Disabled women with a multicultural background and their experiences of the Norwegian society

How are disabled women with a multicultural background treated by the Norwegian society generally and the Norwegian support system in particular?

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Content

Abstract

Disabled people make up about 15% of Norway's population, making them our largest minority group. Despite broad agreement that disabled people should have the same rights as non-disabled people, this group is still subject to discrimination in several areas. Disabled women are particularly vulnerable. Women with a multicultural background are another group that is exposed to discrimination and lack of adaptation in society and experience a lot of stigmatizations in several settings. The aim of this study is to shed light on the challenges faced by disabled women with a multicultural background in the Norwegian society in general, and with the public sector in particular. This applies both as private individuals in encounters with other people, and in encounters with the public support system.

This is a qualitative study in which all data was collected using semi-structured in-depth interviews. The issues are poorly researched, and the target group is challenging to reach, which shows the importance of the study. The informants include five women from the target group, as well as three service providers who have worked with the target group for more than ten years. The study is based on the theories of intersectionality and salutogenesis.

The findings show that there is a great need to address the challenges that the women experience. The women experience not being taken seriously by healthcare professionals and case managers, not being understood, and not receiving the information they need about their rights and possibilities. They talk about many coincidences; both in the form of accidentally encountering an organization that works for their rights and informs them, but also in the form of which caseworker or GP they get.

Both the findings of this study and findings from previous research show grim figures, that disabled women are more exposed to violence and abuse than women without disabilities, and if you have a different ethnic background, you are even more exposed. They are discriminated against in the job and rental market and in their religious communities, at school and in the family. In addition, they experience extra vulnerability related to friendships and love life due to their disability. Repeated bad encounters with healthcare professionals and caseworkers also lead to increasing distrust of the system, and the findings show that there is a great need for a knowledge improvement in several educational programs when it comes to both functional variations and multicultural understanding and communication.

Keywords: disability, multicultural understanding, women, discrimination, intersectionality, empowerment.

Sammendrag

Funksjonshemmede mennesker utgjør om lag 15% av Norges befolkning, og er med det den største minoritetsgruppen vi har. Til tross for at det er bred enighet om at funksjonshemmede mennesker skal ha de samme rettighetene som ikke-funksjonshemmede, blir denne gruppen allikevel utsatt for diskriminering på flere områder. Funksjonshemmede kvinner er ekstra utsatt. Kvinner med flerkulturell bakgrunn er en annen gruppe som er utsatt for diskriminering og manglende tilrettelegging i samfunnet, og opplever mye stigmatisering i flere settinger. Målet med denne studien er å belyse de utfordringene funksjonshemmede kvinner med flerkulturell bakgrunn møter i det norske samfunnet generelt, og med det offentlige spesielt.

Det er en kvalitativ studie hvor all data er samlet inn ved hjelp av semistrukturerte dybdeintervjuer. Problemstillingene er et felt som er lite forsket på, og målgruppen er utfordrende å nå, noe som viser viktigheten av studien. Informantene inkluderer fem kvinner fra målgruppen, samt tre tjenesteytere som har jobbet med målgruppen i mer enn ti år. Studien tar utgangspunkt i teoriene interseksjonalitet og salutogenese.

Funnene viser at det er stort behov for å adressere de utfordringene som kvinnene opplever. Kvinnene opplever å ikke bli tatt på alvor av helsepersonell og saksbehandlere, de opplever å ikke forstått og heller ikke få den informasjonen de trenger om hvilke rettigheter og muligheter de har. De forteller om mange tilfeldigheter; både i form av at de tilfeldigvis støter på en organisasjon som jobber for rettighetene deres og som informerer dem, men også i form av hvilken saksbehandler eller fastlege de får.

Både funnene i denne studien og funn fra tidligere forskning viser dystre tall, nemlig at funksjonshemmede kvinner er mer utsatt for vold og overgrep enn kvinner uten funksjonshemming, og om en har en annen landbakgrunn er en i tillegg ytterligere utsatt. De blir diskriminert i arbeids- og leiemarkedet og i sine religiøse miljøer, på skolen og i familien. I tillegg opplever de en ekstra sårbarhet knyttet til vennskap og kjærlighetsliv grunnet funksjonsnedsettelsen sin. Gjentatte dårlige møter med helsepersonell og saksbehandlere fører også til stadig økende mistillit til systemet, og funnene viser at det er stort behov for et kunnskapsløft i flere utdanninger når det kommer til både funksjonsvariasjoner og flerkulturell forståelse og kommunikasjon.

Nøkkelord: funksjonshemming, flerkulturell forståelse, kvinne, diskriminering, interseksjonalitet, empowerment

1.0 Introduction

1.1 Background

According to the UN, more than 1 billion people worldwide, approximately 1 in 7, live with some form of disability (FN., 2020). Globally, 80 per cent of disabled people live in developing countries, and 50 per cent of them do not have access to healthcare (FN., 2020). As of May 2022, more than 100 million people were displaced. We do not know exactly how many of these people had or have some form of disability, but in 2016 it was estimated that the figure was around 9 million (FN., 2016).

Despite the fact that there is broad agreement that people with disabilities should have equal rights as the majority population, they have historically been grossly overlooked as a group (FN., 2016). In many cultures there is also still a lot of stigmas associated with disabilities, and disabilities are viewed as shameful, which has led to people with disabilities being hidden and locked away in institutions or at home (Skarstad, 2019, p. 19). This in turn means that it "does not exist", and how can you talk about something that does not exist?

In Norway, there are still major challenges related to discrimination against people with disabilities, and women are particularly vulnerable. Disabled women are more likely to be subjected to violence and abuse, in addition to being discriminated against by the support system (Meyer et al., 2022). It is therefore particularly interesting, and important, to look at how the combination of these categories affects these women today.

This study will shed light on the various challenges faced by disabled women with multicultural backgrounds in the Norwegian society today, both in the form of private individuals and in encounters with the public sector. The study does this from an intercultural perspective, as these women are exposed to several forms of discrimination and are part of several minorities at the same time. The study will also use the findings to make suggestions as to how the system can be better facilitated to give these women, and others who fit the target group, a better life situation.

1.2 Context

Traditionally, disability has been about a person's characteristics related to illness or injury, and in this way with a medical approach – it is something that can be repaired. This is often called "the medical model" (Tøssebro, 2021, p. 15). Tøssebro writes about a model that challenges this understanding: "the orientation towards the surroundings", in example how society around you makes you disabled in certain situations (Tøssebro, 2021, p. 15). This thesis will be based on this definition of disability.

Disability may be a consequence of the flight, or it may be the cause of it–you may be permanently injured due to war, hunger or in connection with the dangerous journey. On the other hand, many people experience being neglected precisely because of their disability (FN., 2016). They may experience being neglected in humanitarian aid situations, as there are often physical and environmental barriers to accessing information, health - and social services (FN., 2016). Looking at the proportion of immigrants with disabilities, the figure is roughly the same as for the majority population, around 15% (SSB., 2017). The figure was higher for immigrant women – 17% compared to 11% for immigrant men (SSB., 2017). In the same study, they also show that the general health of immigrant women was poorer than that of immigrant men.

Many immigrants, regardless of gender, experience problems when encountering the Norwegian healthcare system. Language barriers and cultural differences are a big barrier. For example, it is problematic for many immigrant women to have to undress for examinations if a male doctor is present, and more intimate examinations, such as gynaecological examinations and cervical smears, are particularly challenging. In 2016, less than half of immigrant women in Norway turned up for cancer screening (Knezevic, 2016).

This study wants to add more knowledge on a general basis about the combination of being an disabled woman with a multi-cultural background, and to be able to generate knowledge about how the support services and health services can meet this group in a constructive way. The researchers' experience so far is that there is a lack of knowledge about how to meet disabled people, regardless of nationality, and that there is a lack of intercultural understanding. This study aims to contribute knowledge about this in a positive and optimistic way.

1.3 Research question

Looking at the combination of challenges associated with being an immigrant in the encounter with the healthcare system and being a disabled refugee, this study will answer the following questions:

1. *How are disabled women with a multicultural background treated by the Norwegian society?*
2. *What are their experiences with the Norwegian support system?*

1.4 Clarifications of terms

Multi minority: Minority contrasts with majority, which is the largest part of a society. Being part of a minority refers to being in the minority in society, and can apply to religion, sexual orientation, disability, skin colour, ethnicity and more (Wæhle, 2022). In this study, it refers to those who are part of two or more minorities, which can present additional challenges.

Disability: There are many definitions and understandings of disability. In the introduction of this study, it is used one from Tøssebro, but it may be appropriate to include one that is used as a starting point in Norway today, which is this from Parliamentary Notice No. 40 from 2002-2003:

> *Impairment means loss of or damage to a body part or one of the body's functions. This may, for example, involve impaired movement, vision or hearing, impaired cognitive function or various functional impairments due to allergies, heart and lung diseases (St.meld. nr. 40 (2002-2003), p. 8).*

Disability does not necessarily have to mean being disabled, and it must not result in limitations in social participation. For example, if you have severely impaired vision but are fitted with adapted glasses, you are not disabled. Similarly, if you have a broken leg that heals well after a while, you are not disabled. Disability occurs when there is a gap between the individual's abilities and the design or functional requirements of the environment (St.meld. nr. 40 (2002-2003), p. 8).

Multi-cultural understanding: "Intercultural competence" can be described as the ability to communicate appropriately with people from a different cultural background than oneself (Dybedahl, 2007, p. 4). This is related to "intercultural communication", which is about knowing about and using techniques to put yourself in someone else's world. In addition, one must be aware of one's own cultural reality, and the objective reality, and that this can look different from person to person (Jøssang, 2015, pp. 149-150).

Cultural sensitivity: A concept that is important to keep in mind when dealing with other cultures. It implies a sensitivity to both one's own and others' cultural preferences and "provides the opportunity to get behind patterns of feelings, thoughts and actions that the other person uses as a basis for their behaviour" (Qureshi, 2010, p. 209).

Multiple discrimination: A person can be discriminated against on several grounds at the same time, such as disability, orientation, ethnicity and religion (Skarstad, 2019, p. 52). This is called double or multiple discrimination. This also comes under the theory of intersectionality, which will be returned to in chapter 3.2.

Critical social science: One of the three approaches (the two other are *positivist* and *interpretive social science*) (Neuman, 2014, p. 96) to social research that emphasizes combating surface-level distortions, several levels of reality and value-driven activism to empower people (Neuman, 2014, p. 110). The approach means to *"critical process of inquiry that goes beyond surface illusions to uncover the real structures in the material world in order to help people change conditions and build a better world for themselves"* (Neuman, 2014, p. 110).

1.5 Structure

The first chapter covers the background information, the reasons why this study is relevant, the problem statement and research questions. The next chapter shows the theoretical framework of the study, and chapter three looks at the literature used throughout the study and how this has been found. Chapter four shows the method used to collect data and how this was handled. The next two chapters deal with the findings and discussion of the findings in relation to literature and theory. The final chapter is the conclusion and discussion of further research.

2.0 Theoretical framework

This study is based on the theories salutogenesis and intersectionality. These are two theories that may increase the understanding of the situation of the target group in this study. Salutogenesis explains what resources the informants have that can improve their life situation, while intersectionality is a theory that describes the different factors that can make you vulnerable to discrimination on multiple levels at the same time.

2.1 Salutogenesis

Salutogenesis refers to the origins of health, and is a model first described in 1979 by Aaron Antonovsky in his book Health, Stress and Coping (Mittelmark & Bauer, 2017, p. 7). The model is based on the idea that a person's life experiences help to shape their sense of coherence. This should help the person to utilise their resources to deal with stressors in life in a positive way (Mittelmark & Bauer, 2017, p. 7). A strong sense of coherence consists of three factors: comprehensibility, manageability, and meaningfulness (Mittelmark & Bauer, 2017, p. 7). This is about the person perceiving that the world and life are meaningful, that they feel they have the resources and skills required to deal with different situations, and finally that they believe that what is happening is valuable.

Figure 1 shows Antonovsky's way of explaining the health continuum, or "the ease/ dis-ease continuum" as a horizontal line between H- and H+, where H- is the total absence of health and H+ is total health. He believed that the vast majority of people are somewhere in the middle of this line (Lindström, 2020).

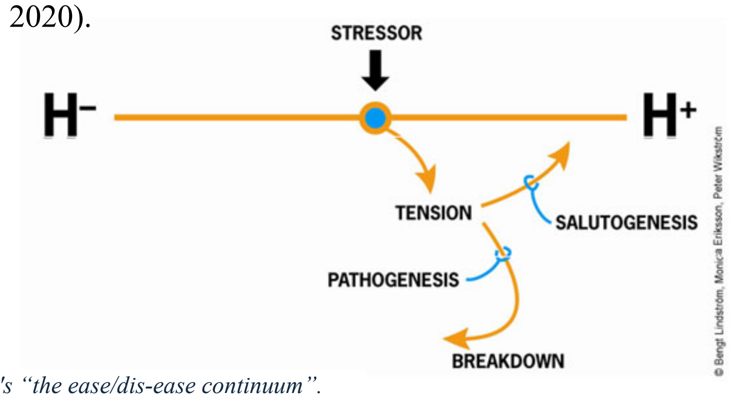

Figure 1: Antonovsky's "the ease/dis-ease continuum".

In 1987, Antonovsky wanted research that could develop the scientific knowledge of how to strengthen the sense of coherence (Mittelmark et al., 2017, p. 71). This can be done by building on resilience resources, which are characteristics of individuals, groups and situations (Mittelmark et al., 2017, p. 71). Resilience resources can be divided into general and specific resilience resources, where general resilience resources are about the extent to which you are able to handle challenging situations. An example of this is the person's social network (Mittelmark et al., 2017, p. 71). Specific resistance resources are, as the word implies, situational tools, such as important phone numbers to help agencies or similar (Mittelmark et al., 2017, p. 71).

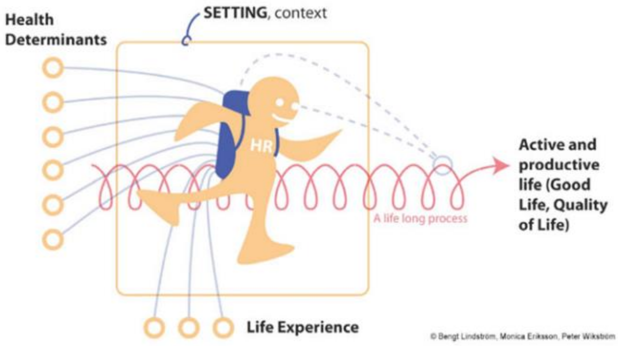

Figure 2: Generalized resistance resources in the knapsack.

Bengt Lindström, Professor of Salutogenesis, is known for developing the cartoon-like figure shown in Figure 2 to explain how people go through life with a knapsack filled with different resources that can be used when faced with resistance (Mittelmark et al., 2017, p. 73). This means that throughout life you will always face challenges, and in these situations, you could pull out various tools from your backpack–if you got the tools.

2.2 Intersectionality

Intersectionality was first introduced as a theory by Kimberle Crenshaw, based on the fact that black women were not included by feminists in the US at the time (1989). She used the struggle for equality for black women in the US as a point of departure to emphasise the fact that black women were left behind in the fight. There was the women's movement which was based on white majority women, and there was the civil rights activists and the anti-racist movement, which was based on black men (Orupabo, 2014).

In that women's movement it was no room to talk about racism, which is an important part of the intersectionality perspective. Racism can be defined as *"the overt, covert, or systemic ac of prejudice or discrimination against an individual or a group based on phenotypical characteristics or "race", an 18th century concept grounded in the historical relationship of colonialism. Inherent in these actions is the belief that one race is superior to another"* (Haslam et al., 2021, p. 574).

The intersectionality perspective is about recognising that there are various factors that play a role in people's experience of marginalisation, such as ethnicity, gender, functional ability, sexual orientation, religious affiliation, and so on (Orupabo, 2014). An immigrant woman will have different challenges than a majority woman, and someone who is disabled will consequently have different challenges than someone who is able-bodied. In turn, a disabled immigrant woman will have completely different challenges than a disabled majority woman, even though they may face the same challenges in several areas.

By incorporating the perspective of intersectionality into the work on salutogenesis, we can gain a more holistic understanding of how the different factors affect the health and well-being of the women in this study. In this way, we can also better address their unique needs and challenges.

3.0 Literature review

The chosen focus is on culture, multi-cultural understanding, intersectionality, human rights as well as discrimination and prejudice. These are all major topics, but topics that are important for answering the research question. As the starting point of this study is the Norwegian society, there is no escaping the fact that there are major cultural challenges associated with being disabled and having a background from another country. It is therefore important to have an intersectional backdrop when dealing with these challenges to better understand the various factors that come into play.

The literature included in this study was found by using search terms such as “disability”, “functional impairment”, “immigration”, “health care”, “women”, “inclusion”, “stigma”, “trust”, “health care workers” and searches were conducted in both Norwegian and English. The literature was found on Google Scholar, idunn.no, by using the bibliographies of related articles in addition to literature I have used in previous work on similar topics.

3.1 Women with disability

Women with a disability are much more vulnerable to violence and abuse than women without a disability (Meyer et al., 2022). A survey from 2005 (Olsvik) shows that there is a significant difference in the extent of violence and abuse against women with disabilities compared to women without disabilities. The total extent of all types of abuse amounted to 53.4% for women with disabilities compared to 37.3% for women without any disabilities (Olsvik, 2005, p. 13). A closer look at the different forms of abuse reveals a more nuanced picture. Women with and without disabilities are about equally likely to be subjected to psychological and sexual abuse. However, when it comes to physical and institutional abuse, women with a disability have a greater chance of being subjected to this compared to women in the control group (Olsvik, 2005, p. 14).

This study also explored the arenas where the abuse took place, and with the exception of “public institution”, there was minimal difference between women with and without disabilities when it came to where they were abused (Olsvik, 2005, p. 17). Corresponding studies conducted in the United States and Canada show similar findings, which is that it is public institutions that stand out as arenas for abuse against women with disabilities (Olsvik, 2005, p. 26). This shows that the difference between women with and without disabilities is that women with disabilities, in addition to being exposed to violence and abuse in the same arenas as women without disabilities, are also particularly vulnerable to abuse in "public institutions" (Olsvik, 2005, p. 26).

Examples of this are to be found in another article by Olsvik (2007), where she talks to several disabled women who have experienced violence and abuse in public institutions. One of the women talked about a night watchman who peeped at her while she was a long-term inpatient in a somatic ward (Olsvik, 2007, p. 15). Another told of being fondled by a doctor at the hospital during one of many treatments due to her disability (Olsvik, 2007, p. 15).

In the same article, three other women talked about being frequently abused by their husbands or partners. All the women were dependent on wheelchairs and, for obvious reasons, had difficulty leaving their abuser (Olsvik, 2007, p. 15).

3.2 Culture, multicultural understanding, and cultural humility

The study is about multicultural women, and as this is a concept that can be difficult to understand the significance of, it is important to define what this study is based on. The concept of culture has been defined by many anthropologists over the years. In this context, the starting point is Thomas Hylland Eriksen's definition, which states that culture is "the skills, perceptions and ways of being that people have acquired as members of a society" (Eriksen, 2010, p. 15). At the same time, he believes that this definition is too ambiguous, as all humans are equally cultural and have something in common that sets us apart from other creatures. On the other hand, humans have acquired different skills and ways of being that distinguish us from each other. Therefore, he believes that there are fundamental similarities and systematic differences between people (Eriksen, 2010, p. 15).

In the article "Man snakker ikke om sånt" ("we don't talk about that") – a qualitative study on non-western immigrants' views on mental illness, Yasmin Therese Walås (2017) explores the importance of understanding culture for healthcare professionals working with immigrant groups. As a healthcare professional, it is important to have knowledge of different cultures to best help people who belong to cultural groups other than your own.

Cultural competence, cultural sensitivity and cultural humility are key concepts in this context, where cultural competence refers to the skills and experience healthcare professionals acquire in order to work with these groups, and cultural sensitivity relates to understanding and attitudes in the encounters (Resnicow et al., 1999, p. 10). Cultural sensitivity can be understood as being sensitive to the people you meet with a different culture than your own, and this is particularly important in the meeting between service provider and service recipient. Cultural humility is about recognizing the power imbalance that exists in a multicultural world, and bringing openness, self-awareness and selflessness into encounters with diverse people (Foronda et al., 2015, p. 213). With cultural humility, you can achieve mutual empowerment and respect, and are better equipped to provide the necessary care and treatment to those in need (Foronda et al., 2015, p. 213).

These are skills that are essential for providing good healthcare to minority groups, which can lead to the reduction of health disparities between minority and majority populations, which in turn can lead to health promotion and prevention (Magelessen, 2008, in Walås, 2017).

Cultural understanding is therefore about understanding where these people come from, not just in a geographical sense, but culturally. This can play an important role in how you deal with coming to a new country with new norms and rules. Nancy Herz is a Norwegian-Lebanese human rights activist, speaker and writer, and has written the book “Skal du ikke gifte deg snart?” based on conversations with her mother about what it was like to flee a country to raise children in a completely unknown culture. Here, her mother talks about how she felt she sacrificed everything when she came to Norway – her education, which was no longer worth anything, her driver’s license, the language, her family, her network (Herz, 2021, p. 101). She sat at home alone while her husband worked long shifts away, and it felt like “walking in a long tunnel where all you see is darkness, where you sacrifice a lot and where you don’t have the finances to rebuild your life either” (Herz, 2021, p. 101).

What she describes about losing oneself when arriving in a new country can also be read in the 2019 Fafo report on “migration, parenthood and social control”. Here, the informants explain that although migration is almost always about searching for something better; safety from war, access to education and work, and generally a higher standard of living, it also almost always involves loss – of belonging, status, identity and community in the country from which you left (Friberg & Bjørnset, 2019, p. 82).

In an article written by Oddhild Bergsli and Ellen Beate Helne-Halvorsen, they interview women with a Pakistani background about their encounters with Norwegian health workers (2020). Among other things, the women are asked about their experience of sitting in the doctor’s office and receiving information from the doctor, and to what extent this is done in a way they understand. They say that “the doctor speaks medical language [...]” which they do not understand, and that they do not dare to ask again because the doctors “[...] get annoyed if

I ask again" and "[...] I'm just a housewife who doesn't understand" (Bergsli & Helne-Halvorsen, 2020, p. 35).

It can be argued that the women have some responsibility for understanding the information provided by telling the doctor that she does not understand, but it is also the doctor's responsibility to facilitate this, for example by using an interpreter. Surveys show that there is inadequate use of interpreting services in Oslo and elsewhere, and that doctors often resort to family members (NOU 2014:8, 2014, p. 42). Language is considered the biggest barrier to providing equitable healthcare (Danielsen et al., 2011, p. 69). The women in Bergsli and Helne-Halvorsen's study also talked about feeling inferior in their encounters with doctors and other healthcare professionals, partly due to their own lack of understanding of their illness. They also said that they did not get answers to their questions or simply felt distrusted when they talked about their own illness experience (Bergsli & Helne-Halvorsen, 2020, p. 35).

How one expresses pain and illness is also different from person to person, and there are major differences when it comes to cultural and religious backgrounds in how a person communicates this (Bjørkli, 2019). Although the physical pain is experienced almost identically regardless of ethnicity, there are major differences in behavior and attitudes when it comes to interpreting the pain symptoms, and not least in how the pain is expressed (Bjørkli, 2019, p. 2). Culture shapes our perception of what is "normal" and gives us a set of norms, values and expectations when it comes to this (Bjørkli, 2019, p. 3).

This can thus lead to challenges when a patient from Pakistan, Vietnam or Somalia comes to a Norwegian doctor's office and is met by a Norwegian doctor. It has been shown that healthcare workers often assess the patient's own pain experience as weaker than the patient does, and that this mismatch increases the stronger the perceived pain is (Bjørkli, 2019, p. 4). Based on this, the Danish doctor Stine Lund mentions a term that is widely used in Danish hospitals–"ethnic pain". This refers to patients from other cultures who express severe pain, but that the patient is exaggerating and that it is not really that serious (Bjørkli, 2019, p. 4).

This is, of course, highly problematic. However, this demonstrates the importance of multicultural competence among healthcare professionals and good facilitation to ensure that patients and service providers understand each other.

3.3 Human rights

Universal human rights are universal in the sense that they are fundamental rights that all people all over the world have. Article 1 of the UN Universal Declaration of Human Rights states that "all human beings are born free and equal in dignity and human rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood" (FN., 1948). Article 2 goes on to state that human rights shall be guaranteed to all, regardless of "race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status" (FN., 1948).

Even though disability is not explicitly mentioned, there is nothing to suggest that the rights of people with disabilities should not be protected in the same way as other people's rights. However, this has not been the case in practice (Skarstad, 2019, p. 17).

Throughout history, people with disabilities have been treated very poorly. Throughout the 20th century, much of the Western world was dominated by the ideas of 'eugenics', and this thinking reached its peak during the extermination policies of Nazi Germany (Skarstad, 2019, p. 18). There was no real reckoning with these ideas after the war, and in 1983 the UN reported that sterilisation and medical experimentation were still common in many countries (Kanter, 2014, in Skarstad, 2019, p. 18).

Human rights abuses against people with disabilities remain widespread across much of the world. In several countries, such as Indonesia, Ghana, and Somaliland, it is common practice to chain people with psychosocial disabilities to wards, often in hazardous and overcrowded buildings (Human Rights Watch, 2012; 2015; 2016, in Skarstad, 2019, p. 19). Reports also show that forced medication without information about the effect, being denied food and psychological and physical abuse are common (Human Rights Watch, 2015). In the European context, in Bulgaria and Slovakia, for example, there is widespread acceptance of violence against disabled people in institutions (Fiala-Butora, 2013, in Skarstad, 2019, p. 19).

3.4 Discrimination, attitudes, and prejudices

Due to the lack of research on disabled people, it is also difficult to quantify the extent to which discrimination occurs. With a few exceptions, this group has not been included in living conditions surveys. When they are not included in the statistics, there is a lack of a knowledge base and the issues do not receive the attention they need to be taken seriously (Olsen et al., 2016, p. 68).

In a report from 2016, a survey was conducted among disabled people and their experiences with hate speech (Olsen et al., 2016). Out of nearly 1,000 respondents, 41% said they had experienced some form of unpleasant experiences, and 32% reported experiencing various forms of hate speech (Olsen et al., 2016, p. 5). A quarter of those who have experienced hate speech also reported having experienced offensive and hateful speech on other grounds of discrimination; gender, ethnic background, religion and so on (Olsen et al., 2016, p. 6). This indicates that people with a combination of these minority groups are particularly vulnerable to offensive and hateful speech.

In a 2021 report from Uloba, we can see that women to a greater extent than men say they are discriminated against, and it has been shown that disabled girls and women are subject to multi-faceted discrimination (Bakke & Skogseth, 2021, p. 33). Women also receive fewer assistant hours on average than men. It is not exactly clear why this is the case, and there may be several factors behind this. However, one of these factors may be that municipalities are reluctant to provide hours for parenting, and this is something that particularly affects women because they are the ones who traditionally have greater responsibility for the children (Bakke & Skogseth, 2021, p. 33).

When a person is discriminated against because of the interaction between one or more factors at once, then we get multiple, or intersectional discrimination (Crenshaw, 1989). The group covered in this study includes women with different ways of being a minority. The sum of these factors can make it particularly challenging when dealing with public bodies. One of the central points of the intersectionality perspective is that “the combination of different statuses means more than the sum of the individual factors would indicate” (Fekjær, 2010, in Orupabo, 2014).

3.5 Research gap and relevance of the study

The information mentioned above is relevant as many people come to Norway from Ghana, Somaliland and Indonesia, or countries that can be assumed to have the same practices. It is important to bear this in mind when meeting these people, as it will most likely have an impact on their trust in public bodies.

As the literature above shows, and as will become clear later in the study, this is a group that can be difficult to reach in purely practical terms. It may therefore be easier to talk about and not include them when the topic is written about. Due to this, in addition to other unknown reasons, are disability combined with immigration and gender is a field that has been poorly studied (Meyer et al., 2022). There are also few studies on disabled people with an intersectional perspective (Kittelsaa et al., 2015). This makes it challenging to find relevant peer-reviewed literature and limits the search of this somewhat. This research aims to help fill this gap.

4.0 Data and methods

This chapter explains the methodological choices made to collect and analyse the data for the study. Inclusion criteria and an overview of the informants are also presented, and finally, ethical considerations, the role of the researcher and challenges that have arisen in the data collection are reflected upon.

4.1 Research Design and Epistemological foundation

As a researcher, one of the first choices you must make is whether to use a quantitative or qualitative research design. With quantitative research the data is in the form of numbers, and can be used to find relationships between variables between groups, or by comparing the variables directly (Punch, 2014, p. 3+206). Qualitative data are usually in form of words, and is a way of doing research where you can go in depth with the material (Punch, 2014, p. 3). Therefore, this study is based on qualitative methods, as it is desirable to really understand the challenges the target group meet, and to understand how the women feel and experience the situation.

Qualitative research is the most common form of social science, and data is often collected through in-depth interviews, observation and the collection of journals (Punch, 2014, p. 86). As a qualitative researcher, you can meet and talk to the participants in their preferred environment, which made it easier to talk freely during the interview, and it was easier to understand and interpret the answers and provide a complex description of the challenges.

As the aim of this study is to examine how disabled, multicultural women experience being received by Norwegian society, it was used a phenomenological approach. This is one of the five key approaches in qualitative research and involves looking at the participants' own experiences and how they want to describe their own life situation (Creswell, 2013, p. 104). In terms of the philosophical approach, the study is rooted in a critical social science. Researchers using CSS aim to criticize and change social conditions by uncovering the underlying causes of social control, power relations and inequality. In this way, CSS can empower people, especially the marginalized and less powerful, but in particular, CSS aims to expose myths and help people improve their lives (Neuman, 2014, p. 111).

Based on the topic of the study, this approach has helped in the design of the questions, and the overall preparation of the study. The researcher started with a hypothesis that the target group was discriminated against, and a desire to uplift this group by shedding light on the challenges they face in everyday life and to make suggestions for improvements based on the informants' experiences. Because of this, and due to the challenges of reaching the target group and the lack of research, it has been important to let the informants in this study be the focus.

4.2 Study area

To obtain a wide range of informants, the study was conducted in Norway as a whole. The informants come from five different cities of varying sizes. This provided a good basis for the study as the informants do not come from the same community and provides a broader understanding of their experiences.

4.3 Informants

The informants in the research is divided into two groups. The biggest group is the target group of this study, disabled women with multicultural background. To be included in the study, they had to be women, have an immigrant background, or parents with an immigrant background, from a country outside Scandinavia and be over 18 years of age.

There are five women with five different cultural background. The other group consists of three people that in different ways works with the target group. It was desirable to research this group, as it is a group that is often forgotten in society. However, this does not mean that they do not exist and are therefore particularly important to research. It was also important to bring out their own voices, not just people working on the issue who can speak for them.

Pseudonym	**Age**	**Country**	**Time in Norway**
Linh	30-40	Vietnam	31 years
Naima	20-30	Somalia	13 years
Hina	30-40	Pakistan	Born in Norway
Myia	30-40	Myanmar	15 years
Aline	20-30	Mexico	12 years

In addition to the women in the target group, some professionals were also included in the study to gain an insight into their everyday working lives.

Profession	**Time working with the target group**
Nurse	Around 10 years
Physiotherapist	Around 15 years
BPA-advisor	Around 25 years

To be included, they had to have an education and/or a job that indicated that they were highly likely to work or have worked with people with disabilities and with a non-Western background. Whether they had a lot or little experience was not of great importance as it would still be interesting to know to what extent there was a focus on these groups during their education and in the workplace.

They were interviewed after the women in the target group, which made it possible to ask questions based on what they said. In this way, it was possible to shed light on several factors related to the research question “how are disabled women with a multicultural background treated by the Norwegian society generally and the Norwegian support system in particular?”.

4.3.1 Recruitment

The recruitment started by creating a flyer with information about the study and contact information, encouraging women who felt they fit into the target group to get in touch. This was printed out and posted in places that would potentially reach the group, in addition to being sent by email with further information to various organizations, such as the Church City Mission, the Red Cross, the Norwegian Disability Association, Bergen Municipality and other workplaces that could be expected to have contact with the group of interest.

All of them responded positively with a desire to contribute and a promise to spread the word to relevant candidates. However, it turned out not to be that simple, as there was nothing more to hear after this. Then the next step was to contact women who fell within the target group directly. As the researcher is an active member of the NDA and have been for a long time, it was easy to get in touch with someone, and once this contact was established, the ball started rolling.

4.3.2 Gatekeeper

After getting in touch with the NDA network, one participant proved to be important, as she plays a key role in the association and knew of several potential candidates. After contacting her, several people showed interest. She acted as a gatekeeper, as the other women trust her due to her position and knowledge (Creswell & Poth, 2018).

4.3.3 Challenges

One participant could not be interviewed by speaking as she has difficulty talking. This was discussed with the supervisor, and it was decided that the best way to conduct the interview was via the SMS function on a computer. This was the most practical and the most secure option, as Facebook and messenger are not safe, and she did not have access to Teams, Zoom or something similar. The advantage of this was that the interview was transcribed continuously, but there were more challenges. Since it was not possible to see each other or hear each other's voices, it was difficult to empathize with what was being said, and it became an unnatural setting where it was difficult to show interest and pay attention other than to write it down. It was also much slower than talking orally, and because of this it took much longer to complete. After four hours the interview had to end, and there were still questions it was desirable to get answers to, but there was not enough time.

As the target group was disabled women, there were also some expected challenges, for example illness. Another participant had to postpone the interview several times due to this. That may also be a sign that there are many people out there who should have been included in various studies but are excluded due to similar challenges. It may be because there is no time to wait for participants to recover enough to take part, and the unpredictability it brings is not compatible with a research project.

4.4 Data collection

The interview is a good method of data collection in qualitative research (Punch, 2014, p. 144). It is a good and relatively easy way to get hold of people's opinions and experiences, and at the same time be able to perceive body language and other signals informants send when they talk about various topics (Punch, 2014, p. 144). There are many ways to conduct interviews – structured, group- and unstructured interviews, and the form of interview chosen is important for the further process of the study (Punch, 2014, p. 146).

Structured interviews are based on a detailed interview guide with pre-set response categories and have little room for in-depth, varied answers. Unstructured interviews are naturally more open-ended, and the researcher has more opportunity to ask follow-up questions in order to go deeper into a topic (Punch, 2014, pp. 146-147). Unstructured interviews therefore allow you to ask open-ended questions without restricting the informants, and you can better understand the complexity of the people you are interviewing. Unlike structured interviews, where the researcher starts with prepared questions, unstructured interviews place greater demands on the researcher’s communication skills, as the ability to listen and ask follow-up questions is essential (Punch, 2014, p. 150).

Based on this, this study has been chosen to use intermediate, semi-structured in-depth interviews. An interview guide was created and used as a starting point for the interview, and follow-up questions were asked along the way to create a flow in the interviews. In this way, none of the interviews were exactly the same, and the informants had the opportunity to talk about what was important to each of them.

There can also be some disadvantages with this type of interview. Since part of the purpose is to create a flow and a conversation, you can forget that you are sitting in an interview setting and therefore forget to ask important follow-up questions (Yin, 2016, p. 143). On the other hand, there can also be cultural challenges, if you are interviewing someone with a different mother tongue and a different culture. In that case, important information may be lost because it is misunderstood or lost in translation (Yin, 2016, p. 144). This was something the researcher had to be aware of in the interviews for this study, as most of the informants did not have Norwegian as their mother tongue.

In order to avoid some of the pitfalls, it was important to be aware of these points from Robert Yin (2016);

1. Speak in modest amounts; it is the informant who is going to tell the story. Do not ask several questions at once and do not ask leading questions. Rather focus on asking simple follow-up questions, in addition to being able to stand for longer pauses to allow the informant to continue on their own (Yin, 2016, p. 144). May be obvious, but it was challenging, as the topics discussed was very engaging.
2. Be nondirective; ask broad and open-ended questions from the start, then the informant is given the opportunity to move in the direction they want, without being coloured by the researcher’s intentions (Yin, 2016, pp. 144-145). The interview guide helped with this, as there were ready-made questions that made it easier to ask open-ended questions that were still within the scope of the study.
3. Stay neutral; this is related to the points above, but also serves as a reminder of the importance of remaining neutral throughout the interview, to not influence the informant. This applies to body language, tone of voice, facial expressions and the like that one

unconsciously sends out (Yin, 2016, p. 146). Despite how conscious you are of this, it will be difficult to remain completely neutral, as you as a human being you always have experiences that will affect you (Crabtree, 2019, p. 928). In a way it was an advantage of interviewing digitally, due to the informants was only able to see the researchers face.

4. maintain rapport. As a researcher, you have created a special situation where the informant is going to talk about potentially difficult topics, so it is extra important to create a safe atmosphere. Avoid using negatively charged words, be serious when the informant is, show that you take what is being said very seriously (Yin, 2016, p. 146). This was an important step in the interview process in this study, as the topics raised were at times serious and emotional (Yin, 2016, p. 146).

It was not just an open-ended conversation, as it was important to make sure to get answers to the topics of the study, such as discrimination, relationships with the healthcare system and Norwegian society, as well as what the informants' thought is positive and what is functioning. All the participants had a lot to tell, and therefore it was unnecessary to ask a lot of the questions because they answered them simply just by talking naturally.

The interviews were conducted on a separate audio recorder, and notes were taken along the way to emphasise particularly important things, as well as noting body language, reactions and other things that do not appear in recordings. No one's real name was recorded or written down, instead everyone got pseudonyms. Age, length of residence in Norway and job title was noted where applicable.

All interviews, except for one, were conducted digitally. As mentioned, one was done via the SMS function on a personal computer, the others via Teams. The physical interview was conducted at Kvinnehelsehuset, the researcher was doing her internship at the time. The informants live in different parts of the country, so that was over all the best solution.

The advantage of being able to conduct the interviews digitally is that it makes it easier to collect information, as you are not dependent on everyone living in relative proximity or having to travel. It also makes it easier for this target group to participate in studies, as it is not as easy for everyone to leave their home. This can be both physical challenges (for example, there was a lot of snow and ice at the end of the interview period), in addition to the previously mentioned health challenges some may have.

The disadvantage of digital interviews was that it disrupts the interpersonal communication that happens between people when they meet in person. The conversations did not flow as naturally as they could have done, and on several occasions, there were some minor technical problems with sound and video.

To transcribe, the ai tool Whisper was used (OpenAI., 2022). After this, all the interviews were gone through by listening at the same time as reading through to double-check that there were as few errors as possible. The interviews were then stored in a password-protected program, and all the informants were anonymised, and everything will be deleted at the end of the study. In addition to this, it has been used the online translation program DeepL to translate the text from Norwegian to English (Kutylowski, 2017).

4.5 Data analysis

In this study it is used thematic analysis, which is not a term for one approach to qualitative analysis, but better thought of as an umbrella term for many different approaches (Braun & Clarke, 2018, p. 108). It is a method for identifying, analysing and reporting patterns, or themes, in data (Braun & Clarke, 2006, p. 6). The NVivo programme was used to code the transcribed interviews, and this was based on the six steps for thematic analysis presented in the article from Virginia Braun and Victoria Clarke (2006).

(1)Familiarizing yourself with your data: To make proper analyses, it is important to become familiar with the content. Therefore, it is necessary to read the transcripts many times before starting to code. In this study, it was conducted using Whisper (Radford et al., 2022) to transcribe, then listen to the interviews and at the same time read through the transcription to correct errors. This meant that in addition to having the interviews fresh in mind, the listening and reading of all the interviews was doubled. In addition, as Yin suggests in his article, the interviews were analysed during the process by noting reflections that emerged along the way (Yin, 2016, p. 147).

(2)Generating initial codes: Codes are the basic elements of the data material, so it is important to find patterns that seem interesting in terms of what is being studied. This phase started after I was familiar with the data, and I made a list with ideas of what the data was and what was interesting about them (Braun & Clarke, 2006, p. 93).

(3)Searching for themes: The themes are wider than the codes and can show several main elements in the data set. Here the codes was separated into different themes, and this was done by making a mind-map on a separate paper to get an overview of all the themes (Braun & Clarke, 2006, pp. 94-95).

(4) *Reviewing themes:* In this phase, the themes had to be reviewed again and looked at which ones should be retained, merged, or separated to ensure that the themes are connected in a meaningful way, and some of them had to be deleted because it was not enough data to support them (Braun & Clarke, 2006, p. 95). The map had to be re-written again and again, and the themes was moved around to ensure which was what.

(5) *Defining and naming themes:* Here, the themes was defined and given names that captured the core elements, so that the informants' general experiences was emphasised, and here the "essence" of the themes was found (Braun & Clarke, 2006, p. 98). Finally, an overview of how the findings should be presented was revealed, and the result was table 1.

(6) *Producing the report:* All the previous phases should now be written in a written report. Here the task was to tell the whole complicated story of the data (Braun & Clarke, 2006, p. 99). This involves extracts that refer to the themes, research questions and the literature presented. This has to be written in a way that convince the reader of the validity of the data. This falls under trustworthiness, which is explained in more detail in the next section.

Global themes	**Organization themes**	**Basic themes**
Norwegian society	Discrimination	Overlooked and ignored
		Labour/ housing market
	Racism	Comments from strangers
	Ableism	Comments from strangers and family
		Challenges in love life
		Comments from strangers and family
	Positive factors	Organized activities
		Religious activities
System challenges	Prejudices	Prejudiced doctors
	Lack of facilitation	Lack of assistance
		Language barriers
		Information flow
	Lack of knowledge	Lack of multi-cultural understanding in education

	The burden of being a migrant family	Loneliness
		The gender burden
	The service providers	To help someone that doesn’t trust you
		Working with traumas
		Causes and solutions, a healthcare workers perspective

Table 1 – themes

4.6 Trustworthiness of research

It is important that those who read a study should be able to trust that what is presented, that the data has been collected in an ethically sound manner, and that the sources can be verified. Ensuring quality and reflexivity in qualitative studies has been written about by many researchers (Crabtree, 2019; Guba & Lincoln, 2005; Tracy, 2010). This is what trustworthiness in research is all about, but to ensure this, some concrete steps are necessary.

Sarah Tracy writes about eight steps to ensure trustworthiness and quality in qualitative studies (2010):

(1)worthy topic, which means the topic of the research is relevant, timely, significant and interesting (Tracy, 2010, p. 840). The topics should provide “educative authenticity” (Guba & Lincoln, 2005, p. 207). Tracy writes that “worthy studies are interesting and point out surprises […], this is why studies of little-known phenomena […] are intrinsically interesting” (Tracy, 2010, p. 841). As the literature review-part of this study shows, the multi-minority aspect of having a disability and a multi-cultural background is a little know subject.

*(2)rich rigor***,** means the study uses sufficient, abundant, appropriate, and complex theoretical constructs, data and time in the field, samples, contexts, data collection and analysis processes (Tracy, 2010, p. 840). As a researcher you should consider if there are enough data to support significant claims, if you spend enough time to gather interesting and significant data and if it was used appropriate procedures in terms of field note style, interviewing process and analysis procedures (Tracy, 2010, p. 841). Due to the sensitivity of the topics of this study, and the fact that there are not that many people that falls into the target group, the data collected should be enough to support the

significant claims. All the interviews were between one and two hours, which conducted a good amount of data.

(3)sincerity, means the study is characterized by self-reflexivity about subjective values, biases, honesty and the transparency about the process of the research (Tracy, 2010, pp. 841-842). During the interview process it was important to mention that the researcher as a majority-Norwegian will never fully understand the problems the informants go through. As the researcher are a member of the NDA, it has also been gathered knowledge about the current situation for disabled in Norway today, and with that also some prejudices about how bad the situation is. This may have made the researcher somewhat biased, and may have contributed to looking for more negative results than there actually were

(4)credibility, means the research is marked by thick description, that it consists of concrete details, explanation of tacit (non-textual) knowledge, and showing rather than telling (Tracy, 2010, p. 840). Credibility refers to the trustworthiness and plausibility of the research findings, and in short, credible reports are those that readers feel trustworthy enough to act on (Tracy, 2010, p. 842). To achieve this, the study is based on the data received by the interviews, and it is the informants of the study that has the main voice. By using a big part of all the interviews, a lot of the details in their story are remained. In addition to this, the data is confirmed with literature that supports the data.

*(5)resonance***,** means the research's ability to influence, affect or move the readers and to meaningfully affect an audience (Tracy, 2010, p. 840 + 844). The researcher should write in a way that engages the readers, through the promoting of empathy, identification and reverberation of the research, even though the readers have no experience with the topic discussed in the study (Tracy, 2010, p. 844). The potential of research in its process and outcomes to transform the emotional dispositions of people and promote greater mutual regard, has been named "empathic validity (Dadds, 2008, p. 280). The meaning of this is to contribute to more positive feelings. Research that are high in empathic validity contributes to more well-being and positive human relationships (Dadds, 2008, p. 280). In addition to this, resonance can be achieved through amongst other aesthetic merit and transferability (Tracy, 2010, p. 844). Aesthetic merit means that the text should be presented in a beautiful way, or at least with clarity and be comprehendible to the target audience (Tracy, 2010, p. 845). With transferability Tracy says that it is achieved when the readers can transfer the story to their own action (Tracy, 2010, p. 845). She uses an example with someone learning

about cruise ship employees' experience of emotional labour, and they can transfer this to their own work situation in for example a theme park (Tracy, 2000, p. 91). This study aims to give the readers the opportunity to recognise the feeling of not being included, and to get the feeling of unfairness, and at the end willingness to do something about the current situation. The quotes show a lot of soreness and hard experiences, which hopefully reaches the reader.

(6)significant contribution, means whether the research provides a significant contribution by asking questions like "does the study extend knowledge?", [...] improve practice?" or "[...] liberate or empower?" (Tracy, 2010, p. 845). To answer these questions one must see whether or not the research will "contribute to our understanding of social life" (Richardson, 2000, p. 254) or "bring clarity to confusion, make visible what is hidden or inappropriately ignored, and generate a sense of insight and deepened understanding" (Tracy, 1995, p. 209). It is four ways of measure the significance of a study; *(1) theoretically;* does the research provide a theoretical contribution by examining how the existing theory make sense in a new and different context? *(2) heuristic;* does the research develop curiosity in the reader and helps inspire new discoveries? *(3) practically;* is the knowledge useful? And *(4) methodically;* to engage the research methodology in a new, creative or insightful way (Tracy, 2010, p. 846). This study aims to show provide knowledge of topics that are easily forgotten and does so by looking at a lot of the literature that already exists and shows this in comparison to the data gathered through interviews.

(7)ethical, means the research considers procedural ethics (such as human subjects), situational and culturally specific ethics, relational ethics and exiting ethics (leaving the scene and sharing the research). Some of the mean practices mentioned above, such as self-reflexivity, are also part of ethical research. However, ethics are more than just means, they are a universal end goal of qualitative quality itself (Tracy, 2010, p. 846). During both the interviews and the rest of the study, it has been important to preserve the dignity of the informants, due to the sensitive nature of the topics. To showing empathy during the interviews, and to assure the informants that they were able to back out any time or to not answer difficult questions.

(8)meaningful coherence. Tracy writes that this means the study "achieves its stated purpose; accomplish what they espouse to be about; use methods and representation practises that partner well with espoused theories and paradigms; and attentively

interconnect literature reviewed with research foci, methods and findings" (Tracy, 2010, p. 848).

4.7 Role of researcher

The role of the researcher is to always stay neutral in meetings with the participants, as of not to impose any guidelines on what is said by the participants. The researcher must be aware of her position as part of the majority population, that she does not have, or will ever have, the same experience as the participants. The researcher also has about eight years' experience of the disability movement, both through working as a personal assistant, working in an assisted living facility, and being a board member of the city's local branch of the NDA. This work has led to several experiences of how disabled people are met in society, from the looks and comments given by strangers to how case administrators have treated clients. It has also led to many good experiences in the form of a strong sense of community and the will to fight against the structures of society.

Against this backdrop, the researcher has been conscious of not letting this colour the data processing, even though it has been challenging not to let prejudice get in the way. The researchers' task is only to bring forward the participants' experiences and thoughts, without any influence. It is important to meet the participants in a professional yet empathetic way, as explained in the data collection chapter 4.4. One of the biggest challenges in the interview setting was to not let any personal opinions and feelings shine through, when the participants talked about their experiences, yet act sympathetic to what was said.

5.0 Ethical Considerations

5.1 Overall ethical issues

Ethical research, despite all the rules and guidelines, is basically about showing responsible, situational judgement (Punch, 2014, p. 37). Given the topic of the thesis, questions will be asked that may be perceived as private and that may put the informants in a somewhat vulnerable position. It will be my task as a researcher to ensure that they feel safe by providing good verbal and written information about what their contribution will be used for, consent forms, providing a safe physical environment where the interviews will take place and acting in a safe and professional manner.

5.2 Informed consent and protection of the rights of the informants

All informants were informed of their rights as participants in this type of study. Everything was made anonymous; they will have the opportunity to withdraw from the study whenever they want, and all information is saved in a password-protected place until the study is completed and then deleted.

To ensure proper and safe processing of the data, I used NSD's (Norwegian Centre for Research Data) data management plan. The plan helped me to ensure compliance with the requirements and guidelines from the Research Council of Norway (Sikt., 2023).

6.0 Findings

The results from the interviews form the foundation for this chapter. There are many themes that are raised throughout the interviews, and they will therefore be divided into various subcategories for clarity. The global themes are divided into groups and can be found in table 1.

6.1 The Norwegian society

as has been emphasized, the overall topic of this study is sensitive, and something that is not talked about much. One of the participants said:

> *"Because people don't want the government involved in their lives. Also [...] that they don't understand that we are a minority within the minority. They think that the general plans and rights also apply to them. [...] But we often experience a form of double discrimination, right, and to solve that we have to come up with some measures. Work on measures, initiate measures, gather knowledge, create databases, research. But they themselves are not interested in that. And part of it may also be due to the fact that they have a lower level of education and don't see the importance of the academic work being done" (Hina).*

This captures some of the essence of what this study is trying to highlight, namely the challenges of this being a group that has been under-researched, while those who want to do something about it struggle to reach those concerned. And this can become a perpetual vicious circle. In addition to this, it is the burden of being a double minority which makes it difficult.

> *"You're doubly handicapped, you lack language, and at the same time you're handicapped, so it's extra difficult without living, without family to live with, so I lived*

> *with my sister, but at the same time we were children, or young people, we didn't know much about Norwegian society and so on" Myia.*

6.1.1 Discrimination

6.1.1.1 Overlooked and ignored

Discrimination can also occur in other settings, such as when it comes to accessibility. And also how being ignored makes you feel unwanted. One informant talks about how she experiences being met by the Muslim community she is originally part of, and how they are withholding information and refuses to answer her questions:

> *"[...]that's a form of discrimination - not getting an answer to the question you're wondering about. And religion is for everyone. I have also encountered discrimination from newly arrived asylum seekers, [...] and they have lived in their environments where they are used to discrimination, where disabled people do not have a natural place in society, so they have distanced themselves, reacted, they have pointed out, asked me to wait to give them space to go first, not the other way around - to give the vulnerable space first, because in their minds they were more important, and not that there is a queue system here" (Hina).*

She continues to talk about the issues people she knows meet when trying to attend to religious meetings:

> *"[...] also this issue of access to religious gatherings, mosques, temples and so on, this is also reported by those in my network, that there are not enough facilities for attending events" (Hina).*

6.1.1.2 Labour/ housing market

Some were also talking about prejudices and what they interpret as discrimination in areas such as the housing and employment market.

> *"I'm met like that once when I went to a viewing, there were the people in charge, four, three units, [...] they have rules that they shouldn't treat people with discrimination, they shouldn't treat people because of illness, but still when I got there, everyone just stood there and stared at the entrance and looked at me like, "oh yeah, are you coming..." so that's the kind of thing I encounter, like at the viewing. But yeah...like that because they're scared, and I think it's mostly because I'm a foreigner, and I'm also in a wheelchair. Also [...] they refuse because they said it's the second floor, and if there's a fire*

> *I can't run. But I said I live on the fourth floor now, so it works fine. But they refuse completely, the three of them, they absolutely refuse if I'm going to live there" (Myia).*

She also talked about sending out a large amount of job applications before getting an interview.

> *"[...] I have sent many applications, but I didn't get an answer. And once I called and asked why I didn't get an answer, and not a job, and they replied "no, because you're in a wheelchair and there's very little space here". Then there was another one, the first interview I was supposed to go to. They called me an hour before the interview and said "sorry, we don't have a lift, you can't come". Things like that. The first interview I went to, I got a job. So that's how it is. I've probably sent 50-100 applications and haven't received an answer at all. [...] They see my name, the wheelchair, out of the pile" (Myia).*

6.1.2 Racism

6.1.2.1 Comments from strangers

Smaller things are also experienced in everyday life, such as prejudice that you have only come to Norway to exploit the welfare system:

> *"[...] everyone thinks you're like that when you look like a foreigner, then it's like you should just take money from the state, get help, right. So, I had someone like that come up to me not so long ago, and "yes, so you came here to get free help" and they look at my car "and yeah, luxury life" and I just said, "I'm working". And things like that I often encounter, like when it's like, yes, your home country... and I know that my home country is difficult to live in, and at the same time I think, I contribute to society, I don't just get help. But as soon as they think you only get help – luxury" (Myia).*

6.1.3 Ableism

Several of the informants describe a feeling of soreness about being different. It is not the disability itself that is the problem, but that they are treated differently by others because of their disability. This can be anything from petty teasing from friends because as a 26-year-old you use a walker and receive "you look like a grandmother" comments, even though these are meant as friendly teasing.

6.1.3.1 Challenges in love life

Or a story about a night out in a bar:

> *"For example, [...] I was invited out for dinner with another friend. And it was, we had to order at the bar. And then I was kind of there, like they were sitting on the table, and I went to the bar, and he sat there while I waited for the waiter. And there was a man sort of came, and he didn't see the walker, […] but he started sort of flirting a bit, and he was sort of very nice and things like that" (Aline).*

She continues:

> *"[…] he was kind of, he wasn't very interested, but still kind of it was, yeah, kind of I flirted back a bit. But I was like, I had ordered the food and stuff, and then I took the walker and then I started walking, and then he was like, ah, yes, yes, yes, yes, nice. And then it was like, yeah, and then it was like, yeah, like I didn't know it was going to, it was going to, it wasn't going to be anything like that. But it's kind of a reminder of that, ah, yeah, right, kind of like that" (Aline).*

Even though there was no desire to date this man, it was still another reminder that "maybe I'll never find love because everyone only sees my disability".

> *"But then I [...] have really low self-esteem and I feel really worthless and everything. But every time I'm kind of reminded of that [...], I kind of know. That I need it. I don't need to feel it once in a while. And of course, sometimes there's [...] like a wave of depression or like I'm just kind of completely shit. And yes, of course, I get a bit dramatic. And maybe like no [...] life is terrible and I'm going to die alone [...]. I'm never going to find love, for example [...]. And somehow rationally speaking, I know [...] that being in a wheelchair or having a disability from an illness or whatever doesn't give you or take away any value from you as a person. [...]" (Aline).*

She knows that she is being disabled not make her impossible to get a partner or a husband, but with the experiences that she describes, that make it harder each time to keep the hope for ever getting a partner.

> *"Yes, of course, like if you say I'll never get a partner, maybe it's not because I use a wheelchair or a walker for example. There are many married couples who [...] one of them uses a wheelchair or something like that. But still, it feels like it's not true" (Aline).*

6.1.3.2 Comments from strangers and family

Another tells of a family that finds it difficult to talk about her situation, and who feel more victimized by family members.

> *"My family, i.e. my parents and my siblings, are exceptionally closed. My parents are overprotective of me, where I and my problems are a very vulnerable topic for them to talk about. It has affected the bond with my siblings because of the great attention I get from my parents. And in Vietnam, the times I've been there, I feel that they take me for being different, a "sick person" in a way. Do you feel that they are jealous of you, in a way? Of the attention? Yes, jealousy, yes. If someone brings up the issue, they get so angry with this comment "you must realize she's sick"" (Linh).*

But she does not feel sick, it is just her body that does not play along with her head.

These are undoubtedly negative situations, seemingly stemming from xenophobic attitudes and a general distrust of immigrants. However, it is not only negative attitudes that can lead to unfortunate situations where people with disabilities experience strangers taking advantage of them. Both the informants and other disabled people can talk about situations where strangers come up to them in the street to pray for them, or simply push their wheelchair across a pedestrian crossing or up a hill. These are things that for most people probably come from a good place, they want to help, but those who are subjected to this "help" are left with a feeling of humiliation and disempowerment.

This can apply to everyone regardless of religious affiliation, but it is natural to think that it occurs to a greater extent in religious environments. For example, Naima says: *"In Somali culture, it was like this: we'll pray for you and God, and God [...]".*

6.1.4 Positive factors

When asked about positive things in life, several of the women talk about the community in organizations and religious gatherings. "This is something that contributes to a meaningful everyday life.

6.1.4.1 Organized activities

Getting involved in various organizations has helped several of the informants, both to find a community and to become familiar with their rights.

> *"When I got a bit more involved in the disability association, for example, and started reading a bit more about it and so on, I started to see... "Okay, what I've experienced with the GP, for example, or with someone from the municipality and so on, it was like.... They violate my rights" Aline.*

She also talks about meeting young people in the hospital who are going through similar situations and want to share her experiences in order to help them.

> *"It's something that gives meaning to life, at least for me. I feel like if I cannot help others, what is the point of existing? [...] Then I become very active in youth mental health and the NDA. I also become active in [...] Christian environmental organizations. But mostly in NDA and youth mental health. And that's also really nice, because even though we don't have the same diagnoses or the same disabilities or the same life situation, it's really nice because we can learn from each other" Aline.*

6.1.4.2 Religious activities

Aline says she was in a very dark place in her life after all the pain she had experienced. She had decided to take her own life. On the way, she saw a church and decided to go in, because "why not? It might be the last thing I do, and I can give God a chance, because what have I got to lose?" After a while, she started at a Bible school, and here she has found a community in her fellow students and in the congregation.

> *"I kind of had the same challenges I had before. But it became much easier to deal with them in a way. Not only with having fellowship with God and having hope and standing together with God through everything. But also, the people around us. We call each other siblings. So, we're like a real family to each other" Aline.*

Miya also talks about the community in her church:

> *"I haven't been involved in Sunday school as much as I used to be, helping, teaching and so on. And I'm very active in the church. [...] it's not just Norwegians in a way, people from different 14-15 countries gather together. So, it's a good place to be" Miya.*

6.2 System challenges

6.2.1 Prejudices

Many also feel that both service providers and people they meet in everyday life are prejudiced against their disability and ethnicity. Among other things, they feel that there is a widespread perception that immigrant families take care of each other to a greater extent than Norwegian families, and that this is a reason for providing less help from the system. This may be due to fewer hours granted for assistance, poorer coverage on TT cards (taxi scheme) and the like, because, for example, they have family members who drive a taxi, so they can help with transportation.

> *“[...] I work as a BPA advisor, and we encounter the same thing, especially with minority families, that they are refused hours, do not get what they need, on the grounds that you have a father who is a taxi driver so he can drive you there, you have a mother who is educated and can help with this and that, you have relatives here and there who can help, and then people must either claim to be sicker than you actually are, or not state that you live with the family. And that doesn’t help” (Hina).*

6.2.1.1 Prejudiced doctors

Aline explains that she got help from a lawyer because of her experiences of violence with her ex-boyfriend. The lawyer has a lot of experience of working with multicultural women who have experienced domestic violence and was able to tell her that it was not unusual for doctors to make prejudiced assumptions about women from other cultures.

> *“He said it [...] was a bit special with Latinas. We talk a lot. Even though we’re completely shattered, it seems like we have a lot of life inside us somehow. Or energy or something. But there’s a big difference; it’s how we are, or how we’ve learned to be. And he said that there are many, especially doctors. [...] people in general, but especially doctors. They think that when you have some health challenges, but you have a lot of energy, or talk a lot, [...]. Then they think it’s actually something mental, and not physical. I’ve experienced this myself, especially in the beginning. When I said I’m in a lot of pain, and I look at my joints when they’re dislocated, and look at my hands, and I’ve fainted several times. Then I also thought that it must be something psychological” Aline.*

6.2.2 Lack of facilitation

6.2.2.1 Lack of assistance

Women generally get less hours of assistance than men. And despite the lack in hours, it is also a difference in the assistive devices:

> *“[...] there is also a big difference when it comes to assistive technology. Men get assistive devices for socializing outside their home, while women get assistive devices for housework and home, cleaning, raising children, cooking. That’s what they get BPA hours for too” (Hina).*

A lack of assistant hours is a major problem for many people with disabilities. Not having enough hours to get help to carry out everyday tasks can present many major problems, from cooking to following up on children. Hina forteller om en kollega som ikke får timene hun trenger til å kunne leve livet sitt utenfor hjemmet.

> *"[...] she was only given BPA decisions for food shopping, cleaning and showers. Apart from that, no decision to go out, participate in activities, attend Norwegian language courses, none of that. And [...] there are so many facilities, institutions and so on that are not adapted, and when she comes with her big wheelchair, she has to be adapted, and it's not always the case that the people who call the meeting are able to facilitate this" Hina.*

Disabled people are also particularly vulnerable to violence and abuse, and although having an assistant does not solve these problems on its own, it can help to prevent them.

> *"I have some help from the municipality, which provides me with home help. They help me with tidying up the house, cleaning, washing clothes and things like that. But they said it was a bit ... difficult for them to calculate how many hours of assistance I need. Because there are some days that could be a bit better, and some days that I really need assistance 24/7 [...]" (Aline).*

She talks about how it was complicated because she lived with her boyfriend, who was controlling of her.

> *"[...] We've been together for three years. Cohabitants. He was very controlling, so I wasn't allowed to do anything. He said he knew I needed help and assistance. The cardiologist said that [...] because of my heart [...] it's very good to have someone with me almost all the time, especially when I go out. Because I can pass out or my heart can just stop. My ex knew about it, so he said he wanted me to be as dependent on him as possible" (Aline).*

She talks about when she moved to a new apartment in a new city. She got to know some of the neighbours and made particularly good contact with one of them. As she lives alone and has no assistant hours at all, she is dependent on help from others to get various things into the apartment, which this neighbour was able to help with. This is what she said:

> *"I was new to the city, but I didn't know anyone. I also needed some help. It was also very difficult to connect with people, especially with corona and things like that. But I had a neighbour who I got to know. He helped me a bit and supported me a bit. [...] and then... He raped me. And he knew I was weak and stuff, so even though I tried to push him away... It was a really bad experience. It was probably because the only person I felt a bit more comfortable with, and who I could ask for help, was the guy who took advantage of*

> *me. And I really thought I was going to die that day, because he also became violent" (Aline).*

Her alternative was to go to a crisis centre, which is also rarely adapted for people with disabilities.

A BPA advisor who has worked with disability rights for many years and who works to ensure that people with disabilities get the help they need, recounts some of his experiences when dealing with the municipality. Among other things, he talks about a woman with multicultural background, and who has cerebral palsy who did not receive the help she undoubtedly needed: *"[...] she couldn't manage herself in any way whatsoever with personal care or anything else. [...] The only caregiver around her was an ex-husband".* He goes on to say that what she got a support order for, what the municipality could offer, was a robot vacuum cleaner to help her with the housework.

This case was eventually resolved after an appeal decision, and she now has a much better life. "[...] It was a whole new arrangement with enough hours and a new life for this lady. She has grown enormously from it [...]. So it shows that when you get it right, it works. But it was a very clear example of, I would say, serious discrimination".

6.2.2.2 Language barriers

> *"You have to go through an interview process when you come to Norway to tell your story [...] and the interpreter was from the northern side of Somalia and had a different dialect to what I was used to, so I struggled to understand. It became such a bumpy conversation. Then I had to do a second round with another interpreter from where I'm from, and since then I've just thought, me and an interpreter won't work" Naima.*

She goes on to say that she moved to another city and got a general practitioner. She finds the doctor unnecessarily difficult, as she knows it is important to learn Norwegian, but that is not why she goes to the doctor, it is to get treatment.

> *"[...] I can't explain a lot of medical stuff in Norwegian, but I can explain it in English [...] he's like, "yeah, okay" and then I explained, and he was so gesticulating, and he was like, "we all, me, the municipality and NAV, we work together". Then he draws circles like this and he's like, "OK, Norwegian is important, you have to learn it". I know that, but why do you have to repeat it?" Naima.*

6.2.2.3 Information flow

Several of the informants talked about the lack of information flow in the support system. Myia talked about when she found out that she could change her GP, after a lot of frustration over things that weren't being done. She had been told how to fill in forms to support an adapted car, but there were still problems, and she felt that the doctor did not do what he said he would. After the switch, the information she had given was not passed on.

> *«I waited for a long time, so I thought okay, I have to call my doctor, and that's it, you have to come. "I've been several times, nothing's happening [...] you said last time you were going to do this". But he hasn't done anything. Eventually I know that I can change doctors, so I changed, it worked, but then I didn't get a decision from NAV. I was told that I should apply for class B, a large car, and they said no, you can manage on your own. I also said, I'm in a wheelchair, I can't manage. I have to get into the car, I can't lift the chair into the car. Because they want to give me a normal car» Myia.*

There were several common themes among the interviewees. A major challenge for all of them was the encounter with the health service and the support system, as they feel that there is little understanding among service providers and that there is little room to ask for help in understanding the system. Nothing goes by itself, and there are complicated application processes for every little thing. This is of course not unique to disabled people or immigrants, but it adds an extra layer of difficulty when the system is initially difficult to navigate.

6.2.3 Lack of knowledge

The BPA advisor continues to talk about how the cultural aspect has an impact in how one may experience the system. He talks about one of his cases with a child:

> *"[...] it was difficult with both women and men as assistants. Women in relation to the fact that it was a boy (who was to receive assistance). Women in relation to the fact that, yes, there was a bit of lifting and grooming. And then it was the case that the female assistant couldn't be in the room alone with the man of the house, for example, the father of the child. Yes, and when there was a male assistant, the woman couldn't be alone in the house" (BPA advisor).*

Why is it so difficult to get the help you need and, in most cases, are legally entitled to? It is difficult for everyone, but especially for those who have multiple layers of challenges working against them.

> *"What we see, when we are private players, we never give up, right? [...] For us, it's all about communication. And that's not the biggest challenge to solve. It's almost always solved when we've got everything out in the open, about how we can carry out an everyday life with an assisted living [...]*

He continues with the municipal sector:

> *"[...] I think it's a nice cocktail of low resources, lack of knowledge and discrimination. It's very tough. And that combination is quite, shall we say, a perfect storm for the applicant. Because you encounter so many layers of resistance. One thing is the legal aspect, what you are entitled to. This often requires a strong will and good communication skills.*
>
> *The other is when you come from another nation and have needs that are often not understood by the culture we live in. And that's a new layer. The third layer is discrimination. It's not so easy to touch and feel. Those of us who work on the issue can see it. Even if you can't quantify it. That's what we see, but it's there" (BPA advisor)*

6.2.3.1 Lack of cultural understanding in education

Being a service provider in relation to the target group in this study can be demanding. With cultures that have different customs and different wishes when, for example, a family member is ill or you yourself need care, can present challenges if you are not aware of these. It is also easy to make mistakes in a hectic work situation when you have several things to consider.

A nurse talks about the role of the family when a family member is needs help:

> *"It's often the user themselves who has an expectation that the family should be the closest and take care of things. Where we often find ourselves offering things and think that it's appropriate for the municipality or the health service to assist, but where they want the family to take care of things, because that's what they're familiar and confident with" (nurse).*

One of the women from the target group previously described an underlying expectation on the part of the support services that the families should assist. This is problematic when it is not desirable or beneficial for the family, and it should not be an expectation, but when the families themselves want it, it is naturally not a problem. If it is healthy. But it can also be argued that it is natural to draw the conclusion that this is what is desirable for most families if they have these experiences.

Furthermore, many multicultural and disabled people are sceptical of the support services. As mentioned above, this is not surprising given the experiences many have been through. The nurse was also able to say that:

> *"[...] I have probably experienced, yes, that both people with a minority background and people with disabilities are sceptical about whether I will deliver what is expected, or almost ordered, whether I have sufficient competence and willingness to do it in the way they want or have been expected. Or a bit of scepticism about whether this is something I or Bergen Municipality and the health service in general can live up to" (nurse).*

When discussing how service providers should meet patients with different challenges, several factors come into play. It is probably difficult to count how many different things can come into play, and it is understandable, and an impossibility, to be able to know absolutely everything. As the nurse commented on wanting in-depth knowledge of many different topics, but this is impossible to achieve in a three-year education.

6.2.4 The burden of being a migrant family

6.2.4.1 Loneliness

One of the women talks about what it was like growing up with Pakistani parents and her own polio diagnosis. She was born in Norway, but her parents came as migrant workers. This meant, among other things, that because she herself was fluent in Norwegian, she had to act as an interpreter in many contexts, both as a child and later as an adult when caring for her sick mother. She also describes how her mother was left alone with much of the responsibility for following up doctor's appointments, physiotherapy and the like, and that she received very little help. In addition, she had to be a mother to her other children, be a wife to her husband and look after the house with all that entails. Even though she (Hina) had an aunt and uncle who helped on a regular basis, the mother was on her own most of the time.

> *"My mom says that my dad doesn't talk much, so he may have repressed it, but also because he was very busy at work [...]. And he struggled, as he told me, to get a job because he was foreign [...]. So he closed himself off. And maybe that's why my mom took more of the responsibility, and also that women often take more of the maternal role, with childcare and raising the children [...]" (Hina).*

She continues to talk about how her mother struggled with all her responsibility:

> *"[...] my mother had no one but her family, she didn't get any offers. She still tells me when she talks about me or health care in some context that she remembers the one doctor who followed me up, before and after Pakistan, one of those specialists, that he asked her "how are you doing" and she said she just cried" (Hina).*

This says something about the scope of being responsible for a disabled child, and the additional challenges that come with not knowing the system and not having a network that can help.

> *"But otherwise, the system around her, which was also supposed to take care of me, didn't take care of her. She was all alone. Didn't know the language, didn't know the rules, was in a new country, had only been in Norway for a year and a half before I got polio [...]. My uncle was good at looking after her, but it's very different with support from your loved ones compared to getting professional help" (Hina).*

6.2.4.2 The gender burden

Hina continues by saying that her mother eventually became ill herself, and that in retrospect this was not really a surprise, given how hard her mother worked for her family.

> *"[...] her body has gone into full gear and hasn't taken care of herself at all, she hasn't had room for it. And in the end, her body tells her off, right. And [...] it's the women it falls on. My mother was concerned with, I have three other siblings, my mother had to be a good wife, a good daughter-in-law, all those roles, while at the same time making sure that I was well dressed, well washed and that I attended all appointments, so that no one could lift a finger and say "you weren't a good mother" [...]" (Hina).*

This also shows something of the gender aspect of these situations. It is typically the women who are left with the care work, both for their children and later the children for their parents.

Naima also talked about how the fact that she was born a girl has also played a role in her childhood. She described how it was a disappointment that she was born a girl, and that when it became known that she had a visual impairment, the disappointment was even greater. Her own father died before she was born, so her grandfather felt a great sadness at having lost his son, and this sadness was magnified when he did not have a grandson either, and that this grandchild was also disabled. Her grandfather died when she was 7 years old, and she said that *"I was kind of relieved that he died early in my childhood, because then I didn't have to deal with him" (Naima).*

6.2.5 The service providers

Being a service provider in relation to the target group in this study can be demanding. With cultures that have different customs and different wishes when, for example, a family member is ill or you yourself need care, can present challenges if you are not aware of these. It is also easy to make mistakes in a hectic work situation when you have several things to consider.

6.2.5.1 To help someone that doesn't trust you

> *"If you ask me now, I can say that I hate doctors, I hate nurses, I hate hospitals. And I know that not all doctors, not all nurses, not all hospitals, but these were really bad experiences. And if you ask me, I think the system is terrible and unfair" Aline.*

A nurse talks about the role of the family when a family member is needs help:

> *"It's often the user themselves who has an expectation that the family should be the closest and take care of things. Where we often find ourselves offering things and think that it's appropriate for the municipality or the health service to assist, but where they want the family to take care of things, because that's what they're familiar and confident with" (nurse).*

One of the women from the target group previously described an underlying expectation on the part of the support services that the families should assist. This is problematic when it is not desirable or beneficial for the family, and it should not be an expectation, but when the families themselves want it, it is naturally not a problem. If it is healthy. But it can also be argued that it is natural to draw the conclusion that this is what is desirable for most families if they have these experiences.

Furthermore, many multicultural and disabled people are sceptical of the support services. As mentioned above, this is not surprising given the experiences many have been through. The nurse also did say that:

> *"[...] I have probably experienced, yes, that both people with a minority background and people with disabilities are sceptical about whether I will deliver what is expected, or almost ordered, whether I have sufficient competence and willingness to do it in the way they want or have been expected. Or a bit of scepticism about whether this is something I or Bergen Municipality and the health service in general can live up to" (nurse).*

The physiotherapist says that it is important to accept that people who have had bad experiences with health care professionals, do not automatically trust other health care professionals.

> *"[...] we must understand that those who have experienced abuse and torture have also been subjected to it by healthcare professionals, in collaboration with the military regime or prison system. Then it's the health personnel who come in with their instruments, often in uniform or coat".*

It is important to recognize that the clothes that service providers wear can trigger painful memories in the patients they meet:

"[...] I have a gown, also a pair of tracksuit bottoms, but in colour. Never white clothes, deliberately so as not to trigger any reactions and memories in relation to other experiences" (physiotherapist).

6.2.5.2 Working with traumas

That said, we can also not address all the different potential factors here, but only those that the study is about, namely being disabled and having a minority background. The physiotherapist talks about how disabilities can manifest themselves, and that it is not always physical, but something that becomes physical due to psychological factors. And why it is then important to have knowledge about what an escape can do to a person, what this person has experienced before the escape and what role they have played in their previous life. There may be reasons why patients do not get better, even though in theory they should.

> *"Yes, well, that the health condition [...] is deteriorating, meaning that none of the patients I had, [...] none of them have improved. And I've followed them for three years or more. And none of them have any really severe injuries. Or any permanent injuries. But what I experience is that what is called somatization, i.e. that you express through a physical disability, you express a disorder that is greater than just the leg that doesn't work. [...] And then it's about grief, it's a loss of role, this is a woman who comes from having lived in a very grand mansion, with employees in the house. And has had a role and an identity" (physiotherapist).*

And she continues:

> *"And then you come to Norway on family reunification. And you don't really have any rights, [...] you are supported by the person living here. Such a huge drop in status. So*

> *that when that icy pain that causes your foot to collapse, [...] that maybe someone who had a network, who had hobbies and other things, you would have been able to cope with life with that foot yourself. But here it's as I say, a walker at the age of 49. And seizures and calls for an ambulance at regular intervals. Extensive examinations. In other words, a lot of symptoms that don't really match the objective findings, if you can call it that. And when I bring the patient in for treatment, there's enormous suffering in terms of, well, loss of role, identity, and hopelessness".*

6.2.5.3 Causes and solutions, a healthcare worker's perspective

> *"How does the doctor who sits like that (facing away) and talks to you, and it's not just the doctor's fault. It's how the healthcare system is set up. There are time limits [...]. When I have patients, it takes ten minutes. I have a time clock for the patients. When they come into my office, the charges start to run in a way. Until they walk out into the hallway" (physiotherapist).*

She talks about all the extra amount of work the doctors need to do that take time away from the patients, like the paperwork they do during the consultation, work that are outside the scope of the tariffs.

> *"So [...] the doctor probably tries to do things here that aren't covered by separate tariffs. They try to do it at the same time as the consultation, [...] and into the medical record and into the system. If there had been a separate fee for journal writing, for example, I'm pretty sure that after each consultation, the GP would have taken an hour's worth of journal writing to catch up, to get some writing done. They could have spent more time with the patient when the patient was present".*

How can it be better? What does she thinks lacks for the patient to feel seen and treated correctly?

> *"Then there is a key word: human contact. What does a person in need, a person in crisis, need? It needs to be regulated. It needs to be stimulated. We are not made to be alone" (physiotherapist).*

We talk about what lies behind the scepticism many immigrants have towards healthcare professionals and the support system. And why it is important to keep this in mind when meeting these people. She talks about a Syrian family she met, who had lived many years in Lebanon in a refugee camp before they came to Norway. They had several children who were badly injured, and one of the children had to have a surgery and needed a blood transfusion. This is what they were met with:

> *" [...]" we won't give it unless you give us money. And then we can't guarantee the outcome". Imagine the desperation of the parents, when they then sort of put their soul up for sale, and go from door to door in the city asking for help, it's a matter of minutes. People bring these experiences with them in their luggage. And it's healthcare professionals, it's the doctor who comes out in his doctor's coat and says that we can operate, but we need NOK 10,000. And it's like, a white coat is a white coat" (physiotherapist).*

As an answer to questions of what it would take to improve the current system, she says this:

> *"I think we need to look at the ambitions of those of us who are going to help them. Because what is the goal? What does it mean to live a good life? [...] the best person to answer that must be the individual themselves. And to achieve that, you must work at the individual level in one-to-one therapy or consultation. But you also need a professional environment [...] for example the pain clinic at Haukeland Hospital, which works with long-term and complex pain conditions, and [...] the Centre for Migration Health, a municipal first-line service" (physiotherapist).*

She continues:

> *"But to be able to have built it up into a competence centre and a rehabilitation centre with professionals who were dedicated. Because it requires something in addition to just being a regular nurse, or a regular physiotherapist, or a regular GP. It requires that you've maybe done a course or two. And just got that mindset of how to understand things a bit more broadly. It doesn't take that much" (physiotherapist).*

She wants some kind of a competence centre, where they can travel around different departments in the hospital:

> *"[...]listen to the experiences, to the health personnel. What's frustrating about these patients? Tell us, vent, get to the bottom of those frustrations and feelings of...inadequacy [...] Because I think that's also important, so that we don't build up a kind of fear of contact, as you say" (physiotherapist).*

7.0 Discussion

The background for this study has been to look at how conditions are for disabled women with a minority background in Norway, and how some of those who work with this group experience this. Some of the findings were expected, such as that there are major challenges when it comes to a perceived lack of multicultural understanding among the support services, and that the women feel discriminated against in various ways. They seem to feel that they are falling outside the systems boarders, and that they encounter resistance from several different quarters.

7.1 Resistance Resources and disabilities

Generalized Resistance Resources (GRR) was first mentioned by Antonovsky, and comprises the characteristics of a person, a group or a community that facilitate the individual's abilities to cope effectively with stressors and contribute to the development of the individuals level of sense of coherence (SOC) (Idan et al., 2017, p. 57). Antonovsky refers to GRR as a set of diverse resources that can provide people with life experiences characterized by participation in shaping outcomes and a under- and overload balance (Antonovsky, 1987, p. 19, in Idan et al., 2017, p. 57). These resources can involve various factors, including material resources (money), coping strategies, social support, cultural stability and religion and philosophy (Antonovsky, 1979, 1987, in Idan et al., 2017, p. 57).

In an article addressing the relationship between sense of coherence and adaptation in people with disabilities, they point to a positive correlation between SOC and adaptation (Lustig et al., 2000, p. 138). The correlation between life satisfaction and the meaningfulness component is particularly strong. Meaningfulness motivates the person to seek resources and solutions, so even if they score high on the comprehensibility and manageability components, they will eventually stop searching for solutions if meaningfulness is not sufficiently high (Lustig et al., 2000, p. 138). Aline and Miya explain their experiences with the religious community, and that it has a big impact in their life. Alines encounter with religion, did not solved her problems, but it provided her with a community that has made it easier to cope with the challenges she experiences in everyday life.

The need for a job was evident among all the informants, whether they were in work or not. "Not being able to enter the labour market is a sore subject, and it brings with it a number of other challenges, such as poor finances, exclusion and the feeling of being of no use to others. Miya could tell that she applied for many jobs but would not get invited to any interviews.

Research shows that there is a lot of prejudice among employers, where disabled people are seen as less suited to work (Lundberg, 2022). At the same time, research also shows that those who employ people with a disability are highly satisfied and can point to employees who are particularly loyal and effective (Lundberg & Solvang, 2022).

GRR refers to resources that have a broad utility, such as your social network, while specific resistance researches (SRR) refer to more specific resources, such as access to the police emergency number (Mittelmark et al., 2017, p. 71). Antonovsky argued that it is GRR that determines the extent to which SRR is available to people when needed (Mittelmark et al., 2017, p. 72). For example, a religious network gives Aline good access to conversation partners who can help her through difficult periods of illness. The same goes for Myia, whose handball team gives her a sense of empowerment, which in turn leads to increased joy in life. With a strong SoC, the ability to recognize and activate the most appropriate SRRs among those available increases (Mittelmark et al., 2017, p. 72).

The cartoon figure with his knapsack filled with life experiences and tools as shown in figure 2, explains how one can use the GRRs when faced with challenges (Mittelmark et al., 2017, p. 73). Aline explains how she uses her experiences to help others who are in similar situations, and how this makes her life meaningful.

The physiotherapist talks about how the lack of said resources may keep one from getting better, in what she said about the illness of the women she meets in her work. Illnesses and injuries that are initially easy to treat and easy to recover from ultimately turn into chronic illnesses and pain, partly due to a lack of resources. A lack of networks, knowledge of the system, knowledge of their own rights, and so on, drastically exacerbates the situation.

This can also affect the families of those concerned, as shown in the example of one of the women, where her mother was left alone with all the responsibility for house and home and with a polio-sick daughter to look after. Having to follow this up without language and knowledge of the culture and system quickly becomes a major burden that can lead to illness later in life.

7.2 Intersectionality

One of the informants describes the comments she receives, such as that she "has only come here to live in luxury at the state's expense", shows the double layer of both underlying racism and ableism. Also, when the women in this study, and others in similar situations, are faced with a system that systematically works against them. They receive fewer hours of assistance because they are women. They have less access to help because they are not Norwegian and do not know the system, and there is no automatic help for forms that are filled in incorrectly due to language confusion. If you have a disability, you also have poorer access to help simply because of accessibility.

When it comes to violence and abuse, this must also be considered through an intersectional lens. It is a consequence of the patriarchal power relations in a (heterosexual) marriage, and between strangers. Because of the disability, it is more difficult for these women to escape their abuser than women who do not have a disability (Olsvik, 2007, p. 17). This is true for Aline, who talked about her neighbour who assaulted her and her ex-boyfriend who was violent. They both took advantage of a particularly vulnerable person who was dependent on help.

7.2.1 Cultural awareness

Here we can also talk about intersectionality, to the extent that culture has a major impact on how people experience being met by the Norwegian support services. It also plays a major role in the way service providers meet them. Like the physiotherapist who talks about never dressing in typical white hospital clothes to avoid provoking trauma in patients. Naturally, this is not an option for all healthcare workers.

We can see from both the literature and what the physiotherapist says in the interview about how migration and the losses it entails can affect a person, and the extent to which it has a bearing on how much resilience one has within oneself. When the informants in the Fafo report (Friberg & Bjørnset, 2019) and Herz's mother talk about how much it meant to them to lose their role and how it affected how they experienced their parental role (Herz, 2021), it is natural to assume that it also has a major impact on how you can cope with illness, injury, and disability.

Possessing cultural competence and cultural humility will significantly increase the chances of a better collaboration with the patient and increased mutual respect (Foronda et al., 2015, p. 212). It also increases the chances of providing better treatment, as cultural competence increases the possibility of better understanding the patient's needs and wishes (Hall et al., 2012, p. 140). This is consistent with what both the nurse and the physiotherapist said, as they felt that they were able to provide better treatment when they were familiar with different customs and traditions from the cultures the patients brought with them. It also increased understanding and patience in situations where patients resisted what the healthcare professional recommended, due to uncertainty and fear because it is not what they are used to from their home country.

7.2.2 Discrimination

Discrimination refers to the unfair treatment of people as a result of prejudice (Haslam et al., 2021, p. 567). Both the women interviewed for this study and what can be seen in previous studies show that there is a lot of undesirable behaviour against this group. Both hate speech and discrimination seem to have a lot to do with a lack of knowledge, and thoughts and prejudices about who can be a fully integrated citizen in the society.

The theory of citizenship was first written about by the famous American sociologist T. H. Marshall in the late 1940s (Turner, 1990, p. 191). The term implies who is considered an equal citizen, and is used to describe citizens who have rights and obligations in a society, and that these citizens can experience a sense of belonging and have the opportunity to participate in society (Lid, 2017, p. 188). Despite these intentions, however, the term has been characterized by stereotypical notions of the citizen as a man (Siim, 2000). In this way, factors such as gender and disability have excluded both individuals and entire groups (Lid, 2017, p. 189).

Historically, women have been excluded from parts of society. For example, even though Norway was one of the earliest countries, women here did not have the right to vote until 1913, and they were excluded from higher education. Disabled people have been excluded to an even greater extent, and were seen as inferior and were disempowered, among other things (Lid, 2017, pp. 189-190). Dependency on others and the need for care has been, and is, an obstacle to recognition as a citizen (Nussbaum, 2007). For citizenship to be universal, it must be understood as rational and with an understanding and aspect of the fact that citizens live in mutual and often asymmetrical dependence on people and society (Lid, 2017, p. 187). Both gender and disability have an impact on the opportunities to participate in society, but as people have fought for the right to participate on an equal footing (like white, able-bodied men), society has also changed into what can be said to be a better society for most people (Lid, 2017, p. 191).

When women were allowed to pursue higher education and take a greater part in working life, society had to adapt, and the care tasks that usually depended on women gradually became the responsibility of the public sector, and kindergartens and nursing homes were developed (Lid, 2017, p. 191). In the same way, society must evolve to enable disabled people to participate.

The adaptation that is required is both universal and individual. Universal design, which is about ensuring that all people can participate in society irrespective of their level of disability, means that the development of products, goods, services and environments must be done in a way that everyone can use them (Kommunal- og moderniseringsdepartementet., 2021). As most people will experience some sort of disability during their lifetime, due to illness or old age, this will benefit everyone.

Disability is defined as society-created barriers that make a person disabled (Tøssebro, 2021). If society is adapted so that, ideally, everyone can use it on an equal footing, this will necessarily lead to a reduction in the degree of disability for some people. The informants talk about experiences of discrimination in working life, that the workplace is not adapted and that colleagues do not understand why a colleague in a wheelchair needs help to carry heavy tools. They also talk about struggling to find housing, as landlords and neighbours do not want to have a wheelchair user in their hallway because it is not adapted in case of fire, and they fear for safety. With universal design, issues like this could be resolved.

7.3 Human rights

Several things the women tell, shows that their basic human rights are being violated (FN., 1948):

"Article 3: Everyone has the right to life, liberty and security of person":

When a person is dependent on assistance to leave their house and move around freely the same way as the majority population, the requirement to be able to live a life in freedom is not met unless this assistance is provided. The system is responsible for providing people who are dependent on this help with the assistance they need. As shown in the interviews, this is not the case for many people with disabilities.

> *"Article 22: Everyone, as a member of society, has the right to social security and is entitled to have the economic, social and cultural benefits indispensable for his dignity and the free development of his personality provided through national measures and international cooperation in accordance with the organization and resources of each State":*

Even when enough assistance is provided to meet basic needs, such as getting dressed, going to the toilet, and eating food, this is not enough. Everyone must prioritize what they want to do with their time, and few people have the time and resources to do everything they want to do. For people with disabilities, however, it is often a matter of having to choose to spend time doing necessary housework, following up on their child's schooling or occasionally being able to go to the cinema, theatre, or a football match. And in a way they are not the one making the choice, the choice is made for them. Because in this case of course you are choosing to follow up your child.

This also applies to the informant who describes living with an abusive boyfriend and experiencing sexual abuse. No one can know if it would not have happened if she had had assistance, but the chances would have been smaller (Meyer et al., 2022) (Olsvik, 2005).

> *"Article 25, 1: Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control".*

All the informants describe challenges in getting enough assistance, which has major ripple effects. Without this help, it is difficult to complete school and education, and to hold down a job, which in turn can lead to financial problems, which may in turn contribute to poorer mental health. A newspaper article from Handikapnytt gives a little insight into what it can be like to live with too few hours when you want to finish school, but because of this you have to stay in bed with a diaper on until late in the day because that is when the assistant starts working (Fjeld, 2023).

7.4 System challenges and potential for improvement

The nurse and physiotherapist talk about the lack of training in multicultural competence. In an article written by Oddhild Peggy Bergsli (2022) she writes about this. The informants are vocational teachers in health subjects, and could tell about little training, that they were lucky if they had an employer who sent them on courses (Bergsli, 2022, p. 85). Furthermore, they talked about unpleasant experiences that arose due to a lack of cultural competence, and that they felt that they were not enough when it was necessary, because they did not understand what the patient needed (Bergsli, 2022, p. 85). Despite the fact that it is emphasized in the plan for learning (*læreplan*) (Utdanningsdirektoratet., 2021) multicultural competence is not implemented in the training of healthcare professionals.

This reflects what the informants in this study say–both the women and the service providers. The physiotherapist's experience with the patient she had in prison, where she had no prerequisites for understanding what problems and, in her eyes, normal treatment session could create, is an example of the importance of cultural competence.

Furthermore, multicultural health communication is also relevant in this context. It’s about ways of communicating that can differ from culture to culture. It also turns out that there is often a big gap between what healthcare professionals assume patients understand and what patients actually understand (Bellander & Karlsson, 2019, p. 15). This can apply in both directions, that the patient understands more than the healthcare professional assumes. Naima experienced this when she came to the refugee reception centre and found it degrading that the doctor was so surprised that she was well informed about her own diagnosis.

Combined with this, the concept of health literacy is relevant as it involves people’s ability to understand medical information, how to interpret it and the extent to which they are equipped to use the information they receive (Jenum & Pettersen, 2014). The importance of providing health information in a way that is understandable to the patient was also demonstrated in the article to Bergsli and Helne-Halvorsen (2020, p. 35), where the women do not understand what the doctor means and do not dare to ask.

7.5 Limitations

As with all studies, this one also has several limitations. Some of these come because of a lack of data in exactly the area that is the focus of this study. Therefore, it is difficult to find relevant and peer reviewed litterature that supports the findings made in the interviews for the study. Furthermore, the fact that it is a target group that is difficult to reach has played a role. This, in addition to the size of the study, has meant that the number of informants has been limited.

Due to the size of the study, it has also not been possible to investigate all the issues that have emerged along the way, which would otherwise have been interesting to research. This applies, for example, to the psychological strain of dealing with the challenges faced by these women, and the extent to which this contributes to worsening their condition. It would also have been interesting to look into the costs to society of providing all disabled people with the assistance they need, compared with the savings this could have made to society in terms of reduced social security benefits, sickness benefits, tax revenues and more.

8.0 Conclusion

The living conditions of people with disabilities is a field that has been little explored, even though this group makes up around 15% of the population. The combination of being disabled and having a multicultural background is less well known. Therefore, this study has aimed to contribute to increasing this knowledge, with a qualitative study conducted with in-depth interviews of multicultural women with a disability, in addition to interviewing people who work with this target group to get both sides' perspective on the issues.

Both the existing literature and the findings from the interview process point to a knowledge gap when it comes to public service providers. Multicultural understanding is listed as a goal in curricula, but despite this, it is not sufficiently implemented in education, leading to trained healthcare workers feeling shortchanged in situations where patients have an unexpected reaction to proposed treatment, or where patients feel they are not taken seriously. In addition to a lack of multicultural understanding, the women feel that their disability is not taken seriously, both in terms of healthcare professionals and caseworkers at NAV. They do not receive the help they need when it comes to assistance and aids, and they experience the system as unnecessarily slow and difficult. The informants from the target group talked about how several years of these types of encounters have led to a lack of trust in both employees in the health sector and NAV and the system.

The service providers interviewed talk about a lack of training, and how it is up to you to learn how to treat different functional variations and how to meet migrants and people who, due to war, flight and other factors, have a bag full of trauma and major reasons for not trusting the Norwegian healthcare system. There is a need for greater cultural sensitivity and multicultural understanding in these sectors, and there is a need for a system that is designed to see the people who come in as people, not expense items. One can only assume that those working in these sectors want to do the best for as many people as possible, but then they must be given the tools needed to do this job.

The interviews conducted for this study gave these women a voice, and several of them expressed delight that someone wanted to talk *to* them, and not just *about* them. They have so much to tell, but then there must be someone who wants to listen.

8.1 Recommendations for further research

Based on the findings made in the study, and issues that have emerged along the way, there are some suggestions for further research. The psychological strain of living as a double and multiple minorities and the challenges this entails. The intersectional nature of being discriminated against in several areas is stressful, and there are several factors that should be included and researched, such as sexual orientation. Furthermore, it would be useful to have more research into how being disabled as a refugee and the extent to which the psychological stresses and traumas this entails make a person more disabled, and how having, or lacking, a network plays a role. Finally, it should be investigated how many disabled people with multicultural backgrounds get the help they need and are entitled to, compared to Norwegians?

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Appendices

Appendix A – recruitment flyer

Flerkulturell bakgrunn og funksjonshemmet?

Vil du ta del i et forskningsprosjekt?

Er du en kvinne med flerkulturell bakgrunn og har en form for nedsatt funksjonsevne? Har du lyst til å dele dine erfaringer, tanker og opplevelser knyttet til dette? Da ønsker jeg å komme i kontakt med deg!

Jeg er student ved Universitetet i Bergen og skal skrive masteroppgave om kvinner med flerkulturell bakgrunn og nedsatt funksjonsevne og deres møte med det norske samfunnet. Jeg ønsker å snakke med deg om hvordan livet ditt er her i Norge, hvordan du opplever å bli tatt imot av det norske hjelpeapparatet og om du møter på noen spesielle utfordringer i hverdagen knyttet til dette.

Å delta i dette forskningsprosjektet innebærer et intervju på 1 – 1,5 timer, enten individuelt eller i en gruppe.

Har du spørsmål og/ eller ønsker å delta? Ta gjerne kontakt!

Vennlig hilsen Toya Scheldt

Mail: t.scheldt@student.uib.no

Telefon: +47 471 74 474

Appendix B – Interview guide target group

Individuelt intervju – kvinner med funksjonsnedsettelse

Innledende: husk at dette er helt frivillig, du kan når som helst avslutte om du ikke ønsker å delta, og også la vær å svare på noe om du synes det er ukomfortabelt. Vi skal inn på litt personlige og private ting, så jeg vil at du skal huske på dette. Jeg vil ikke presse deg til noe du ikke vil.

Spørsmål
Hvor gammel er du/ når er du født?
Hvor kommer du fra?
Hvor lenge har du bodd i Norge?
Jeg vil gjerne høre litt om hvordan du kom til Norge og tiden etter. Hvordan kom du hit?
Har du bodd på asylmottak?
- Hvordan var det?
Nå kommer vi inn på det som er kjernen i oppgaven min, nemlig hvordan du opplever det å leve med en funksjonsnedsettelse i Norge? Vil du fortelle litt om det?
Vet du noe om hvordan det er i hjemlandet ditt? Er det annerledes enn hjemlandet ditt/ der du bodde før?
- Hva er de største forskjellene?
Har du noe særlig erfaring med det norske hjelpeapparatet? (Nav, kommunen generelt, helsevesenet o.l). Hvordan opplever du å bli møtt av det norske hjelpeapparatet?
Forskning har vist at flere med funksjonsnedsettelser generelt, og de med innvandringsbakgrunn spesielt, føler på manglende forståelse fra hjelpeapparatet, og at det ofte er personavhengig hvilken hjelp man får. Er det noe du har opplevd? Er det noe du savner fra de som jobber der?
Nå kommer vi inn på litt mer personlige temaer – du må huske på at om det er noe du ikke ønsker å svare på så er det bare å si ifra. Hvordan er forholdet til familien din?
Føler du tilhørighet i et spesielt miljø i Bergen? (student, politisk, idrett, religiøst etc)
Har du en religiøs tilknytning?
- I forbindelse med det; deltar du i moskeen, tempelet, kirken e.l?

Opplever du noe ubehag i forbindelse med å delta på disse arenaene? Hvis ja, hvordan?
Kjenner du noen andre som er i lignende situasjon som deg? - Hvis ja – er det noe dere snakker om? Utdyp gjerne - Hvis nei – savner du noen å snakke med som er i samme situasjon?
Er du i jobb eller et utdanningsløp? - Hvis ja – hva? - Hvis nei – er det noe du kunne tenke deg? I så fall hva?
Deltar du på noen aktiviteter i byen? - Hvis ja – hvilke/ hva slags? - Hvis nei – hvorfor?
Er det noe du savner der du bor? (aktivitetstilbud, et sted å møte folk i lignende situasjon e.l.)
Hva ønsker du deg for fremtiden? - Hva ser du for deg i fremtiden?
Er det noe mer du ønsker å fortelle?

Appendix C – interview guide service providers

Individuelt intervju – ansatte som jobber med gruppen

Hvor jobber du? - Hva er dine arbeidsoppgaver?
Møter du ofte denne gruppen kvinner? - Fortell gjerne litt om hverdagen din i møte med disse kvinnene - Kan du fortelle litt om din erfaring med arbeid med denne gruppen?
Møter du noen spesielle utfordringer med denne gruppen? Hvis ja – hvilke?
Hva er det beste med å jobbe med denne gruppen?
Flere kan fortelle om vanskelige opplevelser der de føler det er et tungvint system, mistillit til de som tjenestemottakere, og at legens anbefalinger ikke blir tatt hensyn til. I tillegg er det jo alle historiene i media. Opplever du skepsis fra disse kvinnene? - Hvis ja – får du vite/ en følelse av hva det kan komme av? - Hvis nei – er det noe du vet andre i lignende jobbsituasjoner opplever?
Det er jo store kulturforskjeller i mange av disse møtene. Dette kan potensielt føre til noen utfordringer. I hvilken grad blir dere lært opp til å møte disse utfordringene på din arbeidsplass? - (tidligere forskning viser at det er lite kulturforståelse i store deler av helsevesenet/ hjelpeapparatet når det kommer til kombinasjonen innvandrer/ funksjonshemming). Tanker om det?
Er det noe du mener mangler i utdanning/ opplæring på arbeidsplass når det kommer til disse problemstillingene? - Hvis ja – hva? Og hvordan mener/ tenker du det kan bli gjort bedre? - Hvis nei – hva er det som fungerer bra?
Er det noe mer du ønsker å legge til?

Appendix D – consent form

Vil du delta i forskningsprosjektet

Flerkulturelle kvinner med funksjonsnedsettelse?

Dette er et spørsmål til deg om å delta i et forskningsprosjekt hvor formålet er å undersøke dine opplevelser av å være kvinne med flerkulturell bakgrunn og nedsatt funksjonsevne, og hvordan dette påvirker deg i hverdagen i det norske samfunnet. I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

Formål

Formålet med prosjektet er å få innsyn i hvilke utfordringer kvinner med flerkulturell bakgrunn og nedsatt funksjonsevne møter i hverdagen i det norske samfunnet. Hvordan blir de møtt av hjelpeapparatet? Finnes det tilbud i byen som kan gjøre hverdagen bedre? Hvis ja, hvilke og hvorfor fungerer disse, hvis nei, hva er ønskelig?

Dette er spørsmål jeg ønsker å få svar på i forbindelse med min masteroppgave.

Hvem er ansvarlig for forskningsprosjektet?

Universitetet i Bergen er ansvarlig for prosjektet.

Hvorfor får du spørsmål om å delta?

Jeg ønsker å snakke med kvinner som opplever dette selv, i tillegg til mennesker som jobber i ulike sektorer som typisk møter denne gruppen i arbeidshverdagen sin. Til sammen vil utvalget av informanter ligge på 6-8 personer.

Jeg har tatt kontakt med mennesker som passer beskrivelsen av utvalget enten personlig, eller via organisasjoner som jobber med gruppen.

Hva innebærer det for deg å delta?

Metoden som skal brukes for å samle inn informasjon er intervju, enten individuelt eller i gruppe. Disse vil vare i 1,5 – 2 timer.

Intervjuene vil bli tatt opp på en separat lydopptaker, og alle personopplysninger og annen sensitiv informasjon vil bli lagret i et passordbeskyttet program. Dette blir slettet ved studiens slutt.

Det er frivillig å delta

Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykket tilbake uten å oppgi noen grunn. Alle dine personopplysninger vil da bli slettet. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger

Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrivet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket.

Det er bare jeg, student, som vil ha tilgang til opplysningene som blir gitt. Det er også bare jeg som skal behandle disse opplysningene.

Opplysningene som blir gitt vil bli lagret i et eget, passordbeskyttet system.

Hva skjer med personopplysningene dine når forskningsprosjektet avsluttes?

Prosjektet vil etter planen avsluttes i slutten av juni 2024, når oppgaven levers. Etter prosjektslutt vil datamaterialet med dine personopplysninger slettes.

Hva gir oss rett til å behandle personopplysninger om deg?

Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra Universitetet i Bergen har Sikt – Kunnskapssektorens tjenesteleverandør vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Dine rettigheter

Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke opplysninger vi behandler om deg, og å få utlevert en kopi av opplysningene
- å få rettet opplysninger om deg som er feil eller misvisende
- å få slettet personopplysninger om deg
- å sende klage til Datatilsynet om behandlingen av dine personopplysninger

Hvis du har spørsmål til studien, eller ønsker å vite mer om eller benytte deg av dine rettigheter, ta kontakt med:

Ørjan Skaga (veileder), orjan.skaga@redcross.no eller Toya Scheldt (student), t.scheldt@student.uib.no

Vårt personvernombud: Janecke Helene Veim, personvernombud@uib.no

Hvis du har spørsmål knyttet til vurderingen som er gjort av personverntjenestene fra Sikt, kan du ta kontakt via:

Epost: personverntjenester@sikt.no eller telefon: 73 98 40 40.

Med vennlig hilsen

Prosjektansvarlig Eventuelt student

(Forsker/veileder)

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet [flerkulturelle kvinner med funksjonsnedsettelse], og har fått anledning til å stille spørsmål. Jeg samtykker til:

- ○ å delta i intervju
- ○ at mine personopplysninger lagres etter prosjektslutt, til videre forskning – hvis aktuelt
- ○ Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet

(Signert av prosjektdeltaker, dato)

Appendix E – NSD register

Sikt

Vurdering av behandling av personopplysninger

Referansenummer	**Vurderingstype**	**Dato**
850178	Standard	11.10.2023

Tittel
Masteroppgave 2024

Behandlingsansvarlig institusjon
Universitetet i Bergen / Det psykologiske fakultet / Hemil-senteret

Prosjektansvarlig
Ørjan Skaga

Student
Toya Scheldt

Prosjektperiode
02.10.2023 - 20.06.2024

Kategorier personopplysninger
Alminnelige
Særlige

Lovlig grunnlag
Samtykke (Personvernforordningen art. 6 nr. 1 bokstav a)
Uttrykkelig samtykke (Personvernforordningen art. 9 nr. 2 bokstav a)

Behandlingen av personopplysningene er lovlig så fremt den gjennomføres som oppgitt i meldeskjemaet. Det lovlige grunnlaget gjelder til 20.06.2024.

Meldeskjema

Kommentar
OM VURDERINGEN
Sikt har en avtale med institusjonen du forsker eller studerer ved. Denne avtalen innebærer at vi skal gi deg råd slik at behandlingen av personopplysninger i prosjektet ditt er lovlig etter personvernregelverket. Vi har nå vurdert at du har lovlig grunnlag til å behandle personopplysningene.

TYPE PERSONOPPLYSNINGER
Prosjektet vil behandle særlige kategorier av personopplysninger om helse og religiøs overbevisning.

FØLG DIN INSTITUSJONS RETNINGSLINJER
Det er institusjonen du er ansatt/student ved som avgjør hvordan du må lagre og sikre data i ditt prosjekt og hvilke databehandlere du kan bruke. Husk å bruke leverandører som din institusjon har avtale med (f.eks. ved skylagring, nettspørreskjema, videosamtale el.).

Personverntjenester legger til grunn at behandlingen oppfyller kravene i personvernforordningen om riktighet (art. 5.1 d), integritet og konfidensialitet (art. 5.1. f) og sikkerhet (art. 32).

MELD VESENTLIGE ENDRINGER
Dersom det skjer vesentlige endringer i behandlingen av personopplysninger, kan det være nødvendig å melde dette til oss ved å oppdatere meldeskjemaet. Se våre nettsider om hvilke endringer du må melde: https://sikt.no/melde-endringar-i-meldeskjema

OPPFØLGING AV PROSJEKTET
Vi vil følge opp ved planlagt avslutning for å avklare om behandlingen av personopplysningene er avsluttet.

Lykke til med prosjektet!