and Uganda, indicate that preventing disability discrimination is a priority (MFA, 2020b; MFA, 2018a).

Lastly, it is highlighted in the EDF report that "measures to promote the participation of persons with disabilities in the design, implementation, and evaluation of mainstream programming are not yet widespread" in Sweden (Meeks, 2020: 3). Further, there is no focal point at Sida working on disability full-time and Sida's efforts to engage with OPDs in the global

South is limited (Meeks, 2020). This does not align with the disability-inclusive development framework outlined by Stein and Stein (2014) discussed above.

LITERATURE REVIEW

A decade ago, Groce and Kett (2013) argued there was a disability and development gap, and that the well-being of persons without disabilities in the global South have improved while the lives of PWDs have remained the same. Marshall (2012: 54) explains that historically "international development actors, such as bi/multilateral donor agencies and international non-governmental organizations, have over the years demonstrated little interest in disability and disabled people."

Further, Wehbi et al. (2009) and Grech (2016) all found that limited scholarship examining the exclusion of disability and development is available. Below, I highlight past research specifically examining how disability is addressed in development along with the available literature aimed at analyzing the exclusion of PWDs and disability issues in development cooperation.

Understanding Disability

Before diving into past work and research related to disability exclusion in international development specifically, it is important to explore the various models of disability to better understand and analyze how people think about disability overall (Olkin, 2002). According to the international legal framework, PWDs include "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (CRPD, 2006: 4).

Forstner (2022: 540) notes that disability is a "complex, multifaceted, and contested concept, with political, medical, ethical, and psychological aspects." Within the complexity of disability, one can also find widespread debate about the various models of disability that are common in disability-related literature (Forstner, 2022). Forstner (2022) suggests that models can simplify aspects of the real-world. In terms of disability models, Olkin (2002) explains that an individual's view towards disability impacts their perspectives, and these various perspectives can be categorized into a handful of overarching models of disability, including the most common: moral, tragedy/charity, medical, social, and human rights models.

According to Olkin (2002) under the moral model, disability stems from a person's character, past acts, and karma. For example, in some cultures people believe that someone has a disability presently because they were criminals in their past life (Olkin,2002). Also under the moral model, disability can sometimes be seen as an act by God and can carry shame and blame to the person with a disability and their family. On the other hand, disability can carry honor as a disability can be seen as God having faith in a person to live with a disability (Olkin, 2002).

The tragedy, or charity model of disability sees any type of disability as sad, burdensome, and tragic (Olkin, 2002). Amponsah-Bediako (2013: 124) suggests that through the lens of the charity model, "disability is a problem that is inherited in the person who has fallen victim to it" and that PWDs are 'brave' for living with a disability. The charity and medical models are often linked. In their paper analyzing attitudes towards PWDs Ingham (2018: 5) explains under the medical model, people perceive "able bodies to be the desired norm, and disability as something to be pathologized." In other words, the medical model of disability views PWDs as needing to be 'fixed' with medical intervention.

The model that many from the disability rights movement are in favor of is the social model, which Amponsah-Bediako (2013: 125) explains as viewing disability "as a consequence of environmental, social and attitudinal barriers that prevent people with impairments from maximum participation in society." Society creates barriers for PWDs rather than disability itself. To illustrate, if a building has stairs leading to its entrance instead of a ramp, the stairs themselves create a barrier for a person using a wheelchair to access the building rather than the person's disability. The CRDP aligns with the social model of disability and Amponsah-Bediako (2013: 125) explains that:

> The social model implies that the removal of attitudinal, physical, and institutional barriers will not only improve the lives of disabled people but give them the same opportunity as others on an equitable basis. Taken to its logical conclusion, there would be no disability in a fully developed society.

Lastly, the human rights model of disability views PWDs as equals in society and recognizes that PWDs have a political voice to fight against discrimination in society (Amponsah-Bediako, 2013). Retief and Letšosa (2018) offers the following simplification of each model:

- **Moral Model:** Disability as an act of God
- **Tragedy/Charity Model:** Disability as victimhood
- **Medical Model:** Disability as a disease
- **Social Model:** Disability as a socially constructed phenomenon
- **Human Rights Model:** Disability as a human rights issue

These models of disability have been used to conceptualize disability in past academic literature and are useful when analyzing disability-related topics such as disability exclusion international development. Coe and Wapling (2010) suggest that the needs of PWDs in the development sector are still often seen as medical or charity. To some organizations PWDs might be seen as "unproductive, dependent entity who needs to be 'mitigated' or 'dealt with'" (Coe & Wapling, 2010: 881). Coe and Wapling (2010: 881-882) note that:

> People's perceptions of what disability represents (the medical model that they use), cultural beliefs and practices (such as beliefs about what causes impairments), and a deep-rooted fear of how to interact with people with disabilities all contribute to holding back progress on inclusion.

Finally, as Amponsah-Bediako (2013: 130) discusses, these models offer a lens to gather attitudes towards disability, which can then "help identify gaps in public understanding that can be bridged through education and public information" to ultimately change attitudes. Having a clear understanding of the various models of disability is helpful given they are often used as tools in literature discussing disability, including research exploring disability and development, which will be furthered discussed below.

Addressing Disability in Development

Marshall (2012) defends international actors by arguing more organizations have become interested in disability over the years and are now including more PWDs in their projects,

programs, and policies than ever before. Yet, recent research, although slim in the context of international development, points to the continued exclusion even if numbers are increasing (Walton, 2020; Niewohner et al., 2020). Below, I explore the handful of studies that have analytically studied disability and development in the past.

I begin with the study by Wehbi et al. (2009) who conducted a qualitative study on how PWDs were addressed by Canadian international development NGOs. Their study included a thematic analysis of NGOs annual reports, which found that PWDs were rarely included in development discussions, and the few instances where disability was present, ableist language was common (Wehbi et al., 2009). Ableist language included not referring to PWDs when discussing topics related to war, nutrition, or poverty, while referring to other marginalized groups i.e., highlighting and favoring those without disabilities (Wehbi et al., 2009). Furthermore, reports would use terms like 'suffering,' 'maimed,' 'impacted, 'affected," terms prescribed by the medical model of disability (Wehbi et al., 2009).

Wehbi et al. (2009) utilized a postcolonial and neocolonial approach to analyze how Canadian NGOs working in development addressed disability issues noting that North and South power relations needed to be considered when highlighting the disconnect between disability and development. For context, Wehbi et al. (2009: 406) stated that a neocolonial discourse:

> maintains that even if formal colonial relations have ended in a particular context, the legacy of colonialism continues through neo-colonialism, which can be seen in globalization practices, such as current relations of international trade, development and development practices.

Further, Wehbi et al. (2009: 414) suggest that the absence of PWDs by Canadian NGOs can be "theorized as a reflection of a legacy of colonialism that has historically valorized 'normal' bodies and sought to hide from view anything seen to deviate from this norm." The perception of 'normal' bodies is also closely linked to the medical model of disability as explored above, suggesting that PWDs must be 'fixed' to become what society deems as 'normal' i.e., able-bodied. Grech (2012: 52) noted that "postcolonial theories and concepts have injected much needed theoretical and analytical breadth into the study of disability," and themselves

examine disability from a postcolonial and neocolonial lens as well. Chataika (2012) argues that disability, development, and postcolonialism are inherently linked, but too often explored separately. Ghai (2012: 273) explores postcolonial theory as "understanding of the Other, historically and symbolically." Wehbi et al. (2009) concluded that too often people pity PWDs, view them as 'helpless' and as 'vulnerable' persons rather than persons who have rights and deserve dignity.

Grech (2016: 13) further elaborates on the neocolonial tendencies of international development actors in relation to disability and explains that through a neo-liberal lens "development is about the opening up of national economies to participate in the global market." Therefore, when development is purely focused on economic growth, or reducing poverty, too often PWDs are dismissed as not being capable or deemed 'too slow' to be productive when compared to non-disabled people who might require less time and accommodations to succeed as illustrated earlier in this study (Grech, 2016).

Given development agencies and NGOs often want to report their successes, they might prioritize those who they believe they can 'pull' out of poverty quicker, and since PWDs sometimes might require accommodations to ensure equity, development actors dismiss PWDs altogether (Grech, 2016). Grech (2016) suggests that current practices by the development sector such as the lack of prioritizing disability and the limited ODA funds targeting disability maintains these patterns of viewing PWDs as less capable than people without disabilities.

For instance, while reflecting on disability and employment in India, Kumar et al. (2012) explains that PWDs remain trapped between neoliberalism and ableism in terms of seeking employment opportunities. According to Kumar et al. (2012) the neoliberal economy in India coupled with limited social security and few regulations along with preferences for certain 'abilities' over those with disabilities has resulted in the rights of PWDs being silenced. Meanwhile, Sonpel and Kuman (2012: 73) found that disability issues remain underdeveloped in the context of international cooperation, because of the following reasons:

1. that the rights-based approach, in practice, has been restricted within the establishment-defined framework
2. domination of the social welfare paradigm
3. lack of translation from policy to strategy
4. non-enforceability of policies
5. limited dissemination

Similar studies to that of Canadian NGOs included that of Lang et al. (2019) who studied disability inclusion in African Union policies by researching the extent to which disability issues were mentioned in policy documents. Lang et al. (2019: 160) explain that their study relied on a policy analysis framework to detect disability inclusion and noted "it provides an insightful, critical, analytical lens to look at how policymaking happened in practice, encompassing the power relations that exist between all stakeholders involved, and the relative impact of a multi-stakeholder approach to the policy-making process." Following extensive review of the policy documents, Lang et al. (2019) noted that Member States in Africa who drafted the various documents recognized the importance of disability inclusion, but few steps were taken to ensure disability inclusion.

Further, Lang et al. (2019) highlights the need to examine disability from an intersectional perspective. According to Hankivsky (2014: 2) intersectionality "promotes an understanding of human beings as shaped by the interaction of different social locations (for example, 'race'/ethnicity, indigeneity, gender, class, sexuality, geography, age, disability/ability, migration, status, religion)." As such, Lang et al. (2019) argues that solutions to ensure disability inclusion are not always a one size fits all. For example, black women with disabilities are often treated differently than white women with disabilities, emphasizing the need to examine disability and race together to better understand existing power structures and privileges (Lang et al. 2019). Hankivsky (2014: 2) continues by noting that the interaction of different social locations:

> occur within a context of connected systems and structures of power (for example, laws, policies, state governments and other political and economic unions, religious institutions, media). Through such processes, interdependent forms of privilege and

oppression shaped by colonialism, imperialism, racism, homophobia, ableism and patriarchy are created.

More recently, Niewohner et al. (2020) found that PWDs remain largely overlooked by developmental NGOs, small, medium, and large alike. In their study, Niewohner et al. (2020; 1171) found that the main factors for the exclusion of PWDs in development include:

1. lack of awareness,
2. belief that persons with disabilities constitute a separate focus area,
3. assumption that the costs of inclusion are too high, and
4. believing that others, such as governments or families, are responsible for ensuring access and accommodations, rather than the NGO itself.

Grech (2016: 10) echoes what Niewohner et al. (2020) found stating that too often they hear "'we don't do disability here' uttered by development and other organizations working on poverty reduction or gender issues." Additionally, Grech (2016) found that many organizations feel as though they lack disability expertise, disability should be addressed by charitable organizations, disability is unrelated, not a priority or entails to many related costs, also similar to what Niewohner et al. (2020) concluded.

Lastly, Niewohner et al. (2020) noted that many development-related NGOs do not prioritize disability issues despite claiming that their organizations aspire to minimize poverty across the globe. As Stein and Stein (2014) discuss, PWDs living in poverty remain widely neglected. Organizations often appear to expect others to take the lead and opt to shift the blame to others in terms of upholding disability rights (Niewohner et al., 2020).

For example, Niewohner et al. (2020) found that organizations would defend their actions about not prioritizing disability by arguing that if governments they are working with are not prioritizing disability, they do not need to or cannot prioritize disability either, thus they are 'off the hook' so to speak. Grech (2016: 9) suggests that "disability is still to find a legitimate and stable place in humanitarian issues, governance, poverty, education, conflict, environmental degradation and climate change—staple development themes."

THEORETICAL FRAMEWORK

Grant and Osanloo (2014: 12) explain that a "theoretical framework is the foundation from which all knowledge is constructed (metaphorically and literally) for a research study," and that it helps guide research based on theory or theories (Grant & Osanloo, 2014: 13). Abend (2008) explains that theories within social sciences are meant to explain and understand phenomena.

As discussed above, postcolonialism and neoliberalism along with the various perceptions towards disability have often been used to analyze data related to disability and development, highlighting the common practice by development NGOs to value those who are seen as 'normal' and those 'best fit' to develop. However, to expand on past literature this research aims to use the concepts of ableism and disablism to help guide the findings of this study. Both concepts have close ties to past theoretical frameworks used to study the relationship between disability and development but by using ableism and disablism as a tool one can unveil the politics associated with inclusion and highlight how every day practices are usually designed for non-disabled people and view PWDs as inferior to those without disabilities.

As such, given this research is not examining how Swedish development cooperation understands disability instead seeking to understand how Swedish development cooperation navigates the inclusion of PWDs, this study applies the concepts of ableism and disablism instead of the various models. Using the concepts of ableism and disablism I can highlight if current Swedish development cooperation efforts are designed for the "normal" person, and if current development practices frame PWDs as "others" when compared to those without disabilities (Nieminen, 2023). Clifton (2020) explains that ableism is the term used primarily in the United States and is often used as a synonym of disablism. However, in this study ableism and disablism are two separate and distinct concepts.

Ableism

The concept of ableism stems from the disability rights movement in the United States and the United Kingdom in the 1960s and 1970s (Wolbring, 2012). Earlier definitions of ableism included that of Chouinard (1997: 380) who viewed the concept as "ideas, practices,

institutions and social relations that presume 'ablebodiedness', and by so doing, construct persons with disabilities as marginalized…and largely invisible 'others'" (Campbell, 2009). However, today Campbell (2009: 5) is often credited for expanding the concept of ableism within disability studies, where she explains ableism as:

> A network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then is cast as a diminished state of being human.

Clifton (2020: 15) notes that "ableism is another reference to power and its attendant violence, the hierarchy of the abled over and against the disabled." Simply put, ableism is discriminating against PWDs in favor of people without disabilities. Nieminen (2023: 617) explains in their own study unveiling ableism that "ableism refers to the ideology of valuing abilities and 'abledness' over disabilities and 'disabledness' (Baglieri & Lalvani, 2019; Campbell, 2009).

Expanding on the concept of ableism even further, Domage (2017: 7) explains that "ableism renders disability as abject, invisible, disposable, less than human, while 'able-bodiedness' is represented as at once ideal, normal, and the mean or default." However, according to Wolbring (2012) ableism does not inherently have to be negative. Rather Wolbring (2012) argues that ableism simply means someone favors abilities and sees them as more important. For example, it is not unreasonable that someone wants an airplane pilot with good vision. Yet other disability scholars argue that "ableism is another reference to power and its attendant violence, the hierarchy of the abled over and against the disabled" (Clifton, 2020: 15).

In practice and in international development, Wehbi et al. (2009) explain that they found the use of ableist language common amongst Canadian development NGOs. For instance, the researchers reported that while reviewing reports, a specific NGO did not mention disability explicitly, but said "…by providing adequate health care and nutrition, children can 'grow and develop in a *normal* way" alluding that disability is not perceived as normal by society and

there is preference in ensuring that children grow up to be 'normal' rather than disabled (Wehbi et al., 2009: 416).

As discussed earlier, a lack of nutrition can result in disability, and although neither the international development or disability rights community is suggesting that children should not have adequate nutrition, rather by using terminology such as 'normal' as in this case, it signals that people are either normal and do not have a disability, or people are abnormal and have a disability. As Goodley (2014) explains "the valued modern citizen is cognitively able, and thus normal" (Nieminen, 2023: 617).

Ableism fundamentally highlights that ability is what society values, and if a person has a disability, they do not have the ability to participate in all aspects of life. Wolbring (2012) notes that theorizing ableism remains urgent. To further put ableism in the context of development, Grech (2016) argues that development does not appear to be meant for every 'body,' arguing that current practices of disability exclusion in development cooperation highlight this belief. Grech (2016: 626) wrote:

> Neo-liberal globalized development calls for and reconfirms economic growth as the ultimate means and end, a development predicated on normalized, ableist and heteronormative ideologies and practices, a clear paradox in the rhetoric of inclusive development…development necessitates docile able bodies and minds to function and produce; the rest are to be corrected (cheaply) to function and produce or removed— burdensome bodies on individualistic economies.

Clifton (2020: 16) explains that "as a theoretical development, ableism makes the insight of disability scholarship applicable to broader academic disciplines that examine cultural values, practices, and processes," which is ultimately why ableism is used as a guide for this research to better understand what is preventing Swedish development cooperation from being fully inclusive of PWDs and disability issues. Lastly, Goodley (2014: xi) argues that ableism provides the "temperature and nutrients for disablism to grow." Clifton (2020: 16) noted that "it is maintained by abled people's rationalizations and their unwillingness to face up to the way

their social advantage propagates unequal outcomes and hidden violence against people with disability."

Disablism

According to Campbell (2009: 4) disablism "is a set of assumptions (conscious or unconscious) and practices that promote the differential or unequal treatment of people based on actual or presumed disabilities." Campbell (2012) notes that disablism refers to the negative treatment and societal barriers faced PWDs. Meanwhile, Goodley (2014) views disablism as the social, political, emotional and cultural exclusion of PWDs.

Clifton (2020) discusses that disablism focusses on the disadvantages of PWDs when society is not structured to include them, similar to the social model of disability, highlighting that disability itself is not a disability, rather society creates barriers for PWDs by holding negative views towards PWDs and creating environments that are not accessible or inclusive to PWDs. For example, Bê (2019: 181) notes that "in the context of the British Social Model, disablism has been the word used to signify the barriers, exclusion and discriminatory practices experienced by disabled people." For context, disablism is similar to other 'isms' such as sexism is used to describe discrimination based on sex and/or gender (Wolbring, 2012; Clifton, 2020). As the terms disablism and ableism are often used interchangeably in this study I would like to clarify that disablism is devaluing disability (disablism) and ableism refers to upholding ability (Wolbring, 2012; Clifton, 2020).

Finally, like the recent study conducted by Nieminen (2023) who unveiled ableism and disablism in the assessment of student learning in Finish higher education, this study aims to use ableism and disablism as a blueprint to explain why Swedish disability-inclusive development is limited and why might only a small percentage of Swedish ODA funding target disability issues.

METHODOLOGY

An exploratory qualitative case study was deemed to be the most appropriate research design and strategy for this study to better understand why disability inclusion in Swedish development cooperation might be difficult to achieve. Bhattacherjee (2012: 6) explains that exploratory research is helpful when seeking to gather initial ideas about topics and states that this type of "research may not lead to a very accurate understanding of the target problem but may be worthwhile in scoping out the nature and extent of the problem and serve as a useful precursor to more in-depth research." Below I further discuss the selected research design, method, sampling and analysis process of this study.

Research Design & Strategy

Creswell (2014) explains qualitative studies as those that rely on words by using open-ended interview questions rather than relying on numbers and closed-ended questions. The latter drives quantitative research. Qualitative research also aims to explore and understand "the meaning individuals or groups ascribe to a social or human problem" (Creswell, 2014: 22).

Given my research questions seek to understand why PWDs and disability issues are not included in Swedish development cooperation, the data collected in this study relied on words rather than numbers highlighting the need to use a qualitative approach rather a quantitative approach. Further, Kenny et al. (2023) suggest that qualitative research allows the voices of disability to be lifted, which serves as a core element of this research study as well. However, the negative aspects of using qualitative data include data being difficult to analyze and collecting data could be rather time consuming whereas quantitative data can often be rather easy to analyze, precise and can lead to generalization of data (Bhattacherjee, 2012; Creswell, 2014; Kenny et al., 2023).

In terms of the direction for my qualitative study, a case study approach was carefully selected (Creswell, 2014). Case studies includes studying a program, activity or process in detail (Creswell, 2014). Cases are bounded by time and activity, and often the researcher can collect data using various steps (Creswell, 2014). A case study research strategy can highlight a

different social, cultural, and political factor related to a researcher's selected study (Bhattacherjee, 2012).

Case research also allows a researcher to conduct "in-depth investigation of a problem in one or more real-life settings" (Bhattacherjee, 2012: 40). In this study the particular problem and setting include disability exclusion (the problem) within Swedish development cooperation (the setting). In other words, this paper aims to develop an in-depth analysis of the decision-making processes within Swedish development cooperation. Drawbacks, however, associated with case studies can include biases influencing results and inefficient given they often rely on the participation of willing participants who might be unavailable (Creswell, 2014).

Research Method & Data Collection

As this research applied a case research approach, I primarily collected data through semi-structured interviews with experts in the field of international development where I asked open-ended questions. According to Creswell (2014), interviews allow a researcher to collect historical information and allows the research to control the questions. However, he warns that interviews can also result in filtered views and the researcher's presence might bias the interviewees answers (Creswell, 2014).

I collected data while based in Stockholm, Sweden between the end of February 2023 and early April 2023. I purposefully selected and contacted over 20 current or former staff members at Sida and over 50 staff members working at the various SPOs of Sida at the end of February 2023 via email, which included a request to interview, my research proposal and an interview guide (see Appendix 8). I purposely contacted those who are at the forefront of Swedish development cooperation i.e., Sida and SPOs given they help steer the direction of Swedish development (Sida, 2022a). Most people, except for two, I had never met before and had found their contact information via their agency or NGO website.

I received limited responses despite one or two follow up emails. A handful of individuals responded with citing that although they work in development and human rights, they have no expertise in disability and therefore felt uncomfortable participating. For example, one individual responded by writing "sounds like an important and relevant topic for us in Swedish

development aid. However, I do not think I have very much to contribute with, sadly, maybe a symptom of how much need this discussion is."

Meanwhile at the end of March 2023, I contacted six people working within the Swedish disability rights movement including at OPDs who also have some connection to development cooperation. In the end, I conducted a total of 12 semi-structured 30–45-minute interviews all of which were conducted digitally via Zoom or Microsoft Teams. All interviewees provided oral consent to participate in my research and allowed me to record the interviews.

Sampling & Research Participants

As discussed above, a non-random sampling process was utilized to collect data in this study. I interviewed a total of 12 experts all of whom had a connection to Swedish development cooperation. Six of the individuals I interviewed either work at Sida, formerly worked at Sida or work at one of Sida's SPOs. The other six participants work or had worked within Swedish development cooperation focusing on PWDs and disability issues.

Table 1 below offers an overview of the people I interviewed along with their connection to international cooperation. To keep the anonymity and privacy of interview participants, however, I have given research participants new names and I refer to the designated pseudonym names listed in Table 1 in my findings and data analysis section.

Table 1: List of Interviewees with Pseudonyms Names & Relationship to Development

Name	Relationship to Swedish Development Cooperation
Derek	Former staff member of Swedish government agency for development cooperation
Meredith	Current staff member of Swedish government agency for development cooperation
Christina	Current staff member of Swedish government agency for development cooperation
George	Current staff member of Swedish NGO for development cooperation
Isabelle	Current staff member of Swedish NGO for development cooperation
Lexie	Current staff member of Swedish NGO for development cooperation
Alex	Current staff member of international OPD focusing on development cooperation
Amelia	Current staff member of Swedish OPD focusing on development cooperation
Callie	Current staff member of Swedish OPD focusing on development cooperation
April	Current staff member of Swedish OPD focusing on development cooperation
Bailey	Current staff member of Swedish OPD focusing on development cooperation
Mark	Current volunteer of Swedish OPD focusing on development cooperation

Analytical Process

Once all my interviews were complete, I transcribed each of the interviews. Four of the interviews were conducted in Swedish, which also meant that I first transcribed my Swedish interviews and then translated those interviews into English, which were then compared to the original recordings to ensure the translations did not misinterpret any of my data. Once the transcription process was complete, I began thematically analyzing the collected data using the framework offered by Braun and Clarke (2020: 331), which consisted of six phases including:

1. data familiarization
2. systematic data coding
3. generating initial themes from coded data
4. developing and reviewing themes
5. refining, defining, and naming themes; and
6. writing the report

Following the steps outlined by Braun and Clarke (2020), I first became familiar with my data. I read each transcript and listened to each interview recording three times. I then began my coding process. I opted for a manual coding process, which included summarizing each interview, color coding by category, which encompassed a total of 17 categories, linking categories to themes, and selecting useful quotes (Basit, 2003). A manual coding process was deemed appropriate in this study as I am more familiar and comfortable using manual coding versus computer software. Basit (2003) argues that manual coding can be appropriate when the research does not have a large quantity of data to code, which was why I felt a manual coding process in this study was sufficient.

After coding the data and finding the initial themes from the data, I followed step four and five of Braun and Clarke's (2020) thematic analysis framework and further narrowed the themes from the data, resulting in three common themes throughout the data that will be explored in the next section.

Study Limitations

Price and Murnan (2004) highlight the necessity in discussing research limitations such as biases that the researcher could or could not control, which may impact the findings of the study. As such, it is important to note that one of the limits in this study is the constrained scope of generalizability. Prabhu (2020) explains that one of the concerns associated with qualitative data is that it is limited in statistical generalization, which given I only interviewed 12 people, this study is limited in making broader inferences about the factors that inhibit disability inclusion in Swedish development cooperation. Nonetheless, despite the limited scope of generalization in this study, this research can be deemed complimentary to existing research on similar topics as will be highlighted in the next section of this study (Prabhu, 2020).

Furthermore, Mollet (2011: 4) explains that often one concern in social science research is the role of the researcher as a participant observer, highlighting that the research "should be neutral in order to maintain their aim of objectivity." Mollet (2011) also notes it can be difficult to ensure objectivity if the researcher themselves are connected to the respondents. In my case, having worked with a handful of international and Swedish OPDs already, I was personally connected to many of the disability rights experts I interviewed for this study.

Further, given I identify as a disabled person myself, one might argue that I have biases in favor of disability issues, which then could prevent me from being objective in this study. However, to mitigate this I seek to highlight all sides, whether they agree with my personal views or not and link all findings to existing literature and theory to properly analyze the data as an objective participant observer.

Ethical Considerations

According to Creswell (2014) the term worldview, or paradigm, refers to beliefs that steer action and a researcher's orientation about the world may be highlighted in their research. The philosophical worldview proposed in this study is what Creswell (2014: 27) explains as the 'advocacy and participatory worldview' and focusses on "the needs of groups and individuals in our society that may be marginalized or disenfranchised." This research therefore seeks to spark debate about the inclusion of PWDs in Swedish development.

To spark debate, I interviewed 12 people who were willing to share their thoughts and experiences about a rather sensitive issue, the inclusion of PWDs in Swedish development cooperation as no one is likely of the belief that PWDs should not be heard or included. However, as I sought to highlight the realities of today and asked interview participants to be vulnerable and share critical input on the development sector, I had to ensure that participants were comfortable speaking with me and obtaining consent was of the utmost importance. During each interview I confirmed with each participant twice that they were comfortable with me interviewing them and let them know that they did not have to answer any question they did not feel comfortable with, and they could stop the interview at any time.

Mullet (2011: 1) highlights that "social science investigates complex issues which involve cultural, legal, economic, and political phenomena." Therefore, all social science research "must concern itself with "moral integrity" to ensure that research process and findings are "trustworthy" and valid (Mullet, 2011: 1). As such, this research grounds itself in protecting the identity of those I interviewed by using pseudonyms and not specificizing which organization each participant is affiliated with as outlined in Table 1 above.

FINDINGS & DATA ANALYSIS

The following section introduces the findings of this study and highlights common themes through the lenses of ableism and disablism. The main themes of this study include disability not being a priority within Swedish development cooperation along with the various explanations and rationales for not prioritizing disability, power structures, and disability discomfort within Swedish development cooperation today.

Disability is Not a Priority

Prioritization was discussed throughout the entire data collection stage of this research. Each of the 12 people I interviewed explicitly stated or alluded to the idea that PWDs and disability issues are not seen as a priority within Swedish development cooperation. George shared that "to a large extent, it's [disability] sort of forgotten or maybe not taken as seriously as it should be." Bailey and April, both noted it stems from a lack of knowledge. Meanwhile Callie went so far to say that development actors in Sweden and globally "don't care as much about them [PWDs]." Meanwhile, Derek said that PWDs are sort of "invisible" within the space of international cooperation and Alex noted that there is "a lack of interest" in working on disability issues.

Although many of the people I spoke with suggested that interests have increased over the years consistent with Marshall (2012), disability remains relatively low in terms of prioritization. Christina, who works in development, but has personal interest in disability issues, explained that once she asked a partner organization, a non-OPD, about their disability program, the partner was stunned noting that none of their funders had ever asked them about their disability program before nor asked them about the practices they use to ensure disability inclusion. Christina's example exemplifies what Niewohner et al. (2020) found in their own study: a lack of awareness amongst NGOs and agencies about disability inclusive development.

Further, some participants noted that even when organizations try to prioritize disability and better include PWDs in their efforts, disability inclusion might get scrapped if additional accommodations are needed to ensure equal access and space for PWDs, which is also what

Niewohner et al. (2020) noted in their research: the cost of inclusion is too high. To illustrate this latter point I would like to highlight a situation that Callie who wokrs for an OPD shared with me. To set the stage, a Swedish CSO working within the development space contacted Callie a few years back asking if she could recommend a woman with a disability that the CSO could then include for an upcoming event to celebrate International Women's Day. Callie obliged and contacted someone she had worked with in the past, who agreed to speak on their experiences as a disabled woman in the global South. Callie let the CSO know that she found someone who would be a great fit for the speaking opportunity and informed the CSO that the women would be needing a sign language interpreter, because the women is deaf. After being informed that a sign language interpreter would be needed to allow the women to participate the CSO let Callie know that unfortunately the organization could not afford an interpreter and opted not to prioritize the deaf woman's inclusion in this instance.

Isabelle, who works for a Swedish NGO, also offered examples of organizations not prioritizing disability within the context of humanitarian assistance explaining that:

> It is hard for me to think of anything I have worked on where there hasn't been any ableist assumptions….when it comes to basic humanitarian service provisions in crisis and being first come first served for food, sanitary boxes and medical supplies, and you have abled bodied persons at the front of the line and disabled persons at the back, not accessing those basic humanitarian services at all, given the assumption is that everyone will be abled bodied and will be able to access the services without any additional support.

In both examples offered by Callie and Isabelle, I argue those working within international cooperation are favoring those without disabilities over those with disabilities. Take the first example of a Swedish CSO declining the participation of a deaf women, through the lens of ableism and disablism I argue the CSO not only favored someone who is not deaf i.e. 'able' to participate without any accommodations, but also excluded the women and anyone else who might be deaf or hard of hearing from engaging in the event entirely, because the CSO failed to provide access by means of sign language interpretation.

Kuwonu (2021) writes about a similar example of when a blind women wanted to donate to a humanitarian organization's fundraising efforts. However, the website was not accessible to those who use screen readers[7]. As a result, women had to have someone help her donate, since the system was not accessible noting that "maybe that was an accidental barrier for blind donors, but accidental ableism is still ableism" as the website was designed for persons without disabilities (Kuwonu, 2021)

Regarding the example shared by Callie, although limited budget was offered as an explanation in this case, it can be argued that the CSO had someone 'able' or 'other' in mind. Hosking (2008: 11) explains "systematic response to disability which purports to make disability invisible is inherently incapable of effectively protecting the rights of disabled people to be full participants in their communities." The CSO in this case opted to make persons who are deaf 'invisible' as George also noted, but also showcased that they were unable to lead by example in providing accommodations to PWDs.

Below I further discuss in more detail the various reasons offered to not prioritize disability issues within Swedish development cooperation, including limited budget and lack of awareness.

Limited Resources

Limited funding is often the justification given for not prioritizing disability issues within the context of development (Niewohner et al., 2020). In defense of the CSO discussed earlier, if a different disabled person was recommended, perhaps someone who uses a wheelchair and would not require an accommodation during the event, the CSO would have likely welcomed them to join their advocacy efforts, so inherently the CSO just saying "no" to someone who needed an accommodation, discriminating those who are deaf.

This, however, is a tricky slope of preferring someone 'other.' Ingham (2018: 7) notes to avoid exclusion people should "identify inequality and create solutions to enable full participation and inclusion," which was simply not the case here. Further, the structure in place of offering

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[7] Screen readers refers to software, which allows those who are blind and low vision to access text through speech or braille display.

cost as a reasonable excuse further steers people towards the perceived normal in society, if sign language is not commonly offered few might perceive sign language as 'normal' (Dolmage, 2017).

While speaking to Meredith who is an expert in human rights, about resources she explained that:

> We [development organizations] don't always have the resources. For example, you have 100 million Swedish kronor to design programs in a country and you are making the analysis of the root causes to the problems that you see in that country. There are many root causes, there are many groups that are facing hardships and having their rights overlooked…it's just impossible to design programs that cover everything. You just prioritize... I personally feel that having separate programs for persons with disabilities, separate programs for minorities, separate for women, that's just not possible. We just do not have the resources to do that.

Meredith also imagines that other groups representing various marginalized communities feel that Swedish development cooperation actors do not prioritize their issues either. She suggests that one would likely end up with similar data, as other groups are also not well-integrated into development cooperation to the extent they should be, such as LGBTQIA+ persons, indigenous populations, and children. However, Nieminen (2023: 618) explains that "only disabled people are discriminated against through direct forms of ableism, disablism," which are evident in both examples explored above within the context of development cooperation. However, by citing limited financial resources to either not include or prioritize disability, PWDs in development remain being seen as a 'burden' or a 'problem' furthering the idea of 'normal,' 'able' and inferior in the development sector as also explained by Grech (2016).

Further, if one examines certain Sida strategies (Appendix 5, 6 & 7), such as the SRHR Strategy in Africa, women, girls, and LGBTQIA+ persons are mentioned, but PWDs are not. Further,

none of Sida's SPOs represent PWDs specifically. At the same time, Kvinna to Kvinna[8], represents women, and Save the Children[9] and Plan Sweden[10] represent children. Through the lens of ableism, it appears that within Sida they are not directly discriminating against PWDs, but on the surface it appears as though they are indeed favoring those without disabilities. A handful of experts I interviewed indicated this is because OPDs often lack the capacity to offer support and guidance. To further elaborate this point of prioritizing other groups within the context of resource limitations Amelia posed the following questions:

> Would NGOs say they cannot include women, children or LGBTQIA+ persons because of costs? Would a Swedish NGO working to empower women, ever say 'we empower all women but lesbians?' NGOs in other countries, sadly, might still be able to get away in saying this, but a Swedish NGO would likely not given Sweden is seen as one of the most progressive countries in the world, but too often NGOs get a way in saying that they support women, but not women with disabilities because the organization lack the funds to offer access to PWDs, and their existing programs are designed for able bodied people.

Niewohner et al. (2020: 1174) found in their own study that many NGOs believe inclusion costs are too high and one NGO even said, "Our work is… we are working so much with poverty that there are so many other… [laughs] I mean, everything is important, but there are so many issues that we are dealing with."

Limited resources are echoed by George, but who also noted he cannot prioritize any group given the limited budget constrains placed on CSOs by the Swedish government this year (see Käppeli & Calleja, 2022). Yet, Amelia, Mark, Callie, Bailey, and April all noted in their interviews, however, that current budget constrains are no excuse for decades of not prioritizing PWDs and disability issues as outlined by Grech (2016) and Walton (2020).

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[8] A SPO of Sida.
[9] A SPO of Sida.
[10] A SPO of Sida.

Further, if cost is used as an excuse to not prioritize disability, not only are organizations showcasing practices of disability discriminatino, but they are also highlighting the fact that they favor those without disabilities because they cost less. Finally, George highlighted that limited resources and limited awareness both contribute to the lack of disability prioritization noting that:

> In many ways, it's [disability inclusion] heavily dependent on funding. And if we lack funding towards disability specific projects, that will also sort of affect the awareness overall. So, it's sort of like a spiral, but it's hard to say as I think that in order to increase awareness we need to have the funding in place, but in order to increase the funding, we need to have that awareness as well.

The 'Will to Improve' & Lack of Knowledge

Mark believes that money is not the real issue, he suggests that political will on disability in Sweden remains at the heart of the problem and the 'will to improve' remains difficult to amplify if persons do not have sufficient knowledge about disability (Li, 2007). Mark argued people are not yet willing to fully embrace the inclusion of PWDs in development. In other words, Mark argues that disability is still seen as a focus area and not a cross-cutting issue, suggesting that if organizations truly wanted to be inclusive of disability, they would take steps from the beginning. This is like what Niewohner et al. (2020) found in their study as discussed earlier.

For example, I recall a recent meeting with a member of the Swedish embassy staff in Rwanda, who in passing discussed the various thematic priorities of the embassy such as climate, but suggested perhaps this was not of interest to a disability rights expert like me. On the contrary, climate change is of great concern and interest to PWDs given climate change often impacts PWDs at higher rates compared to those without disabilities (see Keogh & Gonzalez, 2020). Thus, the issue remains, ignorance to know that climate change also impacts PWDs.

On the other hand, Lexie suggests that disability has become more of a 'buzzword' arguing that Swedish NGOs are starting to discuss disability, but it remains difficult because they do not know how to ensure inclusion, resulting in not prioritizing disability at all, short of throwing

the term into various documents amongst other commonly marginalized groups (Marshall, 2012). Lexie and Meredith noted there is a will, but organizations do not know how to ensure implement disability inclusive programs alongside everything else. Meredith said that "it's not a lack of political will, it's so many competing priorities." Amelia and April shared similar feelings. April stated that:

> I think there is a curiosity and a willingness to be more inclusive. No one is leaving this [PWDs] group out of spite. At least nobody does it deliberately. It's because they don't have the knowledge.

Meredith and Alex both noted that they had witnessed first-hand the consequences of not having the sufficient knowledge about disability when implementing programs. Although most of the people I interviewed mentioned disability was a cross-cutting issue citing that disability needs to be mainstreamed which could help alleviate the issue with limited resources, the reality of Swedish development cooperations seems to set a different tone in terms of priority setting.

This is similar to what Niewohner et al. (2020) found in their study noting that disability is not a focus of many NGOs. Amelia explained that she is frustrated with the lack of disability prioritization, and few seem to know whose responsibility it is to ensure PWDs are included as prescribed by Article 32 of the CRPD. She asks, "is it Sida, is it NGOs or OPDs, or perhaps everyone?" She noted that she still has not received an answer to this question after working with her OPD for the past seven years.

Derek suggested that although he supports the main Swedish OPD that leads Sweden's disability and development efforts, he warns that this might be seen to others as "enough" in terms of Sweden's efforts in prioritizing PWDs and a rational for not educating themselves more on disability issues. Derek continues by explaining that the OPD is seen as the knowledge hub, and many Swedish NGOs will refer to them instead of doing anything themselves on disability. Derek even mentioned contacting the OPD to get an update on disability-related issues before speaking to me.

Sweden development cooperation actors might often default to what they know and to "able-bodiedness" (Campbell, 2009). Although scarce, as explained by Grech (2016), there are resources and recommendations on how to make development cooperation inclusive to PWDs (see Coe, 2012; Stein & Stein, 2014; UN, 2016; UN, 2018). Yet, Sida has stated for several years now that they lack the knowledge to ensure disability inclusion (see Dahlström et al., 2009; SIDA, 2018; Weibahr, 2021) but continue to state that they lack the necessary knowledge. The static lack of knowledge within Swedish development through the lens of ableism can be seen as "valuing abilities and abledness over disabilities and disabledness" (Nieminen, 2023: 617) or simply viewing PWDs not capable of being included in development as prescribed by Grech (2016). Callie suggests moving forward that:

> Sida must clearly state that persons with disabilities are a target group they seek to reach. Too often, Swedish development defense is, 'that although persons with disabilities are not a direct, or primary objective, we catch persons with disabilities given we work with a poverty tool where disability is included.' However, given they do not measure disability, Swedish development cannot confirm or say for certain that their disability mainstreaming efforts impact the lives of persons with disabilities, but I cannot either claim they do not…however current research shows that if we do not explicitly include persons with disabilities, they will not be reached.

Power Structures

Along with disability not being viewed as a priority within Swedish development cooperation, this study found that existing power structures both within the Swedish development sector and disability rights movement prevent disability inclusion in development today. When asked what they think might prevent disability-inclusive development Lexie said:

> My simple answer would be power structures, because even if we want to work with the people with less power, and people living in poverty, we still work through organizations and people that have been organized already in organizations that are already existing, they might not be the people that have less power in their community. They might already have noticed that 'yeah, if we are organized and we have easier

access to some of the goods that exists in society maybe we can have international donors.' They are people with some kind of power already.

Lang et al. (2017) also emphasizes the role power relations play in ensuring disability inclusion. Below I explore existing power structures within Swedish development cooperation and within the disability rights community.

Isabelle noted that those who create laws and policies, or perhaps even those implementing programs, have massive structural biases as they are often drafted and written by able bodied people. Additionally, Isabelle noted that "male bias, white bias and certainly an ableist bias are built into our society and take a very long time to deconstruct" suggesting that the medical and charity model are still dominant, particularly the medical model. Lexie also noted that there is not full acceptance on PWDs being a part of human diversity there is still this idea that PWDs need fixing and that is still the basis for many interventions including humanitarian interventions as explored earlier. Existing power structures favor those who are not disabled (Grech, 2016). Callie echoed this sentiment and said:

> Established actors overlook people with disabilities and do not include them in the work that is, done. My favorite example of this is how they [Swedish actors] claim to work specifically with the poorest of the poor and use this poverty tool that is supposed to ensure that you reach those who live in the greatest poverty and vulnerability, but they also seek to identify those who have no voice and have no influence in society or their own life. The tool they use is this excellent tool, but the only problem is that they are not including people with disabilities.

Callie discussed that to her it is clear Swedish development actors are overlooking PWDs based of the ODA numbers alone like what Grech (2016) explained. One can also look at Sida's SPOs and see that no organization represents the disability community explicitly, highlighting that those in power do not come from the disability community in Sweden. Derek also mentioned that he believes "organizations and funders like Sida don't push, lobby or influence much on disability issues."

Meredith also said that although many organizations working in the development sector have adopted a rights-based approach, which at its core is meant to be inclusive of the rights of PWDs, disability inclusion in development remains a structural challenge saying that:

> we [development actors] have tried to ensure inclusion by moving away from special advisers on particular topics and groups to strengthen our efforts on a human rights-based approach and a multidimensional poverty analysis, but we [Swedish development cooperation] are not fully there yet.

However, as Meeks (2020) highlights no current staff member is only focused on disability issues i.e., there is no Disability Advisor role at Sida, and the individuals I interviewed from the various Swedish NGOs noted they do not have a disability focal point either and a handful of the annual reports discussed earlier also indicated few organizations had PWDs working there (see Appendix 3).

However, Alex and Christina both mentioned that it is impossible for someone to be an expert on everything, one cannot be a gender expert, climate expert, child expert, disability expert etc. Echoing the idea that not having someone representing the disability community only further limits the power and voice of PWDs within international cooperation which coincides with the findings by Nieminen (2023) that limited representation results in marginalization. Additionally, Derek, Mark and Bailey highlighted the layers of power within Swedish development noting that Swedish ODA funding must go through several channels before reaching OPDs in the global South.[11]

Furthermore, there is a sense among the people I interviewed that the disability rights community must have a stronger voice within international cooperation, and it is their responsibility to ensure the voices of disabled people are heard. However, OPDs often have limited capacity to do advocacy efforts given the current power structures as noted my Meredith and George. Additionally, Mark explains that local disability rights organizations across all of Sweden are already working on limited resources and do not have the capacity to

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[11] First, Sida receives money from the Swedish government, Sida sends it to Forum Civ, Forum Civ sends it to MyRight who then finally sends it to OPDs in the global South (Meeks, 2020).

conduct more advocacy. In summary, power structures in Swedish development are limiting advocacy efforts to increase funding for disability issues, and without funding, organizations have limited capacity to conduct more outreach and advocacy efforts given the current power structures in place.

However, Callie asks if Swedish development cooperation actors would say the same about children and other groups, that these groups also need to advocate for inclusion and funding. She continues by noting the hypocrisy of claiming that PWDs themselves are responsible for ensuring that those with limited voice already, who might be in poverty, need to advocate for better support. Niewohner et al. (2020) too found that NGOs often shift blame onto others in terms of who is responsible for protecting PWDs. Christina shared similar feelings noting that if a family in Sweden has a child with an intellectual disability, they may have other priorities that do not allow them to go out and demonstrate for more funding for international cooperation. By claiming that OPDs and PWDs need to go out and demand more funding like other organizations have done highlights that existing practices remain the norm and that PWDs are expected to follow suit to ensure they are heard (Nieminen, 2023).

Lastly, Lexie notes that existing structures within Swedish development do not always implement an intersectoral approach and organizations tend to focus on one group such as women, but then forgot to include women with disabilities or they focus on children, but then overlook children with disabilities. It is this sense that development cooperation can see through one lens and not see the many characteristics of a person (Hankivsky, 2014).

Callie posed an interesting example, by explaining that if an organization that is working on women-related issues and states they tend to mainstream disability in their efforts yet do not intend to target disability issues specifically, how do they expect to ensure a woman with an intellectual disability or a woman who is deaf-blind is included in their efforts? Callie argues they will not likely reach them, suggesting that power structures within the organization of not thinking about disability and tailoring their efforts to them will prevent them from including some disabled women once again highlighting the practice of people focusing on those who are not disabled or devaluing their capability to participate (Grech, 2016).

Finally, within the context of exploring disability, it is very important to mention power imbalances within the disability rights movement, which was highlighted by many of the people I interviewed. For example, often persons who have a physical disability or sensory disability, especially vision, have much more power within the disability community then persons who have a cognitive or intellectual disability (see Inclusion International, 2020).

Within the context of development, it is common to hear that non-OPDs who stride towards disability inclusion know they need to install a ramp in a school to ensure the inclusion of a person who uses a wheelchair, but NGOs are less aware what a student with an intellectual disability might need to be included within the school. Christina explained that she has witnessed a lack of power of those with cognitive and intellectual disabilities in her work. She continues by clarifying that many people, including the broader disability rights community tend to forget them, since the needs of persons with intellectual disabilities might be much more complex to address, ultimately also resulting in the exclusion of certain PWDs in favor of 'others' (Nieminen, 2023).

Disability Discomfort

One final theme that was common throughout my research was the discomfort associated with disability issues, a theme only briefly discussed in existing literature on development and disability (Coe & Wapling, 2010). Yet, each of the six experts I interviewed not working with disability, either apologized for not using the 'correct' disability language or checked with me if they were using the 'proper' disability term. For example, Meredith said when talking about disability "…you must excuse me, because I'm not updated on all the vocabulary. So, sorry for that, if I step on any toes here…I know the vocabulary can be a little bit sensitive," she continued by saying in comparison to other rights, she is not as familiar with disability rights. Furthermore, Amelia noted that she feels "that a lot people have a fear of offending us [disability community] …people are very afraid of offending 'others'."

Furthermore, multiple people I interviewed indicated their caution for working on disability issues at times. For example, Isabelle explained that in her experience given OPDs and the disability rights community have been firm in their stance, 'nothing about us without us' some CSOs and sometimes certain UN agencies feel anxious about stepping on toes explaining that

she has witnessed the disability community being somewhat territorial. A handful of disability rights experts agreed with this narrative. April shared that she herself has witnessed individuals from disability rights organizations get mad when non-OPDs aspire to work on disability issues without OPDs. April concluded by noting that the disability rights community should also be more active in working with other organizations to support mainstreaming efforts.

Both April and Amelia highlighted that their experience has been that people are fearful to work on disability sometimes, a sentiment echoed by both Christina and Isabelle. Amelia concluded that sometimes development actors believe "it is better to not say anything at all and no nothing, because what if I say something wrong," and continued by explaining that organizations will do nothing to ensure they do not unintentionally insult PWDs. Related to her work in human rights, Meredith, discussed how often their human rights work is criticized by the disability community and said:

> I think we [Swedish development actors] know that we're not doing enough from the disability movement's perspective, we [Swedish development actors] are not doing enough or good enough. And we probably don't do the right thing, either. But I think we also need some advice on how to move the needle forward. I do not think we [Swedish development actors] do not benefit from constantly hearing that we are not doing enough, but rather, we need to hear the entry points for doing more work with greater results.

Fear of doing the wrong thing does little to support PWDs in the global South if it means that people will not do anything at all. Disability discomfort is related to ableism as individuals working in human rights know ableist language is common and they do not want to perpetuate it, which is admirable, but doing nothing is inherently still favoring those without disabilities and ultimately results in discrimination against PWDs. Especially since there are resources that do exist offering guidance and support on the 'right' things to do.

In relation to the disability community, April, Alex and Isabelle's point about the disability community wanting 'nothing about us without us,' all highlighted the historical importance

and significance behind this, but believe moving forward, development actors and disability rights activist within the development community must come together to ensure no 'body' is being favored over another, which currently is the case. Amelia, however, it is her role as an OPD to criticize those in power for not including PWDs in their efforts.

Further, if people are fearful of talking about disability, it will only continue to be a lower priority and existing power structures will continue to dominate. As Niewohner et al. (2020: 1175) noted in their research "many organizations were happy to tout themselves as changemakers in the communities where they worked, almost all, in terms of disability inclusion, were willing to wait for someone else to lead," which I argue is the same here. People are willing to speak up and fight on behalf of others, yet when it comes to disability, they are comfortable keeping quiet and waiting for someone else to organize and lead. Being uncomfortable talking about PWDs is also very much leaning into treating PWDs as 'others' (Campbell, 2012; Grech, 2016).

Finally, as a disabled women myself I recognize that it can be tricky approaching disability-related questions, because it is indeed a fine line of asking too many intrusive questions versus not asking any at all. I find it frustrating when people ask me if I need assistance even if I do not ask for it, and I find it frustrating when people do not ask questions how to be inclusive. Therefore, I encourage individuals to ask questions, but to always do so in a respectful manner, this most often offers the best results.

DISCUSSION & CONCLUSION

PWDs remain overlooked and forgotten in international development cooperation. Although it is important to acknowledge that any development cooperation system and ODA distribution are complex, given the many competing priorities, it is imperative to study why disability inclusion might be difficult to achieve. In the case of Sweden, this study offers insights that this may include, disability not being seen as a priority by Swedish development NGOs due to limited resources and knowledge, existing power structures and a level of discomfort working with disability issues.

Furthermore, priorities set by Swedish development actors, existing power imbalances and limited awareness towards disability issues might all contribute to the lower levels of ODA targeting PWDs and disability issues. Additionally, the fact that disability is not represented within Swedish development strategies, also contributes to the limited ODA funding targeting disability, however, I argue disability is not represented in present strategies, because those drafting the strategies are not PWDs and have little background knowledge-related to disability issues.

Based on the findings of this study though the lenses of ableism and disablism it can be argued that Swedish development actors currently unintentionally or intentionally favor those without disabilities. Swedish development continues to exhibit practices that prevent PWDs from accessing advocacy and outreach efforts along with development programs and services. Further, Swedish actors are prioritizing other commonly marginalized groups while not considering intersectionality and decision-making process that overlook and underestimate PWDs. Disability needs to be better included in development, but to be better included PWDs need to advocate to be prioritized, but for OPDs to better advocate for the rights of PWDs, they need more resources, but for OPDs to receive more resources they must be deemed a priority. It is endless cycle of frustration and discomfort within the development space to include disability.

Moving forward, greater research needs to be conducted related to how to overcome these challenges that may inhibit disability inclusion. Development actors including those working

within the disability-inclusive development space must have greater dialogue with each other. Current practices include disagreement and frustration with one another, fighting back instead of forward. As such, research should examine ways to overcome and strategize best practices given current recommendations offered by Stein and Stein (2014) for example given they are not current being used by Swedish development actors to the extend they should.

In conclusion, it is time for Swedish development actors, disability rights advocates and PWDs to initiate the conversation and strive towards open and effective dialogue to ensure the full inclusion of PWDs in both development outreach and programs to come closer to Agenda 2030 and the SDGs. Without the inclusion of disability issues from development, PWDs will only continue to be left behind, deemed 'less than', viewed as 'other' and unfavored as prescribed by the concepts of ableism and disablism.

I encourage all to consider disability at every step of development cooperation. Swedish development cooperation can be a leader on disability-inclusive development because the will is there, but it must first recognize its ableist and disablist practices and discover disability instead of embracing disability discomfort.

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APPENDICES

Appendix 1: Ten Steps for Inclusive Development

#	Step for Inclusive Development	Source
1	Identify DPOs	
2	Conduct a disability assessment	
3	Designate a disability focal point	
4	Employ people with disabilities	
5	Include the needs of persons with disabilities in project selection	Stein and Stein (2014: 1263)
6	Encourage and facilitate the participation of DPOs	
7	Make certain facilities are accessible	
8	Implement disability-inclusive projects with local DPOs	
9	Enable accountability toward the disability community	
10	Foster collaboration and coordination on disability issues	

Appendix 2: Sida's 17 Swedish Strategic Partner Organizations

Strategic Partner Organization
Forum Civ
Union to Union
Olof Palme International Center
Swedish Mission Council
Afrikagrupperna
Diakonia
We Effect
The Swedish Society for Nature Conservation
Save the Children Sweden
Act Church of Sweden
Plan International Sweden
Riksförbundet för Sexuell Upplysning (RFSU)
WWF Sweden
IM (Individuell Människohjälp)
Kvinna till Kvinna
Civil Rights Defenders

Strategic Partner Organization
Swedish Red Cross

Appendix 3: Sida & SPOs Mainstreaming Disability

Organization	Persons with Disabilities	Source
Swedish International Development Cooperation Agency (Sida)	**Staff Diversity.** SIDA indicates the agency needs to increase the diversity of their staff, including hiring more persons with disabilities (page 17). **Impact Chain.** SIDA includes an image of a wheelchair when exploring the organizations effects over time (page 5). **Internships.** The report flags the mandate by the government to offer more persons with disabilities an opportunity to intern with the organization (page 33). **Democratic Governance.** When referring to the agency's efforts in strengthening democracy in Guatemala, SIDA highlights the agency contributed to greater civic participation amongst women, indigenous communities, LGBTQIA+, and persons with disabilities (page 75). **Human Dignity.** When referencing the respect and human dignity offered to various groups, Sida states that they have witnessed an increase in respect towards persons with disabilities explaining that disability issues have more representation on the international, national, and local levels (page 78). **Women's Rights.** Sida references to one of its strategic partners (Diakonia) and its efforts in ensuring Muslim women, former refugees and women with disabilities run for elected office in Sri Lanka (page 83). **Free from Violence.** Sida highlights its support to a Swedish CSO who led campaigns to end violence in homes. The campaign's goal included ending violence towards women and girls, LGBTQIA+ persons, and persons with disabilities (page 95). **WASH Support.** Sida highlights its support to organizations striving to ensure available WASH facilities to	Sida (2022c)

Organization	Persons with Disabilities	Source
	communities, including persons with disabilities (page 110). **Education.** Sida mentions several reasons children and young adults do not attend school, one reason they mention is disability (page 114).	
Diakonia	**Images.** The report includes a picture of a young boy pushing a woman in a wheelchair up a ramp and another photo of persons with disabilities playing soccer using crutches (page 3 & 27). **Staff Diversity.** The organization states it strives for the organization to be divers including persons with disabilities (page 34). **Emergency Response.** The organization discussed their efforts in providing hygiene and food products to women-headed households and persons with disabilities in Somalia (page 27).	Diakonia (2022)
We Effect	**Vulnerable Groups.** Disability is mentioned with other vulnerable groups including women and children when referring to land tenure opportunities in Zambia (page 12).	We Effect (2022)
Save the Children	**Education.** Disability is mentioned as a part of a broader list as to why children might not be receiving an education (pages 28-30). **Staff Diversity.** The organization also mentions disability as a part of hiring a diverse and inclusive staff (page 49)	Save the Children Sweden (2022)
Plan International Sweden	**Natural Disasters.** The report highlights that girls, teenage girls and girls with disabilities are more likely to be exposed by disasters (page 5). **SRHR.** The organization includes persons with disabilities also benefiting from their efforts on SRHR in Zimbabwe (page 17). **Staff Diversity.** The organization highlights that it seeks to have a diverse staff, including people with disabilities (page 34).	Plan Sweden (2022)

Appendix 4: Sida & SPOs Targeting Disability

Organization	Persons with Disabilities	Source
Swedish International Development Cooperation Agency (Sida)	**Results (IDA).** The report highlights Sida's partnership with IDA (page 55). **Results (Baltic Partnership).** The report highlights SIDA's disability focus within the Baltic Sea region and discusses their partnership with local governments in Russia to ensure the inclusion of persons with intellectual disabilities in culture and art (page 70).	Sida (2022c)
Fourm Civ	**Education & Healthcare.** The report highlights statistics related to persons with disabilities accessing health care services and accessing education (page 22). **Issue Area.** The report highlights how many of their members focus on disability issues (page 25).	Forum Civ (2022)
We Effect	**Food Access.** The report highlights a project aimed at disabled people and their families in rural areas (page 12).	We Effect (2022)
Diakonia	**Palestine Project.** The report highlights the organization's efforts working with an OPD in Palestine on disability rights (page 14).	Diakonia (2022)
Act Church of Sweden	**Children with Disabilities.** The report highlights the organization's efforts running two rehab and resource centers, for children with disabilities who live in Somalia and Ethiopia refugee camps (page 12). **Image.** The report includes a child in a wheelchair in a classroom setting (page 12).	Act Church of Sweden (2022)
IM (Individuell Människohjälp)	**OPD Partnership.** Highlights its partnership with an OPD in Romania that can now stand on its own thanks to their support over the years (page 4).	IM (2022)

Appendix 5: Sida's Thematic Strategies

Strategy	Mention of Disability	Source
Strategy for sexual and reproductive health and rights (SRHR) in Africa 2022–2026	No mention of disability.	MFA (2022a)
Strategy for Sweden's humanitarian aid provided through the Swedish International Development Cooperation Agency (Sida) 2021–2025	No mention of disability.	MFA (2020a)

Strategy	Mention of Disability	Source
Strategy for Sustainable Peace 2017–2022	**Rights-based Approach**. The strategy refers to 'disability' when discussing the approach amongst other identities.	MFA (2018g)
Strategy for capacity development, partnership and methods that support the 2030 Agenda for sustainable development	**Rights-based Approach.** The strategy refers to 'disability' when discussing the approach amongst other identities.	MFA (2019)
Strategy for support via Swedish civil society organisations for the period 2016–2022	**Rights-based Approach.** The strategy refers to 'disability' when discussing the approach amongst other identities.	MFA (2017)
Strategy for Sweden's global development cooperation in the areas of environmental sustainability, sustainable climate and oceans, and sustainable use of natural resources 2018–2022	**Rights-based Approach.** The strategy refers to 'disability' when discussing the approach amongst other identities.	MFA (2018h)
Strategy for Sweden's global development cooperation in sustainable social development 2018–2022	**Rights-based Approach.** The strategy refers to 'disability' when discussing the approach amongst other identities.	MFA (2018i)
Strategy for Sweden's development cooperation in the areas of human rights, democracy and the rule of law 2018–2022	**Rights-based Approach.** The strategy refers to 'disability' when discussing the approach amongst other identities.	MFA (2020b)
Strategy for Sweden's global development cooperation on sustainable economic development 2022–2026	No mention of disability.	MFA (2023)

Appendix 6: Sida's Regional Strategies

Strategy	Mention of Disability	Source
Strategy for Sweden's regional development cooperation with Africa 2022–2026	No mention of disability.	MFA (2022e)
Strategy for Sweden's regional development cooperation with Asia and the Pacific Region in 2022–2026	No mention of disability.	MFA (2022f)

Strategy	Mention of Disability	Source
Strategy for Sweden's regional development cooperation with Latin America 2021–2025	No mention of disability.	MFA (2021a)
Strategy for Sweden's regional development cooperation with the Middle East and North Africa 2021–2025	No mention of disability.	MFA (2021g)
Results strategy for Sweden´s reform cooperation with Eastern Europe, the Western Balkans and Turkey 2014-2020	No mention of disability.	MFA (2015)

Appendix 7: Sida's Bilateral Strategies

Strategy	Mention of Disability	Source
Strategy for Sweden's development cooperation with Bolivia 2021–2025	No mention of disability.	MFA (2021b)
Strategy for Sweden's development cooperation with Burkina Faso 2018–2022	**Rights-based Approach.** The strategy refers to 'disability' when discussing the approach amongst other identities.	MFA (2018b)
Strategy for Sweden's development cooperation with Colombia 2021–2025	No mention of disability.	MFA (2021c)
Strategy for Sweden's development cooperation with Cuba 2021–2025	No mention of disability.	MFA (2021d)
Strategy for Sweden's development cooperation with Ethiopia 2022-2026	No mention of disability.	MFA (2022b)
Strategy for Sweden's development cooperation with Guatemala 2021–2025	No mention of disability.	MFA (2021e)
Strategy for Sweden's development cooperation with Iraq 2022–2026	No mention of disability.	MFA (2022c)
Strategy for Sweden's development cooperation with Kenya 2021–2025	No mention of disability.	MFA (2022d)
Strategy for Sweden's development cooperation with Palestine 2021–2025	No mention of disability.	MFA (2020c)
Strategy for Sweden's support for democracy, human rights and the environment in Russia 2020–2024	**Country Context.** The strategy highlights that although the situation for persons with	MFA (2020d)

Strategy	Mention of Disability	Source
	disabilities in Russia has improved over the years, live remains difficult. **Rights-based Approach.** The strategy refers to 'disability' when discussing the approach amongst other identities. **Priorities.** The strategy states that preventing discrimination against persons with disabilities is a priority.	
Strategy for Sweden's development cooperation with Somalia 2018–2022	**Rights-based Approach.** The strategy refers to 'disability' when discussing the approach amongst other identities.	MFA (2018c)
Strategy for Sweden's development cooperation with Sudan 2018–2022	**Rights-based Approach.** The strategy refers to 'disability' when discussing the approach amongst other identities.	MFA (2018d)
Strategy for Sweden's development cooperation with South Sudan 2018–2022	**Rights-based Approach.** The strategy refers to 'disability' when discussing the approach amongst other identities.	MFA (2018e)
Sweden's regional strategy for the Syria crisis 2016–2020. Amended and extended to apply in 2021–2023	**Rights-based Approach.** The strategy refers to 'disability' when discussing the approach amongst other identities.	MFA (2021f)
Strategy for Sweden's development cooperation with Uganda 2018–2023	**Country Context.** The strategy highlights that discrimination based on disability remains common. **Rights-based Approach.** The strategy refers to 'disability' when discussing the approach amongst other identities. **Priorities.** The strategy highlights that preventing discrimination based on disability is a priority.	MFA (2018a)

Strategy	Mention of Disability	Source
Strategy for Sweden's development cooperation with Zambia 2018–2022	**Rights-based Approach.** The strategy refers to 'disability' when discussing the approach amongst other identities.	MFA (2018f).

Appendix 8: Interview Guide

Interview Guide

Demographic Questions (Optional):

1. Age
2. Gender
3. Do you have a disability?
4. Do you know someone with a disability such as a friend or family member?
5. Are you currently or have you ever worked within the Swedish international development cooperation sector? If so, what type of agency or organization do you or did you work for?

Disability Awareness Questions:

6. How do you feel when talking about 'disabilities?
7. What thoughts come to mind when you think about people with disabilities?
8. Are you ever uncertain as to how to 'behave' around someone with a disability?
9. Is there discrimination and/or prejudices towards people with disabilities? If yes, what are and why do you think that is the case?

Government agency, development consultant, non-disability-specific civil society, or human rights organization they experience (if you do not work at any of these, please disregard):

10. Do you actively work on projects/policies that include or involve people with disabilities? If yes, what type of projects? If not, why not?
11. Are there specific development projects/areas that should include people with disabilities? If yes, why?
12. What comes to mind when one says: "disability & development and/or disability-inclusive development"?
13. Are there barriers to include/involve persons with disabilities in development cooperation and development aid projects? If yes, what are they?
14. In your opinion, what is it possible to include people with disabilities and working towards inclusive development? If yes, what needs to happen?
15. In your opinion, what needs to happen to ensure people with disabilities are included and not overlooked within Swedish development cooperation and aid?
16. From a global perspective, why do you think since 2012, just 0.1% of all international aid has been allocated to projects with a primary disability component? Even when

including data from projects with a secondary objective of assisting or empowering people with disabilities, spending increased to only 0.5% each year.

OPD experiences (if you do not work at an OPD, disregard):

17. What obstacles do you experience while working on behalf of the rights of people with disabilities within the development cooperation sector?
18. What is the main obstacle for including persons with disabilities in development cooperation?
19. Do you have an example of successful program that was disability-inclusive? If yes, describe the project and the contributing success factors.

Swedish Development Cooperation Questions:

20. Why do you think only 0.45 percent of SIDA's grants in 2021 went to projects where people with disabilities were the primary target group?
21. Do you think Swedish development cooperation overlooks and neglects people with disabilities? If yes, what is the root cause?
22. Do you think criticism towards SIDA's lack of supporting and promoting people with disabilities is valid? If yes, why? If not, why not?
23. In your opinion, what role do you believe you and your organization have in supporting and including people with disabilities in your projects/programs/policies?
24. Should more people with disabilities be integrated into development cooperation work? If so, how?
25. How should Sweden promote disability in development cooperation moving forward?
26. What do you expect and what do you need from your partners to improve all-around? How should Sweden proceed in terms of disability-inclusive development? Ask for more funding? What should disability activists do? What should non-disability specific organizations do? What should government agencies do?