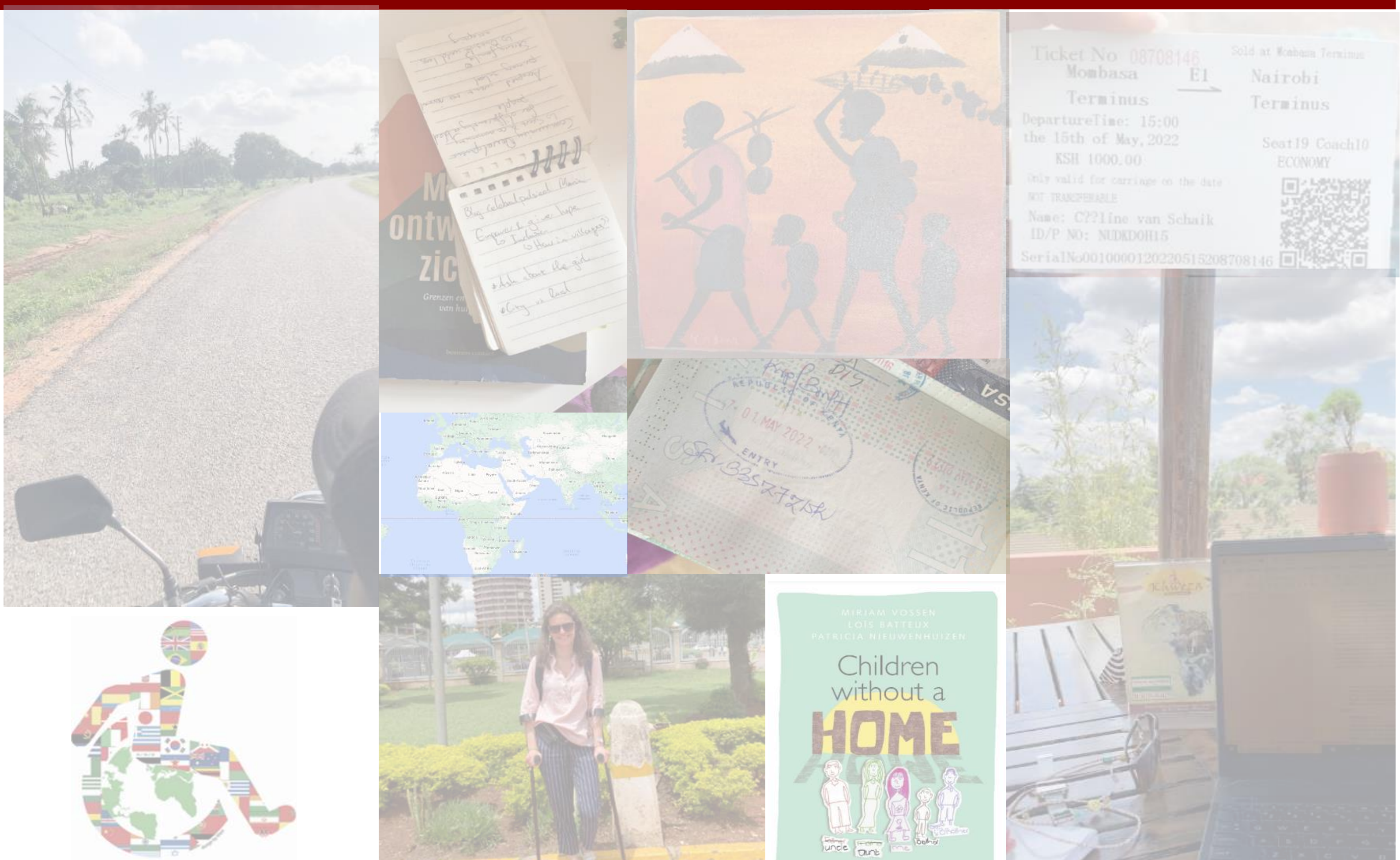
Care for Children with Disabilities in the Global South*

Theorising the context and situation of children with disabilities and their families in the Global South* and defining the positionality of NGOs and PDIs as main care providers

Céline van Schaik, 2023



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Theorising the context and situation of children with disabilities and their families in the Global South* and defining the positionality of NGOs and PDIs as main care providers

Master Thesis MSc Human Geography

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Foreword

I would hereby like to present to you my master's thesis. This foreword is the last part of this thesis that still had to be written, meaning that once this is finished, my thesis is finished. Whilst I am not sure I am ready to say goodbye to this research, I can say that I am proud and happy with what I have achieved to put on paper. When I started working on this topic, I did not know where it would take me but I could have never expected it to have taught me so much.

I would like to take this opportunity to thank my thesis supervisor Prof. Huib Ernste for always providing me with constructive feedback and inspiring meetings and new ideas which helped me to move forward and grow as a researcher. Moreover, I would like to give a very special thank you to Patricia Nieuwenhuizen and Better Care Network Netherlands. Not only for granting me the opportunity to research such an interesting and important topic but also for the good feedback and reflection moments. I truly learned a lot from this thesis and gained a whole world of new knowledge and insights which could have never happened without Patricia. Furthermore, I would like to thank all the interviewees, and especially so Harrie from Imani and Gerard and Lisette from KidsCare for allowing me to visit, and Rita for letting me shadow during my time at KidsCare and for answering all the questions that I had, and taking the time to translate.

It was not always an easy topic to research. As the respondents were telling me heart-breaking stories, it was impossible for me to not be emotionally invested in this research. But, that was also what made it better and more inspiring to keep on going. These are stories that need to be told, and this is research that needs to be conducted. There is still a lot more to discover, and this is perhaps still just a start, but I trust that this research can also have a small addition to improving the livelihoods of children with disabilities and their families.

Thank you for taking the time to read my master's thesis, and I hope you will enjoy reading it as much as I enjoyed writing it.

Abstract

This research contextualises the current situation for children with a (cognitive) disability in the Global South* and the role of NGOs and PDIs in providing care. The study employed constructivist grounded theory and included 16-semi structured interviews with NGOs and PDIs, experience experts, and parents, fieldwork and additional (non-)academic data.

The findings reveal that economic, practical, and cultural challenges including stigma, are the main obstacles for children with disabilities and their families. Children with disabilities are often overrepresented in institutional care following a lack of accessible infrastructure, cultural and family-related issues, and legislative reasons. NGOs and PDIs play a crucial role in providing family-based care. Their often holistic approach simultaneously has a positive effect on reducing stigma. However, many organisations focus on children with disabilities, neglecting the needed support in transitioning into adulthood. The study highlights the importance of family-centred approaches to care. The study recommends the exchange of knowledge and closer collaboration among organisations to improve care provision for children with disabilities.

Limitations of the study include the scope of countries covered. A suggestion for further research is to generalise specific processes among PDIs, seek quality guidelines, and explore the role of organisations in disability prevention.

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PDI	Private Development Initiative
NGO	Non-Governmental Organisation
CP	Cerebral Palsy

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1 Introduction

This paper examines the care for children with disabilities in the Global South*[1]. Approximately 1.3 billion people worldwide experience significant disabilities (*WHO,* 2022). A disability is defined as followed by the UNCRPD: *"Persons with disabilities 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."* (United Nations, n.d., para. 2)It is essential to understand that children may experience unique challenges even within the same disability. Factors such as the severity of the disability, access to resources and support, and cultural attitudes towards disability can greatly affect the experience of the individual.

One in six people currently have a disability, of who most live in the Global South (Ivers, 2022). Despite these large numbers, people with disabilities remain largely underrepresented in academia as there is barely any research conducted regarding this specific group, and even more so people with disabilities from the Global South. In many cases, care and assistance to these individuals are not provided by their (local) governments, despite increasing numbers of inclusive national laws and (international) mandates which are increasingly being ratified all over the world. In this paper, disability inclusion is seen as the aim that in every aspect of their lives, everyone has the same opportunities to participate following their desires and abilities (*Disability Inclusion | CDC,* 2019).

For many people with disabilities in the Global South, the reality of an inclusive society however remains far-fetched. There is a shift towards diversity and inclusion in (inter-) national policies and reports, but the experiences of individuals with disabilities currently does not appear to align with the inclusive legislation. Legislative changes that reduce discrimination, however, are seen as a strong statement against the entrenched cultural values and beliefs, and could help to enforce a shift in practice (Halder & Assaf, 2017, p. 6). These international mandates are therefore seen as a positive trend, as they can enable pressure for change on national governments (Singal, 2016, p. 173).

What is seen despite this, is that these mandates do not translate themselves automatically to a more inclusive reality. This becomes apparent when looking at the convention Rights of Persons with Disabilities, which came to force in 2008 and has been ratified by 185 countries. In this convention, there was a strong focus on care for children with disabilities and their families. They, amongst others, emphasize the fact that *"In no case shall a child be separated from their parents on the basis of a disability of either the child or one or both of the parents."* And *"States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting".* (United Nations, 2006, *Article* 23, *para* 4 & 5) In this convention, and the guidelines and other reports that followed following this convention, there is an important mention of the rights of children with disabilities to not be institutionalized, and to be a part of their community (Committee on the Rights of Persons with Disabilities, 2022). This aligns with the current momentum towards a more family-central way of providing care (Goldman et al., 2020). Due to this momentum, the total number of children living in institutional care has decreased in recent years (van IJzendoorn, et al., 2020). Despite this, around five to six million children are still living in institutions, where this is rather expected to be an underestimate according to Goldman et al., (2020).

Looking specifically at the Global South, van IJzendoorn et al., (2020) found that children with disabilities are 'overrepresented' in institutional care. Also here, exact data regarding the numbers appear to be lacking. A reason for this overrepresentation according to Goldman et al., 2020, p.619) is that "*children with disabilities are often placed in institutions because families have few resources and supports, and the children often face stigma and discrimination in their communities."* This is countering the Rights of Persons with Disabilities mandate from 2006.

Sammon and Burchell (2018) also see that sometimes families cannot afford the additional costs of caring for a child with disabilities, are unable to face the emotional and practical challenges, or they are being advised that a child is better looked after in an institution as reasons for children with disabilities to be institutionalised. The latter however counters the found effects of residency in an institution. These effects namely are substantial delays and deviations in development. This can be seen in physical growth and brain development which is lacking behind, as well as great attention and cognitive problems compared to other children of the same age that are growing up in a family setting. This has to do with the lacking quality of care provided in these institutions (van IJzendoorn, et al., 2020). Whilst there is very little research done which takes different subgroups into

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[1] Global South* refers to a specific area in the Global South which is elaborated on in Chapter 3: Methodology.

consideration when looking at the effect of residential care on a child, Chmelka et al., (2011) conducted research investigating potential differences between children with and without a disability. Here, the behavioural, mental health, and educational characteristics of these two groups were analysed and compared. These results revealed that whilst a lot of the significant risk profiles were similar for both groups, youth with disabilities displayed more social problems at program entry, more placement changes in care, and showed poorer peer and adult relationships as well as higher risk behaviours, such as arrests and probations, after six months. As van IJzendoorn et al. (2020) state, it is important to realise the fact that these children need a lot more support from adult caregivers than their abled peers. *"Because the natural development of a child with disabilities can be slower than a typically developing child, they may require more individual attention."* (Sammon & Burchell, 2018, p. 21) Furthermore, Trout et al. (2009) highlighted that, especially for children with disabilities, important life events that have great impacts, such as having to change school or going through out of home placements which happens when a child is placed in residential care, are additional stress factors which can enlarge the problems of the already vulnerable child. In this, the type and severity of the disability however is paramount to the potential negative impacts. Browne (2009) even showed that more children leave institutional care with disabilities than those who entered (33% to 27%), and that children with disabilities sometimes even become more disabled. Browne (2009) however does not specify what kind of disabilities these children had, as is something that is seen in more research conducted. It does not even specify if it considers physical or cognitive impairments. Furthermore, it fails to recognize the highly variable way in which they could grow up at home.

Looking at the situation of children with disabilities at home, the literature makes weak suggestions of children being hidden at home due to severe stigma in the community. As Katsui and Mojtahedi (2015, p. 564) state, *"Stigma, frequently stemming from an erroneous understanding of disability and its association with moral wrongdoing, compels parents to hide their children with disabilities at home, to be ashamed of them, and to undermine the child's potential to learn and lead an independent life."* NGOs and Private Development Initiatives which focus specifically on children with disabilities, share this experience of severe stigmatization as evident from the content of their websites. From their experiences, they mention children being hidden at home, isolated, excluded from society, neglected and discriminated (CSID, 2020; Friendship Foundation, 2021; Kidscare, n.d.). Because of the lacking (academic) foundation of these statements, *"nobody knows how many are actually excluded, while they remain hidden."* (Katsui & Mojtahedi, 2015, p. 564).

The academic research shows that indeed inclusive laws do not always translate themselves into an inclusive realities. This simultaneously becomes apparent when looking at education. The convention on the Rights of Persons with Disabilities recognizes the right of a person with disabilities to education, without discrimination and based on opportunity. State parties are here mandated to ensure that persons with disabilities can participate, that they *"can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live"* and for example that *"State Parties shall enable persons with disabilities to learn life and social development skills to facilitate their effective education"* (United Nations, 2007 p. 17). Despite this, children with disabilities are the most excluded group and are the least likely to finish school once started (Singal, 2016, p. 172). Plan International found that children with disabilities were ten times more likely to not attend school, compared to their abled peers (Plan International, 2013). This may have something to do with the fact that schools often are unable to ensure the safety and security of these children.

According to Ali et., al. (2015) especially the experience of stigma for children with cognitive disabilities that go to mainstream education is highly prevalent resulting in the fact that the vast majority of children have experienced bullying. On top of this, the physical environment is often not adapted for children that face physical challenges. *"It was as if the built environment was often built to exclude rather than to include students with disabilities"* (Halder, 2009, p. 640). This can for example be seen in buildings which are not wheelchair accessible, and have inaccessible desks, equipment and inadequate bathroom facilities.

Stigma thus causes social exclusion for the child, as it is being shut out of the opportunities to participate in the community. This social exclusion, however, does not limit itself to the affected child, as it is also seen that it is experienced by the family of the child (Bain, 1998, p. 598). Halder and Assaf (2017, p. 5) noticed that having a child with disabilities also poses great implications to its family, as it can result in exclusion and isolation for them as well. Having a disabled child thus may pose a significant threat to the wellbeing of the parents, especially in a social and emotional sense, which may, in turn, negatively impact the children (Kurumei, Tarus & Ngososei, 2016).

This negative effect is especially prevalent in poor families. Eide et al., (2011) concluded from their quantitative research which was conducted in four African countries that within households where there were family members with disabilities, the average household was bigger. As this research showed, this was due to the fact that there was more labour needed to also care for these family members with disabilities. Aside from the direct economic burden of providing care and the loss of the caregiver's potential contribution to the family's income, there are also practical implications. "*Balancing work and home duties becomes a balance of loyalties and resources as well as time management."* (Halder & Assaf, 2017, p. 5).

What we see is that there is a discrepancy between the (inter-) national laws and mandates, and the experienced reality. Solely looking at the laws and mandates, the situation for children with disabilities appears to be inclusive, where the literature suggests a different reality. Making concrete statements about the context and situation of children with disabilities born in the Global South is challenging. How severe the experience of stigma is, what this means for their social position, what the opportunities are, and what the challenges are that families face currently does not rely on strong academic underpinning. This makes it currently not possible to have a clear understanding of the livelihoods of these children and their families. Therefore, it is not possible to determine if these children can simultaneously benefit from the momentum regarding deinstitutionalisation, and how family-based care would look like in this case. The question being raised is what changes are necessary to ensure that children with disabilities are not placed in residential care, and can be reunited with their families.

The 'overrepresentation' in institutional care shows that there is a need for support to the families of these children with disabilities. Considering at the reasons why children are placed in institutions, this support may differ per family. Looking at the provision of care, the case currently still is that in many countries in the Global South care of this kind is predominantly provided by NGOs and Private Development Initiatives (PDIs). As Edwin Phiri (2016, p.1) states in his essay, "*NGOs have become an integral part of the international aid architecture and contribute to the implementation of the multilateral aid agenda. Joint partnerships between governments, NGOs and the private sector are crucial to the development trajectory of any country."* NGOs and PDIs are crucial players that simultaneously often have a lot of experience and knowledge regarding the matter. Despite this, they are often not included in the academic debate regarding care for children with disabilities.

This research aimed to create a better understanding of the context and situation for children with disabilities growing up in the Global South*. Looking at the existing literature regarding the matter, it is not possible to make general assumptions regarding these matters leaving many aspects to the unknown. As long as we are not aware of the potential challenges that these children and their families are facing, it is not possible to provide the needed care and support, and to create an inclusive reality as aimed for in the international policies. Aside from gaining insight in the context and situation, this research also focussed on (predominantly Dutch) NGOs and PDIs that worked with this target group. Where the literature on this subject is weak, these organisations are the ones with the most *on the ground* knowledge regarding this subject. In this research, this rich expertise was analysed in a way to reveal and determine what are the essential elements when providing care for these children, what are the main challenges faced, and to see the different ways in which similar issues were tackled.

People with disabilities, and especially people with disabilities from the Global South remain an unresearched subject whilst it is essential for the wellbeing of these individuals to be included in the academic debate. Not understanding and not being aware of the situation of this marginalized group has a result that adequate care cannot be provided, and that people remain invisible. As long as the main issues are not identified, there is a risk that people may believe that there is no problem. Especially so as the legislative framework may present a different reality.

In order to gain more insights into the different subjects to be discussed and to further analyse the problems, more literature was needed to serve as a foundation for this research. In the theoretical framework (Chapter 1) this foundation will be laid in discussing the primary concepts which were considered essential for the continuation of this research. After which the methodology used to theorise the answers to the research questions is presented followed by the results and conclusion of this research.

2 Theoretical Framework

Continuing on the literature which was presented in the introduction, several key concepts will be explained more in-depth in order to create a better understanding of the existing literature regarding this subject. As previously stated in the introduction, this research is divided into two sections. The first section focuses on the context and situation of children with disabilities in the Global South, while the second section specifically examines the role of NGOs and PDIs in providing care for this group. Naturally there is some overlapping information between the two sections as they directly relate. The literature presented here forms the foundation of this paper.

2.1 Policy and Legislation

As was established in the introduction, there is a rise in legislation and policies that place people with disabilities at the centre. Where these are seen as an important step against discrimination of people with disabilities, the experienced reality appears to be far from the aim presented in these mandates. Despite the discrepancy between policies, legislation, and lived experiences, having an inclusive legal framework can be a first step towards an inclusive society.

In these mandates, there are differences which are specified and separated by Rimmerman (2013) in two types of mandates: 'social protection' and 'disability rights' legislation. Social protection has as a predominant policy aim which focusses on eliminating "*social exclusion related to poverty, unemployment and certain norms of social, economic or political activity applying to individuals, households, spatial areas or population groups.*" (Rimmerman, 2013, p. 178) Disability rights legalisation, is more based on a human rights model which *"rejects the premise that social exclusion is inevitably the consequence of disability"* (Rimmerman, 2013, p. 179), aims to to prevent exclusion from society for people with disability with use of legal intervention and therefore is more of an anti-discrimination tool.

As Rimmerman (2013) states, the best policies are ones that consider both strategies. According to him, the United Nations Convention on the Rights of People with Disabilities (UN CRPD) is a good example of an international effort focussing on these two. *"This comprehensive international instrument has two layers. The first is protection of rights such as expression of speech, thought, religion and political participation. The second is actually the provision of adequate standards of living."* (Rimmerman, 2013, p. 180).

Other examples of international mandates that appear to place focus on both strategies are the United Nations International Year of Disabled persons in 1981 where the main theme was "*full participation and equality, defined as the right of persons with disabilities to take part fully in the life and development of their societies, enjoy living conditions equal to those of other citizens, and have an equal share in improved conditions resulting from socio-economic development.*" (The International Year of Disabled Persons 1981 | United Nations Enable, 1981, *para* 2), and The World Programme of Action (WPA), which is "*a global strategy to enhance disability prevention, rehabilitation and equalization of opportunities, which pertains to full participation of persons with disabilities in social life and national development.*" (U.N., 1982, *para* 2).

Following the convention on the Rights of Persons with Disabilities, which was introduced in the introduction, that focusses on the care for children with disabilities in their own family and community, and therefore against institutionalisation of children with disabilities came *"Guidelines on deinstitutionalization, including emergencies."* These guidelines have as aim to provide guidance and support to State parties in the efforts to realize the rights to live independently and to be included in their community. They are presented as a basis for the planning of the deinstitutionalization processes, and as prevention to institutionalization, including emergencies. This means that even in times of an emergency, as during the COVID-19 pandemic and the war in Ukraine, the processes of deinstitutionalisation and the aims to prevent it from happening should remain priorities (Committee on the Rights of Persons with Disabilities, 2022).

Here, they hold the state parties accountable for the deinstitutionalization process, share that institutionalization is a harmful practice, and provide guidelines on how the deinstitutionalisation process should take place. This includes the development of high-quality and individualised support in all aspects, ensuring the individual to be able to live independently in their community including the provision of accessible housing for care-leavers. An important note that they place, is that persons with disabilities need to be involved in the deinstitutionalization process and that deinstitutionalization should be grounded in the dignity and diversity of these people. In their take on legal and policy frameworks, they state that these *"should enable the development of inclusive community support systems and mainstream services and the creation of a reparations mechanism, and guarantee the* *availability, accessibility and effectiveness of remedies for survivors of institutionalization. States parties should proceed on the basis that a lack of comprehensive legal reform does not excuse inaction."* (Committee on the Rights of Persons with Disabilities, 2022, p. 7) These guidelines have been written in a participatory manner, with the input and contributions of over 500 individuals with disabilities.

As an example of the effects of international mandates, Singal (2006) highlights how, between 1990 – 2000, international declarations created momentum for the focus on children with disabilities in the Indian educational policy. This can for example be seen in the *"The persons with disabilities act"* of 1995 which gave a great impulse to the education of children with disabilities. With that being said, Singal (2006) notes that while having a targeted focus on people with disabilities can be beneficial, there are also potential drawbacks to consider. As he explains, the focus can be seen as essential due to the historical marginalization from participation in all forms. However, a specific focus on disability also can fail to acknowledge the importance of intersectionality between different marginalized groups, and does not consider the heterogeneity of this group *"the identification of children with disabilities as a homogenous group in this way results in an accentuation of their difference, and increases the likelihood of their continued exclusion."* (Singal, 2006, p. 364).

Despite the positive effect of these international mandates on the livelihood options for individuals with disabilities as highlighted by Singal (2006, 2016), there are some important side notes to place on their efficacy. Rimmerman (2013) highlights the fact that the true challenge of these international mandates does not lay within the creation of the policy, but more so in the question if the translation that can be made from abstract rights to national laws which have valuable results, as was established priorly in the introduction. This may be a challenge in certain cases as they might conflict with the cultural perspectives of a country, or even different cultural perspectives *within* a country. Therefore, countries must reflect on these potential conflicts and address the cultural influences with the relevant legislative framework to make this work (Halder & Assaf, 2017, p. 6).

Phelan and Reeves (2021, p. 77) recognize this challenge and highlighted the gap between the theorisation of inclusion, and the lived experiences. A critique regarding these inclusion theories and practices is often *"imbued with normative, ableist, assumptions. Many inclusion initiatives, policies, and conventions around the world are informed by the UN Convention on the Rights of Persons with Disabilities, placing the emphasis on the political and material aspects of inclusion, rooted in rights and citizenship. Although necessary, this approach fails to address the normative underpinnings of inclusion theories and practices, creating a facade of inclusion."*

There is a risk that by solely focusing on the legislative framework, we may create the impression of an inclusive society that does not reflect the reality of lived experiences: *'a façade of inclusion'*. This 'method' of creating an inclusive legislative framework first, could be considered more of a top-down approach. Where this may work in certain cases, and indeed also allows for pressure from the society on national governments, it does fail to recognize the fact that there may not be sufficient support from the society due to potential clashes with their culture. Furthermore, the question raises if and how these inclusive policies to the people, education facilities and local governments are communicated. Therefore, it is more worthwhile to examine the lived experiences of individuals with disabilities to gain a deeper understanding of their realities and to determine whether these align with or diverge from prevailing perceptions.

2.2 Care for children with disabilities

As mentioned in the Introduction, the main care providers of children with disabilities currently are PDIs and NGOs. In this chapter we will take a closer look at what types of care are provided to these children.

2.2.1 A continuum of care for orphans and vulnerable children

As has become apparent, there is a shift towards a more family-central way of providing care (Goldman et al., 2020). Academically, the current narrative would be vowing in strong favour of family-based care whilst highlighting the negative outcomes of care in institutions such as orphanages. In Figure 1 a continuum of care is presented which places the family at the centre. This illustration is used to help understand the different ways a child could receive care.

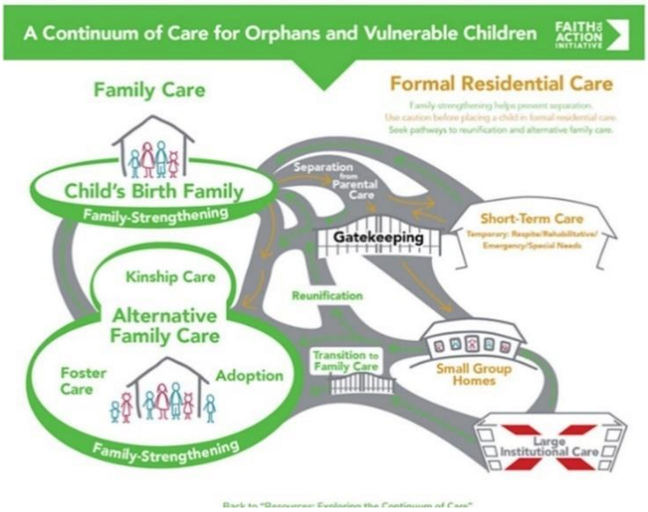


Figure 1: A Continuum of care for Orphans and Vulnerable Children (Cox et al., 2015)

Family Care

This figure should be read as follows: the parts in green are the ones which should be given priority, meaning that priority should be given to family care whenever possible. "*Family strengthening*" encircling both elements of family-care, highlights that supporting the capacity of the family to care and provide for their children helps to prevent unnecessary separation. Family strengthening is also seen as an essential element for alternative family placements such as kinship care, foster care and adoption (Cox et al., 2015).

As Bain (1998) stated, a long-term and daily relationship between a growing child and at least one continuous caregiver is essential in any model of child care. This relationship building is also referred to as *'permanency planning.'* In this way of providing care, the following aims are formulated:

- *"To identify and provide the financial and other supports needed by the birth family to enable the child to stay at home,*
- *For children who have previously been relinquished or placed in institutions to pursue permanent reunification with the natural family as the most desirable option*
- *If parents request an out of home placement, to pursue adoption or long-term placement with a foster family, preferably on an open basis so that the birth parents continue with an informal parenting role"*

(Bain, 1998, p. 598).

Formal Residential Care

Residential care is in essence any *"group living arrangement where children are looked after by paid staff in a specially designated facility. It covers a wide variety of settings ranging from emergency shelters and small group homes, to larger-scale institutions such as orphanages or children's homes."* (Residential Care | Better Care Network, 2022 *para* 1)

The orange parts are showing short-term residential care and small group homes. The orange colour highlights the fact that caution should be used prior to placing a child outside of family care (Cox et al., 2015). These homes should only be on a temporary basis, *"for example while efforts are made to promote family reintegration or to identify family-based care options for children."* (Residential Care | Better Care Network, 2022 *para* 1). Residential care could however also be a living arrangement such as a supported independent living arrangement which, when executed adequately, can be seen as a viable option. This is especially in the case of older teenagers and (young) adults.

Large institutional care is in red to indicate that this is not seen as a viable option for the child's healthy development (Cox et al., 2015). An institutional care facility, later on referred to as an institution, is defined as *"a publicly or privately managed and staffed collective living arrangement for children that is not family-based, such as an orphanage, children's institution, or infant home."* (Goldman et al., 2020, p. 608) The quality of care within these institutions is highly dependent on several dimensions such as the level of staff training and turnover, as well as the child-to-caregiver ratio, and factors such as the provision of engagement and responsible carer behaviour, and varies drastically within different institutions. Often multiple dimensions are not fulfilled, and it is, therefore, said that children in institutions are denied the basic conditions required for positive socioemotional and cognitive development (van IJzendoorn, et al., 2020).

What we derive from this figure and the analysis, is the fact that a child is in essence better off in a family situation. Preferably in their own family and community. Where the line of reasoning of this makes sense, the question does arise to what extent this is similarly attainable and achievable for children with disabilities. The next step, therefore, was to see what the literature highlights regarding the context and situation of children living at home and in institutions. In this we will look at the stigma which they have to encounter, the challenges regarding inclusive education and the impact on families to create a better understanding of the parts in green, and we will then look into institutionalisation and deinstitutionalisation for children with disabilities.

2.2.2 Disability and stigma

As became apparent from the previous sections, one of the main challenges in creating a good environment for the child to be raised in their family has to do with the stigma on disability. Where there is not a lot of academic foundation supporting these statements, the suggestion to the challenges it brings makes it a pivotal subject to further investigate.

According to the NGOs and PDIs, there is a link between stigma and religion. To take a further look into this potential religious foundation, Rimmerman (2013) distinguishes three different themes within the analysis of the Bible, the New Testament and the Qur'an regarding their perception on disability. *"The first theme associates disability with sin and the belief that the sin is a punishment for wrongdoing, which therefore justifies social exclusion. The second theme links disability to suffering and recognises the endurance and passive acceptance of the marginalised role. The third theme identifies the disabled person as an object of charity, in need of support but remote from the public eye."* (Rimmerman, 2013, p.176)

Al-Aoufi, Al-Zyoud and Shahminan (2012) state that, at least within Islam, *"parents tend to deal with disability within their cultural context."* (Al-Aoufi, et al., 2012 p. 215) and that there are therefore contradictions between what is written in the Qur'an and what is seen in several cultural practices. Examples of this can be found in that according to the Qur'an, disability is seen as a natural part of human nature. However, *"cultural perspectives, mixed with religious values, often lead to several courses of action which may be falsely attributed to religious faith, such as embarrassment at having a child with disabilities, attempting to explain the cause of the disability, and looking for fast solutions."* (Al-Aoufi, et al., 2012, p. 214). As a result, parents that see disability as a bidding from God, often refrain from seeking treatment for their child. A further challenge is seen in the fact that a lot of Muslim families which have a child with disabilities experience social embarrassment. In avoidance of stigma and to protect themselves as well as their child, especially girls, disability is often denied, or when the signs of disability are obvious, the child is hidden from society. Even though this contradicts the statements made in the Qur'an which urges to treat people with disabilities equally (Al-Aoufi, et al., 2012).

Looking at the bible, when Jesus encountered a blind man, His disciples asked him why this person was born blind. Was it because he was a sinner himself, or his parents? Jesus responded that this was not the case, but that it was the sin of Adam that resulted in all men being imperfect, and being born with shortcomings, such as blindness (The Bible: New International Version, 1983, John: 9). Also here, there is no grounding in the religion when it comes to disability being a sin.

These two examples highlight how the interpretation of religion indeed can be more cultural and have no grounding in the religion itself. The question remains how much stigma is indeed present against people with disability, and what effect it has on the people with disabilities and their families. The literature, which is limited, but also the experiences of NGOs and PDIs indicate that stigma is still widespread. Given this, a question that arises is what measures can be taken to address and combat it.

2.2.3 Inclusive education

Inclusive education, or access to education is seen as an important element of inclusion, as can also be seen in the international mandates. Despite this, children with disabilities remain the most excluded group. This has to do with several factors, as discussed in the Introduction. Why inclusive education is important, is stated by Halder (2009, p. 641) *"The inclusion of challenged children into mainstream schools will inevitably result in their acceptance into society and also within their own families. Social integration is only possible when there is a motivational and attitudinal change among the teachers, challenged students and their parents."*

Halder and Assaf (2017) highlight that in many countries in the Global South "*people with disabilities remain underprivileged and are unable to access or participate in mainstream education and development programs. There is a scarcity of needs-based support services available for the welfare of people with disabilities, and services remain beyond the reach of most people.*" (Halder & Assaf, 2017, p. 4)

As we saw, the dropout rates for children with disabilities are the highest. Where children with physical disabilities often experience physical barriers due to inaccessible buildings and equipment, children with cognitive disabilities experience the psychological effects of bullying and social exclusion. Furthermore, research conducted in India by Halder (2009, p. 639) showed that the dropout rates for girls with disabilities are higher than for boys.

Ali et., al. (2015) also showcase that the experience of stigma for children with a cognitive disability that go to a regular school is highly prevalent where a vast majority of the children have experienced bullying. In research conducted by Njelesani, Si, and Swarm (2022), this potentially unsafe environment was also investigated. They looked at children with disabilities that were enrolled in the ordinary school system in Zambia. Here it was found that violence against children with disabilities occurred both physically and emotionally, and often went unaddressed. The children experiencing the violence, thus the children with disabilities were often even blamed for posing a risk to others as they were seen as the cause of the violence. Important to note here is that Zambia signed the convention discussing inclusive education in 2011.

Research conducted in India showcased that the risk of experiencing sexual abuse and violence increased when the child with disabilities was a girl, resulting in parents taking the girl out of the school system and being isolated at home as parents become overprotective. This may be one of the causes of why there are higher levels of dropouts for girls compared to boys (Halder, 2009, p. 640). This also despite India signing the convention in 2007.

Moreover, not all teachers are equipped with the right knowledge or tools to provide adequate education for child with special needs. It is not always possible for a teacher to access expertise or help in the adaption of the curriculum, in safety and security, and different ways of learning for the child (Halder & Assaf, 2017, p. 4).

Children with disabilities, cognitive or physical, often are refrained from their right to access education. Looking at the research conducted in Zambia and India, this is a good example in how the legislative framework does not de facto translate itself into an inclusive environment, as predicted by Phelan and Reeves (2022). This follows what Halder (2009) stated regarding the fact that motivational and attitudinal change amongst teachers, students and their parents is needed in order to achieve social integration. The main question here would be how this motivational and attitudinal change is achieved, and how an environment of education can become more inclusive eliminating the physical and psychological barriers.

2.2.4 Impact on Family

It was established in the Introduction that having a child with disabilities poses an important threat to the wellbeing of the family. This being due to stigma, which can lead to social exclusion of the family, and the increasing financial burden which is especially felt by poor families.

Kurumei et al., (2016) highlight that in their specific Kenyan case, there are insufficient legal and political guidelines and resources that aim to help parents of a child with disabilities to adequately take care of their child. The lacking access to the needed resources, such as support and financial aid, is what results in the inability of parents to provide for their child effectively.

Even in the case that financial and personal support is provided at home, it may not always be viable for the child to be able to stay with their family. An Australian review conducted in 1998 stated that in some cases families seek community living for their child with trained staff because they are unable to care for their child. Here, it is stated that important parts of the aforementioned permanency planning can still be achieved with regular visits from and to the family, heavy involvement in the educational and medical issues of the child, as well as its personal development (Bain, 1998, p. 598).

For a child with disabilities to stay at home and to receive the proper support is seen as a challenge, especially so in poor families. The risk of social exclusion could very well be a reason for parents to hide their child at home. Together with the fact that not everyone has access to the needed resources, and the potentially increasing financial vulnerability the position of a family decreases the moment they have a child with disabilities (Goldman et al., 2020, p.619; Sammon & Burchell, 2018).

Looking at these three aspects, the question arises of what is needed to make sure that staying in the (birth) family is indeed the most viable option. In this, it is important to not forget the position of the families, as they appear to experience an increase in vulnerability. It was therefore decided to look at the family as a whole, and not solely the child with disabilities.

2.2.5 Institutionalisation and deinstitutionalisation

We have seen that children with disabilities appear to be 'overrepresented' in institutional care (van IJzendoorn et al., 2020), and that the exact numbers appear to be lacking. This chapter has as a goal to find out more about the specific situation for children with disabilities that reside in institutions. As most of the data concerns larger institutional care, the focus of this chapter will lay on this aspect of residential care. Furthermore, there is a lack of specific information regarding institutional care for children with disabilities. This makes that some knowledge gaps are filled with the use of general statements regarding the effects of institutional care on a child where this was considered suitable. Simultaneously, there is a trend regarding the focus on the more family-oriented way of caring. Therefore, we will look further into the concept of deinstitutionalisation, and how this takes place in several different countries.

Institutional care

The most known form of institutional care is orphanages. Where the name implies that the children living here are orphans, it is important to note that children in this context are considered an orphan when having lost one parent, whereas in the Global North a child is considered an orphan when they have lost both parents (Vossen et al., 2021). 80% of children living in an orphanage have at least one living parent, and the vast majority still have close relatives. As discussed in the Introduction, children with disabilities appear to often be placed in institutions due to the lacking resources and support to the families. Furthermore, stigma and discrimination faced by these children in their communities appear to be important reasons (Goldman et al., 2020, p. 619). Other reasons found are the fact that parents cannot afford the additional cost of caring, the inability to face the emotional and practical challenges, which follow the line of reasoning regarding the 'impact on parents' and the fact that sometimes parents are being advised that a child is better looked after in an institution (Sammon & Burchell, 2018).

The statement that a child indeed is better off in an institution, however, does not find academic underpinning. The general consensus is that growing up in institutional care goes hand in hand with substantial delays and deviations in development (van IJzendoorn, et al., 2020). As was shared in the Introduction, specific research regarding children with disabilities in institutional care is very limited. In the research that is conducted, it is seen that the negative effects of an institution are very similar between children with and without a disability, and that the risk of negative outcomes is elevated for children with disabilities (Chmelka et al., 2011).

These negative effects often follow the lacking quality of care provided in these institutions (van IJzendoorn, et al., 2020). An example of this lacking quality of care is within a study conducted in an orphanage in India. This research showed that only 6% of a child's waking time was spent interacting with caregivers and only 15% of the time in meaningful activity such as playing, whilst these are things which are seen as essential for a child's development (Juffer, van IJzendoorn & Bakermans-Kranenburg, 2017). In the case of a child with disabilities, often a lot more support is needed from the adult care givers than their abled peers (van IJzendoorn et al., 2020).

An important note to make here is that the type of disability is often not mentioned in the research. This makes that it fails to recognize the high variability between and within disabilities, even not distinguishing between physical and cognitive disabilities.

There is no specific research concerning care-leavers, who are children who left an institution to be placed back in a family setting, with disabilities. Due to the suggestion made by Chmelka et al., (2011) that the risk profiles between children with and without a disability are similar, we will look at the general research conducted.

When children are taken out of institutional care, they show rapid recovery in the years immediately after. The recovery is however highly dependent on the length of stay in an institution, the quality of care, and child-related factors such as genetics and characteristics. Children from 6 to 24 months old are especially susceptible to the negative effects of institutional care. Despite the opportunity for rapid recovery, the effects can persist over the long term for severely affected children (van IJzendoorn, et al., 2020). Important to note is the fact that these studies have been done with children that left institutional care whilst still a child and thus do not include children that *have* to leave institutional care at 18 years old. As with the latter, children who grew up in institutions are more likely to end up in prostitution, living on the street, end up with a criminal record and are more prone to psychological issues also resulting in an increased risk to commit suicide (Butterworth et al., 2016; Dickens & Marx, 2018; Koenderink, 2018; Sulimani-Aidan & Melkman, 2018).

These statements made, could make one wonder why there still appears to be a relatively large support for residential care and especially orphanages. One big reason why orphanages continue to exist is the monetary interest. This can for example be seen in the article written by Annemarie Kas in the Dutch newspaper NRC in 2017 which has the title: *“Cambodian orphanages are there for the western people.”* In this article she explains that the volunteers from the Global North provide large revenue streams to orphanages, making it a lucrative business. Parents are often being motivated or ‘tricked’ into bringing their child to residential care with promises that they will be provided with good food and quality education, which are not being followed through: *“private orphanages are often only being built because they bring in money”* (Kas, 2017). This, whilst bringing their child to an orphanage is often seen as the only opportunity for poor (Cambodian) families access to good food and education. In some cases, quality education indeed is provided and children are for example granted the opportunity to learn English which then allows for greater opportunities later in life. Miller and Beazley (2021) speak about a performance-based orphanage in their research. Here, the children get to go to the local Cambodian school and get taught English by ‘voluntourists’ which they generally like. In the trade-off, they have to give a daily hour-long traditional dance performance to tourists and are trained to perform in such a way that they will make the tourists happy and ensure them to donate money. The 2017 Trafficking in Persons Report recognizes the active recruiting of children for an orphanage as child trafficking, due to this practice of recruiting children under false pretences and using them to make money (Department of State & US Government, 2017).

The growing number of orphanages is amongst others a direct result of the increasing tourism in Cambodia (Deen, 2017). In 2017, the government launched a plan to address these ‘fake’ orphanages, which are set up specifically to attract donations and often were home to children that had at least one living parent (Thul, 2017). A challenge which they encounter is that volunteers donate money and give support with their best intentions whilst often being unaware of the alternative options for care for these children (Kas, 2017). The latter is also what Mark Waddington sees as the biggest obstacle in deinstitutionalisation: the fact that the donors and volunteers cannot imagine the alternatives to these institutions (Kwizera, 2020).

It is important to note here that many of the children in the Cambodian case do indeed see the orphanage as a betterment from their lives at home. *“The children accepted the requirement to participate in the nightly public performance because it aligned with the traditional practice of the patronage system and it was strategic in terms of attaining their long-term goal of an education in support of their own and their family’s futures.”* (Miller & Beazley, 2021, p. 60). The authors, however, did mention that their concerns aligned with the statements made above regarding emotional and cognitive development, as well as the fact the volunteers did not require any skills, nor were they vetted before their work at the orphanage.

As Goldman et al. (2020) conclude, “*national child protection systems should be grounded in a continuum of care that prioritises the role of families.”* (Goldman et al., 2020, p. 606) Following the line of reasoning within academic and increasingly so public debates, community- and family-based programmes should be placed at the centre to allow for a child’s best interest to be placed at the centre of the conversation.

The fact that there is limited access to resources which share the specific situation of children with disabilities in institutional care makes it more complicated to draw clear conclusions. In the research that has been conducted, the high variability between disabilities is not acknowledged, where this is essential when analysing the impact. Furthermore, solely presenting institutional care as an unviable option fails to recognize the way in which a child would grow up at home, which also does not appear to always be a stimulating and safe environment.

Deinstitutionalisation

The fact that millions of children are still living in institutions counters the UN-recognised rights of children to be raised in a family environment, as we saw when discussing international mandates. The 2019 UN general assembly resolution on the Promotion and Protection of the Rights of Children acknowledges the statements made above in which it is depicted that a family environment is essential for a “*full and harmonious development of his or her personality and potential”* (United Nations, 2019, p. 9), and with this urges member states to take action to deinstitutionalise and focus on alternative care, and to redirect resources to family and community-based services (United Nations, 2019). Despite this high number of children still living in institutions, there does appear to be momentum towards deinstitutionalisation and family-based alternative care (Goldman et al., 2020). Again, there is no specification of whether or not it concerns children with disabilities. A good example of deinstitutionalisation is from Uganda. Due to research that showed the negative effect on the development of children in institutions, their narrative changed which resulted in governments starting to close down orphanages throughout the country (Oketch, 2018). Another example is from Rwanda, which vowed in 2014 to become the first African nation without orphanages by 2024. They came up with a policy to close orphanages, and to look at family-based care for these children. Around 90% of these children were reconnected with their parents and relatives, and the remaining are currently living in foster care. The National Commission for Children reported that 88,7% of children previously living in orphanages have successfully been reconnected. Since the beginning, out of 38 orphanages, 34 have been closed (Gahigi, 2021). Mark Waddington, CEO of Hope and Homes for Children in conversation with Arnold Kwizera of CNBC Africa, acknowledges these big wins and describes how former orphanages now sometimes are transformed into centres to provide service to the community, such as day care centres for children (Kwizera, 2020). This is an important aspect of the process of closing down orphanages. As Michael Byamukama, president of the National Association of Social workers in Uganda stated in an interview in The Guardian, simply closing the orphanages does not suffice. To change the lives and the prospects of these children, *"transformational social service systems must be created that support families to keep and care for their children."* (Truell, 2019, *para* 5)

Although this is a good and positive trend, the question still remains if children with disabilities can benefit from this. There is a lot more (financial) support needed for the family in the case that a child with disabilities, of course depending on the nature and severity of the disability, would be reunited with their family. In addition, it is possible that parents may resist the idea due to concerns about social exclusion as previously discussed.

2.3 Private Development Initiatives and NGOs

As mentioned previously, the main care providers for this group in the Global South are in many cases PDIs and NGOs. These are important players in this field which simultaneously are expected to have essential knowledge and know-how regarding the care for children with disabilities. As this research has taken place from the Netherlands, the focus will lay on Dutch Private Development Initiatives, which will therefore also receive the most attention in this chapter. The goal of this chapter is to better understand these organisations and their strengths and weaknesses. They are an integral part of the international aid architecture, as stated by Edwin Phiri (2016, p. 1), and therefore are important to take seriously regarding this matter. Phiri (2016) simultaneously acknowledges that NGOs are a highly diverse group, making generalizations difficult due to the wide variety of countries and contexts in which they operate. In this, Phiri holds on to the definition of NGOs with a development focus as organisations either work as small community-based organisations at a more local level, and as large professional development agencies which work at national or state level. These NGOs have as a primary goal to improve social, economic and productive conditions in the areas in which they operate.

Aside from larger more established development organisations, an increasing amount of so-called PDIs, are making their way through the development initiative landscape. As they are different in nature from other development organisations, they will be discussed separately in this review.

PDIs are a philanteral aid channel which operates in a voluntary character. They do not receive funds from the government and are rather small-scale, offering "*structural support for organisations, communities or groups of people rather than one-off individual support."* (Kinsbergen & Schulpen, 2013) These factors are what distinguish PDIs from established development organisations.

2.3.1 Accountability of NGOs and PDIs

These providers of care often provide free help which is paid for by foreign donors and/or governments and thus is structured in a way where the money comes from countries in the Global North to provide care in the Global South.

These donation-receiving entities have dual accountability. Namely, an upward accountability towards the donors, private and/or government, and a downward accountability towards the beneficiaries (Chu & Luke, 2021; Mir & Bala, 2014). This makes that NGOs and PIs do not only need to ensure that the care that they provide is well suited for the beneficiaries, but also fits the expectations of the ones providing money. That this can result in discrepancies, is what was found in research conducted by Mir and Bala (2014) who did a thorough analysis of NGO accountability in Bangladesh. In this research, they found that foreign-funded NGOs predominantly focus on fulfilling their upward accountabilities, towards their (foreign) donors. This resulted in a decrease in downward accountability. That a focus on one harms the other, is also what Chu and Luke (2021) found. What they state, is that when the focus lies on upward accountability, there is often a negative effect on downward accountability. The negative impact includes compromising the core mission to *"satisfy donors' expectations and delivering what is contractually required by donors rather than consulting with beneficiaries to understand the support that they need"* (Chu & Luke, 2021, p. 261) This statement implies that there, therefore, can be a discrepancy between what the donor believes is needed and what the people whom it concerns actually need.

According to Mir and Bala (2014), this focus on upward accountability is not considered the fault of the NGOs themselves, but it does as they state *"reflects the pressures and environment in which they find themselves."* (Mir & Bala, 2014). The findings of Chu and Luke (2021) however do highlight a shift between the focus on a 'vertical' (thus upward vs downward) view of NGO accountability, to more of a balanced interrelationship *"between accountability to self, donors and beneficiaries."* (Chu & Luke, 2021, p. 261, 262) However, they found that the accountability to donors was rather short-term and their accountability to the beneficiaries was more focussed on the long-term.

Whilst this does not mean that all NGOs and PDIs have this challenge, it is important to realise these dimensions as they aid in helping to understand the way how NGOs and PDI work.

2.3.2 (Dutch) Private Development Initiatives

Analysing the position of development corporations, Holmén (2020, p. 525) makes two statements regarding the ways in how corporations, in sub-Saharan Africa for his research, should operate: *"a) if development is to be sustainable, it must come from within, and (b) we should listen to these African voices and take their message seriously. Not only do they see things westerners often are unwilling to see – it is also, after all, their future that is at stake."* The failure to adhere to these statements is also what is seen when organisations predominantly focus on their upward accountability.

As they do not receive government funding, these PDIs rely almost fully on direct donations from Dutch citizens. In 2009, Dutch households provided for around €29 million to PDIs and the average annual budget for PDIs is €50.000. What appeals to the donor of PDIs is the direct type of development corporation and the fast results of these initiatives (Kinsbergen & Schulpen, 2013, p. 54). Often these projects are highly effective in achieving their direct goals which often are concrete matters where the preferred intervention strategy is direct poverty reduction "*like supplying teaching aids, building schools and digging wells."* (Kinsbergen & Schulpen, 2013, p. 56) 47% of the PDI projects are intended to improve the living conditions of children and young people. They are often praised, by their donors and themselves, for the fact that they spent the vast majority of their earnings directly on their projects, as they make only a little overhead costs (Schulpen, 2007).

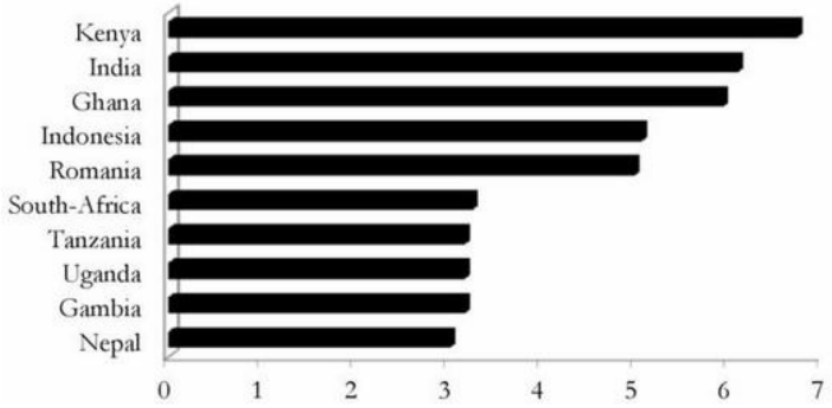


Figure 2 Countries with the most Dutch PDIs (Kinsbergen, 2019)

In Figure 2, the countries with the most PDIs are highlighted. Research shows that areas which are popular tourist destinations, are also popular destinations for development projects (Kinsbergen, 2019). As Kinsbergen and Schulpen (2013, p. 53%) found, 70% of the founders of such a project, did so after they had visited the area as a tourist.

Where these projects often are highly effective in achieving their direct goals, they simultaneously are being critiqued by the fact that the design or implementation of these projects often appears to lack a precedent context analysis and need assessment (Kinsbergen & Schulpen, 2013; Kinsbergen, Schulpen & Ruben, 2017), which are key elements according to Holmén (2020). As Dr Lau Schulpen stated in an interview with the Dutch newspaper *Trouw* (Koch, 2007), the work of PDIs could be seen as constant emergency help, rather than work on sustainable change. They would for example build a school, but do not take into consideration the aspect that the future teachers will need to be paid a salary

Another point of critique is that there is very little control on the ground to see what the organisations actually do (Mir & Bala, 2014) and that there is barely any proper evaluation (Randewijk, 2022). Randewijk (2022) for example stated that African journalists are often hired to publish videos and articles about successful projects, where they get clear instructions about what are the expected results from them, instead of allowing them to explain and broadcast the full story.

The largest challenge for PDIs, both found in studies as mentioned by themselves, is the question of the sustainability of their projects. This is especially the case for PDIs that work on so-called ‘emergency interventions,’ but this is also found to be the case in more development-oriented activities (Schulpen, 2007).

This however does not mean that all the projects and initiatives can never be trusted and do no good at all. Randewijk (2022) also acknowledges this, as do local governments in areas where there are private initiatives (Kinsbergen, 2019), there are great things which are achieved by different projects which thoroughly changed people’s lives. This, as a fact, can however coexist with the fact that there is a necessity for local embeddedness and critical evaluation of the projects.

To conclude, PDIs are often highly effective in achieving their direct goals and the projects are predominantly motivated by the personal experiences of previous tourists to the area. Critiques regarding PDIs, however, can be found in that they often lack embeddedness in the local context, do not work together, and lack critical (self-) reflection. A major challenge for them is the question of the sustainability of their projects. Furthermore, when realizing that most of the care for children with disabilities in the Global South is currently provided by NGOs and PIs, the fact that PIs often are operating in more touristic areas is concerning. This namely means that the care is not necessarily provided to the people who need it the most, but more so to the people who are most visible.

2.3.2 Concluding remarks

As was mentioned previously, the literature presented in this framework served as the theoretical foundation needed to create a better understanding of the subject. Furthermore, this framework allowed to better identify the knowledge gaps regarding this matter. What stands out is that there is still very little research that specifically concerns care for children with disabilities. The research that has been done is from limited quality and lacks critical aspects, which makes questions remaining unanswered.

What can be derived from the literature is that creating a safe and inclusive environment remains a challenge. In this, the challenge does not limit itself to the child with the disability, but simultaneously poses a threat on the family. The effects are not mutually exclusive and all are intertwined to a certain extent which increase the vulnerability of the child and its family as an entity. This is despite legislative frameworks which are often more inclusive than the experienced reality (depending on the country). Despite this, it is not possible to create an exhaustive understanding of the context and situation in which children with disabilities are being raised in the Global South. This also means that, in the light of the deinstitutionalisation processes which have an important momentum at present day, it is unclear if children with disabilities can benefit from this in a similar way as their abled peers.

NGOs and PDIs possess extensive experience in this field and offer the most readily available knowledge for this study. Realising their weaknesses and the risks of these players, it is interesting to see how they work within this domain, what their main challenges are, and how they aim for sustainability, local embeddedness and governmental support. Due to the expected high variety between the organisations, finding overlap in experiences and methods can help in creating general comments regarding the matter.

3 Methodology

It is evident that there is a notable lack of specific knowledge concerning this marginalized group . It is a challenge to create a full picture which allows to understand the context and situation in which a child with disabilities is born, and how this affects the child and their family. Considering previous statements made in the Introduction and Chapter 2.1, it can be said that the international mandates and frameworks show a more positive outlook compared to the reality. Despite the fact that not all specific countries were analysed, general discrepancies were found. The goal of this study is to explore these under researched problems, and to generate new ideas in the form of a new theory. This is to investigate whether certain challenges and situations can be generalized. With this research as the ability to officiate as a basis for care providers and governments in the future. From the conviction that to be able to help, it is necessary to know what the situation is we are dealing with.

Looking at the information which was obtained up to now, the preliminary research questions raised were the following:

- What is the context and situation for a child with a (cognitive) disability to grow up in the Global South*?
    - What are the main challenges encountered by them and their families?
    - Why are these children 'overrepresented' in institutional care, what are the reasons of why they end up in institutional care?
    - What is needed for these children to be raised in a family?
- How do the different non-governmental care providers operate in this domain in the Global South*?
    - What are the predominant challenges in providing care for a stigmatized group?
    - What are considered essential elements of care by these care providers?

Due to the lacking literature regarding this subject, there was a lot of room for flexibility for additional questions which automatically came to light as the research progressed. Following the thin academic underpinning, qualitative research was deemed most suitable. The questions then namely officiate more as a direction from where the research started. As more data was collected along the way, more knowledge was obtained which allowed for new questions to rise. Moreover, this is a subject in which I found it more suitable to allow for open answers and nuance where needed. This made that a method which allowed for direct conversations with a broad scale of people with different experiences and opinions regarding this subject would seem most suitable.

The questions asked thus had as a goal to eventually generate a new theory regarding this subject. The goal here was that this new theory could assist in creating a better understanding of the context and situation for children with disabilities, and to see how these children can grow up in their own families and community in an inclusive matter. In this, there was a clear need for flexibility regarding these questions as the expectation was that during the research more questions would emerge from the newly obtained data. Looking at a qualitative research method which allowed for flexibility and this inductive approach, Grounded Theory seemed most appropriate to fit this research goal. This is a research method designed for writing new theory and allows for both focus and flexibility. It is an inductive approach from which a new theory is written which is solely based on newly collected data (Glaser & Strauss, 2012). In this method, the data is analysed early on in the process: the data is sorted, separated and synthesized from the beginning through qualitative coding (Glaser & Strauss, 2012). *"By making and coding numerous comparisons, our analytic grasp of the data begins to take form. We write preliminary analytic notes called memos about our codes and comparisons and any other ideas about our data that occur to us. Through studying data, comparing them, and writing memos, we define ideas that best fit and interpret the data as tentative analytic categories. When inevitable questions arise and gaps in our categories appear, we seek data that might answer these questions and fill the gaps."* (Charmaz, 2019, p. 4).

Why Grounded Theory appeared attractive for this research has for an important part to do with the flexibility which it allows. The data which is collected, as it is analysed in the process, allows for new questions to emerge and allows for the theory to be 'tested' along the way as the data collection proceeds (Charmaz, 2019; Glaser & Strauss 2012).

To a large extent this method suits the goal of this research as it is the basis of writing new theory, and allows for the needed flexibility. However, writing a new theory solely based on newly obtained data seemed not achievable in this time frame. Furthermore, the question raised to what extent only consulting new data would indeed give the best outcome. Despite the limited amount of research regarding this matter, the expectation was that there were other sources available in forms of newspapers, documentaries, books and websites which could aid with receiving better insights regarding this subject.

Moreover, Glaser and Strauss (2012) operate from a perspective of the researcher as a neutral observer and a value-free expert. This is an element which I find complicated, as I do not believe in the fact that we can be a neutral observer, especially in conducting research as this one. It can be seen as essential (in my opinion) that the reader understands the position of the researcher that is conducting the research. In this case, the perception being of a abled white student who lives in the Netherlands. This therefore is a subject which does not concern me personally. The goal for me was of course to be as little biased as possible, and to allow for different voices to be heard. It is however naïve to think that I am not also shaped by my environment in ways that affect my research.

Looking at these two factors: not writing theory only from newly obtained data and not considering a researcher to be a neutral observer, were the main reasons to take a look at the Constructivist Grounded Theory of Charmaz (2019). Constructivists rather acknowledge the subjectivity and the involvement of the researcher in the interpretation of data, and allow for existing sources to be part of the theory. *"I assume that neither data nor theories are discovered either as given in the data or the analysis. Rather we are part of the world we study, the data we collect, and the analyses we produce. We construct our grounded theories through our past and present involvements and interactions with people, perspectives, and research practices."* (Charmaz, 2019, p. 18).

The social-constructivist approach of Charmaz allows for a greater diversity of different theories to emerge from the same data and permits more emphasis on individual experiences, views and values. Important aspects of constructivist grounded theory as introduced by Charmaz are, amongst others, regarding Inter-relationships, discovering underlying social processes, and developing understanding. The social-constructivist approach thus allows for more emphasis on individual experiences views and values, which can be a result of both already existing data, as newly obtained data. As it is assumed that next to the data, also the ideas and insights of the researcher play an integral role in the research, Constructivist Grounded Theory is more of an abductive approach. Refer to Figure 4 for the theory writing process as has happened in this research.

Figure 3: Creating new theory

Where this figure may simultaneously suggest linearity and some kind of separation between the data sets in the process, this was not the case. The idea of Constructivist Grounded Theory is that you are constantly building on the newly obtained knowledge and that this new knowledge is taken with you in the next step to further build on.

3.2 Data Collection

When determining how to obtain answers to these questions, interviewing emerged as the most suitable method. . Intensive interviewing is one of the qualitative methods that is most used, and was also readily adopted by grounded theorists (Charmaz, 2019, p. 18). This is because conducting interviews in this digital age enabled me to communicate with individuals worldwide using platforms such as Zoom. Aside from the fact that it is a highly effective way to obtain data, it is also an efficient and effective manner when looking at time and effort of the researcher and the interviewee. Due to the limited time and the desire to have a large geographical scope, intensive interviewing was decided to be the first method of data collection. As a starting point for the interviewees, the connections and database of 'Better Care Network Netherlands' was consulted which allowed for connections of (Dutch) NGOs and PDIs that worked in the field. See 3.2.1 for a more extensive overview of the interviewees, and a thorough explanation of the interviewing process.

A downside to this way of communicating however is that there is less room for a personal connection which can help when discussing challenging topics, and that the perspective truly is from the interviewee which may be more biased or partially informed. This made that when it was possible, the decision was made to conduct the interview in real life, which happened with four respondents, and that the decision was made to actually go to

Kenya to get a more complete picture. When being in a country which this research concerns, this allows to better understand the context in which people are making certain statements. Due to the fact that I did not solely wanted to talk *about* people, but also *with* people, and the need to get an insight of operations behind the scenes this was considered a necessary addition to this research.

Due to unfortunate circumstances the time available for fieldwork was limited. Therefore the decision was made to only visit Kenya and two initiatives: Imani and KidsCare, in a time span of three weeks. Aside from visiting the initiatives and learning more about their operations, another goal of this fieldwork was to speak to people that were not per see connected to this subject in order to 'test' the general view and opinion regarding people with disabilities. Please refer to 3.2.2 for a more extensive overview of the fieldwork, including the visited initiatives and the methods used.

The pre-existing data consisted of literature presented in the Theoretical Framework and Introduction, as well as new, non-academic, sources. These being reports of NGOs, documentaries, books, and newspaper articles, but also information obtained during (online) disability-inclusion seminars. These sources were predominantly used as guidelines for interview questions and support to statements that were made in interviews and during the fieldwork.

Refer to Figure 4 for a figurative representation of the data collection process which created the new theory.

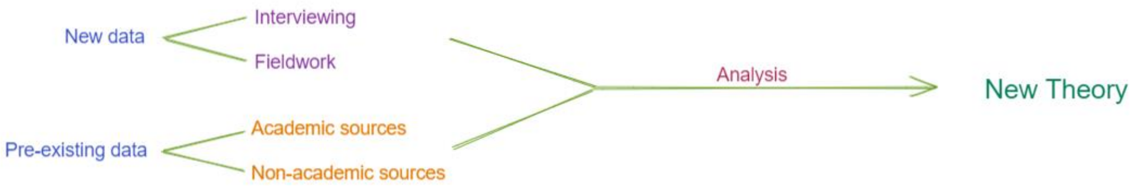


Figure 4: Data collection process to new theory

In order to write a new theory, the goal is in essence to achieve 'theoretical saturation' which is a complicated aspect to be certain of, as it is difficult to know when the theory is complete. In order to avoid collecting an excessive amount of data which has no added value to the theory, discriminant sampling was implemented as a guideline. In essence this means that a theory is developed in the early stage of the research, which is then tested with different participants. The goal here is to find out which aspects of this theory can be generalised. Refer to 3.2.3 for a further analysis of how this was put into practice. The following paragraphs will provide a more in-depth look into how the 'new data' was collected during this process by zooming into the interviewing process and the fieldwork.

3.2.1 The interviews

As mentioned previously in 3.2, intensive interviewing is one of the primary ways in how data is collected in qualitative research, and especially so in Grounded Theory (Charmaz, 2019, p. 18). Typically a new theory is synthesised from the data of around 20 interviews (Glaser & Strauss, 2012). Due to the limited time, and because I also conducted fieldwork, this theory finds foundation from 16 interviews.

The connections provided by Better Care Network Netherlands allowed as a starting point for (potential) interviewees. Here, I was provided with the names of (Dutch) organisations that worked with children with disabilities. Both in Family-based care and in Residential care. The goal was to have a sample which consisted of as many organisations who were active in Family-based care as in Residential care. Unfortunately, residential care facilities appeared to be less eager collaborate making that their voice is underrepresented in this research. Therefore, the additional information regarding residential care for children with disabilities was derived from websites of these facilities.

Multiple of these interviewees then referred me to their connections who they thought would add value to this research. This allowed me to broaden my scope of respondents outside of solely Dutch initiators or employees of organisations. Another way in how interviewees were contacted were via (online) disability-inclusion seminars, after which I contacted them via e-mail or LinkedIn. This allowed me to speak with a variety of people with a different relation to the subject. Such as experience experts with a (physical) disability, parents of children with disabilities, and experts in the field. Furthermore, this created more of a mix between interviewees from the Global

North (ten) and the Global South (six). Ideally seen, the ratio would have been more equal, but unfortunately I did not manage this within this timeframe. The fieldwork conducted allowed for a more equal representation of local voices.

It was deemed unethical for me to speak directly with children regarding this matter. Interviewing children, and especially children with disabilities requires a different skillset which I do not yet possess. Furthermore, I found the risk too high that with this insufficient experience, my questioning would have a negative effect on the child. With the right expertise, this would however have been seen as a good addition to this research. In this case, the respondents were above 18.

In Table 1 the interviewees and their function are shown in chronological order. This is important in this method, as all the interviews are building upon information which was derived from previous interviews.

Interviewee:	**Organisation:**	**Function:**	**Type of care:**	**Country:**
Iftekhar Ahmed	CSID	Director, father of a child with autism	Family-based care	Bangladesh
Harrie Oostrom	Stichting Imani	Founder, active behind the scenes	Institutional care	Kenya
Kirsten Giethoorn	Friendship Foundation	Founder, active behind the scenes	Family-based care	Sri Lanka
Maartje van den Brand	Stichting Japthi	Managing Director	Institutional care	India
Gerard Geenen	KidsCare	Founder, active behind the scenes	Family-based care	Kenya
Antoinette Termoshuizen	Niketan	Founder, project manager	Family-based care	Bangladesh
Anonymous respondent	Dutch NGO	Rehabilitation consultant	Family-based care	Worldwide
Florence Koenderink	Independent Researcher	Independent Researcher	Family-based care	Worldwide, now Kenya
Samuel Nyingcho	Consultant on disability and inclusive development	Consultant, Experience Expert	Family-based care	Cameroon
Hisan*		Experience Expert	Institutional care	Kenya
Salem Bakari	KidsCare (amongst others)	Chairman	Family-based care	Kenya
Maria Njeri	Maria Njeri Foundation	Experience Expert	Family-based care	Kenya
Ellen van Beer	More Africa	Founder and director	Special Education school	Tanzania
Nguyen Phuong Ha		Mother of a child with Cerebral Palsy	Family-based care	Vietnam
Monique Derrez	Dutch Tanzania Foundation	Founder and chairman	Family-based care	Tanzania
Carmen van Bergen	Amara Foundation	Initiator and board member	Family-based care/ institutional care	Kenya

Table 1: Overview of Interviewees

* this is an alias

As can be seen in Table 1, the respondents are not equally distributed and cover only parts of Asia and Africa in the Global South. See Figure 5 for a display of the areas which the respondents cover. Therefore, Latin-America is not included in this research. As there is not an equal representation, solely phenomena which could be verified to take place in multiple different geographical areas were presented as a generality. In the case that this was not possible to verify, but that it seemed relevant to mention, the specific country name was mentioned alongside with the statement. The reference to this area will be Global South*, where the asterisk indicates that this does not cover the full Global South.

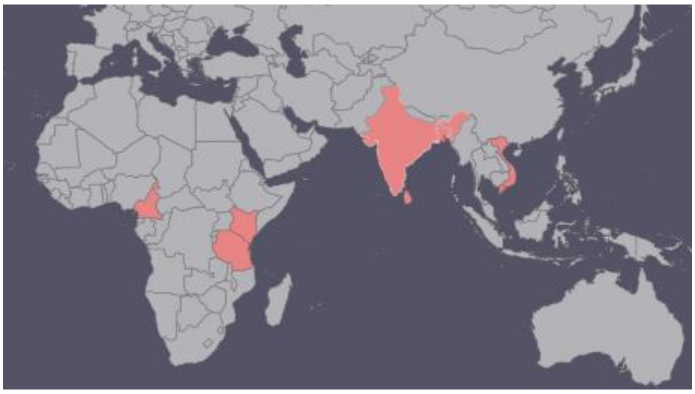


Figure 5: represented countries

The interviews were predominantly via Zoom and a short interview guide was created to guide the interview. Refer to Appendix 1 for an example of an interview guide. This interview guide included an overview of the most interesting and relevant points which were found during the preparatory background research, as well as certain questions and parts of the already written theory which I wanted to confirm.

Right after these interviews I took some time for memo writing, an essential element of Grounded Theory as further elaborated on in 3.3. In these memos I wrote down some aspects which struck me the most during the interview, such as new realizations or additions to the theory and some questions that arose, as well as the feeling that a certain conversation had given me see Appendix 2 for examples of these memos.

The interviews took place over a course of three months, and the analysis of these interviews happened simultaneously, as is the idea with Grounded Theory.

3.2.2 Fieldwork

As the analysis of inter-relationships, the discovering of underlying social processes, and developing understanding are seen as important elements of Constructivist Grounded Theory, solely conducting interviews was not seen as sufficient to be able to have a better understanding of these processes. Fieldwork was decided as an important additional source as this allows for more in-depth and contextual understanding of the subject. Being in another country allowed me to hear other voices, also of people that were not directly linked to the subject, showing how disability was viewed from a cultural perspective. Furthermore, it allowed for a better understanding of the practical challenges, such as the architectural barriers which someone with reduced mobility may encounter.

Due to the limited time and funds available, as well as me still being on crutches, it was decided to only go to one country. I decided to go to Kenya due to the fact that a large part of the population speaks English making it possible for me to go about without needing translation. Moreover, it was not too far away and I had previous experiences in East-Africa which allowed me to focus on the research as I was already familiar with the culture, and basics of Kiswahili. Furthermore, I had already been in contact with an orphanage and a family based care facility in Kenya who both allowed me to visit. Moreover, Hisan and Maria were both based in Kenya which allowed me to interview them in person, as well as with Salem whom I interviewed when visiting KidsCare. Ideally seen I would have visited at least one country in Asia, but this was unfortunately not possible within the limited timeframe.

The two initiatives which I visited were Imani in Nairobi and KidsCare in Lunga Lunga County. At the end of my interview with Harrie and Gerrie I shared my intention to perhaps go and visit Kenya, and asked if I could come to see more of their operations. During my fieldwork, the goal was to visit at least one residential care facility and one family-based care facility for a better representation.

At this point in the research, I had already conducted interviews with eight of the interviewees. This made that I already had a proper preliminary understanding of the subject due to the analysis of the interviews up to that point. This made that I had a clear overview of the additional questions to ask the two initiatives, and the elements of the theory that I wanted to verify.

In Figure 6 we see the preliminary subjects which I planned to get a better understanding off. The colours here are indicating where I expected to find the answers to these questions.

Green	personal observations.
Orange	observations and conversations at the initiatives.
Turquoise	observations and conversations with people from society.

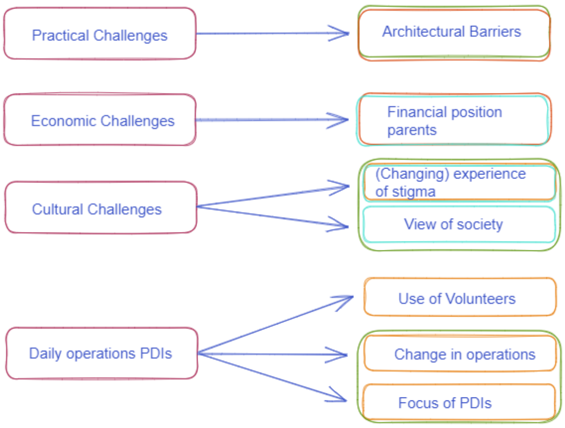


Figure 6: Fieldwork Plan

The analysis of architectural barriers was simplified due to the fact that I was walking on crutches during this period. Whilst this cannot in any way be compared to being wheelchair bound, it does make that simply moving around a country is not something to be taken for granted and that these barriers simply are more easily noticed. These being high sidewalks and large trenches in the middle of the road over which you have to jump to cross the road, but also stairs, inaccessible bathrooms and inabilities to use certain types of public transport.

Observations and conversations at the initiatives consisted of additional questions which I wanted to ask, but also conversations with other employees and the observation of the daily activities. To see the different ways in which the initiatives tackle problems. The goal here was really to create that better understanding sought for in Constructivist Grounded Theory, and also of the inter-relationships that shape the theory.

Stichting Imani

Imani is located in a town near Nairobi and it was the first place I visited. The plan was made to meet up with Harrie and to join him to visit the orphanage for one day. Harrie is originally Dutch, but lives in the neighbourhood already for quite some time, and only does work for Imani which is behind the scenes such as finding funds and speaking to donors. He showed me around and granted me the opportunity to ask additional questions to him and also to the other employees who were all Kenyans. I did not want to interact with the children, as this was not something I considered ethical as the benefits did not way up to the potential downsides. I therefore stayed on the side-lines and simply observed the daily operations and interactions. As can be seen in Figure 7, I wanted to learn more about the practical, economic and cultural challenges, as well as the daily operations of the PDIs. These were therefore the directions of the questions asked. During the day I made notes about the important things that we talked about to make sure that by the end of the day I could write out my observations and findings.

KidsCare

At KidsCare I was given the opportunity to shadow one of the social workers for around a week. Here, I joined her on her activities to get a better understanding of the holistic approach of KidsCare when it comes to family-based care. As they really are working within the community, this allowed me to get a better understanding of the effect that an initiative as such can have on the livelihood of a child with disabilities and its family.

Here I was able to witness the multiple aspects of the organisation in terms of the occupational therapy provided, the special education units, home visits, parent support groups etcetera. As I was shadowing a social worker, I could ask her a lot of questions to help me get a better understanding about how and why she decided to work with children with disabilities, how she saw society change and what she still considers important challenges. Also here I noted down the observations, new information and additional questions during the day, to work them out later on.

3.2.3 Information Sampling and Constructing Grounded Theory

In essence, the process of information sampling and Constructing Grounded Theory is displayed in Figure 7. What we see here is that this process consists of two main elements. The first one being the part which is within the red circle: the theory development phase. As was mentioned previously, discriminant sampling was used as the main sampling method. In this, the first step is to write the theory from the first obtained data, which will then be tested with use of the additional data. Around the first eight interviews were used to write the vast majority of the data in the large lines, and the additional eight interviews as well as the fieldwork was used to test this written theory, which is the part that came after. In this process, nothing was set in stone yet and there was still room for new information if this came up and appeared relevant.

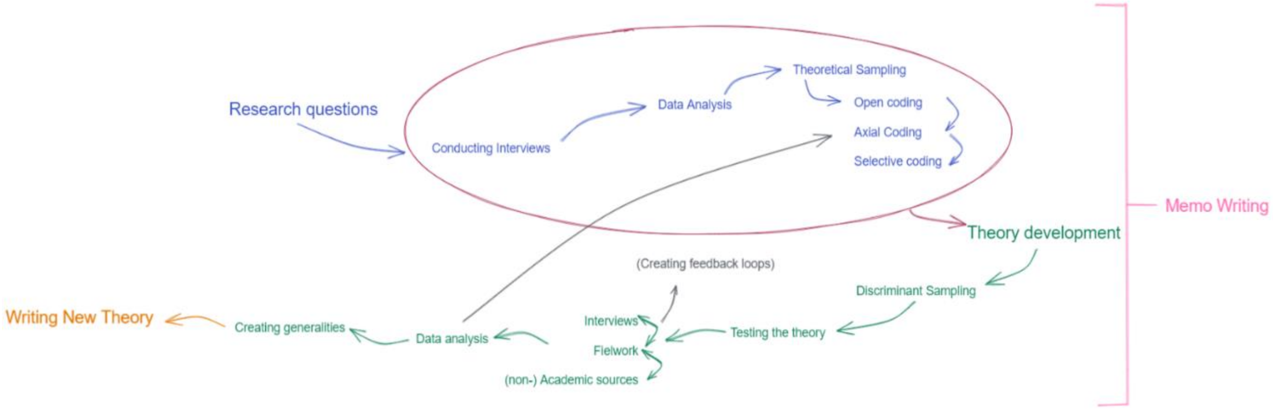


Figure 7: Information Sampling and Constructing Grounded Theory

In this chapter we will first take a more in depth look into the methods used to build and test the theory after which we will look at the process of data analysis and memo writing. The three methods used to test the theory and to build the theory are the following:

Building theory from the interviews

This is what was used especially in the part where the main theory was written. In this, the goal was to find phenomena which overlapped with the experiences of multiple interviewees. These were found by asking similar questions to the interviewees to find out what their answers were. What simultaneously was done, was to present a situation what was brought forward in a previous interview to the new interviewee, to see if elements could be generalized. For example, I asked Kirsten what parents saw as the biggest challenge when having a child with disabilities (see Chapter 4.1.2). She shared that this was their weakened economic position, especially as these children may never grow up to be able to work and provide for them, but will always continue to need the (financial) support of their parents. To see if this was the case not only in Sri-Lanka but also in other countries, I asked a similar question in the other interviews and in the conversations I had during my fieldwork. As all could confirm this to a certain extent, this was considered a general challenge for parents when they have a child with disabilities.

Reflecting on new experiences

Another example is the one of a sole case which presented itself later on in the research process, where I asked people to reflect upon from their personal point of view. An example of this is the case of a girl who had cerebral palsy and was wheelchair bound that lived with her family and received occupational therapy once a week, but could not be brought to school due to the distance and challenging roads (see Chapter 4.2.2 *'Case: Girl in a Wheelchair'*). This case was a good example of the limits and opportunities of family care. She was part of her family, but simultaneously could not go to school, nor receive therapy more often which perhaps made that she did not have opportunity to achieve her full potential. I decided to ask multiple interviewees from different backgrounds (family based care, institutional care, experts, etcetera.) what their views were on what would be the best option for the child. This establish what the different views could be on this specific case, if generalities could be found amongst all, or within different subgroups of respondents.

Fact checking the theory with non-academic data

This was used in the case that someone made a statement which was considered interesting and important, but could not be (sufficiently) supported by the other interviewees or academic data. An example of this is in the case of Mercy Killings (See 4.1.3 *'Acts of Despair'*). This was a concept to which I was introduced in more of an anecdotal manner, and about which other interviewees who I asked also spoke about in terms of something that they indeed heard about but lack concrete or direct examples. In this case, the information presented came from a documentary regarding this subject and news articles that could help with creating an understanding regarding this subject.

These three elements therefore all officiated to create generalisations regarding a phenomenon which could eventually be written in theory. The elements that are presented in this research, therefore are largely generalities regarding this specific phenomenon. In some cases elements were found to be important, but could not sufficiently be tested in the larger geographical scope. In these cases, the specific country is named.

3.3 Data analysis

As thoroughly mentioned, the continuous process of data analysis is the essential element of conducting Constructivist Grounded Theory. The data was therefore analysed in the order it was obtained. After having transcribed the interviews the first step in the analysis was the coding of the interview which was done in Atlas.ti.

As can be derived from Figure 7, the coding process happened in three different rounds: Open Coding, Axial Coding and Selective Coding. The further in the research, and the more the theory was already written, the more the interview was coded selectively right away, unless new contrasting information appeared.

The interviews were divided into four different groups to make sure that the data was organised in a logical manner to help creating an overview. The different groups were:

- Dutch Initiatives: Family-based/Alternative Care
- Dutch Initiatives: Institutional care
- Experts
- Local initiatives: Family-based/Alternative Care

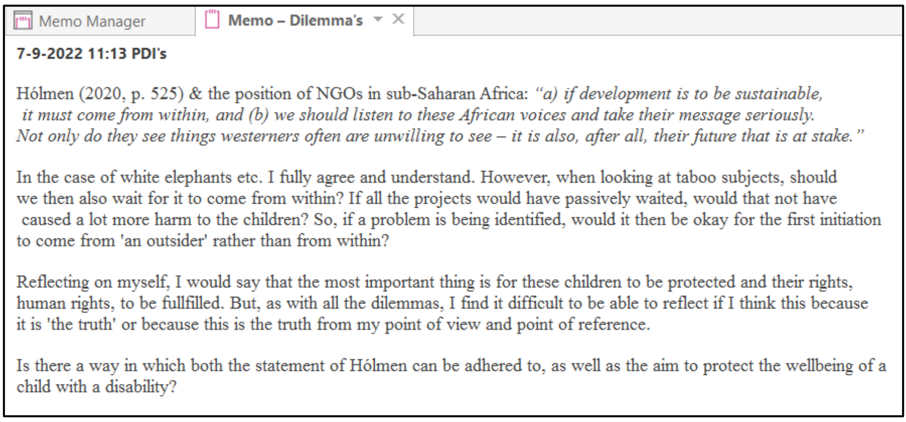
Experts were experts regarding the subject, as well as experience experts including Phuong, the mother of a child with cerebral palsy. Furthermore, some interviewees where placed in multiple groups. For example, Samuel has a family-based initiative in Cameroon, but also being an experience expert.

I analysed the interviews with the use of 81 codes covering 592 quotations which were divided into 13 code groups. Added to this were the observations made, which were written down in the Memos per subject, such as ‘Observation Inclusive Education.’ Furthermore, the main parts which were found relevant from previously and newly obtained literature were also written down in Memos in order to be able to use them as part of the Constructivist Grounded Theory.

Supporting the process

Aside from memos for observations and literature as mentioned above, memos were also used to write down short reflections on the interviews and additional dilemmas and questions which came to mind during the process. This was both already during the writing of the theoretical framework, as in the process of the analysis. This allowed me to remember my thought processes and remain aware of my own learning process.

I made different memo documents concerning different aspects of the research. One of those is called ‘Dilemmas.’ Here, I wrote things down where I was uncertain of to allow for some personal reflection and additional research. Either to then be able to come to a conclusion myself, or to present my dilemma to one of the interviewees. An example of a memo as such is presented in Figure 8.



7-9-2022 11:13 PDI's

Hólmen (2020, p. 525) & the position of NGOs in sub-Saharan Africa: *“a) if development is to be sustainable, it must come from within, and (b) we should listen to these African voices and take their message seriously. Not only do they see things westerners often are unwilling to see – it is also, after all, their future that is at stake.”*

In the case of white elephants etc. I fully agree and understand. However, when looking at taboo subjects, should we then also wait for it to come from within? If all the projects would have passively waited, would that not have caused a lot more harm to the children? So, if a problem is being identified, would it then be okay for the first initiation to come from 'an outsider' rather than from within?

Reflecting on myself, I would say that the most important thing is for these children to be protected and their rights, human rights, to be fullfilled. But, as with all the dilemmas, I find it difficult to be able to reflect if I think this because it is 'the truth' or because this is the truth from my point of view and point of reference.

Is there a way in which both the statement of Hólmen can be adhered to, as well as the aim to protect the wellbeing of a child with a disability?

Figure 8: Memo example

The next step was to add the elements together per subject, and to make them into a network. In order to illustrate this step, an example is presented in Figure 9. Here, I made a Network for ‘Inclusive Education.’ What we see in this network are the most important subjects and links which were found in relation to Inclusive Education. This is a way to sort and create structure within the information regarding this subject which will then be used to write the chapter. What we for example see here, is how Inclusive Education is part of Family-based Care, and how Inclusive Education impacts key elements, especially due to the trickledown effect that it has. This allows to see the interconnectivity between multiple aspects of the research. Aside from the codes, which were used in the analysis of the primary source of new data (interviews), the information obtained from literature and observations are shared in the memos on the right. See Figure 10 for an example of the memo ‘Observation Inclusive Education.’

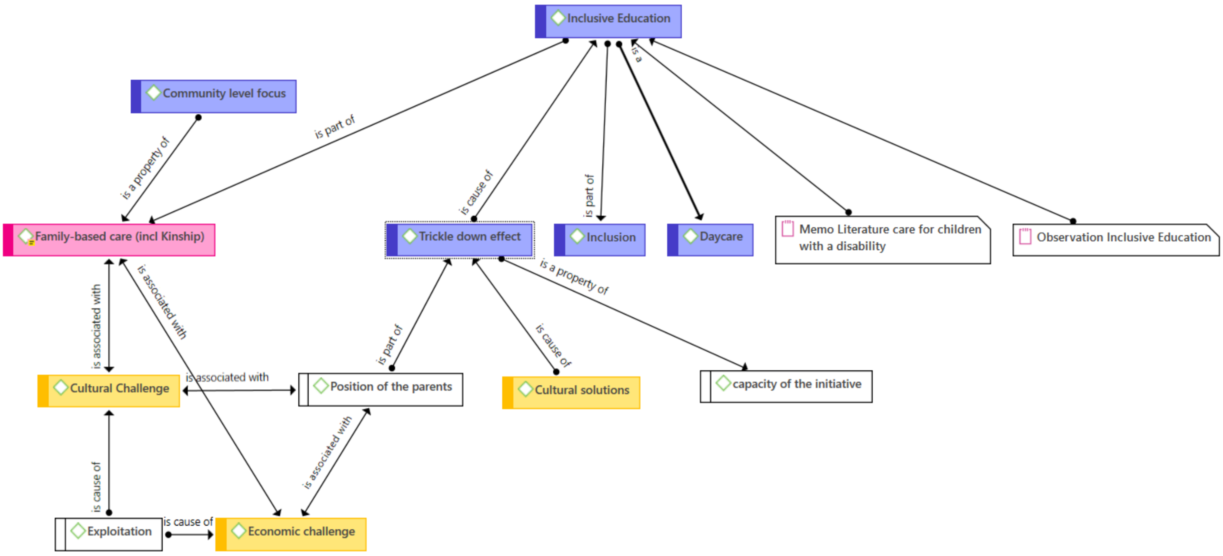
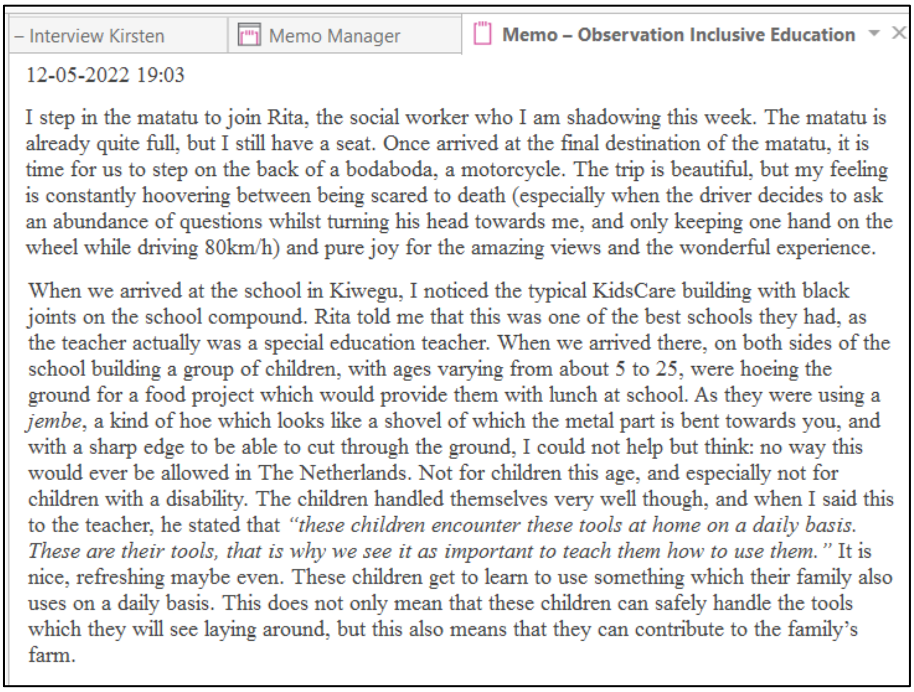


Figure 9: Network Inclusive Education

The combination of the network with the different quotes, the observations and the (additional) literature were the first framework of the chapter. Typically, I started with a short summary from the literature where this was possible, and I looked at the elements of the interviews and observations which supported or contradicted these statements. When the framework of the subject was clear, as well as the main insights, I looked more into specific quotations which I thought show a proper illustration of what I wanted to share in that chapter. This was also a combination between quotations of the interviews and direct quotations from the observations. This makes that the chapters all are formed with use of all the interviews and additional memos, but that only some direct quotations were highlighted.

I chose for more of a story telling kind off way to present my findings as I wanted to make sure that it was easy to read and remained interesting, also for non-academia. This was amongst others done with the use of Story Boxes in which specific elements of conducted interviews were presented. The idea was that within the findings chapter, the reader understands the way in how I wrote it down and how I came to my conclusions, simply by reading it. This suits the Constructivist Grounded Theory approach, which sees the researcher as a key aspect in how the theory is written.



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I step in the matatu to join Rita, the social worker who I am shadowing this week. The matatu is already quite full, but I still have a seat. Once arrived at the final destination of the matatu, it is time for us to step on the back of a bodaboda, a motorcycle. The trip is beautiful, but my feeling is constantly hoovering between being scared to death (especially when the driver decides to ask an abundance of questions whilst turning his head towards me, and only keeping one hand on the wheel while driving 80km/h) and pure joy for the amazing views and the wonderful experience.

When we arrived at the school in Kiwegu, I noticed the typical KidsCare building with black joints on the school compound. Rita told me that this was one of the best schools they had, as the teacher actually was a special education teacher. When we arrived there, on both sides of the school building a group of children, with ages varying from about 5 to 25, were hoeing the ground for a food project which would provide them with lunch at school. As they were using a *jembe*, a kind of hoe which looks like a shovel of which the metal part is bent towards you, and with a sharp edge to be able to cut through the ground, I could not help but think: no way this would ever be allowed in The Netherlands. Not for children this age, and especially not for children with a disability. The children handled themselves very well though, and when I said this to the teacher, he stated that *"these children encounter these tools at home on a daily basis. These are their tools, that is why we see it as important to teach them how to use them."* It is nice, refreshing maybe even. These children get to learn to use something which their family also uses on a daily basis. This does not only mean that these children can safely handle the tools which they will see laying around, but this also means that they can contribute to the family's farm.

Figure 10: Memo Observation Inclusive Education

This chapter in described how this research was conducted, and how I found the answers to the questions which result in the new theory which will presented in the following chapter: Chapter 4. As stated, the process was not linear and the writing of the findings chapter was a continuous process of going back and forth in order to come to the aimed for theoretical saturation. Where there are limitations, such as an unequal representation of residential care facilities and only having visited one country of the geographical scope the elements presented as generalities are done so because of this theoretical saturation. Where there could have been more interviews, especially with respondents from the Global South, it was noticed that the more I moved towards the end the more the aimed for theoretical saturation was achieved, and that there was no true discrepancy between the views of the respondents of the Global North and the Global South.

4 Findings

This chapter consists of two main parts that officiate to answer the main research questions which were:

- What is the context and situation for a child with disabilities to grow up in the Global South*?
- How do the different non-governmental care providers operate in this domain in the Global South*?

The first part allows to create a better understanding of the current situation of children with disabilities that are born in a family in the Global South*. These will be presented with use of three main challenges that can be encountered, as was found in this research. The second part focusses on the care providers and how this care is being provided. Here we take a closer look at (de-) institutionalisation and family-based care. Furthermore, we look at the position of PDIs and NGOs in the aid-infrastructure and the potential effects that this has.

The theory is substantiated through direct quotations from interviews, conversations, and selected parts of observation reports that closely align with the aspect of the theory being presented. Since the theory is based on multiple interviews, not all interviewees are quoted equally.

As mentioned previously, the elements that are presented as a generality are done so in the case that theoretical saturation was noticed. In the case that there was not enough support for a statement, it is presented with the geographical location. This does not mean that it is per definition not a generality, this simply means that within this research no sufficient support was found to present it as such. Furthermore, children with disabilities will often be used as a general term. This is whilst recognizing the high variability between disabilities and the heterogeneity within this group, and how they are experienced differently in each and every individual. Many challenges are intersectional, as we will notice, and how challenges are experienced is highly dependent on the full context of how the child is growing up. Whilst recognizing these elements, general comments are made regarding this group where it was deemed possible. The disabilities which are mostly encountered by the initiatives were (severe) cognitive disabilities or severe physical disabilities, and more specifically cerebral palsy, down syndrome and severe autism. Within the cognitive disabilities, there may also be a physical component which adds to their challenges.

It is worth noting that PDIs tend to adapt and modify their methods rather fast. The way in which they operate which is presented in this research, is how they operated in this specific moment in time. They learn and change along the way, and it is therefore very well possible that depending on when you read this thesis, certain things have changed in the meantime.

4.1 The Challenges of the children and their families

“First thing is the barriers that are associated with disabilities. ‘…’ I usually classify those challenges with my ‘triple A's,’ I call it: Attitude, Access, and Acceptance. Attitude, access, and acceptance. These are the barriers that limit persons with disabilities from going out. Because, you know, in a developing country like us, where inclusion is still being spoken of, but the practicality of it is still farfetched, especially in fact, in infrastructure development, it becomes a huge challenge. Another issue is the economic leverage of it because for somebody to live independently, it's fast, so demanding to those without disabilities not to talk of those with disabilities whose cost of living is often double or even triple in some instances, to be able to meet up with regular life like other persons, those, those are some of the barriers and like I talked about the fear, the fear that they will be stigmatized maltreated, exploited.. is in the minds of the family, especially women and girls with disabilities.” (Interview with S. Nyingcho, May 4, 2022).

We will start off with presenting the findings regarding the challenges of the children and their families in case a child is born with disabilities. As Samuel shared in the citation above, these children and their families face multiple barriers which pose threats to their opportunities in life. In this chapter, I have divided these challenges into three main categories: Practical Challenges, mainly encountered by children with (also) a physical impairment, Economic Challenges, such as the increasing cost of living, and Cultural Challenges, which discusses the issues regarding attitude and acceptance with regard to stigma.

4.1.1 Practical Challenge

Practical challenges will in this case discuss predominantly infrastructural barriers which have an immense impact on people that have mobility challenges which for example make them wheelchair-bound. Where the statements made here are not completely new, it was deemed important to share to be able to create a complete overview of potential the encountered challenges.

Inadequate infrastructure is one of the reasons that can cause children and parents or caregivers to be isolated. Aside from the fact that wheelchairs are not available for everyone, often imported and not adapted to individual needs, even if they are, the environment is often difficult to not accessible for usage. (Interview with Anonymous, April 11, 2022). In this case it is really the environment which plays a defining role when looking at how a disability is experienced by an individual. Making these areas physically accessible is an important element of creating enabling environments.

A personal example of this was when I was in Kenya for this research. Here, I walked on crutches for the first two weeks. Whilst this cannot be compared to being in a wheelchair, it does help with seeing architectural barriers which otherwise would not be an issue. The uneven roads in Nairobi with the extremely high curbs, the sidewalks that became very slippery after the rains, and the squatting toilets with no hand bars to support yourself in Lunga Lunga county making it basically impossible for me to use the toilet. In The Netherlands, the environment defined my ability to move and to be independent a lot less than it did over there in Kenya, as it does even more for people that do not have crutches or a wheelchair that do need them, or do have assisting devices but have to use it within these barriers.

This confirms the statement made by Halder (2009, p. 640) which was shared previously: *"It was as if the built environment was often built to exclude rather than to include students with disabilities."* What Halder already suggest by usage of the word *'students'* is that this excluding environment does not only limit itself to potential mobility challenges. Inaccessible schools are a large challenge as is for example encountered by Antoinette in Bangladesh. Despite it being mandatory for schools to be accessible, this is often not the case. As she shares, schools are often not even aware of this obligation that they have to be accessible (Interview with A. Thermoshuizen, April 7, 2022).

This can cause a situation where a child with only a physical impairment, who would be completely capable to follow mainstream education to go to special education in a residential care facility. *"We also have a girl who is cognitively able, but who did her high school exams with us because there was no proper road to her high school, it was a mud road and the toilets were outside. Who is going to carry her with her wheelchair..?"* (Interview with M. van den Berg, April 4, 2022) .

The space in which one manoeuvres, as well as the assistive tools that they can access are defining factors of how the disability is experienced for the individual. Creating these enabling environments, as well as the provision of assistive tools, can make that the experience of a disability can change thoroughly.

4.1.2 Economic Challenge

When I asked Kirsten (Interview, April 4, 2022) what the biggest challenge was for the parents and what they noticed at the centre, I did not expect it to be so linked to their financial position as can be read in Story Box 1. That the financial position of the family weakened due to the disability of their child was highlighted in the literature (Eide et al., 2011; Halder & Assaf, 2017). The scope of this impact however was not as clear.

Story Box 1

Kirsten – Friendship Foundation, Sri-Lanka

"What we hear in our centre is that.. they all want that their child makes money actually. Not when it's still a small child, but keeping this in the back of their minds that.. especially in the rural areas a child is born as a safety net. The retirement of the parents, or if the parents become disabled themselves and don't make money anymore. '…' this disappears when there is a child being born with disabilities. From the moment that the child is born and has a disability, it is already a financial liability. Because, if a child can go to school, then the parents can go and work. But these children have never been to school, so there always had to be a parent at home. They are often day labourers, which simply means: no income. There are also stories of children who are locked up at home so that both parents can go and work. '…' the primary need of life is above the social need. The financial position is more important for the parents than the social, because they feel the financial situation right away."

This struggle for parents indeed appeared to be one of the most prevalent issues noticed next to stigma. Everyone I spoke to, in every country, recognized this. *"Yes, it is a problem. It's even worse for guys. Because in our culture guys bring the money and go to work, you know."* (Interview with M. Njeri, May 16, 2022)

On top of this, *"some children with disabilities need regular medicine support, some children with disabilities need regular therapeutical intervention.. this is sometimes costly. That's why the parents or caregivers sometimes look more negative to them."* (Interview with A. Ifthekar, , March 31, 2022) Having a child with disabilities, often lowers the financial situation of the family. As Ahmed states, a lot of additional costs come in the case that a child has a disability. As was mentioned by Samuel in the introduction, the costs of living for someone with disabilities sometimes even double or triple (Interview with S.

Nyingcho, May 4, 2022). *“What you see in Kenya, is that families who have a child with disabilities, have a way bigger chance to live under the poverty line, and also a way bigger chance to live under the extreme poverty line.. this is all due to the extra costs which they have.”* (Interview with F. Koenderink, April 14, 2022) Having a child with disabilities can thus cause severe financial distress both in short term due to higher costs of caring and needing to stay at home, as in the long term as their financial safety net is not provided, as is noticed by Kirsten in Story Box 1. As she shares, *“the primary need of life is above the social need.”*

To see what some initiatives do to fulfil this primary need, refer to Chapter 4.2.2.

4.1.3 Stigma

Story Box 2

Antoinette – Niketan, Bangladesh
“Yes, this is still a very big issue and we realize this every time again when we start working in a new village. That’s when you realize: ‘oh, it is still really prevalent.’ A lot of children there get called after as fool.. crazy person.. and even, also parents call their children this. They often still believe that it is a curse by God, and that they are not worth the investment.. that they are sometimes being treated as an animal.. sometimes even worse. And well yes, this is something that you realize every time you start working in a new village.”

I was sitting in a restaurant having lunch with someone I met at the hotel where I was staying in Nairobi. He is originally from the west of Kenya and moved here for work. He gave me a Swahili lesson this morning, and afterwards, he showed me around the city centre.

Whilst having lunch on the terrace, which was located on the balcony of the first floor, we heard a man having a rant by himself on a busy square. My companion was smiling listening to it and understood my questioning facial expression. *“He is just mentally not completely okay,”* he said, with very little judgement in his voice, for as far as I could tell. *“If your city does not have a person like this, you did not come to the right place.”* As we started to talk about this, I decided to ask how people with disabilities were treated here. He said that they were often ignored and that that was wrong. “*they are also human beings.”* I told him that we hear a lot about stigma in these places regarding people with disabilities, and I asked him if I knew why there was a stigma. He said that it comes from the belief that people with disabilities are possessed by the devil, or that they are bewitched. When I asked him if it was something that he believed too he said yes. *“Some people are possessed by the devil or bewitched, but not all of them. Sometimes they are just born like that, genetics, or they get an accident.”*

The questions that rose from the literature were regarding the scope of the potential issue, where it originated from, but especially what the effects are of this stigma. There were suggestions of children being hidden, but proper research regarding this matter was lacking. This, whilst stigma came out to be the largest overarching issue found in this research as it reaches all layers of society. What I found is that stigma stems from different cultural backgrounds, and also finds its foundation in different aspects depending on the country. A disability can for example be seen as a sin from god, witchcraft, a sin from the mother and bad karma in a past life. Often, the link is made between a religious foundation and the stigma, and it is also common that the mother gets the blame for having a child with disabilities. (e.g. in interviews with S. Nyingcho, May 4, 2022; F. Koenderink, April 14, 2022)

That this is a serious issue, is very well explained in the blog of Florence Koenderink with the title *‘Harmful Practices and Children with Disabilities.’* What she explains is that this stigma on children with disabilities results in *“children being denied equal rights, being ostracised, and sometimes even having their whole family rejected by the community and unable to make a living. They can also lead to neglect or physical abuse.”* (Koenderink, 2022a *para* 3) However, the effects of the stigma can even go further than rejection. *“in some places, parents are put under enormous social pressure to kill a child with disabilities or to leave them to die. This might be because the disability is considered to be a sign of evil, or because it is believed that the parents will not be able to bear children without disabilities if they do not kill the child with disabilities.”* (Koenderink, 2022a *para* 4). She, therefore, pleads for the stigma on disability to be recognized as a harmful practice. This will allow for the stigma on disability to be treated the same way as other harmful practices such as child marriage, violence against women, and female genital mutilation (Koenderink, 2022a *para* 5).

The effect of stigma on the child and its family thus is severe. In this chapter, we will further look into the issues encountered with stigma with the use of the interviews conducted, observations, the literature and other sources such as documentaries. This is to create a better understanding of the scope of the issue, and also to share hopeful stories regarding the matter. Stigma appears to be the most prevalent for cognitive disabilities. Salem even made the statement that a stigma on a physical disability is barely present in Kenya anymore. As he explains, the challenge for children with a physical disability is more infrastructural, as we saw in 4.1.1 ‘Practical Challenge.’

As they can essentially perform and communicate the same way as other children do, they experience less of a barrier compared to their peers with a cognitive disability (Interview with S. Bakari, May 11, 2022).

How stigma is perceived remains a culturally sensitive theme. The items which are discussed as a generality, are done so when, from my perspective, sufficient underpinning was found to treat them as general.

Stigma and Religion

As was mentioned previously, a link is often made between stigma and religion. Why this is especially is an issue, is because people that see a disability as a bidding from God, can refrain from seeking treatment for their child (Al-Aoufi et al., 2012), However, as the analysis of the Qur'an and the Bible show, the issue should be more attributed to the cultural perspectives of the individual (Al-Aoufi, et al., 2012; Rimmerman, 2013). *"Cultural perspectives, mixed with religious values, often lead to several courses of action which may be falsely attributed to religious faith, such as embarrassment at having a child with disabilities, attempting to explain the cause of the disability, and looking for fast solutions."* (Al-Aoufi, et al., 2012, p. 214).

What however was found, is that religion can help in understanding the different views that individuals have regarding disabilities, even if their interpretation perhaps is not (fully) in line with what is written in the religious books. Florence (Interview, April 14, 2022) explained that for example Kenya and parts of India, the stigma regarding disabilities is that it is a curse, witchcraft, a punishment by God, or because of the sins of the Mother. However, in Cambodia, which is a Buddhist country, the sin is karma. This means that the disability of the person is seen as a punishment for the bad things done in their past life. When looking at Sudan, a Muslim country, it is considered a crime to have sex before marriage. This results in a lot of children being abandoned, as they serve as proof of the crime committed. Due to this, the abandoned children were not very well taken care of resulting in very high child mortality.

Why this is important to know, is because understanding where the stigma originates from allows for a form-fitted solution which is respectful of the practices of the culture, whilst helping with reducing the stigma. Florence (Interview, April 14, 2022) stated the importance of looking at these problems to find solutions within their own cultural context.

These are a few examples as given by Florence:

- Looking at Christianity, she points to the verse presented in the literature where Jesus explains to his disciples that the blindness of the man has nothing to do with him, or his parents being sinful. And, if a disability is considered a punishment of God, why would Jesus have healed the blind man?
- Within Buddhism you can receive good karma by helping these people with disabilities because this is considered a sacrifice which will aid you in your further life.
- In Sudan for example, she spoke with religious leaders and looked at the Sharia law after which they came to the conclusion that the sins of the parents should not be placed on the children. *"they did this very successfully to a point where the children did not only had a way higher survival rate, but at a certain point a police officer came to deliver a child at an institute and said 'if you don't have a name for him, you can use my name.' This is a very big step."*

This means that where religion is incorrectly seen as the cause of stigma, it can more so be used as a solution against stigma whilst adhering to cultural norms and values.

Impact on the Child

That stigma had an important impact on a child could be derived from the literature to a certain extend. For example in the research which showed the bullying of children with disabilities at school (Ali et al., 2015; Halder, 2009; Njelesani et al., 2022), and the thin evidence of children being hidden at home (Katsui & Mojtahedi 2015). Stigma often stems from an incorrect understanding of disabilities and it being seen as a sign of wrongdoing and a sin (Katsui & Mojtahedi, 2015; Rimmerman, 2013). The goal here was to share the specific impacts that stigma has on a child, in all the different facets of their lives.

Samuel can give a good example of how it was like to be stigmatized when he suddenly lost his sight around the age of 15. This resulted in peers turning away from him and starting to make fun of him. *"Some of my friends didn't even know how to cope with it. A good number of them will mock me. A good number one sympathize with me. But it was very difficult. I survived it. I narrowly survived it..."* (Interview with S. Nyingcho, May 4, 2022).

A solution to this bullying is often to separate the child and send it to a special school. Maria stated that this in return can cause a feeling of isolation from the community. When you are sent away to a special school, you grow up and spend your school years without encountering others from your community. What she saw, is that these children often find isolation in themselves by the time they go to college or university as a coping mechanism. *"People ask: why are they so rude? No, they have found isolation as a coping mechanism. So, before you push me away, I am already pushing you away."* (Interview with M. Njeri, May 16, 2022) This social exclusion and isolation have great effects on the bonds and relationships that the individual can find within their community.

This being said, the most prevalent impact that stigma appears to have on the life of a child, seems to be intertwined with the impact that it has on the lives of the parents, as they may also experience social exclusion and isolation (Halder & Assaf, 2017 p. 5). This unfortunately results in parents acting upon the disability of their child in multiple ways which causes harm to their wellbeing. As explained previously by Koenderink (2022a), stigma puts parents under enormous pressure which can result in harmful practices towards the child. It is important to realise that for most parents the birth of their own child, actually is the first time that they encounter a disability and that what they do, is *"also acting out on of 20 years of stigma."* (Interview with M. Njeri, May 16, 2022) This is a key reason of why Maria pleads for more visibility of children with disabilities. She says: *"we need to burst that bubble and say: it's nothing. It's a condition, simply, you know. '…' they will at least not have to first encounter a disability when it's their own child. Those parents then see these kids can be happy and they see these kids can play.. that could already make a very big difference, I hope."* (Interview with M. Njeri, May 16, 2022) She explains that if parents are more accepting of the fact that their child has a condition, they are also more likely to invest in early interventions and good guidance for their child which can make an enormous difference for the future, as this also happened with her.

That this aspect of acceptance and understanding the disability is of great importance, is also what Samuel experienced. *"It was quite difficult because my family did not believe that a young person could become blind, have been taught that visual impairment was for the elderly. So they did not even accept it. And they didn't really know what to do. I had two years, not knowing what to do or where to go."* He struggled with the lack of understanding and guidance. His parents and family members did not know what to do, *"they thought it was the end of me,"* and as he was the youngest one in the community who had a visual impairment, he felt alone and missed a role model (Interview with S. Nyingcho, May 4, 2022). With adequate guidance and a better understanding, they could have supported Samuel better from the start.

Story Box 3

Ahmed - Bangladesh

"you know, yeah, actually, we go to the field and go to the door to door survey. And sometimes people say that there is a child with disabilities in that house, then we go to that house. Sometimes the parents say, No, we don't have any disabled children, then we request them. Why don't you share? We will provide support to children and to you also. And sometimes we need to go to 10 to 15 times to motivate them. Our field staff has the passions. Yeah, sometimes they shouted at, so many things happen.. But we have to go because there is no option. If we don't provide the support to those hidden children.. it is the violation of human rights."

Stigma in this sense is thus so systematic, that it is very difficult for parents to create a safe and enabling environment for their child to grow up. Due to the lack of knowledge, experience and guidance children and their parents are basically left with nothing else than this stigma as the only way from how they can address their child. The child in turn suffers from this. Ways in how parents deal with these challenges regarding stigma are presented below. Where there are of course also successful anecdotes, such as for Maria, these three categories are shared to highlight what stigma can have as a result on the lives of the children.

Hidden children

I was driving an Uber in the direction to visit Imani. The Uber driver and I started a conversation about what I was doing here. He, coincidentally, actually visited multiple orphanages and also one where there were children with disabilities. As he said "*Stigma is still a big issue in Kenya. Children with disabilities are hidden and put away. That is also why they are left behind."* When I asked him what he thought of that, his answer was that it was wrong. *"These children also deserve a life, they were given life by god. They should be reintegrated into society."*

The literature already showed some subtle evidence that stigma results in a lot of children being excluded from society and being hidden at home: stigma *"compels parents to hide their children with disabilities at home, to be ashamed of them, and to undermine the child's potential to learn and lead an independent life."* (Katsui & Mojtahedi, 2015, p. 564). Whilst the exact numbers are unclear, this was something that appeared highly prevalent amongst all the interviewees and during the fieldwork. *"Stigma is a very big issue in Bangladesh, even the middle and high societies also sometimes hide their children from their community. They think that it is a negative part of their life if they have children with disabilities. This is very common in Bangladesh."* (Interview with A. Ifthekar, March 31, 2022)

Unfortunately, the evidence shows that this is not only common in Bangladesh. The practice of hiding a child with disabilities appears to be prevalent in every country where stigma still is a big issue. The organisations I spoke with that focus on family-based care all shared their experiences with having to actively look for the children hidden at home, such as the experience of Ifthekar in Bangladesh presented in Story Box 3. They all shared how, especially in the beginning, they actively had to go into the field to look for these children *"In the past, we saw it more than now, and then you see that it is changing. But yes, you still see children being locked away at home, attached to a pole and sometimes put away in a toilet."* (Interview with A. Thermoshuizen, April 7, 2022) That these practices have a remaining effect on a child, can for example be seen in that even when they are eventually free to roam around, some children who have spent their entire lives locked up, seek small confined spaces to lock themselves back up again as they do not feel safe in an open space.

Aside from the detrimental effects that the practice of hiding a child has on them, it also enhances the stigma. As Florence explains, *"I think that what is a big cause, '…' is that a big part of it actually becomes a self-fulfilling prophecy. So, these extreme stigmas can only be maintained if you have never actually encountered these people. As long as you don't see these people, you can uphold this, but once you have an interaction with these people, you cannot anymore."* (Interview with F. Koenderink, April 11, 2022).

This is also one of the reasons why Maria pleads for more opportunities for interaction, as introduced above. If a child is participating in the community and can develop themselves the people in the surrounding are already more accepting. This is also something that Phuong noticed. When she started ten years ago, she saw that there was a lot more misunderstanding about cerebral palsy (CP). *"But I think that recently, the people like.. just realise more because we post a lot about CP on Facebook and the information is growing so, so fast.. now parents just aren't as shy as they were in the past. They now tell their children to go out more. The people around see more about the disability or CP, so it becomes a part of the community."* (Interview with N. Phuong Ha, May 26, 2022).

As Florence adds, when a child is hidden, the neighbours often do not even know it exists. So, the moment you encounter someone with disabilities, they will confirm this view that this person has regarding disabilities: that they have no potential and no worth, because these children never learned something, and they consider that proof that the child is not capable. This is a self-fulfilling prophecy. Story Box 4 of Antoinette shows the other side of the story. Once the visibility is increased and the child gets the opportunity to develop themselves, the entire view of them by the community changes as well.

Story Box 4

Antoinette, Niketan. Bangladesh

"But, once you start working there, and you show the difference, and you can show 'look, this child is worth it, and this child can develop itself,' then you also see that it changes really fast within the community. Actually the beautiful part about what we do, is that we work really close to the homes of the children. We started porch schools, and because you are really emerged into the community, and you are on the porch of one of the parents, of the teacher, or the village leader, or whatsoever.. then you can really show the community that a child like this can develop themselves."

Whilst this practice of hiding a child is a terrible one, Florence highlights that it is important to approach this with nuance *"because stigma is so prevalent, it happens a lot that children are being hidden and parents are being judged about this, but I think.. this parent has chosen to not kill the child as the community often wants, and actually wants to keep their child near them, so I think that we should acknowledge this part. If a child is severely being neglected, and can never leave its room, then that's not a good thing, but these are the best intentions of the parents."* (Interview with F. Koenderink, April 14, 2022)

That this goes with the best intentions can be seen in the fact that parents generally are, sometimes after a little time, open towards initiatives which cater for their child. As I for example encountered at KidsCare, there were young adults who had spent their entire childhood hidden in their homes. After the special education units were built in around 2019, their parents did enrol them in school and allowed them to be a part of society. Their parents had cared for them in secrecy for sometimes more than 20 years but did take an opportunity for them when it arose. I think that this does prove the best intentions of the parents. Also, it shows that opportunities can reduce harmful practices.

Acts of Despair

As was mentioned previously, the impact of stigma regarding disabilities do not only affect the child, but has a large effect for the rest of the family due to the experience of social exclusion and isolation. What is interesting, is that in the literature which discusses this, the reference is often made towards parents or the family. In this research I found that the main pressure and challenge lays on the mothers, and that it happens frequently that she is left alone.

"There is so much stigma even into the community.. people think it is a sin.. some that it is the sin of the mother mainly.. many people still believe this." (A. Ifthekar, Personal Communication, March 31, 2022) That the mother is blamed for this, is something that appears to be widespread (e.g. Interviews with Hisan, May 2, 2022; S. Nyingcho, May 4, 2022). This adds to the already increased pressure on the mother when she gives birth to a child with disabilities. Needing to cope with statements such as *"our family* [father and father's family] *does not have disabled children, so this has to be something else. This has to be because of you."* (Interview with Anonymous, April 11, 2022) it cannot only drive the mother into despair but also appears to sometimes give the father a reason to extract himself from the responsibility of being a father. As Carmen (Interview June 2, 2022) stated, *"when you give birth to a child with disabilities '…' it is often the mothers who do something for the child, the fathers are not in the picture anymore."*

"It happens that a mother and child get banned from his family leaving them with major challenges such as finding a house, finding and keeping a job or business, the child not being accepted in school, having money for services, transport, assistive devices. And then there is stigma and discrimination in the community such as stories of community members not wanting to sit next to a parent and child on the bus. Parents indicated often that they lose hope, and their identity in a way. Many parents have many questions about the condition of the child and what it means now and in the future." (Interview with Anonymous, April 11, 2022).

The context and situation in which the mother finds herself can cause them to make a decision out of despair. The acts that we will look into are abandonment and mercy killings. It is important to understand why in some cases these terrible decisions are made, as with understanding the line of reasoning, adequate help can be given. This is not to justify these actions, but to understand the context in which these decisions are made without judgement towards the mother or family.

Abandonment

Harrie – Stichting Imani. Nairobi, Kenya.

"In general I always explain: there is no mother in the world that wants to abandon her child. If you do that, you do it out of necessity, despair, frustration, etcetera. So, the biggest reason is poverty. The poverty question is the main reason. But then out of poverty, there is also.. there are women who have been raped and then don't want the child. And you also have women who got pregnant, but of whom the father left really soon after they found out, and then out of anger toward the father, they also don't want the child. Other reasons could be that they already have a few children and cannot take care of another one, sometimes they 'simply' have postnatal depression which they know very little about over here, and often there is also shame. Young girls get pregnant, which is something that is seen as really bad over here. These girls then walk away from their families, give birth, leave the child behind and then go back to their families. Then it is also shame you know.. There are a lot of reasons why you would abandon your child.. And.. the moment that a child is born with disabilities, some of these reasons increase. If you already have children.. a child with disabilities costs a lot of money.. so when they see that.. sometimes they also get scared up by the disabilities.. what we often see is that in hospitals.. the majority of the labours are in hospitals over here, is that people just disappear when they see that their child has a disability. They cannot handle that. They don't see it as a future with the limited resources that they have, and well yes.. then they abandon the child. But for us it is also difficult.. or well difficult.. but like, some.. most of the children are abandoned on the day they were born. So, we find them with the umbilical cord still attached. And well, then in a lot of cases, the parents could not have known yet that the child had a disability.."

(Interview with H. Oostrom, April 4, 2022)

As Florence explained in her blog, the severe stigma can lead to parents abandonning their child. However, it is not possible to say with certainty that the children in orphanages who also have a disability are indeed being abandonned primarily because of that reason, especially in the cases where the child does not have a disability which is visible from the start, there is most likely another factor playing a more significant role.

As Harrie explains, there are a lot of factors which can drive a mother to abandon her child of which poverty is the main issue. When at birth a disability is noticed, this can be an amplifyer of already existing problems pushing the mother to abandoment, as well as the sole reason for abandonment. Hisan (Interview, May 3, 2022) also said that when asking for her history in the orphanage, the people there always said that she was abandoned because of her condition. *"But then I'm like: oh, you are saying I was abandoned and there are no other details?*

'…' because you don't know.. you don't know if it is because of this." There is a risk in assuming that if a child has a visible disability, this automatically means that this was the primary reason for abandonment. Without parents actually confirming their reason for abandonment, no statements regarding how much of the abandonned disabled children actually were abandonned *because* of their disability, or that they were abandonned *with disabilities* can be made.

This being said, it remains an issue in general that children are being abandonned. Therefore Imani works on prevention in the community. When they get a signal of the chief that someone in the community is falling down in a pattern which they recognize as a first step towards potential abandonment of one of the children, they get a signal. *"The social workers then go up to the mother with a basket of food to start the conversation and often a job is created for that mother within Imani."* Imani often also takes on the school fees of the children. Not everyone however has access to help in this way making that for certain women raising a child can be seen as something truly impossible due to their personal circumstances.

Mercy Killings

Severe situations of despair can push parents to do the unimaginable as was also shared by Florence in the literature, namely the act of a mercy killing (Koenderink, 2022b). Whilst this is an act that should not be justified, it is essential to understand the context which causes this despair. Harrie (Interview, April 4, 2022) also stated: *"A child with disabilities for them.. is just inferior.. the goal is to get a healthy child. And well.. if a child is not healthy, they are sometimes just left behind, or worse things happen.. also with the healthy children.. also there some children are being killed at birth.. healthy or disabled."* Knowing this can aid in the prevention of mercy killings. Simultaneously it shows the current situation in which a lot of parents are needing to take care of their disabled child. The mercy killing of a child with disabilities appears to be a relatively unresearched subject, and it is therefore not possible to provide strong statistics regarding the numbers, nor the geographical scope of this phenomenon. These cases, therefore, are more so to aid with the understanding of what extreme cases of situations without an outlook can drive parents to do, and what the effects can be of severe stigma.

Story Box 5

Mary Iculet, mother of Karen: a child with clubfeet, thinking of committing a mercy killing. Mukura, Uganda.

"When I gave birth to the baby my husband rejected me. He said: you are not my wife. I am not the father of the baby. Now he married another woman who is a Muganda [a tribe in Kampala]. *I tried to go to Kampala to follow my husband but he chased me away. I came back to the village hoping that I would re-join my family, but they also rejected me. My people started looking at my child as the problem in the family. When the food was served, I had to sit with the child on the side. They didn't even give me a cup. I could only drink out of a separate bottle. I decided to leave. Even my brothers said: if you really want to stay here, you have to take her back to her father '…' I was really frustrated and developed an urge to kill this child because I had nowhere to go."*

(*Mercy Killing: Uganda's Hidden Infanticide*, 2018)

In conversations with people in Kenya regarding this matter, it came to light that the act of mercy killings does indeed not appear to be out of the ordinary. The statements however were anecdotally and did not have a lot of factual support. The decision was therefore made to look at additional non-academic sources in order to find out more about mercy killings. One of these sources was a short documentary which was called: *"Mercy Killing: Uganda's Hidden Infanticide"* by Journeyman Pictures (*Mercy Killing: Uganda's Hidden Infanticide*, 2018). The stories which are displayed in boxes 5, 7, and 8 are stories of Ugandan women who show the reason why they thought, or executed a mercy killing.

When these mothers gave birth to their child, this meant for them that their entire lives changed. Looking at the literature, Kurumei, Tarus and Ngosei (2016) showcased how having a disabled child can pose a significant threat to the well-being of the parents, especially in a social and emotional sense. The social exclusion which is experienced by the child simultaneously is experienced by the family members potentially causing exclusion and isolation of the individual (Halder & Assaf, 2017, p.5). The social exclusion here is predominantly felt by the mothers, as they are being rejected by their husbands, their clan, their community, and in one case even the health care workers. As was mentioned previously, it is often the mother who has to carry the burden of the blame of having a child with disabilities, as well as the burden of caring for the child. This all creates an outlook for this mother of hopelessness, feelings of despair and frustration. When there is no social support system on a government level, and your direct social support system fails you, you really are on your own. Moreover, the literature suggests that the negative effect is especially high for poor families (Eide et., al. 2011; Halder & Assaf, 2017).

Another similar story to the ones in the documentary was portrayed in Africa-Press regarding a mercy killing in Lesotho where a woman killed her 5-years-old daughter with disabilities as an act of mercy. Her husband had left her to go to Cape Town and never came back. Her daughter needed close attention at all times, and she had to quit her job to look after her. Because she was on her own, she had been struggling to raise her daughter as she was not financially stable. She told the police *“that she had committed the act to save both of them from a life of agony.”* (cfeditoren, 2021, *para* 5)

Story Box 6

Charles Aoja, Inhabitant Makura Town

“However, a man like me cannot take all his time carrying a disabled child like that one fulltime. Because they are the lame ones. If the man cannot even carry the normal ones.. that one needs time you see? It becomes a shame to me. That’s how some of my colleagues tend to reject those children.”

(*Mercy Killing: Uganda’s Hidden Infanticide*, 2018)

The literature however does not distinguish between mother and father in their statements concerning parents, whereas the documentary and the interviewees do. In the same documentary which highlighted the stories of the three women, a man also took the stage to share his views, as can be seen in Story Box 6. It is also seen here that the fear of social exclusion is also apparent to the father. However, where the mother appears to not really have a choice, he shows his understanding for rejecting the child, and with that rejecting the mother. Interesting to notice from the way this man speaks, is how he perceives it as there is no stigma or shame in actually leaving the mother alone with the disabled child, nor is there any understanding of what leaving means for the mother. The fact that he speaks so openly about his views, in combination with the facts that the women are indeed all rejected by their husbands, makes it more so seems as a commonly adapted view rather than a sole opinion despite the fact that it does miss grounding due to it not being investigated.

Story Box 7

‘Apolot’, anonymous mother who committed a mercy killing. Mukura, Uganda.

She was abandoned by her husband after 9 months leaving Apoplot alone to raise her 4 children. She took care of her disabled daughter till she turned 6 years old, when the care for her became too much.

“When I gave birth to a lame child, my husband did not like this child and even other people were looking at me. People started mocking me, and my husband rejected me. He would not even help me with money, that would have helped me to take the baby to the hospital. As a husband and wife should do. I intended to end her life because I was tired of her and still had other children to look after. There was no help and I had nowhere to go. There was no one else to take care of her. I came up with a plan to kill her.”

(*Mercy Killing: Uganda’s Hidden Infanticide*. 2018)

Whilst most examples are currently from within Africa, this does not per see mean that this does not happen outside of Africa as well. An example is Ms Huang, a Chinese mother who killed her 46-year-old disabled son in 2017 when she was 83 years old. As she grew older and weaker, she could not take care of him anymore and she feared that no one would take care of him after she died. In court, she explained how she sees it as her own fault that she gave birth to him and made him suffer. She did not want to burden someone else with the care of her son, and therefore she decided to kill him (BCC News, 2017).

Story Box 8

‘Akol’, Anonymous mother who committed a mercy killing. Soroti, Uganda.

Akol already had 5 children. When she had her 6th child, he was severely disabled. Her husband left her after 3 months, leaving her to raise her 6 children on her own.

“They said I had produced a disabled child that had no place in the clan [a group of people who share one ancestor, everybody in Uganda is born in one]. *And also my in laws said they don’t produce such a child. ‘…’ because of his condition, I had to treat him every day. I didn’t have any support. Even when I took him to the hospital, the nurses were scared of him and they didn’t treat him properly. They told me my child was Imukama, a feral cat that lives in the bushes of Uganda. Because of that they said, we are not going to waste medicine on him, we prefer to give it to other children. He is meant to die. It started to disturb me that the medication and other needs were not available, I got frustrated and angry..”*

(*Mercy Killing: Uganda’s Hidden Infanticide*, 2018)

What this chapter shows, is how especially the mother is so greatly impacted the moment her child appears to have a disability. This is to a way larger extent than would be expected if we would solely look at academia. In this it can be assumed to a certain extent that in any place where a woman can get banned from her family and abandoned by her husband and family in law for giving birth to a child with disabilities in a situation of poverty, a situation could occur where she can perform an act of despair.

This is however more a point of attention rather than a fact, due to the lacking academic underpinning and statistical facts.

4.1.4 Concluding remarks

The main challenges which were discussed are the practical, financial and especially the cultural challenge regarding stigma. What we see is that these encountered challenges go way beyond what the literature suggested.

The main practical challenges encountered were those of infrastructural barriers. These barriers can cause children to be isolated and not be able to participate in mainstream education with their peers. Despite policies and laws concerning accessibility, schools are often not aware of their obligation towards these.

Families of children with disabilities are more likely to live under the line of poverty or even extreme poverty. This has to do with the fact that the costs of caring are often higher for children with disabilities, and because caregivers need to stay at home to care, for instead of the child going to school which allows caregivers to work. Another issue is that parents have children as a financial safety net. If a child has a disability, this means that instead of the child being able to provide for their parents, parents need to continue to provide for the child, also when they are an adult.

Stigma is the number one reoccurring challenge and problem identified by all the interviewees, and it is a harmful practice (and should be labelled as such). This research showed what kinds of detrimental effects stigma can have on the child, and what sometimes it pushes parents to do to their child. In the effects of stigma on the parents in terms of social exclusion, the impact appears to be the biggest on the mother as she is often being blamed for the disability of the child creating a free pass for the father to abandon her. It is needed to label it as a harmful practice, as this will allow for more widespread action against the issue. Looking at the examples given of children being hidden, abandoned and killed, the conclusion can be made that stigma indeed causes harmful practices.

Where religion often is seen as one of the main causes of stigma, this is not correct as it is more of a cultural interpretation. Religion can also be used in favour of breaking through this stigma as shown in the examples given by Florence. Aside from this, it also appeared that when opportunities were given to children with disabilities, the stigma was reduced. Parents are acting out of years of stigma, and there is nobody there to assist or help the parents making they do not know what to do. Story Box 9 shows what it can mean for a parent to know that they do not have to do it all on their own.

Where it is not possible to say that there are indeed no children being hidden or killed anymore in the places where there are initiatives, there was a pattern noticed in the interviews where they all stated that at the beginning of the initiative they had to actively look for children, but that parents now came by themselves or were referred to them. Another important element is that visibility decreases stigma. When children with disabilities are hidden, abandoned or killed, people do not encounter them which makes that the stigma can continue to exist, as it is a self-fulfilling prophecy. When children are more visible and they can show their development, the negative outlook towards them also reduces. Furthermore, a lot of parents currently still have their first encounter with disabilities when it is their own child that has one. As Maria explains, allowing for moments of interaction also makes people more accepting of the condition, which will result in early interventions and good guidance.

Story Box 9

Anonymous

In a research to see the effectiveness of their project in Uganda they created focus-group discussions were they could respond to one another.

"What most parents said, is that they had they got 'amaanyi' again: hope. And when you asked, "what made the difference?" It was not the CBR-worker, but the CBR-worker strengthened what was inside me already, as a caregiver.."

4.2 Care for Children with disabilities

Now that the context and challenges which children with disabilities and their families faced is more clear, this chapter will focus on the aspect of care for these children. We will look at both sides of the 'Continuum of Care for Orphans and Vulnerable Children' as previously introduced, and shown in Figure 11. We will first look at the right side of the figure, thus formal residential care, and more specifically institutional care, followed by family care, where we will also discuss inclusive education.

As was established previously, NGOs and PDIs are an essential part of the aid infrastructure, and in many cases are the primary care providers for children with disabilities. Despite this, their operations with regards to these children have not yet been researched. As these are the players with ample experience on the ground, they were considered interesting for this research to better understand how care is being provided for children with disabilities.

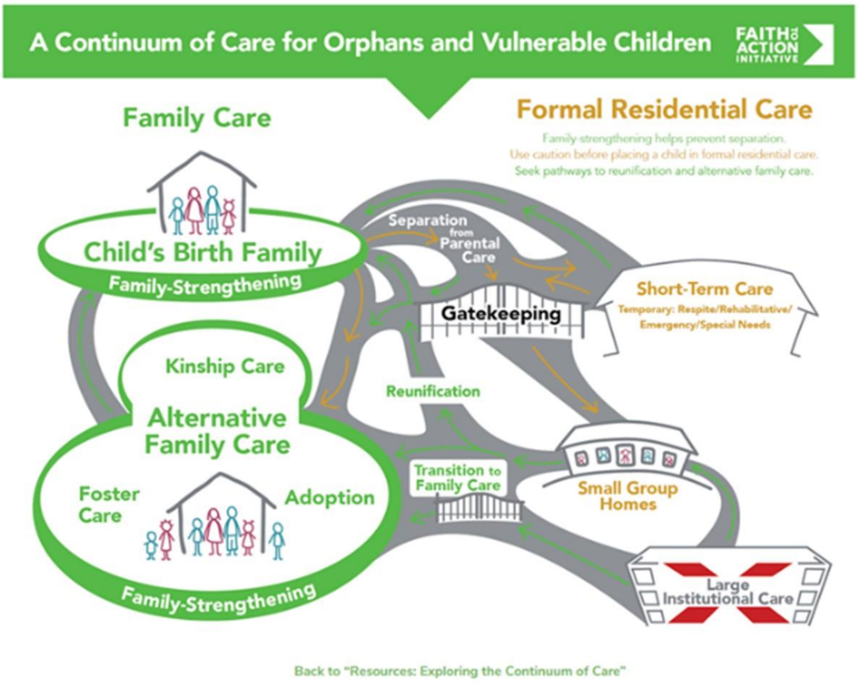

Figure 11: A Continuum of Care for Orphans and Vulnerable Children (Cox et al., 2015)

Important to mention here is that there was no research conducted regarding the quality of the care provided. The experiences combined with the theory regarding this were the guiding principle for this chapter. More in-depth research regarding the quality of care would be suggested.

4.2.1 Institutional care

The literature showed little specific research conducted regarding children with disabilities in institutional care, despite the fact that they appear to be overrepresented (Browne, 2009, p. 8; Trout et al., 2009, p. 111; van IJzendoorn et al., 2020).

Despite this thin academic underpinning, an important to consider finding by Trout et al., (2009, p. 144) and Chmelka (2011) was that the effects of institutional care on children with disabilities appear to be very similar to other children that were raised in institutional care. Where there was an elevated risk found for children with disabilities concerning the development of social problems, aggression, poor attention skills, and disruptive behaviours. The issues themselves were thus not solely attributed to children with disabilities.

Research conducted by Sammon and Burchell (2018) and Trout et al., (2009) attribute this increased risk predominantly to the need for more individual attention for a child with disabilities, which is often not provided, and the fact that great life events such as being placed out of their familiar situation can have an even greater impact on children with disabilities.

These two statements however do not acknowledge the high variability between the disabilities that the children may have. In the majority of the research concerning the effects of institutional care for children with disabilities, it is not mentioned which types of disabilities are being discussed, or if it concerns a physical or cognitive disability, or perhaps both. Another point of critique is that the research is presented in such a way which fails to recognize the highly variable way how the child would grow up at home. Whilst it is important to know the risks and outcomes of these children with disabilities in an institution, it is also important to recognize the fact that the home situation of the child is also not always a safe space with room for personal development. Furthermore, it is challenging to make a distinction between the effects of institutional care, and residential care as a whole when looking at the research conducted. The focus here will predominantly lay on institutional care, the interpretation of the organisations interviewed being considered an institution or a residential care facility may differ.

Whilst the institutional care facilities were underrepresented in this research sample, the general consensus remained among all the people that I spoke with, that a child ideally seen would always grow up in a family, and that good institutional care facilities are extremely hard to find. The goal of this chapter was to find out more about what the specific reasons are for parents to place their child with disabilities in institutional care, where this can be prevented, what the experience is of this type of care on an individual, if the process of deinstitutionalisation is as achievable for these children as for their peers, and if there are cases in which it is considered inevitable, and what should be done in those cases.

Why placed in institutional care?

According to the literature, children with disabilities are placed in institutions due to the following: the few resources and support of the families, the stigma and discrimination faced by the children, poverty; parents that cannot afford the additional cost of care, the inability to face the emotional and practical challenges, and sometimes because parents are being advised that a child is better looked after in an institution (Sammon & Burchell, 2018; Goldman et al., 2020, p. 619). Following the line of reasoning presented in Chapter 4.1.3 *'Acts of Despair'* regarding abandonment, the majority of the reasons presented, can also not solely be attributed to the disability of the child. Also here, poverty appears to be one of the main overarching reasons for a parent to decide that their child is better looked after in an institution. The emotional and practical challenges, such as stigma and discrimination, can more specifically be attributed to disability.

Story Box 10

Kirsten – Friendship Foundation Sri Lanka

Kirsten explains the situation of two girls who come to the centre who could not stay in their homes due to sexual abuse. These children were placed in a former orphanage which is also on the premises of the Friendship Foundation, and now still is the home for 35 women with disabilities who came to live there in the 80s, and are therefore all above 30 years old. These women are the last ones living in this home, and no new inhabitants are added.

"Currently, there are two girls of our centre in this home, they came here during covid. Those were girls.. two girls. One who already had her period, and one that got her period during that time. Their mothers were working in the middle-east. They are not sisters by the way, two separate families. The mothers are working in the middle east, and the father and brothers are at home.. no other women. From both of them.. they said there was sexual abuse.. This is then signalled by the police, and the police then decides if they are being placed out of their homes. '…' It is always the parents.. the adults.. the perpetrator who is free to go, and the child who is placed somewhere else. In Sri Lanka, it is not the common practice that if you are under surveillance by the police, that you are placed in another family setting with neighbours or other people.. this is because of the responsibility of the child that then falls under the government." (Interview with K. Giethoorn, April 4, 2022)

Outside of the literature, some more key reasons were named by the interviewees as to why parents would choose institutional care for their child with disabilities specifically, *"them being unmanageable, father or mother who cannot care for the child anymore, family members that do not accept the child, no availability of schools nearby who can provide the right education to the child.. also sometimes that parents want the best for their child, but are unable to do so themselves because they are not educated enough '…' and the parents then want for their child to get proper support, and they cannot provide this. And also, certain children live in such remote areas.. extremely remote, that even though there might be a school somewhat close, they cannot go there because they need a wheelchair, and they do not have roads. Or, the classes are on the third floor and there are no elevators…"* (Interview with M. van den Berg, April 4, 2022)

Carmen, from Amara foundation, also underpins the challenge of children needing too much care from their parents, especially when they get older. *"where the mother says: it hurts me to say this.. but I actually cannot care for my child at home anymore.. it costs me so much to go to therapy, again and again, and I lose so much of my time that I now cannot even generate my own income anymore, which makes that I cannot even care for my other children."* (Interview with C. van Bergen, June 2, 2022)

Monique (Interview, June 2, 2022) who is currently at an institutional care facility in Tanzania which is aiming to place children back into their families, found the most predominant reason was the lack of suitable education in the direct surroundings. Furthermore, a child could end up in an institutional care facility due to abandonment, and an unsafe situation at home. If a child can be placed in a temporary foster family, or with family members, it also very much depends on the rules and regulations of a specific country. For example, in Kenya, a child who is abandoned, cannot be adopted right away, as they need to wait for six months in case the parents come to collect the child (Interview with H. Oostrom, April 4, 2022). In Sri Lanka, when a child is placed out of their family due to an unsafe situation, they fall under the responsibility of the government, which does not allow this child to be placed in a (temporary) foster family, see Story Box 10 for an example.

The reasons why a child with disabilities can end up in institutional care is due to a multitude of reasons. Figure 12 highlights the different categories in which the reasons can be divided. These reasons, of course, not being mutually exclusive. The colours (green, orange and red) indicate which reasons are expected to be more or less challenging to change to prevent institutionalisation, and to work towards deinstitutionalisation. This however is relative, and of course very much depending on an individual case. Practical reasons are seen as the easiest, as there is no stigma or shame regarding the disability and legislative reasons are considered the most difficult as preventing this from happening needs a reform on a governmental and procedural level. Refer to Chapter 4.2.1 *'Deinstitutionalisation, the challenge'* for a more in-depth analysis of deinstitutionalisation for children with disabilities.

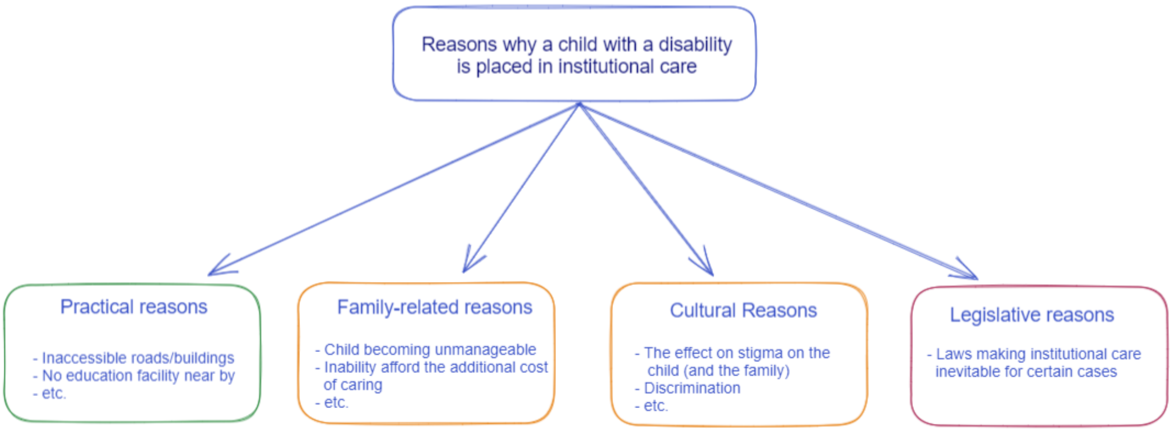

Figure 12: Why a child with disabilities is placed in institutional care

Psychological effects of institutional care

Where the view on whether or not institutional care should be considered an option highly differs, all do agree that the number of good institutional care facilities is very low. "*The quality of care within these institutions is highly dependent on several dimensions such as the level of staff training and turnover, as well as the child-to-caregiver ratio, and factors such as the provision of engagement and responsible carer behaviour, and varies drastically within different institutions. Often multiple dimensions are not fulfilled, and it is, therefore, said that children in institutions are denied the basic conditions required for positive socioemotional and cognitive development* (van IJzendoorn, et al., 2020) Story Box 11 shows an example of an effect of institutional care.

Story Box 11

Florence Koenderink

"one of the effects of institutionalisation is that a child is in a continuous state of high stress because their basic needs are not being covered. For the brain, this is a sign that the child is in danger, making that it is always in a fight or flight mode. In this mode, you only have access to a quarter of your cortex. Sure, you can place a child in a classroom, but think about it.. if there is always a tiger breathing in your neck, and you're given a math's exam.. You cannot learn in this state. You can sit in a classroom, but you cannot learn."

Florence (Interview, April 14, 2022) suggests treating the differences between a child with and without a disability with caution. As she finds, the challenges which occur with abled children, also occur for children with disabilities, which is similar as the literature suggested. Where the difference in impact on the child's development mostly has to do with the age at which they entered an institution. If a child enters after the age of ten, *"then, generally, the foundation of the brain has been laid. Otherwise, there are holes in that foundation which makes everything that you build on top of that, wobbles."* Between 6 months to 24 months old, are seen as most susceptible to the negative effects of institutional care (van IJzendoorn, et al., 2020).

In general, children with disabilities are placed in 'normal' institutions and receive the same care as all the other children. *"This care is already not sufficient for all the children, can you imagine what it is like if a child is in need of special care or special needs? '… 'Children with disabilities, are not a disability, they are children with disabilities. This means that the challenges which you encounter with 'normal' children when taking them out of* *institutions into their own families, such as poverty, and education, those things, are also prevalent here. You should not only look at the disability."* (Interview with F. Koenderink, 14 April, 2022)

Institutional care as a money-making business

As was discussed in the theoretical framework, the orphanage industry can be a lucrative business to be in, due to the large revenue streams provided by the Global North, in terms of donations, as well as for high-paying volunteers. The literature also showed how increasing numbers of orphanages can sometimes even be directly attributed to the increasing amount of tourists in the area (Deen, 2017).

These statements are supported by Florence (Interview, 14 April, 2022), who expressed the following *"The orphanage industry.. there are for-profit orphanages where they recruit children, and take children away from their parents.. so that there are places where people can go to volunteer. That is why those children are in institutional care. For the volunteers to have children to play with. And then, there are people who came to the realisation that if the children are in bad shape, so that they are malnourished for example, that you receive more money.. so then they keep it that way."* About the number of tourists in an area correlating with the number of orphanages, she states that *"when Myanmar opened up, the so-called orphanages increased with 75% in the first five years."*

These statements are not per definition linked to homes for children with disabilities, but concern all children that are in orphanages. This is also what was experienced by Hisan (Interview, May 3, 2022) who grew up in an orphanage with both children with and without a disability. Her story can be read in Story Box 12. What her experience shows, is the discrepancy between the intentions of the donors and the visitors, and the reality of the children. This can be seen as a good example of what was introduced by Chu and Luke (2021) and Mir and Bala, (2014) in Chapter 2.3.1 regarding the focus on upward accountability where the core mission is to focus on what the donors want to see, and not what the children actually need. How the children were acting was not an expression of genuine feelings, they were adapting to what would bring in more money: *"when visitors come but they are telling you, do this, do that when you're taking pictures: please smile. When they visited us at least we used to look a bit neat. But when the visitors left, we were looking like street urchins."* This being said, the children were indeed happy that there were visitors coming "*…and you know, at that time, those were the only people that were making you feel okay. That time you feel happy you know you feel happy and you know the fact you are not being fed enough and these are the only people who are bringing you food."*

One could argue that the people visiting were then indeed doing a good thing, as they were providing food, and as Hisan states, they were the only people that made them feel okay. However, it is because these people keep on coming, that there actually is a business value in having an orphanage. As she also explains, whilst they were looking like street urchins, the manager "*is driving a very big car, living in a lavish house."*

This does not mean that all orphanages are de facto a money-making business, but it does show the fact that it *can* indeed be a very profitable business. One, where the donors may have the best intentions, with terrible outcomes.

Story Box 12

Hisan, personal experience growing up in an orphanage

Hisan explains how their stories were manipulated to make sure that they were most attractive to the visitors. At first, the narrative was one of the sad stories, where they were sharing how the children were abandoned in the garbage. This, was until they realized that Europeans preferred happy faces.

"Now everyone is smiling. You have to smile brightly. That was the thing even for us, even when visitors come but they are telling you, do this, do that when you're taking pictures: please smile. When they visited us at least we used to look a bit neat. But when the visitors left, we were looking like street urchins. I normally say we were living on the street, but there was a wall separating us from those who were outside. That was the only difference. there wasn't a difference between a child roaming the streets sniffing up glue, and us inside the wall. The life we used to live was horrible. But when visitors come they think you're living.. you're living okay, they don't know. They don't know what it is like, like they'll carry you they'll take a picture but they don't know.. and you know.. at that time, those were the only people that were making you feel okay. That time you feel happy you know, the fact you are not being fed enough and these are the only people who are bringing you food. A bond based on necessity, not as we connected with them. You're happy because you know they're bringing you candy or bringing you some new coat. '…' You know at my orphanage, we always hope the visitors will return. There were tourists coming, and also the local donors. the local Hindu, the Indians. You know, these people are rich and they give.. they do a lot of charity. And they used to come here. Every other weekend, so we knew. So if you know you have not had enough food. Then there is the Indian coming, then you're happy because you know that weekend you do not sleep hungry. yeah, that was like.. some orphanages are still like that. '…' the children are still looking like street urchins, and the manager is driving a very big car, living in a lavish house." (Interview with H., May 3, 2022)

Deinstitutionalisation, the challenge

After having analysed the psychological effects of institutional care, as well as the orphanage industry as a money-making business, it could be seen as a good thing that governments are increasingly moving towards deinstitutionalisation. Such as Rwanda, Uganda and in Cambodia, as was shared in the literature (Gahigi, 2021; Oketch, 2018; Thul, 2017). However, caution also may be applied here. As was already slightly touched upon in the literature, simply closing the orphanages does not suffice, as more transformational social service systems should be created which ensure parents the ability to care for their children ((Truell, 2019, *para* 5). This may be even more the case for children with disabilities, as these were not included in previous research.

Even with the best intentions of governments, the success of these programmes is not guaranteed. An example of this is when looking at Kenya. After having adopted the National Care Reform Strategy last year, they requested aid from Florence to ensure that children with disabilities can also be taken out of institutions. After an extensive desk review of policy and legislation, as well as consultations and visits to analyse the current situation when it comes to the ability of parents to take care of their child within the community, and what is actually needed *"the conclusion was made that there is basically nothing at this moment and that it is indeed not even an exaggeration to say that it is impossible now, because there is no support.. which does not mean that institutions are an alternative, as there is no care provided there either.."* (Interview with F. Koenderink, 14 April, 2022). This shows that despite good intentions which we can see in signing policies as we discussed in the Introduction and Chapter 2.3.5, there is indeed a discrepancy between the theorisation and the practice of implementing these policies, where the true challenge lies (Phelan & Reeves, 2021; Rimmerman, 2013)

When looking at the reasons why children with disabilities are being brought to an institutional care facility as presented in 4.2.1 *'Why placed in institutional care?'*, it appears obvious that a child cannot simply be placed back in the family, but that there is more guidance and help needed. Issues of poverty, the practical implications as well as the social pressures which come with for example stigma and discrimination can make the situation remains unattainable for the parents and the child, with all the possible consequences. Closing an institution therefore cannot stand as a solitary goal, but should always be accompanied by a plan which ensures adequate support to the child and the caregivers.

Another issue which is reoccurring with children who return after being institutionalized is the fact that they are alienated from the culture and habits of their community, both in a practical sense, such as not knowing how to use traditional tools, or how to cook on coal, as well as on a social level: *"...yeah, you are taken back to your family, but you feel like a stranger in it because you spent your life in the orphanage.."* (Interview with H., 3 May, 2022)

Furthermore, there is the issue of trauma and disturbed development as mentioned above. To consider this Florence explained: *"one of the main things which happen when children who are going back to a family when coming from an institution, is that they have had a development which is not normal. Thus, there has not been normal brain development because of the way in which they have been growing up. There is significant trauma, and because of this, you get a lot of challenging behaviour. If you do not prepare families for these matters, the biological family, a foster family or an adoptive family, then it eventually becomes unsustainable.. if you a. do not prepare, and b. do not support them in how to handle these situations, it is not sustainable."* (Interview with F. Koenderink, 14 April, 2022).

Story Box 13

Harrie Stichting Imani, Nairobi, Kenya.

The goal of Imani is to have children back in a family setting as soon as possible through adoptions within Kenya. Where this is generally well achieved in most cases, the children with an HIV infection and with disabilities stay behind.

"What you see.. society is harsh.. because if you look at it.. adoptions work as follows: you need to go to a license holder that organises adoptions. That person then examines if you are a good candidate to adopt, if you're healthy, and so forth. And then, you fill in what you want.. Boy/girl, which age, disabled/not disabled, HIV infected/not HIV infected.. that box.. those boxes are barely ever checked.. throughout the years, we have only had one HIV-infected child adopted.. throughout all those years.. so you see that the people here, which is also something you should understand, to adopt has been a taboo for a very long time. Only in the past 5 years, you see that this is something that has been changing. But a check for a disabled child.. that has never happened.."

Moreover, there is a situation where there are no parents or relatives in the picture that can take care of the child. Then, there are the options of foster care and national adoption. In many countries, foster care is a common practice, but it is simultaneously an informal one, and thus is not under governmental supervision. Formal foster care could be a good option, but similar to adoption, finding a family for a child with disabilities appears to be a challenge. Why the focus is on national adoption, is because the people with whom I spoke about adoption, international adoption have a moratorium in those countries due to malpractices that were taking place. Story Box 13 showcases the challenge of adoption for children with disabilities.

Analysing why the box for ‘disabled’ is never checked, in the context of what Florence concluded in her research, is logical. *“Without any support, without access to schooling, with stigma.. it currently is too much to ask from prospective parents to adopt a child with disabilities. If you fix this, eventually this is cheaper than an institution in many ways. It is a big investment, but it is an investment which pays itself back. If you do that, if the stigma is gone, if you can show that children in a family actually do a lot better and that they actually have potential, then you see, this is something that we have seen in many other countries, that parents actually become interested to become a foster parent or to adopt a child. The situation then is completely different.”* (Interview with F. Koenderink, April 14, 2022).

The question then is what happens to these children in the meantime. If there is no place for them to go, but orphanages are simultaneously closing, this can result in distressing situations. Hisan for example explained the situation of an orphanage which was slowly closing down. The majority of the children were brought back home or placed in another family situation, but the last part that remains in the orphanage are those with severe disabilities, both children and adults, requiring highly specialized care. These children are now being split up and sometimes moved far away to other institutions *“now you are denying them the opportunity to connect with the people they know from around the community.. you know, there are people who care about them, but now they are moving them to other places where nobody can reach them.”* The further worry is that the other institution actually cannot provide the care that is needed for certain people, according to Hisan, *“they know for some of them it is like a death sentence.”* (Interview with H., May 3, 2022).

Closing down institutions, should not so much be the goal, but rather the consequence of children being placed back and cared for in a family setting. This is for example what is happening in the institution where Monique currently is helping. The cases of the 40 children that are currently living in the home will be assessed individually in order to see what needs to be done to ensure that these children can go back to their families, as can be seen in Story Box 14. In these cases, the main issue is access to education. Monique also shared a story of a boy who was brought to the institution for the same reason. Within two weeks of his arrival, they had found a solution for this issue where a school bus could pick the boy up to go to a public school in a nearby village with a special education unit. Together with this boy, there will be many children that currently are in institutional care with a reason for which there is a solution to find.

Story Box 14

Monique – Dutch Tanzania Foundation

“The first six that they identified, three of them have two parents that were still together. In two cases the child used to live with its grandmother and mother, and one only with its mother. Well, I think that in four of the cases, education was the issue. In one case, there was a family problem as well. The children in these cases could not go to school during the day, and they were left at home because the parents were farmers who had to walk quite a bit to go to their land. The child was then left there with some food for the day. In those cases, something needs to happen within the community. ‘…’ such as day care for single mothers, where a couple of mothers run this day care, and the other mothers can work. With the money that they make from working, they pay the mothers who run the day care. This way, they support each other.. these are the kind of ideas which you share with the community. ‘…’ Also, as I said, access to education is an issue. Sometimes someone cannot afford the pay of transport for their child to go to another village for education. But, sometimes you can also share these costs with other parents of children who need special education. ‘…’ you need to look for solutions, and sometimes they are there.” (Interview with M. Derrez, June 2, 2022)

An important note to make here is the fact that it costs a lot more money for a child to be raised in an institution than in their family. Research shows that it can be up to ten times cheaper to support the child in the family (Changing the Way We Care – Help Orphans, 2018; Interview with F. Koenderink, April 14, 2022). This means that the money which is typically allocated to care for the child in the institution could be used for therapy, transport to a special education school, and/or organising a day-care facility. Many of the reasons as to why a child is placed in institutional care could therefore be fixed with use of this additional money. First and foremost the practical challenges, and the issue of poverty, but also the cultural challenge. As we saw in Chapter 4.1.3 regarding stigma, we simultaneously saw how visibility reduces the stigma. In the case that this money could be attributed to a day care facility or a school for example, this can aid in reducing the cultural challenge. Furthermore, with help of specialized social workers, a lot of change can be made into the community.

Simultaneously, she states that *“I also see children in this home of whom I know that we are never going to be able to place them back home, they already live there for 15 years.. this is their home.”* The idea here is more to change the objective of the centre, to become more of a rehabilitation centre where parents can come with their children for guidance and therapy, but also where the inhabitants of the centre can get a job when they grow older.

"The children will then become clients, and then employees instead of clients." (Interview with M. Derrez, June 2, 2022) Furthermore, all new children will first be assessed and the goal is to find a way to make sure this child can stay at home.

That deinstitutionalisation for children with disabilities is possible, is also shown by a recent case story which was presented by *Changing The Way We Care* (CTWWC) about a residential centre for children with disabilities, which originally was a centre which provided community-based services in Haiti. However, after the earthquake in 2010, they opened a residential care facility. *"Mostly children were placed in the residential care because their families did not have the resources to care for them or to access services for their disabilities."* (CTWWC, 2022, p. 3) the need amplified because of the earthquake. Whilst the staff did their best, the children did not receive the needed care or attention. It was their initiative to transform back into their original vision of providing community-based care.

The steps for transitioning children followed by CTWWC, the main executor of this project were the following:

> *"1. Holistic assessment of each child's individual needs*
> *2. Complete case files for every child*
> *3. Family tracing to identify family members for reunification*
> *4. Family assessments*
> *5. Development of care or case plans including plans for monitoring follow up*
> *6. Approval from the Haitian government body, Institute of Social welfare and Research*
> *7. Child preparation for reunification (psychological support, counselling, provision of any adaptive equipment and home adaptations, medical and rehabilitative treatment, etc.)*
> *8. Family economic strengthening (business trainings, income generating activity start-ups, access to small loans, etc.*
> *9. Family parent skills training on child protection, nutrition, and positive parenting."*
> (CTWWC, 2022, p. 5).

The facility had already started with reintegration, and after CTWWC joined, they reunified the remaining 26 children and young adults. The centre now fulfilling a role as a day centre for the children. Another aspect of attention now was *"to providing community services that could support entire families, not just one child."* (CWTTWC, 2022, p. 6) In this, economic strengthening is seen as an important aspect, as poverty is one of the main reasons why a child is placed in an institution (CWTTWC, 2022).

With an holistic approach which considers the individual case of every child and its family, it can be possible for children with disabilities to benefit from this momentum. In this, it is however essential to consider the different reasons of why a child is placed in an institution in the first place. Furthermore, the need for a social service system reform is even more prevalent for these children as a lot more support in the community is needed. If the latter is accounted for, it could even mean that children could enjoy (informal) foster care or even adoption in the future. Deinstitutionalisation is never a solitary goal, but it is a result of children being placed back in their, or a, family.

A 'good' institution...

"Some people are very black or white in these kinds of situations.. but it just is not like that. You cannot say: all children have to go home. Yes, that would be amazing, but that just is not possible." (Interview with M. Derrez, June 2, 2022) An important note to place here at the start is the fact that the general consensus in academia is that an institution is never a viable place for a child to grow up. Especially not when they are young. However, there are unfortunate cases, as the citation suggests, where children cannot (yet) live at home for a multitude of reasons. For example, if there are no parents or family members known of the child. As was explained previously, finding an adoptive or foster family for a child with disabilities can be a challenge. Many children could indeed go back to their families if certain solutions are implemented. However, for certain children and families, these solutions will be easier to achieve than for others. It becomes even more challenges in cases where due to governmental procedures the child cannot be placed in another/temporary family as we saw in Story Box 10.

In this chapter, we will discuss two things. The first one is how institutions work towards providing good care, and the second is regarding the option of boarding schools.

Care in an institution

As was mentioned previously, whether or not institutional care should be considered an option highly differs. What however has been established is that a child would preferably indeed grow up in a family and that ‘good’ institutions are extremely hard to find. As the literature already showed, the lacking quality of care is the biggest problem when it comes to the care provided in the institution. For example, Goldman et al., (2020) stated that the effects of institutional care for children with disabilities appear to be predominantly linked to the quality of care within these institutions such as a low caregiver-to-child ratio and little personal attention.

The lack of quality of care is prevalent, but is not necessarily an imperative of institutional care according to some of the interviewees. If there is, amongst others, a proper child-to-caregiver ratio, low turnover of staff, experienced staff, and consistent care, combined with proper facilities, the negative effects can already drastically be reduced. Which is something that Maartje, from Stichting Japthi actively aim to do as can be read in Story Box 15.

Ways how Imani aims to provide good quality care is for example by having one Mama who looks after a small group of children, to ensure consistency and for them to be able to create a small family. Furthermore, there is a lot of attention to making sure that the children can interact with a caregiver, and that there is time for meaningful activities such as playing. As Juffer et al., (2017) explained, these elements are seen as essential for a child’s development. And, there are clear codes of conduct which for example do not allow a care giver to be alone with a child to ensure safety and security. Despite these aims, please refer to Chapter 4.3 for a point of attention regarding this matter.

Story Box 15

Maartje Stichting Japthi

“We do not accept all the children anymore, because otherwise.. it is such hard work to care for these children.. we are a very small school, and I think that every child should grow up in a family, which is not possible for these children. Then I have to be able to give them the attention that they deserve, which results in the fact that the group is very small, and we also do not have the intention to grow.. ‘…’ most of the children can walk, the severely autistic children we can unfortunately not accept because it is simply not possible for the staff, if we do this, we cannot provide the children with the care that they deserve.” (Interview with M. van den Brand, April 4, 2022)

This research however did not investigate the care provided and therefore cannot make any judgements about if the care which is provided indeed is sufficient.

Boarding schools

The literature suggests that despite financial and personal support provided at home, it may not always be possible for a child to stay with the family, and that care elsewhere is sought (Bain, 1998 p. 598). This aligns with what Carmen suggests, as she argues for a customised approach when it comes to the shape in which care is provided for the children. Here, the position of the parents also plays an important role. As was mentioned above, there are cases where the mother states that she does not feel capable of caring for her child anymore. *“Generally speaking, we try for children to go to a day school, and only to a boarding school when they are older. The children are then already high-school age, but then their level of care and type of care is too high to follow regular education at a day school, including the needed care and transport. In those cases, it can give a child more rest to go to a boarding school, where the parents for example come to visit during the weekends if this is possible for them, and they go home during the vacation period.”* (Interview with C. van Bergen, June 2, 2022) In this case, the child will thus already be above 10 whenever they go to a boarding school, which is better for the child according to Florence, and follows the academic consensus that the later a child enters a facility, the less the impact is. Furthermore, Carmen states that this customised approach is constantly evaluated to ensure that it is still the best option for the child and the family. An example of this process is shared in Story Box 16. It is needed in certain cases to look at what is locally possible. If there indeed is no special school in the surroundings, and if the adequate support can be given in a school further away, the decision can be made to look at a boarding school at an older age where the child can come home during the weekend. *“But it depends on the reason the children go there, and not to a nearby school.”* (Interview with Anonymous, April 11, 2022).

Story Box 16

Carmen Amara Foundation

“We now have a boy who is in boarding school, and this boy.. his parents were a very important part in the process to decide for him to go to this pace, and he is currently there for about 2.5 years. And frankly, he is currently feels out of place.. the boy is not happy anymore, which makes that his mother also is not. ‘…’ So then you go look for a place where your child is happy, and eventually we asked the mother: what do you want? Because we can help you search, but would you prefer that your child would partly live at home, and partly go to school, or, is this simply not attainable for you? I think it just is a lot of customised work, case per case.”

Bain (1998, p. 598) also stated that the so-called permanency planning, which is the aim for a long-term and daily relationship between a growing child and at least one continuous caregiver, can still be achieved with regular visits from and to the family and heavy involvement in the educational and medical issues of the child, as well as its personal development.

Important to mention however is that this could only be the case when a child is older, not when still a baby. As Koenderink (2022b) explains, babies need to form attachments to at least one primary caregiver. As this caregiver helps her regulate her anxiety and comfort her, a bond is formed with the primary caregiver. *"The child gradually learns that this is someone she can depend on. She learns this through starting to associate a certain face, smell, and voice with the relief of having the cause of her distress removed, and the pleasure of being comforted and having her stress and anxiety reduced through co-regulation."* (Koenderink, 2022b, p.79) In an institution, the child can often not build this kind of relationship with a caregiver due to the low caregiver-to-child ratio. For the parent to fulfil this role in this stage of the child's life, they would need to be present with the child.

Forming relationships is something that our brain needs to learn. If this does not happen when they are a baby, *"this can make it difficult – and for some children even impossible – to form any kind of normal relationship later in life."* (Koenderink, 2022b, p.81) If a child is placed in an institution at an older age, perhaps permanency planning as mentioned by Bain (1998) can indeed be achieved with the heavy involvement of the parents.

Concluding remarks

The general agreement is that children should grow up in a family and that 'good' institutions are hard to find. The main reasons why children with disabilities are being placed in institutions can be divided into the following main categories: practical reasons, such as inaccessible roads and buildings, family-related reasons, such as poverty and the child becoming unmanageable for the parents, cultural reasons, such as the effects of stigma on the child and its family, and procedural reasons, such as laws which do not allow a child to be placed in a family setting. These reasons not being mutually exclusive. Arguably, the first three could be situations where institutionalisation can be prevented. Where this becomes more of a challenge is when the child is abandoned, or placed in an institution due to an unsafe situation at home where the government does not allow for a family-based solution.

The effects of institutional care on a child can be detrimental, especially in the first two years of their lives. Here it is important to realise that children with disabilities have many of the same challenges as their abled peers, but that their disability can be an amplifier to these problems. Aside from the psychological effects of receiving bad quality care and very little attention from the caregivers, there is also the problem of institutional care sometimes being used as a very lucrative business where donors and volunteers help to maintain terrible living conditions for the children.

Partly due to this lucrative business aspect of the orphanage industry, momentum was created in which governments decided to close down orphanages. Despite this seeming, a good idea, closing an orphanage should not be a goal in itself, but rather a consequence of the aim to reunify children with their families. The issues within families need to be taken care of, and there needs to be adequate support to the caregiver and the child to help work through the abnormal development and trauma which the child experienced and services for this child, like daycare, education, home care, economic strengthening, depending on the needs of the family. Furthermore, some children do not have a family to go to, for which also adequate solutions need to be found.

For these children, but also for parents of whom, the child became unmanageable or the children that cannot live at home due to an unsafe situation, the question arises if an institution (in terms of a boarding school principle) can be good. For this, it must be especially avoided for young children. Furthermore, there needs to be a lot of caregivers per child, and also continuous evaluation if it still is the best possible option for the child. If it is the goal of an institution to provide good care for the child, and it is simultaneously agreed upon that a child should preferably grow up in a family, it is also the responsibility of the institution to evaluate if there is no way in which the child could also grow up at home, as well as constant monitoring if the child could go back home. An important note to place here is that care in a family always is a lot cheaper than in an institution.

4.2.2 Family-based care

As has been repeated many times, children should preferably always grow up in a family setting. This chapter focuses on organisations that aim to fulfil this goal and to provide children with disabilities with the chance to be raised in a family setting.

Referring back to *'A continuum of care for orphans and vulnerable children'* (Cox et al., 2015), this chapter will focus on the 'green' side of this figure. Namely, Family Care and Alternative Family Care. As was explained, the elements in green on this figure are where priority should be given to, prevent unnecessary family separation, and also unnecessary placement in institutional care. Family-based care is divided into two parts: the birth family of the child, and alternative family care which includes kinship care, foster care and adoption. Unfortunately, foster care and adoption for children with disabilities do not appear to happen a lot locally, but more so on an international level. Due to lacking resources, support from the government and stigma families are reluctant to adopt or foster a child with disabilities. Kinship care happens more often, where especially grandmothers care for the child with disabilities, but also still a lot less. *"It happens a lot that children are raised by their grandparents or aunts, but for children with disabilities less. Indeed because of stigma, and the fact that the burden is this large, and the costs this high."* (Interview with F. Koenderink, April 14, 2022) Due to this, this chapter will focus predominantly on the birth family and kinship care.

Looking at family-based or alternative care, we will look at care which is provided by PDIs, NGOs and local initiatives. Unfortunately, in many cases, adequate care is not provided by the government. It was previously shown with Kenya as an example of a country where it is simply not yet possible to provide adequate care for a child with disabilities. As Kurumei et al., (2016) also highlighted, when there is lacking access to the needed resources such as support and financial aid, parents are unable to provide for their child.

A lot of the care provided for children with disabilities thus still comes from non-governmental initiatives. These initiatives, which in this research predominantly are Dutch PDIs, know a lot of different forms in which they operate. The main division can be made in those who operate from a centre within a community. They have a set location from which they offer a variety of services, and from where social workers operate. The other type of organisation is for example an organisation which does not operate in a specific area, but have more of a supporting strengthening role to local initiatives. However, also in the first, some are very much defined by borders of a county or specific area, whereas others have as a primary goal to continuously expand the scope in which they operate.

The overlap between the organisations is that they all have a strong community-based focus and work with local employees. How extensive the services are which the organisations offer depends on their main objectives, but more so also how well established they already are.

With the use of best practices out of the field, we will look into elements of how these organisations work towards strengthening the family, the types of care that they provide, how they work towards inclusion, inclusive education, personal development training, and what happens to the children after they turn 18. When looking at Figure 13, we see the key elements of family-based care as found in this research. The green arrows indicate care and support which is given at the family level with the family, mostly the mother, as an important player in receiving care and support. The purple arrows are more specifically towards care for the child such as education and personal development. In this chapter, a more in-depth look will be taken at these different elements of family-based care and how they are executed by different organisations.

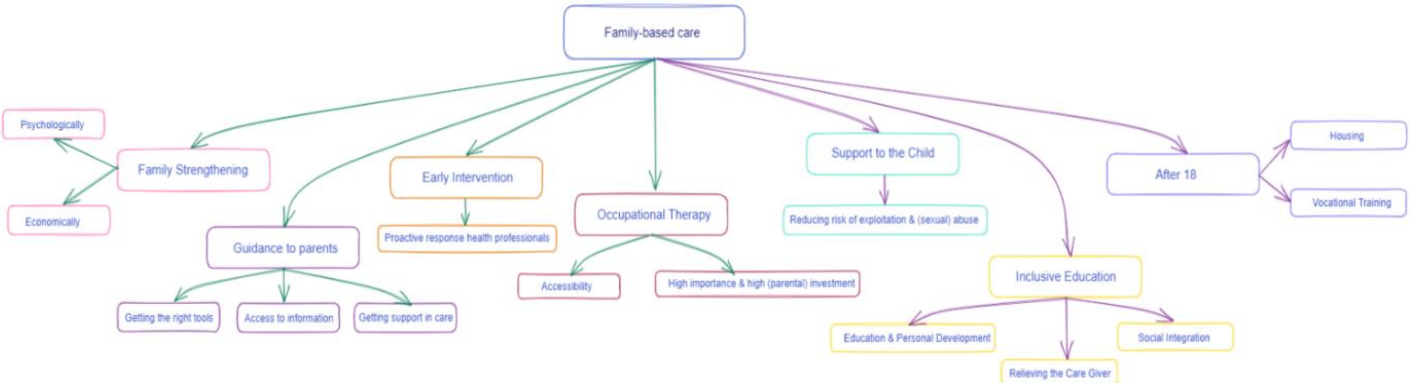

Figure 13: Family-based care

Family strengthening

This research showed how family strengthening is an essential element to prevent unnecessary separation. As we already saw in 4.1.3 regarding stigma, especially mothers are vulnerable when a baby with disabilities is born. This can result in the father leaving her, as well as her being banned from the family. Also in families where the parents are still together, having a child with disabilities can have a strong negative effect on their socioeconomic position.

First, economically. As we saw, having a child with disabilities increases the costs of living drastically. Furthermore, parents will often need to take care of the child for the rest of their lives, instead of the child eventually being able to provide for them. Poverty is one of the main reasons for a parent to bring a child to an institution, and it even results in acts of despair. Where a disability is not per see the main reason for a family to become poor, it is an amplifier of already existing problems. Depending on the financial situation of the parents, the number of children that they already have, and the disability of the child, the impact of this changes.

Secondly, the psychological effect that it has on a parent. *“I say it is a kind of grief.. because, they’ve lost their expectation of a child.. so they have to grieve their loss.”* (Interview with M. Njeri, May 16, 2022), and next to this grief, there is also the stigma and the fear of social exclusion which comes from there. A lot of parents have the feeling that they are alone in this when they get a child with disabilities.

Parent Support Groups

The parent support groups connect parents of children with disabilities with each other. The vast majority are the mothers joining, as they most often are the primary caregivers. How these support groups are organized, for example, if they are initiated by the initiative such as with KidsCare (Interview with G. Geenen, April 5, 2022) and More Africa (Interview with E. van Beers May 19, 2022) or if these were personal initiatives as was seen by Carmen from Amara foundation (Interview with C. van Bergen, June 2, 2022), differs. As well as how often they meet, and what their objectives are.

“This is a support group for them as they come and they talk and share.. and then we see how we can engage them in other ways because we realize they even forgot who they are in the process. ‘…’ they forget their identity. So we ask them, who are you? And you realize that most of them are depressed. Now, when you bring them together and they share, and they laugh with each other.. they create a bond.” (Interview with M. Njeri, May 16, 2022).

What Maria shows in this quote, is how impactful it can be for a parent to have to care for a child with disabilities, especially having to go through this alone. This appears to be a powerful effect of the support groups. Knowing that they are not the only ones going through this, is comforting and also helpful. Helpful in the sense that they can share their challenges and help each other with their experiences. A similar story is shared by Phuong as can be read in Story Box 17.

Story Box 17

Phuong

“You reminded me of a story of a mom in my classroom, the dad said that before the child came to my classroom, the mom had a depression. She used medicine to sleep and you know.. very terrible. But after the child just came to my classroom and started to smile, and the mom was sharing, chatting and talking with the other moms, her mental state became better. She now can sleep, she doesn’t use medicine anymore, and in general her energy went up. This is also very important for the child. Happy mom also means happy child, but happy child also means happy mom.. it’s circular you know.” (Interview with P. Ha Nguyen, May 26, 2022)

Furthermore, groups as such can have an important function in receiving information. As was mentioned previously, there is often a lack of understanding regarding a disability which stems from a misunderstanding. Phuong also realized that information was simply not accessible to parents in her country. She had to really go and look for information herself in order to help her daughter and decided to share this information (online only at first) with other parents in the same situation. *“I think that if they have the power of the knowledge.. of the information.. this circuits around to the children, which will help them grow.”* (Interview with P. Ha Nguyen, May 26 2022) That having an adequate understanding regarding a disability can have an important impact on the ability of how parents can care for their child, is also what was previously shown by Samuel in *‘Impact on the Child’*.

Economic empowerment

This research showed previously that having a child with disabilities can have severe effects on the financial situation of the parents. The risks of having to live under the poverty, or even extreme poverty line augment when having a child with disabilities. This is an important element to consider, as we already established that poverty is one of the main reasons for a child to go to an institution, but also for abandonment and even mercy killings. Therefore, improving the financial situation of the family is seen as an important element when we look at family strengthening.

Aside from the additional costs of caring that the parents need to carry for their child, comes the fact that the time spent caring for a child, cannot be spent on something else. As we already saw in the stories of the mothers in 4.1.1.2, is that because they needed to care for their child with disabilities, they could not work anymore and not provide for themselves and the other children. Therefore, the initiatives which provide a day-care centre and/or education for these children, makes that parents can outsource the care for their child for some time in the week. Refer to 4.2.3 regarding inclusive education for more elaboration on this matter.

Where this is a potential first step, it is key to support parents to generate enough income to provide for their family. In order to achieve this, help can be given to create livelihood options and income generating activities (Interview with Anonymous, April 11, 2022). Examples of this are saving and loan systems which can be arranged within parent support groups. What is often seen, is that individuals lack funding to make larger investments to for example start a business. A saving and loan system can help set up this business to for example become self-sustaining. Another way to improve the buying power of the caregiver is to create collective buying power. The idea here is that a parent support group operate as a collective in which they all invest a small amount of money to be able to buy something together (Interview with G. Geenen, April 5, 2022) .

An example of a collective as such is 'the goat project' by one of the parent support groups of KidsCare. Here, a group of parents is in the process of getting a pregnant doe from KidsCare, for which they will care altogether. The idea is to sell the babies and use the goat for the milk. Other types of collective investments are for example buying pesticides together for their land. What most of the parent support groups at KidsCare do, is that they collect a set amount of money per meeting, which they use to make these collective investments, but also from which for example medicine can be bought. In a system such as this one, the cost of investment, as well as the risk of investment is spread.

Another way in how the families could be empowered economically could be with use of direct cash transfers. This simply is the fact that families are given a set amount of money, with no strings attached which they can spend however they want themselves. This way, families are granted the opportunity to invest in what they need in order to help themselves (Vermeulen, 2022).

Guidance to parents, early intervention, and occupational therapy

Where family strengthening was more about laying a strong social and economic foundation for the families, this chapter discusses the more 'professional' support to families and children. This discusses the support and assistance given to parents to help them stimulate their child and understand their disability better, early intervention, and accessible occupational therapy.

Guidance to parents

As was previously established, having access to proper information and knowing what to do makes a great difference. As Phuong shared, for the parents to have access to the necessary knowledge regarding the disability of their child, will help them react adequately which will help them grow. Samuel explained what the effect was on him when his parents did not know how to react and cope when he became blind.

Story Box 18

Antoinette – Niketan, Bangladesh

"Parents then come with a child because they have the feeling that it is not developing itself properly. And sometimes, it is something very small and then they come for a few months and you can help them ahead.. this is often the case for very young mothers, fifteen or sixteen years old. They have no idea how to raise a baby. '...' To then give them the support and help them to learn how to stimulate a child in their development, and how do you communicate with a baby? A lot of these small things.. and you also have parents with babies who have a very complex disability. But, by teaching parents how to stimulate their child, you can achieve a lot. And a lot of these children eventually go to mainstream education." (Interview with A. Thermoshuizen, April 7, 2022)

Aside from the work that the professionals do with the children, their home is where the child spends most of their time, especially in the first years of their lives. The knowledge that the parents are equipped with is paramount to the future development of the child. Knowing how to stimulate your child, can help in preventing (minor) development disorders to further develop themselves into a disability. As is shared in Story Box 18, Antoinette explains how sometimes minor interventions which help the parents to stimulate their child can already make a difference.

Understanding the disability and the needed care is however also very important for the care givers of children with a more complex disability. The organisation of Ahmed for example provides a ten day caregiver orientation where they help, amongst others, parents understand the disability of the child and explain how to take care of their child (Interview with A. Ifthekar, March 31, 2022).

Early Intervention

When Maria was born, the people at the clinic recognized some signals of cerebral palsy. They told her parents and provided them with information on how they could best move forward. She started therapy right away, and due to the proactive response of the doctor, as well as her parents, Maria was given the opportunity to walk, go to school, graduate from university, and now have started her own organisation (Interview with M. Njeri, May 16, 2022).

Especially for cerebral palsy, early intervention can have a significant impact on the opportunity for the child to develop themselves later in life. Depending on the severity, without occupational therapy children may never be able to walk, sit, roll over, or even chew by themselves. Unfortunately, a proactive approach as was seen with Maria is not the common practice. Even if the doctors know, Maria says, they do not always tell the parents.

"Because some doctors, if they're good doctors, they just see like, the symptom, like, something about CP in very early like six months. And they can, like advise the children to go to rehabilitation. But some are not. Some are just like, maybe it's just like delay or something. And like, parents just don't realise how it works and how it will be. So maybe they miss... most of the time of the early intervention." (Interview with P. Ha Nguyen, May 26, 2022) On top of this, Maria noticed that sometimes doctors do know that the child has cerebral palsy, but they refrain from telling the parents.

There are two important things when it comes to early intervention. At first, there needs to be (affordable) occupational therapy accessible, but perhaps foremost, there needs to be awareness to ensure that all parties involved react adequately. Salem worked on a programme within the hospital addressing these issues, as well as general programmes about safe pregnancy, delivery and motherhood. This is to prevent disability, but also to be able to provide adequate intervention if needed (Interview with S. Bakari, May 11, 2022).

However, Maria stumbles upon resistance when she is trying to implement a similar programme in hospitals in the surroundings of Nairobi. *"We try to work with them. Hospitals and the community. But, I also noticed it is also kind of taboo.. us teaching. So yeah, we're telling the midwives: 'can we educate the mothers, we are not saying they are going to get.. but just in case they get a child with disabilities, they have the information.' But they often don't want that.. it's like they say that we're not supposed to talk about that"* (Interview with M. Njeri, May 16, 2022)

Early intervention is not only important for children with cerebral palsy but is also very much about helping parents to stimulate their child as much as possible from a young age onwards as can be read in Story Box 18. This is also something on which Ahmed focuses *"We provided them how they take care of their children, what is their rights, how they can be included into schools, and into the community."* (Interview with A. Ifthekar, March 31, 2022). *"Because, when a child is born with an impairment, and nobody is telling the family what to do, and how to do it, especially from the hospital, it becomes a big challenge"* (Interview with S. Nyingcho, May 4, 2022).

Accessible occupational therapy

Occupational therapy is seen as a key element in providing care for many cases of children with disabilities. This is also the reason why it often takes a predominant role within the organisation. How often the children have access to therapy depends on where the therapy is given, and how easy it is for parents to bring their child there. KidsCare for example has two occupational therapists who provide occupational therapy once a week in all six special education units spread through Lunga-Lunga county, next to a couple of days at the occupational therapy centre which is located on the premises of KidsCare. This means that all the school-going children who are in need of therapy, as well as the younger children who live closer to the school, go to therapy at least once a week when the occupational therapist is there. If it is possible for them to travel, they might go to the centre another day of the week as well. More Africa provides occupational therapy in their school, which makes children receive customized therapy sessions daily.

However, not for all children, occupational therapy is as easily accessible. *"Some of them came from Kisumu, but some of them came from 50/60 kilometres away and needed to take a matatu, and had to walk with their child for quite a bit to go to therapy."* (Interview with C. van Bergen, June 2, 2022) *"Some parents travel one and a half, to two hours to come to the project. Some of them even come from that far, that they come and live at the project for half a year or a year. They receive the therapy, and when they think: I can do it on my own, they move back to their village."* (Interview with A. Thermoshuizen, April 7, 2022) Phuong also shared how she had to travel to learn more about cerebral palsy and the therapy needed for her to be able to help her daughter (Interview with

P. Ha Nguyen, May 26, 2022). Furthermore, more frequent therapy often does give better results. *"We noticed that three times per week is actually really good for maintaining the possibilities of the child, and sometimes also to not let it diminish. But at the same time, it is also an extreme burden for the parents or mother.."* (Interview with C. van Bergen, June 2, 2022)

Occupational therapy is simultaneously extremely important for the child, and a significant investment for the parent. Giving the option for parents to receive therapy when living on the premises as is possible with Niketan, can be a good solution but is not possible for everyone. If a parent needs to join their child for multiple months, this also means that they cannot work during this time. Also, *"what has been taught in a clinical setting, is not automatically generalised to the home situation. At the same time, going back and forth for therapy also costs a lot of money for transport. Task shifting to community workers can play a role in this. But they often lack access to information, training and support. The use of telerehabilitation, in consultation with health workers, can support them."* (Interview with Anonymous, April 11, 2022) In order to achieve this, Enablement developed *'RehApp'* a *"Rehabilitation Knowledge Base for field workers."* Which is available in several languages and developed for fieldworkers in low- and middle-income countries. *"The RehApp offers fieldworkers basic information on possible causes, signs and symptoms related to a specific impairment and provides practical intervention options at the personal, relational and societal level."* (enablement.eu, 2022 *para* 2). Once downloaded, the app can be used without the internet, and includes an extensive client information system which, among others, aids in analysing the needs of the clients, timely references to health professionals, setting goals, and supporting the family. Along the same line, Niketan also started to develop instruction videos for occupational therapy, both to be able to train more occupational therapists outside of their area of operation, *"and also so that parents can look back at the exercises and do these at home. That we can educate more occupational therapists, and support more parents."* (Interview with A. Thermoshuizen, April 7, 2022). Also for children who can regularly access occupational therapy, Monique (Interview, June 2, 2022) pleads to more actively teach the parents what *they* can do to support their child. She states that occupational therapists should not only focus on helping the child but should also teach the parents on how to continue this therapy at home. This way, children can receive therapy on a more frequent basis which is beneficial for their development, and simultaneously there is less of a burden on the parents.

Inclusive Education

In many areas, the opportunity to follow (suitable) education is not something that can be taken for granted, especially not for children with an (cognitive) disability. As we saw, "*people with disabilities remain underprivileged and are unable to access or participate in mainstream education and development programs. There is a scarcity of needs based support services available for the welfare of people with disabilities, and services remain beyond reach of most people."* (Halder & Assaf, 2017, p. 4) Children with disabilities are the most excluded group in the education system, they are 10 times more likely not to attend school in comparison to their abled peers, and are the least likely to finish school once started (Plan International, 2013; Singal 2016, p.172).

It depends on the country whether or not it is mandatory for a school to accept a child with disabilities. In Kenya and Tanzania, the policy is for example that all children should be accepted (Interviews with E. van Beer, May 19, 2022; F. Koenderink, April 14, 2022) and in Bangladesh *"Children with mild and moderate types of disabilities can enrol into the mainstream schools."* (Interview with A. Ifthekar, March 31, 2022). In Sri Lanka, schools work with special education units within mainstream education (Interview with K. Giethoorn, April 4, 2022).

This being said, having these policies does not automatically mean that children are being accepted, that the building is accessible to them, or that the schools are aware of these laws. *"We inform the schools about this. So, we train the teachers and the board of the schools. And then we counsel them to show what is the law, and what they need to provide. Not all schools know about these laws, so we inform them about this. And after this, we help them with developing things like adapted toilets. We don't pay, but we help them by giving information."* (Interview with A. Thermoshuizen, April 4, 2022)

A large issue is thus also that schools do not know what is actually mandatory for them to accommodate to children with disabilities. This is also what Monique encountered in Tanzania where it is written in the 'Persons with Disabilities Act' that a school is not allowed to discriminate, and thus also not on the premises of a disability. Despite this being written in the law, she encountered directors of schools who were not at all aware of this (Interview with M. Derrez, June 2, 2022)

This results in cases where children who only have a physical challenge which for example makes them wheelchair-bound, have to go to special education due to inaccessibility as we saw in Chapter 4.1.1 (Interview with M. van den Brand, April 4, 2022) Where awareness of these policies, as well as actual follow-up by the schools, would already make an important difference, there are also many cases of children who are not able to follow mainstream education without any additional support. Aside from the challenges that they may encounter due to stigma, following a class with sometimes more than 60 other children is not attainable for all children. Inclusive education here talks about how regular education should be made more inclusive, and special education should be more available.

In the beginning of this chapter, Samuel introduced the three main barriers that are associated with disabilities, the ‘triple A’s’: *Attitude, access* and *acceptance.* These challenges are also encountered when we look at education. As we saw in the literature, especially children with an cognitive disability have a higher chance of experiencing bullying and other types of violence, with often inadequate responses. The teachers however do not always have the access to the needed expertise to adapt and help the different ways of learning of the child, and to aid in ensuring their safety and security: *attitude* (Ali et., al, 2015; Njelesani, Si & Swarm, 2022). Furthermore, as Halder (2009, p.640) stated, and as was discussed in Chapter 4.1.1. there are many infrastructural barriers when it comes to inclusivity. Curbs and stairs in a school building, inaccessible desks, equipment and bathroom facilities: *access.* Children with disabilities are the most excluded group in the educational system and are the least likely to finish school once started (Singal, 2016, p. 172). Children with disabilities are 10 times more likely to not attend school than their abled peers (Plan International, 2013): *acceptance.*

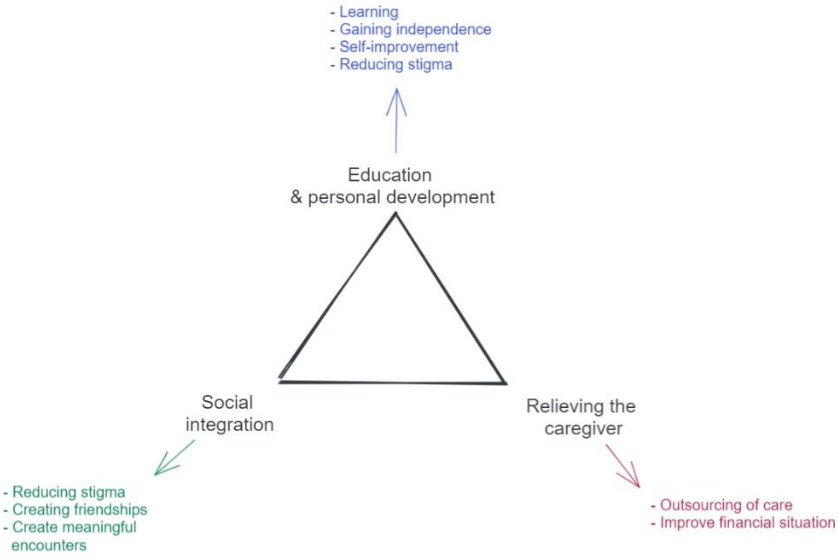

Figure 14: Benefits of Inclusive Education

Accessible education should be considered one of the primary aims when providing care for children with disabilities. This in the first place being as it can help with preventing a child to being placed in an institution as we saw in 4.2.1, and also how it can help against the practice of a child being hidden at home as was seen in 4.1.3.

This perhaps contradicts the idea that the main objective of education perhaps would be to educate the child. I have found in this research that the effects of providing education can actually be divided into three, arguably equally important, elements. Namely, developing and educating the child, relieving the caregiver and social integration. In Figure 14 these different elements are displayed with their most important trickle-down effects, on the child, the family and also the community.

It is depending on a multitude of factors from how the school is organised, to the type of disability that the child has, which of the three pillars is of the highest importance for that individual and for the establishment. Included in this, is access to daycare. There are multiple organisations which have a separate daycare facilities for the youngest children, and the children with the most complex disabilities. However, as the effects on the family and the child are similar I decided to not include the option for daycare separately.

In the following chapter, we will look further into the trickle-down effect of education with the use of three different educational systems provided by PDIs. As often is the case, PDIs have found many different ways in which the same problem should be addressed. For example, some of the initiatives educated the teachers in-house and made their own learning methods, whereas others make use of (special education) teachers who have a government diploma. Both perhaps have their up and downsides, mostly depending on the individual and the specific situation. I did however not research the quality of the education which was provided, and do not aim to make any statements regarding which one of the systems is ‘better’. What we will see, is how different methods will, possibly unconsciously, cause different aspects of the triangle to be favoured over others. This helps to understand which decisions that were made, have an impact on whom.

After having provided these examples, another important aspect of education will be presented. This is regarding the need for additional support for especially children with a cognitive disability. Here we will discuss the importance for children to understand their rights, and help children vocalize what they do and do not like even when they cannot speak to help prevent exploitation and abuse.

Special education schools/units

I step in the matatu to join Rita, the social worker who I am shadowing this week. The matatu is already quite full, but I still have a seat. Once arrived at the final destination of the matatu, it is time for us to step on the back of a bodaboda, a motorcycle. The trip is beautiful, but my feeling is constantly hoovering between being scared to death (especially when the driver decides to ask an abundance of questions whilst turning his head towards me, and only keeping one hand on the wheel while driving 80km/h) and pure joy for the amazing views and the wonderful experience.

When we arrived at the school in Kiwegu, I noticed the typical KidsCare building with black joints on the school compound. Rita told me that this was one of the best schools they had, as the teacher actually was a special education teacher. When we arrived there, on both sides of the school building a group of children, with ages varying from about 5 to 25, were hoeing the ground for a food project which would provide them with lunch at school. As they were using a *jembe*, a kind of hoe which looks like a shovel of which the metal part is bent towards you, and with a sharp edge to be able to cut through the ground, I could not help but think: no way this would ever be allowed in The Netherlands. Not for children this age, and especially not for children with disabilities. The children handled themselves very well though, and when I said this to the teacher, he stated that *"these children encounter these tools at home on a daily basis. These are their tools, that is why we see it as important to teach them how to use them."* It is nice, refreshing maybe even. These children get to learn to use something which their family also uses on a daily basis. This does not only mean that these children can safely handle the tools which they will see laying around, but this also means that they can contribute to the family's farm.

As previously introduced, providing education has three main pillars as a result. These pillars consist of ***education and personal development***, ***relieving the caregiver*** and ***social integration***. These three are considered of equal importance, whilst acknowledging the fact that individual importance is fluid and variable per unique situation. For certain children with an extremely complex disability, the aspect of relieving the caregiver as well as some social interaction may have a way higher priority than for one of its peers who only need a bit more guidance to be able to follow the mainstream education system. Where for the first child a school where they can go during the entire school week would have the most impact on them and their family, the second child would perhaps find more opportunities to thrive in a more hybrid model between special and mainstream inclusive education. We will further discuss these three elements, with the use of three cases of school systems which I encountered during this research. These are presented in Story Boxes 19, 20 and 22, and I would suggest first reading those.

Social integration

The added value of social interactions knows two sides. First of all, the aspect of children being able to interact with their peers and play with them, both their abled and disabled, will automatically have a positive effect on their well-being. The second element is regarding social integration where we see the trickle-down effect that it has on the community, which will be where we will predominantly focus on.

Florence introduced the self-fulfilling prophecy when it comes to maintaining severe stigma regarding disabilities. This is divided into two aspects. The first is, that severe stigma can only be maintained if someone with disabilities remains invisible. Once there are interactions with these people, a stigma as such cannot be upheld (Interview with F. Koenderink, April 14, 2022). As was mentioned in the chapter regarding stigma, the birth of their own child is often the first time a parent encounters a disability. As people do not have interactions with people with disability, they also do not see that they can be happy and that they can develop themselves. As Maria pointed out, when visibility is created and there are more interactions with children and adults with disabilities, parents are also more likely to invest in early interventions and good guidance for their child which makes a great difference for the future of the child. If these children already share a playground or a classroom from a young age onwards, later in life their encounters will not be as fuelled with stigma as it is not something unknown to them. These interactions thus both allow for children to be integrated into the community, as well as for a long-term behavioural change. This is also something which is experienced by Samuel as seen in Story Box 21.

These are key elements in ***social integration***. As Halder (2009, p. 641) found that inclusive education *“will inevitably result in their acceptance into society and also within their own families. Social integration is only possible when there is a motivational and attitudinal change among the teachers, challenged students and their parents.”*

Story Box 19

Veranda schools in Bangladesh

At first, Niketan only had three special education schools. But then the question came from parents who lived too far from these schools if they could not open another school closer by. *“This costs so much money.. to open a school everywhere. You need a building and you can only have a few children in a class, where a normal school can host sixty or seventy children, a special needs class can maybe have six or eight. So then we decided that it is not a solution to open schools everywhere, and then we started our veranda schools. The physical special education school is open three days a week. Then we have shifts, so that we can have multiple children. A veranda school cannot be open for three days as that is too much of a burden on the parents. This is why we decided to open these schools for one day a week, and when you have a team of 6 people, you can have a school like this in 6 villages. This way you can open a lot of schools in a lot of villages. This is how we started. We got more and more schools, and now we have 20, and we just handed two schools back to the community, so actually we have 22.”*

Niketan combines mainstream education with specialized education. The goal is for the children to go to school 6 days a week: either 3 days to special education or 1 day to a veranda school, and the remaining days they go to mainstream, inclusive education. The special education schools are open 3 days a week for children with a mild disability, and 3 days for the more complex cases, where the focus is more on care than education.

In order to ensure that as many children as possible can use this hybrid form of education, Niketan provides training for the regular schools in how to become more inclusive. This way, socialization and acceptance between peers is more readily accepted. The focus on inclusive education also makes that around 35 students transfer to regular education each year.

The time spent in special education is where the child receives more personal attention as well as more focus on personal development. Throughout the year, the parents also receive training so that the child can apply what they have learned at home.

Their flexible approach of education allows them to be proactive and efficient, as was seen during the COVID-19 lockdowns. Where the other schools were forced to close, they managed to open 35 additional veranda schools.

To achieve this motivational and attitudinal change, Niketan currently provides inclusive education training and support in 20 schools. This is to fill the gap, which was previously established, regarding the sometimes inaccessibility of the needed expertise of the teachers to provide a safe and suitable learning environment for the child.

This hybrid model in which many children can follow education together with their peers will have a positive impact on their position in the community, helping to break through the self-fulfilling prophecy which is caused by the lacking interactions.

Furthermore, the visibility of the children is also being increased due to the always central place of the veranda schools in the village. As it is open, it is therefore also possible for other people to see these children and see them evolve over time.

Another example is when we look at KidsCare which placed its special education schools on the premises of the regular governmental schools. As they share the playground together, this opens up the possibility for the children to interact with each other in a very low-key manner. Another benefit of this is that they can go to school together with their siblings and friends from their community. Aside from this helping with potential transportation challenges of the parents, it also helps with the sense of belongingness within their family and community. As KidsCare stated themselves, *‘we brought these children in the light,’* referring to the fact that many of these children were locked up at first, and now are literally playing in the light with other children. Because these children are already playing together at school, the step to playing together at home is smaller.

Having a separate school could therefore be seen as a downside as it reduces the opportunities for meaningful interactions between peers. In the case of More Africa, interactions are being created within the more vocational part of their education such as with the bike shop, but this is then only from an older age onwards.

Education and Personal Development

The second point regarding the self-fulfilling prophecy is that when a child is hidden and does not have the opportunity to develop itself, the view that someone has regarding someone with disabilities as being someone with no potential and no worth is confirmed when there is an interaction. Because these children never learned something, it is considered proof that the child is indeed not capable. Whenever the child however gets the chance to be educated, they will evolve and therefore show that they are indeed capable of learning and will show the potential that they have, proving the contrary to the person projecting the stigma.

Story Box 20

Special education units in Kenya

The special education units of KidsCare all are relatively new, as they were only built around 2019/2020. There are currently six of these units divided throughout entire Lunga-Lunga county and all are located the premises of the regular, governmental school.

The decision to place these buildings on the premises of local schools has been done to motivate socialization between the students of the two schools. As they have breaks together, all children play football together, and they get used to each other and help one another with for example going home.

Whilst the agreement has been made with the Kenyan government that special education teachers will be provided for the six units, currently only one of them has a teacher with a special degree. As the schools are relatively new, and due to COVID-19 this all takes a bit more time. In the meantime, the teachers from the regular school come to educate the children with help from a 'matron': the mother of one of the children in the class and the assistant to the teacher. This means that she for example coordinates the preparation of food during the school time, but also is there to look out when the teacher is not there, and help the children where needed. This however also means that there is no capacity for multiple classes, making that all ages and levels are in the same class.

Furthermore, the schools also have a room for occupational therapy. The occupational therapists come to the school once a week to treat the children who are at school, and also the younger children who live in the surroundings who need therapy. The social workers also visit the schools on a regular basis to discuss the progress of the children, and to see what the challenges are that they are facing.

For each and every child there is room for learning and development. This being said, the range in which this learning and development can take place, will highly differ on the individual. To create an optimal learning environment for a child, it is important that it receives education according to their level. As Ellen (Interview, May 19, 2022) explained, More Africa started with only one class, as all the students basically had the same level. When time passed and they started to learn more, the differences in levels became apparent and they decided to separate into different groups to ensure that all the children can learn on a level and in a way which is suitable for them.

Where having different levels and methods of education available would be ideal, this is often not achievable due to a lack of funding and teachers. This sometimes results in learning situations that perhaps are not ideal for all students, due to large differences in levels within the class.

A potentially sustainable solution to increase the capacity of the schools whilst also creating a sustainable mindset change is making mainstream education more inclusive. Where mainstream education is not achievable for all students, it would be for others which in the long run results that special education units can allocate their scarce funding and capacity to the ones who truly need it. This can have as a result that more children can get an education which is suitable to their level.

Story Box 21

Samuel

"My experience has been that when they start coming together, the other children will start gazing from afar, they will start from afar, and look. And you know, as the days goes by, they come closer, maybe if it is a wheelchair user, they tried to touch the wheelchair, and from time to time they start pushing the wheelchair, and they start interacting with the other children. So the first contact is that amazement, and surprise, and separation. But as time builds on, the interactions becomes (inaudible) it becomes friendly. And especially when children with disabilities become exceeding in, in class work. They do become a point of attraction for the others where they will always come around to learn together and it leads to living together too." (Interview with S. Nyingcho, May 4, 2022)

The accessibility to vocational training and job opportunities, help with the process of gaining independence and also becoming more part of the community. The different aspects of vocational training and access to work will be further explored in *'After 18'*.

Story Box 22

A special education school on Zanzibar

More Africa is a school located in Jambiani, Zanzibar. Ellen, a social worker who lives on the island started off with the idea to begin a day care for children with disabilities for when they came out of school. However, the parents asked her if she could not start a school instead as their children were not understood in school, and also bullied by the other children.

Due to the demand from the parents, she decided to open a school which now accommodates to 25 children and young adults from 1 to 22. All the students who are from the South-East part of the island get picked up at home and dropped off at the end of the day to ensure that logistics are not a reason for the children not to come, and it is free of charge for the parents.

“And then you start to think, what is the best way forward with this? You start talking about learning materials, which is not present here, and the children that we have.. yeah, reading is a no-go for about 95%, writing, about half. ‘…’ so what we decided to do, is to make the learning material ourselves. At first, we did not do this, but for about a year now we have the material both in Swahili and English. The children that are a bit further, they also learn English. Those are only a few though, other children do it all in Swahili.”

Together with specialized volunteers, they educated local staff in house with whom they are now running the school, and educating children on different levels. There is a day-care group, *“for children of all ages with a very low level.”* A group for toddlers, a group for primary school *“children who should go to primary school, but cannot fully keep up,”* a group for children for who it all comes a bit easier, and 16+ training which is more focussed on vocational training.

Depending on the level, they get education accordingly. Where the day-care has a focus on experimental learning with no pressure, the more advanced group gets all the classes which are also given in mainstream education. *“As none of the children had ever been to school, they all had a very similar level. This is why we also started with one class, which stayed like this for quite some time. Until we started to see very large differences and we decided to divide them into different groups.”*

Relieving the caregivers

An equally important aspect of what providing education does is what it can do to a family. As was said in Story Box 1, the first issue with having a child with disabilities is that because they cannot go to school, caregivers cannot work during this time. When I was in Kenya, I heard multiple stories about single mothers or grandmothers who could not work anymore because they had to care for their child with disabilities. The inability to work results in an inability to provide for their family, making the family even more vulnerable. Having a place where these children can go, gives some breathing room to the caregiver, as well as the opportunity to work again.

In this, there is an interesting dilemma to analyse. Easily said, and also applicable to education and personal development, if the goal is to relieve the caregivers, the more days and hours the child could be at school, the better it is. However, as we already saw, capacity is a challenge and the opening of schools is a costly and timely procedure. It is therefore not (immediately) possible to help as *many families* as possible as it is to help them as *many days* as possible.

Niketan for example adopted a highly flexible and hybrid model. Due to this, they managed to open a veranda school in a lot of different villages and react quickly during the COVID-19 lockdown. The scope in which they operate is large, and can relatively easily expand. Where there are a lot of children that can enjoy school six days a week due to their hybrid approach, there are also children with disabilities which is so complex, that mainstream education is not achievable for them. Depending on where they live, and thus if they join a special education school for three days a week, or a veranda school for one day a week their time in school is limited. These parents will therefore have fewer benefits from their child being in school, but the number of parents that have some benefit is larger than in another system.

More Africa only has one school, and they provide transportation for all the children that live in the South-East part of the island. Children get picked up and brought home during the entire school week, relieving the parents from these duties. As is always the case when there is a border created up to where one operates, there will be children who will live just a bit too far who therefore are not being picked up and need to arrange transportation themselves. The latter can become a challenge for parents, as is also seen in the case of KidsCare where transportation is not organised. Whilst the majority of the children do live close to a school, there are children who due to their personal immobility cannot reach the school.

What this shows, is that the different decisions that are made, have an impact on the families. Without being able to say which one is better than another, every system will always in some way benefit certain people over others. In order to draw conclusions as to which system has the best possible outcome for the most people, more research including an assessment of the different systems is needed. Furthermore, the impact that this has, will also highly differ per family. This is due to the financial situation of the family, or the help that one can get from other family members such as older siblings or grandparents.

Support to the child

“And those with cognitive disability, in particular, the understanding of the fear that opportunists can exploit them, maybe even economically, sexually, and all of those things remain a worry in the minds of families, that actually reduces the chances of them going out to explore avenues that can give them a bit of leverage of independence.” (Interview with S. Nyingcho, May 4, 2022)

Aside from educating children, it is also important to take into consideration the position of the child. Children with an cognitive disability are especially vulnerable, and therefore can highly benefit from some more attention which is focused on their personal development which will allow them to have advocacy over their own bodies and choices.

Ahmed (Interview, March 31, 2022) states that providing training which focuses very specifically on children with disabilities, what their rights are, and how to respond if these rights get violated are key. In these training the goal is for them to learn how to take care of themselves, what their response mechanism is, and so forth.

That this is something which is important, and has previously been shown in the story of two girls who were sexually abused at home. The reason why these girls could express themselves regarding what was happening to them was due to a ‘Stop’- programme which they had recently done at the Friendship Foundation. *“If you did not like that, you could point at it, and you gave the stop sign. One of these girls did.. she cannot speak but she did ‘stop’ and pointed at her crouch afterwards. Which was the sign of our staff to take action.”* (Interview with K. Giethoorn, April 4, 2022).

Story Box 23

Antoinette – Niketan, Bangladesh

One of the elements of this training is: how do I ask a question. In the Netherlands, when you give this training it takes about a week until children with an intellectual disability get this. In Bangladesh, this took half a year. Once a week, 1,5 hours to learn how to ask a question. The only question they could ask was ‘what have you eaten,’ and ‘how much does this cost.’ Those are not questions.. we wanted real questions. ‘…’ there was a boy, who had quite a good level, and could do like everything. A very nice boy.. but every night, he wet his bed.. nobody understood.. During the day, he would just go to the toilet, but at night, he would wet the bed.. Until he learned to ask a question. Then he asked ‘can the light in the corridor be changed? It is broken, and I am scared to go to the toilet in the dark.’ Something so simple.. and it is so sad that he could not ask this question.” (Interview with A. Thermoshuizen, April 7, 2022)

Especially for children who cannot use words to express themselves, it is important to provide them with tools which helps them advocate their feelings and experiences. At Niketan, they therefore also provide sexual education, but also training which helps them reflect on themselves. To teach them who they are, and what actually is their personal opinion. These are social skills which they learn with the use of an existing method called *‘een brug naar werk’* (a bridge to work) which they translated into the Bengal language and culture. One aspect of this training was to learn how to ask a question, which is further explained in Story Box 23. A part of this training is also to teach them to be more assertive. This is especially important for people with disabilities, as they are more likely to be exploited. An example of why this is important can be seen in Story Box 24.

Story Box 24

Antoinette Niketan, Bangladesh

“But you actually need job coaches to continuously support them.. and also to help with the communication between employees and the worker. Because often they do get exploited.. because they have issues with saying no. That’s why this training is so important, to make them more assertive. We had a boy for example.. His parents thought, ‘he learned so much at Niketan, we send him to Dhaka to go and work.’ Well.. this boy was fully exploited.. from the very early mornings till the late evenings, only work, which he found extremely scary. He had to work with fire, he was extremely scared and stopped eating and drinking. He kept on saying: ‘I don’t want this. I cannot do this. I do not want to do this.’ And because he kept on saying that he could not do this, they sent him back to us eventually. This was so important, that he could say this. Otherwise.. well.. then it would not have ended well.”

After 18

“But you see that the life for the children and even adults with CP depends on the family.. depends on the parent so much.” (Interview with P. Ha Nguyen, May 26, 2022) This research is focused on care for children with disabilities. However, when we look at children with a (complex) disability, turning 18 will not magically make them independent. Maria explains that parents often express the feeling that *“we’re still stuck with them.. and they’re stuck with this when they get older.. and I realized the commitment it takes.”* (Interview with M. Njeri, May 16, 2022) Especially in the cities, she noticed that people becoming more individualistic, making it even harder for parents to find help. Furthermore, we already discussed the importance for parents that their children can help to provide for the family. The financial aspect is one of the main reasons of why people have a child, and therefore if possible, someone should be given the possibility to work.

Despite these two elements, the majority of organisations currently do not incorporate this in their project. The main reason for this is that the project is still quite new and that the children simply did not reach the age of 18 yet. Moreover, the focus of most initiatives is on children, thus until the age of 18. The demand for vocational training is also prevalent among the students themselves. As Rita told me, a lot of older children and young adults want to learn a skill and would love to work. After 18 discuss these two elements. The challenge of having a child which requires lifelong care, and the opportunity for individuals to be able to contribute to their families.

Supervised Independent Living

In many cultures, it is the common practice that children continue to live with their family or their family-in-law when they are adults. This however is not always the ideal situation for an individual with disabilities, or for their family. It can be due to a multitude of reasons that living at home is not considered the best possible solution. For example, the care may become too complex for the parents due to the physical challenges it brings, the fact that they cannot go to school anymore makes a caregiver need to stay at home again which is not always possible financially, or someone's behaviour may become too challenging. In these cases, it can be considered helpful to look for an alternative way of housing, in more of a Supervised Independent Living situation. As was mentioned in 2.2.1, this is a form of residential care which can be considered a viable option for young adults with de adequate support. However, despite it not being impossible in Kenya, it is something for the long run (Interview with F. Koenderink, April 11, 2022). Therefore, Maria helps parents find solutions within their surroundings, such as training friends and family members to take care of their child so that they can also take some time off (Interview with M. Njeri, May 16, 2022). Kirsten also notices that the struggle is bigger for people that live in the city as *"the families who live with a lot of family members close to each other, then the care is taken care of."* (Interview with K. Giethoorn, April 7, 2022). There are a few examples to find of projects who provide this. One example can be found in the CTWWC project of deinstitutionalisation for the residential care facility in Haiti. A few of the children could not be placed back in their families or to extended families. These were placed in a supervised independent living situation with one-to-one social work support. *"These community houses offered spaces for the youth to grow in autonomy, build life skills and connect with the community while living in a stable, caring and supported environment with their peers and proper supervision."* (CTWWC, 2022, p. 5)

Story Box 25

Antoinette - Niketan

"We have a living facility for boys, and we're hoping to open one for girls.. '…' we provide care for boys from around 15 years old of whom the parents passed away, or where the parents cannot handle the care for the children anymore, or the grandparents can't. A lot grandparents care for them. '…' we have two house-mothers and a farmer on this project, and together they care for each other. There are two boys with a very complex disability, who need to be washed, walked around, all that.. and the others take care of this. They also help at the farm, they do their wash together and some of them work on the wood-group, they keep the building clean, all those kind of things.. they play games together.. It really is a living facility, and we provide all the activities. They get our training, and they can choose if they want to work at the farm, on the wood-group or in the facility itself. Some choose one day here, one day there, and others have a fixed place. They can all choose themselves, and it is discussed every day who will do what that day. It is also better for them eh, because, they see their siblings leaving and starting to have their own lives. But someone like this will always stay at home, which is also not good. This person needs their own development. With this assisted living, he also has the feeling off, 'I left my home, I also have my own room somewhere else.' This gives them a sense of

Another example of this which I encountered is presented in Story Box 25. Here, the objective appears to be quite similar to the one in Haiti. Having places like this for youths and adults to go to after they turn 18 can make a big difference in the lives of the parents and their child.

Vocational training

Within the organisations which do have a programme for older children, vocational training is one of the key aspects. Aside from the view that this is important for personal development, it is also an essential aspect for them to earn a place within their community and especially to be able to provide for themselves and their family as was seen as a key element in 4.1.2. *"Once they can contribute financially, they will be respected and seen. Because, as long as they only cost money, they are a burden. This is why it is so important that they learn a skill."* (Interview with A. Thermoshuizen, April, 7, 2022) This is something which has been recognized by many other interviewees. Here it was explained that many parents have children as financial security.

In this, the essential is to teach the children a skill which they can use later in life. This of course depends on the wishes of the individual, as well as what is possible for them. Here, the vocational training can be focussed on learning a skill to help in and around the household, and also to learn a skill which can later be translated into a job. Both are essential aspects of becoming a valued asset to their families and their communities.

Help around the household

It is a warm day, humid and sunny. It is supposed to be the rainy season, but unfortunately, the rains stayed away already for quite some time now. We step out of the matatu and leave the main road to go into the village to visit the home of a 16-year-old girl with an cognitive impairment. Even though they are surprise visits, the welcome often is so hospitable that you would almost not believe they were. We are sitting down whilst the mother walks away to get us some tea. The tea is delicious. The flavour of the smoke of the open fire in which the water was boiled blends perfectly with the black tea leaves and the sugar. Whilst we are sitting in front of her house drinking the tea, she tells me about how she learned that her daughter was different, and how she did not want to accept this at first. It took her time to adjust to the idea, but now she is very happy that she made this decision. She sees her daughter making big steps forward, and she is looking at me with a big smile on her face, beaming with pride when she says *"she can even go and do groceries all on her own now."*

This very much is about helping the children, for whom it is possible, to be an asset to their family within their own skillset. It cannot be stressed enough how important it is for the child, and for its family to be able to be a part of their family and to contribute. *"This is also why we focus on help for our children in their homes. If they can assist with cooking, the mother can do something else, or work a bit longer.. if they can do groceries, they can already do this whilst their mother is at work. Here I am talking about the older children, above 18."* (Interview with K. Giethoorn, April 4, 2022) Whilst education is important, it is also important to not deny the child the ability to learn these skills and add value to their family in this manner. Especially mothers who have already a lot of work to do with managing their family and the household, as well as simultaneously having to work sometimes to make money, do not have the time to be patient with their special needs child to teach them these things. This is where the school can play an important role. *"A lot of people then say 'but everyone has the right to education..' but education is something which is so broad.. it is not only 1+1=2. Because, if a child cannot do this, please then focus on teaching them to be productive to ensure that they can earn their place in their family."* (Interview with M. Derrez, June 2, 2022)

Learning a skill for work

The other important focus of vocational training is focussed on preparing the adolescent to be able to work. It is important to realise, that the statement that parents have children to ensure that they can be provided for, simultaneously brings pressure on the child, and especially the boy. When I asked Maria about this, she stated that it is indeed even worse for guys, *"because in our culture guys bring the money and go to work, you know."* Same as with the work in the household, creating the opportunity for someone to participate is extremely valuable. *"This is also why we started with vocational training, and also look for types of work with which also people with disabilities can contribute, even if it is only a small contribution."* (Interview with K. Giethoorn, April 4, 2022)

This also follows the line of reasoning of the special educations teacher in 4.2.3.1, where he let the children use the hoe to work the ground around the school. These are skills which can be applied in the family farm later in life, allowing them to contribute to their families, and also to know how to handle tools which could otherwise be dangerous.

The guesthouses which Ellen has alongside the special education school do not only function as a revenue stream to finance the school, it also is there to provide an opportunity for work. From a certain age onwards, they have the opportunity to start the training to eventually work in the guest house. Where one really enjoys walking with a tray to serve the guests, the other is very happy to be the one opening and closing the gate. Also here, the training and the job are very much customized to the wants of the individual, as well as their skillset. The goal is however to expand the vocational training to go further than the guest house. *"This is also why we made an atelier at the new school, to make stuff which we can then sell. Make soap with the children, for example, to sell them, or to put them in the guesthouses. And what else do we have.. oh yeah so we bought bikes last week, and we have some kind of bike shop there too. In a couple of weeks there are some people coming who are going to teach the older boys to fix the tires and stuff.. '…' and also teaching them how to cook and stuff. So, eventually to also prepare them to come work here* [at the guesthouses], *if they and their parents want that. '…' we also want to get some animals to make a small farm. Then we have the guesthouse, the atelier and the farm where they can work if they would like that."* (Interview with E. van Beer, May 19, 2022)

Niketan also has an extensive vocational training programme where they, for example, have woodwork training which takes three years and training about handling livestock, such as cows, goats and chickens. Niketan focuses on providing vocational training in combination with personal development such as how to handle money, how to act at work, and how to be more assertive to help them prevent being exploited. Following the training mentioned in *'Support to the Child'* Antoinette also stresses the importance of proper training when it comes to working. This is why at Niketan, the vocational training is in combination with working on the aforementioned personal development. *"Those practical skills make a boy like this feel a lot better about himself and can better handle himself within his family."* (Interview with A. Thermoshuizen, April 7, 2022).

An important aspect of this is also to consider the trickle-down effect that it has. As Florence stated in 4.1.3 about stigma, is that the view that there is on children with disabilities is a self-fulfilling prophecy, where extreme stigma can only be maintained whenever people with disabilities remain invisible and undeveloped. Allowing these individuals to participate, helps break through this self-fulfilling prophecy.

Case: Girl in a wheelchair

It was the 10th of May, and I was sitting on the back of a motorcycle and we were driving up a very sandy rocky road for a solid 20 minutes. The quality of the road was really bad, and I could imagine that it would be impassable if there would not have been such droughts during the rainy season. When we reached the top of the hill to do a home visit to one of Rita's clients, we were welcomed by a heart-warming scene. A young girl was sitting in a wheelchair and playing with her younger siblings who were pushing her around. Rita explained that she has cerebral palsy and that because of therapy she made great improvements and can now sit in a wheelchair and truly be part of the family. Once a week her grandmother takes her down that same rocky road on the back of a motorcycle to receive therapy at one of the special education units. Unfortunately, the family is not able to organise transport for her to go to school every day, and she, therefore, stays at home.

This case made me realize one essential factor in this research, namely that it is highly dependent on what you personally consider as more important or more of a fundamental right on what you think would be the best for the child in this situation. This child now can sit up, she has a wheelchair and she can play with her siblings. She has a place in her family, receives love, and she has made great steps in therapy. Simultaneously, she does not go to school and only receives therapy once a week. The question is what you see as a more important right. Is it the right for a child to develop as much as possible, both mentally and physically which you see as the most important right? Or, is it the right of a child to grow up in a family including all the psychological benefits this has?

I decided to present this case to multiple people who could react to this from different perspectives. Such as from people that worked in family based care, as for example, Maartje who has a home for children with disabilities.

I thought of this case as the perfect argument for people in favour of residential care to state that this child perhaps is being deprived of an option to further develop herself, to be able to receive therapy daily and maybe even be able to walk and to go to school. However, this was not the case, or at least not for Maartje. As I presented this case to Maartje, she responded *"if I am being honest, I think she is better off at home. Unless you have visited the boarding school and really have a good feeling about it. Many schools only care for the children partly but think about personal hygiene, safety, missing the parents, etc. the best solution would be if she could go to a day school. I visited many boarding schools, and I only saw a few reliable ones. Teach the parents/family members how they can do the exercises."* (Correspondance with M. van den Brand, Aug 2, 2022)

The latter is also what Monique (Interview June 2, 2022) stated as a reaction to this case: *"how can we organise this progress at home?"* It was recognized that it is indeed too much to ask parents to travel back and forth every day due to the costs and time investments. Carmen (interview, June 2, 2022) however does point out that in some cases a short-term investment in intensive therapy can make significant results: *"we had children who received intensive therapy, and eventually could walk, which made them a lot less dependent on their wheelchair."* Teaching the parents or grandmother to do this, would however take even less of an investment.

The narrative, therefore, remained that indeed the child was better off at home. Other aspects which were mentioned are the fact that the school could try more to make it more accessible for them. Such as organising transportation, or helping to find a solution where a child can for example stay with a family member who lives closer by for a couple of days a week (Interviews with M. Njeri May 16, 2022; H. August 3, 2022).

Concluding remarks

Providing family-based care requires for an holistic approach. In this chapter, we looked at seven different elements of family-based care as provided by NGOs and PDIs. In Figure 15, which was previously presented in 4.2.2. the different aspects of family-based care are presented.

What we saw is that Family strengthening is the basis of preventing unnecessary family separation. This strengthening is on both a social level in aid with emotional support, as towards improving the financial situation.

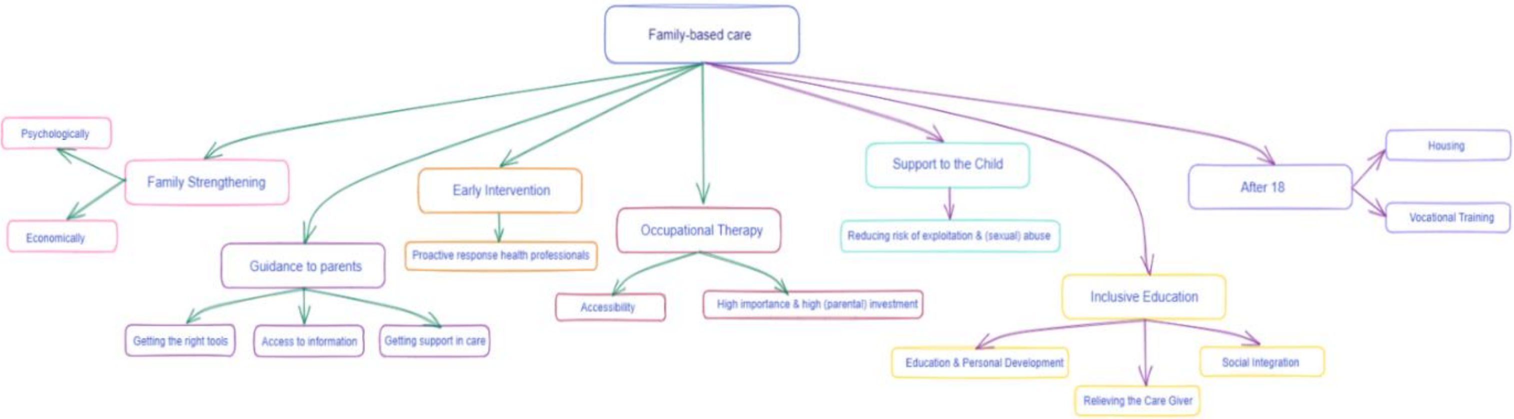

Figure 15: Family-based care

Aside from this, it is key that the child receives the adequate care. A challenge often is that parents are not equipped with adequate knowledge needed to care for their child. Access to the needed information and creating an understanding of the disability of the child is considered key. Not only does this help the child in receiving the right care, it also gives the parents the needed confidence that they can indeed care for their child. As we saw, sometimes parents just need a bit of support to help them on the way.

Moreover, early intervention is extremely important. This can be both in the sense that parents get taught early onwards how to best stimulate their child so that it can be supported in their development, but also when it comes to occupational therapy. The latter can especially have a great effect on children with cerebral palsy. In this, creating awareness for prospective parents and medical professionals is very important, but also a challenge as it is a taboo subject. Often, the more therapy that a child receives, the bigger the effects. Therefore, occupational therapists and the initiatives could shift their focus to also teach the parents and the caregivers how to treat their child. Not only could this result in greater improvement for the child, but it also makes that the occupational therapist time to help more children.

Inclusive education is an important element of family-based care, also as inaccessible education is one of the main reasons for the institutionalisation of children with disabilities. Despite governmental policies, schools are often not aware of the laws that (depending on the country) oblige a school to accept children with disabilities. These schools are often not accessible in terms of architectural barriers, as well as teachers who lack the knowledge needed to educate them. Regular education should be made more inclusive. Such as with the elimination of architectural barriers, so that they can also accommodate children with physical disabilities, as with training of the teachers to create an adequate learning environment for children with minor cognitive challenges. Special education should be available for the ones that

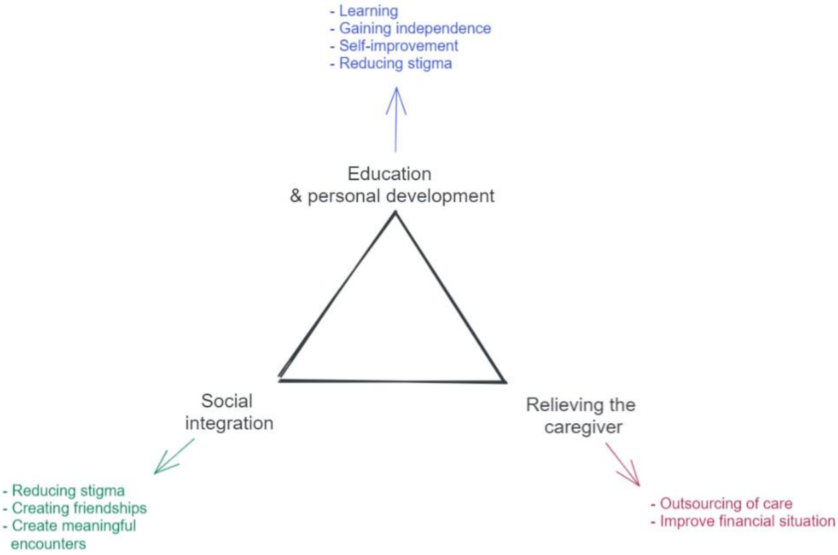

Figure 16: Benefits of Inclusive Education

cannot participate in regular education, either full-time or in a hybrid model.

Aside from education, children with disabilities need to be equipped with adequate tools which help them to express themselves, and to get to know themselves even if they cannot speak. Being able to share whenever someone did something which they did not like, or to ask a question, can make a great difference in the quality of life of the child.

What unfortunately is often not thought of, is what happens to the child after they turn 18. This is important to consider from two perspectives. Either, someone with a very complex disability or increasingly challenging behaviour will always continue to need care, and therefore always put a lot of pressure on the parents. If this is the case, supported independent living would be a great solution for many. This is however a plan which in many cases is something of the future. The other case is that the child can actually learn a skill, either to help in the household or for work. This is very important due to the fact that this allows them to contribute to the family.

4.3 Use of International Volunteers

The literature portrayed the use of volunteers as an essential element in the money-making business aspect of institutional care. Voluntourism is the term used to express the act of individuals who are often from the Global North to go to the Global South to do volunteer work in combination with some travelling. An example of this is presented in Story Box 26. Whilst this does not concern voluntourism in regards to this research, it does show how this can come to practice.

This is the perhaps ‘classic’ case of the voluntourist. Someone who wants to ‘give back,’ whilst also having an interesting experience themselves. What this however does, is maintain a system as it is more lucrative to have people pay to work for you, than to pay people for the work that they are doing.

Story Box 26

06-05-2022 Conversation in the hotel in Nairobi

I am sitting in the hotel in Nairobi with some other guests who were all coming from different parts of Europe as well as some staff members from the hotel who had finished their shift. Whilst drinking some beers, we were all sharing what we were doing here in Kenya. I told them about my research and my objectives, as well as some distressing literature I found regarding for-profit orphanages. A girl from Austria, she was 19 years old and had just finished high school, shared a dilemma that she had with us and was asking my opinion. She said that she was going to the south of Kenya to do some teaching for two weeks. She would be teaching Maths and English at this school which was owned by an Austrian lady. Her dilemma was if she was actually doing good by coming here, or if she could have better given the 500 euros she spent to volunteer there for two weeks so that they could employ someone locally. Where she seemed very sweet, and I thought it was good that she was thinking about this matter, I also frustrated me. It was not like her English was bad, but it was by far not what we would accept as a level of an English teacher at home. She spoke with a strong accent and made grammatical mistakes. The other people were stating that *‘it is for sure better than nothing,’* this, whilst Kenya has English as an official language. It is for sure not impossible to find a good English teacher, it is however impossible to find a Kenyan teacher who will *pay* money to teach. When I asked her if she had to have a code of conduct, she said no.

The majority of organisations which I spoke to about the use of volunteers, did not adopt a system like this one. The narrative is starting to change towards having inexperienced volunteers come to help with something that they actually do not have enough experience in themselves either. This is also what Maartje (Interview, April 4, 2022) recognizes when she reflects on being a volunteer right after her studies, Story Box 27.

What she introduces, is something which is used a lot. Namely, the one using experts to share their knowledge regarding a specific aspect. Often these are people who stay for a longer period of time and have a specific goal of for example teaching something to the local staff members.

Story Box 27

Maartje, Stichting Japthi

“Myself, I went when I was 23, when I had just graduated. I did not know anything. Like, 0. So I think, 23 is actually still too young. You have just finished your studies and you need to start your life. You’re missing experience. So, when I was 29, I went again because then I thought, okay: I have 7 years of experience in the field, I did not have a relationship, I did not need to see India, I did not need to ‘find myself,’ I am really going there to share my knowledge. And this worked out eventually, and became 15 years.. Yes.. and well that’s.. that’s what I believe in.”

Using volunteers are also a less costly way to help in ensuring quality than when it is needed to actually hire someone. As these are organisations which often are based almost fully on donations, it is logical that the choice is being made to use volunteers.

This chapter will discuss both the ‘voluntourists’ and the ‘expert volunteers,’ with the use of examples encountered in the field.

4.3.1 The Voluntourist

Once arrived at Harrie, we departed for Imani with his driver. Harrie explained to me that he usually drives himself, but that it was time for the school fees and he, therefore, tried to create some more work for the driver. It was a short, but slightly hectic drive with a lot happening in the surroundings. Radiant colours, avocados for 0.5 Kenyan Shilling (which is 0.0041 euro cents), motorcycles, busses, houses of corrugated sheets, goats.. too much to see and absorb at once. In the midst of the hectic, there was a large green gate. The driver honked twice and the large gate opened. From the chaos of the street, we entered into serenity.

The place looked nice. Friendly. There were two dogs, places to play and it was clean. This was Imani A where the youngest kids stay. Harrie took me on a tour through the premises, and you could tell that a lot of things were well thought off. He barely is at Imani, as he also stated in the interview “*these are Kenyan problems, which should be fixed by Kenyans”* and they work with mamas for the groups to make sure that there is not that much change for the children. Aside from this, there are also a couple of volunteers working there. I asked him about what he thought of the change in views towards voluntourism in orphanages.

"*For us, it is a pity, we also do not advertise with it anymore as it brings bad publicity. The thing only is, if the donors want us to work without volunteers then fine, but we need more money to employ people locally. We don't have the money to replace them."* He also explained that they work with a lot of rules at Imani when it comes to volunteers. They need to have a declaration of conduct. Furthermore, they are only allowed to work with the babies, not with the older children, there are always two people with the children, so nobody can ever be left alone with the kids, and they are only staying with one group for two weeks maximum to make sure that there is no bonding with the babies. The latter is to prevent creating attachment issues, but Harrie is sceptical if the attachment issues really is due to volunteers as he said that the children that are brought there, already have trauma and attachment issues from the fact that they were abandoned by their parents. And, also children in families encounter people temporarily, an uncle and an aunt that live far away, and a neighbour that moves away. Also in an ordinary family, there is no full consistency for these children. The consistency here is created with the use of having a fixed 'mama' on the group, and also by having everybody that works directly with them wear the same type of clothing.

Harrie explained to me that when the babies first arrive, a lot of them are very keen for attention and reach out to everyone they see. He stated that this is very problematic behaviour, as at that age children typically are very much focussed on one person. Their work with these babies very much is focused on trauma prevention, they give a lot of attention and love to the children. One of the managing staff of the home said to me when I asked her what she thought of having volunteers that it was good as "*we need people to support with giving love and attention to the babies. We have enough staff to make sure that the basics are taken care of, but not enough to make sure all the babies get enough hugs and love."*

Listening to how they went about it, to me it also made sense that they made these decisions. At least they had thought about the need for love and the volunteers needed a declaration of conduct, which unfortunately is quite rare. Trusting the best of intentions, and understanding their line of reasoning, I did wonder if the intentions had the aimed for outcomes. The literature clearly presents cases of attachment issues and the detrimental aspect of volunteers in this. The question therefore automatically rises if this system could indeed be more beneficial to the development of the baby. In order to find the answer to this question, I decided to present this case to Florence as she is an expert on the effects of institutionalisation on children. The answers formulated are partly derived from Chapter 5 of her newly published book (*'Understanding the trauma of institutionalized children: to support the child you adopt'*) and are partly specific answers to this case.

A child needs the opportunity to form an attachment to a primary caregiver, which often is not possible in an institution. What is important to realise, is that especially babies rely on this primary caregiver to relieve discomfort or anxiety. The bond between the baby and the caregiver is formed as the baby learns that she can depend on this caregiver to provide comfort when she feels distressed. In an institution, a bond as such can often not be formed due to a high caregiver-to-child ratio, as well as the fact that someone simply is not always there. There is therefore no opportunity to get to know a particular person, and there is no primary person there to relieve the distress that the baby feels. *"Therefore, while the brain is ready to receive this information and start its development, it does not receive what is necessary to develop the relevant neural networks. No association is formed in the brain between interaction with particular people and pleasure, because that is not something the baby has experienced. This means that in turn, no templates are developed to support positive human relationships."* (Koenderink, 2022b, p. 82) These attachment issues are especially prevalent in children who entered an institution in the first year of their lives, or if they spent most of their childhood in an institution.

In the case of Imani, there are mamas who look after a small group of children to create consistency. These mamas could therefore take on the role of a primary caregiver. The question however is if this role is being fulfilled, as they state themselves as well that they need the volunteers to help with the hugs and love of the children. Furthermore, they say that children encounter a lot of different kinds of people in their lives who come and go. This is also recognized by Florence. She states that indeed secure attachments can also be formed with other people who play an important role in the lives of a child, and on whom they can depend to fulfil their essential basic needs. However, these relationships are more secondary to a child's life *"as the people who come in and out of their lives are much more on the outskirts of a child's experience. When somebody leaves, a child might be disappointed or sad, but she has parents and other dependable people around her whom she can trust to stay and can turn to for comfort. Because of this, other people coming and going does not have as much of an impact on her* *self-esteem. A child growing up in a family, surrounded by protective relationships, does not experience an outsider leaving as a personal rejection or abandonment."* (Koenderink, 2022b, p. 89).

For this coming and going of people not to have this impact, the child needs at least one secure primary caregiver. If this is not fulfilled, as often is the case in an institution, the volunteers actually are the ones coming the closest to meeting the essential basic needs of the child, instead of the fixed caregivers. *"They become central to her hopes for having her needs met, for validation and attachment. It is precisely because volunteers have a role in providing something that is lacking in her daily life that their coming and going has such a devastating effect. The solution to children's needs not being met in institutions is not to send a long line of volunteers to care for them and then abandon them."* (Koenderink, 2022b, p. 90)

The latter is aimed to be avoided by Imani to ensure that the volunteers do not interact with the older children, but also to make that a volunteer only stays in one group for two weeks. This can however have an opposite effect to what is aimed for, as the child may have no opportunity to form any relationship. Where a child who forms a bond and then gets rejected learns that relationships are not sustainable, a child who has not formed any bond, will not have the brain development which will allow the child to make relationships in the first place. Resulting in attachment disorders, instead of attachment issues which will be noticeable for their entire lives (Correspondence with F. Koenderink, 30 September, 2022).

Imani is used as a case in this scenario to sketch an example of how sometimes good intentions may have opposite outcomes. It is important to emphasize here however that the actual effect on the children was not investigated in this research.

4.3.2 Expert Volunteers

With Ellen from More Africa, the school used to actually run fully on experienced volunteers and occupational therapists from the Netherlands. Reflecting back on this, she sees the COVID-19 period as a blessing in disguise, as this forced them to rethink this decision as it was not possible for volunteers to come anymore. Whilst the volunteers did have experience with regard to care and education for children with disabilities, they did not speak the language. *"It is very difficult because, on the one hand, you do need volunteers, especially in the beginning to get your project going. But, if they do not even speak the language in which you need to teach the children.. what are you actually doing?"* The COVID-19 period eventually made the project now runs completely independently with local women (Interview with E. van Beer, May 19, 2022).

Story Box 28

Antoinette, Niketan

"Most of the people get educated within the centre. Only the physiotherapist actually studied somewhere else. But also they get trained by us as the trainings that they get are not based on occupational therapy, and also often are focussed only on adults. So, when they come here after they education we provide them with more training. Also, all our special education teachers and special help, we trained ourselves. '…' These trainers come from The Netherlands and come here voluntarily. A physiotherapist-volunteer had lived in Bangladesh for a couple of years, and then went to Niketan to give training to our staff."

It is important to realize that it is a key element of forming an identity, that the child encounters people from their own culture and that they learn their own local customs and ways of expressing themselves. In the case that the majority of the people that they encounter actually are volunteers from the Global North, this can result in identity confusion for the child (Koenderink, 2022b). Whilst this is a risk that is expressed with regard to volunteers and visitors in institutions, I do also think it is important to realize this when it comes to other important elements in the child their lives. As Ellen reflects upon herself, having a school where the classes provided are in English and by volunteers from the Global North, disregards the local culture.

The usage of volunteers which is displayed in Story Box 28, is the most predominant use of volunteers which I encountered. These are thus volunteers which have a supporting role towards teaching and training the staff, and they do thus not work closely with the children. Which, according to Florence (Interview, April, 14, 2022), should also be avoided as much as possible.

Following the same perspective, KidsCare also uses volunteers with expertise. *"We always say, someone needs to stay at least for three months to actually become productive, and we have a lot of clear rules for this. You need to have a goal towards which you will actively work. If you really want to contribute, then you also need to really be somewhere, that cannot happen 'en passant.'"* (Interview with G. Geenen, April 5, 2022). Having people with a clear assessment helping to contribute to achieving the overall goal of the organisation at no cost, can be very beneficial to the project and also help with the process of becoming more sustainable. It is therefore however essential that there is a clear plan in mind for how these volunteers are used in which part of the process, and if it is aimed for that they will eventually not be needed anymore as they can organise training themselves.

Reflecting on the usage of volunteers who may stay for a longer period of time and will also be encountering children, it can of course very well be that certain attachments are created between the children and the volunteers. In this it is essential to consider the situation of the child. If the child has a proper relationship with a primary caregiver, this will not be as much of a problem as she has the primary caregiver and other people in her surroundings with whom they can find comfort and also confidence that they will stay. If the child however does not have this strong basis, the same devastating effect will occur as mentioned previously. Furthermore, as is the case for people in The Netherlands when they want to work with children, a declaration of conduct should be requested for all volunteers.

4.3.3 Concluding remarks

International volunteers which have some kind of interaction with the child can only be used in the case that the child has a proper attachment to a primary caregiver. If this is not the case, there is a very high likelihood that the effects on the child will be negative rather than positive. Moreover, a declaration of conduct should always be requested.

If these points are met, then using international expert volunteers can allow the organisation to train their staff without making any additional costs. For the best outcomes, it is however important that the volunteers come up with a clear goal and that they truly have something to add which will have a sustainable impact.

4.4 View on NGOs and PDIs

"I think that there are Kenyan parties who are very much able to do this work, but who often work together with non-governmental projects. And.. are we making them lazy? To exaggerate it a bit.. I think that sometimes.. yes. Or at least, that it is not motivating.." (Interview with C. van Bergen, June 2, 2022).

Carmen gave me this answer when I asked her what the effects could be of private initiatives on the willingness of governments to invest in care for children with disabilities themselves. I decided to ask this question, as I realised that I noticed some kind of ambivalence regarding this matter. On the one hand, private initiatives and NGOs have drastically changed the livelihoods of children with disabilities. Simultaneously, these organisations are basically doing the work which governments should be doing themselves. The question that kept lingering in the back of my mind was that, as they are doing the work which a government should actually be doing, are they actually helping or, do they make the government passive *because* they are there anyways?

An example of where the downside of NGOs and PDIs as main care providers can be notices is when looking at medical professionals. As was seen in 4.2.2 *'Early Intervention'* it became apparent that the involvement of medical professionals was often a challenge, whilst they are the first ones which can provide parents with the needed knowledge and support.

What I noticed, is that there is no one clear cut answer to this question. Hisan stated that the current Kenyan mentality is very much dependent on donor funding, even though there are very capable Kenyans (Interview with H., May 3, 2022). Simultaneously, Florence emphasized that currently *"they need proof that it can work. '…' currently there is a lot of scepticism if it is even possible.. that they sometimes say that children with disabilities cannot be at home, but that is just not true. Sometimes they need a lot of support, but it is true."* (Interview with F. Koenderink, April 14, 2022) And also that with this, government buy-in is an imperative for the sustainability of the project. In this way, good working projects could therefore be used as some kind of 'lead-by-example' principle for governments. To have this effect, projects need to open themselves up to government cooperation.

4.4.1 Blind spots

As was cited in the theoretical framework, Holmén (2020, p. 525) makes two remarks regarding the position of NGOs in sub-Saharan Africa: *"a) if development is to be sustainable, it must come from within, and (b) we should listen to these African voices and take their message seriously. Not only do they see things westerners often are unwilling to see – it is also, after all, their future that is at stake."*

With these two statements, Holmén describes what often still goes wrong when looking at development work in sub-Saharan Africa, which could be applicable to the rest of the Global South. Projects that were started not because they were needed, but because people from the Global North *thought* they were needed. Solely the fact that a popular tourist destination appears to consequently be a more popular PDI destination, highlights that PDIs are not per se initiated from a point of view that places the person with the highest needs at the core. This is without saying that people in touristic areas cannot also benefit greatly from initiatives, as they do, but if the quest is to care for the people who are most in need of help of any kind, those would perhaps not always be the people which you encounter first on your travels. The second statement of Holmén highlights the issue of having a lacking precedent context analysis which does not take the voices of locals seriously. This matter we will later on further reflect on with the use of the upward and downward responsibility of NGOs and PDIs. First, we will look more into the positionality of PDIs and NGOs in comparison to the local community.

Betteke de Gaay Fortman however describes in her book *"mensen ontwikkelen zichzelf"* (people develop themselves), that sometimes an idea 'from the outside' is not always accepted by locals, whilst it can still be a good idea. *"Change does not happen if you endlessly wait until the initiative comes from people who live in paralysing circumstances. The issue is often a lack of knowledge: people have no idea what they need to do to get more control over their own lives."* (de Gaay Fortman, 2021, p. 84) What she describes here does not concern examples such as providing computers to areas that barely have any electricity, but discusses the fact that in certain cases the local partners can disagree or not support an idea, which eventually can still become successful.

What Holmén states is true, it is the responsibility of the organisations to listen to the voices of those it concerns, and there needs to be support from within for it to be sustainable. Simultaneously, a lot of people are indeed living in paralysing circumstances from whom it cannot be expected to come up with an initiative themselves.

When I was reflecting on the ways in which the different organisations started their projects with the statements of Holmén in mind I came to the following conclusions. When talking about heavily stigmatized subjects, waiting for change to come from within can also be seen as a violation of human rights. Rights such as the care for children with disabilities, and the right for these children to live a fulfilling and loving life. In these cases, I think that it can be good, and also needed, for organisations to push through a bit for the greater good.

To fully adhere to the statements made by Holmén, would perhaps mean that initiatives could be more passive in their quest to provide aid, as they would more react to the question and needs of the community. When it however comes to taboo subjects, as is the case when it comes to disabilities, the risk could be that waiting for internal development can have detrimental effects on the livelihoods of the children and their families as was shown in 4.1.

In these cases, it could be understood why 'outsiders' would decide to interfere. This being said, internal support still is needed for these projects to be sustainable, and to actually fit the local context in which they will operate. Personal views of what should be provided should not stand in the way of the priorities of the locals. The one does therefore not fully exclude the other. It is always essential that the initiative is aware of cultural sensitivities regarding the topic, and that these are respected. There is always a need for local partners, and if possible, it would be best to support a local initiative.

4.4.3 Sustainability of the project

Story Box 29

Antoinette – Niketan

"We assigned two schools to the community. So, we educated people.. parents and volunteers, to take over these schools. So, actually we have 22 schools, but two of those we do not meddle with anymore, and those are run by volunteers [from the community]. *'…' our wish is that, also this year.. but well because of COVID it was all quite complicated.. but to make more schools independent just like these two. We hope to be able to assign two more to the community."*

Whilst full independence and sustainability still appear to be something of the future to the majority of organisations, there are multiple ways in which organisations aim to generate more revenue streams rather than solely through donors.

KidsCare for example also has meeting rooms which can be rented together with a full board and guesthouses if needed to support the project and, MoreAfrica has guest houses on her premises in Zanzibar where by staying in these guest houses, guests pay for the school.

Despite these goals, the full independence and sustainability of a project is still a challenge. Aside from other revenue streams, projects also need government buy-in for them to become sustainable (Interview with F. Koenderink, April 14, 2022), but this is simply not (yet) attainable for all countries. As Antoinette (Interview April 7, 2022) from Niketan (Bangladesh) explains, government support is especially challenging for their target group: people with complex disabilities. *"…before it is really understood in these countries what their needs are, takes a lot of time. Also from the government, that they are really paying attention to this group, and are willing to invest in them… Which is also something that is complicated."* This being said, she also sees that there is a shift, especially in the last few years. *"we do see that there is more and more attention due to years of lobbying. '…' the attention from the government is growing, but also from the corporate world and individuals in Bangladesh, that they want to support this cause."*

This process however is highly dependent on the country, and perhaps also per region within the country. Niketan is already a very well-established organisation that has been operating since 1998, and they, therefore, have a lot of experience as well as credibility. In Story Box 29 their success story of giving two schools back to the community is shared.

What is also an important thing to take into consideration is that also the corporate world and individuals want to support their cause. What organisations should also focus on finding donors from within the country of operation, is something that Monique also stated. *"There are not always only poor people.. that's what we think 'those are poor countries.' Here in Tanzania Diamond Platnumz, the most famous singer here, bought a very nice Rolce-Royce."* (Interview with M. Derrez, June 2, 2022) Where this would make that there is no donor-dependability anymore, the dependability from foreign donors does reduce. Whilst there are great differences within a country as well, the expectation would be that they are already more aware of the true local needs compared to the foreign donors.

4.4.4 Concluding remarks

PDIs both are effective in achieving direct results, as the main cause of so-called white elephants. The latter is often caused due to a lack of local embeddedness. The critique regarding PDIs which often arises is that local voices are not taken seriously and that development projects are imposed on local communities, rather than letting development start from within.

The question however arises if it is possible to wait for development to start from within when it comes to taboo subjects, such as the care for children with disabilities. It could be said that this is kind of a grey area in which PDIs can operate. This being said, even if this is an idea which comes from an ‘outsider’ internal support is needed for it to be a success.

Another challenge which PDIs endure is their dependability on donors. Especially in the past, the focus often needed to be on satisfying the donor, instead of looking at the needs of the beneficiaries. This luckily has changed over the years, but donor-dependability remains a challenge for many organisations as they are seeking sustainability for their project.

The dependability on donors is reduced by for example generating other revenue streams, such as from guest houses. Furthermore, the suggestion is to look more towards local donors. Aside from ways how to make the revenue stream more sustainable, governmental support is also an essential element.

Especially when it comes to family-based care for children with disabilities, governments need to see that it is possible as they are often still very sceptic towards this. Therefore, also from this aspect including the government is of great importance.

5 Conclusion

With the use of constructivist grounded theory, this research aimed to find the answers to the following questions: What is the context and situation for a child with disabilities to grow up in the Global South*? And, How do the different non-governmental care providers operate in this area? In these questions, there were several sub-questions which were answered with the with use of predominantly interviews and observations and further underpinned with (non-) academic literature.

Looking at the first research question, one of the most important elements to note was the fact that despite the focus on the context and situation of a *child* with disabilities in the Global South*, it is important to consider the impact beyond the child. In answering the first sub-question: *What are the main challenges encountered by them and their families?* we saw that the challenges faced by the child are very much entangled with the challenges faced by their families. Having a child with disabilities poses an important threat to the social and economic well-being of the family, especially to the mother. The reason why the impact is even vaster for the mother has to do with the fact that she often receives the blame for giving birth to a child with disabilities, and also that she is at a greater risk of being abandoned by her partner. Also when this is not the case, the financial position of the family reduces greatly due to the increasing cost of care, the time investment needed to care for the child, and the fact that the child will need continuous care and support for the rest of its life and will in many cases not be able to eventually provide for its family, which often is one of the reasons of why people decide to have children in the first place. Altogether, this makes the risk of families being under the (extreme) poverty line augments. This is also why the direct family of the child with disabilities considers the financial challenge as the most important challenge which has to be faced.

Aside from this main challenge, the other challenges which are encountered are amongst others the practical challenges and cultural challenges such as stigma. Practical challenges are mainly encountered by children with (also) physical disabilities and are aspects such as architectural barriers and inaccessible buildings. When looking at the cultural challenges, the literature already showed some thin evidence towards harmful practices against children with disabilities such as them being hidden at home. This research however showed that the scope of harmful practices is more encompassing than previously suggested. Children being hidden at home appeared to be a common practice, and even more, severe practices such as abandonment and mercy killings appeared. In the case of abandonment, this could not solely be attributed to a disability but was more of a result of (extreme) poverty. Especially the last two harmful practices appear to also go hand in hand with the increased impact on the mother, as she is often abandoned by her husband and being pressured by her surroundings.

The stigma often stems from a misunderstanding regarding the disability. Where the origin of the stigma often differs per country and continent, the outcomes are relatively similar. What is simultaneously seen, is that creating options and an outlook for these children, often appears to reduce stigma. When children with disabilities are hidden, abandoned, or killed, people do not encounter them which makes the stigma can continue to exist, as a self-fulfilling prophecy. When children are more visible and they can show their development, the negative outlook towards them reduces. This also makes that often when a family-based initiative starts in a certain area, they had to actively look for children, but after a while, parents come out of their own initiative or are referred by others.

These are all elements which help to see what the context and situation are of a child with disabilities growing up in the Global South*. These three main challenges are all connected to one another to a certain extent, and it is depending on each individual case what actually has the biggest impact on the child and its family. In providing care to these children it is however essential that the socioeconomic position of the parents is taken into account, as this has a very strong impact on their capacity to take care of their children.

Aside from the harmful practices presented above, parents may also decide to place their children in residential care, which brings us to the second sub-question: *What is the reason for these children to be 'overrepresented' in institutional care, what are the reasons of why they end up in institutional care?* Whilst this research does not answer this question completely, it did help clarify the reasons why children with disabilities are placed in residential in the first place. Important to note here is that there is a general academic consensus that a child is always better off being raised in a family and that especially large institutional care should be avoided. Despite the little academic research which includes children with disabilities in institutions, the negative psychological impact that it has on these children is very similar. This consensus was agreed upon among the respondents, also the respondents that worked in residential care.

The four subcategories of reasons that this research brought to the light why children were placed in residential care were **practical reasons**, such as inaccessible roads/(school) buildings and no special education facility being nearby, **family-related reasons**, such as the child becoming unmanageable and families being unable to afford the additional cost of caring, **cultural reasons**, such as the effect on stigma on the child and the family, and **legislative reasons**, such as laws making institutional care inevitable for certain cases of for example abuse or after abandonment. These reasons are important to know, as they are the basis for the prevention of a child ending up in an institution, and they highlight what should be improved or changed to make sure that a child can be placed back in their family as part of the deinstitutionalisation process.

This brings us to the last sub-question of the first main question which is: *what is needed for these children to be raised in a family?* What we saw regarding the latter, is that deinstitutionalisation should not be a solitary goal, but a result of children being placed back in their families. In this, it is important to realise that this takes more effort than for abled children as the context and situation need to change within the family, referring back to the main challenges encountered by their families and the children. Furthermore, the family needs to be equipped with the right knowledge and tools to be able to care for their child, and need to receive adequate support to be able to work through the trauma and negative effects of institutional care. It is important to realise that care for a child in a family is a lot cheaper than care in an institution. The money that is attributed to caring for the child in an institution can therefore very well be used to fund this process. Moreover, it is the responsibility of the institution to provide the best possible care for the child. Therefore it could be said that it is the responsibility of the institution to see if the child could not remain with their family and to continuously assess this to see when it would be possible. Sometimes minor changes or financial help can cause a child to be able to stay with their family. What is expected, is that the different reasons for the institutionalisation of children with disabilities go from the easiest to fix (practical reasons) to the hardest to fix (legislative reasons).

The fact is however that there currently are many children in an institution who do not have any known family, and due to legislative reasons certain children are forced into an institution. In many cases, there currently is no formal foster care system. It would be interesting to see if this could be developed, especially for children that are abandoned or placed out of their homes due to (sexual) abuse. In these cases, with a lot of one-on-one support from personal caregivers, the needed care and support could be achieved. Furthermore, there is the case of a child becoming unmanageable for their parents. In these cases, a boarding school with a lot of involvement and visits from caregivers could be seen as a viable option at a later age. In many cases, these children are already of high school age, which reduces the negative impact on institutionalisation.

When looking at who provides the predominant care for children with disabilities, the literature already showed that in the Global South, this is mainly done by nongovernmental organisations. In this research, the focus was on NGOs and PDIs. As these are the main caregivers and therefore possess a lot of knowledge on the ground, they were considered important and interesting players to interview for this research. As this angle was not previously researched, the second half of this research focussed on finding out the answer to *How do the different non-governmental care providers operate in the Global South*?* In this research, the division among respondents can be made amongst initiatives that work in family-based care and initiatives that work in residential care. Unfortunately, there is a discrepancy between the number of respondents between the two due to a reduced willingness to participate in initiatives in residential care.

Looking at the family-based care providers, we can separate the ways in which they operate in two: support on the family level and care directly to the child. In answering *what are considered essential elements of care?* The first aspect is the fact that the family should be seen as the essential framework of the well-being of the child, where especially the mother plays a key role. As the social and economic position of the family weakens when they get a child with disabilities, it is especially important to support this framework. Furthermore, it is important to give parents the proper guidance in terms of the tools and knowledge which can help raise their child and stimulate its development, with the opportunity for early intervention as an important element. In the latter, health professionals play a key role to identify possible developmental delays. These tools given to the parents can be in the form of social and economic empowerment which allows them to get the emotional support needed from other parents going through the same challenges (such as with parent support groups), and economic assistance to secure their (often weakened) financial position. Caring for a child with disabilities thus starts with support for its family.

Occupational therapy is the first element of direct care for the child. Especially for children with cerebral palsy, this is of great importance. Unfortunately, in the way how it is currently structured by many organisations, it still requires a large (time) investment from the parents. The suggestion therefore would be to focus more on teaching the parents and caregivers to provide the therapy themselves, either in real life or via instruction videos online. This allows the child to receive therapy more often, which will augment the positive effect, and reduce the time investment of the parents having to travel back and forth. Furthermore, the occupational therapist can provide care to more people.

The second element is inclusive education. Education is provided in a lot of different ways and has different outcomes due to these forms. The outcomes of inclusive education can be subdivided into three categories which are: **education and personal development**, **relieving the caregiver** and **social integration.** These have a trickle-down effect in that stigma will be reduced, and also that the financial position of the family can increase as they can outsource the care for their child for a set amount of hours per day, in which the caregiver can now work. It is important to stress that all these elements are in essence of equal importance and that the personal level of importance truly depends on the specific case. Another focus point is the fact that children with disabilities are more vulnerable to exploitation and (sexual) abuse. It is important that this is considered by the social workers and education facilities, as these are the key players which can help to reduce the vulnerability of this group. Furthermore, education in this sense goes beyond learning how to read and write. Depending on the context, and also the needs and wants of the children and their families learning practical skills which allow them to be a part of their family can and should sometimes be prioritized.

As an important addition, the focus often remains on the *children* with disabilities, and not on the fact that they become adults that will continue to require support. There are individuals that will be able to work to some extent, and would strongly benefit from proper vocational training. This vocational training can be set around working around the household and learning a skill which they can use to for example work on the family farm. For the ones that will not be able to attain this level, an option could be to invest in assisted living. In this case, the parents can continue to outsource a part of their task to care, and their child can also go on to the next step in their lives.

Many of the Dutch initiatives work with volunteers from the Netherlands. In this, the volunteers generally are so-called ‘expert volunteers,’ and thus have something to add in terms of knowledge and expertise to the organisation. This is seen as a low-cost way to provide quality education and assistance to the people on the ground. This can truly be an addition, as long as the needs for a primary caregiver for the child are met and that the volunteer comes with a clear goal and focuses on training the staff to create a sustainable impact. Furthermore, many organisations do not require a code of conduct from their volunteers, despite the fact that this is mandatory when working with children in the Netherlands suggestion here would be to maintain the same standards for volunteers.

Another aspect to note is the fact that because these organisations often are independent, they often have their own methods. I believe that many of these organisations could benefit from more corporations. Instead of all of them separately having the same or similar challenges they have to face, they could benefit from learning from each other. Another element which I found challenging is the fact that in these methods, there often is no clear quality guideline or assessment. As for further research, it would for example be interesting to see what kind of educational method has the best possible outcomes. Furthermore, I think that general quality guidelines with clear assessments could be beneficial for these organisations, and perhaps should be something that we aim for.

The findings presented in this research will help these different initiatives as well as future initiatives and governments to better understand the context and situation of the children with disabilities growing up in their country. This can aid with the development of a structure in how to provide family-based care and translate the inclusive legislative framework into an inclusive reality.

In interviewing different organisations, it allowed me to carefully test the theory and achieve theoretical saturation as aimed for in Constructivist Grounded Theory. This being said, I do see limitations in the scope of this research. It cannot be said with certainty that this is applicable to the rest of the Global South, nor that the outcomes would be the same if the largest part of the interviewees were not from the Netherlands but from another country in the Global North, or predominantly local initiatives. Where the aim was to find as much literature as possible from researchers from the Global South, there is still a significant gap in the knowledge production from the Global South versus the Global North making the lens still more from a Global North perspective. It would therefore be interesting to ‘swap’ the perspective and to have this research conducted from another lens to see to what extent my personal perception coloured the outcome.

Reflecting on the process, I do believe that the choice for Constructivist Grounded Theory was the right one. In the first place as it allowed for a wealth of empirical research combined with literature. Furthermore, I trust that the position of the researcher as not being an unbiased person as placed in Constructivist Grounded Theory is very suitable for this type of research. It allowed for the needed flexibility whilst simultaneously giving guidelines for the process. Ideally seen I would however have visited more initiatives and more countries to complement the theory.

The observations and conversations with people from society were elements that I deem very valuable to this research, as this was something that I could for sure not have achieved from behind my laptop. This really allowed me to better understand these underlying social processes which are considered essential by Charmaz (2019). The approach here was mainly to find ways in how to speak with different people, without asking suggestive questions. These conversations were held with staff at the hotel, uber drivers, people in public transport etcetera. The challenge here however was that in the city people generally all spoke English, where this was not the case in the country side making that there I was more dependent on someone to translate for me.

As a suggestion for further research, I would consider taking a further look into to what extent certain ways of caring and quality requirements can be generalized to make the process of starting an initiative more effective and efficient. As said, many initiatives operate in their own ways and I believe they could benefit from more corporations and quality guidelines. Furthermore, it would be interesting to look at the prevention of disabilities. As we slightly touched upon in the Introduction, the majority of disabilities are in the Global South. These same organisations that now work on care for children with disabilities could perhaps play an important role in the prevention, especially so if they work closely together with medical professionals.

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7 Appendices

Appendix 1: Example Interview Guide

Florence Koenderink

Founder & consultant at family based care.

I am an independent consultant in child protection and alternative care reform.

I am currently under contract with UNICEF Kenya to ensure the inclusion of children with disabilities in the National Care Reform Strategy that will be implemented over the coming decade. For the purpose of this consultancy, I gathered quite a lot of information (it is not officially research) about the situation of children with disabilities in and out of alternative care in Kenya. I have also been working in India over the past 12 years, including with special education schools and government homes for teenagers with intellectual disabilities.

Ik schrijf momenteel mijn scriptie aan de Radboud Universiteit, voor Better Care Network Netherlands via wie ik ook uw contact gegevens heb gekregen en mijn onderzoek gaat over de context en situatie voor kinderen met een beperking waar ik kijk naar kinderen waar voor gezorgd wordt in een thuissetting, met bijvoorbeeld hulp van thuiszorg, en kinderen die opgroeien in een tehuis. We zien dat vaak kinderen met een beperking achter wegen gelaten wordt in onderzoek, en daarom is het juist belangrijk dat het gedaan wordt. Ik spreek zowel met mensen die een stichting met initiatieven voor alternatieve zorg en experts over dit onderwerp, als mensen die institutionele zorg initiatieven hebben. Mijn hoop is dat uiteindelijk met mijn onderzoek, en dus met alle ervaringen en verhalen die ik te horen krijg door interviews, en wellicht later ook door veld onderzoek, dat ik dan wat beter in kaart kan brengen wat nou de situatie en reden is voor een kind om op te groeien in een tehuis, versus in zijn of haar eigen familie en vice versa. Om dan uiteindelijk een bijdragen te leveren aan het verbeteren van de zorg voor kinderen met een beperking.

Tot dusver, heeft u al vragen voor mij?

Zou ik dit interview mogen opnemen? Dit is alleen voor mij om het terug te kunnen luisteren en het te transcriberen, en daarna verwijder ik het. Verder, in het onderzoek, zou ik u en/of uw stichting bij naam mogen noemen, of heeft u het liever anoniem? Dit kan natuurlijk altijd nog aangepast worden als u zich bedenkt.

What are the challenges and obstacles faced when providing alternative care to children with a disability?

a. What are the predominant practical implications faced, and how is this being tackled?

b. What are the cultural challenges faced when the child is taken care of within their own community and how is this being tackled?

c. What are the main challenges of the (extended) family or foster family in raising their child with special needs?

d. Are there situations where institutional care is considered inevitable? If yes, why is this the case, and could it ever be prevented?

- Nairobi → Issues with adoption. *What would be the best option?*
- Cultural differences between India and Kenya?
- Stigma → I read the blog, harmful practices. Different between the countries? How to be tackled? Did something change already in the past few years?
  In the model of alternative care *Awareness-Raising and Advocacy* for removing stigma is named as essential.
    - What do you notice of the effect of stigma on the socioeconomic position of the family?
- Model of alternative care: → Necessity principle, it cannot be adhered to, Suitability principle → Are there difficulties finding a suitable family-based solution?
- Nice how it is mentioned that this is very culturally sensitive, not one way is the best way.
    - How do you see the position of religion in stigma?

- According to suitability principle, institutional care is never an option. Same for children with a disability? Is institutional care sometimes a solution?
    - Do you see differences in effects on children with and without disabilities in your research?

Appendix 2: Observation Memo time in Nairobi

It is the first of May and I arrived in Nairobi around 12 hours ago in the early morning. I had (mentally) planned for a trip to Kenya to do fieldwork for a while now, but I made the final decision to go eight days ago. I have a tiny fracture in my kneecap and I am still walking on crutches, making the trip a bit more of a challenge. This being said, I barely have any pain anymore and I can walk quite easily (with the help of my crutches).

2-5-2022 Staff member at the hotel

I was sitting in a restaurant having lunch with someone I met at the hotel where I am staying. He is originally from the west of Kenya and moved here for work. He gave me a Swahili lesson this morning, and afterwards he showed me around the city centre.

Whilst having lunch on the terrace, which was located on the balcony of the first floor, we heard a man having a rant on his own on a busy square. My companion was smiling listening to it, and understood my questioning facial expression. *"He is just mentally not completely okay"* he said, with very little judgement in his voice, for as far as I could tell. *"If your city does not have a person like this, you did not come to the right place."*

I decided to ask how people with a disability were treated here. He said that they were often ignored and that that was wrong. "*they are also human beings."* I told him that we hear a lot about stigma in these places regarding people with a disability, and I asked him if I knew why there was a stigma. He said that it comes from the belief that people with a disability are possessed by the devil, or that they are bewitched. When I asked him if it was something that he believed too he said yes. *"Some people are possessed by the devil or bewitched, but not all of them. Sometimes they are just born like that, genetics, or they get an accident."*

3-5-2022 Uber driver

I was driving an Uber in the direction to visit Imani. Me and the Uber driver started a conversation about what I was doing here. He, coincidentally, actually visited multiple orphanages and also one where there were children with disabilities. As he said "*Stigma is still a big issue in Kenya. Children with disabilities are hidden, and put away. That is also why they are left behind."* When I asked him what he thought of that his answer was that it was wrong. *"These children also deserve a life, they were given a life by god. They should be reintegrated in society."*

3-5-2022 Imani

Imani is an orphanage for temporary care. Children that come there were found abandoned in Nairobi, often as babies. The goal of Imani is to put the children up for adoption, and for the vast majority of the babies coming in this is successful. Challenge however is with HIV infected children, the older children and also the children with a disability.

There are two main groups in Nairobi, Imani A and Imani B. In Imani A the babies and the young children are, up to 2 years old. This is where we first went to.

The uber driver dropped me off at the house of Gerrie. He lives close to Imani which is located in the West of Nairobi. Driving there was an experience. It was a drive of approximately 30 minutes and driving out of the city towards the west, made that the city transformed in front of my eyes. The car smoothly manouvering through the traffic as if there is some kind of choreography full of unsaid rules that everybody knows about, but is impossible to understand as a foreigner. The closer we were getting, the more life was taking place on the streets. The houses were smaller and provisionally made, the food was sold on the streets, and the cows were grazing alongside the streets. You could say, that the closer we were to arriving, the more it started to look like the Africa we know from the news.

Once arrived at Gerrie, we departed for Imani with his driver. Gerrie explained to me that he usually drives himself, but that it was time for the school fees and the therefore tried to create some more work for the driver. It was a short, but slightly hectic drive with a lot happening in the surroundings. Radiant colours, avocados for 0.5 Kenyan Shilling (which is 0.0041 euro cents), motorcycles, busses, houses of corrugated sheets, goats.. too much to see and absorb at once. In the midst of the hectic, there was a large green gate. The driver honked twice and the large gate opened. From the chaos of the street, we entered into serenity. A group of children gathered themselves and started to sing a song to welcome me and ended with a prayer.

It felt awkward. Having read so much about orphanages, the last thing I wanted is these kids to feel obliged to entertain me. I wanted to be the observing researcher, looking from the side line anonymously. Not being someone that needed entertainment.

But, the place looked nice. Friendly, there were two dogs, places to play and it was clean. This was Imani A where the youngest kids stay. Gerrie took me as a tour through the premises, and you could tell that a lot of things were well thought off. He barely is at Imani, as he also stated in the interview "*these are Kenyan problems, which should be fixed by Kenyans"* and they work with mammas for the groups to make sure that there is not that much changing for the children. Aside from this, there are also a couple of volunteers working there. I asked him about what he thought of the change in views towards voluntourism in orphanages.

"*For us it is a pity, we also do not advertise with it anymore as it brings bad publicity. The thing only is, if the donors want us to work without volunteers then fine, but we need more money to employ people locally. We don't have the money to replace them."* He also explained that they work with a lot of rules at Imani when it comes to the volunteers. They have to fill out a code of conduct and have a (VOG XXX). Furthermore, they are only allowed to work with the babies, not with the older children, there are always two people with the children, so nobody can ever be left alone with the kids, and they are only staying with one group for two weeks maximum to make sure that there is no bonding with the babies. The latter is to prevent creating attachment issues, but Gerrie is sceptical if the attachment issues really is due to volunteers as he said that the children that are brought there, already have trauma and attachment issues from the fact that they were abandoned by their parents. And, also children in families encounter people temporarily, an uncle and an aunt that live far away, a neighbour that moves away. Also in an ordinary family there is no full consistency for these children. The consistency here is created with use of having a fixed 'mama' on the group, and also by having everybody that works directly with them wear the same type of clothing.

What was good to see, is that the children were displaying normal behaviour to me (aside from the singing performance at the beginning). They were shy, did not come run at me, and looked at me from a distance. What should be the case with children of that age, which also consolidated me a bit about the attachment issues part. Gerrie also told me that a lot of babies when they first arrive, are very keen for attention and reach out to everyone they see. He stated that that is problematic behaviour, as babies typically are very much focussed on one person.

Their work with these babies very much is focussed on trauma prevention, they give a lot of attention and love to the children. One of the managing staff of the home said to me, when I asked her what she thought of having volunteers that it was good as "*we need people to support with giving love and attention to the babies. We have enough staff to make sure that the basics are taken care off, but not enough to make sure all the babies get enough hugs and love."*

Walking towards the final floor, we see a man, an occupational therapist, with 4 children with a disability. He comes there to work on the 'learning milestones' of the children as he states. There were two children of around 2.5 who could not walk before, and now can, one boy with cerebral palsy and a girl with autism. He said that there were around 10 children with a disability there with whom he was working to achieve these milestones, together with the main nurse of Imani.

A challenge there appears to be with the question what happens next with these children. From the interview I already understood that these children don't get adopted, but they actually are also not allowed to stay in a home by government regulation. What was explained to me, is that the majority of the more severely disabled children go to another location and get special education there. Someone of the managing staff there said that there, the chief of the village was very pushy about ensuring that all the children go to school in the village, also the children with a disability. However, there is not really an option for these children to live with assistance, or to get their place in society.

The occupational therapist said that the stigma in Kenya was severely reducing, and actually was not really prevalent anymore. He had studied specifically also to work with children with a disability, and he was working on the so called 'learning milestones' of these children. He for example explained that the two girls were 2.5 years old, and could not walk, but now were able to. '*They were not living up to their learning milestones, so that is what we worked on and now they do."*

Talking about prevention for these children to be abandoned, the main issue found is with extreme poverty. That is also why Imani works on prevention within the community. When they get a signal of the chief (XXX) that someone in the neighbourhood is falling down in a pattern which they recognize as to be a first step towards potential abandonment of one of the children, they get a signal. The social workers then go up to the mother with a basket of food to start the conversation, and often a job is created for that mother within Imani, and they take over the school fees from the children. As Gerrie explained to me when we were in the laundry area "*we have two washing machines, but the reason why we don't have more is because it takes a lot of electricity and water, and we do a lot of the washing by hand to create jobs for people in the community."*

In a conversation with one of the staff, she also brought up the option for legal abortion as a way to help these mothers out. She said, that if it would be normal to for example go somewhere where you could discuss your options, that person could also be helped financially to make that it would not be needed, or to indeed have an abortion if that is the only option.

When looking at children with a disability and government help, I asked them about the funds that I know that there are for these kids, and they said that the money was there, but it was impossible to get. Even though attempts are made, the corruption in the government makes it hard, if not impossible, to cooperate with them.

Another question that raised following the interview, was the question of children with Down Syndrome. As I learned later in other conversations with people, children with Down Syndrome are there, but they are just not at Imani. The managing staff also stated that they had indeed never had one in Imani. A reason for this could be that these children are brought directly to homes who are specialized in children with a disability (which Imani in essence is not), as it is easily recognizable. They however stated that they would try to figure it out. This, to ensure that there is not something worse happening to these children.

Then Imani B, this is where the older children go to. The goal actually is for children to not go to Imani B, as they should be adopted before they reach that age. The children that live here could be there for a multitude of reasons, it could be that their parents are temporarily placed out of parental care or that they suffer (sexual) abuse. In the first case, these children will most likely stay there temporarily until their parents can care for them again. In the second case the children will never go back to their abusers, but often will be placed with family eventually.

Another reason could be that they were abandoned at an older age, and therefore are not as attractive for adoption. And then there are the children with a disability and the children with an HIV infection, who were not adopted for this reason.

Important to realize is that the children with a disability that live there, mainly are ones with physical impairments. This would not necessarily be seen as a disability, but an example could be a young girl who had boiling water thrown over her as a baby and still has scarring in her face and misses a couple of fingers. These children are all mixed together and go to local schools, some of them go to private schools. This depends on what their personal needs are.

There they live in small family homes with around 8 children spread over 3 rooms and a fixed mama who sleeps there with them. This is to create a family feeling for them with stability. They can grow up there and eventually get supported through university and keep the connection with their family. As Gerrie said in the interview, they are now the ones that get invited to weddings and at official moments such as graduations.

However, the children that were at Imani B were not the children that had severe disabilities, nor true mental impairments. These children were placed in another location called Imani Malindi. As was explained to me, there they could go to a special education school and enjoy a place with no stigma. The children that go to that school are not only from the home, but also from the village. And as one of the managing staff of Imani B said, "*there is no stigma there. The chief will go to the houses of the people in the village of the disabled children and ensure that these kids go to school."*

But, when I asked them what happens to the kids when they grow up. They could not really answer me. It seems that up to 18 years old they are well taken care off, or at least to the best to their abilities. However after they are adults there is no infrastructure in place which supports them. This is not yet a very big problem as they only relatively recently started accepting children with a disability, but it is something to consider. It seemed that this question also moved them, where does an abandoned child go with a disability who can not live on their own?

8 Dutch Summary

'Zorg voor kinderen met een beperking in het mondiale Zuiden'

Samenvatting scriptie

Céline van Schaik, Radboud Universiteit, januari 2023

In de academische literatuur is de aandacht voor kinderen met een beperking in het mondiale Zuiden beperkt. Er mist veel specifieke data en context, waardoor het eigenlijk niet mogelijk is om een duidelijk beeld te schetsen waar deze kinderen en hun families mee te maken krijgen, en wat ze nodig hebben. In de afgelopen jaren is de hoeveelheid beleid, regelgeving en internationale mandaten[2] gericht op mensen met een beperking wel toegenomen. Het ondertekenen van internationale mandaten, en het aannemen van inclusieve wetten zijn een stap in de goede richting, zeker omdat ze zo ruimte geven tot lobby en kunnen helpen met het uitvoeren van druk op overheden. Tegelijkertijd is het voor veel landen simpelweg nog niet mogelijk om te voldoen aan deze mandaten door tal van oorzaken, zoals beperkte middelen of gebrek aan draagvlak.

Onderzoeksmethodologie

Dit onderzoek had als doel om te onderzoeken wat de context, uitdagingen en situatie is waar een kind met een beperking in het mondiale Zuiden mee te maken krijgt en de rol die buitenlandse initiatieven en NGOs daarin spelen. De resultaten zijn een combinatie van interviews met acht initiatiefnemers van organisaties die werken met kinderen met een beperking (familiegerichte en residentiële zorg), vier werknemers van NGOs (uit Nederland, Bangladesh, Kenia en Kameroen), drie ervaringsdeskundigen met een (fysieke) beperking, twee ouders van kinderen met een beperking (cerebrale parese en autisme), en een expert op het gebied van alternatieve zorg in het mondiale Zuiden. De geïnterviewden kwamen uit zes verschillende landen in het mondiale Zuiden. Ook deed de onderzoeker veldwerk in Kenia en bracht zij o.a. bezoeken aan een weeshuis en aan een initiatief dat zich inzet voor familiegerichte zorg. Samen met academische literatuur, boeken en documentaires vormde dit de basis voor de scriptie.

De context van een kind met een beperking in het mondiale zuiden

Een kind dat geboren wordt met een beperking krijgt met diens familie te maken met uitdagingen die onder te verdelen zijn in drie categorieën. Dit zijn *praktische uitdagingen*, welke gelinkt zijn aan toegankelijkheid, toegang tot hulpmaterialen (zoals rolstoelen en blindenstokken) en gebrek aan kennis over wetgeving (zoals verplichte toegankelijkheid op school). Doordat de omgeving van deze kinderen vaak niet toegankelijk is, worden kinderen met een fysieke beperking die hun mobiliteit vermindert, soms in residentiële zorg geplaatst. *Economische uitdagingen* gaan over (a) zorglast wat er voor zorgt dat een van de ouders thuis moet blijven, (b) toenemende zorgkosten, soms wel 2-3 keer zoveel als een gezin met kinderen zonder beperking, en (c) het wegvallen van een toekomstig financieel vangnet voor ouders omdat ouders soms kinderen krijgen in de hoop dat zij later voor hen kunnen zorgen. Onderzoek in Kenia heeft aangetoond dat gezinnen met een kind met een beperking een veel grotere kans hebben om onder de armoedegrens, of zelfs extreme armoede grens te komen. Deze economische uitdaging is dan ook de prioriteit van de meeste gezinnen. Ten slotte zijn er *culturele/sociale uitdagingen* zoals stigma. Dit gaat over de sociale druk op het gezin en het kind, zoals uitsluiting, wat uiteindelijk negatieve gevolgen heeft op het kind. Dit wordt door veel organisaties gezien als het grootste (initiële) probleem.

Stigma lijkt het meeste aanwezig te zijn voor mensen met een mentale beperking. Hoewel stigma in alle landen voorkomt, heeft het vaak een verschillende basis. Beperkingen worden bijvoorbeeld gezien als een straf van God, slecht karma, hekserij of een gevolg van een zonde van de moeder. In veel culturen wordt de schuld gelegd bij de moeder, en is er een link met religie. Dat laatste blijkt eerder een culturele opvatting te zijn, dan een religieuze onderbouwing te hebben. Met goed begrip van religie, kan het stigma juist doorbroken worden.

De sociale druk die op een gezin komt te liggen na de geboorte van een kind met een beperking is enorm. Veel moeders worden achtergelaten door hun man, uit huis gezet door de schoonfamilie of gezinnen worden verstoten uit de gemeenschap. Hierdoor verslechtert de sociale positie van vooral de moeder, en in veel gevallen ook

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[2] Convention on the Rights of Persons with Disabilities | OHCHR (2006)
N1938707.pdf (un.org) (2019)
Guidelines on Deinstitutionalization, including times of emergency (2022)

haar economische positie. Deze combinatie zorgt er voor dat ouders overgaan tot daden van wanhoop: het verstoppen van kinderen, het achterlaten van kinderen, of zelfs doding, de zogenoemde 'mercy killings'.

Het voort blijven bestaan van stigma ten opzichte van mensen met een beperking lijkt voor een groot deel hand in hand te gaan met de onzichtbaarheid van mensen met een beperking. Omdat er geen interactie is met mensen met een beperking, wordt het (negatieve) beeld dat mensen hebben over beperkingen in stand gehouden. Als er al een interactie is, is dat vaak met individuen die nooit op de juiste manier gestimuleerd zijn waardoor diens potentie niet gezien wordt. Het wordt op deze manier een 'selffulfilling prophecy'.

De respondenten gaven aan dat uitzichtloosheid en het gebrek aan opties een grote rol speelt in hun leven. Op het moment dat er bijvoorbeeld mogelijkheden zijn voor kinderen om naar school of dagopvang te gaan en er hulp en begeleiding is, verandert de houding ook. Initiatieven moeten bij de start van een project vaak actief op zoek gaan naar deze kinderen die thuis verstopt zijn. Na verloop van tijd melden steeds meer ouders zelf hun kinderen aan of worden ouders doorverwezen door vrienden en familie.

Zorg voor kinderen met een beperking

Er zijn veel verschillende manieren waarop voor kinderen met een beperking gezorgd wordt: van zorg binnen de familie tot residentiële zorg. Het is niet bekend hoeveel kinderen met een beperking in het mondiale Zuiden in residentiële zorg wonen. Academici geven aan dat her naar verhouding meer kinderen met een fysieke beperking in residentiële zorg verblijven, maar exacte aantallen zijn er niet. In de meeste gevallen zijn kinderen met en zonder een beperking gemengd. De negatieve effecten van residentiële zorg op kinderen (sociale problemen, hechtingsproblemen, concentratie problemen etc.) worden ook teruggezien bij kinderen met een beperking, waarbij kinderen met een beperking nog een hoger risico lopen.

Waarom een kind met een beperking in een instituut geplaatst wordt, kan worden onderverdeeld in vier verschillende categorieën (willekeurige volgorde):

1. Praktische redenen: zoals ontoegankelijke wegen, geen speciale of toegankelijke school in de buurt, geen therapie.
2. Familie gerelateerde redenen: zoals armoede en de zorg van het kind niet meer aankunnen.
3. Culturele/sociale redenen: het effect van stigma op het kind en de familie.
4. Procedurele redenen: zoals wetgeving die er voor zorgt dat een kind niet in een (tijdelijke) alternatieve gezinssituatie geplaatst mag worden, en naar een tehuis wordt gebracht.

Voor een groot deel kan uithuisplaatsing dus voorkomen worden door het (financieel) versterken van de gezinssituatie, of bijvoorbeeld het oplossen van praktische obstakels. Het is hier belangrijk om te realiseren dat het goedkoper is om een kind thuis op te laten groeien dan in een instelling. Het gebrek aan passend onderwijs is een heel belangrijke reden voor ouders om kinderen in een tehuis te plaatsen. Hulpverleners geven echter aan dat in de praktijk vaak toch mogelijk is om de school toegankelijk en bereikbaar te maken voor kinderen met een beperking.

De genoemde procedurele redenen is een grotere uitdaging. In Kenia is het bijvoorbeeld zo dat als een achtergelaten kind naar een weeshuis gebracht wordt, het pas na 6 maanden geadopteerd mag worden zodat de ouders de kans krijgen het weer op te halen. In Sri Lanka mag een kind dat uit huis is geplaatst omdat er bijvoorbeeld seksueel misbruik plaatsvindt, niet (tijdelijk) ondergebracht worden in een gezin, maar wordt deze ook verplicht in een tehuis geplaatst. In deze gevallen lijkt op de korte termijn plaatsing in een tehuis niet te voorkomen.

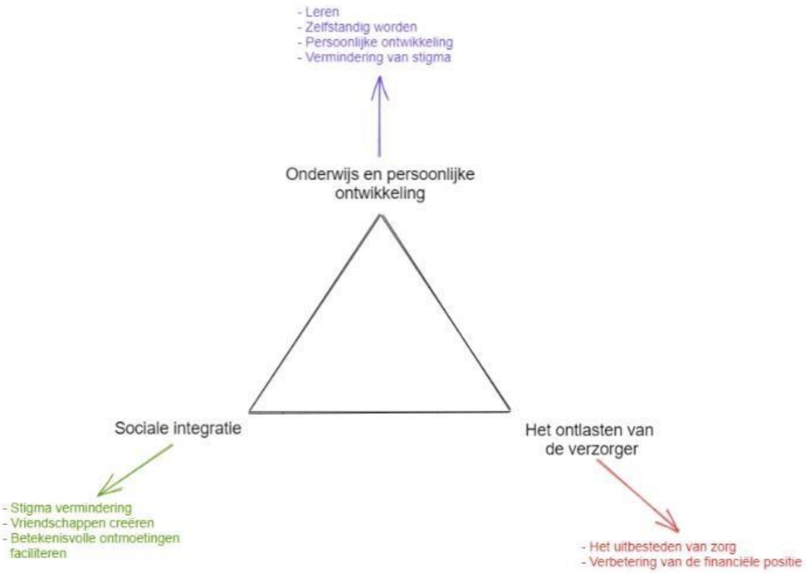
Family-based care

Uit alle data blijkt dat het krijgen van een kind met een beperking veel druk legt op de financiële en sociale situatie van een gezin. Het is daarom in eerste instantie van belang om de financiële en sociale positie van deze gezinnen te versterken. Een eerste stap is vaak om opvang te regelen, in de vorm van een *dagopvang of onderwijs*, om de zorg deels uit te besteden. Door de extra kwetsbare financiële positie van deze gezinnen, is het daarnaast ook belangrijk ouders te ondersteunen bij nieuwe *inkomsten genererende activiteiten, spaargroepen of andere steungroepen*. Deze steungroepen van ouders, vooral moeders, bieden financiële kansen, maar vooral ook een versterking van de sociale positie doordat ze kennis en ervaring kunnen delen en elkaar kunnen steunen.

Andere steun aan ouders, zoals het verstrekken van de nodige *informatie en kennis* om goed te kunnen zorgen voor het kind en het kind te stimuleren in diens ontwikkeling is van groot belang: het leren begrijpen van een beperking, ondersteuning in het verzorgen en grootbrengen van een kind en het controleren en helpen in de thuissituatie. Hoe eerder het opgemerkt kan worden dat een kind meer ondersteuning nodig heeft, hoe groter het effect zal zijn op diens ontwikkeling. Hier speelt vooral de noodzaak tot adequate kennis en handelen van (medische) professionals een grote rol. Er ligt zelfs bij artsen nog vaak een taboe op het bespreken van een mogelijke beperking met de ouders, waardoor dit soms gewoonweg niet gebeurt.

Toegankelijke *ergotherapie* is, vooral voor cerebrale parese (een van de meest voorkomende beperkingen) essentieel. Vaak zijn organisaties afhankelijk van een enkele ergotherapeut die alle therapieën uitvoert. Er kan veel gewonnen worden in het actief aanleren van de ouders hoe ze hun kind kunnen begeleiden. Het distribueren van *video's en apps* aan mensen die niet in de buurt van een plek wonen waar ze therapie kunnen ontvangen is ook behulpzaam. Dit zorgt er voor dat kinderen zich beter kunnen ontwikkelen, en ook dat de professionals meer kinderen kunnen helpen.

Ook van groot belang is het om het reguliere onderwijs toegankelijker te maken. Dit kan worden gerealiseerd door architectonische obstakels weg te nemen en leraren te trainen en te ondersteunen in hoe ze een veilige leeromgeving kunnen creëren voor kinderen met een mildere mentale beperking. Speciaal onderwijs moet daarnaast beschikbaar zijn voor kinderen die (nog) niet regulier kunnen meekomen, of in een hybride model.



Toegang tot onderwijs heeft drie belangrijke effecten die gepresenteerd zijn in het figuur hiernaast. Er wordt hier gesproken over onderwijs, maar hier valt dagopvang ook onder. Deze drie effecten zijn in principe even belangrijk, maar zullen verschillende prioriteiten hebben per vorm van onderwijs, per kind, en per gezin. Voor een kind met een extreem complexe beperking, is het aspect van educatie minder belangrijk, maar wegen het ontlasten van de verzorger en sociale integratie weer meer dan voor een kind dat maar net niet mee kan komen met regulier onderwijs en wat meer persoonlijke aandacht nodig heeft.

Binnen de organisaties die inclusief onderwijs verzorgen die voor dit onderzoek geïnterviewd zijn, zijn er weinig scholen die op alle drie de aspecten gelijk scoren. De vorm van onderwijs is verschillend, en de prioriteiten daarmee ook. Vanuit dit onderzoek is het niet mogelijk om te zeggen of er een systeem is dat 'beter' is, zeker omdat ieder systeem voor een ander persoon een andere uitwerking zal hebben.

Het aanbieden van onderwijs gaat dus verder dan het aanleren van alleen maar de lesstof. Het geeft kinderen een plek in de maatschappij, vermindert daarmee het stigma en het ontlast ouders. Wat nog een stapje verder gaat, is onderwijs gericht op persoonlijke ontwikkeling. Hier leren kinderen zichzelf beter kennen en zich uit te drukken, wat vooral essentieel is voor kinderen die niet kunnen spreken. Mensen met een beperking zijn kwetsbaarder voor allerlei vormen van misbruik. Het is daarom van belang dat deze doelgroep leert over en zich bewust wordt van hun rechten en hoe ze duidelijk kunnen maken als ze iets wel of niet willen. Het kunnen delen wanneer iemand iets heeft gedaan wat ze niet fijn vonden, het kunnen stellen van vragen, of voor zichzelf op kunnen komen kan een groot verschil maken in levenskwaliteit.

Aanbevelingen aan PI's

- *Focus op doelgroep 18+*. Het is van groot belang het kind en diens familie voor te bereiden op het leven als volwassene en eventuele zelfstandigheid. Door vaardigheden te leren zoals bijvoorbeeld houtbewerking, omgang met vee en werken op het land kunnen ze (deels) aan deze verwachtingen voldoen van de ouders. Ook als ze economisch niet kunnen bijdragen is het van belang dat ze vaardigheden leren die ze kunnen toepassen binnen het huishouden, zoals schoonmaken, koken, en boodschappen doen. Voor kinderen met complexe handicaps is het belangrijk op de lange termijn te zoeken naar bijvoorbeeld begeleid wonen of dagbesteding met leeftijdsgenoten.
- *Betrek de lokale overheid*. Deze organisaties doen in principe het werk van de overheid, met geld wat voornamelijk uit het mondiale Noorden komt. Hier zit een dualiteit in waar gezocht moet worden naar een

balans. In veel landen is zorg voor kinderen met een beperking nog geen prioriteit. Door dit soort particuliere initiatieven hebben veel kinderen een kans gekregen zich te ontwikkelen, maar soms is het de vraag of deze organisaties daarmee tegelijkertijd bijdragen aan het creëren van een passieve overheid.

- *Focus op duurzaamheid.* De hoofdinkomsten komen momenteel vaak nog van donateurs uit het mondiale Noorden, en worden soms ondersteund door andere geldstromen uit bijvoorbeeld verhuur of guesthouses. Wat vaak vergeten wordt is dat in veel gevallen er best gevraagd kan worden om een kleine bijdrage, door de gebruikers van de zorg, het dorp, het district of overheden. Ook kan er gezocht worden naar lokale donateurs en bedrijven.
- *Zorg er voor dat projecten binnen de lokale context passen*. Zeker bij taboe onderwerpen kan het van belang zijn om als organisatie het voortouw te nemen, maar het is en blijft essentieel dat wat er gedaan wordt, past bij de lokale cultuur en dat er draagvlak is binnen de gemeenschap.

Meer info?
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