Incorporating the Perspectives of Disabled African Adults and Parents of Disabled African Children in Aotearoa New Zealand's Healthcare System Design

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Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor used artificial intelligence tools or generative artificial intelligence tools (unless it is clearly stated, and referenced, along with the purpose of use), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signed:

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13 November 2024

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Abstract

The purpose of this study was to explore the experiences of African people with disabilities and African parents of children with disabilities with healthcare services in Aotearoa New Zealand. Although participation in healthcare system design in Aotearoa New Zealand is known to improve health outcomes for communities involved, little is known about the experiences of African people with disabilities and African parents of children with disabilities.

In recent years, new government departments and ministries have been established to increase the participation of people with disabilities and ethnic[1] minorities. However, none of these discussions have addressed the participation of African people with disabilities. This showed that the narratives about an inclusive society did not necessarily address the cultural barriers that African people with disabilities face in Aotearoa New Zealand, including healthcare services. To explore this gap, a qualitative case study was conducted in the North Island of Aotearoa New Zealand, Auckland, and Waikato, to shed light on the experience of African people with disabilities and African parents of children with disabilities in the healthcare system.

The case study included a focus group in Auckland with three adults who identify as African and live with disabilities. They shared personal stories about what it means to be African and live in Aotearoa New Zealand. Additionally, individual face-to-face interviews were conducted with two of the same focus group participants to focus specifically on their experiences of living with disabilities. This approach respected the participants' privacy, as discussions about disabilities were not always appropriate in a group setting.

The case study also included African parents of children with disabilities. Individual online interviews were conducted to explore their experiences with healthcare services in the Waikato region of Aotearoa New Zealand. The semi-structured interview questions did not focus on their children's disabilities; instead, they centred on the parents' experiences with healthcare services and their perspectives on what an intersectional approach to healthcare system design would look like.

The research used intersectionality as a theoretical framework, social constructionism as a

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[1] The term “ethnic,” in the context of this research, refers to those who are migrants, refugees, long-term settlers, and those who identify as Asian, Continental European, Middle Eastern, Latin American, and African, regardless of their birth country (Nakhid, 2016)

philosophical position underpinning the data gathered in the focus group and individual interviews were analysed using narrative analysis. Through narrative analysis, a number of themes and subthemes were generated. Under the main theme of being African, subthemes were being part of Aotearoa New Zealand society, being diverse, and being collective. Several sub-themes emerged from the main theme of cultural barriers to the participants' access to appropriate healthcare services in their respective regions. These sub-themes were lack of appropriate community organisation for African and Muslim people with disabilities, lack of control over their disability support, lack of agency, lack of awareness of disability resources, and perception of discrimination.

1. Chapter One: Introduction

Aotearoa New Zealand’s disabled community is the largest minority group in the country, making up 1.1 million people, or 24% of the population (Statistics NZ Tatauranga Aotearoa, 2014). Statistics NZ Tatauranga Aotearoa (2014) categorised the rate of disability within different ethnic groups: Māori (26 percent), European (25 percent), Pacific (19 percent), and Asian (13 percent). Although the available data on disability shows a breakdown within the European, Māori, Pacific and Asian communities, there is an absence of available data on the percentage of African people living with disabilities.

People with disabilities represent the highest user rates in the healthcare system, highlighting the importance of accessible and equitable healthcare services (Office for Disability Issues, 2022). According to the 2018 Aotearoa New Zealand census, 6,890 African people reside in the country, with a median age of 26.5 years, and an almost equal gender distribution (8,619 males compared to 8,265 females). Yet no specific statistics exist on the prevalence of disability within this group (Statistics NZ Tatauranga Aotearoa, n.d.).

Despite Aotearoa New Zealand’s advanced standing on the United Nations’ Human Development Index (United Nations Development Programme, 2024), incorporating the needs of domestic disabled communities, particularly ethnic minorities, has seldom been prioritised or emphasised in major policy frameworks. In 2020, the Heather Simpson report on the health and disability system review did not address disability until page 150 (Health and Disability System Review, 2020). This has led to feelings of exclusion within the disabled community, who felt marginalised in a review that was meant to encompass their concerns. Human rights lawyer Dr. Huhana Hickey (Waikato and Ngāti Tahinga) highlighted this saying,

> Nobody I know – and I know quite a few in the network – has heard a thing. If there's consultation, it’s definitely not been reaching us yet—unless they plan it for September—because we've heard nothing (Radio NZ, 2021)

In response to the review, Dr. Hickey added, “We don’t know what to do, where to go, we don’t know what the services are going to look like, we don’t know what the future is” (Radio NZ, 2021). This shows that despite Aotearoa New Zealand ratifying the Convention for People with Disabilities in 2008, it remains unclear how the disabled community was included or consulted in decisions affecting their lives.

Moreover, African people living with disabilities in Aotearoa New Zealand face even further alienation and marginalisation. The recent development of the Enabling Good Lives (hereafter EGL) framework[2] did not consult with disabled ethnic minorities, including African people with disabilities and their families, according to an Official Information Act request (Official Information Act Request, May 5, 2022, see Appendix 1). This exclusion reflects broader systemic issues of underrepresentation and marginalisation in policy-making, which extend to healthcare service design.

The exclusion of African people with disabilities from key frameworks like EGL, raises critical questions about the participation of disabled ethnic minorities in programmes that are aimed at improving the lives of all people with disabilities in Aotearoa New Zealand. This type of exclusion highlights the need for intersectionality - a concept introduced by African American legal scholar Kimberlé Crenshaw. Intersectionality offers a framework for "understanding the ways that multiple forms of inequality or disadvantage sometimes compound themselves and create obstacles that often are not understood among conventional ways of thinking" (Crenshaw, 1989, p. 149).

Although intersectionality has appeared in several government reports, such as "Negotiating Multiple Identities" (Roy et al., 2020) as a means of addressing the overlapping identities and the lack of privilege in groups within ethnic minorities, which includes Africans and their families, there remains a significant gap in how this is applied in practice, particularly in the context of healthcare system design. In the case of African people with disabilities, their experiences of marginalisation are shaped not only by their disability but also by their ethnic and cultural background. This gap underscores the urgent need for a more inclusive and intersectional approach to healthcare system design that acknowledges the unique experiences of African people with disabilities in Aotearoa New Zealand.

This research aims to explore the intersectional challenges faced by African people with disabilities

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[2] The Enabling Good Lives (EGL) framework is an approach developed in partnership between Aotearoa New Zealand Government and the disability sector to inform the disability system transformation . It is intended to shift power and authority from the government to disabled people and their families. For more information, refer to https://www.enablinggoodlives.co.nz/about-egl/egl-definition/

and African parents of children with disabilities in accessing healthcare services in Aotearoa New Zealand. It will investigate how current health service design excludes their voices and what can be done to create more equitable and culturally competent systems that respond to the needs of all disabled people, regardless of their ethnic background. Through this study, the goal is to contribute to a better understanding of the ways that healthcare system design can integrate both disability and cultural considerations, using intersectionality as a guiding framework for more inclusive practices.

The thesis will be organised in the following way:

Chapter One will provide brief statistics about the disabled communities in Aotearoa New Zealand, along with their representation in the healthcare systems. It will also highlight the lack of statistics specific to African people with disabilities, along with the background of the number of African people in Aotearoa New Zealand. Secondly, the introduction chapter will highlight the lack of consultation with disabled ethnic minorities in major disability frameworks, such as EGL programmes. This chapter will also point to the lack of an intersectional approach to Aotearoa New Zealand's healthcare system design to provide a rationale for advocating for intersectionality in healthcare system design to ensure holistic and more inclusive access to disability services for all disabled people in Aotearoa New Zealand, including Africans with disabilities. The aim of the research will also be stated, along with the desired outcome to ensure equitable access to healthcare services for African people with disabilities and African parents of children with disabilities.

Chapter Two will provide a summary of the NZ Disability Strategy to provide context to the larger strategy that guides disability work in Aotearoa New Zealand. That will be followed by a brief history that preceded the evaluation and adoption of the EGL framework into the larger systemic change in Aotearoa New Zealand’s government departments and community organisations, specifically in the Aotearoa New Zealand health context.

The literature review will also include research from Australia, which was conducted by the Melbourne University Institute of Disability, to hear from Australian Africans who live with disabilities. Following that, the cultural perspective in the context of health service design in Aotearoa New Zealand will also be explained in relation to research conducted by Waitemata DHB’s Child Development Service, along with other DHBs and agencies, working with disabled people from the Muslim community in Aotearoa New Zealand. The literature review chapter will conclude with a number of crucial concepts such as co-design, disability design, and design justice. These will provide background to the processes behind the various government and community organisations as initiatives to ensure the participation of all people in Aotearoa New Zealand, including people with disabilities and their families, and people from ethnic minorities.

This chapter will also include detailed explanations of three paradigms. These are intersectionality, social constructionism, and stratification theory. Social constructionism will also be used to provide a philosophical underpinning for understanding the social environment in which African people with disabilities and parents of African children with disabilities find disabling. The stratification theory of disability will provide context for how disability was not seen as a social identity in the same way as others, such as race, gender, socioeconomic class, and others. This will justify the need for considering disability as a social identity that should occupy equal space within healthcare system design as other social identities.

Chapter Three will include the research methodologies to generate an understanding of how the research participants, African people with disabilities and African parents of children with disabilities in Auckland and the Waikato region, experienced the healthcare systems in Aotearoa New Zealand. In this qualitative research, purposive sampling was used to recruit adult members of the African communities in Auckland and the Waikato regions, who either lived with disabilities or had a child living with a disability. Community outreach and online advertisements were utilised in the recruitment process, and potential participants were screened against different categories that will be further explained in the methodology chapter.

The data collection will include a focus group, individual face-to-face interviews, and individual online interviews with parents of children with disabilities. In Auckland, the focus group involved three African adults with disabilities to explore their African cultural background and their experience of living in Aotearoa New Zealand. Furthermore, individual face-to-face interviews were conducted at different times and locations with two of the focus group members, who provided written consent to discuss their lived experience with disabilities. In the Waikato region, two African parents of children with disabilities took part in individual online interviews to discuss their lived experience with healthcare services in Aotearoa New Zealand. Narrative analysis was used in the data analysis stage and was guided by intersectionality and social constructionism as theoretical frameworks.

Chapter Four will contain the themes and subthemes that were generated from the participants' answers. Theme one, being African, will consist of three subthemes: we are part of Aotearoa New Zealand society, we are diverse, and we are collective. Theme two, cultural barriers to accessing disability support services, consisted of five subthemes: lack of appropriate community organisation for African and Muslim people with disabilities, lack of control over their disability support, lack of agency, lack of awareness of disability resources, and perception of discrimination.

Chapter Five will discuss the intersectionality of disability with other social identities that arose in the data analysis as social factors that influenced the participants' experience with healthcare services. These are ethnicity, religion, age, socioeconomic class, and gender. The chapter will conclude by answering the main research question in relation to the existing disability framework by incorporating principles from the EGL approach and applying intersectionality enablers to the themes. These links will add an intersectional lens to the principles of EGL from the perspectives of African people with disabilities and the African parents of children with disabilities.

1.1. Researcher's Position

On a personal level, I am African, and I also have a disability known as dyslexia. My primary experience comes from my experiences as a consumer of disability and health services. I arrived in Aotearoa New Zealand in March 2004 to join my mother, who had one child with cerebral palsy. This was a full-time job for my mother to provide care for my brother at home, which was also part of my experience as a family member. My mother was frequently imprisoned in Africa due to her political orientation, and my younger brother was born with physical disabilities because of the insufficient care within the harsh environments she lived in during her pregnancy.

On a community level in Aotearoa New Zealand, I did not find disability services that worked with people from African backgrounds in culturally appropriate ways that holistically considered disabling factors in the consumers' lives. For example, in my experience, the Disability Needs Assessment was accessible only to those who had a disability representative body within their community, such as social workers, counsellors, or general practitioners, who would initiate the process by referring those who are suspected to have a disability for a Disability Needs Assessment. At the systemic level, the disabling factor was the lack of such a service in the African community, due to the disability organisation working under the umbrella of Maori, Pasifika, Asian, and other ethnic backgrounds that did not include African people.

Within the African community, including families, disability was viewed as a medical condition that needed medical attention. Therefore, the narratives that influenced the available disability services were either based on a medical model, which defined disability as something inherently wrong with the individual, or social models that were based on Eurocentric views of the social environment, which differed from that of African people.[3] Being at the intersection of all these factors was disabling, in that it compromised my access to disability resources that were necessary for me to achieve equal access to social goods, such as health and education.

The knowledge available about which practices are most effective for disabled people from diverse ethnic backgrounds in Aotearoa New Zealand was developed in consultation with community leaders who lacked experience with disability, with no input from those with lived experience of disability. This was clear in the Working with Muslim Families and Disabilities toolkit, where healthcare practitioners were advised to refer Muslims with disabilities and their families to the Muslim Imam as the first point of contact for those diagnosed with disability (Waitemata DHB, n.d., p. 5).

My involvement in activism in Sudan shaped my worldviews. Sudan is a Northeast African country with a population of about 45 million, and an area expanding 1.886 million square kilometres. It has been going through a civil war for almost 40 years, which has caused significant mental disabilities, as well as physical disabilities, to those affected by the conflict. I am professionally involved with civil rights organisations in Sudan. My organisation is called Technologies for Sustainable Development, with almost 500 members performing various tasks across the different levels of the organisation, from frontline members making physical contact with Sudanese people, including people with disabilities, to others who work in the background in matters related to policy, design, and funding. Through my involvement in this organisation, I have developed some expertise in the area of disability, including communication skills with vulnerable people, where kindness, soft manners and active listening to others have been the keys to effectively engaging with this population group.

Locally, I am active in my community and advocating for the participation of people with

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[3] This finding was based on my experience while looking for an African disability organisation in the community.

disabilities and parents of people with disabilities in all aspects of life, including fairer access to healthcare services. I belong to the African community of Aotearoa New Zealand as well as the Muslim community of Aotearoa New Zealand. My immediate family is of African and Japanese origin, and multiculturalism is an integral part of my identity.

Academically, I graduated from the University of Canterbury in Christchurch with a Bachelor of Arts with a philosophy major. I also completed a postgraduate certificate in Social and Community leadership from the University of Auckland, where I learned social innovation frameworks and systems thinking. Following that, I obtained a Postgraduate Diploma in Human Rights from Auckland University of Technology. I applied these skills in my organisation and engagement with stakeholders, including Sudanese people with disabilities, refugee camp staff, local government, and other civil rights groups, to effectively include the voice of disabled people in matters relating to them, including healthcare service design.

2. Chapter Two: Literature Review

2.1. Introduction

This literature review aims to explore key publications that have influenced the participation of people with disabilities in healthcare system design. Following this, a summary of research focused on disabled African Australians will be provided to contrast the epistemological landscape to that of Aotearoa New Zealand's, along with primary design concepts that guide Aotearoa New Zealand's healthcare and disability service design, specifically focusing on co-design and participatory design.

Additionally, the review seeks to identify and highlight the gap in these frameworks, particularly the absence of intersectional analysis, which is essential for addressing the complex needs of disabled ethnic minorities, including African people with disabilities and parents of African people with disabilities. This will be followed by the theoretical framework underpinning the research project.

2.2. The New Zealand Disability Strategy 2016-2026

The New Zealand Disability Strategy 2016-2026 is based on the current use of the Te Tiriti o Waitangi and the Convention on the Rights of Persons with Disabilities to ensure that disabled people participate in the decision-making that directly impacts them (Ministry of Social Development, 2016). The United Nations Enable (n.d.) defines disability as "…those who have long-term physical, mental, intellectual, or sensory impairments that, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others."

The strategy serves as a key framework guiding government agencies in meeting their human rights obligations (Ministry of Social Development, 2016). It aims to enable disabled people to reach their potential and ensure their full participation in the community by eliminating barriers to achieving these outcomes. Based on the partnership between the government and the disabled community, several mechanisms were developed for independent monitoring and engagement with recommendations from the Committee on the Rights of Persons with Disabilities (Ministry of Social Development, 2016).

The strategy identifies eight main key outcome areas, including health and well-being, with the aim of improving the quality of life of all disabled people, regardless of gender, ethnicity, sexual orientation, and all other protected characteristics (Ministry of Social Development, 2016). Furthermore, it emphasises the need for treating disabled people with dignity and respect by healthcare professionals, being seen as individuals, and having all their health needs met with appropriate and timely care instead of focusing on their impairment in isolation from other health needs. The strategy calls for reducing barriers to accessing mainstream health services and gives due regard to sexual and reproductive health services for disabled women and girls. Furthermore, the strategy outlines timely access to specific services for disability impairment, including habilitation, rehabilitation, and early recovery services for specific impairments (Ministry of Social Development, 2016).

However, despite these positive interventions, the strategy overlooks some of the unique challenges faced by people with disabilities from ethnic minority groups, particularly from the African community. These groups face multiple forms of marginalisation in health system design, including systemic racism and discrimination, which compound the difficulties of navigating the healthcare system.

2.3. Development Within the Ministry of Health's Services

In the broader context of Aotearoa New Zealand's healthcare system, the Ministry of Health, alongside the Ministry of Social Development, were invited in 2011 by then Minister for Disability Issues Dame Tariana Turia to work with an independent group of stakeholders from the disability sector to develop a clean sheet approach to community participation (Were, 2016, p. 10). Through initiatives such as Day Services and community participation services, these Ministries provide support for daily living skills, education, social activities, and recreational opportunities for disabled individuals. These discussions have led to proposals aimed at restructuring the disability system to provide better access to services that align with the principles of the EGL approach (Were, 2016).

The proposal to shift from group-based services to a facilitation support model reflects a broader move towards individualised care. This model focuses on four key principles: self-directed planning, cross-government individualised portable funding, strengthening family support, and fostering community building. These principles are intended to offer greater autonomy to disabled individuals, allowing them to take more control over the services they receive. Meanwhile, pilot programmes in the Waikato region, supported by Gordon Boxall, the Director of the EGL programme in Christchurch, and Mark Benjamin, an Evaluator from Standards and Monitoring

Services, have begun implementing these models, encouraging government departments to explore flexible contracts and service combinations to improve outcomes for disabled people.

2.4. The Enabling Good Lives (EGL) Approach

In 2010, the EGL approach started as a grassroots initiative informed by disability organisations, disabled people, and their families. This collaborative approach included the Independent Working Group, the collective influence of the "Coalition," the Christchurch Plan Material (nine independently coordinated community forums), the Waikato Plan Material, and the EGL National Leadership Group (Wilson & Benjamin, 2022).

The EGL framework is dynamic and complex, involving multiple stakeholders and evolving processes. The EGL framework was evaluated in Waikato and Palmerston North in the North Island of Aotearoa New Zealand and Christchurch in the South Island of Aotearoa New Zealand and to understand the experience of people with disabilities who participated in a pilot project in Palmerston North in the North Island of Aotearoa New Zealand and Christchurch in the South Island of Aotearoa New Zealand to assess ongoing innovations and adaptations.

The EGL approach encourages a future where disabled children, adults, and their families have greater choice and control over their lives (Wilson & Benjamin, 2022). It is underpinned by eight principles that guide the partnership between disability communities and the government: self-determination, beginning early, person-centred, ordinary life outcomes, mainstream first, mana enhancing – mana being a Māori concept defined as "power, authority, and dignity" (Mika et al., 2022, p. 441) – easy to use, and relationship building (Wilson & Benjamin, 2022). These principles guide the change that happens at the government level, the organisational level, and the healthcare services that are delivered to disabled individuals and their families.

Designing healthcare services across two different contexts, such as disability and health, can be complex, especially when, traditionally, these services have lacked a disability service design centred around the needs of the individual. By adopting the EGL principles, health service designers can adjust their service co-design practices to align with the principles of the EGL approach.

2.4.1. Developmental Evaluation and the EGL Approach

One of the main practices used to ensure the effectiveness of the EGL framework was developmental evaluation. Its main aim was to inform present and future systemic change within the healthcare systems and the larger government level, where the experiences of disabled people and their families were evaluated against the principles of the EGL. The goal is to include all disabled people in Aotearoa New Zealand by informing frameworks that give them control over the change they seek and what that change looks like for people with disabilities and their families.

Developmental evaluation - also called real-time, emergent, action, and adaptive evaluation – is an approach that informs and supports the development of innovations and adaptation in complex and dynamic environments. It asks, for example, evaluative questions and applies evaluation logic through collecting and presenting data to provide feedback for projects, programmes, products, and organisational development. The context influences how development evaluation is made and understood by considering the outcome and impact, including formative and summative assessment (Patton, 2010).

To ascertain the effectiveness of EGL, Were and Crocket (2019) conducted an evaluation based on 55 interviews with disabled people and their families in the North Island of Aotearoa New Zealand. The results showed that 95 per cent of the participants who participated in the pilot project of the EGL programme in the Waikato region thought they achieved their desired outcomes, indicating that the EGL approach led to positive outcomes for disabled people.

Despite these positive results, there were notable limitations in the inclusion of ethnic minority groups, particularly African people with disabilities and African parents of people with disabilities. As mentioned earlier, African people with disabilities and African parents of children with disabilities did not participate in this evaluation. This highlights the lack of participatory processes for disabled ethnic minorities in the health and disability design and implementation of disability services in Aotearoa New Zealand. As a result, the development of the EGL framework and the Ministry of Disabled People are limited in their applicability to these communities.

2.4.2. Phases of Evaluation in the EGL Programme

Between 2015 and 2019, there were a number of ways in which the EGL programme was demonstrated. Between July 2015 and June 2017, the EGL programme was evaluated to understand the effectiveness and how EGL may lead to positive change for disabled people and their families, organisations, and systems. The evaluation went through three phases with a focus on the extent to which disabled people, and their families, felt/thought they had achieved the outcomes that they desired or expected.

The Evaluation of the Waikato EGL Phase One was published in February 2016, when Louise Were, a local evaluator, prepared the report for EGL Waikato Leadership Group and Joint Agency Group. This evaluation identified emerging outcomes and key learnings from the implementation of the EGL approach in the Waikato region. It also offered a reflection on the progress made by disabled people and their families in navigating the new system and how it compared to previous models of care (Were, 2016).

The Evaluation of the Waikato EGL Phase Two was published in October 2016 and focused on identifying "possibilities" such as creating opportunities that were easier to implement within the community than previous systems. It also focused on fostering relationships at the system level to ensure continuous support for participants. Connecting with others was seen as an effective way to provide ongoing support, especially for those with complex social and health needs. It highlighted the role of young people in doing "ordinary things" as opposed to parents and grandparents being the sole caregivers (Enabling Good Lives Waikato, 2016).

The Evaluation of the Waikato EGL Phase Three, published in April 2019, was based on three main evaluation questions to explore the experiences of the disabled people and their families who participated in the demonstration phase. It focused on the most valuable and less valuable parts of participants' and their families' engagement with the EGL framework. It also focused on what worked for them and the challenges they encountered during the demonstration and the way they dealt with these problems and changes (Were & Crocket, 2019).

The EGL also included tools for organisational self-review. These tools shift authority from systemic control to empowering disabled people and their families to have control of their choices and own livelihood. They enable organisations to identify their areas of strength and areas of potential development guided by the EGL principles. These include:

- Enabling disabled persons, families, and support staff to contribute to service development.
- Determining areas of current strength.
- Gathering the experiences and perspectives of individuals related to how they believe the

service is contributing to their creating a good life for themselves.

- Identifying the ‘next steps’ for development.
- Providing a framework for organisations to prioritise actions that are intended to assist them in becoming more fully aligned with an EGL-based approach.
- Assisting organisations to identify what “guidelines”/resources will be of most value.
- Enabling the measurement of “change over time”, according to an outcomes approach, directly related to the EGL approach.

The key evaluation questions as well as the evaluative framework, were co-developed with the participants. The way of gathering information about people's needs and the ecosystem was also co-developed with participants. The participants were also included in the review of the information to gain more insight into the journey of disabled people and their families, as well as the EGL Waikato partners.

These evaluation phases were key to understanding the experience of the EGL programme, which informed the design theories and practices of disability services, including healthcare services. The first question was focused on the extent to which disabled people effectively achieved their desired outcomes and whether there have been any unexpected outcomes during the demonstration phase. According to Were and Crockett (2019), 91% (37 out of 41 respondents) thought that they achieved at least half or more of the things that the participants had set out to achieve in the past year or two, with others expressing that they are making progress, albeit slowly. It was largely a successful demonstration, with the majority of the participants providing positive responses to achieving positive outcomes.

The second question was focused on the extent to which the EGL Waikato demonstration supports disabled people and their families having more control over their own lives. It focuses on outside factors that are related to disabled people and families reaching their desired outcomes and what supports or hinders them from achieving these outcomes. The third question focuses on the EGL Waikato demonstration itself, its delivery, and ways to improve it.

The respondents felt much more independent and able to focus on things that matter to them. There was also a focus on disabled Māori people who felt that the EGL programme made them feel safe and supported in comparison to the disability services they experienced previously. For example, they felt that the creation of Kaitūhono/Connectors validated their Māori identity. EGL Connectors are people assigned to support people with disabilities to navigate complex situations and systems. It is a facilitative approach that applies to all participants, including those with very high and complex social and health needs. Through ongoing facilitation, coaching or intensive support, these Connectors link the EGL participant through services. The Connectors used a multidisciplinary approach, emphasising new connections and exchanging ideas of what a fulfilling life looked like for the participants.

The relationship between the Māori participants and the Connectors allowed for open and ongoing communication as ways to strengthen the relationship. Mātauranga informed practice was perceived as responsive to Māori participants. Mātauranga is "the body of knowledge originating from Māori ancestors, including the Māori world view and perspectives, Māori creativity and cultural practices" (Te Aka Māori Dictionary, n.d.). Among the participants, 7% were of Pasifika background who felt they had more opportunities, choice and freedom and viewed EGL as family-focused. It was seen as an asset in terms of connecting with the extended family as well as the community, which made them find a place they belong to whilst also feeling accepted.

The participants' experience was positive in that the EGL framework provided more flexibility, freedom, and control over their own lives. The demonstration process enabled them to receive their own budget and operate under the EGL principles, which related to the increase of independence, building confidence and relationships. Furthermore, it included providing people with disabilities with the choice of who comes to their home, which included educational and sporting spaces, and other aspects of their social lives, such as cultural activities. One of the principles underpinning the EGL approach was self-determination. According to the participants who took part in the evaluation phase, although they felt that their workload in managing their own work support increased compared to previously being handled by agencies, they thought the advantages of managing their own budget were worth the time they spent.

2.5. Aotearoa New Zealand Ministry of Disability and Ethnic Minorities

In 2022, the Aotearoa New Zealand government established a new Ministry of Disabled People - Whaikaha. It adopted the EGL Approach as the overarching service and organisational design framework to achieve the full participation of all people with disabilities (Ministry of Disabled People Whaikaha, n.d.).

A similar focus has been initiated to include ethnic minorities across all levels of Aotearoa New Zealand society, and hence the establishment of the new Ministry of Ethnic Communities. Nevertheless, neither the focus on disability nor the ethnic communities have led to frameworks that recognise those who are at the intersection of these social groups – disabled Africans and parents of disabled Africans. This shows the gap in the inclusion of disabled ethnic minorities within the larger ethnic communities in Aotearoa New Zealand.

2.6. Cultural Perspectives in the Context of Health Service Design in Aotearoa New Zealand

Waitemata DHB child development service (Waitemata DHB, n.d.), along with other DHB and agencies, created a toolkit for working with disabled people from the Muslim community. The toolkit that informed working with disabled individuals from the Muslim community was produced mainly by referring to the cultural views and how they differed in different Muslim communities due to cultural differences.

For example, Muslims from African countries may differ from those of Asian backgrounds due to the distinct cultural and political contexts of their countries of origin. One key difference lies in gender roles, which are shaped by varying political landscapes where religious values influence social policies. These religious and political dynamics determine the extent of freedom or oppression experienced, which in turn shapes differing perspectives on gender (Wormald, 2024).

The guiding framework of working with people with disabilities from a Muslim background was largely focused on an Islamic perspective on disability in that reasonable accommodation was seen in their way of accommodating the Islamic way of being. Together with emphasising interconnectedness, the role of family members, and the hierarchy in the families and communities, the framework highlighted the importance of the Imam in the Muslim community. Moreover, it provided an Islamic perspective on health and emphasised the importance of seeking medical treatment as a duty that Islam lays on people of Islamic faith.

The toolkit highlighted the roles of Imams and community leaders in the Muslim community and regarded them as the first point of contact, which included those who have recently been diagnosed with a disability. It also referred to the New Zealand Disability Strategy 2001, which emphasised a fully inclusive society and adopted the social model of disability as opposed to regarding it as a medical model. Furthermore, the toolkit drew on the United Nations Convention on the Rights of Persons with Disabilities as a guiding framework for achieving justice for all disabled people in Aotearoa New Zealand, including those of Muslim background. However, the toolkit did not explain how the perspectives of Muslim people with disabilities informed the development of a social model of disability and matters that relate to them, including the choice of who they should be referred to when they are diagnosed with a disability.

2.7. Research with Disabled African Australians

Although the experiences of disabled Australians were found to be challenging across the board, looking through the lens of African contexts highlighted the intersectional nature of the exclusion of African Australian people with disabilities from participating in healthcare system design in Australia (Spivakovsky et al., 2020).

Research funded by the Institute of Disability at the University of Melbourne, and conducted in partnership with Abundance Community, a community organisation dedicated to supporting disabled Africans in Australia, generated an understanding of the experience of being an African Australian in accessing the National Disability Insurance Scheme (NDIS). The research drew on their experiences with the National Disability Insurance Scheme (NDIS) as well as their worldview of NDIS as a scheme that could potentially facilitate their access to other opportunities such as employment, housing, and social activities. Gaining such an insight into their experience also highlights the intersecting factors African Australians with disabilities experienced with other social sectors, such as housing, employment and others.

This research, in partnership with a local social support service dedicated to supporting Africans with disabilities, generated a number of findings where its contribution went beyond the NDIS as a sole agency, into a systematic approach to other social issues such as housing, family violence, and social development, which resided beyond disability services in their technical sense. For example, although family violence was discussed in many research studies and policies across Australia, this research found some specific concerns that were not otherwise known in the general population. The result of this research generated knowledge about family violence against disabled African Australians and brought context to their specific needs (Spivakovsky et al., 2020).

2.7.1. Social Attitudes Towards Disability in the African Australian Context

Stigma and shame were also found to be issues that the participants faced (Spivakovsky et al., 2020). Stigma and shame in the African context had other causes that were not common in the general population, including non-African disabled Australians (Spivakovsky et al., 2020). For example, disabled African participants explained their struggle with some traditional African beliefs which regarded disability as a way of spiritual punishment that a higher being, such as God, created this disability in the person because of a bad deed. The benefit of an intersectional approach to aid understanding of the experiences of disabled persons with intersecting identities supported the participants in highlighting their cultural context, where their environment is influenced by reasons that were not common in other cultures. The meaning of shame and guilt among participants was thus constructed in such a way that was relevant to their cultural identities.

2.7.2. Finding Awareness of the National Disability Insurance Scheme

Researching the experiences of African Australians with disabilities found a lack of awareness of the National Disability Insurance Scheme among the participants. The limited approach to raising awareness of the mainstream NDIS, and the challenges the community-led initiatives for raising awareness were also brought to light by co-researching with community-led organisations such as Abundance Community, where disabled African participants were involved.

2.7.3. Process Challenges

The research also found that the participants from this community experienced challenges with the NDIS process such as applying for assistance, the amount of time that they had to wait for an outcome on their application, the type of information required by the NDIS and their lack of clarity of such process was also brought to the fore by researchers and the variety of reasons for their applications to be declined due to insufficient evidence, and the required documents not being easily obtainable by people from refugee backgrounds. This highlighted the need for a system-led approach to facilitating this process, where participants have fairer outcomes for disability support and services that they apply for.

2.7.4. Refugee Experience

From these findings comes the experience of being a refugee, and what that means in terms of the overall challenges that refugees face in the host country, including cultural and linguistic tensions that most, if not all, refugees face. This tension asserts meaning to the cultural and linguistic context needed for effectively including disabled people from this particular background. The type of concerns that brought anxiety and issues of trust among the African Australian people with disabilities was mainly seen in the perception of the government's actions, such as taking their children or family members away from them as a result of having a disability.

2.7.5. Australian Research Outcomes

2.7.5.1. Recommendation 1: Need for Specialist, Representative Community Organisations and Sustainable Funding

The research partners emphasised the need for a specialist representative for sustainable funding to support their multifaceted work with the African Australian communities.

2.7.5.2. Recommendation 2: Appreciation of African Needs and Backgrounds

Another recommendation was formed on the basis of the difficulties that the participants found with the application process, and the finding of this problem was the basis of an alternative process where the participants suggested that the NDIS come and see them and visually see their physical disabilities to alleviate the burden of the application process. It also highlighted the desire for African community workers to create processes and practices that are more culturally sensitive.

2.7.5.3. Recommendation 3: Employment Opportunities for African Australians in the NDIS

The final recommendation was to increase the disabled African community's representation with the NDIS as part of the overall concern for cultural sensitivity and strengthening community organisations that are culturally competent, through which issues such as cultural safety are sustained.

Although this research with African Australians with disabilities was the only research that included the participants' voices, the community organisation is still advocating for fair access to health services for disabled Africans in Australia. The fact that there was a community organisation advocating for disabled African Australians in Australia shows a positive form of leadership, advocacy and research focusing specifically on the intersection of disability.

International research highlighted the intersecting factors that the participants experienced with other social sectors, such as housing, employment, and others. It showed that working in partnership with local social support services dedicated to supporting Africans with disabilities generated several findings with its contribution that went beyond the NDIS as a sole agency to contribute to a wider change into a systematic approach beyond disability services (Spivakovsky et al., 2020). This included social services such as housing, a family violence approach to disabled African people in Australia, and administrative challenges that the participants found in engagement with health and disability services (Spivakovsky et al., 2020).

2.7.6. Summary of Research with Disabled African Australians

To support an intersectional approach to understanding the barriers and exclusion that the disabled ethnic minorities in Aotearoa New Zealand face in accessing health services, I drew on research in Australia focusing on disabled African Australians and their experience with mainstream services such as Disability Insurance Schemes (NDIS). The research found that disabled African minorities had unique problems that the health and disability services were not aware of due to their exclusion from the initial consultation processes with people with disabilities (Spivakovsky et al., 2020).

The difference between the research conducted by the EGL project, and the Abundant Community Organisation in Australia is that in the former case, the research used a singular axis to refer to the participants' identities as only being disabled while in the latter case the research included the participants to factor in their cultural background to understand the overlapping identities and the privilege among the disabled communities. The literature indicates the differing methodologies used in researching disability and disabled communities. It is mainly seen in the literature on intersectionality.

2.8. Design Concepts and Practices

Design refers to design at the policy, service, and research levels. Many design theories and practices claim to support the principles of achieving social justice. They base their accounts on premises such as inclusive designs and fair participation of all social groups (Dombrowski et al., 2016). Similarly, full participation of historically marginalised groups such as people with disabilities and people of ethnic minorities has been at the centre of many discussions on local, regional, and national levels, particularly since the establishment of the Ministry of Disabled People and the Ministry of Ethnic Communities. Furthermore, there have been several initiatives and programmes that aim to achieve these values by including these populations in the design of healthcare systems that they access. In what follows, the concepts of co-design, co-design in Aotearoa New Zealand, disability design, and design justice will be explained.

2.8.1. Co-Design

In Aotearoa New Zealand, co-design is defined as

> The involvement of people in the design of health-related processes, services, information, models of care, strategies, environments and policies that impact them. It may also be called participatory approaches, co-creation and co-production, each of which can be interpreted slightly differently. Co-design intentionally brings consumers, whānau, communities and staff together to understand their experiences and gather their ideas for improving the health system and achieving more equitable health outcomes for all New Zealanders. (Te Tāhū Hauora Health Quality & Safety Commission, 2023, paras. 2–3)

2.8.2. Co-Design in Aotearoa New Zealand

The current development in the disability sector has brought co-design into the centre of theoretical and practical change within the disability sector in Aotearoa New Zealand (Office for Disability Issues, 2019). The multifaceted change requires a deeper reflection on the co-design context and processes across the various health and disability systems and how these changes may feed into The Strategy's ultimate goal. The recent development of government programmes specific to disability sectors focuses on the shift from designing for the disabled community to designing with the disabled community (Office for Disability Issues, 2019).

In health service design in Aotearoa New Zealand, co-design is based on the patient's involvement; it is centred around providing high-quality, effective and safe care for patients. The co-design practices revolve around the development of a design toolkit to guide co-designers through the methods of patient involvement. Health NZ uses this framework to guide those who are starting new service improvement projects, new processes, products, or services. These include starting a new service improvement project, developing a new process, product or service., exploring a specific service issue and deciding what to do about it, e.g., reducing waiting times, wanting to understand services from the patient perspective, undertaking exploratory work where you may not exactly know the nature of the problem or how you are going to tackle it, and implementing changes (Boyd et al., 2010).

The Department of Prime Minister and Cabinet produced a factsheet named Services for Disabled People (Department of Prime Minister and Cabinet, 2021). This fact sheet for disabled people refers to the health system as a system that consists of two related but distinct areas. One is support services that are specifically designed for disabled people, and the other part is the health service provision to disabled people. This fact sheet highlighted a gap in terms of equitable health outcomes for the disabled community. It emphasises the need for a stronger consumer voice in the design of locality services and planning, which would give disabled people opportunities to shape services that better suit their needs and help them stay well in the community.

The factsheet refers to disability transformation as the backbone of improving performance and outcomes for the disabled community. As such, the new Ministry for Disabled People was established in 2022 for the delivery of disability support services and the overall development of the disability system transformation as a whole. It also includes a "whole of life" approach, which was one reason for the Ministry of Disabled People to be hosted by the Ministry of Social Development.

Another major change was seen in the Ministry of Health replacing 20 district health boards with one nationwide health system under the umbrella of Health NZ. This is based on improving quality and consistency when caring for people with disabilities. The focus on better practice has shifted from regional coordination to national coordination, in which all communities, regardless of where they are located, can access such services.

The disability transformation and the disability strategies have been developed for better outcomes in the context of the Ministry of Health, Māori Health Authority, and Health NZ. An example of this is the networking and integration of primary and community services to make care more coordinated, minimise repetition, and ensure carers have a better understanding of users' needs. For example, Health NZ would advocate nationally to ensure that best practice and service design reflect the diverse interests and needs of disabled people, ensuring that disabled people have access to more specialised care when needed, regardless of where they live in Aotearoa New Zealand.

2.8.3. Disability Design

Participatory design emphasises the direct involvement of the end users and stakeholders, for example, patients, community organisations, such as health promotion and disability service providers, hospital staff, health and disability support workers, in the co-design processes. Tools, products, environments, businesses, and social institutions are built through direct involvement where all concerned parties have participated. The design standard practice and tools used to further progress the process include information, communication technologies, and other kinds of services and products.

2.8.4. Design Justice

Design justice is a field of theory and practice that is concerned with how the design of objects and systems influences the distribution of risks, harms, and benefits among various groups of people (Costanza-Chock, 2020).

Costanza-Chock (2018) defines design justice as

> A field of theory and practice that is concerned with how the design of objects and systems influences the distribution of risks, harms, and benefits among various groups of people…Design justice is also a growing social movement that aims to ensure a more equitable distribution of design's benefits and burdens; fair and meaningful participation in design decisions; and recognition of community-based design traditions, knowledge, and practices. (p. 2)

Design justice focuses on the ways that design reproduces, is reproduced by, and/or challenges the Matrix of Domination (white supremacy, heteropatriarchy, capitalism, and settler colonialism). Design justice is also a growing social movement that aims to ensure a more equitable distribution of design's benefits and burdens; fair and meaningful participation in design decisions; and recognition of community-based design traditions, knowledge, and practices. One of the concerns of Design justice is the concept of intersectionality. An intersectional approach to design theories and practices is intimately connected with the principles of Design for Justice. Designers who subscribe to this framework view design processes as often reproducing inequalities faced by minorities and marginalised groups (Costanza-Chock, 2020).

Many theories and practices can be viewed as intersectional, in that they base their analysis on more than one characteristic, for example, gender, sexuality, social class, race, etc. Some are more explicit than others. Collins (1990) provides her analysis in The Matrix of Oppression. The Matrix of Domination, often called the Matrix of Oppression, arose from Black feminist epistemology which aims to approach the interlocking systems of oppression that marginalised and "othered" groups are categorised in these interlocking systems as race, gender, class as interlocking systems of oppression. It views power as one structural through disciplinary, hegemonic, and interpersonal. As such, it aims to support marginalised groups coming to the forefront. Concepts such as the Matrix of Oppression (Collins, 1990) have also influenced designers whose work focused on design justice, where intersectional concerns are sought to be addressed in the design process. They view the current design process as practices that reproduce inequality, written about by the lack of an intersectional approach, as explained by the Black feminist scholars (Costanza-Chock, 2020).

This chapter used perspectives from design justice and discussed the methodologies needed for the inclusion of disabled African minorities in health service design in Aotearoa New Zealand. Although the research design was built on the work done by African-American feminist theorists, it considered the historical differences between the scholars in the U.S. and the participants' context in Aotearoa New Zealand. It did so by considering the issues of alienation from the lens of disability and the cultural perspectives of the disabled African minorities in Aotearoa New Zealand.

2.9. Theoretical Frameworks

This research uses three main ideas to understand the experiences of disabled African people and parents of African people with disabilities in Aotearoa New Zealand. The ideas underpinning the theoretical framework of this research are intersectionality, social constructionism, and the stratification theory of disability. They help explain how different identities, such as race, gender, and disability, all work together to affect how people experience healthcare systems in Aotearoa New Zealand.

2.9.1. Intersectionality

The theoretical framework of this research is underpinned by the concept of intersectionality, which can be viewed as a paradigm to highlight the multifaceted identities and social factors that influence the rights of people (UN Partnership on the Rights of Persons with Disabilities & UN Women, 2021). Additionally, intersectionality considers the intersections between identities and social aspects, and how privilege and power structures are present in our society, which are influenced by patriarchy, ableism, colonialism, homophobia, and racism. The lens of intersectionality is used to contextualise the compounding nature of discrimination to understand the differing experiences of disability between gender, ethnicity, and other protected characteristics (UN Partnership on the Rights of Persons with Disabilities & UN Women, 2021).

Crenshaw proposes intersectionality with the marginalisation of African American women as the most explicit framework on intersectionality as an analysis model. This framework was coined due to a lack of an analytical framework to explain how different social forms of marginalisation intersect, in legal analysis where personal characteristics such as race and gender were viewed separately, overlooking the multiple forms of marginalisation that African American women experienced (Crenshaw, 1989).

Crenshaw does not view race and gender as mutually exclusive categories of experience and analysis (Crenshaw, 1989). This was seen in her critique of anti-discrimination law, where the focus was on issues that dealt with gender, and antiracist policies that focused on race. The problem with these policies, Crenshaw explains, was that they relied on a single axis of analysis where the attention was either on gender or race, but not both. Coming from an antiracist African American feminist perspective, Crenshaw (1989) found that to be problematic because these frameworks did not capture the core of the problems that Black African American women had tried to explain. Furthermore, she referred to Black women's experience as being misrepresented with the single-axis analysis that ignored the multidimensionality of their experience (Crenshaw, 1989).

Crenshaw argues that single-axis analysis creates a theoretical gap in these laws and policies and limits feminist and Black feminist theorists from broadening their frameworks of antiracist analysis, exposing them to simultaneous forms of social alienation. Single-axis analysis is used to describe how anti racist and anti-discrimination frameworks only view legal claims based on a single identity, such as gender, without considering its intersection with others, such as race. On this basis, she coined the phrase intersectionality as a way to describe the experience of those who remained invisible as a result of being at the intersection of these identities such as African American women who face discrimination on more than one background for being of African American background as well as being women (Crenshaw, 1991).

The intersectional approach to remedying such multiple types of invisibility was also discussed in Crenshaw's metaphor, where race is depicted as a street that often intersects with other streets, such as gender or age. The burden that she found was in the way that African American women had to prove their racial claims within the existing anti-racism framework while dealing with another claim of gender discrimination within the anti-discrimination law and policies. The dilemma that Crenshaw was trying to conceptualise came out of these analytical frameworks that did not consider the intersection of the multiple types of invisibility (Crenshaw, 1991).

Moreover, intersectionality is also explained in relation to the experiences of the privileged group members, causing intersectional concerns for those who were silent within the group. For example, Crenshaw (1989) refers to the differing experiences between Black African women and Black African men, where women are oppressed in the race category as well as the gender category, as opposed to Black men who are only marginalised due to their racial background but not their gender. In other words, the antiracist laws only benefited Black African American men, while the anti-discrimination laws only benefited white women, leaving Black African American women out of both laws.

2.9.2. Social Constructionism

The research study is also framed around social constructionism. It focuses on defining disability according to the participants' lived environment (Andrews, 2012). The study argues that the context and processes of the intersectional approach to health service design should come solely from those with lived experience. This contrasts with religious and community leaders, who have historically been the main, and often the only, sources of knowledge about disabled African minorities and their families in Aotearoa New Zealand.

It is the researcher's position that disability is socially constructed, and hence, the inclusion of disabled people in healthcare system service design will be guided by the social group with the lived experience of disability and exclusion. This will enable the researcher to understand how all the participants view their social environment and how disability is constructed. Inclusive methodologies within the health and disability field often employ social constructionism as a theoretical framework (Ollerton, 2012). Social constructionism regards disability as a socially constructed identity (Garland-Thomson, 2008). Social constructionists adopt this paradigm to challenge essentialism, which argues that "things have an essence which can be defined and understood in the same way by all rational people" (Ollerton, 2012, p. 3).

Social constructionism rejects the notion of a fixed reality and instead adopts the perspective that the world is continuously shaped through social processes, emphasising the role of individuals' interactions and interpretations in constructing their understanding of the world as well as the interpretation of others (Garner, 2007; Gergen and Gergen, 2004, as cited in Ollerton, 2012). While the understanding of disability is mainly influenced by the medical model of disability (Altman & Meltzer, 2016), social constructionism aligns with social theories of disability; it describes disability as a societal failure to consider human diversity as opposed to a failure of individuals with disabilities (Pfeiffer, 2001). Baynton (2001) emphasises this account by arguing that the social context, social norms, the built environment, and institutional practices typically experience biological differences. Fish (as cited in Shifrer & Frederick, 2019) further argues that poverty, state violence, and dangerous workplaces are explicit social factors that are direct causes of disability.

Such societal failures have also occurred in Aotearoa New Zealand. The lack of inclusion of minority groups in matters that relate to them was a reincarnation of frameworks that separated people into separate and unequal groups. Dr Oliver Sutherland, a founding member of the Auckland Committee on Racism and Discrimination, pointed to the overrepresentation of Māori children in psychiatric institutions, when people with mental illness or disabilities were institutionalised in facilities such as the Lake Alice Unit, where serious abuse, such as physical violence, sexual and emotional abuse, neglect, and threats were practices commonly perpetuated by staff, including psychiatrists (Every-Palmer & Sutherland, 2023).

Although the psychiatric and disability institutions did not explicitly target people of Māori background, it was in the broader sense that children who identified as Māori were more likely to be admitted to these facilities as part of a wider healthcare system design approach that discriminated against Māori based on their racial background, which increased their likelihood of acquiring a disability as a result of various types of physical, emotional and sexual abuse within these institutions. This shows that the construction of disability as a social identity should not be conceptualised separately from other social identities, such as race, as one form of discrimination might contribute to other forms in equal measure.

2.9.3. Stratification Theory of Disability

To combine social constructionism with intersectionality, this research will use the stratification theory of disability. The stratification theory advocates for social constructionism in that it views dominant characteristics such as race, class and gender as socially constructed, and points to how social patterns have shaped the cultural values of normalcy and disability. Additionally, they view disability as integral to the construction of the stratifying axis, such as race, class, and gender, in such a way that it must be considered in conjunction with other categories from the starting point (Altman & Barnartt, 2001; Omansky Gordon & Rosenblum, 2001).

Carey (2009) and Trent (1994) highlight how intellectual disability and mental illness were often associated with criminal behaviour. Disability was also more common amongst poor people, and there exists a perception that associates poor people with disability. "Ugly Laws" were enacted in the US from 1867 to 1974, where poor people, people with disabilities, people who were diseased, those who were maimed and mutilated, or deformed, were compared to unsightly and disgusting objects, who should not appear in public view (Schweik, 2009). The association of intellectual disability and mental illness with criminality gave momentum to grouping disability and poverty as contrary to the American ideals of self-reliance and "rugged individualism' (Schweik, 2009).

Erevelles (1996) argues that the conceptual category of disability produces social hierarchies that are normalised in capitalist societies. Therefore, scholars point to the way in which disability was closely connected with the classical legitimisation of the stratification theory of social class.

The stratification theory of disability views intersectionality as the basis of the stratifying categories that should be considered in the analysis of the axes at the beginning as opposed to the end. For example, considering the intersectionality of disability and other social identities at the beginning of the research or design project as opposed to researching or designing for single identities separately, such as race, gender, and socioeconomic class, and then combining them at the end.

2.10. Focus of the research study

In the previous chapter, the literature review identified the exclusion of disabled African minorities from participating in the development of the EGL programmes, and as a result, their voice is not heard in the design processes of health and disability systems in Aotearoa New Zealand. The research study is focused on what health service design looks like for those who were excluded on both disability and cultural background by considering the intersections of disability and cultural aspects, and how the social factors that support or hinder their access to health services in Auckland and the Waikato areas.

2.11. Conclusion

The chapter summarised reports from the New Zealand Disability Strategy 2016-2026, the EGL framework, including a summary of the evaluation process underpinning the findings of the EGL pilot project, where the participants shared their experience using the EGL principles that had informed the Disability System Transformation. These summaries provided a brief background of the various frameworks for the inclusion of all disabled people and their families in controlling their own disability resources. The literature review also included research from Australia to contrast the research design carried out in Aotearoa New Zealand, to highlight the difference between disability research in Aotearoa New Zealand that focused only on disability as a single identity as seen in the EGL and the research in Australia that included other social identities, such as African and migrants. The difference was in the outcome that was generated in the Australian research, where other social problems that were unique to African Australians came into light.

This justified the researcher's reliance on the Australian research as the single source, as the reason was only to provide contrast to disability research design in Aotearoa New Zealand, which required an extensive summary of the findings. Moreover, this chapter briefly explained key design concepts to contextualise the research within the design theories and practices.

3. Chapter Three: Methodology

3.1. Introduction

To answer the main research question - What does an intersectional approach to healthcare system design look like for disabled African minorities and African parents of children with disabilities in Aotearoa New Zealand? - this thesis adopts a qualitative approach to explore the lived experiences of African people with disabilities in Aotearoa New Zealand. Qualitative research, which focuses on understanding the social world through the words and experiences of participants (Tenny et al., 2024), is particularly suited to this research as it allows for in-depth insight into how disabled African minorities perceive and interpret their identities within the healthcare system. The study seeks to understand how these individuals view their world, particularly in relation to their inclusion or exclusion from healthcare service design in Aotearoa New Zealand.

To ensure a holistic understanding of the participants' environments and experiences with healthcare systems in Aotearoa New Zealand, five research sub-questions were formulated to achieve this goal:

1. What does African identity mean to the participants?
2. What support systems do the participants rely on for accessing healthcare in Aotearoa New Zealand?
3. What are the positive and negative impacts of the current healthcare system design?
4. What does a fair and equitable healthcare system look like to them?

(See full questions in Appendix 2 – Indicative Questions for Semi-Structured Interviews).

To further contextualise intersectionality in this research, the identity model of disability will be employed. This model affirms disability as a positive identity, enabling the researcher to examine where and how it intersects with the participants’ cultural background and other protected characteristics such as age and religious belief (Brewer et al., 2012, as cited in Retief & Letšosa, 2018). This will enable the researcher to define concepts using qualitative data that are relevant to the participants' environment. Doing so will support this research, building concepts that are aligned with the EGL principles, which is the guiding framework underpinning all design practices involving people with disabilities in Aotearoa New Zealand, including Africans, but adding the cultural lens to their voice.

By combining social constructionism and intersectionality, this study aims to uncover how African people with disabilities experience healthcare services and how their identities shape and are shaped by their interactions with the healthcare system. The research will explore how intersecting factors—such as disability, race, age, and cultural background—contribute to participants' exclusion from recent frameworks like the EGL programme.

During the data collection phase, intersectionality will guide the structure of the interviews and focus groups. Questions will probe participants' experiences with healthcare services and how these experiences have been shaped by their combined identities as African, disabled, and often immigrants or other forms of identities that arise in the open-ended questions, such as religions, age, and gender. By considering intersectionality in the starting point of analysing the participants' experience with healthcare providers and their social environments, the research will identify key themes that reveal how the multiple identities interact with the lived experience of the research participants and the unique barriers or opportunities within the healthcare system and what the participants consider as disabling.

3.2. Sampling

Purposive sampling was used in this research, which is suited to the study of African people with disabilities living in Aotearoa New Zealand. Purposive sampling allows the researcher to identify individuals who are especially knowledgeable about the social world of disability, and experience disability from the perspective of being African living in Aotearoa New Zealand (Bazun et al., 2021). These participants have a lived experience of the social world of disability and how it intersects with their African cultural background. Its meaning is embodied in their lived experience. Therefore, purposefully selecting participants from this background supports this research by identifying and selecting those who can provide rich information about their experience with health service design in Aotearoa New Zealand.

Although participants' knowledge and experience are necessary for purposive sampling, availability and willingness are also necessary for researchers to consider purposive sampling along with the participant's ability to articulate, express and reflect on their lived experience in such a way that can positively contribute to and inform the research outcome.

3.3. Selection Criteria

There are two categories of research participants. The first category included individuals living with a disability, who could share their personal experiences of being consumers of the health and disability services in Aotearoa New Zealand. The second category of participants comprised parents whose children live with disabilities. It should be noted that the participants in the second category are not the parents of the participants with disabilities in the first category.

The first category of participants includes those who are:

- From an African background.
- Living with a disability.
- Current or past users of health and disability services in Aotearoa New Zealand.
- Living in Auckland or the Waikato region.
- Between the ages of 18 and 65.
- Able to communicate in the English language and understand the contents of the consent forms and research questions.

The second category includes participants who are:

- From an African background.
- Living in Auckland or the Waikato region.
- Parents of children with disabilities living in Aotearoa New Zealand.
- Involved in the care of their children, regardless of whether they are the primary caregiver.
- Able to communicate in the English language and understand the contents of the consent forms and research questions.

3.4. Participant Recruitment

The research participants were recruited through two primary methods. The first method was through community outreach, where the researcher approached community organisations to distribute the research invitation to potential participants. The second method involved online advertisements, primarily through social media platforms such as Facebook, using public pages associated with community organisations. The advertisements included the researcher's contact details and information about the study to inform the community about the research and how to contact the researcher (see Appendices 3 and 4 – Invitation and Participant Information Sheet).

3.4.1. Recruitment Difficulties

Both community outreach and online advertisements presented challenges in reaching participants, especially since the researcher was unable to initiate direct contact. Community leaders, who were instrumental in disseminating information, often had other priorities and were unable to follow up with potential research participants.

Additionally, potential participants were hesitant that their involvement in the research would not lead to a tangible outcome that would benefit the community. This concern stemmed from previous experiences in which individuals participated in community research that primarily served the researcher or organisation, with no positive outcomes for the participants themselves.

To overcome these difficulties, I liaised with community leaders to ensure the fair distribution of the research advertisement to reach the wider African community. This included follow-ups regarding the advertisement placement on their Facebook pages and other online platforms.

Potential participants who expressed concerns about the research outcome were asked to contact the researcher at a later date should they decide to participate. This was done to avoid pressuring potential participants to participate in this research.

3.5. Research Methods

3.5.1. Focus Group

One of the techniques used for collecting qualitative data is focus groups. These can be used as a stand-alone method or in combination with other methods such as individual interviews. Due to the complexity of this research topic, focus groups were used as well as individual interviews which allowed for a more in-depth exploration of each participant's experiences while addressing privacy issues.

The focus group centred on discussing the participants' cultural backgrounds without any direct questions regarding their disabilities, to respect their privacy. Discussions about disability were reserved for individual interviews where participants could speak more openly in a one-on-one setting. The focus group session lasted about three hours, while the individual interviews took one hour, except for one interview that extended to two hours.

The focus group consisted of three participants, two males and one female, who identified as Africans with disabilities. The session took place at a local community centre in Central Auckland.

3.5.2. Individual Face-to-Face Interviews

Two of the three participants who participated in the focus group indicated in the consent form that they would engage in an individual face-to-face interview on a separate day, at a separate location. One of the interviews was held at a community centre in West Auckland; another took place at a private meeting room at McDonald’s. This allowed for privacy as the public could not hear the conversation.

3.5.3. Individual Online Interview with Parents of Children with Disabilities

Four parents of children with disabilities responded to the research invitation for either a focus group or online individual interviews. However, due to technical issues, two attended individual interviews via mobile phone, which took place on different days. The other two were unable to attend an individual online interview due to changes in their schedules.

This case study was designed to provide insight into the unique challenges faced by African people with disabilities and African parents of children with disabilities when interacting with healthcare services. The research question is what does an intersectional approach to healthcare system design look like for African people with disabilities and African parents of children with disabilities?

3.6. Data Collection

3.6.1. Structure of Focus Group and Individual Interviews

The semi-structured questions were divided into smaller sections, with each section focused on a general question related to a specific theme (see Appendix 2). These questions guided the conversation about being disabled in Aotearoa New Zealand. While disability will be the centre of the discussions, the researcher will also gather demographic information such as gender, age, sexual orientation, and socioeconomic class from the audio-digital transcription used in the interviews with the participants.

The interview structure was designed to follow a sequence, beginning with introductions. This was followed by an opportunity for participants to share the following:

- Personal stories about their experiences with health services in Aotearoa New Zealand, especially times when they felt excluded.
- Reasons for exclusion, exploring whether participants believed it was due to their disability, African identity, age, religion, gender, or a combination of these factors, allowing them to articulate their intersectional experiences.
- Reflect on their experiences and suggest solutions. including thoughts on how their concerns can be addressed in future health system design, and describe what an ideal healthcare system would look like to them.

The overall structure of the focus group consisted of five main parts: building rapport, context focus, process focus, understanding the antecedent conditions, and answering the research questions. The first set of questions was about building rapport. This section centred on getting to know the group members. Along with building trust and openness among the focus group, the data gathered in this part is crucial to this research because it guided the later stages of data analysis by relating the experience of the speaker to their intersectional identities. For example, a lived experience that tends to come through the lens of gender will help find the relevance of gender to their context and place it in the general understanding of the intersectional experience. This is not to say that gender is the only intersecting factor with disability. Other intersectional concerns influence social experience such as race and religion.

3.7. Transcription of Interviews

3.7.1. Focus Group

A voice recorder was used to record the focus group interviews, and the data was transcribed verbatim.

3.7.2. Individual Face-to-Face Interviews with African Participants with Disabilities

The individual face-to-face interviews were recorded using a voice recorder and were transcribed verbatim.

3.7.3. Individual Phone Interviews with Parents of Children with Disabilities

The individual phone interviews were recorded using the recording function within the phone and were transcribed verbatim.

3.8. Ethical Considerations

3.8.1. Informed Consent

3.8.1.1. Focus Group

All participants were provided with a Participant Information Sheet (see Appendix 4) that detailed the purpose, scope, and procedures of the research. For the focus group, the consent forms were signed and returned at the start of the focus group (see Appendix 5 – Consent form –Interviewees). The forms also included a separate section to consent to individual face-to-face interviews at a later date and a different location. Participants were given time to review the information before giving their informed, voluntary consent. Consents for the focus group and the individual face-to-face interviews were obtained in writing, with participants signing the consent form, which was returned to the researcher before any data collection began. One member of the focus group who did not give consent to an individual face-to-face interview was not contacted for an individual face-to-face interview.

3.8.1.2. African Parents of Children with Disabilities

For parents of children with disabilities, the process was slightly adjusted to ensure that the participants did not have to travel to different locations for a face-to-face interview and instead could choose the location in which they would be comfortable, physically and emotionally, to participate in the interview (see Appendix 6 – Updated Ethics Approval). For example, they were given the option of participating by phone instead of face-to-face. Furthermore, they were provided with the information sheet before their interviews, and consent was given and recorded at the start of the phone interview; the researcher read the consent form to the participants, and the participants gave verbal consent. They were then informed that the recording would stop, and a new recording would start for the interview. The researcher also ensured that recordings could be paused if necessary and explicitly informed the parents that a new recording would start only after they were fully comfortable and ready to begin the formal interview. This structured and clear consent process ensured that participants were fully aware of their rights and the nature of their participation, safeguarding their autonomy throughout the research (see Appendix 7 – Online Consent Protocol).

3.8.2. Confidentiality and Anonymity

Given the relatively small size of African communities in Aotearoa New Zealand, privacy and confidentiality are of utmost importance. Participants were given control over the level of personal information they wished to share during the individual interviews and focus group. They were informed that they had the right to withhold any information they were uncomfortable disclosing, thereby influencing the scope of their participation based on what they felt comfortable sharing.

To further ensure confidentiality, participants were invited to choose pseudonyms that would represent them in the research, protecting their identities. This gave participants the power to decide how they wished to be identified. The researcher also took steps to anonymise any identifying information in transcripts and reports, ensuring that participants could not be linked to specific statements or experiences.

3.8.3. Cultural Sensitivity and Reflexivity

Given the cultural and social significance of the research context, cultural sensitivity is a crucial ethical consideration. As a Sudanese Muslim male researcher, it is important to acknowledge my own positionality and how it may influence the research process. Throughout the study, I engaged in reflexivity, actively reflecting on how my background might affect my interactions with participants, particularly when discussing sensitive topics related to disability, healthcare, and identity.

To reflexively acknowledge my positionality in this study, I reflected on my personal, social, and political assumptions that shaped my views of disability services in Aotearoa New Zealand. On a personal level, I reflected on my experience as a Sudanese Muslim male, where my personal experience of discrimination due to my social identity impacted my access to disability resources, employment, and healthcare services in Aotearoa New Zealand. As a person of Sudanese origin, my experience of racism was mainly from other Sudanese people living in Aotearoa New Zealand who espoused the belief that not all Sudanese were born equal. This form of racism was overt and practised by Northern Sudanese who perceived themselves as superior to those Sudanese from the East, South and the West of Sudan. I am from the East of Sudan.

Within the Muslim community, I also faced discrimination from other Muslims due to my race and lack of wealth. The privilege within the Muslim community was unevenly distributed, according to the size of one's racial group as opposed to faith alone. With this being the case, disability was not even mentioned in these communities. In the larger community of Aotearoa New Zealand, I belonged to communities that were generally marginalised, such as the African community, the Muslim community, and those who identified with a disability.

Having lived in such a complex community and felt marginalised within my own communities, my positionality in relation to social identities such as age, socioeconomic class, tribalism, and discrimination on the basis of religion and gender was formed by my intersectional experience within my communities and the larger Aotearoa New Zealand society.

To reflexively acknowledge my positionality, I reflected on my research ethics chapter and methodologies, including the research questions, to ensure that the participants were not led to provide answers that would necessarily support or reinforce my assumptions.

Furthermore, to honour the cultural diversity of the participants, I took steps to ensure that the interview questions and data collection processes were respectful of cultural norms and practices and that participants were provided with the opportunity to express themselves in ways that were most comfortable for them. This included acknowledging participants' diverse religious, cultural, and social backgrounds, and tailoring the research methods to respect these differences.

3.8.4. Co-Creation and Participant Involvement

In line with the EGL framework, the participants were positioned as co-creators in the research process. They were not just subjects of the research, but active agents whose insights and experiences influenced the outcomes of the study. This participatory approach emphasises shared ownership over the knowledge produced and the design of healthcare services that may result from this work.

The participants' lived experiences served as the foundation for challenging existing health service design structures, which often overlooked the unique needs of African people with disabilities. By working together to create a shared understanding of disability within their specific cultural environments, this research aimed to promote more inclusive and intersectional-aware healthcare practices.

3.8.5. Minimisation of Risk

3.8.5.1. Psychological Impact

Exploring questions about their inclusion in society may have been distressing because of possible existing trauma and potential further emotional discomfort (Rau & Baykara-Krumme, 2024) which might have been due to the possibility of a longstanding exclusion from accessing services in their home country, Aotearoa New Zealand, throughout and elsewhere (i.e., transitional countries). This can happen in cases when they fear negative reactions from individuals or community organisations who hold racial biases against ethnic people living in Aotearoa New Zealand.

Thus, I communicated my concern about the potential psychological impact on the potential participants to the Manager of Student Counselling and Manager at AUT City Campus, who suggested possible avenues for supporting participants who might be emotionally impacted as a result of participating in this research. I received some suggestions for services that could provide support at no cost to the participants (see Appendices 8 and 9 – email correspondence with the Manager of Student Counselling and Manager at AUT City Campus, and a resource entitled "Helplines and local mental health services").

I followed up with the advice I received from the AUT counselling service and contacted each service included in the link. With all these resources available, I had the opportunity to source support for those who were psychologically impacted at no cost to them.

3.8.5.2. Power Imbalance

There were no coercive influences or power imbalances between the researcher and the participants or between external bodies such as community organisations.

3.8.5.3. Immigration

The participants were not asked to disclose their immigration status, and information about their immigration background was removed from the transcripts in case a participant inadvertently shared information about their immigration background.

3.8.6. Social and Cultural Sensitivity Including Commitment to the Principles of Te Tiriti o Waitangi

Although the research is centred on African individuals with disabilities, and African parents of children with disabilities, it acknowledges the Tangata Whenua – indigenous people (Te Aka Māori Dictionary, n.d.) – in the way that Māori with disabilities are partners in Te Tiriti o Waitangi - the Treaty of Waitangi (Orange, 2012). It also acknowledges that Africans in Aotearoa New Zealand also come under Te Tiriti o Waitangi as Tangata Te Tiriti – people belonging in Aotearoa New Zealand via Te Tiriti o Waitangi (Dam, 2022, p. 313). This will provide context for mentioning and explaining the approach of the current disability system towards Māori with disabilities, Africans with disabilities and parents of Africans with disabilities. It acknowledges the importance of the participation of Māori in healthcare system design and highlights the lack of focus on African minorities as a topic of concern.

3.9. Methodologies and Data Analytical Methods

3.9.1. Sharing Circle

Jeffery et al. (2021) suggest that the traditional sharing circles of the Canadian First Nations may be therapeutically useful. Sharing circles focus on problem-solving, emotional openness, and the disclosure of feelings, creating an interactive process that evolves throughout the focus group as more information is shared.

According to Jeffery et al. (2021), sharing circles consists of several key components:

1. The need to declare author positionality.
2. Communication of group interpretations.
3. Guiding principles.
4. Relationship building with the inclusion of Indigenous advisory committees and knowledge holders, who continue to guide the community in the use of traditional knowledge-gathering techniques.
5. Collaborative community-involved data analysis and interpretation making meaningful and lasting relationships.

To acknowledge the participants' cultural backgrounds, this research will use a sharing circle approach to create an atmosphere that validates their African Indigenous environment. Sharing circles within this context will emphasise shared principles or morals common to the marginalised African groups, with a focus on collective agreement. While acknowledging the diversity within the broader African identity, this method will ensure participants feel comfortable contributing within a culturally familiar framework.

An essential part of this process is the researcher's declaration of positionality to support rapport building between the group members and the researcher. The researcher, a Sudanese male and practising Muslim who has lived in Aotearoa New Zealand for 20 years, shares a background that participants may relate to. This positionality enables the participants to see possible biases. For example, the research participants might have learned about the researcher's advocacy for a grassroots disability organisation that is specific to African people with disabilities. The researcher actively works to isolate or negate these biases and is open to receiving knowledge from participants that the researcher might not agree with.

3.9.2. Two-Eyed Seeing Approach

Bartlett et al. (n.d., as cited in Jeffery et al., 2021) also suggest using the Two-Eyed Seeing Approach, which refers to

> Learning to see from one eye with the strengths of Indigenous knowledge and ways of knowing, and from the other eye with the strengths of Western knowledge and ways of knowing ... and learning to use both these eyes together, for the benefit of all. (Para. 2)

This research applied the Two-Eyed Seeing approach to consider the participants' African background and their lives in Aotearoa New Zealand. The approach emphasises seeing the world through interconnected perspectives to strengthen the diversity of values within the group. It reflects the multifaceted cultural backgrounds of participants and the complexity of their being in both African and Western cultures.

Respect, relevance, reciprocity, and responsibility are the ethical principles that guide the Two-Eyed Seeing approach (Jeffery et al., 2021). In this research, participants share their Indigenous knowledge while being regarded as equal contributors, sharing information, spirituality, and emotionality among circle members and the researcher. Although the Two-Eyed Seeing approach emphasises the role of the Indigenous advisory committees, this research regards the participants as the source of cultural understanding of disability as opposed to non-disabled members of the African community. This is because the focus is not on what knowledge should be considered Indigenous or African; rather, it is on how disabled Africans in Aotearoa New Zealand view their personal experiences with healthcare systems while being Africans who live with disabilities. This includes the desire to bring their cultural contexts to design practices in which they wish to be included.

3.9.3. Narrative Analysis

This research employed narrative analysis frameworks as provided by Clandinin and Connelly (2000, as cited in Bright & Du Preez, 2023), Lieblich et al. (1998, as cited in Bright & Du Preez, 2023) and Zilber et al. (2008, as cited in Bright & Du Preez, 2023), which suggest flexibility and deep engagement with data as tools that produce deeper meaning as new insights emerge throughout the data analysis phase. Crossley (2000, as cited in Bright & Du Preez, 2023) proposed multiple readings of transcripts, themes, and categorisation for constructing meaningful narratives from the data.

The narrative analysis applied Lieblich et al.'s (1998, as cited in Bright & Du Preez, 2023) modes of reading. These are reading narratives holistically, considering the entire narrative and focusing on specific elements in regard to the form (structure) and content (themes and meaning).

Furthermore, the research utilised Zilber et al.'s (2008, as cited in Bright & Du Preez, 2023) contextual framing of narrative analysis. These are the immediate intersubjective relationship (between narrator and audience), the collective social field (societal structures and historical contexts), and broader cultural meaning systems (metanarratives).

The participants shared their lived experience with health services in Aotearoa New Zealand, and the times when they felt that the challenges and advantages they found were relevant or related to their characteristics. For example, how the inclusion of their cultural background or the lack thereof impacted the quality of the service they received from the health and disability providers. Furthermore, participants explain how their disability and African cultural background may have intersected with one another in such a way that had a positive or negative impact on the help they received from health service providers.

3.10. Conclusion

This chapter has described the research methodologies used in this research. Qualitative research was selected to answer the research question. This allows the findings to emerge from the data gathered from the participants in such a way that describes the participants’ lived experience with healthcare services in their respective regions.

4. Chapter Four: Findings

4.1. Introduction

This research focused on the participation of disabled African minorities and African parents of children with disabilities in Aotearoa New Zealand healthcare systems. Inductive reasoning informed the narrative analysis of the participants' data. The narratives were further analysed using intersectionality and social constructionism interchangeably; intersectionality was employed to focus on narratives related to the participants' lived experiences, while social constructionism was used to provide context to the participants' social environments, such as the processes that the participants engaged in with as opposed to social identities. Finally, social stratification of disability was employed to create a holistic understanding of the participants’ experience in healthcare services and how their lived experience with disability emerged within a larger form of marginalisation, such as ethnicity, religion, immigration, age, or gender. This helped to explore the participants' own definitions of what they found disabling in that environment.

The findings chapter will introduce the research participants, the themes and subthemes that emerged from this analysis. Following the rapport-building stage, the participants were asked to tell us about their support network to provide context for their lived experience within the support environments that they wished to speak about, such as healthcare services and facilities, general practitioners, social services, religious or ethnic communities, special interest groups such as sports, musical or any other network that the participants drew support from. As with the rapport-building stage, the participants were given the opportunity to choose who they spoke about, and the extent to which they wished to explain their involvement with them. Both the positive and negative impacts of the current disability support arrangements were discussed with the participants, as well as their perception of what they thought was the cause behind their perception of those experiences. Finally, the participants shared their understanding of what an intersectional approach to healthcare system design looked like for them.

4.2. Introducing the Participants

Participants in the focus group were all of African descent, had disabilities, and resided in Auckland. To protect their privacy, their disabilities were not mentioned, and pseudonyms were used in place of their real names: Khadija (an adult African female), Nick Love (an adult African male), and Uncle Rambo (an adult African male). Each participant was offered the option of a follow-up, semi-structured face-to-face interview at a mutually agreed-upon location. Two participants, Nick Love and Khadija, accepted this invitation, while Uncle Rambo was unable to attend and sent his apologies.

In the Waikato region, four African parents of children with disabilities responded to the invitation to participate in individual online interviews. Of these four respondents, two withdrew due to unforeseen circumstances, while two, Pullo Adamawa and Yassir, attended. Both Pullo and Yassir, African parents of children with disabilities, did not have disabilities themselves. Furthermore, they expressed a preference to discuss their desired disability support system from both a Muslim and an African perspective. These parents were not known to the participants in Auckland, Nick Love, Khadija, and Uncle Rambo.

The participants were asked to tell us about themselves, and they decided what they felt comfortable sharing. The section on building rapport focused on getting to know the participants. Along with trust and openness between the researcher and the participants, the data gathered in this part was crucial to the data analysis because it guided the discussion chapter by relating the speakers' experiences to their intersectional identities. For example, building rapport with the African parents of children with disabilities encouraged them to discuss how their Muslim identities shaped their worldview of disability and their interpretation of their lived experience as African parents of children with disabilities.

4.3. Being African

Under the main theme of being African, three sub-themes emerged from the narratives that they shared about their lived experience as African people living in Aotearoa New Zealand: we are part of Aotearoa New Zealand society, we are diverse, and we are collective.

4.3.1. We are Part of Aotearoa New Zealand Society

Although the participants felt strong connections to their African identities, they also felt strongly connected to Aotearoa New Zealand. Their daily activities demonstrated their participation in Aotearoa New Zealand's social and economic growth. For example, Pullo Adamawa and Yassir work full-time and contribute to their respective fields equally with others. Similarly, Khadija contributes to society by holding a full-time job and making a meaningful impact through her work.

Nick Love is involved in many skilled paid and unpaid opportunities, collaborating with people from diverse backgrounds. He continues to develop both his personal and professional skills, enhancing his engagement with society. Uncle Rambo joined the workforce shortly after arriving in Aotearoa New Zealand, and maintained full-time employment for 11 years. Unfortunately, he had to stop working due to a housing issue; his tenancy was terminated while he was overseas during COVID-19 restrictions, preventing his return to Aotearoa New Zealand.

These examples challenge the perception that people with disabilities or individuals from other countries primarily rely on government support or do not contribute to Aotearoa New Zealand society. Despite their efforts to improve their lives and those of their families, the participants face marginalisation in healthcare services due to belonging to community groups that are either marginalised within the larger healthcare system, such as people with disabilities, or within their respective communities where disability is not included in their social services.

4.3.2. We are Diverse

Three participants in the focus group discussed their African backgrounds: Khadija, Nick Love, and Uncle Rambo. Their experiences reflect diverse paths of identity formation and their relationship with their African heritage, shaped by migration to Aotearoa New Zealand and different levels of exposure to African culture.

Pullo Adamawa and Yassir shared their experiences of navigating professional and family life in Aotearoa New Zealand while supporting their children with complex needs. Both participants have lived in the Waikato region for an extended period and have developed a sense of belonging to the community, though they continue to face challenges related to disability services.

Yassir, who has been living in Aotearoa New Zealand for over 30 years, described himself as feeling “pretty much part of it” and well-settled in the Waikato region. Although Yassir does not have a disability, he is the parent of children with intellectual disabilities and autism. His narrative reflects a long-term adaptation to both the community and the support systems in Aotearoa New Zealand for children with disabilities. Similarly, Pullo Adamawa is a parent of an autistic child and shared his concerns about finding appropriate disability services for his son, particularly as his son approaches adulthood.

Nick Love and Khadija were both born outside the countries of their parents' origin and moved to Aotearoa New Zealand at a very young age. Their parents and media representations initially shaped their understanding of Africa, with their first real encounters with their African heritage happening later in life. For Khadija, learning English was straightforward, but she always felt different as the only Black person in her class. She spent most of her childhood in Aotearoa New Zealand, but it was during her teenage years, after visiting Africa, that she began to truly connect with her African identity. She described this experience as profound, noting that she "really" learned what it meant to be African when she interacted with extended family members who spoke her language and shared family stories. While she valued the closeness of her immediate family in Aotearoa New Zealand, it was the sense of extended family, shared language, and ancestral knowledge that deepened her sense of belonging to Africa.

Nick Love moved to Aotearoa New Zealand at a younger age and thus had fewer memories connected to his African heritage. His parents, however, ensured that he visited Africa during his teenage years, which transformed his understanding of his background. He described his earlier perception of Africa as one dominated by media portrayals of poverty and conflict. His firsthand experience, however, allowed him to see Africa in a different light—one filled with joy, love, and respect. These experiences, especially the relationships with his African relatives, reshaped his sense of belonging to his ancestral land. He reflected on how those relationships brought "a great deal of clarity" to his state of mind, contrasting the communal warmth of Africa with the busyness of life in Aotearoa New Zealand.

4.3.3. We are Collective

The collective nature of African living was also apparent in the answers given by the participants. For example, when Nick Love was asked what caught his attention about the collective nature of African living, he instantly referred to his cousin, who took the donkey to get water. It was his first time getting water from the river. As he described his experience, "I was very thirsty. One of my cousins gave me water from the river, which was very clear and clean."

That experience also raised questions for Nick that he had not previously considered during his life in Aotearoa New Zealand such as how people carried water vessels on their head without spilling them. When he asked his aunt how they managed this, she answered, "You don't have to think this way. If you live here every day, you will know why." For Nick, this experience triggered his curiosity about the differences that he was trying to balance between his life in his home country and his life in Aotearoa New Zealand.

In contrast, Uncle Rambo, born and raised in Africa, migrated to Aotearoa New Zealand as an adult. Having spent his formative years in his home country, he brought with him a deep knowledge of African history and culture. His transition to life in Aotearoa New Zealand was emotional, particularly as he struggled with homesickness and the differences in cultural values, especially around respect for elders. He noted that in his country of origin, respect within the family and community is deeply ingrained: “My sister had respect for me, and I had respect for her.” He found this cultural norm lacking in his experience with younger generations in Aotearoa New Zealand, African or otherwise. Despite these differences, he emphasised the strong sense of collectivity that defined his upbringing, both within his family and his tribe, which continues to shape his worldview.

Thinking of others was also part of being collective and was common among the participants. They thought that was not typical in an individualistic society of Western tradition. It was intriguing to ask why Khadija had to consider others, instead of focusing on herself and being unconcerned about others not getting attended to.

Khadija answered,

> I grew up in an African household that thinks about collective societies. I would go to the dairy and buy lollies, I would share it with my sisters because it is not all about me. I always have to think about others because it is my culture.

Thinking of others also impacted her personal well-being due to the impact her condition had on her family.

> At one point I saw a counsellor because I had so much guilt from my parents needing to take time off from work and thinking about the impact that my disability was having on them. It is not something that I control. But it is something that impacts them.

Khadija was not only concerned about the physical pain she endured as a result of her local hospital's lack of adequate equipment to take her blood sample, but also about the impact on her famil,y who had to witness her treatment.

> My mom hates seeing blood tests and she hates seeing the doctors poking me numerous times to draw blood from me. I go to the hospital by myself and I get treatment by myself because I know it would impact my mother. My family has plans for things they want to do and I have plans for things I want to do, we don't have time for me to have a crisis. I probably miss them as they didn't come into my support network. But they are the most important pillar of support system for me. She was always there when I was young and I cannot take care of myself and she has been impacted a lot.

4.4. Cultural Barriers to Accessing Disability Support Services

4.4.1. The Complexity of Immigration

Although the participants did not discuss their immigration background in the focus group or the individual interviews, the narratives they shared about their lived experience with New Zealand healthcare services pointed to the complexity of immigration as a social factor influencing the participants' experience in accessing disability support services in New Zealand.

The challenge for the participants who moved to Aotearoa New Zealand at a mature age often differed from those who arrived in Aotearoa New Zealand at a younger age. It was the change from an environment where they were used to a social system that relied on self-sufficiency and family systems that were tightly connected, to a system where they need start rebuilding their life, not only in the social sense but also in the economic sense, where they had to adjust to a whole new, different type of living, that they were not used to in their country of origin. Such a challenge lay in adjusting to moving from an environment where one could draw on one's family and tribe to cooperatively manage their social and economic circumstances, to being in a country where he had to rely on government support systems to lead an independent life. This was especially difficult in healthcare systems that excluded disabled people from minority groups, such as Africans who do not have an entity of their own, from participating in healthcare design practices.

For example, the lack of inclusion of people from Uncle Rambo's demographic in understanding the social environment in which he can no longer be disadvantaged has created a situation where he is prone to losing his independence solely due to government departments not fully understanding the extent to which Uncle Rambo would be affected by systemic actions, such as terminating his tenancy, which was a direct cause for him to lose his independence and full-time employment respectively. In his home country, the government did not control his housing. He grew up with full ownership of his land and how he planned his living situation, including building their own home. Although the focus group did not focus specifically on disability, it was within the stories that Uncle Rambo told about his life in Africa that he acquired a disability while living in his country of origin.

For Khadija and Nick Love, the complexity of immigration was seen in their families' experiences of moving to a new country where their families had to learn a new language and a new culture while trying to instil African culture in their children. This came with both positive and negative impacts on the younger participants when viewed within African culture, including their view of disability. The positive side encompassed African values such as accepting diversity, thinking of others, and taking care of family members, including parents and the extended family. The negative impact, however, was due to their families' views of disability as being biological instead of social. While the positive side of the African culture supported Khadija and Nick Love feeling secure, nurtured and proud of their African heritage, the medical view of disability had left them vulnerable to a healthcare system that relied on their parents' understanding of disability as opposed to the participants' perception of their own social environment, including their understanding of disability.

The complexity of migration was also a factor in the families' lives in that it influenced their lack of knowledge about what support was available for African parents of children with autism. This was seen in the way Yassir found himself in unfamiliar disability services with little access to information about what was available to his children with disabilities. Within this limited access to information about disability resources, such as respite care and support within the context of education, it was the change in the mindset that Yassir had highlighted in his quest to familiarise himself with the disability services in Aotearoa New Zealand. This might mean understanding the difference between the disability systems in his African country of origin and those of Aotearoa New Zealand.

4.4.2. Lack of Appropriate Community Organisation for African and Muslim People with Disabilities

From the start, the parents stated that they do not perceive their children's disabilities as a burden. This is due to their cultural and religious background, where they feel the duty to look after them as long as they can. Within their living arrangement, this in part translates into a cultural perspective where their commitment towards their children has often overridden their desire to find other resources outside of the family context.

There was also another part where the lack of a culturally or religiously appropriate disability service in the broader system of disability has created a gap in accessing information or resources that he could have otherwise been open to receiving. As he stated:

> We love them, and we attend to their needs. But then, you know, if there is support out there, it would be really good to know about them. But what other support systems there are, whether it's for, you know, long-term basis or after we're gone, what is going to happen to them, we haven't fully explored that option. We don't know what is out there.

The lack of understanding of what is available in the broader disability support systems for African adults with special needs leaves the parent and the family worried about the future of their children when they, the parents, are no longer able to look after them. This, according to Yassir, can be due to ageing or passing on.

> Therefore, you kind of ask yourself, so what is next? What is going to happen to my children? Who's going to look after them? How is the government going to support my children if I'm gone, if I'm no longer here for them?

With these concerns being common between Pullo Adamawa and Yassir, their concerns have prompted them to think about ways of understanding or learning about the broader disability services to utilise such services as their adult children will require long-term assistance of some form. For example, Yassir explains that his wife does not allow their children to spend the night at the home of an unfamiliar person who is not part of the family. This stems from her concern for her children’s safety, and her lack of trust in and understanding of the respite services provided to them, and the vetting process that the disability services use to screen caregivers and staff that they employ. Furthermore, mistrust of the cultural and religious appropriateness, together with the vetting process, of these services has been a challenge for the family, which has compromised their use of the hours allocated to them for respite. Both Yassir and Pullo Adamawa highlighted the importance of bridging that gap and bringing together the African, Muslim, and ethnic people’s perspectives at the systemic level in Aotearoa New Zealand.

Khadija, Nick Love and Uncle Rambo also shared their experiences with various community organisations they accessed. One community organisation provided support to Khadija during her university studies by offering counselling and regular follow-ups on how she was managing her condition while studying full-time and working part-time. They also connected her with different group therapy sessions. Although Khadija appreciated the organisation's support, she noted that it was not specifically designed to support people with her condition. Instead, it catered to a broader range of patients but extended care to her, as no other service options were available for Khadija. Additionally, she relied on support from pediatric services. However, she often felt that she was placed in programmes not specifically tailored to her needs, yet adequate for the healthcare system to consider sufficient.

The context for Uncle Rambo was also similar. The only community organisation Uncle Rambo could engage with was the Aotearoa Resettlement Community Coalition (ARCC), a grassroots umbrella organisation representing 26 member groups from diverse ethnic backgrounds. Through the ARCC, his situation was brought to the attention of the Ministry of Social Development and Kāinga Ora, giving him a platform to share the impact of living in a garage and the subsequent loss of his independence. Although Uncle Rambo found the ARCC helpful in supporting him in feeling heard, and was later provided with adequate housing support.

The gap, he explained, is in the lack of a disability community organisation to support him in navigating through the systems, and for that reason, he found himself with no option but to speak to the media. Uncle Rambo's reliance on ARCC and his general practitioner became critical in his struggle to maintain the medical certification needed to continue receiving financial assistance from the Ministry of Social Development. While ARCC and his general practitioner were supportive, Uncle Rambo found himself with no other options and little guidance from the broader support network.

> You see, because these people they're working with the community in case something is weak from your side, as you are from a community, they will stand up for your rights and you have to explain to them what the reason is and then they will take a statement.

Although this might show that Uncle Rambo was receiving support with his disability, neither the general practitioner nor the ARCC have a dedicated support system for ethnic people with disabilities. They did, however, provide support within the limits of their organisations, and the ARCC supported him to the extent where Uncle Rambo would have equitable access to adequate housing, while the need for a disability-focused service remains outstanding, as Uncle Rambo remarks:

> Something we forget, you know, is that Pacific people here—those of Tonga, Māori, Islander, Samoan—have their own disability administration for their people. That’s why they are very strong, and you can see their things move very quickly. But for us, we don't have a competitive title like the African continent; everybody has to depend on themselves. So, what I can say for myself is that I stand up for my rights. I know we don’t only need to be strong for ourselves; we have to fight for our rights. I’m qualified, and I know there is something down there, but there is no way unless you stand up for your rights. If we had an African disability organisation, it would be very easy for someone like me. I could just go to them, knock on the door, present my case, and they would consult my care. But no, we don’t have anything like that. So, what do you do? You put your mind to it, stand up for your rights. Yeah, this is what I can say.

The African parents of children with disabilities shared their experience with disability support their children received at school through the Ministry of Education’s Ongoing Resourcing Scheme (ORS) funding. Yassir views accessing these services as a “standard procedure.” He explains that with a referral from his doctors and a confirmation letter, ORS funding becomes straightforward for eligible families. He describes his experience as “easy; there wasn’t any difficulty in accessing the service from my point of view.”

Pullo Adamawa also found disability support funding helpful. One reason he valued this support is that he once spoke with a ministry representative who had a personal understanding of disability. However, he notes that he refrains from using many available services, such as respite care, due to the lack of options that align with his Muslim beliefs. The primary support he currently receives involves support from his child's school, exploring available services for adults with autism. His son’s school connected him with a key worker who helps his family navigate potential resources for his son as he approaches adulthood. In addition to this, Pullo Adamawa is working to establish a parent-to-parent support group for families with children with autism in his town due to the lack of a service that is appropriate for Muslim adults with autism.

In Aotearoa New Zealand, healthcare is accessible through two main avenues: public and private. For Khadija, even though she could afford private insurance, she could not apply for it due to her condition, which carries a higher risk of hospital admission. As a result, she has no choice but to rely on the public health system. Khadija explains that, in her experience, the quality of care in both the public and private health sectors is similar, with waiting times being the only significant difference. Therefore, investing in private healthcare insurance does not make financial sense to her, as her concerns revolve around the quality of care rather than the waiting times. She also expresses concern over the strain on hospital resources. She believes that receiving treatment at home in the community would improve the availability of hospital beds for those in urgent need. As she reflects:

> I'm taking the place of someone else who needs it, and that has weighed on my mind when I am deciding between going to the hospital or staying home to seek treatment. That should not be something that I should consider when I'm making decisions between receiving treatment or not.

The invisibility of disabled African people within the healthcare system is a recurring issue, which extends to various government departments, including the Ministry of Social Development and the Ministry of Housing and Urban Development. For example, Uncle Rambo's struggle is a powerful illustration of this. He is forced to live in a garage because these departments failed to recognise his needs or provide adequate support.

Moreover, Uncle Rambo points out the absence of a disability support network within the African or broader ethnic communities, making it difficult for him to navigate government services such as Work and Income and housing. Even though these departments are meant to coordinate and assist each other, he faced significant challenges accessing the required information and processes. The lack of a disability-focused organisation within the African community exacerbated these struggles, leaving him without essential support.

For the participants, the main challenges occur at the community level, where there is a lack of access to disability services that align with their cultural and religious needs. Yassir, for instance, only has access to Disability Link services, which primarily offer respite hours. His limited awareness of other available services stems from “not knowing what else is available for [his] family to access.” He learned about these services only after his children were diagnosed with autism. He acknowledges that his ability to speak English and his long residency in Aotearoa New Zealand have gradually helped him discover and understand the support options for his family.

However, accessing respite care hours remains difficult for many parents in the study, largely due to concerns about the safety of their children with autism. Participants highlighted a gap between the design of these services and the cultural and religious needs of their families. They stressed the urgency of re-evaluating disability services from cultural and religious perspectives to ensure they are appropriate and accessible for diverse communities.

While Pullo Adamawa has had positive experiences with disability support at his son’s school, he struggles when his needs extend beyond that context. For example, his religious obligations, such as prayer, present additional challenges. His son’s speech impairment and inability to communicate effectively make Pullo Adamawa feel uncomfortable leaving him with anyone other than trusted individuals.

> And it's very difficult for me to, you know, take him to just a new place that I don't know the people. I can trust, you know, him with the school and then family members and that's about it. Otherwise, there's nowhere else I send him.

Pullo Adamawa highlights the limited and inadequate support options available to him, expressing discomfort with leaving his son in the care of anyone outside his close circle of family friends or extended network. This lack of accessible and trusted disability support poses significant challenges, particularly when school is out of session or family members are unavailable to help. Pullo Adamawa explains,

> Even within our community, there's no place I can go and just leave him or a home I can leave him and then go unless that home is part of the friend circle that we have, the family that we have.

Khadija’s condition compromised her quality of life as a teenager, often forcing her to focus on health instead of engaging in fun activities typical of her age. Beyond the support from a community organisation, she lacked additional support except for an online group based overseas that shared experiences through meetings and conferences.

Khadija found the support she accessed online helpful for connecting with others who had insights into her specific condition. She says:

> When you are in your head and your own space thinking, ‘Oh my God, it’s just me, why me? Nobody understands me,’ and you see other people online talking about their experiences, you think, ‘Oh yeah, that’s me too, yeah, that happened to me, too.’

Pullo Adamawa speaks highly of the current school his child attends, praising the various programmes the school provides for the children, which include trips to holidays within Aotearoa New Zealand and Australia. However, an example of a challenge arose during Ramadan when Pullo Adamawa was invited by the Saudi Arabian government to perform Umrah, a pilgrimage of great spiritual significance for Muslims. The invitation came at a time when the school was closed, and none of his family members were available to care for his son. Despite the immense value Pullo Adamawa places on performing Umrah, he chose to decline the opportunity to stay home and care for his son. This decision was not made lightly, as Pullo Adamawa emphasised that “no Muslim would want to miss” such an event. However, the absence of a trusted support option left him with no choice. Reflecting on this experience, Pullo Adamawa stated, “I didn't feel good that I missed it, but I will definitely not leave my son with anybody that I don't trust simply because I want to go and perform Umrah.”

Like is the case with Yassir, Pullo Adamawa’s lived experience of navigating health and disability services in the Waikato region has been largely impacted by the lack of appropriate disability services for African Muslim parents with children with autism.

These limitations in employment arrangements stem from the restrictive terms imposed by disability organisations and the Ministry of Health. For example, Pullo Adamawa must use his funding solely for respite care services designed and created by existing health and disability providers that did not consult disabled ethnic communities and their families. He is unable to choose who to bring into his support circle, such as family members or trusted individuals.

> You just have to use what is available. Yeah. So we don’t, for instance, there’s no respite care organisation that I know would say, for instance, I can go and drop [my son], who is a Muslim kid.

One of Pullo Adamawa’s major concerns, which is shared by other parents of children with autism, is the permanent nature of his son’s condition, which requires constant care and supervision. He explains that, unlike neurotypical children who become more independent over time, his son will always require the same level of attention and support.

> But for him, he is constantly, you know, like a child that doesn’t grow. That means a lot of times, as a parent, as your children grow, you become less and less responsible for their day-to-day activities. At some point, they go and do their own thing. Sometimes they don’t even want you to be around. But with him now, he is permanently at that level where everything that will be done, you know, you cannot leave him alone.

4.4.3. Lack of Control over their Disability Support

Both Yassir and Pullo Adamawa emphasise the need to rethink how disability support services are designed, advocating for a more personalised, family-centred approach. They recognise that each family has unique needs, shaped by cultural and religious contexts, which cannot be adequately addressed by a one-size-fits-all system. Yassir notes that from a Muslim and African perspective, the complexities and diversity of families require tailored solutions that respect these differences.

As a result, families express a desire for greater control over how and when they use their respite hours. They feel that current services are not genuinely family-driven but rather dictated by agency-defined guidelines that often conflict with their priorities. The parents want flexibility in using their respite hours for activities that align with their cultural, religious, and personal commitments, such as attending religious events, social gatherings, or fulfilling work-related obligations. Currently, they often must choose between these commitments and staying home to care for their children. Yassir elaborates on this limitation:

> It's not entirely in the hands of the parents, for example, how they want to use the funding. It's got its guidelines and its parameters and all of that. So, it's very much the service provider's perspective.

Furthermore, parents point to the lack of options in hiring support workers who share their cultural or religious background. This lack of choice can make it harder for families to feel comfortable and confident in the care their children receive. Additionally, parents feel that the number of respite hours allocated does not adequately reflect the complexities of their situations or the specific needs of their children. They believe these hours should be determined based on the severity of disabilities and the family's overall life demands, such as employment and social obligations.

Ultimately, the systemic, agency-centred focus of current disability services leaves families struggling to fit their needs into rigid schedules and predetermined structures. This often results in parents having to prioritise the service provider's agenda over their own, further complicating their ability to balance caregiving with other essential aspects of their lives.

4.4.4. Lack of Agency

Nick Love's feeling of being excluded from achieving his dreams and wishes has deeply affected his sense of well-being. He described his experience as feeling like he was “somewhere else instead of being in the world.” In his words, “My mind would scream if I’m stuck and not doing anything about it.”

Living with a disability in an environment where it is often perceived as an inability to make decisions independently or to pursue personal goals without family support has been challenging for Nick. The impact of his impairment is compounded by the lack of inclusion in decisions and plans related to his well-being, as well as by the assumptions made by his family, which he feels limit his ability to manage his own environment. He expressed the frustration of this double burden, describing it as “twice harder to think that I could not do it.”

Both Nick Love and Khadija also experience a sense of invisibility within their family contexts. Although Nick finds his cultural environment enriching and full of opportunities for exploration, he feels alienated when his disability intersects with how his family views his capacity to achieve things on his own. Despite his accomplishments in sports like wheelchair rugby and wheelchair basketball, which his family supported and encouraged, there was always an underlying assumption that he could not succeed in other areas without their approval. He explains,

> My difficulty was the family not supporting me because I asked my family to support me. If they say ‘No, we wouldn’t support you,’ I would be in the tight spot there, basically. I would be stuck.

For Khadija, the challenge extended beyond simply learning about her impairment; she also had to navigate a complex healthcare system. Health practitioners, including general practitioners and specialists, often lacked the understanding necessary to manage her healthcare condition, which left Khadija responsible for educating herself about her condition. Many practitioners openly admitted their limitations, stating they did not know how to manage her healthcare.

This sense of invisibility was further exacerbated by her condition requiring frequent hospital visits, treatments, and navigation through a complex specialist healthcare system, particularly as her condition worsened during the final two years of primary school. As a result, Khadija felt vulnerable to doctors and medical staff, pressured by healthcare practitioners who placed the responsibility of being the medical expert solely on her, despite being the patient in need of care.

Uncle Rambo described his journey as moving from being fully functioning and part of the larger society to becoming dependent on a complex system that does not adequately understand his circumstances. He shared:

> I can walk, don’t care. I can run around like before when I used to work. Got a HOP card, or just catch the bus and go back to work and come back. This is what, I don’t have anything at all. But my problem now, as I say, I need the support only to get my house. And then after that, I’ve got to save and look for another job.

4.4.5. Lack of Awareness of Disability Resources

Despite the relative ease of accessing ORS funding, Yassir described difficulties in understanding and accessing support services within the broader context of disability services. He struggled to find respite services that were culturally and religiously appropriate for his children, stating, “Obviously I wasn't able to understand that initiative, and I didn't know what else existed.”

Yassir acknowledged that while he was provided with the standard resources available for families with children with disabilities, he has not “explored what other options there are or if there's any additional support," highlighting the need for better access to community-level disability resources.

Nick Love and Khadija noted the lack of a holistic approach to health and well-being in health services catering to patients from African backgrounds. They observed that many conditions experienced by people from their community were not fully understood by clinicians trained in the Western education system. For Nick, the medical staff seemed physically distant, leading him to feel they were reluctant to engage closely with him due to his recent arrival from Africa.

Khadija also expressed concerns regarding the lack of specialist knowledge and the scarcity of medical practitioners familiar with her condition who could provide information about new treatments that could enhance her health and well-being. Most troubling was the feedback from a specialist experienced with patients with similar conditions, who raised concerns about the dosage of medication and the care she had previously received in Aotearoa New Zealand. The trauma deepened when she faced a dismissive response from Aotearoa New Zealand doctors after sharing this feedback, as they failed to acknowledge the concerns raised by the other doctors. This experience left her questioning the quality of care she had received and feeling silenced within the healthcare system.

In his home country, the responsibility for attending to children's needs fell to parents and families. This mindset shaped Yassir's reluctance to consider broader support systems, leading him and his wife to rely solely on themselves to care for their children without engaging with government-level support. Yassir noted, "So I guess having that kind of background in any way makes you less inclined to seek support because you don't know what is out there." He believes his African background played a significant role in instilling the belief that it was his responsibility to care for his children, regardless of their disabilities.

The cultural understanding of disability and the available support outside of funding originated in Yassir's African environment, where the responsibility for children with special needs primarily resided within the family unit. Caring for family members was deeply embedded in the relationships between family members and the larger community. This perspective influenced Yassir's view of his duty toward his children, leading him to avoid relying on or inquiring about the larger disability system as the primary service provider for his children. As such, he expressed,

> So, having that background, you tend to do the best you can for your family without relying much on outside assistance. So, I have no knowledge or good information about what is really out there that we could tap into that would assist my family. I understand there are, for example, ways of supporting families with special needs where maybe the child can spend the night or some nights away from you so that you get that respite and support.

For this reason, Yassir emphasised the necessity of fully grasping and understanding the services available within the wider disability system in Aotearoa New Zealand:

> So, I guess the gap is really that lack of understanding because the system that we're using, or we're supposed to use, is very much from a Western perspective and whatever that entails. And for us, as a cultural group, as African or Muslim, I guess we need to be assured that whatever support that's going to be available is actually appropriate for my children.

4.4.6. Perception of Discrimination

While the African parents of children with disabilities did not report direct experience of discrimination and racism, data from the younger participants Nick Love and Khadija revealed different forms of racism; institutional, where the experience took place within public healthcare facilities such as hospitals, and government department such as the Ministry of Social Development, and societal, where Nick Love experienced discrimination in public places such as the street of Auckland.

Reflecting on her personal experiences, Khadija acknowledges that while she was fortunate to access a higher standard of care within a more privileged hospital setting, she could not ignore the disparities she observed across different healthcare environments.

Khadija shared her experience in one hospital, which she regarded positively, noting that the patient demographic was predominantly older men who were Pākehā – New Zealanders of European descent (Te Aka Māori Dictionary, n.d.). In contrast, her experience at another hospital, where the patients were predominantly Māori, Pasifika, and other ethnic minorities, was negative. She emphasised that these communities consistently experience worse health outcomes compared to those in wealthier, predominantly Pākehā communities. This disparity, she believes, is a clear indication of institutional discrimination.

Khadija describes the institutional discrimination embedded within the healthcare systems in Aotearoa New Zealand: “If I, and I have in previous situations, tried to rationalise and make meaning and understanding of certain experiences, I think I have no choice but to come to the conclusion that this is the reason why.” She asserts that “the postcode lottery exists in New Zealand.” For example, she recalled a time when she was sick and waiting at the hospital for a nurse to take her observations, such as her blood pressure and temperature, so that the doctors could see her. While she waited for a considerable amount of time, an elderly white couple arrived and waited only five minutes before being attended to by the nurse. As they were seen, the doctor inquired about Khadija's observations, prompting the nurse to apologise and promise to address her case. Khadija perceived this experience as an example of racism, as she could not identify any other reason for the disparity in treatment. She noted that the other patients did not exhibit symptoms that warranted immediate attention, such as bleeding or other urgent conditions.

> I was waiting here for a much longer time with a nurse who did not even say hello to me or give me the time of day until she was told by the doctors that she actually needed to see me and to prioritise me now.

Khadija does not perceive institutional racism or discrimination as limited to the services she receives, but also as inherent in the policies established at the institutional level. She highlights the absence of critical questions, such as how we care for this segment of the community, meaning disabled African communities—what constitutes good care, and how this standardised form of care applies to everyone. She regards the healthcare system as a colonialist Westminster biomedical male system that primarily benefits Pākehā, providing them with better health outcomes.

Nick Love also shared a similar experience.

> Sometimes, when people look at me, they think that I could not do anything, so people judge me for who I am. People stare at me and call me names. They will call me ‘crooked’ and ‘crippled’—offensive words.

In addition to grappling with the emotional burden of having visited his family back home and the ongoing grief of leaving them behind, Nick also wonders how he can maintain his livelihood without financial support. He faces emotional challenges stemming from feeling abandoned by a process that relies on a complex network of communication between his general practitioner and the Ministry of Social Development (MSD).

He described his interactions with MSD as particularly difficult due to the lack of communication and the feeling of being unheard. He believes that the shortcomings of MSD affected him emotionally, partly because of his ethnicity. Moreover, he found a degrading and racist encounter with staff particularly distressing when he overheard a staff member using the N-word to refer to him. Outraged, he requested to see another staff member.

Nick Love lodged a complaint with the staff in charge and was subsequently transferred to a different case manager who resolved his concerns and supported him in receiving the appropriate type and amount of payment to which he was entitled. Emotionally, Nick explained that he drew on his skills to self-manage his frustration and calm himself to avoid misusing language toward the staff.

Nick Love finds the use of such language counterproductive when used by staff against service consumers. To clarify the context behind the use of the N-word, I asked if the staff member identified as Black. This inquiry stemmed from the general understanding that people of Black backgrounds may use the term among themselves without racist intent. However, when used by others towards a person of Black background, the meaning changes and could be perceived as racist. Nick Love clarified that the language was not used by another Black person, which contributed to his view of it as racially motivated.

4.5. Conclusion

This chapter presents the findings that emerged from the data analysis. Two main themes, along with subthemes, respectively, were identified as the main findings that underpinned the participants' experience with the healthcare systems in Auckland and the Waikato. The first main theme, being African, provided background to the participants' social identities and was later used to inform the second main theme – cultural barriers to accessing disability support services. The chapter was structured in this way to provide practical inputs into the healthcare system design in such a way that leads to real-life change as opposed to producing a new theory of design.

5. Chapter Five: Discussion

5.1. Introduction

The themes and subthemes stated in the findings chapter highlighted the unique experiences that the participants face in the healthcare system in Aotearoa New Zealand. Their experience was unique in that their engagement with healthcare services in Aotearoa New Zealand was impacted, not only by the marginalisation of the disabled community in Aotearoa New Zealand, but also by the multiple forms of marginalisation within the disability sector. The disability system transformation plans did not consider how, for some, disability was not separate from the broader context of being of African background or from other social categories such as immigration, ethnicity, religion, age, socioeconomic class, and gender.

This chapter will discuss the intersectionality of disability and ethnicity, disability and religion, disability and age, disability and socioeconomic class, and disability and gender, as experienced by the participants. The complexity of immigration was a central factor in the social constructionism of all the participants' intersectional experiences with disability and other social identities. The chapter will also discuss the participants' view of what an intersectional approach to healthcare system design looks like for them.

The chapter will conclude by providing the researcher's recommendations for incorporating the EGL principles and the intersectionality enablers into the participants' environments, as a means to realising the participants' vision of an intersectional approach to healthcare system design. Intersectionality will guide the discussion about how disability intersects with other social identities.

In addition, social constructionism will be employed as a philosophical theory underpinning the participants' experience within the complexity of immigration as an additional factor that was unique to the research participants in such a way that provides context to their intersectional experience as opposed to a theme on its own.

5.2. Disability and Ethnicity

One of the key findings related to the participants' ethnicity was their collective way of living, where families, including extended families, play a central role in their lives. Participants consistently identified themselves as Africans and described their families, including extended relatives, as an integral part of their African identity. The way they spoke about their relationships with their families suggested a close connection between the nuclear and extended family structures.

Nick Love and Khadija had to navigate both a convoluted health and disability system and complex family dynamics. Data analysis revealed that both Nick Love and Khadija were excluded from participating in decision-making about their disabilities, both within their families and at the systemic level. The EGL programmes and the evaluation frameworks used to assess the user experience of the EGL pilot projects across Aotearoa New Zealand did not recognise the lack of agency among younger African people with disabilities. This oversight can be attributed, in part, to the fact that health and disability service designers do not actively engage with disabled individuals from ethnic minorities, including those of African descent, to fully understand the power dynamics between children and their parents in diverse populations such as the African community.

As a result, healthcare system designers often define self-determination based on participants' cultural identities and their relationships with their families (Waitemata DHB, n.d.), which adds another layer of complexity. This social environment, where narratives privileged by older family members shape the understanding of disability, compromises the voices and perspectives of younger family members who live with disabilities.

For disabled African participants who arrived in Aotearoa New Zealand at a mature age, self-determination was more in the context of living within their home environment in a way that they could manage independently, as in the case of Uncle Rambo. For Uncle Rambo, there was no disability organisation in the African community to advocate for the social impact of government departments’ decisions to terminate his tenancy, which included losing his independence and his job by association. The power dynamics, in this case, were in how other people with disabilities identified with communities that had access to disability support systems, such as the Chinese Disability Support Group. This points to the power dynamics within the disability services in such a way that living with a disability on its own was not sufficient to receive support as much as being of a certain racial background to access disability services in Aotearoa New Zealand.

In the case of the African parents of children with disabilities, the intersection of disability and ethnicity was different from that of the focus group - Nick Love, Uncle Rambo, and Khadija. The African parents of children with disabilities did not consider their racial background as central to their cultural identities as much as that of their Islamic faith. On the face of it, they regard their African heritage as one that they are proud of. Nevertheless, it was their religious background that they associated with to the extent that their understanding of disability support systems and healthcare system design was underpinned by Islamic principles. This points to the diversity within the participants' perception of whether their racial background should be considered in health and disability system design on its own, or if their religious background should also be included.

5.3. Disability and Religion

African parents of children with disabilities have also found themselves at the intersection between disability and religion. This was because neither the African nor the Muslim communities considered disability as a need that is part of these communities. Instead, disability was seen as a separate system in other places, such as the Ministry of Health and the Ministry of Social Development. The challenge was that these ministries did not discuss disability issues with the African or the Muslim communities, leaving Pullo Adamawa and Yassir at the intersection of a complex system that did not have a framework to see their problems.

For African parents of children with disabilities, the intersectional nature of their social exclusion is evident in how health and disability systems fail to consider the religious restrictions affecting their children. This oversight results in their exclusion from accessing disability support services that are readily available to others without these religious requirements. The lack of access to these services has forced parents to use their own resources to care for their autistic children, which has significant social and economic impacts on both the parents and, by extension, their children. This highlighted the gap of knowledge created about the health and wellbeing of the Muslim community in Aotearoa New Zealand in that it considered the social and economic impacts of those with no disabilities, while leaving the Muslim parents and their disabled children relying on their personal resources to meet the needs of their families.

Another key issue was related to what the African parents of children with disabilities have told us about the fact that many Muslim parents, including those with high incomes, do not own their properties because Islam forbids them from taking out interest-bearing mortgages. Consequently, their inability to access home ownership, combined with their financial responsibilities toward their children, creates anxiety about the future, specifically, concerns that their autistic children may lack appropriate housing when the parents are no longer present.

As Pullo Adamawa explained, while his autistic child cannot obtain employment now or in the future, the disability support services do not adequately address the social aspects of Muslim families with children who have disabilities. He highlighted the importance of an appropriate housing environment for his children, one that aligns with their religious restrictions and social context.

Due to the specific requirements of his Muslim child, Pullo Adamawa relies heavily on family support to meet his child's religious needs, especially regarding nutrition. For example, Muslims cannot consume meat that is not Halal, nor can they eat food prepared in environments where non-Halal products are processed; this situation extends beyond participation in social or religious events; it also impacts his financial situation. Pullo Adamawa shared that he had to reduce his working hours from full-time to 60 per cent to care for his autistic child adequately. He frequently faces the dilemma of choosing between staying home to provide care and going to work. Often, he must leave work early to pick up his child from school.

This shows that the experience of Muslim families of children with disabilities is different from Muslim families with no children with disabilities. In the former case, the parents have to give up some of their working hours to care for their disabled children. In the latter case, the Muslim families with no children with disabilities do not have the same commitments, and as a result, the Muslim parents of children with autism are at higher risk of economic hardship and less contact with their social lives.

The intersectional concerns raised by Pullo Adamawa and Yassir stem from a lack of frameworks addressing the unique challenges faced by Muslim families with children who have autism. The experiences of these families are closely tied to their cultural heritage, emphasising their religious faith. Although Yassir and Pullo Adamawa both proudly identify with their African roots, it is their Islamic faith that prominently influences their narratives, particularly concerning family relationships and disabilities. Their desire for care options in an Islamic environment, such as respite care, adds a dimension to health and disability service design that is often overlooked by agencies involved in developing and providing disability services to broader African and Muslim communities. This highlights the privilege present in both health and disability system designs, as well as within the Muslim community in Aotearoa New Zealand, where Muslims without disabilities are more likely to participate in research and design initiatives aimed at promoting community well-being. In contrast, Muslim parents of children with disabilities are often excluded from these efforts.

With this in mind, the intersectionality of disability and religion, as experienced by these participants, underscores the need to consider the interplay of diverse identities and how they create unique social effects that vary according to time and place, rather than viewing identities as distinct, additive, or singular. This perspective aligns with the EGL principles, including the person-centred approach, which emphasises tailored supports that address individual needs and goals while adopting a holistic perspective rather than segregating services across different programmes.

The intersectional dilemma becomes apparent when the transformation of disability systems, including healthcare system design, is framed within cultural backgrounds such as Pākehā, Māori, Pasifika, Asian, or European perspectives, which differ significantly from those of African and Muslim communities. Participants frequently report that they abandon their efforts to seek support because existing services do not adequately address the needs arising within their social environments. Additionally, concerns about their children's safety are not effectively addressed in the employment and vetting processes which organisations use to recruit support workers who will have close contact with their children. These issues raise critical questions about what a whole-of-life approach looks like for African people with disabilities.

5.4. Disability and Age

The EGL programmes, as well as the evaluation frameworks used to evaluate the users' experience of the EGL pilot projects in different parts of Aotearoa New Zealand, did not see the lack of self-determination in younger African people with disabilities. One reason is that health and disability service designers do not actively seek to engage participants from segments of the disabled community, including ethnic minorities, including African backgrounds, to understand what self-determination means to them. Consequently, healthcare system designers define self-determination in relation to those who participated in research and development that focused on Pakeha, Māori, Pasifika, Europeans, and Asians and ethnic minorities while overlooking the needs of younger African people with disabilities. This added complexity to understanding the social environment of disabled younger people from African backgrounds. Much of the change in the health and disability sector is influenced by narratives that had some form of privilege over younger family members of their families and how they define disability. This compromised the views of the younger African generation living with disability.

5.5. Disability and Socioeconomic Class

The intersection between disability and socioeconomic class was evident in the feedback collected from participants. For Khadija, despite being financially secure, living in a socioeconomically disadvantaged area of Auckland affected her access to health services. The local hospital lacked appropriate equipment, leading to increased struggles and physical pain for her. This experience highlights that health service designers did not incorporate the perspectives of those living with disabilities in lower socioeconomic areas. Individuals like Khadija endure greater physical and emotional pain compared to those seeking similar or the same treatment in more privileged areas. This underscores the necessity for healthcare system designers to acknowledge how privilege and disadvantage are fluid and influenced by location and social positioning.

5.6. Disability and Gender

Although the intersectionality of disability and gender was less pronounced than other forms of intersectionality, Khadija's narrative highlighted her need for medical treatment that respects her Muslim religious requirements. She expressed a desire for an environment where she is not forced to be alone with a male staff member, as this contradicts her religious practices; this form of intersectionality illustrates the multiple overlapping identities that influence individuals' experiences, encompassing not only disability and gender but also religion.

5.7. An Intersectional Approach to Healthcare System Design

An intersectional approach to healthcare system design, in the context of this research, considers the complexity of immigration as explained in the findings. The participants tell us about the need for a community organisation that caters for African people with disabilities and African parents of children with disabilities. Such need speaks to the intersectional design where the need is discussed in the precise part of the desired organisation. For example, the intersectional approach to healthcare system design at the community level would require community organisations to consider intersectionality enablers such as Diverse Knowledge in their “Strategic Apex,” which refers to the part where managers and executives who oversee the systems reside (Mintzberg, 1989, p. 98). Diverse Knowledge is defined as prioritising and learning from those excluded from expert roles

(UN Partnership on the Rights of Persons with Disabilities & UN Women, 2021, p. 14).

As such, the design process inclines the managers and executives within the community organisations to address the unique challenges that the participants face. This includes questions such as how to gather and apply Diverse Knowledge in matters that relate to African people with disabilities and the African parents of children with disabilities. For example, matters relating to the timing, enabling younger Africans with disabilities to have a voice within their families, the ethnic communities, which include the African community, and the larger systems, which include the Ministry of Health and the Ministry of Social Development. This will contribute to empowering African people with disabilities in the knowledge production, which in turn ensures the participation of these communities in healthcare system design in ways that suit them as opposed to that of the organisations.

5.7.1. A Disability Organisation

For the focus group, establishing an organisation dedicated to African people with disabilities could address many issues overlooked by the current system, which often fails to acknowledge the invisibility of disabled Africans within broader support systems, including health and disability services. Engaging with others who share the lived experience of disability in Aotearoa New Zealand would empower the disabled African community to advocate for their rights and participate fully in society.

For African parents of children with disabilities, there is a need for an organisation that specifically caters to the Muslim community, focusing on the unique religious requirements of their disabled children. Nonetheless, their participation in healthcare service design remains intertwined with other services such as the Ministry of Social Development, which includes housing and disability services.

5.7.2. Funding

Both the focus group, which included Nick Love, Uncle Rambo and Khadija, and the African parents highlighted the importance of community funding for African people with disabilities. While the focus group emphasised funding for the broader African community, parents focused on funding within an organisation that addresses the specific needs of the Muslim community in Aotearoa New Zealand. They also stressed the necessity for individualised funding to enable effective participation in health and disability services, such as funding their own respite services, and choosing who to employ to care for their autistic children.

5.7.3. Data

Participants articulated the need for data on the number of disabled individuals identifying as African. They pointed to the way in which data can serve as evidence to influence local or central governments to fund initiatives pertaining to the participation of African people with disabilities, and African parents of children with disabilities in healthcare system design. Additionally, they emphasised the importance of policies, laws, and legislation being more flexible to meet the needs and circumstances of ethnic and religious communities, including those with disabilities and their families.

5.7.4. Education and Leadership

The focus group and African parents of children with disabilities underscored the need for education and leadership specifically aimed at African individuals with disabilities; this would enable the African people with disabilities and the parents of African children with disabilities to define disability according to their understanding, rather than relying on others to advocate on their behalf. Building connections with other members of the African community who live with disabilities for motivation and sharing experiences would contribute to co-designing leadership and a self-advocacy framework that addresses the needs of those with lived experiences of disability in Aotearoa New Zealand.

Taking leadership was another resource that Nick Love found useful when engaging with service providers. This had particular importance to him because his father did not speak English nor did his mother. That put him in a situation where he had to learn and understand the language for himself and for his family, to avoid being disadvantaged in communicative practices.

Nick Love also elaborated on the spiritual aspect of his experience, where he pointed to the importance of shifting from the negative energy to the positive energy, referring to his mind as being the main determinant in finding the balance between his emotional reactivity and the difficulties he finds in the physical world. For example, he believes that working with negative people will not provide him with the support he needs, such as receiving the correct payment, whereas positive energy will bring good people who will be passionate about supporting him.

5.7.5. Healthcare Systems Working Together

Participants noted that healthcare systems often operate in silos. They envisioned a cohesive, interconnected healthcare system that facilitates communication among various sectors, including government departments and community organisations. For Khadija, this means having all her data, information, and previous treatments centralised for easy access, eliminating the burden of repeatedly sharing her health history.

Involvement in healthcare decision-making and having her concerns and suggestions taken seriously are essential to Khadija's experience. She believes that consulting specialists overseas should be an option if her Aotearoa New Zealand specialist lacks the necessary expertise. Moreover, she seeks empowerment in linking with overseas specialists to share experiences. In her view, there is no excuse for incorrect dosages or inadequate care when doctors can communicate and collaborate.

Khadija desires agency in co-creating and co-designing her treatment plan, wanting specialists to consider her feedback and include her knowledge about what works for her body in final decisions. Khadija wishes to have access to quality healthcare plans in her regional hospital similar to those in more privileged hospitals. Ideally, she envisions receiving treatment within her community, such as having a nurse visit her home instead of enduring the painful process of repeatedly recounting her health story at the hospital. She believes her condition can be managed at home, reserving hospital visits for more urgent care.

For her, justice means not needing to go to the hospital for manageable symptoms, alleviating the mental and emotional burdens of navigating hospital systems and enduring long waits in emergency departments, often at the risk of encountering staff unfamiliar with her condition. Furthermore, she feels that receiving treatment at home would also alleviate pressure on hospitals, freeing up resources for those in more urgent need. She struggles with the moral dilemma of taking up space in the hospital that could be utilised by someone else who requires immediate assistance. This weighs heavily on her when making decisions about seeking treatment.

5.7.6. Having Autonomy in Controlling their Healthcare Plan

While the participants pointed to the healthcare systems as working in silos, they provided a vision for their participation in a cohesive, connected healthcare system that communicates and talks to each other, including with other government departments and community organisations. For example, for Khadija, it is a system where all her data and information and previous treatments are in one place so that they are accessible so that she is not expected to have the burden of telling her health story time and time again and that it does not "fall on her" to do so.

Being involved in the decisions in her healthcare and having her concerns and suggestions taken seriously involved the option of consulting specialists overseas if her specialist in Aotearoa New Zealand does not have the level of expertise that they are expected to have. Moreover, it is a question of how Khadija might be empowered to link in with the other specialists overseas, to draw on experience. She argues that she does not think there should be any excuse in today's world for being given the wrong dosage or not the right dose, because doctors are connected, and they have the options and tools to communicate with other specialists. Moreover, Khadija wants the agency to co-create and co-design her treatment plan, and for specialists to take the time to explain why or why not her suggestions are being taken into account. It makes her feel powerless when her feedback and concerns are being dismissed, and makes her feel that she does not have the agency to control what happens to her and to her health.

Khadija also feels that she should be equal with her specialists, despite where the clinical knowledge is less relevant, for example, removing the barrier of having to go through a lengthy process before seeing a specialist. Examples of lengthy processes include emergency departments and general practitioners. Furthermore, having access to similar quality plans in her current hospital as other privileged hospitals, as she does not see a reason those plans cannot be implemented at her regional hospital.

Khadija would like to be seen as a source of knowledge about what works for her and her body, and having these considerations taken into the final decisions that are made, and the flexibility of options available to her. Ideally, she would like to receive the treatment where she is in the community, such as having a nurse come into her house and provide these treatments at home, instead of going through the painful process of having to repeat her stories again and again to the nurses and the hospital before she sees the specialist. She regards her condition as one that can be managed at home, as hospitals are required for a more tertiary level of treatment and emergencies. She wants to feel trusted and empowered with managing her treatment, to be treated in the community at home or even by her local GP and only go to the hospital for other specialised treatments. For her, it is more about moving from hospital care into the community care setting, such as home or the general practitioner. Justice for her is about not having to go to the hospital for symptoms that can be managed in the community. That comes from the mental and emotional demands that the condition puts her under when going through the hospital systems, and the long hours that she must endure at the emergency department as well as the challenge of being seen by medical staff who do not know her condition. For her, it is the trade-off that she must make between the physical and emotional pain that she is going through.

5.7.7. Incorporating Enabling Good Lives Principles (EGL) and Intersectionality Enablers into the Participants' Environment

To achieve the intersectional approach to healthcare system design, as envisioned by the participants, the researcher recommends an approach that is grounded in EGL principles and reinforced by intersectionality enablers,[4] as a way to provide a practical step toward the realisation of the participants' view of equitable healthcare for African individuals with disabilities. This approach not only respects cultural diversity but also fosters true self-determination, ensuring that healthcare systems are as diverse and inclusive as the communities they serve. Throughout the findings and discussion chapters, the need for broadening the EGL approach to include intersectionality enablers was clear. An intersectional approach to healthcare system design reinterprets EGL principles to address the unique needs of African communities with disabilities. This approach is especially relevant to fostering inclusivity and equity in healthcare systems, ensuring that African individuals and families can shape services that reflect their values, needs, and aspirations.

One key EGL principle, "Beginning Early," advocates "investing early in families and whānau to support them in being aspirational for their disabled children, building community and natural supports, and promoting independence, rather than waiting for a crisis before providing support" (Enabling Good Lives, n.d.). For African families, early intervention involves actively including the

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[4] The UN's Intersectionality Resource Guide and Toolkit identifies eight enablers to help people and organisations address intersectionality in their policies and programmes: this research only uses "Diverse Knowledge" and "Dignity, Choice and Autonomy" as illustrations of their usefulness to EGL principles.

dreams and wishes of younger Africans with disabilities in decision-making processes. The complexity of family systems in this context requires a deeper consideration of the control families exercise over their children's lives. This includes how disabilities are defined and managed by healthcare providers and schools in a way that is inclusive of the younger African generation in matters relating to their health and disability. African parents of children with autism, on the other hand, often find their choices overridden by system-centred approaches, with healthcare services rarely designed to accommodate family-centred perspectives. The Beginning Early principle also has long-term implications for African families, as parents of disabled children face anxiety about their children's futures. Specifically, concerns about appropriate housing and support options for their autistic children after they are no longer around remain unanswered in current healthcare design. Addressing these concerns requires that system designers consider both immediate and long-term needs for a more holistic approach.

Another essential EGL principle, the "Whole-of-Life Approach," emphasises reducing the adverse effects of fragmented support systems on people with disabilities. For African individuals with disabilities and their families, systematic marginalisation within healthcare systems impedes the realisation of this principle. The scarcity of community organisations that address the intersection of disability with other factors, such as religious requirements, compounds this issue. Existing organisations often adopt a single social identity framework, focusing on issues related to migrants, women, or refugees, while viewing disability as a separate domain. This fragmented approach places an added burden on the participants to navigate disability support independently. For a Whole of Life Approach to be truly effective, systems must accommodate these intersecting identities, reflecting participants' goals of cohesive, lifelong support across all aspects of life.

"Relationship Building," another foundational EGL principle, emphasises that support systems should foster relationships between disabled individuals, their whānau – family members and friends who may not have kinship ties to other group members (Te Aka Māori Dictionary, n.d.) – and the broader community. Yet findings reveal that people of disabled people of African descent often feel isolated and marginalised in the design of disability support systems. Relationship-building efforts are frequently restricted to interactions with African or Muslim community leaders, overlooking those at the intersection of African identity and disability. This exclusion leaves the unique concerns of disabled African individuals largely unaddressed, reinforcing feelings of invisibility and marginalisation in the healthcare system. Nakhid and Farrugia's (2021) research with African diasporic communities showed that sharing knowledge had the potential to strengthen relationships, build solidarity, sustain community, and promote equity. It was also a political act and an act of resistance against individualism.

The findings also highlighted cultural barriers, which point to the need for intersectionality enablers to be considered alongside the EGL principles in healthcare system design. For example, the diverse experiences of participants highlighted the importance of Diverse Knowledge, which underscores the critical relationship between knowledge production, design, and power. Empowering African individuals and families to contribute to knowledge production would allow healthcare systems to reflect the realities of their social environments better. For instance, the experiences of African parents in accessing respite care illustrate systemic limitations: inflexible scheduling, lack of choice in care providers, and a system-focused rather than family-centred model. Without integrating Diverse Knowledge into healthcare system design, the power dynamics remain unbalanced, with those designing services having limited insight into factors that support or hinder those at the intersections.

Another intersectionality enabler is Dignity, Choice, and Autonomy (UN Partnership on the Rights of Persons with Disabilities & UN Women, 2021, p. 13) which emphasises Self-Determination, asserting that decision-making should not be assumed on behalf of others. For healthcare designers, this means recognising the unique family dynamics within African cultures, where families may have distinct expectations that differ from Western norms, especially regarding children's autonomy. Integrating these principles enables healthcare providers to respect cultural expectations, resulting in a system that supports rather than imposes upon African families.

5.7.8. Summary

This chapter discussed the complex intersections of disability and immigration, ethnicity, religion, age, socioeconomic class, and gender, as experienced by African migrants with disabilities and African parents of children with disabilities in New Zealand. Drawing on the findings, the discussion explored the systemic barriers within healthcare, the influence of cultural perspectives on disability, and the need for an intersectional approach in healthcare design. This chapter also discussed the intersectional impact experienced by the participants within their social environment. Their experiences were analysed through the lens of social constructionism to summarise how their social identities intersected, creating unique experiences specific to the participants. The intersectionality between disability and factors such as ethnicity, religion, socioeconomic class, age, and gender was explored. This analysis aligns with the research question, aiming to illustrate what an intersectional approach to healthcare system design might look like for these participants.

5.8. Research Limitations

This research was conducted in the Auckland and Waikato regions with participants who have resided in Aotearoa New Zealand for an extended period. Therefore, certain limitations in this study should be acknowledged.

The participants resided in larger cities, and their experiences may not fully represent those of African people with disabilities and African parents of children with disabilities living in rural areas of Aotearoa New Zealand. The participants had a strong command of English and were able to clearly articulate their experiences with healthcare services. As a result, the findings may not fully reflect the experiences of individuals with limited knowledge of the English language.

This research relied on statistics from the 2013 and 2018 surveys and was conducted before the release of the latest 2023 statistics.

5.9. Conclusion

This research explored the experiences of African people with disabilities and African parents of children with disabilities in accessing healthcare services in Auckland and the Waikato region in Aotearoa New Zealand's North Island. The main goal was to provide an understanding of what an intersectional approach to healthcare system design looks like for African people with disabilities and African parents of children with disabilities.

The literature review highlighted key government initiatives aimed at increasing the participation of people with disabilities in healthcare system design, such as the EGL framework and the New Zealand Disability Strategy 2016-2026. It also examined progress in involving ethnic communities in decision-making processes, particularly within healthcare systems.

The thesis then briefly discussed design concepts such as co-design, participatory design, and justice design to add theoretical depth to tools used to include health consumers in design practices. A case study from Australia was included to contrast Aotearoa New Zealand’s approach, emphasising the value of integrating the intersections of different social identities—such as ethnicity and disability—into the research design from the outset, rather than conducting separate studies to be combined later, as has been done in Aotearoa New Zealand. This was followed by a discussion on the outcomes of the Australian study, illustrating the benefits of incorporating multiple social identities throughout a research project.

Intersectionality was employed as a theoretical framework to demonstrate how intersecting identities can produce unique social experiences, thereby highlighting the distinct challenges faced by Africans with disabilities and African parents of children with disabilities when interacting with healthcare services in Aotearoa New Zealand.

Additionally, social constructionism was used to contextualise the participants' social environments, particularly during the development of semi-structured interviews and the focus group. This approach helped to gain insights into their surroundings, such as support systems and community engagement. Social constructionism was interwoven with intersectionality to provide a nuanced understanding of the participants' unique experiences, distinguishing them from Africans without disabilities and individuals with disabilities from other cultural backgrounds who may not share similar concerns.

This approach also guided the narrative analysis in the findings chapter. The findings chapter was organised around two main themes, being African and cultural barriers to accessing disability support services. Being African included we are part of Aotearoa New Zealand society, we are diverse, and we are collective. Cultural barriers to accessing disability support services included lack of appropriate community organisation for African and Muslim people with disabilities, lack of control over their disability support, lack of agency, lack of awareness of disability resources, and perception of discrimination. Themes were further analysed to understand how factors such as race, gender, and age intersections influenced the participants' experiences of disability. The discussion chapter concluded by addressing the disabling factors in the parents’ social environments, such as immigration, ethnicity, religion, socioeconomic class, age and gender, in relation to the research question in that it presented several participant-driven recommendations to ensure their inclusion in healthcare system design.

The results of the study showed that a cohesive system that facilitates communication across sectors, combined with targeted statistics and data on African individuals with disabilities and African parents of children with disabilities, is needed. Community funding and personalised support funds were also important from the perspective of the research participants.

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