NEURO-UNITY: A REALIST SYNTHESIS OF NEURODIVERSITY AND THE ESTABLISHED CLINICAL MODEL OF AUTISM SPECTRUM DISORDER

by

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Abstract

The purpose of this realist synthesis study is threefold: (a) to examine the relationship between young autistic adults between 18 and 30 years of age and their clinical providers (e.g., doctors, therapists, educators, caregivers, etc.), (b) to understand what conditions contribute to trusting and inclusive relationships between young autistic adults and their clinical providers, and how more trusting and inclusive relationships can be maintained, and (c) to develop a new conceptual framework to address what was believed to be conflicting ideologies between proponents of the Neurodiversity movement and their clinical providers—what the researcher calls Neuro-Unity. Using a systematic search and review process, the researcher searched, screened, and reviewed an initial set of 262 qualitative studies published in the U.S. and U.K. between 1980 and 2022 to select 23 qualitative studies that met all inclusion criteria for data extraction. Following the multi-stage extraction process of a realist synthesis according to the RAMESES I protocol, findings were coded into themes of empathy, respect, and dignity; integrated support systems; inclusion of autistic voices; and education about autism spectrum disorders. Themes were used to develop the Neuro-Unity conceptual framework. This new framework describes how to facilitate, form, and maintain trusting and inclusive relationships between young autistic adults and their clinical providers. Implications for future theory development and practice, study limitations, and recommendations for future research are also provided.

Dedication

To all those who came before me, your voices have been heard.

To all those who are yet to come, I hope I have prepared a better world for you.

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CHAPTER ONE: INTRODUCTION

Background

Autism spectrum disorder (ASD) is classified in the American Psychiatric Association's (2013) *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM-5*) as a neurodevelopmental disorder characterized by impaired social communication and social interaction and restricted, repetitive patterns of behavior (pp. 50-59). The *DSM-5* clarifies such symptoms are present from early childhood and impair everyday functioning, and they cannot be explained by intellectual disability (American Psychiatric Association, 2013).

What the *DSM-5* neglects to consider is how autism spectrum disorder affects the physiology of the brain, and vice versa. Proponents of Neurodiversity might point to anomalies in their brains' structure as evidence of their claim that autism spectrum disorders are a natural variation of human development, rather than the abnormal disorder described in the *DSM-5* (Lathe, 2006; Ha et al., 2015; Herringshaw, 2016; Chandran et al., 2021; Di Martino et al., 2014; O'Reilly et al., 2017). Researchers have found abnormalities in the hippocampus, amygdala, cerebellum, cortex and other regions of autistic brains (Lathe, 2006; Ha et al., 2015; Herringshaw, 2016). Most of what Lathe (2006) discovered were smaller and more densely packed neurons, as well as enlargement, in some areas of the brains. Chandran et al. (2021) found that regional grey matter variations in several parts of the brain could be correlated with traits of autism spectrum disorders. Furthermore, Di Martino et al. (2014) and O'Reilly et al. (2017)

found that hypoconnectivity between various parts of the brain could be linked to autism spectrum disorders.

This is not to necessarily imply that any differences in brain structure are problematic; merely, this is to say differences exist in the brain structure of an individual who may exhibit behaviors related to an autism spectrum disorder diagnosis. Measurements of the brain are to be considered as tools to help identify any variations from typical development. Any such variations found must be interpreted under the proper context—for example, an enlarged amygdala may be related to a pattern of aggressive behaviors, but the individual's team of clinical providers must determine the specific contexts of when an enlarged amygdala may be beneficial to the individual (if an aggressive individual might be more inclined to advocate for their needs) and when it might impede their functioning (if the individual's fight-or-flight response from an enlarged amygdala influences an individual's decision to resort to physical violence during a stressful confrontation). That is to say, some differences are beneficial in some ways and impairments in other ways. A difference, in and of itself, is just a difference unless interpreted in its proper context.

Thus, neither the *DSM-5* (American Psychological Association, 2013) nor the Neurodiversity movement (Sinclair, 1993/2012a; Singer, 1998/2017) have all the answers. From this realization, it can be concluded that the more complete model of autism spectrum disorder is a combination of the two descriptions—that is, a natural variation of human development which can affect neurodevelopment in a variety of atypical ways—whether positive, negative, or indifferent—and may require accommodation to enable a more typical level of functioning. Neurodivergent individuals, such as those diagnosed with an autism spectrum disorder, may need varying levels of accommodations (Sarrett, 2016). Neurodivergent individuals are not so eager to rely on the well-oiled machine, the established clinical model of autism spectrum disorder, that was designed to provide those accommodations (Sarrett, 2016). Decades of exclusion and, in some cases, isolation have eroded neurodivergent individuals' faith in the established clinical model of autism spectrum disorder to manage their lives (Sarrett, 2016). Clinical providers can include doctors, therapists, educators, direct support professionals, family members, caregivers, and so forth.

Statement of the Problem

Many neurodivergent individuals often express feelings of discrimination and exclusion, contending that autism spectrum disorders are simply a natural variation of human development rather than a disorder (Hughes, 2021; Nelson, 2021; Singer, 1998/2017). The Autistic Self Advocacy Network (ASAN; n.d.-b) argues that autism spectrum disorder is a disability, therefore neurodivergent individuals are not required to change themselves, rather they must be accommodated by neurotypical society. Neurotypical society has often accepted the idea that the clinical providers decide what types of interventions, if any, are necessary and when they should be implemented. However, the prevailing instinct is to exclude the individual from these decisions. As a result, some neurodivergent individuals prefer to diagnose themselves, rather than to seek the advice of trained medical experts (Sarrett, 2016). Many neurodivergent individuals would view their self-diagnosis to be a non-issue, but they would still expect accommodations from neurotypical society.

However, in rejecting an official clinical diagnosis, neurodivergent individuals run the risk of excluding themselves from the accommodations which may otherwise have been made available to them due to a lack of credible documentation (Kuangparichat, 2010). Neurodiversity thus results in further neurodivergent distrust of neurotypical society, failing to resolve any of the issues it seeks to alleviate.

Furthermore, most accommodations the established clinical model of autism spectrum disorder and neurotypical society have provided are only offered to autistic youth—typically expiring once they reach age 21 (Kuangparichat, 2010; Silberman, 2016). Silberman (2016) refers to the expiration of accommodations as “falling off a cliff” (para. 8). In refusing an official clinical diagnosis of an autism spectrum disorder, some neurodivergent individuals essentially refuse what little accommodations are left available to them as autistic adults (Kuangparichat, 2010; Sarrett, 2016). Furthermore, with the most recent changes to the diagnostic criteria in the *DSM-5*, the very real possibility of comorbid conditions—for example, depression, anxiety, and suicidal thoughts—are now considered in tandem with an autistic spectrum disorder diagnosis and may go untreated in individuals rejecting clinical intervention (American Psychological Association, 2013). These comorbid conditions may also follow individuals into their adulthood, as well.

With the autism spectrum disorder prevalence rate approaching two percent of society (approximately 1 in 44), the need for accommodations to follow neurodivergent individuals into adulthood only intensifies the urgency of the problem (Maenner et al., 2021). This urgency contributes to a set of circumstances which can be referred to as *the Great Schism of Autism*.

The Great Schism of Autism

The rise of ASAN and the Neurodiversity movement has been historically problematic for the established clinical model of autism spectrum disorder and neurotypical parents of neurodivergent children (Donvan & Zucker, 2016). Since the days of Jim Sinclair's (1993/2012a) original manifesto, parents who have spent over three decades between the 1960s and the early 1990s fighting for their neurodivergent children's rights have felt betrayed by the insinuation they, themselves, may now be considered the societal hinderance to their children's success due to their fear-based search for a cure for autism spectrum disorder (Donvan & Zucker, 2016).

When the American Psychiatric Association announced the removal of Asperger's Syndrome from the upcoming *DSM-5* to be combined into the autistic spectrum, some parents backlashed against the notion their children's autism spectrum disorder could be lumped in with forms of autism spectrum disorder with fewer or less severe symptoms (Donvan & Zucker, 2016). They began to refer to their children's severe range of symptoms as "real autism" in retaliation to the Neurodiversity movement's rejection of a "cure for autism" (Donvan & Zucker, 2016).

The *DSM* has invoked backlash before. By the *DSM-III*'s printing in 1980, an anti-psychiatry sentiment had swept the court of popular opinion (Silberman, 2015). The anti-psychiatry movement of the 1960s and 1970s largely centered around the works of

R. D. Laing, though the movement also influenced other researchers, for example, Thomas Szasz. Laing's opinions that psychiatry's focus on individuals' psychological and emotional weaknesses directly contradicted its dutiful necessity to develop and encourage the corresponding strengths of the individuals it serves helped influence the biopsychosocial model, which in turn, helped inform the social model of disability used as a basis for the current Neurodiversity movement (Crossley, 1998; Desai, 2005; Double, 2002, 2006).

By 1988, the film, *Rain Man* had raised attention back to the severe symptoms of autism spectrum disorder, defining the condition in terms of "savant syndrome" (Donvan & Zucker, 2016; Silberman, 2015). Asperger's Syndrome was added to the DSM-IV in 1994, indicating the recognition that some autistic individuals were not as profoundly affected by the autism spectrum (Silberman, 2015).

Enter Jim Sinclair (1993/2012a), proclaiming:

> Continuing focus on the child's autism as a source of grief is damaging for both the parents and the child, and precludes the development of an accepting and authentic relationship between them. For their own sake and for the sake of their children, I urge parents to make radical changes in their perceptions of what autism means. (p. 16)

The process of attempting to define what autism spectrum disorder is suddenly became more daunting, as nobody could agree on what autism spectrum disorder even was and how it affects the individual (Donvan & Zucker, 2016). For the neurotypical parents of neurodivergent children with an additional diagnosis of an intellectual disability, the rejection of a search for a cure was a major step in the wrong direction, and it needed to be addressed quickly (Donvan & Zucker, 2016). To the neurodivergent members of the Neurodiversity movement, a cure would undermine everything they have fought against and everything they could ever potentially be (ASAN, n.d.-b).

Purpose of the Study

The purpose of this study was to attempt a realist synthesis examining the relationship between young autistic adults and their clinical providers (e.g., doctors, therapists, educators, caregivers, etc.). This study looked to understand what conditions contribute to trusting and inclusive relationships between young autistic adults and their clinical providers, and how more trusting and inclusive relationships can be maintained. This enabled the researcher to develop a new conceptual framework to address what was believed to be conflicting ideologies between proponents of the Neurodiversity movement and their clinical providers—what the researcher calls *Neuro-Unity*.

Realism is a methodological orientation utilizing social mechanisms, triggered by the specific contexts in which they operate, and which generate outcomes (Wong et al., 2013). Realist synthesis systematically reviews a body of pre-existing research information to refine theory and determine what works for whom, under what contexts, and why (Pawson, 2002; Pawson et al., 2005). The product of realist synthesis is a new conceptual framework and the potential it has for practical applications in policymaking (Pawson, 2002; Pawson et al., 2005).

Research Questions

- What are the characteristics and perspectives relevant to the relationship between young autistic adults and their clinical providers—for example, doctors, therapists, educators, caregivers, and so forth?
- What are the characteristics and perspectives that make some relationships between young autistic adults and their clinical providers more trusting and inclusive than others?
- How can trusting and inclusive relationships between young autistic adults and their clinical providers be facilitated, formed, and maintained?

Significance of the Study

While much has been written about Neurodiversity as it relates to neurotypical society and the established clinical model of autism spectrum disorder (Hughes, 2021; Nelson, 2021; Sarrett, 2016; Silberman, 2016), this study is the first research to examine how to reconcile the ideological clashes between Neurodiversity and the established clinical model of autism spectrum disorder. Although both the Neurodiversity movement and the established clinical model of autism spectrum disorder have valid and thoughtful opinions on how to move forward in the autism spectrum disorder community (Kapp et al., 2013; Silberman, 2016), neither by themselves have all the elements necessary to resolve the main issues—that is, how neurodivergent individuals access the appropriate level of supports they need to be able to function in society, who decides what type of supports are appropriate and when they are appropriate, how supports deemed appropriate are implemented, and how changes in individual needs are communicated across the support team.

For example, a neurodivergent individual would ideally be able to receive a clinical diagnosis to establish credible documentation of how their neurological differences affect the level of support they need, build a team of clinical providers to help assess what types of supports are appropriate to meet those needs, determine the most appropriate way of implementing those supports, and communicate changes in their needs. An obvious example of this scenario would be if a neurodivergent individual wants to seek employment but lacks proper hygiene, skills pertaining to forming interpersonal relationships, and comprehension of the complex social cues necessary to interview well. A clinical diagnosis would help provide credible documentation of their needs relating to seeking employment and enable access to supports like job coaching and behavioral cognitive therapies to help develop better hygiene, better interpersonal skills, and better comprehension of the complex social cues informing the hiring process. If the individual's needs were to change—for example, getting a job offer—the individual could communicate that resume-building skills are no longer appropriate, but maybe more emphasis could be placed on interpersonal skills and navigating the social cues of the workplace.

On the other hand, if a neurodivergent student is constantly harassed by their classmates in the classroom, the instructor might decide to separate the student from the rest of their classmates by isolating their desk closer to the instructor, which could exacerbate the harassment, as it would single out the victim of the harassment. A potentially more ideal solution could be developing a way for the neurodivergent individual to anonymously report harassment to be dealt with privately between the neurodivergent student and their classmates harassing them out of the public eye and without the neurodivergent individual being segregated from their peers.

To that end, a new conceptual framework was required—one named, *Neuro-Unity*, with the hope that it can and will be used to increase trust in the established clinical model while bolstering more neurodivergent inclusion when working together toward the common goal of determining the appropriateness of support systems, how and when they are to be implemented, and how to communicate changes in the level of need for certain supports. Both Neurodiversity and the established clinical model can work towards the same goals in a unified framework and mission, but some initial work must be done to lay the foundation for *Neuro-Unity.*

Operational Definitions

Autism Spectrum Disorder

Autism spectrum disorder is classified in the *DSM-5* as a neurodevelopmental disorder characterized by impaired social communication and social interaction and restricted, repetitive patterns of behavior from early childhood, which cannot be attributed to intellectual disability (American Psychiatric Association, 2013).

Identity-First Language

Ordinarily, person-first language would be used to describe individuals on the spectrum. However, many such individuals prefer identity-first language—that is, autistic person rather than person with autism (Kapp et al., 2013; Sinclair, 1999/2012b). The argument for identity-first language assumes people cannot separate themselves from aspects of their being central to their identity (Sinclair, 1999/2012b). To not disturb this assumption—perhaps even in agreement with it—the researcher will use identity-first language when speaking of autistic individuals.

Realist Synthesis

Realist synthesis is an emergent methodological approach to combining, aggregating, and integrating primary research findings to create a new conceptual framework (Schick-Makaroff et al., 2016). Realist synthesis focuses on how the complex mechanisms by which outcomes are produced and how outcomes are affected across different contexts (Pawson, 2002; Pawson et al., 2005).

Neurodiversity

Neurodiversity is an ideology grounded in the social model of disability and adopted by neurodivergent individuals seeking recognition, civil rights and an end to discrimination, and disability services appropriate to their level of functioning on the spectrum (Singer, 1998/2017). Its underlying philosophy is informed by the biopsychosocial model of psychiatry developed from the anti-psychiatry movement of the 1960s and 1970s (Crossley, 1998; Desai, 2005; Double, 2002, 2006). Prominent voices of Neurodiversity include John Elder Robison, Temple Grandin, and Jim Sinclair (Donvan & Zucker, 2016). The largest group representing the interests of Neurodiversity is the Autistic Self Advocacy Network (n.d.-a, n.d.-b).

Advocate

Advocates are any groups or individuals who represent the interests of autistic individuals and their interests in public discourse and may include autistic self-advocates representing their own interests, members of their family (e.g., parents, siblings, etc.), their friends, or a legal representative hired to support an autistic individual's interests all working together towards the common goal of representing the interests of an autistic individual.

Established Clinical Model of Autism Spectrum Disorder

The established clinical model of autism spectrum disorder is an ideology adopted by neurotypicals, professionals, and caregivers seeking normalization, reduction, and elimination of symptomatic behaviors of autism spectrum disorder which impair functioning in major life activities (Kapp et al., 2013). The largest and most influential voice for this model is Autism Speaks (n.d.-a, n.d.-b, n.d.-c). Though Autism Speaks has a storied history of advocating for a cure for autism spectrum disorders (Donvan & Zucker, 2016), a change in leadership in 2016 resulted in a cure no longer being sought as a priority, indicating a shift in priority pertaining to the established clinical model's desire to cure autism spectrum disorder (Autism Speaks, n.d.-a).

Clinical Provider

Clinical providers are any group or individual providing services or support to an autistic individual and may include doctors, therapists, educators, direct support professionals, employers, family, community support servicers, caregivers, and so forth.

Neuro-Unity

Neuro-Unity is the proposed synthesis of Neurodiversity and the established clinical model of autism spectrum disorder with the goal of increasing trust in the established clinical model of autism spectrum disorder to make it more inclusive of neurodivergent individuals.

Conclusion

The autism spectrum disorder community seems to be under stress from what can be described as a general distrust of neurotypicals, professionals, and caregivers and the potential exclusion of autistic individuals from the decision-making process affecting their lives (Donvan & Zucker, 2016). Such levels of distrust are not limited to just autistic individuals, but their parents and siblings often report feeling these emotions, too (Boshoff et al., 2018, 2019). DePape and Lindsay (2016) found that self-advocates and their families reported feeling alienated when clinical providers without lived experience are more often considered to be more credible experts than the actual self-advocates and their families with their lived experiences. Such disenfranchisement and alienation sometimes leads to delays in implementing crucial early intervention supports (Boshoff et al., 2018, 2019). Both Neurodiversity and the established clinical model of autism spectrum disorder need each other to heal the Great Schism of Autism and move the community forward (Frazier, 2019). A new conceptual framework—namely, *Neuro-Unity*—is necessary to synthesize both ideologies to achieve such a goal.

CHAPTER TWO: LITERATURE REVIEW

Introduction

This chapter presents a review of the literature to examine what is already known about autism spectrum disorders, Neurodiversity, and the established clinical model of autism spectrum disorders. Additionally, it examines where more research may be required to bolster the current understanding of the autism spectrum (Pawson, 2002; Pawson et al., 2005).

This review of the literature will begin by putting the understanding of the autism spectrum into its historical contexts, followed by analysis and synthesis of existing knowledge organized into the themes of *Trust Issues with Professionals*, *Relationships Across the Autism Spectrum*, and *Validation and Acceptance*. Afterward, relevant theoretical frameworks—namely, Neurodiversity and the established clinical model—will be analyzed to explore how they can be synthesized into a new conceptual framework—that is, *Neuro-Unity.*

Background and Relevant Literature

Two databases were checked for current systematic reviews of pre-existing empirical studies to connect this review of the literature to the breadth of pre-existing knowledge. EBSCOhost was searched through Saint Joseph's University's Francis A. Drexel Library using the search terms: "(autism or autistic or adhd or dyslexia) AND synthesis AND patient experience." Search terms returned 41 results, only eight of which, were relevant to the purpose of the research based on their being syntheses and based in the United States. Of these eight results, only seven were deemed relevant based on subject matter.

Additionally, the same search terms were run through Google Scholar. Search terms returned 1,780 results, which were then filtered to results within the past 20 years—between 2001 and 2021. This returned 1,660 results, which were filtered to results within the past 10 years—between 2011 and 2021. 1,150 results were returned; the results were further filtered to results within the past five years—between 2016 and 2021. 708 results were returned, which were then filtered to 498 results within the past three years—between 2018 and 2021.

Filtering to include only review articles returned 81 results. Initially, only eight of these results were selected for analysis, as they were relevant to the research topic, were syntheses, and pertained to attitudes about autism spectrum disorders. Only two of the original eight articles contained data which could be synthesized. The other six articles the researcher did not include in the literature review were not conducted systematically—that is, through a defined process such as the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Preferred Reporting Items for Systematic Reviews and Meta-Analyses, n.d.) or the Critical Appraisal Skills Programme (CASP; Critical Appraisal Skills Programme, 2021)—and therefore, they could not provide reliable information to the review of the literature.

Out of the nine syntheses selected for review, four of them were conducted as meta-syntheses (Boshoff et al., 2018, 2019; DePape & Lindsay, 2016; Williams et al., 2019), three as thematic syntheses (Berridge & Hutchison, 2021; Leedham et al., 2020;

O’Connor et al., 2018), one as a narrative synthesis (Coughlan et al., 2020), and one as a systematic review (Granville, 2020). All nine syntheses adhered to PRISMA guidelines when searching databases, four utilized the CASP programme for evaluating the quality of included studies (Boshoff et al., 2018, 2019; DePape & Lindsay, 2016; Leedham et al., 2020), one used Spencer et al.’s (2003) Quality Framework for Assessing Qualitative Research (Williams et al., 2019); one used the NICE Checklist for Qualitative Studies (Berridge & Hutchison, 2021), one used the MMAT tool (Coughlan et al., 2020), and one used the PICOS system (Granville, 2020). O’Connor et al. (2018) only used PRISMA. For more information on the methodological characteristics of the reviewed syntheses, see Table 1.

Table 1

Methodology of Reviewed Syntheses

Author, Year	Analysis	Objective	Sampling Strategy	Sample Size
Berridge & Hutchison, 2021	Thematic Synthesis	Assess quality of research on staff experiences of implementing intensive interaction in their workplace	PRISMA NICE Checklist for Qualitative Studies	n=9
Boshoff et al., 2018	Meta-Synthesis	Explore complexity of parental experiences of advocating for their autistic children	PRISMA CASP	n=31

Table 1, continued.

Author, Year	Analysis	Objective	Sampling Strategy	Sample Size
Boshoff et al., 2019	Meta-Synthesis	Describe parents' experiences of advocating for their autistic children	PRISMA CASP	n=22
Coughlan et al., 2020	Narrative Synthesis	Explore issues around identifying autism in children and managing care	PRISMA MMAT	n=17
DePape & Lindsay, 2016	Meta-Synthesis	Synthesize research about lived experiences of autistic individuals	PRISMA CASP	n=33
Granville, 2020	Systematic Review	Evaluate effectiveness of emotional regulation interventions for autistic children and young people	PRISMA PICOS	n=9
Leedham et al., 2020	Thematic Synthesis	Review research on lived experiences of siblings of autistic individuals	PRISMA CASP	n=18
O'Connor et al., 2018	Thematic Synthesis	Synthesize how diagnosis affects self-concept and social identity	PRISMA	n=38

Table 1, continued.

Author, Year	Analysis	Objective	Sampling Strategy	Sample Size
Williams et al., 2019	Meta-Synthesis	Investigate experiences of autistic students' school life to further research and guide policy and practice	PRISMA Spencer et al.'s (2003) Quality Framework for Assessing Qualitative Research	n=17

One of the syntheses reviewed focused on clinical practitioners' perspectives (Coughlan et al., 2020), two focused on parents' perspectives (Boshoff et al., 2018, 2019), one focused on siblings' perspectives (Leedham et al., 2020), three focused on autistic individuals' perspectives (DePape & Lindsay, 2016; O'Connor et al., 2018; Williams et al., 2019) and two focused on best practices for treatment (Berridge & Hutchison, 2021; Granville, 2020). Each syntheses' findings could be deconstructed into themes. For more information on the findings of these syntheses, see Table 2.

Table 2

Findings of Reviewed Syntheses

Author, Year	Themes	Conclusions	Limitations
Berridge & Hutchison, 2021	Personal Doubt, Discordance & Discomfort A Turning Point Needing Implementation at All Levels	Intensive interaction consistently found to be rewarding for staff and helpful to those they work with	Did not collect original data Partially dependent on quality of included research Researcher bias No standardized implementation

Table 2, continued.

Author, Year	Themes	Conclusions	Limitations
Boshoff et al., 2018	Seeking a diagnosis Seeking self-education Taking action (Seeking, access, and use of support services Community engagement and educating others)	Positive experiences with first-line professionals significantly impact diagnosis process, and these experiences lay the foundation for all future experiences with other service providers	Age of participants limited to early childhood Scope of studies limited to Westernized countries
Boshoff et al., 2019	Pathway to diagnosis—Confusion and not feeling heard Pursuing diagnosis—resilience and commitment	Parents experience intense emotional journey during identification of initial concerns and formal diagnostic process and perceive not being supported by others	Contexts limited to English language Scope of studies limited to Westernized countries Search and selection criteria focused specifically on diagnostic process—limited perspective of parental advocacy

Table 2, continued.

Author, Year	Themes	Conclusions	Limitations
Coughlan et al., 2020	Prototypical image of an autistic child Experience, sources of information, and managing care Barriers to identification Strategies to aid in identification Characteristics that facilitate expertise	Mixed picture of general practitioner knowledge and experiences in identifying autism and managing care Some general practitioners never heard of autism or endorsed outdated theories Others demonstrated sound knowledge but limited confidence in ability to identify autism Call for more training amongst general practitioners and researchers	Some included studies were not peer reviewed Adults not considered for participation Lack of consistency across definitions of "autism" Variations in international primary care systems Epistemological concerns
DePape & Lindsay, 2016	Perception of self Interactions with others Experiences at school Factors related to employment	Some autistic individuals did not want to understand the implications of their diagnosis, while others struggled with it in adolescence Many adults accepted their diagnosis and could not imagine life without being autistic	Sex ratio not always reflected in research Only verbal individuals with high-functioning ASD included in research Limited cultural and socioeconomic contexts Majority of articles do not reflect changes in understanding of ASD

Table 2, continued.

Author, Year	Themes	Conclusions	Limitations
Granville, 2020	Cognitive Behavioral Therapy-based interventions Mindfulness-based interventions Behavioral interventions	Encouraging evidence suggests Cognitive Behavioral Therapies can be effective at improving emotional regulation abilities in autistic children Mindfulness techniques demonstrated promising findings for application to emotional regulation treatments Parental participation likely to be a key component in effective emotional regulation treatments	Four studies lacked an active control group No second-rater means a risk of bias Grey literature should have been explored
Leedham et al., 2020	Roles and Responsibilities Impact of behaviors Process of adjustment Interpersonal experiences	Love and empathy found to be present but strained by significant difficulties affecting siblings' mental health	Researcher bias Participants limited to undiagnosed or neurotypical siblings Small sample size

Table 2, continued.

Author, Year	Themes	Conclusions	Limitations
O'Connor et al., 2018	Self-concept Social identity	Diagnosis can threaten and devalue young people's self-concept, while facilitating self-understanding, self-legitimation, and self-enhancement Diagnosis can lead to social alienation, invalidation, and stigmatization, while promoting social identification and acceptance	No grey literature was referenced Restricted to studies published in English Lack of standardized terms Systematic review protocol not registered in advance of review Precise ways results differ from each other across age, gender, culture, and diagnostic category unclear
Williams et al., 2019	Difficulties linked to autism spectrum disorders Interpersonal relationships Accessibility of school environment.	Autistic students view themselves as different, while inclusive mainstream settings may accidentally accentuate differences from peers	Gaps in literature Methodological limitations of included studies

Before reporting the information gleaned from the reviewed literature, historical contextualization supports understanding how autism spectrum disorder has been defined and understood, and how these definitions and understandings have evolved since it was first described in 1937 (Donvan & Zucker, 2016). The information contained in the historical analysis has been provided mainly by Donvan and Zucker (2016).

Historical Context

Autism spectrum disorder has been defined and understood in various ways over the past eighty years. Donvan and Zucker (2016) conveniently provide a timeline of the history of autism spectrum disorder (pp. 553-562). The history of autism spectrum disorder can be divided into three distinct generations: Discovery (1937-1961), Autistic Rights (1962-1992), and Self-Advocacy (1993-Present). Furthermore, a fourth generation seems to await beyond the horizon with implications for the future of autism spectrum disorders. The history of autism spectrum disorder began with the first diagnosed child born in 1933, Donald Triplett (Donvan & Zucker, 2016, p. 553).

Generation I – Discovery: 1937-1961

It should be noted that in 1924, a prominent Soviet psychiatrist named Grunya Sukhareva received a visit from a 12-year-old boy Sukhareva would later describe in the same terms that the *DSM-5* describes autism spectrum disorder, thus creating a point of contention about the actual date of discovery of autistic traits. However, Donvan & Zucker (2016) describe the Discovery Generation as beginning with four-year-old Donald Triplett's behavioral symptoms presenting in 1937 (p. 553). A year later, his parents reached out to a child psychiatrist at John Hopkins Hospital, Leo Kanner, with a detailed account of Donald's behavioral symptoms (p. 553). Around the same time, Hans Asperger spoke of highly intelligent patients with social and behavioral symptoms similar to Donald Triplett's (p. 554). He calls the collection of symptoms "autistic psychopathy" (Donvan & Zucker, 2016, p. 554).

Donvan & Zucker (2016) posit that Kanner, came to a similar discovery; diagnosed Donald Triplett with what he called "Autistic Disturbances of Affective Contact" and published his findings, leading to autism coming to be recognized as a distinct psychological condition (p. 554). While Asperger's work would be largely ignored for the next 36 years, Kanner's remarks in a 1948 *Time* magazine article coins the phrase, "refrigerator mother," blamed uncaring or unloving parents for causing autism (p. 554). Mildred Creak attempted to define the criteria for diagnosing what she called "Schizophrenic Syndrome in Childhood" in her 1961 paper, *Nine Points* (Donvan & Zucker, 2016, p. 555).

Generation II – Autistic Rights: 1962-1992

Whereas the Discovery Generation focused on defining diagnostic criteria, often blaming parents as the root cause of autism spectrum disorder, the second generation, Donvan & Zucker (2016) explain that the Autistic Rights Generation, was underscored by said parents fighting back for their diagnosed children's rights (pp. 555-558). In 1962, a group of British parents founded the National Autistic Society to lobby for autistic rights (p. 555). A year later, British psychologists, Beate Hermelin and Neil O'Connor, began experiments which would last until 1970 (p. 555). Their research led them to believe autism spectrum disorders were caused by biological factors (p. 555). During this time, Bernard Rimland, a psychiatrist, and parent of an autistic son, published his findings, criticizing Kanner's theory of refrigerator mothers (Donvan & Zucker, 2016, p. 555).

Donvan & Zucker (2016) mention the famous 1964 study known as the "Dicky Study" which popularized Applied Behavioral Analysis, helping an autistic child retain his eyesight (p. 555). The same year, O. Ivar Lavaas used a combination of Applied Behavioral Analysis and electrical shocks to modify autistic behavior (p. 555). Proponents of Neurodiversity would later use Lovaas's experiments to stake the claim

Applied Behavioral Analysis is inherently abusive to neurodivergent individuals (Vivian, 2009/2012). *LIFE* magazine published an article about Lovaas's experiments in 1965, making the world aware of Applied Behavioral Analysis (Donvan & Zucker, 2016, p. 555).

Donvan & Zucker (2016) include that while Lovaas was making his rounds in the media, American parents continued advocating for their autistic children's rights through the newly established National Society for Autistic Children (NSAC; Donvan & Zucker, 2016, p. 555). The first school specifically serving the needs of autistic children opened in the United Kingdom in 1965 (p. 555). Despite the backlash against Kanner's "refrigerator mother theory," Bruno Bettelheim, then the director of Orthogenic School at the University of Chicago, published his book, blaming autism spectrum disorders on psychological trauma inflicted by parents during childhood; the book quickly became a bestseller (p. 556). At the same time, the conditions inside several American institutions serving autistic children were exposed as "hell on earth" by an educator named Burton Blatt and his photographer, Fred Kaplan (Donvan & Zucker, 2016, p. 556).

Donvan & Zucker (2016) mention that Blatt's and Kaplan's exposé seemed to spur further backlash against the "refrigerator mother theory," which Kanner recanted during a 1969 speech at the National Society for Autism in which he "exonerated" parents as the root cause of autism spectrum disorders (p. 556). Within a year, psychiatrist and parent of an autistic daughter, Lorna Wing, published the first book about raising an autistic child (p. 556). The next few years were spent on lawsuits and legislation providing public education to all children, including autistic children and children with other disabilities (pp. 556-557). The Federal Education for All Handicapped Children Act was passed in 1975; it would later be renamed the Individuals with Disabilities Education Act (Donvan & Zucker, 2016, p. 557).

Donvan & Zucker (2016) go on to explain that while advocating for their children's rights, parents and researchers also focused their efforts on further research into the causes of autism spectrum disorders, resulting in Michael Rutter's and Susan Folstein's "Twin Study" (p. 557). Rutter and Folstein published their study, equating autism spectrum disorders with a strong genetic component (p. 557). In 1979, Lorna Wing argued autistic symptoms should be considered as part of a spectrum, thus the autism spectrum as we know it is born (p. 557). During this period, the 1980 *DSM-III* included autism as a mental disorder for the first time (Donvan & Zucker, 2016, p. 557).

According to Donvan & Zucker (2016), more developments in the autistic community would define the 1980s (p. 558). A 1985 landmark study determined autistic individuals possess an impaired "Theory of Mind," lacking the ability to read the mental states of other people (. Firsthand accounts of autistic life begin appearing with Temple Grandin's first book, *Emergence: Labeled Autistic*, in 1986 (p. 558). Grandin's book marks the beginnings of the transition into the third generation, though autism would not be legally classified as a disability until the Individuals with Disabilities Education Act's passage in 1990 (Donvan & Zucker, 2016, p. 558).

Generation III – Self-Advocacy: 1993-Present

Donvan & Zucker (2016) go on to explain that by 1993, parents had spent much of the previous three decades fighting for their autistic children's rights and resources (pp. 555-558). However, thirty years of parental advocacy would soon have to make way for autistic children who grew into autistic adults to begin advocating for themselves (pp. 559-562). In 1993, the self-advocacy movement officially began when Jim Sinclair delivered his famous “Don’t Mourn for Us” speech. (p. 559). His speech provided the underlying foundation for what would become known as Neurodiversity (Donvan & Zucker, 2016, p. 559).

While Judy Singer (1998/2017) presented her thesis, putting a name to Sinclair’s self-advocacy movement—namely, Neurodiversity, Donvan & Zucker (2016) explain that a British gastroenterologist named Andrew Wakefield published his infamous study blaming the MMR vaccine for causing autism spectrum disorders (p. 560). *The Lancet* would retract Wakefield’s study in 2010, after several of his ethical violations when conducting the research came to light (p. 562). Wakefield’s accusations spurred several autism organizations to investigate research attempting to prove a link between vaccines and autism (Donvan & Zucker, 2016, pp. 560-561).

One such organization, Autism Speaks, would go further by funding research into curing autism spectrum disorders The search for a cure for autism would catch the attention of Ari Ne’eman, an activist and founder of the Autistic Self Advocacy Network (ASAN; Donvan & Zucker, 2016, p. 561). ASAN would gain influence after its successful campaign to force New York City to pull ads depicting autism as kidnappers holding children hostage (Donvan & Zucker, 2016, p. 561).

ASAN would continue to gain influence as several lawsuits determined no link between plaintiffs’ vaccinations and their loved ones’ autistic symptoms (Donvan &

Zucker, 2016, p. 562). While *The Lancet* scurried to retract Wakefield's study, accusations were levied against Hans Asperger over his likely ties to the Nazi regime and its role in murdering children with disabilities during World War II (Donvan & Zucker, 2016, p. 562). While Asperger, himself, never actually joined the Nazi party, he was determined to have pledged his loyalty to the Third Reich (Furfarro, 2018).

Asperger's Syndrome, named after Hans Asperger, was officially removed from the *DSM-5* when several disorders linked to the autism spectrum—including Asperger Syndrome—were reorganized under the umbrella term autism spectrum disorder in 2013 (American Psychiatric Association, 2013; Donvan & Zucker, 2016, p. 562). This was done for reasons not related to the accusations against Hans Asperger (Furfarro, 2018). Historians are still split on whether to continue using Asperger's name eponymously with the milder forms of autism spectrum disorder (Furfarro, 2018).

Generation IV – Implications for the Future

While Donvan and Zucker's (2016) timeline ends with the removal of Asperger's Syndrome from the *DSM-5* (p. 562), more developments have occurred since then. In 2013, German software company, SAP, announced to *Reuters* their intention to hire 600 autistic employees worldwide by 2020 (Kelland, 2013). As of the present moment, SAP no longer provides an exact number of employees hired through the program on the Autism at Work page on their website (SAP, n.d.).

SAP's announcement of their Autism at Work initiative seems to suggest a growing wave of support for the Neurodiversity movement. Even Autism Speaks (n.d.-a) announced they are no longer seeking a cure for autism in 2016. Saint Joseph's

University's Kinney Center for Autism Education and Support (n.d.)—which still uses Applied Behavioral Analysis as a treatment to modify autistic behavioral symptoms—now offers trainings rewarding participants with a Neurodiversity at Work Certificate for successful completion of the training.

With Neurodiversity seeming to grow in prominence, all the recent developments seem to indicate another shift toward a new paradigm. The hope is the new paradigm will involve more coexistence between autistic self-advocates and their professional caregivers. Several issues must be resolved before such a paradigm shift can occur.

Trust Issues with Professionals

Arguably the largest issue to resolve surrounds several interested parties across the autism spectrum possibly harboring potential trust issues with medical professionals and educators (Boshoff et al., 2018, 2019; Coughlan et al., 2020; DePape & Lindsay, 2016). At the root of feelings of distrust lies the diagnostic process (Boshoff et al., 2018, 2019). Some parents have reported dismissive attitudes from their diagnosing medical professionals (Boshoff et al., 2018, 2019). Additionally, the diagnostic process can result in an over-emphasis on negative traits of autism spectrum disorders and either no emphasis or under-emphasis on positive traits (Boshoff et al., 2019). These unfortunate circumstances may not be entirely avoidable (Berridge & Hutchinson, 2021; Coughlan et al., 2020).

Some medical professionals have indicated a need for more time and space for more training in subjects relevant to autism spectrum disorders (Berridge & Hutchinson, 2021; Coughlan et al., 2020). These medical professionals have reported feeling overloaded with their caseloads due to time constraints, and the fact that there are just too many individuals to diagnose which limit their ability to provide more careful attention to clients (Coughlan et al., 2020). The prevailing fear is too much emotional attachment will result in emotional overload; thus, many professionals feel the need to emotionally distance themselves from their clients (Berridge & Hutchinson, 2021).

Because of the emotional distance between some professionals and their autistic clients (Berridge & Hutchinson, 2021), many such clients feel a stronger lack of trust in the established clinical model (DePape & Lindsay, 2016). Clients with lived experience with their autism spectrum disorders may feel they are rarely considered experts, yet their caregiving professionals (ranging from healthcare to education), lacking in personal, lived experience with autism spectrum disorders, are much more often considered the only experts in the field (DePape & Lindsay, 2016).

Additionally, some autistic students in educational settings have expressed feeling left behind by educators (DePape & Lindsay, 2016). These emotions can stem from not understanding their coursework to the inability to keep up with the pace of their classes (DePape & Lindsay, 2016). Some students have indicated the desire to demonstrate the level of their knowledge of course-related content, if only to “prove themselves” to their neurotypical classmates (DePape & Lindsay, 2016).

Relationships Across the Autism Spectrum

DePape & Lindsay (2016) and O’Connor et al. (2018) posit similar ideas about interpersonal relationships being rather difficult across the autism spectrum, especially where neurotypical peers are concerned. Many autistic individuals reported feelings of social isolation and incidents of bullying from their peers, and some autistic individuals reported difficulties forging friendships (DePape & Lindsay, 2016; O'Connor et al., 2018).

However, providing more opportunities for socialization was found to increase the likelihood of positive outcomes (DePape & Lindsay, 2016; O'Connor et al., 2018). Some autistic individuals reported camaraderie with other neurodivergent individuals with similar talents and interests, though not all talents and interests carried positive results. Their neurotypical peers sometimes felt a level of discomfort from odd or weird interests, forming stereotypes about their own understandings of autism spectrum disorders (DePape & Lindsay, 2016).

Relationships with educators also carried recommendations for improvement (Boshoff et al., 2018, 2019; DePape & Lindsay, 2016). Some autistic students felt they needed more specialized services than they were presently receiving and felt more discreet attention from educators would lead to less unwanted attention from neurotypical peers (DePape & Lindsay, 2016). Circumstances at school sometimes necessitated parents to act as chief advocates and support systems for their autistic children (Boshoff et al., 2018, 2019). Boshoff et al. (2018, 2019) believed parental advocacy to be a key driver in their children's development which could be fostered by a support network of professionals and caregivers.

Language and cultural barriers confound the situation, at times inhibiting the level of professional diagnosis and care autistic clients receive (Berridge & Hutchinson, 2021). Advocacy is described as an ongoing, lifelong process, whether autistic individuals advocate for on their own behalf, or their close family members do it for them (Boshoff et al., 2018, 2019).

Familial relationships can be strained by a diagnosis of an autism spectrum disorder (Boshoff et al., 2018, 2019; Leedham et al., 2020). Siblings find they must sometimes act as a constant guardian or protector of their diagnosed loved ones, causing emotions to run high with feelings of exhaustion and burden, as well as a conflicting mixture of love and resentment about their role and responsibilities in the family (Leedham et al., 2020).

The siblings of autistic individuals may be easily overlooked while contending with the unique challenges each diagnosis introduces to the family dynamic (Leedham et al., 2020). Other times, miscommunications and misunderstandings can raise tensions and strain familial relationships, as fragile as they may already be prone to be (DePape & Lindsay, 2016).

Validation and Acceptance

Familial relationships can also be strained when parents feel they are not heard or acknowledged during the diagnostic process (Boshoff et al., 2018, 2019). Parents have sometimes been known to report negative emotions during diagnosis—that is, despair, depression, frustration, grief, and so forth (Boshoff et al., 2018, 2019). The vast array of negative emotions can lead some parents to seek alternative opinions and options, at times delaying or putting at risk the critical timeline early intervention requires (Boshoff et al., 2018, 2019).

Emotions can be difficult for autistic individuals to process and regulate without processing the emotions they perceive from the people closest to them (Granville, 2020). Autistic individuals seem to depend on the initiative of others to regulate their emotions; however, cognitive behavioral therapy and mindfulness techniques were found to help improve emotional regulation and overall functioning in autistic clients (Granville, 2020).

Williams et al. (2019) found many autistic participants were acutely aware of their uniqueness, citing feeling outcast by society or otherwise “different from others” and wishing for their own normalization. However, DePape and Lindsay (2016) found parental acceptance and affection paired with opportunities for socialization fostered coping skills. Ironically, the mainstream settings intended to foster greater inclusivity accentuated the differences between autistic individuals and their neurotypical peers instead (Williams et al., 2019). Complicating matters are ideological differences across the autism spectrum—that is, Neurodiversity (Silberman, 2016; Sinclair, 1993/2012a; Singer, 1998/2017) and the established clinical model of autism spectrum disorders (American Psychiatric Association, 2013; Kapp et al., 2013).

Conceptual Framework

Given the researcher’s interest in exploring what conditions create trusting and inclusive relationships between young, autistic adults and which of their clinical providers and why, it may be helpful to understand the two main ideologies defining opposite ends of the neuro-political continuum—viz., Neurodiversity and the established clinical model of autism spectrum disorder.

Neurodiversity

While Jim Sinclair (1993/2012a) can be considered the *Father of Neurodiversity*, it was Judy Singer (1998/2017) who first put a name to what began as a philosophical ideology grounded in the social model for disability—that is, autism spectrum disorder is only a disability because an ableist neurotypical society thought of it as a disability (Nelson, 2021, p. 341)—and evolved into political activism in the form of ASAN (n.d.-b).

ASAN's (n.d.-b) dependency on trends of the past to define the actions of present-day neurotypical society—which, itself, has evolved over time—is highly problematic for several reasons—not the least of which being the passage of the Americans with Disabilities Act (1990) prohibiting much of the past trends ASAN (n.d.-b) takes issue with. People change over time, as does life, itself, and to hold others to a standard they, themselves, no longer hold themselves to is not only unfair, but also logically unsound (ASAN, n.d.-b; Autism Speaks, n.d.-a).

ASAN's (n.d.-b) stance on neurotypical society seems to forget R. D. Laing's anti-psychiatry movement, without which, the biopsychosocial model's ideas informing the Neurodiversity movement may never have been expressed and adopted and the paradigm shift towards neurodivergent rights which occurred in Generation II may never have gained traction. Laing's example of encouraging a person diagnosed with schizophrenia on their voyage into their inner self to make sense of the madness of the outside world around them seems to echo the demands of the Neurodiversity movement. Laing believed psychiatry should encourage the strengths of the individual instead of merely focusing on eliminating the weaker traits the individual possesses (Crossley, 1998; Desai, 2005; Double, 2002, 2006). To exclude this piece of history is to greatly weaken the Neurodiversity movement.

While Neurodiversity tends to acknowledge the unique needs of varying degrees of different autistic individuals (ASAN, n.d.-b), it can sometimes seem to lump its constituents together under the assumption they all possess the same level of cognitive functioning and capability to make and understand the ramifications of the decisions affecting their lives—an assumption contrary to both the evidence available (Lathe, 2006) and the definition of autism spectrum disorder as printed in the *DSM-5* (American Psychiatric Association, 2013).

Established Clinical Model

The established clinical model of autism spectrum disorder can assign decision-making responsibilities to the medical professionals in the cases of underage patients and severely disabled patients who may lack the ability to understand such responsibilities (Kapp et al., 2013). This can become problematic during the transition to adulthood, as clients age out of many previously available therapeutic resources and accommodations once they reach 21 years of age (Kuangparichat, 2010). One such therapy parents and professionals can utilize in force until the age of majority is reached is Applied Behavioral Analysis, in the hopes the child will appear to behave more typical of their age group (Kapp et al., 2013).

Applied Behavioral Analysis

The established clinical model of autism spectrum disorder seems to have long relied on Applied Behavioral Analysis to treat symptomatic behaviors associated with autism spectrum disorder (Donvan & Zucker, 2016; Ithriyah, 2018). Proponents of Neurodiversity might seem to oppose the use of Applied Behavioral Analysis on autistic individuals, sometimes citing Lovaas's Applied Behavioral Analysis trials and the Judge Rotenberg Center's use of electric shock as examples of Applied Behavioral Analysis being abusive toward autistic individuals (Vivian, 2009/2012).

What Neurodiversity seems not to recognize is Lovaas used a modified form of Applied Behavioral Analysis, adding in the electric shocks on his own. The use of electric shocks has never been a condoned form of Applied Behavioral Analysis as it was originally conceived in the 1960s (Donvan & Zucker, 2016).

Neuro-Unity

The researcher hopes to use this data to propose a more balanced conceptual framework combining elements of Neurodiversity and the established clinical model of autism spectrum disorder, to increase trust and inclusion among neurodivergent individuals and neurotypicals alike. In doing so, both neurodivergent individuals and neurotypicals can band together and learn from one another on a deeper emotional level (Dinishak, 2019; Silberman, 2016), and can, at the very least, begin to heal what can be described as a fractured autism spectrum disorder community. Healing this rift in ideologies along this neuro-political continuum will involve answering simple questions with complex answers—that is, what is autism spectrum disorder? Who gets to decide that definition? What, if anything, should be done about it? Who makes that decision? As no one person or group can speak for the entire autism spectrum disorder community, is it even possible for there to be a generalized answer to any of these questions (Hens et al., 2019?

Perhaps, these are the questions that can be worked on together during Generation IV to come to some conclusions on the ethics of the autism spectrum disorder community if the established clinical model and Neurodiversity can find a way to look past their differences. Cascio et al. (2020) had called for the formation of a task force of researchers, clinical providers, self-advocates, and their families to perseverate on the ethical ramifications of the answers to some of the above questions. In homage to the naming convention Singer (1998/2017) popularized in coining *Neurodiversity*—and perhaps even in an attempt to answer Cascio et al.'s (2020) call to action, the researcher proposes a new framework to be called *Neuro-Unity*.

The researcher is not the only neurodivergent individual who feels the autism spectrum disorder community has become too highly politicized by public opinion. A highly respected self-advocate had the following to write in response to an interview question in his book of essays:

> As my diagnosis took place in the early 1990s, I was the first person with a higher functioning autism diagnosis [in] most of the communities I lived in. As such, my identity as an autistic individual predates much of the current autism politicking. For example, I fail to see a reason to choose either identity-first or person-first terminology, and I do not see what the fuss is about between the two options. I

> believe we have become overly obsessed with language and terminology, and that it hinders our ability to properly represent ourselves. (Frazier, 2019, p. 161)

To Frazier (2019), advocacy involves campaigning for causes, whereas activism involves protests, demonstrations, and zealousness. What the autism spectrum disorder community should aim for, then, is advocacy without the rejection of self-determination of Autism Speaks and the “disability supremacy” of ASAN (Frazier, 2019, p. 162). Frazier (2019) believes in more peaceful means of advocacy—that is, negotiation and mutually beneficial compromise—to confront oppression, especially where disability rights are concerned—e.g., the autism spectrum disorder community.

Conclusion

If proponents of Neurodiversity feel positive traits of autism spectrum disorders are under-emphasized, focusing on the differences between neurotypicals and neurodivergent individuals can exacerbate the problem (ASAN, n.d.-b). Based on the review of the literature, the established clinical model needs to recognize the independence of autistic clients capable of making their own life decisions and foster their quest for self-sufficiency (Boshoff et al., 2018, 2019; DePape & Lindsay, 2016). This can mean the need for self-education (Boshoff et al., 2018, 2019), as relying solely on personally lived experience does not necessarily equate into expertise, as much as ASAN (n.d.-b) would like its members to believe it to be so.

The understanding and definition of autism spectrum disorders have evolved several times over the decades since the first known case was discovered (Donvan & Zucker, 2016, pp. 553-562). First understood to be a result of a lack of care and attention from parents, researchers were able to point to more genetic links to autistic behaviors as parents started advocating for the rights of individuals with disabilities—that is, autism spectrum disorders (Donvan & Zucker, 2016). Self-advocates like Temple Grandin (Donvan & Zucker, 2016), Jim Sinclair (1993/2012a), and Judy Singer (1998/2017) began to speak out in the late 1980s through the 1990s, as the Neurodiversity movement was born (Donvan & Zucker, 2016).

Suddenly, it was no longer apropos to simply be aware of autism, so much as accepting of it as a natural variation of the human experience (ASAN, n.d.-b; Sinclair, 1993/2012a). However, even this has its logical limits, occasionally strained by the Neurodiversity movement's own philosophies, at times unwilling to coexist with the established clinical model (ASAN, n.d.-b; Dinishak, 2019; Sarrett, 2016).

The established clinical model is inherently limited by lack of time, resources, and training (Coughlan et al., 2020). In many cases studied, such limitations to clinically provided services have had an adverse effect on the levels of trust in their expertise (Coughlan et al., 2020; DePape & Lindsay). Many clients identifying as self-advocates even oppose the most prevalent therapy available—that is, Applied Behavioral Analysis (ASAN, n.d.-b).

While Neurodiversity openly recognizes Singer's (1998/2017) original objectives of recognition and civil rights and an end to discrimination (p. 55), its opposition to the established clinical model flies counterproductively and counter-intuitively to Singer's (1998/2017) third objective—that is, disability services appropriate to their level of functioning on the spectrum (p. 55). Proponents like ASAN (n.d.-b) want to believe every autistic individual is at the level of functioning to be capable of making their own decisions; however, as prominent self-advocate and professor of special education at Adelphi University, Dr. Stephen Shore, is quoted on the Autism Speaks (n.d.-c) website, “if you’ve met one person with autism, you’ve met one person with autism” (para. 11)—that is, not all autistic individuals are on the same level of functioning, and all have their own unique needs, separate from those of other autistic individuals.

The unique nature of the various ways autism spectrum disorders affect different individuals has historically led to much conflict over what autism spectrum disorders are and who has the final say over an individual’s treatment plan (Donvan & Zucker, 2016). Many autistic individuals are proud of their identity on the autism spectrum, while others wish for more “normalcy” in their lives (DePape & Lindsay, 2016).

This review of the literature was conducted as part of the systematic process of a realist synthesis (Pawson, 2002; Pawson et al., 2005). The objective of which, is to help unify the autism spectrum disorder community by increasing trust in the established clinical model while creating and providing an environment more inclusive of neurodivergent self-advocates (Silberman, 2016). From the synthesis of the established clinical model and Neurodiversity, the hope is a new conceptual framework—that is, *Neuro-Unity*—will rise and become the prevailing philosophy surrounding the autism spectrum in the future.

Remaining Questions for Future Research

While a review of prior systematic reviews and syntheses helped answer questions about autism spectrum disorders, how they have been understood and defined by different scholars, and how those understandings and definitions have evolved over time, some questions remain and require further research before *Neuro-Unity* can be fully established as a viable conceptual framework. Questions about how caregivers—that is, parents, siblings, and friends—and professionals—that is, medical professionals and educators—can cooperate and contribute more meaningfully to the diagnostic process and treatment plans across cultures and socio-economic status concern researchers who have found a need to increase trust during the process of determining a diagnosis (Boshoff et al., 2018, 2019). Other concerns include the breadth of first-hand accounts of autistic individuals as framed with a positive connotation (DePape & Lindsay, 2016), the breadth of first-hand accounts of autistic individuals across all levels of functioning (DePape & Lindsay, 2016), and ensuring future research is more representative of the sex ratio for autism spectrum disorders—boys and men are four times more likely to obtain a formal diagnosis than girls and women (DePape & Lindsay, 2016).

Additionally, more research could focus on the autistic label, itself, and how it affects individuals' sense of self and their mental and emotional health (Williams et al., 2019). Furthermore, not much is known about the relationship between the diagnosis and the onset of autistic behaviors and how they affect other ramifications of the diagnosis—that is, clinical, practical, social, emotional, and so forth (O'Connor et al., 2018). Williams et al. (2019) expressed interest in using data from such research to explore improvements to self-identity and the physical environments in which autistic individuals function in the context of their sensory reactions to inform more effective policy and practice affecting the autism spectrum.

In short, questions left to be explored concern the relationship between young autistic adults and their clinical providers and what conditions contribute to trusting and inclusive relationships between young autistic adults and which of their clinical providers and why some relationships are more trusting and inclusive than others. A realist synthesis can systematically review existing research using tools like PRISMA (n.d.) or CASP (2021) to answer these questions (Pawson, 2002; Pawson et al., 2005).

CHAPTER THREE: METHODOLOGY

Introduction

Rather than utilizing the PRISMA (n.d.) or CASP (2021) tools to conduct this study, the researcher instead utilized the Realist and Meta-narrative Evidence Synthesis: Evolving Standards (RAMESES) I project protocol guidelines. This was used to examine qualitative studies of the relationships between young adults on the spectrum and their clinical providers, and what circumstances contribute to trusting and inclusive relationships between young adults on the spectrum and their clinical providers and why some relationships are more trusting and inclusive than others—that is, what works for whom under which circumstances and why (Greenhalgh et al., 2011).

A *young adult on the spectrum* can be defined as an autistic individual between the ages of 21 and 26 years of age—21 years being the age most childhood resources expire for autistic individuals (Kuangparichat, 2010), and 26 years being the age dependents are, under typical circumstances, required by the Patient Protection and Affordable Care Act (2010) to stop receiving coverage under their parents' insurance plans. However, the researcher has expanded this definition to the range between 18 years—the legal age of majority in the United States—and 30 years—the culmination of the first full decade of adulthood. This ensured that more research was available to the study. Using a realist synthesis design to address the research questions has enabled the researcher to review and mediate between rival theoretical frameworks and drive changes in policy (Schick-Makaroff et al., 2016, p. 211).

Review Design

For this study, the researcher used a realist synthesis design to attempt mediation between Neurodiversity and the established clinical model of autism spectrum disorder to design a new conceptual framework with the intent to improve feelings of trust and inclusion within the autism community.

Realist Synthesis

Realist syntheses review complex theoretical frameworks and paradigms and seek to understand (a) the mechanisms by which complex interventions produce outcomes and (b) the contexts under which this process occurs (Schick-Makaroff et al., 2016, p. 211). To be more succinct, a realist synthesis seeks to explain and answer the questions of what interventions work for whom under which conditions and why (Pawson et al., 2005, p. 32).

Realists believe the efficacy of a given intervention is influenced by the context in which the intervention is administered (Pawson et al., 2005, p. 23). Various factors—that is., cultural differences, organizational leadership, policy timing, and so forth—can affect the efficacy of a given intervention across contexts; thus, outcomes will also vary across contexts (Pawson et al., 2005, p. 23).

To facilitate the process of conducting a realist synthesis, the researcher used the RAMESES I project protocol guidelines developed by Greenhalgh et al. (2011). RAMESES I was used to conduct the realist synthesis, as opposed to the RAMESES II project protocol, which outlines guidelines for realist evaluation (RAMESES Projects, 2013). Whereas meta-narrative analyses focus primarily on quantitative research, realist syntheses focus primarily on qualitative research (RAMESES Projects, 2013).

Review Steps

Per the RAMESES I project protocol's methodological guidelines, a realist synthesis typically consists of a systematic review and multiple rounds of a virtual panel of readers called a Delphi panel (Greenhalgh et al., 2011; Wong et al., 2014). A Delphi panel is a group of external readers providing critical feedback for inclusion in the systematic review (Greenhalgh et al., 2011; Wong et al., 2014). In this instance and for simplicity's sake, a Delphi panel was not consulted.

Systematic Review

The first step of the RAMESES I methodology was to conduct a review of seminal research and gray literature through database searches and snowballing. Snowballing uses the references cited in index papers to identify further research for consideration (Greenhalgh et al., 2011).

The results of the literature review were coded into thematic categories attempting to address the following research questions:

1. What are the characteristics and perspectives relevant to the relationship between young autistic adults and their clinical providers—that is, doctors, therapists, educators, caregivers, and so forth?
2. What are the characteristics and perspectives that make some relationships between young autistic adults and their clinical providers more trusting and inclusive than others?

3. How can trusting and inclusive relationships between young autistic adults and their clinical providers be facilitated, formed, and maintained?

Systematic Search for Research

A review of existing literature was conducted by systematically searching databases and gray literature—that is, books written by self-advocates, policy documents, self-advocate websites, and blogs, and the like. A combination of the following databases was searched: the Francis A. Drexel Library at Saint Joseph's University, ERIC, PsycINFO, JSTOR, and MEDLINE. Searches of the preceding databases were conducted using the following search terms: "(young adult AND autism OR neurodiversity AND clinical practice) AND (attitudes OR opinions OR perspectives) AND (qualitative)." In addition, a search of dissertation abstracts between 1980—the year the *DSM-III* first included criteria for diagnosing "Infantile Autism" (Rosen, 2021)—and 2022 via ProQuest were conducted using the same search terms listed above.

Data were extracted through the following process of identification: data extraction and mapping, critical appraisal for inclusion in the systematic review, and synthesis of remaining research into the literature review according to RAMESES I guidelines (Greenhalgh et al., 2011; Wong et al., 2014). For an outline of the search and review process the researcher utilized, see Figure 2. The researcher required certain criteria to be met to be included in this realist synthesis review following the systematic search for the research phase of the study.

Inclusion Criteria

All research to be included were limited by the following criteria:

1. Studies published in English.
2. Studies utilizing a qualitative research design.
3. Studies published between 1980 and 2022.
4. Studies examining the opinions or attitudes of young adults on the spectrum—aged between 18 and 30 years—toward their clinical providers.
5. Studies published inside the United States and the United Kingdom.

Exclusion Criteria

To construct the sample for systematic review, the researcher excluded the following:

1. Studies not published in English.
2. Studies utilizing a quantitative or mixed methods research design.
3. Studies published prior to 1980 or after 2022.
4. Studies not examining the opinions or attitudes of young adults on the spectrum—aged between 18 and 30 years—toward their clinical providers.
5. Studies published outside the United States or the United Kingdom, as fundamental differences in healthcare exist between the United States and other countries, and remnants of a strong anti-psychiatry movement from the 1960s and 1970s still linger in the United Kingdom (Crossley, 1998; Desai, 2005; Double, 2002, 2006).

The researcher did not undertake any independent screening or audits of random subsets for the purposes of quality control and appraisal.

Mapping

Data extracted from each selected study included the study's research questions; its methodology, rigor, and transparency; its underlying theoretical frameworks; its main findings; and its contributions to the understanding of this systematic review's research questions.

Critical Appraisal

Selected studies were critically appraised for eligibility and relevance according to the RAMESES I protocol and inclusion and exclusion criteria. Studies deemed ineligible or irrelevant were excluded from the synthesis process of this systematic review (Greenhalgh et al., 2011).

Synthesis

The findings of the remaining studies were synthesized into a new systematic review addressing the research questions, which revolved around the relationships between young adults on the spectrum and their clinical providers and why some relationships are more trusting and inclusive than others.

Review Analysis Steps

A systematic review of the synthesized findings produced the following outcomes: (a) guidelines and best practices for improving trust and inclusion within the broader autism spectrum disorder community and (b) a new conceptual framework synthesized from Neurodiversity and the established clinical model of autism spectrum disorders.

Output of Realist Synthesis

The results of the study could ideally produce the following outputs: (a) guidelines and best practices for improving trust and inclusion within the broader autism spectrum disorder community and (b) a new conceptual framework—namely, *Neuro-Unity*—designed to facilitate applications of the first output.

Positionality Statement

Neuro-Unity is the culmination of life experiences with the researcher's own diagnosis of an autism spectrum disorder. The researcher received their original diagnosis of Asperger's Syndrome in 1998, prior to the release of the *DSM-5*. As Neurodiversity continues to rise in prominence, the researcher feels a new paradigm shift is about to emerge. The autism spectrum disorder community must plan for this paradigm shift to ensure the broader community is able to move forward with a greater consensus.

When beginning this realist synthesis, the researcher had been unaware of the issues related to time and resources that some clinical providers regularly face. The researcher had been more closely aligned with the Neurodiversity movement at the time. However, the researcher had since read statements from proponents of the Neurodiversity movement on social media hat seemed to divide or, at the very least, seemed to advocate for division between autistic individuals and neurotypical society.

When the researcher learned about the issues clinical providers face when providing service to autistic individuals and their families, it came as a revelation. The researcher was surprised to learn that even some clinical providers feel that the services they provide could be much improved and that they share the same opinions about the quality of the services they provide as the individuals and the families they serve.

To account for personal bias that may affect research such as this study, the researcher tried harder to keep an open mind when reading through the synthesized research and interpreted each source at face value as much as possible. The researcher recognizes the potential for some personal bias to go unnoticed. As a result, the researcher accepted most feedback and suggestions for revision from external readers where applicable.

Conclusion

The researcher conducted a realist synthesis review with the intent of planning for a new paradigm shift. Advance planning will enable the broader community to unify and move forward with a greater consensus. Utilizing the RAMESES I project protocol guidelines enabled the researcher to address research questions concerning the relationships between young adults on the spectrum aged 18 through 30 years and their clinical care providers—that is, doctors, therapists, educators, caregivers, and so forth—and what circumstances create trusting and inclusive relationships between young autistic adults and their clinical providers, why some relationships are more trusting and inclusive than others, and how to facilitate more trusting and inclusive relationships.

The RAMESES I project protocol guidelines included a systematic review (Greenhalgh et al., 2011; Wong et al., 2014). The outputs of this realist synthesis review were a set of guidelines and best practices for improving the relationships between young adults on the spectrum and their clinical providers facilitated by a new conceptual framework borne from the Neurodiversity movement and the established clinical model of autism spectrum disorder.

CHAPTER FOUR: FINDINGS

Introduction

The goal of this realist synthesis was to examine the relationship between young autistic adults and their clinical providers (e.g., doctors, therapists, educators, caregivers, etc.). The researcher sought to understand what conditions contribute to trusting and inclusive relationships between young autistic adults and their clinical providers, and how more trusting and inclusive relationships can be maintained. This enabled the researcher to develop a new conceptual framework to address what has been perceived by current advocacy movements as conflicting ideologies between proponents of the Neurodiversity movement and their clinical providers—which the researcher calls *Neuro-Unity*.

Throughout this realist synthesis, two specific outputs were produced for future theory and their practical applications:

1. a set of guidelines and best practices for improving trust and inclusion between young adults on the spectrum and their clinical providers, and
2. a new conceptual framework, *Neuro-Unity*, designed to facilitate practical applications of the first outcome.

The research conducted for this realist synthesis attempted to answer the following research questions:

1. What are the characteristics and perspectives relevant to the relationship between young autistic adults and their clinical providers—that is, doctors, therapists, educators, caregivers, and so forth?

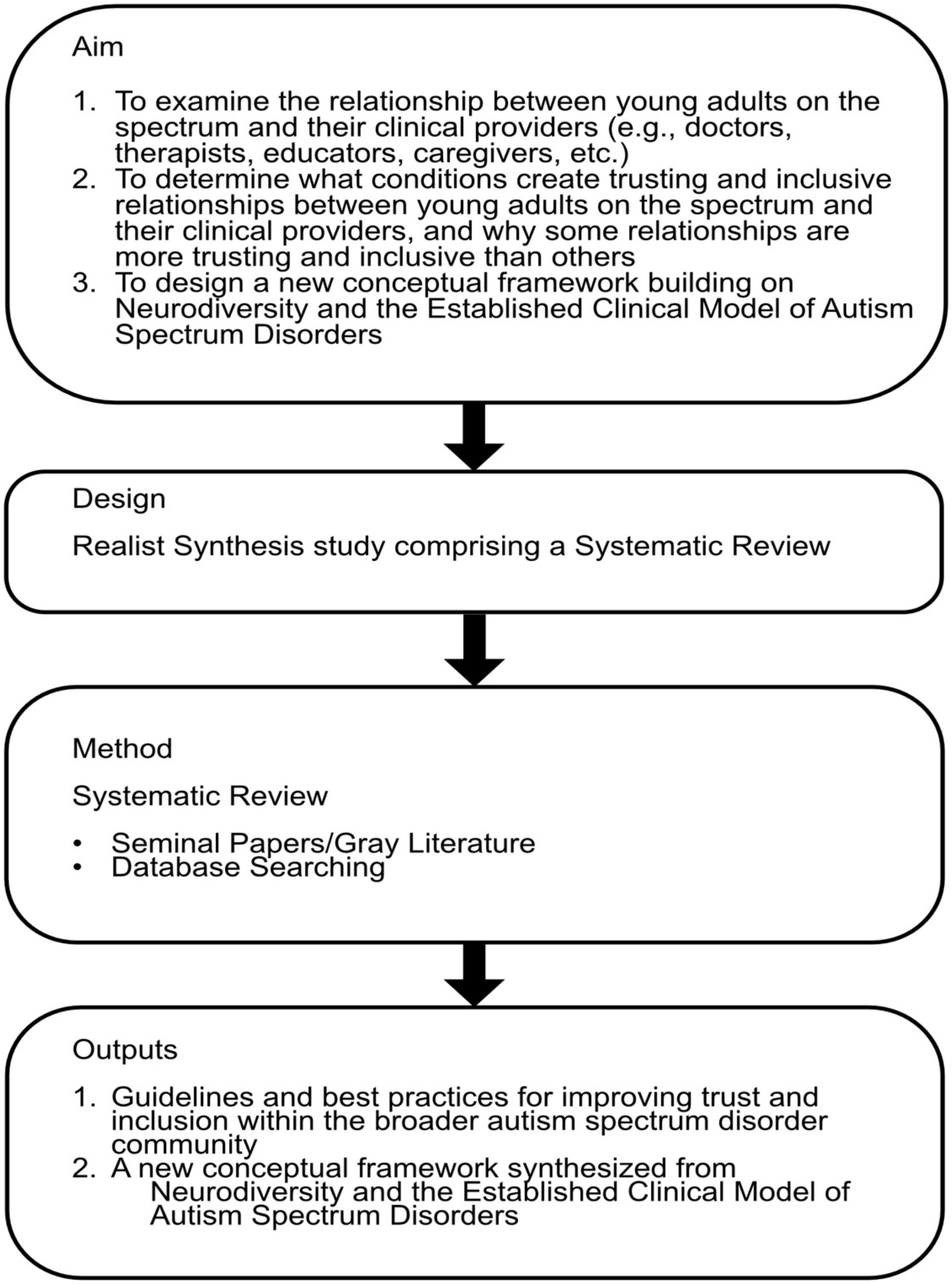
2. What are the characteristics and perspectives that make some relationships between young autistic adults and their clinical providers more trusting and inclusive than others?
3. How can trusting and inclusive relationships between young autistic adults and their clinical providers be facilitated, formed, and maintained?

These research questions were designed to help drive the underlying theory behind the realist synthesis being conducted.

This chapter presents and discusses the findings from synthesized literature. First, the database search process is described. Afterward, the researcher details the results of the screening and eligibility processes, followed by data extraction and the synthesis of data. Findings are synthesized for each research question. Ultimately, the researcher arrived at the creation of a new conceptual framework, namely, *Neuro-Unity*. For an overview of the methodological process, see Figure 1.

Figure 1

Overview of RAMESES I Methodological Process



Aim

1. To examine the relationship between young adults on the spectrum and their clinical providers (e.g., doctors, therapists, educators, caregivers, etc.)
2. To determine what conditions create trusting and inclusive relationships between young adults on the spectrum and their clinical providers, and why some relationships are more trusting and inclusive than others
3. To design a new conceptual framework building on Neurodiversity and the Established Clinical Model of Autism Spectrum Disorders

Design

Realist Synthesis study comprising a Systematic Review

Method

Systematic Review

- Seminal Papers/Gray Literature
- Database Searching

Outputs

1. Guidelines and best practices for improving trust and inclusion within the broader autism spectrum disorder community
2. A new conceptual framework synthesized from Neurodiversity and the Established Clinical Model of Autism Spectrum Disorders

Discussion of Findings

Database Search

The research began with a search of various databases for sources to be included in the realist synthesis. As mentioned previously, five online databases were searched: the Francis A. Drexel Library at Saint Joseph’s University, ERIC, PsycINFO, JSTOR, and MEDLINE. The search used the following terms: “(young adult AND autism OR neurodiversity AND clinical practice) AND (attitudes OR opinions OR perspectives) AND (qualitative).” Dissertation abstracts published between 1980 and 2022 were also searched on ProQuest using the above search terms. A total of 270 sources were identified through the database search process.

Screening and Eligibility

Of these 270 sources, 262 were published studies. The remaining eight sources were books that the researcher had identified for inclusion in the realist synthesis. After removing duplicates and screening for inclusion, a total of 44 sources were screened for eligibility for inclusion in the realist synthesis. Of these 44 sources, 38 were qualitative research studies, and six were books and essays written by self-advocates. See Table 3 for screening inclusion data.

Table 3

Screening Inclusion Data

Source	Number of Studies Included
	Published in English
Francis A. Drexel Library at SJU	194
ERIC	6
PsycINFO	45
JSTOR	12
MEDLINE	5
Books/Essays Written by Self-Advocates	8
Totals	270
	Methodology Design (Qualitative Studies/Reviews/Syntheses, excluding MM; Books/Essays written by self-advocates)
Francis A. Drexel Library at SJU	160
ERIC	6
PsycINFO	42
JSTOR	4
MEDLINE	3
Books/Essays Written by Self-Advocates	8
Totals	223
	Published between 1980 and 2022
Francis A. Drexel Library at SJU	160
ERIC	6
PsycINFO	42
JSTOR	4
MEDLINE	3
Books/Essays Written by Self-Advocates	8
Totals	223
	Participants are ASD YA (ages 18–30)
Francis A. Drexel Library at SJU	77
ERIC	6
PsycINFO	31

Table 3, continued.

Source	Number of Studies Included
MEDLINE	2
Books/Essays Written by Self-Advocates	8
Totals	127
	Focus is Attitudes about ASD
Francis A. Drexel Library at SJU	44
ERIC	6
PsycINFO	25
JSTOR	2
MEDLINE	2
Books/Essays Written by Self-Advocates	8
Totals	87
	Published in USA/UK
Francis A. Drexel Library at SJU	32
ERIC	6
PsycINFO	23
JSTOR	1
MEDLINE	0
Books/Essays Written by Self-Advocates	6
Totals	68
	Not Duplicates
Francis A. Drexel Library at SJU	31
ERIC	0
PsycINFO	6
JSTOR	1
MEDLINE	0
Books/Essays Written by Self-Advocates	6
Totals	44

Scoring System

The researcher scored the 44 sources that passed the screening process by their credibility, dependability, confirmability, transferability, reflexivity (Korstjens & Moser, 2017; Stenfors et al., 2020), and relevance (Wong et al., 2014) on a scale of zero through three. The scores were then added together across categories. A sum score of 11 or under resulted in disqualification. Any category scoring a zero or one automatically disqualified the source from consideration. For books, only the relevance category was considered. For all other sources, all categories were considered. See Table 4 for the eligibility rubric used for this process.

Table 4

Eligibility Rubric

	Credibility (Korstjens & Moser, 2017; Stenfors et al., 2020)	Dependability (Korstjens & Moser, 2017; Stenfors et al., 2020)
Definition	Plausibility and trustworthiness (Korstjens & Moser, 2017; Stenfors et al., 2020)	Ability to be replicated in similar conditions (Korstjens & Moser, 2017; Stenfors et al., 2020)
3 – Clear/ Meticulous	Clear alignment between theory, research question, data collection, analysis, and results.	Procedural steps are meticulously documented such that another researcher could follow the documented steps and reach the same conclusions.
2 – Sufficient	Alignment between theory, research question, data collection, analysis, and results is sufficient, though not directly clear.	Procedural steps are sufficiently documented such that another researcher could follow the documented steps and reach similar conclusions.
1 – Vague	Vague alignment between theory, research question, data collection, analysis, and results.	Procedural steps are vageuly documented such that another researcher could follow the documented steps but reach variable conclusions.
0 – Nonexistent	No alignment between theory, research question, data collection, analysis, and results exists.	Prodedural steps are not documented or are not detailed enough for another researcher to follow.

Table 4, continued.

	Confirmability (Korstjens & Moser, 2017; Stenfors et al., 2020)	Transferability (Korstjens & Moser, 2017; Stenfors et al., 2020)
Definition	Relationship/link between data and findings (Korstjens & Moser, 2017; Stenfors et al., 2020)	Ability to generalize findings to other settings, contexts, or groups (Korstjens & Moser, 2017; Stenfors et al., 2020)
3 – Clear/Meticulous	Researchers meticulously note how they reached their conclusions through detailed descriptions and the use of quotes.	The context in which the research was performed and how this shaped conclusions is meticulously described.
2 – Sufficient	Researchers sufficiently note how they reached their conclusions through clear descriptions and the use of quotes.	The context in which the research was performed and how this shaped conclusions is sufficiently described.
1 – Vague	Researchers minimally note how they reached their conclusions through vague or unclear descriptions and/or exclude the use of quotes.	The context in which the research was performed and how this shaped conclusions is vaguely described.
0 – Nonexistent	Researchers do not note how they reached their conclusions, do not provide descriptions, and/or exclude the use of quotes.	The context in which the research was performed and how this shaped conclusions is not described.

Table 4, continued.

	Reflexivity (Korstjens & Moser, 2017; Stenfors et al., 2020)	Relevance (Wong et al., 2014)
Definition	Positionality of the researcher and context of research (Korstjens & Moser, 2017; Stenfors et al., 2020)	Contribution to theory building and/or testing (Wong et al., 2014)
3 – Clear/ Meticulous	Positionality of the researcher and the context of the research are meticulously engaged with and articulated.	Contribution to theory building and/or testing is clearly evident.
2 – Sufficient	Positionality of the researcher and the context of the research are sufficiently engaged with and articulated.	Contribution to theory building and/or testing is sufficiently evident.
1 – Vague	Positionality of the researcher and the context of the research are vaguely engaged with and articulated.	Contribution to theory building and/or testing is vaguely evident.
0 – Nonexistent	Positionality of the researcher and the context of the research are not engaged with and articulated.	Contribution to theory building and/or testing is not evident.

Pilot of the Eligibility Process

Four sources were evaluated as part of a pilot of the eligibility process with initially haphazard scores. Once research criteria were identified, the eligibility process was streamlined.

Research Criteria

The research criteria were measured across all categories. The research criteria were:

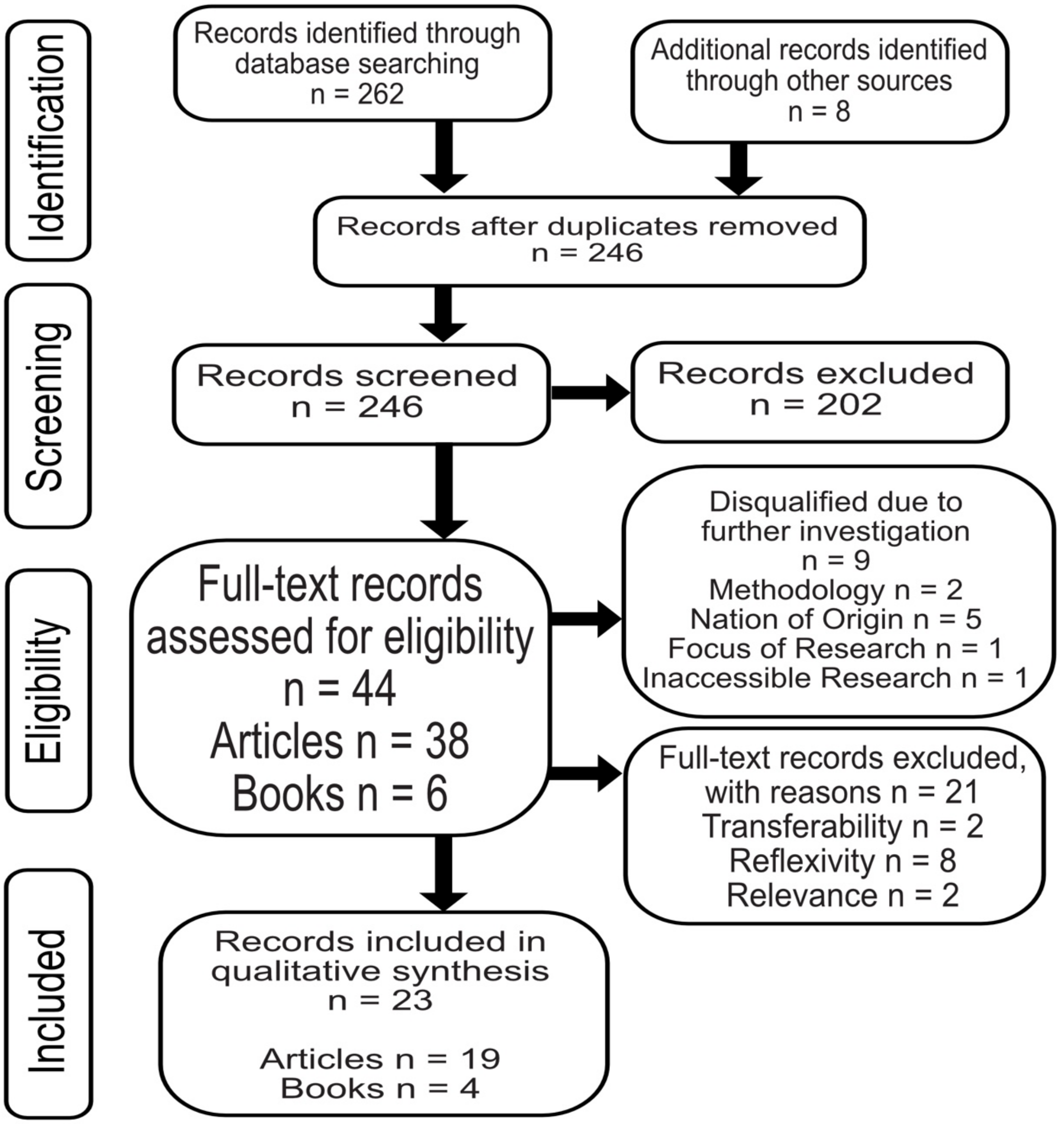
1. Perspectives of young autistic adults aged 18–30 years who have received a clinical diagnosis.
2. Perspectives of clinical providers, such as doctors, therapists, educators, caregivers, and.
3. Alignment between the perspectives of young autistic adults and clinical providers.
4. Differences between the perspectives of young autistic adults and clinical providers.
5. Practical examples of how relationships between young autistic adults and their clinical providers can be more trusting and inclusive.

Final Scoring

After applying the research intercepts to the eligibility process, 21 sources were removed. Nine of these sources were disqualified due to further investigation into the research prior to consideration for eligibility. At the completion of the eligibility process, only 23 sources were deemed eligible for inclusion in the thematic summary. This included 19 articles and four books. For more information on the eligibility process, see Figure 2.

Figure 2

Search and Review Flow Diagram



Data Extraction and Synthesis

Contents of each source were embedded in an evidence table for data extraction. If a source did not address one of the research questions, the researcher indicated so in the table. For sources that did address the research question, a short summary of the article's relevance and an accompanying direct quote was entered into the entry in the evidence table. This process was repeated for each theory area driving the research. One source was unable to answer any of the research questions with any relevance (Vincent, 2019).

Relationships Between Self-Advocates and Their Clinical Providers

The first theory area examined the characteristics and perspectives relevant to the relationship between young autistic adults and their clinical providers (see Table 5). Themes derived from this theory area included disagreements over defining disability, young autistic adults' dependence on clinical providers, self-advocacy, exclusion of young autistic adults from decisions about support, education about autism spectrum disorders, and lack of support for young autistic adults.

Table 5

Evidence Table 1

THEORY AREA 1—What are the characteristics and perspectives relevant to the relationship between young autistic adults (YAAs) and their clinical providers (CPs)—for example, doctors, therapists, educators, caregivers, and so forth?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
1 Robison, 2011	This book does not specifically focus on the characteristics and perspectives relevant to the relationship between YAAs and their CPs, per se. However, it does offer advice on how to guide those relationships into being more trusting and inclusive.	N

THEORY AREA 1—What are the characteristics and perspectives relevant to the relationship between young autistic adults (YAAs) and their clinical providers (CPs)—for example, doctors, therapists, educators, caregivers, and so forth?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
2 Frazier, 2019	This book does not specifically focus on what the characteristics and perspectives relevant to the relationship between YAAs and their CPs are, only what those characteristics and perspectives should be.	C + N
3 Autistic Self Advocacy Network, 2012	This book identified that the current relationship between YAAs and their CPs is strained by factors involving the use of Applied Behavioral Analysis, the myth that vaccines cause ASD, and the search for a cure for ASD. In this book, various self-advocates plead with neurotypicals (or the CPs) to accept that YAAs will always be autistic, no matter what interventions are taken to cure them of their ASD. Awareness is seen as fearmongering to fundraise for the elimination of ASD. Self-advocates also ask that neurotypicals (or the CPs) respect YAAs as human beings deserving of dignity. “Respect starts by understanding that we are full and complete human beings, with individual personalities, life experiences, goals, and preferences. . . . We deserve to live without fear of being abused, manipulated, or hurt. We are not less than.” (p. 364)	N written from the N perspective CPs (characterized as neurotypicals) to accept ASD as a natural variation of the human experience

Table 5, continued.

THEORY AREA 1—What are the characteristics and perspectives relevant to the relationship between young autistic adults (YAAs) and their clinical providers (CPs)—for example, doctors, therapists, educators, caregivers, and so forth?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
4 Singer, 1998/2017	This book identified that while ASD is a natural variation of the human experience and human diversity, disability is often looked down upon by society. In this book, Singer (1998/2017) argued that disability is a form of ethnicity rather than pathology. She viewed the concept of "normalcy" as highly subjective social construct meant to pathologize disability. "Disability theorists repeatedly stress that what we currently call the norm, is actually a rarely achieved ideal" (p. 37).	N written from the N perspective the two groups need to learn and accept the different ways they are defining "disability" Neurodiversity views "Normalcy" as a harmful social construct

Table 5, continued.

THEORY AREA 1—What are the characteristics and perspectives relevant to the relationship between young autistic adults (YAAs) and their clinical providers (CPs)—for example, doctors, therapists, educators, caregivers, and so forth?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
5 Sosnowy et al., 2018	The study identified perspectives of parents and YAAs, who both view outcomes of the postsecondary transition process as complex and interconnected with one another. In this study, researchers found that YAAs wanted to achieve independence to make their own decisions and have a general sense of future goals—moving away from parents, employment, romantic relationships, and so forth. They are aware of challenges to goals and the specific supports needed to achieve their goals (e.g., academic supports, organizational skills, social support systems tailored to the autistic experience). YAAs experienced social barriers to employment (e.g., interview process) but were able to succeed when the proper accommodations were provided (quiet workspace, predictable routine, etc.). Self-employment was another option YAAs explored. Parents want YAAs to approach the transition to adulthood (goals, and independence) cautiously and strategically and are worried about their children's needs when they are no longer able to manage support needs for their children. Primary concerns included long-term supports and quality of life, relative to needs. Family plays a pivotal role in long-term care for YAAs. Parents feel more holistic supports are needed in educational systems and must take an active role in children's lives to ensure academic success, emphasizing more strategic support systems are needed to support their children. Parents want employment opportunities to align their children's needs with their desires and express that social interaction is crucial to helping their children leverage strengths and interests into their careers. However, parents feel not enough support currently exists to facilitate their children's professional success. "For parents, having opportunities for their child to work was valued for social benefits or for the sense of self-worth it conferred and not solely as a means to achieving financial independence. Young adults also acknowledged the social and emotional benefits of working but emphasized that financial independence made other goals more achievable." (p. 36)	C + N written from the C perspective, but is also applicable to the N perspective. C and N agree that independence is the end goal for ASD, but ASD creates barriers to developing independence

Table 5, continued.

THEORY AREA 1—What are the characteristics and perspectives relevant to the relationship between young autistic adults (YAAs) and their clinical providers (CPs)—for example, doctors, therapists, educators, caregivers, and so forth?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
6 Santomauro et al., 2017	This study identified common triggers of distressing emotions that contribute to barriers to emotional regulation. Bullying and social anxiety trigger negative emotions. Assessment tasks, disorganization and procrastination, unsupportive work/school environments provoke anxiety. Sensory overstimulation elicits negative emotions in young adults with ASD. Hunger and lack of sleep also play a role in triggering negative emotions. Major life changes and a fear of failure especially trigger anxiety and other negative emotions. In this study, CPs recognized the challenges young adults with ASD face when attempting to recognize and label their emotions. Young adults with ASD rely on others for guidance with recognizing and labelling their emotions as they have been known to misidentify their own emotional cues. Some young adults with ASD were not aware of their own emotional cues until they became extreme. “Alexithymia was mainly discussed by parents, teachers, and psychologists, describing the difficulties adolescents and young adults with ASD face when it comes to articulating their emotions” (p. 279).	C Written from the C perspective. Many YAAs depend on their ability to trust their caregivers and CPs to help identify and regulate their emotions.
7 Anderson et al., 2021	This paper does not specifically focus on the relationships between YAAs and their CPs. However, the fear of employers’ misunderstanding of ASD and the possibility of discrimination and stigma are robustly discussed. In this study, researchers found that the decision to disclose ASD often contributes to much anxiety during interviews (e.g., fear of discrimination and rejection). Accommodations are also a challenge to employment (employer expectations for employees, lack of employer understanding or empathy, etc.). “Deciding whether or not to disclose their disability was a difficult question for young adults with ASD-CA who sought employment without the assistance of any disability-focused agency. . . . They had to weigh the understanding that might be elicited from others in the workplace against potential stigma and discrimination.” (p. 99).	C + N Written from the C perspective, but also applicable to the N perspective. Many YAAs have apprehensions about disclosing their ASD to their employers and are afraid to ask for the accommodations they may need to be successful on the job.

Table 5, continued.

THEORY AREA 1—What are the characteristics and perspectives relevant to the relationship between young autistic adults (YAAs) and their clinical providers (CPs)—for example, doctors, therapists, educators, caregivers, and so forth?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
8 Milner et al., 2019	This study identified differences in the social expectations placed upon young autistic women compared to those placed upon their male counterparts. With the added challenges associated with the experience of being autistic, the social expectations placed upon young autistic women are amplified. In this paper, autistic women suggested that autistic men are subjected to less pressure to mask or camouflage their symptoms, and that autistic women are more successful at doing so. Masking their behavior during the diagnostic screening process can mean women are misdiagnosed or their ASD is not diagnosed at all. Autistic women have expressed that they sensed they were different in some way, but they could never identify what their difference was. Many autistic women expressed their relief when they were finally diagnosed with an ASD. “The women and girls in this study reported adopting strategies to mask and camouflage their autistic behaviours. During discussions women who believed they successfully masked their symptoms reported how they might learn stock phrases in social etiquette or consciously study the ‘appropriate’ amount of time to maintain eye contact.” (p. 2399)	C Written from the C perspective. Many young autistic women have negative associations with their CPs due to how difficult it is to get a diagnosis and necessary supports.
9 Cheak-Zamora et al., 2017	This study identified concerns about YAAs’ ability to independently address their own healthcare needs (e.g., identifying a medical need, making an appointment, transportation to the appointment, attending the appointment, and following up on medical instructions). In this study, YAAs expressed their anxiety over the lack of experience in taking control over their health care needs. Their caregivers were concerned for their children’s ability to do so. Caregivers also expressed uncertainty over what their role was to best support their child’s autonomy. Caregivers agreed that the end goal for YAAs was their independence, but many felt forced to remain involved in their child’s care. “Decisions about guardianship—the legal appointment of someone to make decisions for another person who is unable to make those decisions on their own—were particularly problematic” (p. 1033).	C Written from the C perspective. Many YAAs experience anxiety over their lack of experience with communicating their needs with CPs, complicating their relationship with CPs.

Table 5, continued.

THEORY AREA 1—What are the characteristics and perspectives relevant to the relationship between young autistic adults (YAAs) and their clinical providers (CPs)—for example, doctors, therapists, educators, caregivers, and so forth?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
10 Lam et al., 2020	This study identified a novel method (viz., Photovoice) for YAAs to express their understanding of their relationships with their families. In this study, YAAs described their relationships with family members as transcendent of time and space. Participants described the small circles of friends who were considered dear to them and supportive of each other. “Participants did care very much about their families, but they described how they may not always communicate it effectively” (p. 1252).	C + N Written from the C perspective, but also applicable to the N perspective. YAAs have a complicated relationship with their caregivers. They consider their families to be near and dear to them, but they cannot find the ways to communicate it effectively.
11 Vincent, 2019	This paper did not specifically focus on the relationships between YAAs and their CPs.	C
12 Cheak-Zamora & Teti, 2015	This study identified frustrations over perceptions of little support being available to YAAs during the transition from pediatric care to adult-oriented care. In this study, caregivers expressed their perceptions that healthcare providers did not understand ASD, how ASD affects each individual differently, and their children’s needs. Both YAAs and their caregivers agreed that the transition to independence is important and worrisome, but they were not in agreement on their opinions about transitioning. “Both caregiver and youth felt anxious about moving from pediatric to an adult provider. Caregivers regretted losing a valued and trusted provider. Having a provider that the youth was comfortable with was important to caregivers which they believe would be lost with an adult provider.” (p. 998)	C Written from the C perspective. YAAs and their caregivers agree that CPs do not effectively understand the nuances of ASD and how it affects each autistic individual, but they cannot agree on basic opinions about transitioning to adulthood.

Table 5, continued.

THEORY AREA 1—What are the characteristics and perspectives relevant to the relationship between young autistic adults (YAAs) and their clinical providers (CPs)—for example, doctors, therapists, educators, caregivers, and so forth?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
13 Alverson et al., 2019	This paper does not specifically focus on the relationships between YAAs and their CPs.	C
14 Hedley et al., 2018	This study does not specifically focus on the relationships between YAAs and their employers. However, this study identified accommodations employers can make to facilitate a better relationship with young autistic employees.	C
15 Kuo et al., 2018	This study identified a need for more research on how to better support YAAs before and during the transition to adulthood. In this study, participants expressed the desire for more information on which skills CPs should be working on during childhood to better prepare YAAs for life after high school. Participants also wanted more research on interventions and models that benefit YAAs, and the types of supports that need to be developed for YAAs. "Ten participants (80%) discussed the current lack of information and research being conducted on individuals with ASD in adulthood and the need to know more to make better-informed decisions. Examples included the need to know more about skills that should be targeted in childhood that would lead to better outcomes in adulthood, interventions and models that should be duplicated, and the types of adult programs that should be developed." (p. 295)	C Written from the C perspective. CPs want to learn more about how they can best support the YAAs they serve so they can provide a better, more helpful relationship with them.
16 Koffer Miller et al., 2018	This study identified gaps in resources and supports available for YAAs to enable them to integrate within their communities. In this study, integration in the community and the opportunity to socialize with peers were identified as essential to maintaining a quality of life. However, many YAAs reported participating in day programs and sheltered workshops, segregated from their broader communities. "Previous research has indicated the overwhelming majority of adults with ASD are largely participating in segregated, disability-specific activities, such as adult day programs and sheltered workshops. However, with the appropriate support, guidance, and skills, adults with ASD can and should be meaningfully integrated into the community." (p. 353)	C Written from the C perspective. Many YAAs are not receiving social opportunities, and their relationships with their communities are effectively nonexistent as a result.

Table 5, continued.

THEORY AREA 1—What are the characteristics and perspectives relevant to the relationship between young autistic adults (YAAs) and their clinical providers (CPs)—for example, doctors, therapists, educators, caregivers, and so forth?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
17 Franklin et al., 2019	This study identified parental concerns about the amount of time it takes to find support for their autistic children in adulthood. In this study, parents expressed concerns that while they were seeking adult services for their children, their children were experiencing limited community integration, lack of structured activities, and reduced opportunities to socialize. “This mom described the 10-year waitlist, initially projected as a 5-year waitlist, for the waiver to receive adult services. Another mother described how their AYA waited 9 years for a waiver.” (p. 153)	C Written from the C perspective. Caregivers are pleading with CPs for much needed supports for YAAs, while the YAAs begin to lose their relationships with their peers and their community.
18 First et al., 2019	This study identified that many YAAs look to their caregivers and educators as a source of guidance to help them through their problems. In this study, YAAs reported discussing their problems, opinions, and emotions with older adults, who provided a safe environment to discuss these topics. Some YAAs reported feeling that these discussions helped them surmount their problems in high school in ways that would not have been possible otherwise. “Specifically, participants discussed how parents were a resource who assisted in the problem-solving coping process by helping youth understand a problem situation and explore possible causes and solutions” (p. 609).	C Written from the C perspective. Many YAAs look to their caregivers and educators whom they trust to provide advice and guidance in a safe environment. These relationships are credited as an essential resource.
19 MacLeod, 2017	This study identified an important distinction between “independence” and “interdependence” that needs to be clarified. In this case study, the subject acknowledged that part of becoming independent means knowing when to seek the resources and support necessary to remain independent. “Here, Brian’s ability both to recognize his needed supports and to ask for those supports illustrates valuable self-determination and self-advocacy skills” (p. 202).	N Written from the N perspective. YAAs need guidance to develop the skills to advocate for the supports they need to remain independent. Thus, an interdependent relationship can help foster independence in other areas.

Table 5, continued.

THEORY AREA 1—What are the characteristics and perspectives relevant to the relationship between young autistic adults (YAAs) and their clinical providers (CPs)—for example, doctors, therapists, educators, caregivers, and so forth?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
20 Brede et al., 2022	This study identified a general lack of effective services available to YAAs, which created tensions in their personal relationships. In this study, YAAs struggled with accessing the types of services to meet their individual needs. This meant family members and caregivers had to provide the types of support necessary on their own. Families without a robust support system struggled to manage their daily lives in addition to providing the necessary support system. “Family member’s involvement in autistic adults’ care also caused tension due to power imbalances and disparity in family’s and autistic adults’ expectations and desired outcomes” (p. 16).	C Written from the C perspective. Some YAAs experience strained personal relationships as a result of strained relationships with CPs who do not provide necessary supports.
21 Chambers et al., 2020	This study identified YAAs and expressed a positive self-relationship exists due to their sense of identity associated with an ASD diagnosis. In this study, YAAs expressed relief after an ASD diagnosis. Some YAAs felt that the diagnosis provided an explanation for why they were so different from their peers. Others felt that a great sense of personal identity and pride associated with their ASD diagnosis. “He described it as giving his life ‘meaning’ and helping him find his ‘particular special area’ of talent. Asper also found comfort in the AS identity during his adolescence, as it gave him a sense of belonging.” (p. 10)	N Written from the N perspective. Some YAAs feel that having an ASD diagnosis helps foster their relationships with others and with themselves.
22 Pearson, 2012	This study identified strained relationships between YAAs receiving state-funded residential services and their families. In this study, some YAAs expressed painful emotions when asked about their families. For one participant, these emotions translated into verbal fury and a raised voice when referring to his perception of his mother’s rejection of him. “Five participants seemed avoidant of any in-depth discussion of their families, even with researcher probing” (p. E80).	C Written from the C perspective. Many YAAs experience negative relationships with their families as a result of feeling rejected due to their receipt of state-funded residential services.

Table 5, continued.

THEORY AREA 1—What are the characteristics and perspectives relevant to the relationship between young autistic adults (YAAs) and their clinical providers (CPs)—for example, doctors, therapists, educators, caregivers, and so forth?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
23 Galler, 2013	This study identified YAAs' feelings of exclusion and isolation from their communities. In this study, YAAs expressed their feelings of being left behind by their neurotypical peers for typical developmental milestones. One participant discussed a loss of friendships as neurotypical peers had less time due to learning essential life skills. "She feels that she was left behind as other peers went off to jobs, college, and fun activities. Her friends are 'now too busy for me, they are learning how to drive, cook and how to get a job, and even though I am older than they are, they are moving ahead of me rather quickly.'" (p. 79)	N Written from the N perspective. YAAs often feel excluded from having relationships with their communities.

Disagreements over Defining Disability

Autistic self-advocates, as far back as Sinclair's (1993/2012a) original essay to parents, have long expressed their concerns that clinical providers have been trying to cure something that is not a pathological disease. Since then, self-advocates have pled with clinical providers to accept that young autistic adults will always be autistic, no matter what interventions are taken to cure them of their autism spectrum disorders. Awareness was seen as fearmongering to fundraise for research to effectively eliminate autistic spectrum disorders (ASAN, 2012). Self-advocates have also asked that neurotypicals (or the clinical providers) respect young autistic adults as human beings deserving of dignity (ASAN, 2012).

Singer (1998/2017) argued that disabilities like autism spectrum disorders were a form of ethnicity, as opposed to a pathology to be cured. She viewed the culturally reinforced concept of "normalcy" as a highly subjective social construct meant to pathologize disability: “disability theorists repeatedly stress that what we currently call the norm, is actually a rarely achieved ideal” (Singer, 1998/2017, p. 37). Taken at face value, Neurodiversity and the established clinical model of autism spectrum disorders have seemed to be at odds over the definition of disability as it relates to autism spectrum disorders (Singer, 1998/2017; ASAN, 2012).

Dependence on Clinical Providers

Even as this disagreement continued to rage on, some self-advocates seemed to forget that they were partially dependent on their clinical providers for emotional regulation and support (First et al., 2019; Santomauro et al., 2017). Common emotional triggers such as bullying and social anxiety made emotional regulation difficult (Santomauro et al., 2017).

Young autistic adults have often faced challenges when attempting to recognize and label their emotions, and their clinical providers have acknowledged these challenges (Santomauro et al., 2017). Some young autistic adults recognize that they sometimes misidentify their own emotional cues, at times being unable to properly recognize and label the emotions they are feeling (Santomauro et al., 2017). According to Santomauro et al. (2017), “alexithymia [difficulty feeling emotions] was mainly discussed by parents, teachers, and psychologists, describing the difficulties adolescents and young adults with ASD face when it comes to articulating their emotions” (p. 279).

Autistic self-advocates also look to their clinical providers for guidance in other ways (First et al., 2019). Young autistic adults sometimes preferr to discuss their problems, opinions, and emotions with older adults in a safe environment (First et al., 2019). Young autistic adults often attribute their ability to surmount otherwise insurmountable problems to these discussions (First et al., 2019).

While proponents of Neurodiversity have often voiced their desire to be fully independent from their clinical providers, this phenomenon seems to imply a distinction between “independence” and “interdependence” (MacLeod, 2017). The case study MacLeod (2017) presented demonstrated how part of becoming independent means knowing when to seek the resources and support necessary to remain independent. Young autistic adults and their clinical providers could learn from this that young autistic adults needed guidance from their clinical providers to develop skills to advocate for the supports they need to remain independent. In other words, an interdependent relationship in some areas can help foster independence in other areas (MacLeod, 2017).

Self-Advocacy

The ability to advocate for one’s needs is an important skill for young autistic adults to learn, though doing so can lead to anxiety during employer interviews (Anderson et al., 2021). A study by Anderson et al. (2021) showed that deciding whether or not to disclose their disability is a difficult question for young adults with ASD-CA who seek employment without the assistance of any disability-focused agency. They have to weigh the understanding that might be elicited from others in the workplace against potential stigma and discrimination (Anderson et al., 2021, p. 99).

Young autistic adults have expressed their anxiety in other uncertain or unfamiliar situations, often citing their lack of experience in self-advocacy and self-determination skills when taking control of their healthcare needs (Cheak-Zamora et al., 2017). Their anxiety over their lack of experience with interacting with healthcare providers confounds the role of caregivers who want to support their charge's autonomy but feel compelled to remain in charge of healthcare decisions (Cheak-Zamora et al., 2017).

Lam et al. (2020) reported that using novel methods such as Photovoice facilitated the development of self-determination and self-advocacy skills by fostering more effective communication skills. Young autistic adults described how they care very much about their families and close friends, yet they acknowledged their inability to communicate it effectively (Lam et al., 2020).

Exclusion from Decisions About Support

Without support from clinical providers and the independence they help young autistic adults develop, other relationships may suffer (Galler, 2013; Pearson, 2012). Pearson (2012) found that some young autistic adults receiving state-funded residential services felt isolated from their families, at times even perceiving their living arrangements as rejection from their families (Pearson, 2012).

Galler (2013) identified young autistic adults who expressed that they felt left behind by their neurotypical peers for typical developmental milestones such as getting a job, learning to drive, and learning to cook. The achievement of these developmental milestones had negative effects on friendships with neurotypical peers, who had less time for their autistic friends while learning essential life skills (Galler, 2013).

Education About Autism Spectrum Disorders

Other frustrations also confound the relationship between young autistic adults and their clinical providers (Chambers et al., 2020; Cheak-Zamora & Teti, 2015; Kuo et al., 2018). While transitioning from pediatric care to adult-oriented care, young autistic adults and their caregivers agreed that clinical providers did not effectively understand the nuances of autism spectrum disorders and how they affected each autistic individual. However, they could not agree on basic opinions about transitioning to adulthood (Cheak-Zamora & Teti, 2015). According to Cheak-Zamora and Teti (2015),

> Both caregiver and youth felt anxious about moving from pediatric to an adult provider. Caregivers regretted losing a valued and trusted provider. Having a provider that the youth was comfortable with was important to caregivers which they believe would be lost with an adult provider. (p. 998)

Kuo et al. (2018) found that clinical providers wanted to learn more about how they could best support the young autistic adults they serve so they could provide a better, more helpful relationship with them. Clinical providers expressed the desire for more information on which skills clinical providers should be working on during childhood to better prepare young autistic adults for life after high school. Participants also wanted more research on interventions and models that benefit young autistic adults and the types of supports that need to be developed for young autistic adults (Kuo et al., 2018).

For some, just receiving an autistic diagnosis at all alleviated anxieties (Chambers et al., 2020). Some young autistic adults felt that the diagnosis provided an explanation for why they were so different from their peers, while others felt that a great sense of personal identity and pride associated with their autism diagnosis (Chambers et al., 2020). Such feelings of relief would not have been made possible without the assistance of a clinical provider.

Lack of Support for Young Autistic Adults

Even with a clinical diagnosis, the proper support systems are not always available when they were needed. Sosnowy et al. (2018) elaborated on the importance of receiving the necessary support, noting that social barriers to the ambitions and goals of young autistic adults were often lifted when the proper accommodations were provided.

Young autistic adults reported struggles with accessing the types of services to meet their individual needs, meaning family members and caregivers had to provide the necessary types of support on their own (Brede et al., 2022). Families without a robust support system struggled to manage their daily lives in addition to providing the necessary support system (Brede et al., 2022). Their caregivers expressed concerns that during the extended periods of time they were seeking adult services for their loved ones, they experienced limited community integration and fewer opportunities to socialize with peers (Franklin et al., 2019; Koffer Miller et al., 2018).

Of the limited supports and resources available in adulthood (Brede et al., 2022; Franklin et al., 2019), autistic women often experienced barriers not experienced by their male peers (Milner et al., 2019). Autistic women suggested that autistic men are subjected to less pressure to mask or camouflage their symptoms and that autistic women were more successful at doing so (Milner et al., 2019).

Masking their behavior during the diagnostic screening process could mean women are misdiagnosed or their autism spectrum disorder is not diagnosed at all (Milner et al., 2019). Autistic women expressed that they sensed they were different in some way, but they could never identify what their difference was, and they expressed their relief when they were finally diagnosed with an autism spectrum disorder: “During discussions women who believed they successfully masked their symptoms reported how they might learn stock phrases in social etiquette or consciously study the ‘appropriate’ amount of time to maintain eye contact” (Milner et al., 2019, p. 2399).

The first research question pertaining to the characteristics and perspectives relevant to the relationship between young autistic adults and their clinical providers has been extensively answered.

Trusting and Inclusive Relationships

The next theory area examined the characteristics and perspectives relevant to trusting and inclusive relationships (see Table 6). Themes derived from this theory area included treating young autistic adults with empathy, respect, and dignity, accommodations for young autistic adults and the expectations their clinical providers have for them, and the coordination of clinical providers across support systems used by young autistic adults.

Table 6

Evidence Table 2

THEORY AREA 2—What are the characteristics and perspectives that make some relationships between young autistic adults (YAAs) and their clinical providers (CPs) more trusting and inclusive than others?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
1 Robison, 2011	This book does not specifically focus on the characteristics and perspective that drive the relationships between YAAs and their CPs so much as it describes what some trusting and inclusive relationships can look like.	N
2 Frazier, 2019	This book identified actions everybody can take to ensure more trusting and inclusive relationships between YAAs and their CPs. In this book, Frazier (2019) urges CPs to treat YAAs with respect and human dignity rather than approaching diagnosis and screening as a search for a disease. Informing and educating others about ASD reduces stigma. "If you treat diagnosis and screening as if you are looking for a sickness or disease, then you are attaching unnecessary stigma to both the condition and the individual being screened and diagnosed. Autism is a form of diversity, not a sickness and not a disease." (p. 148)	C + N Written from the C perspective, but also applicable to the N perspective. Treating YAAs with respect and human dignity can help create a trusting and inclusive relationship for CPs.
3 Autistic Self Advocacy Network, 2012	This book identified that the concept of "normalcy" is a myth due to its highly subjective nature and that the autistic spectrum is not linear. In this book, autistic self-advocates argue that some of the behaviors and social cues expected of them may need to be modified based on the individual. Some individuals find forcing eye contact to be more distracting to them during conversations. Likewise, some individuals find that self-stimulation—or "stimming"—can help them focus on a task. While some individuals may use adaptive equipment, this does not mean that adaptive equipment is needed in every setting. "Drawing squares is a great way for me to listen. . . . Drawing during a conversation helps me to relax and I can focus on what the other person is saying if I am not forced to look at him/her or the surroundings." (p. 306)	N Written from the N perspective. Accommodating unique needs and modifying some social expectations can help create a trusting and inclusive relationship between YAAs and their CPs.

Table 6, continued.

THEORY AREA 2—What are the characteristics and perspectives that make some relationships between young autistic adults (YAAs) and their clinical providers (CPs) more trusting and inclusive than others?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
4 Singer, 1998/2017	This book identified objectives that autistic self-advocates wish to see implemented across society. In this book, Singer (1998/2017) writes that autistic self-advocates want recognition that they function differently based on the way their brains are "wired." Self-advocates also want their civil rights respected and an end to discrimination. Furthermore, Singer (1998/2017) argues that disability services should be made available and be appropriate to an individual's level of functioning on the spectrum. "Autistics want widespread recognition of the reality of pervasive neurological differences, and an end to being expected to perform in ways for which they are simply not 'wired'" (p. 55).	N Written from the N perspective. YAAs want more recognition that their brains are neurologically different and twant he accommodations necessary for trusting and inclusive relationships to thrive.
5 Sosnowy et al., 2018	This paper does not specifically focus on trust in relationships. However, this paper does identify the need for parents and YAAs to coordinate together on the postsecondary transition to adulthood.	C + N
6 Santomauro et al., 2017	This paper does not specifically focus on the relationships between YAAs and their CPs. However, YAAs have been found to rely on external cues from trusted allies to identify and regulate their emotions. "External cues included other people's behaviours, feedback from others, and the monitoring of their own involuntary behaviour (such as observing that they are being aggressive or their hands are shaking)" (p. 279).	C
7 Anderson et al., 2021	This paper does not specifically focus on increasing trust or inclusivity in relationships. However, characteristics and perspectives that make relationships less trusting and inclusive are identified.	C + N

Table 6, continued.

THEORY AREA 2—What are the characteristics and perspectives that make some relationships between young autistic adults (YAAs) and their clinical providers (CPs) more trusting and inclusive than others?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
8 Milner et al., 2019	This paper does not specifically focus on describing a more trusting and inclusive relationship between young autistic women and their CPs. However, this paper does allude to how this type of relationship could be made more trusting and inclusive.	C
9 Cheak-Zamora et al., 2017	This paper does not specifically focus on describing more trusting and inclusive relationships between YAAs and their CPs. However, several suggestions were raised that may help facilitate more trusting and inclusive relationships.	C
10 Lam et al., 2020	This study identified characteristics in their relationships with animals that can be applied to human relationships. In this study, YAAs described their relationships with animals as more empathetic than with some humans. Some participants went so far as to draw inspiration from their pets, and some pets were even considered the participants' best friends. "Participants felt trust, mutual respect, unconditional care, and shared understanding in their relationships with animals. They felt a sense of reciprocity with their pets as if animals also knew how much people love them and appreciate their company." (p. 1254)	C + N Written from the C perspective, but also applicable to the N perspective. Some YAAs have a more trusting and inclusive relationship with animals than with other humans due to the unfiltered empathy of their animal companions.
11 Vincent, 2019	This paper did not specifically focus on the characteristics of trusting and inclusive relationships between YAAs and their CPs.	C
12 Cheak-Zamora & Teti, 2015	This paper does not specifically focus on describing trusting and inclusive relationships between YAAs and their CPs. However, the need for more input from YAAs in the transition of their healthcare providers has been identified.	C
13 Alverson et al., 2019	This paper does not specifically focus on describing trusting and inclusive relationships between YAAs and their CPs.	C

Table 6, continued.

THEORY AREA 2—What are the characteristics and perspectives that make some relationships between young autistic adults (YAAs) and their clinical providers (CPs) more trusting and inclusive than others?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
14 Hedley et al., 2018	This study identified several factors that can help or hinder more trusting and inclusive relationships between YAAs and their employers. In this study, workplace accommodations were identified as factors that facilitated the success of young autistic employees at work. Such accommodations included strategies implemented by support staff, environmental modifications, and organizational support. Young autistic employees receiving these accommodations in the workplace reported increases in their independence, sense of purpose, positive social interactions and relationships, the quality of their work productivity, and their awareness of the manifestations of their own ASD. “Not only were trainees motivated to maintain a high standard of work, they also showed insight into the work environment and to some of the challenges posed by ASD symptoms. One trainee commented on the insights into his own symptoms that he had gained by working with others like him, who also faced similar challenges. Trainees socialised with each other both at work and outside of work, suggesting that work may provide increased opportunities for social interaction.” (p. 537)	C Written from the C perspective. Providing empathy and accommodations at work helped maintain a trusting and inclusive relationship between YAAs and their employers.
15 Kuo et al., 2018	This study identified a need for providers and caregivers to better coordinate expectations when supporting YAAs through the transition to adulthood. In this study, researchers found that the relationship between providers and caregivers has the ability to affect the outcomes of their children’s transition to adulthood. More coordination was found to have a positive effect on their children’s lives. “In addition, participants discussed the importance of provider and parent expectations and perceptions of individuals on the autism spectrum (i.e., capable of being independent or working after high school) and how this can negatively or positively impact the trajectory of transition planning and preparation” (p. 296).	C Written from the C perspective. Coordination between CPs and caregivers had the effect of trusting and inclusive relationships with YAAs.

Table 6, continued.

THEORY AREA 2—What are the characteristics and perspectives that make some relationships between young autistic adults (YAAs) and their clinical providers (CPs) more trusting and inclusive than others?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
16 Koffer Miller et al., 2018	This study identified the importance of integrating the voices of YAAs into service plans affecting them. In this study, YAAs reported needing more services in adulthood than they were receiving. One in four adults needed vocational services, and one in five adults needed career counseling or supported employment. Neither group received the services they needed. “An important consideration that has been identified from this study, across all of the findings, is the importance of integrating the voices of the program participants effectively into service plans in order to meet the federal requirements for person-centered planning” (p. 353).	C Written from the C perspective. Providing necessary supports affects whether the relationship between YAAs and their CPs is trusting and inclusive.
17 Franklin et al., 2019	This study identified peer support for parents as a key resource in broadening perspectives and providing knowledge of resources and new strategies. In this study, parents reported that parent-to-parent support groups helped provide connection to resources, motivation, and hope. Such parent peer-coaching has the potential to revolutionize the healthcare transition for YAAs. “Parent-to-parent peer mentorship and parents as transition experts have shown positive impacts for parents of youth with ID and other disabilities as they have the critical element of the shared experience that health care providers commonly lack. Including parent peer coaches as a member of this care delivery team is particularly promising within the context of value-based care models.” (p. 155)	C Written from the C perspective. Peer support groups have the potential to revolutionize the relationship between CPs and YAAs.
18 First et al., 2019	This paper did not specifically focus on describing trusting and inclusive relationships particularly. However, participants did discuss the type of relationships they had, some of which may well have been trusting and inclusive.	C

Table 6, continued.

THEORY AREA 2—What are the characteristics and perspectives that make some relationships between young autistic adults (YAAs) and their clinical providers (CPs) more trusting and inclusive than others?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
19 MacLeod, 2017	This study identified a balance between the world YAAs envision for themselves and the world their caregivers envision for them, a balance that needs to be maintained. In this study, the subject's parents understood that they must walk a fine line between how the subject defines his world and the life they want him to lead. This walk is best accomplished by guiding YAAs to develop the skillsets necessary to self-advocate. "Anthony expressed that they push and nudge Brian forward, just as any parent might with their child, they also have to be careful because they are navigating both their understanding of how Brian is defining his own world and the world they envision for him" (p. 203).	N Written from the N perspective. The ability to self-advocate can determine whether or not a relationship between a YAA and their CPs is trusting and inclusive.
20 Brede et al., 2022	This study identified that the more positive the relationship between YAAs and their therapists, the more positive the outcome of therapy. In this study, therapists and YAAs agreed that forming trusting and inclusive relationships with each other was a high priority for them all. YAAs expressed that they felt the relationship with their therapists was the most important aspect of therapy. "Autistic adults who were satisfied with the relationship with their clinician experienced these relationships to be 'reciprocal and responsive to [their] needs' and were appreciative of the support they had received. Clinicians described 'being humbled' and feeling a 'sense of fulfilment' from successfully establishing such relationships" (p. 18).	C Written from the C perspective. Both YAAs and their CPs want trusting and inclusive relationships with each other, as this has been identified as key aspect of support.
21 Chambers et al., 2020	This study identified a need for CPs to provide needed supports quickly for YAAs. In this study, YAAs expressed that their ASD diagnoses enabled them to seek and receive the supports they needed to be successful. Many YAAs expressed gratitude for the supports they were able to receive, implying that not every YAA is as fortunate to have such a relationship with their CPs. "There was a general sense of gratitude from participants for the support they received, but a feeling that they were 'lucky' (Ethan) or 'fortunate' (Asper), and therefore that perhaps others had not been. Several participants noted that without that support, things would not have turned out so well." (p. 12)	N Written from the N perspective. Having the appropriate support system for YAAs' needs has had a positive effect on their trusting and inclusive relationships with their CPs.

Table 6, continued.

THEORY AREA 2—What are the characteristics and perspectives that make some relationships between young autistic adults (YAAs) and their clinical providers (CPs) more trusting and inclusive than others?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
22 Pearson, 2012	This study identified positive relationships between some YAAs and their families as facilitated by their residential staff. In this study, some YAAs described positive relationships with their grandparents, or parents who were no longer healthy and independent enough to care for their needs. One participant described a strained relationship with his mother being repaired through staff intervention. "One participant described separating from his mother during an argument and then renegotiating a healthier relationship several months later with staff assistance" (p. e80).	C Written from the C perspective. CPs have the potential to help heal strained personal relationships in YAAs' lives in a trusting and inclusive way.
23 Galler, 2013	This paper did not specifically focus on describing trusting and inclusive relationships between YAAs and their CPs.	N

Empathy, Respect, and Dignity

When discussing trusting and inclusive relationships, the topics of empathy, respect, and dignity must be addressed. Frazier (2019) addressed these topics while urging clinical providers to treat young autistic adults with respect and human dignity rather than approaching diagnosis and screening as a search for a disease:

> If you treat diagnosis and screening as if you are looking for a sickness or disease, then you are attaching unnecessary stigma to both the condition and the individual being screened and diagnosed. Autism is a form of diversity, not a sickness and not a disease. (p. 148)

Frazier's (2019) assessment of the diagnostic process implied a point that should be obvious: treating people with respect and human dignity can help create a trusting and inclusive relationship. On the topic of empathy, some young autistic adults found their animal companions more empathetic than their human companions (Lam et al., 2020). Young autistic adults expressed that they felt mutual respect and unconditional compassion in their relationships with animals due to an unfiltered sense of empathy: “They felt a sense of reciprocity with their pets as if animals also knew how much people love them and appreciate their company” (Lam et al., 2020, p. 1254).

Even in their relationships with humans, empathy has been found to facilitate trusting and inclusive relationships between young autistic adults and their clinical providers, as young autistic adults reported their opinions that forming trusting and inclusive relationships with their therapists was the most important aspect of therapy (Brede et al., 2022). As Brede et al. (2022) contended, “autistic adults who were satisfied with the relationship with their clinician experienced these relationships to be ‘reciprocal and responsive to [their] needs and were appreciative of the support they had received’” (p. 18). The healing effects empathetic clinical providers have on their relationships with young autistic adults extends beyond therapy, as Pearson (2012) found.

Pearson (2012) found that strained relationships between young autistic adults and their families could be repaired through staff intervention. One participant Pearson interviewed described clinical staff facilitating the renegotiation of a healthier relationship with his mother after separating during an argument.

Hedley et al. (2018) found that when empathetic employers provided workplace accommodations for their autistic employees—such as environmental modifications and organizational support—autistic employees reported increases in their independence, sense of purpose, and positive social interactions and relationships. The quality of their work productivity also improved as a result of the accommodations (Hedley et al., 2018).

Accommodations and Expectations

Accommodations may be necessary when enforcing neurotypical society's expectations of young autistic adults seems to have a counterproductive effect (ASAN, 2012). In such cases, expectations may need to be modified based on how an individual's brain functions (ASAN, 2012; Singer, 1998/2017). Some individuals found forcing eye contact to be distracting to them during conversations. Likewise, some individuals found that self-stimulation—or "stimming"—could help them focus on a task (ASAN, 2012).

Autistic self-advocates want recognition that they function differently from others based on the way their brains are "wired" (Singer, 1998/2017). Disability services should be made available and be appropriate to an individual's level of functioning on the autism spectrum (Singer, 1998/2017). To quote Singer, "autistics want widespread recognition of the reality of pervasive neurological differences, and an end to being expected to perform in ways for which they are simply not 'wired'" (1988/2017, p. 55).

Coordinating Across Support Systems

When supporting young autistic adults through the transition to adulthood, clinical providers and caregivers must coordinate expectations better (Kuo et al., 2018). The relationship between providers and caregivers has the ability to affect the outcomes of their loved ones' transition to adulthood (Kuo et al., 2018). Kuo et al. (2018) found more coordination to have a positive effect on the lives of young autistic adults.

Franklin et al. (2019) concluded that coordination between parents can prove to be a key resource when providing support for young autistic adults. Peer support groups for parents had the effect of broadening perspectives and providing knowledge of resources and new strategies, which then were leveraged to provide support for their loved ones (Franklin et al., 2019). Such parent-to-parent support groups were reported to help provide connections to resources, motivation, and hope (Franklin et al., 2019).

According to Franklin et al., "parent-to-parent peer mentorship and parents as transition experts have shown positive impacts for parents of youth with [intellectual disabilities] and other disabilities as they have the critical element of the shared experience that health care providers commonly lack" (2019, p. 155). Parent peer-coaching has the potential to revolutionize the healthcare transition for young autistic adults (Franklin et al., 2019).

As important as coordination between clinical providers and caregivers is to autistic support systems (Franklin et al., 2019), young autistic adults must also participate in this process (Koffer Miller et al., 2018). Young autistic adults needed more services in adulthood than they were currently receiving (Koffer Miller et al., 2018). One in four adults needed vocational services but had not received them, and one in five young autistic adults needed career counseling or supported employment and had not received these services (Koffer Miller et al., 2018). For those who received support from an early age, Chambers et al. (2020) acknowledged that clinical providers needed to provide necessary supports more quickly for young autistic adults.

According to Chambers et al. (2020), young autistic adults expressed that their diagnoses enabled them to seek and receive the supports they needed to be successful. Many self-advocates expressed their gratitude for the support systems they were provided, recognizing that not every autistic adult has had the good fortune to have such a relationship with their clinical providers (Chambers et al., 2020). The notion that not all autistic adults are able to receive much-needed supports was not lost on self-advocates (Chambers et al., 2020).

When providing necessary support systems, a balance between the world that young autistic adults envision for themselves and the world that their caregivers envision for them must be maintained (MacLeod, 2017). In a study by MacLeod (2017), parents understood that they must walk a fine line between how individuals define their worlds and the life they wanted their loved ones to lead. This walk was best accomplished by guiding young autistic adults to develop the skillsets necessary to self-advocate. What this implies is that the ability to self-advocate can affect how trusting and inclusive a relationship has the potential to be (MacLeod, 2017).

The researcher is convinced that the second research question pertaining to the characteristics and perspectives relevant to trusting and inclusive relationships has been substantially answered.

Making Relationships Trusting and Inclusive

The next theory area examined how trusting and inclusive relationships between young autistic adults and their clinical providers can be formed, facilitated, and maintained (see Table 7). Themes derived from this theory area included treating young autistic adults with empathy, respect, and dignity; the expectations their clinical providers have of young autistic adults; the inclusion of autistic voices in decisions about support systems; the coordination of clinical providers across support systems used by young autistic adults; and how clinical providers can leverage young autistic adults' personal strengths and interests into their support systems.

Table 7

Evidence Table 3

THEORY AREA 3—How can trusting and inclusive relationships between young autistic adults (YAAs) and their clinical providers (CPs) be facilitated, formed, and maintained?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
1 Robison, 2011	The book identified actions that neurotypicals and YAAs can take to facilitate, form, and maintain trusting and inclusive relationships with each other. In this book, Robison (2011) advises that neurotypical adults can explain the social cues that their autistic children may not understand to prepare them for the transition to adulthood. Understanding what ASD is and how it affects different people can help YAAs learn to better understand themselves and their own needs. YAAs should always strive to improve themselves and better understand the world around them. Practicing social cues can improve competency and self-efficacy. "Asperger kids today still face that problem, but if grown-ups are aware, they can do a whole lot to help by explaining what the kids are missing. That's so important—that and not condemning the kids for what they don't even understand." (pp. 85–86)	N Written from the N perspective. Understanding expectations can help form, facilitate, and maintain trusting and inclusive relationships between YAAs and their CPs.

Table 7, continued.

THEORY AREA 3—How can trusting and inclusive relationships between young autistic adults (YAAs) and their clinical providers (CPs) be facilitated, formed, and maintained?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
2 Frazier, 2019	This book identified some guidelines for facilitating, forming, and maintaining trusting and inclusive relationships between YAAs and their CPs. In this book, Frazier (2019) writes about functioning labels and their use to discriminate against various types of institutionalized patients. CPs should aim to describe the individual person rather than use functioning labels. YAAs can inform and educate the world around them and advocate—both for themselves and for others—to help reduce the stigma associated with ASD. “Remember that being autistic is not a fault, and no one is to blame for the child’s condition. Remember that the condition is genetic, and staying away from various substances or vaccinations would not have prevented it.” (pp. 118–119)	C + N Written from the C perspective, but also applicable to the N perspective. Describing each individual person, as opposed to using functional labels, helps form, facilitate, and maintain trusting and inclusive relationships.
3 Autistic Self Advocacy Network, 2012	This book identified some guidelines to help improve the relationship between YAAs and their CPs. In this book, autistic self-advocates requested that discussion be open-minded and two-sided. Self-advocates want the support and accommodations necessary for them to succeed to be provided and made available to them. YAAs want to be included in conversations and planning about their ASD and to be valued as human beings. “Too many conversations about us and issues that affect our lives take place without any of us present” (p. 365).	N Written from the N perspective. Open-minded and two-sided discussion can help form, facilitate, and maintain trusting and inclusive relationships between YAAs and CPs.

Table 7, continued.

THEORY AREA 3—How can trusting and inclusive relationships between young autistic adults (YAAs) and their clinical providers (CPs) be facilitated, formed, and maintained?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
4 Singer, 1998/2017	This book does not specifically focus on how to facilitate, form, and maintain relationships between YAAs and their CPs.	N
5 Sosnowy et al., 2018	This paper does not provide specific recommendations for facilitating, forming, and maintaining trusting and inclusive relationships. However, this paper does allude to methods to facilitate, form, and maintain such relationships between YAAs and their parents, even if such methods are not explicitly mentioned.	C+N
6 Santomauro et al., 2017	This paper does not specifically focus on the relationships between YAAs and their CPs, although such relationships are described in detail throughout the paper.	C
7 Anderson et al., 2021	This study identified a need to identify potential challenges to YAAs' employment during childhood and adolescence and to address them before the transition to young adulthood in preparation for employment as a young adult. Aligning YAAs' strengths and career paths needs to be a focus of future research. Services to assist parents in supporting YAAs to achieve employment milestones need to be improved and more varied and robust. Identification of and access to existing services for YAAs to find and keep employment must be improved. Services in childhood and adolescence must be improved and more varied and robust in order to prepare autistic students for the transition to young adulthood. Social skills, daily living skills, and other challenges to YAAs' employment must be addressed prior to the transition to young adulthood. Lessons must be learned from other successful initiatives designed to improve the transition to young adulthood for YAAs. "An urgent question is to what extent these programs are reaching young adults with ASD. Few of the families and young adults interviewed seemed to have accessed the opportunities envisioned in this legislation." (p. 99)	C + N Written from the C perspective, but also applicable to the N perspective. Identifying potential challenges prior to the transition to adulthood can help facilitate, form, and maintain trusting and inclusive relationships between YAAs and CPs.

Table 7, continued.

THEORY AREA 3—How can trusting and inclusive relationships between young autistic adults (YAAs) and their clinical providers (CPs) be facilitated, formed, and maintained?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
8 Milner et al., 2019	This study identified generalized feelings that young autistic women could have more support once they were eventually diagnosed with an ASD and that the diagnostic process itself is designed to preclude their diagnosis, unlike their male counterparts. In this study, some women expressed that there was support they could have had, but they were never offered the same supports that autistic boys were offered. Some autistic women stated that they were often referred to as a “naughty child” or a “slow learner” rather than being offered the type of supports they needed. “The participants suggested that females are able to disguise their autism symptoms which can mean clinicians often misdiagnosed or completely missed diagnoses” (p. 2396).	C Written from the C perspective. Treating YAAs consistently when providing supports can determine whether the relationship between YAAs and their CPs is trusting and inclusive.
9 Cheak-Zamora et al., 2017	This study identified several suggestions that can help facilitate, form, and maintain more trusting and inclusive relationships between YAAs and their CPs. In this study, the importance of coordination between YAAs, their caregivers, and their medical providers during the transition to adulthood. Any transitional interventions should be tailored to the YAA’s needs. Caregivers need guidance on how best to support their independence and transition to a more facilitative role within their child’s life. Healthcare providers have the critical role of promoting autonomy by communicating directly with their patients. “Other adjustments to the health care visit may include alterations to the clinic environment (e.g., providing adolescent with clinic room on arrival), allowing alternative communication methods, and using specific and precise language and instructions” (p. 1037).	C Written from the C perspective. Tailoring supports to individuals’ needs and coordinating support systems can help facilitate, form, and maintain trusting relationships between YAAs and their CPs.

Table 7, continued.

THEORY AREA 3—How can trusting and inclusive relationships between young autistic adults (YAAs) and their clinical providers (CPs) be facilitated, formed, and maintained?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
10 Lam et al., 2020	This study identified suggestions for facilitating, forming, and maintaining trusting and inclusive relationships between YAAs and their CPs. In this study, the researchers acknowledged the need to listen to YAAs' first-person perspectives and to recognize their agency as unique human beings. Interventions should focus on their personal strengths, interests, and assets to help them achieve meaningful long-term goals. "Listening to their first-person perspectives recognizes their agency and rights to speak for how they desire to thrive and achieve outcomes that match their unique profiles. Intervention efforts focusing on their assets, character strengths, and personal values can help them achieve long-term goals that are meaningful to them." (p. 1256)	C + N Written from the C perspective, but also applicable to the N perspective. Focusing on personal strengths and interests can help YAAs facilitate, form, and maintain trusting and inclusive relationships with their CPs.
11 Vincent, 2019	This study did not specifically focus on facilitating, forming, and maintaining trusting and inclusive relationships between YAAs and their CPs.	C
12 Cheak-Zamora & Teti, 2015	This paper does not specifically focus on the steps to facilitate, form, and maintain trusting and inclusive relationships between YAAs and their CPs. However, the need for more research and input from YAAs was discussed in great detail.	C

Table 7, continued.

THEORY AREA 3—How can trusting and inclusive relationships between young autistic adults (YAAs) and their clinical providers (CPs) be facilitated, formed, and maintained?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
13 Alverson et al., 2019	This study identified steps caregivers can take to facilitate, form, and maintain trusting and inclusive relationships with YAAs. In this study, researchers established a clear relationship between caregiver involvement, high expectations, and educational outcomes in YAAs. By balancing their children's autonomy and setting expectations for their outcomes as adults, some caregivers were better able to facilitate their children's independence and self-efficacy in taking accountability for their adult lives. "These 'middle ground' families facilitated their sons' independence by encouraging them to complete tasks independently, thereby developing the skills and confidence to navigate the college environment. Interestingly, these same two families kept their children in general education classes in public schools throughout high school, a decision that may have fostered an expectation of success within mainstream education environments." (p. 61)	C Written from the C perspective. Compromising and balancing individuals' autonomy and expectations for adulthood outcomes can help facilitate, form, and maintain trusting and inclusive relationships between YAAs and their caregivers.
14 Hedley et al., 2018	This study identified the steps employers can take to facilitate, form, and maintain more trusting relationships with their young autistic employees. In this study, researchers acknowledged the need for employers to be willing to recognize the individual talents of YAAs and provide the necessary accommodations to engender success as employees. Workplace attitudes and understanding of ASD contributed the most to barriers to successful employment of young autistic employees. "We found that co-workers who worked closely alongside the trainees developed positive attitudes and understanding of their colleagues with ASD, which may well have contributed to the trainees' success at work, including their feelings of being accepted, their confidence and their enthusiasm for their work. The inclusion of dedicated support staff, in particular the inclusion of an individual with experience working with individuals with ASD, emerged as an important ingredient of the programme." (p. 537)	C Written from the C perspective. Recognizing employees' strengths and providing necessary accommodations can help facilitate, form, and maintain trusting and inclusive relationships between YAAs and their employers.

Table 7, continued.

THEORY AREA 3—How can trusting and inclusive relationships between young autistic adults (YAAs) and their clinical providers (CPs) be facilitated, formed, and maintained?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
15 Kuo et al., 2018	This study identified a need for more coordination between support systems designed for YAAs. In this study, participants expressed a perceived disconnect between various support systems. Furthermore, participants felt that there was a lack of communication between pediatric and adult systems supporting their autistic children. “Participants felt that current policies do not support or accommodate the unique social needs and ongoing support required for some individuals on the autism spectrum. In addition, many felt that there was a lack of communication and continuity of care from pediatric to adult systems.” (p. 296)	C Written from the C perspective. Consistency and continuity between support systems helps form, facilitate, and maintain trusting and inclusive relationships between YAAs and their CPs.
16 Koffer Miller et al., 2018	This paper did not specifically focus on facilitating, forming, and maintaining trusting and inclusive relationships between YAAs and their CPs. However, the need for more methods of facilitating, forming and maintaining these relationships was discussed in depth.	C
17 Franklin et al., 2019	This study identified that partnerships between YAAs, their caregivers, and their CPs help facilitate, form, and maintain more trusting and inclusive relationships across all groups. In this study, researchers acknowledged that it is crucial to recognize the various transitions YAAs and their families undergo at the same time and for CPs to implement strategies to address the various needs that may present themselves in order to provide quality care and support for YAAs and their families during the healthcare transition. “Partnerships with AYAs with ID and their parents that foster collaboration among life course systems are necessary to facilitate successful transitions to adulthood” (p. 155).	C Written from the C perspective. Collaboration across support systems can help form, facilitate, and maintain trusting and inclusive relationships between YAAs and their CPs.

Table 7, continued.

THEORY AREA 3—How can trusting and inclusive relationships between young autistic adults (YAAs) and their clinical providers (CPs) be facilitated, formed, and maintained?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
18 First et al., 2019	This study identified the importance of allowing YAAs to voice their input when planning for future decisions that affect their lives. In this study, researchers acknowledged that YAAs are the experts in their lives. Using their input to drive the study, researchers found that many participants reported a feeling of camaraderie and positive peer support through their participation. “The pictures provided youth participants with a new form of communicative expression and an outlet to discuss their daily challenges and solutions. The pictures also provided the group facilitators with a focal point in which to start a discussion about the meaning of the photos and how they related to aspects of the participant’s life.” (p. 615)	C Written from the C perspective. Self-advocacy and participation in research can help facilitate, form, and maintain trusting and inclusive relationships between YAAs and their CPs.
19 MacLeod, 2017	This study identified the need to train educators and caregivers on guardianship and its alternatives to promote self-determination where possible. In this study, researchers acknowledged that genuinely including YAAs in their transition to adulthood increased the likelihood of YAAs developing self-advocacy and self-determination skills. “Like Brian’s teacher, school teams should make the effort to bring these agencies and professionals to the school whenever possible (i.e., facilitating transition fairs, alternatives to guardianship workshops, connecting students with self-advocates, and inviting agency representatives to IEP meetings)” (p. 205).	N Written from the N perspective. Collaboration and including individuals in their transition to adulthood can help facilitate, form, and maintain trusting and inclusive relationships between YAAs and their CPs.

Table 7, continued.

THEORY AREA 3—How can trusting and inclusive relationships between young autistic adults (YAAs) and their clinical providers (CPs) be facilitated, formed, and maintained?		COMMENTS Clinical Model (C)/ Neurodiversity (N)
20 Brede et al., 2022	This study identified a need for clinical services to be more flexible, comprehensive, and holistic. In this study, YAAs considered continuity of care to be very important to their ability to facilitate, form, and maintain trusting and inclusive relationships with their therapists. "Building trusting relationships, listening to autistic adults, and empowering them to take agency, are fundamental steps towards more successful mental health care provision. Improvements to mental health care informed by autistic adults' unique experiences will likely also benefit other services users as well as improving conditions for professionals providing treatment." (p. 20)	C Written from the C perspective. Continuity between CPs and support systems can help facilitate, form, and maintain trusting and inclusive relationships between YAAs and their CPs.
21 Chambers et al., 2020	This paper did not specifically focus on facilitating, forming, and maintaining trusting and inclusive relationships between YAAs and their CPs.	N
22 Pearson, 2012	This paper did not specifically focus on facilitating, forming, and maintaining trusting and inclusive relationships between YAAs and their CPs.	C
23 Galler, 2013	This study identified a need for CPs to recognize and acknowledge the talents and unique potential of YAAs. In this study, Galler (2013) advised that facilitating, forming, and maintaining more trusting and inclusive relationships between YAAs and their CPs involves listening to autistic voices. Furthermore, Galler (2013) views the unique talents and potential of YAAs as a gift to be harnessed to ensure their success in adulthood. "In light of what participants have said, listening to the voices of those affected by ASD is at the heart of helping to solve the problem stated in this research. As educational professionals, we must realize that people with ASD have unique potential and tapping into those traits is a gift for us all." (p. 133)	N Written from the N perspective. CPs must listen to YAAs' voices and acknowledge their unique talents and potential for success to form, facilitate, and maintain trusting and inclusive relationships with YAAs.

Empathy, Respect, and Dignity

Frazier (2019) warned against the use of functioning labels, which were often used to discriminate against various types of institutionalized patients. Instead, clinical providers should aim to describe the individual person (Frazier, 2019). Channeling Jim Sinclair’s (1993/2012a) essay, Frazier (2019) advised clinical providers to “remember that being autistic is not a fault, and no one is to blame for the child’s condition. Remember that the condition is genetic, and staying away from various substances or vaccinations would not have prevented it” (pp. 118–119). Young autistic adults could facilitate such a paradigm shift by informing and educating the world around them and advocating—both for themselves and for others—to help reduce the stigma associated with their autism diagnoses (Frazier, 2019).

When educating and informing others about autism spectrum disorders, the discussion is best served by being open-minded and two-sided (ASAN, 2012). Self-advocates want the support and accommodations necessary for them to succeed to be made available to them (ASAN, 2012). To provide these accommodations and support systems required input from autistic self-advocates, but as ASAN contended, “too many conversations about us and issues that affect our lives take place without any of us present” (2012, p. 365).

Setting Expectations

Even with the proper accommodations, autistic individuals may not understand the social cues and expectations neurotypical society have set of them (Robison, 2011). Understanding what autism spectrum disorders are and how they affect different people could help young autistic adults learn to better understand themselves, their own needs, and the social expectations their clinical providers have of them (Robison, 2011). Clinical providers ought to explain the expectations they have so that autistic individuals can practice social cues and improve their competency and self-efficacy (Robison, 2011). According to Robison,

> Asperger kids today still face that problem, but if grown-ups are aware, they can do a whole lot to help by explaining what the kids are missing. That’s so important—that and not condemning the kids for what they don’t even understand. (2011, pp. 85–86)

Alverson et al. (2019) established a clear relationship between caregiver involvement, high expectations, and educational outcomes in young autistic adults. By balancing their loved ones’ autonomy and setting expectations for their adulthood outcomes, some caregivers were better able to facilitate their loved ones’ independence and self-efficacy in taking accountability for their adult lives:

> These “middle ground” families facilitated their sons’ independence by encouraging them to complete tasks independently, thereby developing the skills and confidence to navigate the college environment. Interestingly, these same two families kept their children in general education classes in public schools throughout high school, a decision that may have fostered an expectation of success within mainstream education environments. (Alverson et al., 2019, p. 61)

In other words, compromising and balancing individuals’ autonomy and expectations for adulthood outcomes can help facilitate, form, and maintain trusting and inclusive relationships between young autistic adults and their clinical providers (Alverson et al., 2019).

Inclusion in Decisions About Support

Expectations seemed to differ between autistic men and their female counterparts, such that women often experienced additional challenges and additional social expectations set for them compared to autistic men (Milner et al., 2019). Many autistic women felt that autistic men were subjected to less pressure to mask or camouflage their symptoms and that autistic women were more successful at doing so (Milner et al., 2019).

Masking their behavior during the diagnostic screening process means women are often misdiagnosed or their autism spectrum disorders are not diagnosed at all (Milner et al., 2019). In Milner et al.'s (2019) study, autistic women shared that they sensed they were different in some way, but they could never identify what their difference was. Many autistic women expressed their relief when they were finally diagnosed with an autism spectrum disorder (Milner et al., 2019). In other words, even when autistic voices are included in conversations about autism spectrum disorders, autistic women have still been excluded from such conversations (Milner et al., 2019).

To ensure that all young autistic adults develop the self-advocacy and self-determination skills necessary to thrive in adulthood, they all must be genuinely included in their transition to adulthood (MacLeod, 2017). This means training educators and caregivers on guardianship and its alternatives to promote self-determination where possible for all young autistic men and women (MacLeod, 2017).

In practicality, MacLeod felt that “school teams should make the effort to bring these agencies and professionals to the school whenever possible (i.e., facilitating transition fairs, alternatives to guardianship workshops, connecting students with self-advocates, and inviting agency representatives to IEP meetings)” (2017, p. 205). Milner et al. (2019) would have argued that this must be done for all autistic students, not just the male students.

There exists a strong need for clinical providers to recognize and acknowledge the talents and unique potential of all young autistic adults, as noted by Galler (2013). Facilitating, forming, and maintaining more trusting and inclusive relationships between young autistic adults and their clinical providers involves listening to autistic voices (Galler, 2013). The talents and potential of young autistic adults are gifts to be harnessed to ensure their successes in adulthood (Galler, 2013): “As educational professionals, we must realize that people with [autistic spectrum disorders] have unique potential and tapping into those traits is a gift for us all” (Galler, 2013, p. 133).

Coordinating Between Support Systems

Individually providing necessary support systems with the input of young autistic voices is not enough to truly form, facilitate, and maintain trusting and inclusive relationships between young autistic adults and their clinical providers; the necessary support systems must be provided in coordination with each other (Brede et al., 2022; Franklin et al., 2019; Kuo et al., 2018). According to Kuo et al. (2018), a perceived disconnect exists between various support systems.

In Kuo et al.'s (2018) study, some caregivers felt that there was a lack of communication between the pediatric and adult systems supporting young autistic adults. Franklin et al. (2019) acknowledged that it is crucial to recognize the various simultaneous transitions young autistic adults and their families undergo. That way, clinical providers can implement strategies to address the various needs that may present themselves in order to provide quality care and support for young autistic adults and their families during the healthcare transition. Young autistic adults consider continuity of care to be very important to their ability to facilitate, form, and maintain trusting and inclusive relationships with their therapists:

> Building trusting relationships, listening to autistic adults, and empowering them to take agency, are fundamental steps towards more successful mental health care provision. Improvements to mental health care informed by autistic adults' unique experiences will likely also benefit other services users as well as improving conditions for professionals providing treatment. (Brede et al., 2022, p. 20)

Leveraging Personal Strengths and Interests

Coordination between support systems across all settings during the transition to adulthood is important, but any transitional interventions should be tailored to young autistic adults' needs (Cheak-Zamora et al., 2017). Caregivers need guidance on how best to support young autistic adults' independence and need support transitioning to a more facilitative role within their child's life. Healthcare providers have the critical role of promoting autonomy by communicating directly with their patients (Cheak-Zamora et al., 2017). According to Cheak-Zamora et al., adjustments to healthcare visits must be provided as necessary and “may include alterations to the clinic environment (e.g., providing adolescent with clinic room on arrival), allowing alternative communication methods, and using specific and precise language and instructions” (2017, p. 1037).

Lam et al. (2020) acknowledged the need to listen to young autistic adults’ first-person perspectives and to recognize their agency as unique human beings. Lam et al. believed interventions should focus on personal strengths, interests, and assets to help young autistic adults achieve meaningful long-term goals:

> Listening to their first-person perspectives recognizes their agency and rights to speak for how they desire to thrive and achieve outcomes that match their unique profiles. Intervention efforts focusing on their assets, character strengths, and personal values can help them achieve long-term goals that are meaningful to them. (2020, p. 1256)

Employers, especially, need to be willing to recognize the individual talents of young autistic adults and provide the necessary accommodations to engender their success as employees (Hedley et al., 2018). Workplace attitudes and lack of understanding of autism spectrum disorders were believed to have contributed the most to barriers to successful employment of young autistic employees:

> We found that co-workers who worked closely alongside the trainees developed positive attitudes and understanding of their colleagues with ASD, which may well have contributed to the trainees’ success at work, including their feelings of being accepted, their confidence and their enthusiasm for their work. The inclusion of dedicated support staff, in particular the inclusion of an individual

> with experience working with individuals with ASD, emerged as an important ingredient of the programme. (Hedley et al., 2018, p. 537)

The third research question, pertaining to how trusting and inclusive relationships between young autistic adults and their clinical providers can be formed, facilitated, and maintained, has been fully answered.

Chains of Inference and Hypotheses

After the extracted data were organized into evidence tables, data were coded into themes. The themes were then used to develop chains of inference at the theory and sub-theory levels. At the theory level, the nature of the relationship between young autistic adults and their clinical providers depends on the empathetic characteristics of the relationship, whether there is some integration of the support systems, and the extent to which autistic voices are included. Sub-theory level chains of inference were broken down into four categories: empathy, respect, and dignity; integrated support systems; the inclusion of autistic voices; and education about autism spectrum disorders. Chains of inference were tracked and linked with their respective sources for each research question (see Table 8).

Table 8

Chains of Inference

Relationships between Young Autistic Adults (YAA) & Clinical Providers (CP)	Derived these themes from the evidence table	Article No.
RQ1:	Disagreements over defining disability	3, 4
Any characteristics/perspectives relevant to YAA and CP relationships	YAA dependence on CP	6, 18, 19
	YAA self-advocacy	7, 9, 10
	Exclusion of YAA voices from decisions about support	22, 23
	Education about ASD	12, 15, 21
	Lack of support for YAA	5, 8, 16, 17, 20
RQ2:	Treating YAA with empathy, respect, and dignity	2, 10, 14, 20, 22
Characteristics/perspectives of inclusive and trusting relationships	Accommodations for YAA and expectations for CP	3, 4
	Coordinating across YAA support systems	15, 16, 17, 19, 21
RQ3:	Treating YAA with empathy, respect, and dignity	2, 3
Ways to maintain, form, and facilitate trusting and inclusive relationships	Expectations CP have of YAA	1, 13
	Inclusion of YAA voices in decisions about support	8, 19, 23
	CP coordinating between YAA support systems	15, 17, 20
	YAA personal strengths and interests were leveraged by CP	9, 10, 14

Three hypotheses were developed using the chains of inference (see Table 9):

1. Relationships between clinical providers and young autistic adults become more trusting and inclusive when clinical providers treat young autistic adults with empathy, respect, and dignity; support systems for young autistic adults are made available and coordinated between clinical providers; and young autistic adults’ interests and voices are incorporated into their support systems across clinical settings.

2. Clinical providers can educate themselves on how to best support young autistic adults' needs and provide those support systems.
3. Young autistic adults can use input from clinical providers to better understand themselves, who they are, and how their minds function.

Table 9

Table of Hypotheses

Hypotheses	Chain of Inference (theory level)	Chain of inference (sub-theory level)	Themes from the literature	Papers addressing the theme
HP1: Relationships between CP and YA become more trusting and inclusive when CPs treat YA with empathy, respect and dignity; support systems for YA are made available and coordinated between CPs; and YAs' interests and voices are incorporated into their support systems across CP settings.	The nature of the relationship between CP and YA depends on the characteristics of the relationship, whether there is some integration of the support systems, and the inclusion of the YAs' voices.	Empathy, Respect, and Dignity	Empathy, Respect, and Dignity 1. Trust 2. Mutual respect 3. Unconditional care 4. Shared understanding 5. Appreciating each other's company 6. Working to heal strained relationships 7. Open-mindedness 8. Listening to each other	Empathy, Respect, and Dignity (6 papers: Frazier, 2019; Autistic Self Advocacy Network, 2012; Lam, 2020; Hedley, 2018; Brede, 2022; Pearson, 2012)

Table 9, continued.

Hypotheses	Chain of Inference (theory level)	Chain of inference (sub-theory level)	Themes from the literature	Papers addressing the theme
HP2: CP can educate themselves on how to best support YA's needs and provide those support systems.		Integrated Support Systems	Integrated Support Systems 1. Should be appropriate to individual YA's needs 2. Coordination and collaboration between CPs 3. Need to be made available to YAs 4. CPs and YAs are both accountable for implementation 5. Pediatric care should transition to adult care 6. Should be tailored to individual YA's interests, strengths, and needs 7. Should promote YA autonomy	Integrated Support Systems (14 papers: Anderson et al., 2021; Brede et al., 2022; Chambers et al., 2020; Cheak-Zamora et al., 2017; First et al., 2019; Franklin et al., 2019; Hedley et al., 2018; Koffer Miller et al., 2018; Kuo et al., 2018; Lam et al., 2020; MacLeod, K., 2017; Milner et al., 2019; Sosnowy et al., 2018; Santomauro, 2017)
HP3: YA can use input from CP to better understand 'themselves, who they are, and how their minds function.		Inclusion of YAs' voices	Inclusion of YAs' voices 1. Accommodating communication methods 2. Using specific and precise language and instructions 3. Leveraging and engaging with YA's personal strengths and interests into planning	Inclusion of YA's voices (11 papers: Alverson et al., 2019; Autistic Self Advocacy Network, 2012; Cheak-Zamora et al., 2017; Galler, 2013; Hedley et al., 2018; Lam et al., 2020; MacLeod, 2017; Milner et al., 2019; Pearson, 2012; Robison, 2011; Singer, 1998/2017)

Table 9, continued.

Hypotheses	Chain of Inference (theory level)	Chain of inference (sub-theory level)	Themes from the literature	Papers addressing the theme
		Education	Education 1. YA and CP need to agree on a universal definition of disability 2. YA and CP need to agree on planning for the transition to adulthood	Education (5 papers: Autistic Self Advocacy Network, 2012; Chambers et al., 2020; Cheak-Zamora, 2015; Kuo et al., 2018; Singer, 1998/2017)

Using these hypotheses, a visual model was developed to describe the Neuro-Unity framework this realist synthesis aims to develop.

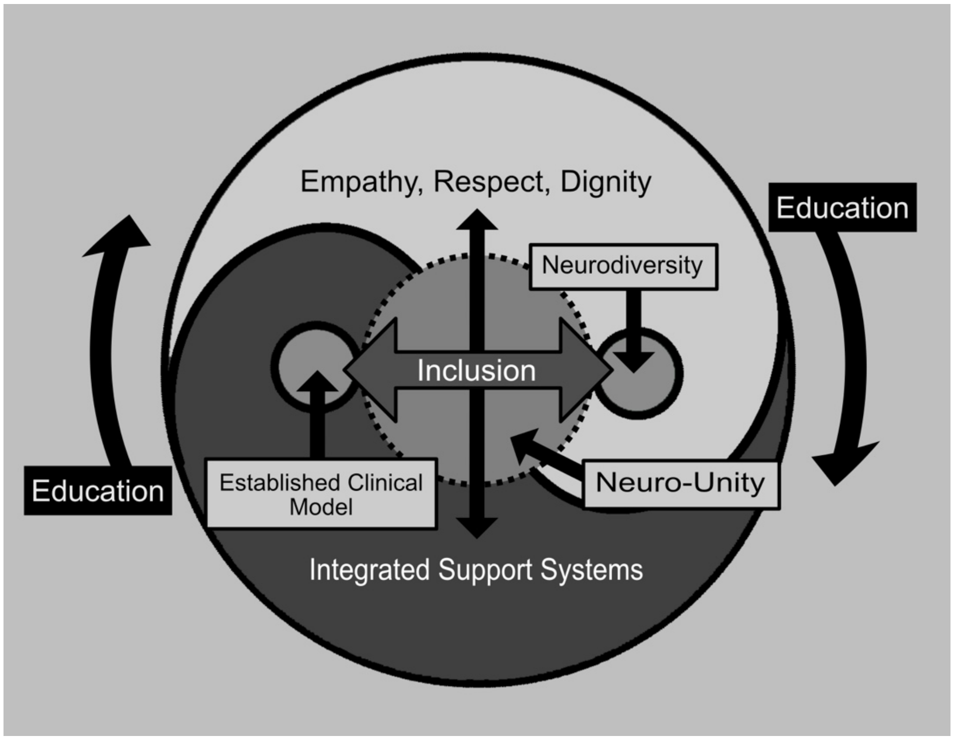
Neuro-Unity Framework

The Neuro-Unity framework uses the sub-theory level chains of inferences to unify proponents of the Neurodiversity movement as informed by empathy, respect, and dignity and proponents of the established clinical model of autism spectrum disorder offering integrated support systems as clinical providers to young autistic adults. Empathy, respect, and dignity complement integrated support systems; both are necessary in tandem for the Neuro-Unity framework to fulfill its purpose as intended. Furthermore, the principles of Neuro-Unity integrate the established clinical model of autism spectrum disorder and the Neurodiversity movement. Education on the part of both frameworks drives the Neuro-Unity framework and facilitates more trusting and inclusive relationships between young autistic adults and their clinical providers (see Figure 3).

This framework satisfies the chains of inference at the theory level and demonstrates the practical application of all three generated hypotheses.

Figure 3

Neuro-Unity Framework Model



Note. The Neuro-Unity framework integrates proponents of the Neurodiversity movement with the established clinical model of autism spectrum disorder by including each other's voices. Proponents of both ideologies educate each other about integrated support systems and empathy, respect, and dignity.

Conclusion

The hypotheses generated by following the RAMESES I protocol and the resulting generation of the Neuro-Unity framework formed the foundational basis for this realist synthesis and represented the synthesized statements central to the ideas presented in this chapter. Sub-theory level chains of inference were incorporated into the Neuro-Unity framework and include autistic self-advocates educating their clinical providers as informed by empathy, respect, and dignity and clinical providers educating autistic self-advocates of available integrated support systems in a cycle of inclusion and education about the needs of self-advocates and how they can best be served.

All research conducted was driven by three research questions, each of which were explored extensively by the generation of three hypotheses attempting. The theory-level chains of inference informing these hypotheses fully addressed and answered the research questions at the core of this realist synthesis, allowing a more robust discussion of the findings to follow.

CHAPTER FIVE: DISCUSSION

Introduction

The purpose of this realist synthesis was to examine the relationship between young autistic adults and their clinical providers (e.g., doctors, therapists, educators, caregivers, etc.), to understand what conditions contribute to trusting and inclusive relationships between young autistic adults and their clinical providers, and to understand how more trusting and inclusive relationships can be maintained. As a result of the research conducted, a new conceptual framework was developed to address what was believed to be conflicting ideologies between proponents of the Neurodiversity movement and their clinical providers—what the researcher calls *Neuro-Unity*.

In this chapter, the hypotheses generated through the RAMESES I protocol developed by Greenhalgh et al. (2011) are listed, and each chain of inference at both the theory and sub-theory levels are discussed. Implications for practice will be discussed for both autistic self-advocates and their clinical providers, followed by implications for theory. Limitations of the study are also discussed, and recommendations for future research are presented.

Interpretation of the Findings

Using the RAMESES I protocol (Greenhalgh et al., 2011), hypotheses were generated using the developed chains of inference at both the theory and sub-theory levels. These hypotheses are listed as follows:

1. Relationships between clinical providers and young autistic adults become more trusting and inclusive when clinical providers treat young autistic adults with empathy, respect, and dignity; support systems for young autistic adults are made available and coordinated between clinical providers; and young autistic adults' interests and voices are incorporated into their support systems across clinical settings.
2. Clinical providers can educate themselves on how to best support young autistic adults' needs and provide those support systems.
3. Young autistic adults can use input from clinical providers to better understand themselves, who they are, and how their minds function.

The chains of inference used to derive these hypotheses exist at the theory and sub-theory levels. At the theory level, the nature of the relationship between young autistic adults and their clinical providers depends on the following criteria:

1. empathetic characteristics of the relationship,
2. the degree of integration of the support systems, and
3. the extent to which autistic voices were included.

At the sub-theory level, the chains of inference identified through this realist synthesis included the following:

1. empathy, respect, and dignity,
2. integrated support systems
3. inclusion of autistic voices, and
4. education about autism spectrum disorders.

Chains of Inference

The chains of inference can be applied to previous research. Boshoff et al. (2018), for example, contended that first impressions of first-line professionals significantly affected the diagnosis process and laid the foundation for all future experiences with other clinical providers. When support systems are coordinated and integrated with each other, the experience becomes more positive and sets the tone for interactions with other clinical providers (Boshoff et al., 2018). Unfortunately, Berridge and Hutchinson (2021) found that clinical providers felt the need for emotional distance from their clients to prevent emotional overload from becoming too emotionally attached. This occurred at a time when more empathy with caregivers is crucially needed (DePape & Lindsay, 2016).

Boshoff et al. (2019) elaborated on the intense emotional journey that caregivers experience when seeking a clinical diagnosis for their loved ones. According to Boshoff et al. (2019), being treated with empathy, respect, and dignity would make a tremendous difference in their perceptions of future clinical providers. Many caregivers reported feeling that they were not being acknowledged by their clinical providers (Boshoff et al., 2019). Coughlan et al. (2020) found that many clinical providers had no experience or knowledge of autism spectrum disorders. Berridge and Hutinson (2021) expanded on this lack of knowledge that even clinical providers felt they required more resources for training in subjects related to autism spectrum disorders.

Regarding including autistic voices, DePape and Lindsay (2016) discovered that many of the self-advocates they interviewed felt their personal experiences were largely ignored in their interactions with clinical providers. Granville's (2020) research on emotional regulation in autistic individuals closely aligns with Santomauro et al.'s (2017) findings that autistic individuals struggle to properly identify and label their emotions and look toward their clinical providers for assistance in regulating them.

Implications for Practice

The discussion thus far of Neuro-Unity has merely hinted at the education chain of inference at the sub-theory level. Not much has been discussed about what kind of education is necessary for Neuro-Unity to fulfill its promise. Implications for practice can be organized into two sub-sections: implications for self-advocates and implications for clinical providers.

Implications for Self-Advocates

For young autistic adults, working with their clinical providers can help them develop their sense of identity and better understand who they are as autistic individuals and why they feel they are so noticeably different from their neurotypical peers (Chambers et al., 2020). Frazier (2019) contended that peaceful advocacy can help reduce the stigma attached to an autism diagnosis and foster more trusting and inclusive relationships.

Using the Neuro-Unity framework can help autistic self-advocates educate clinical providers about their specific needs and how best to support them (Cheak-Zamora, 2015; Kuo et al., 2018). As a practical example, self-advocates can talk to career counselors or job coaches about their career goals and ambitions and work with their clinical providers to determine what kind of education and training would be necessary to meet these goals, and then determine together what life skills are necessary in order to meet their career aspirations.

Implications for Clinical Providers

The Neuro-Unity framework can help clinical providers reciprocate and educate self-advocates and their colleagues about the support systems they can provide to autistic individuals. According to Kuo et al., some clinical providers have opened their minds to the idea of additional training and education if it means being able to better support autistic individuals:

> Ten participants (80%) discussed the current lack of information and research being conducted on individuals with [autism spectrum disorders] in adulthood and the need to know more to make better-informed decisions. Examples included the need to know more about skills that should be targeted in childhood that would lead to better outcomes in adulthood, interventions and models that should be duplicated, and the types of adult programs that should be developed. (2018, p. 295)

The first major obstacle to such education is the need for self-advocates and their clinical providers to agree whether autism spectrum disorders are disabilities or pathologies (ASAN, 2012; Singer, 1998/2017). Frazier (2019) and Singer (1998/2017) would argue they are disabilities and that clinical providers can help guide the public conversation about autism spectrum disorders to reduce the stigma society attaches to disability.

Clinical providers must be willing to honestly and genuinely come to an understanding with autistic self-advocates about how their autism spectrum disorders affect them and how clinical practice can help them to achieve their life goals. Furthermore, clinical providers must be willing to use their platform of expertise to advocate against the stigma associated with an autistic diagnosis both to other clinical providers and to society in general. Autistic individuals deserve the same respect and dignity from their clinical providers as any other individual. To quote ASAN (2012), "[autistic individuals] are not less than" (p. 364).

Implications for Theory

This realist synthesis has helped the researcher to develop a new conceptual framework that can be used to drive theory. The researcher calls this newly generated conceptual framework *Neuro-Unity*. Both Neurodiversity and the established clinical model of autism spectrum disorder have strengths to offer each other and therefore must strive to include each other. Autistic self-advocates must respect the expertise of their clinical providers, and in turn, clinical supports must genuinely listen to and incorporate feedback from autistic self-advocates into the support systems they provide.

The sub-theoretical chains of inference—that is, empathy, respect, and dignity and integrated support systems—must complement each other in tandem for Neuro-Unity to function as designed. Support systems must be made available and integrated across all clinical settings and be provided with empathy, respect, and dignity. Autistic self-advocates must be willing to educate their clinical providers on their specific needs and how best they can be supported. In turn, clinical providers must be willing to educate autistic individuals on how their support systems can be used to help them better understand who they are and articulate why they feel so different from their neurotypical peers. The underlying theory to the Neuro-Unity framework needs to be tested more thoroughly before it can be applied to generalized theory and practice.

Limitations of the Study

As with any synthesis, this realist synthesis has several limitations. This dissertation study presented the first stage of theory development using realist synthesis. The underlying theory to Neuro-Unity is now poised for the second stage of theory development, which is to be fully tested and explored in the level of detail that usually accompanies a realist synthesis.

Another limitation of this research is the depth of the systematic search for sources to be synthesized into the study, per the RAMESES I protocol (Greenhalgh et al., 2011). For this study, only research conducted in the United States and the United Kingdom were considered for inclusion. Furthermore, only research conducted between 1980 and 2022 were considered for inclusion. While these limitations were useful to help this researcher conduct a focused realist synthesis on research conducted between 1980 and 2022 in the United States and the United Kingdom, future syntheses may want to include research conducted outside these two countries across a broader period of time.

A more in-depth search for literature could have been performed by including quantitative and mixed methods research, which were not considered for inclusion for this study. Additionally, the age demographics for participants in included studies could have been expanded, as only research studying autistic self-advocates between 18 and 30 years of age and their clinical providers were considered for inclusion in this realist synthesis. Studies published in other languages could also have been considered for inclusion; for this realist synthesis, only research published in the English language was considered for inclusion. These limitations allowed this researcher to conduct a more focused synthesis to address the posed research questions. However, a broader synthesis in the future may consider expanding beyond these parameters for a more global perspective.

Recommendations for Future Research

This realist synthesis has helped the researcher to develop a new conceptual framework that can be used to drive theory. This theory is now poised for additional testing. An external panel of readers called a Delphi panel is typically consulted to review and provide critical feedback for realist syntheses (Greenhalgh et al., 2011; Wong et al., 2014). A modified Delphi panel was initially planned for this realist synthesis. However, it was determined that conducting the panel would have extended beyond the scope and limitations of this stage of theory development.

Should a Delphi panel be consulted in the future to expand on this realist synthesis, researchers could conduct the panel via two rounds of online review and critical feedback, per the RAMESES I protocol guidelines (Greenhalgh et al., 2011; Wong et al., 2014). From this feedback, more practical applications and theoretical implications could be streamlined across a variety of settings.

The first round of the modified Delphi panel could consist of discussion between panel members and the researcher, in which panel members would provide critical feedback and express ideas on theory and practice and provide suggestions for further consideration. After that, an online survey would be distributed to panel members to rank a set of provisional statements according to a Likert scale (1 = strongly disagree to 5 = strongly agree) twice. Panel members would rank the set of provisional statements once for relevance of included research and once for validity—that is, agreement with statements as worded.

After feedback from the first round of the modified Delphi panel was incorporated into the realist synthesis review, the process could be repeated for a second round of discussion and ranking. Numerical results of the second round of ranking could be averaged, and feedback from the modified Delphi panel would be incorporated into a final version of the results of the realist synthesis review. Any remaining dissent among panel members would be reported alongside the nature of such dissent as limitations of the realist synthesis review to be explored with future research in the interest of full honesty and transparency. Careful consideration should be taken in selecting members of the modified Delphi panel.

Conclusion

This chapter focused on the theoretical and practical implications of Neuro-Unity. Neuro-Unity is not without its limitations and can be improved through future exploration in research. Neuro-Unity can be used as a model for bridging ideological differences and building more trusting relationships between autistic individuals and their clinical providers.

The concept of Neuro-Unity has the potential to revolutionize the cultural conversation around autism spectrum disorders. In the 1990s, the concept of Neurodiversity was borne of the various backlashes to the modern psychiatric approaches established in the 1960s. However, conflicting ideologies and attitudes surrounding autism spectrum disorders created the “Great Schism of Autism,” dividing the broader autism community (Donvan & Zucker, 2016). The time for a new paradigm to unify the autism community has come. Neurotypes unite!

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