Ethical Perspectives on the Adoption of the Neurodiversity Paradigm in the Field of Autism

Research

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### Abstract

The field of autism research is currently undergoing a major paradigm shift. It is moving away from traditional biomedical models, which frame autism as being the result of an internal deficiency that directly hinders individual well-being, towards the neurodiversity paradigm, which recognizes autism as being the result of a natural variation in human cognitive function. The neurodiversity model, in accordance with social and interactionist models of disability more broadly, reframes the challenges faced by autistic individuals. These are understood as the result of an incompatibility between the autistic person's dispositions and the environments in which they find themselves. This thesis will consider the ethical ramifications of this paradigm shift. It argues that traditional biomedical approaches have directly contributed to and reinforced widespread inequalities that negatively impact the well-being of autistic individuals and communities. I identify and elaborate two forms of inequality - distributive and relational - and argue that the neurodiversity paradigm offers a way forward in overcoming both forms of inequality. Chapter one will offer a brief overview of the history of autism research and the rise of the neurodiversity movement. It examines the various ways in which traditional biomedical models have failed to account for aspects of autistic experiences, prompting the need for the paradigm shift. Chapter two will show how the proliferation of biomedical models has directly contributed to distributional equalities in the quality of care offered to autistic people by medical institutions. It will also examine relational inequalities in the treatment of autistic people in both institutional and interpersonal contexts. Chapter three will consider how the neurodiversity paradigm promises to overcome these inequalities by improving empirical understandings, encouraging the implementation of participatory and emancipatory research practices, and reframing cultural narratives about what it means to be autistic.

# Résumé

La recherche sur l'autisme connaît actuellement un changement de paradigme majeur. Elle s'éloigne des modèles biomédicaux traditionnels, qui considèrent l'autisme comme le résultat d'une déficience interne qui entrave directement le bien-être de l'individu, au profit de la neurodiversité, qui reconnaît que l'autisme est le résultat d'une variation naturelle des fonctions cognitives humaines. Le modèle de la neurodiversité, conformément aux modèles sociaux et interactionnistes du handicap en général, recadre les défis auxquels sont confrontées les personnes autistes. Ces défis sont considérés comme le résultat d'une incompatibilité entre leurs dispositions et les environnements dans lesquels ils se trouvent. Cette thèse examine les ramifications éthiques de ce changement de paradigme. Elle soutient que les approches biomédicales traditionnelles ont directement renforcé et contribué à des formes d'inégalités généralisées qui ont un impact négatif sur le bien-être des personnes et des communautés autistes. À ce titre, j'identifie et j'élabore deux formes d'inégalité – distributive et relationnelle – et j'affirme que le paradigme de la neurodiversité offre un moyen de les surmonter. Le premier chapitre présente un bref aperçu de l'histoire de la recherche sur l'autisme et de l'essor du mouvement pour la neurodiversité. Il examine les différentes façons dont les modèles biomédicaux traditionnels n'ont pas réussi à rendre compte de plusieurs aspects de l'expérience autistique, d'où la nécessité d'un changement de paradigme. Le deuxième chapitre montre comment la prolifération des modèles biomédicaux a directement contribué aux inégalités de distribution dans la qualité des soins offerts aux personnes autistes par les institutions médicales. Il examine également les inégalités relationnelles présentes dans le traitement des personnes autistes dans des contextes institutionnels et interpersonnels. Le troisième chapitre examine de quelle façon le paradigme de la neurodiversité promet de surmonter ces inégalités en améliorant les connaissances empiriques, en encourageant la mise en œuvre de pratiques de recherche participatives et émancipatrices, et en recadrant les récits culturels sur ce que signifie être autiste.

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# Introduction

The field of autism research currently finds itself on the cusp of a major paradigm shift. Autism research has historically operated within a biomedical paradigm which conceives of the differences associated with autistic minds (as compared to their non-autistic peers) in terms of disorder. The struggles autistic people face, under this model, are seen as the direct result of some internal disorder or deficiency which prevents successful functioning. As a result, autism is often framed as a problem which must be solved in order to 'fix' the autistic person and restore normal function. However, biomedical approaches to autism research are increasingly being called into question for both methodological and ethical reasons. Due to a highly circumscribed focus on internal factors, the biomedical paradigm has overlooked a number of key aspects of autistic experiences, including the impact of disabling socio-political and environmental factors. (Pellicano and den Houting 2022). I argue that this limits empirical understandings of how autistic minds and bodies function, limiting the potential to meaningfully support autistic wellbeing. Moreover. I argue that the deficit-focused models of autism produced within the biomedical paradigm also contribute to widespread relational inequalities by contributing to stigmatizing cultural narratives which position autistic people as inherently broken and incapable of meaningful social connection. The is a growing push to shift away from the traditional medical paradigm and embrace approaches grounded in the neurodiversity paradigm might offer a way forward in mitigating these concerns.

The neurodiversity movement first arose within an online community of autistic advocates who objected to the pathologizing attitudes they saw as pervasive in the field of autism research (Botha et al 2024). They took issue with the prevailing narrative that autism entailed a

uniquely disordered mode of cognition, and questioned whether the deficit-focused approach of the traditional biomedical paradigm could offer meaningful benefit to the lives and well-being of the average autistic individual. Although they acknowledged that their autistic minds functioned differently than those of their non-autistic peers, they contended that these differences could be accounted for by a natural variation in human cognitive function. This diversity of human minds which resulted in this variability of cognitive function was referred to as 'neurodiversity', a form of biodiversity considered to be as natural and beneficial as any other (Dekker 2020). The neurodiversity paradigm provided a philosophical foundation for the growing neurodiversity movement. This paradigm views neurodiversity as a valuable part of human diversity more broadly, rejects the culturally constructed belief that there exists one superior mode of human cognition, and recognizes that the social dynamics which manifest in response to neurodiversity parallels the social dynamics which manifest in relation to other forms of marginalization. The neurodiversity paradigm also affirms that neurodiversity, when properly embraced, functions as a valuable source of creative potential for society as a whole (Walker 2014).

This thesis argues that the shift towards the neurodiversity paradigm provides the opportunity to not only improve empirical understandings of autism, but also to uphold a commitment to currently accepted bioethical principles. Autistic people are currently subject to persistent, systemic injustices, and many of these injustices can be understood as a direct result of the failures of biomedical research. While traditional approaches to biomedical ethics have concerned themselves primarily with distributive conceptions of justice (that is, understanding justice in terms of the fair distribution of certain key benefits and burdens), I argue that a strong commitment to bioethical justice should also attend to concerns of relational injustice. Within a

relational framework, justice requires maintaining relations of equality among citizens through the elimination of unjust social hierarchies (Anderson 2018). This thesis will argue that autistic people are subject to both distributive and relational injustices on a broad scale and that the neurodiversity paradigm offers a path forward in overcoming those injustices. Embracing the neurodiversity paradigm creates the opportunity to better understand autistic people and develop novel approaches to supporting autistic well-being. It also provides the opportunity to ensure social equality for autistic people by centering autistic humanity and recognizing the value autistic people can contribute to society.

This thesis will be presented in three chapters. Chapter one will provide a brief introduction to the history of autism research and the neurodiversity movement. The neurodiversity paradigm will be introduced, and the current shift towards neurodiversity models in autism research will be situated within the context of broader shifts in disability modelling. Increasingly, mainstream approaches to disability modelling are moving away from biomedical understandings of disability and towards the social and interactionist frameworks which have long been championed by disability studies scholars and activists (Oliver 2004). This chapter will also outline several empirical failures of the traditional biomedical paradigm in the context of autism research, arguing that these failures have necessitated the current paradigm shift for methodological reasons. It will be argued that in the context of human sciences such as psychiatry, sociopolitical and relational factors are relevant to the choice of scientific models for both methodological and ethical reasons. That is to say, it is important to recognize the way scientific models are shaped by entrenched cultural assumptions and how, in turn, the labels created by those models might influence the lived realities of those labelled by them. Finally, this chapter will expand on the concept of neurodiversity, giving an overview of the philosophical foundations of the neurodiversity paradigm and outlining some implications of the current paradigm shift for autism research and care.

Chapter two will outline multiple bioethical concerns which arise as a direct result of the characteristic approaches of the biomedical paradigm, with a particular focus on the bioethical principle of justice. It will be argued that the limitations of the traditional biomedical paradigm have contributed both directly and indirectly to a wide range of distributive and relational injustices. From a distributive perspective, poor distribution of resources has led to the needs of autistic people being overlooked. Moreover, limited understandings of and erroneous assumptions about autism have led to autistic people receiving a lower standard of healthcare than their allistic peers. Autistic people are also subject to various relational injustices in both institutional and interpersonal contexts. These relational inequalities are the result of stigmatizing attitudes which position autistic people as inferior to their allistic (that is, non-autistic) peers, reinforced by deficit-focused biomedical models of autism.

Chapter three will consider how the neurodiversity paradigm might offer a way forward in challenging these inequalities. It will be argued that the adoption of neurodiversity-affirming approaches to autism research will allow for a more equitable distribution of resources in research and improve the standard of medical care available to autistic patients, overcoming existing distributive inequalities in healthcare. The adoption of less deficit-focused models of autism and emancipatory research methods will also help enhance the relational equality of autistic people in both institutional and interpersonal contexts. Emancipatory research methods serve to dismantle existing hierarchies of power and esteem in research institutions, and challenge cultural narratives which position autistic people as inferior to their allistic peers.

# **Chapter 1: Introducing Shifting Paradigms in Autism Research**

The field of autism research is currently undergoing a major paradigm shift. It is moving away from traditional biomedical models, which frame autism as the result of an internal deficiency that directly hinders individual well-being, towards the neurodiversity paradigm, which recognizes autism as the result of a natural variation in human cognitive function (Pellicano and den Houting 2022). This chapter aims to introduce and contextualize the factors which have contributed to this shift. Section one will offer a brief history of autism research and the rise of the neurodiversity movement. Section two will situate the rise of neurodiversity theory within the context of more widespread changes in disability modelling. Over the course of the last several decades, mainstream approaches to disability modelling, taking cues from disability scholars and activists, have shifted away from medical models of disability and towards social and interactionist models. The neurodiversity paradigm aligns itself with these social and interactionist models insofar as it recognizes how social and relational factors contribute to individual disablement. Section three will outline the shortcomings of traditional biomedical approaches which have necessitated a paradigm shift. It will be argued that such biomedical approaches have failed to meaningfully define autism or identify a causal mechanism which accounts for a full range of autistic expression. This failure is illustrated both by a lack of effective diagnostic resources and by the inadequacy of current care approaches in supporting the well-being of autistic individuals and communities. Section four will introduce Thomas Kuhn's theory of paradigm shifts as one framework for understanding shifting approaches in autism science. However, it will be argued that, whereas Kuhn's theory was primarily concerned with empirical factors, in the context of human sciences, sociopolitical and relational factors are

relevant to choosing a particular approach to scientific enquiry, for both methodological and ethical reasons. Finally, section five will give an overview of key concepts related to neurodiversity theory and consider the effects the current paradigm shift might have on approaches to research and medical care.

#### 1.1 A Brief History of Autism Research and the Rise of the Neurodiversity Movement

The term "autistic" was originally used to describe a certain kind of social withdrawal which was often associated with schizophrenia. (Fletcher-Watson and Happe 2019) However, in the 1940s, the parallel investigations of the American Leo Kanner (Kanner 1943) and the German Hans Asperger (Asperger 1944) called attention to groups of children whom the researchers described as displaying 'autistic' behaviours despite the absence of other traits consistent with a schizophrenic profile. Both researchers described the children they studied as being socially withdrawn, displaying stereotyped motor movements, having highly circumscribed interests and insisting on sameness and routine. However, there were also some discrepancies between the two accounts. Kanner described the children he studied as having highly limited verbal communication skills, whereas Asperger noted fluency and capability of speech, comparing the children in his cohort displayed advanced fine motor skills despite difficulties with gross motor control, whereas Asperger described the children he worked with as particularly clumsy, struggling with both fine and gross motor control.

These discrepancies between Kanner's and Asperger's accounts of the key traits associated with their 'autistic' subjects reflects what is now understood as the highly

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heterogeneous nature of autistic traits and experiences, a complexity which must be addressed and accounted for in any good definition of 'autism' as a concept (Masi et al. 2017). There have been several approaches to reconciling this complexity. In the 1990's, the American Psychiatric Association's Diagnostic and Statistical Manual (DSM) listed a series of sub-classifications of autism, the most well-known of which was Asperger's syndrome. The 'Asperger's' label designated individuals who displayed a significant number of autistic traits without the delays in language development typically associated with autism. (American Psychiatric Association 1994) More recently, however, these sub-classifications were collapsed into a single overarching diagnosis of 'autism spectrum disorder.' (American Psychiatric Association 2022)

When talking about the autism spectrum it is crucial to understand that this is not meant to describe a linear spectrum which runs between extremes of 'more autistic' and 'less autistic'. Rather, it is referring to the fact that autistic individuals display a wide variety of traits which manifest to different degrees in different contexts for each autistic individual over the course of their lives. For this reason, some have argued that it would be more accurate to refer to a "constellation" of autistic traits rather than a spectrum (Fletcher-Watson and Happe, 2019) This understanding of autism as a spectrum or constellation of traits calls attention to the unique experiences, strengths, and weaknesses of each autistic individual, and challenges the assumption that all autistic people will behave a certain way.

Historically, the majority of proposed definitions for autism have fallen within a medical model, conceiving of autism as a problem which must be solved. Under this model, autism is understood to be the result of some internal deficiency leading to impairments in communication, social interaction, and imagination (Pellicano and den Houting 2022). Significant amounts of

research have been devoted to investigating the aetiology of autism as a condition (Cervantes at al. 2021). Having established that genetic factors play a significant role in determining whether an individual will be autistic (Tick et al 2016), the last two decades have seen a significant rise in genetic research searching for specific biomarkers (See for example Geschwind and State 2015, Loth et al. 2016). Approaches to autism care have focused primarily on normalization of the autistic individual, often through the use of behavioural modification techniques and other early intervention approaches designed to "guide brain and behavioural development back toward a normal pathway" (Dawson 2008, p.776).

The neurodiversity movement arose from discussions between autistic advocates on the early internet forum Independent Living (often referred to as InLiv) which was founded by Martijn Dekker in 1996 (Dekker 2020). The members of this forum took issue with the pathologizing attitudes which had become pervasive within the field of autism science and questioned whether biomedical approaches offered meaningful benefit to the lives and well-being of the average autistic individual. While they acknowledged that their autistic minds functioned differently than their peers at some fundamental level, they challenged the persistent social narrative that this constituted some kind of tragedy. In Dekker's words:

Biological diversity of all kinds is essential to the survival of an ecosystem - so why should neurological diversity, which is one aspect of biological diversity, be any different? The objective fact that neurological diversity exists emerged as a strong argument for the acceptance of autistics and other neurological minorities as distinct classes of people among many, who have something valuable of their own to contribute, and who are as inherently worthy of equal rights as anyone (Dekker 2020, p.46) The concept of neurodiversity was first introduced to the wider public sphere with a 1997 New York Times article by Harvey Blume (Blume 1997) and to academic circles with Judy Singer's 1998 thesis and 1999 book chapter on the subject (Singer 1998, 1999). However, it is important to recognize that the concept was developed collectively by a diverse group of autistic thinkers and activists and cannot be directly credited to any single individual (Botha et al. 2024).

It took time for these ideas to become more widely understood and accepted, but in recent years there has been a boom in support for the movement among researchers, medical practitioners, and the general public. The field of autism science is now shifting rapidly towards the neurodiversity paradigm, leading to significant change in approaches to research and care (Pellicano and den Houting 2022).

#### **1.2 Modelling Disability**

The rise of the neurodiversity paradigm is connected to shifting approaches to disability modelling more broadly. Disability is generally understood as being associated with physical or mental differences, judged against species-typical and culturally situated norms. These differences are in turn connected to certain limitations which compromise the individual's ability to achieve an otherwise expected level of success in areas of basic functioning or social participation. Disability modelling has two main functions. Firstly, models of disability serve to create a classification, by characterizing disabilities and in some cases determining who should be identified as disabled. Secondly, models offer a causal account of disabilities, explaining why the limitations associated with disability manifest. In turn, this causal explanation can allow for the determination of how best to address or alleviate those hardships (Silvers 2010). While these two functions are often interrelated, the arguments of this chapter are primarily concerned with the latter.

By the mid-20th century, disability had come to be understood primarily through a biomedical model focused on individual impairment. The medical model frames the difficulties associated with disability as the direct result of internal disorder or deficiency grounded in biological abnormality. The solution to the problem of disability is therefore primarily understood to lie in medical intervention which aims to 'fix' the internal defect and restore 'normal' functioning. In cases where medical interventions are not available or are insufficient to cure or otherwise overcome the biological impairment, compensatory benefits or social accommodations may be offered to minimize the negative impact of the disability of the individual. At the most extreme, this conception of disability leads to the assumption that disabled individuals are fundamentally incapable of leading so-called 'normal' and fulfilling lives. A more moderate approach to biomedical modelling of disability may acknowledge the significant impact which accommodations within the social environment can have in helping a disabled person to achieve a certain degree of 'normal' well-being, but nevertheless maintains a primary focus on individual impairment. In this context, social accommodations are understood as a way of compensating for the hardships inherently associated with such impairments, rather than a direct alleviation of the hardships associated with disability themselves (Smith 2008).

Social models of disability arose out of the disability rights movement's critiques of how these traditional biomedical models overlook the way social and political factors directly contribute to individual disablement. It was argued that, by focusing exclusively on individual impairment as the locus of the hardships associated with disability, these approaches foster the assumption that disabled people themselves are somehow fundamentally 'broken' or less-than. Social models of disability address these concerns in two main ways: firstly, by decoupling the concept of disability from the impairment associated with a particular mental or physiological condition. Secondly, by recognizing disabled people as an oppressed group who are negatively impacted by aspects of their sociopolitical environments in much the same way as those affected by other forms of systemic oppression. Proponents of social models of disability argue that the main source of the hardships associated with disability is the social exclusion which results from oppressive social and political systems. As such, they contend that these hardships can largely be alleviated through changes to one's sociopolitical environment. The social model has proven itself to be an effective tool in many ways. Being easily understood and offering a clear agenda for social change, it offered an ideal foundation on which to build a social movement. Moreover, by shifting focus away from the individual deficit model and instead foregrounding the detrimental impact of sociopolitical barriers on the everyday lives of disabled people, it introduced a moral responsibility for society to alleviate the barriers it has imposed on disabled people and helped disabled people themselves to recognize their moral worth and value within society. (Shakespeare 2006)

While the social model offered a welcome alternative to the medical model, it has itself been the subject of certain criticisms. It has been argued that the very simplicity which has made it such an effective tool for political progress also prevents it from capturing a full picture of the ways in which disability emerges and manifests itself. (Shakespeare 2006) Just as the biomedical model fails to account for the role of sociopolitical factors on the material conditions of the lives of disabled people, it is argued, the social model fails to recognize the direct impact of the impairment associated with certain mental and physiological conditions on the daily lives of many (if not all) disabled individuals. The most straightforward example of this would be conditions which cause significant physical pain, and as such create significant barriers to individual well-being irrespective of one's sociopolitical environment. This has prompted a growing push to move away from the social model and towards models which recognize the complex interrelation between internal and external factors and their impact on the lives and well-being of disabled people (Petasis 2019).

Early theorizing within the neurodiversity paradigm relied heavily on the ideas forwarded by social models of disability, and many proponents of neurodiversity theory remain focused on the social framework. (den Houting 2019, Pellicano and den Houting 2022). Nonetheless, there has been a push within the neurodiversity paradigm to embrace interactionist models, recognizing the effects biological factors may have on individual quality of life (Whelpley et al. 2023). For example, differences in sensory processing may lead some autistic people to struggle with naturally occurring sensory stimuli, a concern which cannot be explained or resolved through an appeal to sociopolitical factors. While this author recognizes the value of embracing an interactionist conception of the neurodiversity model, the primary focus of this thesis will be on the neurodiversity paradigm's recognition of how social factors contribute to autistic disablement. This focus on social factors is the main way in which the neurodiversity model differs from traditional biomedical models, and as such is the most relevant characteristic of neurodiversity theory to the discussion of the impacts of the current paradigm shift.

#### **1.3 Empirical shortcomings of Biomedical Models of Autism**

I argue that the current paradigm shift within the field of autism research is necessitated by shortcomings of the traditional biomedical paradigm along both ethical and empirical dimensions. Chapter two will consider the ethical failures of biomedical modelling in autism research. The current section will consider how traditional biomedical approaches have failed, on an empirical level, to meaningfully define autism and develop care approaches to address the needs of autistic individuals and communities. One aim of autism research, at a theoretical level, is to develop a model which explains a causal mechanism (or a set of causal mechanisms) and accounts for the various presentations of the condition. On a practical level, the goal of autism research is the development of effective tools which might allow practitioners to accurately identify autistic people. While identification of autistic individuals has the potential to be used for eugenic purposes, ideally it might instead be leveraged to offer meaningful support and ensure the individual well-being of those identified as autistic (Chown et al. 2023, Natri et al. 2023). I argue that the traditional biomedical approach has failed to achieve these goals. As of yet, there exists no empirically accurate definition of autism which accounts for all recognized aspects of autistic experiences (Fletcher-Watson and Happe 2019). This failure of the biomedical paradigm is further exemplified by an overwhelming lack of effective tools and approaches for diagnosis and support.

Since the first conception of autism as a diagnosis, numerous attempts have been made to identify a specific causal mechanism which might explain the differences in development between autistic people and their allistic counterparts. Early theorizing suggested that autism may develop at some point after birth. For example, the 'refrigerator mother' theory proposed that autism developed as a result of poor parenting. More recently, claims that childhood vaccines led to otherwise 'normal' children developing autism were widely circulated in popular discourse. However, both these claims have now been thoroughly debunked (Fletcher-Watson and Happe 2019). Thanks in large part to groundbreaking twin studies which show much higher correlations of autism in pairs of monozygotic twins as compared to dizygotic twins (Tick et al 2016), it is now understood that genetic factors play a significant role in determining whether a given person will be autistic. This suggests that autism is not an acquired condition, but rather the result of innate biological predispositions. As a result of this new understanding, there has been a significant uptick in biomedical research which seeks to identify specific biomarkers associated with autism, although as of yet no such biomarkers have been found. (See for example McPartland et al 2020, Webb et al 2023).

There are a number of potential benefits to genetic research and the knowledge it may produce. For example, it may help in developing more efficient or precise methods of diagnosis, as well as helping to identify and understand different sub-types of autism and their prevalence (Loth et al. 2016). There is also the potential that, with a better understanding of certain genetic factors, it may be possible to develop biomedical interventions which could improve the wellbeing of autistic people, either by addressing co-occurring medical concerns which are often associated with autism, such as epilepsy, or by mitigating some of the more distressing symptoms sometimes associated with autism directly, such as intense sensory sensitivities. However, there are also significant limitations to these approaches. Firstly, genetic research can be difficult to conduct because large sample sizes are crucial to developing meaningful insights, meaning large pools of genetic data must be developed through collaboration with autistic communities (Muhle et al. 2018). This is further complicated by a history of eugenics associated with autism research, which has led to a widespread sense of mistrust which makes many potential autistic participants reticent to engage with or support such projects.<sup>1</sup> Secondly, this kind of genetic research is still relatively new, and these studies often take years to complete. Even if researchers are able to identify genetic biomarkers, at a practical level, it is still unclear how genetic research might actually be leveraged to develop biomedical treatments (Muhle et al 2018). This means that any meaningful practical benefits from this type of research are unlikely to materialize for years, or even decades.

Identification of genetic biomarkers for autism would also only offer one level of explanation for autism. While biomarkers may help identify why certain people are autistic while others are not, they would not provide a meaningful explanation as to why and how the various traits associated with autism manifest in the way they do. For this reason, efforts continue to develop a cognitive model which might account for both behavioural and biological traits observed in the autistic population (Fletcher-Watson and Happe 2019). Autism is generally characterized by differences in three main areas: social interaction, communication, and restricted or repetitive patterns of behaviour. These differences have traditionally been understood in terms of a disadvantageous deviation from an idealized neurotypical norm, being described in the International Statistical Classification of Diseases and Related Health Problems (ICD) as "abnormal functioning" (WHO 1994, F84.0) and in the American Psychiatric Association's Diagnostic and Statistical Manual (DSM-V) as "deficits" which lead to "clinically

<sup>&</sup>lt;sup>1</sup> For one example of the autistic community's pushback against ethically dubious genetic research, see the response to the Spectrum10k study (Aucademy 2021). See also Natri et al. 2023 for an overview of ethical concerns with genomic autism research.

significant impairment" (American Psychiatric Association 2022, F84.0). Although it has been recognized that many autistic people demonstrate a high degree of proficiency in certain areas, these strengths have historically been referred to as "islets of ability" (Shah and Frith 1983, p.614), suggesting that they entail specific, relatively minor exceptions to an otherwise blanket deficiency. This conceptualization of autism as being rooted in some form of deficiency has led to decades of research attempting to identify a particular, over-arching deficit which might serve as an explanatory model which can account for the various differences in social interaction, communication, and behaviour which are associated with autism. Proposed models have included deficits in theory of mind (the inability to interpret complex mental states in oneself and others), weak central coherence (an inability to synthesize small details into a cohesive whole, or, in other words, to see the 'big picture'), and impaired executive function (the constellation of capacities necessary to decide on and execute a series of actions necessary to accomplish a particular goal)(Fletcher-Watson and Happe, 2019). While each of these models offer a reasonable explanation for at least some aspects of autistic behaviour, none is able to fully account for all recognized aspects of the autistic experience. Notably, none of these proposed explanatory models account for autistic strengths in a number of areas, including visuo-spatial performance (Muth et al 2014, Samson et al 2012) and auditory capacity (Remington and Fairnie 2017).

The biomedical paradigm's failure to develop a meaningful and empirically accurate model of autism is further evidenced by the current lack of effective diagnostic resources. At present, the most reliable available method of identifying and diagnosing autism is through behavioural factors. Generally, the diagnostic process depends on a neuropsychologist or a similar medical practitioner analyzing an individual's behaviour as revealed through both direct observation, formal testing, and consultation with both the subject themselves and, in many cases, their families. The diagnostician will then compare the subject's behaviour profile to a standardized set of diagnostic criteria in order to identify the presence of common autistic traits. The most widely used diagnostic reference is the American Psychiatric Association's Diagnostic and Statistical Manual (or 'DSM', American Psychiatric Association 2022), which offers a system of five diagnostic criteria for the identification of 'Autism Spectrum Disorder' or ASD, where the first two identify categories of behavioural traits commonly associated with autism (deficits in social communication and restricted or repetitive patterns of behaviour) and the latter three specify certain conditions which must be met for someone exhibiting those traits to be clinically diagnosed with autism (traits must be present in early developmental stages, must cause clinically significant impairment, and must not be better explained by intellectual disability or global developmental delay). These diagnostic criteria reflect the biomedical model's conception of disability as disorder. There is a presupposition of internal deficiency reflected by the focus on individual deficits and impairment, with little consideration of how external socioenvironmental factors may contribute to the difficulties faced by autistic people.

There are inherent limitations when trying to define autism through a behavioural checklist, especially given what is known about autistic masking (that is, the ability to camouflage autistic behavioural traits through a variety of learned strategies), but here I will focus more specifically on how the DSM criteria in particular fail to account for certain crucial aspects of autistic experiences, and thus fails empirically as a practical tool for identifying autism within a wider population. I raise two main concerns: firstly, the DSM diagnostic criteria

presuppose a poor quality of life as being an inherent feature of autism. Secondly, the DSM diagnostic criteria lack the degree of specificity required to effectively identify autistic behaviour in a meaningfully objective way.

The DSM diagnostic criteria explicitly frame the difficulties autistic people experience as being the direct result of possessing an autistic mind through criteria D, which requires "clinically significant impairment" to "important areas of current functioning" (American Psychiatric Association 2022, F84.0) for a diagnosis to be made. Under this conception of autism, the idea of a happy and thriving autistic person is entirely excluded. Several moral concerns arise when considering the ramifications of this framing on the lives of autistic people, and these will be discussed in chapter 2. However, I argue that this 'disorder' model of autism also has significant empirical limitations, because it fails to account for the possibility of autistic thriving, despite the fact that some autistic people do, in fact, live happy and fulfilled lives. Under a strict interpretation of this diagnostic criterion, an autistic person who has found a strong, healthy community and support system (likely comprised at least in part of other autistic individuals, with whom they are more likely to share a natural sense of rapport) and has developed coping strategies which help to accommodate their unique needs and difficulties in order to achieve personal goals, would no longer qualify for a diagnosis of ASD.<sup>2</sup> Given that autism is known to be a lifelong condition, that a person who is born autistic cannot be 'cured' or

<sup>&</sup>lt;sup>2</sup> While this may not be a concern which manifests in practice, the theoretical possibility remains problematic.

become allistic later in life, this represents an empirical inconsistency between what is known to be true about autism and the way it is defined by the DSM.<sup>3</sup>

A second concern with the DSM diagnostic criteria is that, although they purport to be an objective tool, they lack the specificity required to be effectively applied without over-reliance on preconceived cultural assumptions around normalcy. While it is important to keep diagnostic criteria relatively broad in order to account for the wide diversity of autistic experiences, those criteria must also be specific enough to pick out behaviours which one might not otherwise associate with autism. Phrases such as "abnormal social approach" and "abnormalities in eye contact and body language" (American Psychiatric Association 2022, F84.0) give little indication of the specific ways in which autistic communication and social expression differ from those of their allistic peers at a more fundamental level. Instead, diagnosticians are forced to rely on their own culturally influenced perceptions of what it is to behave 'normally' in order to identify certain behaviours as 'abnormal', and risk overlooking less stereotypical forms of autistic expression. The same can be argued about the categorization of "restrictive and repetitive patterns of behaviour." Many neurotypical people perform certain repetitive or "stereotyped" patterns of behaviour which are considered entirely normal, even if somewhat idiosyncratic, such as raising a hand to wave or giving a quick nod when entering a room or encountering a friendly acquaintance, or frequently inserting certain words or phrases in one's speech. What the diagnostic criteria are trying to draw out here is a particular and uniquely autistic way of expressing oneself and relying on routine and sameness for emotional regulation, but without a

<sup>&</sup>lt;sup>3</sup> The framing of autism as a disorder which directly hinders individual quality of life is consistent with the DSM's overall approach to defining psychiatric conditions. For the purposes of the current argument, this author will remain neutral as to whether this constitutes an inherent problem with the DSM's approach as a whole, or whether autism is uniquely ill-suited to inclusion in this resource.

clear communication of this, diagnosticians are likely to be biased towards recognizing only those autistic expressions which conform to pre-conceiver cultural stereotypes of autistic behaviour.

This is particularly important in light of the way stereotypes about autism intersect with culturally situated stereotypes relating to other identity markers such as gender and race. For example, a young boy's fascination with trains may be more likely to be read as a manifestation of autistic traits than a young girl's fascination with her favourite pop band, although both may be examples of autistic special interests. This discrepancy is (at least partly) due to the fact that early research on autism focused disproportionately on white boys, meaning that medical understandings of autism are often framed around certain presentations which manifest most often in that limited population. A cyclical problem has thus arisen: a lack of diversity in historic autism research has lead to the proliferation of oversimplified and potentially inaccurate stereotypes of autistic behaviour, which in turn impacts the way diagnosticians interpret the diagnostic criteria. As a result, those who do not conform to that cultural stereotype are far less likely to be recognized and diagnosed, a problem which has already manifested in disproportionally high rates of misdiagnosis or late diagnosis among women, people of colour, and members of other marginalized communities. (Bargelia et al 2016, Diemer at al 2022). Without access to proper diagnosis, these communities remain underrepresented in research, leading to further bias. This shows that current diagnostic approaches are untenable if the goal is to gather knowledge about and improve material circumstances for the autistic community as a whole. The neurodiversity paradigm offers a way forward by reframing medical understandings

of what it means to be autistic, focusing on a holistic picture of the unique ways autistic people experience and interact with the world around them as compared to their allistic peers.

In addition to the limitations of available diagnostic tools, the failures of the biomedical paradigm are also reflected in the lack of effective methods for treatment and support which offer meaningful benefit to autistic people. With few alternatives available, behavioural methods of 'autism treatment' have become ubiquitous, the most notable (and controversial) of which is Applied Behavioural Analysis or ABA (Devita-Raeburn 2016). This approach utilizes a system of rewards (ranging from simple verbal praise to being given food, water, or access to comfort objects which would otherwise be withheld) and, in some cases, punishment, in order to encourage behaviours which are seen as desirable and extinguish those deemed undesirable (Wilkenfeld and McCarthy 2020). The earliest form of ABA was developed by Ole Ivar Lovaas beginning in the 1960s. Lovaas explicitly aimed to make autistic children "indistinguishable from their normal friends" (Lovaas 1987, p.8) by extinguishing visibly autistic behaviours and encouraging desired behaviours such as verbal communication, interaction with peers, and "appropriate" expressions of emotion. Although many of the most extreme aspects of Lovaas's approach, such as the use of physical punishment to discourage undesirable behaviour, have been largely (though perhaps not universally) rejected by the psychiatric community, modern-day ABA practices still rely on the basic principle of operant conditioning to alter individual behaviour, with success or failure measured exclusively through the observable behaviour of the individual as compared to specific list of behavioural targets (Wilkenfeld and McCarthy 2020).

The focus of ABA therapy is the alteration of behaviour, ostensibly with the goal of improving autistic well-being by helping patients assimilate more effectively into their

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neurotypical environments. This is in direct alignment with the biomedical paradigm's preoccupation with individualistic medical interventions. Working off the assumption that the difficulties autistic people face are a direct result of internal disorder resulting from innate biological factors, behavioural methods of treatment focus on attempting to 'fix' the autistic person by reducing stereotypically autistic behaviours (Wilkenfeld and McCarthy 2020).

The problem with this approach is that it can only be said to be effective in an extremely narrow sense - although it has been shown that ABA is effective in changing its subject's behaviour (Makrygianni 2018), it is not clear that these behavioural changes have a meaningful positive impact on the subject's well-being. In fact, there is reason to believe that the practice may actually have detrimental effects, based both on anecdotal accounts shared by many autistic advocates with firsthand experience (e.g. Sequenzia 2016) and recent academic research. One 2018 study showed that autistic individuals who experienced ABA were eighty-six percent more likely to develop post-traumatic stress disorder than those not exposed (Kupferstein 2018). This aligns with evidence that shows camouflaging autistic traits (as one is arguably taught to do through ABA) is associated with increased suicidality (Cassidy et al. 2023).

As will be argued in chapter 2, ABA and similar approaches fail to offer meaningful benefit to autistic patients because they rely on a superficial understanding of what it means to be autistic, overlooking the unique way autistic people experience and make sense of the world around them and how this might impact behaviour. By focusing purely on behaviour itself without investigating the underlying motivation for those behaviours, behaviourist approaches overlook crucial aspects of the autistic experience which are relevant to ensuring individual wellbeing. These approaches rely on the false assumption, rooted in the medical paradigm from which they have emerged, that the hardships experienced by autistic people are the result of an individual's inability to conform to societal expectations barring them from participation in 'normal' society, and that these hardships can be overcome or alleviated by teaching autistic individuals to perform in socially expected ways.

The failure of behaviourist interventions to meaningfully improve autistic patient's subjective well-being is particularly concerning in light of their ubiquity and the relative lack of alternative therapeutic approaches accessible to the vast majority of autistic individuals and their families (Devita-Raeburn 2016). Even allowing for the fact that behavioural interventions may be subjectively helpful in certain circumstances, the fact that few families have access to any alternative therapies to support their autistic children is concerning. Moreover, there is a notable lack of support available for autistic adults (Camm-Crosbie et al. 2019). The majority of available interventions focusing on the mitigation of specific 'deficits' in social interaction, with little available evidence that such interventions improve individual well-being and mental health (Lorenc et al 2017).

There is a clear need to develop therapeutic interventions which have a meaningful positive impact on the subjective quality of life of autistic patients on a wider scale, and in order to do so researchers must move beyond a behaviourist paradigm and embrace a more holistic approach to understanding and addressing the unique needs of autistic populations. The neurodiversity paradigm promises such a way forward by recognizing how socio-environmental factors contribute to the difficulties experienced by autistic people. This allows for the development of new approaches to support autistic well-being, including interventions aimed at reducing external barriers which have a negative impact on autistic well-being. For example,

peer-education programs designed to reduce stigma towards autistic community members have shown some promise, although further research is required to ensure efficacy (Kim et al 2023).

#### **1.4 Choosing a Paradigm**

One way of understanding the current changes in approaches to autism research is in terms of the kind of scientific paradigm shift described by Thomas Kuhn (Pellicano and den Houting 2022). Thomas Kuhn presented the history of science in terms of a cyclical process of scientific revolution, allowing for the creation of paradigms which act as a universal foundation for group inquiry. A paradigm offers a basic set of assumptions, principles, and priorities which unifies a scientific community within a shared context and allows for intellectual progress on a communal scale. When the currently accepted paradigm is unable to explain certain relevant observable facts, science enters a period of crisis until a new paradigm arises to take the place of the old. Paradigm shifts are therefore a gradual process through which more and more members of the scientific community embrace a new paradigm, leading to shifting communal priorities and approaches. While some will always cling to the old paradigm, their work will naturally become obsolete insofar as it loses its relevance to contemporary scientific debate. This is not to say, however, that all knowledge developed under previous paradigms is discarded. Certain ideas and approaches may remain relevant across a paradigm shift, and even where ideas and approaches may be rejected in the context of the new paradigm, the new paradigm is shaped by the way the previous paradigm failed, and so each iteration contributes to the production of knowledge in a cumulative way. (Kuhn 1962)

For Kuhn, however, paradigm shifts (and, resultantly, widespread approaches to scientific modelling) are primarily associated with empirical factors- that is, shifts come about because existing scientific models do not align with observable attributes of the entities and processes being studied (Kuhn 1962). In contrast to this view, I argue that, in the context of human sciences such as psychiatry, sociopolitical and relational factors are often also relevant to paradigm choice, for both methodological and ethical reasons. If the goal of scientific modelling is to accurately model and classify particular aspects of human behaviour and cognition, then it is crucial to recognize and account for how sociopolitical environments affect the behavioural expressions of the subjects being observed. Moreover, the impact scientific models have on the humans whom those models seek to classify must also be considered. This is firstly because medical labels operate as interactive kinds, in the sense that those who are classified by these labels respond to that labeling, as do those around them (Hacking 1999). The category of interactive kinds can be understood as a subset of 'human kinds', because the responsiveness of those being labelled is a uniquely human phenomenon. When humans are labeled as being, for example, autistic, this influences their own self-understanding, the ways in which they act, and the ways in which others perceive them and act towards them.<sup>4</sup> The interactive nature of human kinds leads to a looping effect, wherein the changes caused by this response to the classification in turn changes the way that classification is understood and defined. As Hacking explains, "New

<sup>&</sup>lt;sup>4</sup> Hacking considers autism to be "a human kind that is inaccessible to people of that kind" (Hacking 1996 p. 375), arguing that although autistic people are unresponsive to being labelled, others are responsive to the labelling of autistic people, affecting the way they perceive of and act towards them. The idea that autistic people are unresponsive to labelling is based upon the assumption that autistic people are fundamentally incapable of the kind of social understanding necessary for a socially-constructed label to impact self-understanding. I object to this stance and argue that autistic people do, in fact, understand when they are labelled as autistic and that this has an impact on their self-understanding. This position is supported by research which shows that autistic people's attitudes towards autism have a significant impact on their self-esteem (Ferenc et al. 2023)

sorting and theorizing induces changes in self-conception and in behaviour of the people classified. Those changes demand revisions of the classification and theories, the causal connections, and the expectations. Kinds are modified, revised classifications are formed, and the classified change again, loop upon loop." (1996, p.370)

The looping effect arises because, as classifications of human kinds are constructed and become socially entrenched, moral norms become attached to them. As a result, Hacking argues, human kinds "are kinds that people may want to be or not to be, not in order to attain some end but because the human kinds have intrinsic moral value." (1996, p.367) . For example, the construction of the label 'Autism Spectrum Disorder' is influenced by cultural norms which understand difference as disorder, and position deviation from 'the normal' as being inherently problematic. Having been classified as 'disordered', all aspects of autistic expression come to be understood through a lens of deficiency. These deficit-focused understandings of autistic expression become self-reinforcing, with autism research focusing almost exclusively on the deficiencies perceived as being characteristic of autistic cognition. In turn, the classification of autism as a disorder affects both autistic people's self-understanding and others' perceptions of autistic people.

Recognizing how psychiatric labels operate as interactive kinds should prompt the academic community to rethink its approaches to modelling those conditions. If the goal of psychiatric modelling is to create a classification which accurately characterizes and explains the manifestation of psychiatric conditions, it is crucial to consider how the creation of that classification impacts the manifestation of those conditions. Thus, researchers should account for the impact of sociopolitical and relational factors in order to properly evaluate the efficacy of

scientific models in facilitating the understanding of biomedical and psychiatric conditions. The way humans relate to each other, themselves, and the world around them influences the academic community's choice of scientific models, because these factors directly affect the validity of those models. The looping effect should be accounted for within the basic set of assumptions, principles, and priorities which guide scientific inquiry.

From an ethical perspective, it is also important to recognize the impact the choice of scientific models may have on the lived realities of those who will be classified by the labels those models create. This is just one of many reasons why approaches within biomedical science are typically constrained by commonly accepted principles of biomedical ethics. Scientific approaches which pose a significant risk of harm ought to be avoided regardless of potential empirical value. For example, although randomized placebo-controlled trials are considered to be the most rigorous available method for testing the effectiveness of therapeutic interventions, their use is constrained by the ethical imperative to protect the human subjects participating in such trials. (Millum and Grady 2013). In cases where foregoing or delaying treatment for the condition under study can cause significant harm, assigning human subjects a placebo would not be ethically permissible. I argue that bioethical concerns are therefore relevant to paradigm choice in biomedical sciences because they operate as guiding principles which constrain the techniques and avenues of investigation available to us. The methodological merits of scientific approaches ought to be weighed against their ethical shortcomings, and research priorities should be shaped in accordance with the ethical framework established by the scientific community.

#### 1.5 Defining Neurodiversity: Implications for Research and Care

The neurodiversity paradigm offers a unifying set of basic assumptions, principles, and priorities which guide research approaches across a scientific community. The current section will outline some of the foundational assumptions which underpin the neurodiversity paradigm and consider the practical implications of adopting a neurodiversity framework in autism research. Nick Walker offers a helpful glossary of basic terms which will help anchor this discussion. The term 'neurodiversity' itself refers simply to the biological fact that there exists a diversity of human minds and a corresponding variation of neurological function. Although the neurodiversity movement was born out of autistic advocacy, the concept of neurodiversity encapsulates all human minds, including both those considered 'neurotypical' (that is, conforming to cultural and social measures of 'normality') and allistic 'neurodivergent' people whose mental and neurological function differ in a variety of ways from that of those considered to be neurotypical.<sup>5</sup> The 'neurodiversity movement' is a social justice movement which strives to promote the full societal inclusion and equality of all neurodivergent individuals. The philosophical foundation for this movement is provided by the 'neurodiversity paradigm', a perspective which views neurodiversity as "a natural and valuable part of human diversity," (Walker 2014, p.1) rejects the culturally constructed belief that there is one ideal of neurological and mental function, and recognizes that "the social dynamics that manifest in regard to neurodiversity are similar to the social dynamics that manifest in regard to other forms of human

<sup>&</sup>lt;sup>5</sup> While the neurodiversity movement aims to reframe mainstream understandings of neurodivergence on a broad scale, this thesis is focused on the impacts of the neurodiversity paradigm within the specific context of autism research and care.

diversity," (Walker 2014, p.1) both in terms of the potential for power inequalities to arise and of the potential for diversity to have a meaningful positive impact on society when properly embraced. (Walker 2014)

The adoption of the neurodiversity paradigm has several implications for the direction of autism research and care approaches. The neurodiversity paradigm is not inherently incompatible with medical or psychological interventions, provided that the aims of those interventions prioritize the subjective well-being of the patient while at the same time respecting and fostering the patient's individual autonomy (den Houting 2019). In order to properly achieve these goals, attention must be paid to the specific needs of each potential patient. The appropriateness of a given intervention is highly context-dependant, as each individual will have not only their own unique set of skills, abilities, challenges, and limitations, they will also each have their own individual interests and desires, all of which will influence which kinds of support and intervention will have a meaningful positive impact on that individual's life (Nicolaidis 2012).

Neurodiversity-affirming practices will also attend to the issue of reciprocity. Proponents of neurodiversity theory believe that medical interventions for autistic individuals should never be tools in a project of normalization (den Houting 2019). Interventions which seek to make the patient "less autistic" are considered both ineffective and morally unacceptable because they fail to recognize the fundamental differences in autistic brain function which make autistic people who they are (Wilkenfeld and McCarthy 2020). This is perhaps best understood in the context of Damian Milton's double empathy problem hypothesis, which re-contextualizes the social disconnect which so often occurs when autistic and allistic people interact. The difficulties associated with this kind of cross-neurotype communication have historically been attributed to a

shortcoming on the part of the autistic person which renders them unable to properly read and respond to 'normal' social cues, leading to the proliferation of 'autism treatments' which aim to modify the autistic person's perceptions and behaviours in order to better 'fit in' in mainstream society. However, Milton reframes the issue in terms of a mutual disjuncture in social positionality which renders both parties incapable of intuitively recognizing the other's social cues. (Milton 2012) This perspective is consistent with recent empirical studies which show that autistic peer-to-peer information transfer is highly effective (Crompton, Ropar, et al 2020) and that neurotype-matching plays a more significant role in subjective measures of interpersonal rapport than whether one or more participants engaged in a social interaction is autistic. (Crompton, Sharp, et al 2020)

Recognizing the importance of reciprocity should influence which medical interventions and social practices are deemed acceptable, but it also ought to have broader implications for the way medical institutions interact with autistic people by prompting researchers to consider the experiential expertise of autistic individuals in understanding autistic minds. Throughout the history of autism research, it has often been the case that allistic researchers treat autistic people as objects of study to be observed and reported on, rather than participants and collaborators in the production of knowledge. Not only does this prompt certain moral concerns (which will be considered in more detail in chapter 2) it also leads to a significant risk of empirical failure when those allistic researchers do not properly account for their own limitations in intuitively understanding autistic behaviour and social expression. From the allistic perspective, many autistic behaviours will be perceived as strange or nonsensical, despite many such behaviours being rationally meaningful to the autistic person performing them. One example of this is
autistic self-stimulatory behaviour, often referred to as 'stimming'. Stimming, captured in diagnostic criteria under the category of 'restrictive and repetitive motion', has often been considered a disruptive and maladaptive behaviour which a variety of 'therapeutic' approaches have aimed to extinguish. However, the perspective of autistic adults reveals stimming to be an important method of self-regulation which allows autistic people to communicate and soothe intense emotions. (Kapp et al 2019) This reveals a need to center autistic perspectives in research, both through methods of participatory research which encourage input from autistic professionals to help guide and design studies. These are just a few of the ways the context of the neurodiversity paradigm might affect approaches to autism research and care. The implications of adopting a neurodiversity framework on future approaches to research and treatment will be discussed in more detail in chapter 3.

# Conclusion

This chapter has aimed to offer a brief introduction to the paradigm shift which is currently unfolding in the field of autism research. The field is moving away from the traditional biomedical paradigm, which conceives of autism as the exclusive result of some internal deficiency, and towards the neurodiversity paradigm, which frames autism in terms of a natural variation in human cognitive function. Section one offered a brief history of autism research and the rise of the neurodiversity movement. Section two connected the rise of the neurodiversity paradigm to wider changes in mainstream approaches to disability modelling. Understandings of disability are moving away from biomedical models and towards social and interactionist models of disability, recognizing the impact of disabling socio-political and environmental factors. Section three outlined the empirical failures of traditional biomedical approaches which have necessitated the current paradigm shift. It was argued that the biomedical paradigm has failed to develop an accurate model of autism which accounts for all recognized aspects of autistic experiences. As a result, available diagnostic tools and care approaches which support the well-being of autistic people are severely limited. Section four introduced Thomas Kuhn's theory of paradigm shifts as one framework through which to understand the current changes in the field of autism research. However, it was argued that, for both methodological and ethical reasons, sociopolitical and relational factors, including the ways people respond to being classified by medical labels, are relevant to decisions concerning acceptable approaches (and hence to paradigm choice) in human sciences. Finally, section five expanded on the concept of neurodiversity, outlining the philosophical foundations of the neurodiversity paradigm and considering some of the implications of the shift towards this paradigm for autism research and care.

The intention of this thesis is not to argue that the biomedical paradigm has failed wholesale at offering insights into autistic modes of cognition. Yet, in many respects, biomedical approaches have routinely failed in offering the tools and approaches necessary to fully understand and support autistic people. Accordingly, it may not be necessary to reject all facets of biomedically-focused research. In some cases, the neurodiversity paradigm offers an opportunity to enhance, rather than simply replace, existing approaches. However, it is crucial to recognize the shortcomings of the biomedical paradigm in order to improve future research. The adoption of the neurodiversity paradigm allows for the introduction of novel approaches which may help in developing more holistic and actionable models of autism as a condition.

In addition to these methodological benefits, there are compelling ethical reasons for embracing the neurodiversity paradigm. Chapters two and three will consider in more detail the ethical ramifications of the shift towards the neurodiversity theory, with a particular focus on the bioethical principle of justice. It will be argued that traditional biomedical approaches has contributed significantly to both distributive and relational injustices faced by autistic people, and that the neurodiversity paradigm offers a way forward in rectifying those injustices.

# Chapter 2: Bioethical Concerns Arising in the Context of the Biomedical Paradigm

Chapter 1 introduced the ongoing shift towards the neurodiversity paradigm in the field of autism science. This included an overview of the empirical and methodological shortcomings of the biomedical paradigm which contributed to the need for this paradigm shift. It was also argued that, in the field of biomedical science, sociopolitical and relational factors are relevant to paradigm choice for both methodological and ethical reasons. The current chapter will expand on the ethical concerns which have arisen from the medicalization of diagnoses like autism, with a primary focus on the bioethical principle of justice. It will be argued that traditional biomedical approaches in autism research have led to persistent distributional and relational inequalities for autistic individuals and communities. Such approaches have led to both empirical misunderstandings and stigmatizing attitudes pervading academic literature about autism, which in turn reinforces unjust social hierarchies and has a negative impact on autistic people's overall quality of life.

Section one will introduce the bioethical principle of justice. Many traditional bioethical approaches have conceived of justice as an implicitly distributive principle, concerned with the fair distribution of certain benefits and burdens.<sup>6</sup> I argue, however, that this understanding of justice is insufficient and must be supplemented to account for concerns of relational justice. A bioethical commitment to justice should extend to ensuring social relations of equality and respect. Section two will consider the distributive injustices which have arisen as a result of

<sup>&</sup>lt;sup>6</sup> see for example Beauchamp and Childress 2013, Santos 2020

traditional biomedical approaches to autism research. It will show that empirical deficiencies in medical understandings of autism lead to a lower standard of care for autistic patients as compared to their allistic counterparts. It will also argue that an unjust distribution of resources available for medical research have led to the needs of autistic populations being routinely overlooked. Section three will outline two manifestations of relational inequality which autistic people (and disabled people more generally) routinely face: ableist social hierarchies characterized by widespread stigmatization and disrespect towards disabled people, and systematic epistemic injustices which prevent fair epistemic interactions. Section four will consider relational injustices which arise in the institutional context as a result of the way research and medical institutions define autism and interact with autistic individuals and communities. It will be argued that the prevalence of deficit-focused definitions of autism, combined with the routine exclusion of autistic voices in the field of autism research, contribute to both routine epistemic injustices and unjust hierarchies of esteem, power, and standing. Finally, section five will consider relational injustices which arise in interpersonal contexts as a result of cultural narratives informed by medical definitions. It will be argued that the deficitfocused models of autism developed within the context of traditional biomedical research approaches reinforce stigmatizing attitudes which position autistic people as fundamentally inferior to their allistic counterparts. These disrespectful attitudes, further entrenched through negative representations of autistic people in popular media, affect how allistic lay people perceive of and interact with their autistic peers. As a result, autistic people are routinely subject to ableist hierarchies and epistemic injustices in their everyday interactions with allistic members of their communities.

## 2.1 Bioethical Justice: Distributive and Relational Conceptions of Equality

Concerns of justice and equality are central to many bioethical debates, but the precise meaning of these terms remains contested. Beauchamp and Childress, in delineating their highly influential principalist framework, define justice most broadly as "Fair, equitable, appropriate treatment in light of what is due or owed to a person." (Beauchamp and Childress 2013, p.226) They frame justice as an implicitly distributive concept, considering justice to demand the fair distribution of certain benefits or burdens. Within this framework, disagreements about the requirements of justice generally revolve around the kinds of benefits and burdens justice is concerned with and the metrics by which the appropriate distribution of those benefits and burdens might be established. For example, some prioritize the fair distribution of certain material goods, while others are more concerned with the distribution of more abstract benefits such as opportunity or welfare (Beauchamp and Childress 2013). While principalism does not reflect the only framework through which bioethical concerns might be understood, its influence on mainstream bioethical debates remains significant. Moreover, even non-principalist bioethical frameworks tend to focus on distributive concerns, including the fair distribution of benefits and burdens and the assurance of individual rights and freedoms (Santos 2020) Such distributive conceptions of equality offer an important perspective, especially in the context of care rationing and triage, where the equal distribution of scarce resources is of utmost importance. However, distributive frameworks do not reflect the only way in which the concept of justice can be understood. There is a growing push in the field of bioethics to embrace a relational conception of equality (Kelleher 2016). In accordance with this position, I argue that current mainstream

definitions of bioethical justice are insufficient insofar as they account for only distributive concerns. Fair and equitable treatment requires not only the appropriate distribution of key benefits and burdens, but also that all citizens treat each other as equals in a fundamental sense. Therefore, such distributive conceptions of bioethical justice should be supplemented with a principle of relational justice. Relational egalitarianism provides a helpful framework to ground this principle.

In contrast to distributive frameworks of justice, relational egalitarianism focuses on the importance of maintaining relations of equality among citizens. For relational equality to be achieved, it is not enough to offer the same resources or opportunities to all. There are multiple ways in which relational equality can be defined, and there are disagreements within the field over a number of aspects of that definition. What is of key importance to all relational egalitarians, however, is that all individuals regard each other as equals and interact in a manner which reflects this recognition respect. In order to achieve this goal, relational egalitarians generally seek to eliminate unjust social hierarchies, which can take the form of hierarchies of standing, of power, or esteem (Anderson 2016). In hierarchies of standing, one group's strong interests<sup>7</sup> are valued more highly than those of another group, and the subjugated group's legitimate claims are not treated as if they hold the same weight as those of the privileged group. In unjust hierarchies of esteem, one group is subjected to stigmatizing judgements and is not offered fair recognition for their achievements and abilities, while another group is held in high esteem regardless of merit. In hierarchies of power or authority, one group is afforded more

<sup>&</sup>lt;sup>7</sup> 'Interests' can be understood as referring generally to a person's needs, values, and preferences (Scheffler 2015, p.25). By 'strong interests' I refer to those interests which hold particular importance for an individual's well-being, such as the interests of survival and self-determination. Strong interests can be contrasted against, for example, aesthetic preferences, which might be considered interests in a broad sense but do not carry significant moral weight.

power by virtue of their superior social status. As a result, they are able to exercise arbitrary authority over the members of subjugated groups, thereby engaging in a relationship of domination (Anderson 2016). Although some hierarchical relationships are unavoidable and can exist without threatening relational equality (for example, it is reasonable to esteem one person more highly than another on the basis of their actions and accomplishments) hierarchies are problematic when they are the result of unfairly stigmatizing judgements based on group identity and when they become deeply entrenched in a way which negatively impacts the members of the subjugated group. The three forms of hierarchy often coincide, as privilege in one domain often leads to the affordance of privilege elsewhere, but it is possible for one person or group to be subjected to only one or two of the three. For example, a person might be afforded a high level of esteem as a result of their possession of certain abilities while simultaneously being subject to unjust hierarchies of standing resulting in their resulting in their occupying a position of inferior moral standing. This is exemplified by the way so-called 'autistic savants' who achieve a high degree of proficiency in particular societally valued skills are esteemed highly for those abilities while simultaneously having their fundamental value as humans questioned or dismissed (note that the trope of the autistic savant and its implications for relational equality will be considered in more detail in section 2.5).

Relational egalitarians are primarily concerned about relations between individuals, but also of concern are the ethical implications of institutional or state action insofar as that action supports or threatens the goals of relational equality. Of concern is not only the practical outcomes of institutional actions and policies, but also an expressive dimension of the impact of those actions. That is to say that when an institution's policy or action expresses certain negative

attitudes towards a subjugated group, whether or not that group's material needs are being met, an injustice has been committed. For example, Anderson (1999) argues that policies of racial segregation in educational settings would be morally wrong even if they did not have a measurable negative impact on the black students affected by those policies. In her words, "such action is wrong on account of the principles of contempt or inferiority that it expresses, whether or not it has a negative impact on others' welfare" (p.1). The same argument can be made in reference to any institutional policy which expresses stigmatizing attitudes of contempt or inferiority towards a particular social group.

I take the view that a bioethical commitment to justice should extend beyond the specific contexts of resource allocation and direct patient care - it should also be responsive to relational egalitarian concerns regarding how the actions and policies of healthcare institutions might contribute to the marginalization of certain groups in society more broadly. The current chapter aims to show that autistic people, both historically and currently, are routinely subject to both distributive and relational inequalities. I argue that biomedical definitions of autism, which are empirically deficient and serve to reinforce stigmatizing attitudes about autistic people, have contributed both directly and indirectly to those injustices.

#### **2.2 Distributive Injustices**

Autistic people in our society are subject to a multitude of distributive injustices. On average, autistic people face lower rates of employment (Black et al. 2019), higher rates of poverty (Cai et al. 2022), and worse physical and mental health outcomes than their allistic counterparts (Croen et al. 2015; Howlin and Magiati 2017, Cashin et al. 2018, Hirvikoski et al.

2016, Mason et al. 2019). Autistic people also face high rates of institutionalization (Hollins 2021), significant barriers to inclusion in mainstream education (Bailey and Baker 2020), and in some countries can be barred from immigration on the basis of their diagnosis (Ivaturi 2023). The arguments of the current section are focused primarily on distributive injustice within the specific contexts of medical research and care. Firstly, I argue an unfair distribution of resources in research means autistic needs are overlooked. Secondly, I argue that autistic people are subject to an unfair distribution of opportunity for welfare as compared to their allistic peers due to routinely experiencing a lower standard of medical care. One might argue that this failure of medical institutions to offer an appropriate standard of care to autistic patients results from insufficient understandings of autistic minds and bodies, the pervasive assumption that autism constitutes an inherent barrier to quality of life, and a focus on internal factors as the locus of autistic difficulties.

Research funding and the skilled labour required to conduct research are both limited resources, and as such decisions must be made by research institutions as to which projects are pursued. At present, resources for autism research are disproportionately allocated to hard science research focused on genetics and aetiology. Little funding is allocated to projects exploring immediate needs of the autistic population, despite community feedback indicating the importance of prioritizing applied research foci (Roche et al. 2020). Cervantes et al. (2021) found that aetiology represented the overriding research priority for US funding bodies from 2008-2018, while Warner et al. (2019) reported that 44% of UK autism research funding for the year of 2016 was allocated to animal research, indicating a focus on genetic factors.

The prevalence of research focused on basic science reflects the biomedical paradigm's focus on internal factors as the primary locus of difficulties for autistic people. However, it is still unclear how the results of genomic research might be practically leveraged to improve health outcomes for autistic patients (Muhle et al. 2018), suggesting a relatively low probability that basic science research focused aetiology and genetics will lead to timely, realworld benefit to autistic individuals and communities. Given this, it is important to consider whether it is morally justifiable to focus so many resources on such projects rather than investing in research which centers the daily lived reality of autistic people and seeks to address concerns raised by that population. Although there may be value in the scientific knowledge gained from such research, the potential benefit of this knowledge for supporting autistic people in their everyday lives is limited. This is especially concerning considering that such research often relies on the participation of autistic study participants. When autistic people are asked to contribute to research, whether actively or through the provision of access to their personal medical information, without promise of meaningful benefit, they are treated as mere tools of a scientific endeavour. After all, autistic people are asked to shoulder the burden of participation by allowing their bodies to be used as resources for study, while the priorities of the autistic community are routinely overlooked by institutions allocating funding for research. This constitutes a clear failure of distributive justice.

I argue that this unfair distribution of resources results in a lack of understanding of the needs of autistic people. In turn, this lack of understanding contributes to a second distributive concern: autistic people are often offered a lower standard of care from medical institutions than their allistic counterparts. This is evidenced by the significant barriers to access faced by autistic

people seeking medical care (Nicolaidis et al. 2015, Mason et al. 2019). This can be understood as a distributive concern in terms of opportunity of welfare, with autistic patients not being offered the support necessary to achieve an equivalent level of well-being to their allistic peers. Persistent difficulties in properly diagnosing and managing pain in autistic patients (Liu et al. 2020) offer one example of how insufficient understandings of autistic experiences prevent autistic patients from accessing effective care. Differences in how autistic people experience and react to pain have been speculated upon since the earliest study of autism as a condition, but the exact nature of those differences remains unclear. A significant portion of the limited research which has been done concerning autistic responses to pain has focused on relative sensitivity to pain, with researchers speculating since as early as 1952 that autistic people are hypo-sensitive to pain (Mahler 1952). The idea that autistic people are hypo-sensitive to pain has persisted, and "apparent indifference to pain" is still listed in the DSM as an example of "hyper- or hyporeactivity to sensory input." (American Psychiatric Association 2022, F84.0) Yet systematic reviews of the relevant literature from 2013 (Allely) and 2014 (Moore) failed to find sufficient evidence to suggest widespread insensitivity or hyposensitivity to pain among autistic populations. There has been comparatively little research done on whether there is a difference in kind, rather than merely a difference of degree, in the way autistic people and allistic people experience pain. However, recent brain imaging studies suggest that there may in fact be physiological differences in the way autistic brains respond to painful stimuli (Failla et al 2018), and a number of potential explanations for these differences have been raised, with some suggesting differences in certain sensory processing pathways (Green et al 2015, Yasuda et al 2016), while others propose that the difference may lie in the process of interception, wherein the

various aspects of sensory processing are integrated to become understandable to oneself. (Dubois et al 2016)

In addition to these differences in the physiological aspects of autistic pain, problems also arise when researchers and clinicians fail to account for differences in how autistic people express their internal experiences of pain to others. Given what is known about the differences in expression and communication more generally, it stands to reason that autistic people would also express their experiences of pain differently than their allistic counterparts. Yet, no existing tools for objective pain assessment have been proven to be effective for use with autistic patients over the age of four years. (Liu et al. 2020) This means that, with the exception of specific tools designed for use in paediatric contexts, there exists no reliable standardized method of assessing pain as it is generally experienced and communicated by autistic patients.

Pain is just one example of how differences in autistic experiences and expressions can lead to difficulties in recognizing and diagnosing medical conditions in autistic patients, and similar concerns arise in a number of other areas of medical practice. For example, in the context of psychiatric care, differences in emotional expression and high rates of alexithymia (characterized primarily by difficulty in identifying and describing internal feelings, Poquérusse et al 2018) in autistic populations are likely to lead to similar problems in the effective recognition and treatment of a number of psychiatric conditions. Thus, the unfair distribution of resources in autism research can directly contribute to autistic people experiencing a substandard level of medical care as compared to their allistic counterparts. If practitioners are not able to properly identify medical conditions, be they physiological or psychiatric, they will not be able to treat those conditions effectively and appropriately. As a result, autistic people are less likely

to be afforded access to appropriate and effective care, leading to greater and more sustained suffering overall. In this sense, autistic people are not offered equal opportunity to achieve a suitable level of welfare as are their allistic peers.

There is a corollary concern which arises when considering the compounded inequalities faced by autistic members of otherwise marginalized groups, including women and people of colour, as a result of significant disparities in rates of autism diagnosis. Even if the scientific community is able to develop tools and methods which allow practitioners to effectively recognize and diagnosis a variety of medical conditions within the autistic population, those tools can only be effectively implemented in cases where an individual patient has been correctly identified as autistic. This is of particular concern because the same groups of people who are least likely to have their autism recognized are also more often subject to more widespread healthcare inequalities, and those existing inequalities have in turn led to underrepresentation in research which exacerbates the problem of misdiagnosis within these populations (Diemer et al. 2022, George and Stokes 2018). For this reason, it is crucial that practitioners are able to recognize a wide range of autistic expressions and experiences, particularly as they relate to identity factors such as race and gender identity, in order to ensure that all autistic patients might be afforded the same opportunity for welfare as their allistic counterparts.

In addition to limited understandings of how particular medical conditions manifest and present in autistic populations, persistent misunderstandings about autistic quality of life and well-being hinder effective medical care, limiting opportunities to achieve welfare. Arguably, one of the primary goals of medical care is to address medical conditions in order to mitigate negative effects on a patient's well-being. As such, the relative success or failure of medical interventions for non-life-threatening conditions is often conceived of in terms of their impact on 'quality of life', the measurement of a person's overall level of satisfaction with their life, experiences, and environment. Quality of life is a complex concept, and there has been longstanding debate surrounding how it might effectively be measured (Hunt 1997). Although there are a number of objective, measurable factors which will have a significant impact on any person's quality of life (for example, one's access to basic survival needs), quality of life is a fundamentally subjective concept. Internal psychological factors can have a significant impact on individual well-being, and the conditions of positive well-being will vary from person to person.

I argue that misunderstandings about autistic well-being negatively impact the quality of care autistic people receive (thus, unjustly constraining autistic people's opportunities for welfare) in two main ways. On the one hand, it is assumed that autism itself constitutes an inherent barrier to quality of life and that the hardships associated with autism are the result of internal deficiency and a failure of normal cognition. The resulting belief that autistic thriving is impossible may be used to excuse a lesser overall standard of care, as it is assumed that a lower overall quality of life is the result of the internal disorder associated with autism, rather than the result of ineffective medical care. Secondly, this focus on internal deficiency leads to the proliferation of highly individualistic treatment approaches<sup>8</sup> which prioritize efforts to normalize the autistic person, with little consideration of how autistic well-being may differ from the

<sup>&</sup>lt;sup>8</sup> 'Individualistic' refers to the way in which these approaches aim primarily to effect change on the individual subject, with comparatively little consideration of how external factors may contribute to the difficulties experienced by autistic people. Such approaches are often not highly individualized in the sense of being tailored to the specific needs of a particular subject.

neurotypical norm, or how external socio-environmental factors might impact autistic quality of life.

Current understandings of autistic well-being are limited (Chown et al 2023), but there is reason to believe that, given the subjective nature of quality of life judgements and the recognized differences in autistic cognition, trends in the factors which influence individual wellbeing will differ between autistic and allistic populations. As Milton and Bracher (2013) argue, the exclusion of autistic voices in autism research means that current understandings of autistic well-being tend to be framed by third-person observers. Consequently, there is little consideration of how the overall wellbeing of many autistic people is impacted by their social environment and the limitation of opportunities to engage with ways of being which align with their natural dispositions. This significantly limits the potential applicability of such research in contributing to real-world improvements in the quality of life of autistic people. Current tools for assessing quality of life often reinforce normative ideals of what it means to live a good life and fail to account for characteristically autistic ways of engaging with the world. (Smith et al. 2019, McConachie et al. 2020, Lam et al. 2021). In one study, autistic participants reported that a positive autistic identity, other people's (mis)understandings of autism, sensory issues, and autistic people's contributions to society were all factors that significantly impacted their quality of life. None of these measures are captured by the World Health Organization's Quality of Life Questionnaire (WHOQOL-BREF, Skevington at al. 2004) or its accompanying disabilities module (Power and Green 2010), a set of tools which purports to offer a standardized assessment of individual quality of life (McConachie et al. 2020). Without a proper understanding of the unique factors which influence autistic quality of life, it will not be possible to design medical

interventions which offer meaningful benefit to autistic patients. Poor quality of life will continue to be seen as an inherent result of autistic condition, and approaches for care and support will continue to prioritize the normalization of autistic individuals, despite evidence that such approaches can in fact be detrimental to autistic peoples' mental health (see for example Kupferstein 2018). As a result, autistic people will continue to receive a lesser standard of medical care as compared to their allistic counterparts and will therefore not be afforded fair opportunity to achieve a meaningful level of personal well being.

To summarize, this section has argued that autistic people are subject to systemic distributive injustices in the contexts of medical research and care. This includes an unfair distribution of resources in autism research, with the priorities of the autistic community being routinely overlooked in favour of research focusing on basic science, genetics, and the aetiology of autism. Such projects offer little potential benefit in terms of improving the daily lives of autistic people, while placing a burden of contribution on autistic communities through their reliance on autistic study participants. This unfair distribution of resources contributes to a further distributive concern: autistic people are not afforded equal opportunity for welfare as a direct result of medical institutions' failure to offer autistic patients an equivalent standard of care as compared to their allistic counterparts. Lack of understanding of how autistic minds and bodies function hinders medical institutions' ability to appropriately diagnose and treat autistic patient's medical conditions, while a lack of understanding of autistic well-being means that medical interventions are not appropriately targeted to address the most pressing threats to autistic quality of life.

#### 2.3 Relational Injustice: Ableist Social Hierarchies and Epistemic Disablement

Section 2.2 gave an overview of some of the many distributional inequalities faced by autistic people in our society, arguing that traditional biomedical modelling in autism research has contributed significantly to those inequalities. However, as discussed in section 2.1, distributive equality is not the only perspective from which the principle of justice can be understood. As humans are fundamentally relational creatures, justice also requires relational equality. All people should be regarded with an equal level of respect, and that respect should be reflected in the attitudes expressed through the treatment of individuals by institutions and other members of society. Autistic people are routinely subject to relational inequalities in the form of unjust hierarchies of standing, power, and esteem, or so I now argue.

It should be noted that the distributive injustices outlined in the previous section also have implications for relational equality. There is often a complex interrelation between the two kinds of injustice. The way research and medical institutions define and respond to autism directly contributes to unjust hierarchies of power, standing, and esteem. For example, while autistic patients receiving a lesser standard of medical care as compared to their allistic counterparts is undoubtedly an issue of distributive justice, it can also be understood in the context of an unjust hierarchy of standing which positions autistic people's strong interests as less deserving of consideration than those of their allistic counterparts.

Sections 2.4 and 2.5 will outline relational inequalities faced by autistic people in institutional and interpersonal contexts, respectively. The current section will outline two manifestations of relational inequality which I argue are relevant in both contexts, those being

ableist social hierarchies and epistemic injustice. The two are intimately connected, as the disrespectful attitudes associated with ableist social hierarchies directly contribute to the identity prejudice (Fricker 2007, p.155) which in turn underpins the routine epistemic injustices experienced by autistic people.

# 2.3.1 Ableist disrespect

Jeffrey Brown defines ableism as "a durable group hierarchy between people perceived as 'normal' and those perceived as 'disabled,' in which people with disabilities are subject to public stigmatic disadvantages in relation to non-disabled individuals." (Brown 2019, p. 333) This hierarchy results from cognitive biases which lead to non-disabled people perceiving disabled people as internally deficient, universally dependent, and infantile, even when these perceptions directly conflict with the first-personal experiences of disabled people and the testimony of social theorists of disability (p.334-335). These negative perceptions are often exacerbated by the spread effect, wherein the perception of a specific deficit leads to the perception of more widespread deficiencies (p.335). Owing to these cognitive biases and the disrespectful attitudes they give rise to, non-disabled people tend to treat their disabled peers in one of two ways - either the non-disabled person feels compelled to 'help' the disabled person, even when this help is not needed or welcome (for example, attempting to push a person's wheelchair without permission), or they will tend to ignore the non-disabled person completely. While this is not the case in every interaction between a disabled person and non-disabled person, it is common enough to have a significant impact on the daily lives of all disabled people, both because of the direct impacts of specific interactions and because the continued

exposure to these biases can lead to internalized stigmatization (p.336). These conditions clearly violate the principles of relational equality because disabled people are subject to undue hierarchies of standing, power, and esteem.

While ableism often manifests in the context of interpersonal interactions, institutional action can also express disrespectful attitudes, contributing to widespread ableist hierarchies. In order to clarify the relationship between institutional action and deeply entrenched social hierarchies such as ableism, Brown introduces the egalitarian contribution principle. This principle states that social and political institutions can be held responsible for a given objectionable social hierarchy when they have contributed to bringing such states about or contribute to maintaining them, even when other factors such as individual impairments might also play a role (Brown 2019, p.344). This is because, although the mere existence of these impairments is not morally relevant, the way humans choose to respond to the existence of those impairments is. There are two criteria by which one can determine whether a social institution can be considered responsible for a given social hierarchy: first, the institution's actions must be causally relevant to the existence of that social hierarchy. Secondly, the institution can be held responsible if it did not "merely allow", but "initiated, facilitated, or sustained" the hierarchy (Brown 2019, p.345), which is to say that there would not be a high antecedent probability that the hierarchy would exist and cause harm independently of any action the institution might take. In the case of ableism, social and political institutions have played a key role in bringing about the conditions necessary for this social hierarchy to develop and persist; it is unlikely that this hierarchy would have developed independently of institutional decisions that have been made and very likely that institutional action could reduce these inequalities significantly. For these

reasons, ableist social hierarchies can be understood as a failure of relational equality which our social and political institutions have a responsibility to address.

Although Brown's argument is primarily concerned with the experiences faced by those with physical disabilities, the same framework of ableist disrespect can be applied to understand the dynamics which often arise in interactions between autistic and allistic people. I argue that autistic people are routinely subject to systemic disadvantages stemming from attitudes of disrespect which position them as both internally deficient and infantile. Often, these disrespectful attitudes are intertwined with empirical misunderstandings about what it means to be autistic and how autistic people understand their own minds and their experiences of interacting with others in society. For example, widespread assumptions regarding autistic people's supposed associality and inability to empathize with others persist despite first-personal testimonies asserting otherwise (Jaswal and Akhtar 2019). As a result, autistic people are often subject to social exclusion (Sasson et al.2017), and when included in social interactions regularly encounter attitudes of dehumanization (Cage et al. 2019). I argue that the persistence of such negative and often misguided stereotypes about autistic people can be tied directly to narratives created and maintained by medical and research institutions which treat autism as a problem which must be solved, rather than as a natural variation in cognitive function. Thus, it can be argued that these institutions ought to be held responsible for their contribution to the relational inequalities routinely experienced by autistic people, and as such have a duty to work towards alleviating those inequalities to whatever extent possible.

## 2.3.2 Epistemic Injustice

The concept of epistemic injustice, popularized by the work of Miranda Fricker, refers to a particular type of injustice which is done to a person when they are not properly recognized in their capacity as an epistemic agent and producer of knowledge (Fricker 2007). This is to say that when a person's capacity to engage meaningfully in the production of knowledge is not properly recognized, a kind of harm is done to that person. On Fricker's account, epistemic injustice typically appears in one of two forms: testimonial injustice and hermeneutical injustice.

Testimonial injustice refers to those situations where a speaker's credibility is unfairly diminished as a result of some prejudice which the hearer holds, consciously or unconsciously, towards the speaker. It arises in the context of individual-to-individual testimonial exchanges, in which the hearer must make some judgement in regard to the credibility of the speaker. In this sense, testimonial injustice is something committed by one individual towards another. However, of primary concern to Fricker are those instances of testimonial injustice which can be understood as 'systematic'- that is, testimonial injustices which "are produced not by prejudice *simpliciter*, but specifically by those prejudices that 'track' the subject through different dimensions of social activity-economic, educational, professional, sexual, legal, political, religious, and so on." (p.27) The type of prejudice which tracks its subject in this way is almost always relating to some aspect of that subject's social identity, which Fricker accordingly refers to as 'identity prejudice' (p.155). There is a direct connection between the kind of routine testimonial injustices which result from identity prejudice and social power hierarchies. As Fricker explains, "the influence of identity prejudice is a matter of one party or parties effectively

controlling what another party does—preventing them, for instance, from conveying knowledge —in a way that depends upon collective conceptions of the social identities in play" (p.28).

Autistic people routinely experience testimonial injustices as a result of the negative stereotypes about autistic people which have proliferated across our culture, casting autistic people as universally incapable of certain forms of understanding. For example, the popularization of theory of mind models of autism has led to the myth that autistic people are unable to understand not only the minds of others, but also their own minds (Gernsbacher and Yergeau 2019). When allistic people are influenced by these stereotypes, they may be more likely to dismiss autistic individuals' attempts at interaction and epistemic contribution and may be unwilling to engage with autistic speakers at all as a result of the biased assumption that they have little or nothing of value to contribute.

Much like testimonial injustice, hermeneutical injustice results from similar power imbalances relating to widespread identity prejudice. However, unlike testimonial injustice, hermeneutical injustice is not the result of an individual hearer's bias towards an individual speaker, and so has no individual culprit. Rather, it is structural problem which arises from the way systemic identity prejudice influences collective hermeneutical resources, resulting in members of a socially disadvantaged group being unable to communicate important aspects of their subjective experience (Fricker 2007, p.159). This can occur either because the concepts and language required to express certain ideas do not exist, or because that language or those concepts are not recognized by the dominant group (p.150-152). In either case, the lack of understanding which characterizes hermeneutical injustice can be understood as resulting from the exclusion of a particular group from the dominant discourse. As Fricker explains, "a

hermeneutical injustice is done when a collective hermeneutical gap impinges so as to significantly disadvantage some group(s) and not others, so that the way in which the collective impoverishment plays out in practice is effectively discriminatory." (p. 162)

Importantly, the hermeneutical gap which leads to such hermeneutical injustices can involve not only the content of what can be intelligibly expressed, but also the form. As such, "the characteristic expressive style of a given social group may be rendered just as much of an unfair hindrance to their communicative efforts as an interpretive absence can be." (p. 160) Autistic people regularly experience hermeneutical injustice when their attempts at epistemic contribution are misunderstood or dismissed as a result of the ways in which they are expressed. There are a number of ways in which autistic communication may differ from what is generally expected in neurotypical social environments, including differences in vocal expression (pitch, inflection, cadence, etc.) and body language, and these unique modes of expression are often overlooked or misinterpreted by interlocutors. For example, certain types of autistic expression, such as echolalia (the repetition of certain heard words or phrases) are often assumed to be meaningless, when in actuality such expressions are often conscious attempts to communicate emotions, perspectives, and beliefs (Jaswal and Akhtar 2019).

Hermeneutical injustices can also manifest in the form of contributory injustice (Dotson 2012), wherein a marginalized group has themselves developed the conceptual resources required to communicate important aspects of their shared experience, but those conceptual resources are not recognized or accepted by dominant social groups. Contributory injustice arises in the case of the routine exclusion of autistic people from meaningful participation in autism research. Autistic people are uniquely situated to meaningfully reflect on and interpret their own

subjective experiences and mental states, and autistic communities have made great strides in developing collective understandings of the autistic experience. However, autistic people's perspectives are rarely regarded as authoritative within the sphere of autism science (Milton 2014), and as such the conceptual resources developed by autistic communities are often overlooked by academic research.

Systematic epistemic injustice can be understood as a concern of relational equality because it is characterized by an unjust imbalance of power, standing and esteem related to individual identity connected to membership in a particular social group. The harm of routine epistemic injustice can be further compounded by a resulting loss of epistemic confidence, which can in turn prevent an individual from gaining new knowledge and developing crucial epistemic virtues, including intellectual courage (Fricker 2007, p.163). The following sections will consider in greater detail the systematic epistemic injustices faced by autistic people in both institutional and interpersonal contexts, reflecting on the impacts this has on autistic individuals' self-esteem and epistemic confidence.

# 2.4 Relational Inequalities in Institutional Contexts

The way medical and research institutions define autism and interact with autistic individuals is one manifestation of relational inequality. Deficit-focused definitions of autism communicate disrespectful attitudes which position autistic people as fundamentally inferior. This is compounded by the exclusion of autistic voices in the field of autism research (Milton and Bracher 2013, Milton 2014, Botha 2021), as well as by the prevalence of behavioural

methods of 'autism treatment' which treat autistic expression as inherently problematic (Devita-Raeburn 2016, Wilkenfeld and McCarthy 2020).

As I have suggested earlier, biomedical models of autism focus on internal deficits as the primary locus of the difficulties experienced by autistic individuals. Such deficit-focused definitions communicate attitudes of disrespect by positioning autistic people as fundamentally inferior or broken and inherently incapable of well-being. One of the most widely-used resource for the diagnosis of autism is the American Psychological Association's Diagnostic and Statistical Manual, which offers diagnostic criteria for 'Autism Spectrum Disorder' (American Psychiatric Association 2022, F84.0). Labeling autism as a disorder itself has problematic implications, because it suggests that autistic minds are merely a 'broken' or deficient version of so-called 'normal' (that is to say, allistic) minds. The specific content of the diagnostic criteria also contributes to negative biases towards autistic people, both by labelling autistic communication as universally deficient and by requiring an impairment in functioning for a diagnosis to be made.<sup>9</sup> When autistic people are labeled as having "deficits in social communication" (American Psychiatric Association 2022, F84.0), it is implied that autistic people are to blame not only for their difficulties in understanding allistic communication, but also for allistic people's difficulties in understanding autistic people. In turn, this absolves allistic people of the responsibility to be responsive to autistic people's strong interests. When autism is defined as necessarily entailing "clinically significant impairment in social, occupational, or other important areas of current functioning" (American Psychiatric Association 2022, F84.0)

<sup>&</sup>lt;sup>9</sup> This is not meant to imply that the identification of clinically significant impairments is inherently problematic, nor to deny that many autistic people do experience such impairments. Rather, the concern is with the assumption that autism *necessarily* entails impairment and deficiency.

the ways in which social and environmental factors threaten autistic well-being are more likely to be overlooked. This directly contributes to hierarchies of standing and esteem which position autistic people as less competent and deserving of respect.

Relational injustices in the institutional context also manifest in the routine exclusion of autistic voices in autism research. This exclusion is due at least in part to ableist assumptions of autistic deficiency leading to the value of autistic contributions being overlooked or underestimated (Botha 2021). However, the difficulties allistic researchers may have in understanding autistic modes of expression owing to mutual communicative barriers are overlooked. As a result, distorted narratives about autistic ways of being are introduced uncritically. Autistic behaviours which appear 'odd' or 'bizarre' to the allistic observer are often pathologized, with no consideration of how such behaviours might be considered meaningful to the autistic person performing them (Milton and Bracher 2013). This creates a cyclical problem: assumptions of autistic deficiency lead to exclusion in the field of autism research, and the exclusion of autistic voices leads to the perpetuation of distorted, deficit-focused narratives of autistic expression proliferating throughout the literature.

The exclusion of autistic voices can be understood from the perspective of epistemic injustice. Not only does this exclusion of autistic voices constitute a form of contributory hermeneutical injustice in and of itself, but it also leads to further hermeneutical injustice by giving rise to academic misunderstandings of characteristic autistic modes of communication. Autistic researchers are also subject to routine testimonial injustices, including being accused of lacking objectivity, and having their autistic struggles minimized based on their ability to achieve academic success (Botha 2021).

The exclusion of autistic voices directly reinforces hierarchies of power. Allistic researchers are considered to be authorities on autism, despite autistic people's direct access to tacit knowledge of the autistic experience (Milton 2014). As a result, autism research has historically been viewed as something done about autistic people by allistic researchers, rather than a shared project of knowledge production. This is further illustrated by the fact that autistic community priorities are rarely considered when guiding research agendas. Despite studies showing that autistic community research priorities are primarily focused on applied research foci, the majority of autism research funding is directed towards basic science (Roche et al. 2020). It is also important to note that even projects which do seek to investigate 'community' stakeholder' research priorities often focus disproportionately on the perspectives of allistic professionals who work with autistic clients and the parents of autistic children, with comparatively little input from autistic people themselves. One review found that autistic adults comprised as little as 10% of participants in such studies (Chown et al. 2023). Without meaningful inclusion of autistic people in all levels of autism research, from guiding research direction to interpreting study results, unjust social hierarchies will continue to be reinforced within research institutions.

Autistic patients also experience disrespectful attitudes and epistemic injustice in their interactions with healthcare professionals (Nicolaidis et al. 2015). While these relational inequalities manifest across a wide range of medical contexts, they are perhaps most evident in the case of behavioural therapies which are widely considered to be the 'gold standard' autism treatment (Wilkenfeld and McCarthy 2020). As I have suggested earlier, behavioural methods of treatment rely on the assumption that the difficulties autistic people face within our society are

primarily the result of a failure of appropriate communication and behavioural expression which prevents meaningful participation in one's social environment. These methods therefore focus exclusively on the alteration of behaviour, with little or no consideration of how environmental and relational factors may contribute to many of the difficulties commonly associated by autism. It will be argued that, as a result of this focus, such methods often serve to reinforce hierarchies of social standing by undermining autistic people's autonomy and placing a disproportionate level of responsibility on autistic people to alter their behaviour to conform with allistic norms without reciprocity. The way these treatments are routinely employed leads to violations of the principles of relational equality in a number of ways. On an individual level, ABA often involves the undermining of its subjects' autonomy, meaning that practitioners are not treating those subjects as epistemic equals in a fundamental sense. On a broader scale, efforts to 'normalize' autistic subjects by demanding conformity to neurotypical social norms without offering reciprocal effort on the part of society to accommodate the unique needs and expression of autistic people contributes to widespread stigma and marginalization. Additionally, when ABA approaches proliferate, with minimal alternative options for autistic patients to receive support or therapy to address autistic people's subjective concerns (Devita-Raeburn 2016), it signals to autistic populations that their subjective wellbeing and quality of life are not seen as important enough to be addressed by healthcare professionals or the medical institution.

The ethical concerns raised by Wilkenfeld and McCarthy (2020) in reference to the use of ABA therapy in children help illustrate the threats such methods pose for relational equality. Although their arguments do not explicitly appeal to relational conceptions of equality, they are concerned with a right to equality of interests and self-determination which is central to

achieving relational equality. Their main argument revolves around the fact that dominant forms of ABA therapy infringe upon the autonomy interests of patients in a morally significant way. These infringements upon individual autonomy are relevant even in cases involving young children, they argue, because even young children have autonomy interests, including "an interest in freedom from interference on their ability to act on their desires, and an interest in freedom to develop preferences that can be cultivated into more substantive passions or pursuits."(Wilkenfeld and McCarthy 2020, p.42) While the moral requirement of non-interference with these interests is weaker in the case of a child than it might be for an adult, they nonetheless cannot be completely disregarded (p.43).

Wilkenfeld and McCarthy argue that ABA infringes on its subjects' autonomy in one of two ways, depending on whether their success involves a genuine change to a person's identity and the way they experience the world (deep change) or whether it simply changes the way they behave by training them to act against their natural impulses (superficial change) (Wilkenfeld and McCarthy 2020, p.44). If ABA affects deep change on its subjects, then it violates their autonomy by closing off certain paths of identity formation through (at least moderately) coercive means (p.44-47). If it merely effects shallow change (which seems more likely given the testimonies of autistic adults who were subjected to ABA as young children) then it is teaching its subjects that their natural desires, impulses, and passions - integral elements of their identities - are somehow 'wrong' or 'bad' and must be suppressed and controlled for the benefit of others (p.47-51). In either case, the subject's autonomous interests in being free to act on their desires and to explore their desires and preferences in order to cultivate an internal, selfdetermined sense of identity are violated. These violations of autonomy extend beyond the

(morally acceptable) interference with children's desires and preferences which is characteristic of healthy parent-child (and indeed therapist-client) relationships, both as a result of the excessive burdens imposed on subjects and because of ABA's targeting of harmless aspects of its subjects' core identities (p.59). Thus, I argue that relations between ABA practitioners and subjects can be understood in terms of an unjust relationship of domination characterized by a hierarchy of authority which extends beyond what is commonly deemed acceptable in healthy therapist-client or parent-child relationships.

In addition to the individual harm associated with this kind of behavioural therapy, the proliferation of such approaches, particularly in combination with the relative lack of alternative therapeutic approaches to address the unique needs of autistic populations, serves to reinforce more widespread social hierarchies. As I have suggested earlier, by framing the mutual communicative barriers which manifest between autistic and allistic people as the result of autistic deficiencies, frameworks like ABA place a disproportionate level of responsibility on autistic people to overcome those barriers. This sends the message to autistic people that they must fundamentally change themselves in order to order to achieve social respect, and that they cannot expect a reciprocal degree of accommodation or support from medical institutions or societal institutions more broadly to address their unique needs. In this way, medical institutions have directly contributed to widespread hierarchies of standing, wherein autistic people's strong interests are routinely disvalued.

#### **2.5 Relational Inequalities in Interpersonal Contexts**

Autistic people are also subject to ableist disrespect and routine epistemic injustice in interpersonal interactions in the context of their everyday lives. While these injustices manifest in interpersonal settings outside the medical context, they are directly connected to the way autism is defined by the medical establishment, so are relevant to a discussion of ethical ramifications of model choice in autism research. Deficit-focused biomedical models of autistic cognition amplify ableist stigma towards autistic people through the spread effect, leading to many perceiving of autistic people as wholly incompetent. As a result, allistic lay people often exhibit dehumanizing attitudes towards autistic people (Cage et al. 2019). It has also been shown that allistic people form negative first impressions of autistic people based on thin-slice judgements, even when they are unaware of the autistic person's diagnosis (Sasson et al 2017). These experiences of marginalization have significant implications for autistic peoples' mental health (Cage et al. 2018, Botha and Frost 2020).

The way non-speaking autistic people are often treated is a clear example of how misguided perceptions of deficiency, exacerbated by the spread effect, create and reinforce inequalities in social standing, power and esteem. These individuals are often labelled as unable to communicate, despite many being able to communicate in ways other than spoken voice, including written words, sign language, body language and gestures, and more. Social disrespect limits their opportunities to develop those alternative communicative skills and their chances of being listened to and understood when they do communicate. In the introduction to the collection Typed Words, Loud Voices, Amy Sequenzia describes her experience growing up as a nonspeaking autistic person as follows: I have always been non-speaking. As a young child, I could say a few words, but I mostly echoed others. I could never speak words to convey what was in my mind, or how I felt.

Then I found facilitated communication and everything changed. I didn't have to cry in frustration anymore and I could show that I was listening and learning.

My life as a typist was inconsistent and I did not always have a facilitator that could work with me, allowing my voice to be heard. For a long time the bias kept me out of my own life: people who look like I do, people who are very disabled like I am, people who are nonspeaking as I am, we are immediately graded as lesser valuable. Having the need of physical support adds to the bias. How can we be typing coherent thoughts? The assumption is that we are so incompetent, someone must be doing the typing for us. (Sequenzia 2015, Emphasis added)

Sequenzia explains how difficult it was to be a child without access to the tools she needed to express herself, and the relief she experienced when she found a method of communication that allowed her to do so. Yet even once she was able to communicate her thoughts and feelings, those she attempted to engage with did not take her seriously as a rational agent as a direct result of pre-existing negative biases about her capabilities as a non-speaking autistic person. This aligns with Brown's account of the spread effect (Brown 2019, p.335), with interlocutors assuming that an inability to speak (in this case, particularly in combination with a need for physical support) also implies an inability to think or understand. Even when presented with evidence to the contrary, they refuse to accept that the disabled person in front of them is capable of rational thought.

The experience described by Sequenzia reflects the kind of persistent epistemic injustices previously discussed; the limitations of our collective hermeneutical resources prevent nonspeakers from effectively communicating crucial aspects of their subjective experiences as a

result of their characteristic expressive style deviating from the culturally accepted norm. Moreover, the biases held by those with whom non-speakers interact leads to persistent testimonial injustices, with those allistic interlocutors treating them with an undue credibility deficit. By reasonable implication given what I have described, it is also clear that such persistent epistemic injustices, fuelled by biases reinforced by poorly constructed definitions of autism, contribute to ableist social hierarchies which violate the principles of relational equality. These biases contribute to an unjust hierarchy of standing, with one group being routinely unresponsive to the other's legitimate claims and unfairly disregarding their interests. They also contribute to a hierarchy of esteem, with one group being unfairly labeled as incompetent and their achievements dismissed without merit. Finally, ableist biases towards non-speaking autistic people contribute to a hierarchy of power, as autistic people are routinely excluded from positions of power as a result of the hierarchies of standing and esteem which position them as incapable non-authoritative.

These injustices are not exclusively experienced by non-speaking autistics. Social stigma affects all autistic people and can be compounded by stigma relating to other facets of an autistic person's identity, including gender and race (Diemer et al. 2022). This stigma affects the way society perceives and treats even those autistic people who demonstrate a high degree of proficiency in particular socially valued skills, as evidenced by the trope of the autistic or 'idiot' savant. By the twenty-first century, the trope of the idiot savant has become inextricably linked to autistic ways of being and gained widespread societal recognition as the result of an explosion of popular media featuring depictions of characters who typified such 'autistic savantism', the most notable of which being the 1988 film *Rainman*. (Murray 2008). Despite the cultural

fascination with autistic savants, the overall abilities of those who display such skills are nonetheless disvalued. These stigmatizing attitudes are perhaps best captured by a quote by Edouard Séguin, who in 1870 characterized the 'idiot savant' as demonstrating "the useless protrusion of a single faculty, accompanied by a woeful general ignorance" (p.519). Autistic savants are set apart from 'normal' people, being seen as generally deficient, and the value of their particular skills dismissed as mechanistic rather than a demonstration of creativity. Rather than being seen as a unique strength directly connected to uniquely autistic modes of cognition, savant skills are framed as an outlying ability that manifests in spite of an otherwise deficient cognitive style. (Straus 2014).

The societal treatment of non-speaking autistics and autistic savants (two groups which in fact overlap) are symptomatic of the widespread stigmatization experienced by autistic people. This stigmatization can be directly connected to the way deficit-focused biomedical models of autism position autistic people as fundamentally deficient in areas central to human functioning. As I have suggested earlier, explanatory models for autism developed within the biomedical framework conceive of autism as being the result of an internal deficit which directly impairs individual functioning. These explanatory models reinforce perceptions of autistic people as deficient, dependent, and infantile, and this has a direct impact on the way autistic people are treated both in the specific context of medical care and in society more broadly. When these clinical models position autistic people as inherently deficient in some way, the allistic layperson is far more likely to internalize this belief in ways which affect the way they relate to autistic people in their everyday life. Moreover, when autistic communication is labelled as less

effective, allistic people are given leave to not make the necessary effort to understand when the autistic person communicates their needs.

Theory of mind models offer one example of such deficit-focused explanatory models of autistic cognition leading to widespread social stigma. Theory of mind models suggest that autism results, wholly or in part, due to a specific, universal deficit in autistic individuals' ability to understand that both themselves and others have a mind and to reflect on the content of those minds. The claim that autistic people lack a theory of mind has been pervasive throughout decades of psychological literature, although more recent scholarship calls the empirical legitimacy of the claim into question (Gernsbacher and Yergeau 2019). While the theory of mind hypothesis is only one of many cognitive theories which have been used in an attempt to define autism, it is useful example because there is a clear connection between the claim that autistic people lack a theory of mind and a number of persistent, harmful narratives about autistic people. These include the myth that autistic people are fundamentally incapable of empathy and the idea that autistic people are not able to fully understand their own minds and make rational decisions in regard to their own autonomous interests. In addition to having direct implications for patient care, the widespread acceptance of theory of mind models of autism within psychiatric circles has led to these false understandings proliferating throughout society at large, impacting the ways in which allistic people perceive and respond to their autistic peers in everyday life (Gernsbacher and Yergeau 2019, p.110). Social narratives position autistic people as lacking the capacity for empathy or rational, autonomous decision-making, with the implication that autistic people are somehow less than fully human, and as such less deserving of the respect and
consideration due to all people. Such a stance is inherently incompatible with the requirements of relational equality.

#### Conclusion

This chapter has argued that a strong commitment to the bioethical principle of justice requires consideration of not only the fair distribution of certain key benefits and burdens (distributive justice), but also the maintenance of relations of equality and respect among citizens (relational justice). It has been argued that autistic people in our society are subject to both distributive and relational inequalities, and that deficit-focused biomedical models of autism directly contribute to those injustices. The disproportionate amount of autism research funding directed towards basic science, while projects focusing on the immediate needs of the autistic population remain underfunded, constitutes an unfair distribution of resources. In turn, this leads to an unfair distribution of opportunity for welfare due to inequalities in the standard of medical care offered to autistic patients as compared to their allistic counterparts. Autistic people also face relational inequalities in both institutional and interpersonal contexts in the form of ableist disrespect and routine epistemic injustices. In the institutional context, deficit-focused models of autistic cognition, the exclusion of autistic voices in research, and the proliferation of behavioural methods of 'autism treatment' contribute to the marginalization of autistic people through the communication of stigmatizing ableist attitudes. The deficit-focused approaches of the biomedical paradigm also frame cultural narratives around autistic people, reinforcing unjust social hierarchies and leading to persistent epistemic injustices in interpersonal contexts.

# Chapter 3: Overcoming Inequality by Embracing the Neurodiversity Paradigm

Chapter 2 examined how the medicalized definitions of autism which arise within the traditional biomedical paradigm contribute to and reinforce both distributive and relational injustices which have a significant negative impact on autistic individuals and communities. The current chapter will explore how the shift towards the neurodiversity paradigm creates opportunities to overcome these systemic inequalities. Section one will consider how the shift towards the neurodiversity paradigm can reduce distributive inequalities by redirecting resources towards community research priorities and deepening understandings of autistic modes of cognition and communication. As implied earlier, expanding the focus of autism research beyond basic science, recognizing the impact of socio-environmental factors on autistic well-being, and embracing the experiential expertise of autistic research partners will open new avenues for autism research. In turn, improved understandings of autistic minds and bodies can allow for the development of novel care approaches to support autistic well-being. Section two will consider how embracing neurodiversity theory creates opportunities to dismantle unjust social hierarchies within the institutional context by embracing emancipatory research approaches. This will offer autistic individuals and communities a forum through which to express their self-determined strong interests with an expectation of meaningful responsiveness from research and medical institutions. Finally, section three will consider how changes to scientific approaches to understanding autism can change societal narratives about autistic people, reducing relational inequalities in interpersonal contexts.

#### 3.1. Improving Distributive Equality: Distribution of Resources and Quality of Care

The shift towards the neurodiversity paradigm fundamentally changes scientific communities' approaches to defining autism. In doing so, it offers the opportunity to explore new avenues of research, to better align research priorities with the needs of autistic communities, and to improve empirical understandings of the condition. In turn, this will allow for the alleviation of a number of distributive inequalities faced by autistic people in the context of healthcare. As discussed in chapter 2, the limited focus of the biomedical paradigm on internal disabling factors has led to an unfair distribution of resources which prioritizes scientific curiosity over the immediate needs of the autistic population. It has also hindered progress in developing a holistic<sup>10</sup> understanding of how autistic minds and bodies function and of the conditions required to achieve autistic well-being. In this section, I will consider how the shift towards the neurodiversity paradigm can help overcome these distributive inequalities, both by recognizing the value of autistic people's contributions to autism research and by expanding conceptions of autism beyond traditional deficit-focused models.

The neurodiversity paradigm recognizes autism as a natural variation in human cognitive function, rather than a problematic deviation from an idealized neurotypical norm. This understanding of autistic minds as different to allistic minds, but not inferior, allows for the recognition of the mutuality of autistic-allistic communication barriers, as described by Damian Milton's double empathy problem. Whereas the communicative barriers between autistic and allistic people have traditionally been understood as resulting from a specific communicative

<sup>&</sup>lt;sup>10</sup> That is, accounting for the full spectrum of autistic traits, including not only deficits but also strengths and neutral differences in cognitive function as compared to allistic cognition.

deficit on the part of the autistic person, the double empathy problem reframes the problem in terms of a mutual disjuncture in social positionality which renders both parties incapable of intuitively recognizing the other's social cues. (Milton 2012) This hypothesis is supported by empirical research showing that autistic peer-to-peer information transfer is highly effective (Crompton, Ropar et al 2020) and that allistic adults struggle to interpret the mental states of autistic adults (Edey et al. 2016).

The double empathy problem model of cross-neurotype communication barriers reveals that allistic researchers are likely to face significant barriers in understanding the autistic people they study and makes clear that autistic people are uniquely positioned to contribute to scientific understandings of autism. There are various ways in which autistic people can (and should) be encouraged to contribute to the research process. There exist a number of autistic professionals who, through education and applied experience in research contexts, have developed particular skills and knowledge which afford them the ability to lead and contribute to projects as researchers.<sup>11</sup> Additionally, autistic laypeople tend to have an above-average level of understanding of autism science (Gillespie-Lynch et al. 2017), and even those who are not familiar with formal, scientific understandings of autism nonetheless have direct access to certain tacit knowledge about what it means to be autistic (Milton 2014).

As will be discussed in section 3.2, recognizing autistic people's unique understanding of the autistic experience helps address the routine epistemic injustices faced by autistic people in

<sup>&</sup>lt;sup>11</sup> There already a number of autistic researchers who are properly regarded as experts within their fields. Monique Botha, Michelle Dawson, Jac den Houting, Steven Kapp, Damian Milton, and Nick Walker are examples of autistic autism researchers cited in this thesis. However, autistic autism researchers remain vastly outnumbered in their field, face significant barriers to entry, and often feel alienated or undervalued by their allistic peers (Botha 2021)

the field of autism research. However, it also has two important consequences which are relevant to overcoming distributive inequalities in healthcare. Firstly, it shows that autistic people are uniquely positioned to identify the needs of their communities<sup>12</sup>, prompting consideration of the importance of using community input to guide research directions, overcoming inequalities in resource distribution. Secondly, it allows for the recognition of autistic experiential expertise as an under-utilized epistemic resource for improving scientific understandings of autism as a condition and of the conditions necessary to achieve autistic well-being. In turn, this will lead to the development of more effective approaches to care and support, overcoming distributive inequalities in quality of medical care between autistic and allistic populations.

Recognizing autistic people's expertise in understanding autistic experiences is just one example of how the neurodiversity paradigm encourages allistic researchers to move beyond traditional deficit-focused models of autism, acknowledging a number of autistic strengths and neutral differences which cannot be accounted for by such models. For example, deficit-focused models assume that autistic communication is uniquely deficient, but more and more it is coming to be understood that autistic communication is often both highly effective and adaptive, although it may be difficult for allistic interlocutors to interpret. If autistic communication were inherently deficient, then it stands to reason that communication between two autistic people would be particularly inefficient, yet it has been shown that autistic peer-to-peer information transfer is highly effective (Crompton, Ropar, et al. 2020) and that autistic people tend to have better rapport with fellow autistic people than with allistic people (Crompton, Sharp, et al. 2020). Moreover, deficit-focused models tend to assume that autistic people are either incapable of or

<sup>&</sup>lt;sup>12</sup> Standpoint theories, as defended by Sandra Harding (Harding 1998) provide one argument in support of the epistemic benefits of diversity and representation in research.

uniquely uninterested in socialization and community building, but research which engages directly with autistic subjects has shown that many autistic people have a deep interest in social interaction (Jaswal and Akhtar 2019). Autistic people may have unique ways of socializing and creating shared understandings (Brownlow et al. 2015, Heasman and Gillespie 2019), but this does not mean that they are fundamentally incapable of social connection.

Similarly, it has often been assumed that the restricted and repetitive patterns of behaviour commonly associated with autism are either maladaptive or meaningless, but more recent studies reveal that many autistic people understand many of these behaviours to be useful mechanisms for coping with anxiety and other negative emotions (Joyce et al. 2017, Kapp et al. 2019). The assumption that restrictive and repetitive patterns of behaviour are inherently problematic results in part from an over-reliance on behavioural observation combined with insufficient consideration of core differences in cognitive function and information processing. For example, the DSM-V diagnostic criteria list "Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment" (American Psychiatric Association 2022, F84.013) as an example of restricted or repetitive patterns of behaviour. This framing focuses on the individual's reaction to sensory stimuli, with little consideration of what those reactions may reveal about how such stimuli are perceived by the individual. This suggests an implicit assumption that allistic people process and respond to sensory stimuli in the 'right' way, whereas autistic people do not. Moving away from a deficit-focused approach prompts consideration of how autistic behaviours might alternatively be understood as meaningful, adaptive responses

<sup>&</sup>lt;sup>13</sup> The DSM-V-TR diagnostic criteria for Autism Spectrum Disorder can be found at <u>https://doi-org.proxy3.library.mcgill.ca/10.1176/appi.books.9780890425787.x01\_Neurodevelopmental\_Disorders</u> (Accessed Sept. 2024)

resulting from differences in sensory processing which affect the ways in which autistic people experience the world around them (see Mottron et al. 2013, Jacques et al. 2018 for examples of strength-focused research on autistic perception and behaviour).

One potential alternative explanation for the cognitive differences associated with autism is the theory of monotropism, which links defining features of autism to differences in attentional focus. This theory suggests that autistic and allistic people differ in how the limited attentional resources available to a given individual are distributed. Autistic individuals tend towards monotropism, with attention being tightly and intensely focused on a small number of interests, while allistic individuals more often demonstrate polytropic tendencies, with attention distributed over a broader number of interests at a lesser degree of focus. Autistic monotropism can account for the recognized differences in social interaction, communication, and restricted and repetitive behaviours demonstrated by autistic people (Murray et al. 2005). Crucially, this theory suggests that there is no superior way of processing information or focusing attention. Rather, both monotropic and polytropic modes of cognition are associated with unique benefits and drawbacks. Monotropic individuals will generally have more difficulty turning attention between tasks but will be better able to develop a deep level of expertise on subjects which interest them. Polytropic individuals will tend to excel at shifting attention and a higher degree of generalized knowledge but are less likely to develop the level of mastery in specific areas of knowledge which is demonstrated by monotropic individuals. Although more research is required to confirm the validity of the monotropism model of autism, at least one study has found that autistic individuals self-reported higher levels of monotropism on a standardized questionnaire (Garau et al. 2023).

Less deficit-focused explanatory models of autistic cognition such as the monotropism hypothesis offer a novel perspective through which to evaluate and interpret the results of existing and future research. For example, Grissom, Finke, and Zane (2023) used the theory of monotropic attention to reinterpret data from seventeen studies comparing the performance of autistic and allistic participants on verbal fluency tasks. Each study included a category fluency task, which asked participants to produce a list of unique words which fit within a given semantic category, the results of which were analyzed primarily based on the total number of correct words (TNCW) produced. Of the seventeen studies, four found no significant difference in TNCW between autistic and allistic groups, while twelve found that the autistic group produced a significantly smaller TNCW. The final study found no difference between autistic and allistic bilinguals but did report significant differences between autistic and allistic monolinguals. Of the thirteen studies which reported a standard deviation, nine found a significantly larger standard deviation for the autistic group. These studies universally interpreted differences in autistic performance on verbal fluency tasks through a deficit-focused lens, with all differences in autistic performance being interpreted as indications of impairment. However, these interpretations failed to account for a high degree of variability in performance among autistic participants within each study, as well as a high degree of inconsistency in results reported across studies. Additionally, when no significant differences were observed in TNCW produced by autistic participants (as compared to the allistic control) researchers were more likely to question the generalizability of the results, rather than conclude that results suggest autistic populations do not demonstrate higher rates of impaired verbal fluency. Grissom, Finke, and Zane propose that inconsistencies within and across verbal fluency task studies can be better

explained through the framework of monotropism, as monotropic individuals will tend to have "distinct areas of deep semantic knowledge" (Grissom et al. 2023, p.332) but comparatively less generalized knowledge across a broad range of subjects. As a result, when the semantic category chosen for a verbal fluency task aligns with a particular area of interest, the monotropic person will tend to perform exceptionally well. However, when the chosen semantic category does not align with an individual's interests, a lower TNCW can be expected. Whether or not the specific theory of monotropic attention proves valid, these results reflect the importance of reflection on potential bias in the interpretation of data and the limitations of a deficit-focused approach in developing a holistic understanding of autistic cognitive function.

Moving away from deficit-focused models of autism in this way allows for the to reframing of mainstream understandings of autistic well-being, which can in turn improve the level of care and support offered to autistic people by medical institutions. Conceiving of autism as a neutral difference in cognitive function challenges the idea that autistic people are fundamentally incapable of well-being, and prompts exploration of how the necessary conditions for a high quality of life may differ for autistic people as compared to their allistic peers. Through the use of participatory research methods which ensure the meaningful inclusion of autistic voices, it may be possible to develop a better understanding of the specific factors which contribute to uniquely autistic forms of well-being. This may in turn allow for the development of novel approaches to medical care and support which address the specific needs of autistic patients. For example, this might include interventions designed to reduce stigma towards autistic people (Kim et al. 2024).

# **3.2. Dismantling Institutional Hierarchies Through the Adoption of Emancipatory Research Approaches**

A paradigm shift offers the opportunity to reevaluate and adjust research approaches, not only to maximize the empirical validity of findings but also to ensure scientific practices conform to the core ethical values of beneficence, non-maleficence, respect for autonomy, and equality. Section 1 considered how the exclusion of autistic voices from autism science and the exclusive focus on deficits has hindered empirical progress and led to distributive injustices in quality of care, and discussed how the shift towards the neurodiversity paradigm can offer a path forward in mitigating these injustices. However, as discussed in chapter 2, the current state of affairs is not merely unjust by distributive standards. There are also relational inequalities which the shift towards a neurodiversity framework and the adoption of participatory and emancipatory research methods can help to overcome. Institutional approaches to autism science have routinely served to construct and maintain objectionable hierarchies of power, standing, and esteem, hindering autistic self-determination, reinforcing the idea that autism constitutes a unique and universal cognitive deficiency, and demonstrating an insufficient degree of responsiveness to the autistic community's communicated strong interests. By recognizing the unique contributory expertise which autistic people have in understanding and helping to accurately define autism, the neurodiversity paradigm embraces the use of participatory research methods which allow autistic people direct input in the direction of research. Moreover, by framing autism as a natural variation in human cognitive function, rejecting explanatory models which focus exclusively on deficits, and acknowledging that elements of the social environment

can (and often do) constitute disabling factors for autistic people, neurodiversity approaches facilitate the adoption of research methods which are not only participatory, but also emancipatory - that is, methods which allow for autistic ownership of projects of knowledge production, ensure reciprocal accountability between autistic and allistic researchers, and enact social change for the benefit of the autistic community. (Chown et al. 2017) The current section will begin by offering a brief definition of emancipatory research and presenting an argument for why the adoption of emancipatory research practices align with the core tenets of the neurodiversity paradigm, before going on to consider two main ways in which the adoption of emancipatory research methods in autism sciences challenges relational inequalities from within the institutional context. Firstly, emancipatory research methods help dismantle hierarchies of power and esteem by allowing autistic communities a meaningful level of control over how autism is defined, increasing the potential for community self-determination and challenging stigmatizing attitudes at an institutional level. Secondly, these methods disrupt hierarchies of standing by providing autistic individuals and communities a forum through which they can communicate their strong interests with an expectation of responsiveness from medical and research institutions.

#### 3.2.1 Defining Emancipatory Research

Emancipatory research is research which intentionally and meaningfully supports the societal and intellectual emancipation of the groups being studied. Principles of emancipatory research build on participatory research frameworks to encompass not only the meaningful inclusion of those who are directly affected by matters being investigated in research projects,

but also a commitment to social change, reciprocal accountability, and ownership of research by affected communities. While the line between participatory and emancipatory research practices is often blurry, it is possible for research to be participatory without also being emancipatory, but research cannot be truly emancipatory without meaningful inclusion of the voices of affected community members (Chown et al. 2017). Stone and Priestly (1996) offer a framework for emancipatory research in the field of disability studies. This framework consists of six core principles:

- the adoption of a social model of disablement as the epistemological basis for research production;
- the surrender of claims to objectivity through overt political commitment to the struggles of disabled people for self-emancipation;
- 3. the willingness only to undertake research where it will be of practical benefit to the selfempowerment of disabled people and/or the removal of disabling barriers;
- the evolution of control over research production to ensure full accountability to disabled people and their organizations;
- giving voice to the personal as political whilst endeavouring to collectivize the political commonality of individual experiences;
- 6. the willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people. (p.707)

Although Stone and Priestley's six principles of emancipatory research were developed independently of and prior to the rise of the neurodiversity movement, the two projects arose

from connected conversations in the burgeoning field of disability studies. As such, the six principles can be understood as being consistent with the core tenets of the neurodiversity paradigm: the recognition of natural variations of cognitive function as a valuable form of human diversity, the rejection of the notion that there exists one 'normal' or superior kind of mind, and the understanding that neurodivergent people, including autistic people, are subject to social power inequalities similar to those which affect other marginalized groups. The neurodiversity paradigm is grounded in social and interactionist models of disability which recognize how disabling environmental and socio-political factors can negatively impact individual and community well-being. Moreover, the neurodiversity perspective recognizes that the autistic community (and other neurological minorities) represents a marginalized group, made up of a broad range of individuals who are collectively impacted by widespread social power inequalities. In all of these ways, the principles of emancipatory research are closely aligned with the aims of the neurodiversity movement.

Chown et al. (2017), a team comprised primarily of autistic researchers, expand on Stone and Priestly's six principles<sup>14</sup> to create a draft framework for emancipatory research in the autism field, comprised of 30 principles relating to all traditional stages of academic research (research design, data collection, data analysis, reporting, and publishing.) These reflect the importance of the commitment to emancipatory research practices being shared by funding bodies, researchers, and study participants alike. It is important to note that a commitment to emancipatory research must be inclusive of a wide range of autistic voices from a variety of socioeconomic and cultural

<sup>&</sup>lt;sup>14</sup> Chown at al. also refer to the six elements of emancipatory research proposed by Mike Oliver (1997), but found that Stone and Priestly incorporate all the requirements encompassed by Oliver's criteria while also including additional criteria relating to emancipation, self-empowerment, and the deconstruction of disabling social barriers.

backgrounds, as well as including non-speaking autistic people and those with co-occurring intellectual disabilities. While there will no doubt be challenges in both recruiting diverse participants and tailoring research approaches to ensure accessibility of meaningful participation from all participants and research projects, it is surely possible to develop creative solutions to support the involvement of a wide range of perspectives. Progress has already been made in this area, with a number of participatory research projects offering insights into adaptive methodologies which seek to overcome barriers to participation (see for example Nicolaidis et al. 2011, Beaumont 2019, Nicolaidis et al. 2019, Jose et al. 2020,).

#### 3.2.2 Hierarchies of Power and Esteem

As discussed in section 1.2, the field of autism science has historically been dominated by the voices of allistic researchers, with the unique contributory expertise of autistic people often going unrecognized (Milton 2014). This exclusion arises, at least in part, from a lack of reflection on allistic researchers' limitations in understanding autistic behaviour and communication on one hand, and a disregard for the unique knowledge which autistic people possess by virtue of their lived experiences on the other. This creates a significant imbalance of power, with allistic researchers being treated as authorities on the subject of autism while autistic people are routinely treated as mere objects of study. Autistic people are seldom afforded opportunities to make meaningful contributions to communal projects of knowledge production about autism, despite the significant benefit they are likely to experience by participating.

The exclusion of autistic voices in research constitutes an unjust hierarchy of power characterized by relations of domination between allistic researchers and autistic communities.

Allistic researchers are afforded a position of power which allows them an unjust level of authority over the way autism is defined, which in turn has a meaningful effect on autistic people's self-understanding and the societal treatment they experience. Allistic researchers also exercise an unjust degree of authority over decisions relating to the direction of research, leading to a stark disconnect between autistic community research priorities and trends in the allocation of research funding. Emancipatory research practices directly challenge existing hierarchies of power by ensuring the autistic community retains control over the production of autism research. In this way, more autism research can become a shared project of knowledge production, rather than something that is about autistic people, done by allistic researchers. As a result, autistic communities will be empowered to exercise justified authority over the creation of the scientific models which shape the way autistic people understand themselves and their relationship to the world around them.

Hierarchies of power in autism research are reinforced by unjust hierarchies of esteem, which are in turn bolstered by the persistent categorization of autistic differences through a deficit-focused lens, positioning autistic people as inherently inferior and incapable of making meaningful contributions. The core values of neurodiversity theory directly challenge the assumptions which underlie and reinforce these unjust hierarchies of esteem by positioning autistic ways of being as a natural variation in human cognitive function, as a different but not necessarily deficient way of being. In turn, the recognition of autistic people as capable epistemic agents whose unique perspectives enable them to make meaningful contributions to communal projects of knowledge production, in combination with the understanding that many of the challenges faced by autistic people are the direct result of disabling social and environmental

factors, prompts consideration of how significant imbalances of power in the field of autism science have limited the potential impact of the knowledge produced in this field and further contributed to the widespread oppression of autistic people as a social class.

### 3.2.3 Hierarchies of Standing

The routine exclusion of autistic voices in the field of autism science leads to unjust hierarchies of standing characterized by a lack of responsiveness towards the strong interests of autistic people. Therapeutic interventions are often designed with little consideration of the needs and priorities communicated by autistic individuals and communities. As noted earlier, funding for autism research is disproportionately allocated to projects focused on basic science, despite community feedback indicating the importance of prioritizing applied research foci (Roche et al. 2020). This might signal a prioritization of scientific curiosity over attempts to address the immediate and pressing needs of the autistic community, which would in turn communicate to autistic people that their self-identified strong interests are not seen as weighty enough to warrant the attention of public research institutions.

There has been some progress in recent years in identifying community research priorities, prompting calls for increased prioritization of research into matters which impact the daily lives of autistic people across their lifespans, including research which focuses on frequently co-occurring medical conditions and the overall health and wellbeing of autistic individuals (See for example Benevides et al. 2020, Pellicano et al. 2014, Warner et al. 2019). Yet, even those projects which specifically seek to gain insight on community or 'stakeholder' research priorities in the field of autism often focus disproportionately on the perspectives of

allistic professionals who work with autistic clients and parents of autistic children, with comparatively little input from autistic people themselves, autistic adults comprising as little as 10% of participants in such studies (Chown et al. 2023). While it is true that allistic professionals and parents may have valuable insights to offer (especially in reference to young children who may be unable to articulate their needs or advocate for themselves) autistic people themselves, as one autistic co-researcher in a recent collaborative research project stated, are "the stakeholders with the most at stake." (Jose et al. 2020, p.11) As such, it is crucial to conduct further research on community research priorities which explicitly centers the direct input of autistic adults.

Adopting emancipatory research practices will allow autistic people direct control over the direction of research, ensuring that their voices are heard, and their concerns addressed. In turn, this communicates to autistic people that institutions are cognizant of and responsive to their strong interests, fostering equality of social standing. Ensuring meaningful involvement in research can also help to safeguard against the influence of ableism in research (Botha and Cage 2022), preventing further reinforcement of stigmatizing attitudes in academic literature. Finally, the adoption of emancipatory research practices sheds light on the value of autistic contributions, which have historically been overlooked or minimized. In all of these ways, emancipatory research practices serve to reinforce cultural perceptions of autistic people as human equals deserving of respect.

#### 3.3. Dismantling Unjust Social Hierarchies by Changing Cultural Narratives

Section 2 considered how the shift towards the neurodiversity paradigm creates opportunities to dismantle unjust hierarchies within the institutional context. In addition to

dismantling problematic hierarchies within the specific contexts of medicine and scientific research, it can reasonably be expected that the increased participation of autistic people in projects of knowledge production and the reimagining of medical understandings of autism as a condition can have a significant positive impact on widespread cultural narratives about autism, changing the way autistic people are perceived, and consequently how they are treated, by society at large. As discussed in chapter 2, biomedical models of autism produced by medical and research institutions have shaped cultural understandings of what it means to be autistic, leading to the proliferation of harmful myths (e.g. 'autistic people are fundamentally asocial' and 'autistic people are incapable of empathy.') When medical understandings of autism are rooted in a framework of deficiency, cultural narratives inevitable arise which position autistic people as deficient, broken, or even in some way less than human. The current section will consider how the adoption of the neurodiversity framework can challenge unjust social hierarchies in interpersonal contexts by foregrounding the humanity and resulting inherent moral worth of autistic people, increasing awareness of autistic strengths, and drawing attention to the societal benefits which result from embracing diversity.

#### 3.3.1. Hierarchies of Standing

As discussed in chapter one, medical labels like 'autism' operate as interactive kinds (Hacking 1999) in the sense that the act of labelling someone as autistic influences how that person is perceived by both themself and others, which in turn affects how that person acts and how others act towards them. For this reason, shifting scientific understandings of how conditions such as autism manifest can have meaningful effects on the actual material

circumstances and moral status of those labelled as autistic. In chapter two it was argued that the widespread acceptance of biomedical models of autism reinforce stigmatizing attitudes which position autistic people as having inferior moral standing. The current chapter argues that the adoption of the neurodiversity paradigm can help dismantle this unjust hierarchy of standing in three ways. Firstly, neurodiversity theory explicitly affirms autistic humanity, forcing us to reimagine our ideas of what it means to be fully human and worthy of respect. Secondly, neurodiversity approaches encourage embracing autistic modes of communication, ensuring autistic people are heard and understood. Finally, neurodiversity theory reframes medical understandings of autistic quality of life, ensuring that autistic people's distinct well-being related strong interests are recognized and respected.

The first way that the adoption of the neurodiversity paradigm challenges interpersonal hierarchies of standing is by explicitly affirming autistic humanity, forcing the reevaluation of cultural narratives surrounding what it means to be a human deserving of moral respect. Within the biomedical model's framework, autism is understood in terms of a problematic deviation from normal human functioning. Autistic modes of cognition and communication are seen as fundamentally flawed. In combination with the spread effect (that is, the perception of a specific deficit leading to the perception of more widespread deficiencies), this negative framing contributes to the proliferation of the belief that autistic people are incapable of possessing certain abilities which are necessary to engage in human society as moral equals, such as communication, empathy, and creativity. In this way, social narratives position autistic people as being somehow less than human, and as such undeserving of equal moral standing.

In contrast to deficit-focused approaches, the neurodiversity paradigm's conception of the autistic experience as being the result of a natural variation in human cognition explicitly centers the inherent humanity of autistic people. As a result, the acceptance of the core tenets of neurodiversity theory forces us to reevaluate our understanding of what it means to be a human worthy of equal moral standing, calling into question moral frameworks which conceptualize human moral status as being inextricably tied to certain inherent properties, as any such framework will necessarily exclude certain individuals who are nonetheless inarguably human (Kittay 2017). This change of perspective is crucial to the social and political emancipation of autistic people and communities (as well as that of members of disabled communities more broadly.) Recognizing autistic people's humanity and capacity for self-determination necessitates acknowledgement of their right to have their strong interests heard and respected. Moreover, the neurodiversity paradigm's recognition of the value of embracing this natural variation in human cognitive function leads to the reframing of the support required by autistic people in terms of mutually beneficial community care. Autistic people can be seen not as a burden, but as valuable members of the community with something meaningful to contribute.

The second way the adoption of neurodiversity-affirming approaches can help dismantle interpersonal hierarchies of standing is by legitimizing and supporting autistic modes of communication, ensuring autistic people can communicate their strong interests and that those interests will be respected. The biomedical model labels autistic communication as inherently deficient. As noted earlier, as a result of the looping effect, labelling autistic people as being incapable of effective communication affects both autistic people's self-understanding and others' perceptions of autistic people, often in a self-reinforcing manner. Allistic people are more likely to dismiss autistic people's attempts at communication, assuming it is pointless to attempt to understand someone incapable of intelligibility. Autistic people, in turn, are likely to respond to routine experiences of hermeneutical injustice either by attempting to force themselves to adopt socially accepted allistic modes of communication (leading to further difficulties in expressing themselves and worsening mental health, Cage et al. 2018) and may even abandon attempts to communicate altogether. In this way, the biomedical model's labelling of autistic communication as inherently deficient leads to persistent, systemic epistemic injustice which prevents autistic people from communicating legitimate claims regarding their own strong interests.

Neurodiversity theory recognizes that uniquely autistic modes of communication can be both highly adaptive and effective, and that there is a mutuality to autistic-allistic communication barriers. Thanks to the looping effect, the very act of amending the label of 'autism' to decouple autistic communication differences from a conception of deficiency is likely to have beneficial consequences in terms of overcoming social hierarchies of standing. Allistic lay people, whose perceptions of autistic people are influenced by the psychiatric models constructed by medical institutions, are less likely to underestimate autistic people's abilities and are more likely to attempt to understand autistic expression. The recognition of autistic communication and ease the burden of cross-neurotype communication barriers. On one hand, researchers can investigate the modes of communication which come most naturally to autistic people and find ways to support autistic people in engaging with those modes of communication. It is reasonable to conjecture that this will provide autistic people with the appropriate tools to effectively communicate their interests without being forced to alter their modes of expression in accordance with the neurotypical 'norm'. On the other hand, it might also be possible to introduce peer-education interventions to help improve allistic community members' understanding of autistic expression. Such peer-targeted interventions may help ensure that the burden of overcoming cross-neurotype communication barriers is shared and that allistic people will be more likely to understand and embrace autistic modes of communication. In turn, this may facilitate communication between autistic and allistic community members, and in so doing may help ensure autistic people's legitimate claims are understood and respected, reducing unjust hierarchies of standing.

Finally, the adoption of the neurodiversity paradigm can help alleviate unjust hierarchies of standing in the interpersonal context by reframing medical conceptions of autistic quality of life, increasing awareness of the unique factors which contribute to a characteristically autistic form of well-being. All people have a strong interest in quality of life. However, as discussed in previous chapters, for autistic people well-being requires being able to engage in naturally autistic modes of expression and connection to the world (Milton and Bracher 2013). As noted earlier, within the framework of the biomedical model, autism is seen as a fundamental impediment to quality of life resulting from internal impairment. Under this view, autistic well-being is either dismissed as an impossibility, or understood to only be achievable through the use of interventions which seek to alter the autistic individual's modes of communication and cognition in order to align with an idealized neurotypical norm. As a result, autistic people's interests in self-determination are not seen as morally weighty, nor are their interests in ensuring a high quality of life while expressing themselves authentically and engaging in natural modes of

being. Autistic people are denied the right to live and express themselves in ways which come naturally to them, and as such are not treated as moral equals.

In contrast, the neurodiversity view recognizes that challenges to autistic well-being are as much a result of disabling social environments as they are a result of individual characteristics and that autistic modes of cognition are distinct but not deficient. As such, it can be understood that not only is autistic well-being possible, but it is also dependent on the ability of autistic people to both embrace and express uniquely autistic ways of being to which they are naturally inclined. This understanding allows the medical community to reframe its approach to autistic care and support, recognizing that autism is not an inherent barrier to well-being and that external socio-environmental factors can negatively impact autistic well-being. Through this change of perspective, autistic people might come to be seen not as fundamentally broken or deficient, but as a socially marginalized group. The scientific community might then begin to imagine novel approaches to overcoming that marginalization, shifting focus towards the reduction of social stigmatization using interventions designed to educate allistic community members about autistic communication and expression. In turn, the application of such community-focused educational interventions might lead to a measurable impact on the way allistic lay people perceive and interact with their autistic peers (Kim et al. 2023).

#### 3.3.2 Hierarchies of Esteem and Epistemic Injustice

While the adoption of the neurodiversity paradigm invites an understanding of humanity and, accordingly, moral status as independent of the possession of certain inherent abilities, it also allows us to recognize skills and abilities many autistic people possess which have historically been overlooked or dismissed as a result of stigmatizing attitudes which reinforce unjust hierarchies of esteem. Even when moral worth is understood as independent of a person's abilities, there is a clear injustice done to a person when they are assumed to be incompetent based on their membership in a particular social group or the manner in which they express themselves, rather than recognizing that individual's competence based on an unbiased evaluation of their abilities. Moreover, such assumptions of incompetence can have a detrimental effect on a person's abilities. This can be understood as a consequence of the looping effect, wherein the perceived lack of ability associated with the human kind labelled 'autistic' becomes self-reinforcing. As a specific example, many non-speaking autistic people are able to communicate effectively through the use of alternative and augmentative communication (AAC) tools such as communication boards and speech-output devices. Yet, for years, the prevailing belief among medical practitioners was that spoken voice was a superior form of communication and that the introduction of AAC hindered further speech development, a claim which has been subsequently disproven (Romski and Sevcik, 2005). When children who would otherwise benefit from the use of AAC are deprived access to these tools as a result of such erroneous beliefs, their ability to develop communication skills is often, in fact, hindered.

When biomedical models position autistic people as inherently deficient, incapable of effective communication, meaningful human connection, or individual well-being, they reinforce problematic cultural narratives which lead allistic lay-people to treat their autistic peers in ways incompatible with relational equality. Autistic people are viewed as objects of pity, as unworthy social interlocutors, and as unreliable narrators of their own subjective experiences. These cultural narratives reinforce unjust hierarchies of esteem which position autistic people as

inherently inferior, leading to widespread social exclusion and the subjection of autistic people to persistent epistemic injustices.<sup>15</sup> The adoption of social and scientific practices which align themselves with the core tenets of the neurodiversity paradigm could encourage the recognition of, and in turn the nurturing of, the natural strengths and abilities possessed by autistic people which have historically been overlooked. By recognizing the mutuality of communicative barriers between autistic and allistic people, autistic communication can be understood as offering unique and valuable perspectives, rather than as a 'broken' or fundamentally deficient way of interacting with the world. Autistic people can be understood as capable of making meaningful contributions to society and their communities, even when those contributions do not conform to traditional expectations. When these understandings are incorporated into mainstream cultural narratives about what it means to be autistic, allistic laypeople may become more likely to regard the autistic people with whom they interact as capable epistemic agents and worthy social interlocutors, challenging unjust hierarchies of esteem.

#### Conclusion

This chapter has argued that embracing the neurodiversity paradigm in autism research can help overcome some of the many inequalities faced by autistic people in our society. The neurodiversity paradigm recognizes autism as a natural variation in human cognitive function.

<sup>&</sup>lt;sup>15</sup> Although the primary focus of the present argument involves the detrimental effects of relational inequality for autistic people in particular, it should also be noted that this state of affairs has a detrimental effect for society as a whole. Although it is important that autistic people are respected and valued independently of their potential contributions to society, it has also been argued that embracing the inarguable diversity of human cognitive function serves as a source of creative potential which drives social and scientific progress, and the epistemic disablement which results from excluding certain kinds of people from communal projects of knowledge production therefore hinders this progress (Armstrong 2015, Osler 2022, Axbey et al. 2023).

This perspective allows for the development a more holistic understanding of autism that recognizes strengths and neutral differences. It also prompts acknowledgement of autistic people's unique positionality to understanding autistic ways of being and recognize the value of autistic people's contributions to research. In turn, the adoption of participatory research methods which center autistic voices and ensure research priorities are tailored to the needs of the autistic community will ensure a more equitable distribution of resources. It may also allow for improvements in medical care for autistic people by deepening empirical understandings of autistic cognition and communication and fostering the development of novel approaches to support uniquely autistic manifestations of well-being. In addition to helping overcome distributive inequalities in healthcare, the adoption of neurodiversity-affirming research methods may support the relational equality of autistic people in both institutional and interpersonal contexts. Novel approaches to scientific modelling which challenge the traditional focus on autistic deficits and emancipatory research methods which center autistic voices serve to dismantle existing hierarchies of power and esteem in research institutions, and challenge cultural narratives which position autistic people as inferior to their allistic peers.

# **Final Conclusion**

This thesis has argued that the shift towards the neurodiversity paradigm in autism research is important for both methodological and ethical reasons. This shift provides the opportunity for the development of more holistic and actionable explanatory models of autistic cognition, as well as the introduction of novel approaches to care and support. Expanding scientific understandings of autism beyond the traditional deficit-focused lens of the biomedical paradigm will also foster the conditions required to achieve both distributive and relational equality for the autistic community.

Chapter one provided a brief introduction to the current paradigm shift in the field of autism research. This chapter gave an overview of the history of autism research and the rise of the neurodiversity movement. The current trend towards neurodiversity-affirming approaches in autism research was situated within the context of changing approaches to disability modelling more broadly. An overview was provided of the methodological and empirical failures of biomedical approaches in autism research which have necessitated a change in approach. Thomas Kuhn's concept of paradigm shifts was introduced as one way contextualize the current trends in autism research. However, it was argued that in, the case of human sciences, sociopolitical and relational factors are relevant to choice of scientific models for both ethical and methodological reasons. Finally, the core tenets of the neurodiversity paradigm and the practical implications of its adoption were considered in more detail.

Chapter two offered a detailed consideration of a number of distributive and relational inequalities which can be directly connected to shortcomings of the biomedical paradigm. It was argued that there currently exist inequalities in the distribution of resources available for

research, with the autistic community's research priorities being routinely overlooked. Moreover, autistic people are offered an inferior standard of medical care compared to their allistic peers due to limited understandings of autistic well-being. This results in the unfair curtailment of their opportunities to achieve welfare. It was also argued that autistic people are subject to relational inequalities in both institutional and interpersonal contexts. These relational injustices are characterized by ableist social hierarchies and persistent epistemic injustices and can be directly connected to the deficit-focused definitions of autism developed within the biomedical paradigm.

Finally, chapter three considered how the shift towards the neurodiversity paradigm offers a path forward in overcoming both distributive and relational inequalities. It was argued that the adoption of the neurodiversity paradigm encourages the scientific and medical communities to move beyond a deficit-focused conception of autism and embrace the value of autistic contribution in the field of autism research. The recognition of autistic people's experiential expertise on the subject of autism motivates the use of participatory and emancipatory research approaches, challenging established hierarchies of power, standing, and esteem in both institutional and interpersonal contexts.

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