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Autism Paradigms and Mental Well-Being Among Autistic Adults: A Quantitative Exploration

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AUTISM PARADIGMS AND MENTAL WELL-BEING AMONG AUTISTIC ADULTS: A QUANTITATIVE EXPLORATION

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by

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AUTISM PARADIGMS AND MENTAL WELL-BEING AMONG AUTISTIC ADULTS: A QUANTITATIVE EXPLORATION

This dissertation, by Libbey Walker, has
been approved by the committee members signed below
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Antioch University New England in partial fulfillment of
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DOCTOR OF PSYCHOLOGY

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ABSTRACT

AUTISM PARADIGMS AND MENTAL WELL-BEING AMONG AUTISTIC ADULTS: A QUANTITATIVE EXPLORATION

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Autistic populations experience significant mental health challenges. A growing body of research supports addressing autistic mental health problems using the framework of minority stress theory, the social model of disability, and the neurodiversity paradigm (e.g., Botha & Frost, 2018; Cage et al., 2018). This quantitative study explored how identification with the neurodiversity paradigm versus the pathology paradigm related to mental well-being in autistic adults. Participants (N = 135) completed an online survey in which they rated their identification with autism descriptions representing both paradigms. Participants also completed measures of psychological distress, self-esteem, personal autism acceptance, and internalized autism stigma. Most participants (81%) preferred the neurodiversity paradigm, while 6% preferred the pathology paradigm. Identification with the neurodiversity paradigm was correlated with higher autism acceptance and lower internalized stigma. Stronger identification with the pathology paradigm was correlated with higher internalized stigma and lower self-esteem. The results of this study suggest that autistic adults' mental well-being might be improved by a multi-systemic shift to the neurodiversity paradigm. Clinical implications and future directions for research are discussed. This dissertation is available in open access at AURA (http://aura.antioch.edu/) and OhioLINK ETD Center (https://etd.ohiolink.edu/etd).

Keywords: Autism, mental well-being, neurodiversity, internalized stigma, critical autism studies

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CHAPTER I: INTRODUCTION

The Centers for Disease Control and Prevention report that 1 in 44 children in the United States is autistic (Maenner et al., 2021). In addition, it is suspected that many go undiagnosed or are diagnosed later in life (Gillespie-Lynch et al., 2017). As the number of identified and diagnosed autistic individuals increases, so does the importance of understanding and addressing the challenges and access needs of this population.

Mental health problems, particularly depression, are a significant and under-addressed challenge that negatively impact the quality of life of autistic individuals of all ages (Lever & Geurts, 2016; Robertson, 2009). Autistic advocates and disability scholars draw a connection between autistic mental health and the dominant autism narrative (the pathology paradigm), as the dominant narrative shapes professional and public perceptions and treatment of autistic people, perpetuating stigma and other facets of minority stress that are both experienced and internalized (Botha & Frost, 2018; Han et al., 2022; Huws & Jones, 2010; Walker, 2021).

Autistic advocates, activists and scholars assert that an adaptation of the social model of disability and adjacent neurodiversity paradigm could improve autistic mental health by addressing the harmful effects of experienced and internalized autism stigma, discrimination, and dehumanization (Bascom, 2012; Walker, 2021). A small body of research exploring the neurodiversity movement and autistic mental health supports the assertion that the social model and minority stress theory best explain the high rates of autistic mental health problems. This research also highlights the neurodiversity paradigm’s potential for improving autistic mental well-being (Botha & Frost, 2018; Cage et al., 2018; Kapp, 2018).

This study sought to integrate findings on autistic mental health, autism acceptance, and minority stress to examine how identification with autism paradigm (the neurodiversity paradigm or the pathology paradigm) relates to mental well-being among autistic adults. New understandings of the relationship between autistic mental well-being and identification with autism paradigm hold implications for treatment, research, and advocacy.

A Note on Language

It is important to clarify why this author uses identity-first language (e.g., “autistic person”) rather than person-first language (e.g., “person with autism”). While language preferences vary within and across disability communities, autistic individuals overwhelmingly prefer identity-first language, while allistic (non-autistic) individuals, especially those with no autistic relatives, tend to prefer person-first language (Bagatell, 2010; Bonnello, 2015; Kenny, 2016; Sinclair, 1999). The APA Style guidelines on language around disability permit both person-first and identity-first language, and use of a group’s preferred language approach when referring broadly to a group or community is encouraged (American Psychological Association, 2019). In their paper on avoiding ableist language, Bottema-Beutel et al. (2020) suggest that autism researchers use identify-first language as an alternative to person-first language. Autistic people who critique person-first language argue that it reinforces the deficit-based narrative that autism reduces a person’s value by suggesting that autism is a condition that can and should be separated from the individual (Walker, 2021). Some autistic adults use identity-first language as a tool for coping with stigma and dehumanization (Botha et al., 2022). Autistic disability rights activist Lydia X. Z. Brown (2011) writes, “it is impossible to affirm and value the worth of an Autistic person without recognizing [their] identity as an Autistic person” (para. 15). This study uses identity-first language for two reasons. First, this author seeks to “affirm and value the worth” of autistic people, which requires knowing and respecting their language preferences. Second, as an allistic researcher abiding by the principles of critical autism studies (see Method chapter), this author's use of identity-first language serves to inherently challenge the dominant autism narrative by rejecting dehumanizing rhetoric and deferring to the expertise of autistic people. In the same vein, the current study uses "non-autistic" and its synonym "allistic" interchangeably to reference non-autistic people.

Key Constructs Defined

Autism

The *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5; American Psychiatric Association, 2013), and many of the professionals who rely on it, describe developmental disabilities using the language of the medical model of mental illness and disability; the medical model operates within the pathology paradigm (Robertson, 2009; Walker, 2021). The DSM-5 defines autism as a neurodevelopmental disorder called autism spectrum disorder (ASD), characterized by deficits in social, verbal, and nonverbal communication and restricted, repetitive patterns of behavior such as "failure of normal back and forth conversation," and "abnormalities in eye contact," as well as repetitive or stereotyped movements and use of speech, "restricted fixated interests that are abnormal in intensity or focus," and hypo- or hyper-reactivity to sensory input (American Psychiatric Association, 2013, p. 50). According to the neurodiversity paradigm, autism is a genetically-based neurodevelopmental variant (Walker, 2021). Autistic people follow a different developmental trajectory than allistic people, have atypical sensory experiences and ways of processing information, different capacities for language, different ways of communicating and moving (many have dyspraxia and apraxia of speech), and most practice "stimming," which serves various functions including sensory and emotional self-regulation and expression (Schaber, 2015).

Dominant Narrative

Dominant narratives, or dominant cultural narratives, are stories communicated through large social institutions that shape cultural norms and social perceptions (Hasford, 2016; Rappaport, 2000). Dominant narratives contribute to the marginalization of minority groups by providing myths that justify unequal relationships between dominant and minority groups (Sidanius & Pratto, 2012).

Medical Model of Disability

The medical model views disability as a deficit existing within the individual; it advocates for symptom reduction and normalization of individuals so that they fit in with their environment (Kapp et al., 2013). The medical model is the basis for the pathology paradigm and is the lens through which most autism professionals and others view autism. In a study by Gillespie-Lynch et al. (2017), autistic individuals were more opposed to the medical model than were non-autistic individuals.

Pathology Paradigm

The dominant autism narrative is characterized by what autistic scholar Nick Walker has termed the pathology paradigm (Walker, 2021). The pathology paradigm is based on the medical model and assumes that there is a “normal” brain with one “right” or “healthy” type of neurocognitive functioning. From this assumption, autism and other variations of neurocognitive functioning are viewed as disorders that require intervention and eradication (Walker, 2021). Autistic advocates, scholars, and some allistic researchers state that most lay people, allistic people involved in autism advocacy, and autism professionals operate within the pathology paradigm (Bagatell, 2010; Robertson, 2009; Rosqvist et al., 2015). The American Psychiatric

Association presents autism through the lens of the pathology paradigm in the DSM-5 (American Psychiatric Association, 2013).

Social Model of Disability

Rooted in the Disability Rights Movement, the social model of disability defines disability as the limitation of opportunities to participate in the life of a community on a level equal with others (Burchardt, 2004, p. 736). Counter to the medical model, the social model focuses on how the environment can be changed to allow disabled people access to society along with nondisabled people, correcting the oppressive relationship between the individual and the unimpaired majority (Burchardt, 2004). The social model distinguishes between "impairment" and "disability." An individual has an impairment when they lack a specific capacity that the majority possesses, and they are disabled to the extent that those specific access needs are not accommodated within an environment (Walker, 2021, p. 62). For example, participants at the autistic-led Autism Network International "Autreat" annual conference and similar gatherings around the world commonly reported that they did not feel disabled while attending these accepting and autistic-accessible events (Silberman, 2015).

Neurodiversity Paradigm

The neurodiversity paradigm is an application of the biological phenomenon of neurodiversity, or the naturally occurring variations of human brains, coined by sociologist Judy Singer in the late 1990s (Silberman, 2015). In 2000, multiply neurodivergent activist Kassiane Asasumasu coined the term "neurodivergence" to encompass the myriad ways that brains/body-minds diverge from dominant societal standards, as well as its adjective "neurodivergent," which describes people whose brains diverge significantly from the dominant standard of "normal" (Walker, 2021).

The neurodiversity paradigm views neurodiversity as valuable and rejects the idea that there is a “normal” brain with one “right” or “healthy” type of neurocognitive functioning (Walker, 2021). Those who share this perspective also understand that neurodiversity is subject to the same social dynamics that manifest around other forms of human diversity (Walker, 2021). In this way, just as the pathology paradigm stems from the medical model of disability, the neurodiversity paradigm draws upon the social model of disability to see autism and other types of neurodivergence, such as attention-deficit/hyperactivity disorder (ADHD), dyslexia, giftedness, and Tourette syndrome, as body-mind variations that might come with impairments but which are challenging primarily because of disabling social structures. The neurodiversity paradigm pushes against the dominant autism narrative by recognizing the oppressive effects of the socially constructed “normal” and critically approaching beliefs and practices limited by a neuronormative worldview (Orsini & Smith, 2010; Walker, 2021). It is important to highlight that the neurodiversity paradigm is not anti-therapy, nor does it exclude individuals who have been labeled “low functioning” or as needing “very substantial support” (American Psychiatric Association, 2013, p. 52). Rather, the neurodiversity paradigm advocates for neurodivergent-informed services and supports that are guided by values of acceptance, accessibility and inclusion over tolerance and normalization.

Statement of Purpose

The current study aimed to explore how personal identification with the neurodiversity paradigm versus the pathology paradigm relates to mental well-being in autistic adults. Mental health problems, particularly depression, are a significant and under-addressed challenge for autistic adults that negatively impact the quality of life of this population (Lever & Geurts, 2016; Robertson, 2009). Autistic activists and disability scholars draw a connection between autistic mental health and the dominant autism narrative (the pathology paradigm), as the dominant narrative shapes professional and public perceptions and treatment of autistic individuals as well as their self-perceptions (Huws & Jones, 2010). An adaptation of the social model and adjacent neurodiversity paradigm could improve autistic mental health by addressing stigma and other facets of minority stress (Bascom, 2012; Walker, 2021).

A small but growing body of research exploring the neurodiversity movement and autistic mental health supports the assertion that autistic mental health problems are best approached using the social model and minority stress theory, and that the neurodiversity paradigm holds potential for protecting and improving autistic mental well-being (Botha & Frost, 2018; Cage et al., 2018; Kapp, 2018; Kapp et al., 2013). This literature has also improved researchers' understanding of the relationships between autism acceptance, autistic social identity, mental health, and minority stress processes.

There have been no studies to date that integrate findings on autistic mental health, autism acceptance, and minority stress to examine how identification with the neurodiversity and pathology paradigms relates to mental well-being among autistic adults. New understandings of the relationship between autistic mental well-being and identification with autism paradigm hold implications for treatment, research, and advocacy.

CHAPTER II: LITERATURE REVIEW

The State of Autistic Mental Health

The autistic population experiences high rates of mental health problems; 70%–79% of autistic children, adolescents, and adults experience problems such as mood and anxiety disorders (Lever & Geurts, 2016; Simonff et al., 2008). One of the most common mental health problems affecting autistic people is depression (Strang et al., 2012). Studies have found rates of depression as high as 30% among samples of autistic children and adolescents, and 57.2% among a sample of autistic adults (Lever & Geurts, 2016; Strang et al., 2012). A recent meta-analysis found that the lifetime prevalence rate of depression among autistic people is four times higher than the lifetime prevalence rate among allistic individuals (Hudson et al., 2018). These statistics are particularly concerning given the high rates of suicidal ideation and suicide attempts among autistic adults with depression; 35% of adults in the study group had made plans or attempted suicide (Cassidy et al., 2014). A study by Hirvikoski and colleagues (2016) found that autistic people are at higher risk for premature death compared to their non-autistic peers, and that suicide was one of the leading causes of early death among autistic individuals.

Autistic Mental Health Through the Lens of the Social Model

High rates of depression and other mental health problems in the autistic population can be viewed through the lens of the social model of disability. By this understanding, mental health problems stem primarily from the inaccessibility of autistic people's environments and their interactions with an oppressive society. The social model posits that autistic mental health problems are primarily a consequence of living as autistic individuals in a society built by and for people with a different type of neurocognitive functioning, a portion of whom are actively hostile towards autistic people (Gross, 2012; Kelter, 2016; Sequenzia, 2012). The social model is contrasted by the medical model, which understands autistic mental health problems as the result of individual deficits or as traits inherent to autism (American Psychiatric Association, 2013). A clinician who identifies with the medical model might be inclined to treat autistic mental health problems by improving perceived deficits or changing autistic traits in an effort to make the individual fit in better with allistic society. A social model identified clinician might consider this approach harmful; Cassidy et al. (2020) found that the association between autistic traits and lifetime suicidal thoughts and behaviors was significantly mediated by thwarted belonging as a result of "camouflaging" autistic traits.

The latter is the most common conceptualization and approach, because the current dominant autism narrative is based on the medical model and the pathology paradigm (Robertson, 2009; Walker, 2021). This dominant narrative is reflected in the behavior of the allistic neuromajority (Walker, 2021), who tend to make significantly less favorable first impressions based on thin slice judgements that lower their intentions to interact with autistic peers (Sasson et al., 2017). These perceptions contribute to experienced and internalized autism stigma, which play a role in autistic individuals' identity formation (Han et al., 2022; Huws & Jones, 2010).

Autism Acceptance and Minority Stress

Qualitative research on the emotional experiences of autistic adults has found common themes of depression, alienation, and acceptance, with depression identified as a central emotion (Jones et al., 2001). Autistic people have written about feeling hated by society, citing personal interactions and larger scale reflections of the dominant autism narrative such as negative media representation, the popularity of allistic-run autism charities that promote "combatting" and "curing" autism, researchers arguing for eugenics, the legal use of contingent electric shocks and other forms of torture, discrimination, and public sympathy for allistic parents who kill their autistic children (Barnbaum, 2008; Gross, 2012; Neumeier, 2012; Sequenzia, 2012). Research has found that allistic people dehumanize autistic people (Cage et al., 2019). Autistic people have indeed reported lifetimes of dehumanization; many recall being taught by educators, clinicians, peers, and society at large that they were inherently deficient, lacking bodily autonomy, and that their value depended on how successfully they complied with allistic people (Bascom, 2012; Milton & Moon, 2012; Winter, 2012). In a recent study on stigma, autistic adults described discrimination, infantilization, dehumanization, and stigma rooted in stereotypes of autistic people as white, male, violent, and incompetent (Botha et al., 2022). The participants shared that they had experienced the damaging effects of stigma since childhood, regardless of whether they had a diagnosis.

While negative, deficit-based messages might contribute to a number of mental health problems, internalized messages about value and worth might be especially relevant when considering depression in autistic people, as feelings of worthlessness are commonly associated with depression (American Psychiatric Association, 2013). Research on autistic experiences of autism acceptance seems to support a meaningful relationship between mental health problems, particularly depression, and autism acceptance. In one study, only 7% of participants said they felt accepted by society as an autistic person (Cage et al., 2018). In the same study, lower scores of personal and external autism acceptance were significant predictors of depression, but not of anxiety, and higher personal acceptance predicted lower depressive symptoms.

An application of Meyer’s (1995) minority stress theory to the autistic population sheds further light on the relationship between autistic mental health, stigma, and autism acceptance. Minority stress theory was originally developed by Meyer as a model for understanding mental and physical health disparities in sexual minority groups, and was later adapted for racial and ethnic minority groups as well as transgender populations. In brief, these groups experience higher stress burdens and higher rates of physical and mental health problems that stem from being stigmatized and devalued by society (Meyer, 2003; Meyer & Dean, 1998). Stigma, like that to which autistic people are subjected, has been shown to produce long-lasting effects, including a negative impact on self-worth (Wright et al., 2000). Botha and Frost (2018) tested the usefulness of minority stress theory as an explanation for autistic mental health problems, and found that minority stress (e.g., discrimination and internalized stigma) predicted diminished well-being and higher psychological distress in a sample of autistic adults.

The Potential of the Neurodiversity Paradigm

The relationship between autism acceptance, minority stress, and mental health leads to questions about the potential of the neurodiversity paradigm as a pathway to improving autistic mental health and quality of life. Walker (2021) sees the neurodiversity paradigm as one solution to the internalized oppression autistic people face after growing up steeped in pathologizing language (p. 235). Familiarity with the neurodiversity paradigm, as well as the resources and affirming community it brings, might help mitigate some of the internalized stigma and other painful emotional experiences tied to being autistic in an allistic society (Bascom, 2012; Jones et al., 2001). Kapp and colleagues (2013) found that awareness of the neurodiversity paradigm was associated with viewing autism as a positive identity rather than as a disorder, and participants who identified as autistic and knew about neurodiversity endorsed positive as well as negative emotions regarding autism, overall framing autism as value-neutral instead of negative. In Linton's (2014) phenomenological study of posts on an online autism forum, individuals diagnosed with autism and Asperger's discussing the removal of Asperger's from the DSM-5 noted the impact of the pathology paradigm’s language on autism-related stigma. Discussion participants suggested that the DSM-5’s description of autism shapes societal stigma towards autistic people as well as internalized stigma, and one wished for more carefully chosen diagnostic language, with the hope that improved perception of autistic people would “trickledown” from professionals to the general public (Linton, 2014). Among both autistic and non-autistic people, neurodiversity paradigm-aligned beliefs have been associated with lower autism stigma, while medical model or pathology paradigm-aligned beliefs were associated with higher stigma (Gillespie-Lynch et al., 2017).

There is evidentiary and applied support for the social model of disability and minority stress theory as a means of understanding and responding to the high rates of mental health problems in the autistic population. A review by Kapp (2018) supported the social model and the neurodiversity paradigm’s framing of autistic people’s challenges with social communication and subjective well-being, concluding that such challenges seemed to stem from cross-neurotype dynamics between autistic and allistic people, rather than from an autistic person’s perceived deficits. Findings from studies such as Botha and Frost’s (2018) analysis of autistic minority stress and Cage et al.’s (2018) examination of autism acceptance and depression support the extension of minority stress theory to autistic people. Finally, alignment with the neurodiversity paradigm might facilitate access to group-level resources like “minority coping” (Meyer, 2003). Phenomenological research on autistic well-being echoes the original minority stress literature about lesbian, gay, and bisexual mental health and coping with stigma; autistic adults communicated a sense of “otherness” and exhaustion from camouflaging their autistic traits, but found relief from these experiences by spending time in a community with other autistic people who accepted themselves (Bagatell, 2007; Jones et al., 2001; Milton & Sims, 2016).

Research Questions

1. Does mental well-being differ between autistic adults who identify with the neurodiversity paradigm and those who identify with the pathology paradigm?
2. What is the relationship between strength of identification with autism paradigm and mental well-being of autistic adults?
3. What are the relationships among the four domains of autistic mental well-being measured in this study?
4. Does internalized stigma influence the extent to which autistic mental well-being differs between paradigm identification groups?

Hypotheses

H1: The neurodiversity paradigm-identified group will show greater mental well-being (higher personal autism acceptance, higher self-esteem, lower psychological distress, and lower internalized stigma) compared to the pathology paradigm-identified group.

H2: Stronger identification with the neurodiversity paradigm will be associated with greater mental well-being, while stronger identification with the pathology paradigm will be associated with worse mental well-being.

H3: Reported autism acceptance and internalized autism stigma will be negatively correlated. Internalized autism stigma will be positively correlated with psychological distress and negatively correlated with self-esteem.

H4: Internalized stigma will moderate the relationships among psychological distress, self-esteem, autism acceptance and paradigm group.

CHAPTER III: METHOD

The current quantitative study operates within the critical autism studies framework because it addresses the power imbalance between the autistic population and researchers (most of whom represent the neurotypical and allistic majority), challenges the dominant narrative, and seeks to amplify the voices of autistic communities by pursuing their research interests and engaging with autistic individuals on and off-line throughout the research process. While the field of critical autism studies is a valuable tool for improving and expanding autism research, one could argue that psychologists, as members of a field that created and perpetuates the dominant narrative, have an ethical responsibility to approach and apply research to practice through a critical autism studies lens. Because the pathology paradigm-based dominant narrative characterizes mental health problems as products of an autistic person's individual deficits rather than as products of an unaccepting and inaccessible society, research shaped primarily by this narrative may carry that bias. For example, Mottron (2011) showed that when an autistic group outperforms an allistic group on a task, researchers are more likely to view strengths as compensatory for deficits, even when there is no evidence that the deficit is present. Conversely, critical autism studies research that is not limited by the biases of the dominant narrative makes way for new understandings that actually reflect the lived experiences of autistic people. For instance, findings from studies that examined social interactions between autistic and allistic individuals (Crompton et al., 2020; Heasman & Gillespie, 2018; Morrison et al., 2020; Sasson et al., 2017) challenged the assertion that autistic people have social cognition and communication deficits. Similarly, a critical review of theory of mind literature concluded that the empirical evidence did not support the claim that autistic people lack a theory of mind (Gernsbacher & Yergeau, 2019). This matters not only because the theory of mind deficit often goes unquestioned in autism research, but because this unsupported assumption contributes to societal stigma and shapes popular interventions like behavioral approaches and social skills training (Dinishak & Akhtar, 2013; Milton, 2012a, 2012b).

It is notable that only a relatively small portion of autism research explores the mental health and quality-of-life concerns of autistic adults; most scholarly articles found on major academic databases focus on genetic and environmental etiological factors (Robertson, 2009). However, the pool of research addressing real-life concerns of autistic people has grown since the emergence of the critical autism studies field in 2010 (Davidson & Orsini, 2013; O'Dell et al., 2016). Critical autism studies research aims to make a positive difference in the lives of autistic people through its neurodiversity paradigm-informed principles, which include attending to the influence of power relations, challenging dominant deficit-focused narratives, including the autistic community in projects, and maintaining a project ethos characterized by the social model of disability (Chown et al., 2017; O'Dell et al., 2016).

Participants

Recruitment

Participants for this study were recruited through online advertisements. The Internet is a popular communicative medium for autistic people (Benford & Standen, 2009), and using online platforms to recruit and conduct research with autistic individuals helps make participation accessible for autistic adults with a wide range of support needs, disabilities, and methods of communicating. A link to the Google Forms survey accompanied by a brief message inviting autistic adults to participate was posted on the websites of various autism organizations as well as groups on the social media platform Facebook. The rationale for and process of selecting these organizations is described below.

To mitigate sampling bias, the author selected four autism organizations with a focus on balancing neurodiversity paradigm-oriented and pathology paradigm-oriented groups. While some organizations explicitly promote one model over the other, others demonstrate the use of one model over the other through their mission statements, financial decisions, and the way they engage in conversations around topics like disability rights and research into genetic markers and “cures,” as these issues represent key differences between the models (Walker, 2021). Kapp et al. (2013) recruited a diverse sample for their study on the neurodiversity and medical models by advertising on websites that take stances on the importance of researching a cure for autism as well as self-advocacy groups that stood against such research.

Following a similar process, this study attempted to recruit through organizations with a widespread online presence: Thinking Person’s Guide to Autism (TPGA), Autistic Self Advocacy Network, Autism Science Foundation, and Autism Speaks. These groups were chosen from TPGA’s “Useful Autism Organizations” page. TPGA is “a one-stop source for carefully curated, evidence-based, neurodiversity-steeped information from autistic people, parents, and autism professionals” (Des Roches Rosa, 2019a). On the “Useful Autism Organizations” page (most recently updated in June 2019), the editors outline their guidelines for endorsement of organizations and list organizations they do and do not recommend. The guidelines reflect the values of the neurodiversity movement and are (a) Support, not cure; (b) Autism-community informed supports and therapies; (c) Inclusiveness; (d) Acceptance, not stigmatization; and (e) Advocacy for the human and civil rights of all autistic people (Des Roches Rosa, 2019b). The Autistic Self Advocacy Network is listed as one of the recommended organizations, while the Autism Science Foundation and Autism Speaks are listed as not recommended due to their messaging and cure-and-cause-oriented research (Des Roches Rosa, 2019b).

A letter of request (Figure 3.1) was emailed to representatives of the four selected autism organizations seeking permission to share the survey link on their websites, Twitter, and/or Facebook accounts. TPGA shared the link on their Facebook account. Autism Speaks only shares research they are funding on their social media accounts, but upon completion of an application they posted the link on the “Participate in Research” page of their website. Autistic Self Advocacy Network declined to share the link because this study does not meet their criteria of using Community Based Participatory Research methodology, which is unfortunately not feasible for this single-author dissertation. There was no response from Autism Science Foundation. Due to Autism Speaks’ website layout and the navigation needed to access their “Participate in Research” page, engagement and participant recruitment appeared to be higher on the TPGA Facebook page. In an effort to recruit a sample that represented a range of autism paradigm affiliations and autistic communities, the survey link along with a brief message (Figure 3.2) was posted in three additional Facebook groups: “NLVD/NLD and Neurodivergence – Discussion and Support,” “Autism and Asperger’s Awareness,” and “Autism Spectrum Disorder, Through My Eyes Discussion Group.” These groups were chosen based on their relative size and apparent range of neurodiversity and pathology paradigm-oriented statements in recent posts. The survey was open from late December 2021 to late March 2022.

Figure 3.1

Letter of Request for Recruitment

Dear ____________,

My name is Libbey Walker, and I am a doctoral candidate in clinical psychology at Antioch University New England in Keene, NH. I am working on my dissertation. My study looks at the well-being of autistic adults and how they relate to descriptions of autism. Participants will complete online surveys. Participants will not be asked for their names or any other information that could be used to identify them. This project has been approved by the Antioch University Institutional Review Board.

I am writing to ask your permission to recruit participants (autistic individuals age 18 and older) through your website and/or social media page. To do this, I would provide the link to my survey. Please let me know if you'd be willing to help and if you have any questions.

Sincerely,

Libbey Walker, M.S.
Clinical Psychology Doctoral Candidate
Antioch University New England

Figure 3.2

Facebook Discussion Groups Recruitment Message

Hello! My name is Libbey Walker, and I am a doctoral student at Antioch University New England. I am seeking participants to take part in a study that looks at autistic mental health and how autistic adults relate to descriptions of autism. To participate, you must be 18 years or older and identify as autistic or on the autism spectrum. Participants will be asked to complete an anonymous online survey. To access the survey, please go to [Survey URL]

Thank you for your interest in this research!

Inclusion Criteria

To be included in this study, participants had to be 18 years or older, have access to a computer with Internet, and identify as autistic. A formal diagnosis of autism was not required so that those without access to a diagnosis due to financial barriers or other circumstances would not be excluded. Related studies, such as Kapp et al. (2013) and Botha and Frost (2018), have included "self-diagnosed" participants for the same reason. In Kapp et al.'s study (2013), participants were administered the Autism Spectrum Quotient (AQ) and no significant difference in scores was found between formally diagnosed and self-diagnosed autistic participants. Participation was voluntary and no compensation was provided.

Sample Size

The ideal sample size was determined using Cohen's statistical power analysis for a bivariate correlation with a medium effect size and a power of .80, at a .05 level of significance (Cohen, 1992; Lani, 2021). Per Cohen, a sample size of 85 is required to detect a significant correlation. As will be explained in the following section, the proposed analysis included the calculation of correlation coefficients within both the pathology paradigm-identified group and the neurodiversity paradigm-identified group. Based on the author's prediction that the total sample would be near evenly distributed among the two paradigm groups with the possibility of a small neutral group, an ideal sample size of 200 was determined. However, after three months, data collection ended with a sample of 136, the majority of whom fell within the neurodiversity paradigm-identified group. One respondent was excluded because they did not rank both autism descriptions, thus could not be sorted into a paradigm identification group. Because the pathology paradigm group was too small for within and between-group analysis, rank-order correlations were conducted using the strength of identification ratings and personal well-being scores for all participants as a single group. This resulted in a sample size of 128–135 depending on the variables, which exceeded the minimum of 85 required for significant results in a bivariate correlation.

Quantitative Design

When individuals followed the link to the Google Forms survey, the first page was the informed consent form (Figure 3.3), which explained that participation was confidential and that participants must be at least 18 and identify as autistic/on the spectrum/having ASD. The informed consent letter also described the purpose of the study in language that was meant to minimize the possibility of experiment bias. At the end of the form, individuals who chose to participate were asked to confirm that they met the selection criteria of being 18 years or older and identifying as autistic/having ASD. Participants then moved on to the next page, where they were asked to complete the four mental well-being questionnaires described in the Measures section. Next, participants were presented with two descriptions of autism; one description represented the pathology paradigm, and the other represented the neurodiversity paradigm. After each description were two items that asked participants to rate how strongly they identified with the description on a scale of 0-5 and again on a scale of 0–100. Next, participants completed the demographic questionnaire described in the measures section. The survey ended with links to relevant mental health resources (Figure 3.4).

Figure 3.3

Informed Consent

Dear Participant,

This study looks at how autistic adults feel about different descriptions of autism. The study also looks at your mental health and how you feel about yourself. Your participation in this study helps non-autistic researchers better understand the mental health experiences of autistic people.

This study is part of my dissertation research at Antioch University New England’s Clinical Psychology program. The information may be used for future research without additional consent.

While no study is completely risk-free, there is very little risk to you from being part of this study. It is possible that you might experience some emotional discomfort related to questions about your mental health, your feelings about autism, and your feelings about yourself. There are links to mental health resources at the end of this survey.

You will not be asked for any personally identifiable information. There will be no way to know who you are from your responses.

This study contains six brief questionnaires and will take about 30 minutes to complete. You will not be paid or compensated for completing this survey.

Your participation is voluntary. You can leave the study or skip an item at any time for any reason. If you have any questions or concerns about the study, please feel free to email: [REDACTED].

This project has been approved by the Antioch University Institutional Review Board. For questions about your rights as a research participant, please contact Kevin Lyness, IRB Chair of Antioch University New England, at [REDACTED] or [REDACTED]. You may also contact Shawn Fitzgerald, Ph.D., Provost, at [REDACTED] or [REDACTED].

By clicking "Next,” you are confirming that you understand this consent form and that you are 18 years old or older. You are also confirming that you identify as autistic/on the spectrum/having autism spectrum disorder.

Please print a copy of this page for your records.

Thank you for your participation!

Figure 3.4

Mental Health Resources

Thank you for participating! Here are some optional mental health resources:

Mental Health Autism Safety Plan:
http://mhautism.coventry.ac.uk/wp-content/uploads/2017/02/MHAutism-Safety-Plan-.pdf

Autism and Safety Toolkit (includes information on abuse, neglect, and thoughts of suicide):
https://autisticadvocacy.org/wp-content/uploads/2017/11/Autism-and-Safety-Pt-2.pdf

Emotional Well-Being, Regulation, Communication and other Supports:
https://autismlevelup.com/category/supports-resources/

Autistic Burnout:
https://awnnetwork.org/wp-content/uploads/2020/08/autistic-burnout.pdf

Coping with Meltdowns and Self-Harm:
https://neuroclastic.com/what-is-self-harm-why-does-it-happen-and-what-to-do-about-it/

Crisis Text Line:
Text HOME to 741741
https://www.crisistextline.org/about-us/where-we-are/ (or message through Facebook if outside of the United States)

Suicide Prevention Lifeline (US only):
Call 1-800-273-8255
https://suicidepreventionlifeline.org/talk-to-someone-now/

Trans Lifeline (trans and nonbinary operated):
Call 877-565-8860 in the US
Call 877-330-6366 in Canada
https://translifeline.org/hotline/

Variables

Within this correlational design, identification with autism paradigm (the pathology paradigm, neurodiversity paradigm, or neutral) was meant to function as a categorical predictor variable, while strength of identification with paradigm was meant to function as a continuous predictor variable. The purpose of this was to allow for analysis of variance and correlational analysis based on both identification with a paradigm (categorical) and strength of identification with a paradigm (continuous). The pathology paradigm description consisted of the diagnostic criteria for ASD from the DSM-5 (American Psychiatric Association, 2013). The neurodiversity paradigm description consisted of an autism definition from autistic self-advocates in the neurodiversity movement (Autistic Self Advocacy Network, 2019). Following each description were two items. The first item asked, “On a scale of 0–5, how much do you personally identify with this description of autism?” The 0 on the scale was labeled “not at all” and the 5 was labeled “completely.” The second item asked, “On a scale of 0–100, how much do you personally identify with this description of autism? Please rate on a scale from 0 to 100 by entering a number below 0 = “not at all” and 100 = “completely.” Participants responded by selecting a rating on the 0–5 scale and typing in a rating on the 0–100 scale. The sample was sorted into three groups: pathology paradigm-identified, neurodiversity paradigm-identified, and neutral. Identification with paradigm was operationalized as difference scores of 1 or more between the scale ratings (i.e., the data from participants who favored the neurodiversity description with a difference score of 1–5 was sorted into the “neurodiversity-identified” group during analysis). The data from participants who favored neither description (i.e., had a difference score of 0) was sorted into the “neutral” group. The strength of paradigm identification was operationalized as the 0–100 ratings. See Figure 3.5 for both autism descriptions and paradigm rating scale items.

Figure 3.5

Autism Descriptions with Paradigm Rating Scale Items

Now, you will be asked to read two descriptions of autism. After each description, you will be asked to rate how strongly you identify with the description.

Here is one description of autism:

Autism spectrum disorder (ASD) is a neurodevelopmental disorder. To be diagnosed with ASD, individuals must show A: Deficits in social communication and interaction as well as B: Restricted, repetitive patterns of behavior, interests, or activities.

A. Deficits in social communication and interaction include:

   a. Deficits in social-emotional reciprocity ranging from abnormal social approach and failure of normal back-and-forth conversation to reduced sharing of interests or emotions, to failure to take part in social interactions.

   b. Deficits in nonverbal communication behaviors used for social interaction ranging from poorly integrated verbal and nonverbal communication, to abnormalities in eye contact and body language or deficits in understanding and use of gestures, to total lack of facial expressions and nonverbal communication.

   c. Deficits in developing, maintaining, and understanding relationships, ranging from difficulties adjusting behavior to suit various social contexts, to difficulties in sharing imaginative play or in making friends, to a lack of interest in peers.

B. Restricted, repetitive patterns of behavior, interests, or activities include:

   a. Repetitive motor movements, use of objects (such as lining up toys or flipping objects), and speech (such as echolalia or repeating phrases).

   b. Insistence on sameness, inflexible following of routines, or ritualized patterns of behavior, such as extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day.

   c. Highly restricted, fixated interests that are abnormal in intensity or focus, such as a strong attachment to or preoccupation with unusual objects and excessively limited or single-minded interests.

   d. Hyper or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment, such as apparent indifference to pain/temperature, negative response to specific sounds or textures, excessive touching or smelling of objects, and visual fascination with lights or movement.

Figure 3.5 (Continued)

The next two questions both ask how much you personally identify with this description of autism, but on two different rating scales. The first scale is 0-5, and the second is 0-100.

Question 1: How much do you personally identify with this description of autism? Please rate on a scale from 0 to 5.

	0	1	2	3	4	5	
not at all	○	○	○	○	○	○	completely

Question 2: How much do you personally identify with this description of autism? Please rate on a scale from 0 to 100 by entering a number below. 0 = "not at all" and 100 = "completely."

[Number entry box]

Here is another description of autism:

Autism is a neurodevelopmental disability that affects how we think, communicate, and interact with the world. Autism is a normal part of life. There is no one way to be autistic. Every autistic person experiences autism differently, but there are some things that many of us have in common.

1. We think differently. We may have very strong interests in things other people don't understand or seem to care about. We might be great problem-solvers, or pay close attention to detail. It might take us longer to think about things. We might have trouble with executive functioning, like figuring out how to start and finish a task, moving on to a new task, or making decisions.

   Routines are important for many autistic people. It can be hard for us to deal with surprises or unexpected changes. When we get overwhelmed, we might not be able to process our thoughts, feelings, and surroundings, which can make us lose control of our body.

2. We process our senses differently. We might be extra sensitive to things like bright lights or loud sounds. We might have trouble understanding what we hear or what our senses tell us. We might not notice if we are in pain or hungry. We might do the same movement over and over again. This is called "stimming," and it helps us regulate our senses. For example, we might rock back and forth, play with our hands, or hum.
3. We move differently. We might have trouble with fine motor skills or coordination. It can feel like our minds and bodies are disconnected. It can be hard for us to start or stop moving. Speech can be extra hard because it requires a lot of coordination. We might not be able to control how loud our voices are, or we might not be able to speak at all–even though we can understand what other people say.
4. We communicate differently. We might talk using echolalia (repeating things we have heard before), or by scripting out what we want to say. Some autistic people use Augmentative and Alternative Communication (AAC) to communicate. For example, we may communicate by typing on a computer, spelling on a letter board, or pointing to pictures on an iPad. Some people may also communicate with behavior or the way we act. Not every autistic person can talk, but we all have important things to say.

Figure 3.5 (Continued)

5. We socialize differently. Some of us might not understand or follow social rules that non-autistic people made up. We might be more direct than other people. Eye contact might make us uncomfortable. We might have a hard time controlling our body language or facial expressions, which can confuse non-autistic people or make it hard to socialize.

   Some of us might not be able to guess how people feel. This doesn't mean we don't care how people feel! We just need people to tell us how they feel so we don't have to guess. Some autistic people are extra sensitive to other people's feelings.

6. We might need help with daily living. It can take a lot of energy to live in a society built for non-autistic people. We may not have the energy to do some things in our daily lives. Or, parts of being autistic can make doing those things too hard. We may need help with things like cooking, doing our jobs, or going out. We might be able to do things on our own sometimes, but need help other times. We might need to take more breaks so we can recover our energy.

The next two questions both ask how much you personally identify with this description of autism, but on two different rating scales. The first scale is 0-5, and the second is 0-100.

Question 1: How much do you personally identify with this description of autism? Please rate on a scale from 0 to 5.

	0	1	2	3	4	5	
not at all	○	○	○	○	○	○	completely

Question 2: How much do you personally identify with this description of autism? Please rate on a scale from 0 to 100 by entering a number below. 0 = "not at all" and 100 = "completely."

[Number entry box]

In the present study, the broad construct of autistic mental well-being was defined by four discrete outcome variables: psychological distress, self-esteem, internalized autism stigma, and personal autism acceptance. Specifically, autistic well-being was indicated by low psychological distress, high self-esteem, low internalized autism stigma, and high personal autism acceptance. Psychological distress was operationalized as scores on the Depression, Anxiety and Stress Scale (Lovibond & Lovibond, 1995), self-esteem was operationalized as scores on the Rosenberg Self-Esteem Scale (Rosenberg, 1965), internalized autism stigma was operationalized as scores on the Internalized Stigma Scale adapted by Botha and Frost (2018), and personal autism acceptance was operationalized as scores on the Personal Autism Acceptance scale by Cage et al. (2018).

Measures

Data consisting of demographic information and responses to items on self-report measures of psychological distress, self-esteem, internalized autism stigma, and personal autism acceptance were collected through an online questionnaire using Google Forms. These measures are described following the order in which they were completed by participants.

Psychological Distress

Psychological distress was measured using total scores from the Depression, Anxiety, and Stress Scale (DASS-21; Lovibond & Lovibond, 1995), a short version of the original 42-item self-report scale that measures depression, anxiety, and stress. The 21-item version consists of three 7-item subscales (Depression, Anxiety, and Stress) and maintains the good validity and reliability of the long version, with a Cronbach’s alpha of 0.94, 0.87, and 0.91 for the depression, anxiety, and stress subscales respectively (Antony et al., 1998; Ng et al., 2007). The items consist of statements accompanied by Likert scales. Respondents are asked to select how much the statement applied to them within the past week. Statements include “I found it hard to wind down,” and “I felt that I had nothing to look forward to” (Lovibond & Lovibond, 1995). The DASS-21 has been used in research with autistic adults with acceptable to good internal consistency (Maddox & White, 2015). Cage et al. (2018) found that internal consistency for the depression subscale (Cronbach’s alpha = 0.919) and stress subscale (Cronbach’s alpha = 0.842) in their sample was within the range found in non-autistic samples, and the consistency for the anxiety subscale (Cronbach’s alpha = 0.790) was slightly lower but acceptable. Gloster et al. (2008) tested convergent validity for general distress as represented by total DASS-21 score.

They found significant positive correlations between total DASS-21 scores and the Penn State Worry Questionnaire (PSWQ), the negative affect scale of the Positive and Negative Affect Schedule (PANAS-N), Beck Anxiety Inventory (BAI), and Beck Depression Inventory (BDI-II), as well as significant negative correlations with the Quality of Life Inventory (QOLI) and the positive affect scale (PANAS-P; Gloster et al., 2008). The mean scores on all subscales within both autistic samples (Cage et al., 2018; Maddox & White, 2015) were similar and significantly higher than means found in the non-autistic population (Henry & Crawford, 2005).

Self-Esteem

Personal self-esteem was measured using the Rosenberg Self-Esteem Scale (RSES; Rosenberg, 1965), a 10-item scale that has a long history of use due to its simplicity and accessible language (Schmitt & Allik, 2005). The items consist of statements with Likert scales ranging from "Strongly Agree" to "Strongly Disagree." Statements include "I feel that I have a number of good qualities" and "I certainly feel useless at times" (Rosenberg, 1965). The RSES has good item convergent (0.57–0.79) and discriminant (0.27–0.52) validity (Sinclair et al., 2010) and internal reliability (Cronbach's alpha = 0.88; Schmitt & Allik, 2005). The RSES has been used successfully in research to measure self-esteem in autistic adults (e.g., Cooper et al., 2017).

Internalized Autism Stigma

Internalized autism stigma was measured using the ten-item Internalized Stigma Scale adapted by Botha and Frost (2018) from the Internalized Homophobia Scale (Meyer & Dean, 1998) to measure internalized autism stigma in autistic adults. Each item consists of a statement accompanied by a Likert scale ranging from "Never" to "Often." Respondents select how often the statements applied to them within the past year. Statements include "You felt it best to avoid personal or social involvement with other people who are on the Autism Spectrum” and “You have tried to stop being autistic” (Botha & Frost, 2018).

Personal Autism Acceptance

Personal autism acceptance was measured using the Personal Autism Acceptance scale by Cage et al. (2018). The scale asks participants to rate “On a scale of 0 to 10, how much have you personally accepted yourself as an autistic person?” The 0 is marked “Not at all” and the 10 is marked “Completely.” Cage et al. (2018) also measured perceived societal acceptance and acceptance from family and friends and found that personal acceptance correlated with perceived acceptance from family and friends but not with perceived societal acceptance. Results of a principal component analysis on the three items measuring autism acceptance indicated that the items measuring acceptance from family and friends and from society should be combined into a measure of “external sources of acceptance” while personal acceptance should remain a separate construct.

Demographic Questionnaire

Participant’s demographic information was gathered using a questionnaire consisting of closed and open-ended items (Figure 3.6). Participants were asked to provide information on their age, gender, race, primary methods of communicating, diagnosis (Autism/ASD, Asperger’s, or Other) and whether they were formally diagnosed or self-diagnosed. Participants were also asked to list any types of treatment or therapy they have experienced, if any. The purpose of this question was to gain a sense of the sample’s personal exposure to institutions and clinicians, the majority of which operate within the dominant pathology paradigm.

Figure 3.6

Demographic Questionnaire

---

1. How many years old are you?

   [Fill in the blank]

2. What is your gender?
   - ☐ Woman
   - ☐ Man
   - ☐ Non-binary
   - ☐ Other (please specify):____________

3. What is your race and/or ethnicity?
   - ☐ White (including European American)
   - ☐ Black (including African American)
   - ☐ Asian (including Asian American
   - ☐ Hispanic/Latino
   - ☐ American Indian or Alaska Native
   - ☐ Native Hawaiian or Pacific Islander
   - ☐ Multi-Ethnic
   - ☐ Other (please specify):_____________

4. How do you communicate on a typical day? (Select all that apply)
   - ☐ Speaking (mouth-speaking)
   - ☐ Aided Augmentative and Alternative Communication (AAC) systems such as pen and paper, typing, letterboard, PECS board, or speech-generating devices
   - ☐ Unaided AAC systems such as sign language or gestures

5. Please select your diagnosis/disability/neurotype:
   - ☐ Autism or autism spectrum disorder (ASD)
   - ☐ Asperger's syndrome
   - ☐ Other (please specify): _____________

6. How did you come to identify as autistic or on the spectrum?
   - ☐ Formally diagnosed by a professional (e.g., pediatrician/primary care physician, psychiatrist, psychologist)
   - ☐ Self-diagnosed or self-discovered as autistic/on the autism spectrum

7. What types of treatment or therapy have you experienced? (Examples include occupational therapy, speech therapy, Floortime, SCERTS, applied behavior analysis (ABA) or other behavioral interventions, individual psychotherapy or counseling, social skills groups.)

   [Fill in the blank]

CHAPTER IV: RESULTS

The current chapter will discuss the quantitative findings of this study. First, the demographic data of the sample will be presented, followed by the results of correlational analyses and t-tests. The research questions will be referenced to contextualize the results. All statistical analyses were conducted using JASP (JASP Team, 2022).

Participant Characteristics

One hundred and thirty-six individuals completed the online survey, all of whom indicated they were age 18 or older and autistic/on the autism spectrum by selecting “yes” at the end of the consent form. One respondent was excluded because they did not rate both autism descriptions, thus could not be sorted into a paradigm identification group. The total sample consisted of 135 participants. Scores from the four mental well-being measures were calculated using Microsoft Excel. Missing items were noted for eight distinct participants within three of the measures; four participants missed items on the DASS-21, two on the RSES, and two on the Internalized Stigma Scale. In accordance with the scoring guidelines for each of the measures, the number of missing items did not affect the validity and so the total scores of all 135 participants were included in analysis. Six participants did not rate their strength of identification with the neurodiversity paradigm, and seven did not rate their strength of identification with the pathology paradigm. Thus, cases were excluded pairwise for correlations between strength of identification and mental well-being scores.

Sample demographic data are illustrated in Table 4.1 below. Race and gender data were missing for two participants, and age was missing from one participant. The vast majority of the sample was white; participants of other races were poorly or not at all represented. Women (both cisgender and transgender) were the largest gender group represented in the sample, followed by non-binary individuals and men (both cisgender and transgender). Eight percent of responses were specified as “Other,” and included “autigender,” “Two Spirit,” “agender,” and “Fluid.” This sample’s overrepresentation of women might be a reflection of evidence suggesting that women are more likely to respond to online surveys (Smith, 2008). It is also possible that, due to the gender disparity in autism diagnosis, women are more likely to seek autistic community in online spaces and to participate in research related to autistic mental health. This sample’s representation of non-binary genders is consistent with findings in recent literature on the overlap between autism and gender diversity (Warrier et al., 2020). The majority of participants identified their diagnosis/disability/neurotype as Autism or autism spectrum disorder (ASD). About a quarter identified with Asperger’s, and 8.1% specified using the “Other” option. These responses included “ASD, ADHD,” “PDDNOS,” “Official dx is NVLD but I identify most closely with Asperger’s,” and “I clearly have a mild case, but I don't use the term Asperger’s due to the historical connection of that person to Nazism.” More than half of the sample indicated they were formally diagnosed, and the rest were self-diagnosed or self-discovered. Mouth speaking was the typical communication method used by all 135 participants, with aided and unaided AAC also used by 14 and 10 participants, respectively. The majority of the sample reported a treatment history of interventions for autism and non-autism related challenges; responses included individual psychotherapy, occupational therapy, speech therapy, psychiatric medication, social skills groups, and behavioral interventions (including physical and emotional suppression of autistic traits by family members and professionals). Participants ranged from 18 to 72 years old, and the sample’s mean age was 42.2 years (SD = 13.4).

Table 4.1

Sample Demographics

Characteristic		Percentage	n
Race/Ethnicity (n = 133)			
	White	94	125
	Multi-Ethnic	3	4
	Hispanic/Latino	0.8	1
	Other	2.3	3
Gender (n = 133)			
	Woman	61.7	82
	Man	14.3	19
	Non-binary	18	24
	Other	6	8
Diagnosis/Disability (n = 135)			
	Autism or ASD	66.7	90
	Asperger's	25.2	34
	Other	8.1	11
Diagnosis Source (n = 135)			
	Formal/Professional	63.7	86
	Self-Discovered	36.3	49
Communication Methods (n = 159)[a]			
	Mouth-speaking	100	135
	Aided AAC	10.3	14
	Unaided AAC	7.4	10
Treatment Experience			
	Yes	71.1	96
	No or no response	28.8	39
Age in Years (n = 134)		M = 42.2	SD = 13.4

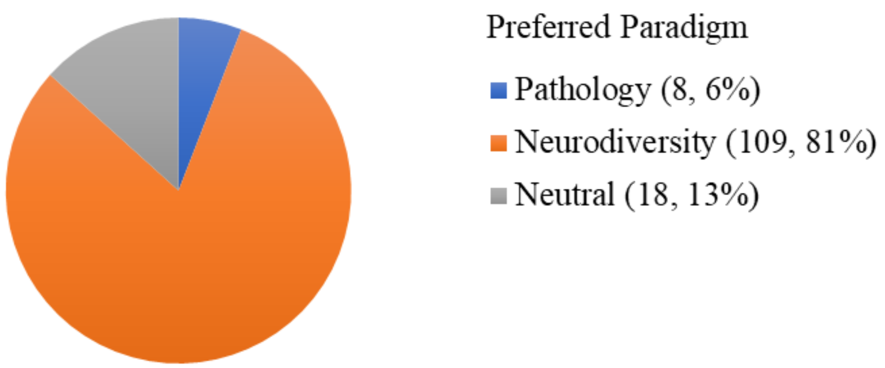
[a] Participants were given the option to select all communication methods used on a typical day, resulting in a total greater than N = 135.

Paradigm Ratings and Mental Well-Being Measures

The first research question was concerned with differences in mental well-being between neurodiversity paradigm-identified and pathology paradigm-identified autistic adults. As was described in the previous chapter, identification with autism paradigm was operationalized as difference scores of 1 or more between the 0–5 rating scales that followed both of the autism descriptions. Participants who preferred the Autistic Self Advocacy Network's description were sorted into the "Neurodiversity" group, while participants who preferred the DSM-5 description were sorted into the "Pathology" group. Participants who favored neither description (i.e., had a difference score of 0) were sorted into the "Neutral" group. Figure 4.1 illustrates the sample's paradigm preferences; the Neurodiversity group made up the majority of the sample (81%), followed by the Neutral group (13%), and the Pathology group (6%). Overall, ratings were higher for the neurodiversity description (M = 4.5, Mdn = 5, Mode = 5, SD = .78), and lower for the pathology description (M = 2.71, Mdn = 3, Mode = 3, SD = 1.38).

Figure 4.1

Autism Paradigm Identification Among Participants



Note. N = 135.

This study initially proposed to use an ANOVA to compare mental well-being scores among the three groups, however due to the small size of the Pathology group, the Pathology group (n = 8) and the Neutral group (n = 18) were combined to create a single Non-Neurodiversity group (n = 26) that represented participants who did not show a preference for the neurodiversity paradigm. Levene's test was not significant (p > .05) for any of the well-being scores, indicating that the assumption of homogeneity of variance had been met. The Shapiro-Wilk test was not significant (p > .05) for either group's DASS-21 or RSES scores, but it was significant (p < .001) for autism acceptance and internalized stigma scores, indicating that the assumptions of normality were met for the DASS-21 and RSES scores, but not for the autism acceptance or internalized stigma scores.

Table 4.2

Neurodiversity and Non-Neurodiversity Group Descriptives

Well-Being Measure	Group	N	Mean	SD	SE	Coefficient of variation
Depression Anxiety & Stress	Path/Neut [a]	26	52.769	23.352	4.580	0.443
	ND [b]	109	52.257	21.843	2.092	0.418
Self-Esteem	Path/Neut	26	24.769	5.279	1.035	0.213
	ND	109	25.661	5.767	0.552	0.225
Autism Acceptance	Path/Neut	26	7.500	2.064	0.405	0.275
	ND	109	8.404	1.727	0.165	0.206
Internalized Stigma	Path/Neut	26	21.077	6.997	1.372	0.332
	ND	109	16.459	6.269	0.601	0.381

[a] Path/Neut = the combined Pathology and Neutral groups, or the Non-Neurodiversity group.

[b] ND = Neurodiversity.

Based on the results of these assumptions checks and the difference in group sizes, Welch's t-test was used to compare DASS-21 and RSES scores, and a Mann-Whitney test was used to compare autism acceptance and internalized stigma scores. For DASS-21 scores, the groups did not differ significantly, *t*(36) = .10, *p* = .92, *d* = .02. For RSES scores, the groups did not differ significantly, *t*(41) = -.76, *p* = .45, *d* = -.16.

Table 4.3

DASS-21 and RSES Scores Between Paradigm Groups

						95% CI for Cohen's d	
	Test	Statistic	df	p	Cohen's d	Lower	Upper
Depression Anxiety & Stress	Student	0.106	133	0.916	0.023	-0.405	0.451
	Welch	0.102	36.16	0.920	0.023	-0.405	0.450
Self-Esteem	Student	-0.719	133	0.473	-0.157	-0.585	0.272
	Welch	-0.760	40.504	0.452	-0.161	-0.589	0.269

The autism acceptance and internalized stigma scale scores both differed significantly between groups. A Mann-Whitney test indicated that autism acceptance scores were higher for the Neurodiversity group (Mdn = 9) than for the Non-Neurodiversity group (Mdn = 8), W= 1019.5, p = .023. Internalized stigma scores were higher for the Non-Neurodiversity group (Mdn = 22) than for the Neurodiversity group (Mdn = 15), W= 1962.5, p = .002.

Table 4.4

Internalized Stigma and Autism Acceptance Scores Between Paradigm Groups

					95% CI for Hodges-Lehmann Estimate		
	W	df	p	Hodges-Lehmann Estimate	Lower	Upper	Rank-Biserial Correlation
Internalized Stigma	1962.5		0.002	6.000	2.000	9.000	0.385
Autism Acceptance	1019.5		0.023	-1.000	-2.000	-5.861e-5	-0.281

Note. For the Mann-Whitney test, effect size is given by the rank biserial correlation.

The next research question asked if there was a relationship between strength of identification with autism paradigm and mental well-being. This study initially proposed to utilize a Pearson product-moment correlation test to examine strength of identification for the entire sample prior to group sorting as well as within each paradigm group. However due to the small size of the Pathology group (n = 8), a within-group correlation could only be conducted for the Neurodiversity group (n = 109). Analyses were completed using the strength of identification scores (ratings on the 0–100 scale) and participants' mental well-being scores (DASS-21, RSES, internalized autism stigma scale, and personal autism acceptance). A Shapiro-Wilk test found that the assumption of normality was not met for personal autism acceptance, internalized stigma, or strength of identification scores (p < .001), so Kendall's tau and Spearman's rho were used in place of a Pearson correlation. Kendall's tau and Spearman's rho are very similar non-parametric rank-order tests, though Kendall's is slightly more robust and efficient than Spearman's (Croux & Dehon, 2010). The results of both tests are reported in tables 4.5–4.7, but the Kendall’s tau results are highlighted. There was no significant correlation between strength of identification with the pathology paradigm and DASS-21 score, τ_b(128) = .07, p = .263, nor between strength of identification with the pathology paradigm and autism acceptance rating, τ_b(128) = -.09, p = .189. There was a significant negative correlation between strength of identification with the pathology paradigm and self-esteem score, τ_b(128) = -.13, p = .046, and a significant positive correlation between strength of identification with the pathology paradigm and internalized stigma score, τ_b(128) = .23, p = <.001. There was no significant correlation between strength of identification with the neurodiversity paradigm and DASS-21 score, τ_b(129) = .10, p = .127, nor was there between strength of identification with the neurodiversity paradigm and self-esteem score, τ_b(129) = -.04, p = .534. There was a significant positive correlation between strength of identification with neurodiversity paradigm and autism acceptance rating, τ_b(129) = .20, p = .006, and a significant negative correlation between strength of identification with the neurodiversity paradigm and internalized stigma score, τ_b(129) = -.16, p = .015.

Table 4.5

Strength of Identification with Autism Paradigm and Mental Well-Being

Variable		Depression Anxiety & Stress	Self-Esteem	Autism Acceptance	Internalized Stigma
Strength of Identification-Pathology					
	n	128	128	128	128
	Spearman’s rho	0.099	-0.169	-0.107	0.326***
	p-value	0.266	0.056	0.228	< .001
	Kendall’s Tau B	0.069	-0.125*	-0.087	0.233***
	p-value	0.263	0.046	0.189	< .001
Strength of Identification-Neurodiversity					
	n	129	129	129	129
	Spearman’s rho	0.131	-0.052	0.231**	-0.211*
	p-value	0.138	0.557	0.008	0.016
	Kendall’s Tau B	0.098	-0.040	0.191**	-0.157*
	p-value	0.127	0.534	0.006	0.015

Note. Cases excluded pairwise. *p < .05, **p < .01, ***p < .001

Within the Neurodiversity group, none of the mental well-being scores were significantly correlated with strength of identification with the neurodiversity paradigm (see Table 4.6).

Table 4.6

Strength of Identification with Neurodiversity Paradigm and Mental Well-Being Within Neurodiversity-Identified Group

Variable		Depression Anxiety & Stress	Self-Esteem	Autism Acceptance	Internalized Stigma
Strength of Identification-Neurodiversity					
	n	104	104	104	104
	Spearman's rho	0.124	0.012	0.132	-0.063
	p-value	0.211	0.907	0.181	0.528
	Kendall's Tau B	0.094	0.004	0.115	-0.049
	p-value	0.190	0.959	0.139	0.503

Note. Cases excluded pairwise.

$^*p < .05$, $^{**}p < .01$, $^{***}p < .001$

The third research question was concerned with the relationship among mental well-being measures. As Table 4.7 illustrates, all four measures were significantly correlated. DASS-21 and self-esteem scores were significantly negatively correlated, $\tau_b(135) = -.39$, $p < .001$, as were DASS-21 and autism acceptance scores, $\tau_b(135) = -.17$, $p = .01$, internalized stigma and self-esteem, $\tau_b(135) = -.25$, $p < .001$, as well as autism acceptance and internalized stigma scores, $\tau_b(135) = -.48$, $p < .001$. There were significant positive correlations between DASS-21 and internalized stigma scores, $\tau_b(135) = .22$, $p < .001$, and autism acceptance and self-esteem scores, $\tau_b(135) = .26$, $p < .001$.

Table 4.7

Correlations Among Mental Well-Being Domains

Variable		Depression Anxiety & Stress	Self-Esteem	Autism Acceptance	Internalized Stigma
Depression Anxiety & Stress					
	n	—			
	Spearman's rho	—			
	p-value	—			
	Kendall's Tau B	—			
	p-value	—			
Self-Esteem					
	n	135	—		
	Spearman's rho	-0.530***	—		
	p-value	< .001	—		
	Kendall's Tau B	-0.391***	—		
	p-value	< .001	—		
Autism Acceptance					
	n	135	135	—	
	Spearman's rho	-0.216*	0.337***	—	
	p-value	0.012	< .001	—	
	Kendall's Tau B	-0.165**	0.260***	—	
	p-value	0.010	< .001	—	
Internalized Stigma					
	n	135	135	135	—
	Spearman's rho	0.318***	-0.341***	-0.608***	—
	p-value	< .001	< .001	< .001	—
	Kendall's Tau B	0.221***	-0.246***	-0.482***	—
	p-value	< .001	< .001	< .001	—

*p < .05, **p < .01, ***p < .001

The fourth research question asked the extent to which internalized stigma might moderate the relationships among psychological distress, self-esteem, autism acceptance and paradigm group. As mentioned previously, the small size of the Pathology group (n = 8) precluded this statistical analysis from being conducted as proposed.

CHAPTER V: DISCUSSION

Autistic scholars and communities have suggested that a paradigm shift is both necessary and a potential route for addressing the high rates of mental health problems historically considered intrinsic to autism. This study explored how personal identification with the neurodiversity paradigm versus the pathology paradigm related to mental well-being in autistic adults. The results of this study indicate that some but not all domains of mental well-being differed between paradigm identification groups, and that strength of identification with autism paradigm was associated with most mental well-being domains. This chapter will explore these results in the context of the research questions, discuss the limitations and implications for future research, and summarize the current study’s findings.

Autism Paradigm Identification

Although the number of participants who preferred each of the autism paradigms was not initially a research question, the paradigm identification ratings and sizes of the paradigm groups were noteworthy. The overwhelming majority of participants (81%) identified more with the neurodiversity paradigm than with the pathology paradigm, and only 6% preferred the pathology paradigm. A closer look at the data revealed that the dramatically different group sizes did not result from minor preferences (difference scores of 1); on the 0-5 scale, the modal rating was 3 ($M = 2.71$) for the pathology description and 5 ($M = 4.51$) for the neurodiversity description. It is also likely that, had the rating scale questions been more direct, some of the participants who were sorted into the Neutral group would have been sorted into the Neurodiversity group. The language on the survey did not state that the 0–5 ratings were used to sort into a paradigm group, while the 0–100 ratings were used to measure strength of paradigm identification. Given this design flaw, it is not surprising that multiple participants gave “neutral” 0–5 ratings followed by “neurodiversity” 0–100 ratings.

While the existing literature predicted that the Neurodiversity group would be larger than the Pathology group, it also predicted more overlap between neurodiversity and pathology paradigm-based understandings of autism (e.g., Gillespie-Lynch et al., 2017). Participants in the current study seemed to draw a clear boundary between these two descriptions, endorsing the neurodiversity paradigm and dismissing the pathology paradigm. It is possible that sampling bias contributed to this discrepancy, as most autistic-led online spaces skew towards the neurodiversity paradigm. It is also possible that the small number of pathology paradigm-identified participants is a rejection of the diagnostic criteria produced by allistic people who operate within the medical model at multiple levels. While this sample was limited in size and representation, such a mismatch between the dominant definition of/diagnostic criteria for autism and autistic adults’ definition of autism is concerning and worthy of further examination, especially by allistic professionals who aim to support autistic people.

Mental Well-Being Between Paradigm Groups

The results of this study partially support the hypothesis that autistic adults who identify with the neurodiversity paradigm would experience better mental well-being than those who identify with the pathology paradigm and those who do not prefer the neurodiversity paradigm (due to the small size of the Pathology group, the Pathology and Neutral groups were combined into one Non-Neurodiversity group). Neurodiversity-aligned participants reported greater well-being in two domains: personal autism acceptance and internalized autism stigma. Due to the small sample size, small Non-Neurodiversity group, and aforementioned survey design flaw, all results should be interpreted with caution. These results are consistent with existing research on stigma and attitudes about autism, which found that neurodiversity paradigm-aligned beliefs were associated with lower autism stigma, while medical model or pathology paradigm-aligned beliefs were associated with higher stigma. However, this study was the first to use Botha and Frost's (2018) internalized autism stigma scale to compare internalized stigma on the basis of autism definitions.

Neurodiversity-aligned participants did not report greater mental well-being in the domains of self-esteem and psychological distress; the paradigm groups did not differ significantly on these measures. Considering the significant correlations between all four mental well-being domains in the predicted directions, it is possible that the small size of the Non-Neurodiversity group meant that significant but less robust group differences went undetected. It is also possible that the sample's high psychological distress reflected the mental health impacts of the COVID-19 pandemic. While pandemic-related mental health and substance use problems were and are widespread, studies have shown that disabled adults have been disproportionately affected by mental health and substance use outcomes as well as increased difficulty accessing care compared to nondisabled adults (Czeisler et al., 2021). Data collection for this study took place during the four-month period when the first Omicron variant was rampant throughout the U.S. and U.K. If participants were experiencing these challenges during data collection, that might explain the absence of group differences in psychological distress and self-esteem.

Strength of Identification with Paradigm

The next hypothesis was that stronger identification with the neurodiversity paradigm would be associated with greater mental well-being, while stronger identification with the pathology paradigm would be associated with worse mental well-being. Again, the data partially support this hypothesis. Stronger identification with the pathology paradigm was associated with lower self-esteem and higher internalized autism stigma, but there was no significant relationship between strength of identification with the pathology paradigm and psychological distress or personal autism acceptance. Stronger identification with the neurodiversity paradigm was associated with higher personal autism acceptance and lower internalized autism stigma, but there was no significant relationship between strength of identification with the neurodiversity paradigm and psychological distress or self-esteem. While causality cannot be inferred, these findings suggest a potential benefit to identifying with the neurodiversity paradigm as well as a potential risk to identifying with the pathology paradigm, echoing autistic self-advocates and researchers such as Botha et al. (2022) who assert that the dominant medical model perpetuates stigma which could be ameliorated by the neurodiversity paradigm.

Of particular interest here is the discrepancy between personal autism acceptance and internalized stigma in relation to pathology paradigm identification. Because these two constructs are so highly correlated with each other, it was surprising to find a strong relationship ($p < .001$) between pathology paradigm identification and internalized stigma, yet none between pathology paradigm identification and autism acceptance. One explanation might be that although personal autism acceptance is certainly related to internalized stigma, it is closer to a measure of conscious stigma than internalized stigma. Another way to phrase the personal acceptance question might be “How much unconscious bias do you think you have?” while the internalized stigma scale gets closer to asking “How much unconscious bias do you actually have?” Jones et al. (2021) observed a similar phenomenon when their autism acceptance training reduced explicit but not implicit anti-autistic biases among non-autistic participants.

The results of paradigm identification strength correlations within the Neurodiversity group indicate that for those who identify most with the neurodiversity paradigm, the extent to which they identify with it doesn’t relate to mental well-being. This could be a reflection of the almost uniformly high strength ratings within the Neurodiversity group. It might also be true that beyond a distinct preference for the neurodiversity paradigm, strength of identification does not matter when it comes to the mental well-being domains addressed in this study.

Relationships Among Mental Well-Being Domains

The third hypothesis was that personal autism acceptance and internalized autism stigma would be highly negatively correlated, while internalized autism stigma would be positively correlated with psychological distress and negatively correlated with self-esteem. The results support this hypothesis and are consistent with the literature on autism acceptance, stigma, and psychological distress. This study was particularly interested in the strong relationships between internalized autism stigma and the other domains of mental well-being, as most of the research that measured internalized autism stigma used the Internalized Stigma of Mental Illness Inventory (ISMI; Hammer & Toland, 2017), and only Botha and Frost (2018) have used an adapted version of the Internalized Homophobia Scale (Meyer & Dean, 1998) to measure internalized autism stigma.

Limitations

The current study contained several limitations. The first and perhaps most significant was that it did not follow a community based participatory research model. With no autistic people as equal partners in every phase of the project, the research questions, method, and interpretations of the results were negatively impacted by the inherent allistic bias of this author as well as the lack of autistic expertise. The co-created knowledge that comes from meaningful community participation in autism research is more likely to improve the lives of autistic people and their allies (Fletcher-Watson et al., 2019). This study’s sample size was small and did not represent the racial and ethnic diversity of the autistic population. Other limitations in representation included variations in support and access needs, education, income, employment, and nationality. The small size of the Pathology group was also a limitation. As was previously described, an effort was made to mitigate sampling bias by recruiting participants from a mix of neurodiversity and pathology paradigm-based online spaces. It is unclear whether this effort was successful, in part because it was difficult to find autistic adult-led spaces where the medical model was dominant.

Implications for Future Research and Practice

The present study’s findings contribute to an emerging body of literature concerned with autistic mental health and well-being, stigma, identity, and neurodiversity from an autistic perspective. Future research should continue to address the limitations of this and similar studies; accurate representation across racial and ethnic groups and the heterogeneity of autistic support/access needs, especially regarding autistic people with co-occurring intellectual and learning disabilities, would increase the likelihood that the findings translate into practice and improve the lives of autistic individuals on their own terms. It is also important that future research centers the experience of autistic people with intersecting marginalized identities, as Botha and Frost (2018) emphasize the possibility of “double discrimination” effects in this population (Grollman, 2014).

Another direction for future research is to expand and elucidate the construct of autistic mental well-being and its relationship to autistic quality of life. There is much more to autistic mental health and well-being than the four domains this study attempted to capture, and autistic-specific measures, such as Raymaker et al.'s (2020) work on autistic burnout, are needed to properly explore all domains identified by autistic individuals. For instance, Milton and Sims (2016) found four themes that broadly characterized well-being for autistic adults: meeting personal needs, living with the consequences of an othered identity, connection and recognition, and relationships and advocacy. The present study did not directly measure how these themes relate to autism paradigm alignment. Though important, mental well-being is only one aspect of autistic quality of life, which might be a more relevant and applicable area of concern for future research. Even if future research demonstrated that identification with the neurodiversity paradigm played a role in reducing internalized stigma, internalized stigma is only one facet of minority stress. Reducing internalized stigma does not necessarily help an autistic person get appropriate support, accommodations, or equal access to an allistic-dominant society.

A better understanding of autistic mental well-being and quality of life would shed light on potential pathways to improving and protecting autistic well-being. One path is to consider the associations between paradigm identification and mental well-being domains in the context of minority stress theory, which emphasizes social connectedness as a protective factor and tool for coping and healing. Cooper et al. (2017) found that autistic social identification was a protective mechanism against depression and anxiety, and that a positive relationship between autistic social identification and personal self-esteem was mediated by collective self-esteem. In another study, stronger feelings of social identification with other autistic people were associated with greater mental well-being (Maitland et al., 2021). The power of autistic social connection is further articulated in Crompton et al.'s (2020) thematic analysis of autistic same and cross-neurotype relationships, titled with a participant's quote "I never realised everybody felt as happy as I do when I am around autistic people" (p. 1438). Further research could explore what it might look like to facilitate positive autistic identity development and autistic community connections.

While this study was limited in its construction of mental well-being, the results support a shift from the pathology paradigm to the neurodiversity paradigm across clinical practice and research. The pathology paradigm-rooted criteria used to diagnose or identify autism should be changed so that they reflect the heterogeneous experiences of people with autistic neurology rather than the subjective observations of people with allistic neurology. Everybody, especially clinicians, educators, and allistic caregivers of autistic children, should learn about autism through the neurodiversity paradigm. Teaching autistic individuals about the neurodiversity paradigm could be considered an intervention to prevent or reduce internalized autism stigma. However, given that the stigmatizing paradigm is upheld by the allistic neuromajority, a more effective approach might focus on educating allistic individuals so that changes can be made on an individual and systems level simultaneously. In the interest of reducing minority stress and fostering autistic well-being, the neurodiversity paradigm should be the basis of all therapies and supports for autistic people.

Allistic psychologists should be aware that autistic and otherwise neurodivergent organizations are already doing this neurodiversity paradigm-based work, and have been for many years. One example is Foundations for Divergent Minds (FDM), a multiply neurodivergent autistic-led nonprofit that provides training and consultation to practitioners, parents, and other groups using their neurodivergent-designed educational model for supporting neurodivergent people of all ages. FDM’s model uses the neurodiversity paradigm as the framework for its five foundations: sensory regulation, emotional regulation, communication, socialization, and executive function (Foundations for Divergent Minds, 2020). In a webinar hosted by the New

Jersey Autism Center of Excellence, FDM Content and Coordination Director Kassiane Asasumasu describes the intention behind their initiatives, “A lot of the autistic community right now—the whole thing is ‘we’ll put your kid back together,’ but FDM says ‘what if we never broke autistic kids in the first place?’” (Latimer et al., 2022).

Conclusion

Mental health problems are a significant and under-addressed challenge for autistic adults that negatively impact their quality of life. Autistic activists, self-advocates, and scholars draw a connection between poor autistic mental health and the dominant autism narrative (the pathology paradigm), as the dominant narrative shapes allistic perceptions of autistic individuals as well as their own self-perceptions. The neurodiversity paradigm, based in the social model of disability, is one potential solution to the problems associated with the pathology paradigm. A growing body of research supports addressing autistic mental health problems using the framework of the social model of disability and minority stress theory. This study explored how personal identification with the neurodiversity paradigm versus the pathology paradigm related to mental well-being among autistic adults. Most participants identified strongly with the neurodiversity paradigm while very few identified with the pathology paradigm. Those who identified with the neurodiversity paradigm were more accepting of their autistic neurology and experienced less internalized stigma than those who identified with the pathology paradigm or had no preference. Stronger identification with the pathology paradigm was associated with higher internalized stigma and lower self-esteem. These results suggest that autistic adults’ mental well-being might be improved through a multi-systemic shift from the pathology paradigm to the neurodiversity paradigm in research, clinical practice and beyond.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed). https://doi.org/10.1176/appi.books.9780890425596

American Psychological Association. (2019). *Disability*. American Psychological Association. https://apastyle.apa.org/style-grammar-guidelines/bias-free-language/disability

Antony, M., Bieling, P. J., Cox, B. J., Enns, M. W., & Swinson, R. P. (1998). Psychometric properties of the 42-item and 21-item versions of the Depression Anxiety Stress Scales in clinical groups and a community sample. *Psychological Assessment, 10*(2), 176–181. https://doi.org/10.1037/1040-3590.10.2.176

Autistic Self Advocacy Network. (2019a). *Position statements*. Autistic Self Advocacy Network. https://autisticadvocacy.org/about-asan/position-statements/

Autistic Self Advocacy Network. (2019b). *About autism*. Autistic Self Advocacy Network. https://autisticadvocacy.org/about-asan/about-autism/

Bagatell, N. (2007). Orchestrating voices: Autism, identity and the power of discourse. *Disability & Society, 22*(4), 413–426. doi:10.1080/09687590701337967

Bagatell, N. (2010). From cure to community: Transforming notions of autism. *Ethos, 38*, 33–55. https://doi.org/10.1111/j.1548-1352.2009.01080.x

Barnbaum, D. R. (2008). *The ethics of autism: Among them, but not of them*. Indiana University Press. http://public.eblib.com/choice/publicfullrecord.aspx?p=415343

Bascom, J. (2012). Speech, without a title. In J. Bascom (Ed.), *Loud Hands: Autistic People, Speaking* (pp. 192–195). The Autistic Press.

Benford, P., & Standen, P. (2009). The internet: A comfortable communication medium for people with asperger syndrome (as) and high functioning autism (hfa)? *Journal of Assistive Technologies, 3*(2), 44–53. doi:10.1108/17549450200900015

Bonnello, C. (2018). *11,521 people answered this autism survey. Warning: The results may challenge you.* Autistic Not Weird. https://autisticnotweird.com/2018survey/

Botha, M., Dibb, B., & Frost, D. M. (2022). 'Autism is me': An investigation of how autistic individuals make sense of autism and stigma. *Disability & Society, 1*–27. https://doi.org/10.1080/09687599.2020.1822782

Botha, M., & Frost, D. M. (2018). Extending the minority stress model to understand mental health problems experienced by the autistic population. *Society and Mental Health, 10*(1), 20–34. https://doi.org/10.1177/2156869318804297

Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2020). Avoiding ableist language: Suggestions for autism researchers. *Autism in Adulthood*. https://doi.org/10.1089/aut.2020.0014

Brown, L. (2011). *The significance of semantics: Person-first language: Why it matters*. Autistic Hoya. http://www.autistichoya.com/2011/08/significance-of-semantics-person-first.html

Burchardt, T. (2004). Capabilities and disability: The capabilities framework and the social model of disability. *Disability & Society, 19*(7), 735–751. https://doi.org/10.1080/0968759042000284213

Cage, E., Monaco, J., & Newell, V. (2018). Experiences of autism acceptance and mental health in autistic adults. *Journal of Autism and Developmental Disorders*, *48*(2), 473–484. https://doi.org/10.1007/s10803-017-3342-7

Cage, E., Di Monaco, J., & Newell, V. (2019). Understanding, attitudes and dehumanisation towards autistic people. *Autism: The International Journal of Research and Practice*, *23*(6), 1373–1383. https://doi.org/10.1177/1362361318811290

Cassidy, S., Bradley, P., Robinson, J., Allison, C., McHugh, M., & Baron-Cohen, S., CLASS Clinic, Cambridgeshire and Peterborough NHS Foundation Trust, Cambridge, UK. (2014). Suicidal ideation and suicide plans or attempts in adults with asperger's syndrome attending a specialist diagnostic clinic: A clinical cohort study. *The Lancet Psychiatry, 1*(2), 142–147. https://doi.org/10.1016/S2215-0366(14)70248-2

Cassidy, S. A., Gould, K., Townsend, E., Pelton, M., Robertson, A. E., & Rodgers, J. (2020). Is camouflaging autistic traits associated with suicidal thoughts and behaviours? Expanding the interpersonal psychological theory of suicide in an undergraduate student sample. *Journal of Autism and Developmental Disorders*, *50*(10), 3638–3648. https://doi.org/10.1007/s10803-019-04323-3

Chown, N., Robinson, J., Beardon, L., Downing, J., Hughes, L., Leatherland, J., & Macgregor, C. (2017). Improving research about us, with us: A draft framework for inclusive autism research. *Disability & Society, 32*(5), 720–734. doi:10.1080/09687599.2017.1320273

Cohen, J. (1992). A power primer. *Psychological Bulletin*, *112*(1), 155–159. https://doi.org/10.1037/0033-2909.112.1.155

Cooper, K., Smith, L. G. E., & Russell, A. (2017). Social identity, self-esteem, and mental health in autism. *European Journal of Social Psychology*, *47*, 844–854. https://doi.org/10.1002/ejsp.2297

Crompton, C. J., Hallett, S., Ropar, D., Flynn, E., & Fletcher-Watson, S. (2020). ‘I never realised everybody felt as happy as I do when I am around autistic people’: A thematic analysis of autistic adults' relationships with autistic and neurotypical friends and family. *Autism: The International Journal of Research and Practice*, *24*(6), 1438–1448. https://doi.org/10.1177/1362361320908976

Croux, C., & Dehon, C. (2010). Influence functions of the Spearman and Kendall correlation measures. *Statistical Methods and Applications, 19,* 497–515. https://doi.org/10.1007/s10260-010-0142-z

Czeisler M. É., Board, A., Thierry, J. M., Czeisler, C. A., Rajaratnam, S. M. W., Howard, M. E., & Clarke, K. E. N. (2021). Mental health and substance use among adults with disabilities during the COVID-19 pandemic—United States, February–March 2021. *Morbidity and Mortality Weekly Report 2021,* 70, 1142–1149. http://dx.doi.org/10.15585/mmwr.mm7034a3

Davidson, J., & Orsini, M. (2013). Critical autism studies: Notes on an emerging field. In J. Davidson & M. Orsini (Eds.), *Worlds of Autism: Across the Spectrum of Neurological Difference* (1–28). https://doi.org/10.5749/minnesota/9780816688883.003.0001

Dinishak, J., & Akhtar, N. (2013). A critical examination of mindblindness as a metaphor for autism. *Child Development Perspectives, 7,* 110–114. https://doi.org/10.1111/cdep. 12026

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J. R., & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism, 23*(4), 943–953. https://doi.org/10.1177/1362361318786721

Foundations for Divergent Minds. (2020, November). *What is Foundations for Divergent Minds (FDM)?* Retrieved from https://www.divergentminds.org/wp-content/uploads/2020/11/What-is-Foundations-for-Divergent-Minds-2020.pdf

Gernsbacher, M. A., & Yergeau, M. (2019). Empirical failures of the claim that autistic people lack a theory of mind. *Archives of Scientific Psychology, 7*(1), 102–118. https://doi.org/10.1037/arc0000067

Gillespie-Lynch, K., Kapp, S., Brooks, P., Pickens, J., & Schwartzman, B. (2017). Whose expertise is it? Evidence for autistic adults as critical autism experts. *Frontiers in Psychology, 8,* 438–438. https://doi.org/:10.3389/fpsyg.2017.00438

Gloster, A. T., Rhoades, H. M., Novy, D., Klotsche, J., Senior, A., Kunik, M., Wilson, N., & Stanley, M. A. (2008). Psychometric properties of the Depression Anxiety and Stress Scale-21 in older primary care patients. *Journal of Affective Disorders, 110*(3), 248–259. https://doi.org/10.1016/j.jad.2008.01.023

Grollman, E. A. (2014). Multiple disadvantaged statuses and health: the role of multiple forms of discrimination. *Journal of Health and Social Behavior*, *55*(1), 3–19. https://doi.org/10.1177/0022146514521215

Gross, Z. (2012). Killing words. In J. Bascom (Ed.), *Loud hands: Autistic people, speaking* (pp. 238–240). The Autistic Press.

Hammer, J. H., & Toland, M. D. (2017). Internal structure and reliability of the Internalized Stigma of Mental Illness Scale (ISMI-29) and brief versions (ISMI-10, ISMI-9) among Americans with depression. *Stigma and Health*, *2*, 159–174. https://doi.org/10.1037/sah0000049

Han, E., Scior, K., Avramides, K., & Crane, L. (2022). A systematic review on autistic people's experiences of stigma and coping strategies. *Autism Research*, 15(1), 12–26. https://doi.org/10.1002/aur.2652

Hasford, J. (2016). Dominant cultural narratives, racism, and resistance in the workplace: A study of the experiences of young Black Canadians. *American Journal of Community Psychology*, *57*(1-2), 158–170. https://doi.org/10.1002/ajcp.12024

Heasman, B., & Gillespie, A. (2018). Perspective-taking is two-sided: Misunderstandings between people with Asperger's syndrome and their family members. *Autism*, *22*, 740–750. https://doi.org/10.1177/1362361317708287

Henry, J. D., & Crawford, J. R. (2005). The short-form version of the Depression Anxiety Stress Scales (DASS-21): Construct validity and normative data in a large non-clinical sample. *British Journal of Clinical Psychology*, *44*(2), 227–239. https://doi.org/10.1348/014466505X29657

Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry: The Journal of Mental Science*, *208*(3), 232–238. https://doi.org/10.1192/bjp.bp.114.160192

Hudson, C. C., Hall, L., & Harkness, K. L. (2018). Prevalence of depressive disorders in individuals with autism spectrum disorder: A meta-analysis. *Journal of Abnormal Child Psychology*, 47(1), 165–175. https://doi.org/10.1007/s10802-018-0402-1

Huws, J., & Jones, R. S. P. (2010). 'They just seem to live their lives in their own little world': Lay perceptions of autism. *Disability & Society*, *25*(3), 331–344. https://doi.org/10.1080/09687591003701231

JASP Team. (2022). JASP (Version 0.16.3) [Computer software].

Jones, D. R., DeBrabander, K. M., & Sasson, N. J. (2021). Effects of autism acceptance training on explicit and implicit biases toward autism. *Autism: The International Journal of Research and Practice*, *25*(5), 1246–1261. https://doi.org/10.1177/1362361320984896

Jones, R., Zahl, A., & Huws, J. (2001). First-hand accounts of emotional experiences in autism: A qualitative analysis, *Disability & Society, 16*(3), 393–401. https://doi.org/10.1080/09687590120045950

Kapp, S. (2018). Social support, well-being, and quality of life among individuals on the autism spectrum. *Pediatrics,141*, 368. https://doi.org/10.1542/peds.2016-4300N

Kapp, S., Gillespie-Lynch, K., Sherman, L., & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology, 49*(1), 59–71. https://doi.org/10.1037/a0028353

Kelter, M. (2016). *The effects of stigmatizing language on suicidal Autistics*. Thinking person's guide to autism. http://www.thinkingautismguide.com/2016/07/the-effects-of-stigmatizing-language-on.html

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20, 442–462. https://doi.org/10.1177/1362361315588200

Lani, J. (2021, July 27). *Sample size for bivariate correlation, Pearson correlation, and Pearson product moment correlation*. Statistics Solutions. https://www.statisticssolutions.com/sample-size-for-bivariate-correlation-pearson-correlation-and-pearson-product-moment-correlation/

Latimer, O., Onaiwu, M. G., Asasumasu, K., Martin, M., & Schonger, J. (2022). *Harm reduction through education & practice with foundations for divergent minds* [Webinar]. New Jersey Autism Center of Excellence. https://njace.us/big-fish-even-bigger-ocean/#

Lever, A., & Geurts, H. (2016). Psychiatric co-occurring symptoms and disorders in young, middle-Aged, and older adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 46*(6), 1916–1930. https://doi.org/10.1007/s10803-016-2722-8

Linton, K. F. (2014). Clinical diagnoses exacerbate stigma and improve self-discovery according to people with autism. *Social Work in Mental Health,* 12(4), 330–342. https://doi.org/10.1080/15332985.2013.861383

Lovibond, S. H., & Lovibond, P. F. (1995). *Depression Anxiety Stress Scales (DASS--21, DASS—42)* [Database record]. APA PsycTests. https://doi.org/10.1037/t01004-000

Maddox, B. B., & White, S. W. (2015). Comorbid social anxiety disorder in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *45*(12), 3949–3960. https://doi.org/10.1037/t01004-000

Maenner, M. J., Shaw, K .A., Bakian, A.V., Bilder, D. A., Durkin, M. S., Esler, A., Furnier, S. M., Hallas, L., Hall-Lande, J., Hudson, A., Hughes, M. M., Patrick, M., Pierce, K., Poynter, J. N., Salinas, A., Shenouda, J., Vehorn, A., Warren, Z., Constantino, J. N. … Cogswell, M. E. (2021). Prevalence and characteristics of autism spectrum disorder among children aged 8 years—Autism and developmental disabilities monitoring network, 11 Sites, United States, 2018. *Morbidity and Mortality Weekly Surveillance Summer 2021*, *70*(No. SS-11): 1–16. http://dx.doi.org/10.15585/mmwr.ss7011a1

Meyer, I. H. (1995). Minority stress and mental health in gay men. *Journal of Health and Social Behavior*, *36*(1), 38–56. https://doi.org/10.2307/2137286

Meyer, I. H. (2003). Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: Conceptual issues and research evidence. *Psychological Bulletin, 129*(5), 674-697. doi:10.1037/0033-2909.129.5.674

Meyer, I. H., & Dean, L. (1998). Internalized homophobia, intimacy, and sexual behavior among gay and bisexual men. In G. M. Herek (Ed.), *Stigma and sexual orientation: Understanding prejudice against lesbians, gay men, and bisexuals* (pp. 160–186). Sage Publications, Inc. https://doi.org/10.4135/9781452243818.n8

Milton, D. (2012a). *So what exactly is autism?* Autism Education Trust.

Milton, D. (2012b). On the ontological status of autism: the 'double empathy problem', *Disability & Society*, *27*(6), 883–887. https://doi.org/10.1080/09687599.2012.710008

Milton, D., & Moon, L. (2012). The normalisation agenda and the psycho-emotional disablement of autistic people. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, *1*(1). http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/9

Milton, D., & Sims, T. (2016). How is a sense of well-being and belonging constructed in the accounts of autistic adults? *Disability & Society*,*31*(4), 520–534. https://doi.org/10.1080/09687599.2016.1186529

Morrison, K. E., DeBrabander, K. M., Jones, D. R., Faso, D. J., Ackerman, R. A., & Sasson, N. J. (2020). Outcomes of real-world social interaction for autistic adults paired with autistic compared to typically developing partners. *Autism*, 24, 1067–1080. https://doi.org/10.1177/1362361319892701

Mottron, L. (2011). Changing perceptions: The power of autism. *Nature, 479*(7371), 33–35. https://doi.org/10.1038/479033a

Neumeier, S. (2012). Inhumane beyond all reason. In J. Bascom (Ed.), *Loud hands: Autistic people, speaking* (pp. 204–217). The Autistic Press.

Ng, F., Trauer, T., Dodd, S., Callaly, T., Campbell, S., & Berk, M. (2007). The validity of the 21-item version of the Depression Anxiety Stress Scales as a routine clinical outcome measure. *Acta Neuropsychiatrica*, *19*(5), 304–310. https://doi.org/10.1111/j.1601-5215.2007.00217.x

O'Dell, L., Rosqvist, H. B., Ortega, F., Brownlow C., & Orsini, M. (2016). Critical autism studies: Exploring epistemic dialogues and intersections, challenging dominant understandings of autism, *Disability & Society*, *31*,(2), 166–179. https://doi.org/10.1080/09687599.2016.1164026

Orsini, M., & Smith, N. (2010). Social movements, knowledge and public policy: The case of autism activism in Canada and the US. *Critical Policy Studies, 4*(1), 38–57. https://doi.org/10.1080/19460171003714989

Rappaport, J. (2000). Community narratives: Tales of terror and joy. *American Journal of Community Psychology*, 28, 1–24. https://doi.org/10.1023/A:1005161528817

Raymaker, D. M., Teo, A. R., Steckler, N. A., Lentz, B., Scharer, M., Delos Santos, A., Kapp, S. K., Hunter, M., Joyce, A., & Nicolaidis, C. (2020). "Having all of your internal resources exhausted beyond measure and being left with no clean-up crew": Defining autistic burnout. *Autism in Adulthood*, *2*(2), 132–143. https://doi.org/10.1089/aut.2019.0079

Robertson, S. M. (2009). Neurodiversity, quality of life, and autistic adults: Shifting research and professional focuses onto real-life challenges. *Disability Studies Quarterly*, *30*(1). https://doi.org/10.18061/dsq.v30i1.1069

Rosa, S. (2019a). *Mission*. Thinking Person's Guide to Autism. http://www.thinkingautismguide.com/p/mission-statement.html.

Rosa, S. (2019b). *Position*. Thinking Person's Guide to Autism. http://www.thinkingautismguide.com/p/position.html

Rosenberg, M. (1989). *Society and the adolescent self-image*. Revised edition. Wesleyan University Press.

Rosqvist, H. B., Brownlow, C., & O'Dell, L. (2015). "An association for all"– Notions of the meaning of autistic self-advocacy politics within a parent-dominated autistic movement." *Journal of Community & Applied Social Psychology*, *25*(3), 219–231. https://doi.org/10.1002/casp.2210

Sasson, N. J., Faso, D. J., Nugent, J., Lovell, S., Kennedy, D. P., & Grossman, R. B. (2017). Neurotypical peers are less willing to interact with those with autism based on thin slice judgments. *Scientific Reports, 7*, 40700. https://doi.org/10.1038/srep40700

Schaber, A. (2015). *Ask an Autistic #23— What is Autism?* [Video]. YouTube. https://www.youtube.com/watch?v=Vju1EbVVgP8&ab_channel=AmythestSchaber

Schmitt, D. P., & Allik, J. (2005). Simultaneous administration of the Rosenberg Self-Esteem Scale in 53 nations: Exploring the universal and culture-specific features of global self-ssteem. *Journal of Personality and Social Psychology, 89*(4), 623–642. https://doi.org/10.1037/0022-3514.89.4.623

Sequenzia, A. (2012). Why *Autism S*peaks hurts us. In J. Bascom (Ed.), *Loud hands: Autistic people, speaking* (pp. 275–278). The Autistic Press.

Sidanius, J., & Pratto, F. (2012). Social dominance theory. In P. A. M. Van Lange, A. W. Kruglanski, & E. T. Higgins (Eds.), *Handbook of theories of social psychology* (pp. 418–438). Sage Publications Ltd. https://doi.org/10.4135/9781446249222.n47

Silberman, S. (2015). *Neurotribes: The legacy of autism and the future of neurodiversity*. Avery, an imprint of Penguin Random House. https://doi.org/10.1353/anq.2015.0057

Sinclair, J. (1999). *Why I dislike person first language*. Jim Sinclair's Website. https://web.archive.org/web/20090201090612/http://web.syr.edu/~jisincla/index.html

Sinclair, S. J., Blais, M. A., Gansler, D. A., Sandberg, E., Bistis, K., & LoCicero, A. (2010). Psychometric properties of the Rosenberg Self-Esteem Scale: Overall and across demographic groups living within the United States. *Evaluation & the Health Professions*, *33*(1), 56–80. https://doi.org/10.1177/0163278709356187

Smith, W. (2008). *Does gender influence online survey participation? A record-linkage analysis of university faculty online survey response behavior*. Online Submission. https://eric.ed.gov/?id=ED501717

Solomon, A. (2008). The autism rights movement. *New York Magazine*. http://nymag.com/news/features/47225/

Strang, J., Kenworthy, L., Daniolos, P., Case, L., Wills, M., Martin, A., & Wallace, G. (2012). Depression and anxiety symptoms in children and adolescents with autism spectrum disorders without intellectual disability. *Research in Autism Spectrum Disorders, 6*(1), 406–412. https://doi.org/10.1016/j.rasd.2011.06.015

Walker, N. (2021). *Neuroqueer heresies: Notes on the neurodiversity paradigm, autistic empowerment, and postnormal possibilities*. Autonomous Press.

Warrier, V., Greenberg, D.M., Weir, E., Buckingham, C., Smith, P., Lai, M. C., Allison, C., & Baron-Cohen, S. (2020). Elevated rates of autism, other neurodevelopmental and psychiatric diagnoses, and autistic traits in transgender and gender-diverse individuals. *Nature Communications*, *11*(1), 3959. https://doi.org/10.1038/s41467-020-17794-1

Winter, P. (2012). Loud hands & loud voices. In J. Bascom (Ed.), *Loud hands: Autistic people, speaking* (pp. 115–125). The Autistic Press.

Wright, E., Gronfein, W., & Owens, T. (2000). Deinstitutionalization, social rejection, and the self-esteem of former mental patients. *Journal of Health and Social Behavior, 41*(1), 68–90. https://doi.org/10.2307/2676361