‘Much better set up to do my best work’: What does ‘neurodiversity-affirming practice’ mean to the autistic community?

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Abstract

The term ‘neurodiversity’ has had a substantial impact on research, policy, practice and discourse since being coined in 1998. More recently, literature has begun to discuss neurodiversity-affirming (NDA) practice, while some professionals advertise their services as NDA. However, what is meant by NDA practice is presently unclear, with little research on the topic. The neurodiversity movement has emerged from the autistic self-advocacy movement, which argues for autistic empowerment in the development of autism research and practice. Thus, this thesis argues that to conceptualise NDA practice, insight should be sought from the autistic community.

A novel qualitative survey was co-produced with 7 autistic community collaborators. Responses from 44 autistic individuals, including 19 autistic professionals describing their practice as NDA, were analysed using reflexive thematic analysis. Six themes were generated. These related to NDA practices as a philosophical orientation, with professionals engaging reflexively with the neurodiversity perspective of autistic differences. Learning from autistic community-generated knowledge, and redefining “normal” to include autism, rather than seeking to normalise autistic people, were interpreted to be fundamental to NDA practices. It seemed NDA practices would include a ‘culture of acceptance’, embracing the strengths, needs and complexities of individuals and neurodivergent communities, and would seek to reduce autistic minoritisation. Potential benefits of this approach were viewed as reduced anxiety, a reduced need to ‘mask’ with professionals and a reduced sense of burdensomeness; all potentially facilitating greater access to, and engagement with services.

It is suggested professionals may reflexively consider the values, beliefs and paradigms that are reflected in their choice of interventions, language and outcomes. To develop NDA practices, professionals and researchers should consider co-production with the autistic community. Further work is necessary to understand NDA practices from the perspective of non-autistic neurodivergent communities.

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Lastly, thank you to my family – a magnificent constellation of neurodiversity – for starting me on this quest to understand and celebrate the complexities of human development. My endeavour to solve the mystery of “the Naylor Gene” is, in part, the reason my interest in psychology began at age 13, and why, years later, I connected so powerfully with the notion of neurodiversity. The human tapestry is a beautiful one, in which we all belong. I hope I have done us proud.

Chapter 1: Introduction

Through this research, the researcher aimed to develop insight into the concept of neurodiversity-affirming (NDA) autism practices, from the perspective of the autistic community. This thesis begins with a review of literature, focusing on the growth of the neurodiversity paradigm and related concepts, the conceptualisation of autism over time and the influence of the neurodiversity movement on current autism research and practice (Chapter 2). Chapter 3 begins with the philosophical foundations of the research. It then describes the qualitative research design, the co-creation of a novel survey, the survey respondents, and the reflexive thematic analysis approach to interpreting the data. Outcomes of the analysis are presented in Chapter 4. Findings are then discussed in Chapter 5, in relation to existent literature, the researcher's positionality, and implications for researchers, professionals and the autistic community. Chapter 6 presents the summary and conclusions of this research.

1.1. Relevance and Value

Since its emergence 25 years ago (Singer, 1998) the concept of neurodiversity has had a notable influence on research, policy and public perception of neurodevelopmental differences. Within academia, recent years have seen the creation of major neurodiversity-focused research centres, such as Durham University's Centre for Neurodiversity and Development (Durham University, n.d.), and new interdisciplinary research journals focusing on neurodiversity (e.g., *Neurodiversity*, established by Sage Publications (Sage, n.d.)). Noteworthy organisations are also beginning to publish neurodiversity policies, including GMB Union (representing 500,000 UK workers; GMB Union, n.d.) (GMB Union, 2018), the Royal College of Nursing (2022) and health insurer Bupa (2022). The influence on public media is also apparent, with major news outlets, such as ITV, having pages dedicated to reporting neurodiversity-related articles (ITV News, n.d.). News articles have included spreading public awareness of a recently conceived 'Neurodiversity Celebration Week' (Smith, 2022, March 23), occurring in March of each year, which aims to 'change the narrative' on neurological differences (Neurodiversity Week, n.d.).

Despite the clear relevance of neurodiversity to today's society, it will be demonstrated through this thesis that neurodiversity remains an under-researched area and its meaning is still unclear in many ways. While groups (particularly autistic advocacy groups) campaign for practice and policy to be informed by the neurodiversity concept (Autistic Self

Advocacy Network (ASAN), 2021), there is very little research on what this may look like. The present thesis makes a novel contribution to the fields of neurodiversity and autism research by gathering insights from the autistic community on how NDA practice is conceptualised. Implications can be drawn for a wide range of professionals, including educators and Educational Psychologists.

1.2. A Note on Language Choices in this Work

Throughout this work, “autistic people” is used in place of “people with autism”. This follows guidance published by the National Autistic Society (n.d.), NHS England (n.d.) and the National Institute for Health and Care Excellence (NICE, 2023), among other influential organisations. The use of identity-first language (IFL; “autistic person”) follows a wealth of evidence that IFL is preferred over person-first language (PFL) by a majority of the autistic community, across numerous countries (e.g., Bonnello 2018; Bonnello 2022; Bury et al., 2023; Crane et al., 2021; Geelhand et al., 2023; Kapp et al., 2013; Keating et al., 2023; Kenny et al., 2016; Taboas, Doepke & Zimmerman, 2022). While much of the existing evidence comes from adult samples, recent evidence from an international survey including 832 under 19s suggests this age group, on the whole, also prefer to be described as “autistic” (endorsed by 92.5% of respondents), rather than young people with autism (endorsed by 23.7%) (Bonnello, 2022). Young people preferring ‘autistic child/young person’ to replace PFL was also found by the UK’s Autism Education Trust (AET), after consulting their ‘Autistic Young Experts’ panel (AET, 2021). While using IFL throughout this writing, the term “autistics” is also occasionally used, where this flows better than “autistic people”. “Autistics” to refer to autistic people is increasingly used as part of autistic community discourse (Bonnello, 2022; Keating, 2023).

Additionally, many terms frequently applied to autism, such as ‘deficit’, ‘disorder’, ‘impairments’ and ‘condition’ are generally not used in this work, except where necessary to the context (for example, where medical terminology is discussed). As will be elucidated further throughout the chapters of this thesis, evidence indicates such terms are not widely accepted by autistic people (e.g. Keating et al., 2023). As will become clearer, they also do not align with the researcher’s views or attitudes. Where such terminology has been used in this work, it is generally surrounded by inverted commas, to indicate this is not the author’s own language choice. It has been argued that language cannot be neutral; that language is inherently tied to an ideology, and actively constructs meaning (Bottema-Beutel et al., 2021).

The terms used throughout this thesis have been intentionally chosen, not just to respect community preferences, but as a form of resistance to discourse that has traditionally defined the community without their input.

1.3. Introduction to Key Terms

Note that the key terms ‘neurodiversity’, ‘neurodiversity-affirming practice’ and ‘autism’ are defined here only briefly and loosely, as they are discussed and problematised throughout this work.

Autism – Constructs of autism differ widely. For example, some define autism by the Diagnostic and Statistical Manual 5th Edition (DSM-V) diagnostic criteria for Autism Spectrum Disorder; a neurodevelopmental disorder characterised by social communication deficits and restricted and repetitive patterns of behaviour (APA, 2013). Others define autism as a form of human diversity best considered in terms of strength and difficulty, and the extent to which societal factors may exacerbate difficulties (Gillespie-Lynch et al., 2017). These conceptualisations, and others, are discussed in Chapter 2.

Autistic community – There is limited literature attempting to define the notion of an autistic community, but Botha (2019) offers some discussion of the concept. This research adopts an understanding of autistic community which aligns with descriptions by Botha (2019); people with a shared identity (i.e. ‘autistic’) who exist within a shared space, whether physical, virtual, or ideological.

Disability – The term ‘disability’ can be understood through different paradigms (described in Chapter 2). It is recognised that ‘disability’ means different things to different groups. This work uses the term ‘disability’ to refer to it as being the outcome of a social process through which a person becomes disabled by unaccommodating environments (as used by Oliver, 1990; the social model of disability). It is also used to refer to an aspect of a person’s identity, in place of terms such as ‘condition’ or ‘disorder’; i.e., ‘*neurodevelopmental disability*’, as opposed to neurodevelopmental disorder. Many autistic advocates align with disability rights advocates, and consider both autism and ‘disability’ to be an (aspect of) identity, and something which is neither good nor bad (Andrews et al., 2019; Price, 2022). Others consider themselves to have limitations that contribute to disabling them; this is discussed in section 2.3.3.2. regarding the social-relational model of disability (Thomas, 1999).

Epistemic (in)justice - Epistemic injustice refers to the dismissal or devaluation of knowledge generated by certain groups, in favour of knowledge created by other groups (Catala, 2015). Conversely, 'epistemic justice' is discussed in this thesis in relation to valuing lived experiences and (autistic) community-generated knowledge as valid sources of knowledge about autism.

Epistemology – The philosophical study of knowledge, what constitutes knowledge, and how something can be known (Moore, 2005). See also, ontology.

Minoritisation – Selvarajah et al. (2020) define minoritisation as a process of actively diminishing the 'cultural, economic, political and social power' of a nondominant group, based on their identity (e.g. ethnicity, geographical location), to maintain the power of a dominant group. The term concerns distributions of power, not group size; groups can be minoritized even where they constitute the numerical majority (Selvarajah et al., 2020).

Neurodivergent – falling outside of social expectations for typical neurocognitive development (Kapp, 2020). It is argued in this thesis that neurodivergent can be considered to be a social category referring to people who are minoritised through being socially and/or medically seen as 'disordered'.

Neurodiversity – It is argued 'neurodiversity' is generally used in three contexts (as proposed by Hughes, 2020): 1) a positivist assertion of human neurological variation as fact; 2) a set of assertions about diversity in human neurocognition, which form the paradigmatic foundation of the neurodiversity movement; and 3) a social movement aiming to change the ways neurological differences are conceptualised by society.

Neurodiversity-affirming (NDA) practice – loosely, the author considered NDA practice to mean a style of practice that is discussed by, and advocated for by those who align with a neurodiversity perspective. This is explored and further conceptualised throughout this thesis.

Othering – 'the act of treating someone as though they are not part of a group and are different in some way' (Cambridge Dictionary, n.d.).

Ontology – The philosophical study of the nature of reality (Moore, 2005). This is closely linked with epistemology (how reality can be known) (Moore, 2005). Ontology (and epistemology) are considered at several points within this thesis, in relation to whether concepts (such as autism) are objectively real entities that can be understood in their own right, or whether they are socially constructed, with their meaning being inseparable from those who identify with them.

1.4. Researcher’s Personal and Professional Interest in the Topic

The researcher first encountered the concept of neurodiversity during a Master’s lecture on childhood ‘disorders’ of development. Having only encountered medical, deficit-based discourse about autism during undergraduate study, work with autistic children, and societal discourse, the brief recognition of an alternative conceptualisation was intriguing. Several years later, neurodiversity seemed to appear more regularly in public discourse. This prompted many hours of research and reflection, leading to an interrogation of everything the researcher previously learned and understood. It also led to discoveries and new insights within the author’s personal life.

Upon starting Educational Psychology training, the author was interested in deepening their understanding of how the neurodiversity paradigm relates to psychology and education. Early in the training, they connected deeply with the idea of epistemology (i.e., what constitutes knowledge, and how can it be generated) and, particularly, epistemic (in)justice. This provided language through which to reflexively consider the role of the Educational Psychologist in creating knowledge about children and social groups. The author perceived there to be an opportunity for further discussion within the field about how groups (particularly those identifying as neurodivergent) are defined, and who has the right to define them.

Through ongoing engagement with the literature, and with neurodiversity and autistic advocates, the author developed an interest in a neurodiversity-aligned educational psychology practice. This was considered when generating a research topic, however, it became apparent that a neurodiversity-aligned (often referred to in literature as ‘neurodiversity-affirming’ (NDA)) style of practice had yet to be clearly conceptualised. It therefore seemed that, to create a strong foundation for NDA educational psychology work to be explored, the researcher ought to first consider what NDA practice might mean more generally.

The researcher recognises their position as closely connected to autism and the autistic community. They have close relationships with autistic individuals and otherwise neurodivergent individuals. They have encountered various views on what it means to be autistic after 9 years of education in psychology, but until relatively recently, none of these had come from autistic people themselves. Deliberate and active engagement with autistic voices over recent years has motivated the researcher to centre autistic voices in autism knowledge generation, and the development of policies and practices concerning autistic people. Given also that autistic people have been the trailblazers of the neurodiversity movement, it was decided that this community would be a good place to start to understand NDA practice.

Chapter 2: Literature Review

2.1. Introduction to Chapter

In the following chapter, the concepts of neurodiversity, autism, and neurodiversity-affirming (NDA) practice are situated within their historical and present contexts. First, the emergence of neurodiversity as a concept, paradigm, and movement is discussed in relation to socio-political forces influencing discourse within society (such as the influence of psychiatry and medicine on conceptualisations of difference). As the present research focuses on autism as a subgroup of neurodiversity, evidence pertaining to autistic people (rather than other neurodivergent groups) is discussed throughout.

Secondly, the concept of autism is discussed. This is situated within its historical context, before a discussion of competing ontological and epistemological conceptualisations of autism is presented. Various attempts to explain autism-related differences are considered, comparing those which originated from accounts of lived experience, with those generated through researchers’ observations of autistic people.

Lastly, the present context of autism policy and practice is discussed. Consideration is given to how ‘good autism practice’ is defined. The sparse nature of literature and research addressing NDA practice is considered along with its practical implications. It is concluded that the field of NDA practice is in its infancy, with work needed to clearly articulate what is meant by the term. It is proposed that researchers should defer to neurodivergent communities for this. The research question is set out, before a brief discussion of this topic in relation to educational psychology practice.

2.2. Search Strategy

A narrative approach was taken to synthesising and reviewing existing literature. To understand the depth and scope of current research on autism, neurodiversity and related practice, both online databases and grey literature were searched. Databases searched included Web of Science, and Ovid Databases such as APA PsychArticles. Grey literature searched included the academic search engine Google Scholar and EThOS, the British Library thesis repository. Additional papers were identified by searching reference lists of relevant articles. Searches occurred in June 2022 and further searches occurred in January 2023, to identify newly published literature. A systematic literature review of research on NDA practice was also planned, as described in section 2.5.3.

2.3. ‘Neurodiversity’ and the Neurodiversity Movement – What Does it Mean?

2.3.1. Rise of an Ideology

The term ‘neurodiversity’ (credited to autistic sociologist Singer, 1998) emerged from discussion between Singer and journalist Blume (1998) about the importance of biodiversity for a species’ survival (as evidenced in, for example, Johnson et al., 2010) (Singer, 2017). This sparked the idea of neurologically-based human diversity, or *neuro*diversity (Singer, 2017). In their original thesis, Singer (1998) wrote of a vision of neurodiversity as a protected characteristic, like class, gender and race. By 2002, this idea was involved in academic debate; for example, the journal Feminist Disability Studies printed an article calling for the intersection of neurological differences and gender to be considered within the feminist movement (Huff, 2002). Since then, not-for-profit organisations (e.g. Neuroclastic), professional groups (e.g. Therapist Neurodiversity Collective) and advocacy networks (e.g. Autistic Self Advocacy Network (ASAN)) have been organised around the ideology.

As the neurodiversity ideology has grown, new terminology has expanded the concept. For example, the term ‘neurodivergent’ (ND; coined by Kassiane Asasumasu; Walker & Raymaker, 2021) has been introduced to describe those falling outside cultural norms for ‘typical’ neurocognitive functioning (ND) (Kapp, 2020). Conversely, ‘neurotypical’ refers to those conventionally considered to conform to socially normative neurocognitive functioning (Kapp, 2020). Some discuss other subcategories (‘neurotypes’) within neurodiversity, most commonly considered to be autism (see glossary of terms), dyslexia (difficulty with development of literacy; Snowling, Hulme & Nation, 2020) and attention deficit hyperactivity disorder (ADHD; disability related to the regulation of executive functions; APA, 2013) (Kapp, 2020). There is seemingly no consensus on who is considered neurodivergent, with some applying the term primarily to those with neurodevelopmental disabilities (e.g., Durham University, n.d.) and others extending it beyond this, for example, to acquired brain injury (e.g., Izuno-Garcia, McNeel & Fein, 2023) and some mental health diagnoses, such as bipolar disorder (e.g., Baker, 2011).

The precise meaning of ‘neurodiversity’ and its related terminology is currently unclear. Singer (2017) suggested the meaning of neurodiversity lies implicitly within the “myriad narratives” (p.19) of those who identify with it, making it difficult to define. The remainder of this section will examine the usage of the term across literature. It is argued ‘neurodiversity’ is generally used in 3 contexts (as proposed by Hughes, 2020): 1) a positivist assertion of human neurological variation as fact; 2) a set of assertions about diversity in human neurocognition, which form the paradigmatic foundation of the neurodiversity movement; and 3) a social movement aiming to change the ways neurological differences are conceptualised by society.

2.3.2. Neurodiversity as a Fact of Biology

At its most literal level, Singer’s concept of neurodiversity – that there is diversity within human neurological development, appears well supported. Neuroscientific evidence suggests brains can be distinguished from each other with a high degree of accuracy (Valizadeh et al., 2019), as brain structure and function is highly individual (Valizadeh et al., 2018). In this sense, many claim neurodiversity to be a scientific fact (e.g., Legault et al., 2021).

The claim of ‘neurotypes’ (i.e. clusters within neurological diversity), however, is less clearly evidenced. The prefixing of ‘neuro’ to ‘diversity’ has been argued to reflect laypersons’ growing awareness of neuroscience (Ortega, 2009; Rose, 2007) and increasing attribution of the human condition to a biological organ (Sarrett, 2016). Fletcher-Watson (2022) described category labels like autism and ADHD as referring to clusters of neurological differences. Neurodiversity appears to be used in such discussions to refer to a concept of ‘cerebral pluralism’; an assertion that all brains are different, but some are more different than others (Tougaw, 2018).

There is ongoing debate around the empirical existence of such clusters. While prominent medical texts (e.g., DSM-V; APA, 2013) categorise ‘conditions’ such as autism based on common phenotypic features (e.g. social communication difficulty; APA, 2013), other approaches reject the validity of discrete diagnostic categories. Transdiagnostic approaches dismiss the idea that diagnostic categories reflect ontologically distinct profiles (Astle et al., 2021). Diagnostic categories lack specificity – for example, needs, difficulties and experiences can vary widely among people with the same diagnosis - and often overlap (e.g., between 30-70% of people with either ADHD or autism diagnoses, also fit criteria for the other; Joshi et al., 2017) (Astle et al., 2021).

Neuroscientific research investigating neurological correlates of neurodevelopmental diagnoses finds mixed results. Kushki et al. (2019), following analysis of neuroimaging data, did not find evidence of autism or ADHD as neurologically distinct groups. However, a recent, large-scale analysis of neuroimaging data (Vandewouw et al., 2023) did evidence clustering within neurology. Based on analysis of 551 participants' data, where participants either had an autism, ADHD, or OCD diagnosis, or no diagnoses, homogenous groups of neurobiological features were identified. These features did not cluster around diagnoses (i.e. participants with autism diagnoses did not consistently share neurobiological features), but were associated with behavioural phenotypes; phenotypic commonalities were associated with similar neurological differences. This appears to suggest there are some potential clusters within human neurodiversity. However, this is a recent study that requires replication to test the robustness of these findings. Currently, whether 'neurotypes' have any basis in neurology remains unclear.

Some suggest establishing a factual basis for cerebral pluralism is unnecessary to the neurodiversity paradigm, or neurodiversity movement. Fletcher-Watson (2022), for instance, argued neurodiversity has relevance to autism research whether or not autism represents an empirically discrete category. Neurodiversity may be best considered as a set of values, rather than assertions about human neuroanatomy.

2.3.3. Neurodiversity as a Social Condition

Some define neurodiversity in relation to social dynamics, such as power. 'Neurodivergent' is argued to be a social category that results from groups being assigned a status of 'disordered' (e.g., Legault et al., 2021). In this way, neurodivergent refers to groups minoritised through social and medical stratification of people into 'normal' and 'abnormal'. It is argued, therefore, that neurodiversity represents a resistance to this minoritisation, and a way to redefine and feel pride in a minoritised identity (Jaarsma & Wellin, 2012). This section considers the values and beliefs asserted by the neurodiversity paradigm and movement.

2.3.3.1. Neurodiversity as a Paradigm.

The neurodiversity paradigm does not have unified claims or arguments, making it difficult to define (Chapman, 2019; Hughes, 2020). However, autistic academic and neurodiversity proponent, Walker (n.d.), proposed 3 principles that have been influential in academic debate (Hughes, 2020). The first claim is that neurodiversity is natural and valuable. Research suggests many autistic people consider autism to be part of their biological make-up (Botha et al., 2020; Kapp et al., 2013). This has received criticism, however, given that 'natural' is an ambiguous term and therefore claims of neurodiversity as a natural entity are difficult to validate (e.g. Hughes, 2020; Nelson, 2021). This claim also appears to be predicated on empiricism, thus shares the same difficulties as the claims for neurodiversity as fact, discussed above (Chapman, 2020). Some therefore reframe the assertion of ‘naturalness’ as community rhetoric (e.g. Hughes, 2020).

Regarding value, there are assertions that neurodiversity is essential for humanity to ‘survive and flourish’ (Chapman, 2019, p.374) and for ‘cultural stability’ (Singer, 2017, p. 67). Some support this by highlighting autistic people have led innovation in a range of fields (Baron-Cohen, 2011). However, this introduces an ethical difficulty, in that it appears to predicate the value of neurodiversity on its usefulness to society. This perhaps risks devaluing neurodivergent people who are unable to contribute capitalistic value to society (Fletcher-Watson, 2022). Others appear to argue neurodiversity is valuable by virtue of its existence. Anderson (2013) compared the range in human neurodevelopment to the range in cultures and languages, framing neurodiversity as inherently deserving of respect, rather than something to be valued solely for its utility.

The second claim of the neurodiversity movement, as asserted by Walker (n.d.) is that assertions of “normal” and “right” neurodevelopment are social judgements, rather than empirically supported. Psychiatry is widely accused, within and beyond the neurodiversity movement, of being influenced by politics and society, rather than science (e.g. Latif, 2016; Nelson, 2021). Some argue psychiatric diagnoses (such as autism; APA, 2013) create and enforce social norms, with psychiatric categories being ratified by psychiatry’s association with medicine, rather than by scientific evidence (Latif, 2016). Examples of social norms perhaps influencing psychiatry include the past pathologisation of homosexuality (Drescher, 2015) and female ‘hysteria’ (now widely considered the pathologisation of behaviours that were undesirable to straight men; Devereux, 2014). The validity of autism’s inclusion in psychiatric diagnostic manuals is questioned by some who suggest, for example, that autistic people’s distress is an expression of a lack of acceptance and accommodation, rather than an inherent disorder (Jaarsma & Wellin, 2012). The neurodiversity paradigm offers a ‘corrective to the historical dominance of medical approaches’ (Hughes, 2020, p.48), making way for alternative perspectives to be heard.

The final assertion of the neurodiversity paradigm is that social dynamics, such as power inequalities, affect neurodiversity just as they affect other human characteristics (e.g., gender and race) (Walker, n.d.). Oppression is frequently discussed by neurodiversity proponents as a social dynamic disproportionately affecting neurodivergent individuals. It has been argued that autistic people experience oppression in several ways, for example, through marginalisation (a process of exclusion resulting in lower social status) and violence (Milton, 2016, building on work by Young, 1990)

Recent research would appear to support this assertion. For example, bullying and social rejection are evidenced to be common experiences for autistic people. Pfeffer (2016) found 61% of 262 children involved in the research, according to parental report, had experienced ‘teasing or emotional bullying’, and 40% experienced other forms of bullying. Overall, 89% of autistic children in this sample had experienced victimisation of some form, including sexual and physical violence. Though data was gathered through parental report methods, and children may have reported differently, the parent- and self- report versions of the measure used have high agreement (Finkelhor et al., 2005). Supporting Pfeffer’s (2016) findings, Gibbs et al. (2021), in a survey of 300 autistic and non-autistic people, found autistic respondents were significantly more likely to have experienced a history of childhood physical or sexual victimisation. Further, a recent systematic review of experiences of sexual victimisation suggests, particularly for autistic girls, disproportionately high rates of sexual victimisation also occur in adult life (Dike et al., 2022).

There is purported to be an ‘autism mental health crisis’ (Mandy, 2022), with suicide being substantially overrepresented as a cause of early mortality among autistic people (Cassidy et al., 2014; Hirvirkovski et al., 2016). Evidence suggests a high correlation between victimisation and suicidality in autistic people (Holden et al., 2020), while others’ acceptance of autism (as perceived by autistic people) is found to be predictive of better mental health (Cage, DiMonaco & Newell, 2018). Together, this research begins to suggest ‘marginalisation’ and ‘violence’, at least, are forms of oppression frequently experienced by autistic individuals, with negative outcomes. The neurodiversity paradigm has become the foundation of a social movement advocating for this to change.

2.3.3.2. Neurodiversity as a Movement.

Walker (n.d.) defines the neurodiversity movement as: ‘a social justice movement that seeks civil rights, equality, respect, and full societal inclusion for the neurodivergent’. This aligns with the original usage of the term ‘neurodiversity’, which was primarily an argument for equal rights for those who experience ‘othering’ (see section 1.3.) because of their cognitive functioning (see Singer, 1998). Some objectives of the neurodiversity movement, as described in literature, will be briefly discussed.

According to den Houting (2019), the neurodiversity movement asserts that different thinking and processing styles should be respected as an integral aspect of personhood. Research suggests autistic people commonly view autism as biologically and psychologically inseparable from who they are (Botha et al., 2019); the perceived association between autism and the self may explain neurodiversity proponents' resistance to medical definitions of autism. Casanova & Widman (2021) argued that the brain and behaviour are intimately associated with ones' core sense of self. Thus, classifying autistic features as disordered is, perhaps for some, tantamount to labelling one's whole personhood disordered (Hodge, Rice & Reidy, 2019).

Other literature (e.g. Mandy, 2022) suggested the neurodiversity movement advocates for disability to be understood through an assessment of the person-environment fit. This appears to align with the social model of disability, which is frequently preferred by neurodiversity advocates over medicalised definitions of disability (Chapman, 2020). Social models of disability assert that people are disabled, or restricted, not by their individual limitations but by a failure of society to accommodate them (Oliver, 1990; 2013). This is in contrast to medicalised approaches to disability, where disability is considered to be directly caused by one's physical or cognitive differences (Thomas, 2004). Research appears to support arguments that the environment can be disabling; for example, 18 autistic school students interviewed in a qualitative study (Costley et al., 2021) reported the sensory environment and unpredictability within school prevented their wellbeing and full participation.

However, some criticise the social model's denial of a causal relationship between disability and individual limitations (or 'impairments'; Oliver, 1990; as explained in Section 1.2., 'impairment' is not preferred terminology of the autistic community). Morris (1991), for instance, argued that physical and intellectual limitations can play a significant role in determining the life experiences of disabled individuals; not just society's response to a person's limitations. Moreover, In regards to autism, autistic writer Mitchell (2007) has criticised the model, asserting that his status as a non-speaking person means he has a limitation that would detrimentally impact his life even if society were more accommodating of non-speaking people. The social-relational model of disability is therefore proposed as an alternative, which opposes the dualism of both the medical and social models' arguments about society *or* 'impairments' as the cause of disability. Instead, it argues that some individual limitations (such as being non-speaking; Mitchell, 2007) can be disabling in and of themselves, but social factors play a key role in either exacerbating, or ameliorating a person's disability (Thomas, 1999). Neurodiversity advocates, Dawson, Franz & Brandsen (2022, p. 839) argued that: 'if we are a society that values diversity, the onus should be on society to change, not the autistic individual.' Both social and social-relational models of disability seem to support this idea, by highlighting the crucial role that society has in accommodating diverse needs.

A further objective of the neurodiversity movement has been identified as reducing the stigma neurodivergent people experience (Dawson et al., 2022). There is a range of evidence suggesting stigma is regularly experienced by neurodivergent people. Wood and Freeth (2016) surveyed layperson's perceptions of autism and found the 5 most common responses were negative stereotypes (e.g. 'difficult personality') and usually deficit-based (e.g. 'poor social skills', 'poor emotional intelligence'). A systematic investigation into experiences of autism stigma found the prevalence of stigmatised views negatively impacted the wellbeing and social inclusion of not only autistic people, but their carers (Kinnear et al., 2016). It therefore seems unsurprising that qualitative research suggests autistic people's sense of self is negatively impacted by others' stigmatised attitudes (Botha et al., 2019). Examples of stigmatised views frequently reported by caregivers of autistic people include: beliefs that autistic people cannot be good friends, are a threat to others, and cannot have a job or marry (Kinnear et al., 2016).

Finally, another common goal of those identifying with the neurodiversity movement is increasing the inclusion of autistic people in decisions about autism-related research, policy and practice (Dawson et al., 2022). Advocacy for greater involvement of neurodivergent individuals in research appears to have had a substantial impact. Numerous guidelines have recently been published for the ethical and meaningful inclusion of neurodivergent people in research (e.g., Cascio et al., 2020; Fletcher-Watson et al., 2019, 2021; Nicolaidis et al., 2019; Strang et al., 2019). Research by Pellicano, Dinsmore & Charman (2014) suggested autistic people commonly share priorities for future policies and practices. Through interviews, focus groups and a survey of autistic people's views on the future of autism research, consensus emerged on a number of priorities; primarily, that research should focus on improving autistic quality of life, rather than ‘curing’ autism (Pellicano et al., 2014).

2.4. Autism

2.4.1. Situating Autism Within its Past

‘Autism’ derives from the Greek ‘autos’ (Silberman, 2015), meaning ‘self’, or to describe being by oneself (etymonline.com, 2022). Paediatric psychiatrist, Kanner, is credited with first describing an “autistic” child in 1943 (Kanner, 1943). He identified 11 children in his clinic who seemed happiest in their own company, enjoyed the repetitive motions of objects and seemed to exist in their own world (Silberman, 2015). Many were non-speaking and were assessed as delayed in their learning (Wing, 1997b).

Autism became a diagnostic term in 1977, initially described as a childhood psychosis (International Classification of Disorders 9th Edition (ICD-9), WHO, 1977). Autism was then redefined as a ‘pervasive developmental disorder’ (PDD), with the publication of the 3rd Edition of the Diagnostic and Statistical Manual (DSM-3; APA, 1980). Multiple autistic diagnoses were described; “infantile autism” (describing signs of autism identified by Kanner), “residual” infantile autism, (children or adults who presented with infantile autism early in life but developed to have predominantly social difficulties), and “atypical PDD” (features of autism not fitting full criteria for infantile autism or other PDDs) (APA, 1980). Though the present spectrum concept of autism (Wing & Gould, 1979) had yet to be formalised, it appeared a range in autistic presentations was recognised by 1980.

Autism diagnoses were further reconceptualised with the addition of Asperger’s Syndrome in ICD-10 (WHO, 1992) and DSM-4 (APA, 1994). Asperger’s Syndrome was classified as a subcategory of autistic conditions (APA, 1994; WHO, 1992) based on descriptions of patients at Austrian physician, Asperger’s, clinic (Wing, 1997b). Asperger’s observations were similar to those of Kanner, though patients presented with good verbal skills (Rosen et al., 2021). The addition of Asperger’s Syndrome seemed to represent a broadening of the range of recognised autistic presentations.

The most recent major shift in medical definitions of autism occurred with the publication of DSM-V (APA, 2013; recently revised; APA, 2022) and ICD-11 (WHO, 2018). Existing autistic diagnoses were replaced with ‘Autism Spectrum Disorder’ (ASD) to locate all presentations within one ‘spectrum’ (Wing, 1997a). The change followed debate that

Asperger's Syndrome represents a 'milder' autism (Wing, 1997a). Accordingly, a 3-level severity indicator was introduced with ASD (1 being least, 3 being most 'severe symptoms' of ASD; APA, 2013). However, the validity of this has been questioned, with findings that there is no clear distinction between the levels (Weitlauf et al., 2014), making them somewhat arbitrary.

Autistic writer, Lynch (2019), argued assigning levels to a spectrum is conceptually inconsistent, suggesting levels imply a gradient rather than spectrum, with autism existing in degrees. Rather, they argued the autism spectrum is multidimensional, with each trait varying along its own spectra, much like the colour spectrum (Lynch, 2019). This alternative model has also been proposed by academics (e.g. Pickles and Angold, 2003). Criticism of the linear spectrum concept seems prevalent within the autistic community; fewer than 7% of respondents in a survey of 7,491 autistic people supported the use of 'mild/moderate/severe' (see Bonnello, 2022). Severity labels are still used in the recently revised edition of DSM-V (APA, 2022), suggesting some inconsistency between those with lived experiences as autistic, and institutions (e.g. the APA) with the power to define the diagnosis.

2.4.2. How Many People are Autistic?

As conceptualisations of autism have shifted, so have prevalence estimates. Early prevalence rates estimated 2-4 people in every 10,000 were autistic (APA; 1980). Between 2000 and 2023, the Centre for Disease Control (CDC) estimates of autism diagnoses in 8-year-olds increased from 1 in 150 to 1 in 36 (CDC, 2023). However, there is evidence that many adults fit the current diagnostic criteria but remain undiagnosed (Lilley et al., 2021). Additionally, females appear to experience more delays in accessing diagnostic assessments on average (Gesi et al., 2021). Therefore, the CDC prevalence estimate of 1 in 36, which is based on diagnoses by age 8, may not reflect the total population prevalence.

While prevalence estimates have changed drastically, official estimates by sex have remained stable. The current ratio of 4:1 (boys:girls; CDC, 2023) has been quoted since Kanner's observations (Kanner, 1954). Increasingly, however, research has proposed females may be disproportionately more likely to hide autism traits, and be missed for diagnosis (e.g. Bargiela et al., 2016). Evidence suggests females, more than males, employ behavioural and cognitive strategies to compensate for (camouflage) autism traits (Wood-Downie et al., 2021). This may contribute to assessment delays, and females being significantly more likely than males to be misdiagnosed prior to autism diagnosis (Gesi et al., 2021).

Statistical modelling has recently contested evidence that there are more autistic males than females. McCrossin (2022) analysed autism diagnosis rates for families of attendees to an Australian clinic concerned with paediatric behavioural difficulties. From the data of 1711 families, it was calculated the prevalence of autism diagnosis among siblings of those first diagnosed at the clinic was 4 females to 3 males. It was assumed caregivers would be more aware of autistic traits in their other children where one child has already been diagnosed, thus the researcher assumed this sample to reflect the ‘true’ sex ratio in the general population. There are limitations to this research, for example, most diagnoses were given by the same practitioner. Therefore, is it unclear whether the diagnostic ratio represents the ‘true’ ratio, or the rate at which this particular practitioner diagnoses. However, it was reported that second opinions were sought where there was diagnostic uncertainty, and statistics were provided suggesting strong interrater agreement. Further research is needed to validate this finding across other settings and practitioners. Nevertheless, the wide discrepancy between the official CDC estimate, and the findings of this study, raises questions about the validity of evidence that there are substantially more autistic males than females.

Furthermore, some people self-identify as autistic without a formal diagnosis, and this is often accepted within the autistic community. Sarrett (2016) investigated this phenomenon by analysing discourse on a forum for autistic people. Reasons for community validation of self-diagnosis included decentring medical professionals as the experts on autism, and the utility of the autism label for facilitating self-understanding (Sarrett, 2016). The CDC (2023) statistic of 1 in 36 thus also does not capture those who are considered by the community to be autistic but who are not diagnosed. This does however raise important questions around who is autistic, who is not, and how and by whom this can be determined.

2.4.3. Ontology of Autism; is it ‘Real’?

‘Even if autism is no more than a social construct, we should not underestimate the power of social constructs’

- Bovell (2005, p. 87)

Ontology is a branch of philosophy concerned with defining the nature of reality (is there an objective reality, or is reality subjective?), while epistemology asks how knowledge can be known, and what counts as knowledge (Moore, 2005). Philosophical questions about knowledge and reality can be applied to the concept of autism - is ‘autism’ an empirically real entity that can be understood through scientific enquiry (Verhoeff, 2012), or a socially constructed, culturally contingent concept?

The idea that autism is ontologically real is pervasive (Verhoeff, 2012), and inherently linked with medicalised definitions of autism, which attempt to define a biomedical entity (Latif, 2016). Attempts to understand autism through a biomedical lens have included genetic (e.g. Bai et al., 2019) and neuroscientific investigation (e.g. Kushki et al., 2019, see section 2.3.2.). Bai et al. (2019) analysed genetic data from 2 million people (including 22,000 autistic people) across 5 countries. It was concluded that autism had a median average heritability of 80.8%, ranging from 50.9% (Finland) to 86.8% (Israel). These findings, from a large and culturally diverse sample, support previous estimates of autism's genetic inheritability (e.g. Frietag et al., 2010; Tick et al., 2016). According to such studies, autism would appear to be biologically mediated to some extent.

However, attempts to convincingly establish that autism is an ontologically real biological entity have had little success, such that many argue identifying a biological 'cause' is an impossibility (e.g. Kourti, 2021). Though genes have been implicated, no specific genes appear to be reliably associated with autism diagnosis. In a review of genetic autism research, Schaaf & Zoghbi (2011) concluded the number of autism-predictive genes could be in the thousands, and still these accounted for only 1% of diagnoses.

As many argue there is insufficient evidence to conclude autism is ontologically 'real', some suggest it is therefore clinically meaningless. Latif (2016), for example, argues that with the absence of any biomedical diagnostic tools, autism diagnoses cannot be objective. Since autism diagnoses are given partially on the basis of violating social norms (e.g. for eye contact), and social norms are culturally dependent (Perepa, 2014), the diagnosis inherently depends on who is being assessed, and who is assessing (Latif, 2016). If the term is inconsistent and lacking objective meaning, its utility as a diagnostic term is perhaps questionable (Latif, 2016).

Others argue the meaningfulness and utility of the term 'autism' is independent of its clinical validity. Hacking (2009) for example, posited that the meaning of psychiatric labels such as autism change as people interact with them. The addition of sensory differences to the DSM-5 (APA, 2013) diagnostic criteria for autism perhaps illustrates this; as people diagnosed with autism communicated a common experience of sensory differences, the diagnostic criteria for autism changed, now meaning sensory differences are part of the psychiatric definition of autism. This interaction between definition and the people being defined is described by Hacking (1995) as a ‘looping effect’. Through Hacking’s looping effect, the meaning of autism is not tied purely to biology, nor entirely to psychiatry, but involves the narratives of those who identify with the term.

Research gathering the views of autistic people about autism demonstrate that autistics are actively constructing new meanings from their experiences. The recently characterised concepts of autistic burnout (Raymaker et al., 2020) and autistic inertia (Buckle et al., 2021) in academic literature have emerged from qualitative research into autistics’ lived experiences. Such research into autistic people’s narratives also suggests autism is a powerful and meaningful term to the community (e.g., Lewis, 2016; Hickey et al., 2017; Kelly et al., 2022; Lilley et al., 2021).

Chapman (2020) separated the meaning of autism from empiricism by defining it as a ‘serial collective’ (Young, 1994). A serial collective defines belongingness to socially contingent groups (e.g. ‘autistic’ versus ‘not autistic’) by the relationship each group member has to a social condition. For example, autism-group belongingness could be defined by shared experiences of being disabled by, or disadvantaged by, particular social norms and structures (Chapman, 2020). In this way, autism has meaning and utility by uniting people with shared experiences of social exclusion. A serial collective definition appears to offer an alternative to medical or biological definitions, which face challenges from both the autistic community (Sarrett, 2016) and medical community (Latif, 2016). Furthermore, Hacking’s ‘looping effect’ (1995; 2009) provides a framework for understanding how the meaning of autism can be continually shaped and defined by those interacting with the term. The following section will discuss new meanings that have emerged from attempts to explain autism, and address questions about whose experiences of autism are considered meaningful.

2.4.4. Epistemologies of Autism; who can ‘Know’ Autism?

> *‘[R]ight from the start, from the time someone came up with the word ‘autism’, the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced’*
>
> - Williams (1996, p. 14)

Historically, knowledge about autism has been generated by non-autistic observers of autistic behaviour (Botha, 2021), based on how observers experience a person’s autistic traits (Kourti, 2021). In contrast, a number of accounts are emerging based on the internal experience of being autistic (Kourti, 2021). Accounts of autism based on observation of autistic behaviours have been criticised for typically attributing them to a presumed underlying pathology. For example, Hu et al. (2021) concluded autistic people were impaired in flexibility of thought and their regard for social reputation, based on an experiment that found autistic participants were less likely than non-autistic participants to privately endorse an immoral cause for personal gain. Autistic advocates (e.g. Autistic Science Person, 2020) have argued this could equally have been framed as a strength of autistic people, such as high integrity. Such different interpretations of the same result necessitate an exploration of differing perspectives on autism, and what is offered by them.

2.4.4.1. Accounts from Observation

It has been argued that etic (outsider) accounts of autism could be the only valid source of autism knowledge, based on assertions that autistic people lack insight into their own internal world, or the ability to meaningfully communicate it (Costley et al., 2021; Frith & Happè, 1999). Researchers have traditionally, therefore, observed autistic behaviours and theorised about their origin and nature. Influential examples have included: weak central coherence (suggesting autism results from deficits in perceiving and integrating contextual information; Frith, 1989), executive dysfunction (autism results from poorly regulated cognitive skills; Ozonoff, Pennington & Rogers, 1991), lack of social motivation (autism results from disinterest in making social connections; Chevalier et al., 2012), theory of mind deficit (ToM; autism results from an inability to infer other people’s mental states (e.g. emotions); Baron-Cohen, 1989) and the empathising-systemising hypothesis (EST; autism results from an inclination towards logic over empathy; Baron-Cohen, 2003). Each of these prominent theories share a commonality; defining autism in terms of deficits, or what is assumed to be ‘missing’.

Each of these theories however have been heavily criticised, in that they lack specificity to autism, do not apply to all autistic people, and do not fully account for the differences they assert to explain (e.g., Milton, 2012). ToM for instance was offered as an explanation for social differences (Baron-Cohen 1989). Some evidence for this included findings that autistic children were less likely to correctly infer others’ mental states than non-autistic children (Baron-Cohen, 1989). However, difficulty inferring mental states does not account for all social-related differences, such as atypical neurological responses to faces in infants later diagnosed with autism (Dawson et al., 2005; Tager-Flusberg, 2007). Additionally, autistic young people frequently perspective-take successfully under naturalistic conditions (Kremer-Sadlik, 2004), and many other groups exhibit difficulty with ToM. These include children with Fragile X (Cornish et al., 2005), language difficulties (Loukusa et al., 2014) and Deaf (Moeller & Schick, 2006) and Blind (Brambring & Asbrock, 2010) children.

Some of these theories have also been criticised on ethical grounds. Researchers have asserted that suggesting autistic people lack empathy, for instance, has caused harm: ‘non-autistic people should not need to deploy a great deal of empathy to understand how damaging this narrative has been…to autistic people’ (Fletcher-Watson & Bird, 2020, p. 5). Research has found one of the most commonly held beliefs about autistic people is that they lack emotional intelligence (Wood & Freeth, 2016). However, this conflicts with many autistic people’s perceptions of their own emotional skills. Bonnello’s (2022) large scale survey of autistic people and autism stakeholders found a wide discrepancy between autistic and non-autistic perceptions; autistic people tended to report experiencing intense empathy, while caregivers tended to believe autistic people experience a lack of empathy.

Such discrepancies highlight the potential value of learning from autistic people. Far from assertions that autistic people may be incapable of meaningfully communicating their internal experiences (Costley et al., 2021), recent research has found autistic people demonstrated greater knowledge about autism than autism stakeholders (Gillespie-Lynch et al., 2017). This suggests autistic people could be considered experts by lived experience, with much of value to contribute to the field of autism research. Bonnello’s (2022) finding – that non-autistic people may be underestimating autistics’ capacity for empathy - may also position this as an ethical imperative; or else, we risk misrepresenting lived experiences and ‘undermining the core human experiences of autistic people.’ (Chapple et al., 2022, p.2).

2.4.4.2. Accounts from Lived Experience

‘I didn’t realise I was autistic until I heard people talk about what it felt like, not what it looked like’

- (unknown)

Autistic-generated theories of autism include the double empathy problem (DEP; Milton, 2012), monotropism (Murray, Lesser & Lawson, 2005) and the autistic language hypothesis (ALH; Cullen, 2018). DEP in particular has received significant research attention (e.g., Alkhaldi, Sheppard & Mitchell, 2019; Crompton et al., 2020a; 2020b; 2020c, Sheppard et al., 2016). Unlike the etic accounts described above, DEP does not presume autistic communication difficulties are deficits. Instead, DEP conceptualises communication as a bidirectional process, with difficulties arising between communicative partners (not within one), due to conflicting social-communication styles (Milton, 2012). This theory has been influential in countering the dominant autism-as-deficits conceptualisations of autistic communication difficulties (Jellett & Flower, 2023).

Evidence in support of this theory comes from Heasman and Gillespie (2018) who found autistic people were more effective than non-autistic people at recognising autistics' intentions. This may suggest non-autistic people experience difficulty understanding autistic people, rather than that autistic people fail to communicate effectively. Crompton et al. (2020a; 2020b; 2020c) presents further evidence for this hypothesis. Across 4 studies (2 within Crompton et al., 2020c), facets of communication, such as effectiveness of information sharing, and observer perceptions of rapport, were assessed within and between autistic and non-autistic people. The research found autistic people tend to feel more comfortable and at ease with other autistic than with non-autistic people (Crompton et al., 2020a). Further, communication of information between autistic groups was reportedly as effective as between non-autistic groups, with significant differences in communicative effectiveness only where groups combined autistic and non-autistic people (Crompton et al., 2020b). Also, autistic dyads perceived higher interpersonal rapport with each other than did autistic-non-autistic dyads (Crompton et al., 2020c) and observers rated autistic partners higher for inter-communicator rapport than they rated non-autistic dyads (Crompton et al., 2020c). This may contest assumptions that autism inherently involves communication skill deficits, suggesting instead that autistic people have particular difficulty communicating with the non-autistic majority. This perhaps helps to explain qualitative evidence that autistic people prefer interacting with autistic people over non-autistic people (Morrison et al., 2019).

However, some evidence counters claims of the DEP. For example, Edey et al. (2016) found that, while non-autistic participants had greater difficulty understanding autistic people than other non-autistic people, autistic participants had equal difficulty with both groups. This suggests that while there may be a mutual difficulty in communication between autistic and non-autistic people, autistic communication skills are not necessarily equally strong as neurotypical communication skills. Additionally, some research presenting evidence for DEP has been accused of making unsupported claims (see Chown, Hughes & Baker-Rogers, 2020 critique of Alkhaldi et al., 2019). While evidence for DEP is not incontrovertible, it may be sufficient to strengthen arguments for social or social-relational models of disability. Whether communication deficits are inherent to autism, or a product entirely of conflicting communication styles, it appears the socio-communicative context influences how well autistic people are understood.

Other insider accounts of autism, such as monotropism and ALH are less well researched. A search of the literature suggests the present literature-base is sparse, such that there is little evidence for or against their validity. For example, monotropism, though first proposed in 2005 (Murray, Lesser & Lawson, 2005) has seemingly not yet been empirically tested. With calls for increased support for autistic people to participate in, or lead autism research (Botha, 2021), perhaps more research on emic accounts of autism will emerge. It is argued this could lead to richer insight into what it means to be autistic (Kourti, 2021). The final paragraphs within this section will discuss what is meant by ‘autistic community’, and its relationship to the neurodiversity movement.

2.4.5. Autistic Community, Culture and Advocacy

> *‘We individuals, with our cultures of one, are building a culture of many’*
> - Dawn Prince-Hughes (2004), cited in Jaarsma & Wellin (2012, p. 8)

A sense of community among autistic people arguably began to emerge with the popularisation of the internet, where communication barriers associated with face-to-face interaction did not apply (Kras, 2010; Leadbitter et al., 2021). Through the medium of the internet, what has been described as an ‘autistic culture’ began to develop (Davidson, 2008). The concept of autistic culture has received some academic attention (e.g., Begon & Billington, 2019; Jaarsma & Welin, 2012; Ortega, 2009; Runswick-Cole, 2014), with qualitative research suggesting that developing an understanding of autistic culture is important in the formation of young autistic people’s identity (Creswell & Cage, 2019). Autistic culture is also beginning to be discussed in relation to autism practice, and the education of autistic children. For example, Bass (2019) argued classroom practices must make room for autistic culture in order to truly be inclusive. Accordingly, a notion of ‘culturally competent’ autism practice is beginning to be discussed in literature (Ne’eman, 2021, p. 570).

Though academic writing on the topic is limited, some have attempted to define what is meant by ‘autistic community’. Botha (2019), in an original thesis, described community as being linked with a shared identity (i.e. ‘autistic’) and existing within a shared space - whether physical, virtual, or ideological. Following examination of available grey literature, Botha (2019) identified central features of autistic community discourse: 1) a belief that autistic people represent a natural variation in the human condition; 2) attempts to ‘cure’ autism are tantamount to eugenics; 3) an assertion that autistic people deserve equal rights to non-autistic people, and 4) non-autistic stakeholders in autism are part of a wider ‘autism community’, but the *autistic* community is exclusively for autistics.

The autistic community have been active advocates for the neurodiversity movement (den Houting, 2019), with some arguing autistic advocacy solidified the neurodiversity movement’s status as being owned by, not run for, the broader disability community (Kras, 2010). Autistic rights activism is argued by prominent autistic autism researcher, Kapp (2020), to be its own distinct branch of the neurodiversity movement, making the two closely related. Autistic activism seeks the rights and respect of all autistic people within society (Orsini & Smith, 2010). It also seeks autistic empowerment in autism knowledge generation, as exemplified by the most recent annual report from a prominent autistic advocacy group (The Autistic Self-Advocacy Network; ASAN, 2021, p.3): “who decides what happens to autistic people? Who decides what research is done about us? Who decides what therapies are used on us? This year, we’ve made our answer loud and clear: we decide.”. The neurodiversity movement, as discussed in section 2.3.3.2., seems to provide an agenda through which to advocate for autistic empowerment in autism discourse and practice.

2.5. Autism Policy and Practice, and the Influence of the Neurodiversity Paradigm

Thus far, it has been demonstrated that the neurodiversity paradigm presents an alternative to medicalised conceptualisations of neurodevelopmental disability. The final section within Chapter 2 will consider the influence of the neurodiversity paradigm on autism policy and practice. Current standards for autism practice will be discussed, as will the notion of NDA practice.

2.5.1. UK Autism Policies

Several policies concerning autism have been published by the UK government in recent years. The most recent (DfE & DHSC, 2021) appears to have changed substantially since the first edition (DoH, 2010), seemingly becoming more closely aligned with the beliefs and values of the neurodiversity and autistic self-advocacy movements. For example, the current policy, the National Strategy for Autistic Children, Young People and Adults (DfE & DHSC, 2021) names as priority outcomes the improved public understanding and acceptance of autistic people, and improved access to education, healthcare and employment for autistic people. This seems to align with the autistic community's priorities for the future of autism strategies, as reflected in research by Pellicano et al. (2014). It also appears to align with autistic self-advocates' aims of promoting the rights and respect of autistic people in society (Orsini & Smith, 2010). The policy appears consistent with social models of disability, in that it considers changing systems to better accommodate autistic people, rather than changing autistic people to fit existing systems. This aligns with one of the central goals of the neurodiversity movement, as described by Mandy (2022) (see section 2.3.3.2).

In contrast, the UK's first autism policy (DoH, 2010) set out plans to improve young children's access to early intervention services; a priority notably absent from the current policy (DfE & DHSC, 2021). Some forms of early intervention are perceived by the autistic community to be an attempt to change autistic children to conform to neurotypical expectations (e.g. Mottron, 2017), thus may be seen to be reflecting a medicalised perspective towards autism. Other notable differences between the first and most recent government autism policies include the shift to using identity-first language ("autistic people"), (see section 1.2.) and the use of neurodiversity language (e.g., 'increasing recognition and representation of neurodiversity', DfE & DHSC, 2021, p.15). The 2010 policy, on the other hand, adopts person-first language ("people with autism") throughout and includes no reference to the concept of neurodiversity (DoH, 2010). This may indicate an influence of the neurodiversity movement and autistic self-advocacy on UK autism policy.

Other possible indicators of the influence of the neurodiversity and autistic rights movements can similarly be seen in national healthcare policy. NHS England (n.d.) published a policy for talking about autism, clearly evidencing alignment with the neurodiversity movement. For example, stating 'Autism is a difference rather than a disorder'. It also states its alignment with identity-first language, to reflect autistic community preferences. The NHS England (n.d.) policy on talking about autism also addresses functioning labels (e.g., "high functioning" and "low functioning" autism) and severity labels ("severe" versus "mild" autism). The policy states that neither functioning nor severity labels are supported by the autistic community, thus does not endorse them. This is evidence by, for example, Bonnello's

(2022) survey of over 7000 autistic people, with fewer than 7% endorsing the use of the terms ‘mild/moderate/severe’, only 2% endorsing ‘low functioning’, and 12.5% endorsing ‘high functioning’. With the most recent government policy similarly avoiding these terminologies (DfE & DHSC, 2021; in contrast to the first government policy; DoH, 2010), it would appear the influence of the autistic community on UK autism policy has been significant.

2.5.2. Autism and Current Practice

‘[T]here is an increasing complacency around the idea that lead professionals and practitioners have a good understanding of what ‘good autism practice’ entails; for me this is an ongoing imperfect process of interaction and should never be seen as a given’

- Milton (2012, p. 886)

Research has indicated autistic people are critical of currently available support. A qualitative study interpreted that autistic people perceive some policies, resources and services to fail to understand or adequately meet autistic needs, and that this can be a barrier to their full participation in life (Malenfant, 2020). This is supported by research comparing autistic and non-autistic persons’ experiences of health care services, which suggested autistic people face particular barriers to health care (Strömberg et al., 2021). Strömberg et al. (2021) reported that barriers identified by autistic people included aspects of the sensory environment (e.g. noise levels), feeling misunderstood by professionals, perceiving their concerns not to be taken seriously, and their nonverbal signals being misinterpreted by professionals, leading to miscommunication. This may suggest a need to consider the suitability of existing practices for autistic clients.

Regarding specific interventions developed to support autistic people, approaches vary widely; research has not identified one approach as being superior to others (Bond et al., 2016). Like all research, research on autism practice is influenced by the researcher’s philosophy and values (Guldberg, 2017). Typically, autism intervention research has aligned with a medicalised philosophy, where autistic traits are considered symptomatic of disorder (DfE, 2014), with desirable intervention outcomes therefore being ‘symptom’ reduction (Milton, 2014). For example, some evidence-based practices (EBP; practices supported by research; AET, 2019) involve explicit teaching of typical social skills and physically preventing autistic children from engaging in stimming (i.e. repetitive behaviours) (Odom et al., 2010).

The concept of EBP has been influential in the field of autism intervention research (Guldberg, 2017). However, the relationship between 'good autism practice' and autism research is complex, for several reasons. For example, what is considered 'evidence' is subjective. Traditional scientific research considers an effective intervention to be evidenced by statistically favourable outcomes for the group receiving the intervention, compared to one that did not (Gulliford, 2015). However, others argue 'evidence' should include testimony from the people receiving the interventions (AET 2019; Lounds Taylor, 2017). Further, there is disagreement over what constitutes 'good' outcomes. It has been argued that when researchers select outcome measures, this is inherently a value judgement on what they consider to be a desirable outcome for participants (Lounds Taylor, 2017). Who defines 'good' outcomes is central to the discussion on 'good autism practice'.

The difficulty with selecting outcomes and defining good autism practice is exemplified by current debates around Applied Behavioural Analysis (ABA). ABA has been applied to autistic individuals, aiming to change behaviours by using operant conditioning (Eckes et al., 2023). Autism 'symptom' reduction is a desired outcome of some ABA interventions (Eckes et al., 2023). The approach is considered by some as 'best practice' in autism (e.g. Anagnoustou et al., 2014, p. 515) and is commonly used, particularly in the United States (Cumming, 2020). Experimental ABA research continues to find favourable outcomes on a range of measures (e.g., Molnár & Eldevik, 2017), which may be seen as strengthening ABA's status as an EBP.

However, ABA studies are found to be consistently of poor methodological quality, with a high risk of bias and, when aggregated, show no efficacy on a range of outcomes (e.g., Eckes et al., 2023). Such findings from meta-analyses have led the UK's National Institute for Health and Care Excellent (NICE) to conclude the evidence-base for early behavioural interventions for autism, including ABA, is weak (NICE, 2013). Additionally, ABA is heavily criticised by the autistic community on ethical grounds (Bonnello, 2022; Cumming et al., 2020; Jabaut, 2022; McGill & Robinson, 2020; Sandoval-Norton, Shkedy & Shkedy, 2019). A large scale survey of autistic people found that 62% of 341 people who had personally experienced ABA therapy "strongly disagree" with its use. Some argue reducing autism trait expression is not a helpful, desirable or ethical intervention goal (e.g. Ne'eman, 2021). Qualitative evidence suggests autistic people can learn to suppress, and cognitively compensate for (camouflage) autistic traits, such that 'symptoms' are apparently reduced (Wood-Downie et al., 2021), but that doing so can be harmful to mental health (Hull et al., 2017). Further, research has suggested autism trait suppression may inhibit a sense of belongingness, perhaps through feeling that one's interactions with others are inauthentic (Cassidy et al., 2020). Consequently, some literature argues for a 'neurodiverse philosophy of well-being' (Rodongo, Krause-Jensen & Ashcroft, 2016, p.406) which considers that outcomes from a neurotypical perspective may not align with autistic people's perspectives of what makes for a 'good autistic life' (Rodongo et al., 2016, p. 407).

It may be, therefore, that those receiving services should be consulted when deciding what constitutes good autism practice. When setting goals, existing autism practice guidelines recommend considering individuals' needs and aspirations (AET 2019; Lounds Taylor, 2017) and wider contextual factors unique to the individual, such as family dynamics and education settings (AET, 2019). Autistic people have also expressed, in qualitative research, a view that professionals should seek informed consent from clients before involving them in interventions (Sterman et al., 2022). The Autism Education Trust (AET), an organisation endorsed by the UK Department for Education (autismeducationtrust.org.uk, n.d.) have published the 'Good Autism Practice Report'. They define 'good autism practice' by 4 overarching themes, and 8 principles (AET, 2019):

Theme 1: Understanding the individual

1. Understanding the individual's profile of needs, strengths and interests
2. Empowering autistic people to collaborate on decisions made about their support

Theme 2: Positive and effective relationships

3. Collaborating with those who care for the autistic person
4. Increasing knowledge and understanding of autism among professionals working with autistic people

Theme 3: Enabling environments

5. Good autism practice as top-down, from management within organisations
6. A socially inclusive organisational ethos

Theme 4: Learning and development

7. Targeted support for the young person, and measuring their progress

8. Prioritising wellbeing and positive outcomes through adaptation of the academic curriculum

The British Psychological Society (BPS) has also recently published best practice guidelines for ‘working with autism’ (BPS, 2021). The guidance document, targeted towards psychologists working with autistic children or adults, highlights examples of best practice throughout, such as for approaches to psychological intervention. Principles of ‘best practice’ according to BPS guidelines (2021) include: understanding individuals’ perspectives and views, empowering them to achieve their aspirations, acknowledgement of individuals’ strengths, supporting people to develop more ‘acceptable’ (p.23) behaviours, and creating a comfortable environment. Neither AET (2019) or BPS (2021) guidance make explicit links to NDA practice, necessitating further consideration of what such practice may look like, and whether this differs from existing ‘good practice’.

2.5.3. Neurodiversity in Practice

To illustrate the present context of practice in relation to the neurodiversity concept, a systematic literature review was planned. Inclusion criteria for papers were: primary research, and investigating practical implications or applications of the neurodiversity paradigm. Four databases containing published literature were searched in July 2022. (APA PsychArticles Full Text, Embase (1980-2022), Ovid Medline® ALL (1996-2022), and APA PsycInfo). All search terms (Appendix 1) were entered into each database, using the Boolean ‘or’. Search terms were extracted from existing literature (found through the preceding literature review) and reading of non-academic sources regarding the neurodiversity paradigm.

This yielded 20 returns, 4 of which were duplicates. None of the research papers met inclusion criteria. Grey literature was also searched. A scoping search was carried out on Google Scholar, and reference lists were searched for relevant publications. Ethos was searched using the above search terms. None of the identified papers met criteria. It was therefore concluded a systematic review of literature on the practical application of neurodiversity could not be conducted. Further searches were run in January 2023, again yielding no papers fitting the inclusion criteria. It appears there has been no empirical research into practical applications of neurodiversity.

This is despite research suggesting alignment with the neurodiversity paradigm could be associated with greater autism acceptance (Walker, 2022), more positive self-esteem, self-efficacy and aspirations for the future (Griffin & Pollak, 2009). Research also suggests pathologised views of autism may be associated with poor self-worth (Lilley et al., 2021, Hickey et al., 2017, Creswell, Hinch & Cage, 2019, Sonuga-Barke & Thapar, 2021), poorer mental health (Sonuga-Barke & Thapar, 2021) and lower self-esteem (Walker, 2022). Further, alignment with the neurodiversity view may be associated with more positive attitudes towards autism (Kapp et al., 2013). Organisations are also beginning to advertise NDA services, suggesting generating a shared understanding of the concept of NDA practice, and its implications, is important (e.g., Occupational Therapy provider Learn Play Thrive (n.d.) and autism training provider Ausome Training (n.d.)).

Some literature has begun to theorise about practical applications of the neurodiversity paradigm. Leadbitter et al. (2021), for instance, described intervention programmes considered by the authors to be compatible with a neurodiversity perspective. Recently, a number of publications (Dallman, Williams & Villa, 2022; Izuno-Garcia, McNeel & Fein, 2023; Jellett & Flower, 2023; Rutherford & Johnston, 2022) have proposed guidelines for applying neurodiversity principles to practice (which they term ‘neurodiversity-affirming practice’). Jellett and Flower (2023) propose the foundation of NDA psychological practice is ‘a space where the client can be their authentic self and be *seen and valued by another for who they are’* (p.2). More specific descriptions of NDA practice, as proposed by the aforementioned authors, include:

- **Goals and outcomes:** Intervention goals do not encourage the individual to present as neurotypical (Dallman et al., 2022; Rutherford & Johnston, 2022), and do not prioritise compliance (Dallman et al., 2022). Goals should prioritise clients’ aspirations and views (Izuno-Garcia et al., 2023) and may include, for example, facilitating self-awareness of needs (Rutherford & Johnston, 2022) and developing self-advocacy skills (Dallman et al., 2022). Facilitating meaningful and active engagement with day-to-day life, and involvement with communities who have similar interests and experiences, should be a priority (Rutherford & Johnston, 2022).
- **Interventions:** Approaches do not have a normative agenda (Izuno-Garcia et al., 2023) and do not follow a professional-imposed agenda (Dallman et al., 2022). Approaches should be ceased if they are against the client’s wishes, and should be responsive to the client’s day-to-day motivation, energy and interest (Dallman et al., 2022). Approaches are informed by (Dallman et al., 2022) and co-developed with (Rutherford & Johnston, 2022) the wider autistic/neurodivergent community.

- **Communication and language:** Authentic autistic behaviours are encouraged (Dallman et al., 2022; Rutherford & Johnston, 2022) and clients are encouraged to communicate in ways that feel natural to them (Izuno-Garcia et al., 2023). Non-autistic professionals should learn autistic social norms and styles to facilitate authentic cross-neurotype communication (Dallman et al., 2022). Professionals should avoid deficit-based language (Izuno-Garcia et al., 2023), use the language of the neurodiversity paradigm, and normalise dialogue about diversity and difference (Rutherford & Johnston, 2022).
- **Understanding the individual client:** Approaches should be responsive to client preferences (Rutherford & Johnston, 2022) and interests (Izuno-Garcia et al., 2023). Professionals should understand clients' strengths, so these can be fed back to them (Izuno-Garcia et al., 2023). Professionals should strive to understand the meaning of clients' behaviours, by asking them directly about this, or gaining insight from family and the wider autistic community where this is not possible (Dallman et al., 2022).
- **Understanding autism:** The environment should be adapted to support inclusion, and there should be clear communication about what to expect, to provide predictability (Rutherford & Johnston, 2022; Izuno-Garcia et al., 2023).
- **Professionals:** Reflect critically on assumptions and values in relation to autism and what successful intervention outcomes may be (Dallman, et al., 2022). A neurodiversity perspective should be adopted by the professional, where neurodiversity is celebrated (Rutherford & Johnston, 2022). There should be a unified approach from NDA practitioners across disciplines (Dallman et al., 2022)

However, these practice recommendations are based on narrative literature reviews rather than primary research. Without gathering the autistic community's perspective on what is meant by NDA practice, it is unclear the extent to which the existing practice recommendations reflect community views and priorities. An attempt has been made to investigate professionals' perspectives of NDA practices (Guyon, 2022) however the results are currently unpublished and concern professionals' rather than neurodivergent community views. As the concept of neurodiversity itself challenges the authority of professionals and researchers to unilaterally define autism policy and practice (see Chapter 2, section 2.3.3.1.), arguably, autistic voices should be directly involved in the development of neurodiversity-aligned autism practices. The present research intends to extend the recent literature on NDA practice by gathering primary data on what this style of practice means to the autistic community.

2.6. Chapter Summary and Rationale

It has been demonstrated through this literature review that ‘neurodiversity’ represents a wide variety of distinct, but often overlapping, positions. Literature and research appear to suggest neurodiversity tends to refer to a) claims of diversity in human neurological functioning which, to some, can be subdivided into clusters of neurological ‘types’, such as autism b) a paradigm, making a set of claims about people who are socially or medically perceived as disordered as a result of their neurocognitive functioning, and/or c) a social justice movement striving for equal social status for those that proponents see as having been ‘othered’ by society. While the neurodiversity concept and its related movement is difficult to define, there was evidence that many autistic people, at least, experience minoritisation and oppression as a result of stigmatisation of their neurodivergence, and that the neurodiversity movement seeks to change this.

Further, it was discussed that autism, like neurodiversity, is not clearly defined. Arguments were presented around autism as ontologically real, or alternatively, as a socially predicated category of difference. It was theorised that the meaning of autism is not necessarily predicated on an essentialist existence, as it has personal meaning to many of those to whom the term applies. Additionally, it was discussed that a range of theories of autism have been generated, and these seemingly tend to differ according to whether they were generated based on observation of autistic people, or from an autistic person’s own lived experience. While observer accounts seem to often consider autism a constellation of deficits, several emic accounts resisted this. There appears to be an emerging autistic culture and community, from which researchers and practitioners can gain insight into how autistic people conceptualise autism.

Finally, it was argued that the neurodiversity movement has begun to influence UK autism policy and practice. This is despite a lack of clarity over what is meant by neurodiversity or what NDA autism practice might look like. Some themes have been suggested based on literature reviews, however, a clear picture of how the autistic community conceptualise neurodiversity-affirming practice has yet to be developed.

2.7. Research Question

Autistic people’s views on what constitutes NDA practice were gathered using an online qualitative survey. This was developed in collaboration with the autistic community to ensure it reflected community priorities and values. The research question was: *What can be learned from the perspective of members of the autistic community about ‘neurodiversity-affirming practice’ in relation to autism?*

2.8. Research Purpose

The purpose of the research is to elucidate understandings of the concept of NDA practice, as generated within the autistic community. The researcher was motivated to elevate the voice of this group and help to locate future discussions about autism practice around the views of the community it relates to. It is hoped this will influence decision making around policy and practice in Educational Psychology and beyond. It is also hoped the findings will be useful to the autistic community.

2.9. Implications for Psychology and Education

> *‘There is no greater responsibility than constituting people – and we as psychologists do this.’*
>
> - Botha (2021, p. 9)

There is substantial overlap between education, psychology and autism practice (Mesibov & Shea, 2011). Additionally, a substantial proportion of educational psychologists’ (EPs) work relates to autistic students (Robinson, Bond & Oldfield, 2018). This may explain why neurodiversity is beginning to influence EPs’ practice (see Sewell & Park, 2021) and conceptualisations of autism (see Begon & Billington, 2019).

EPs are guided by a professional code of ethics (BPS, 2021b) which states psychologists must respect communities and their values, and consider issues of power that arise from the authority afforded to psychologists. EPs are afforded epistemic privilege through their professional status (Sewell, 2016), meaning others tend to accept EPs’ asserted knowledge as valid and meaningful. It is important therefore that EPs carefully consider whether their use of power is respectful of community values. Given the apparent importance of the neurodiversity paradigm to the autistic community, EPs should be aware of and informed about such discourse.

EPs may also consider NDA practice relevant to their work within the education system. Qualitative research with autistic school children suggests schools are ‘a critical site of development’ of self-identity (Hodge et al., 2019, p. 1355). Identity for autistic students was reportedly influenced by others’ perceptions of, and attitudes towards their autistic traits (Hodge et al., 2019). As medicalised, deficit-based models of autism are reported to be harmful to autistic people’s identity and overall mental health (e.g., Mitchell, Sheppard & Cassidy, 2021) and may perpetuate stigma (Black, 2022; Gillespie-Lynch et al., 2017), EPs may consider which paradigms they sustain through their practice. The medical model is argued to be reinforced during psychological education and training, through explicit teaching of early autism theories (e.g. empathy deficit, theory of mind deficit; Botha, 2021). Neurotypical communication styles (e.g. eye contact) are also centred as the norm and ideal in psychological and therapeutic training (Jellett & Flower, 2023). Professionals, including EPs, may therefore implicitly hold some pathologised views of autism. For those wishing to support young people’s identity and wellbeing, seeing what is offered within the neurodiversity paradigm, including NDA practice, may be a helpful starting point.

Chapter 3: Methodology

3.1. Introduction to Chapter

This section provides a detailed overview of the research aims, purpose, and procedures. First, the research is considered in relation to philosophical assumptions of the researcher; the alignment with constructivist and transformative paradigms is justified. Particulars of the research design are described, including the data collection tool and respondent demographics. The use of reflexive thematic analysis (rTA) as an analysis method is explained, with consideration of its strengths and limitations. Finally, ethics of the research are carefully considered.

3.2. Methodological Orientation

3.2.1. Ontological and Epistemological Assumptions

Research processes are necessarily tied to the philosophical study of reality and knowledge (Moore, 2005). Ontology is a branch of philosophy concerned with defining the nature of reality, while epistemology asks how knowledge can be known, and what counts as knowledge (Moore, 2005). Quality research should be founded on a researcher's assumptions about the nature of reality and knowledge, and have consistency between the nature of the research question, methodological choices, and methods of enquiry (Yeganeh et al., 2004).

Research in the social sciences has traditionally been grounded in the positivist paradigm (Gelo et al., 2008), which asserts there to be a single, objective reality. It is presumed this reality can become known through scientific experimentation and measured through numerical data (Cohen et al., 2007). The generated evidence is therefore judged against how likely it is to be 'true' knowledge, thus requiring methods that tightly control variables and the chance of spurious findings (Gulliford, 2015). Positivist research therefore has an associated evidence hierarchy (Gulliford, 2015). Less rigid methods of enquiry, such as testimony based on lived experience, are considered less valuable (Gulliford, 2015), thus knowledge production becomes a privilege reserved for those with access to scientific education. It has been argued that this systematically oppresses the voices of minoritised groups (Moore, 2005).

Consequently, many social science researchers with interests in lived experiences reject the positivist paradigm (Robson & McCartan, 2016). Constructivism is an alternative to positivism, supposing humans play an active role in constructing their own realities (Cohen et al., 2007). Unlike positivist research, constructivist research purports the richness of human experiences cannot be captured numerically (Cohen et al., 2007). Constructivist research aligns with a relativist ontology; the notion that realities are constructed by, and therefore inseparable from, the individuals experiencing them (Yeganeh et al., 2004) and are only knowable by gaining the perspective of those individuals (Mertens, 2020). In contrast to positivist-aligned research, then, personal testimony is valued as a compelling source of knowledge.

Constructivist researchers increasingly position social justice as an important value in their work, however, constructivism as a paradigm does not prioritise any particular value set (Mertens, 2020). The freedom to interpret the words of others, and present it as knowledge, is a powerful position to hold (Karnieli-Miller, Strier & Pessach, 2009). Many argue researchers must consider who these interpretations help, and whom they could harm (Mertens, 2020). This warrants exploration of alternative paradigms.

The transformative paradigm encompasses diverse perspectives, all focusing on examining and resisting societal oppression (Mertens, 2020). Transformative researchers view knowledge production as a political act (Mertens, 2020). They are primarily concerned with the impact of power and privilege on what becomes considered as knowledge, and the consequences for the groups being studied (Mertens, 2020). A transformative methodology, then, explicitly seeks the voices of groups traditionally excluded from the knowledge production process (Mertens, 2020). Transformative paradigms encompass a range of theorists and foci (e.g. women (feminist theories), disabled people (disability theories), and minority ethnic groups (critical race theory); Mertens, 2020). The values of the transformative paradigm are therefore consistent with a range of research approaches, where they are concerned with social and epistemic justice for the researched group/s.

3.2.2. Philosophical Consistency of Research Approach

The researcher positioned the present research within the constructivist paradigm, while explicitly prioritising the values and assumptions of the transformative paradigm. The nature of this research – elucidating the concept of neurodiversity-affirming (NDA) practice – required careful consideration to ensure justice-doing; the concept of ‘neurodiversity’ arose from a minority group’s attempt to decentralise and challenge knowledge generated about them by powerful groups (see Singer, 1998). The researcher considered it necessary to understand this concept through the lens of those who created it, rather than through the voices of the epistemically privileged groups of professionals which the concept intends to challenge. This research therefore includes the following assumptions:

- Ontology: A relativist ontology is assumed. The social world is created through, sustained by, and changed by human interaction and experience (Bottema-Beutel et al., 2021). It is dependent on socio-cultural variables, such as language (Bottema-Beutel et al., 2021).
- Epistemology: The research assumes a subjectivist epistemology based on constructivism, while centring the values of the transformative paradigm. It is assumed the process of knowledge generation is inherently tied to human interpretation. Constructs of reality are subjective and dependent on underlying assumptions and values (Mertens, 2020). Power, therefore, affects what is considered knowledge, as assumptions and values are tied to those holding the power to define and influence them (Mertens, 2020). Knowledge about the social world is not (and cannot be) correct or incorrect, but can increase or reduce harm for a group (Mertens, 2020). Knowledge generation should avoid doing harm and, where possible, seek to reduce harm to already marginalised groups.
- Methodology: Gathering views of a marginalised group, which enables the researcher to develop insight into the group's understanding of a concept that originates from it, is a fair and just endeavour.

An extract taken from the researcher's reflexive journal, critically locating the researcher's beliefs and assumptions in relation to ontology, epistemology and methodology, can be found in Appendix 2.

As constructivists are concerned with personal testimony, qualitative methodologies are typically chosen. Qualitative research gathers non-numerical data; often respondents' own words (Coolican, 2009). From this, researchers take an inductive approach to generating knowledge, attempting to generate statements about the topic based on interpretations of respondents' words (Coolican, 2009). Such an approach can produce a rich insight into phenomena (Gelo et al., 2008).

Unlike quantitative, positivist research, which tends to be formulaic, qualitative research is inherently flexible (Braun & Clarke, 2022). It is however underpinned by frameworks to ensure rigour and quality (Braun & Clarke, 2022). Braun and Clarke (2013,

2022) have generated key researcher skills and perspectives that are necessary for successful qualitative research:

- A philosophy that: values processes, meaning, questioning and criticality; that elucidates and highlights the role of assumptions (‘a cultural commentator’; Braun & Clarke, 2022, p. 7); and listens analytically rather than passively (Braun & Clarke, 2013).
- Uncertainty tolerance; embracing multiple interpretations as valid knowledge without seeking a singular truth
- Appreciating that ‘understanding’ is complex, nuanced and sometimes contradictory (Braun & Clarke, 2022).

3.3. Design

3.3.1. Data Collection Method

An online qualitative survey was developed as the data collection tool. Target questions were open ended and self-administered by respondents, who typed into open textboxes. Qualitative surveys are effective tools for gathering the views of people with stigmatised identities (Braun et al., 2021), including the autistic community (Charlton et al., 2021). Interviews and focus groups were also considered, but these methods introduce a social demand, which may have created a barrier to participation or expression for some within the autistic community. Autistic community advisors in other research, such as Charlton et al. (2021) indicated a survey could be a more appropriate approach, circumventing social demands.

Qualitative surveys can create their own barriers to engagement; they demand internet access, a level of technological proficiency (Braun et al., 2021), and sufficient literacy and cognitive skill to comprehend the question and articulate thoughts in writing (Braun et al., 2021). To alleviate these barriers as far as possible, alternative methods of participation were offered. Respondents had the option to record responses in a text document, via speech-to-text software, or audio-record their responses and send them via email. The option of a structured interview was also available, where questions could be read aloud by the researcher and responses recorded via transcription software. It was expected this would make the research accessible to as many people within the diverse population as possible. No respondents elected to use these options.

Additionally, qualitative surveys can support accessibility by being easily enhanced by technology; the use of screen-reader software would mean questions could be replayed as many times as needed, accommodating literacy and cognitive needs. They can also be returned to at a later time, allowing greater processing time than may be afforded in an interview. Therefore, it was felt a survey had the potential to elicit more considered responses. The research is founded in values of co-production and epistemic justice, therefore the most ethical way to develop this survey was through collaboration with community advisers.

3.3.2. Survey Development Process

Collaborators were recruited via Facebook. A digital recruitment poster (Appendix 3) was shared in 2 Facebook groups; 1 for neurodivergent psychologists and 1 for autistic autism researchers. The group for neurodivergent psychologists was open to all identifying as neurodivergent and working within a psychology-related field. The autistic autism researchers' group described itself as open to all autistic people with an interest in emic theories of autism, thus not exclusively researchers.

Seventeen people expressed interest in collaborating on the project. Fourteen emailed the researcher and were subsequently sent the collaborator information sheet and consent form (Appendices 4 and 5). Nine returned completed consent forms, and 7 contributed to the development of the survey.

The collaborative survey development procedure was iterative and responsive to collaborator preferences. Four chose to communicate exclusively via email, while 3 opted for virtual meetings. Collaborators were free to contribute as much or as little as they wanted. Some were involved throughout the process, others contributed to one or two stages. Table 1 summarises the development process.

Table 3.1.

Summary of Collaborative Survey Development Process.

Stage	Summary of steps
1	Initial questions tentatively suggested by researcher based on descriptions of other types of “affirming practice” (see Bizub & Allen, 2020). Original survey can be seen in Appendix 6.
2	Questions reviewed by each collaborator, with edits made by researcher. Additional qualitative and demographic questions, and comment boxes, added based on feedback. Additional context added to the introduction to questions.
3	Discussions about culturally appropriate language resulted in changes to wording. Demographic questions amended for relevance based on feedback. Text formatted to increase accessibility. Two collaborators provided unprompted ideas for practice; these were coded by the researcher to review suitability of current questions.
4	Further amendments based on feedback around language in, and relevance of, questions. Further formatting and reduction of information presented in the introduction to questions, to increase accessibility. Prompt added to extra comments box to ask respondents to consider the concept of ‘general good autism practice’.
5	Question added to gather respondent views on what ‘neurodiversity’ means to them. Finalisation of wording. Collaborative decision making using adapted 5-finger voting method (AASPIRE, n.d.), to agree to the final version of the survey. This was repeated after edits were made in response to points raised during the voting process.
6	Piloting resulted in a minor change to wording, and a question added to gather data on the professions of those answering professionals’ questions. Pilot responses were included in the final dataset. Pilot respondent consented to their profession being added to the dataset.

3.3.3. Final Survey

The full, final survey, including instructions, is contained in Appendix 7. The final survey consisted of 9 demographic and 6 target questions for all respondents, and an additional 1 demographic and 2 target questions for professionals. This was kept in line with the typical length for a qualitative questionnaire (Braun et al., 2021) to reduce response fatigue. Demographic questions were agreed between the researcher and collaborators to be important indicators of who within the autistic community the survey responses represent. For example, some within the community (e.g. non-speaking people; Jack & Pelphrey, 2017) are often underrepresented in research, which may impact the applicability of findings to these groups.

Demographic data collected were:

- Identification as autistic (survey ended automatically if ‘no’ selected)
- Timing of autism (self-)identification (childhood, adolescence or adulthood)
- Self-perceived need for support in daily life
- Extent to which respondent identifies as ‘non-speaking’
- Gender, sexuality and race
- Country currently lived in
- Whether the respondent identifies as an autistic professional working with autistic people in a neurodiversity-affirming way and, if yes, their profession

Question wording was influenced by Nicolaidis et al. (2020), who published guidance on creating accessible survey instruments for autistic and/or intellectually disabled adults. Their guidance was produced through ethnographic review of community advisors’ feedback on research surveys (Nicholaidis et al., 2020). Recommendations made were:

- Avoid complex vocabulary, ambiguous terms or figurative language;
- Reduce complexity of sentence structure and grammar;
- Closed response options should be precisely accurate to the question posed and provide sufficient options to cover the full range of potential responses;
- Any relevant context to questions is made clear;
- Ensure the absence of ableist language and concepts.

The above guidance was implemented through co-production with collaborators. Guidance on ‘avoiding ableist language’ from Bottema-Beutel et al. (2021) was also consulted. Question wording was also influenced by guidance on the development of survey questions published by Braun et al. (2021). Recommendations included the use of broad questions, secondary questions to provide clarity on the focus of the question, and providing a final open text box for any other comments.

The final qualitative questions, exploring constructions of NDA practice, were:

1. Please briefly describe what you understand 'neurodiversity' to mean.
2. If a professional worked with **you** in a neurodiversity-affirming way, what would **you see**?

(prompt: what things in the environment tell you professionals work in a neurodiversity-affirming way?)

3. What do **you hear** that tells you they are working in a neurodiversity-affirming way?

(prompt: what do professionals say?)

4. What do **professionals do** that tells you they work in a neurodiversity-affirming way?

(prompt: how do they behave differently to professionals who are **not** working in a neurodiversity-affirming way?)

5. If the professional was neurodiversity-affirming, what would **you** be **thinking**, **feeling** and/or **doing** when you are interacting with them?

(prompt: how might this be different to when you're with a professional who is **not** working in a neurodiversity-affirming way?)

6. Extra space: If there is **anything else** you think 'neurodiversity-affirming practice' means, please enter it here (e.g. how you think it differs to general good practice):
7. **Space for any other comments.**

And for professionals only:

1. What do you do in **<u>your</u>** practice specifically to make sure it is neurodiversity-affirming?
2. (If applicable) What do you do differently now that you work in a neurodiversity-affirming way, compared to when you did not?

3.3.4. Respondents

3.3.4.1. Recruitment and Selection of Respondents.

Respondents were autistic people accessing autism-related spaces online. As a subgroup within this population of autistic people, autistic professionals who identify themselves as working with autistic clients using a NDA approach were specifically recruited. The purpose of this was to gain a range of perspectives on what NDA practice means; both from those accessing it, and those using it in their own practice. Respondents were recruited using volunteer and snowball sampling methods. A recruitment poster (Appendix 8) and link to the survey were posted in eight Facebook groups, selected for their relevance to autistic people, and autistic professionals working with autistic people. The original post asked viewers to share the link with anyone who may be interested in participating. The survey link was posted to each group on 2 December 2022 and a second post was made (14 December 2022), to remind potential respondents.

Each group provided a platform for members to discuss topics relating to autism and/or neurodiversity. Specific group foci were:

- A network for professionals to discuss NDA practice in therapeutic, educational and/or helping professions;
- A platform to discuss neurodiversity/neurodivergence in a UK context;
- A network for neurodivergent individuals working within a psychological profession;
- A platform to discuss and promote autism research and practice that prioritises lived experience as evidence.

Three groups were exclusively for those identifying as autistic, and 4 were designed as support networks for professionals working with neurodivergent (including autistic) clients. It was expected therefore that the survey would reach a large audience of autistic people with views on the neurodiversity paradigm and its application to practice, including those who purport to practice in a NDA way with autistic clients.

3.3.4.2. Inclusion Criteria.

Inclusion criteria were:

- Being autistic (self-identifying or professionally diagnosed), and
- Self-selecting as a person with views on the neurodiversity paradigm and its relation to autism practice.

No specific exclusion criteria were set. No limits were placed on the age of respondents or the country they were based in. No restrictions were set around who is and is not autistic, other than respondents' own identification. Responses of those identifying as autistic without professional diagnosis were treated the same way as professionally diagnosed respondents. Previous research comparing self-identifying and professionally diagnosed members of the autistic community found no significant differences between groups on self-report measures of autistic traits (social interaction, communication, sensory sensitivity, repetitive behaviour, cognitive rigidity, social camouflage; English et al., 2021), experiences of stigma, self-esteem, quality of life, or perceptions of and identification with autism (McDonald, 2020). Therefore, the researcher considered the possibility of distinguishing between these two groups as both culturally insensitive, and not meaningful for the purposes of this research.

3.3.4.3. Description of Respondents Included in Final Analysis.

Eighty-one people began the survey, and 45 completed at least one target question (qualitative questions 2-8). One respondent was removed from the final analysis despite completing the survey, due to indicating they did not consent to participate or to the use of their data.

Respondents lived across five westernised countries and most identified with a white ethnicity. Respondents represented a wide range of diverse gender and sexual identities. Most respondents were professionally diagnosed in adulthood, though respondents who were self-identified are also represented, as are people diagnosed or self-identified before adulthood. The majority of respondents considered themselves to be mostly independent, while others reported a greater need for support. All respondents noted being able to speak reliably all or most of the time.

Twenty of the final 44 respondents indicated they were autistic professionals working with autistic people in a NDA way. Of these, 19 completed at least one qualitative question for professionals. These 19 respondents represented a range of professions across health, psychology, education, research, and others. Appendix 9 presents respondents' demographic information in more detail.

3.4. Methods of Analysis

3.4.1. Reflexive Thematic Analysis

Reflexive thematic analysis (rTA; Braun and Clarke, 2022) was selected as the analysis method. Thematic analysis (TA) is a collection of systematic approaches to qualitative analysis, each supporting the generation of themes within a dataset (Braun & Clarke, 2022). 'Themes' are defined as patterns with underlying common ideas, meanings or concepts (Braun & Clarke, 2022).

Thematic analysis is inherently theoretical as it is inseparable from the researcher's ontological and epistemological assumptions (Braun & Clarke, 2022). However, it is theoretically flexible, in that it is not restricted to a particular underpinning theory (Braun & Clarke, 2022). *Reflexive* TA is theoretically constrained to the degree that it rejects positivism and its assumptions, including assumptions that researchers should strive for objectivity (Braun & Clarke, 2022). In rTA, researcher subjectivity is embraced, as it is considered to enhance the interpretive process, provided the researcher actively and critically evaluates their own positionality and role within the analysis (Braun & Clarke, 2022). Thus, researcher reflexivity (described as 'a subjective, situated, aware and questioning researcher'; p.5) is a defining feature of the approach (Braun & Clarke, 2022).

The rTA approach can be applied to a wide range of designs and is not restricted to a specific research question type or data collection style (Braun & Clarke, 2022). It can be used where the dataset consists of relatively short qualitative responses, such as from qualitative surveys (Braun & Clarke, 2022). The method of rTA is flexible, thus can be approached differently depending on the research aims, and can adapt as the researcher engages critically with the process (Braun & Clarke, 2022).

3.4.2. Process of rTA

The analytic process of rTA, according to Braun & Clarke (2022), follows 6 phases:

1. Data familiarisation: Immersion with the data through repeated re-readings and other methods of engagement; brief notes kept of any insights or ideas occurring.
2. Data coding: Assigning short, descriptive labels to pertinent information within the dataset, through systematic and thorough reading. Segments are collated by code label.

3. Initial theme generation: Collating data by codes interpreted to have a shared core idea or concept.
4. Theme development and review: Reviewing candidate themes in relation to the overall dataset; assessing suitability and meaningfulness through re-engaging with the full dataset.
5. Theme refining, defining and naming: Reassessment of organisation of themes before assigning names to the central organising concepts.
6. Writing up: Refining writing and incorporating pertinent quotes to illustrate themes.

The process, combined with the values, assumptions and practices of rTA, and the researcher's engagement with it, comprise the rTA method (Braun & Clarke, 2022).

3.4.3. Variations of rTA

Approaches to rTA vary across 4 dimensions (Braun & Clarke, 2022):

1. orientation to data: whether generation of codes and themes is deductive, based on existing theory, or inductive, coming from within the dataset
2. focus of meaning: analysis is semantic (at a surface meaning-level) or latent (at an implicit level)
3. qualitative framework: themes capture respondents' perspectives and understanding (experiential) or focus on the meanings around the topic (critical)
4. theoretical frameworks: alignment with philosophical assumptions about knowledge and reality

Approaches to rTA typically evolve throughout the research process. The approach/es taken in this analysis will be elucidated in section 3.4.5.

3.4.4. Other Methods Considered

A number of other qualitative analysis methods were considered. Qualitative Content Analysis was considered for its utility for describing phenomena discussed in written text (Elo & Kyngäs, 2008). It is used to generate categories through which novel insights about the phenomenon are represented, and inferences about wider contextual features can be drawn (Elo & Kyngäs, 2008). This may have been a valuable way to represent participant views relating to NDA practice, allowing inferences to be generalised from the immediate respondent pool to the wider autistic community. However, content analysis is atheoretical

(Braun & Clarke, 2021) and applies positivist principles of reliability and validity (Elo & Kyngäs, 2008), thus was not philosophically aligned with the researcher.

Interpretative Phenomenological Analysis is a popular method within psychological research, useful for interpreting language to make sense of experiences described by it (Pringle et al., 2011). The views and experiences of the participants are held at the heart of the process (Pringle et al., 2011), which aligns with the values of the present researcher. However, it was inconsistent with the research aims, in that details of personal life experiences were not being sought.

Grounded Theory is useful for generating new theories about phenomena, based on evidence gathered through real-world situations (Oktay, 2012). This has the potential to guide practice, based on empirical evidence (Oktay, 2012). This may have utility in relation to NDA practice, in that it could potentially facilitate implementation. However, at this stage, the aim was to understand how the autistic community conceptualise NDA practice, rather than develop theories about implementation.

Discourse Analysis describes a range of approaches to studying the use of language in text (Gill, 2000). It assumes language actively constructs social life, rather than being used to passively describe it (Gill, 2000). This inherently rejects realist ontological assumptions (Gill, 2000) and adopts a social constructivist epistemology (Gill, 2000) and, in this sense, is ontologically aligned with the researcher. However, it is primarily useful for understanding the effect of language (Braun & Clarke, 2021) rather than phenomena, therefore would not sufficiently address the present research question.

Various forms of TA were considered. These include rTA, coding reliability TA and codebook TA (Braun & Clarke, 2022). Coding reliability and codebook TA were excluded for being most closely aligned with a positivist epistemological stance (Braun & Clarke, 2021; 2022) thus not philosophically aligned with the researcher. Reflexive TA, in contrast, is compatible with a relativist ontology, and constructivist epistemology with transformative values (Braun & Clarke, 2022). It also provided a method with which to address the research question and purpose.

3.4.5. Approach to Analysis in this Research

The process of rTA, including recommendations by Braun & Clarke (2022), was carefully followed (see 3.4.2.). The researcher engaged in a visual familiarisation exercise to support immersion in the dataset during phase 1 (see Appendix 10), following repeated re-readings of the full dataset. In phase 2, coding occurred through printing the dataset, segmenting each extract, and grouping them together with tentative labels (Appendix 11). These were repeatedly reviewed and reorganised over time. Phase 3 involved organising code labels into groups with a shared meaning, with thematic maps produced to support the interpretative process. Themes and, at times, code labels, were reorganised between thematic maps (see appendices 12-14). A table containing code labels and associated extracts was produced during phase 4 (Appendix 15), which supported further theme development as each extract was considered in relation to its theme. Attempts to define themes (phase 5) allowed tentative theme names to be further refined, with some additional reorganisation of themes, resulting in thematic map 5 (Appendix 16). Supervision was also sought in this phase to interrogate interpretations and justifications. A reflexive journal was kept throughout the process, to critically interrogate implicit assumptions and values that may affect interpretations of the data (see section 5.5.5. (Box 1) for example extracts). The full process took place over several months to allow time for critical reflection and review.

3.4.5.1. Orientation to Data.

Braun & Clarke (2022) argue code and theme generation is typically both deductive and inductive, as was the case in the present analysis. The researcher brought their own experiences of engaging in discourse around neurodiversity and practice with autistic people, wider readings on the topic (academic and non-academic sources) and knowledge of the range of meanings around ‘neurodiversity’ that have emerged within the autistic community (see literature review section 2.3.). This will have influenced interpretations, making them, at times, more deductive. However, reflexive journaling and critical re-engagement with the dataset over time provided the researcher with space to consider a range of potential interpretations, allowing inductive interpretations to be drawn.

3.4.5.2. Focus of Meaning.

Interpretations were a mix of semantic and latent. Some codes were semantic, reflecting explicit meanings where these felt pertinent to the research question. Others focused on underlying meanings, where the connection of the extract to the research question was less immediately apparent. Generated themes captured latent meanings, combining both latent and semantic code labels to interpret the meaning behind their relevance to respondents.

3.4.5.3. Qualitative Framework.

Themes aim to capture respondents' understanding and perspectives. This was essential to addressing the research question and aligning the themes with the research aims and values.

3.4.5.4. Theoretical Frameworks.

Respondent responses sometimes appeared to reflect a belief in a singular reality where truth statements could be made about what is and is not neurodiversity, or NDA. However, in alignment with the researcher's philosophical values and assumptions, statements were interpreted as reflecting one of an infinite number of realities (though valued for its realness to the respondent). Reflexive journaling was used to ensure diversity within the views expressed was valued.

3.5. Credibility and Value of Qualitative Research

3.5.1. Strengths and Limitations of Qualitative Research

Qualitative research can offer rich insights into the lived experiences and perspectives of individuals and groups (Braun & Clarke, 2022). It can also help to illuminate the precise qualities of a phenomenon or construct (Gulliford, 2015). This may be of growing value and importance, as social and health policies, for example, increasingly prioritise patient voices in decision making (Braun & Clarke, 2019b).

However, some criticise qualitative research for its lack of generalisability beyond the specific study context. Qualitative inquiry generally takes place in a natural, highly variable, culturally dependent context, unlike the artificial experimental conditions of most quantitative research (Coolican, 2009). While this may make results more true-to-life, the utility of such results is questioned, as they cannot be assumed to apply beyond the study context (Coolican, 2009).

In response, some qualitative researchers reject the importance of generalisability altogether, arguing the value of qualitative findings should not be judged against positivist notions of statistical generalisability (Braun & Clarke, 2022). Others propose a similar concept of 'transferability' of findings (Braun & Clarke, 2022, p.144), or "reasonable extrapolation" (Polit & Beck, 2010, p. 1451). Discussion of conclusions beyond the immediate dataset are therefore dependent on the views of the researcher, who must consider this in relation to their philosophical assumptions, and be critical about any conclusions drawn (Braun & Clarke, 2022). Given the present researcher’s alignment with both constructivist and transformative paradigms, they have considered it appropriate to discuss possible implications of findings for social justice in relation to the autistic community.

Others have criticised qualitative research for ‘lacking scientific rigour’ (see for e.g., Noble & Smith, 2015, p.34). Some may consider this an epistemic fallacy (incongruence between ontology and epistemology; Cruickshank, 2016), since qualitative researchers generally reject positivist scientific principles (Braun & Clarke, 2022). Rather, its philosophical distance from science and empiricism has been argued to be one of its strengths; researcher subjectivity, when engaged with reflexively, can bring additional depth to knowledge generation (Braun & Clarke, 2022). This said, qualitative research is not without standards for ensuring its credibility and value; standards of enquiry must also be considered with alternative research paradigms in mind (Robson & McCartan, 2015).

3.5.2. Quality Control in Qualitative Research

There is ongoing debate about the standards against which qualitative research should be evaluated (Baillie, 2015). Quantitative research has well established standards, based on traditional scientific principles (Coolican, 2009) of reliability (consistency of the findings) and validity (accuracy of study findings) (Robson & McCartan, 2015). Various attempts have been made to translate principles of reliability and validity into the qualitative domain. For example, Noble and Smith (2015) listed common strategies for ensuring the ‘credibility’ of qualitative research and ‘trustworthiness’ of the results. Lincoln and Guba (1985) published criteria for ensuring ‘rigour’ in qualitative research. These principles and strategies are presented in Table 2.

The appropriateness of the recommendations in Table 2 were considered in relation to rTA. Some elements appear consistent with the rTA approach. For example, clearly articulating the researchers’ relationship to the research is necessary to contextualise their interpretations (Braun & Clarke, 2022), and retaining an audit-trail through thematic maps and reflexive journals is useful evidence of deep engagement with the data (Braun & Clarke, 2022). Additionally, coherence between assumptions and methodology is essential for rTA (Braun & Clarke, 2022).

Table 3.2.

Principles of, and Strategies for Ensuring Quality Qualitative Research.

Criteria (from Lincoln & Guba, 1985)	Components	Strategy (from Noble & Smith, 2015)
Truth value	Recognises that multiple realities exist	• Accounting for personal biases • Actively looking for differing perspectives within the dataset • Working with other researchers to reduce bias • Invite respondents to check analysis for accuracy • Provide rich evidence of respondent views to support interpretations
	Researcher outlines personal experiences and viewpoints that may bias the research	
	Respondent perspectives are articulated clearly and accurately	
Consistency	Researcher maintains a ‘decision-trail’ to establish fidelity with which methods have been followed	• Clear and detailed record keeping • Critical reflection around methods
	If replicated, independent researcher should be able to produce comparable findings	

Confirmability	Researcher's philosophical assumptions, experiences and perspectives should be consistent with the methodology, and clearly differentiated from respondents' accounts	• Triangulation of data from multiple sources • Clearly articulating thought process during analysis
Applicability	Extent to which findings can be applied across contexts	• Transparency around issues of bias in sampling

However, other elements are philosophically incompatible with both rTA and the present research. For example, researcher subjectivity is embraced by rTA, meaning seeking to reduce 'bias' through multiple coders, or by asking respondents to confirm the accuracy of interpretations, does not necessarily enhance the analysis (Braun & Clarke, 2022). Similarly, the notion of biased sampling is rejected by rTA, though transparency about the specific context in which interpretations have been made is important for any findings to be transferred beyond the immediate research context (Braun & Clarke, 2022). These discrepancies in philosophical bases for evaluating qualitative research necessitate that criteria more specific to rTA be considered, in conjunction with the recommendations of Lincoln and Guba (1985) and Noble and Smith (2015) above.

3.5.3. Quality Control in rTA

Braun and Clarke (2022) recommend that rTA is evaluated against 15 points. Although Braun and Clarke (2022) present a list of evaluative statements as a checklist, they noted the points are better considered as tools for deepening engagement with, and reflexivity regarding theory and data. The checklist presented in Table 3 has been used here to promote reflection throughout the analysis, interpretation, and writing process, and as a general guide for what constitutes quality rTA.

Table 3.3.

Quality Control Criteria for Reflexive Thematic Analysis.

Process	Criteria	Researcher engagement
Transcription		
1.	Transcription of the data has been done to an appropriate level of detail and checked for accuracy	N/A
Coding and theme development		
2.	Data items given thorough and repeated attention	Multiple systematic readings of dataset and each data item during phases 1 and 2, including visual familiarisation (see Appendix 10)
3.	Coding process was rigorous and comprehensive. Theme generation was not restricted to a small number of pertinent examples.	Each data point segmented into extracts during coding. All extracts and subsequent codes carefully considered and reconsidered. Very small minority of extracts and codes excluded after careful consideration. See Appendix 17.
4.	For each theme, all contributing extracts from the dataset have been collated	See extract in Appendix 15.
5.	During theme development, candidate themes were checked against both the coded data and the original dataset (phase 4).	Use of Braun and Clarke (2022) guide and reflexive journal to support depth of analysis during phase 4.

6.	Themes were generated from codes that share a central organising concept, and are each distinctive from other themes. Any subthemes share the same central organising concept as the theme.	Use of Braun and Clarke (2022) guide and reflexive journal to support phases 4, 5 and 6. See examples of thematic maps in Appendices 12-14 and 16.
Analysis and interpretation		
7.	Data is interpreted, not simply summarised, described or paraphrased	Use of Braun and Clarke (2022) guide and reflexive journal to support interpretation. See Chapter 4.
8.	Coherence between interpretation and data extracts	Use of Braun and Clarke (2022) guide and reflexive journal during interpretation and write up, to support self-assessment of this criteria. See Chapter 4.
9.	Analysis addresses the research question and tells an organised and convincing story about the data and topic	Use of Braun and Clarke (2022) guide and reflexive journal during interpretation and write up, to support self-assessment of this criteria. See Chapter 4.
10.	Balance of data extracts and interpretation	Use of Braun and Clarke (2022) guide and reflexive journal during interpretation and write up, to support self-assessment of this criteria. See Chapter 4.
Overall		

	11.	Sufficient time allocated to each phase of analysis, allowing for depth of analysis, and returning to earlier phases if needed	Analysis spanned several months, allowing time to reflect and rework earlier phases. (E.g., code 'validate lived experiences' was divided into 3 codes during the theme generation phase).
Written report			
	12.	Approach to rTA, theoretical positions, and assumptions, are made clear	See sections 3.2. ('methodological orientation') and 3.4. ('methods of analysis') within methods section.
	13.	Coherence between what was claimed, and what was carried out	Evidenced particularly by section 3.3. ('Design') and Chapter 4 (results).
	14.	Language and concepts within the report are consistent with philosophical assumptions	Use of reflexive journaling to support this. Coherence evidenced particularly by sections 3.2. ('methodological orientation') and 3.4.5. ('approach to analysis in this research')
	15.	Researcher is positioned as actively generating themes, not passively identifying them	See section 3.4.5. ('approach to analysis in this research') for the approach to theme generation.

3.5.4. Critical Evaluation of rTA

One potential limitation of rTA is its reliance on the skills and knowledge of the analyst. While this can be a limitation of all research, rTA does not offer prescriptive rules (Trainor & Bundon, 2021), instead relying on the researcher being guided by the founding principles and assumptions (Byrne, 2022). The lack of prescriptive rules can create confusion, such as around how many participants are required for a thematic analysis (Fugard & Potts, 2015). It has also led researchers to question the utility and trustworthiness of some published rTA research, arguing interpretations of the process have failed to produce trustworthy interpretations (Nowell et al., 2017). Additionally, the principles have not always been clearly articulated (Braun & Clarke, 2019a). Consequently, some research espousing the use of rTA may not adequately follow rTA principles (Byrne, 2022). However, when executed well, rTA provides an opportunity to tell a rich story about the data, informed by a researcher's deep engagement with the dataset and their wider experiences and values (Braun & Clarke, 2022). Further, good quality, trustworthy rTA research can be achieved by applying quality control criteria (Nowell et al., 2017).

3.6. Ethical Considerations

The research followed principles of ethical human research as described by the British Psychological Society (2021a; 2021b). The University's code of research conduct and ethics was also observed (Research Integrity, Risk and Compliance team, 2023). An illustration of how principles of research ethics were applied is given below.

3.6.1. Informed Consent

Valid consent means respondents having the information necessary, in an accessible format, to make an informed decision about their involvement (BPS, 2021a). An information sheet and consent form were produced (Appendices 18 & 19) using the standardised form provided by the university. To facilitate informed consent for all potential respondents (recognising the significant overlap between autism and intellectual disability; Baio, 2014) an Easy Read version of the respondent information sheet was produced (Appendix 20) and available on request. This was developed using guidance from the Department of Health (2010). The consent form also requested consent from parents/carers, if the respondent was under 16, following BPS guidance (BPS, 2021a).

3.6.2. Right to Withdraw

To respect the autonomy, privacy and dignity of individuals participating in research, they must retain a right to withdraw their data for as long as possible (BPS, 2021a). To address this, the information sheet (Appendix 18) stated respondents could withdraw at any time before submitting the survey, by closing the browser. Additionally, respondents were asked to confirm their understanding that participation was optional. This was also explicated in the respondent recruitment poster (Appendix 8) and information sheet.

3.6.3. Confidentiality

Personal information gathered through research must remain confidential (Research Integrity, Risk and Compliance team, 2023). Respondents were advised they did not need to include any sensitive or identifying information, and that, if they did, this would be redacted in quotes shared in the final report. Raw data were stored securely and processed according to GDPR guidelines. The privacy notice for research participants was linked at the beginning of the survey (see Appendix 18).

3.6.4. Harm Reduction

Researchers must maximise potential benefits of the research for respondents, while mitigating risks to their wellbeing, privacy, dignity and values (BPS, 2021a). Guidelines for professional psychologists also expect psychologists will avoid harm, or the abuse or misuse of professional power and authority (BPS, 2021b). The research topic had the potential to evoke distressing emotions or memories for respondents. To mitigate this risk, it was stated in the respondent recruitment poster that there was no need to include personal memories or circumstances. The information sheet stated respondents could choose to leave any question blank for any reason. To support respondents in the event they had been adversely affected by the survey, the debrief sheet (Appendix 21) linked a range of mental health helplines and sources of autism-related information. The researcher’s and supervisor’s email addresses were linked, with respondents encouraged to make contact if they had any concerns about their participation.

3.6.5. Other Considerations

Guidelines for conducting ethical autism research were considered. Relevant guidance from the AASPIRE (Academic Autism Spectrum Partnership in Research and Education) group was implemented (see Nicolaidis et al., 2019). Their advice was co-constructed with autistic collaborators and emerged from reflections of co-creating the AASPIRE group. Guidelines were applied to the inclusion of community collaborators, and recruitment of respondents, in the present research. Table 4 details the guidance and steps taken to implement it. Note that some guidance was irrelevant to the scope or nature of the project (e.g. maximising accessibility of interviews) or unfeasible within the constraints of an independent thesis project (e.g. providing opportunities for collaborators to pursue education or training).

Table 3.4.

Implementation of Guidelines for Ethical Autism Research.

Guidance (from Nicolaidis et al., 2019)	Steps taken to meet standards
Guidance for ethical inclusion of collaborators	
Transparency around goals of the partnership	• Recruitment poster and initial email clearly stated that collaborators were being sought for the survey development process only.
Clearly defined roles	• Clearly and repeatedly stated that collaborators could cease their involvement at any time without giving a reason. • Collaborators advised that their values and perspectives were being sought and would be valuable in shaping the development of the survey, but that, due to the project being an independent thesis, the researcher must retain power to make final decisions.
Establish processes for effective communication and sharing of power	• Early emails agreed how collaborators would communicate (email, virtual meeting, or a combination). • An adapted version of AASPIRE's 5-finger method for shared decision making was used (AASPIRE, n.d) to collaboratively agree on the final version of the survey. • Email communication used elements of the format recommended by AASPIRE (n.d.), including: bolded headings for each new piece of information, Q&A format, bullet points, key statements at the top.

Establishing and maintaining trust as a priority	• Every effort was made to respond promptly to emails. • Updated versions of the survey were shared regularly, clearly evidencing collaborator advice being implemented. • Avoiding rigidity during virtual meetings, enabling natural conversation to flow outside of the survey development (e.g. toward more general discussion about neurodiversity-related topics).
Fairly compensate collaborators for their work	• Working within the constraints of an independent thesis project, compensation took the form of dissemination of results, via an executive summary produced specifically for collaborators. • Collaborators also named in the acknowledgements section where they have consented to this.
Guidance for ethical inclusion of respondents	
Maximise accessibility of consent process	• Easy Read version of the information sheet produced. • Standard consent form used simple language and short sentences to reduce comprehension and processing demands.
Offer multiple modes of participation	• Potential respondents made aware in the recruitment post that other options for participation were available.
Adapt or create survey instruments with autistic people	• Survey co-designed with autistic collaborators, with their advice implemented around question style, phrasing, language, and formatting. • Implementing AASPIRE guidance on creating accessible surveys (Nicolaidis et al., 2020).

Chapter 4: Analysis

4.1. Introduction to Chapter

The previous chapter provided an overview of the methodological approaches taken to this research. This was to analyse, using reflexive thematic analysis (rTA), survey responses from autistic people about their conceptualisation of neurodiversity-affirming (NDA) practice. The philosophical assumptions underpinning the research are a relativist ontology, with a constructivist epistemology prioritising the transformative paradigm's values of social justice.

In the following chapter, the analysis of the survey data is presented. This begins with an overview of the range of views expressed about the concept of neurodiversity, to provide context to the main analysis, which focused on conceptions of NDA practice. The six themes generated from the data on NDA practice are then discussed.

4.2. Respondents' Conceptualisations of Neurodiversity

All 44 respondents addressed the question: 'Please briefly describe what you understand 'neurodiversity' to mean.'. The rTA approach was used to code the data. To provide a broad overview of the range of views, a narrative approach was taken to summarising the codes. The range of views are described in relation to 6 topics: 1) What is neurodiversity? 2) Ontology of neurodiversity, 3) Value of difference, 4) Assertions of the neurodiversity paradigm, 5) What counts as neurodivergence?, and 6) Ongoing debates.

4.2.1. What is Neurodiversity?

Neurodiversity appeared to be conceptualised in a range of ways across respondents. Most descriptions of neurodiversity appeared to represent it as a categorical construct. For some, neurodiversity seemingly could be divided into two groups, of either '*neurotypical*' and '*neurodivergen*t' or '*majority*' and '*minority*'. For others, neurodiversity seemed to include a wide range of different categories (sometimes described as '*neurotypes*'), where '*neurotypical*' was just one. A few responses specified that subcategories of neurodiversity could intersect and coexist. For other respondents, neurodiversity did not appear to be considered a categorical concept, and it was described seemingly as referring to the infinite ways for a brain to develop. Occasionally, responses made an explicit distinction between concepts of 'neurodiversity' and 'neurodivergence', for example: '*I'd definitely see being autistic as a matter of being neurodivergent, not neurodiverse' (r.21).'*. This seems to suggest some within the autistic community consider there to be subtle but important differences in the meaning of terms related to the neurodiversity paradigm.

4.2.2. Ontology of Neurodiversity

The nature of neurodiversity was described differently across the responses. Frequently, neurodiversity seemed to be considered an empirically real, observable variation in human development (*'the biological fact…', r.10*). Some seemed to assert that differences were biological, while others appeared to root it in psychology (*'minds that work differently', r.5).* Occasionally, neurodiversity was described as a variation in both biology and psychology (*'diversity in brains and thinking', r.1)*. A few responses seemed to offer a more relativist view of the nature of neurodiversity by, for example, comparing neurodiversity to the socially constructed categories of *'sexuality, gender etc' (r.32)*.

4.2.3. Value of Difference

Some respondents appeared to consider neurodiversity as *'crucial to our (society's) success and optimization.' (r.19)* while others seemingly described neurodiversity as neutral (*'nobody is 'wrong' but we are naturally different.', r.12).* None of the comments from the respondents in this dataset seemed to frame neurodiversity as negative, even where neurodivergence was explicitly described in relation to disability.

4.2.4. Assertions of the Neurodiversity Paradigm

A common thread that united most responses was that neurodivergence was not described in terms of disorder. Beyond this, a range of responses seemed to describe what they saw as the assertions of the neurodiversity paradigm. These are encapsulated by the following:

1) Dichotomising the human neurodevelopmental trajectory as either 'typical' or 'atypical' is inaccurate (*'neurodiversity is normal', r.18).*

2) Medical diagnosis does not define belonging in the neurodivergent community ('[Neurodiversity] *rang[es] from those described as neurotypical to those of neurodivergent (either self identified or diagnosed)', r.44).*

3) Differences in neurological development do not need to be eradicated (*'Neurodiversity means defining autism, and related conditions […] as a natural part of human diversity […] rather than as a disease or disorder which needs to be treated or "cured"', r.32).*

4) Those who may be seen as different should have the right to celebrate their differences: '*[Neurodiversity means] a way to celebrate our difference and not see it as wrong or pathological' (r.12).*

4.2.5. What counts as Neurodivergence?

From least to most inclusive, definitions of neurodivergence were given as: Autism only (*'those with autism', r.23*); neurodevelopmental disabilities only (*'autism, ADHD, dy[s]lexia, dyspraxia, tourettes etc', r.16*); neurodevelopmental disabilities plus mental health disorders (*'autism, adhd, dyslexia, bipolar, depression, Anxiety', r.43*); all psychological disabilities and differences, whether permanent or temporary (*'neurodivergent includes anyone whose mind is (currently) functioning significantly differently from the norm [...] adhd/ autism/ dyslexia [...] dementia, mental illnesses, learning disabilities, brain injuries, etc.', r.5*).

4.2.6. Ongoing Debates

Given the range in views described above, it appeared there is not a consensus within the autistic community on the concept of neurodiversity. Some respondents seemed to explicitly address this. For example: (*'I want it to mean [...] however, when I hear it I assume it to mean [...] so it's not a term I use much myself, because I don't want to be a part of that.' r.5).* This seemed to convey a feeling that their views were not shared by the majority within the community. The implications of this will be considered in the following chapter.

4.3. Thematic Analysis: Neurodiversity-affirming Practice from the Perspective of the Autistic Community

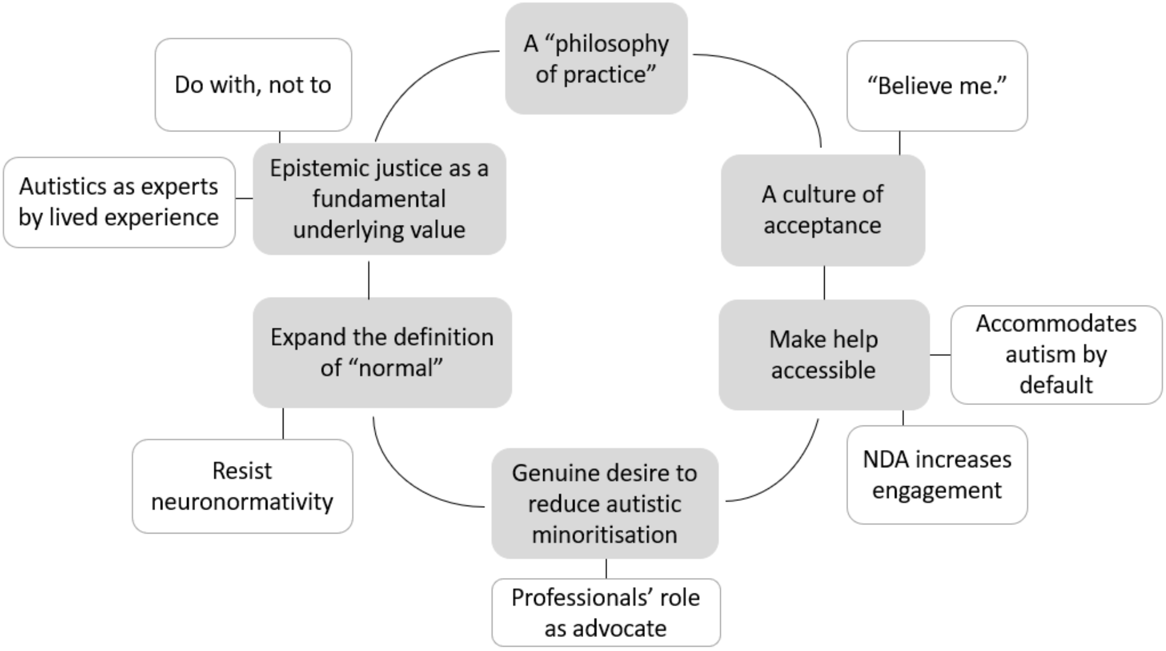
The analysis generated 6 themes, with a total of 7 subthemes. Themes with their subthemes are represented in Figure 1. An extract of the collated themes, subthemes, codes and extracts can be found in Appendix 15.

4.3.1. Theme 1: A "Philosophy of Practice"

Across the dataset, descriptions of NDA practice tended to suggest it is not a singular practice with clearly definable borders. Rather, it may be better described as a style personal to the professional and service, that is developed around the foundations of the concept of neurodiversity.

Figure 4.1.

Thematic Map Representing Themes and Subthemes Generated within this Analysis.



Responses suggested that, for practice to be NDA, it should be obvious the professional is influenced by the neurodiversity paradigm. Respondents felt that symbolism (*'show the rainbow infinity symbol', r.11*), aspects of the environment (*'Neurodiversity affirming books', r.9*), and discourse (*'talk about neurodiversity', r.40*) represent the professional's position. The language used by professionals was commented on especially frequently. Respondents seemingly considered the terminology originating from the neurodivergent community (*'for example [...] Neurodivergent and Neurodiverse', r.28*) to be the most valid, up-to-date and appropriate. It seemed respondents expect NDA practitioners to use this terminology. For instance, *'language [...] tells me if a person knows about neurodiversity and has respect for/up to date information [about] autistic people' (r.33)*. Use of alternative terminology seemed to be an indicator that a professional was considered unsafe or untrustworthy. For example,

> *If a professional I am working with uses dated language, even if meant well, I would be less likely to tell them about my neurotype or ask for accommodations since I would be scared they would react based on negative stereotypes. (r.33).*

Although neurodiversity language appeared to be a key part of NDA practice, respondents seemed to reflect that the language is not what makes practice NDA. Neurodiversity language could seemingly be (mis)used, as *'buzz words' (r.18)*, to (mis)represent a service. For instance, *'It could easily still be problematic, as people are co-opting the words and concepts.' (r.30).* This reflected a more general sense that NDA practice *'isn't something you SAY [you] are, it's something you DO.' (r.18).* However, it also seemed an existing non-NDA style cannot simply be amended or added to until it qualifies as NDA (*'I don't think this is something you can quantify as presenting as affirming', r.30*). It appears that an NDA approach may begin with a philosophy of practice, and the underpinning values of the service; simply adapting a service to be more accessible to autistic people, for example, was not considered NDA: *'Re-thinking everything you think and do from scratch. 'Adaptations' are a half measure [...] you need to start with your philosophy of practice' (r.41).*

An example of a neurodiversity-aligned philosophy of practice, which was repeated across the dataset, was a professional sharing responsibility for effective communication. Rather than simply providing the autistic person with accommodations for their communication difficulties (though these were important to participants; see theme 'make help accessible'), responses suggested the professional would consider communication success to be the equal responsibility of both communicators (*'understanding and accepting of the double empathy problem', r.27*). (For discussion of the double empathy problem refer to Chapter 2, section 2.4.4.2.). In practice, this may look like *'frequent checking we had the same understanding of the conversation' (r.26)* and learning and using neurodivergent communication styles (*'Keep very aware of how people communicate and reflect that back to them, even if it's not my [professional's] natural pattern.', r.21).*

Being clear about the practice philosophy seemed to mean, to respondents, recognising where some existing practices or organisations are fundamentally incompatible. NDA and behaviourist approaches were highlighted by respondents as having conflicting values and goals, which an NDA professional would typically not endorse. For example, *'Most CBT/behavioural/ABA approaches are in conflict with neurodiversity affirming practice because they are based on the premise of abnormality and that the person needs to change' (r.40).* This seemed to reflect a view many respondents shared when defining the neurodiversity paradigm; that neurodiversity is not a developmental fault. Some indicated that a professional practising Applied Behavioural Analysis (ABA), or similar, would make them question the professional's espoused priorities and values;

> *I ALWAYS look at the [service's web]site first to see if they offer ABA. I avoid any place that offers it (or any of the other things ABA is called). It doesn't matter how good their reviews are, that is an immediate flag that this practice prioritizes "normality" above the health and safety of its pts [patients] (r.36).*

Through the comparison to approaches considered non-NDA, responses suggested that NDA practice locates autism-related difficulties outside the person, instead considering the social and environmental context as disabling (*'most of the distress I experience as a neurodivergent person is in the context of other's expectations for my behaviour', r.40*). In other words, it seemed that an autistic person may not be considered to *possess* a disability, but to be disabled in their interaction with the environment.

An integral part of NDA practice, to respondents, seemed to be a professional who engages reflexively with neurodiversity theory. An NDA professional was characterised as a person who not only aligns with the neurodiversity paradigm in their values, but who is conscious of, and reflective when their practice, latent beliefs or attitudes are incongruous with them. A respondent, who was a professional reporting they shifted their practice from non-NDA to NDA, stated: *'I now feel that everything I do is now inline with my own beliefs and values rather than going along with things that I was trained in but felt uncomfortable with.' (r.2).* Views indicated an NDA professional would also be willing to continually develop their knowledge. For example: *'Have a humble attitude of wanting to learn more about neurodiversity.' (r.12).* Knowledge gained through professional training should, according to respondents, also be interrogated. Responses expressed concern about the utility of professional training on autism, its relevance to the lived experience (*'not just go by whatever they might have been taught about autism.', r. 38*) and its implicit values *('committed to unlearning their ableism.', r.4).* An NDA style could then be characterised as an ongoing, reflexive process between a professional and their practice, in relation to the neurodiversity paradigm. What the professional brings to the process would, accordingly, be central to whether it is considered NDA (*'You have to be prepared to be challenged about your very self. Most professionals don't get this but at least being willing and open is a good start', r.41).*

While NDA practice may be incompatible with some approaches, respondents suggested it is not entirely distinct from all existing practices (*'they are working from an anti-oppression framework' (r.4); 'they would have a trauma-informed approach' (r.11)).* Neither may it require a whole new skillset; transferrable professional skills were listed (e.g., *'active listening (r.20)'; 'occasional reflections to demonstrate they understand me' (r.41); 'have empathy and respect', (r.2)).* It seemed NDA practice could also be built around the service/professional context, making it widely variable (*'unique to individuals/organizations', r.13).* According to such descriptions of NDA practice, offering any clear criteria for NDA practice could be both impracticable and restrictive. It would seem, from the perspective of this group of autistic people, NDA practice could perhaps be better reframed as 'neurodiversity-affirming practices*',* reflecting that professionals would develop their own style, based on their own personal values and philosophy, rather than around a checklist of criteria. When practices are built with the neurodiversity paradigm as the foundation, by a reflexive professional, it seems the practice may begin to be considered NDA.

4.3.2. Theme 2: Expand the Definition of "Normal"

Meanings across the dataset seemed to reflect a sense that autism is commonly excluded from society's understanding of what is normal for a human (e.g., *'[NDA professionals] don't turn me into a problem because they behave in a normal way and I don't', r.12)*. It seemed NDA was conversely positioned as normalising autistic people, not by changing them to fit an exclusionary definition of "normal", but by expanding the definition of normal to include neurodivergence (e.g., *'It centres the autistic/ND experience as accurate and correct without trying to change it', r.40)*.

Across the theme, meanings seemed to position NDA practices as normalising aspects of autistic experiences, by seeing them as unremarkable, while still recognising and validating their significance for the client. An NDA professional may integrate a client's autistic identity into their existing knowledge about them, rather than changing their perspective about the client after learning they are autistic. For example, *'When you say you're autistic etc they don't grab a pad and make notes or switch into formal mode. They just accept it as a neutral part of your character (like having brown hair)' (r.12).* Sensory tools may be available to all clients as standard practice ('*they have fidget toys and other stuff like that', r.12*), without them being reserved as disability accommodations. Accommodations (*‘reasonable adjustments’, r.32, 26)* were seemingly an important component of being NDA, but respondents suggested offering adjustments should be seen as a routine procedure that does not ‘other’ autistic clients; *‘Initiating those conversations on the assumption that it’s normal practice to be making adjustments, not exceptionalising/a bother in any way.’ (r.20).*

Autistic profiles could perhaps also be normalised by accepting authentic autistic expression; respondents seemed to reflect that autistic authenticity should not be remarkable or unusual. For example, *‘No reaction if I stim etc, I’m stimming so what?’ (r.26).* Not only could authenticity be normalised, but responses suggested it could be actively encouraged. For example, a professional may proactively ‘*let students know all forms of listening are valued, and that they are welcome to move, stimm, wear headphones, look at a screen, or use any other methods of self-regulation they need.’ (r.28).*

Some respondents stated explicitly that NDA practices should not be exclusively for neurodivergent clients. Specialising in neurodivergence was apparently seen as exclusionary by some, by exceptionalising autistic individuals and placing them outside of the norm. For instance,

> *It [NDA] means providing space to make room for neurodiversity WITHOUT compromising the majority. That does NOT mean the majority shouldn’t have to get used to different forms of engagement, but that the practice shouldn’t become so attuned to neurodiversity-needs that it only really works for neurodiverse people! If engagement becomes that specialised, then perhaps two different spaces are required… but that can quickly lead down the path of segregation and exclusion…* (r.17)

This extract perhaps summarises the theme of expanding the definition of normal, which seems to suggest NDA practices include autistic people as their authentic selves, without them being seen as different. Autistic people may be included not just by accommodating autistic needs, but by viewing autistic differences as a normal feature of humanity and the human condition.

4.3.2.1. Resist Neuronormativity.

The theme ‘expand the definition of normal’ included one subtheme; ‘resist neuronormativity’. ‘Neuronormativity’ is used in literature to refer to an idea that neurotypicality is the expectation of society, and that dominant social norms and values are defined by neurotypicality (e.g. Goldstein Hode, 2012; Huijg, 2020). It is being used here specifically to reflect what seemed to be an assumption of respondents; that society considers neurotypical development to be the ideal and preferred trajectory for human (neuro)development *(‘I am working toward understanding and accepting myself as a neurodivergent person in a neuronormative world’, r.14*).

Respondents seemingly reflected that an NDA professional would decentralise neurotypical experiences as the default. For example, incoming clients would not be presumed neurotypical, and neurotypical experiences would not be centred as the standard by which other experiences are contrasted (*‘not making assumptions that I am neurotypical’ (r.1); ‘No assumptions about how I see the world, it’s constructs, or comparisons to neurotypical norms.’, (r.23)).* Similarly, responses from both autistic professionals and non-professionals indicated NDA practices remove any expectation of neurotypical behaviours. For instance, *‘[if the practice is NDA] I don’t feel the pressure to conform to societal norms, like sitting still, not stimming etc.’ (r.34).* It seemed, for some participants, assumptions made about them by professionals, when based on neurotypical norms, can do them an injustice; it appears that basing judgements of an autistic client’s pain, emotions or level of engagement, for example, on how these are typically expressed by a neurotypical person, may cause them to be misunderstood. For instance, *‘[not] making assumptions that lack of eye contact or stimming mean I’m feeling stressed – often it means I feel more safe and comfortable’ (r.9).*

Finally within the subtheme of resisting neuronormativity, many responses appeared to reflect that encouraging the client to assimilate into neurotypical standards of thinking or behaviour should not be the goal. Some compared this to attempting to change core aspects of their identity (*‘not trying to change the underlying person I am’, r.14)* with assertions that the person should become more ‘normal’ being damaging to their sense of self (*‘some try to change thought patterns/behaviours that are just part of how my brain processes information. This is really harmful to perception of self and self esteem’, r.31).* Respondents seemed to suggest that, alternatively, goals might involve, for example, *‘developing strategies […] which will help my day to day life experience’ (r.3)* or *‘understand[ing] what their neurodiversity means to them and how this impacts their interactions with the world’ (r.31).* Meanings within the subtheme ‘resist neuronormativity’ appeared to reflect a desire for professionals’ expectations not to be defined by neurotypicality, or for neurotypicality to be assumed to be the ideal way to develop.

4.3.3. Theme 3: Epistemic Justice as a Fundamental Underlying Value

This theme relates to a pattern of meaning noted across the dataset that appears to position the autistic voice – individually and collectively - as important, valuable, and capable of creating and conveying knowledge. Epistemic (in)justice refers to knowledge generated by some groups being devalued or dismissed (Catala, 2015). Conversely, 'epistemic justice' is used here to mean valuing the knowledge autistic people have about (particularly) autism and themselves. For instance: *'They [NDA professionals] would understand that the lived experience of others represents high quality knowledge' (r.1).* The theme contains 2 subthemes; 'do with, not to', characterised by involving autistic clients and the wider community directly in processes, and 'autistics as experts by lived experience', reflecting that the professional regards lived experience as knowledge valuable enough to inform and shape their practice.

Within the broader theme of epistemic justice as a fundamental value, it seemed that respondents see NDA practices as making them feel valued and equal to non-autistic people. It seemed important that clients are taken seriously regardless of communication differences *('They don't treat me like an idiot just because I need to ask "obvious" questions, might need them to repeat things or say things in an exact way.', r.18).* Likewise, respondent descriptions of how they would feel when professionals use a NDA approach seemingly implied that they often feel their voice is devalued, or even dehumanised, by some non-NDA practices. For instance, *'they address me as a person' (r.13), 'not condescending' (r.35) and '[t]hey do not ever infantilize or shame me' (r.3).* Practical examples of things that seemed to make respondents feel valued were: *'speak directly to me rather than my carer' (r.7)* and resisting *'ideas around how someone is "inspirational" or "impressive" for doing a normal thing "despite being ___".' (r.13)* The latter was further described as '*indicative of prior underestimation or devaluation' (r.13).*

4.3.3.1. Do with, not to.

Responses suggested that centring the client's voice in the process is crucial, such that any intervention is completed with them, not done to them. Regarding the goals of the involvement, respondents appeared to indicate professionals should not make unilateral decisions (*'Not [...] insisting "professional judgement"', r.29)* and should support clients to achieve their own goals. For instance, *'they collaborate with me on treatment goals and accept my goals.' (r.14).* Linking with the theme of expanding the definition of normal, one response suggested professionals should be mindful of neurotypical norms (e.g. for social interaction) influencing their intervention priorities; *'if they [the client] aren't concerned about their social skills or making friends, then don't try and work on that with them because you think it's something they should improve.' (r.11).* As well as centring client goals, responses also suggested seeking feedback from the client could be standard practice, to ensure they have control over the process (e.g., *'Asking questions of the client [...] means the client can give feedback as to how to steer the interaction', r.17)*. However, it was suggested this should not be merely tokenistic (*'they are willing to follow my requests about how I want to work.', r.14).* Professional transparency seemed explicitly important to a few commenters (e.g., *'read back their notes to me' (r.26)* and ensure clients' *'informed consent and knowledge if an assessment is occurring in the appointment' (r.29)),* perhaps to facilitate the client's sense of involvement in the process.

Also relating to the subtheme 'do with, not to', collaboration was seemingly important to several respondents. 'Collaboration' was referred to at the individual level, in terms of collaboration with the client, and at a community level. At the individual level, respondents appeared to conceptualise NDA practices as supporting autistic people to make changes in their life that are relevant to them. One respondent said, for example, *'Focus on collaborative effort to make life better all round.' (r.26).* At a community level, respondents emphasised a need to develop the practice with neurodivergent people *('Collaborate with other ND people', r.12)* and NDA communities (*'Work with other neurodiversity affirming people to continuously improve what I'm doing', r.30)*. The latter extract further suggested that, not only should professionals avoid developing NDA approaches in isolation, but that it is an ongoing, iterative process that is open to change, as highlighted within the theme 'a philosophy of practice'.

4.3.3.2. Autistics as Experts by Lived Experience.

The second subtheme within the pattern of 'epistemic justice as a fundamental underlying value' concerned valuing autistic lived experiences as a source of knowledge. Across this subtheme, respondents seemed to position autistic people as having the right to define autism, and themselves, based on their own self-knowledge. Many responses appeared critical of medicalised language and conceptualisations, which some comments suggested position autism as a disease or defect (*'Well not [saying]: "you suffer from autism" as one* *doctor actually said', r.26)*, and autistic people as broken (*'no "fix" or "cure" language', r.37)*.

While appearing to reject medical institutions' construct of autism as a disorder (*'no reference to symptoms or deficits', r.26)*, some respondents emphasised explicitly that the autistic community, and autistic individuals, should be afforded the power to define who 'autism' applies to. For example, *'Treat self diagnosis as just as valid as professional' (r.25).* This was interpreted to suggest that self-diagnosis, when valued by NDA professionals, relocates the power to define belongingness from professionals to the community itself.

Respondents frequently encouraged professionals to learn from autistic clients. This was discussed in relation to '*openness and curiosity about' (r.32)* the unique experience of the individual (e.g., *'Listening, trying to understand, and asking questions about my experience as an autistic person rather than going off assumptions', r.9)*, and valuing self-insight above observations made by others (*'Prioritize gathering self-report information', r.40).* Similarly, respondents seemed to express the importance of learning from the individual, to avoid relying on heuristic shortcuts (*'They don't stereotype' (r.8); 'Avoid blanket/overgeneralized statements about "people with ___" or "___ people"' (r.13)).* However, one respondent in particular seemed to suggest that being positioned as a teacher, when insight into autism and autistic minoritisation can be learned elsewhere, could become laborious for the client; *'I'm in therapy with a therapist who doesn't specialize in autism and/or ADHD. It's a learning curve to educate about my autistic behaviours and how being seen as the weird kid has impacted me.' (r.42).*

One other way an NDA professional could grow their knowledge of lived experiences of autism, according to responses, may be to seek community-generated knowledge *(e.g., 'informed by listening to autistic voices.', r.27).* Responses suggested a professional who draws on community knowledge may, for example: become *'familiar with terms like masking, special interests, stimming, etc.' (r.14),* able to *'discuss neurodivergent culture' (r.28)* and be *'understanding of autistic burnout, meltdowns, shutdowns and their causes' (r.27).* A professional may then also have the insight required to be culturally sensitive in their practice – something else that appeared important to respondents. Responses emphasised NDA professionals would be *'respectful in the way they talk' (r.12)* and suggested some things are inherently inappropriate; *'I look for a lack of problematic things.' (r.30).* For instance, multiple responses suggested NDA professionals would not use the puzzle piece symbol to represent autism (e.g., *'Not puzzle pieces', r.24)*. Others suggested an NDA professional would avoid certain sources or organisations (e.g., *'They don't talk about [A]utism [S]peaks as a reliable source of information', r.25)* and would not attempt to divide the autistic community (*'They don't distinguish [A]sperger's from autism', r.36).*

4.3.4. Theme 4: A Culture of Acceptance

This theme reflects a pattern of meaning across the dataset that emphasised 'acceptance' as a characteristic of NDA practices. This is related to accepting, validating, and holding space for worldviews and perspectives that differ from the professional's own (linked to a subtheme titled "believe me." (r. 18)), and fostering a culture within individual- and service-level practice that accepts the multifaceted constructs a client may hold about themselves.

As part of the broader theme, it was interpreted that recognising and accepting strengths is important. This was at a client-level (*'They help me understand my strengths as well as difficulties.' r.31)* and group-level (*'Authentically holding a positive view about the strengths of neurodiversity which informs their practice.' r.1).* As well as accepting strengths, it seemed it was important to respondents that NDA practices embrace intersectional identities. Respondents described respecting gender diversity, racial and cultural identities, sexual orientation (*'Pride-related symbolism' (r.36); 'they check in with my pronouns on a frequent basis.' (r.25)), 'Take one's culture identities into account and is queer friendly', r.42),* significant lifestyle choices (*'affirm my childfree status', r.42)* and co-occurring disabilities *('accessible to people with reduced mobility', r.28).* It could therefore be suggested that NDA practices are not exclusively about neurodiversity, but about accepting the person as a whole. This would align with interpretations discussed in earlier themes, such as that NDA can include other styles of practice, and could be applied broadly to all people, not exclusively to neurodivergent clients. It seemed that acceptance was fundamental to NDA practices; an NDA professional's acceptance appeared to be unconditional (e.g., *'Sensory, cognitive and emotional differences mean that often we will not understand someone else's experience; that should not be a hinderance to acceptance.' (r.22)).*

Some responses suggested validating and accepting autism as a meaningful identity is integral to NDA practices. For instance, *'I'm bringing it [being autistic] up to help them understand something about me' (r.8).* Respondents repeatedly stated *'identity-first language' (e.g., r. 37)* would be used, either exclusively, (*'using words like 'autistic' rather* *than 'person with autism', r.41)* or combined with person-first language (*'use a mix of identity-first and person-first language, unless the person they were talking with indicated a preference.', r.19)*. The latter extract seems to suggest client preference should determine the language used at an individual client-level. This may mean that NDA approaches accept identity both at a group level, where a community identifies as autistic, and at a client level, accepting the right not to identify in this way.

4.3.4.1. "Believe me."

Also within the theme 'a culture of acceptance', some patterns of meaning seemed to relate to believing and accepting a neurodivergent individual's constructs of reality. This was sometimes described using the term 'gaslighting' which was understood by the researcher to mean causing someone to lose trust in the validity of their thoughts, memories or perceived reality (Mirriam-Webster, 2023). For example, one respondent said if an NDA approach was used, they could *'open up and be vulnerable about my experiences and differences without concern about being gaslit' (r.40).* Others conveyed an apparently similar meaning, stating *'They don't question my thoughts or feelings or experiences.' (r.38)* and *'they listen and acknowledge the neurodivergent experience, rather than dismissing or downplaying it.' (r.27).* Some responses seemed to specifically discuss (in)validation, with regards to lived experiences and minoritisation. For example, one respondent (a professional) stated within their NDA practice they *'reassure clients that all responses are valid, whether they are the same as other people's or not, and that the way in which neurodivergent brains perceive and describe the world differently is beautiful and valuable, not faulty.' (r.32).* This was interpreted to mean they believe it to be important to accept an individual's constructs, as well as any differences there may be in seeing and experiencing the world across the neurodiverse spectrum. Similarly, respondents reflected that an NDA professional would not invalidate perceptions of minoritisation; they might *'validate and accept my experiences of ND trauma' (r.11)* and be actively *'understanding and naming ableism as something I experience' (r.9).* While discussing acceptance and validation of neurominority experiences, one response indicated that taking a strengths-based perspective could become incompatible with this:

> *It's so frustrating and invalidating when I state something I have severe difficulty with, and I am met with "o but you're so smart, you can do anything you*

> *want". YUCK. I think this is something that well intentioned therapists trying to take a strengths focus could easily do. (r.11)*

This appeared to be a contrast with the majority view, that recognising strengths was seemingly an important aspect of NDA practices. This could be interpreted as suggesting that, while recognition of strengths is seen to be important in NDA practices, strengths should not be seen as dismissing clients' perceptions of their difficulties. Overall, this theme seems to capture respondents' views that NDA practices should involve the unconditional acceptance of the whole person, and whole communities, with all the complexities they may contain.

4.3.5. Theme 5: Make Help Accessible

This theme captures patterns of meaning across the dataset relating to the perceived value and benefits of NDA practices. Participants tended to suggest that this style of practice may make it more likely that they would access a service, because needs relating to autism would be met by the nature of the practice (subtheme 1: 'accommodates autism by default'). Additionally, it captured apparent meanings that NDA practices are perceived as supporting autistic clients' engagement with services (subtheme 2: 'NDA increases engagement').

4.3.5.1. Accommodates Autism by Default.

Respondents seemed to reflect that it can be difficult to manage feelings of uncertainty when accessing services, but that NDA practices would be designed to address this. For example, professionals would routinely *'let [clients] know all the important things before [they] arrive (practice photos, photo of themselves, bio, how they work, protocol, what they've done to make their practice sensory safe etc.)' (r.10).* Respondents also suggested there should be *'advance notice for any changes' (r.40),* however, another meaning noted across the dataset suggested that, ideally, NDA practices should be as consistent as possible. For instance, *'keep to arrangements and agreements' (r.21),* and *'They don't promise adjustments then don't make them' (r.12).* This was interpreted to mean NDA professionals should be generally reliable and predictable, practising an awareness that autistic clients may find changes more challenging to manage than non-autistic clients.

It was also suggested that autistic needs could be accommodated in NDA practices by designing the environment with sensory differences in mind (*'A sensory-friendly environment', r.28).* Responses indicated this would consider visual, auditory, olfactory and tactile differences; the ‘sensory friendly’ environment might: *‘keep the lighting low’ (r.25), ‘have lots of soft objects lining the walls of their office to absorb sound’ (r.15),* provide *‘comfy seating’ (r. 7, 10)* and avoid strong scents (*‘avoid wearing perfumes, colognes, scented deodorants [...] or any other fragrances’, r.15).* However, some comments appeared to conflict, such as *‘visually pleasing decorations to look at (for those who like visual stimms!)’ (r.28)* and *‘checking for distractions like wonky abstract pictures’ (r.21).* The use of the phrase ‘for those who like visual stimms’ was interpreted to mean that autistic people with a (visuo-)sensory seeking profile may have different environmental needs to those with sensory sensitive profiles. It was interpreted that this seeming conflict spoke to a separate meaning across the dataset; the importance of having options. Many responses suggested (conflicting) autistic needs could be met by creating an environment that is designed to accommodate options; for example, where *‘different chairs [are] set out so that there’s choice of style’ (r.20)* and the client is invited to *‘please set this room up as works best for you.’ (r.20).* Some seemed to suggest options are an important part of being NDA because they promote autonomy and empowerment (e.g. *‘Visible in the room – so I can choose to us[e] them if I want, without having to ask’, r.10).*

Respondents also referred to communication options as being important (e.g. ‘*have a booking system with option to book online (but also option to contact them via email and phone!)’ (r.28)*. This seemed to be associated with another interpreted meaning; accommodating communication differences. As discussed within the theme ‘a philosophy of practice’, it seemed important to respondents that NDA practices position autistic communication not as defective, but as qualitatively different to neurotypical communication. A large number of extracts suggested NDA professionals need to have an understanding of autistic communication (*‘They speak directly and not in subtext.’ (r.3)* and use *‘clear, literal and concise language.’ (r.17)),* but also personalise their approach to the client: ‘*They ensure their approach fits in with my preferred communication style’ (r.31).* This leads into another interpreted meaning; it appears important that the individual client is centred at the heart of the NDA process.

Responses seemed to reflect a feeling that an NDA style should be adaptable to the client. One response explicitly stated, *‘Each situation with a client is unique, so the professional has to be adaptable with the individual concerned’ (r.17).* Examples of how this may be achieved – in addition to the discussions above (options are important, collaborating with the client, etc.) – seem to include NDA professionals getting to know the client on an individual level as early as possible (*'Spend time before I [the professional] meet anyone […] finding out what will make them most comfortable and if they have a special interest.', r.1).* Knowledge of the unique individual could then be incorporated into the practice (e.g., engaging the client through *'interest based learning.', r.2).*

Lastly within this subtheme, respondents seemed to reflect that NDA practices would prioritise creating a safe physical and emotional environment (e.g. *'I inform my clients […] that the most important thing about therapy is for them to feel comfortable to be in the space', r.32).* This seemed to be a combination of '*creating a sensory safe/comfortable space' (r.29)* and the professional's interpersonal approach. For example, respondents suggested NDA professionals should adopt a non-judgemental approach (e.g. *'Non-judgemental questions' (r.18); 'NO comments on my appearance' (r.29))* and be explicit that they are able and willing to tolerate discomfort while clients work through their thoughts (*'Be very explicit about being comfortable with awkwardness, so that people feel safe with me and allow me to coach them through issues even when [i]t's uncomfortable.', r.21).* It was repeatedly expressed that an NDA approach to practice may make autistic clients feel safe: *'I would be able to relax and feel safe and be able to trust them. This is a rare experience in general' (r.1).*

4.3.5.2. NDA Increases Engagement.

Another pattern of meaning within the theme 'make help accessible' seemed to relate to the consequences of NDA practices for autistic clients. Various responses suggested NDA approaches make the service more accessible to autistic people by increasing their ability and/or willingness to engage with it. This is perhaps unsurprising if NDA, unlike non-NDA practices, appear to make autistic respondents feel safe.

Some responses suggested NDA approaches reduce autistic clients' anxiety. For instance, respondents said *'I wouldn't be so terrified' (r.18), 'I would not be in a state of nervous system dysregulation' (r.4)* and *'I would not be feeling fearful.' (r.11).* From the respondents' perspectives, it would appear that NDA approaches improve engagement with services by reducing the emotional demands involved in accessing them. Additionally, a few respondents indicated they would have greater respect for, and be more willing to work with, a professional who practices in an NDA way. For example, *'[I'd be] more willing to listen to them as I won't think they're an idiot' (r.24).* For one respondent, it seemed they could not accept the professional unless the professional accepted them: *'What would "affirm"* *me…after a life time of being any thing but, just to be and for that to genuinely be ok by them. Then, I can reciprocate for them.' (r.26).*

Overall, the analysis of respondents' views seemed to suggest NDA approaches remove barriers to support (*'I can't picture the sights or sounds of affirmation, only the absence of obstacles.', r.26).* Several respondents suggested they would be *'more able to advocate for myself.' (r.10).* It was further interpreted that, linked to the other elements of this subtheme, NDA approaches may mean autistic clients feel more able to engage than they otherwise might ('*In other words, much better set up to do my best work', r.20*). For example, respondents stated they would be *'able to think more clearly' (r.20), 'able to dissociate less' (19),* and '*able to focus on the reason for seeing the professional' (r.16).* Some respondents specifically addressed the phenomenon of masking, saying, for example, *'I am more likely to spend less energy on masking – I can then utilize that energy elsewhere' (r.39).* This links to the final interpretation offered within this theme: the reduced pressure to appear neurotypical creates more authentic engagement.

Respondents seemed to suggest they would be able to present as (or closer to) their authentic selves if the professional uses an NDA approach. For example, *'I would feel safe to be the real me, not the masked one.' (r.37)* and *'I don't have to hide my identity and can be myself around them' (r.36).* This may mean, for instance, clients *'using [their] natural communication style and body language' (r.24), 'feeling comfortable to stim' (r.9),* or *'talk about personal or sensitive topics if relevant' (r.28).* This perhaps means less mental energy is expended on *'pretending to be someone I'm not to please them' (r.12),* and neurodivergent clients speaking more transparently about their difficulties *('I would be able to give full and honest answers to questions instead of worrying [a]bout saying the right thing', r.16).* It appears that NDA practices may enable autistic clients to engage more openly, honestly and authentically with services that may, in turn, help to make neurodivergent individuals' lives easier.

4.3.6. Theme 6: Genuine Desire to Reduce Autistic Minoritisation

This theme reflects views expressed that seemed to suggest reducing the oppression and marginalisation of autistic people is a core underpinning value of NDA practices. Respondents appeared to describe a range of ways this may be reflected in practice. For example, NDA professionals could embrace an advocacy role beyond the immediate context of their work (a subtheme called 'professionals' role as advocate').

Several respondents directly considered NDA practices in relation to general good autism practice. Responses were interpreted to mean that NDA is raising the bar for 'good autism practice', with some seeming critical of the current standard for good practice in autism. For instance, *'It doesn't differ from general good autism practice. It is general good practice. Maybe you mean, average services that most autistics receive. For me, this is the standard for general good practice. And it's a low bar.' (r.30).* Another commented, '*'General good practice' that wasn't neurodiversity-affirming has harmed my mental health a great deal.' (r.31).* Consequently, it appears NDA practices are considered by some to be a new, higher standard of the services autistic clients should receive. This can maybe be best understood in light of the following two meanings.

Several respondents seemed to reflect that, as a consequence of NDA approaches, they may experience alleviation of a sense of burdensomeness they frequently experience when working with non-NDA professionals. For example, *'[I] would have less thoughts that I was the 'problem'.' (r.31),* and *'I would not feel like I was being a burden/difficult/awkward' (r.7).* In addition, some responses suggested NDA approaches reduce a pervasive fear of being misunderstood by professionals. For instance,

> *With a professional who is NOT working in a neurodiversity affirming way, I would be feeling scared that if something goes wrong during the appointment (such as sensory overload or situational mutism), that I wont be able to explain it to them in a way that wont make them offended or critical. By contrast, with a professional who IS neurodiversity-affirming, I would be feeling confident and secure in the knowledge that if something goes wrong, they will not misread my attempts to communicate the problem as "impoliteness" or "being dramatic". (r.15)*

The final meaning interpreted within the broader theme of 'genuine desire to reduce autistic minoritisation' is NDA approaches being seen as promoting belonging through shared ingroup identity. It appeared that working with professionals with a shared identity as neurodivergent could be a powerful resource, according to respondents. Neurodivergent professionals were positioned as intuitively NDA by some (*'I think I have always identified with this way of working. Since my diagnoses I know why!', r.31*), with their shared experiences being seen as a helpful way to connect with autistic clients (*'Share (within professional scope) their own sensory processing differences or support needs', r.40).*

Perhaps it makes sense then that some responses suggested NDA approaches begin at recruitment. For instance, *'I'd love for organizations to have neurodiversity-affirming hiring practices' (r.19); 'Have staff members with lived experience', r.37)*.

4.3.6.1. Professionals' Role as Advocate.

Some patterns of meaning within the theme 'genuine desire to reduce autistic minoritisation', seemed to position NDA professionals as having an advocacy role. This seemed to be reflected, in one sense, as professionals advocating for clients within their support networks. For instance, *'I [the professional] help their network practice acceptance.' (r.31).* It was also suggested NDA practices may offer training for the networks supporting autistic people, to help them better understand the lived experience of being neurodivergent: (*'[My service] Train families, parents and schools about what it means to be (insert here: our specialities are Autistic, ADHD, OCD, and Tourette Syndrome)', r.37).*

Further, respondents seemed to position NDA professionals as having an advocacy role at the individual, community, and systems levels. The professional was positioned by some as advocating for the client beyond the immediate professional-client relationship (*'I am open to being more involved practically in people's lives and proactively in advocacy for them where that is needed.', r.41),* and at a community level, through engagement with self-advocacy organisations: *'They should be involved with advocacy and activism, like supporting Neuroclastics, ASAN, etc.' (r.36).* Additionally, a NDA professional seemed to be positioned, at a systems level, as raising the profile of the neurodiversity paradigm and NDA styles within and beyond their work context; (*'Advocating for and spreading awareness of neurodiversity and neurodiversity affirming practices amongst [...] their professional community and society at large.', r.27).* Overall, this subtheme, and broader theme, seemed to suggest NDA practices can have a positive impact on autistic people as a minoritised group, by supporting not just clients, but their support networks, and the efforts of the autistic self-advocacy movement.

Chapter 5: Discussion

5.1. Introduction to Chapter

In the preceding chapter, the researcher’s analytic interpretations of autistic community views on neurodiversity-affirming (NDA) autism practice were presented. It was interpreted that NDA practices were conceptualised as being fundamentally grounded in a philosophy, with the practitioners’ values and attitudes being important to whether their practice is NDA. It seemed important to respondents that the practices centred autistic clients as valuable and acceptable in and of themselves, without a need for them to assimilate into neurotypical expectations. NDA practices seem to be informed by the lived experience of autistic clients and the knowledge generated by the autistic community, with clients being centred in any processes. Respondents seemed to highlight some potential benefits of NDA practices; that they may help autistic people to engage more meaningfully with services, and to access help. It also appeared that practices, when they are NDA, are concerned not just with the individual client but about reducing the minoritisation of the autistic population as a whole.

The following chapter discusses the above interpretations of autistic community members’ views on NDA autism practices, in relation to wider literature, followed by considerations in relation to current practice recommendations. Due to limitations of the body of existing literature, in which there is little research on the potential relevance of neurodiversity to practice, and seemingly none on NDA practice itself, the findings are discussed in relation to a range of literature types in addition to primary research.

This leads to a summary of the original contribution of this thesis. The research is then evaluated, before implications are discussed for researchers, practitioners (including education professionals) and the autistic community. Conclusions drawn about the research question – *What can be learned from the perspective of members of the autistic community about ‘neurodiversity-affirming practice’ in relation to autism?* – can then be found in the concluding chapter (Chapter 6) of this thesis.

5.2. Discussion of Literature

Within the present research, NDA practices seemed to be conceptualised as intrinsically linked with a professional’s attitudes and beliefs in relation to neurodiversity. Although respondents varied in how they understood the concept of neurodiversity (section

4.2.), they overwhelmingly seemed to describe it as either a neutral or positive (as opposed to disordered) variation in neurological and/or psychological processes. Accordingly, it seemed important that professionals aligning with NDA practices held a difference, rather than deficit, view of autism. This complements research (Kapp et al., 2013) reporting results from a survey of 657 autistic people and autism stakeholders, which suggested autism was largely considered in terms of difference, rather than deficits. It similarly aligns with research finding that 654 autistic people, on average, preferred the terminology ‘difference’ over ‘deficit’ or ‘impairment’, and ‘neurological/brain difference’ over ‘disorder’ (Keating et al., 2023). The preferred terminology was consistent across all 6 countries from which data was analysed (Keating et al., 2023), suggesting this preference is widespread. Together with the present findings, it seems the autistic community consider a ‘difference’ over ‘deficit’ conceptualisation of autism to be integral to NDA autism practices.

The present findings contribute to debates on the meaningfulness of the term ‘autism’, and suggest that NDA practices consider autism to be meaningful. Autistic traits were discussed by some respondents as an integral part of their identity, with attempts to eliminate them described as harmful to their core self. This supports the interpretations of Botha (2019) and Kapp et al. (2013), that autism is perceived by some autistic people as inherently tied to their sense of self. The interpretation that autism was perceived by respondents as a meaningful identity also correspond with the findings of Malenfant (2020), who concluded that the concept of autism can offer autistic people a helpful framework for self-understanding. It seemed that acceptance and validation of the meaningfulness of autism to autistic people was an important feature of NDA practices. This conflicts with assertions of some medical professionals (e.g. Latif, 2016) that autism lacks utility as a term. By applying Hacking’s (1995) ‘looping effect’ it could be considered that the meaning of autism shifts as people interact with it, and that, perhaps, the validity of the term lies within autistic community narratives. It seems, through understanding the present findings in relation to extant literature, that NDA practices are conceptualised as valuing what autism means to those who identify with the term, and that this is separable from whether it has meaning in a clinical sense.

Furthermore, it seemed NDA practices were conceptualised as viewing autistic differences as a “normal” part of human diversity, without attempting to reduce or eradicate them, or comparing them unfavourably to neurotypical norms. This seems consistent with reports that the autistic community, in general, opposes attempts to ‘cure’ autism (Botha,

2019) and interventions targeting autism ‘symptom’ reduction (Ne’eman, 2021). The interpretation is also consistent with the finding that autistic people did not consider research into ‘curing’ autism to be a priority for future study (Pellicano et al., 2014). For some respondents, an important feature of NDA practices was the employment of neurodivergent professionals within services. It is therefore concerning that research noted autistic school staff, for example, report leaving the profession or withholding their autistic identity due to stigma and a lack of acceptance in the workplace (Wood & Happè, 2021). Similarly, autistic people working across the range of psychological professions have reported feeling a pressure to withhold their diagnosis from colleagues, employers and training courses, from requesting reasonable adjustments for their disability, or from pursuing a psychology career at all, as a result of autism stigma (Hawker et al., 2022). To this extent, it seemed NDA practices were conceptualised by respondents as creating a culture of acceptance of autism within professional teams, as well as while working with clients.

An NDA approach to autism, involving acceptance of autism and autistic traits as a neutral part of a person’s identity, seemed to be perceived by respondents as associated with reduced pressure to mask while working with professionals. This adds to research that reported the inverse finding; that a perceived lack of acceptance of autistic authenticity was associated with autistic participants reporting an increased need for masking (Bradley et al., 2021; Denomey, 2022). The present research finding that NDA practices may be conceived by autistic community members as reducing a need for masking may be of importance, given research that has found masking can be detrimental to autistic people’s wellbeing. Autistic research participants have previously described attempts to conform to neurotypical expectations as being stressful, physically and mentally exhausting, negatively impacting on sense of self (Hull et al., 2017) and mental health (Cage & Troxell-Whitman, 2019). Respondents in the present study appeared to indicate that their experiences of masking are similarly stressful, tiring, and harmful to their mental health and identity. Together with the research, it seems NDA practices are perceived by autistic community members as a style of practice that could support autistic wellbeing, through unconditionally accepting and embracing autistic authenticity.

In addition to reducing a perceived need to mask, respondents seemed to indicate that an NDA approach to practice could reduce a feeling of being burdensome to professionals. This may be an important interpretation considering that both masking and perceived burdensomeness are positively correlated with suicidality in autistic people

(Cassidy et al. 2020), and that death by suicide (Cassidy et al., 2014; Hirvirkovski et al., 2016) and suicidal ideation (Cassidy et al., 2014) are overrepresented within the autistic population. The present study does not confer evidence that NDA practices are associated with reduced suicidality, however, it does contribute novel findings to the field, which seems to suggest NDA practices are perceived by some autistic people as reducing both a need to mask and a sense of burdensomeness. As evidence suggests these phenomena may be risk factors for suicidality, these findings may be of relevance in furthering the understanding of what has been termed the ‘autism mental health crisis’ (Mandy, 2022).

It seemed to be important that NDA practices were built on knowledge derived primarily from within the autistic community. This is perhaps best understood within the context of wider literature, which has argued knowledge generated by observers of autistic people may not accurately represent the autistic lived experience (Kourti, 2021). Further, research involving both autistic people and autism stakeholders suggests autistic people, and observers of autistic people, may arrive at different interpretations of the autistic experience (Bonnello, 2022). The present research suggests NDA practices align with an epistemic position that autistic people are capable of creating and conveying valuable knowledge about autism. This conflicts with some researchers’ assertions that autistic people may be incapable of meaningfully understanding and communicating their lived experiences (Costley et al., 2021). In contrast, the views expressed in this study seemed to complement evidence that autistic people possess expertise on the subject of autism (Gillespie-Lynch et al., 2017). The findings of the present study suggest an important characteristic of NDA practices is seeking and applying community knowledge, and considering this to be at least as informative as autism research findings.

Furthermore, involving autistic people, both as individual clients and as a community, seemed integral to the development and application of NDA practices. This extends existing research (Pellicano et al., 2014) which noted autistic people want to be involved in decisions about the future of autism research, and corresponds with assertions that autistic people want to influence autism practice (Dawson, Franz and Brandsen, 2022). This is a sentiment also shared by the Autistic Self Advocacy Network (ASAN) in their annual report, asserting ‘Who decides what therapies are used on us? […] we [autistic people] decide’ (ASAN, 2021, p.3). The findings of the present survey, much like ASAN’s assertion, seem to challenge a perceived role for professionals to define ‘good practice’, rather than co-constructing this with the autistic community.

NDA practices seemed to involve an ethos of ‘doing with, not to’ and resisting the influence of neurotypical ideals on decisions around interventions and goal setting. Respondents’ suggestions that professionals could work with clients’ goals, rather than setting goals based on neurotypical norms, seem to align with arguments in literature. Rodongo, Krause-Jensen and Ashcroft (2016), for instance, suggested a ‘good autistic life’ (p.407) may be best understood through a neurodiversity philosophy, recognising that autistic people’s priorities for their future may not align with conventional goals and ideals. Further, an ethos of ‘doing with, not to’ autistic people seemed for some to extend to seeking full and informed consent from autistic clients. This is consistent with findings of Sterman et al. (2022) which suggested that the autistic community encourage professionals to seek participants’ informed consent where an autistic adult or child is expected to partake in an intervention. Research on autistic community online discourse helps contextualise this finding; there are concerns expressed within the community that teaching autistic people to comply with professionals, against their wishes, may be a risk factor for sexual victimisation among autistic people (Jabaut, 2019). Evidence across a number of studies indicates autistic people are more likely than non-autistic people to be victims of sexual abuse and assault (e.g. Dike, 2022; Gibbs et al., 2021; Pfeffer, 2016). It seemed that, ultimately, NDA practices were conceptualised as being designed with, and for, neurodivergent individuals, with the intention to promote their right to full autonomy and to live a fulfilling, authentic autistic life.

The interpretation that some respondents appeared critical of current standards of ‘good’ autism practice is concerning, particularly within the context of other research. Reports that autistic people perceive services currently to be ill-equipped to meet autistic needs, thus preventing their access to services (Strömberg et al., 2021) and full participation in life (Malenfant, 2020) suggests there may be room to improve current practice. The present survey respondents seemed to suggest elements of NDA practices could address some of the barriers identified by participants in previous research. For instance, Strömberg et al. (2021) described autistic participants as feeling they had been misunderstood and not taken seriously by professionals, that the sensory environment provided by services was a barrier, and that their nonverbal communication had been misinterpreted. Present survey respondents seemed to consider NDA practices as involving learning autistic communication norms to avoid (mis)interpreting them through a neurotypical perspective, designing an environment to accommodate a range of sensory differences, and valuing the clients’ voice and perspectives. Similarly, autistic school students highlighted the sensory environment and unpredictability of school as barriers to their access to education (Costley et al., 2021), while the present respondents discussed the apparent importance of creating a service that is as predictable and consistent as possible. It seems, when considering each theme together and within the context of previous research, NDA practices appear to be conceptualised as meeting diverse needs by building an understanding of autistic people's needs into the service, from the ground up, rather than through individualised adaptations to the standard provision offered. The latter was interpreted as positioning autistic clients as 'other' and potentially creating feelings of burdensomeness.

In addition to designing services that are knowledgeable about, and responsive to autistic needs, NDA practices are interpreted as including sensitivity to autistic culture. This aligns with Ne'eman's (2021) suggestion that autism services could strive to become 'culturally competent' (p. 570). Though autistic culture has received limited research attention, its relevance to practice has been discussed in academic literature. Bass (2019), for instance, proposed inclusive classrooms should embrace expressions of autistic culture. This research supports arguments for the existence of an autistic culture (Davidson, 2008, Creswell & Cage, 2019; Jaarsma & Wellin, 2012), with respondents in the present study describing particular practices, beliefs and values specific to the autistic community. These appeared to include an acceptance of self-identification as autistic, the rejection of the puzzle piece symbol to represent autism, as well as rejecting certain organisations (e.g. Autism Speaks). Additionally, there seems to be terminology of significance to the community (e.g. special interests, burnout, shutdowns). In this sense, NDA practices seemed to be conceptualised by autistic respondents as being a form of culturally sensitive practice, that is knowledgeable and respectful of the values and beliefs of the community.

5.3. Discussion of Current Practice

The interpretations made here, of what can be learned about NDA practice from members of the autistic community, can be helpfully considered in relation to existing practice guidelines. This may be particularly pertinent, given a few respondents stated explicitly that they experienced 'good practice' as being harmful.

5.3.1. Existing NDA Practice Recommendations

Existing guidelines for NDA practice (Dallman, Williams & Villa, 2022; Izuno-Garcia, McNeel & Fein, 2023; Jellett & Flower, 2023; Rutherford & Johnston, 2022) are informed by a review of literature. The present findings extend literature on NDA practices by contributing knowledge generated from views of members of the autistic community. Interpretations of what the autistic community consider to be NDA practices seem to broadly overlap with, and complement existing NDA practice guidelines. For instance, current recommendations, and the present survey respondents, both described using language originating from the neurodiversity paradigm (Rutherford & Johnston, 2022) in place of deficit-based language (Izuno-Garcia et al., 2023). Professionals being encouraged to critically reflect on their attitudes and beliefs in relation to autism (Dallman et al., 2022) and engage with other professionals who share an NDA philosophy (Dallman et al., 2022) were other features of existing guidance, all consistent with the theme 'a philosophy of practice'.

Existing NDA practice guidelines also appear to overlap with other themes generated during this thesis. Both 'expand the definition of normal' and 'epistemic justice as a fundamental underlying value', in particular, seem to be prominent in published NDA practice recommendations. For instance, both the guidance, and the present survey respondents, suggested autistic people should not be encouraged to present as neurotypical (Dallman et al., 2022; Rutherford & Johnston, 2022) and authentic autistic behaviours (Dallman et al., 2022; Rutherford & Johnston, 2022) and communication styles (Izuno-Garcia et al., 2023) should be embraced. Further, it is recommended by both respondents and existing guidance that NDA approaches should be informed by (Dallman et al., 2022), and co-developed with autistic/neurodivergent communities (Rutherford & Johnston, 2022), and ceased if it is against the client's wishes (Dallman et al., 2022). The commonalities between existing NDA practice guidance and responses of individual autistic people in this study may be seen to support existing guidance in a range of ways.

However, the findings of this research also add to existing NDA practice guidelines in several ways. Respondents seemed to emphasise practice would reflect 'a genuine desire to reduce autistic minoritisation', while present guidance seems to give this less explicit attention. For instance, spreading awareness of the neurodiversity paradigm and NDA practices among colleagues, seemingly important to some survey respondents, does not appear to be emphasised in NDA practice recommendations. This may reflect an area for additional attention in literature. Further, while existing NDA recommendations suggest recognising an individual's strengths is important (Izuno-Garcia et al., 2023), present survey respondents seemed to emphasise, more holistically, the importance of accepting, appreciating and embracing the whole person, with their strengths, difficulties, and diverse intersecting identities.

In addition, while existing guidance emphasises making adaptations to the environment to support inclusion (Rutherford & Johnston, 2022; Izuno-Garcia et al., 2023), autistic people in this survey seemed to prioritise accommodating autistic people by design, rather than through individual accommodations, which may mark them out as 'other'. Further, the interpretations offered in this research are distinct in that, though neurodiversity-aligned language may be perceived as the most up to date and appropriate, it may be seen as misrepresenting a service if it does not also draw on NDA practices. These differences between existing guidance and the views expressed by some respondents, interpreted as being potentially important elements of NDA practices, may be avenues for further investigation.

5.3.2. Existing Good Practice Guidance

NDA practices as described in this thesis seem to share some common features with existing good practice guidelines. For instance, some practice examples given by respondents, as part of the theme 'epistemic justice as a fundamental underlying value' also appear in guidance from the Autism Education Trust (AET; 2019; e.g. understanding the individual's strengths, needs and interests, and empowering them to collaborate on decisions about their support) and British Psychological Society (BPS; 2021; e.g. respecting and empowering individuals to achieve their aspirations). Similarly, some specific elements of the theme 'make help accessible' echo good practice guidance, which appear to contain elements of a social (Oliver, 1990; 2013) or social-relational (Thomas, 1999) approach to understanding disability. Both the AET (2019) and BPS (2021) emphasise creating environments that are inclusive of people with social and sensory differences. To this extent, there appear to be areas of overlap between autistic community views on NDA practices, as described in this research, and existing good practice guidance.

There are also notable differences between the themes generated in this research, and recommendations made by some existing autism practice guidelines. Firstly, autistic people within the present study described NDA practices as a specific practice orientation, or '*philosophy of practice' (r.41),* rather than a set of quantifiable guidelines. The paradigmatic underpinnings of other good practice (AET, 2019; BPS, 2021) appear to be less explicit. Neurodiversity is acknowledged in BPS (2021) 'best practice' guidance as 'a new way to talk about autism' (p. 10), while in the present research, respondents' sentiments appeared aligned with the concept of neurodiversity as '*not something you SAY'*, but '*something you DO*" (r. 18). Current AET (2019) guidance considers autism to be a 'different rather than disordered way of being' (p. 10), though this is not positioned explicitly as a value that should underpin professional practice. For instance, while staff training on autism, and autism awareness interventions for peers are recommended (AET, 2019), NDA practices may enhance this by incorporating the neurodiversity paradigm, and drawing on autistic community-generated knowledge (e.g., the Double Empathy Problem; Milton 2012). Further, as NDA practices seem to centre autistic people in the development and delivery of autism practice and policy, existing good practice guidance could be enhanced by advising autistic people are involved in creating and presenting autism-related training.

Unlike BPS (2021) guidelines, current AET (2019) guidance specifically refers to the Double Empathy Problem (Milton, 2012), though NDA practices as interpreted in the present research may be seen to extend its relevance to practice. AET (2019) guidance advises that those working with autistic young people understand autistic and non-autistic people have different experiences of the world that can be difficult for each other to understand. Additionally, it suggests autistic people may be taught social skills to help them understand and communicate with others. However, NDA practice seems to take the application of the Double Empathy Problem further, by sharing the responsibility for effective cross-neurotype communication equally. For instance, respondents recommended that professionals learn, and use, autistic communication styles, rather than expecting autistic people to adapt to neurotypical communication styles.

A further difference between existing good practice and NDA practices as described here may be in the extent to which practice is underpinned by knowledge generated within the autistic community, and is sensitive to autistic culture. Current AET (2019) guidance recommends professionals seek insight from individual autistic students, and BPS (2021) guidance similarly advise gathering individuals' perspectives on their needs and current support. However, NDA practices as described in the present study seem to extend this by also suggesting practices be developed through collaboration with the wider autistic community, and learn directly from the autistic community about what it means to be autistic.

Further, it seemed NDA practices, as opposed to general good practice, would be sensitive to the cultural practices, values and beliefs of the autistic community, such as avoiding the use of certain symbolism, rejecting certain organisation, and accepting self-identification as autistic. BPS (2021) and AET (2019) practice recommendations do not appear to provide clear guidance to professionals working with autistic people on where to seek community-generated knowledge or for working sensitively with autistic culture. The present findings suggest this may be perceived by the autistic community as a helpful way to enhance good practice.

Additionally, descriptions of NDA practices offered by autistic people in the present study seem to place a greater influence on the role of the professional as an advocate, than may existing good practices. AET (2019) guidance suggests staff should support the inclusion of autistic young people, and be informed by their support networks. Further, BPS (2021) guidelines recommend psychologists offer support to staff working with autistic people. NDA practices seem to extend this by encouraging professionals to increase others' awareness of the neurodiversity and NDA practice philosophies, and to work to increase the acceptance of autism among autistic people's support networks.

5.4. Original Contribution of this Thesis

This thesis created a novel survey, through collaboration with autistic community members, to gather autistic community views on what is meant by NDA practices. Resulting from this, the thesis presents findings on autistic community conceptualisations of NDA practices in relation to autism. It is believed this research is the first to offer a detailed exploration of autistic community conceptualisations of NDA practices. The research has generated new knowledge about NDA practices, that may be useful for researchers, professionals (including Educational Psychologists) and others with an interest in neurodiversity.

Some of the novel findings which extend existing knowledge and research on the topic of NDA practices include:

1) NDA practices may be better understood as a philosophy, than a method of practice;
2) Learning from autistic community sources, and meaningfully involving the autistic community, seems important to developing NDA practices;
3) Accommodating autism through NDA practices may involve designing the service with autistic individuals in mind, rather than adapting services in response to individual needs, which could risk some feeling othered, and burdensome;
4) NDA practices seemed, according to respondents' reports, to be associated with reducing a need to mask – this seems to be an important perspective to consider,

given that research suggests masking is experienced as harmful to autistic wellbeing and mental health (Hull et al., 2017).

Further, the interpretations made in this study have been shown to have overlaps with existing practice guidelines, particularly with published NDA practice recommendations developed by Dallman et al. (2022), Izuno-Garcia et al. (2023) and Rutherford and Johnston (2022). However, the novel insight generated within the present study suggests there may be areas where good NDA practice guidelines can be extended, to reflect community priorities:

1) A genuine desire to reduce autistic minoritisation could be a core value of NDA practices;
2) It may be important that professionals aligning with an NDA philosophy of practice engage in advocacy work, including spreading awareness of NDA practices among colleagues;
3) While recognising strengths seemed to be important in both existing recommendations and to the present respondents, this research emphasised the importance of accepting and validating the whole person, including difficulties intersecting identities, and by ensuring that strengths-based approaches are not experienced as invalidating clients’ perceived difficulties;
4) While both existing guidelines and the present research supports accommodating autistic needs, respondents within this study seemed to emphasise the importance of building an awareness of autistic needs into the design of the service;
5) Use of neurodiversity language, while seemingly integral to NDA practice, could be perceived as being inconsistent with services that do not genuinely align with a neurodiversity perspective.

Finally, the present research contributes knowledge that helps to understand possible distinctions between NDA practices and existing good autism practice. These included:

1) NDA professionals seem to draw directly and explicitly upon the neurodiversity paradigm in their practices, as well as spread awareness of this within their professional context;
2) NDA practices should be informed by, and responsive to cultural beliefs and values shared within the autistic community, and are built on knowledge gained

directly from autistic voices, which is not mentioned in existing guidance documents discussed here;

3) (Non-autistic) professionals aligning themselves with NDA practices appear to see effective communication with autistic clients as a shared responsibility, by learning autistic social communication norms.

5.5. Evaluation of the Present Research

In the following section, the strengths and limitations of this thesis will be considered in relation to Lincoln and Guba's (1985) criteria for the evaluation of qualitative research. Quality control criteria for evaluating reflexive thematic analysis (Braun & Clarke, 2022) will also be considered throughout. Finally, the research will be evaluated in relation to the researcher's philosophical and social positionality, values and beliefs.

5.5.1. 'Truth value'

The researcher adopted a constructivist epistemology, meaning that theirs and survey respondents' perceptions of social reality are interpreted to be one of an infinite number of realities, with none being more, or less 'real'. This supported the development of a critical distance from their own views, and the words of survey respondents and previous literature. The views expressed by respondents in direct quotes throughout Chapter 4 are considered to reflect a diverse array of different perceptions of reality. The interpretations of respondents' words made throughout Chapters 4 and 5 are the views of the author only based upon a process of deep engagement with the data, and the researcher's own lived experiences and perspectives. The researcher reflexively considered the influence of their own perspectives (see section 5.5.5) to enhance the rigour of the interpretations, but it should not be assumed that the interpretations are 'correct', and it is recognised that another researcher may have interpreted the same dataset differently. However, through a relativist ontological stance, the interpretations can be considered meaningful knowledge by offering an interpretation about NDA practice as conceived by the autistic community members represented in this thesis.

5.5.2. Consistency

Throughout the process, records were retained in the form of photos and documents, which are appended. These records evidence that the process, as recommended by Braun and Clarke (2022) was followed accurately and consistently. The analysis method usefully provided the researcher with a structure for systematic analysis of the data, which supported the rigour of the research and the plausibility of the findings and interpretations offered. However, it is not claimed that replication of this process is likely to result in the same findings, as the views, attitudes and identity of the researcher are inseparable from the generated outcomes (Braun & Clarke, 2022). Instead, consistency was improved by adhering to the quality control criteria for rTA (Braun & Clarke, 2022). See Table 3 in section 3.5.3. for steps that were taken to support a quality analysis.

5.5.3. Confirmability

While rTA findings do not strive to be confirmable (Braun & Clarke, 2022), steps were taken to improve the trustworthiness of the interpretations made. Reflexive journaling was used as a tool to create distance between the researcher's own views and respondents' words – this was also supported through supervision. Philosophical assumptions of the researcher were carefully considered at each step to support coherence between the epistemological position of constructivism, and the approach to answering the research question. The principles of rTA (Braun & Clarke, 2022) were also adhered to. This is seen, for example, in the language used to discuss themes, such as 'themes were generated' rather than 'themes emerged'. Themes, and each interpretation made within them, are also supported throughout the analysis with extracts. This allows others to evaluate their trustworthiness and plausibility. As can be seen in Appendix 17, only a very small minority of extracts were excluded from the analysis, evidencing that interpretations were based on a wide and rich dataset.

5.5.4. Applicability

Applicability refers to the extent to which the study findings and conclusions can be applied outside of the immediate study context (Lincoln & Guba, 1985). Braun and Clarke (2022) have articulated that researchers may find it appropriate to draw implications for practice from rTA. Those interested in the extent to which the present findings can inform their own practice should be aware of whose views were represented. To consider the extent to which implications can be drawn, the representativeness of survey respondents, and the suitability of the sampling and data collection strategies, will be considered.

Recruitment of respondents did not aim to be representative of the whole autistic population, as qualitative research does not strive for this (Braun & Clarke, 2022). However, the range of identities of those contributing to the survey may be relevant to the extent to which findings can be extrapolated to the autistic community as a whole. In many respects, the respondents represent a diverse range of identities. This may be reflected by respondents noting that respect for intersectional identities (specifically cultural, gender, sexuality and disability identities and stigmatised lifestyle choices, such as being child-free) was seemingly an important aspect of NDA practices. This warrants mention of groups not represented in this research. Notably, no respondents identified as non-speaking, and it is possible that non-speaking autistic people would describe different priorities for NDA practices. Additionally, the demographic questions did not ask specifically about learning or intellectual disabilities. As such, it is not known how transferrable the research findings are to people with these life experiences.

The recruitment strategy was successful in reaching autistic people, and specifically autistic professionals working with autistic clients, with knowledge of the concept of NDA practice. This has led to what are hopefully valuable interpretations of the concept of NDA practices from the perspectives of autistic people and professionals. However, the chosen recruitment strategy limits the transferability of findings. By surveying people who had joined Facebook groups for autistic people and/or centred around discussing the neurodiversity paradigm, it is likely most people viewing the recruitment poster may have had a strong sense of belonging to the autistic community, a strong identity as autistic, aligned with the neurodiversity paradigm, and had an overall positive perception of the value of NDA practice. In this sense, the views and attitudes of the respondents are likely to be reflective of the group sampled rather than the wider autistic population. This was a valuable recruitment strategy in that it meant autistic community discourse could be captured, but it should not be assumed that all, or even the majority of autistic people, endorse the idea of NDA practice. The neurodiversity paradigm is not universally known about among autistic people (Kapp et al., 2013), and among those who are aware, not all endorse it (Kapp et al., 2013; Ortega, 2009). This research has hopefully begun to elucidate what is meant by NDA practice according to those who endorse it, but other work should be undertaken to evaluate its acceptability to the wider autistic population. This is particularly pertinent, given that respondent descriptions of neurodiversity (section 4.2.) varied, with indications that there are ongoing debates among autistic people, even within this relatively homogenous group of respondents (section 4.2.6.).

Also relating to limitations of the recruitment strategy, the group of respondents, by nature of having articulated their views in writing and online, are likely to have a good level of competency in English literacy and to be computer literate. This is likely to mean the views of non-English speakers, and those who are unable to access computers, are not represented. It should not be assumed the interpretations in this research can be transferred to these groups.

It is possible that participation of non-speaking, non-English speaking, and learning-disabled people may have been limited by the recruitment strategy. Firstly, while an attempt was made to post the recruitment poster in a Facebook group for non-speaking individuals (not exclusively autistic), this was not approved by group administrators. It is possible there were very few non-speaking people in the groups in which the survey was advertised. Additionally, the researcher may have inadvertently added a barrier to participation for some people as access to alternative means of participation, and the Easy Reading information sheet, were available only by directly contacting the researcher (due to limitations around attaching files to Facebook posts). It is possible that this step made the survey less accessible to those who would have benefited most from these accommodations. To address these limitations, and the potential homogeneity of views and attitudes among the survey respondents, alternative recruitment strategies should be considered in future, such as working in partnership with large organisations (e.g., the National Autistic Society).

Furthermore, this research specifically explored discourse about NDA practice among autistic community members. Some respondents indicated having other neurodivergent identities, such as ADHD, but nevertheless respondents were asked to specifically consider NDA practice in relation to autism. It is likely there will be other views and considerations in applying the neurodiversity paradigm to other neurodivergent groups.

An additional consideration that should be made in regards to transferring the present findings beyond the context of this survey is that it is unclear whether it reflects views of autistic children and young people. Respondents were not asked for their age, however, almost all respondents were either professionals, or indicated first learning of their autism in adulthood, suggesting few if any children were involved. It may be the case that autistic children and young people would express different views or priorities in relation to NDA practices.

5.5.5. Researcher reflexivity

The following section is written from a first-person narrative to centre the author's voice in the reflexive process.

I was very aware throughout this work that, by virtue of being a doctoral researcher, I have been afforded an epistemic privilege to create knowledge about the autistic community. For me, this necessitated very careful consideration about how my privilege was used. I am mindful that many autistic people, who have invaluable insight into the lived experience of autism, have traditionally been afforded little influence over autism discourse. As such, I was concerned that this work should centre a wide range of voices from within the autistic community. I aimed to do so by including pertinent quotes at the start of some sections, most of which come from autistic people, to orient the reader towards real-world autistic narratives, in their author's/speaker's own words. I have also aimed to state explicitly where knowledge being cited was generated by (openly) autistic scholars. I also included some non-academic sources, to recognise that much of the autistic community's expertise cannot be found within scholarly literature due to the historic (and, in many ways, ongoing; Botha, 2021) exclusion of autistic voices from research, and additional barriers autistic people face in accessing education or entering academia (Botha, 2021).

Throughout the research process, I used reflexive journaling to consciously locate myself within the research. This helped me to recognise the extent to which my own personal views and experiences may impact on the interpretative analytic process, and to create some distance from this. I was aware that my positionality as aligning with the neurodiversity perspective and having been engaged with autistic community narratives and discourse before beginning this thesis may influence my interpretations. For example, I interpretated respondents' statements that NDA professionals would not use the puzzle piece symbol for autism as a form of cultural sensitivity because, through my engagement with the community, I am aware that the puzzle piece is a contentious symbol that many find offensive. Other researchers without this background may have interpreted the same statements differently. I believe, as written by Braun and Clarke (2022), that a researcher's position and background can be a strength, adding richness and depth to interpretations. Nevertheless, it was important that I took a critical perspective toward the interpretations I made, to enhance their rigour and trustworthiness. I worked to create distance by considering questions such as 'how does the person make sense of what they are discussing?', 'why might they be making sense of it this way and not another way?' and 'how am I reacting to the data? Why might I be reacting this way?' (question prompts from Braun & Clarke, 2022). Examples of my use of reflexive journaling can be seen in Box 1.

Box 1. *Extracts from Researcher's Reflexive Journal*

Extracts from entry dated 11 Jan 2023.

> 'I observed myself to be subconsciously doubting [some] responses […] because this does not align with my own perspective, but I must keep at the forefront of my mind that I am interested in participants' constructions, not my own.'
>
> 'As someone with a personal interest in the topic and research area, I thought it could be difficult to critically examine it if it aligned with my views, but have been surprised at how useful the [Braun & Clarke's] questions are at helping me to distance my interpretations of respondents' meanings from my own views. I need to be conscious not to become complacent about this, and continue to use the questions.'

Extract from entry dated 13 Jan 2023.

> 'For me, I can relate to what seems to be a feeling of simply wanting to be known; to be recognised and accepted as who I am. I am imagining that this is the latent meaning the participant was conveying – but I cannot know, and must consider this critically to explore other meanings.'

I was also concerned that, with the autistic community representing such a diverse group of people, with widely varying traits, views and needs, I may present an account that represents only a relatively homogenous group and ignores others within the wider autistic population. This is something I have had to repeatedly consider more widely in relation to my alignment with the neurodiversity paradigm, given that some critics accuse neurodiversity advocates of failing to consider those with the highest needs (see den Houting, 2019; Ortega, 2009). To address this, I have been explicit in the limitations that the findings should not be assumed to apply to those with intellectual disabilities or who are non-speaking. I have also considered my own position in relation to this criticism of neurodiversity. Assertions that autistic people capable of articulating their views cannot and should not represent the wider autistic population have been described as 'weaponised heterogeneity' (Doherty, 2023); either an autistic person is unable to express their views, or their ability to articulate them is used as a reason not to listen. Either way, the autistic voice is not heard, and autism continues to be defined by those without lived experience as autistic. This is inconsistent with my values, beliefs and ethics. I have therefore prioritised minimising harm to those less able, or unable to express their own views on neurodiversity. I align with literature that suggests a society which values and accepts all autistic people simply because they exist, and where autistic people are accommodated as their authentic selves, also helps those most visibly autistic to exist without stigma or discrimination (Milton, 2016).

I perceived the collaborative survey development process to be a rewarding experience. One of the challenges I faced was in setting and maintaining clear boundaries around the extent to which collaborators could be involved. I was extremely fortunate to have such enthusiastic and generous people offer their support. I felt uncomfortable at times with having to explicitly ‘own’ this project, when I felt my values aligned better with a flatter power structure, where autism research is owned equally by a team of academic(s) and community collaborators. This was an ethical tension, as having read guidelines for ethical autism research, I was conscious that some would advise a participatory approach to be taken throughout the entire research process, including research question development and data analysis. It was necessary for me to balance my alignment with participatory approaches with the need to produce an original thesis that reflects my own independent work. Ultimately, I decided that a partially-participatory approach aligned better with my values than not involving the community at all. My overwhelming feeling, despite the challenges, was that this was an important process that shaped the survey into an effective, useful research tool that also (I hope) was sensitive to, and respectful of autistic community views and values. Should I engage in further autism research, I intend to apply my reflections on this experience to creating a more completely participatory research design.

Another ethical dilemma I experienced while carrying out this research was what to do with the findings. It felt important to me that, if autistic people’s views were to be gained on a topic of importance to the community, I should do more than process them for my doctoral accreditation. I recognised that respondents generously invested their time and, for some perhaps, emotional labour into generating data for this project. I therefore intend to disseminate my research findings in talks, both within my professional sphere (aligning with views reflected by respondents, that NDA practice involves increasing awareness of NDA practices among colleagues), and within predominantly autistic spaces. I also aspire to continue to research this topic, as illustrated by this extract from my reflexive journal: ‘*I reminded myself that I always saw this survey as a starting point to understanding how the* *autistic community conceptualise ND-affirming practice, and am excited to do more research (and see others do more research) on this in future.*'

5.6. Implications of this Research

5.6.1. Summary of Analytic Interpretations

This research asked the question: *What can be learned from the perspective of members of the autistic community about 'neurodiversity-affirming practice' in relation to autism?* The interpretations suggest NDA practices may be conceptualised by some autistic people as, fundamentally, being about a philosophy of practice, rather than a specific method that can be defined through quantifiable criteria. It seemed, therefore, that NDA practices require professionals to reflexively engage with their implicit and espoused attitudes and beliefs in relation to autism and neurodiversity. It also seemed that NDA practices could be developed through collaboration with the autistic community, and be informed by community-generated knowledge. Core values of NDA practices seem to relate to redefining what is "normal" for a human (recognising and challenging where societal norms may be determined by neuronormativity, and how this risks minoritising autistic persons) and actively holding space for worldviews, norms and experiences different to one's own. As a consequence of being supported through an NDA philosophy of practice, it seemed autistic people may anticipate being better able to access help and support, in a way that embraces their authentic selves, and does not mark them as 'other'.

Specific implications of these interpretations may be most usefully, and ethically, generated through consultation with autistic community members, perhaps with the present findings being used to facilitate discussion. However, some points of reflection for researchers and professionals are tentatively suggested below. Implications for the author, and the autistic community are also considered.

5.6.2. Implications for Future Research

There are a range of directions for further development of this area of research. First, the procedure could be replicated with other groups identifying as neurodivergent, such as the dyslexic and Attention Deficit Hyperactivity Disorder (ADHD) communities (Kapp, 2020). This would enable any differences in the conceptualisation of NDA practices across neurodivergent groups to be elucidated. This may provide a clearer insight into what NDA practices could look like. To further explore the concept of NDA practices in relation to the autistic community, the present procedure could be replicated, or different approaches taken (such as focus groups) with more autistic people, to see whether different interpretations can enhance those offered here. Consideration could also be given to how to meaningfully include autistic people with intellectual disabilities, and/or who are non-speaking, to ensure their views are incorporated into new knowledge about NDA practices. Further, gathering views of non-English speaking people may help to elucidate any differences across national cultures. Additionally, gathering views of autistic children and young people will be important to understand how such a practice may apply to this demographic. The present research could also be extended by measuring the acceptability of this style of practice to autistic people who do not align themselves with a neurodiversity perspective.

Some researchers may wish to evaluate the impact of NDA practices as described here. For example, an action research approach could be taken to adapting and evaluating service provision for services working with autistic clients who would like to be supported with NDA practice. Some existing measures may help with this, such as the Neurodiversity Attitudes Scale (VanDaalen, 2021), as a tool to promote reflection on professionals' attitudes towards neurodiversity (as respondents seemed to suggest this is an important part of whether practice can be described as NDA). Measures of engagement, camouflaging, perceived burdensomeness and mental health may be useful outcome measures, to assess whether NDA practices are associated with meaningful change in any of these areas, as discussed above. Given the emphasis on epistemic justice and, specifically 'doing with, not to' in this study, it may be most appropriate to collaborate with autistic people on the development of NDA autism practice research projects.

Further, work could be done to consider the relevance of this research to other minoritised and oppressed groups. Researchers may consider the extent to which the themes interpreted from the autistic community in this work overlap with other practices; some respondents, for example, indicated that NDA practice, to them, is anti-oppressive practice. The procedures used here, such as collaborative survey development with community members, could be replicated to explore how other minoritised groups envisage anti-oppressive, culturally sensitive care. Commonalities between the present findings and the views of other oppressed groups could also help in understanding what quality care may look like for people with intersecting identities of autistic and, for instance, Black or transgender.

5.6.3. Implications for Professionals

The findings of this research seem to suggest NDA approaches could be valuable when working with autistic clients. It may therefore be of interest to a wide range of disciplines that engage with autistic clients, including both specialist (e.g., Speech and Language Therapists, Occupational Therapists, mental health providers) and universal services (e.g., General Practitioners, educators). Autistic people included in this survey suggested being supported through an NDA style may support their engagement with and access to services that can then help them. As research and the present survey respondents indicate autistic people experience barriers to accessing services, professionals could consider the philosophy of practice described here.

It seemed that NDA practices were conceptualised as a way of supporting and interacting with autistic people that values their differences and unconditionally accepts their identities. As NDA practices seemed to be rooted in a philosophy, rather than a set of quantifiable criteria, services may need to consider what it could look like within their specific context. The extracts from respondents' survey answers may highlight some practical strategies that could be implemented. Given the apparent emphasis on services being developed with, not done to, autistic people, services may consider hosting focus groups with their clients.

NDA practice can seemingly be enhanced by widely transferrable professional skills such as empathising, listening and validating. Professionals may consider whether their awareness of community-generated knowledge and autistic/neurodivergent culture could be further enhanced, as this seemed to be a core feature of NDA practices. In addition, developing skills in communicating through autistic, rather than neurotypical social norms seemed to be of importance. Consulting with autistic clients on what a good (autistic) life looks like to them could also support professionals in co-creating meaningful intervention goals and outcomes that support autistic wellbeing.

It should be recognised that, while some education and health professionals were represented among the survey respondents, the survey did not ask respondents to consider how NDA practices may look in relation to any specific sector. Further work will be required to understand any potential implications specific to, for example, schools and Educational Psychologists (EPs) – the present findings would suggest this could be most ethically done in partnership with the autistic community. A self-advocate identifying with several neurodivergent identities (including autistic) has recently published their own conceptualisation of NDA practice online (Lived Experience Educator, 2023), which shares features similar to the views reflected in this study - demonstrating the availability of rich emic-generated knowledge for professionals who wish to learn from it. Professionals may wish to consider how the findings of this survey, and the voices of autistic individuals expressed throughout this thesis and beyond, may resonate with their own practice.

For EPs and educators interested in what may be offered by an NDA approach, or how this may look in their setting, the findings indicate that a helpful starting point is to reflect on one's own values, attitudes and beliefs in relation to neurodiversity and autism. Further, it may be helpful to reflexively consider the paradigms and norms communicated and sustained by one's practice – for example, the language used, agreed outcomes for a child, and assessment tools utilised. For instance, whether these locate the problem within a child or the wider systems, and whether children are measured against neuronormative standards or outcomes. Some professionals have begun to develop assessment tools reflecting the values of the neurodiversity paradigm (such as an NDA observation schedule, and a celebratory framework for use in consultations with parents of autistic children (Murphy, 2022) and neurodiversity strengths cards Baldacchino, n.d.). These resources may be of interest to education professionals. Some may even be inspired to create new assessment tools, based on a neurodiversity philosophy.

Further, there may be implications for professionals' own communities, given autistic community members highlighted the value of being supported by professionals who share their neurodivergent identity, and called for NDA hiring practices. As both school staff (Wood & Happè, 2021) and psychologists (Hawker et al., 2022) for example, have expressed concern about autism stigma being a barrier to their being openly autistic in these professions, and, for some, to working in these professions at all, professionals may consider the relevance of NDA to those they work alongside. Those with a leadership position in particular may be interested in further exploring approaches that could support neurodivergent staff to feel accepted and valued as their authentic selves, creating a neurodiverse workforce to support neurodiverse clients.

5.6.4. Implications for the Researcher's Perspectives and Practices

The following section is written using a first-person narrative to centre the author's voice in the reflexive process.

As a result of this research, and engaging deeply with the responses of autistic community members in developing and responding to this survey, my thinking has shifted in some key ways, which has also impacted upon my current and future practice. As a professional who would describe myself as drawing on principles of the neurodiversity paradigm in my practice, I now feel I have a much richer appreciation for what this might mean to the autistic community. If asked before to characterise NDA practice, from my perspective, I would have likely provided superficial (though seemingly important) features, such as avoiding the use of medicalised terminology. The themes I generated here have already influenced the way I discuss NDA practice with colleagues, instead reflecting on the underlying values and beliefs of the professional, consciously prioritising epistemic justice, and reframing autistic individuals as a ‘normal’ part of human diversity. This has led to plans to further develop this area in my Educational Psychology Service, which will be written into my professional development plan.

Since finishing the analysis, I have actioned respondents’ suggestions to reflexively consider their espoused values and beliefs in relation to implicit attitudes, and decisions made in practice. I recognised some tensions between my personal alignment with the neurodiversity perspective, and my practice, and have taken steps to resolve any incongruence. For example, I am working on ways to conduct assessments that align more closely with apparent values of respondents (such as, that neurotypical should not be considered the default). I have also considered that NDA practices involve professionals advocating for a neurodiversity perspective of difference, therefore, I plan to proactively discuss neurodiversity and NDA practices with school staff and colleagues, and develop training that can share the voices of respondents to the survey.

5.6.5. Implications for Members of the Autistic Community

It is sincerely hoped that this research has generated some useful implications for the autistic community and individuals within it. The numerous practical examples of NDA practices suggested by survey respondents have highlighted the value of autistic people being involved in developing and advocating for NDA support. It is hoped that the experiences described by respondents may resonate with others, and support them to articulate and make sense of similar ideas and experiences. Similarly, the interpretations offered by the researcher about patterns of meaning within the dataset, such as ‘resisting neuronormativity’ and promoting ‘epistemic justice’ may perhaps resonate with some people. Some autistic academics may identify an area to further develop as research, and autistic professionals already identifying with an NDA approach may perhaps identify some new strategies to implement. If any of the interpretations offered within this thesis can assist the autistic community in advocating for the care they would like to receive from professionals, it will have been a worthwhile project.

Chapter 6: Summary and Conclusions

This thesis involved a qualitative survey of autistic community members' views on neurodiversity-affirming (NDA) practices in relation to autism, interpreted through reflexive thematic analysis. The research purpose was to learn from members of the autistic community about what is meant by NDA practice. It is believed to be the first study to contribute data about NDA practices to the fields of autism and neurodiversity research. The research was based on the philosophical assumption of relativism, drawing from the constructivist paradigm, and was influenced by the social justice values of the transformative paradigm. It was assumed that, for autism practice research to be just, autistic people's voices should be at the heart. The research question posed was: *What can be learned from the perspective of members of the autistic community about 'neurodiversity-affirming practice' in relation to autism?*

A collaborative approach was taken to developing a novel qualitative survey on views of NDA practices. Based on the researcher's interpretation of survey responses, the following description of what may be meant by NDA practice in the autistic community is offered. An NDA approach seemed inseparable from the beliefs, values and attitudes of the professional who practices it, requiring them to engage reflexively with neurodiversity as a philosophy. Accordingly, NDA practices may be personalised to the specific service, and not easily translated into rigid criteria that can simply be transferred between settings. It seemed NDA practices were not about marking certain groups out as 'different' to, or outside of what is 'normal', but about considering such diversity and difference within human development as normal in itself. NDA practices appear to acknowledge that a good neurodivergent life may look different to conventional, neuronormative standards, and support clients to work towards outcomes that are relevant to them. NDA practices also seem to recognise and validate perceptions that neurodivergent identities are minorisited in society and to highlight the importance of building truly inclusive practices that resist clients being positioned as 'other'. Developing NDA practices in conjunction with neurodivergent communities appears important, as well as practices being informed by community-generated knowledge and cultural beliefs, values and practices. Fundamentally, NDA practices appear to offer a space where all identities, needs, and experiences of the world are validated and embraced.

This research does not attempt to offer a complete definition of NDA practices. As expressed by Singer (2017), who first coined 'neurodiversity', its meaning lies within the ‘myriad narratives’ (p. 19) of all who identify with it. The researcher suggests that to understand NDA practices more deeply, further research must consider the views of those not represented in this research. This includes non-speaking individuals, non-English speaking individuals, people with learning disabilities, and children and young people. It will also be important to gather views from other communities who identify as neurodivergent, as conceptualisations may differ with different needs and experiences. A definition of NDA practices may then be constructed by, or through collaboration with, neurodivergent people.

Chapter 7: References

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Chapter 8: Appendices

Appendix 1: Search Terms Entered for Planned Systematic Literature Review

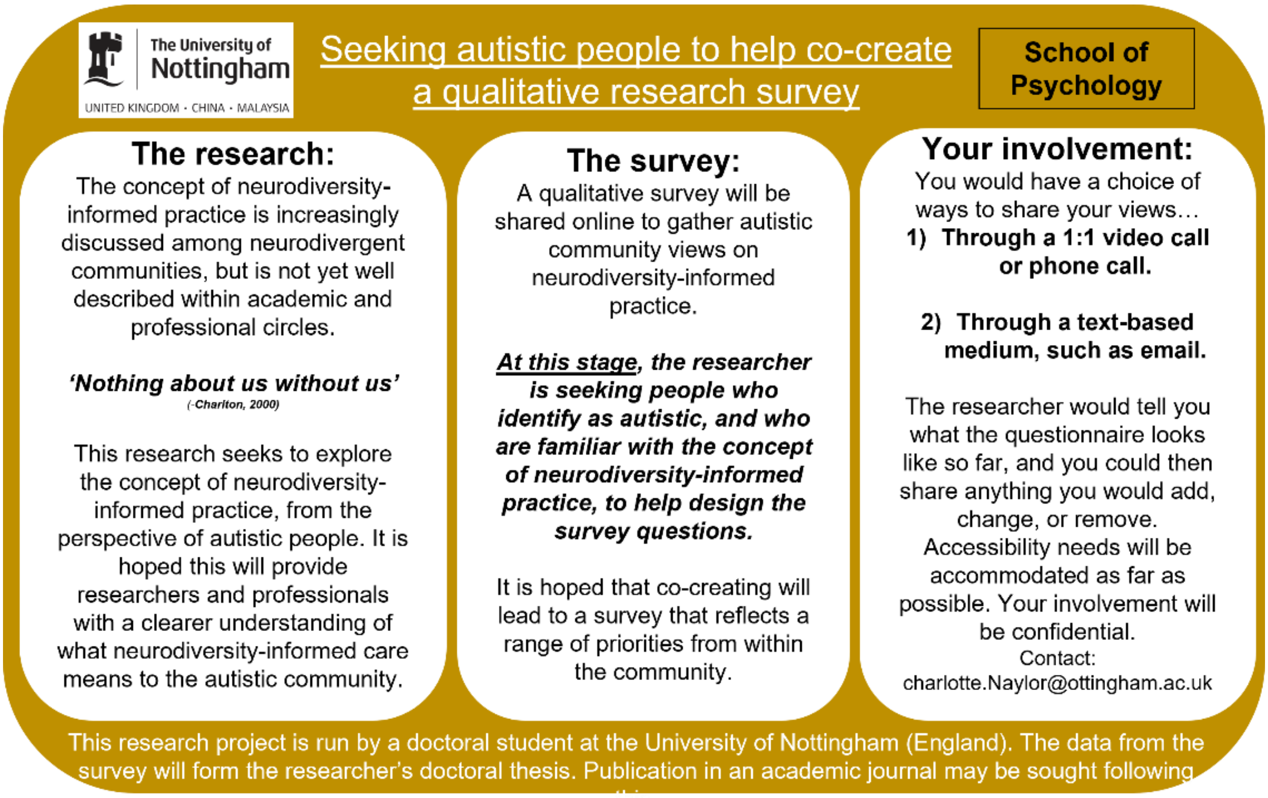
1. neurodiversity affirming
2. neurodiversity-affirming
3. neurodivergent affirming
4. neurodivergent-affirming
5. neurodiversity informed
6. neurodiversity-informed
7. neurodivergent informed
8. neurodivergent-informed
9. autistic identity affirming
10. autistic identity-affirming
11. autism informed
12. autism-informed
13. ND-informed
14. ND informed
15. ND-affirming
16. ND affirming
17. Neurodiv* informed
18. Neurodiv* affirming
19. Neurodiversity practice*
20. ND-practic*
21. ND practic*

Appendix 2: Reflexive Journal Extract Locating the Researcher's Ontological, Epistemological and Methodological Assumptions

'I studied philosophy at A Level and was very interested in the debates around reality, knowledge/knowing and free will versus determinism. My views used to align more closely with positivism/empiricism, and this was reinforced through my undergraduate research training. We were taught almost exclusively positivist approaches to enquiry, and stringent scientific methods. Qualitative methods were discouraged and devalued as being less scientifically valid and 'softer'. At the time, I saw myself as a scientist and was defensive of psychology's status as a science. I therefore had little interest in qualitative methods and, perhaps, even saw them as a threat to psychology's scientific reputation.

In the years following my undergraduate research I learned more about relativism and, as I gained more real-world experience of different views and perspectives, I realised that much of the time, it was not possible to prove or disprove someone's constructions through scientific enquiry. Further, I realised that it was rarely constructive to do so - as I worked more with people, I realised that intending to change someone's (construction of) reality, through reason and empiricism, was rarely helpful in moving anyone forward. Rather, I eventually learned that a positive difference was made by working *within* a person's construction of reality. Further reading, experience and reflection has led me to believe that there is no singular reality – at least not social reality – and that social constructionism is the most appropriate approach to investigating the social world. Therefore, I would say that I now align most closely with a relativist ontology and qualitative methods, and asking research questions about people's world view, so I can better understand how to work with them.'

Appendix 3: Collaborator Recruitment Poster



The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

Seeking autistic people to help co-create a qualitative research survey

School of Psychology

The research:

The concept of neurodiversity-informed practice is increasingly discussed among neurodivergent communities, but is not yet well described within academic and professional circles.

'Nothing about us without us'
(-Charlton, 2000)

This research seeks to explore the concept of neurodiversity-informed practice, from the perspective of autistic people. It is hoped this will provide researchers and professionals with a clearer understanding of what neurodiversity-informed care means to the autistic community.

The survey:

A qualitative survey will be shared online to gather autistic community views on neurodiversity-informed practice.

At this stage, the researcher is seeking people who identify as autistic, and who are familiar with the concept of neurodiversity-informed practice, to help design the survey questions.

It is hoped that co-creating will lead to a survey that reflects a range of priorities from within the community.

Your involvement:

You would have a choice of ways to share your views…

1) **Through a 1:1 video call or phone call.**

2) **Through a text-based medium, such as email.**

The researcher would tell you what the questionnaire looks like so far, and you could then share anything you would add, change, or remove. Accessibility needs will be accommodated as far as possible. Your involvement will be confidential.

Contact:
charlotte.Naylor@ottingham.ac.uk

This research project is run by a doctoral student at the University of Nottingham (England). The data from the survey will form the researcher's doctoral thesis. Publication in an academic journal may be sought following

Appendix 4: Collaborator Information Sheet

School of Psychology

Information Sheet

Title of Project: Neurodiversity-informed approaches to autism as defined by autistic people.

Ethics Approval Number: S1456

Researcher: Charlotte Naylor

Supervisor: Dr Nicholas Durbin.

Contact Details: charlotte.naylor@nottingham.ac.uk ; Nicholas.durbin@nottingham.ac.uk

This is an invitation to be involved in the development of a research survey, which intends to gather autistic people's views on neurodiversity-informed practice.

Before you decide if you wish to be involved, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

The purpose of the research is to understand what autistic people mean by the concept of neurodiversity-informed practice. This is because it is a term often used within neurodivergent communities but is less talked about in research and professional communities. It is hoped that autistic people's voices in this study will lead to the concept of neurodiversity-informed practice being more clearly understood by researchers and professionals.

If you choose to collaborate in the development of this research survey, you will have options for how you do so. You can choose whether to type your thoughts in an email (or on a document attached to an email) to the researcher, or to interact directly with the researcher on a live Microsoft Teams video, or voice-only call. There are no minimum expectations for the extent of your involvement; you can contribute as many or as few thoughts as you wish to. All contributions will be valued. Suggestions of each collaborator will be considered, however, the researcher cannot guarantee that all suggestions will be implemented. For example, where one collaborator's suggestions conflict with the views of the majority of other collaborators.

Your involvement in the development of this survey is totally voluntary and you are under no obligation to take part. You are free to cease your involvement at any point before or during, without giving a reason why. All data collected will be kept confidential and used for research purposes only. It will be stored in compliance with the Data Protection Act. As an online participant in this research process, we are obliged to make you aware that there is always a potential risk of intrusion by outside agents, for example through hacking, and therefore the possibility of being identified.

If you have any questions or concerns please don’t hesitate to ask now. We can also be contacted after your involvement at the above email addresses.

If you have any complaints about the study, please contact:

Stephen Jackson (Chair of Ethics Committee)

stephen.jackson@nottingham.ac.uk

Appendix 5: Collaborator Consent Form

School of Psychology

University of Nottingham
UK | CHINA | MALAYSIA

Title of Project: Neurodiversity-informed approaches to autism as defined by autistic people.

Ethics Approval Number: S1456

Researcher: Charlotte Naylor; charlotte.naylor@nottingham.ac.uk

Supervisor: Nicholas Durbin; Nicholas.durbin@nottingham.ac.uk

The collaborator should answer these questions independently:

- Have you read and understood the Information Sheet? YES/NO
- Have you had the opportunity to ask questions about your involvement? YES/NO
- Have all your questions been answered satisfactorily (if applicable)? YES/NO
- Do you understand that you are free to cease your involvement with the development of this research at any time without giving a reason? YES/NO
- I give permission for any information I provide through collaboration in the development of this research project to be used in the final survey, provided that my anonymity is completely protected. YES/NO
- Do you agree to collaborate with the researcher during the development of this research project? YES/NO

By selecting yes for all above questions and returning this form to the researcher, I indicate that the study has been explained to me to my satisfaction, and I agree to be involved. I understand that I am free to withdraw at any time.

Signature of the Collaborator: Date:

Name (in block capitals):

If the collaborator is under 16 years old, please also complete this section:

Signature of the collaborator's parent/carer: Date:

Name (in block capitals):

I have explained the study to the above collaborator and he/she/they has agreed to take part.

Signature of researcher: Date:

Appendix 6: First Draft of Survey Questions Suggested by Researcher

Demographic questions

1. Are you Autistic / do you describe yourself as having autism? (including self-diagnosed?): Yes / No
2. If you are comfortable sharing, please enter your age in the box below
3. If you are comfortable sharing, please state at what age you first identified as autistic/having autism. You can enter an estimate if you're not sure of the exact age.
4. If you are comfortable sharing, please describe your level of support needs (from your perspective): Very high, high, moderate, low, very low or none, can be high or low depending on the day, I'd describe it a different way…
5. If you are comfortable sharing, please describe how you typically communicate: am fully speaking, I am semi-speaking (for example you may experience situational mutism), I am nonspeaking for the majority or all of the time, I'd describe it a different way…
6. Are you a professional who works with autistic clients and describes their work as being informed by the neurodiversity paradigm?: Yes / No

Target questions

1. What might you see that tells you they work in a neurodiversity-informed way?
2. What might you hear that tells you they work in a neurodiversity-informed way? (prompt: what do they say?)
3. What are they doing that tells you they are neurodiversity informed?
4. What might you be feeling that tells you they are working in a neurodiversity-informed way?
5. For professionals only: What is it about your style of practice that makes it neurodiversity-informed?

Appendix 7: Final Draft of Survey Developed Through Community Collaboration

The following questions tell the researcher how well the survey results represent different groups of people. You do not have to answer questions you are uncomfortable answering.

Note: It is understood that people within the Autistic community describe themselves in different ways. This survey uses identity-first language, in line with the majority preference, but the views of all people are welcome and valued, however you identify.

1. Are you Autistic?
    - Yes, and am professionally diagnosed
    - Yes, I am self-identifying/self-diagnosed
    - I'm not sure
    - No
    - Anything else you would like to comment…

2a. [displayed if indicated professional diagnosis] If you never self-diagnosed: When were you formally diagnosed?

OR

If you self-identified before being diagnosed: Please indicate when you first self-identified.

- Childhood (before age 13)
- Adolescence (age 13-17)
- Adulthood (age 18 or later)
- Anything else you would like to comment…

2b. [displayed if indicated self-diagnosis] When did you self-identify as Autistic?

- Childhood (before age 13)

- Adolescence (age 13-17)
- Adulthood (age 18 or later)
- Anything else you would like to comment…

3. Thinking about the support you need (regardless of whether you are currently accessing this), which statement describes **you** most accurately?

  - I do not need any support; I am completely independent
  - I need **some** support with a few aspects of my life, but am **mostly independent**
  - I need **some** support with most things in my life
  - I need **some** support in **almost every** part of my life
  - I need **a lot** of support with **every** aspect of my life, including dressing, eating, etc
  - None of these describe me (please describe it a different way)...

3. I consider myself to be non-speaking...

   Note: Non-speaking, in this context, refers to being unable to speak using mouth words, or finding it extremely difficult to speak, such that you use an alternative method of communication.
   - Never, or only on rare occasions
   - Some of the time
   - Most of the time
   - Always
   - Anything else you would like to comment...

4. What label/s do you use to describe your gender?
5. What label/s do you use to describe your sexuality?
6. How would you describe your race?

7. In which country do you live?
8. Are you a professional who works with Autistic people, **and** describes their approach as neurodiversity-affirming?
    - Yes
    - No
9. [If yes] What is your profession?
10. Space to provide any other comments...

[Displayed if respondent answered 'no' when asked if they are a professional]

This section will ask you questions about the concept of neurodiversity-affirming practice. The purpose of the questions is to understand what this style of practice looks like to you.

The term 'neurodiversity-affirming' may mean different things to different people. Some people might use other terms, such as 'neurodiversity-informed'. Neither term is clearly defined yet. For this survey, 'neurodiversity-affirming' has been chosen. This was because feedback while developing the survey suggested 'affirming' means the professional is both informed of the neurodiversity paradigm and putting their knowledge into practice. Any thoughts on this are welcome at the end of the survey.

There are 5 key questions, plus space for additional thoughts.

You do not have to answer any questions you are uncomfortable answering.

Most questions have a prompt. This is to give you ideas, and to provide context to the question. You can choose to write only about the prompt, write about the prompt and other things, or to ignore the prompt.

In this context, ‘practice’ refers to the way any professional **works with, supports or interacts with** an Autistic person in a professional capacity, where the **Autistic person is receiving their services**. This can include, for example, a teacher, medical professionals, psychologists or therapists. This is deliberately broad, so that the views collected by this survey can be applied to lots of different settings.

[Displayed if respondent answered ‘yes’ when asked if they are a professional]

This section will ask you questions about the concept of neurodiversity-affirming practice.

Please respond to the next 6 questions from the perspective of an Autistic person receiving services. Then answer the last section (questions 7-8) from your perspective as a
professional **delivering** services.

The purpose of the questions is to understand what this style of practice looks like to you.

The term ‘neurodiversity-affirming’ may mean different things to different people. Some people might use other terms, such as ‘neurodiversity-informed’. Neither term is clearly defined yet. For this survey, ‘neurodiversity-affirming’ has been chosen. This was because feedback while developing the survey suggested ‘affirming’ means the professional is both informed of the neurodiversity paradigm and putting their knowledge into practice. Any thoughts on this are welcome at the end of the survey. There will be space for any extra comments.

You do not have to answer any questions you are uncomfortable answering.

Most questions have a prompt. This is to give you ideas, and to provide context to the question. You can choose to write only about the prompt, write about the prompt and other things, or to ignore the prompt.

In this context, 'practice' refers to the way any professional **works with, supports or interacts with** an Autistic person in a professional capacity, where the Autistic person is receiving their services. This can include, for example, a teacher, medical professionals, psychologists or therapists. This is deliberately broad, so that the views collected by this survey can be applied to lots of different settings.

1. Please briefly describe what you understand 'neurodiversity' to mean.
2. If a professional worked with **you** in a neurodiversity-affirming way, what would **you see**?

(prompt: what things in the environment tell you professionals work in a neurodiversity-affirming way?)

3. What do **you hear** that tells you they are working in a neurodiversity-affirming way?

(prompt: what do professionals say?)

4. What do **professionals do** that tells you they work in a neurodiversity-affirming way?

(prompt: how do they behave differently to professionals who are **not** working in a neurodiversity-affirming way?)

5. If the professional was neurodiversity-affirming, what would **you** be **thinking**, **feeling** and/or **doing** when you are interacting with them?

(prompt: how might this be different to when you're with a professional who is **not** working in a neurodiversity-affirming way?)

6. Extra space: If there is **anything else** you think 'neurodiversity-affirming practice' means, please enter it here (e.g. how you think it differs to general good practice):
7. **Space for any other comments.**

And for professionals only:

8. What do you do in **<u>your</u>** practice specifically to make sure it is neurodiversity-affirming?
9. (If applicable) What do you do differently now that you work in a neurodiversity-affirming way, compared to when you did not?

Appendix 8: Respondent Recruitment Poster

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

SEEKING PARTICIPANTS:
Research on neurodiversity-affirming autism practice.

School of Psychology

What would I be asked to do?

You would be given access to an online survey. It is a qualitative survey, meaning you **type your answers.** You can write as much or as little as you want. If a survey is not accessible to you, you can contact the researcher to share your views in an alternative way.

If you are a (Autistic) professional who describes their work as neurodiversity-affirming, there is an additional question about this.

Who can participate?

- Anybody who is diagnosed as, or self-identifies as Autistic,

AND

- Feels they have views on this topic. You do **not** need to be an expert on it!

If you are under 16, a parent/carer will need to provide consent for you to take part.

The research

This study is about neurodiversity-affirming practice in autism. **It is seeking the views of** people who identify as Autistic on what the concept of neurodiversity-affirming practice means to them.

The purpose

The concept of neurodiversity-affirming practice is often talked about in Autistic communities. However, it is discussed less among academics and professionals. **This research aims** to increase professionals' and researchers' understandings of what it means, while making Autistic people's views the priority.

What are the benefits of taking part?

There are no direct benefits for you if you participate, though some people might find it rewarding to contribute their views to research.

Are there any risks to me?

The questions will **not** ask you about your own life experiences. However, while thinking about the questions, you might reflect on your own experiences. This may be uncomfortable or distressing to you. Links to places to find support are provided at the start and end. You are in charge of how you complete this survey. You do not need to type anything personal or distressing, you can leave questions blank, leave the survey at any point, and **you do not have to participate if you do not want to.**

This research project is run by a doctoral student at the University of Nottingham (England). The data from the survey will form the researcher's doctoral thesis. Publication in an academic journal may be sought following this. **Contact: Charlotte.Naylor@nottingham.ac.uk**

Appendix 9: Detailed Respondent Demographic Information

Participants lived across 5 countries: the United Kingdom (21, including 8 who responded with ‘England’), the United States (14), Australia (5), Canada (3) and New Zealand (1). One did not record the country in which they live.

Self-described race

Race	Labels used by participants	Frequency
White	White	18
	White British	9
	Caucasian	4
	Mixed British/Irish	1
	Mixed Irish/English/Italian	1
	European	1
	White European	1
	White, non-Hispanic	1
Total participants who identified as white		**36**
Hispanic		1
Asian		1
Mixed		1
Jewish		1
Earth’s Child		1
Total participants identifying with a race other than white		**5**
Total did not respond or answered ‘human’		3

Terms used to describe gender

Gender identity	Self-assigned label	Frequency of label use
Self-assigned labels indicating binary gender identity		
	Female	14
	Woman	5
	Male	4
	Trans man	1
Total participants identifying with binary gender identity		**24**

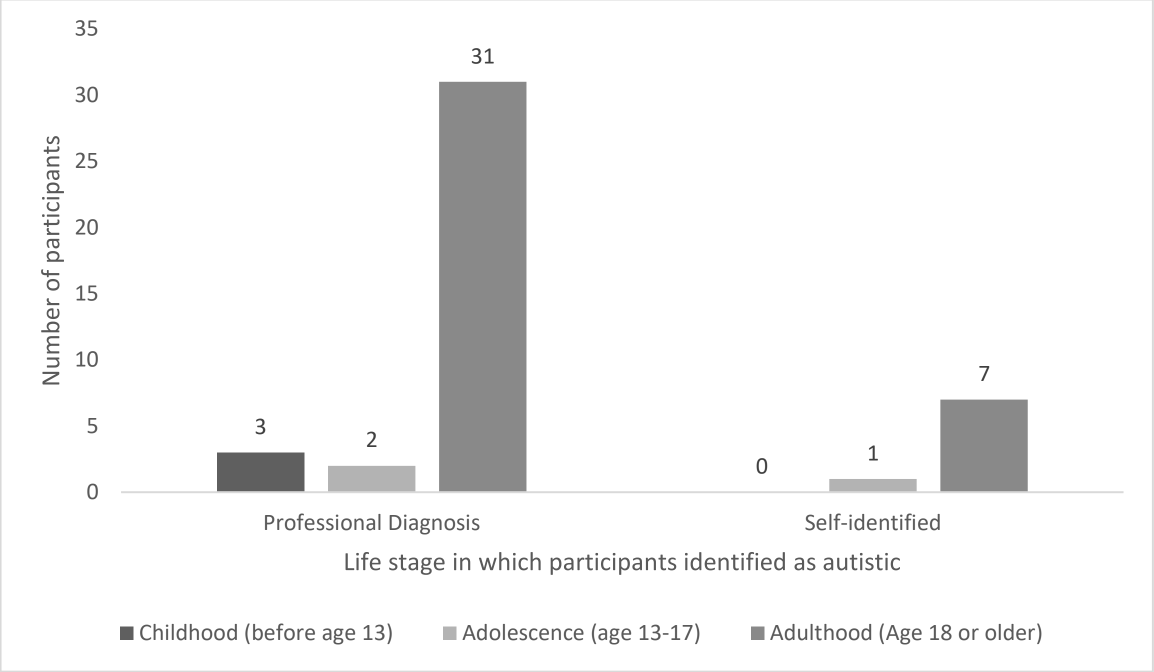
Self-assigned labels indicating non-binary gender identity		
	Non-binary	8
	Autigender	6
	Neuroqueer	2
	Agender	1
	Genderqueer / queer	2
	Demigirl	2
	Neutrois	1
	Gendervague	1
	transmasculine	2
Total respondents identifying with non-binary gender identity *		**17**
Total did not respond or entered only pronouns		3

* Note respondents identifying with labels outside the binary gender system frequently used more than one, so total respondents identifying with non-binary gender identity is not equal to the sum of labels used.

Terms used to describe sexual orientation

Sexuality	Self-assigned labels	Frequency
Heterosexual	Straight	6
	Heterosexual	7
Total identifying with heterosexual sexuality		**13**
Bisexual		6
Queer		8
Asexual	Asexual	5
	On asexual spectrum	1
	‘probably asexual’	1
Total identifying with the label ‘asexual’		**7**
Pansexual		5
Lesbian		5
Gay		4
Demisexual		3
Polysexual		1
Diamoric		1
Omnisexual		1
Total did not respond, answered ‘it depends’ or described sex (not sexual orientation)		**4**

Timing of autism diagnosis/self-identification



Professions

Profession	Participant description of role	Frequency
Psychology practitioner	Trainee Educational Psychologist	1
	Clinical Psychology Intern	1
	Psychologist	1
Total frequency for psychology practitioner		**3**
Education	Specialist outreach teacher	1
	Lecturer	3
	Teacher	2
Total frequency for education		**6**
Health	Counsellor	1
	CBT Therapist	1
	Music Therapist	1
	Student Occupational Therapist	1
	Child Wellbeing Practitioner	1
Total frequency for health		**5**
Research	Researcher	1
	Postdoctoral Fellow in Clinical Psychology	1
Total frequency for research		**2**

Other	Coach	1
	LPC Associate	1
	Mentor	1
	Autism Advocate	1
	Neurodivergent Educator/Family Support	1
	Outdoor Instructor	1
Total frequency for ‘other’ professions		**6**

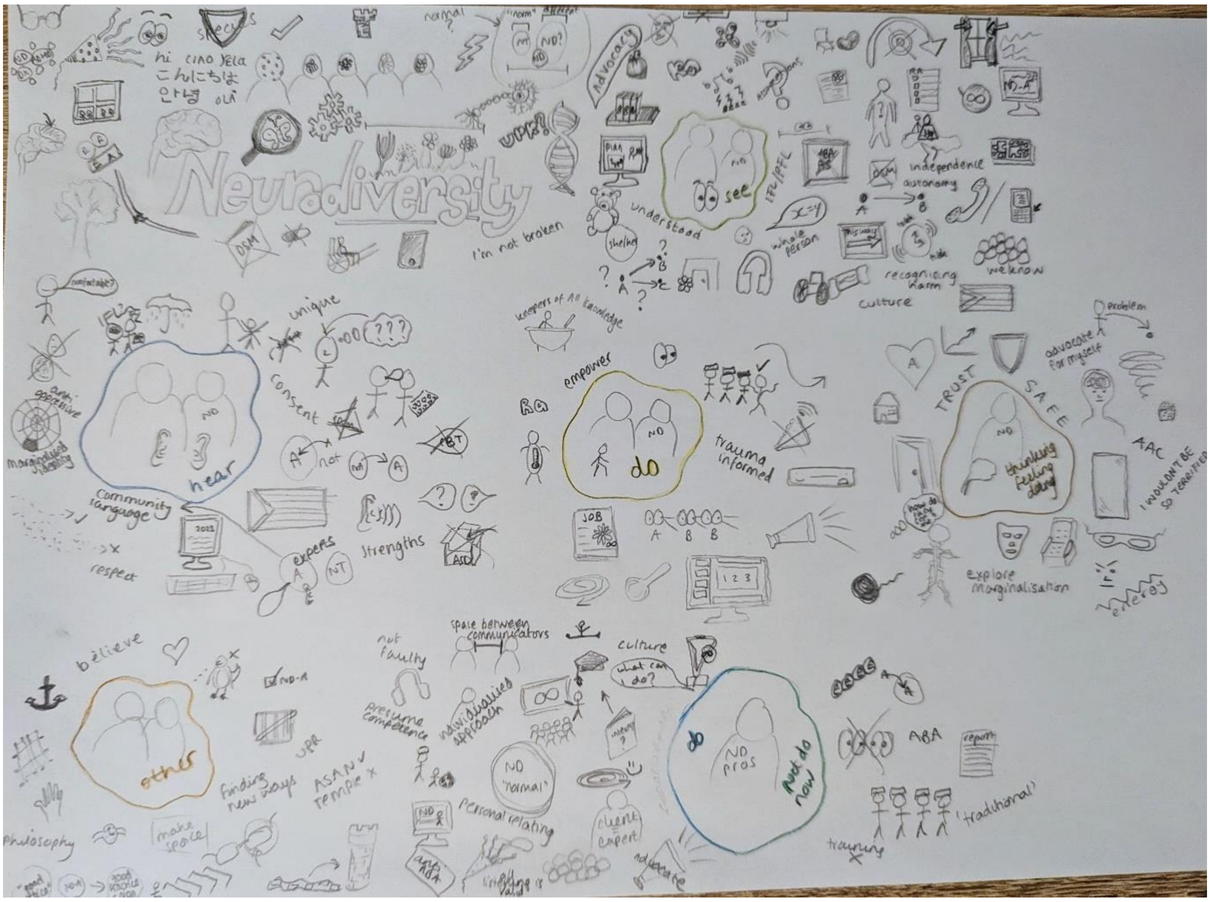
Support needs

Participants indicated a range in support needs, though, as noted by 2 participants in the additional comments box, support needs may relate to other disabilities in addition to autism. Most frequently, participants reported needing ‘some support with a few aspects of life, but being mostly independent’ (20). Twelve reported needing ‘some support with most things in life’, 2 needing ‘some support with almost every part of life’, 2 needing ‘a lot of support with every aspect of life, including dressing, eating, etc’, and 5 reporting that they are completely independent and need no support.

Communication by mouth words

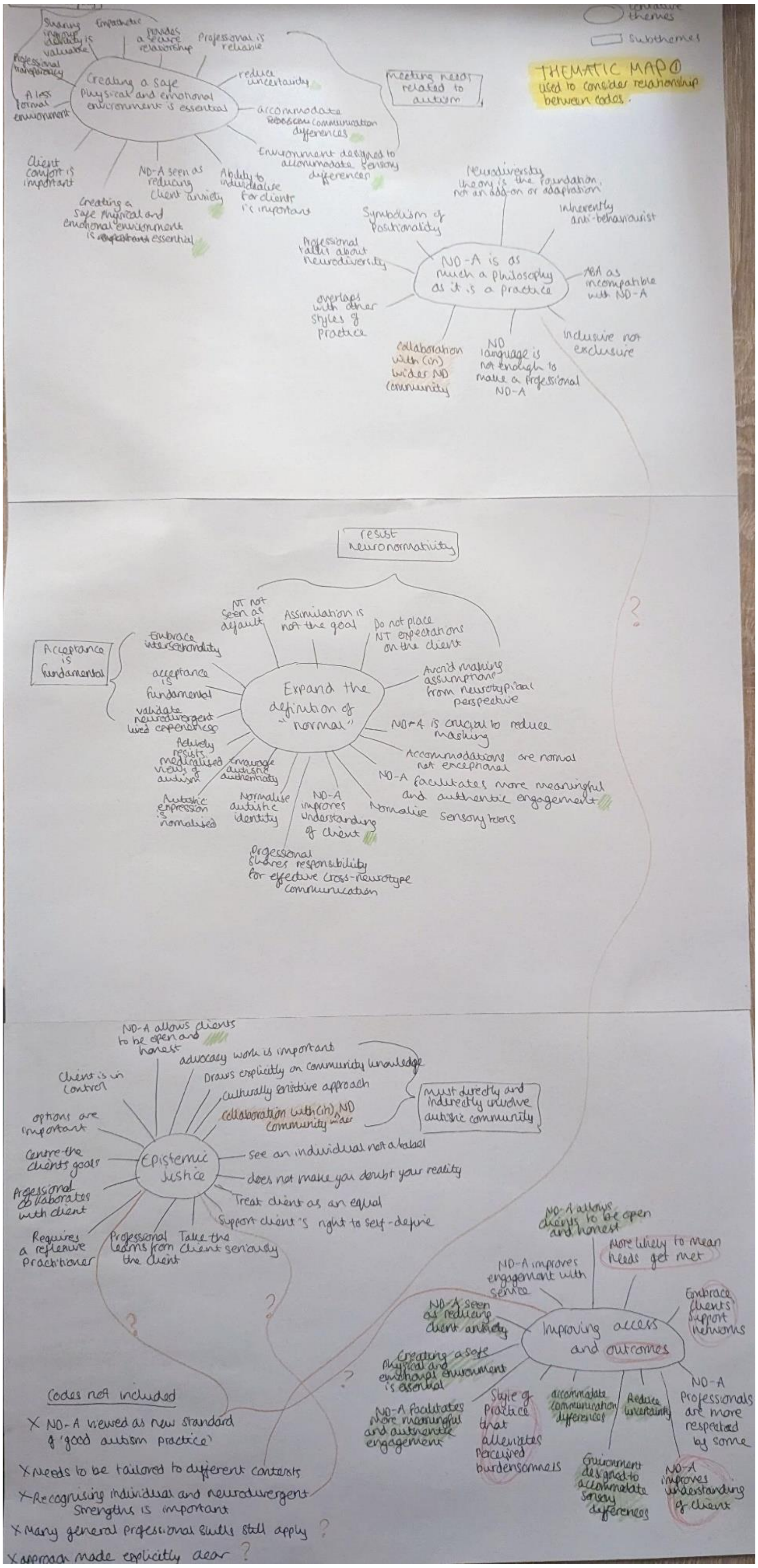
No fully non-speaking people responded to the survey. Most commonly, participants reported that they are non-speaking on rare occasions or never (32), and 12 reported being non-speaking some of the time. Notes in the additional comments box included: that periods of being non-speaking were linked to extreme distress or overwhelm (2) or shutdowns and burnout (1); that they may be able to speak but their speech becomes more difficult to understand (1) and that an AAC app on their phone is used as an alternative to speech, at times (1).

Appendix 10: Visual Familiarisation Exercise

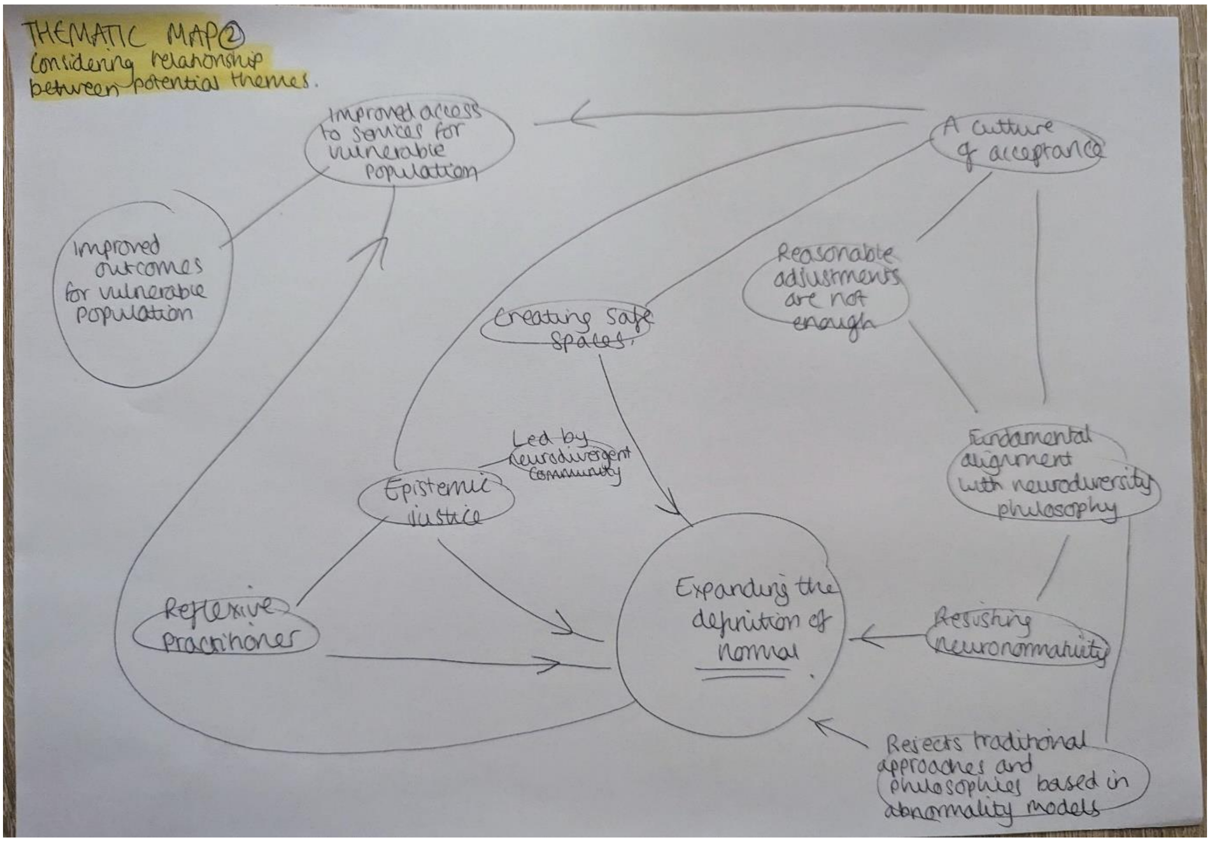


Appendix 11: Coding Process

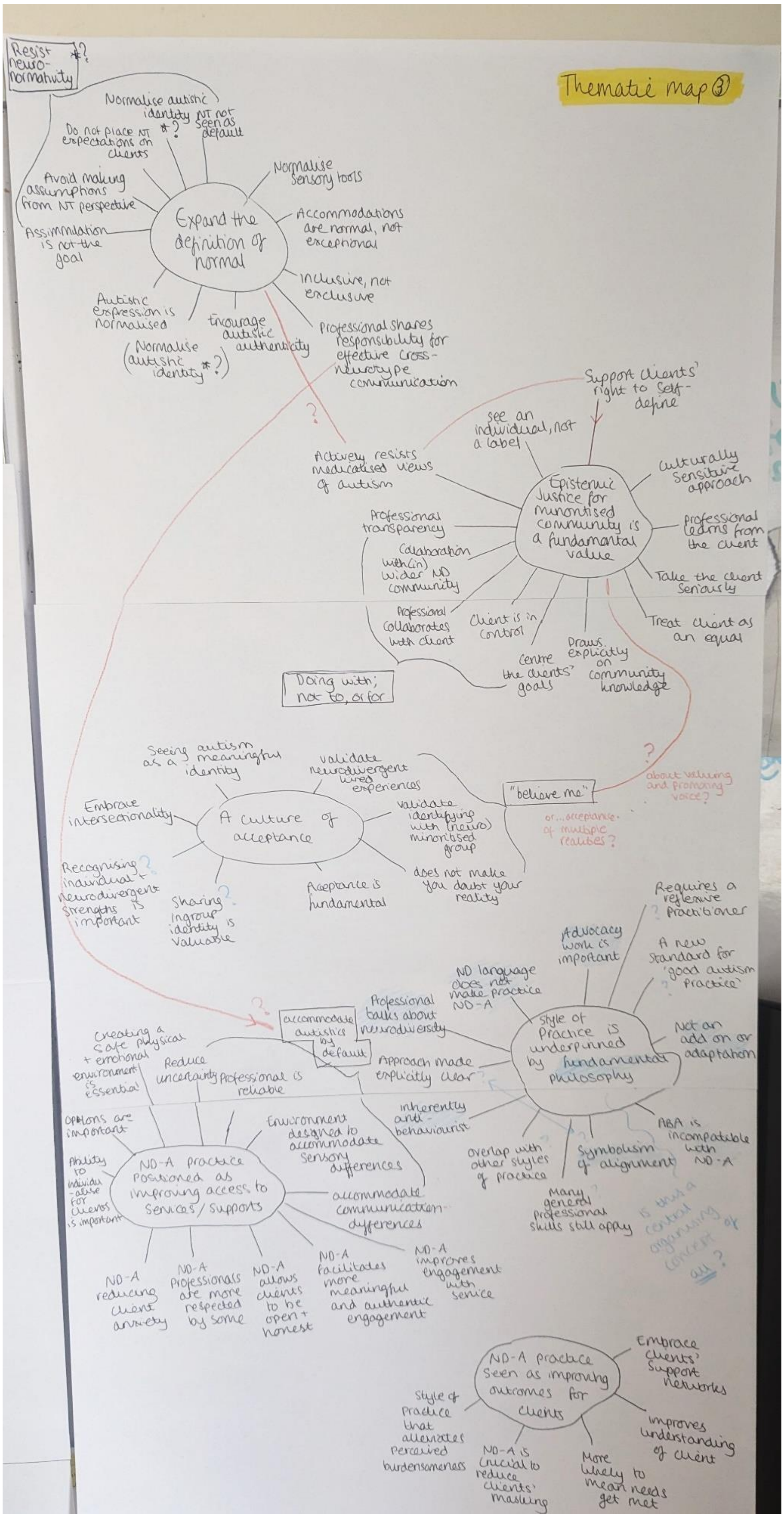
Appendix 12: Thematic Map 1



Appendix 13: Thematic Map 2



Appendix 14: Thematic Map 3



Appendix 15: Example of Generated Theme with Code Labels with Extracts

Theme 1: A 'Philosophy of Practice'

Code	Extracts
Professional uses neurodiversity language	In terms of language, use of language aligned with the Neurodiversity Paradigm would be welcome, for example, identity-first language, using Neurodivergent and Neurodiverse correctly, etc.
	I would look for working on their professional site.
	Use of neurodiversity informed language.
	Use of neurodiversity based terminology, including terminology today has come from the neurodiversity community.
	Language is a really big deal for me, since it tells me if a person knows about neurodiversity and has respect for/up to date information autistic people
	Where appropriate (e.g. with adult clients), I may give some information about the neurodiversity paradigm, to help clients tackle any internalised ableism they may be experiencing
	If a professional I am working with uses dated language, even if meant well, I would be less likely to tell them about my neurotype or ask for accommodations since I would be scared they would react based on negative stereotypes.
Should obviously draw on neurodiversity paradigm	During intake and feedback, I talk about neurodiversity
	Deliver lessons to all pupils on neurodiversity, accommodations and barriers. Normalise differences.
	They state their position.
	Telling me they're neurodiversity affirming (this may seem silly but I won't necessarily know otherwise!)
	They may advertise themselves as ND affirming
	I display my prioritising of inclusion and neurodiversity-affirming practice on my lanyard with the rainbow infinity image.
	Symbolism from organizations like ASAN, AWN, etc
	[I would see] Neurodiversity affirming books
	Show the rainbow infinity symbol.
	ND affirming posters (eg those which use infinity symbols[)]
	An object or wall decoration involving neurodiversity pride
	Explicitly say we celebrate neurodiversity.
NDA is not something you say, 'it's something you do'	It could easily still be problematic, as people are co-opting the words and concepts.
	Not claiming to have neurodiversity-affirming practice if it's not (I wish there was some kind of accreditation)

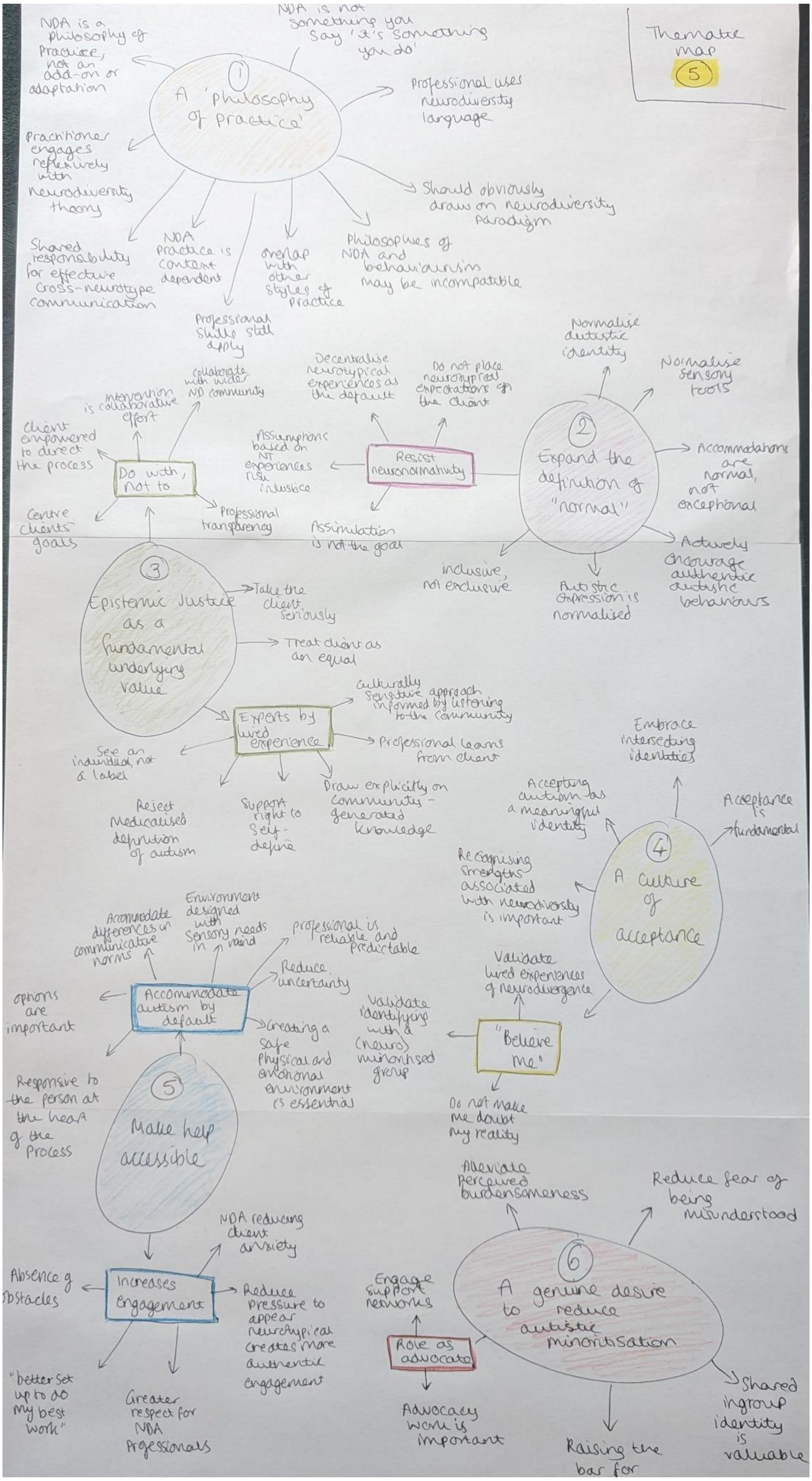
	Words in this context are really unhelpful---because being neurodiversity-affirming isn't something you SAY are, it's something you DO.
	Although obviously not by itself an indicator that the provider is Neurodiversity-affirming.
	If they use the words "neurodiversity-affirming", I have two immediate thoughts. One—is this just another corporation using buzz words for optics and they don't actually give a shit? Or two, are they genuine?
	People are co-opting the words and concepts and misusing them. I would look for things that indicate they are not neurodiversity affirming.
	Lots of places claim to be accessible, claim to be safe spaces for queer folks etc—and in reality they are *not* because all they've done is the bare minimum.
	Another problem is buzzwords as labels. Since they're buzzwords, they get overused very quickly and lose meaning and confidence in the people using them.
	You don't want a professional to be viewed by the [neuro]majority as "woke", particularly if the majority are their cliental.
Philosophies of NDA and behaviourism may be incompatible	Most CBT/behavioural/ABA approaches are in conflict with neurodiversity affirming practice because they are based on the premise of abnormality and that the person needs to change or shift their approach in order to not experience distress. Rather, most of the distress I experience as a neurodivergent person is in the context of other's expectations for my behaviour and my (sometimes successful) efforts to assimilate with society.
	Would not use behaviourist approaches.
	[before being ND-A I] used to suggest reward based strategies.
	Overtly acknowledging what does not work (e.g, types of therapy such as cbt or other behavioural therapies)
	A lot may come from what they DON'T say – IE no gaslighting, hardcore CBT approaches
	When looking for new practitioners, including PT, PCA, PCP, therapists, etc., I ALWAYS look at the site first to see if they offer ABA. I avoid any place that offers it (or any of the other things ABA is called). It doesn't matter how good their reviews are, that is an immediate flag that this practice prioritizes "normality" above the health and safety of its pts.
	They should not be willing to partner with or work with any ABA-associated people, groups, or programs. This includes Temple Grandin.
	That they acknowledge ABA is abuse and won't use it
	When I was teaching swimming lessons as a teen I used ABA approaches which I know now is harmful and refuse to do

NDA is a philosophy of practice, not an add on or adaptation	Re-thinking everything you think and do from scratch. ‘Adaptations’ are a half measure and too often offered as all that neurodiverse people need – actually you need to start with your philosophy of practice, look at things from a ‘whole society’ standpoint and be prepared to do what people need, not what you think they need.
	It’s more what they don’t do.
	I don’t think this is something you can quantify as presenting as affirming. There’s such a huge diversity of affirming practices and actions, it's hard to list them. It’s much easier to talk about what is not neurodiversity affirming. That’s a smaller list.
	Actually, this is a really hard survey. I initially wrote a lot more but soon realised I was writing a list of reasonable adjustments which have often been denied me. That is not exactly what you asked for, is it? Yes, they need to know a lot more about that stuff.
Practitioner engages reflexively with neurodiversity theory	Have a humble attitude of wanting to learn more about neurodiversity.
	Willing to learn, not just go by whatever they might have been taught about autism.
	Listening, trying to understand, and asking questions about my experience as an autistic person rather than going off assumptions or only things they’ve learned/read about autism.
	Committed to unlearning their ableism
	Understands that if they are neurotypical they are outside the neurodiversity group and therefore their power as a professional is likely to be out of all proportion to the qualifying knowledge.
	Being willing to learn if they didn’t know something I was talking about (not defensive or know-it-all)
	General good practice in a capitalist world are based off ableist, racist, classist “good practices”.
	I know feel that everything I do is now inline with my own beliefs and values rather than going along with things that I was trained in but felt uncomfortable with.
	All the things I’ve mentioned above were probably reflective of a general attitude to working with my clients but I do them much more explicitly now and feel very justified in doing them whereas before would have stuck to ‘traditional’ approaches
	Being flexible in their approaches and willing to adapt, recognizing that a lot of the approaches were created with neurotypical people in mind and may not work in the same way for autistic people
	You have to be prepared to be challenged about your very self. Most professionals don’t get this but at least being willing and open is a good start

	They are willing to listen to new ideas and information that may differ from their training, and willing to change their practice rather than insisting that they are the professional so they must be right.
Professional shares responsibility for effective cross-neurotype communication	Sometimes it's about tone of voice. Comforting someone who's neurodivergent is different to comforting someone who's neurotypical, and being able to modify tone to suit the person is critical.
	Considers how to meet me midway to address the double empathy problem (sf Damian Milton) rather than expecting me to do it all.
	I think I make more of an effort to reduce the burden from people I work with to process things as best suits them
	If they were neurotypical, frequent checking we had the same understanding of the conversation.
	Keep very aware of how people communicate and reflect that back to them, even if it's not my natural pattern.
	Understanding and accepting of the double empathy problem.
NDA practice is context dependent	Neurodiversity is such a broad category, and the needs of neurodivergent people vary so widely, that I don't think there are standard things that would help every neurodivergent person
	Context is vital to this kind of expectation!
	Unique to individuals/organizations in its physical layout and requirements for contents.
	It would depend on the setting what I would see because different contexts require different needs.
Professional skills still apply	I don't think anything different is needed. Being interested and proactive is probably a requirement for any interaction.
	Being on the receiving end of empathy is always a welcome experience, even if only cognitive empathy
	Have empathy and respect.
	Validate and empathise
	Often a 'why do they do that?' complaint about neurotypical people.
	Professional
	Listens
	Communication is key
	Active listening to the individual.
	They are supportive
	They pay attention to more than just verbal, vocal communication
	They check in with me. Ask how things are going
	Occasional reflections to demonstrate they understand me, prompts to help me get back on track if I need to.

	Being prepared to describe to me what they can see happening in me, thus bringing my attention to any negative changes in me (e.g. getting too stressed)
Overlap with other styles of practice	Neurodiversity affirming therapy that also takes one's culture identities into account and is queer friendly
	Recognize that being autistic doesn't mean that I can't really be trans or consent to gender affirming medical care.
	A trauma informed environment where I feel safe
	I work in a trauma informed matter
	They would have a trauma-informed approach and be highly knowledgeable about ND trauma – eg a life of not having sensory needs met = trauma
	Anti-oppressive practices
	That they are working from an anti-oppression framework

Appendix 16: Final Thematic Map (map 5)



Appendix 17: Codes and Extracts Excluded from Thematic Analysis

Coded but not included within a theme

Code label	Extracts
More informal	They are more informal.
	Sit in nonformal ways (like cross their legs, take their shoes off and sit criss cross, sit on the floor)
Consideration given to the nature of the professional-client relationship	Therapists etc should not operate in a time limited fashion with the goal of getting things done asap. There should be no rush. An ND affirming therapist should keep in mind that they may be the only person in an Individual's life who has ever been validating and supportive, providing unconditional positive regard. This type of relationship may be the only true stable secure type of attachment they have ever had, and this is powerful for healing from trauma and burnout. Thus, it is important that the therapist is open to a long term therapeutic relationship (if the client has the funds/access) even if it isn't super frequent at times. I don't mean an enmeshed relationship, I mean just having that stable figure as a "secure base" where you can return and discuss life experiences and how to navigate is super empowering in ways that are difficult to describe. It's almost like reparenting for a late diagnosed ND adult. There is too much desire for "efficiency" within healthcare under capitalism which has made its way into university training, and psych therapy specifically often morphs into something completely divorced from what it was supposed to be in the first place.
	I plan for sustainability and lifelong support rather than expecting them to 'get better and move on' even though they will need to 'move on' from my support at some point.
Understanding others	Affirming that other people are different to me so I should treat them how they would want to be treated, not how I would want to be treated
Potential complication of knowing neurodivergent "condition"	When I did not, I learned not to talk about neurodiversity as I worked with state mandated offenders who would be further ordered for evaluation if I had expressed a concern. I learned that their ignorance of their condition was better than further harming them with more to worry about.

Not coded due to lack of analytic richness or ambiguity

Universal design built in
respect for no-contact hours/days
Coherence - not breaking off or suddenly changing tack.
In comms: BAD = 'Hello, I hope you are well'. SHOWS THEY'RE TRYING = 'Hello, I hope things are going as well as can be expected today'. GOOD = 'Hello... this is what I need to say, and the important information and timeframes'.
giving space
It means neurodiverse welcoming.
I've seen it so rarely I couldn't comment in more detail.
I do all the things I'd like to see in other professionals' practice (mentioned on previous page).

Appendix 18: Participant Information Sheet and Privacy Notice

Participant information sheet

Please email charlotte.naylor@nottingham.ac.uk for an easy read version of this information sheet.

Title of Project: Autistic community views on neurodiversity-affirming autism practice.
Ethics Approval Number: S1456
Researcher: Charlotte Naylor
Supervisor: Dr. Nicholas Durbin.
Contact Details: charlotte.naylor@nottingham.ac.uk ; Nicholas.durbin@nottingham.ac.uk

This is an invitation to take part in a research study gathering Autistic people’s views on neurodiversity-affirming practice.

Before you decide if you wish to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

The purpose of this study is to understand what Autistic people mean by the concept of neurodiversity-affirming practice. This is because it is a term often used within neurodivergent communities but is less talked about in research and professional communities. It is hoped that Autistic people’s voices in this study will lead to the concept of neurodiversity-affirming practice being more clearly understood by researchers and professionals.

If you participate, you will be given an online survey with 6 questions for everyone, and 2 more if you are a professional working with Autistic people in a neurodiversity-affirming way. The questions will have an open response box, meaning you can type whatever you want to say in response to the question. You can type as little or as much as you like; responses of any length will be valued. If you wish to leave any of these questions blank, you can.

If an online survey format is not accessible to you, you can participate in a different way - please email the researcher about this.

This questionnaire is likely to take you between 15 and 45 minutes to complete, depending on how much you write, and how long it takes you to write it.

Participation in this study is totally voluntary and you are under no obligation to take part. You are free to withdraw at any point before or during the study by closing the survey without submitting your answers. Once submitted, data cannot be deleted. All data collected will be kept confidential and used for research purposes only. It will be stored in compliance with the Data Protection Act. As an online participant in this research, we are obliged to make you aware that there is always a potential risk of intrusion by outside agents, for example through hacking, and therefore the possibility of being identified.

If you have any questions or concerns please do not hesitate to ask now. We can also be contacted after your participation at the above email address.

If you have any complaints about the study, please contact: Stephen Jackson (Chair of Ethics Committee) stephen.jackson@nottingham.ac.uk

It is possible some questions will lead you to think about your own life experiences. You do not need to include any personal experiences in your answers. If at any point you need support, here are some sources:

If you feel you cannot keep yourself safe, phone 999 or go straight to A&E.
1. Phone Samaritans - 24-hour helpline for any concern: 116 123
2. Text the word SHOUT to 85258 to talk about any concern
3. Phone Papyrus suicide prevention hopeline (for under 35s): 0800 068 4141
4. Phone Young Minds if you are a parent/carer of a young person who completed this survey: 0808 802 5544
5. Phone Childline with any concern, or access their website for other ways to get in touch (if you are 25 years old or under): 0800 1111

For further information and resources specific to autism:
1. Autistic Self Advocacy Network (ASAN)
2. Autistic Women’s and Nonbinary Network
3. National Autistic Society

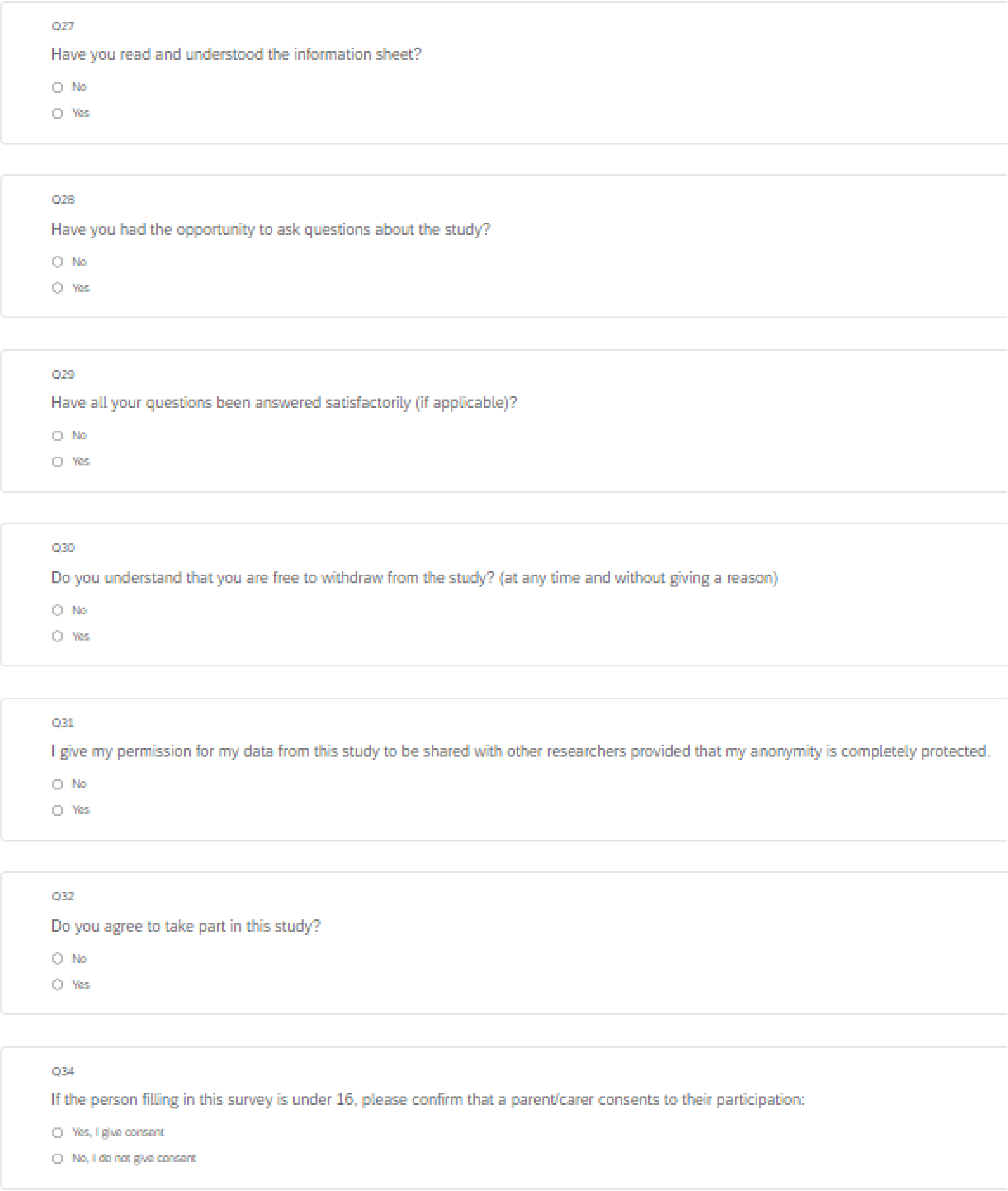
4. Neuroclastics

Research participant privacy notice
Privacy information for Research Participants
For information about the University’s obligations with respect to your data, who you can get in touch with and your rights as a data subject, please visit: www.nottingham.ac.uk/utilities/privacy/privacy.aspx.

Why we collect your personal data: We collect personal data under the terms of the University’s Royal Charter in our capacity as a teaching and research body to advance education and learning. Specific purposes for data collection on this occasion are to gather participant views to be analysed for research in a Doctoral thesis.
Legal basis for processing your personal data under GDPR: The legal basis for processing your personal data on this occasion is Article 6(1a) consent of the data subject.
Special category personal data: In addition to the legal basis for processing your personal data, the University must meet a further basis when processing any special category data, including: personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person’s sex life or sexual orientation. The basis for processing your sensitive personal data on this occasion is Article 9(2a) the data subject has given explicit consent to the processing.
How long we keep your data: The University may store your data for up to 25 years and for a period of no less than 7 years after the research project finishes. The researchers who gathered or processed the data may also store the data indefinitely and reuse it in future research. Measures to safeguard your stored data include anonymisation of data (no identifying features will be stored with the data or used in dissemination of the data), encryption of data stored by the researcher, and access to the data restricted to only the researcher and research supervisor.
Who we share your data with: Extracts of your data may be disclosed in published works that are posted online for use by the scientific community. Your data may also be stored indefinitely on external data repositories (e.g., the UK Data Archive) and be further processed for archiving

purposes in the public interest, or for historical, scientific or statistical purposes. It may also move with the researcher who collected your data to another institution in the future. : e.i.williams@surrey.ac.uk

Appendix 19: Participant Consent Form



Q27

Have you read and understood the information sheet?

○ No

○ Yes

Q28

Have you had the opportunity to ask questions about the study?

○ No

○ Yes

Q29

Have all your questions been answered satisfactorily (if applicable)?

○ No

○ Yes

Q30

Do you understand that you are free to withdraw from the study? (at any time and without giving a reason)

○ No

○ Yes

Q31

I give my permission for my data from this study to be shared with other researchers provided that my anonymity is completely protected.

○ No

○ Yes

Q32

Do you agree to take part in this study?

○ No

○ Yes

Q34

If the person filling in this survey is under 16, please confirm that a parent/carer consents to their participation:

○ Yes, I give consent

○ No, I do not give consent

Appendix 20: Easy Read Version of Participant Information Sheet

You have been invited to answer questions on a survey.

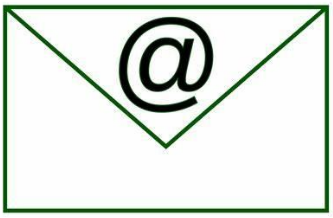
The questions will ask about neurodiversity and what this means to you.

You will be asked whether you think neurodiversity should affect how professionals work with autistic people.

You will also be asked why you think that.

This survey is for people who are autistic or who have autism.

You might want to share your thoughts a different way if online surveys are a problem for you.



You can contact the person running the study to ask for a different way to be involved.

You do not have to be involved at all if you do not want to.

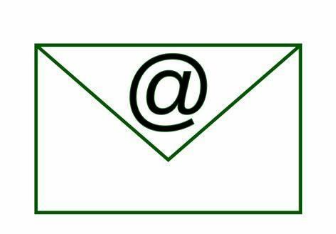
If you choose to fill in the survey, you do not have to answer all the questions.

You can write as much or as little as you want for each question.

You can stop the survey at any time for any reason.

Some people might find the questions stressful to answer.

You will be given links to support services in case you need help with your feelings after the survey.



You can contact the person running the study if you have questions or worries about it.

The person running the study is a student at the University of Nottingham.

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

Appendix 21: Debrief Sheet

Debrief Statement

Name of researcher: Charlotte Naylor
Email of researcher: charlotte.naylor@nottingham.ac.uk
Name of supervisor: Nicholas Durbin
Email of supervisor: Nicholas.durbin@Nottingham.ac.uk
Email of Chair of Ethics Committee (Stephen Jackson): stephen.jackson@nottingham.ac.uk
Title of Study: Autistic community views on neurodiversity-affirming autism practice.

Purpose of study:
The purpose of this study is to understand what the concept of neurodiversity-affirming practice means to the Autistic community. This is so that the practical implications of the neurodiversity theory of autism can be discussed by academics and professionals, while being led by experts by lived experience (Autistic people).

Please email the researcher at the email address above, if:
- You have questions about this survey or study
- You have concerns about this survey or study and would like to speak to the researcher about them
- You would like to be emailed a link to the final thesis/research report once it is completed

Where to seek support if you have concerns following this survey:
It is possible that the questions asked in the survey prompted memories about your own life experiences. Some of these may have caused you to experience unpleasant emotions or distress. If you feel this way, please consider seeking support.

Here are some ideas:
If you feel you cannot keep yourself safe, phone 999 or go straight to A&E.

1. Phone **Samaritans** - 24-hour helpline for any concern: 116 123
2. Text the word **SHOUT** to 85258 to talk about any concern
3. Phone **Papyrus** suicide prevention hopeline (for under 35s): 0800 068

4141
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5. Phone **Childline** with any concern, or access their website for other ways to get in touch (if you are 25 years old or under): 0800 1111

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3. National Autistic Society
4. Neuroclastics