The good, the bad, and the ugly: Finding self and belonging after a late diagnosis of Autism Spectrum Disorder.

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Abstract

The aim of this study was to explore how receiving a late diagnosis of Autism Spectrum Disorder (ASD)[1] impacts an individual's sense of identity and belonging. Through a qualitative methodology using online surveys and semi-structured interviews, the study investigates how diagnosis functions as a transformative life event. Grounded in Victor Turner’s concepts of liminality and communitas, diagnosis is conceptualised as a contemporary rite of passage initiating a process of identity rupture, reflection, and reintegration.

The findings revealed that diagnosis often follows a prolonged period of emotional distress and social disconnection. While initially destabilising, the diagnosis offers a framework through which individuals can reflect on their past experiences with compassion leading to increased self-understanding, coping mechanisms, boundary-setting, and the formation of meaningful connections with other autistic individuals. The sense of communitas that the meaningful and affirming relationships provide offers emotional solidarity during the transition into a more authentic self. The study contributes to the growing body of literature that centres autistic voices and highlights the need for more accessible, affirming, and timely diagnostic pathways for adults. It positions late diagnosis as the beginning of an ongoing and powerful journey toward self-acceptance and belonging.

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[1] Refer to Glossary of terms, p 41

1 Introduction

This research project stems from my own experience of receiving an autism diagnosis as an adult. I had spent many years in therapy for anxiety, depression, and trauma, with much less progress than I felt there should have been. I was still feeling overwhelmed by the “simple” things in life and misreading social dynamics. It all came to a head after having experienced a social situation that deeply upset me. I was tired of feeling like a failure, like I just missed getting things right and succeeding in life. It was then that my psychologist gently asked if I had ever considered that I might be autistic. She provided me with online resources, and I soon found myself going down a rabbit hole. So much of what I read resonated with me, yet I kept swinging between clarity and self-doubt, struggling with severe imposter syndrome. Eventually, I decided to pursue a formal diagnosis. Receiving the results was deeply emotional, it brought a profound sense of validation, but also left me asking: what now?

This personal experience made me realise how transformative late diagnosis can be. It is not just a label; it’s a profound shift in self-understanding. It prompted my desire to explore more fully what it means to receive an autism diagnosis in adulthood. I wanted to know how other autistic adults made sense of this turning point in their lives, how they processed the diagnosis, reinterpreted their pasts, and began to integrate this new understanding of themselves into their identities and relationships. I became particularly interested in how diagnosis intersects with identity, self-conception, and a sense of belonging. For many, diagnosis marks the beginning of a process of re-evaluating one’s past, their relationships, struggles, misunderstandings and coping strategies. Yet despite the relief that a diagnosis can bring, it can also provoke grief, confusion, anger, and a deep sense of loss for a self that was never fully recognised or supported.

Since it was first coined by German psychiatrist Eugen Bleuler in 1911, the concept of autism has undergone major shifts in definition and public perception. Thirty-two years later, Leo Kanner wrote an article that landmarks autism as a diagnostic concept as ‘infantile autism’. Kanner believed that the relevant characteristics only appeared in young children who lacked social instinct and were obsessed with objects and sameness (Evans, 2013: 4). However, a paper by Hans Asperger in 1944 suggested that autistic characteristics can be found in people of all ages (Chown & Hughes, 2016:

2272). As a result, Asperger's syndrome (AS)[2] was introduced into the DSM-4, drawing attention to the possibility of "high functioning" autism. However, the DSM-5 published in 2013 absorbed AS into Autism Spectrum Disorder (ASD) (Cascio, 2020: 793).

Most recently, the absorption of Asperger's Syndrome into the broader category of Autism Spectrum Disorder (ASD) reflects a significant turning point in how autism is conceptualised (Cascio, 2020: 793). This change emerged alongside growing debates about whether autism is best understood as a disability or as a form of neurodivergence. While conventional medical theory and practice continues to frame autism as a deficit or disorder, the absorption of AS into the broader category of ASD, and emergence of the neurodiversity paradigm, reflect a significant turning point in how autism is conceptualised (Cascio, 2020: 793). This change emerged alongside growing debates about whether autism is best understood as a disability or as a form of neurodivergence. The neurodiversity paradigm argues that autism is a natural part of human variation. From this perspective, the challenges autistic people face are often rooted more in inaccessible environments and social expectations than in autism itself. Anthropology, as a discipline attuned to diversity and cultural meaning-making, contributes to this perspective by emphasising how disability and difference are shaped by both biological and sociocultural conditions (Devlieger, 2018: 2).

A growing area of research is concerned with the increasing prevalence of late diagnosis. With the broadening of the understanding of autism, previously overlooked characteristics are increasingly being noticed, making it possible for individuals to receive diagnosis. For example, Bargiela found that females are at a substantial risk of their autism not being recognised and diagnosed (2016: 3281). This trend is attributed to the differences between how autism typically presents in males and females. For example, females are less likely to have externalising behaviours such as impulsivity and conduct issues, and more often internalise and mask their characteristics to fit in (Bargiela, 2016: 3282).

Many studies have shown that receiving an autism diagnosis in adulthood can cause significant psychological adjustment and self-reflection as people try to reconcile this new self-understanding with a lifetime of misunderstanding, masking, and marginalization (Leedham et al., 2020; Punshon et al., 2009; Stagg & Belcher, 2019;

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[2] Refer to Glossary of terms, p 41.

Pellicano et al., 2020; Lilley et al., 2021). Thus, Diagnosis can provide a powerful framework for making sense of these experiences and help shift self-perception from "deficient" to "different."

Although the literature on diagnostic processes is growing, there is a need for deeper understanding of how late diagnosis affects an individual's identity and sense of self. Studies by Hickey et al. (2018), Belek (2022) and Botha & Gillespie-Lynch (2022) highlight that being diagnosed later in life often prompts a complex identity negotiation, as individuals begin to reframe their past through the lens of autism. These studies suggest that although diagnosis can bring clarity and validation, it may also provoke grief, anger, and uncertainty.

This research aims to contribute to that growing body of work by focusing specifically on how adult autism diagnosis shape’s identity, self-conception, and belonging. Using a qualitative approach, it draws on both surveys and interviews with late-diagnosed autistic adults. In doing so, it centres the voices of autistic people themselves and seeks to illuminate the transformative, and at times turbulent, process of post-diagnostic reflection.

Chapter 2 provides a theoretical foundation by tracing the historical evolution of autism, discussing the models through which it has been understood, and situating the neurodiversity movement within wider anthropological discourse. Chapter 3 outlines the methodological approach and ethical considerations. Chapter 4 presents the research findings, which are then discussed in Chapter 5 in relation to key themes and relevant literature. Chapter 6 draws together the study’s core insights and reflects on their implications for future research and practice.

2 Background and Context

2.1 Defining Autism

In recent years, the understanding of Autism Spectrum Disorder (ASD also referred to as autism in this study) has evolved significantly. The term 'autism' was first used by Eugen Bleuler in 1911 to describe a severe symptom of schizophrenia (Evans, 2013: 4). In the 1940s, Leo Kanner introduced 'infantile autism' as a diagnostic concept. He believed that autism only occurred in children (Evans, 2013: 4). Later, in the 1980s, psychiatrist Lorna Wing developed a theory recognising autism as a 'triad of impairments' affecting social interaction, communication, and imagination (Verhoeff, 2013: 451). Wing’s research influenced how autism was understood and classified, highlighting the need for a flexible and developmentally orientated approach that would be applicable across various ages and developmental levels (Rosen et al., 2021: 4255).

This led to the 1987 revision of the third edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-3), which expanded the diagnostic criteria. It introduced a polythetic model with 16 detailed criteria grouped into 3 domains under the category of Pervasive Developmental Disorders not otherwise specified (PDD-NOS). However, later studies found that the category was too broad and did not align with the World Health Organisation’s (WHO) diagnostic guide, the *International Classification of Diseases* (ICD) (Rosen et al., 2021: 4256).

ASD is now classified as a neurodevelopmental disorder and is defined by developmental deficits that impair personal, social, occupational, or academic functioning (APA, 2013: 31). The DSM-V defines ASD as a disorder characterised by "persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, non-verbal communicative behaviours used for social interaction, and skills in developing, maintaining, and understanding relationships" (APA, 2013: 31). To receive an ASD diagnosis, an individual must also show repetitive patterns of behaviour, interests, or activities, with symptoms appearing in early childhood and impacting daily functioning (APA, 2013: 53).

The presentation of autistic traits varies significantly from person to person, ranging from hypersensitivity to certain stimuli to hyposensitivity in other areas. For example, an individual may be highly sensitive to touch but less sensitive to sounds, while another may experience heightened sensitivity to light but reduced sensitivity to smells. These diverse and variable characteristics result in each autistic individual being unique (De Jaegher, 2013: 1).

Although autism is classified as a disability from both medical and legal points of view, not all autistic individuals identify as disabled. During the development of the DSM-5, debates arose about whether autism should be viewed as a disability or as a natural variation of human cognition, commonly referred to as neurodivergence. Many within the autistic community advocate for the neurodiversity perspective, which challenges the traditional deficit-based narrative of autism. Rather than viewing autistic individuals as "dysfunctional" or "problematic," this perspective emphasises the unaccommodating nature of social structures to cognitive diversity. Understanding autism through this perspective promotes greater acceptance, inclusion, and support tailored to individual needs rather than attempts to 'normalise' autistic behaviour.

2.2 The Neurodiversity Movement and Models of Autism

Historically, autism has been viewed through the medical model, which assumes that autistic traits are deficits that should be treated or cured (Chapman, 2020: 58). For more than fifty years, this model has been the most prominent discourse of disability. Disabilities, such as autism, are considered to be a direct result of an individual’s biological make-up and functioning, implying that a typical level of ability and functioning exists and is the ideal state of health, and that any deviation is unfavourable and defective (Pellicano & den Houting, 2022: 381). Disabilities are thus treated as needing to be cured and eliminated through medical advances. However, not all disabilities, including autism, can be cured, or eliminated.

As a result, the medical model has been criticised for its emphasis on pathology and its inability to recognise the strengths that often accompany autism, such as pattern recognition, deep focus, and creativity. The medical model often excludes autistic voices in decisions regarding their care (Anderson-Chavarria, 2021: 3). The neurodiversity movement directly challenges the medical model, arguing that autism is not a disorder to be "fixed" but a natural part of human variation (Gillespie-Lynch et al., 2020: 3).

In 1992, autistic scholars Jim Sinclair, Donna Williams, and Kathy Grant founded Autism Network International (ANI), the first autistic-led advocacy organisation with the goal of developing a civil rights movement for autistic people (Gillespie-Lynch et al., 2020: 3). The trio had been corresponding through a pen pal list and during Donnas book tour for *Nobody Nowhere,* they decided to meet up in St. Louis, Missouri, USA. They found that besides autism conferences, which were run by and tailored for neurotypical[3] parents and professionals, there were no other way for autistic people to meet other people like themselves. They decided to start their own organisation to help autistic people to find each other and to provide autistic friendly spaces to meet (Sinclair, 2005). ANI also played a key role in the development of the neurodiversity

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[3] Refer to Glossary of terms, p 41

movement, which challenges deficit-based conceptualisations of autism by reframing it as a valuable minority identity rather than a disorder that requires a cure (Gillespie-Lynch et al., 2020: 3).

The neurodiversity paradigm, a term first coined by Judy Singer in the late 1990s, aligns with the social model of disability, arguing that autism itself is not inherently disabling, but rather that social barriers create the greatest challenges for autistic individuals (Kapp, 2020: 46). Like other disabilities, autism is a socially constructed category shaped by historical and cultural contexts. Hacking introduced dynamic nominalism, arguing that diagnostic categories influence how individuals understand themselves and how society perceives them (1999: 34). This perspective suggests that autism is not only a medical diagnosis, but also a label shaped by diagnostic criteria and societal norms (Verhoeff, 2013: 445). For example, the absorption of Asperger's syndrome into Autism Spectrum Disorder in the DSM-5 reflects how classifications evolve over time, influencing self-identification as well as public discourse.

Replacing definitions of autism that rely on neurotypical expectations with ones stemming from autistic lived experiences, would align with the neurodiversity movement's assertion that autism should be understood as a natural human variation rather than a disorder in need of a cure (Chapman, 2020: 60). Thus, although autism has a biological basis, social attitudes, diagnostic frameworks, and cultural contexts shape what it means and how it is perceived.

The social model of disability was first introduced by Mike Oliver in 1980 (Oliver, 2013: 1024). He challenges the medical model by shifting the focus from the individual to the structural and social barriers that create disability. Where the medical model frames the individual as a problem, the social model asserts that society should adapt to accommodate and include disabled individuals (Chapman, 2020: 62). This model has been the foundation for the disability rights movement (Oliver, 2013: 1025). For example, the movement was pivotal in the formulation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (Lawson & Beckett, 2021: 370 – 371). The UNCRPD is an international human rights convention that aims to set out, promote and protect the fundamental human rights of people with disabilities (Australian Human Rights Commission, n.d.).

However, the social model does have limitations. While social barriers are a significant issue, the model overlooks the other challenges autistic people face (Chapman, 2020:

63). Many autistics also experience intrinsic issues such as sensory sensitivities, executive dysfunction, and other co-occurring conditions such as anxiety, epilepsy, and chronic pain, which cannot be resolved solely through social change (Anderson-Chavarria, 2021: 3). Furthermore, the model focuses on impairment, reinforcing the idea that autistics are 'other', perpetuating an 'us versus them' narrative (Chapman, 2020: 64).

Other models have emerged in response, for example, Elizabeth Barnes' (2016) Value-neutral Model, which views disability as neither distinctively good nor bad. Instead, it considers that characteristics are dependent on both environmental and social contexts (Chapman, 2020: 64). This perspective recognises that autistics thrive in the right environments, suggesting that differences are not inherently harmful and are likely impacted by environmental factors. Chapman names bright lights in working environments and social practices such as clapping, as environmental factors that may cause an autistic person to experience sensory overload or sensory fatigue (2020: 811). However, the model overly focuses on the dependency on context and fails to recognise the intrinsic struggles that autistic people face (Chapman, 2020: 68).

Anderson-Chavarria proposes the Predicament Model of Autism to provide a more balanced perspective by acknowledging the strengths and challenges faced by autistics (2021: 4). The model moves away from framing autism as purely a deficit or social construct and recognises the complex and individualised reality of being autistic. It suggests that autistic identity is shaped by both internal and external factors (Anderson-Chavarria, 2021: 6). The model provides a more flexible understanding of being autistic as it rejects the notion of a 'high-low functioning' spectrum and acknowledges the highly variable experiences of autistics.

Although the medical model frames disabilities such as autism as a disorder that must be treated, the social model argues that society must change to accommodate autistic individuals. However, both models have limitations. The Value-Neutral Model challenges deficit- based perspectives but fails to fully address the struggles of disability. The Predicament Model provides a holistic approach by acknowledging both the strengths and challenges associated with autism. As discussions around neurodiversity continue to evolve, it is essential that autistic voices are prioritised.

2.3 The Role of Anthropology in Autism Research

Anthropology is well known for its embrace of diversity. The ethnological approach to otherness and difference is unique and compelling, making the field well suited to explore new avenues of knowledge creation (Anderson-Chavarria, 2021: 2). Anthropology studies human variation across cultures, and autism challenges traditional ideas of identity and sociality. This makes autism an ideal subject for anthropological inquiry (Ginsburg & Rapp, 2020: 5).

Interdisciplinary perspectives of critical disability studies consider how cities, societies and institutions both systematically and socially 'dis-able' people (Ginsburg & Rapp, 2020: 5). By moving beyond medical models, anthropology helps redefine disability and neurodivergence as forms of human diversity rather than pathology.

Anthropologists argue that difference does not merely exist between societies, but that multiple realities are enacted through lived practices. Different people inhabit the world in profoundly distinct ways, and autism exemplifies this variation (McKearney & Zoanni, 2018: 7). For example, autistic scholar Temple Grandin describes autism as producing radical alterity, a fundamentally different way of being in the world (McKearney & Zoanni, 2018: 8). This raises the question: Does autism constitute an ontological difference?

Ontology is the study of being, existence and reality (Kohn, 2015: 312). In anthropology it refers to how cultures and societies construct and experience reality (Henare et al., 2007: 11). Ontological anthropology considers that multiple realities can emerge from the interaction between lived experiences, beliefs, and social structures (Kohn, 2015: 315). This is particularly relevant to the study of autism. For example, it could be argued that autism represents an ontological difference as autistic individuals have a distinct way of processing, perceiving, and interacting with the world around them (McKearney & Zoanni, 2018: 8). Although medical experts and parents often view autism as a collection of 'deficits', a growing number of autistic individuals have embraced their traits as a natural human variation rather than a disorder (McKearney & Zoanni, 2018: 10).

The use of ethnography allows for a deeper engagement with lived experiences of autistic people and provides insights that medical and psychological models often overlook. Ethnographic research examines how autistic people define their own identities and social worlds, rather than focusing on diagnosis and intervention (Solomon, 2010: 244). For example, Cascio (2015: 208) explores how autism is conceptualised across different cultural contexts, revealing how therapy, education and self-advocacy movements vary globally. Such research avoids Western bias in autism studies and highlights alternative frameworks for understanding neurodivergence.

The field of psychological anthropology has studied disability for many years, employing comparative and contextual approaches to the mind and culture (Fein & Rios, 2018: 263). Bagatell notes that autism intersects with key anthropological themes such as identity, sociality, and cognition (2010: 51). The concept of identity in anthropology is seen as multifaceted, fluid, and constructed. It explores how individuals and groups define themselves and how they are perceived by others (Hall, 1996: 2). Historically, anthropology as a discipline linked the concept of identity to ethnic identity, where it was focused on group membership rather than individuality (Sokefeld, 1999: 417). This structural-functionalist view saw identity as preexisting homogenous and directly linked to culture (van Meijl, 2008: 169). It was understood that identity was inherited from an individual's cultural group, making it stable and unchanging. Poststructuralists later deconstructed the notion of a stable and coherent self, arguing that identities are shaped by power structures and were not autonomous subjects. This paradigm shift brought about the contemporary understanding of self as fragmented, fluid, and relational (Sokefeld, 1999: 424).

Stuart Hall (1996) saw identity as an ongoing process, suggesting replacing identity, which alludes to a fixed state, to identification, representing an ongoing process (van Meijl, 2008: 175). He argued that individuals constructed their identity rather than inherit it (2008: 175). Sokefeld argues that identity gains meaning through its contrast with other identities, as individuals actively engage in identity management. He believes that identity is more than a passive reflection of culture; it is an active and negotiated process that requires a sense of self (1999: 424).

Autism anthropologist Ben Belek (2019: 4) examines the ontological status of ASD, noting that social values, definitions of normality, and classification systems shape how autism is understood. Studies on social cognition and autism by Milton (2014: 795) and Fletcher-Watson & Crompton (2019: 272) further challenge deficit-based models. Their research finds that communication difficulties arise more prominently between neurotypicals and neurodivergents than among neurodivergents themselves. This contradicts the medical model, which believes that autism is fundamentally a communication deficit by suggesting instead that autistic people simply communicate differently (APA, 2013: 31).

The anthropological study of autism contributes in three key ways (Solomon, 2010: 244). First, it conceptualises intersubjectivity and empathy as practice-based, allowing for close observation of culturally relative experiences. Second, it employs hermeneutic and interpretive methods to authentically understand autistic lived experiences. Third, ethnographic methodologies examine the production and recirculation of knowledge in various settings, shedding light on how autistic individuals navigate and challenge social norms.

Beyond individual identity, anthropology studies how material culture and technology shape autistic experiences. The rise of assistive technologies, alternative communication devices (AAC), and digital communities has transformed autistic self-expression (Ginsburg & Rapp, 2020: 12). Online spaces allow autistic individuals to reject neurotypical norms and create self-defined cultural identities (Davidson & Orsini, 2013: 12). By studying these spaces, anthropology expands the scope of autism research to include the role of material and digital culture in the formation of identity.

In addition, anthropology provides crucial cross-cultural insights into autism. For example, autism is often framed as a disability in western countries, whereas in India, it may be understood through a spiritual lens (Daley, 2002: 534). In France, psychoanalytic traditions shape autism interventions differently than in the Anglo-American world (Chamak, 2008: 78). In Brazil, debates continue over whether autism should be classified as a disability or a mental health condition (Cascio, 2015: 208). This highlights the influence social and cultural contexts has on the perception and treatment of autism, reinforcing anthropology’s role in challenging deficit-based narratives.

Anthropology also contributes to broader discussions of personhood, a key concern in autism studies. Personhood is defined differently in different societies. Some emphasise cognitive independence, while others prioritise relationality (McKearney & Zoanni, 2018: 8). Autism complicates traditional notions of agency, selfhood, and intelligence, making it a vital subject for anthropological inquiry. By anthropology studying how different cultures accommodate or exclude autistic individuals, it assists in shaping how human diversity is understood.

Thus, anthropology as a field challenges the dominant ideas of normality and sociality, making it a powerful tool to understand autism in new and transformative ways. By embracing various modes of being, anthropology not only expands the study of autism and disability but also challenges what it means to be human.

3 Research Methods and Ethical Considerations

This chapter will look at the methods this study utilised and the ethical considerations that were taken into account. Firstly, the recruitment of the research population will be discussed. Secondly, the study design will be explained and lastly the ethical considerations will be laid out and discussed.

3.1 Research Participants

3.1.1 Recruitment of Participants

The research used purposive sampling as it required participants to meet specific criteria to be eligible for participation. Criteria included that participants must (1) be over 18 years at the time of participation, (2) have received a formal diagnosis of ASD after the age of 18 and before participation, and (3) complete a written informed consent form. The inclusion criteria served to ensure that participants were formally diagnosed with ASD as adults.

Participants were recruited through two avenues. First, through a collaboration with the Neurodiversity Centre (NC) in Cape Town. The NC is a centre with a multidisciplinary team of professionals that offer research-based neurodevelopmental and educational assessments and diagnoses, as well as individual, family and couple support, post-diagnostic support environmental adaptation support, psychoeducation, and training. Second, through online autistic spaces run by autistic people. These included Facebook pages like *Autistic Researchers Researching Autism* and *I've been autistic all along!? (private group)*.

101 people responded to the survey. Unfortunately, 2 responses did not align with the criteria. Both responses were deemed ineligible to participant in the study because the individuals were self-diagnosed and had not received a formal diagnosis. In total 99

survey responses are represented in this study.

Out of the 99 survey responses 83 respondents indicated that they would be interested in participating in the next phase of the study. Participants were selected to participate in the interview phase based on getting the most representative pool of individuals in relation to age, age of diagnosis, length of diagnosis and nationality. 55 respondents were contacted to organise an online interview via Zoom, 25 responded, but only 20 interviews took place due to cancellations and no shows.

3.2 Study Design

For this study, a qualitative approach was used. The first phase included an online survey (Appendix A) as it is efficient in gathering relevant background information (Jeffery & Konopinski, 2014: 26). The survey also identified participants who would be willing to participate further in the study in the form of a semi-structured interview (Appendix B).

The survey aimed to collect demographic information as well as information related to their lived experiences of being late diagnosed autistic. Participants were asked about their age, age of diagnosis, nationality, the birth-assigned sex, gender identity and preferred identity language.[4] The longer questions asked about how a late autism diagnosis affected how they saw themselves their personal and professional lives, and their relationships, and how it ultimately impacted their identity and sense of belonging. The final question of the survey asked participants if they would be willing to participate further in the research, and if they answered yes, they could leave an email address to be contacted through.

3.3 Ethical considerations

Representativity in terms of gender and economic status was difficult to achieve. The majority of participants were female, this may be due to the fact that late diagnosis is more prominent amongst women. Leedham et al. (2020) found that females are more likely to mask their characteristics to attempt to fit into wider society, which causes their autism to go undetected until adulthood. They also found that the stereotyped understanding of autism as only affecting adolescent boys caused females to be misdiagnosed with other conditions (Leedham et al., 2020: 136).

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[4] Refer to Glossary of terms, p 41

In terms of economic status, the data was skewed towards more affluent individuals, which can probably be attributed to the high cost of the diagnostic process. Waiting lists to be diagnosed through government health care plans can be long, with people sometimes needing to wait up to 5 years before being assessed. Thus, those who can afford it, choose to be diagnosed through the private sector.

The gatekeepers for this study included the Neurodiversity Centre (NDC) administrative team and the administrative teams for the Facebook pages where the survey was posted. An explanatory letter was emailed to the NDC with a request to have the recruitment poster and the link to the online survey posted on their Facebook page. After a period of time, it was approved and the information for my study was posted on their Facebook page.

To gain gatekeeper permission for the Facebook groups, *Autistic Researchers Researching Autism* and *I've been autistic all along!? (private group),* I first attempted to private message individuals listed as administrators on the group's information section but got no response from either group's administrative teams. As all posts must first be approved by the administrative team. I then submitted a post request that contained the explanatory letter for the study, the recruitment poster, and the link to the online survey. Both Facebook group administrative teams approved the post, allowing it to be posted in the group.

The risk of harm was carefully considered. The potentially triggering nature of the topics being discussed may have a negative impact on participants. Thus, participants were informed about the nature of the questions that would be asked before participating. To further ensure the well-being of participants, the services of a neurodiverse psychologist was made available should any participant feel distressed and need a professional's intervention.

The privacy and confidentiality of all participants was carefully considered. Names and contact information was stored securely and separate from the survey and interview data. The raw data was stored in a password protected cloud and is only available to myself and my research supervisor. Furthermore, participants names are not used in the write up, only pseudonyms.

These issues together with details of what participants could expect during research interactions should they choose to participate were laid out in an informed consent form. The informed consent process began with obtaining ethical clearance from

Rhodes University Human Research Ethics Committee (RU-HREC / Ethics Clearance Number 2024-7267-90-81). The informed consent declaration laid out the purpose of the research, the intended research procedures, risks and benefits associated with the study, the ethical clearance number and contact information of the researcher and the research ethics committee.

The vulnerability of autistic people in research is also considered in this study. According to Dark (2024: 3) research has failed to reflect the lived realities of autistic people. Historically, research on autism has perpetuated stereotypes by using derogatory and pathologizing language that affects how autistic people are treated in society and clinical settings (Dark, 2024: 2). This study has taken care to avoid the use of stereotypical and stigmatising language. For example, the term symptoms has been replaced with characteristics. Another issue that makes autistic people vulnerable is communication bias in research (Phan, 2025: 134). Bias is often skewed toward socially intuitive communication styles, although many autistic people prefer structured and precise written communication. To ensure that participants felt safe, comfortable, and heard in this study, a direct line of communication via email was provided between participants and the researcher. For example, one participant was more comfortable communicating in the chat section of Zoom with the camera off, so that is how the interview took place. The researcher also made sure to reach out to participants if there was any uncertainty in what the participant meant versus what the researcher was understanding. Another participant felt that they thought of more relevant information after completing the survey and emailed to add to their response, which was included in the data.

This chapter outlined the methodological approach undertaken in this study, including the recruitment process, participant demographics and data collection methods. It also addressed the ethical considerations, with particular attention to informed consent, participant well-being, confidentiality, and communication accessibility. Additionally, the historical marginalisation and misrepresentation of autistic individuals in research was carefully considered. Particular care was taken to adopt respectful, inclusive, and neuro-affirmative practices. By centring the voices of participants and remaining responsive to their needs throughout the research process, this study aims to contribute meaningfully and ethically to the growing body of knowledge concerning adult autism and identity.

The following chapter will present the research findings, thematically exploring participants' experiences of late diagnosis and the ways in which it has shaped their identities, relationships, and sense of belonging.

4 Research Findings

All 20 interview participants indicated that they had experienced a longstanding sense of being different from those around them. For many, this culminated in a crisis that led to their discovery of autism which invariably marked a profound turning point, initiating a period of reflection and emotional processing that ultimately led to an emotional recalibration. This chapter explores how participants felt and what they did leading up to their being diagnosed with autism as adults, how the diagnosis made them feel at the time and how they have subsequently processed it.

4.1 Out of Sync: Lifelong Feelings of Difference and Disconnection

Feeling different from others from early childhood is a common experience among autistic people. Sara[5] stated that she had believed that she felt this way from a young age.

> ***Extract 1 (Sara)***
> Prior to being diagnosed I had, from childhood, known I was different and a bit "separate" from others.

De Broize et al for example, found that the perceived differences often manifested as confusion about communication styles, social rules, and emotional experiences (2022: 133 - 134). For example, Lucy shared that she often unintentionally upset or offended others in social interactions. This emphasises the disconnect between her intentions and others' reactions. Not understanding what had upset them left her feeling isolated and eroded her sense of belonging.

> ***Extract 2 (Lucy)***
> I really try to be a kind person and I would never be malicious. I just didn't understand the way some people think.

Similarly, participants in this study described a range of social, communicative, sensory, and cognitive differences that made them feel "out-of-sync" with their peers.

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[5] All participant names are pseudonyms.

These persistent difficulties were frequently interpreted as personal failings. Participants described internalising their struggles in deeply negative ways, for example, Liam saw himself as “lazy”, Cameron felt “broken”, Alex believed they were “stupid,” and Lucy believed she was a “bad person”. These labels contributed to a negative self-perception and persistent feelings of shame.

> ***Extract 3 (Liam)***
> There are things that, like, me and a lot of other people struggle with that, like, don't make me, like, a bad or lazy person.
>
> ***Extract 4 (Cameron)***
> The knowledge that a lot of what I've thought about myself as being weird or different or broken or whatever is actually just perfectly normal autistic stuff.
>
> ***Extract 5 (Alex)***
> I blamed myself for being stupid, a lot.
>
> ***Extract 6 (Lucy)***
> I blamed myself for the stuff that happened because I felt like I was a bad person. And I was like, oh, I must be this like evil, like narcissist.

The participants’ difficulties with fitting in also led to a profound sense of alienation. Many participants described feeling misunderstood which increased feelings of being different from those around them, giving them a deep sense of disconnection. Alex, for example, compared themselves to an alien from a different planet. This mirrors the findings of Lupindo et al. who found that a lack of understanding around their autistic traits made forming meaningful connections more difficult (2022: 14).

> ***Extract 7 (Alex)***
> I had made peace with being from outer space and forever alone … when I was four or so.

Many participants described developing strategies to mimic neurotypical behaviour in an attempt to avoid judgment or social exclusion. Masking, where participants consciously or unconsciously suppress their autistic traits, served as a coping mechanism (Evans et al., 2024: 230). It allowed individuals to “pass” in social contexts, but often came at a significant emotional and cognitive cost. Max discussed how masking delayed their autism diagnosis and caused them to go through many misdiagnoses.

> ***Extract 8 (Max)***
> I've been diagnosed with a long list of other things throughout my life and no one ever even considered autism since I was masking so heavily.

The long-term effects of masking were described by several participants as contributing to a deep sense of disconnection from their own identities. In trying to meet external expectations, individuals often felt they had lost touch with who they were underneath the strategies they had developed to cope. This struggle to maintain a consistent self-image, while managing the demands of masking, led some to describe their sense of self as fragmented or confused. For example, Kai highlighted how navigating authenticity after masking had a deep impact on their ability to make sense of themselves.

> ***Extract 9 (Kai)***
> I'm struggling a lot currently as I try unmasking my experience of being in the world is harder. I'm exhausted.

These experiences often occurred decades before participants were diagnosed. The absence of earlier identification and support caused their challenges to be viewed as personal inadequacies, rather than neurodiverse traits. Thus, receiving an autism diagnosis as an adult allows individuals to reframe a lifetime of struggles, but also evokes complex emotions such as grief for spending a large portion of their lives believing they were defective.

4.2 Pathways to Diagnosis: Routes to Adult Autism Identification

Participants described a variety of pathways that led them to consider and ultimately receive an autism diagnosis. 4 common pathways emerged from the data, (1) Self-discovery through online research, (2) Recommendations from others, (3) Misdiagnosis or prolonged mental health treatment and (4) Parental identification.

In the first pathway, participants encountered neurodivergent content through interaction with online media, social platforms, and informal screening tools. 3 participants recognised similarities between themselves and the autistic traits that people in their lives portrayed. For example, Zoe realised she may be autistic after talking to her recently diagnosed friend and seeing similarities between her and the friends' experiences and traits.

> ***Extract 10 (Zoe)***
> She [my friend] got a diagnosis and she described a lot of the

> questions to me, and I was like, oh wow! I talked to my mom about it and decided that I would go too.

For others digital spaces became unexpected sources of self-recognition. Jesse described how their journey began with memes. They saw posts by neurodivergent content creators on social media platforms such as Tiktok and Instagram, and found themselves identifying with much of what they saw.

> ***Extract 11 (Jesse)***
> It sounds weird. It started with memes. I had a bunch of friends posting neurodivergent memes … And I'm like, well, that hits a little close to home, and it just kind of snowballed from there.

Eventually, they took a self-assessment test “just for giggles”. Surprised that their resulting scores were high, they brought the results to their psychologist, which initiated the formal diagnostic process.

The second pathway involved external recognition. 3 participants reported having either a friend, family member, or therapist suggest that they might be autistic. Lily, for instance, had been working with a community mental health team for a year when a clinician suggested she explore the possibility of autism.

> ***Extract 12 (Lily)***
> I'd had mental health issues for a long time, through most of my adult life, and to the point that I was under the care of a community mental health team … And she [mental health worker] said to me that she thought that I was autistic, and that it might, I might find it helpful if I had a diagnosis.

In the third pathway, 7 participants reported having spent years in therapy or psychiatric care, frequently misdiagnosed with conditions such as anxiety, depression, agoraphobia, or Post Traumatic Stress Disorder (PTSD). Often the lack of improvement would trigger a deeper look into what may be causing the individuals distress. For example, Anna shared that she began struggling with her mental health at a very young age. At 18 years old, she was formally diagnosed with anxiety and depression but found that the treatments did not help her.

> ***Extract 13 (Anna)***
> I had struggled all my life, I started self-harming when I was six years old and was diagnosed with anxiety and depression when I was about 18 years old and I tried all of the medications, the antidepressants, the anxiety meds, nothing helped, and I was still really struggling.

It wasn't until years later that autism was considered, providing a more accurate framework for understanding her persistent difficulties.

Finally, the fourth pathway involved parental identification, where 4 participants recognised autistic traits in themselves after their children were diagnosed. Emma, for example, saw many of her daughter's struggles reflected in her own life. The fear and shame that her daughter expressed prompted her to seek a formal diagnosis. Her intent was to model for her daughter that autism is not something to be ashamed of.

> ***Extract 14 (Emma)***
> I actually thought, I have a family, I have a job … now I'm different, but I can do the same things as everybody else. I wanted to show her, see, I'm officially autistic as well, and you can do all those things.

These diagnostic pathways highlight the reality that autism often goes unrecognised well into adulthood, especially for those who have spent years adapting, masking, or being misdiagnosed.

4.3 Breaking Point: Psychological Collapse and the Path to Recognition

Out of the 20 participants 11 reported experiencing mental health issues. These included anxiety, depression, burnout, suicidal ideation, post-traumatic stress disorder (PTSD), eating disorders, borderline personality disorder (BPD), and agoraphobia.

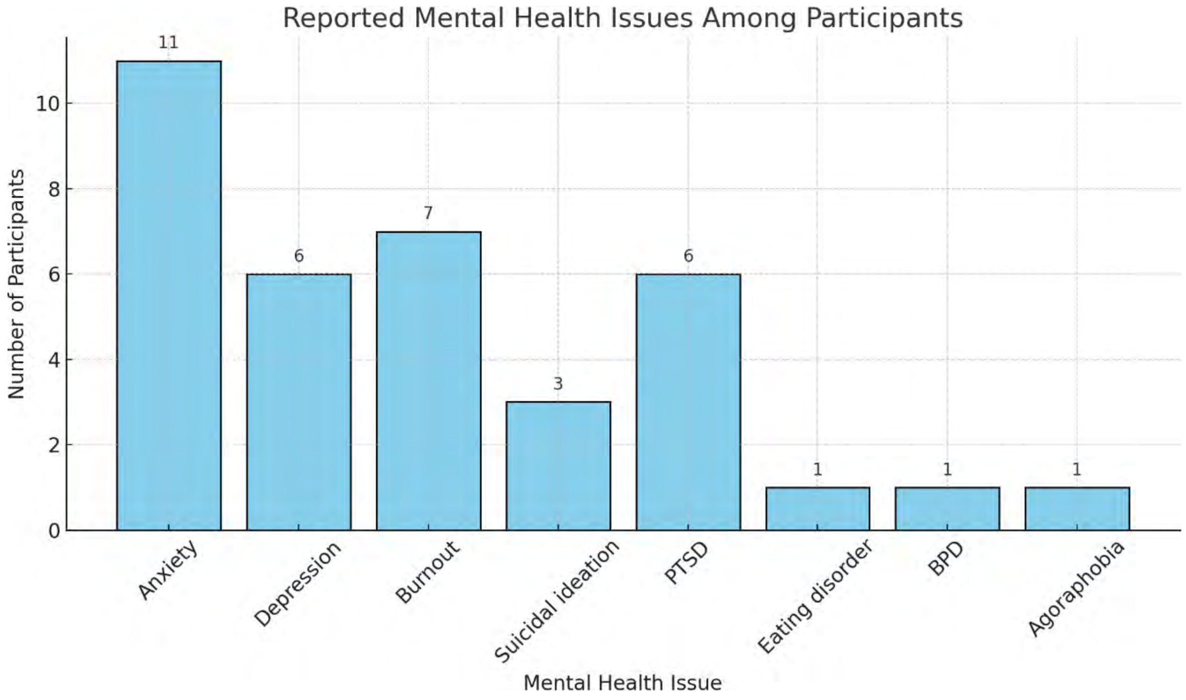

Figure 1: Reported Mental Health Issues Among Participants

After years of navigating their perceived differences, many described reaching a crisis point in their mental health. These moments were often experienced as profound personal ruptures where the self-narratives they had relied to make sense of themselves, broke down. Participants spoke of these episodes not only as crises but as turning points that forced them to confront the possibility that their struggles might stem from something deeper than individual failure or mental illness. For example, Ava described experiencing such severe burnout that she was forced to leave her teaching career.

> ***Extract 15 (Ava)***
> I was, quote, unquote, successful in that I did well in school, I was able to hold down a job. I got married, I had kids, and then things started to sort of unravel when all those responsibilities started piling up. I ended up in a really bad burnout in 2009. I was off work for a while, and it resulted in me having to leave my teaching career in 2011.

This breakdown acted as a threshold, disrupting her former sense of identity and prompting her to search for an explanation that would later lead to an autism diagnosis. Similarly, Clara shared that she reached a point of intense emotional exhaustion that led to suicidal ideation

> ***Extract 16 (Clara)***
> I was just so low, and I've never experienced it in my whole life. It's the lowest I've ever been, where I literally just did not want to live.

At her partner’s encouragement, she began therapy, where she first encountered the concept of autistic burnout. These accounts were not isolated, many participants described years of internalised shame, confusion, and self-blame culminating in emotional collapse. For them, the moment of crisis was simultaneously the breakdown of a familiar but painful identity and the beginning of a re-evaluation process that would eventually lead to diagnosis. While offering clarity, diagnosis also upended participants lives as they were left to reinterpret their past and renegotiate who they were in light of this new information. For some, this process was both relieving and deeply unsettling.

4.4 “I’m Not Broken”: Post Diagnosis Reflection and Emotional Recalibration

Receiving a late autism diagnosis marked a turning point for participants, who then entered a period of intense reflection and emotional processing. Many began to re-evaluate their life experiences through an autistic lens. They reinterpreted past difficulties not as personal failures, but as understandable responses to environments that were misaligned with their needs. This resonates with the work of Seers and Hogg, who describe the process of reflecting on past experiences through an autistic lens as shifting the blame from themselves to a broader understanding of what it means to be neurodivergent in a neurotypical society (2022: 11). Mia found that her diagnosis gave her the information which allowed her to “recontextualise” her past experiences.

> ***Extract 17 (Mia)***
> Basically, everything about my experiences made sense with this new lens, and it helped me recontextualise past experiences as me struggling because of being autistic in a world that is not designed for me, rather than me just failing at things for no reason.

This process is usually emotionally complex and is often described as an “emotional roller coaster” (Leedham et al., 2019; Stagg & Belcher, 2019; Pellicano et al., 2020).

Many initially report feeling validated and relieved, as they finally had an explanation for their differences and experiences. Stella shared that her diagnosis validated that her struggles were real.

> ***Extract 18 (Stella)***
> Everything I find hard, there is an actual reason, and I’m not just making up an excuse.

While Max was relieved to gain more insight into their life and have explanations.

> ***Extract 19 (Max)***
> It was one of the biggest reliefs I've ever felt; finally, I could understand so much of my life, why I do things a certain way, why my interactions with people tend to go this or that way, why some things are difficult for me and some things not.

These findings align with Kiehl et al. who also found that diagnosis provides individuals with an explanation and clarity for their differences and struggles. Ruby powerfully expressed this shift, “This is actually what it is, I’m not [expletive] up, bad, mad or sad”.

However, while diagnosis brought clarity, it also brought difficult and painful emotions to the surface. Four discussion points emerged in relation to participants’ emotional responses post-diagnosis:

Firstly, participants expressed anger and frustration that their autism was undetected for so long. These emotions were often directed at teachers and health professionals who either dismissed their struggles or misinterpreted them as deviancy or an unrelated mental health condition. Participants believed that if someone had taken a more empathetic look and tried to be more understanding, much of their suffering could have been avoided. For example, Ava recalled a teacher who treated her harshly for behaviours that were later understood as autistic traits.

> ***Extract 20 (Ava)***
> … the anger still bubbles up for me … there was a specific teacher when I was in, going from primary school to high school, that if maybe we knew this, she wouldn't have treated me as harshly or been as frustrated with me or pushed me into situations that ended horribly for me.

Anna’s anger was directed toward the psychotherapist whose care she had been under for almost a year. Although they had described a meltdown,[6] they had not realised that Anna was autistic.

> ***Extract 21 (Anna)***
> I was so angry for such a long time that this had been missed. I'd been under a psychotherapist for a year, and at the end of that year she said to me I don't think we've got to the bottom of things with you, we've not got to the bottom of these episodes that you have, where you scream, and you bang your head on the wall and you can't think, and you can't speak. Well yeah, she's describing a meltdown there and I was furious that it wasn't, you know [I had been] seeing this woman every week for a year, it wasn't picked up.

Secondly, participants experienced grief for time they had lost and opportunities that had been missed. Many mourned the years they had lived not understanding themselves and choices that they made under false assumptions. Diagnosis prompted reflections of “what could have been” if they had been diagnosed earlier. Ava, who was diagnosed at 54, felt that a lot of pain and suffering could have been avoided if she had been diagnosed earlier and that she could have achieved more in her life.

> ***Extract 22 (Ava)***
> There's been a lot of grief and anger because of all the "would have, could have, should haves" and "if only I had known sooner" kinds of reflections. There's sometimes a feeling that at my age it's too late to fulfil my potential. That part is really hard to handle.

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[6] Refer to Glossary of terms, p 41.

Grief also encompassed the trauma participants endured due to misattributed behaviours and untreated sensory challenges. Zoe shared that she developed a panic disorder from years of forcing herself to cope with overwhelming sensory environments, pain she now understood was the result of undiagnosed autism.

> ***Extract 23 (Zoe)***
> I developed panic disorder along with my autism because I never knew what was wrong with me. So, all of these senses, the sensory overload, and then I would be weird and get a panic attack and just not know why it's happening.

Third, participants experienced self-doubt and imposter syndrome, questioning whether they were autistic enough. This internalised doubt led to guilt, minimisation of their struggles, and reluctance to fully embrace their identity. Liam, for instance, hesitated to accept the label because “other people have it worse”.

> ***Extract 24 (Liam)***
> It's again, the thing with the imposter syndrome of like, Oh, other people have worse.

These types of comparisons undermined their ability to feel legitimate in their diagnosis, perpetuating a sense of not measuring up, even within the autistic community.

Fourth, participants had anxiety around disclosure and social acceptance. They were concerned about how others would respond to their diagnosis. Many feared they would be dismissed and not believed by family, peers and employers. For example, Zoe was deeply hurt when her family compared her to her non-verbal autistic cousin and dismissed her diagnosis.

> ***Extract 25 (Zoe)***
> I do have a cousin who also is autistic, but much more severely than I am, like non-verbal and everything. So, they [family] see me and I'm kind of like this overachiever at school. Everything has to be perfect; the prodigy child gets everything right. They just couldn't get the two together … it feels a bit [expletive] it really dismisses everything I’m going through.

She mentioned that she “…cried a lot about that” as she described the subsequent fallout and the impact it had on her family relationships. Others feared professional consequences. Stella chose not to disclose her diagnosis on a job application, stating, “People get a negative view of you”.

> ***Extract 26 (Stella)***
> I didn't disclose it on my application, because I do feel that people get a negative view of you. And they think maybe that you can't work if you're autistic. I know that more and more people are starting to understand it better, but I do still feel like I can't take the risk.

This materialised into workplace discrimination for Jane. A week after disclosing her diagnosis she was sent home and has since been working remotely under tense circumstances. Her case escalated to involve the workplaces occupational health officer and her union, highlighting the real risks of disclosing neurodivergence in professional settings.

> ***Extract 27 (Jane)***
> It has caused me extreme problems at my work … I was basically sent home a week later, after I disclosed [my autism diagnosis], that was October 2022. We're in a process now where I'm supposed to return to work, but some of my colleagues, because I've had communications problems with some of them, not all of them, are hesitant for me to return. It's a whole process at the moment and the university's occupational health person is finally also involved, as well as my union.

Although diagnosis provided validation and clarity, it also revealed unresolved anger, grief, and fear. Participants questioned their identity, processed missed opportunities, and weighed the risks of disclosure. While diagnosis promoted self-compassion, it also required relationships, career choices and self-perceptions to be renegotiated. In this way, diagnosis is not the end of the journey but the beginning of a transformative, often turbulent process of self-understanding and acceptance.

While the sub-themes are presented distinctly for clarity, the participants' experiences often overlap across the categories. This demonstrates the complex nature of their post-diagnostic experiences. For example, Ava's story spans across anger and grief. She grieved lost time and unacknowledged suffering and was angry at the systemic failures that delayed her diagnosis. Her experience shows ow these emotions can coexist and are often intertwined.

Similarly, Zoe's sensory trauma and family dismissal reflects a combination of grief, anxiety and invalidation. Her experience highlights how the consequences of late diagnosis manifested across multiple emotional dimensions. Additionally, Liam's struggle with imposter syndrome encompassed self-doubt, internalised grief and social anxiety, as his comparisons to others caused him to be reluctant to claim his own autistic identity. These overlaps prove that diagnosis is not experienced as a series of separate emotional responses, but rather as a complex and evolving emotional landscape.

4.5 Identity Integration and Empowerment

Following the emotional upheaval of diagnosis, many participants gradually moved towards accepting their autistic identity through self-understanding, lifestyle adaptions, and community. 3 common ways in which this was achieved during this stage of the process were identified: (1) Learning about autism and themselves, (2) Setting boundaries and redesigning life, (3) Finding and building community.

In the first place, participants actively learnt about autism and themselves by reading books written by autistics, joining autistic led communities and following autistic advocates on social media. This self-directed learning fostered clarity and confidence, offering language and frameworks that helped them understand their traits and needs. Leo, who recognised his own autism through his son's diagnosis, described how shared learning strengthened their entire family.

> ***Extract 28 (Leo)***
> The more we know, and the more we learned, and the more we have to check in, the better for the whole family … it just helps the whole system.

Secondly, participants realised and acted upon the need to set boundaries and redesigning their lifestyles. Greater self-awareness inspired participants to tailor their lives and environments to be more in tune with their needs. Participants made changes to their environments, routines, and relationships to support their sensory and emotional well-being. For example, Anna stopped drinking alcohol shortly after her diagnosis because she realised it was an unhealthy coping mechanism. She also began to avoid environments that triggered overwhelm, acknowledging that this created distance in some friendships but ultimately benefited her mental health.

> ***Extract 29 (Anna)***
> I realised that the only reason I was drinking was to try and just cope in social situations … I don't go out as much, I'm just not willing to stress myself out as much anymore so yeah, my relationship with my friends is more distant.

Meanwhile, Nora took a strategic approach to protecting her energy. She avoided large gatherings, instead opting for quieter, one-on-one interactions.

> ***Extract 30 (Nora)***
> if I meet with a group of friends and they bring their kids and everything and we meet for like four or five hours, I feel overwhelmed … I was so lonely. I wasn't really connected to anyone. But if I meet each of them one by one, then that's amazing. Since I really know this is how it works for me, I just told them: [If] there's a group, I might come for maybe an hour. And then I'd love to meet each one of you separately, let's go for a walk on some different dates, and slowly that's starting to kick in.

Additionally, to manage the tension between her need for order and her husband's ADHD-related disorganisation, they hired household help and created separate personal spaces.

> ***Extract 31 (Nora)***
> Now slowly he's [husband] accepting that he's got ADHD and he needs help … So now we're finally getting help in the household, because I cannot clean up all his mess and his chaos and his clutter. I can't. I'm just too tired … I'm in the back of the garden in a tiny house, I'm sitting here where everything's organised … It saved our marriage. It saved my mental health.

Thirdly, participants began to find and build a community for themselves. They found that connecting with other autistic individuals, online or in person, was validating and cathartic. Being able to share their experiences and perspectives amongst like-minded people helped reduce the isolation many had felt pre-diagnosis. For Morgan, online communities became their primary source of support. This sense of belonging allowed participants to feel seen and affirmed in ways they had not previously experienced.

> ***Extract 32 (Morgan)***
> I've also spent a lot of time interacting with autistic social spaces online. I think that's been helpful that now there is also a community of people I'm with online where we're autistic and this is just normal, this is who we are.

Through learning, boundary-setting, and community, participants began to embrace their autistic identity, accepting their autism as a valid and often, central, part of their identity. This shift allowed them to integrate their diagnosis into their identity positively as a framework for self-expression and authenticity, allowing identity coherence, emotional strength, and self-respect. The journey toward empowerment was not immediate but was reached by reclaiming their agency, internal narratives and adapting their lives to align with their neurodivergent needs.

4.6 Intersections of Emotion, Gender Identity and Nationality

The experiences described across the findings do not occur in a vacuum. In terms of sex assigned at birth, the majority of participants (89 out of 99) were assigned female at birth (AFAB), with only 10 participants assigned male at birth (AMAB). Among AFAB participants, there was significant gender diversity. While 66 individuals identified as female, the remaining 23 identified with a range of non-cisgender identities, including non-binary, agender, transmasculine, and genderqueer. In contrast, all AMAB participants either identified as male (n=9) or preferred not to disclose their gender identity (n=1), with no representation of gender diversity within this group. The higher prevalence of AFAB and gender varied individuals in the population can be attributed to their increased likelihood of going undiagnosed until adulthood, often due to misdiagnosis or lack of awareness of their autistic traits (Bargiela et al., 2016: 3281; Tien et al., 2025: 3). Instead, the AFAB specific manifestation of autistic characteristics do not align with the male-based conceptualisation that autism is founded on (Bargiela, 2016: 3282).

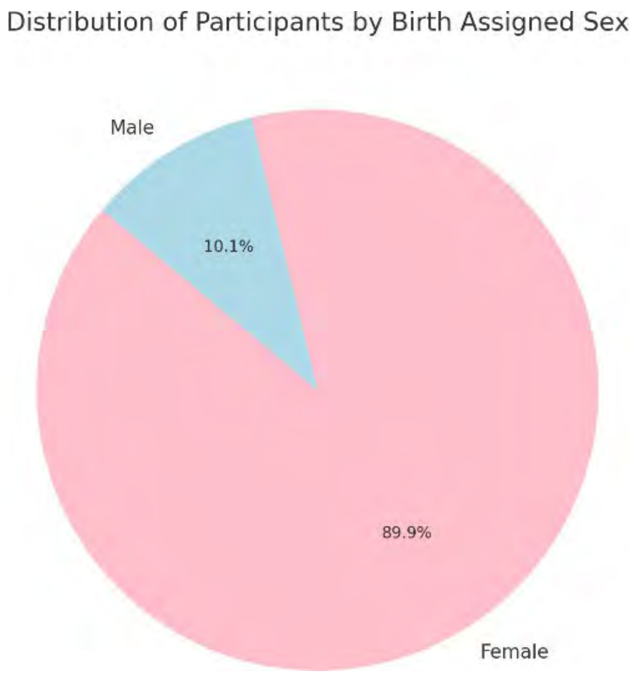

Figure 2: Distribution of participants by birth assigned sex

Participants in this study represented a diverse range of nationalities, however, certain regions were more prominently represented. The largest group identified is South

African (n=23), second largest is British (n=16), followed by American (n=21) and Australian (n=10). Other nationalities included Dutch (n=5), Canadian (n=5). Smaller numbers were recorded from Belgium (n=2). Germany (n=1), France (n=1), Sweden (n=1), Scotland (n=1), India (n=1), New Zealand (n=1), Austria (n=1) and Malta (n=1).

A small subset of participants held dual citizenships, such as British-Australian and German-UK (n=3), while five participants did not disclose. Nationality plays a significant role in shaping the pathways to diagnosis. This is due to differences in healthcare systems, cultural understandings of mental health and neurodiversity, and diagnostic availability.

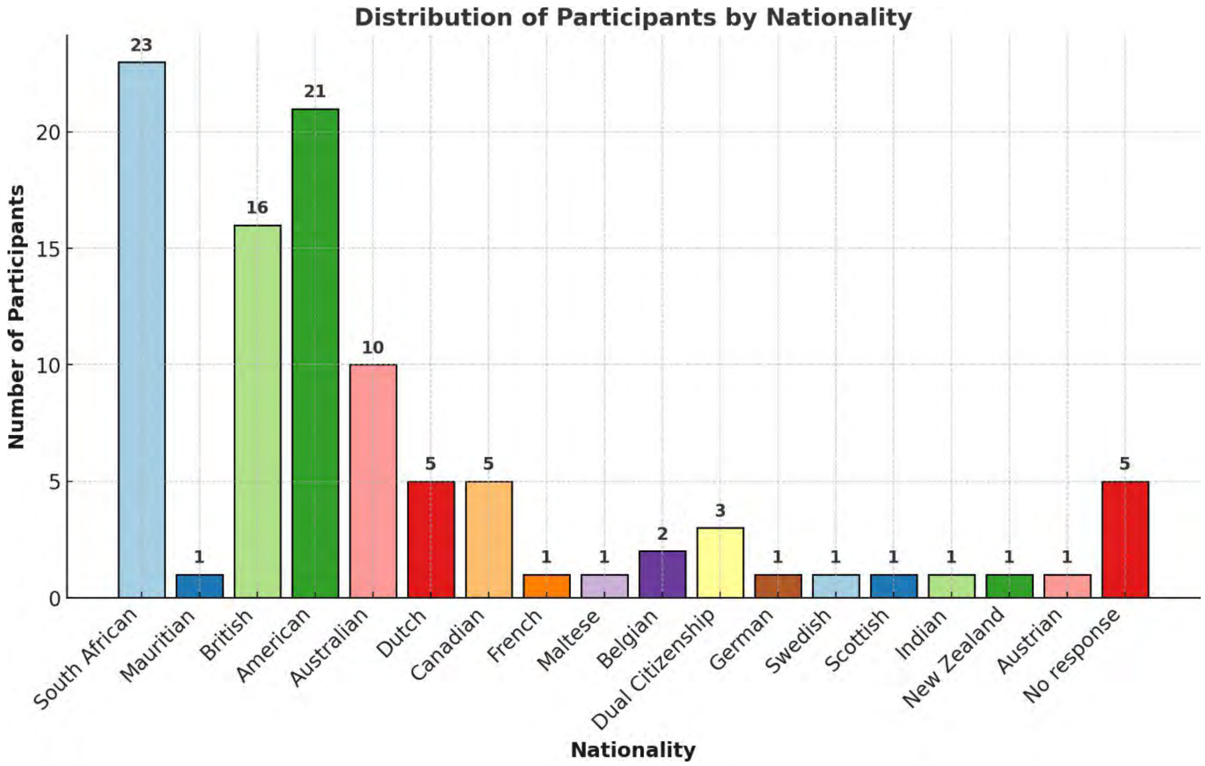

Figure 3: Distribution of Participants by Nationality

The age at which participants received their diagnosis ranged from 19 to 67 years old. There is a clear clustering around the 30s and 40s, with 39 years old having the highest number of diagnoses (n=7). This aligns with Huang et al.'s concept of a "lost generation" of autistic adults, a group of individuals who may have been overlooked due to subtle presentations of autistic traits, diagnostic overshadowing, or systemic healthcare inequalities (2021:5).

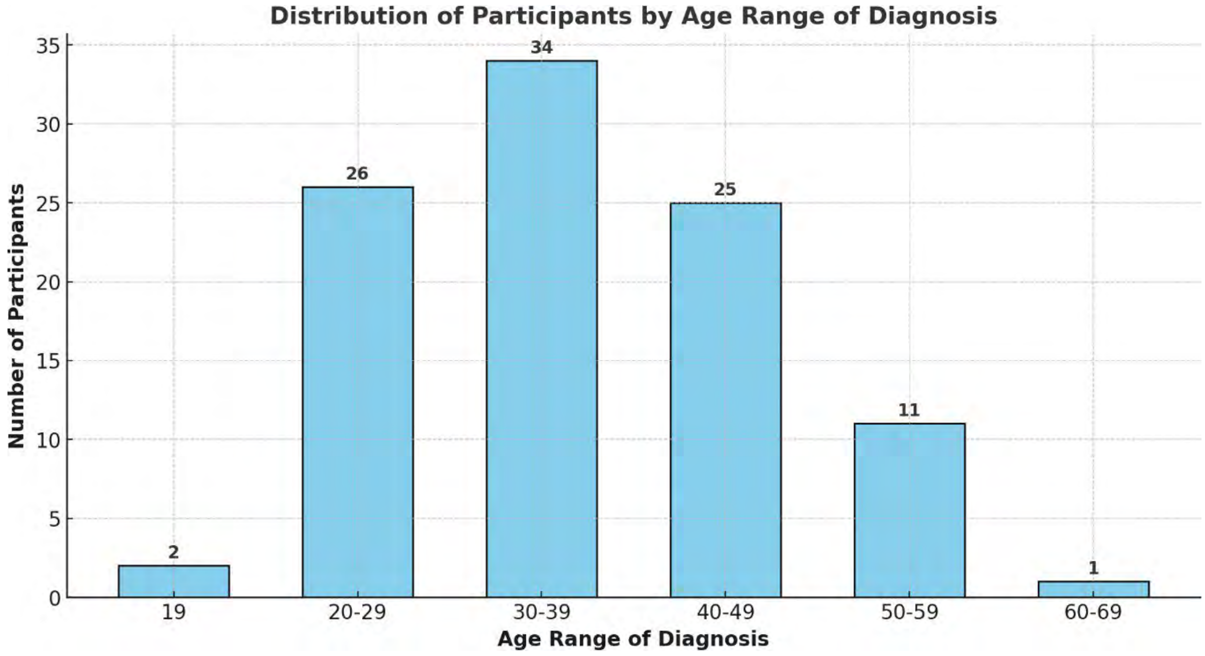

Figure 4: Distribution of Participants by Age Range of Diagnosis

This chapter has explored the diagnostic journey of the 20 interview participants, who have shown remarkable consistency, but also some variations in their experiences and feelings as they have negotiated the road to and from an autism diagnosis received during adulthood. The distinct phases that mark the emotional journey experienced by participants in this study resonate with the symbolic anthropologist Victor Turner's concepts of separation, transition, and incorporation, as will be explored in the next chapter.

5 Discussion

This chapter explores the journey of late autism diagnosis in adults through the lens of Victor Turner's concepts of liminality and communitas. Turner's work offers a powerful framework for understanding the emotional, psychological, and social transformations experienced by participants. Drawing on the tripartite structure of rites of passage originally developed by Arnold van Gennep—separation, liminality, and reintegration—the chapter follows the arc of participants' diagnostic journeys as a process of identity rupture and reconstruction.

Turner's concept of communitas is used to emphasise the significance of shared experience in navigating this transitional process. For many participants, connection with others undergoing similar transformations became vital for meaning-making, affirmation, and emotional support.

By examining these personal transformations within broader sociocultural and structural contexts, the chapter underscores that identity reconstruction is not merely an individual or cognitive shift, but a deeply relational and socially mediated process. The diagnosis of autism is understood not solely as a clinical classification but as a contemporary rite of passage—one that disrupts and ultimately reconfigures how individuals understand themselves and relate to the world around them.

The chapter begins by outlining the concepts of liminality and communitas, before applying them to the study's findings on late autism diagnosis.

5.1 Liminality and Communitas

The concept of liminality was introduced in 1909 by French anthropologist Arnold Van Gennep in his work *The Rites of Passage*. His theory proposed that individuals transition from one identity or social status to another by moving through three successive ritual phases: separation, liminality, and reincorporation (Beech, 2011: 287). Van Gennep initially applied this tripartite structure to ethnographic case studies, identifying patterns in rites such as initiations, marriages, and funerals (Maierhofer, 2023: 12). However, he also acknowledged the concept's broader implications, suggesting that liminality could be interpreted as a framework for understanding the nature and meaningfulness of life itself (Thomassen, 2016: 3). These rites which symbolically portray death and rebirth, highlight the ability of society and individuals to regenerate and renew themselves (Thomassen, 2016: 1).

In the mid-20th century, British anthropologist Victor Turner expanded van Gennep's work by focusing specifically on the liminal or transitional phase (Hockey, 2002: 215). Turner described liminality as a transitional space characterised by ambiguity, equality, and transformation, where an individual is in-between social states (Ross in Turner & Turner, 1978: xxx). Turner famously described liminal individuals as being "betwixt and between," emphasising that liminality is not merely a passage but a powerful state of suspension and receptiveness (Long, 2021: 590). For Turner, this threshold experience was not only disorienting but also generative, allowing for new social arrangements and personal transformations to emerge (Ibarra & Obodaru, 2016: 4).

It is important to understand that liminality is not limited to ritual contexts. It is fundamentally concerned with how humans experience and navigate change

(Thomassen, 2016: 1). The liminal phase often upends social norms and hierarchies through ritual activity, creating spaces where individuals are compelled to question and challenge their assumptions and beliefs (Foster & McCabe, 2015: 48). It is in these suspended moments that the usual rules of behaviour may be loosened, enabling experimentation, imagination, and the potential for radical change.

Contemporary scholars have extended the concept of liminality far beyond its anthropological origins, applying it to contexts such as psychology, politics, art, and digital culture. In psychological terms, life transitions such as adolescence, career change, grief, or motherhood can represent liminal phases, where one's sense of self is destabilised but open to growth (Beech, 2011: 287; Ibarra & Obodaru, 2016: 48). In political discussion, revolutions, transitional justice processes, or post-colonial restructurings are liminal moments where existing structures are suspended and new forms of governance and identity are negotiated (Thomassen, 2014: 17; Turner, Abrahams & Harris, 2017: 155).

Similarly, literature, performance, and film often depict liminal themes to challenge the boundaries of reality and fiction (Fischer-Lichte, 2008 :95). Even digital spaces, such as social media and virtual environments, create liminal zones in which conventional categories of identity, presence, and communication are blurred (Takhar, Bebek & Jamal, 2023: 5)

Turner continued to build on the notion of liminality as a transformative and destabilising phase by introducing the concept of communitas to describe the intense emotional experiences of equality and connection that emerge among individuals experiencing liminality together (Haggar, 2024: 2). While liminality disrupts social hierarchies and norms, communitas represents a form of anti-structure. However, it is important to note that anti-structure is not the opposite of structure. In this context, it refers to the absence of structure, or the space outside of it (Haggar, 2024: 10). This creates a moment where social divisions dissolve and individuals are able to connect on a deeper level without status or authority (Haggar, 2024: 3).

5.2 Diagnosis as a Liminal Disruption

Participants in this study consistently described a deep-rooted sense of difference throughout their lives, often perceiving themselves as fundamentally flawed (see Extracts 1, 3 – 6). These results are in line with Kiehl et al. study who found that the feeling of being different and desire to fit in intensified when their difference was noticed by others and resulted in exclusion or bullying (2024: 1069). To manage this, many engaged in extensive masking behaviours, attempting to suppress or conceal traits they perceived as socially unacceptable. However, over time this masking had a detrimental effect on their mental health (see Extract 8). Similar trends have been reported by Evans et al. who found that masking created cognitive dissonance as they were compelled to mask but felt inauthentic and exhausted by the practice (2024: 230 – 231).

Alongside the mental health struggles individuals experience an identity rupture, where their self-concepts became unmanageable. They no longer understood themselves through the narratives that had previously framed their lives; instead, they found those narratives collapsing under the weight of their experiences (see Extract 9). As participants faced emotional collapse, they also began to confront the possibility that their fundamental assumptions about who they were had been misaligned with their actual experiences. This simultaneous unravelling of psychological stability and self-understanding created a uniquely disorienting liminal moment.

This moment included reaching a crisis point in their mental health (see item 8), which functioned as a catalyst to seeking an autism diagnosis (Cage et al., 2024: 6). This phase is marked as a separation from their pre-diagnosis identity. As participants consider the possibility that they are autistic, they begin to question the past interpretations of their lives. What they had previously considered personal failures, such as social difficulties, meltdowns, and burnout, were now possibly expressions of undiagnosed autism. As participants begin to see similarities between themselves and autism, they begin the journey of identity deconstruction which sets the stage for liminality to unfold.

5.3 Living in-between: Identity Disorientation and Emotional Crisis

The moment of diagnosis marked a critical threshold for participants, where they crossed from a known identity into a new, uncertain one. This initiates a rupture in their self-concept which often coincides with a mental health crisis (see Extract 15). Individuals experienced a fracturing of their long-standing internal narratives and a destabilisation of their familiar social identity, thrusting them into a space of ambiguity. This is evident in Ruby's statement, "I'm not [expletive] up, bad, mad or sad", which powerfully illustrates how diagnosis disrupted her negative self-narratives she had internalised, ultimately opening an opportunity for transformation. Being cast out of their old identities without establishing a stable new one is a hallmark of the liminal phase.

While diagnosis brought a sense of relief (see Extracts 17 - 19) by providing long sought-after explanations for lifelong challenges (de Broize, 2022: 136), this clarity was accompanied by emotional dislocation. For many, the relief was not a resolution but a destabilising realisation that recontextualised their lived experiences. What had once been interpreted as personal failures, social awkwardness, or emotional instability were now recast as manifestations of undiagnosed autism (see Extract 19). This re-framing disrupted participants' long-held self-narratives, producing a sense of ambiguity about who they truly were.

Thus, individuals found themselves suspended ‘betwixt and between’ their former selves and their unfamiliar emerging identity. This psychological in-betweenness aligns with Thomassen's (2016: 1) description of liminality as a state in which the usual boundaries of self-understanding are loosened, creating both vulnerability and possibility. The moment of diagnosis acts as a rupture in the self-narrative of the individual that calls into question the continuity of self. In this space, they reinterpret the past and renegotiate their future. While ambiguity can be unsettling, it can also foster regeneration by opening a liminal space that makes transformation possible. Despite the regenerative potential of the ambiguous liminal space, there is still emotional turbulence. Individuals experienced anger, grief and imposter syndrome (see Extracts 20 - 24). However, according to Lertzman, these uncomfortable and at times painful emotions are necessary precursors to transformation (2002: 6)

Additionally, individuals' experiences with dismissal and discrimination (see Extracts 25 - 27) reveals how liminality is not only internal but socially mediated. When social contexts failed to validate participants' transitions, they intensified the disorientation. Conversely, when participants found affirming communities, these became critical sites of healing and identity reconstruction. These nascent relationships foreshadow the emergence of communitas.

5.4 Reclaiming Self through Integration and Transformation Beyond Liminality

For many, the liminal phase was not a permanent state but a threshold toward meaningful reintegration. The reintegration did not see individuals return to their pre-diagnostic identities but rather saw them come into a redefined and more coherent neurodiverse identity. It entailed both a self-reclamation and a reorientation of life based on freshly comprehended needs and values. By learning about autism, setting boundaries, restructuring their environments, and engaging with other autistic people, individuals were able to move forward from their emotional crisis and find clarity and empowerment (see Extracts 28 – 32).

The role of community remains significant in the post liminal phase. Connecting with other late-diagnosed autistic people provides validation and understanding that many participants had not experienced before. Sustained engagement with autistic peers, especially in online spaces (see Extract 32), helped participants maintain their sense of belonging. These communities validate the liminal experience and create a space where individuals can explore their emerging identities freely and without judgement. In this sense, elements of communitas persists beyond the liminal phase, offering ongoing emotional support and affirming the legitimacy of their redefined identities.

Arguably, embracing an autistic identity has more to do with recovering from being misunderstood and misunderstanding oneself than becoming someone entirely new. This process required individuals to unlearn internalised ableism[7], cultivate self-compassion and make space for vulnerability. However, it also demanded navigation of the external world through a transformed sense of agency and purpose. This is evident as individuals became more selective about their relationships, advocating in the workplace and redefining success on their own terms.

It is important to note that the challenges associated with being autistic in a predominantly neurotypical world, do not simply cease to exist once individuals had reintegrated. Many continue to encounter misunderstanding, ableism, stigma, and systemic barriers. However, their relationship to these challenges has shifted. Instead of masking or assimilating, they now reshape their environments and expectations to align with their neurodivergence.

This chapter has explored the post-diagnostic journeys of late-identified autistic individuals through the lens of liminality and communitas, illustrating how diagnosis initiates a profound and multifaceted transition.

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[7] Refer to Glossary of terms, p 41.

6 Conclusion

This study set out to explore how receiving a late diagnosis of autism impacts an individual's sense of identity and belonging. Drawing on the narratives of autistic adults, the research examined how diagnosis served as a significant turning point in their lives. A thematic analysis revealed that diagnosis often triggers a period of profound emotional adjustment, ultimately leading to greater self-awareness, the setting of personal boundaries, and the discovery of autistic community. Victor Turner's concepts of *liminality* and *communitas* were employed as a theoretical framework to interpret participants' experiences of identity rupture, reflection, and reformation.

The findings show that receiving an autism diagnosis in adulthood often marks the beginning of an ongoing journey toward finding a more authentic self. Prior to diagnosis, participants commonly described longstanding feelings of difference and disconnection, which often culminated in personal crises that led them to seek answers. The formal diagnosis allowed them to reframe their pasts through a more compassionate lens, replacing internalised blame with understanding. For many, connecting with affirming neurodivergent spaces and other autistic adults was crucial in building a positive sense of identity and belonging. This research contributes to a growing body of literature that centres autistic voices and underscores the need for more inclusive, accessible, and supportive diagnostic pathways for adults.

Diagnosis is not a singular event; rather, it functions as an essential turning point that disrupts negative self-narratives and compels individuals to reconsider their personal and social identities. Drawing on Turner's liminal framework, this transformation unfolded in overlapping phases: separation from a former identity, entry into a liminal state marked by ambiguity and destabilisation, and eventual reintegration marked by agency, coherence, and authenticity.

While diagnosis initially generated emotional turbulence, it also enabled participants to reinterpret past experiences with greater compassion. This reframing did not provide closure in the traditional sense but instead opened space for personal growth, self-understanding, and connection. Community was particularly transformative engagement with other autistic people offered validation and a sense of *communitas* that contrasted sharply with the broader social world, which often remained unaccommodating and alienating.

Reintegration was not presented as linear or complete. Rather, it was described as an ongoing negotiation between internal transformation and external realities. Participants did not return to their pre-diagnostic identities; instead, they moved forward with a reconstructed neurodivergent identity more closely aligned with their lived experience.

Thus, the diagnostic journey of late-identified autistic adults can be understood as a profoundly social and existential transition. It moves beyond simply naming a difference, toward deliberately and authentically living it - often in resistance to normative expectations. What initially appears as a crisis can, through the lens of liminality, be reinterpreted as a space for emergence and growth. In this way, diagnosis becomes not an endpoint, but the beginning of a generative and transformative process.

Glossary of terms

Ableism – refers to practices, biases, and prejudices that discriminate against individuals with disabilities, both visible and invisible. It encompasses a range of attitudes, actions, and institutional policies that devalue or limit the potential of people based on their perceived physical, intellectual, or psychological disabilities. Ableism often manifests in societal norms and structures that prioritise “typical” abilities and marginalise or exclude those who do not conform to these standards. This can lead to reduced accessibility, lack of accommodation, and social stigma, affecting various aspects of life including employment, education, and access to services. Challenging ableism involves recognising these biases and working towards a society that is more inclusive and values diversity in abilities and experiences (Neff, n.d.).

Asperger’s Syndrome (AS) – “one of five pervasive developmental disorders (PDDs) known as Autism Spectrum Disorders”. AS was originally regarded as 'high functioning autism’ as people diagnosed with this neurobiological disorder typically have average to high intellectual functioning. However, they also experience some “extreme interpersonal deficits resulting from underdeveloped adaptive behaviours, social competencies, and communication skills” (Higgins et al., 2008: 291 – 292).

Autism Spectrum Disorder - "Persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, non-verbal communicative behaviours used for social interaction, and skills in developing, maintaining, and understanding relationships" (APA, 2013: 31).

Autistic burnout – “Autistic burnout is characterised by debilitating mental, physical, and emotional exhaustion, which occurs because autistic people experience more difficulties in everyday life than non-autistic people.” (Mantzalas et al., 2022: 1418).

Autistic community – “The term ‘autistic communities’ designates communities formed by autistic people themselves, usually made for them and by them.” (Antunes & Dhoest, 2019: 2).

Birth-Assigned Sex – the designation that refers to a person’s biological, morphological, hormonal, and genetic composition. One’s sex is typically assigned at birth and classified as either male or female. “Assigned-at-birth” serves to imply that sex assignment is without the agency of the individual. Birth-assigned sex is often mistakenly confused with gender (Michigan State University, n.d.).

Deficits-based approach – Focuses on the perceived weaknesses or deficits of an individual; assigns the responsibility for perceived deficits to the individual; used in the “medical model” of disability and Autism.

Disability – “Disability is a form of difference that is created when the social participation of someone with an impairment is ‘disabled’ by normative expectations and material conditions.” (Devlieger, 2018: 1)

Executive function – The ability to plan, organise and follow through, as well as the ability to inhibit actions, delay responses, regulate emotions and reactions, make appropriate choices and shift attention. Autistic individuals, as well as those with learning disabilities and other neurological and neurodevelopmental conditions, often have significant differences in executive functioning, e.g., in the ability to transition between tasks and states (Reframing Autism, 2025).

Functioning labels – Use of the terms such as “high functioning” or “low functioning” to describe the levels of severity of challenge/difficulty that an individual faces.

Gender – A social construct used to classify a person as a man, woman, or some other identity. Fundamentally different from sex assigned at birth, gender is often closely related to the role that a person plays or is expected to play in society (The Annie E. Casey Foundation, 2023).

Gender diverse – A person who does not conform totally to society’s norms for their assigned gender at birth (Hines & Taylor, 2018).

Gender Identity – A person’s internal identification as male, female, something in between or something other than the two conventional gender options. A person’s gender identity is not visible to others and can match or differ from their assigned sex at birth (The Annie E. Casey Foundation, 2023).

Genderqueer – A gender identity term for people who conceptualise their gender as beyond, existing outside of, or not included within the gender binary. This term is linked to the academic discipline of Queer Theory and carries a political and/or disruptive connotation. As an identity term, genderqueer is sometimes conceptualised as a type of nonbinary identity. Genderqueer is sometimes written as GenderQueer (Michigan State University, n.d.).

Hypersensitivity – Unusually sensitive, often painful reaction to everyday auditory, visual, or tactile stimuli such as bright lights or loud noises (Reframing Autism, 2025).

Hyposensitivity – An unusual insensitivity to recognising to everyday stimuli (Reframing Autism, 2025).

Identity-first language vs person first language – Naming someone by their neurotype or condition first vs naming someone as having that neurotype or condition, e.g. Saying someone is autistic vs someone has autism. Many people use identity first language to describe themselves. It is a personal choice (Inclusive Employers, 2025).

Imposter syndrome – A psychological experience, often felt very deeply, that you are undeserving of an identity or achievement, and that you are fraudulent or a ‘fake’ despite evidence to the contrary (Reframing Autism, 2025).

Internalised ableism – when people with disabilities absorb and accept negative beliefs and attitudes from society about disability. This can lead to self-doubt, low self-esteem, and feeling less worthy or capable because of their disability. It's essentially adopting society's often limiting and negative views about disabilities as one's own (Neff, n.d.).

Lost generation - “The rise in autism prevalence, in part prompted by an expansion of the diagnostic criteria to include those without a clinically significant delay in language, cognitive development or adaptive behaviour, has led to an identification of previously undiagnosed adults as autistic, who were either misdiagnosed in childhood or not diagnosed at all.” (Lilley et al., 2022: 1).

Masking – “Masking refers to the conscious or unconscious suppression of autistic traits and the adoption of socially acceptable behaviours across interaction, sensory, cognitive, movement, and behavioural domains. Masking is linked to negative outcomes like late diagnosis, mental health issues, burnout, and suicidality, necessitating deeper exploration of its roots in stigma rather than framing it as a voluntary social strategy." (Pearson & Rose, 2021: 52 - 53).

Medical model of disability – a perspective that views disability primarily as a health issue, focusing on individual impairments and advocating for medical intervention to address these deficits (Mitra, 2006: 236).

Neurodevelopmental Condition – This is a condition, usually referred to as a disorder, that develops before birth, in infancy or early childhood. It references differences in cognition that develop differently from 'the norm.' Examples are Attention Deficit Hyperactivity Disorder (ADHD), Autism, Speech and Language disorders, and Tourettes Syndrome. This differs from mental illness. Note that these conditions are classified differently in various countries (Fitzell, 2022).

Neurodivergence – This is a general term that describes the different manifestations of neurodivergent thinking in a neurodiverse world. It is literally the "state of being neurodivergent." You could say, for example, that dyslexia and dyspraxia are specific types of neurodivergence (Fitzell, 2022).

Neurodivergent – This word describes an individual whose way of thinking falls outside of society's defined version of normal. Oftentimes you will see it abbreviated as ND (Fitzell, 2022). Other examples of neurodiversities include the neurodevelopmental conditions above.

Neurodiversity - "Presents a different perspective on autism, not focusing on diagnostic criteria but on differences in the autistic brain, which has particular challenges and strengths" (Antunes & Dhoest, 2019: 4).

Neurodiversity movement – A self-advocacy movement that developed out of the recognition that "autistic people are mostly limited by the fact that society is tailored by and for the neurotypical, is not inclusive of diversity and creates barriers for people who process the world in different ways." (Antunes & Dhoest 2019: 4). The term was coined by Judy Singer in the late 1990s (Kapp, 2020: 46).

Neurotype – The type of brain a person has in terms of whether it is 'neurotypical' or 'neurodiverse'. (Michigan State University, n.d.).

Neurotypical – "People with a mainstream brain." (Antunes & Dhoest, 2019: 2).

Nonbinary – A gender identity term for a person who identifies outside of the gender binary. Nonbinary is also conceptualised as an array of genders at some distance form the gender binary. Nonbinary is sometimes written as “non-binary.” A common abbreviation for nonbinary is enby (Michigan State University, n.d.).

Predicament model of autism – moves away from framing autism as purely a deficit or social construct and recognises the complex and individualised reality of being autistic. It suggests that autistic identity is shaped by both internal and external factors (Anderson-Chavarria, 2021: 6).

Social model of disability – sees disability as a social construct. Disability is not the attribute of the individual; instead, it is created by the social environment and requires social change (Mitra, 2006: 237).

Stimming – is short for ‘self-stimulatory’ behaviour. Stimming can be a repetitive movement, repeating words, hand movements and making noises. Some stims are barely noticeable and some are very visible. Stimming behaviours are a way of self-regulating and shouldn’t be stopped or reduced as they are an autistic person’s way of managing a situation (NHS Kent community Health, 2019).

Transmasculine – Abbreviated as Transmasc. An adjective describing a transgender person assigned female at birth with a primarily masculine-spectrum gender identity. This term is inclusive of both binary and nonbinary transgender people (Michigan State University, n.d.).

Triad of impairments - “individuals have impaired social interaction and verbal and non-verbal communication, and repetitive and stereotyped behaviour.” (Botha et al., 2022: 428).

Unmasking – The process of an Autistic person “unlearning” the ways in which they have altered, hidden or “masked” their true Autistic identity to fit into the world; allowing themselves to be their full selves (Reframing Autism, 2025).

Value-neutral model of disability – views disability as neither distinctively good nor bad. Instead, it considers that characteristics are dependent on both environmental and social contexts (Chapman, 2020: 64).

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Appendix A: Participant Informed Consent Declaration

PARTICIPANT INFORMED CONSENT DECLARATION

(To be signed by research participant/s)

Project title: The good, the bad, and the ugly: Finding self and belonging after a late diagnosis of Autism Spectrum Disorder.

Eloise Rennie from the Department of Anthropology, Rhodes University has requested my permission to participate in the above-mentioned research project

The nature and the purpose of the research project and of this informed consent declaration have been explained to me in a language that I understand.

I am aware that:

1. The purpose of the research is to explore the realities of autistic adults who received a late diagnosis and to understand how individuals incorporate their diagnosis into their identity and personal and professional lives.
2. Rhodes University has given ethical clearance to this research project (2023-7267-8060) and I have seen/may request to see the clearance certificate by contacting the Ethics Coordinator (ethics-committee@ru.ac.za)
3. By participating in this research project, I will be contributing towards knowledge creation about late diagnosis for autism spectrum disorder.
4. I will participate in the project by completing the questionnaire/interview.
5. My participation is entirely voluntary and should I at any stage wish to withdraw from participating further, I may do so without any negative consequences.
6. I will not be compensated for participating in the research, but my out-of-pocket expenses will be reimbursed.
7. The following risks are associated with my participation: I may feel emotionally triggered or embarrassed by some of my reflections and experiences during the interviews.
8. The Researcher intends to publish the research results in the form of an honours thesis. However, confidentiality and anonymity of records will be maintained and my name and identity will not be revealed to anyone who has not been involved in the conducting of the research.

9. In terms of the Protection of Personal Information Act (No. 4 of 2013) it remains my right to request the Researcher to provide me with a detailed explanation of exactly how confidentiality and anonymity of the data I provide will be achieved.
10. Data collected from me during the interviews will be stored in a secure password protected location in the cloud for 5 years, accessible only to the researcher and research supervisor in case this data is requested by the Rhodes University Research Ethics Committee during this period.
11. Data collected from me during the interviews might be used by the researcher in the future for a longitudinal or follow up study.
12. In terms of the POPI Act, I possess the right to receive feedback about this research. This will take the form of key research findings being emailed to me.
13. Any further questions that I might have regarding the nature of the research and/or my participation in it will be answered by Eloise Rennie g19d5713@campus.ru.ac.za. Additional queries can be addressed to the Rhodes University Human Ethics Committee ethics-committee@ru.ac.za
14. By signing this informed consent declaration, I am not waiving any legal claims, rights, or remedies. A copy of this informed consent declaration will be given to me, and the original will be kept on record by the Researcher.
15. I understand that if I am interviewed via an online video platform (e.g. zoom), the meeting will be recorded to ensure an accurate record of the interview and that recordings will be used for purposes of data analysis only and will not compromise my anonymity.
16. I agree to the Researcher recording my interviews, to ensure an accurate record of my views/responses. Furthermore, I have the right to request a copy of the interview transcriptions to confirm that my opinions are accurately recorded

I understand that by clicking on the ‘Accept’ button below I will be confirming the following:

I have read the above information/the above information has been explained to me in a language that I understand, and I am aware of this document’s contents.

I have asked all questions that I wished to ask, and these have been answered to my satisfaction.

I fully understand what is expected of me during the research.

I have not been pressurised in any way and I voluntarily agree to participate in the above-mentioned project.

Appendix B: Survey

1. Name.
2. Age.
3. Birth assigned sex (Male/Female/prefer not to say).
4. Gender identity (Male/Female/Non-binary/prefer not to say).
5. Nationality.
6. Age when Autism Spectrum Disorder (ASD) diagnosis was received.
7. Preferred language
    a. Identity-first language
    b. Person-first language
8. Please describe why you prefer Identity-first language or person-first language.
9. Did your diagnosis positively or negatively affect how you saw yourself?
10. Please describe how it positively or negatively affected how you saw yourself?
11. After your diagnosis, were you able to develop coping strategies for day-to-day life?
12. What areas in life did you feel the need to develop coping strategies for? (e.g. time management, organisation, executive function
13. Did you find it was easier to develop these strategies with the knowledge you gained through diagnosis?
14. Do you feel that your diagnosis affected how you interacted within your personal life?
15. If so, please describe how.
16. Do you feel that your diagnosis has affected your professional life?
17. If so, please describe how.
18. How do you believe wider society views autism?

19. How does this impact you’re your ability to incorporate your diagnosis into your identity?
20. What are your thoughts on late autism diagnosis?

Appendix C: Interview

1. What prompted you to seek formal autism diagnosis?
2. How did you find a professional who was able to carry out the formal diagnostic assessment?
    a. What type of professional were they? (psychologist, psychiatrist, other specialist etc).
3. How long did you wait for your diagnosis appointment after joining the waiting list?
4. What was your experience of the diagnostic process in terms of cost, availability etc?
5. What was your response when you first received the diagnosis?
6. How do you feel about the diagnosis now?
7. Did you ever feel ashamed of your ASD characteristics before diagnosis?
8. Have you felt ashamed of your ASD characteristics since being diagnosed?
9. Has anyone you have disclosed your diagnosis too ever dismissed your diagnosis?
    a. If so, how did that impact you?
10. Has your diagnosis had any impact on your relationships?
    a. If so, which relationships and how?
11. Do you fear that having an autism diagnosis will negatively affect job opportunities, getting health care or any other insurance etc?
12. Have you ever experienced discrimination due to your diagnosis? Can you tell me about that incident?
13. What therapy or additional support have you been able to access? How has it impacted you?
    a. If none: do you feel that you have coped alright without support or do you feel that support would have made things easier?
14. Has your diagnosis impacted how you view yourself and your life?
    a. If so, how?
15. What do you wish people understood about being autistic?

Appendix D: Research Recruitment Poster

CALL FOR PARTICIPANTS

For a study investigating life after the late diagnosis of Austism Spectrum Disorder (ASD)

To participate you need to be

- **Be over the age of 18.**
- **Formally diagnosed with ASD**
- **Diagnosed as an adult (18+)**
- **Confident in discussing potentially triggering aspects of diagnosis and life after diagnosis**

For more information

Contact: Eloise ellanrennie1@gmail.com