“It is with others I feel most alone”

A qualitative study on health promoting communities for autistics

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Foreword

With this thesis, I complete my music therapy education at the Greig Academy in Bergen. The journey I have been on from back in 2017, when I first started my studies to where I am now has been a highlight of my life. With all the knowledge and memories I have gained, I know this will be a time to look back on with fondness. In saying that, there are some people I would like to thank for accompanying me through this odyssey.

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To all the educational staff at GAMUT; thank you for all the knowledge and encouragement you have provided in my pursuit of becoming a music therapist. Without you, this thesis would not exist.

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"*Understanding is the first step to acceptance, and only with acceptance can there be recovery." (Albus Dumbledore in Rowling, 2015, p. 572).*

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Abstract

Autistics have been excluded and mistreated by society for decades, due to a fundamental misconception of what the lived experience of autism entails. Alienated by their environment, autistics have been left alone to deal with their resulting crippled mental health and a staggering suicide rate. For this thesis I have conducted two focus group interviews with five other autistics about what they think the future should hold in terms of health care services. In response I got plenty of insight and suggestions. Most notably was the general emphasis on meeting other autistics, as well as sharing knowledge and insight with non-autistics. Thus, I discuss how community music therapy might provide a suitable arena for addressing the issues and goals raised by the informants. However, before community music therapy presents a viable option for promoting autistics health, I suggest the discipline needs to be further developed in three main aspects, (1) the affordance of a safe space and framework for conducting community music therapy; (2) providing autistics with diverse environments where they can nurture distinct relationships; and (3) implement the autistic voice into music therapy education, and teach students how to reflexively incorporate clients' voices into the shaping of community music therapy practice.

Table of content

List of Figures

«In the history of autism studies, expertise has been claimed by many differing academic schools of thought, practitioners, parents, quacks and so on. Yet, the one voice that has been traditionally silenced within the field is that of autistic people themselves.» (Milton, 2014, s. 800).

1.0 Introduction

I was diagnosed with autism at the age of 10. Before my diagnosis I remember feeling alienated, like I did not quite fit in with everybody else. Still, I did not know how or why I was different, let alone how to express and describe the frustration that arose whenever others did not seem to understand me either. Coming from a world where misunderstandings were aplenty and usually at my expense it may be of little surprise that anger issues arose and, consequently, became one of the main reasons for my parent's referral to the clinic where I got my diagnosis. When I was diagnosed with what was then called Asperger's syndrome, both me and my family made a big sigh of relief – at last I was not an alien anymore! Now everybody could understand why I was different and try to help me overcome my daily challenges. At least, we thought so. However, it did not take long before the joy turned into disappointment. No one in our community had ever heard of Asperger's before. And so, what we had thought would be my ticket to inclusion, many people turned to a sentence of further exclusion. The information we were given by the clinic about my diagnosis was initially intended to assist the environment in adapting to me. Yet, it turned more into an instruction manual of what I needed to hide about myself to be accepted. After years spent creating masks to cope with what felt like a threatening world around me, I was eventually able to hide my autism to the point where others could not tell that I was struggling.

Unfortunately, most of my experiences are not isolated, individual incidents but seem to be rather common. Claims made by both autistic self-advocates like Jim Sinclaire (1993), authors such as policy advisor Scott M. Robertson (2010), and political proclamations (NOU 2020: 1, 2020) point to misinformed views of the autistic lifeworld as well as health care services not addressing autistics rights or needs.

When brought to light that the established system is failing, a logical question is: what needs to change? During my time as a music therapy student, I have gathered a clearer understanding of the structure and perspectives surrounding both autism as well as the autistic population, and the treatment thereof.

This understanding has also cultivated a hypothesis of how music therapy and in particular aspects of community music therapy as taught and practiced in Bergen can be developed to provide a different perspective, that challenges and contradicts established approaches and narratives.

1.1 A Modern Concept of Autism

The term "modern" in the header refers to how the current system of autism treatment is not only failing, but is also outdated. Currently, autism is often being defined by researchers and health care systems in terms of its pathological characteristics, such as social, communicative and cognitive deficits in the individual (Helsenorge, 2020). These characteristics stem from the three main theories that have been dominating the field of autism for the last decades: 'theory of mind,' 'executive dysfunction,' and 'weak central coherence theory,' (Milton, 2012b; Jaegher, 2013) which together form a complete picture of autism, according to pioneer Uta Frith (Baron-Cohen, 2003).

However, there has been an increasing adherence to theories underlining a more complex understanding of autism during at least the last three decades. Hanne De Jaeger (2013) clarifies that the three mentioned theories certainly provide some insight into the autism phenomenon, but will at best only depict portions of the autistic whole. The main issue with these theories is that they all reduce autism to a neurological disability within the individual. An increasingly number of theories now suggests autism as something much broader, and sometimes even communal. Examples for this are Jaegher's theory about 'embodiment' (2013) and Damian Milton's theory about a 'double empathy problem' (2012b), whom both build on Jim Sinclaire's concept of "[a]utism as a way of being" (1993, n.p.).

Jaegher (2013) suggests that autism is a bodily phenomenon that includes perception, sensitivity, motion, and emotion-affectivity, as well as the already mentioned cognitive, social and communicative difficulties. Following the differences in how autistics and non-autistics experience the world, meaning is constructed and communicated differently. This coincides with Milton's theory (2012b), that the social challenges autistics face do not come from autism itself nor the autistic individuals but instead occur in the interaction between the two differing experiences of the world. Double empathy derives from the notion that empathy is a two-way street where it is the responsibility of *every* participant to establish a mutual relationship. The problem arises when one party tries to force their own worldview onto others. Sinclaire demonstrates this problematic interaction as follows: [Y]ou're assuming a shared system, a shared understanding of signals and meanings, that the [autistic] child in fact does not share" (1993, n.p.).

Considering these perspectives and theories, it stands to ask whether or not autism actually can be classified as a disability. The Social Department of the Norwegian government made a statement in 2003 claiming that disability is created in the gap between the individual's preconditions and society's demands (St.meld. nr.40 (2002-2003), p. 5). This view solidifies disability not as something inhabited by the individual. However, it is somewhat rather akin to the double empathy problem, in that it represents a two-way street between the individual and its surrounding society. In this context, autistic people have, been forced into striking a Faustian bargain where they give up their individualistic freedom in exchange for societal and social acceptance (Hull et al., 2017; Milton & Moon, 2012). It is likely because of this bargain that autistics often end up feeling lonely, in addition to the severely high rates of depression, anxiety and suicide found in autistics compared to the general population (Robertson, 2010; Hirvikoski et al., 2016; Mitchell et al., 2021).

While attempting to minimise the disabling gap between society and individual, it is easy to create an idealistic, generalising norm which all parties should strive towards, and by that disregarding the benefits of individual differences and diversity in autistics as well as the general population. Norms become problematic in many but the issue is clearly demonstrated by anyone who relates to autism and uses the common but false dichotomy of high and low-functioning autistics. The reason for calling this a *false* dichotomy is based on the stereotype that autistics who seem to align more with the societal norm are deemed *high-functioning*, and those who fall outside this norm are thought being *low-functioning* (Milton & Moon, 2012). As a result of this, *high-functioning* autistics often experience their diagnosis and actual challenges as being downplayed (Griffith et al., 2011), whereas *low-functioning* autistics have their abilities and strengths undermined if not ignored by other people's perception of their being (silentmiaow, 2007). Research shows that the support system needs to address and adhere to the individual's challenges and abilities (Robertson, 2010). Meaning, in pursuit of providing support to people labelled with a disability, it is crucial that one does not seek normalcy but rather invite for and acknowledge diversity.

1.2 The Purpose of this Thesis

Prior to this thesis, I worked on a research project with the title “Tendenser i behandlings- og oppfølgingstjenester for autister i Norge [Tendencies in treatment and follow-up services for autistics in Norway].” This project set out to establish an understanding of what information is provided online to people looking up Norwegian health care services. The project’s aim was to map several previous and current treatment offers for autistic individuals in Norway (Nilssen, 2022). I elaborate more on the findings of this project in the literature review of this thesis, but to give a summary; The view on autism has been severely behaviouristic, with treatment usually focusing on training autistics to adapt to certain societal norms, and a focus on autonomy. A lack of information and availability is a decisive factor for some autistics not getting the help they are entitled to in the Norwegian support system. Due to missing information, many autistics do not get their needs or rights met. While the environment ignores the shared responsibility of disabling factors, by expecting that autistic people strive for an unobtainable normalcy.

While my previous study positions itself critical as critical to the established health care services, it needs to be addressed that these services are only a product of the reality they are situated in. People on the autism spectrum find themselves so stigmatised by society that even the systems meant to help them is failing to recognise both autistics strengths and struggles. Some will argue that autism still remain quite the mystery (Milton, 2012a), so it may be only logical that information and interventions are lacking.

1.2.1 Aim of this Thesis

In this thesis, I have gathered the perspectives from a focus group consisting solely of autistics, with the aim to amplify their voice with regards to recent and future health care services for autistics. Welded with relevant literature, these perspectives render a clear-cut account of how current health care services for autistics are intrinsically flawed and suggest alternatives that might better suit their needs and wants. This thesis aims to contribute to a foundational understanding of autistic health and needs, from which society can build a stronger understanding and agenda for inclusion of diversity.

1.3 Thesis Statement

For this thesis I will be operating with two research questions.

The main question being:

According to Norwegian autistics between the age of 18-35: What should health promoting services for autistics encompass?

The sub-question is:

How can community music therapy be adapted and further developed to address and accommodate the points brought forth by the informants in relation to the main research question of this thesis?

The main research question will be explored using a thematic analysis of two focus group sessions, whereas the sub-question will be discussed in chapter 5 to further enlighten the findings and how they can potentially be met in and through community music therapy.

1.3.1 Terminology

To clarify and distinguish some of the wording used in the thesis statements, I will now elaborate on some of the terminology vital to this thesis, particularly “autistics”, “health promoting services” and “aspects of community music therapy.”

Autistics rather than people with autism

First of all, it is important to give reason for why I chose to use the label ‘autistics’ rather than ‘people with autism’, since the latter appears to be more widely used in academic and medical literature (Vivanti, 2020). Sinclair argued: «Autism isn’t something a person *has,* or a ’shell’ that a person is trapped inside. Autism is a way of being» (1993, n.p.). And in agreement with Sinclair (2013), many autistics, including myself, seem to prefer being called ‘autistic person’ rather than ‘person with autism’, to call attention to our autistic identity. Therefore, in this thesis I will be referring to people diagnosed with an autism spectrum diagnosis as ‘autistic people’ or ‘autistics’, formally known as identity-first language.

Promoting autistic’s mental health rather than treating autism

One of the fundamental perspectives for this thesis is that autism is not an appendage but something innate in the individual, just like any other human capacity and process. With that in mind, this thesis wants to divert attention away from health care services *for autism* which seek to treat symptoms defined by the diagnosis. To the contrary, the focus of interest will in this thesis be shifted to health promoting services defined *by autistics themselves*. In other words, the goal is to map out ways in which to help the human, not the diagnosis.

Rather, this thesis sets out to address how we can optimise the health of autistic people through health promoting services. With that in mind, it is essential to have a common understanding of what I mean by the terms ‘health’, ‘promotion’ of health, and ‘health promoting services’. Following the music therapy background of this thesis, I will mostly refer to Kenneth Bruscia’s third edition of *Defining Music Therapy* (2014) as a basis for my definitions.

By writing that: «Health is the process of becoming one’s fullest potential of individual and ecological wholeness,» (Bruscia, 2014, p. 105) Bruscia points out that health is a continuum rather than a dichotomy between sick and healthy. In other words, to achieve «one’s fullest potential» is not limited to being deemed healthy, but instead means to ‘optimise’ health in the context of one's predispositions. While I agree with Brescia’s idea of working with health as a continuum, situated in the individual and ecological context, I will for this thesis be using the term ‘promote’ instead of ‘optimise’ to differentiate between working to support and encourage autistics’ health rather than continuously striving towards reaching their fullest potential.

The predisposing factors providing the context for a person’s health are defined by both individual and ecological factors of a person’s life. Thus, ‘ecology’ is defined as «the contexts in which the person lives» (Bruscia, 2014, p. 107), like their family, work, and culture. Using such a broad perspective on health necessitates an equally broad perspective on health promoting services. The commonly used intervention called «treatment», where a health care provider steps into an authoritarian role with the purpose to induce change within the patient, will, in this case, therefore not be applicable. Instead, Bruscia (2014) suggests that the health promoting process is about helping the client to reach their goals themselves. In this thesis, I draw out several suggestions from autistics themselves on how a health care professional may consider helping autistics in this health promoting way, as well as how aspects of community music therapy in particular show potential for addressing this issue.

Health musicking and other aspects of community music therapy

More specifically, the meaning of aspects of community music therapy and the idea of health musicking (Stige & Aarø, 2012) are themes like resource orientation, destigmatisation, and inclusion. None of these themes are exclusive to community music therapy; however, they all stand as key features of the theory and practice of community music therapy. The seven core qualities pinning themes like destigmatisation and inclusion to community music therapy are often conveyed using the acronym PREPARE, which stand for: Participatory, Resource-oriented, Ecological, Performance, Activist, Reflective, Ethics-driven (Stige & Aaron, 2012). Each of these seven qualities and how they relate to specifically destigmatisation and inclusion of autistics are discussed further down in this thesis (see Chapter 5).

1.4 Thesis' structure

In this thesis, I use the aforementioned investigation on tendencies in treatment and follow-up services for autistics in Norway (Nilssen, 2022) as a starting point for finding out more about what autistics themselves express as needs and wants for future support systems. The study provides a historical foundation for understanding the current support system autistic people find themselves in when seeking professional help. Additionally, the study also serves as a base point for illustrating the disability studies discourse.

After displaying the theoretical frame in chapter 2 in this thesis, I will present and give reason for the preparation and implementation of my research method in chapter 3. In chapter 4, I will present my findings from the two focus group sessions. My former work, "Tendenser i behandlings- og oppfølgingstjenester for autister i Norge", formed a starting point to initiate the first focus group discussion. Based on this, the main topic for the second focus group session was how future health care services for autistic people can be developed to address the wants and needs of autistics themselves.

The reasons behind focusing so explicitly and solely on autistic voices in this thesis is firstly related to the increasing demand for autistic voices to be implemented into autism research (Milton, 2014; Pellicano, 2012). And secondly, autistics have a right to influence any health care services provided to them, as inscribed in Norwegian law dating back to 1999 (pasient- og brukerrettighetsloven, 1999, § 3-1). Additionally, the Norwegian Ministry of Health and Care Services also concluded in 2009 that user involvement needs to be a factor at both the systematic and individual levels of health care services (St.meld. Nr. 47 (2008-2009), p. 140).

As mentioned in chapter 1.2, this thesis aims to set the course for a sustainable future for autistic individuals by putting their voices in the spotlight for further development of both practice and theory (Milton, 2014). Only by listening to the autistic voices can we start to form a path where society and individuals can work together to remunerate the disability of autism with an inclusive and diverse ecology.

2.0 A Theoretical Spectrum

Before going into the method and findings for this thesis in relation to how the health care services for autistics need to change, it is important to have a firm understanding of the past and current landscape from which we can learn. As I have already pointed out, a discourse has come underway concerning what autism actually is and where the 'disability'-factor of the diagnosis is located. This discourse on what constitutes disability is known as disability studies, and will in this thesis be discussed in terms of comparing different models of disability. Upon having established a sense of the different ways we can view disability, I will follow up with an account of how the disability-aspect of autism thus far has been addressed by the Norwegian health care system. Following the general treatment methods used with autistics in Norway, I will look at how none of these seem to address autistics' mental health. Then, to wrap up the theoretical part of this thesis, I will present some approaches to community music therapy that are currently being explored in relation to service autistics.

2.1 Disability Studies

When looking at how disability has been perceived by society throughout the years, certain perspectives have emerged and brought to question our understanding of what it entails to be disabled.

Even though different perspectives may in general be defined by their unique nuances, most if not all perspectives on disability are characterised by three underlying ideas: disability as an individual problem, a social problem, or a political problem (Oliver, 1992). While several perspectives can be found within these ideas, the biomedical model is often associated with framing disability as an individual problem. In contrast, the social model shifts the focus away from the individual and blames society as the disabling party (Grue, 2011). Both the biomedical and the social model of disability have received extensive criticism for their apparent exclusion of one another, to which the gap model seems to answer with a possible compromise.

2.1.1 Three Models of Disability

For this explanation of the three models of disability I will touch on the foundation behind each model, elaborate on the language and descriptions they use to orient disability in relation to the individual and society, as well as mentioning some of the criticism surrounding them.

2.1.1.1 The Biomedical Model

Diving more into what these three models entail and how they each relate to either the individualistic, social or political ideologies, I start with the biomedical model. In his paper on models of disability, Jan Grue's (2011) shares his understanding of how the medical model is not a solidified model, but rather serves as straw man argument used to elevate other perspectives. By insisting that the biomedical model strictly follows a pathological way of thinking, people adhering to other perspectives spotlight their own humanitarianism by viewing disability as something more than the biomedical model (Grue, 2011). There is no getting away from the biomedical perspective which dominated the Western scientific thinking during the nineteenth and most of the twentieth century (Strickland & Patrick, 2015). However, in the current climate, Grue asserts that: "Although the term itself is extensively used, it is difficult to find any discussions that are not critical or wholly dismissive of it. In fact, it may be an open question whether the medical model is even a model" (2011, p. 540).

The biomedical model is generally based on the premise, that states: "[I]dentification of a disease (whether physical or mental) entails finding the biological deviation from the norm associated with that disease, and treatment of the disease entails correction of that biological deviation." (Strickland & Patrick, 2015, p. 1). Implicit in this view is the understanding of 'biological deviation' as strictly physiological or biochemical disruptions, and that the norm is entrenched in “optimal, healthy functioning of physical systems.” (p. 1). To contextualise, disability is seen solely as a deviation within the individual’s biological systems equivalent to a lack in expected human capabilities.

Definitions of autism have, to this point, been a prime example of how the biomedical model is reflected in our understanding of disability. As an example, the ICD-11, which was put into effect on January 5th, 2022, defines “autism spectrum disorder” as: “[C]haracterised by persistent deficits in the ability to initiate and sustain reciprocal social interaction and social communication, and by a range of restricted repetitive, and inflexible patterns of behaviour, interests or activities that are clearly atypical or excessive for the individual’s age and sociocultural context.” (World Health Organization, 2022, n.p.). In close relation to such a type of definition are the theories mentioned above that have been said to explain autism - theory of mind, executive dysfunction, and weak central coherence theory. All three signify and manifest a strong biomedical understanding of autism.

2.1.1.2 The Social Model

The social model of disability has derived its name from viewing disability “not as personal tragedy but rather as social oppression.” (Oliver, 1984, p. 22). Arguments made by self-advocates and sympathetic others are based on societal norms and structures as the disabling factors alienating certain people; comprising everything from social interactions to infrastructure. An example of the social model’s premise is that, “someone deaf is not considered disabled in a deaf community” (Rolvsjord, 2014, n.p.). Conversely, one of the strongest criticism to the social model is that, “it has been slow and reluctant to embrace the aspects of disability that are intrinsically embodied” (Grue, 2011, p. 538).

Contextualising autism within the social model, we encounter the ‘neurodiversity’ movement, whose main goal is to “increase acceptance and inclusion of *all* people while embracing neurological differences.” (Baumer & Frueh, 2021, n.p., italics in original). Applying the social model of disability, neurodiversity advocates argue that “disability results not from autism itself but instead from living in a society which tends to be physically, socially and emotionally inhospitable towards autistic people.” (den Houting, 2019, p. 271). And, while autism is undeniably a significant part of neurodiversity (Kapp, 2020), the neurodiversity concept encompasses the entire dynamic range of neurological constellations. So, while certain diagnosis[1] often are specifically mentioned, the overarching issue of “a poor fit between the (physical, cognitive or emotional) characteristics of a given individual and the characteristics of their social context” (den Houting, 2019, p. 271), remains universal.

2.1.1.3 The Gap Model

Simply put, the gap model might be seen as an extension of the social model, where the biomedical deviation is acknowledged as part of a diverse society. Stating that a gap will always exist between society and part of its population (Grue, 2011, p. 540), the gap model widens the scope of the discontinuity between individuals and their context from being seen as merely socially to societally conditioned. With this, the gap model puts focus back on individual deviation. However, unlike the biomedical model, it distributes the responsibility for any shortcomings evenly between society and its population, and claims that “disability is therefore something that can and should be addressed by the full spectrum of policy tools” (Grue, 2011, p. 540).

What a closure of the gap specifically implies is often left unaccounted for (Grue, 2011, p. 540). Yet, the general political notion is to reduce disabling barriers by building on the individual’s preconditions while at the same time making society more accessible (St.meld. nr. 40., 2002-2003, p. 5). On the one hand, this political notion seems to comply with the social model’s idea that “disability often can be minimised or avoided through environmental change and the provision of appropriate assistive tools.” (den Houting, 2019, p. 271). Though, on the other hand, implementation of the gap model is rather shown to be realised in terms of a normalisation agenda, exemplified by the Norwegian government in their use of the model as will be further demonstrated in chapter 2.2 (St.meld. nr. 40., 2002-2003). Thus, rather than attempting to normalise the autistic population, interventions aimed at closing the gap between autistic people and their societal context should, according to the neurodiversity movement, be concerned with providing tools to deal with issues important to the autistic community (den Houting, 2019, p. 271). But, how the gap model thus far has been put into practice have not always been in accordance with the neurodiversity perspective (St.meld. nr. 40., 2002-2003).

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[1] Most notably: autism spectrum disorder, Attention Deficit Hyperactivity Disorder, Tourette’s syndrome and dyslexia.

2.1.2 Summary

Directing us to the biological aspects of disability, the biomedical model serves as a reminder that biological factors do play a role in disabilities even though the biomedical explanation might never be seen as a complete account of what constitutes any specific disability. Similarly, the social model articulates the role society plays in disabling a person but often fails to recognise certain biological aspects of disability. Finally, in its definition the gap model seems to unify the biomedical and social models of disability, sharing the burden of disability equally between society's expectations and individual preconditions. By viewing disability as a shared responsibility, the gap model offers a perspective where both society and individuals should work towards a closure of the disabling gap, but Norway has up to this point mostly reinforced this responsibility on the individuals side.

2.2 The Norwegian State of Affairs

Considering the Norwegian government supports the gap model in practice, and since the present thesis is situated in Norway, I think it is relevant to establish a foundational understanding of what the Norwegian arrangements currently look like for autistic individuals. Coincidentally, during the summer of 2021, I started conducting an extensive literature search and mapping of previous and current health care services for autistics in Norway, "Tendenser i behandlings- og oppfølgingstjenester for autister i Norge" (Nilssen, 2022). My intention for that study was to get a clearer understanding of what was currently common practice regarding health care services for autistics. As partially answered in the introduction to this thesis, I also wanted to see if the lack of services I had personally experienced was just a case of bad personal luck or factually more representative for the services generally offered to autistics in Norway.

2.2.1 Early Intervention

My initial findings showed that all public services offered to autistic people living in Norway are concerned with children in kindergarten or primary school. Before starting any interventions to address an individual's challenges, the health care system requires a formal diagnosis for further support. Because of this focus on starting with a diagnosis, getting diagnosed is the most available service for autistic children (Blaalid, 2011, p. 41). The majority of autistics in Norway is thought to receive their diagnosis between the ages of 2 and 8 (Surén et al., 2019). Still, statistics show a significant discrepancy between genders and counties in the number of children diagnosed with autism. Many young autistics, especially girls, are thereby thought not to be noticed (Surén et al., 2019).

Following a potential diagnosis, the Norwegian health care services provided to autistics have so far focused on support for communication and social participation, and helping the affected families deal with their autistic child (Nilssen, 2022). The most prominent method to improve communicative and social skills in autistic children is the 'Early Intensive Behavioral Intervention' (EIBI). Another is the 'Treatment and Education of Autistic and Communication Handicapped Children' (TEACCH). EIBI is an intensive intervention put in place to work on the autistic child's behaviour from an early age. Which autistic behaviours that should be treated by the intervention are based on the individual's level of functioning. Moreover, it is recommended to start as early as possible by working on the key symptoms of autism, namely social motivation and interaction, communication and flexibility in their behavioural repertoire (Nordlandssykehuset, 2015).

Additionally, as means of accommodation for autistic children, the focus is often put into creating a structured everyday life. This is done through means like providing them with a daily or weekly schedule, letting them visit and familiarise themselves with any kindergartens or schools they will be transitioning into prior to their actual start in these institutions, and supplying them with tools for communication.

In sum, services meant to close the disabling gap between autistic children and their environment are being offered to them already in kindergarten. While they are being offered some accommodations from their environments, the main focus is on behaviouristic interventions addressing their challenges in social communication and interactions.

2.2.2 Services in Adulthood

Services meant to help close the disability gap decrease considerably as autistics leave school and enter adulthood. Throughout their educational run, children have access to at least some form of facilitation in the vein of extended time on tests or distinct service providers like pedagogical-psychological services (PPT). However, when I was researching available services for autistic adults, the most substantial offer I found was the possibility for an informative discussion with a health care provider about what autism generally entails (Nilssen, 2022). Other services concerning in autistic adults were their right to an 'individual plan,' which provides an overview of their composite services and goals, habilitation services, and assisted living. Beyond this, autistic adults were expected to make use of the general health care services.

2.2.3 The Problem with Services for Autistic Individuals and Their Families

Now, even though my literature search at first showed several services seemingly being tailored to autistic people, a report published by the Norwegian ministry of health and care services in 2020, showed that information about services available are poor and cluttered, and a consistent flaw in most services is an overall lack of competence (NOU 2020: 1, 2020). As a result, many autistic adults and families of autistic children cannot find any information about what is available for them, and often have neither the time, energy, or resources required to attain access to potential services. Hence, the autistic population in Norway is too often left single-handedly to figure out how to deal with the rift separating them from society. Furthermore, pointing to the intensive training of children to resign their autistic social identity, as well as the lack of specific support in adolescence and adulthood, it seems likely that autistics are vulnerable of developing mental health issues.

2.3 Autistic Mental Health

The mental health of autistics is undeniably in a critical state, with up to 79% of autistics meeting the criteria for a psychiatric condition and close to 72% experiencing suicidal desire (Mitchell et al., 2021, p. 9). For reference, only around 20% of U.S adults reportedly have a mental illness (National Institute of Mental Health, 2022). Furthermore, a Swedish study from 2016 found that suicide rate is 7.5 times higher for autistics compared to the non-autistic population (Hirvikoski et al., 2016, p. 235). Considering the significantly increased probability for autistics to develop mental health problems, many researchers questioned, why? Moreover, several have been looking at autistics' level of acceptance and their social identity as possible answers.

2.3.1 The struggle for acceptance

The critical state of autistic mental health is reported to stem from negative personal and collective self-esteem (Cooper et al., 2017). The cause for this low self-esteem is argued by Cooper and colleagues to be rooted in a negative perception of autistic traits and attributes (Cooper et al., 2021, p. 712). This notion is presumably linked to the fact that research show autistic people to be socially unfavourable (Sasson et al., 2017). To give a rundown of how these aspects play into one another and create a negative spiral for the autistics self-esteem through their social identity, Mitchell, Sheppard, and Cassidy (2021, p. 8) demonstrate:

> "[…] how the behaviour of autistic people is perceived by neurotypical others (negatively), influences how they behave towards autistic people (unwelcoming), which is then perceived by autistic people (that they are not welcome), which then impacts on the behaviour of autistic people (perhaps wariness, mistrust, low self-esteem, lack of social ability due to lack of positive and rewarding social experience). This in turn will impact on how autistic people are perceived by neurotypical others (negatively), and so on."

An example of the possible ramifications of such a negative spiral was found in a research project where participants were asked, if they felt accepted as autistic individuals in society. Merely 7% answered yes, and 48% responded with only "sometimes" (Cage et al., 2017, p. 477). The same study also found a clear correlation between perceived autism acceptance and depression (p. 478), underlining the argument that perceived social identity is undoubtedly linked to autistic detrimental mental health.

Because of the stigma attached to autism, some families choose not to pursue an autism diagnosis even when offered as a possibility (Punshon et al., 2009, p. 274). However, while many autistics do find it hard to take pride in being associated with a stigmatised group (Cooper et al., 2009), the sense of outsiderness is still experienced prior to receiving a diagnosis (Punshon et al., 2009, p. 271), and so, ignoring or denying the diagnosis remains a futile effort in autistics struggle for acceptance.

Coming to terms with a world not accepting their congenital social identity, therefore, means a lot of autistic people develop strategies to camouflage their autistic behaviour (Mitchell et al., 2021; Puncheon et al., 2009; Hull et al., 2017; Cage et al., 2017; Pearson & Rose, 2021). These strategies are often referred to as 'masks' or 'masking' to highlight the inauthentic nature of these strategies. Moreover, unlike traditional masks, these camouflaging strategies are not always put on intentionally or even knowingly, and once they are in place, some might seem close to impossible to remove (Pearson & Rose, 2021, p. 57). Worse yet, is the fact that although these masks at times may make the autistics more socially favourable, they come with a hefty price for the autistics themselves, as the need for a mask in order to fit in usually solidifies the underlying alienation and thwarts any sense of belonging gained (Mitchell et al., 2021).

Confronted with the fact that a significant portion of autistics' "Emotional pain does not come from autisticy itself [as] much as stigma, accumulated traumas and micro-traumas of not being accepted, and being different in an unforgiving world built to accommodate the conventional mainstream" (Gates, 2019, p. 136), it seems not too much to ask, that a "Wider societal acceptance should also be strived for to reduce the need for autistic adults to camouflage, and instead be accepted as they are" (Cage et al., 2017, p. 482).

2.3.2 A Social Deficit, or a Double Empathy Problem

How we are supposed to work towards this kind of societal acceptance presumably starts with spreading awareness and knowledge about the lived experience of autism, as this has already been proven to positively correlate with the attitude non-autistics hold towards autistic peers (Sasson & Morrison, 2019). Based on this, autistics being socially unfavourable may not be because of their own innate 'social deficit', but rather interfere with non-autistics ability to read and understand the unique ways in which autistics engage socially (Alkhaldi et al., 2019). As pointed out earlier, the lacking ability to read and understand others social motivation - known as the 'theory of mind' has been one of the most dominant theories used to describe autism through the last decades. However, such a lack of reading and understanding the other is equally present in both non-autistic and autistic social actors, and, as such, proposes a double empathy problem (Milton, 2012b).

Though autistics often have needed to develop masks to cope with their environment, as well as interventions like EIBI consistently being used to train autistics in the theory of mind, probably, autistics generally may have more experience in understanding non-autistics than vice versa (Milton, 2012b, p. 886). Considering both EIBI and masking strategies are aimed at concealing autistic behaviour rather than increasing the acceptance of autistic social interaction, neither should be seen as serviceable efforts (Mitchell et al., 2021).

On the other hand, what can be seen as workable approaches to solve the double empathy problem and develop a reciprocal theory of mind are efforts that help to increase knowledge about the lived experience of autism, as well as positive experiences between non-autistics and autistics. A prime example of how this can be done, is getting together in different social situations to provide multiple social meeting points, a proven method to increase collective self-esteem and prevent both physical and mental health problems (Jetten et al., 2012; Mitchell et al., 2021). One such type of social situation that has been increasingly used for people in all walks of life is music therapy (Ansdell, 2002).

2.4 The Music Therapy Angle

For the most part, music therapy in the context of autism has been used in similar ways to the previously discussed interventions, like EIBI, with a primary focus on reducing observable autistic traits in children, such as social communication, adaptive behaviour and total autism symptom severity (Geretsegger et al., 2022; Reschke-Hernández, 2011). In addition, autistics in all ages have, as mentioned, been able to make use of services open to the general public. One instance of this is a music therapy driven workshop in Bergen, where youths who have experience with the child welfare services can gather to socialise in different musical activities (Krüger & Strandbu, 2015). A key presumption in this workshop is that people create and work on their social identities through the activities and social communities they take part in. Following this, the youths make use of the musical activities to work towards making themselves understood as well as understanding others (Krüger & Strandbu, 2015, p. 91).

2.4.1 Elaborating on the Concept of Community Music Therapy

The key qualities of community music therapy practice, such as the workshop in Bergen, is in theoretical terms described by the PREPARE-acronym, branding community music therapy as: Participatory, Resource-Oriented, Ecological, Performative, Activist, Reflective, and Ethics-driven (Stige & Aarø, 2012). Being a participatory and resource-oriented discipline highlights that community music therapy affords and supports individual and social participation based on personal, societal, cultural, and material resources. The ecological and performative qualities refer to individuals' positioning and interaction with themselves and their environment. An important note on the performative quality is that performance, in this context, entails both the act of performing for an audience but also how a person performs themselves in any other social interaction. Furthermore, the activist quality signal peoples' position in a limiting society, and that community music therapy may be used to afford people freedom from some of these limitations. Lastly, the reflective and ethics-driven qualities represent the constant evaluation process that takes place, to ensure that practice, theory, and research is based on human rights and the intention of realising these rights (Stige & Aarø, 2012).

Contextualised to working with autistics, these qualities make out how, in short, an ethics-driven discipline, focusing on autistics resources and ecology may set the stage for participating in activism and developing performances, working towards including autistics in society and tearing down the stigma that currently surrounds the autistic lifeworld.

2.4.1.1 Health musicking

Following his tale of the solitary flute player, Small (1998) argues that, music, is an ineluctable social activity, regardless of the physical presence of others. To music is, as he describes, “to take part, in any capacity, in a musical performance, whether by performing, by listening, by rehearsing or practicing, by providing material for performance (what is called composing), or by dancing.” (Small, 1998, p. 9). Furthermore, as mentioned above, music serves to connect us with ourselves and the world we inhabit (Ruud, 1997; DeNora, 1999). This connection, according to Small (1998), is not based on a person’s passive use of musical mediums, but is rather an active participation with the music phenomenon and all its complex relationships with our society, culture and history. Music is, in other words, not a separate entity we engage *with* but is rather a verb - something we engage *in.* So, in place of the commonly used term ‘music,’ Small (1998) presents the term ‘musicking.’

Elaborating on the idea of musicking, community music therapy theory conceptualises the term ‘health musicking’ to account for the ways and contexts where engaging in music may be used as a health resource (Stige & Aarø, 2012). Health musicking is related to several aspects of musical engagement, especially relevant to this thesis are the aspects are ‘agenda’ and ‘agents,’ (Stige & Aarø, 2012, p. 132) as discussed in chapter 5.1. Simply put, ’agenda’ relates to short-term and long-term issues and goals that health musicking may be used to address, and ’agents' are the participants collaborating in musicking, which may include individuals, dyads, groups, or communities. Hence, by linking agenda and agents as the key components for this thesis, health musicking can be seen as taking part in a musical performance with the intent of addressing a goal or an issue.

2.4.2 The Musical Identity

Music and identity are thought by many to share an inseparable bond, with music being described as "a device for the reflexive process of remembering/constructing who one is" (DeNora, 1999, p. 45) and the suggestion that music is a "metaphor of identity" (Ruud, 1997, p. 11). By making use of this bond, taking part in health musicking opens the possibility of exploring ourselves to the far ends of our identity. Music thereby serves as a nexus between ourselves and the world we inhabit (Ruud, 1997; Small, 1998; DeNora, 1999).

Talking then about developing social identities through musical activities becomes as much about the personal 'musical flourishing' (Ansdell & DeNora, 2012) as the interpersonal "linking of individuals and communities" (Stige & Aarø, 2011, p. 27). The term 'musical flourishing' is derived from participants thriving in musical contexts, nurturing positive relationships with themselves and others using these experiences (Ansdell & DeNora, 2012, p. 101-102). Consciously working with health musicking to produce and maintain these kinds of nourishing communities, where participants engage in musical activities in order to kindle and explore different identities, is an essential aspect of what is known as community music therapy (Ansdell, 2002; Stige & Aarø, 2011).

Similar to the workshop for youths mentioned above, further examples of music therapists working in a community music therapy setting, focusing on exploring different identities, are Trygve Aasgaard (2001) and Lars Tuastad (Tuastad & Stige, 2015). To demonstrate; in his work, Aasgaard has made several efforts to help hospitalised children, separated from their peers and usual way of living, use health musicking to find joy and as a tool for communicating to hospital staff, families, and outside audiences, their identity and hard-felt emotions tied to their taxing routine at the hospital (Aasgaard, 2001). Tuastad's band of ex-inmates, on the other hand, based their music-making on their personal history and used this music as a means of expressing themselves to a larger community from which they could derive new identities as musicians (Tuastad & Stige, 2015).

2.4.3 Autism-Friendly Music Workshop

Moving somewhat away from the explicit discussion of identity, Grace Thompson and colleagues have investigated using community music workshops akin to the one mentioned above but with a stronger focus on accommodating neurodiversity. They have thus investigated the possibility of an autism-friendly music-making workshop (Thompson et al., 2020). In their study, Thompson and her colleagues asked autistic young adults about their interest level and other important factors for a music-making workshop. Although wanting to attend a music-making workshop was primarily to expand on their musical repertoire, many also considered the social aspects as important (p. 125). When talking about specific qualities to spark participation, the overarching theme was to create a safe space where everyone could be included as they are and not be judged by other participants or the facilitators (p. 134). Additionally, making sure the group size was not too big and ensuring everyone had the option to step back and take breaks was highly valued by the participants (p. 133). The authors concluded that autistics might be interested in participating in music-making workshops, especially if they have a pre-existing interest in music, and if certain conditions are met.

2.5 Summary; Where Does This All Lead?

How we view disability, both on a personal and societal level, consequentially informs the ways we relate to and deal with potential challenges. Autism has since its conception been defined by deficits located in affected individuals. However, in modern times, increasingly more thought is being put into what role society plays in the disabling process. How we view disability, both on a personal and societal level, consequentially informs how we relate to and deal with potential challenges. Although some aspects of a condition are intrinsically biological, others might be a ramification of society's standardisation of human beings, and the resulting disability, thus might be amendable by building acceptance and accommodations for our naturally diverse species.

Currently, the Norwegian government acknowledges that disability stems from a gap between individual preconditions and societal expectations. However, in their efforts to close this gap, almost all the responsibility to change is put on the individual. In the case of autistic people, interventions are being put in place as early as possible to ‘normalise’ the individual’s behaviour. If at all, accommodations suited to the individual are only being facilitated in kindergarten and their educational run. To make matters worse, basic information about available services and overall competence on autism have been proven scarce, ending up with autistics and their caretakers often left to themselves in this ‘inhospitable’ society.

In their strife to then deal with their unwelcoming surroundings, and in efforts to align with expected social norms, many autistics have found the best solution is to camouflage their true selves, putting on masks to portray the absence of abnormality. The culmination of this autistic alienation is low personal and collective self-esteem, leading to several mental health issues including suicide. Recognising that the incongruity in social interactions between autistics and non-autistics is a symptom equally present in both parties, the neurodiversity movement points to a double empathy problem that advocates for increased information and knowledge about the lived experience of autism.

Music therapy is one way people can explore, develop, and perform their social identities in a safe space designed to elicit reciprocal understanding. To further explore how health care services can evolve to better identify and address the actual needs of autistic people, I have asked Norwegian autistics about their experiences with the current health care system and how they would like things to change. Not asking specifically about identity or music therapy, I aimed to cultivate a more general discussion with the informants, open to talking about all aspects of autism and health care.

3.0 Method

This chapter will explain how I, with help from my network of supervisor and critical friends, approached the research process, as well as give reason for the decisions made while planning and conducting the interviews and subsequent data analysis.

3.1 Methodology

As discussed below, the history of disability studies and autism self-advocacy have both shown the importance of critical reflection concerning the researcher’s role and power. This thesis builds on qualitative research questions and answer them by focusing on the first-hand experience of autistics. Following both of these aspects, I have made significant steps to keep a critical reflexive attitude throughout the research process. Accordingly, before describing the method I have used to approach the research questions, I will elaborate on the methodology underpinning my preconceptions and role as an autistic researcher.

3.1.1 Epistemology

Although ‘disability’ has been defined as a relational issue for several decades, knowledge about disability has dominantly been produced by positivist research often conducted by non-disabled people (Oliver, 1992, p. 106; Milton, 2014). According to Mike Oliver (1992), the progression of trends in research on disability can be summarized in a three-step structure (Figure 1).

(Figure 1)

Firstly, the positivist paradigm is based on a belief where, “there is a unity of method between the natural and social sciences.” (Oliver, 1992, p. 106). The positivist paradigm thereby consists of several assumptions relating to the idea that “knowledge obtained from such research is independent of the assumptions underpinning it and the methods used to obtain it.” (p. 106). Secondly, as a backlash to the positivist suggestion that the social world is constructed of passive objects akin to the natural world, the interpretive paradigm claim that, “all knowledge is socially constructed” and situated in a world of active subjects (p. 106). Third and lastly, the emancipatory paradigm stems from the criticism that even within the interpretative paradigm, “research still has a relatively small group of powerful experts doing work on a larger number of relatively powerless research subjects.” (p. 106).

As an answer to the criticism of the interpretative paradigm, emancipatory research directs attention to reciprocity between the researcher and the researched through, “a recognition of and confrontation with power which structures the social relations of research production.” (Oliver, 1992, p. 110). Simply put, this means giving more power to the researched group regarding both the issues researched as well as the methods used. The intention behind giving more power to the researched is to capture the actual struggles of these groups in the framework of research production and policy-making.

3.1.1.1 Knowledge Production In Autism Studies

As the opening quote of this thesis states, the majority of expertise on autism has been claimed by non-autistics (Milton, 2014). Additionally, out of the perspectives offered by autistics, another power imbalance has been established with some autistic self-advocates claiming to speak on behalf of everyone on the spectrum, ignoring the diversity and heterogeneity within the autism spectrum

(Jager, 2010). With this in mind, the emancipatory paradigm needs to be further nuanced to account for the diversity in autistics when working towards knowledge production and policymaking. Therefore, the present thesis will therefore opt for a critical autism perspective, because it directs attention to the nuances in autism important to research. Also, it highlights the need for autistic participation in knowledge production (Waltz, 2014; Wood et al., 2018).

Akin to the critical attitudes towards existing cultural and political structures found in post-structuralism (Matey, 2019, p. 12), critical autism studies draw from "investigating power dynamics that operate in discourses around autism, questioning deficit-based definitions of autism, and being willing to consider the ways in which biology and culture intersect to produce 'disability.'" (Waltz, 2014, p. 1337).

Milton (2014) refers to Collins (2011) as an example of how the current research politics has not only stagnated the research itself but also insists upon its own understanding of autistic deficits and uses this to further damage autistic ethos when discussing autism in research; basically, comparing the autistic lifeworld to domesticated animals immersed in human society (Milton, 2014, p. 798). This comparison between autistics and animals was drawn from the idea that autistics do not have the sociality to participate in collective tacit knowledge, something Milton argues is a false statement (p. 798). Although the animalistic comparison might be an obvious overstatement, Collins is not alone in patronising the autistic lifeworld and its inherent knowledge. The Brief Report by Post et al. (2013) stands as a clear example of how the autistic voice has been falsely represented and intrinsically discredited in research and policymaking (Milton et al., 2014). By stating the importance of dialogue with those 'primarily affected' and claiming that their guidelines are based on such dialogue, before revealing that only family members of autistics have been part of the dialogue (Post et al., 2013). A worthy side to note here is that some of the goals put within these guidelines contradict what many autistics want, primarily the pursuit of a cure for autism (Milton et al., 2014). Therefore, it is of utmost importance that we form new structures free from such misrepresentations, and rather seek to "[a]ppreciate the distinctive knowledge autistic people possess and to build more constructive ways of relating to it." (Milton, 2014, p. 798).

3.1.2 Personal Involvement and Role: Being an Autistic Researcher

As previously mentioned, I have an autism diagnosis and experience with the Norwegian health care services offered to autistics. I have also spent a significant amount of time familiarising myself with the online autism community. Seeing how a big chunk of the autistic community feels dehumanised and discriminated against in their society led me to explore disability studies. With this as a starting point for this thesis, there is no getting away from personal prejudice against certain service programs and perspectives - particularly those advocating for a cure to autism or minimising autistic traits. From my understanding such perspectives may be one of the causes for autistic demoralisation.

By following the progression of trends in research on disability (Oliver, 1992, p. 106), it becomes clear that, as a member of the autistic community, I should not seek to free myself from my preconceptions. Rather than striving for the sense of objectivity that is valued in positivistic research, I should adapt to the social constructionism found in the interpretative and emancipatory paradigm. After all, through my role as an autistic researcher, with first-hand experience in the topic for this study, I hold a unique position to approach the research process. Being on the autistic side of the double empathy problem I am naturally empathetic and understand the “felt, embodied, intersubjective experience” of my informant’s autistic lifeworld (Finlay, 2005, p. 272). However, applying a hermeneutical approach also emphasises the importance of reflexivity and keeping a controlled subjectivity (Johansson, 2016). Through my process of hermeneutic reflection, I can begin to capture the way of the informants, me myself, and the intersubjective space between us are entangled (Finlay, 2003/2005). It is of significance that I systematically elaborate on my personal preconditions throughout this thesis, to account for how my subjectivity stands in relation to the literature and statements made by the informants.

To assist with reflections on my subjectivity and involvement, I sought to constantly dialogue with my supervisor and critical friends, including group supervisions as part of the music therapy training course. A critical friend has their role best described as, a trusted fellow student who has taken the time to familiarise themselves with my research process and further contributes by asking thought-provoking questions and using their knowledge to aid the progress (Costa & Kallick, 1993). Kindred to the help I got from my supervisor and critical friend, I also routinely took part in colloquium groups led by a university employee, where I could discuss my research process and preliminary findings. Perhaps most importantly, both during and after conducting the focus group sessions, I consulted with the informants regarding their thoughts on the execution of the focus groups as well as the formulation and implementation of their statements in this thesis.

Although I have already given a short narrative of the initial confrontation with my diagnosis, I will now disclose a more tailored account of my relationship to my autism diagnosis, to establish a baseline of my preconditions from which the discussions can take hold:

I am what many would classify as a high-functioning autistic. Even though the medical team setting the diagnosis said I checked every box for Asperger's syndrom, everyone else tells me it is not apparent that I am autistic. Due to this seemingly lack of empirical 'evidence,' my parents and I have struggled to get others, including health practitioners, to grasp my challenges. Also, upon receiving my diagnosis my parents and I were not given any substantial information or guidance on what autism entailed or how to cope with the world I found so difficult. No matter who we asked, both knowledge, acceptance, understanding and even effort proved scarce. Through multiple phases of depression, some quite severe, and other undiagnosed mental health issues, I was met with the sentiment that it looked as if I were doing just fine and that there was nothing more they could do. Through all my years of struggling and fighting with both people and institutions, I have always felt my troubles was my fault, and that it is my responsibility to adjust and adapt to everyone else, regardless of how impossible that is for me. It was not until I started reading academic discourse and looking for communities of self-advocates online that I started to regain some self-esteem as an autistic individual. After a few years of familiarising myself with the double empathy debate, I have begun to reconcile with my autistic self. As an extension of this reconciliation, and looking back at my childhood and earlier experiences, I feel a strong sense of criticism concerning the established attitudes towards autism and the autistic population; both within society but especially within the health care system that is supposed to help. In quite simple terms, my personal beliefs have shifted from viewing autism as a problem that needs fixing to something that should be embraced as part of a diverse society.

Being aware of both the value and limitations of my own preconditions, reflectively deciding when to actively implement my own experiences and opinions have been an important consideration throughout the research process. When deciding on what method would best fit the undertaking of my data collection, I was conscious of not wanting my own prejudgements to affect the views of my informants while also thinking that both my personal and my academic insight, as well as a political understanding of the debate surrounding autism, could be beneficial to the discussion. And so, aiming for a less structured moderating approach and finding a method that would invite my informants to influence the research process became paramount, serving the double purpose of firstly keeping the research within an emancipatory paradigm and secondly, providing a form of guidance for my own input.

3.2 Choosing a Method for Data Collection

Discussing the research method for this thesis with my supervisor, the possibility of doing a focus group came to my mind, as this is a method where participants' dynamic perspectives are not only taken into consideration but are highly valued (Morgan, 2019, p. 22). Elucidating any consensuses and differences that would arise in the discussions, using a focus group would set the stage to facilitate an elaborate conversation between all participants, opening the floor to both highlighting and challenging the informants' perspectives (Morgan, 2019, p. 18).

Alternatively, conducting individual interviews would afford a deeper dive into each informant's perspective, possibly providing additional ideas targeted directly at the thesis statement (Morgan, 2019, p. 20). Individual interviews would also provide a more predictable atmosphere for the informants, having fewer people to deal with and letting me as moderator, being able to focus on each individual. However, considering the political aim of this thesis - to grow a body of autistic knowledge meant to elicit a change in norms (see 3.1.1.1) - I thought the perspectives evolving and discussed in a group setting would be more beneficial than individual narratives.

After deciding on using focus group as my method for this project, I designed two group discussions with the same group: In the first discussion, I provided a short presentation of my findings from the project I have been working with earlier (Nilssen, 2022), before the informants shared and discussed their own experiences. Based on that, in the second discussion the informants were invited to further elaborate on their experiences as well as share and discuss ideas for future health care services.

3.3 Recruitment and Participants

Prior to recruitment, I decided on aiming for five participants, as this had the best prospect of providing rich data material from each participants, considering it was likely the informants would have strong feelings on the subject (Krueger & Casey, 2009). Also, keeping a relatively small group size meant it would be more manageable for both me and the other informants to keep track of everyone throughout the conversations. Furthermore, before starting recruitment process, I had the project evaluated and approved by the Norwegian Centre for Research Data [Norsk senter for forskningsdata] (see Attachment 1).

To start with recruitment for the research, I enlisted the help of Norway's national autism association [Autismeforeningen i Norge], to share an open invitation to the project on their Facebook page. The invitation contained miscellaneous information about the project, as well as disclosed contact information for people to report their interest (see Attachment 2). The autism associations original Facebook-post was then shared by multiple people on their private Facebook wall, including my own.

A total of five people meeting the inclusion criteria responded, these criteria being: the informant must identify as being on the autism spectrum, must be a Norwegian citizen, and be between the ages of 18 and 35. All respondents were met with an initial response from me, thanking them for their interest and letting them know that more information, and an informed-consent form, would be sent to them at the end of the recruitment period. Upon reaching the due date, seeing as the number of respondents matched the number wanted for the study to be implemented, no process for exclusion was necessary.

3.3.1 Informed Consent

The informed-consent form sent out to all informants contained short, concentrated descriptions of what the purpose for this thesis was, including the working research question: “Hva mener norske autister i alderen 18-35år at et helsefremmende tilbud for autister burde ha som fokus, og hvordan står dette i forhold til samfunnsmusikkterapeutiske kvaliteter? [What do Norwegian autistics in the ages 18-35 think a health promoting service for autistics should have as focus, and how does this stand in relation to community music therapy qualities?].” Moreover, the form included a description of what was expected of the informants and the procedure for the interviews, noting that both interviews would be audio recorded and transcribed. Miscellaneous information on privacy, including how their data and personal information would be stored and anonymised, was described. Additionally, the form elaborated on the informants' right to withdraw their consent at any time, either written or verbally, to my supervisor or me. In order to provide their written consent, informants had to check a box stating that they consented to participate in the two group interviews and sign the document (see Attachment 3), before sending it back to me.

By the time we met for the first session, four out of five participants had responded with their signed consent form, and the one missing assured me they had signed it. An image of their signed consent form arrived a few weeks after the last session.

While all five participants had agreed to partake in the first session, only four attended. After ending the first session, a message was sent to the missing participant, using their previous means of communication, asking if they still wanted to participate in the remaining session. This participant gave no reply, but all five participants attended the second session.

3.3.2 Participants

Out of the five participants recruited for this study, three identified as female and two as male, with one female specifying that they are currently transgender. During our conversation everyone presented themselves using their real name. However, in line with the anonymisation process described in the informed-consent form (see Attachment 3), all participants have been given pseudonyms. All participants have been given the opportunity to decide themselves what they wanted to be called, but I have decided for those who did not suggest any specific names. The names chosen for my informants were: Karoline, Jonas, Sofie, Luna, and Christian.

3.4 Conducting the Focus Group Sessions

Before conducting the first focus group interview, I prepared a presentation of the findings from my previous work, "Tendenser i behandlings- og oppfølgingstjenester for autister i Norge [Tendencies in treatment and follow-up services for autistics in Norway]," as well as practicing and receiving feedback on this presentation from my closest critical friend. Additionally, I drafted and revised an interview guide (see Attachment 4) for the second session, with help from my supervisor and closest critical friend.

To accommodate a few common autistic traits, I made sure both sessions were arranged for both verbal and written participation. Moreover, to let my informants know what was coming up, and give them time to get familiar with the topic for discussion, I sent out my notes for the first session, approximately three and a half hours before the session started. Realising in hindsight that this might be a brief timeframe, I decided to send out the interview guide, which would serve as a template for the second interview, after wrapping up the first session. This gave the participants over two weeks to read through it and prepare for our next session.

For the first interview, the focus was on providing the group with a 15-minute presentation of the findings from my study on previous and current treatment and follow-up procedures for autistics in Norway (Nilssen, 2022). The intention of this presentation was two-fold. Firstly, it was meant to provide the group with the information presented online regarding available services in Norway for autistics, in case some had no previous knowledge or experience with the health care system for autistics apart from receiving their formal diagnosis. Secondly, the information provided was intended to serve as motivation and a starting point for the discussion of the informants' own experiences.

During the second interview, I introduced the session with a short abstract from our previous session before handing the word over to the informants to start discussing their thoughts. Throughout the conversation I sometimes chimed in with a question from the interview guide (see Attachment 4) if a topic of interest was touched on or if the conversation went stale. Each interview lasted approximately 110 minutes.

3.4.1 A Digital Solution

When carrying out the focus group sessions for this thesis, restrictions to prevent the spread of COVID-19 were still impeding opportunities for physical gatherings. Because of this, both focus group sessions were conducted digitally using the video conference software Zoom. Coincidentally, this digital solution also addressed other practical considerations; most notably, allowing everyone to participate from the comforts of their own homes, or wherever else they fancy, regardless of geographical location (Morgan, 2019, p. 121). Also, to accommodate for my informants to participate both vocally and by using the built-in chat function. In other words, by means of conducting the sessions digitally, every participant had the opportunity to control their own situation to best suit their needs and preferences.

3.5 The Aftermath of the Completed Focus Groups

After both interviews, I got down to transcribing the audio recordings of them. For the transcription I decided to focus on the content of the informants' statements to most effectively sort through and convey the information relevant to the research questions. After I had completed the transcription process, I always checked back with the original audio recordings when inserting or altering written punctuation, and when I later contextualised the statements within this thesis. In this way, I made sure that the informants' account was represented as directly as possible. I also made sure to anonymise the data material while transcribing it to ensure the informants' privacy was accounted for.

Already, while in the process of transcribing the group's discussions I made mental notes of quotes of interest and began thinking of potential codes that could summarise some of the informant's statements. Both interviews were conducted in Norwegian. Thus, the transcription, codes and subsequent themes formed during data analysis (see Chapter 3.6) were all written in Norwegian. I then translated all themes and chosen quotes into English for the present document. To avoid the transcription method and the translation process from blurring the intent and meaning of the included statements, all participants were given a chance to read this thesis and give their feedback prior to it being handed in. Only one informant responded, stating that they approved of how their statements were represented.

3.6 Following the Steps of a Thematic Data Analysis

After a discussion with my supervisor, I concluded that a thematic data analysis, following the step-by-step guide provided by Braun and Clarke (2006), would most accurately help to focus on the statements made by the informants while still giving room for the hermeneutical approach chosen (see Chapter 3.1.2). The guide to analysis provided by Braun and Clarke consists of six separate phases. However, before presenting the guide, they precede by stating: "[A]nalysis is not a linear process where you simply move from one phase to the next. Instead, it is [a] more recursive process, where you move back and forth as needed, throughout the phases." (2006, p. 16). The phases for the analysis are: (1) familiarising oneself with one's data; (2) generating initial codes; (3) searching for themes; (4) reviewing themes; (5) defining and naming themes; (6) producing the report.

In compliance with Braun and Clarke, the first step of familiarising myself with the data material started during the transcription process. It was later followed by reading back through the transcription and listening to parts of the audio as I worked through the other phases. Before starting the coding process, I consulted with my colloquium group on how to start marking noteworthy statements with different coloured post-it notes on the first few pages of the second transcription, after that I continued this process with the rest of the data material by myself.

Moving into the second phase of generating codes. Before systematically going through the transcription once more, to generate initial codes, I converted the transcription into a table using Microsoft Word's built-in function to allocated each statement in its own cell. From there, I could read through the entire script and easily assign each statement with a code in the adjacent row. All statements were assigned a code during the first read through. Statements deemed irrelevant to the further analysis were assigned a simple "x".

Having marked every statement with an initial code, I sorted the table alphabetically so that all the rows being marked with an "x" were moved to the bottom of the table. I then began the third phase, which consisted of searching the codes and corresponding statements for themes. Throughout the third phase of the analysis procedure, both main themes and sub-themes were conceived, with sub-themes gathering together similar codes, and the main themes sorting the different sub-themes into overall categories. Noticing and forming themes to encompass the overlapping and relating codes were done using a latent thematic analysis (Braun & Clarke, 2006, p. 12). Not letting existing theoretical frameworks as well as my own preconceptions steer this excursion meant to rather provide new insight. Related to the previously discussed surrounding my preconditions, "data are not coded in an epistemological vacuum." (Braun & Clarke, 2006, p. 12).

For the most part, phase five was done simultaneously with phase four and phase six. While some codes changed themes and most sub-themes saw significant revisions before finalising the analysis, the main overarching themes were formed relatively early in the process and remained without any significant changes. Before starting with phase six of the analysis, I consulted with my supervisor and closes critical friend on their thoughts of my analysis.

The sixth and final phase was done directly into this thesis paper. First, listing all the main themes and their respective sub-themes. Then going systematically through the final analysis, handpicking the quotes and general statements made that I thought would best serve to answer the main research question of this thesis: “According to Norwegian autistics between the age of 18-35: What should health promoting services for autistics encompass?”

3.6.1 ‘Giving Voice’

I align with the sentiment that it is not possible for me as a researcher to take on a passive role in the analytical process and let the themes simply ‘emerge’ (Braun & Clarke, 2006, p. 7). Using a thematic analytical approach, I, as the researcher am taking on the responsibility of “identifying, analysing and reporting patterns (themes) within data.” (Braun & Clarke, 2006, p. 6). However, in line with the importance of listening to the autistic voice when conducting research, it is not within my role as the researcher to give voice to these autistics. Highlighted by the potentially abusive power dynamic between researcher and research subjects (Oliver, 1992, p. 106), including cases where autistics with a more apt capability to self-advocate have claimed to speak on behalf of all autistics (Jager, 2010) - the idea of ‘giving voice’ may be seen as nothing more than further disabling the research subjects, as it merely underlines the researcher’s power in knowledge production.

3.7 Limitations

One inclusion criterion for this study was an official autism diagnosis. To minimise what gets “lost in translation,” (Milton, 2014, p. 799) I opted not to allow for proxies, which in this case means, I did not let relatives or other care providers answer on behalf of any of the informants. As a result of this exclusion criteria any autistic voice without the means for independent verbal or written participation was shut out from taking part in the research. The fact that the voices of these autistics were not accommodated for, is something I deem as a significant weakness to this thesis. There has already been expressed dissatisfaction on how people with the capability for self-advocacy end up talking for the entire autistic population (Jager, 2010). The voices of autistic people with reduced or no ability to share their opinions and experiences are just as important as those of other autistics. Hence, they must not be excluded from the body of knowledge and practice. Thereby, I encourage other research projects to facilitate for inclusion and focus on the autistic voices that, unfortunately, are excluded in this study.

Still, with the group of informants included in this thesis, where all would be considered "high-functioning," the scope of my findings thereby becomes concerned with the lifeworld of autistic who typically experience having their challenges trivialised or ignored (Milton & Moon, 2012). This is not to say my findings will not be relevant to those autistics deemed "low-functioning." Besides, we are all autistics. By using a group of those typically deemed "high-functioning," emphasis was mostly put on health care services' ability to recognise and accommodate autistic challenges that are routinely overlooked.

4.0 Findings

Upon completing the first couple of steps in Braun and Clarke's guide to doing a thematic analysis (see Chapter 3.6), I began forming what would eventually become the themes evolving from my research during the third phase. When creating and assigning my themes, I noticed that all the construing themes contained statements fitting together like a short story - with a beginning, telling the informants previous experiences; a middle, concerning their thoughts on the current situation; and an end, looking forward to how things might change. To stay with the diversity and progression of information contributed and discussed by the participants in the two focus group interviews, I have therefore decided to call the themes for narratives. Not to be confused with a narrative analysis, as I have conducted a thematic analysis for this thesis, but with the resulting themes now referenced as narratives, including a diversity of statements and nuances provided by the informants.

Based on the analysis of the data material, I formed a total of five main narratives, named: "The autistic lifeworld," "Social structures," "Institutional encounters," "Expanding knowledge," and "Belonging". Within these main narratives, multiple sub-themes were produced to provide and illustrate nuances and diversity within the main narratives (see Chapter 3.6). The sub-themes were allocated in the sorting process by expanding on similar repeating codes mentioned by several informants and connecting different codes, as shown in Table 1.

Statements	Examples for Codes	Sub-themes	Narratives
Jonas: “Then, what I think is, that if future teachers and politicians and people who are gonna work with autistics… if people get knowledge, that is the whole essence here, right?”	Informing others about autism	Insight into autistic Perspectives	Expanding knowledge
Sofie: “It's these kinds of things I feel should be better integrated into general education. It takes so, so little effort, it takes two minutes out of science class, and it can save lives.	Fighting prejudice	The sharing of knowledge	
Karoline: “I think a common mistake to make is to evaluate based on, to what extent a person manages to persevere in their environments as is.”	Evaluating based on personal experience	Evaluating services	Institutional encounters
Christian: “At the same time, I believe it is quite valuable to have someone with personal experience on the team; whether that be in school, commune or hospital. I think it is really important to actually have people who got those life experiences, as a part of their staff.	Autistic practitioner	Understanding autism	

Statements	**Examples for Codes**	**Sub-themes**	**Narratives**
Jonas: "It is really important to create a safe framework from when they arrive at school until they're heading back home. Because that makes it safer, and then perhaps one gets it better at home too if school goes well, this is also something a lot of parents think are important."	Safe framework	Societal accommodations	Societal structures
Christian: "What exists in terms of accommodations, both in health care services and the working life, have in general addressed us poorly and there is plenty of room for more targeted services for autistic people."	Under prioritised	Resource distribution	
Karoline: "When you are autistic with verbal language and IQ equal to or above average, it is easy for others to overestimate what you can and cannot handle. Also, one often meets demands and expectations which are too high and having to continuously reach at these high demands and expectations really eats away at your health."	Wrongly judged	Defining autistics	The autistic lifeworld
Luna: "I need structure in everything."	Autistic trait	Living with autism	

Statements	Examples for Codes	Sub-themes	Narratives
Karoline: "We both had suicidal periods because our day to day life was so difficult, and it was that understanding and acceptance only people who experience the same reality can give that helped us both through it."	Interconnection	Meeting other autistics	Belonging

Table 1: Examples to illustrate the process of data analysis

4.1 Narrative 1: The Autistic Lifeworld

The autistic lifeworld is a narrative comprising the informants' experience of living with autism, dealing both with the socially situated act of living with autism as well as the personal experience of trying to define oneself in light of the diagnosis. Thus, this narrative is split into the two corresponding sub-themes, 1) Living with autism and 2) Defining autistics.

4.1.1 Living With Autism

All informants agreed that living with an autism diagnosis came with its fair share of challenges. Although these challenges were mostly talked about in relation to other narratives, these primarily being the Social Structures and Institutional Encounters narratives, talking from personal experiences and the current state of having to live with an autism diagnosis, Karoline suggested: "*Actually, I wanna go as far as to say it is more common for us [autistics] to have traumas than it is to not have it. As a consequence of living in a world not fit for us, where we learn to suppress ourselves and our needs and continuously being put situations we experience as harmful to ourselves.*" Coupled with this, Karoline disclosed her feeling: "*I have to say, there are times I wish I'd rather been without.*" However, looking to the future, Jonas shared his hopefulness by telling us: "*I'm optimistic, since autism becomes more and more known.*"

Touching also on how the current situation is, in terms of the more day to day challenges Luna confessed to "*function at work, not at home,*" a sentiment several other informants agreed with, among them Karoline, who told us: "*I can be really good at work, but those dishes can often be left stand-*

ing a few days." Which was built on a point previously made by Sofie, when talking about the general experience of having autism: "*And, if you are to be an attorney, you may quickly become the best attorney in the whole bureau, but then you are not as good at putting things in the dishwasher or other things.*" As Luna summarised: "*We all have our strengths and weaknesses*" and therefore, "*When you've met one, you have not met all.*"

Trying to define autistics as a homogenous group then, might prove difficult, and Luna's point of differences among autistics and heterogeneity of the community was further illustrated by Jonas, as he shared:

> "*I think comparing autistics are kind of like comparing Americans, to put it bluntly. Because, in the USA there are like fifty states, kind of like fifty countries in one country, and autism is actually a little bit similar to the USA because every state has like their own things, and that's how it is with every person with autism too, right? Like, in some places in the USA it is really cold, with tall mountains covered in snow and bettering cold, and in other places there are like palm trees, and like in Hawaii, completely exotic, right? But, so is it with autism. That there are wildly with differences, or that we are very different in a lot of areas*."

4.1.2 Defining Autism

Being autistic is, as Jonas so eloquently depicted, a highly individualistic experience. This individuality also extends to how one personally defines and identifies with the diagnosis. While some of the informants shared the notion put forth by Karoline:

> "*Yes, I think that how I as autistic think, is such a fundamental part of who I am, and it affects absolutely one hundred percent of the aspects in my life and basically everything I do, that I don't feel it's right to say it is something I have, like it can be separated from who I am as a person, in a way*."

Others, like Jonas, contested this point by arguing: "*I think that we are first and foremost humans; we are not diagnoses.*" To this sentiment, Karoline divulged: "*That is what I am, first and foremost after being human, is autistic. So, I'm very proud of that being something that I am.*" To round out this debate, Christian made clear the point we all agreed on: "*I think it is very health for people to* *have different viewpoints to this question in particular. […]. By the same token as gender identity, it is the person in question who should be the one to decide, right?*"[2]

4.1.3 Summary

In summarising the first narrative about the autistic lifeworld, living with autism in the current climate, as exemplified through Karoline's experiences and point of view, is often marked by hardship from living in a world where acceptance and comfort fit the autistic community are rare. Still, while autistics certainly do have their challenges, they also have places where they excel. This often being at work rather than at home, as mentioned by Luna and Sofie. For some this might also be the other way around seeing as though autistics are so different. Among these differences is also how they relate to our common factor, the autism diagnosis. All informants agree that they are first and foremost humans, and while some choose to see autism as a mere extension of this and something that cannot be separated from who they are, others prefer to see it not as a defining factor of who they are. Anyhow, the most important thing is to listen to what each individual prefers, both in terms of how to best accommodate for them as well as how they would like to be addressed. And as Jonas points out, the future might be bright as people become more aware of what autism is.

4.2 Narrative 2: Social structures

Autistics, like everyone else taking part in society, are encapsulated in social structures providing much of the foundation regarding to what opportunities are given, and which accommodations are made. To help sort through the topics discussed in relation to social structures, two interrelated sub-themes were created, 1) Resource distribution and 2) Societal accommodations.

4.2.1 Resource Distribution

The resource distribution sub-theme is based on the position autistics hold in society, and from there to what end they should be prioritised in terms of distribution of resources and accommodations. Addressing the current state of this resource distribution, Christian adduced:

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[2] To this point, I want to disclose that all participants made clear that they were okey with identity-first language being used to address them in this thesis.

> "*I think we are an under-prioritised group that has been too little investment in, and there is still a way to go until we actually receive equally valued services, so I don't think we have to worry about taking up too many resources compared to others. The Norwegian society has done a poor job following up on people on the autism spectrum; maybe in particular those one calls high-functioning autistics. What exists in terms of accommodations, both in health care services and at work, have generally addressed us poorly, and there is plenty of space for more targeted efforts for people with autism*."

Akin to Christian's statement about where autistics have been and currently find themselves, Karoline voiced her opinion for the future by saying that "*[...] health needs to be prioritised ahead of other wishes and preferences no matter whose health is on the table.*" Adding that:

> "*All who associate with autistics have to some degree a responsibility to their health. Because when you take part in affecting anyone's health, whether that be as healthcare professionals, as a teacher or as a family or social circle, then you have a responsibility for what you do, whether the person is autistic or not.*"

Building on the sentiments shared by the other informant, Sofie explained her understanding of future possibilities:

> "*What I feel is that there are pretty smooth surfaces in today's society, in that there are very few accommodations in general. Making it so that there are more accommodations for autistics, also makes it so that there are more accommodations for other people who might need them as well. So, I think it is a good idea to get more accommodations available in education and the health care system regardless, and then I don't see how further accommodating some things can hurt the accommodation of others.*"

4.2.2 Societal Accommodations

As the group reached the topic of autistics attending specialised schools contra ordinary schools, the discussion turned from focusing on resource distribution to the actual state of societal accommodations. Here, Sofie was quick to mention:

> "*What I'm afraid of in relation to specialised schools is that they don't quite provide the best prerequisites for entering the working life. Kind of like, if you are used to such a comfortable envir-*

onment where people are understanding and have the same diagnosis as you, then you finish school and then things don't go as well anymore. Then there might be a large dissonance from leaving one school and switching to another school or entering the working life. So, I feel it is somewhat two-sided, that it might make things more comfortable for the students but being so different from ordinary living that it might come with consequences."

To this, Karoline responded: "*I see your point, but I'm thinking comfortable is a good thing and that we should rather strive for the rest of society to also become like that.*"

4.2.3 Summary

To summarise this narrative, previous experiences told of autistics routinely being an under-prioritised group, as pointed out by Christian, with the current state being no different, according to Sofie. Looking to the future, specialised schools might be one option to help accommodate autistics in their educational run but providing this level of comfort may also result in a bigger clash as the autistics then would leave school and enter other areas of society. However, as Karoline suggested, maybe this level of comfort should be strived for in the rest of society as well. Besides, all informants agree that not enough resources are currently provided for autistic accommodations and that implementing structures to help autistics in the future may also prove beneficial to others. Regardless, as Karoline stated, when looking at what should be done to develop and maintain future social structures, health should always be a priority.

4.3 Narrative 3: Institutional Encounters

Being the most substantial narrative by a margin, five sub-themes was created for adequately sorting through the data. These six sub-themes were named, 1) Contact with institutions, 2) Understanding autism, 3) Therapeutic perspective, 4) Possible services and 5) Evaluating services. Additionally, some informants shared thoughts and experiences not fitting any particular sub-theme. These, these sub-themes are without further categorisation than being part of this narrative.

Talking about institutional encounters refers to the meeting between the individual service taker and the institutional service provider. In this narrative, institutions are seen as any establishment or organisation working directly with individuals, with schools and health care services being the most prominent. In addition to discussing the informants' personal experiences with these institutions, this narrative also deals with the underlying assumptions and perspectives thought to influence the services provided.

4.3.1 Contact With Institutions

In order to embark on an encounter with any of the institutions mentioned in this narrative, the first step is a point of contact. All informants shared personal experiences regarding getting in contact with some of these institutions. Christian being one of them, told: "*I can say that my only experience with psychiatry for adults is that I have been rejected every time I have been referred to them.*" Karoline also tidily summarised most of the stories told when she said:

"*I think it is really important and very true what you all are saying. It can be really difficult asking for help, and perhaps more so for us than others, but also, when you first take that big step and ask for something and get rejected or undermined, then I also think it's really easy to just interpret that as 'oh well, then that's not gonna work' or 'then that service doesn't exist' and then you give up.*"

To which Luna added: "*We fall between two stools*."

To be clear, getting rejected was also often because the informant was autistic. So, when they asked for help with other issues, like for instance severe depression, Christian revealed:

"*[...] I was burnt out and taken out on a long-term sick leave, ended up losing my job and was very depressed and didn't know what I was gonna do with my life. Then my doctor referred me to DPS where I was rejected with the reasoning that 'you are already diagnosed and so there is nothing more we can do for you.'*"

On the contrary, Christian shared a more positive experience and told of how he later was accepted into the communal health services. However, he followed this up by telling how he has kept getting rejected by other services in more recent times. Christian additionally pointed out that one likely reason as to why autistics keep getting rejected:

"*I think the problem actually is that none of these departments have the expertise they need in order to provide us with the services we need or that we have use of.*"

4.3.2 Understanding Autism

This sentiment also reflects many of the thoughts discussed surrounding the second sub-theme, institutions understanding autism. As Karoline exemplified from when she was getting her diagnosis:

“*The process of getting my diagnosis was bullshit! Because, if I hadn’t known so much about autism myself, to the point where I could explain my challenges outside of the schemas they applied then I would probably just have been given a ‘well, then this wasn’t for you.*’”

Adding to this, Karoline also told:

“*The psychiatrist that diagnosed me pretty much told me, out of her own regard, that ‘do you think this is relevant to you? Since you know more about this than I do.*’”

Still, thoughts shared about the future on this topic were for the most part optimistic:

Jonas: “*Previously not a lot of people had it [an autism diagnosis], nobody talked about it, whereas like now when it is more and more common and people gain more knowledge, then I think it will be easier to get services as well.*”

Sofie: “*I think there’s little possibility of it getting worse as a direct consequence of us having increasingly more research on the subject.*”

4.3.3 Therapeutic Perspective

Regarding the relevance for research, Christian expressed a clear desire for how this should inform the perspectives underlying services offered to autistics:

“*I think more research should be put into how we can use recovery more goal-oriented with people with autism. I think there is a lot of potential for this now, though given that there is little knowledge about this at the moment.*”

Further distinguishing on the topic of having a recovery-perspective in working with autistics, Christian elaborated:

“*You have psychotherapy, psychoeducation, you got habilitation, and you have recovery-oriented work. Out of these, I get a really good impression from providing people with autism with follow-up services based on a habilitation perspective, as this practically targets how to deal with* *your day-to-day life and don't have so much focus on trying to get inside and tamper with people's brains, as psychologists and psychiatrists perhaps do. But rather to give people the tools they need in order to deal with the challenges they face in their everyday lives. [...]. This whole 'recovery' term isn't really relevant to us. Since if you look up recovery in an English-Norwegian dictionary, as I of course already have done since I'm autistic, then it is translated into 'gjennoppretning' [re-establishing], and we don't have anything that shall be re-established; we are looking to grow. Hence, I prefer this 'habilitation' term compared to something like 're-habilitation' because we don't need that. As I said, we don't have anything to re-habilitate, but everyone can be habilitated.*"

Encompassing Christian's idea of treatment perspectives being aimed at helping the person to grow, Luna added that all treatment models should have a "holistic approach." In harmony with both Christian's and Luna's perspectives, Karoline shared:

"*The focus and goal with treatment for autistics have to be our health and wellbeing. For us to feel good as we are, and not be expected to become like everyone else. That is not possible, and should also not be the goal.*"

4.3.4 Possible Services

Subsequently, to the sub-themes concerning the informants' previous experiences, the next sub-theme points to what the informants could picture for the future. Karoline was the first to answer with the possibility of autistics getting a life coach:

"*Autistics should be offered a life coach. Someone who meets you on your terms, whether that be they visiting you at home, having a video call, online chatting, or whatever works best for the autist, regularly, like for instance, once a week, and goes through your daily schedule with you. [...]. Someone to relieve you of some of the executive functioning basically, and help you plan out for things that might be difficult for you to figure out because of your autistic functioning.*"

The option of making use of such a life coach was supported by many others in the group as well. Otherwise, most of the discussion was centred around creating communities for autistics to meet others on the spectrum. Christian gives an example of this that they currently have in Bergen, and prefaces that: "*It is first and foremost just a social gathering place without much like courses or* *anything like that. I have a very good impression of the community they have been able to achieve there.*"

4.3.5 Evaluating Services

Following these ideas of potential future services, an important question becomes how to evaluate if services are successful in their pursuit of aiding autistics' health and wellbeing. Raising the question for this fifth and final sub-theme, all participants agreed with Luna and Sofie:

> Luna: "*Hard to say, it depends.*"
>
> Sofie: "*That is one of the hardest questions you have asked this entire time.*"

The reason for this being a tricky question may refer to autistics being different from one another. Thus, several informants agreed to a sentiment mentioned by Jonas': "*Then you'll pretty much have to go around asking each and every one,*" and from there, Karoline impelled: "*Well it has to be evaluated based on whether the person is in a better spot, or rather, how the person themselves feel they have it better.*" Multiple informants attested to the current situation being far from good enough, with Karoline even attesting: "*Actually, I have rather felt any help I have gotten so far, actually have just made things worse*." And so, the question of evaluation was not deemed imminent, as Sofie demonstrated:

> "*I also think it is very prominent that we clearly see we are discontent and that there is a lot of room for improvement. [...]. So, this is not good enough; we shouldn't be asking ourselves now if we have succeeded.*"

4.3.6 Summary

To summarise this narrative on institutional encounters, all informants taking part in this research were willing to share their personal experiences. They told plenty of stories of being rejected, and while some found help after a while of searching, others also reported that if they got offered help, this often only made things worse for them. Most informants mentioned that their bad experiences might be a result of lacking knowledge and competence about autism in service providers. Furthermore, seeing as how continuously more varied and inclusive research is being conducted in the field of autism, many informants were optimistic about the future. Relating to this increasing body of research and possibilities for the future, Christian brought forth the point of habilitating autistics and how, like Karoline also made clear, the idea of treatment should be focused on helping the individual feel content in their environment.

4.4 Narrative 4: Expanding Knowledge

The importance of sharing insight into and knowledge about the lived experience of autism with the surrounding world was a consistent narrative during the informants' discussions. Several of them admitting to working purposefully in their free time to achieve this. Like Jonas so hearteningly stated:

> "*I think that if future teachers and politicians, and anyone who is to work with autistics, if people gain knowledge, that is the whole essence here, right? Knowledge about this? Then we will be on the right course, and that is why I am willing to meet other students who are writing their bachelor thesis, exams, you name it, about this - so people gain knowledge.*"

Although all topics discussed, fitting under this narrative, can be deemed as generally expanding knowledge, a slight distinction seemed to exist between what kinds of knowledge the informants talked about; as Jonas explained: "*[...] reading about autism is something completely different than talking to an autistic.*" Thus, two corresponding sub-themes were discerned, differentiating between 1) Insight into autistic perspectives and 2) The sharing of knowledge.

4.4.1 Insight Into Autistic Perspectives

Providing insight into autistic perspectives, on the other hand, deals with how the general public can obtain knowledge about the autistic lifeworld - like, for instance, through this thesis, as Karoline firmly put it:

> "*And, I think it is really nice and very important that you do this. Because, it is so many of these topics that we have discussed, that we generally take for granted, that needs to be documented so that those who are to help us shall accept the way it is. It is such a simple yet important thing to just document what we are saying. Listen to us!*"

4.4.2 The Sharing Of Knowledge

The sharing of knowledge is concerned with how general knowledge about autism is shared, disseminated, and built upon in society. When discussing the way ahead, some informants were concerned with the role politicians play in developing and building on knowledge in society, with Jonas clearly stating: "*I think politicians have a great responsibility here.*" Similarly, Sofie, engaging some in politics herself, revealed: "*It's like, the easiest way of getting anything into the political arena is getting an expert on the subject to talk to a politician on the news.*"

Others were also preoccupied with the need for incorporating more teaching on diagnosis as a whole in formal education. In this context, Sofie said: "*It is these kinds of things [how to relate to different kinds of diagnosis] I feel should be better integrated into public education.*" Adding: "*So, I feel like most of the discussion surrounding autism is basically just that we want five to ten minutes extra time in a science class. There are so many problems that can be fixed by that.*" Regardless of who is left with the responsibility, Luna solidified: "*One has to be open to helping the new generation.*"

4.4.3 Summary

In her statement, Karoline summarised the overall narrative about expand knowledge. Previous experiences indicate a lack of knowledge about the autism diagnosis and understanding autistic perspectives. However, the situation seems to work towards increasing both knowledge of and insight into the lived experience of autism. Moreover, Christian shared how he himself is actively doing this: "*I have contributed to a handful of assignments and reports and so on, and I actually always think it is alright to be able to share my experiences.*"

4.5 Narrative 5: Belonging

Because of its fundamental connection with health, belonging can and should also be seen as a subtheme of the institutional encounter's narrative. Still, social identities was identified as a prominent narrative during the analysis process, and hence, belonging became a separate narrative. Besides, belonging is something to be strived for outside the context of institutional encounters, and thus may be considered both by itself as well as part of the institutional encounters narrative.

Important in distinguishing belonging from any kind of relationships, Karoline pointed out:

> "*But, not any kind of social interaction will do the job. It is important to have access to a milieu where one can meet people that are like oneself, where one can be part of a community, and*

not be left as 'the odd one out'. A milieu where one can be oneself and be accepted and understood for who they are."

In this statement, Karoline talks about finding an accepting community, but she also explicitly calls out having access to a milieu with people who are like herself. While Karoline talked interchangeably about the accepting community and finding a milieu containing people like oneself, our group discussion often differentiated between being part of a diverse community and the importance of meeting other autistics specifically. Hence, this narrative of belonging was split into two subthemes, 1) Meeting Other Autistics and 2) Diverse Communities.

4.5.1 Meeting Other Autistics

Although both parts of the belonging narrative seemed to be important to all informants, the act of meeting other autistics was the most desired aspect.

Jonas: "*It is really cool then, being able to meet others finding themselves in the same situation, that is worth its weight in gold.*"

Karoline: "*It is really important for our self-acceptance and mental health and wellbeing that we come in contact with other autistic adults. [...]. We need to feel being part of a community and be seen and understood in a way that only those who experience the same reality as we ourselves can offer.*"

Having the possibility to engage with other autistics in communities built up of peers is thusly deemed as an essential part of autistics' health. Sadly, moving into discussing the current situation, the informants commonly understood that such experiences are hardly happening. Karoline exemplified this by telling:

"*It is something neurotypicals take for granted since the world is full of people like them, and they find them [milieus where one can be accepted and understood] everywhere. But for us who are in an overwhelming minority this is a much less available commodity. This has been crucial to me and my health. The first time I ever met another autistic with similar functioning like me, I was 15 years old.*"

Imagining the future, Jonas thereby suggested: "*creating some form of a joint arena where autistics can get involved in a community. I think that is really important.*" Moreover, Karoline supported this by talking about the need for autistic ‘neurofriends’, and how: “*It might seem like leisure activities, but this is both preventative and alleviating health care.*”

4.5.2 Diverse Communities

Moreover, Sofie also told of personal benefits gained from participating in other welcoming communities, not restricted to autistics only:

> “*I engaged with adults in a safe atmosphere, which wasn’t something I could do much prior to that [to finding a welcoming community], but after given the possibility to actually engage with someone who wasn’t completely out of my field of interest and I out of their field of interest, then things went a lot better. I managed to develop a lot of social knowledge and social competence; skills I did not have before then and had struggled with prior to being diagnosed.*”

4.5.3 Summary

This narrative of *belonging* tells a story of inclusive communities being experienced as difficult to find. Karoline exemplified this by telling how she could not find a like-minded individual to whom she could feel a proper connection before she was well into her teens. However, these communities do exist and Sofie shared her experience of finding such an inclusive community and the benefits this provided in gaining social knowledge. Even though such general communities as described by Sofie are all well and dandy, all informants also expressed the need for like-minded communities where one could meet and engage with other autistics. Currently, such communities are often taken for granted by neurotypicals and the outside society. For the future, the informants are concerned with the importance of developing more options for autistics to find and participate in accepting and understanding communities comprising both a diversity of individuals as well as some exclusive to autistics.

4.6 Summary of Findings

The informants contributing to this research were recruited using the national autistic association’s Facebook page. After collecting informed consent from all informants, I conducted two focus group interviews. The first focused on everyone’s prior personal experiences with the Norwegian health care system. The second built upon the previous interview to discuss how things could be changed for the better. Both sessions were audio-recorded, so they, upon completion, could be transcribed and the transcription analysed using thematic analysis.

In the data analysis, five narratives were presented, all related and intertwining yet separable to the point of providing themes in response to the main research question, “According to Norwegian autistics between the age of 18-35: What should health promoting services for autistics encompass?” Throughout all five narratives, it appeared consistent that the informants have had few notable positive experiences living with autism. However, these often faded in light of all the negative experiences they had with the services provided and the society at large. Starting with the narrative of the autistic lifeworld, much of the group discussion was concerned with how autistics are a heterogenous group of individuals sharing similarities, as well as being diverse - as Jonas illustrated in his comparison of autistics with Americans. However, even though autistics are different in how well they function at work or at home, a common factor is, as Karoline grimly stated, the probability of trauma as a result of routinely being put in situations deemed harmful by the autistic individual. A statement only further driven home in the second narrative, social structures, where it was solidified that autistics are an under-prioritised group and that currently very little effort is being put into making society more comfortable for autistics. As a result of this lack of comfort, all informants sharing their experiences, had previously tried to reach out for help. Unfortunately, most of their encounters with different institutions have resulted in rejection or even sometimes just making matters worse. Thus, the two concluding thoughts gathered from the narrative of the institutional encounters were, primarily, that health care services for autistics should be more focused on habilitating autistics in their environments, making their everyday life more manageable, and secondly, that there is a need to disseminate more general knowledge about the lived experience of autism in society, by listening to what autistics themselves have to say. Subsequently, the fourth narrative told about how this general knowledge should be achieved.

Finishing the data analysis with the fifth narrative, belonging, many of the points discussed throughout all the other narratives were brought together when discussing developing accepting and understanding communities for autistics to partake in. Although most of the conversation was about forming communities where autistics could meet other autistics, Sofie also made a point to express the benefits of other, more diverse, communities.

Taking a quick peek back at chapter 2.4 shows us that the Bergen music therapy environment is supportive in the development of arenas and communities built and formed by peers (Krüger & Strandbu, 2015). Moving into the discussion in the next chapter, the statements, and experiences presented in this chapter will provide a backdrop to the discourse on how music therapy can be serve as an example for how to create accepting and inclusive communities for autistics.

5.0 Discussion

In the discussion chapter, I will answer the sub-question to the thesis statement, "*How can community music therapy be adapted and further developed to address and accommodate the points brought forth by the informants in relation to the main research question of this thesis?*", by contextualising the stories and first-hand experiences shared by the informants with the existing research and theories mentioned in chapter 2. With the sub-question, a consistent focus throughout this chapter will be on how community music therapy can advance to fit with the wants and needs expressed by the informants presented in chapter 4. Furthermore, in this discussion, I will be taking advantage of my role as an autistic music therapist researcher and building on first-hand experiences, knowledge, and thoughts for the future, as explained in chapter 3.1.2.

5.1 Advocating Autism

Chapter 2 of this thesis presented theories of how identity is intrinsically linked to music was presented. Music may be used as a means of connecting us to the world around us, as Ruud describes:

> "Music may serve as raw material in the building process of values and life orientations, as a way of anchoring important relationships to other people, as a way of framing our situatedness in a certain time and space, and as a way of positioning the person within the culture thus making explicit our position in relation to ethnicity, gender and class." (Ruud, 1997, p. 11)

Building on Ruud's list of cultural positioning, one could add *functioning*. Following the social model of disability, the Neurodiversity movement is similar to ethnical diversity movements and the LGBTQ+ movement, framing functioning as an integral part of an individuals culture and social positioning (Davidson, 2008). In reference to its aim, to further include and accept people of all neurological functioning, Neurodiversity is first and foremost a social justice movement (Baumer & Frueh, 2021). Aligning with the concept of a social justice movement, Dekker (1999) proclaims advocacy and self-advocacy to be an essential part of establishing the autistic culture. Because advocacy and self-advocacy serve the purpose of generating recognition and respect for the needs of autistics, as well as encourage the provision of solutions to meet these needs (Dekker, 1999).

Keeping Dekker's view of self-advocacy in mind, and given music's affordances as described by Ruud (1997), health musicking is in a prime position to be used as means for self-advocacy. In community music therapy, the key quality *performance* includes "performances of self and social-systems." (Stige & Aarø, 2012, p. 22). Performance of self, however, is not necessarily the same as self-advocacy because the latter calls for a strategic socio-political agenda in its use of performances. Autism is for many a fundamental part of who they are: "*That is what I am. First and foremost after human, is autistic,*" as Karoline said. Considering the fact that non-autistics still forward a view on autism that is exclusionary and ignores autistics natural social interaction (Gates, 2019; Cage, et al., 2017; Mitchell, et al., 2021; Geretsegger, et al., 2022; Nilssen, 2022), autistics performance of self and social-systems is as much about being an activist as a performer.

Stige and Aarø (2012) describe activism as as another pivotal quality of community music therapy. Playing into the community music therapy agenda for social change, the activist quality is concerned with acknowledging and working against people's limitations in society. Nevertheless, the activist role gets interwoven with the performer by using health musicking as means to advocate and self-advocate. Through performance, autistics are given the possibility to prove their capabilities as well as communicate their challenges - contradictory to current definitions of autism that frame autistics as having "persistent deficits in the ability to initiate and sustain reciprocal social interaction and social communication," (World Health Organization, 2022, n.p.). Where music therapy predominantly has been working towards subduing autistic traits (Reschke-Hernández, 2011; Geretsegger, et al., 2022), community music therapy offers a platform where these traits can be shared and celebrated.

While Dekker (1999) argues that self-advocacy is a fundamental part of the autistic culture, and as the numbers of advocates and self-advocates increase in both academic (i.e. Milton & Moon, 2012; den Houting, 2019) and online influencer spheres (i.e. silentmiaow, 2007; Layle, 2021). I personally will argue that self-advocacy should not be taken for granted and I do not encourage leading autistics into self-advocacy unless they express this wish themselves. Still, the potential for autism advocacy and self-advocacy during social interactions and musical performances may be considered when developing music therapy services for autistics.

5.1.1 Ramifications Of Autistic Advocacy

Following the concept of autistic advocacy and self-advocacy in music therapy, the individual's personal, relational, and environmental levels are affected. At the personal level, community music therapy can serve as an arena for 'musical flourishing', where the individual can establish themselves as social actors capable of artistic discovery and expression (Ansdell & DeNora, 2012). On the relational level, health musicking attests to autistics being motivated and able to form reciprocal social interactions and communication with others (i.e. Krüger & Strandbu, 2015). Finally, at the environmental level, advocacy and self-advocacy through health musicking can provide a medium for which autistic individuals can share first-hand insight and knowledge about the lived experience of autism with the world around them (i.e. Aasgaard, 2001).

5.1.1.1 The personal level

A recently conducted study showed that most autistics associate social skill difficulties and communication issues with their diagnosis (Cooper et al., 2021). The same study also reported a correlation between how individuals viewed autistic attributes and their respective collective self-esteem and attachment to autistic identity. However, in music therapy, one can develop self-efficacy (Ruud, 2008, p. 18). Working with a resource-oriented quality (see Chapter 2.4.1) involves accommodating the therapeutic context to ensure that participants can achieve a sense of empowerment (Rolvsjord, 2004). Thus, community music therapy can provide an arena for autistics to develop and perform a more positive sense of their autistic selves.

5.1.1.2 The relational level

In the current day and age, autistics are proven to be socially unfavourable as a result of non-autistics missing insight into autism and autistic behaviour (Sasson et al., 2017; Sasson & Morrison, 2019). According to the double empathy problem, autistics become socially disadvantaged when others perceive their behaviour in social interactions as a breach of the traditional way non-autistics are used to (Milton, 2012b). However, as people get more knowledge about and experience with autism, they become less judgemental of autistics in social interactions (Sasson & Morrison, 2019). Through their performance of self by using health musicking that communicates and shares their experience, advocacy, and self-advocacy, autistics give insight and share knowledge about the lived experience of autism with the outside world (i.e. Aasgaard, 2001; Tuastad & Stige, 2012). Moreover, the most common reason autistics reported interest in participating in a music-making workshop was to meet new people with similar interests (Thompson et al., 2020). Community music therapy thus can afford social participation where participants can experience each other in a safe environment to develop social capital (see Chapter 5.2.1; Stige & Aarø, 2012).

5.1.1.3 The environmental level

A prominent narrative among the informants for this thesis was the expansion of knowledge about the lived experience of autism, both in terms of developing new insight as well as sharing it with others, so that the environment autistics find themselves in can be more understanding and accepting (see Chapter 4.1.4). Using community music therapy as a platform for advocacy and self-advocacy to expand knowledge, affords autistics' environment with insight and understanding of the autistic lifeworld, similar to a broadening of the relational level mentioned above. Then, based on this increased knowledge and insight, autistics and their surrounding environment might be better predisposed to approach many of the challenges mentioned in this research, for instance, maintaining an accepting and understanding milieu. Another example is to provide more accommodations at home or in school (see Chapter 4.1).

5.2 Resolving A Traumatising World

The implications and consequences from stigmatisation and traumatisation become obvious when looking at current descriptions of social interactions between autistics and non-autistics (Milton, 2012b; Gates, 2019; Griffith et al., 2021). Karoline argued that autistics are probably more likely to be traumatised than, non-autistic people. Keeping this in mind, it stands to reason those services aimed at accommodating autistics should use principles underlying trauma-informed care, like safety and connections (Krüger et al., 2015).

Community music therapy has to this point mainly explored the topic of trauma-informed care in child welfare and refugee settings (i.e. Krüger et al., 2015; Zharinova-Sanderson, 2004). Of these two, I personally believe the perspectives gathered from child welfare settings are the most applicable to autistics'. Because autistics' trauma is typically the result of perceived attacks on our personhood (Gates, 2019, p. 16), I will primarily be using the literature on trauma-informed care gathered from the context of child welfare in this thesis. Still, it is important to consider the differences in traumatic experiences autistics encounter compared to others. Karoline outlined: "*It needs to be recognised and acknowledged that the fact that autistics experience the world differently may also lead to us experiencing situations and experiences as traumatic, even if they're not considered as potentially traumatic by the general population.*" For that reason, future trauma-informed care related to autistics should be explored independently.

Following the research on trauma-informed care in child welfare settings, community music therapy can provide users with a safe environment to connect with others (Krüger et al., 2015). A safe environment for autistics will most likely be multi-faceted and involve both the relational and emotional safety provided through positive interactions with others (Krüger et al., 2015). Furthermore, when working with autistics, it also includes accommodating the autistic lifeworld, such as providing a separate room for taking unsolicited breaks from the group activities (Thompson et al., 2020). It is also essential to consider how connections with others are established. Providing a space that is inclusive and considerate of differences is crucial (Thompson et al., 2020).

5.2.1 Creating A Safe Space

In the context of child welfare, Krüger et al. (2015) accounts for community music therapy as a place where safety is established through musical interactions with peers. However, being part of a socially unfavourable minority, autistics are often left 'the odd one out' in social interactions (see Chapter 4.1.5). Paramount in community music therapy settings with autistics is then to establish an environment that is inclusive and considerate of differences (Thompson et al., 2020). Keeping in mind that autistics are a heterogenous group (see Chapter 4.1.1.1), acknowledging and including differences in musical creativity and health musicking need to be done on an individual basis and not solely based on the diagnosis. In this way, community music therapy may provide safe arenas where people dare to be themselves.

When talking about accommodating individual differences, it is important to note that autistics do not always have insight into their own support needs. They might even have trouble recognising what challenges are caused by having an autism diagnosis and what everybody else, autistic or not, has to deal with. Still, during this process the responsibility lies on the music therapists to facilitate understanding and provide a balance between structure and flexibility (see Chapter 5.3). Thompson et al.'s (2020, p. 134) study framed this as "Have group rules but work around the individual" and "Encourage people but don't force them." A community music therapy arena might provide a safe place for autistic individuals to explore and investigate how their challenges and resources relate to others'.

While it is important to remember the heterogeneity of autism, the need for a clear, communicated structure and overview of the service may be more general. Among the informants for this thesis, Luna mentioned how she needs structure and clarity in everything. Moreover, in the study of Thompson et al., (2020, p. 134), four out of five informants answered that getting information about what to expect and what was expected from them as participants in the group was crucial. Overall, a clear and structured service, welcoming of individual needs and performances of self, provides a good foundation for creating a safe space for autistics to participate in community music therapy.

5.2.2 Establishing Connections

In line with accounts of stigma and the traumatic repercussions for autistics (Milton, 2012b; Gates, 2019; Griffith et al., 2021), Karoline talked about the probability of autistics being traumatised by an unwelcoming society and the subsequent need for camouflaging their behaviour (see Chapter 4.1.1.1). Tied in with this, Karoline also highlighted the need for social experiences and relationships in which one can feel safe:

> "*Taking part in a company of other people where one has to hide, exert oneself and pretend in order to play the others' game, will never be equally rewarding to a party where one communicates and socialises in the way that is natural to oneself. The autistic way. I have often thought that it is with others I feel the most alone. That was until I met other autistic people who function and communicate in a way that feels natural to me and where I can be social just the way I am and be understood and appreciated without being judged or frowned upon for not being like them.*"

Community music therapy offers the possibility for autistics to engage with other autistics as well as more diverse communities. Amongst the informants for this thesis, most emphasis were put on meeting and connecting with other autistics (see Chapter 4.1.5.1). Because, despite needing to be accepted and understood by society in general, being able to bond with others of similar background and functioning is highly valued by autistics. Karoline has put it this way:

> "*It may be somewhat similar to differences in culture. That, even if you may move across the globe and socialise with the people there, contact with those who share your own culture, your upbringing and your experiences and understanding of reality, will always be important and will always be able to offer something only they can give.*"

Moreover, based on the current status of the double empathy problem, a community consisting solely of autistics can provide an atmosphere where autistics can communicate and socialise in the way that feels most natural to them, without worrying about how other parties might perceive such behaviour and understandings of reality. Hence, affording autistics with an arena where they can come together in solidarity to gain positive experiences with a shared autistic identity and increase collective self-esteem should be considered as a potential goal in community music therapy.

Still, creating such groups is inherently exclusionary. Drawing a parallel back to the informants' discussion on specialised schools (see Chapter 4.1.2.2), pure autistic communities may provide a higher level of comfort, but as Sofie argued, such communities are not representative of the rest of society. "In society, broader forms of solidarity are necessary." (Stige & Aarø, 2012, p. 193). Besides, the ideology of Neurodiversity is to increase the inclusion of *all* types of functioning. The study of Krüger et al. (2015) found that community music therapy provided arenas for participants to gradually test and show sides of themselves that "are not just perfect" (p. 7) and so, "*Through* music therapy, the adolescents can help each other and create belonging to a community of peers." (p. 8, italics added for emphasis by Nilssen). Thus, while affording autistics with arenas to meet other autistics and share their world experience is certainly important, community music therapy may also serve to bridge connections between autistics and a more diverse society.

5.3 Role and Competencies Of The Music Therapist

Resource-oriented music therapy theory argues for equalising the relationship between therapist and clients. Opposing the expert therapist-weak client binary, music therapists highlight the need to recognise clients as competent (Rolvsjord, 2014), and put patients ‘in the driver’s seat when deciding on the contents of the therapeutic process (Solli, 2012). As discussed above, giving clients autonomy and the power to influence their therapeutic process needs to be extended to autistics. Furthermore, constructing a safe space for the therapeutic process to take place is dependent on taking autistic perspectives into account. Coincidentally, Solli (2012, p. 37) indicates that including clients in constructing the therapy may itself be therapeutic. One of the primary roles of the music therapist when working with autistics, is therefore, to accommodate for sufficient autistic involvement when preparing and conducting music therapy.

With that being said, as music therapists, we must remember the inevitable division of roles in the therapeutic relationship. In the process of recognising our clients as competent, it is important to remember that “[a] therapist, by definition, has specific knowledge and skills and offers [their] expertise to help the client.” (Bruscia, 2014, p. 70). By enlisting the help of a therapist, our clients are trusting us to honour our therapeutic responsibility and execute our competencies throughout the therapeutic process to provide them with the best service possible. Not to say the client themselves do not hold responsibility for the therapeutic process - it is well established that the responsibility for change lies within the client (Bruscia, 2014, p. 75).

Acknowledging a shared responsibility for the therapeutic process it becomes apparent that the therapeutic relationship does not benefit from being separated into dichotomous descriptions, like the weak client-expert therapist binary nor the driver-passenger analogy. Contradictory to the mutual relationship said to characterise the therapeutic process, these descriptions seems to consider one party as either more able (Rolvsjord, 2014) or responsible (Solli, 2012) than the other. Instead of this, I would personally like to suggest that the client and therapist may be seen as coworkers complimenting each others strengths and weaknesses to achieve the best possible flourishing, health, and wellbeing of the client.

Considering then, the therapist’s preconditions as either a non-autistic or autistic music therapist when working with autistic clients. Regardless of the therapist’s own functioning or diagnosis, it is critical for the therapist to remember the heterogeneity among autistics. Hence, the clients' perspective and individual performance should always be considered without being judged by their diagnosis, or lack of diagnosis. Yet, to some extent, autistic music therapists may, be more apt for embodied empathy with the clients' autistic lifeworld than non-autistic therapists (Finlay, 2005). Nonetheless, a prime focus for educating music therapists to work with autistics should be to implement autistic voices into the teaching material further. During my music therapy education, practically all teaching was based on second-hand interpretations of the autistic lifeworld, mostly by music therapists' analysis of an autistic child's behaviour. Furthermore, another focus for education should be to coach music therapy students in how they can promote and implement further involvement of clients and client groups in a constructive way when shaping the therapeutic process and contents.

6.0 Conclusion

Predominantly autistics have been excluded from research, health care services, and society. Talking from personal experiences, and from the stories told by five other autistics over the span of two focus group interviews, the world we inhabit tends to alienate our identity and mental health problems based on a lack of knowledge, understanding, and acceptance of the lived experience of autism. Medical definitions and first impressions of autism have influenced the public to view autistics as socially deficient and unmotivated. Contrary to such views, in the two focus group interviews I conducted with other autistics, it became apparent to me that everyone involved had a deep desire to meet and engage with others. Especially the dire to meet other autistics, as they were thought to share common experiences and understandings as the informants. Furthermore, all informants talked extensively about their wish for more insight and knowledge on their lived experience with autism to be shared with the general public, and health care services so that autistics can be more accepted and included as part of a diverse society.

Speaking of autistics' identity, both autism and music can be seen as intrinsically linked to a person's identity. Surrounded by people and environments with little knowledge and experience of autism, autistics are often deemed socially unfavourable and left to tackle their daily life challenges single-handedly. However, community music therapy practice presents a potential platform for health musicking, possibly resulting in increased knowledge, understanding, and acceptance of autism at both personal, relational, and environmental levels.

Following the topics discussed in this thesis, community music therapy practice provides several possibilities for working *with* autistics rather than working to *cure* autistics. Still, when discussing the provision of community music therapy for autistics, a few points for future improvements arise. In this thesis, three main points of concern have been made, with suggestions on how to address them.

Firstly, the challenge of creating a safe space attuned to both group and individual needs. When accommodating space to fit community music therapy services for autistics, it is crucial to not only consider the relational safety that may come from engaging musically with others. Additionally, it is important to keep in mind that autistics are all different and might have unique challenges that need to be addressed. For instance, many autistics are prone to overstimulation; thus, making accommodations to ease their sensory perception will be necessary and beneficial. One of the most common traits for autistics is the need for a clear structure and overview of what will happen; setting rules that are accustomed to the group is therefore necessary. Hence, I suggest to include autistic perspectives when creating the space and framework for community music therapy services, and to welcome the idea of making individual adjustments and exceptions on the way.

Secondly, many autistics are used to not feeling accepted and understood by others. Due to such negative experiences with the double empathy problem, autistics might struggle with forming close connections with peers. The autistic experience often results in that it is with others we feel the most alone, as Karoline stated. In light of this, community music therapy can provide autistics with a platform for advocating and self-advocating their perspectives by exploring and performing themselves in social and musical settings. Accordingly, future services for autistics should strive toward establishing positive connections between autistics and their autistic self, their autistic community, and non-autistic peers. This can and should be done by affording autistics with a balance of both mutual bonding with other autistics, as well as facilitate building bridges with a more diverse, non-autistic, selection of peers.

Thirdly, when considering our role and preconditions as music therapists building a working relationship with autistic clients, we need to be aware of how we relate to the context and people around us. Building on modern theories of the competent client, I call for the means to provide autistics with a competent therapist - someone who possess the expertise to honour their therapeutic responsibility, which includes knowing how to meet autistics' needs and wants. To help establish this knowledge, I suggest starting to implement more autistic voices and perspectives in the education of music therapists. Furthermore, to provide future music therapists to work reflexively with autistic clients and perspectives when shaping and conducting music therapy.

To conclude, one aim of this thesis was to provide music therapists with a mindset of how they can take into account the autistic lifeworld when designing music therapy interventions meant to help integrate autistics into new or existing social structures, institutions and communities. While this thesis presents a basis for further discourse, continuing to initiate and maintain dialogue with autistics on what they want and need remains of the utmost importance in both research and practice.

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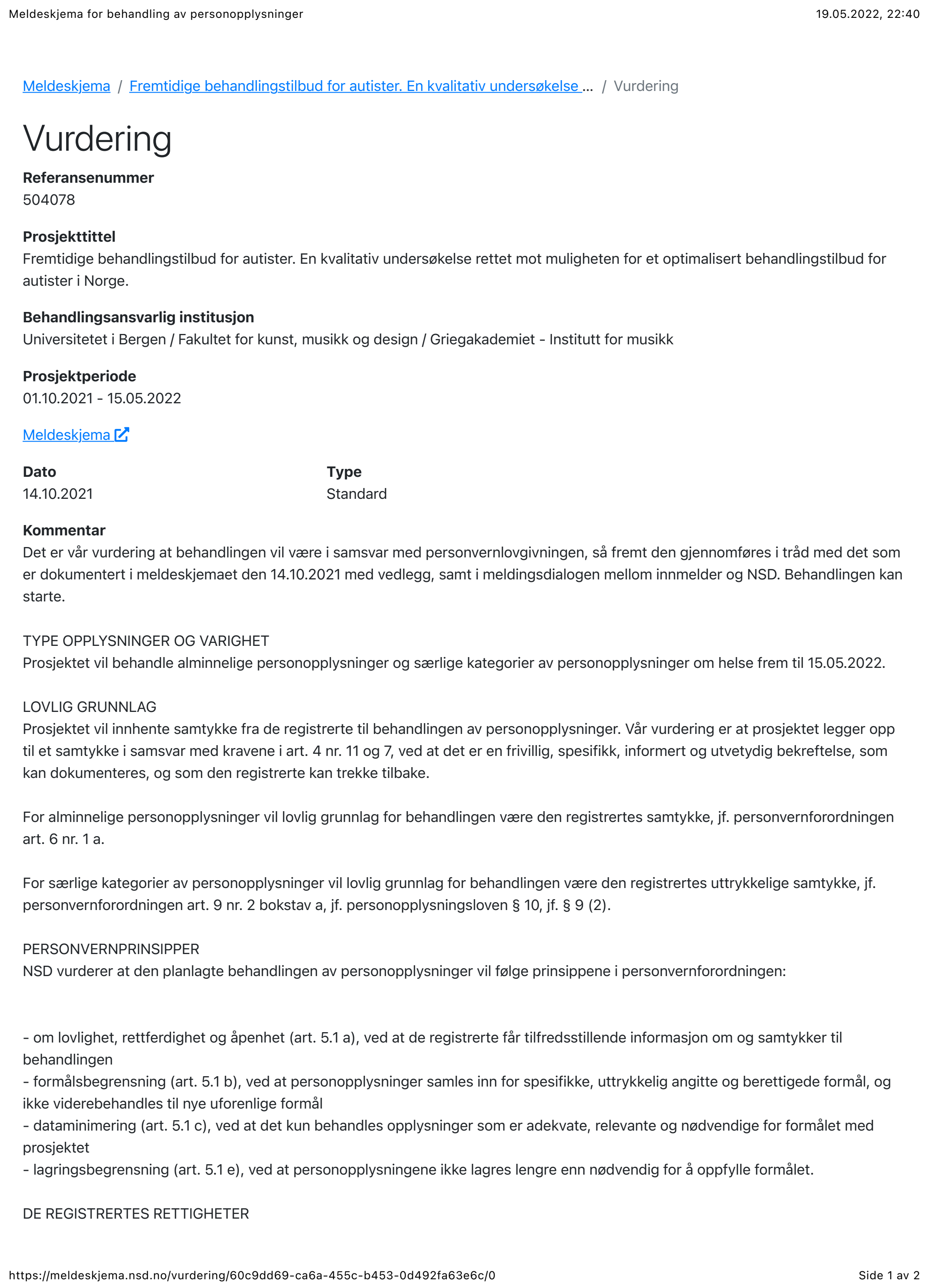
Attachment 1: Norwegian Centre of Research Data, Approval



Meldeskjema for behandling av personopplysninger 19.05.2022, 22:40

Meldeskjema / Fremtidige behandlingstilbud for autister. En kvalitativ undersøkelse ... / Vurdering

Vurdering

Referansenummer
504078

Prosjekttittel
Fremtidige behandlingstilbud for autister. En kvalitativ undersøkelse rettet mot muligheten for et optimalisert behandlingstilbud for autister i Norge.

Behandlingsansvarlig institusjon
Universitetet i Bergen / Fakultet for kunst, musikk og design / Griegakademiet - Institutt for musikk

Prosjektperiode
01.10.2021 - 15.05.2022

Meldeskjema

Dato	**Type**
14.10.2021	Standard

Kommentar
Det er vår vurdering at behandlingen vil være i samsvar med personvernlovgivningen, så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet den 14.10.2021 med vedlegg, samt i meldingsdialogen mellom innmelder og NSD. Behandlingen kan starte.

TYPE OPPLYSNINGER OG VARIGHET
Prosjektet vil behandle alminnelige personopplysninger og særlige kategorier av personopplysninger om helse frem til 15.05.2022.

LOVLIG GRUNNLAG
Prosjektet vil innhente samtykke fra de registrerte til behandlingen av personopplysninger. Vår vurdering er at prosjektet legger opp til et samtykke i samsvar med kravene i art. 4 nr. 11 og 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse, som kan dokumenteres, og som den registrerte kan trekke tilbake.

For alminnelige personopplysninger vil lovlig grunnlag for behandlingen være den registrertes samtykke, jf. personvernforordningen art. 6 nr. 1 a.

For særlige kategorier av personopplysninger vil lovlig grunnlag for behandlingen være den registrertes uttrykkelige samtykke, jf. personvernforordningen art. 9 nr. 2 bokstav a, jf. personopplysningsloven § 10, jf. § 9 (2).

PERSONVERNPRINSIPPER
NSD vurderer at den planlagte behandlingen av personopplysninger vil følge prinsippene i personvernforordningen:

- om lovlighet, rettferdighet og åpenhet (art. 5.1 a), ved at de registrerte får tilfredsstillende informasjon om og samtykker til behandlingen
- formålsbegrensning (art. 5.1 b), ved at personopplysninger samles inn for spesifikke, uttrykkelig angitte og berettigede formål, og ikke viderebehandles til nye uforenlige formål
- dataminimering (art. 5.1 c), ved at det kun behandles opplysninger som er adekvate, relevante og nødvendige for formålet med prosjektet
- lagringsbegrensning (art. 5.1 e), ved at personopplysningene ikke lagres lengre enn nødvendig for å oppfylle formålet.

DE REGISTRERTES RETTIGHETER

https://meldeskjema.nsd.no/vurdering/60c9dd69-ca6a-455c-b453-0d492fa63e6c/0 Side 1 av 2

NSD vurderer at informasjonen om behandlingen som de registrerte vil motta oppfyller lovens krav til form og innhold, jf. art. 12.1 og art. 13.

Så lenge de registrerte kan identifiseres i datamaterialet vil de ha følgende rettigheter: innsyn (art. 15), retting (art. 16), sletting (art. 17), begrensning (art. 18) og dataportabilitet (art. 20).

Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har behandlingsansvarlig institusjon plikt til å svare innen en måned.

FØLG DIN INSTITUSJONS RETNINGSLINJER
NSD 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).

For å forsikre dere om at kravene oppfylles, må prosjektansvarlig følge interne retningslinjer/rådføre dere med behandlingsansvarlig institusjon.

MELD VESENTLIGE ENDRINGER
Dersom det skjer vesentlige endringer i behandlingen av personopplysninger, kan det være nødvendig å melde dette til NSD ved å oppdatere meldeskjemaet. Før du melder inn en endring, oppfordrer vi deg til å lese om hvilken type endringer det er nødvendig å melde:
https://www.nsd.no/personverntjenester/fylle-ut-meldeskjema-for-personopplysninger/melde-endringer-i-meldeskjema
Du må vente på svar fra NSD før endringen gjennomføres.

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

Kontaktperson hos NSD: Markus Celiussen

Lykke til med prosjektet!

Attachment 2: Invitation text

Invitasjon til forskningsprosjektet: «Fremtidige helsefremmende tilbud for autister»

Dette er for norske autister (inkludert de med Asperger Syndrom) i alderen 18-35 år. Forskningsprosjekt tar for seg videreutviklingen av helsefremmende tjenester for autister. Prosjektet inngår i en masteroppgave som setter autistenes stemme i fokus med å spørre autistene selv hva de mener helserelaterte tilbud og tjenester for autister burde fokusere på.

Som deltager kommer du til å skulle ta del i to gruppeintervjuer på omlag 90 minutter hver, hvor du får anledning til å samtale med fire andre deltagere pluss ordstyrer, om hva dere mener er viktig når det kommer til autistenes helse. Intervjuene vil finne sted digitalt via Zoom, og det vil være mulig å delta både verbalt i videosamtalen og skriftlig i chat.

Intervjuene er planlagt å finne sted kl. 1900, mandagene 6. og 13. desember.

Hvis dette høres interessant ut og du ønsker mer informasjon, vennligst ta kontakt med Mathias Nilssen per epost: [redacted], eller telefon: [redacted].

Frist for å melde interesse er fredag 26. november kl. 1200.

Attachment 3: Informed-Consent form

Vil du delta i forskningsprosjektet

Fremtidige helsefremmende tilbud for autister

Dette er et spørsmål til deg om å delta i et forskningsprosjekt som er del av en masteroppgave i musikkterapi og hvor formålet er å undersøke hva fremtidige helsefremmende tilbud for autister burde fokusere på i følge autister. I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

Formål

Prosjektet ønsker å heve de autistiske stemmene i temaer som angår de, her med spesiell vekt på hvordan autister selv mener de helsefremmende tilbudene de har til rådighet burde se ut. Måten dette vil bli gjennomført på er at det vil bli satt sammen én fokusgruppe på omslag 5 autistiske mennesker pluss forskeren, som skal møtes to ganger for å diskutere hvordan helsetilbudene ser ut i dag og diskutere hvordan deltagerne mener ting burde endres. Utgangspunktet for prosjektet er at det skal inngå i en masteroppgave hvor det undersøkes hvordan dataene hentet fra fokusgruppen kan informere samfunnsmusikkterapeutisk praksis. Den konkrete problemstillingen lyder: «Hva mener norske autister i alderen 18-35år at et helsefremmende tilbud for autister burde ha som fokus, og hvordan står dette i forhold til samfunnsmusikkterapeutiske kvaliteter?».

Den endelige masteroppgaven kommer til å bli publisert i artikkelform, og kan inngå i pensum.

Hvem er ansvarlig for forskningsprosjektet?

Wolfgang Schmid er ansvarlig for prosejektet ved Universitetet i Bergen, telefon: 45200271; e-post: wolfgang.schmid@uib.no. Det er Mathias Nilssen, masterstudent i musikkterapi, som er forsker i prosjektet, telefon: 48353609; e-post: huw006@uib.no.

Hvorfor får du spørsmål om å delta?

Du blir spurt om å delta fordi du er en norsk statsborger i alderen 18-35år med en Autismespekter-diagnose. Det endelige utvalget kommer til å bestå av cirka fem personer, og det ønskes stor variasjon mellom deltagerne når det gjelder aspekter som kjønn og etnisitet.

Hva innebærer det for deg å delta?

Som deltager skal du delta på to 90 minutters gruppeintervju i løpet av høsten 2021 sammen med resten av utvalget, ledet av masterstudenten. Under det første møtet kommer det til å bli gitt generell info om tidligere og eksisterende behandlingstilbud for autister i Norge, i tillegg til at du blir oppfordret til å samtale litt om dette samt dele dine egne erfaringer med tilbudene du har fått selv. Når vi samles til det andre møtet er det opp til deg som deltager å fremme dine tanker rundt hva helsefremmende tilbud for autister burde innebære. Ved behov stiller masterstudenten spørsmål for å videreføre diskusjonen.

Under diskusjonen er vi hovedsakelig ute etter hva du som autist ønsker i form av helsefremmende tilbud, og vi setter også pris på utfyllende informasjon som for eksempel *hvorfor* du mener det du mener. Intervjuene er lagt opp til å finne sted digitalt, og det vil være mulig å delta enten vokalt eller i et integrert chatterom. Det vil bli gjort lydopptak av samtalen og chatten vil bli lagret, slik at masterstudenten kan lage en transkripsjon av intervjuene som alle deltagerne skal godkjenne før dataene blir inkludert i masteroppgaven.

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 kun masterstudenten og veilederen som vil ha tilgang til dine opplysninger. Navnet og kontaktopplysningene dine vil bli erstattet med en kode fra masterstudenten og lagret på egen navneliste adskilt fra øvrige data. Alt datamaterialet blir lagret på en kryptert forskningsserver tilhørende UiB.

I den endelige masteroppgaven kommer alle deltagerne til å bli anonymisert slik at de ikke kan gjenkjennes i publikasjonen. Du vil bli tildelt et alias som knyttes til utsagnene dine gjort under intervjuene.

Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?

Opplysningene anonymiseres når prosjektet avsluttes/oppgaven er godkjent, noe som etter planen er 15. mai 2022. All informasjon du har oppgitt, inkludert personopplysninger og opptakene fra intervjuene, vil bli fullstendig slettet ved prosjektslutt.

Dine rettigheter

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

- innsyn i hvilke personopplysninger som er registrert om deg, og å få utlevert en kopi av opplysningene,
- å få rettet personopplysninger om deg,
- å få slettet personopplysninger om deg, og
- å sende klage til Datatilsynet om behandlingen av dine personopplysninger.

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 NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Hvor kan jeg finne ut mer?

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

- Universitetet i Bergen ved Wolfgang Schmid per e-post: wolfgang.schmid@uib.no eller på telefon: 45 20 02 71
- Vårt personvernombud: Janecke Helene Veim ved personvernombud@uib.no

Hvis du har spørsmål knyttet til NSD sin vurdering av prosjektet, kan du ta kontakt med:

- NSD – Norsk senter for forskningsdata AS på epost (personverntjenester@nsd.no) eller på telefon: 55 58 21 17.

Med vennlig hilsen

Wolfgang Schmid *Mathias Nilssen*
(Forsker/veileder) (Masterstudent)

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet *Fremtidige helsefremmende tilbud for autister*, og har fått anledning til å stille spørsmål. Jeg samtykker til:

○ å delta i to gruppeintervju

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet

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(Signert av prosjektdeltaker, dato)

Attachment 4: Interview guide

Hovedspørsmål	**Underspørsmål**
Har noen av dere tidligere eller pågående erfaringer med autismebehandling/behandling av autisme i Norge?	- Hva gikk behandlingen ut på? - Er vedkommende fornøyd med behandlingen de fikk? - Er vedkommende fornøyd med resultatet av behandlingen?
Hva inngår i autistenes helse?	- Handler helse kun om fysisk og psykisk tilstand?
Hvem har ansvaret for autistenes helse?	- Autistene selv, politikere, lærere, helsepersonell, eller andre? - Hvordan burde autistenes helse/utfordringer prioriteres i forhold til ikke-autister?
Trengs det egne tjenester/tiltak spesifikt for autister?	- Klarer autistene seg med de samme tjenestene som alle andre, hvis disse tjenestene får større kunnskap om autisme? - Burde tjenestetilbudene basere seg på diagnose eller behov?
Hva burdet fokuset være for å bedre autistenes helse?	- Er normalitet verdt å sikte mot? Kan autisme kureres? - Ønskes det en større sosial/samfunn inkludering, eller klarer autister seg best alene? - Psykoedukasjon og atferdsendring har tidligere vært et hovedfokus, burde dette forbli?
Hvordan burde man evaluere effektivitet av tilbud?	- Hvilke mål skal bedømme om et tilbud er suksessfullt eller ikke? - Hva kan samfunnet forvente å få ut av å hjelpe autister? - Hva hadde dere håpet å få ut av en helsefremmende tjeneste?