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Moving Toward Neurodiversity-Affirming Services for Autistic Individuals: Social Validity, Autistic Perspectives, and Measuring Attitudes

A dissertation submitted in partial satisfaction of the
requirements for the degree Doctor of Philosophy
in Education

by

Rachel Kathleen Schuck

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June 2023

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ABSTRACT

Moving Toward Neurodiversity-Affirming Services for Autistic Individuals:
Social Validity, Autistic Perspectives, and Measuring Attitudes

by

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Intervention and education programs for autistic individuals have been greatly informed by the medical model of disease/disability. Under this model, autism is seen as something to be fixed or remediated, and interventions have often focused on reducing autistic traits in an effort to get the autistic person to appear more “typical.” Autistic advocates have denounced this, and there is still much debate on what kind of interventions are best for autistic individuals. A viable alternative to the medical model is the neurodiversity approach, where neurological differences such as autism are seen as a valuable contribution to human diversity and should be accepted. Though it has been argued that early intervention can in fact be compatible with the neurodiversity approach, the field still has much work to truly become neurodiversity-affirming. This dissertation discusses three ways to ensure interventions move toward being more neurodiversity-affirming: considering intervention social validity (i.e., acceptability) from the autistic perspective, gathering feedback on interventions from autistic adults, and assessing professionals’ attitudes toward neurodiversity.

The first paper herein is a systematic review of social validity assessment in Pivotal Response Treatment research, with an emphasis on assessment of the autistic point of view. The second is a qualitative investigation of 214 autistic adults’ feedback on common intervention goals for young autistic children. The third paper presents the development and validation of an instrument designed to measure professionals' attitudes toward neurodiversity. Findings from the first two studies suggest that autistic perspectives need to be included much more frequently when designing and implementing interventions, and that professionals need to consider the importance of developing autistic identity, autonomy, and self-advocacy skills. Finally, the neurodiversity attitudes questionnaire (NDAQ) presents a valid way of measuring professionals' attitudes such that neurodiversity training needs can be assessed, which will hopefully ultimately lead to more neurodiversity-friendly interventions.

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Dissertation Introduction

The disability rights movement has a saying: *Nothing About Us Without Us* (Charleton, 1998). This slogan highlights the fact that disabled people have been systematically left out of decisions regarding disability initiatives and policy. This has had the effect of further disenfranchising an already marginalized population, and disabled activists call for disabled people to have a meaningful seat at the decision-making table. When it comes to autism research, this has historically been (and still is) far from the truth. Autism research has rarely included the perspectives of autistic people, and many advocates argue that research agendas set by non-autistic researchers often do not have the autistic community's best interests at heart (Pellicano & den Houting, 2022). Autism is usually conceptualized using the medical model of disability, wherein autism is a *disorder* that needs *treatment* (American Psychiatric Association, 2013). The medical model of disability locates disability *within* the individual, meaning that it is the person themselves who requires fixing (Marks, 1997). This conceptualization of autism, which emphasizes people's deficits (Pellicano & den Houting, 2022), has disenfranchised autistic individuals and kept them out of the autism knowledge-generating process (Milton & Bracher, 2013).

The effects of this disenfranchisement are not inconsequential. The medical model view of autism has permeated research on intervention services and educational programs for autistic individuals, with many studies focused on techniques to reduce autism "symptoms" (see Sandbank et al.'s [2020] review, where "diagnostic characteristics of autism" are a common intervention target). However, autistic self-advocates have pointed out that autism should not necessarily be seen as a bad thing, and that acceptance of an autistic "way of being" (Sinclair, 1993) is necessary in order to promote quality of life. Robertson (2009) similarly argues that, instead of focusing interventions on normalizing autistic people so that they resemble non-autistic people, services should focus on enhancing quality of life. However, many intervention programs continue to be designed to make autistic children seem more like typically-developing children, and emerging research demonstrates how some autistic adults have had negative experiences with early interventions as children (e.g., Cumming et al., 2020; McGill & Robinson, 2021). While researchers, clinicians, and teachers undoubtedly want the best for their clients and students, viewing autism as something to remove or remediate can lead to stigma and prejudice, which in turn is associated with social exclusion and mental health problems. Indeed, many autistic people report feeling stigmatized (Botha et al., 2020) and often feel the need to mask their autism (i.e., their true selves) in order to fit in (e.g., Hull et al., 2017).

In order to truly meet the community's needs, we as researchers and interventionists must a) *ask* the community what they desire, b) *listen* to what they say, and c) find ways to *implement* their feedback. One way to do this is to conduct participatory research (Fletcher-Watson et al., 2019), where autistic people are actively involved in the research process (including setting the research agenda/goals, implementation of the project, data analysis, and writing of reports). Another method is to ensure social validity (the degree to which an intervention's goals, procedures, and outcomes are acceptable to stakeholders; Wolf, 1978) is assessed in *all* intervention contexts. When considering social validity, it is especially important to prioritize autistic perspectives and lived experiences (DePape & Lindsay, 2016), instead of only relying on non-autistic "experts," such as clinicians, researchers, or parents (Gillespie-Lynch et al., 2017). Furthermore, the neurodiversity paradigm presents a useful tool for reconceptualizing autism as a natural, neutral part of our species' biological diversity as opposed to a disorder. Adoption of this paradigm could lead to greater understanding and acceptance, as well as encouraging researchers and clinicians to ensure their work is truly in the service of the autistic individuals they wish to support.

The importance of taking a neurodiversity-affirming approach to intervention with autistic individuals permeates the following three papers in this dissertation. It is thus prudent to define "neurodiversity" and related terms. Neurodiversity, first and foremost, refers to the biological fact of diversity in human neurology (Singer, 1998; Walker, 2014). The term was coined by autistic sociologist Judy Singer in her 1998 thesis and was popularized in an *Atlantic* article by Harvey Blume (1998) the same year. Because neurodiversity refers to the diversity of the human species, it encompasses *all* individuals, including both *neurotypical* people (i.e., those who fit society's standard of what it means to have a "typical" brain) and those who are *neurodivergent* (those whose neurology does not fit society's standard). However, oftentimes, when people use the word "neurodiversity," they are actually invoking the *neurodiversity paradigm* (or "*neurodiversity approach[es]*"; Dwyer, 2022a), which is the perspective that neurodiversity—particularly with regards to those whose brains are different—is something to be accepted and even celebrated (Walker, 2014). Though autistic scholar Robert Chapman calls neurodiversity a "moving target" because different people define it slightly differently (Chapman, 2020a, p. 219; sentiment echoed in Dwyer, 2022a), many generally agree that the neurodiversity paradigm entails the following principles (from Walker, 2014):

1. Differing neurology is useful for our species
2. There is no such thing as a "normal" or "correct" brain and therefore individuals with different types of brains or neurological disabilities should be accepted (see

Chapman's [2020b] use of the phrase "value-neutral" to describe neurodiversity as neither good nor bad)

3. Neurodiversity is subject to the same kind of social pressures as are other forms of diversity, such as race or gender

Though the concept of neurodiversity was borne out of the autistic rights movement (Silberman, 2015), it is important to note that neurodiversity refers to *all* brain differences, not just autism. While there is no formal agreement as to *exactly* which kinds of brains fall under the neurodiversity umbrella—Is it just those who are born with a different brain? What about acquired neurodivergence, such as psychiatric conditions or strokes? (see Dwyer [2022a] for more discussion on this topic)—it has been argued that the best criterion to use when determining whether someone is neurodivergent is whether the individual feels validated by identifying as such (Chapman, 2020a).

While neurodiversity *advocates*—those who are in favor of the neurodiversity approach, whether they are autistic themselves or non-autistic allies—push for adoption of this perspective, there are some prevalent misconceptions about neurodiversity. One of the most common misconceptions is that neurodiversity proponents are erasing disability and think that neurodivergent people do not need any kind of support or intervention (Jaarsma & Welin, 2012). However, many advocates actually *do* highlight disabling aspects of neurodiversity (e.g., Ballou, 2019; den Houting, 2018) as well as the need and desire for support for autistic and otherwise neurodivergent people (e.g., den Houting, 2018; Dwyer, 2022a; Robertson, 2009). Dwyer (2022a) in fact suggests that neurodiversity hinges upon the fact that disability occurs via the *interaction between* an individual and their environment, and that disability can indeed be addressed by focusing on *both* society and the individual. It is thus entirely possible to approach interventions for autistic people from a neurodiversity perspective.

In keeping with a neurodiversity perspective, this dissertation uses identity-first language (e.g., “autistic person”) to describe autistic individuals (whether they have a clinical diagnosis or self-identity as such) as opposed to person-first language (e.g., “person with autism”). While opinions on these two phrasings differ, both are actually meant to empower the disabled individual: identity-first language emphasizes that whatever disability or diagnosis a person has is an integral and acceptable part of them and is not going to go away, whereas person-first language is meant to emphasize that a person is more than their diagnosis. Research has indicated that English speaking autistic adults tend to prefer identity-first language (Bury et al., 2020; Kenny et al., 2016). It has also been suggested that using person-first language to refer to autism can actually lead to increased stigma, since person-first language is more often used when discussing more stigmatizing conditions, whereas identity-first language is used for less stigmatizing things (e.g., “gifted children” are rarely called “children with giftedness”; Gernsbacher, 2017). Similarly, person-first language is usually used to describe people with undeniably negative, unwanted diseases, such as cancer (e.g., “man with prostate cancer”). Nonetheless, it should be acknowledged that there is no real consensus on which terms should be used. For example, some self-advocates use “autistic person” and “has autism” interchangeably (Hammond, 2022), and recent research with a Dutch-speaking sample suggested that person-first language is actually preferable in the cultural and linguistic context of the Netherlands (Buijsman et al., 2022). It is thus imperative to adopt the language that is preferred by the population or individual that one is talking about/to (as is now suggested by the American Psychological Association [2020]).

Because this dissertation focuses on neurodiversity, particularly autism, and most neurodiversity and autism advocates promote identity-first language (e.g., Botha et al., 2023; Dwyer, 2022b; The Autistic Self Advocacy Network [Brown, n.d.]), it is used most often throughout this dissertation.

This dissertation contains three papers that all aim to tackle some of the issues with autism services that have been identified by the autistic community. In particular, the dissertation takes a multimethod approach to considering: 1) social validity from the autistic perspective, and 2) how the neurodiversity approach can inform professionals' views of autism and intervention. The first paper presents a systematic review of the assessment of social validity in research on Pivotal Response Treatment (PRT; Koegel et al., 2016), a common naturalistic behavioral intervention for autistic children. The second is also focused on social validity, yet from a different angle: a qualitative analysis of autistic adults' feedback on intervention goals for young autistic children. The third paper is focused on developing an instrument to assess attitudes toward neurodiversity such that training needs amongst helping professionals (e.g., doctors, teachers, therapists, etc.) can be identified. All lines of research have been undertaken with the ultimate goal of improving services such that they promote understanding, improve quality of life while presuming autistic individuals' competence, and embrace the concept of neurodiversity.

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Paper 1:

Social Validity Assessment in Pivotal Response Treatment Research: A Review of the Literature

Abstract

The social validity of an intervention refers to how interested parties perceive its goals, procedures, and outcomes. Social validity is a key component of behavioral intervention, as it ensures interventions do not just lead to objective behavioral changes, but also that they are acceptable and meaningful. More recently developed behavioral models for autistic children, Naturalistic Developmental Behavioral Interventions (NDBIs), are seen by researchers and clinicians as socially valid due to their strengths-based approach and emphasis on child motivation and choice. While this makes logical sense, it is unknown the degree to which social validity is actually being assessed in NDBI research studies. Thus, a systematic review of Pivotal Response Treatment (PRT), a popular NDBI, was conducted in order to learn more about how social validity is assessed in the literature. Findings suggest that a little over a third of PRT studies assessed social validity; doctoral dissertations were more likely to report on social validity than published reports. Parents were the most common participants in social validity assessment, whereas less than 5% of studies directly assessed social validity from the perspective of the autistic intervention recipient. PRT researchers must conduct more social validity assessments in future research, including listening to the feedback directly from autistic people.

Social Validity Assessment in Pivotal Response Treatment Research: A Review of the Literature

The concept of social validity was borne out of the field of applied behavior analysis (ABA) in the 1970s. Historically, behavioral intervention—which has its roots in the behaviorist principles of reinforcement and punishment—has been very data-driven and grounded in “objectivity”; that is, only things that can be observed are assessed and intervened upon. Thus following, if behaviors change after an intervention, the intervention can be deemed a success. However, in his seminal article on the topic, Wolf (1978) introduced readers of the *Journal of Applied Behavior Analysis* to *social validity*, explaining that the field needed to move beyond just demonstrating the effectiveness of behavioral intervention programs—researchers and clinicians also needed to show that these interventions were of social importance to society, including, of course, intervention recipients. He saw this as necessary not just because it was ethical to participants, but also because social validity could be related to program effectiveness and might affect the likelihood that a program is adopted by potential participants (it is for this reason that Schwartz and Baer [1991] refer to social validity as a “defensive technique” (p. 191) that can help ensure the survival of an intervention program).

Social Validity Assessment

Wolf (1978) laid out three dimensions of social validity that should be assessed: 1) significance of treatment goals; 2) appropriateness of intervention procedures; and 3) importance of all intervention outcomes, both expected and unexpected. It is crucial that all three dimensions are assessed, as it is possible to have an intervention that appears socially valid with regards to one or two dimensions, but not all three. For example, an intervention that uses electric shock to reduce aggressive behavior may have a socially valid goal (reduce aggression) and outcome (fewer aggressive episodes) but is likely to not have socially valid procedures (because electric shocks are inhumane). Schwartz and Baer (1991) argue that these dimensions of social validity must be assessed early and continually, and results of such assessments should be used to modify interventions as needed; it is not sufficient to simply determine that something is not socially valid—it must then be fixed.

In the decades since Wolf (1978) introduced social validity, there has been ample attention given to how to assess it. Generally, the methods for assessing social validity fall into two categories: those that are more "objective" versus those that are more "subjective." Some argue for the use of consumer (i.e., participant) satisfaction ratings (e.g. Wolf, 1978) or in-depth interviews (e.g. Leko, 2014) to understand how interventions are impacting recipients, whereas others suggest looking at behavioral data (such as whether the intervention was maintained after a research study ended [e.g. Kennedy, 2002] or comparing outcomes to normative populations [e.g., Ennis et al., 2013; Kazdin, 1977]) to determine whether the intervention resulted in socially important changes. Often, participant opinions are considered "subjective" (and therefore unreliable, according to behaviorists, e.g., Hawkins 1991), whereas behavioral observations are seen as more "objective." However, researchers have been somewhat inconsistent in their use of these terms, and it has not always been clear which methods fall into each category (e.g., What about the use of a validated satisfaction questionnaire? What about rigorous qualitative interviews?; Snodgrass et al., 2021).

Just as there are many methods for assessing social validity, there are many persons who might be asked to participate in social validation of an intervention. Schwartz and Baer

(1991) break up potential stakeholders into four categories: direct consumers (i.e., intervention recipients, which could include the disabled person themselves and others such as parents or teachers if they are learning to implement an intervention), indirect consumers (i.e. those who paid for or sought out the intervention, such as school boards or parents), members of the immediate community (e.g. family members, neighbors, etc.), and members of the extended community (e.g. taxpayers, journalists, etc.). Each of these groups has a place within social validity assessment, depending on the specific intervention and the kind of information hoped to be gleaned by assessing social validity. Those who favor more "objective" measures of social validity tend to think that social validity is best assessed by those who are not direct consumers. For example, Kazdin (1977) and colleagues (Kazdin & Matson, 1981) do not mention consulting with intervention recipients themselves (except in a one sentence footnote in the 1977 article that simply mentions that some researchers have done this), even when they discuss "subjective" evaluation. Their aim is still to keep subjective evaluation as objective as possible by having those not involved in the intervention rate its social validity (whether that be "experts" or stakeholders who know the client). Hawkins (1991) argues that subjective ratings of consumer satisfaction—while potentially informative—are not necessarily predictive of actual behavior change or maintenance of behavior change, and thus should only be used to supplement more objective social validity assessment. He emphasizes the importance of functional outcomes, not feelings or personal opinions. However, though such outcomes may be "objective," it should be noted that social validation techniques that assess desirability of autistic individuals' behaviors by comparing them to neurotypical people are unlikely to be in line with calls from the autistic community to professionals to stop encouraging masking of autistic traits (e.g., Kapp et al., 2019; Roberts, 2020).

However, not all who favor “objective” social validity do so without including the participants themselves. Part of Hanley’s (2010) motivation for supporting the use of participant choice as a measure of social validity is an ethical imperative to enact the Golden Rule: “We would probably agree that if someone was charged with improving our behavior, we would like to have a say in how that change would be achieved, rather than exclusively rely on the values of others” (p. 14). In his seminal paper, while Wolf (1978) does give examples of normative comparison (where behavioral outcomes for disabled children are compared to typically developing children’s behavior so that we know how much more “typical” the disabled child now appears), he focuses mostly on subjective evaluation, and often mentions obtaining feedback from both indirect and direct consumers. He even refers to clients being “happy with our efforts and effects” (p. 213) as one of the ideal outcomes of proper social validation. Accordingly, some researchers have used child affect ratings as an indicator of social validity (e.g., Robinson, 2011). This is an especially appealing method when it might be difficult to directly ask the autistic intervention recipient for their opinions, either due to young age or challenges with spoken/written language (Schuck et al., 2022). In *The Social Validity Manual*, Carter and Wheeler (2019a) note that asking participants themselves to rate an intervention’s acceptability helps to ensure client dignity and foster a sense of respect. It therefore seems prudent to conclude that, regardless of any other methods used, it is always a good idea to get feedback from the client/participant in order to validate their feelings and ensure ethical treatment.

Social Validity Assessment in Practice

The importance of social validity has been widely accepted in the field of ABA, with many agreeing that social validity should not simply be an optional add-on to a project. In fact, it has been argued that social validity should be one of the criteria used to determine whether an intervention can be considered “evidence-based” (Horner et al., 2005; Reichow, 2011). However, though social validity is supposed to be an integral part of behavioral intervention, it is not assessed as frequently as it should be. For example, Callahan et al. (2017) found that of the over 800 studies identified by the National Autism Center and the National Professional Development Center on Autism Spectrum Disorders as being evidence-based practices (EBPs) or “emerging” EBPs, only 26.7% assessed social validity. Similarly, Snodgrass and colleagues (2018) found that, of all the single-case studies published in the top six special education journals, only 26.8% assessed social validity. Other reviews have found somewhat higher percentages of studies reporting on social validity (e.g., 44% of the studies in Ledford et al.’s [2016] review of social skills programs for autistic children and 46% in Carter and Wheeler’s [2019b] review of studies in *Education and Training in Autism and Developmental Disabilities*), though the number is still woefully low. Prior reviews of social validity in autism intervention suggest inclusion of the autistic perspective is rare (e.g., D’Agostino et al., 2019; Hurley, 2012), though many reviews do not even touch upon this subject.

Autistic Perspectives

Inclusion of autistic perspectives in intervention studies is key to ensuring interventions do no harm and are seen as acceptable. Unfortunately, many autistic advocates have been vocal critics of behavioral intervention, with critiques centered around the use of aversive punishments in ABA (particularly in the past, such as electric shocks, e.g. Simmons & Lovaas, 1969, but also less extreme aversives used nowadays, such as holding autistic students’ hands down to prevent flapping (Bascom, 2011), using ABA to promote the masking of autistic traits (Michael, 2018), and the use of behavioral principles to emphasize compliance with adult demands (Des Roches Rosa, 2020; Sandoval-Norton & Shkedy, 2019; Wilkenfeld & McCarthy, 2020). Though advocates have been complaining for years, emerging research has started to corroborate some of their claims about potential negative consequences of ABA, such as symptoms of PTSD (Kupferstein, 2018), loss of self-agency (McGill & Robinson, 2021), and learning to “fake” their way through life (Cumming et al., 2020).

Naturalistic Developmental Behavioral Interventions

There is no denying that ABA has a history of using techniques that were not socially valid, including abuses such as electric shocks and slapping (Lovaas & Simmons, 1969; Moser & Grant, 1965; Simmons & Lovaas, 1969) as well as less egregious offenses such as having young children engage in repeated, discrete trials often while sitting at a table for long periods of time (see Bogin et al., 2010 for a description of how to implement behavioral intervention). When researchers realized that autistic children seemed to be more engaged and learn faster when they were *interested* (Koegel et al., 1998), newer interventions were developed that capitalized on child motivation, as opposed to repetitive drilling. These child-centered, play-based, and naturalistic interventions were collectively named Naturalistic Developmental Behavioral Interventions (NDBIs; Schreibman et al., 2015).

Following the child’s lead, allowing for child choice, and focusing on strengths as opposed to weaknesses are all hallmarks of NDBIs (Schreibman et al., 2015). This child-centered, strengths-based emphasis should in theory lead to more socially valid interventions. Indeed, researchers and clinicians who study and implement PRT see its naturalistic nature as a strength with regard to social validity (Gengoux et al., 2020). However, some advocates remain critical of NDBIs (Des Roches Rosa, 2020), and research with autistic adults has identified areas of NDBIs that may need to be reformed before they can be considered socially valid (Schuck et al., 2022). While the perspectives of stakeholders external to the intervention (e.g., advocates and uninvolved autistic adults) are valuable when considering social validity, it is arguably most important to capture the perspectives of the intervention recipients themselves. Currently, no studies have systematically assessed the extent to which NDBI intervention studies measure social validity (though D'Agostino et al. [2019] did include social validity in their review of classroom-implemented Pivotal Response Treatment (PRT), this review was very specific in scope and only included a total of 23 studies). Furthermore, because we have little understanding of the frequency of social validation in NDBI studies, it is unknown the extent to which autistic intervention recipients themselves are involved in the social validation process.

Current Study

The purpose of the current study was to assess the frequency and methods of social validity assessment in intervention studies using a popular NDBI, Pivotal Response Treatment (PRT; Koegel et al., 2016). The review addresses the following research questions:

- What is the *frequency* of social validity assessment?
- What *methods* are used to assess social validity?
- *Who* is asked to provide social validity assessment (i.e., who is asked to answer questions; (how) is data gathered from/regarding the autistic perspective?)?

Method

Abstract Searching

Because this paper is reporting on a subset of a larger systematic review on all NDBIs, the abstract searching and screening procedures are not specific to studies focusing on PRT.

To be included in the initial screen, papers needed to 1) report findings from a study where an intervention was given to at least one individual; 2) the intervention was one of the six NDBIs discussed in the *Considering NDBI Models* chapter (Minjarez et al., 2020a) of the *Naturalistic Developmental Behavioral Interventions for Autism Spectrum Disorder* book (Bruinsma et al., 2020) (i.e., Pivotal Response Treatment (PRT), Early Start Denver Model (ESDM), ProjectIMPACT, Joint Attention, Symbolic Play, Engagement, and Regulation (JASPER), Incidental Teaching (IT), and Enhanced Milieu Teaching (EMT); 3) include at least one autistic participant; and 4) be written in English. Reports did not have to be peer reviewed to be included in order to reduce publication bias (Hammerstrøm et al., 2010). The following Boolean search terms were used:

> (ab(autis*) AND (ab(NDBI) OR ab("naturalistic developmental behavioral") OR ab(PRT) OR ab("Pivotal response") OR ab("natural language paradigm") OR ab(NLP) OR ab(esdm) OR ab("early start denver model") OR ab(JASPER) OR ab("project impact") OR ab("Joint Attention, Symbolic Play, Engagement, and Regulation") OR ab("enhanced milieu") OR ab("incidental teaching") OR ab(EMT)))

Abstracts were obtained from ProQuest (which included PsycINFO, PsycArticles, and Education Information Resources Center (ERIC)), Academic Search Complete, and Web of Science (similar databases were used in a recent systematic review of autistic perspectives in adult social skills intervention; Monahan et al., 2021). This search resulted in 721 unique abstracts (see Figure 1 for more details).

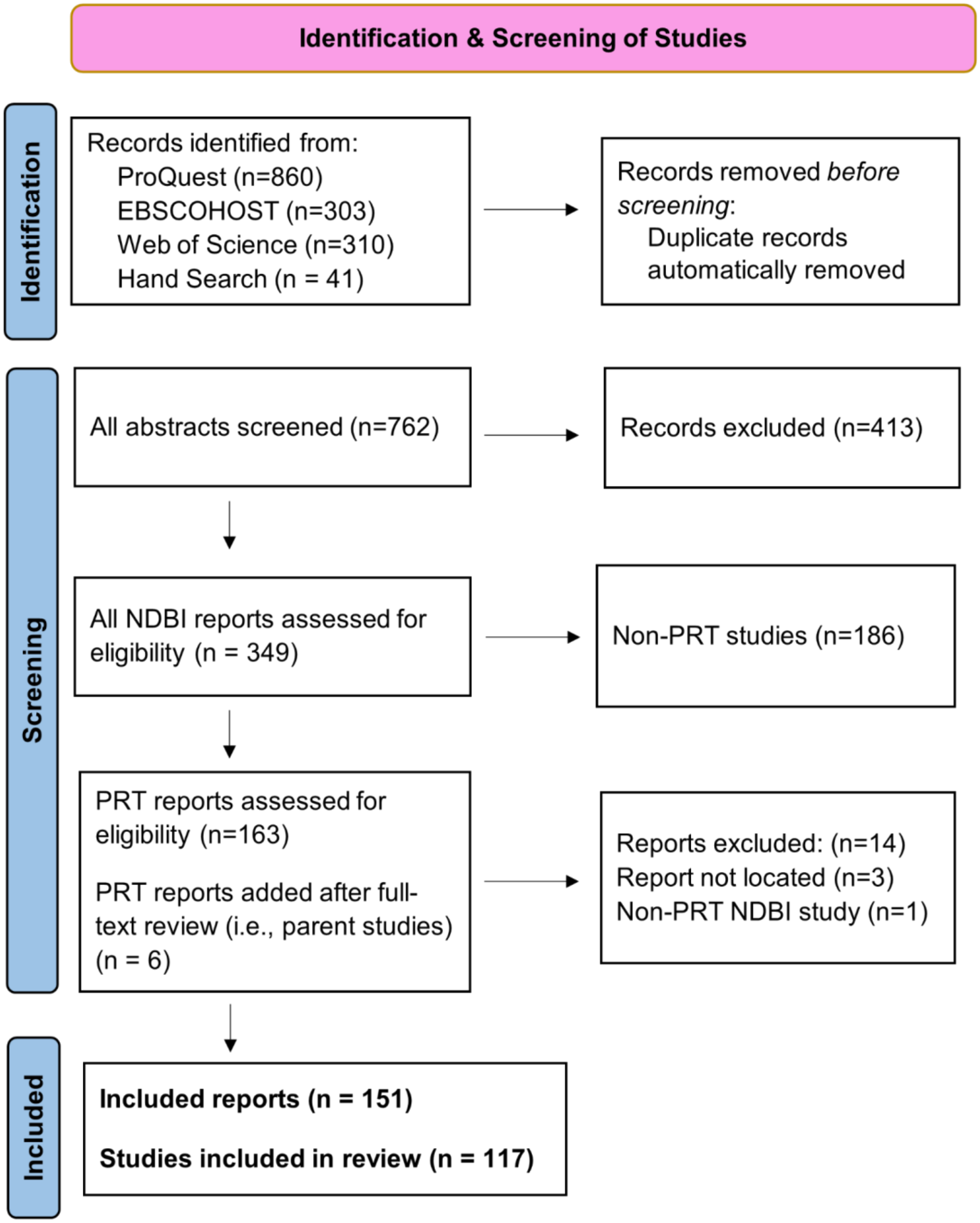
To find articles that the initial search may have missed, citations from several review papers were manually searched. This included reviews of group-design NDBI studies (Crank et al., 2021), family-mediated social communication (Pacia et al., 2022), the *Considering NDBI Models* chapter of the NDBI textbook (Minjarez et al., 2020), ESDM (Baril & Humphreys, 2017), JASPER (Waddington et al., 2021), PRT (Cadogan & McCrimmon, 2015) and IT (McGee, 2022). Publications lists available on Google Scholar were reviewed for the developers of Project IMPACT (Brook Ingersoll) and Enhanced Milieu Teaching (Ann Kaiser). An additional 41 abstracts were found. Six additional papers were identified during the full text coding phase, as reports already identified as eligible mentioned that their paper was a secondary analysis from another project.

Abstract Screening

All abstracts were screened using Rayyan.ai (Ouzzani et al., 2016), a free online tool designed to assist with systematic review and meta-analysis. Each abstract was screened for the three inclusion criteria (intervention study, use of an NDBI, autistic participants). Abstracts were coded as *definitely eligible*, *maybe eligible*, and *not eligible*. During screening, abstracts were flagged if they were non-intervention, non-NDBI, not written in English, or did not include an autistic participant. Labels were applied to each abstract according to which of the six NDBIs were used. All abstracts were reviewed by the author of this dissertation and an undergraduate research assistant (RA). The author and RA met multiple times to resolve coding discrepancies by consensus. The full text of all abstracts rated *maybe eligible* were reviewed to determine inclusion. See Figure 1 for a PRISMA flow chart (Page et al., 2021) on the inclusion/exclusion of studies.

Figure 1

Social Validity Assessment in PRT Research PRISMA Flow Chart



Full Text Coding

Full article texts that were labeled in Rayyan as including PRT as the intervention were extracted for full text coding. Articles were coded for relevant study information and social validity information (see Figure 2 for the coding scheme). Both the author and the RA coded all studies independently. To code the articles, each coder filled out a separate Qualtrics (2023) survey that included questions regarding all relevant information. After all reports were coded, the codes were exported from Qualtrics and compiled into an Excel sheet; the author then reviewed each report for discrepancies between the coders (at this point, the author was blinded to the identity of the coder in order to not be influenced by knowing how she herself had coded). Each discrepancy was resolved by reviewing the full-text article. Some variables were recoded after full text coding by the author. For example, age of participants was collapsed into ≤10 (preschool/elementary), 11-17 (middle/high school), and >18 (adult). Assessment of child affect was further coded (from yes/no) to determine the justification of the measure (e.g., was it related to social validity or not). To increase trustworthiness, these post-hoc codings were reviewed multiple times by the author.

Figure 2

Full Text Coding Scheme

General Study Information

<u>Information</u>	<u>Codes</u>
NDBI	PRT, ESDM, ProjectIMPACT, JASPER, EMT, IT
Age group	age range; or average age if range not available (entered manually)
Methodology	Single-subject design, RCT, other
Number of participants	# (entered manually)
Interventionist	researcher, community clinician, community teacher, paraeducator, parent, peer, other

Parent study	Does the paper mention that the current study is part of a larger study, is a secondary data analysis, or have overlapping participants with another study?
Social Validity Information	
Information	*Codes*
Child affect assessed	yes, no
SV assessed (document searched for “social valid[ity]/[ation]”, “satisf[ied]/[faction]”, “accept[ability]/[able]”)	yes, no, unsure (coded “yes” if SV discussed in method section; coded “unsure” if discussed elsewhere [e.g., discussion] but not methods)
→ *if yes* →	
Time of assessment	pre-intervention, during intervention, post-intervention
Who participated in SV assessment	autistic intervention recipient, parent, clinician, teacher, paraeducator, peer, person external to the study, other
For each person involved, method of assessment	questionnaire, interview, observation, normative comparison, maintenance data, participant choice, unclear/not mentioned

Reports were grouped into a study group if it was mentioned in a report’s methods section that it was a secondary data analysis or that some or all participants came from another study. There were 117 unique studies represented by 151 reports (56 reports overlapped with another report and were collapsed into 22 study groups). Thirty-five reports were doctoral dissertations. Twenty-five studies were stand-alone dissertations (the other 10 dissertation reports were collapsed into study groups). If at least one of the reports in a group indicated that there was social validity assessment, the whole study group was considered to be assessing social validity.

Reports that were coded as eliciting social validity assessment directly from autistic participants were qualitatively described in order to make recommendations for future research.

Results

An overview of all reports can be found in the Appendix.

Description of Studies

All but one study included participants who were either preschool or elementary school age (i.e., up to 10 years of age; the one that did not was looking at the combination of risperidone and PRT; the mean age of participants was 12 years of age). Fifteen studies included participants of middle/high school age (11-17 years of age) in addition to the younger age group. No studies included adult participants.

The most common interventionist was parents (n = 56 studies), followed by researcher clinicians (n = 42), community teachers (n = 23), peers (n = 11), community paraprofessionals (n = 11), and community clinicians (n = 8). Many included multiple types of interventionists (e.g., researcher-clinicians provided in-home sessions and also trained parents; see Gengoux et al., 2019 as an example). The majority of studies reported on single-subject design studies (n = 64). Seventeen studies reported on randomized controlled trials, and 35 studies were coded as “other” (e.g., non-randomized pre-post group design, case study, etc.).

Social Validity Assessment

Frequency of Social Validity Assessment

Just over a third of studies (n = 45/117) were coded as intentionally assessing social validity (i.e., social validity, satisfaction, or acceptability assessment was described in the methods section of the paper). Most reports (n = 71) did not explicitly assess social validity/satisfaction/acceptability.

Some studies that did not explicitly include assessment of “social validity”, “acceptability,” or “satisfaction” in their methods implied in their discussion sections that some of their data should be interpreted as evidence of social validity (e.g., Eichenbaum (2007) stated, “It may be important to note that the children in the current study did not appear to experience the PRT with model prompt sequence as aversive, thus lending support for the clinical significance and social validity of this study,” even though the child affect coding is never described in the methods as being part of social validity) or were found to generally be about things related to social validity, acceptance, and satisfaction, but did not frame the research in this way (e.g. the whole purpose of Buckley et al.’s (2014) report was to get feedback about parents’ perspectives with PRT but the words “social validity,” “acceptability,” or “satisfaction” were never used). However, because this was not systematically coded, no specific tallies are provided for this. It should be noted that one *study group* (i.e., a doctoral dissertation and a published report on the same study) was coded as intentionally assessing social validity due to the inclusion of an unpublished doctoral dissertation (Sherer, 2002); however, the published report associated with this dissertation did *not* include any social validity assessment.

Doctoral dissertations were more likely than published papers to assess social validity, both in terms of overall, non-grouped reports ($\chi^2(1) = 8.57$, $p = .003$) and unique studies ($\chi^2(1) = 5.94$, $p = .015$). (Note that for the unique study analysis, Sherer (2002) was considered as a unique study separate from its study group since it assessed social validity, though the other published reports associated with it did not.)

Characterization of Social Validity Assessments

Most studies (n = 39) assessed social validity at post-intervention only, though some assessed it at multiple time points (e.g., at pre- and post- intervention) or throughout the duration of the intervention. A few studies were coded as "unclear" about when social validity was assessed but most likely assessed social validity at post-intervention.

The most common type of social validity instrument was questionnaires (n =38 studies), followed by interviews (n = 9 studies) and observation (n = 7 studies). Six studies used normative comparison as a means of social validity assessment, though four also included other measures such as parent questionnaires.

Parents were the most frequent participants in social validity assessment (n = 29), followed by teachers/clinicians (n = 14), paraeducators (n = 7), persons external to the study (e.g., undergraduate students who rated video clips; n = 6), and siblings/peers (n = 5). Only five studies (4.3%) indicated that the autistic intervention recipients were directly consulted for social validity assessment.

Child affect was assessed in 22/117 studies. Of the 22 studies, four explicitly indicated that assessing child affect was done with the intention of measuring social validity. For example, Robinson (2011) stated, "student affect was examined to determine whether the intervention appeared acceptable to the students and whether the paraprofessional training resulted in a change in students' affect" (p. 113). Three additional studies did not indicate in the methods section that child affect data was collected as a measure of social validity, but in the discussion indicated that child affect is indeed an indicator of social validity. For example, Kim and colleagues (2019) state in the methods that, "interest and happiness were rated by the researchers to evaluate the enjoyment of social interaction" (p. 67), yet say in the discussion that, "the positive results in child affect, along with the social validity results reported by teachers, suggest that the intervention was meaningful and socially valid" (p. 81). The remaining 15 studies did not frame child affect data as part of social validity, acceptance, or satisfaction.

In addition to assessing child affect, reports were also reviewed for whether non-autistic participants (e.g., parents, clinicians, etc.) were asked to take the perspective of the autistic person, for example by asking them to estimate how much the autistic child enjoyed the intervention. This proved difficult to code, as many reports did not include the exact questions on social validity questionnaires or interviews. Therefore, tallies are not provided for this aspect; however, it should be noted that some studies did clearly state the way they asked others to assess autistic perspectives (e.g., by asking "To what extent does this procedure treat the child with ASD humanely?" (Kim, 2015); "Did you feel that your child enjoyed the motivational techniques that were used during the play activities? If so, which ones?" (Abda, 2021)).

Description of Reports Eliciting Social Validity Assessment from Autistic Participants

As discussed above, only five studies assessed social validity directly from the autistic participant's point of view. These exemplary studies (at least in terms of social validity assessment) were investigated in more detail so that the social validation process could be better understood. The five studies were all published in the past six years (Brock et al., 2018; Kim et al., 2017; Silveira-Zaldivar, 2019; van den Berk-Smeekens et al., 2020; Vincent et al., 2022). Two were published in the *Journal of Autism and Developmental Disorders,* one in the *Journal of Positive Behavior Interventions,* one in *Scientific Reports*, and one was a doctoral dissertation. Four of the five studies were focused on social interaction with peers; the fifth was focused on PRT more generally. Two studies used interviews to elicit feedback from autistic participants (Brock et al., 2018; Vincent et al., 2022), two used questionnaires (Kim et al., 2017; Silveira-Zaldivar, 2019), and one used a questionnaire but also asked follow-up interview questions (van den Berk-Smeekens et al., 2020). Each study is described in more detail below.

Brock et al. (2018). The purpose of this study was to assess the feasibility of peer-mediated PRT delivered at school recess by an adult recess facilitator. A total of 11 autistic children participated in this pilot RCT, with six randomized to intervention and five to control. The participants were 8-12 years old, and the average IQ was 76.6 for the intervention group and 83.5 for the control group. Students in the intervention group were interviewed after the intervention regarding their opinions of the program. All said they liked going to recess, five enjoyed playing with the neurotypical peers, half said the peers taught them a new way to play, five now saw the trained peers as their friends, and all participants wanted to keep hanging out with the peers. The researchers did not discuss how feasible it was to conduct the interviews (given that the average IQ of the intervention group was 76.6, it is possible that some children could have had limited spoken language skills).

Kim et al. (2017). The purpose of this study was to assess the impacts of a PRT program focused on socialization delivered by paraprofessionals. Three students participated in this single-subject design study. The cognitive level of the three participants was, respectively, “average”, “above average”, and “superior”. Students were surveyed post-intervention about the lunch club where the PRT was provided. All rated the lunch club positively and indicated they enjoyed it and that it made them happy. However, two out of the three participants said they did not make new friends in the club.

Salveira-Zaldivar (2019). In addition to conducting qualitative research to assess the needs of public school teachers and other stakeholders, Salveira-Zaldivar (2019) conducted a single-subject design experiment to assess the impact of social skills programs amongst autistic elementary students. Three students participated in the study (all seven years old). All participants had “average cognitive abilities” and were able “to converse in complete sentences.” Only one of the three received PRT; the other two received a more generalized peer-mediated intervention. For the student who received PRT, the researcher came to the school two hours a week for a total of eight sessions. Students were interviewed at the end of the intervention and were asked whether they enjoyed the program, what their favorite part was, what they learned, and whether they would want to participate again. Interviews lasted an average of four minutes. All of the participants said they enjoyed the intervention, and three out of five (including both the three autistic students and two neurotypical peers) indicated it was fun, though it is unclear whether the student who received PRT was one of them. The only quote attributed to the student who received PRT was, “I learned how to make a friend.”

van den Berk-Smeekens et al. (2020). The purpose of this study was to explore the adherence and acceptability of PRT delivered in part by a robot. The study included 25 autistic participants between 3-8 years old. The inclusion criteria included an IQ above 70 and the ability to speak at least one-word sentences. The average IQ of the final sample was 101.8, with only three scoring in the below average range. Participants received 20 sessions of PRT (14 parent-child sessions, 4 parent sessions, and 2 teacher sessions). A robot that was controlled by the PRT therapist was used at the beginning of each of the parent-child sessions. To assess social validity of the robot, before and after the session children were given a Visual Analog Scale question that asked, “How happy are you today?” (with smiley faces as response anchors). Children were also given the question “Did you like the robot today?” (with thumbs up/down as response anchors) after the session. When possible, children were asked to verbally elaborate on their responses. Child affect and robot likability were generally positive, though the school-age children were more positive than the preschool ones. Most of the post-session positive affect ratings were related to the therapy sessions themselves, even if the children did not indicate that it was the robot that made them feel that way.

Vincent et al. (2022). Vincent and colleagues (2022) evaluated a PRT social skills intervention in a pull-out special education setting, with the purpose of seeing whether improvements in interactions with peers would generalize to the general education classroom. This single-subject design study included four participants (6-8 years old). Two children were categorized as having no (verbal/vocal) words, one was categorized as having some words, and one had phrase speech. Autistic students were interviewed before and after the intervention regarding intervention goals, procedures, and outcomes. Two students did not answer any pre-intervention questions, and another said “no” to everything. The fourth child answered the questions. At the post-intervention interview, one student again did not answer any questions, though the other student who had not answered at the first interview now used a speech device and was able to answer. The third child (who had initially said “no” to all questions) received the post-intervention questions in written format and responded verbally in more detail. The fourth child again answered all interview questions. Two of the children indicated in the post-intervention interview that they enjoyed the playgroup and that their teacher helped them interact with their peers, but that they did not enjoy interacting with peers at recess. The child who verbally answered questions at both time points brought up challenges interacting with peers during both interviews. Before intervention, she mentioned that she did not play with peers because no one liked her. Though she still mentioned difficulties in interaction after the intervention, she said she now had friends. However, she did also indicate that she did not want to continue the playgroup.

Discussion

Social validity is a crucial component of behavioral intervention research (Horner et al., 2005; Reichow, 2011), as it can help ensure stakeholders find an intervention's goals, procedures, and outcomes acceptable (Wolf, 1978). Even so, prior reviews of social validity in behavioral intervention and autism research have found that it is not assessed nearly as often as it should (e.g., Callahan et al., 2017; Carter & Wheeler, 2019b; Ledford et al., 2016). Pivotal Response Treatment (PRT) was developed to be a play-based, strengths-based, naturalistic intervention that focuses on child-led learning opportunities that seemingly has a high capacity to be socially valid (Schuck et al., 2021). However, it is unclear how interested parties—particularly intervention recipients—actually feel about it. This systematic review thus sought to characterize social validity assessment in Pivotal Response Treatment (PRT) research with a specific focus on the autistic perspective.

Despite social validity being a factor to be considered in deeming interventions evidence-based, almost two-thirds of reports/studies included in this review did not include an explicit assessment of social validity. This is particularly surprising since "social validity of the natural environment" is seen as a strength of NBDIs (Gengoux et al., 2020, p. 65). While the natural environment *may* actually be seen as socially valid by autistic people, it does not appear that the PRT research base has adequately assessed this. This is especially true in terms of published research, as published research was found to be less likely to include social validity assessment than doctoral dissertations. This could perhaps be explained by journal limits on manuscript lengths, whereas doctoral dissertations typically have almost unlimited length (and are frequently over 100 pages). It is possible that some of the studies that were published actually did collect social validity data, but the authors felt that they were unable to include it due to space limitations, and therefore cut it out of their final drafts. While social validity itself is only complementary to primary outcomes (and is not viewed as primary in and of itself—indeed, why would we need to assess social validity if an intervention had no effect on primary outcome measures? Schwartz & Baer, 1991), it is unfortunate that it is often left unassessed and/or unreported, perhaps dropped in order to allow space for discussion of primary outcomes. Therefore, researchers must not only do a better job of assessing social validity, but they must also ensure that social validity data is presented in published manuscripts.

Of the studies that did include social validity assessment, most collected social validity data from parents. This is in line with the family-centered approach that PRT and other NDBIs take. NDBIs such as PRT are often focused on parent education and training (Minjarez et al., 2020b), as evidenced by the fact that the most common interventionist in the included studies was parents. Since parents were often participants in the intervention (as both direct recipients of training in PRT and as interventionists), it makes sense that their feedback should be sought. However, it is alarming that less than 5% of studies sought to assess social validity directly from the perspective of the autistic intervention recipient. Over 20 years ago, Finn and Sladeczek (2001) stated, “treatment acceptability from the child's perspective remains an area of research that is largely unexplored” (p. 202), and unfortunately that appears to still be the case, at least in terms of PRT. It can be argued that it is difficult to assess social validity in young children, especially when there are co-occurring language or intellectual disabilities. However, some of the participants in the five studies that directly elicited autistic intervention recipient feedback did appear to have intellectual disability and/or were minimally verbal. For example, the average IQ in the intervention group of Brock et al.'s (2018) study was 76.6, suggesting that some participants may have qualified for an intellectual disability diagnosis. The authors did not state that any children had difficulty with the interview, which suggests that all were able to participate regardless of IQ. Though some participants in Vincent et al.'s (2022) study had difficulty participating in the social validity interview at the beginning of the study, altering the means of communication (e.g., by writing questions down for one child and allowing another child to answer with a speech device) at post-intervention allowed these children to contribute. Though most of the participants in van den Berk-Smeekens and colleagues' (2020) scored in the average intelligence range, use of a visual analog scale with smiley faces and thumbs up signs likely supported the children's capacity to participate. These studies demonstrate that children do not necessarily have to have high intelligence scores or advanced verbal ability to participate in social validity assessment.

Nonetheless, there are still children who would not be able to participate in either a questionnaire or interview. It has been argued that a viable alternative to using these measures with young children is to assess the child's affect during intervention as a proxy for acceptability (e.g., Schuck et al., 2021). This is an important aspect to consider, given that autistic advocates have been vocal about behavior intervention's potential harm. However, in this review, a similarly small number of studies (n=4) took this route to assess social validity. While affect is certainly not an ideal indicator of acceptability (particularly due to the fact that autistic individuals' facial expressions may not match their internal states in the way that neurotypical people might expect [Trevisan et al., 2018]; also see Social Skills for Autonomous People, n.d. for a discussion on why autistic children might appear happy during behavioral intervention even if they are not), it is at the very least a crude way of determining whether the child is responding adversely to the intervention procedures. Thus, while neutral or even positive expressions are not necessarily enough to label an intervention as socially valid, displays of serious negative affect, such as screaming, crying, or trying to move away from the interventionist, should certainly be considered as an indicator of *lack* of social validity.

Limitations and Future Directions

While this review highlights important gaps in social validity assessment in PRT research, there are, however, several methodological limitations to consider. Firstly, while double coding during screening and full-text article review helps to ensure accuracy, it does not guarantee it. Similarly, it is likely that studies were missed during the screening phase due to the search terms used. For example, during the hand search phase, several eligible studies were identified where the intervention (PRT) was described generally in the abstract but was not explicitly labeled as an NDBI or PRT, which thus would not have gotten picked up by the database search. Even though the hand search was fairly robust in that attempts were made to find additional articles from multiple sources, it is probable that other studies with similar abstracts were not found by either the database search or the hand search. Though the current review did find a large number of reports (151), future research on social validity in PRT research should cast a wider net in order to ensure *all* relevant research is found.

It is also likely that some studies assessed something akin to social validity but did not use the terms used herein to be indicative of social validity (i.e., *social valid[ity][ation], accept[able][ability], satisf[action][ied]*) in their method section. Authors may have also thought that it was clear that something like child affect could be used as an indicator of acceptability even if they did not state so outright. For example, it is likely that normative comparison was used in more than five reports, but if it was not discussed in the context of social validity/satisfaction/acceptability, it would not have been captured. It is thus possible that some of the articles coded as *not* assessing social validity would have been coded otherwise if other, less stringent criteria were applied. (Though it should be noted that normative comparison is not a neurodiversity-affirming method of assessing social validity and was not the focus of this review.)

Future research should also look into the degree to which the three areas of social validity (goals, procedures, and outcomes) are assessed in PRT research. Additionally, although the purpose of this review was to identify gaps in assessment of social validity, it is also important to have an understanding of what the outcomes of these assessments are. This will be especially important as more studies elicit social validity assessments from the autistic intervention recipients.

Conclusion

Strengths of PRT include its naturalistic procedures, focus on child-led learning opportunities, and strengths-based principles. While these principles suggest PRT might be highly socially valid, many PRT studies are not assessing social validity at all. Assessment of social validity is particularly infrequent with regards to taking the autistic person’s perspective into account, whether it be a direct elicitation through a questionnaire or interview or through behavioral coding of affect. This should be a call to researchers and clinicians to take steps to elicit opinions from their autistic participants/clients and listen to what they have to say.

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Appendix

Summary of Included Reports

Authors (year)	**Age Group**	**Method**	**Interven-tionist**	**SV ?**	**SV: Time**	**SV: Who**	**SV: Method**	**Child Affect?**	**Affect as SV?**
Williams et al. (2002)	Pre/El	Other: pre-post group	Teacher, Para/Aide	No				No	
Poyser (2021)*	Pre/El, M/H	SSD	parent	Yes	unclear (likely post)	parent	Quest	No	no
Abda (2021)*	Pre/El	SSD	parent	Yes	Post	parent	Quest, Int	No	
Tagavi (2021)*	Pre/El	Other: pre-post group	researcher, parent	No				Yes	no
de Korte et al (2021)	Pre/El, M/H	RCT	researcher, parent, Teacher	No				No	
Melgarejo et al. (2020)	Pre/El	Other: pre-post group	Teacher, Para/Aide	No				No	
Al-zayer (2015)*	Pre/El	SSD	parent	Yes	Post	parent	Int	No	
Gouvousis (2011)*	Pre/El	SSD	Teacher	No				No	
Bruinsma (2004)*	Pre/El	SSD	researcher, parent	No				No	
Oliver (2018)*	Pre/El	SSD	parent	Yes	Post	parent	Int	No	
Jensen (2016)*	Pre/El	SSD	researcher	No				No	
Krasno (2014)*	Pre/El	SSD	parent	No				Yes	no
Russell (2013)*	Pre/El	SSD	parent	Yes	Pre, During, Post	parent	Int	Yes	no
Voos et al. (2013)	Pre/El	Other: case study	researcher	No				No	
Jobin (2012)*	Pre/El	SSD	researcher	No				No	

Authors (year)	Age Group	Method	Interven-tionist	SV ?	SV: Time	SV: Who	SV: Method	Child Affect?	Affect as SV?
Rocha (2011)*	Pre/El	SSD	researcher	Yes	Pre, Post	parent, External	Quest, Obs	No	
Tsao (2009)*	Pre/El	SSD	peer	Yes	Pre, Post	parent, teacher	Int	No	
Labbe-Poisson (2009)*	Pre/El, M/H	SSD	peer	Yes	Pre, During, Post	teachers	Quest	No	
Shaw (2001)*	Pre/El	SSD	researcher	No				No	
Sullivan (1999)*	Pre/El	SSD	other	Yes	During, Post	parent, sibling	Quest	Yes	yes
James (2019)*	Pre/El	SSD	Para/Aide	Yes	Post	Para/Aide	Quest	No	
Duifhuis et al. (2017)	Pre/El	Other: pre-post group	parent	No				No	
Versch-uur (2020)	Pre/El, M/H	Other: pre-post group	Clinician, Teacher	No				No	
Versch-uur (2020)	Pre/El, M/H	SSD	parent	Yes	Post	parent	Quest	No	
Meza et al. (2019)	Pre/El	Other: pre-post group	Teacher, Para/Aide	No				No	
Nuske et al. (2019)	Pre/El	Other: pre-post group	Teacher	No				No	
Silveira-Zaldivar (2019)*	Pre/El	SSD	researcher	Yes	Post	Autistic pt, parent, teacher, peer, parents of peers	Quest	No	
Lei et al. (2017)	Pre/El	Other: pre-post group	researcher, parent	No				No	
Venkat-araman (2016)	Pre/El	Other: pre-post group	researcher, parent	No				No	
Vaughn (2014)*	Pre/El	SSD	Clinician	No				No	

Authors (year)	**Age Group**	**Method**	**Interventionist**	**SV ?**	**SV: Time**	**SV: Who**	**SV: Method**	**Child Affect?**	**Affect as SV?**
Randolph et al. (2011)	Pre/El	SSD	parent	Yes	unclear (likely post)	parent	Quest	No	
Coolican et al. (2010)	Pre/El	SSD	parent	Yes	Post	parent	Quest	No	
Tran (2008)	Pre/El	SSD	parent	Yes	Post	parent	Quest	Yes	no
Sze (2007)*	Pre/El	SSD	researcher	No	During	External	Obs	Yes	Only in discussion
Suhrheinrich et al. (2007)	Pre/El	Other: pre-post group	Teacher	No					
Winter (2006)*	Pre/El	SSD	parent	Yes	Post	parent, External	Quest, Obs	Yes	yes
McNerney (2003)*	Pre/El	SSD	Teacher, Para/Aide	Yes	Post	teacher	Quest	No	
Ventola et al. (2015)	Pre/El	Other: pre-post group	researcher, parent	No				No	
Stahmer et al. (2013)	Pre/El	SSD	Teacher	No				No	
Schreibman et al. (2009)	Pre/El	SSD	researcher	No				No	
Kuhn et al. (2008)	Pre/El	SSD	peer	No				No	
Eichenbaum (2008)*	Pre/El	SSD	researcher	No	Pre, During, Post	External	Obs	Yes	Only in discussion
Sherkat (2006)*	Pre/El	Other: Case study	researcher, parent	No				No	
Schreibman et al. (1991)	Pre/El, M/H	RCT	parent	No	During	External	Obs	No	

Authors (year)	**Age Group**	**Method**	**Interven-tionist**	**SV ?**	**SV: Time**	**SV: Who**	**SV: Method**	**Child Affect?**	**Affect as SV?**
Kucskar (2017)*	Pre/El	SSD	peer	Yes	Post	parent, teacher, parents of peer	Quest	No	
Jones & Feeley (2009)	Pre/El	SSD	parent	No				No	
Bryson et al. (2007)	Pre/El	Other: pre-post group	Clinician, parent	Yes	unclear (likely post)	parent, clinician	Quest	No	
Ball (1996)*	Pre/El	Other: pre-post group	Teacher	No				No	
Bradshaw et al. (2017)	Pre/El	SSD	parent	Yes	Post	parent	Quest	No	
Yang et al. (2016)	Pre/El	Other: pre-post group	researcher, parent	No				No	
Prelock et al. (2011)	Pre/El	Other: pre-post group	parent	Yes	Post	parent	Quest	No	
Harper et al. (2008)	Pre/El	SSD	peer	No				No	
Koegel et al. (2002)	Pre/El	SSD	parent	No				No	
Thorp et al. (1995)	Pre/El	SSD	researcher	No				No	
Ebrahim (2019)	Pre/El	Other: pre-post group	researcher, parent, Teacher	No				No	
Kim et al. (2017)	Pre/El	SSD	peer	Yes	Post	teacher	Quest	Yes	Only in discussion
Koegel et al. (1996)	Pre/El	RCT	parent	No				No	
Rezaei et al. (2018)	Pre/El, M/H	RCT	researcher	No				No	

Authors (year)	**Age Group**	**Method**	**Interven-tionist**	**SV ?**	**SV: Time**	**SV: Who**	**SV: Method**	**Child Affect?**	**Affect as SV?**
Kim et al. (2014)	Pre/El	Other: Case study	other	No				No	
Rezaei et al. (20018)	M/H	RCT	researcher	No				No	
Liu & Mao (2022)	Pre/El	SSD	researcher	No				No	
Kim et al. (2014)	Pre/El	Other: Case study	researcher	No				No	
Kala et al. (2021)	Pre/El	Other: pre-post group	other	No				No	
Vincent et al. (2022)	Pre/El	SSD	Teacher, Para/Aide, peer	Yes	Pre, Post	Autistic pt, teacher, Para/Aide, peer comparison data	Quest, Int, Obs	No	
Buckley et al. (2014)	Pre/El	SSD	parent	No				No	
Koegel et al. (2012)	Pre/El	SSD	researcher	No				Yes	no
Koegel et al. (2014)	Pre/El	SSD	researcher, parent	No				No	
Koegel et al. (2009)	Pre/El	SSD	researcher, parent	No				Yes	no
Versch-uur et al. (2017)	Pre/El, M/H	SSD	Clinician	Yes	Post	clinician	Quest	No	
Jones et al. (2006)	Pre/El	SSD	Teacher, parent	Yes	unclear	External	yes	no	
Moham-madza-heri et al. (2022)	Pre/El, M/H	RCT	researcher, parent	No				No	
Williams et al. (2019)	Pre/El	Other: pre-post group	Teacher, Para/Aide	No				No	

Authors (year)	**Age Group**	**Method**	**Interven-tionist**	**SV ?**	**SV: Time**	**SV: Who**	**SV: Method**	**Child Affect?**	**Affect as SV?**
Dahiya et al. (2021)	Pre/El	SSD	Clinician	No				No	
Steiner et al. (2013)	Pre/El	SSD	parent	Yes	Post	parent	Quest	No	
Moham-madza-heri et al. (2022)	Pre/El	RCT	researcher	No				No	
Bozkus-Genc and Yucesoy-Ozkan (2021)	Pre/El	SSD	researcher	Yes	Post	parent	Int	No	
Feldman & Matos (2013)	Pre/El	SSD	Para/Aide	Yes	Post	Para/Aide	Quest	No	
Versch-uur et al. (2021)	Pre/El, M/H	SSD	Teacher	Yes	Post	teacher	Quest	No	
Lin & Koegel (2018)	Pre/El	SSD	parent	No				Yes	no
Vismara and Lyons (2007)	Pre/El	SSD	parent	No				Yes	no
Jobin (2020)	Pre/El	SSD	researcher	No				No	
Moham-madza-heri et al. (2014)	Pre/El, M/H	RCT	researcher	No				No	
Suhr-heinrich (2015)	Pre/El	SSD	Teacher	Yes	Post (though not explicit)	teacher	Quest	No	
Koegel et al. (2014)	Pre/El	SSD	parent	No				Yes	no
McGarry et al. (2020)	Pre/El	Other: pre-post group	parent	Yes	Post	parent	Quest	Yes	no

Authors (year)	Age Group	Method	Interven-tionist	SV ?	SV: Time	SV: Who	SV: Method	Child Affect?	Affect as SV?
Bo et al. (2019)	Pre/El, M/H	Other: pre-post group	researcher	No				No	
Brock et al. (2018)	Pre/El, M/H	RCT	peer	Yes	Post	Autistic pt, peer, adult recess supervisor	Quest	No	
Baker-Ericzen et al. (2007)	Pre/El	Other: pre-post group	parent	No				No	
Kim et al. (2017)	Pre/El	SSD	Para/Aide	Yes	Post	Autistic pt, teacher, Para/Aide, peer	Quest	No	
Koegel et al. (1999)	Pre/El	Other: pre-post group	researcher, parent	Yes	Post	External	Obs	No	
Stahmer et al. (2016)	Pre/El	SSD	Teacher	Yes	Post	teacher, Para/Aide	Quest	No	
Symon (2005)	Pre/El	SSD	parent	No				No	
Lydon et al. (2011)	Pre/El	SSD	researcher	No				No	
Aksh-oomoff et al. (2010)	Pre/El	Other: pre-post group	researcher, parent	No				No	
Stahmer & Ingersoll (2004)	Pre/El	Other: pre-post group	Teacher, parent	No				No	
Ventola et al. (2014)[a]	Pre/El	Other: pre-post	researcher, parent	No				No	
Ventola et al. (2015)[a]	Pre/El	Other: Case study as part of larger RCT	researcher, parent	No				No	

Authors (year)	**Age Group**	**Method**	**Interven-tionist**	**SV ?**	**SV: Time**	**SV: Who**	**SV: Method**	**Child Affect?**	**Affect as SV?**
Minjarez et al. (2011)[b]	Pre/El	Other: pre-post group	parent	No				No	
Minjarez et al. (2013)[b]	Pre/El	Other: pre-post group	parent	No				No	
Vernon (2014)[c]	Pre/El	SSD	parent	No				Yes	no
Vernon et al. (2012)[c]	Pre/El	SSD	parent	No				Yes	no
van Straten et al. (2015)[d]	Pre/El	Other: pre-post group	researcher	No				Yes	no
van Otterdijk et al. (2020)[d]	Pre/El	RCT	researcher	No				Yes	no
van den Berk-Smeekens et al. (2021)[d]	Pre/El	RCT	researcher, parent, Teacher	No				No	
de Korte et al. (2020)[d]	Pre/El	RCT	researcher, parent, Teacher	No				No	
van den Berk-Smeekens et al. (2020)[d]	Pre/El	RCT	researcher, parent, Teacher	Yes	During	Autistic pt, parent	Quest	Yes	yes
Li (2014)*[e]	Pre/El	RCT	parent	No				No	
Oberling (2017)*[e]	Pre/El	RCT	parent	No				No	
Hegarty et al. (2019)[e]	Pre/El	Other: Pts came from RCT and pre-post	researcher, parent	No				No	

Authors (year)	Age Group	Method	Interven-tionist	SV ?	SV: Time	SV: Who	SV: Method	Child Affect?	Affect as SV?
Hardan et al. (2015)[e]	Pre/El	RCT	parent	No				No	
Gengoux et al. (2015)[e]	Pre/El	RCT	parent	No				No	
Wang (2015)*[e]	Pre/El	RCT	parent	No	Post	parent	Quest	No	
Stahmer et al. (2006)[f]	Pre/El	SSD	researcher	Yes	Post	External	Obs	No	
Stahmer (1995)[f]	Pre/El	SSD	researcher	No				No	
Fossum et al. (2018)[f]	Pre/El	Other: pre-post group	Clinician, parent	No				Yes	no
Smith et al. (2015)[f]	Pre/El	Other: pre-post group	Clinician, parent	No				No	
Sherer (2002)*[g]	Pre/El	SSD	researcher	Yes	Post	parent	Quest	No	
Sherer & Schreibman (2005)[g]	Pre/El	SSD	researcher	No				No	
McDaniel et al. (2020)[h]	Pre/El	RCT	researcher, parent	No				no	
Gengoux et al. (2019)[h]	Pre/El	RCT	researcher, parent	No				no	
Suhrheinrich et al. (2013)[i]	Pre/El	Other: pre-post group	Teacher	No				no	
Suhrheinrich (2011)[i]	Pre/El	Other: pre-post group	Teacher	No				No	
Pierce (1996)[j]	Pre/El	SSD	peer	No				no	
Pierce and Schreibman (1995)[j]	Pre/El	SSD	peer	No				no	

Authors (year)	**Age Group**	**Method**	**Interven-tionist**	**SV ?**	**SV: Time**	**SV: Who**	**SV: Method**	**Child Affect?**	**Affect as SV?**
Pierce and Schreib-man (1997)[j]	Pre/El	SSD	peer	No				no	
Pierce and Schreib-man (1997)[j]	Pre/El	SSD	peer	No				no	
Flanagan et al. (2019)[k]	Pre/El	Other: pre-post group	Clinician, parent	No				no	
Smith et al. (2019)[k]	Pre/El	Other: pre-post group	Clinician, parent	No				no	
Stahmer et al. (2019)[l]	Pre/El	Other: Archival review of two SSDs and one RCT	researcher, Teacher	No				no	
Schreib-man and Stahmer (2014)[l]	Pre/El	RCT	researcher, parent	Yes	Post	parent	Quest	no	
Robinson (2008)*[m]	Pre/El	SSD	Para/Aide	Yes	Post	Para/Aide	Quest	Yes	yes
Robinson (2011)[m]	Pre/El	SSD	Para/Aide	Yes	Post	Para/Aide, External	Quest, Obs	Yes	yes
Kim (2015)*[n]	Pre/El	SSD	peer	Yes	Pre, During, Post	parent, External, other	Quest, Int	Yes	no
Kim & Trainor (2020)[n]	Pre/El	SSD	peer	Yes	Pre, During, Post	parent, other	Quest	No	
Kim (2019)[n]	Pre/El	SSD	peer	Yes	Pre, During, Post	parent, External, other	Quest, Int	Yes	no
Nefdt (2007)*[o]	Pre/El	RCT	parent	Yes	Post	parent	Quest	No	

Authors (year)	**Age Group**	**Method**	**Interven-tionist**	**SV ?**	**SV: Time**	**SV: Who**	**SV: Method**	**Child Affect?**	**Affect as SV?**
Nefdt et al. (2010)[o]	Pre/El	RCT	parent	Yes	Post	parent	Quest	no	
Suhr-heinrich et al. (2020)[p]	Pre/El, M/H	RCT	Teacher	Yes	Post	teacher	Quest	no	
Suhr-heinrich et al. (2020)[p]	Pre/El	RCT	Teacher	Yes	Post	teacher	Quest	No	
Suhr-heinrich & Chan (2017)[p]	Pre/El	RCT	Teacher, Para/Aide	Yes	Post	teacher, Para/Aide	Quest	No	
Suhrh-einrich et al. (2016)[p]	Pre/El, M/H	RCT	Teacher	No				No	
Brad-shaw et al. (2019)[q]	Pre/El	RCT	researcher, parent	No				No	
Vernon et al. (2019)[q]	Pre/El	RCT	researcher, parent	Yes	Post	parent	Quest	no	
Pelle-cchia et al. (2015)[r]	Pre/El	RCT	Teacher	No				no	
Mandell et al. (2013)[r]	Pre/El	RCT	Teacher	No				no	
Ruiz (2019)*[s]	Pre/El	RCT	researcher, peer	No				No	
Gengoux et al. (2021)[s]	Pre/El	RCT	researcher, peer	No				no	
de Korte et al. (2022)[t]	Pre/El	Other: Qualitative analysis of pre-post group	parent	No	Post	parent	Int	no	
de Korte et al. (2022)[t]	Pre/El	Other: pre-post group	parent	Yes	Post	parent	Quest	no	

Authors (year)	**Age Group**	**Method**	**Interven-tionist**	**SV ?**	**SV: Time**	**SV: Who**	**SV: Method**	**Child Affect?**	**Affect as SV?**
Smith et al. (2010)[u]	Pre/El	Other: pre-post group	researcher, community clinician, parent	Yes	unclear	parent	Quest	No	
Stock et al. (2013)[u]	Pre/El	Other: pre-post group	researcher, community clinician, parent	No				No	

Note. *Indicates dissertation study. Teacher, Clinician, and Para/Aide all refer to *community* interventionists. [a-u]Study groups are indicated by a superscript letter; studies that have the same letter were grouped together for analysis. Clinicians provided by the research team (e.g., graduate student assistants, staff members, professors) are labeled "researcher." Pre/El = preK-elementary aged students; M/H = middle-high school aged students; External = person external to the study (e.g., undergraduate observers); Quest=questionnaire; Int=Int, Obs=observation; SSD=single subject design; RCT=randomized controlled trial.

Paper 2:

A Qualitative Investigation into Autistic Adults' Opinions of Intervention Goals for Young Autistic Children

Abstract

Intervention programs for autistic children target a variety of goals ranging from communication, academic, and daily living skills. A key component of all interventions is social validity, the extent to which interested parties find the program goals, procedures, and outcomes acceptable. However, past research indicates that social validity is rarely assessed from the autistic point of view. Thus, while intervention goals may be acceptable from parent or clinician perspectives, little is known regarding autistic individuals' views of these goals. In this study, autistic adults were presented with common intervention goals and asked to provide written feedback on them. Though these open-ended questions were presented as an optional survey question, each goal received feedback from 120-189 participants (out of a total 214). Responses were analyzed using reflexive thematic analysis by a team of non-autistic and autistic researchers. Three themes were identified: Autistic Identity & The Double Empathy Problem; Supporting Autonomy, Self-Advocacy, and Interdependence; and Implementation Matters. Findings will hopefully aid providers in developing intervention goals that are aligned with the perspectives of the autistic community.

A Qualitative Investigation into Autistic Adults' Opinions of Intervention Goals for Young Autistic Children

Intervention and educational programs for autistic children hinge upon the goals that clinicians and educators create for them. Program goals cover various skill domains, such as social, communication, daily living, academics, and behavior (Kurth & Mastergeorge, 2010). However, it has been argued by autistic individuals and other stakeholders that many intervention and educational goals are ableist (i.e., they discriminate against those with disabilities) in that they are focused on "normalizing" autistic children such that they appear less autistic (e.g., Roberts, 2020; Robertson, 2009; Shyman, 2016). These normalization goals can have the effect of teaching autistic children that their natural way of being is considered wrong. While researchers and advocates in the autism community have pointed this out, there has been little empirical research into what makes an acceptable versus unacceptable intervention goal from autistic people's point of view.

Ableist intervention goals are those that encourage autistic individuals to go against what Sinclair (1993) describes as their autistic "way of being" (Schuck et al., 2021). Examples of such goals include forcing eye contact (Dalmayne, 2017) and prioritizing spoken language above other communication modes (Schuck et al., 2022). Focusing on normalization can lead to masking—the suppression of autistic traits (Hull et al., 2017)—which has been linked to poor mental health outcomes (Cage & Troxell-Whitman, 2019) (though causal connections have yet to be established; Williams, 2021). Acceptability of intervention goals is one of the three domains of *social validity* (i.e., the degree to which stakeholders find an intervention's goals, procedures, and outcomes acceptable; Wolf, 1978) and should be evaluated whenever an intervention is delivered (Horner et al., 2005; Reichow, 2011). However, multiple systematic reviews have found that the acceptability of intervention goals is rarely assessed in behavioral intervention research (Ferguson et al., 2019; Hurley, 2012). It is thus perhaps not surprising that intervention goals that can lead to negative outcomes are perpetuated. Furthermore, despite Wolf (1978) arguing in his seminal paper that intervention recipients should be “happy with our efforts and effects” (p. 213), autistic research participants are rarely consulted on the development and implementation of intervention programs (D’Agostino et al., 2019; Hurley, 2012; Monahan et al., 2021). This lack of input has likely contributed to the serious controversy surrounding behavioral intervention, with critics claiming that such interventions are unethical and harmful (Dawson, 2004; Mottron, 2017).

It is thus necessary to evaluate intervention goals from the perspective of autistic individuals. While it is important to gather such feedback directly from intervention recipients, this is not always possible when the recipients are very young and sometimes non-speaking. Therefore, a viable alternative is to ask autistic adults to provide their feedback with the aim of improving such goals. It is important to note that this approach is not only rooted in social validity, but also in neurodiversity—the idea that there are no “normal” brains, and all brains should be accepted (den Houting, 2018; Dwyer, 2019; Walker, 2014). When viewed through this lens, it becomes increasingly clear that autistic people themselves must be included in all intervention decision-making, something that has historically not been the case.

Social Validity

The concept of social validity has its roots in behavioral intervention. Behavioral intervention is one of the most common forms of intervention for autistic children (Monz et al., 2019). Applied behavioral analysis (ABA), as it is often referred to, uses reinforcement contingencies (i.e., repetitions of antecedent-behavior-consequence sequences) to teach new skills and is usually used with young autistic children in in-home therapy, though it is also utilized in classrooms (see Leach, 2010). In the 1970s, as a reaction to an overreliance on "objective" behavioral data in intervention research, social validity was introduced as a crucial aspect of interventions (Kazdin, 1977; Wolf, 1978). Wolf (1978) pointed out that teaching behavioral contingencies may result in a desired behavior, but the behavior change was not meaningful unless stakeholders *thought* it was. He defined social validity as the social significance of intervention goals, the social appropriateness of intervention procedures, and the social importance of the effects. This was revolutionary for a behaviorist, given that Wolf was suggesting researchers focus on *subjective* feelings and thoughts rather than strictly observable behavior.

Social validity can consist of both objective and subjective evaluations of whether an intervention's goals, procedures, and outcomes are seen as acceptable and feasible. Assessment of social validity can take many forms, such as questionnaires (see Carter & Wheeler, 2019 for a comprehensive list of instruments), direct observation, normative comparison (Kazdin & Matson, 1981), data on whether the intervention procedures and outcomes have been maintained (Kennedy, 2002), and qualitative interviews (e.g., Leko, 2014). These assessments can be made by both direct consumers (those who are directly receiving the intervention, such as autistic children and, if parent education/training is involved, their parents) and indirect consumers (e.g., other family members or peers who interact with the intervention recipient (Schwartz & Baer, 1991). However, there is little standardization of social validity evaluation in the field, and researchers disagree about who is the ideal candidate for such assessments (Snodgrass et al., 2021).

Social validity is listed as one of the criteria for determining whether an intervention should count as evidence-based (Horner et al., 2005; Reichow, 2011). However, recent reviews of behavioral intervention publications have shown that few articles actually report on social validity (e.g., Callahan et al., 2017; D'Agostino et al., 2019; Ledford et al., 2016, Snodgrass et al., 2018). This especially seems to be the case with regards to intervention goals, which have been found to be assessed particularly infrequently across studies (e.g., Ferguson et al., 2019; Hurley, 2012). Even when social validity is assessed, it is often measured by asking parents or teachers/clinicians their opinions as opposed to asking the participants themselves (D'Agostino et al., 2019; Hurley, 2012). It is therefore vitally important to assess the social validity of autism intervention and educational practices from the autistic point of view. This is an especially salient topic given the fact that many autistic individuals have been vocal about potential damaging effects of behavioral intervention (e.g., Dawson, 2004; Michael, 2018). One potential reason the field of ABA has been slow to assess social validity from the autistic perspective is its adoption of the medical model of disability, as opposed to the neurodiversity approach.

Neurodiversity

Neurodiversity refers to the brain differences inherent in the human population (literally the *diversity* of our *neuro*logy). In order to understand why neurodiversity is relevant to autistic individuals' perspectives on intervention goals, it is first necessary to understand the dominant model of disease and disability utilized by our healthcare and education systems: the medical model. The medical model identifies disability as being located *within* an individual and thus identifies that person as being in need of *remediation*

(Marks, 1997). This is evident from the long list of deficit-based symptoms describing developmental "disorders" such as Autism Spectrum *Disorder* or ADHD (Attention Deficit Hyperactivity *Disorder*) in the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013). While the medical model makes sense for medical issues where a cure is sought (e.g., cancer, epilepsy, diabetes, etc.), it runs into issues when it is applied to those with differing neurology.

The term "neurodiversity" was first introduced by autistic sociologist Judy Singer in 1998 and was popularized in an *Atlantic* article that same year (Blume, 1998). While the concept was borne out of the autistic rights movement, neurodiversity covers the entire spectrum of neurological differences and is not synonymous with autism (Silberman, 2015). Neurodiversity advocates generally argue against the medical model, suggesting that diversity of neurology contributes to the advancement of our species, just as does ecological diversity (Singer, 1998). Thus, *neurodivergent* individuals (those who do not conform to society's standard of "normal"; term coined by Kassiane Asasumasu) do *not* need to be cured. Though there is no centralized definition of neurodiversity amongst the movement's proponents, many see neurodiversity as encompassing the following ideas: 1) there are no "typical" or "correct" brains; 2) neurodiversity should be accepted and seen as beneficial; 3) society affects the ways in which neurodivergent individuals are disabled (e.g., den Houting, 2018; Dwyer, 2019; Walker, 2014). Neurodiversity proponents thus demand acceptance of neurodivergent people, but also recognize the need to provide supports where they are needed (den Houting, 2018; Dwyer, 2022; Robertson, 2011).

Though they recognize the importance of support, many neurodiversity advocates are fierce critics of behavioral intervention (e.g., des Roches Rosa, 2020; Michael, 2018; Milton, 2020; Sequenzia, 2016). Modern behavioral intervention, or ABA, has its roots in research done by Ole Ivar Lovaas at UCLA in the 1980s. His seminal paper, which effectively changed the course of autism intervention research for decades to come, claimed that about 50% of the children in his study "recovered" from autism after his 40-hour-a-week intervention, describing participants as "indistinguishable from their normal friends" (Lovaas, 1987, p. 8). Though much research has been done to show the efficacy of ABA in teaching certain skills to autistic children (e.g., Landa, 2018), Lovaas' astounding results have yet to be replicated (see Sandbank et al., 2020, for a meta-analysis of behavioral intervention research indicating its effectiveness may be overstated). In an effort to promote the ultimate goal of "recovery," many of Lovaas' interventions involved long hours (essentially a full-time job of ABA) and aversive stimuli (such as slaps and painful electric shocks) applied as punishment in order to get children to stop problem behavior (e.g., Simmons & Lovaas, 1969).

Two of the major criticisms put forth by neurodiversity advocates (including those who are autistic as well as those who are not) are 1) the historical use of aversive stimuli (and in some cases current use, such as the Judge Rotenberg Center which still uses electric shocks to enforce compliance from its clients [Neumeier & Brown, 2020]), and 2) intervention goals that imply reduction of autistic characteristics and attainment of "normality" are desired. Research has shown that autistic people are less likely to endorse a medical-model view of autistic individuals needing to be cured than do neurotypical people and are also more likely to reject the notion that autistic people should strive to appear "normal" (Gillespie-Lynch et al., 2017; Kapp et al., 2013). Self-stimulatory behavior, which is often a target of behavior reduction techniques in intervention (Leekam et al., 2011), is recognized by autistic individuals to be involuntary, in some cases soothing, and unnecessarily stigmatized (Kapp et al., 2019). Another common goal of behavioral intervention, improvement of eye contact, is also subject to criticism in light of the finding that some autistic individuals find eye contact to be uncomfortable and distressing, even if they are able to fool others into thinking their eye contact is natural (Trevisan et al., 2017). Nonetheless, normalization goals continue to be written into behavioral and education plans. This is likely in part due to the "double empathy problem" (Milton, 2012), which refers to the idea that autistic people are expected to have tremendous "empathy" for non-autistic people (in that they are expected to conform to neurotypical standards), whereas the reverse (neurotypical people learning about and conforming to autistic norms) is almost never expected. Furthermore, ABA's emphasis on normalization has led some advocates to call ABA "autistic conversion therapy" (Sequenzia, 2016), a comparison that is bolstered by Lovaas' involvement in a study to reduce "feminine traits" in young boys (Rekers & Lovaas, 1974).

It has been argued that behavioral intervention could *in theory* be aligned with the neurodiversity perspective (Schuck et al., 2021). For example, Naturalistic Developmental Behavioral Interventions (NDBIs; Schreibman et al., 2015) emphasize following the child's lead, play-based learning opportunities, and reinforcing attempts as opposed to pushing children to be perfect. All of these principles align well with neurodiversity, and autistic adults also agree that these are strengths of NDBIs (Schuck et al., 2022). Nonetheless, there are still criticisms of NDBIs from neurodiversity advocates (e.g., des Roches Rosa, 2020) and much reform is needed before NDBIs and other behavioral interventions can be considered acceptable practices (Schuck et al., 2021). One reform that is sorely needed is an increase in the assessment of social validity, particularly from the autistic perspective. As mentioned previously, even when social validity is assessed, the autistic intervention recipients are rarely consulted (D'Agostino et al., 2019; Hurley, 2012). It is likely that the lack of autistic perspective is the key to understanding why so many autistic advocates decry ABA, despite social validity supposedly being such an integral part of behavioral intervention. Social validity assessments made by parents, teachers, and other (usually non-autistic) stakeholders cannot be used in place of those made by the autistic persons themselves, as it is impossible for them to really know what it is like to be an autistic person. Assuming that autistic and non-autistic perspectives are equivalent can lead us to assume that goals, procedures, and outcomes favored by clinicians and parents are the same as those that are favored by autistic people, and that is very unlikely to be true. Indeed, emerging research on autistic perspectives is beginning to provide evidence that behavioral interventions can promote masking and lead to negative side effects such as mental health issues (e.g., Cumming et al., 2020; Kupferstein, 2018; McGill & Robinson, 2021). Nonetheless, more research in this area is still needed, especially with regard to the different aspects of social validity. For example, an intervention may utilize procedures that autistic people are okay with (e.g., some aspects of naturalistic behavioral interventions, such as following the child's lead or reinforcing attempts; Schuck et al., 2022), but if those procedures are used to work on unacceptable goals, the intervention cannot be considered socially valid.

Current Study

The current study aims to directly address the lack of autistic perspectives on intervention and education, particularly with regards to program *goals*. While it is imperative that researchers and clinicians address social validity from the perspective of autistic intervention recipients themselves, it can be challenging to do so when interventions involve young, sometimes nonspeaking children. Though methods to do so exist (e.g., Robinson, 2011; Tesfaye et al., 2019), asking autistic adults for their perspectives can also give valuable feedback. In the current study, autistic adults were asked to provide written feedback on common intervention goals via an online survey. While this limits our sample to individuals who are able to type using written language, many advocates argue that speaking autistic adults' perspectives can still shed useful light on issues that are relevant to nonspeaking individuals (Des Roches Rosa, 2019; Thornton, 2021). Participants' open-ended text responses were analyzed using reflexive thematic analysis (Braun & Clark, 2006; 2019) in order to answer the initial overarching research question of: How do autistic adults evaluate common intervention goals for autistic children and why? After analysis commenced, the following additional research question was added based on the content of participants' responses: What improvements can interventionists and educators make to ensure goals are in line with the needs of the autistic community?

Method

Participants

To be eligible to participate, participants needed to be 18 years or older and identify as autistic (participants could report either having a clinical diagnosis or self-identify as autistic without a formal diagnosis). A convenience sample was recruited online via social networking sites (e.g., Facebook, Reddit) and by reaching out to autism organizations to see if they would send the advertisement to their listserv. A variety of organizations were targeted (for example, some groups were specifically for autistic behavior therapists, whereas others had explicitly anti-ABA stances espoused on their websites) in order to elicit a wide range of perspectives.

This report focuses on the 214 participants who answered at least one open-ended answer about intervention goals. Participants had a mean age of 34.86 years (SD = 11.27); 108 identified as female, 51 as non-binary/genderqueer, 37 as male, and 18 identified as other or did not state their gender. Most participants (n=161) reported having a clinical diagnosis of autism, whereas the remaining (n = 53) self-identified as autistic. The majority of participants identified as White (n = 180). The remaining participants identified as mixed race (n = 6), Hispanic (n = 6), Asian (n = 4), Native American (n = 3), and Black (n = 2). Thirteen participants did not answer the ethnicity/race question or indicated that they preferred not to state their ethnicity/race. Most participants reported living in the United States (n=135). Participants' average score on the RAADS-14 (Eriksson et al., 2013), a measure of autistic traits, was 32.43, well above the autism cut-off of 14. Two participants scored less than 14, though they both reported clinical diagnoses. Just over a quarter of participants (n = 62) reported receiving behavioral intervention as a child; 105 reported not receiving any and 41 were unsure if they had or not.

Procedure

Participants who were interested in participating could access the study consent form on Qualtrics by clicking a link in the advertisement. After consenting, participants were directed to the study questionnaires. Participants first filled out the RAADS-14 (Eriksson et al., 2013), an autism screening instrument designed to assess autism traits. Though a cut-off score of 14 is indicative of autism, participants were not excluded if they scored below 14. Next, participants were directed to the study survey and, at the end of the survey, asked to provide demographics.

Survey

The portion of the survey that will be analyzed for this report was focused on eliciting feedback about various common intervention goals for autistic children. Before answering these questions, some participants also participated in a related study in which they viewed videos of autistic children engaged in an intervention and were asked to provide feedback (see Schuck et al., 2022, for more details).

To assess perspectives on intervention goals, participants were presented with 19 statements (see Figure 1) about intervention goals and asked to rate the degree to which they agreed with the statement. All statements were worded, "[Goal] is a good intervention goal." Goal statements were generated by a team of four graduate students, two with behavioral intervention experience (including a BCBA who has experience with developing and addressing goals in behavioral intervention plans and Individualized Education Programs) and two who identified as autistic and are involved in neurodiversity research and advocacy. After rating how much they agreed with the statement, participants were provided with a text box and asked, "OPTIONAL: Is there anything you'd like to add regarding your feelings toward this statement?" This report will focus on participants' text responses to this open-ended question. A separate analysis of the participants' agreement ratings generated an empirically-derived three-factor structure of goals (Baiden et al., under review). The three factors were named *Uncontroversial Goals, Controversial Goals*, and *Social Goals* based on the fact that the first factor was composed of goals that were rated highly, the second factor was composed of goals that were rated poorly, and the third factor had varying endorsement ratings, yet were all related to social skills (see Table 1 and Baiden et al., under review). Though the survey requires further validation, the qualitative research questions for the current study are answerable regardless of the quantitative instrument's validity.

Figure 1

Intervention Goals

_____________ *is a good intervention goal.*

1. Building communication skills
2. Learning the rules of social interaction
3. Building interpersonal skills
4. Improving conversational ability
5. Reducing stimming/repetitive motor movements (like hand flapping)
6. Reducing vocal stimming/repetition of phrases (like lines from TV shows)
7. Reducing fixation on certain objects/interests
8. Reducing dangerous behavior (such as running into a busy street)
9. Reducing picky eating
10. Promoting eye contact with others
11. Reducing self-injurious behavior
12. Improving quality of life
13. Promoting independence
14. Reducing noncompliant behavior
15. Toilet training
16. Teaching school-readiness skills (such as sitting in a chair during a lesson)
17. Improving flexibility and acceptance of change (for example if a routine is broken)
18. Reducing inattention and hyperactivity
19. Improving tolerance of sensory stimuli (such as lights, sounds, or smells)

Data Analysis

Participant responses were analyzed using Braun and Clark's (2006; 2019) approach to reflexive thematic analysis. Their analytic process entails the following six steps: 1) getting familiar with the data; 2) data coding; 3) generating initial themes from data; 4) developing themes; 5) refining and naming themes; 6) writing up the results in a report. This process is iterative, as work in one step may necessitate going back to a prior step (e.g., you might realize during theme generation that there is an important aspect of your data that was not yet coded, so you have to go back to data coding).

Due to the large amount of data (over 100 participants responded to each of the 19 open-ended questions), responses to the two most and two least endorsed goals from each factor (Uncontroversial, Controversial, Social; see Table 1) were coded and analyzed. As such, responses to 12 out of the 19 goals were coded.

All coding took place via Microsoft Excel. Six individuals took part in coding data. The lead coder was the author (a fourth-year doctoral student in education), three were undergraduate research assistants (RAs), one was a postgraduate RA, and one was a first-year graduate student in education. Two undergraduate RAs both identified as autistic (and one further identified as having ADHD). To start, five of the coders independently read participant responses to the 19 statements, each taking notes in an analytic memo (Miles et al., 2020). Such memos included: a summary of the data, initial patterns in the data, potential codes, and questions about the data (Miles et al., 2020). The coders then met to discuss their memos and brainstorm initial codes, which were added to an initial codebook. The five coders subsequently met multiple times to practice applying codes. Codes were applied at the individual response level; that is, every response to each question was analyzed separately from the other responses. It was possible that some responses did not have any codes applied to them or that multiple codes were applied to a single response. During this practice, codes were added, removed, and refined based on discussion amongst the coders. This process continued until the coders felt that the codes adequately fit the data.

Table 1

Factor Structure of Intervention Goals Derived from Exploratory Graph Analysis

Factor	% Endorsed[a]	Mean (SD)[b]
Uncontroversial		
Reducing Danger*	96.2	5.4 (1.0)
Improving Quality of Life*	91.3	5.3 (1.2)
Reducing Self-Injurious Behavior	90.9	5.1 (1.2)
Increasing Independence*	88.3	4.7 (1.3)
Toileting*	87.9	4.8 (1.3)
Controversial		
Reducing Inattention/Hyperactivity*	49.1	3.3 (1.5)
Improving Sensory Tolerance*	36.7	2.7 (1.7)
Reducing Picky Eating	32.2	2.7 (1.5)
Reducing Noncompliance	26.8	2.4 (1.6)
Increasing Eye Contact	20.1	2.0 (1.5)
Reducing Vocal Stimming	19.0	2.0 (1.4)
Reducing Motor Stimming*	11.9	1.7 (1.3)
Reducing Fixations*	9.0	1.7 (1.2)
Social		
Improving Communication Skills*	91.5	4.9 (1.2)
Improving Interpersonal Skills*	80.3	4.5 (1.4)
Learning Rules of Interaction	68.8	4.0 (1.5)
Improving Conversation Ability*	63.6	3.9 (1.5)
Increasing School Readiness*	49.1	3.3 (1.6)

Note. *Indicates open-ended responses to these goal statements were analyzed in the current study. [a]Endorsement of a goal was defined as a participant saying that they somewhat agreed, agreed, or strongly agreed that it was a good goal. [b]Scores ranged from 1-6, with 1=strongly disagree and 6=strongly agree that the goal was good. Table replicated from Baiden et al. (under review).

Next, the lead researcher coded responses to all 12 goal questions. These codes were then sent to the research assistant coders. The coders were instructed to review the author's codes and identify places where they disagreed with the coding. Disagreements could include disagreeing with the lead researcher's code application or identifying places where additional codes should be added. In some cases, RAs suggested entirely new codes. RAs reviewed responses to between one and four goal statements.

The lead researcher then reviewed and incorporated the coders' feedback. The researcher made notes as to when she agreed or disagreed with the RAs' suggestions. Note that the purpose of "double coding" in this project was not to become "reliable" at uncovering some "hidden truth" within the data; it is instead to ensure that multiple distinct, diverse minds were coming together to make sense of the data. As Braun and Clarke (2019) say, "If more than one researcher is involved in the analytic process, the coding approach is collaborative and reflexive, designed to develop a richer, more nuanced reading of the data, rather than seeking a consensus on meaning" (p. 594).

The author then generated initial themes based on the codes. These themes were then discussed with the RAs in order to update, refine, and name themes. Themes and exemplar participant quotes were then presented to the rest of the study team in order to ensure the theme structure made sense. Such peer debrief amongst team members from different backgrounds and perspectives help strengthen the trustworthiness and credibility of these findings.

Author Positionality

In qualitative research, the meaning making process is affected by each team members' prior knowledge, background, and theoretical lens. While our team consists of individuals from a variety of different fields and backgrounds, it is still important to acknowledge our positionality and how it may affect our interpretation of the data. The author of this dissertation is a non-autistic doctoral student in education whose research focuses on intervention social validity and neurodiversity acceptance. The author has experience providing naturalistic behavioral intervention but is not currently involved in any clinical services. Four other team members are also doctoral students—two in education (one a Board Certified Behavior Analyst, the other a former special education teacher), one in developmental psychology, and one in an MD/PhD program specializing in psychiatry. Three are undergraduate students and one is a postgraduate research coordinator. Four of the team members (two graduate students and two undergraduate students) identify as autistic. Three team members have experience delivering naturalistic behavioral intervention to autistic children and their families, and two undergraduates were involved in peer support/mentoring at a university autism center. Our backgrounds thus provide us with a mix of perspectives, including those who may be familiar with implementing some of the goals discussed in this study, as well as those who are more immersed in the neurodiversity movement and the autistic community. That said, all team members are proponents of the neurodiversity movement and aim to reduce potential harm done to autistic individuals as a result of intervention.

Findings

Though the open-ended question presented after each goal statement was labeled as optional, the majority of participants provided a response. The number of responses per statement ranged from 120 responses to *Toilet training is a good intervention goal* to 189 in response to *Reducing motor stimming is a good intervention goal*. Analysis of participant responses generated three themes: 1) Autistic Identity & The Double Empathy Problem; 2) Supporting Autonomy, Self-Advocacy, and Interdependence; and 3) Implementation Matters. Each theme is discussed below along with illustrative participant quotes.

Autistic Identity & The Double Empathy Problem

A common thread across many of the responses was the idea that autistic people are inherently different—but not less—than neurotypical people. Participants expressed concerns that working on some common goals could encourage autistic children to mask their autism, which could lead to negative outcomes. This led participants to call for recognition amongst professionals that autistic traits are not by default worse than neurotypical traits (a notion in line with the double empathy problem; Milton, 2012). With this increased understanding, a more authentic autistic identity could be supported via intervention services.

Participants referred to things such as quality of life or interpersonal skills in relation to being autistic (for example, “quality of AUTISTIC life—not NT [neurotypical] life”; “Autistic interpersonal skills will always be different than neurotypical interpersonal skills - and that’s ok.”). A common concern was that pushing neurotypical standards onto autistic children via intervention (whether it be through, for example, social skills training or reducing stimming) would lead them to mask, which could further lead to negative outcomes. One participant explained, “It's difficult and depressing to be forced to emulate skills that are not typical for my neurotype.” One participant brought up research on masking and mental health: “Research has very clearly demonstrated that active suppression of ASD ("masking") traits have correlations with depression and anxiety. To suppress stims would undoubtedly be a detriment to the psychological wellbeing and mental health of an autistic person.” Some participants brought up the importance of consent and following the lead of the autistic person, while still highlighting the need for services to be autism-affirming: “I think it [improving conversational ability] can be [a good goal] if that's one of the child's own goals, but... it's important that ‘conversational ability’ is not interpreted as ‘conformity to non-autistic expectations in conversation.’”

A majority of participants also mentioned how different people might interpret a goal differently, and that a goal’s acceptability hinged upon its definition being in line with an autistic identity. For example, participants stated: “Who is deciding what interpersonal skills are, and how will that be measured? Is it just ‘to taste’, judged by a Neurotypical person?”; “Be mindful of what you label as ‘inattention’ and ‘hyperactivity’ - all too often natural autistic behaviour (stimming, lack of eye contact) get labelled as that”; “This [reducing dangerous behavior] is a really slippery slope, and my experience tells me you'll probably use this as an example but mean lots of other things.” It was thus difficult for participants to clearly identify goals as “good,” as they felt many of them could be misinterpreted by professionals.

A thematic corollary to the notion that autistic people should be accepted for who they are was that acceptance is often elusive amongst professionals. This was chalked up to professionals exhibiting a fundamental misunderstanding of autistic people. As one participant put it: “I don't trust NTs to teach conversational skills to neurodivergent people in a respectful way.” Across multiple goals, participants’ responses evoked the double empathy problem (Milton, 2012). For example, one participant described how neurotypical people often make little effort to understand how to best interact with autistic people: “NTs need to learn the interpersonal skills to interact with autistics and treat us with respect, but they almost never do.” This notion led many participants to suggest neurotypical people learn more about autism and neurodiversity. For example, a participant agreed that learning interpersonal skills was an important goal, “but there should be just as much focus on the allistic (non-autistic) learning as there is on the autistic learning.” Another felt that the goal “can be good as long as the other person is also expected to do some labor.” One participant drew a parallel between neurotypicals’ lack of understanding and masking:

> Making autistics more palatable to neurotypicals by masking our autism doesn't do anything to help spread awareness and de-stigmatize autism. This is not helpful, and can result in a lot of stress and anxiety disorders as we try to mask and hide these traits... we should focus our attention on making neurotypicals less judgmental of autistic kids and adults than trying to make us look more neurotypical to be accepted.

This kind of cross-neurotype education was also seen as a solution to improved communication skills in general:

> Again it's a problem of why is the autistic person the only one that needs to be flexible? Helping both autistic and non autistic people understand how others experience empathy and listening differently and using that understanding as a lens to be more accepting and supportive improves communication skills for everyone.

In addition to teaching neurotypicals about autism, some participants also suggested that providers *explain* neurotypical/societal norms and expectations to autistic children while making it clear that they were not required or expected to conform. One participant suggested the following as something providers could say to autistic clients when presenting such expectations: “‘Here are some tools you'll find useful, but the way you do it is fine and shouldn't be stopped, you're just getting an extra set of stuff to use.’” Another similarly suggested “fram[ing] these skills as ‘the things you need to learn to deal with neurotypicals’ and not ‘the things that every person is supposed to know to be normal.’” Another explained: “Children should still understand that while not everyone (especially strangers or acquaintances) will appreciate brutal honesty and conversations dominated by special interests, good friends should be able to engage with them at this level.” Framing neurotypical and autistic norms in this way could help show both autistic and non-autistic individuals that neither neurotype is preferable—they are simply different.

Supporting Autonomy, Self-Advocacy, & Interdependence

Some participants questioned whether *independence*—the notion that people should do things *on their own*—was a goal for which autistic people should strive. Participants brought up two related ideas: first, that *autonomy*—the idea that people should be able to have agency and choice in their life—and *self-advocacy*—being able to ask for what you need—were more important than independence, and second, that *inter*dependence (i.e., relying on others) is an undervalued concept in our society.

Some participants recoiled at the idea that support professionals should be pushing independence (e.g., “The idea that disabled people are only successful when fully independent physically and that full independence means financially being able to support themselves is outdated and gross frankly, a better word would be autonomous”; “Usually, when someone says "promoting independence" they're talking about taking away things that someone needs in order to function.”), with some pointing out that independence as it is often defined by society may not always be possible for some autistic people. These participants instead thought autonomy and self-advocacy should be promoted as routes for autistic people to access whatever level of support they need. This idea was described by multiple participants:

> Yes! Allowing the autistic person to drive that [increasing independence] while being there to offer support in helping them to make those decisions (including helping them to make better informed decisions and helping them to have more tools/options to choose from).
>
> Attempts to obtain someone else's idea of independence often leads to poor mental health and burnout as we hit adulthood… Independence comes from autonomy- the ability to think and act for one's own self.

The idea that autistic people should be encouraged to exert their autonomy and ask for what they need was related to the notion of embracing interdependence. Indeed, some participants emphasized the idea that no human is truly independent and that interdependence and support from others is an important part of the human experience: “We are all interdependent and expecting people with disabilities to go it alone is silly. Like, yes, independence in a lot of areas is great, but I would prioritize choice and autonomy”; “Even the neurotypicals I know aren't completely independent…Independence is a spectrum. But we only pathologise one's position on it if one is disabled.” Accordingly, supports should not be deprived just because an autistic person appears to have the capability of something independently. As stated by a participant: “Be careful about the ‘you can do this, so you should’ trap - something that’s exhausting without support shouldn’t be done without support all the time.” Another participant echoed this sentiment, “Codependence is a reality for many autistic people and should be accepted and embraced. Those with more needs are right to accept support where they need it and don’t deserve to be stigmatised for doing so.” Yet another participant further highlighted how focusing on independence as the ultimate goal could inadvertently promote stigma:

> It's okay to rely on others and need support—even very high levels of support—it doesn't make anyone less deserving of life or respect or fair treatment. Saying promoting independence is a good goal is inadvertently saying those without independence are somehow defective; this is clearly not the case. So while I agree independence should be promoted where it can and is appropriate, forcing people to be independent before they are ready or able to is cruel.

Implementation Matters

While some goals were clearly controversial (see Table 1 for the quantitative ratings), participants often brought up the notion that a goal *might* be acceptable, but—in addition to it being dependent on the definition of the goal (as discussed above)—it also depends on the specific intervention techniques employed by provider:

> Improving conversational skills as a goal is not exactly the problem. The approach to improving conversational skills is the problem. Does that mean forcing a child to constantly verbally orally confirm what it is they want when their body language and other communication is obvious?

Though participants were almost unanimously in favor of reducing dangerous behavior, they were still wary of blanket endorsement: “Absolutely, reducing dangerous behaviors is a good thing. However, it needs to be done the right way. Never punish the person, as they probably don't know better.” Participants also worried that some intervention procedures might cause harmful side effects, such as “exhaust[ion], demorali[zation] and detriment[s] to mental health” due to masking. With regard to stopping stimming, some participants mentioned how reduction of stimming could lead autistic individuals to channel their stims into more harmful behavior (e.g., “My stimming became hidden and destructive by correction.”). Another participant described difficulty recognizing their own needs such as hunger due to learned helplessness from years of hiding their needs for neurotypical convenience and to avoid punishment. Some participants specifically talked about how interventions that emphasize compliance could put autistic people at risk for being taken advantage of, with seven participants explicitly mentioning sexual abuse.

Two distinct subthemes related to Implementation Matters were identified: Moving Beyond Behavior, and Positive Educational Strategies.

Moving Beyond Behavior

Participants made it clear that providers need to look beyond behavior in order to understand how to best support autistic people. Many mentioned trying to understand the root cause of the target behavior. This was especially true for reducing dangerous behavior and toileting goals. For example, in response to the statement about reducing dangerous behavior, a participant stated: “Yes [it is a good goal], but the underlying reason also needs to be addressed. No one runs into the street for the sheer fun of it, there’s usually an underlying sensory or communication issue that needs to be fixed.” Similarly, a person responded about toileting by saying: “Difficulty with the toilet is 99% of the time sensory, not behavioral. Don’t approach a sensory problem with behavior therapy.” Participants encouraged providers to consider, “‘Why is the kid doing this, what need are they filling?’ and addressing that, not just reducing the behavior.” Another participant suggested educators should consider the following when students elope or engage in dangerous behavior such as running into a street: “What is happening at the school that has this child in fight-flight-or-freeze so often that they have to run into the street to get away? Maybe work on *that* and the kid will stop running.” The suggestion to consider root causes seemed to be based not only in respect for people’s inner thoughts and feelings but also in practicality—that is, the interventions simply would not be as effective if only behavior was considered. A participant explained how, without identification of root causes, developing positive coping strategies would be difficult:

> I have unintentionally put myself in dangerous situations because I was overstimulated, in meltdown, and physically incapable of knowing where I was and making rational decisions...Telling me in the moment or preventing me in the past isn't going to reduce that behavior because in the moment, it isn't a rational choice. Help me identify and reduce the impact of stressors that would cause me to do such a thing.

In response to other goal statements, participants pointed out that outward behavior can actually be misinterpreted. This misinterpretation can thus lead providers to target behaviors that are functional and/or non-harmful. For example, many participants saw stimming (e.g., hand flapping) as a coping/self-regulation mechanism and/or as communication. One participant stated:

> Stimming helps me regulate, if you want me to stop you'd better give me a different way to do that. But I've yet to find anything that works as well. I have tried not stimming and it just means that I'm anxious and unproductive for the next hour.

Another echoed this sentiment: “Removing an autistic person's coping mechanism is just cruel, and will likely result in increased anxiety and/or a meltdown.” Some participants also identified stimming as an expression of joy (e.g., “If I'm waving my arms this is an expression of emotion; it is a smile I make with my hands”). If providers try to reduce stimming, it could have detrimental effects that are likely antithetical to many intervention goals:

> You're literally trying to eliminate the very thing you would be claiming to want to improve simply because it doesn't fit someone else's preconceived ideas of what "happy" looks like. My daughter is very clear and tells me verbally that when she flaps her hands it means she is happy.

The other behavior that appeared to often get misinterpreted by providers was the need to move around (both in terms of reducing hyperactivity/inattention and increasing school readiness). Participants who made this point felt that moving around was often misinterpreted as inattention, when in reality, movement could facilitate learning for autistic people. A participant explained: “When I'm the most engaged, I often look the most tuned out. I get concerned when ‘paying attention’ turns into a set of expected behaviors that might be more for show.” Another participant felt similarly: “A lot of what was labeled inattentiveness were actually things I was doing to be able to pay attention, and those tools were taken away from me because frustrated teachers assumed I wasn't paying attention.” Instead of discouraging movement, participants suggested educators allow students to learn in ways that are suited to them (e.g., “Children need to be allowed to stim (including non-disruptive walking and vocal stimming) in stressful situations, like classrooms”; “Why can’t they have ‘being able to move about’ as part of their IEP [Individualized Education Program] when they go to school?”).

Positive Intervention/Educational Strategies

Participants provided several suggestions for providers to ensure intervention goals could be addressed without causing harm. The first was to alter the environment and provide accommodations instead of solely focusing on the child. For example:

> Allowing the child to move instead of staying seated, for example, and offering a calm and supportive learning environment with a high quality flexible curriculum that sets the child up to succeed according to their own strengths would likely alleviate inattention and hyperactivity without requiring reinforcement.
>
> Traumatizing a child into using a toilet when they have unknown co-occurring issues that make it difficult (for example, proprioception difficulties making it impossible for the person to sense the need to eliminate) when accommodations are readily and easily available is needless traumatization.

Similarly, participants highlighted the importance of offering alternative behaviors when a behavioral modification goal was deemed appropriate. For example, if a stim was deemed dangerous or distracting, a fidget toy might be introduced as a viable alternative.

Finally, a small number of participants specifically mentioned taking a strengths-based approach with autistic children. This was both in terms of allowing children to pursue their passions (“If they can do things they like to do, they will feel joy and life will feel worth living”) as well as capitalizing on interests to attain some sort of goal (e.g., “Ivy League universities are full of students with reduced attention and hyperactivity…Do we want to teach people compliance at sitting in chairs, or do we want to empower people to work with their neurology to their maximum potential?”; “If they like trains, try to creatively incorporate trains into the lesson”; another participant explained how focusing on minute details—a strength of theirs—is an important part of their job).

Discussion

This qualitative investigation aimed to answer the following research questions: What do autistic adults think about common intervention goals for autistic children and why? What improvements can interventionists and educators make to ensure goals are in line with the needs of the autistic community? Intervention goals were clearly an important topic for the autistic adults who participated in this study, as evidenced by the fact that between 120-189 of participants chose to respond to each open-ended question, even though they were presented as optional. Thematic analysis of responses generated three themes related to the social validity of intervention goals for young autistic children: 1) Autistic Identity & The Double Empathy Problem; 2) Supporting Autonomy, Self-Advocacy, and Interdependence; and 3) Implementation Matters. These themes are discussed below with particular attention to practical take-aways to improve intervention social validity.

Implementation Matters: Practical Take-Aways

Many participants indicated they had trouble answering the rating scale questions due to the fact that certain implementation methods or differing interpretations of a goal could ruin an otherwise acceptable goal. This idea was encapsulated in the *Implementation Matters* theme. In particular, participants were worried about negative side effects from interventions. These concerns echo others who have written about the harm that current intervention techniques can incur (e.g., des Roches Rosa, 2020; Michael, 2018; Milton, 2020; Sequenzia, 2016; Williams, 2018). This is particularly worrisome given that autism behavioral intervention research has done a poor job of assessing adverse events during clinical studies (Bottema-Beutel et al., 2021; Dawson & Fletcher-Watson, 2022). Participants were also concerned that, while some goals might be socially valid, they are only acceptable insofar as the professionals actually address the root problem. If root problems are ignored, distress and discomfort may linger even if the outward behavior does not. This is connected to the issue of side effects, too: by focusing more on what is happening beneath the surface of behavior, professionals will by definition be cued into when clients/students are unhappy or distressed. If it is determined that the root cause of an individual's distress is the intervention itself, then it is time to change the intervention strategy.

Participants provided several concrete suggestions regarding the implementation of intervention: providing appropriate accommodations and environmental changes, offering alternatives, and adopting a strengths-based approach. These suggestions will likely sound familiar to educators and interventionists. For example, provision of reasonable accommodations in educational environments is mandated by law (e.g. 504 plans via Section 504 of the Rehabilitation Act of 1973; the Individuals with Disabilities Education Act, 2004). Offering alternatives when a behavior is modified is also something that most special educators and behavioral interventionists are familiar with, for example via functional behavior assessment and identification of replacement behaviors (e.g., Matson et al., 2011). And adopting a strengths-based approach is integral to many current intervention and educational models (e.g., naturalistic developmental behavioral interventions, Schreibman et al., 2015; Universal Design for Learning [UDL], Hall et al., 2012; see Urbanowitzc et al., 2019, for a roundtable discussion about incorporation of strengths into research and practice). However, these strategies are not always executed. For instance, a recent review of accommodations for autistic students in mainstream settings revealed that accommodations often focus on academic and social outcomes but do little to address the physical environment (for example, changes to accommodate for auditory sensory sensitivities) or children's quality of life (Leifler et al., 2021). With regard to offering alternatives, providers may actually be doing this *too* often by replacing behaviors that are not harmful. Lastly, while strengths-based programs can be immensely beneficial (e.g., Lee et al., 2020; 2023), lack of environmental adjustments as well as lack of acceptance have been identified as barriers to autistic children being able to capitalize on their strengths (Clark & Adams, 2020).

To combat these issues and ensure interventions are socially valid, professionals may benefit from taking an approach that combines individualized, strengths-based learning with listening to the child's needs and desires. One such approach is to utilize UDL along with design thinking (DT). UDL can provide a way for educators and interventionists to design learning opportunities that are accessible to all children, while DT provides an explicit process for ensuring whatever is designed actually meets students'/clients' needs (Lambert et al., 2021). By starting from a point of empathy (a core component of DT), social validity is likely to increase.

Autistic Identity, Autonomy, Interdependence as Guiding Concepts

The two remaining themes, *Autistic Authenticity & The Double Empathy Problem* and *Supporting Autonomy, Self-Advocacy, and Interdependence* highlight concepts that must be integral to any intervention or education program. Participants were worried about the costs of the masking that would ensue if they were forced to work on goals that were antithetical to their neurotype, a theme echoed in previous research (e.g., Cumming et al., 2020; McGill & Robinson, 2021; Schuck et al., 2022). Thus, interventionists would benefit from seeking out information about autistic identities in order to broaden their view of what it can mean to be authentically (and successfully) autistic. Even if a client themselves chooses not to adopt the neurodiversity approach and does not see their autism as an integral part of them, having a clinician or teacher who approaches the issue with sensitivity and acceptance is far better than the opposite.

Participants also brought up the double standard that autistic people face with regard to being expected to conform to neurotypical society (whereas the opposite is rarely true; Milton, 2012). Participants thus strongly encouraged neurotypical professionals to learn more about neurodiversity and autism. This was intimately tied to the social validity of intervention goals, as goals seen as acceptable to autistic people might be interpreted differently by professionals. This could then lead to a lack of social validity even though autistic people might say they agree that it is a good goal. For example, the autistic people in this study endorsed goals that enhanced quality of life, but only to the extent that it supported *autistic* quality of life (see Milton, 2020 for a similar point). It is therefore imperative that professionals realize that their interpretation of a goal may not match that of an autistic person. It will also be necessary for neurotypical professionals to recognize that their interpretation is not necessarily the right one. Thus, it will not be sufficient to look at a list of "acceptable" goals and start implementing; providers must ensure that the interpretation of the goal is in line with an "autistic way of being" (Sinclair, 1993; see a discussion of this in Schuck et al., 2021). Some participants endorsed the idea of professionals *teaching* neurotypical norms and expectations while simultaneously making it clear that there was no expectation for the autistic person to conform. A similar point was made by a participant in Cumming et al.'s (2020) study when she mentioned that she appreciated learning about "ways to respond normally" but also "would have liked to have someone explain to me the reason why these interactions were necessary" (p. 78). This strategy represents a pathway to acknowledging areas where neurotypicals and autistic people diverge in a manner that is respectful to all neurotypes. A straightforward way for professionals to learn more about autistic identities and the double empathy problem is to seek out information about neurodiversity. Both concepts are intricately connected to the idea of accepting people for who they are.

Finally, pushing for clients to become autonomous self-advocates was a critical point running through responses about many goals. While autonomy and self-advocacy are generally seen as important skills for all children to develop, participants made it clear that autonomy was not synonymous with independence. According to participants, autonomy and self-advocacy should coexist harmoniously with whatever level of support is needed. This is related to the idea of *relational* autonomy (Davy, 2015) and must be applied when working with autistic children. This is especially true given that autistic individuals are likely to display a spiky developmental profile (Doyle, 2020) that can fluctuate even day by day (den Houting, 2018). Ultimately, it may be socially valid to work on a specific goal with a child, but if a provider insists that the child display a skill independently *all* the time, the social validity may decrease.

Limitations & Future Directions

Though this study sheds light on how autistic adults feel about common intervention goals for autistic children, several limitations need to be discussed. First, while large for a qualitative study, our convenience sample was overwhelmingly White and female. Thus, some of the findings may not apply as well to other racial/ethnic groups or males. For example, it has been argued that, currently, truly “un-masking” is only a realistic, viable option for some White autistic people, as displays of autistic traits in Black and brown people may lead to harm due to the color of their skin (Cerda, 2023; Hammond, n.d.). Hammond (n.d.) makes the case that Black people are *always* enacting ABA as they navigate a world built on white supremacy. In this view, ABA is simply a “symptom” of a broken system which simultaneously serves Black people—since altering their behavior can save their lives—and oppresses them. While the current findings regarding the double empathy problem and acceptance would likely still hold for minority groups, it is possible that some findings, such as concerns about masking, may present differently in other groups. Similarly, masking may have been particularly important to the participants in this study since most identified as female or non-binary/genderqueer. Since studies have shown that masking is more common in autistic women and non-binary individuals as opposed to men (Cook et al., 2021), it is possible autistic men might focus on other aspects of intervention goals. It is also crucial that future research recruit more participants who received behavioral intervention as a child and/or elicit perspectives directly from children or adolescents engaged in such programs.

Also of note is that 11 participants indicated in their open-ended responses that they disliked the word “intervention.” While the survey questions were designed to apply to services beyond behavioral intervention, it is possible that this language may have turned people off and put them on the defensive. It may be preferable in future research on this topic to use other language such as “providing support.”

Lastly, due to resource and space limitations, responses to only 12/19 goal statements were analyzed and reported. While it is likely that we have reached or are near saturation given the vast amount of data that was reviewed, it is possible that new perspectives/themes would have been uncovered in the unanalyzed portion of the data.

Conclusion

In this study, autistic adults gave feedback on common intervention goals for young autistic children. They highlighted several areas where professionals could help autistic children obtain a high quality of life, namely: understanding and emphasizing autistic identity, encouraging autonomy and self-advocacy, and using appropriate intervention procedures that do not incur psychological or physical harm. It is safe to say that there are some intervention goals that are likely to be *unacceptable* to a large proportion of autistic people (e.g., reducing stimming). On the other hand, identifying *acceptable* goals requires much more nuance and careful consideration. However, put quite simply: in order to ensure goals are delivered in a socially valid manner, professionals would benefit from adopting the neurodiversity perspective and embracing autism acceptance.

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Paper 3:

Developing & Validating the Neurodiversity Attitudes Questionnaire (NDAQ)

Abstract

Neurodiversity refers to the idea that all brains—no matter their differences—are normal, valuable, and should be accepted. Attitudes toward the neurodiversity perspective can have real-life impacts on the lives of neurodivergent people, such as those who are autistic or dyslexic or have ADHD. This includes effects on daily interactions and acceptance, as well as how clinical providers and educators deliver their services. In order to identify negative attitudes toward neurodiversity and potentially intervene to improve them, it is first necessary to develop an instrument to measure these attitudes. This paper describes the development and validation of such an instrument: the Neurodiversity Attitudes Questionnaire (NDAQ). Methods used to build the NDAQ's validity argument included theoretical work in defining the construct with a construct map, expert review, systematic evaluation of participants' response process, and fitting of NDAQ pilot data to the Rasch model to assess fit. Analysis of an initial pilot with 283 current and future helping professionals indicates that the NDAQ has good construct validity, is well understood by participants, and fits a multidimensional Rasch model with minimal misfit. While the NDAQ represents the first instrument designed to assess attitudes toward the broad idea of neurodiversity, further validation work is still needed.

Developing & Validating the Neurodiversity Attitudes Questionnaire (NDAQ)

People whose brains work differently than the “norm” often face stigma and prejudice from others. Such stigma and prejudice are precipitated in part by negative attitudes toward the minority group. When such negative attitudes are used to “other” a minoritized group, it can ultimately result in not just individual discrimination (someone treating someone else poorly due to negative stereotypes and “otherness”), but also structural discrimination (e.g., certain groups of people not getting hired for jobs or consistently unable to access proper healthcare) (Link & Phelan, 2001). For autistic people, stigma has been theoretically and empirically linked to decreased well-being and masking of autistic traits (Perry et al., 2021; Turnock et al., 2022). Other “neurominorities” (those whose neurology makes them a minority compared to the “standard” neurological makeup of the majority; Walker, 2014) also face a host of negative outcomes due to stigma and prejudice.

Helping professionals such as doctors, teachers, therapists, etc., are in a unique position to combat this stigma, both in terms of individual and structural discrimination. This is because many helping professionals interact directly with neurodivergent individuals but also have a say in the way systems are structured. For example, doctors may go into administration and enact hospital policies that affect neurodivergent people. Teachers are often charged with training preservice teachers, thus passing down their attitudes to the next generation of teachers. While it is helpful to understand helping professionals’ attitudes toward specific neurodivergent groups (e.g., people with ADHD or Tourette’s), we cannot be content knowing that professionals have sufficiently positive attitudes toward particular groups of people. It is thus important to look at the common denominator: attitudes toward neurodiversity overall, as these attitudes will permeate helping professionals’ work with *all* clients/patients/students, etc., regardless of neurotype.

Models of Disability & Neurodiversity

The predominant lens of viewing brain differences such as autism, intellectual disability, and attention deficit hyperactivity disorder (ADHD) is through the medical model of disease/disability. The medical model sees differences as abnormalities that need to be prevented, fixed, or cured (Marks, 1997). These issues are seen as being located *within* the disabled person, and it is thus the individual who is in need of remediation. For example, a person who exhibits hyperactivity may be prescribed medication to calm them down, or a person who does not speak may be enrolled in speech therapy. Widespread use of this model leads to particular attitudes amongst the public, for example seeing disability as something sad and shameful (Chapman, 2020a). On the other hand, an alternative view of disability, the social model, sees disability as being caused by one's social environment (Marks, 1997). In the social model, impairment (a loss of or an abnormal bodily or psychological function) is separated from disability (the problems one faces in society; Crow, 1996). A person is therefore not disabled due to a physical or psychological impairment—they are disabled to the extent that the world oppresses them due to a poor fit between their needs and the environment (den Houting, 2018). Thus, societal changes (for example, curb cuts, access to alternative communication devices, etc.) can have a "de-disabling" effect.

Both models of disability have strengths. The medical model has the potential to treat genuine medical issues that often co-occur with other diagnoses (for example, many autistic people complain of gut issues [Leader et al., 2022], which the medical model has the capacity to improve). The social model has had the effect of pushing the onus of disability off of individuals and onto society, which has led to more equal rights for disabled people in many cases (e.g., curb cuts, wheelchair ramps). However, both models also have weaknesses. As stated above, the medical model can induce shame and guilt and potentially lead to the identification of intervention targets that are seen as unacceptable by society but that do not actually cause harm (e.g., the medical model identified homosexuality a mental disorder until 1973; Drescher, 2015). On the other hand, the social model of disability can have the effect of ignoring disabled people's physical embodiment of their impairments. For example, individuals with chronic pain may feel disabled by both society (for being unaccommodating) *and* their own bodies (for being in pain) (Crow, 1996). Similarly, autistic people with severe sensory sensitivities may feel that society can never properly accommodate their needs no matter what accommodations are provided (Ballou, 2018).

The concept of neurodiversity presents an alternative to both models of disability (Dwyer, 2022). The term *neurodiversity,* coined by Judy Singer (1998) and popularized by Harvey Blume (1998), refers to the array of differences in human neurology (literally *neuro-diversity*). When Singer originally discussed the subject, it was within the context of highlighting how neurodiversity is similar to ecological diversity in that, firstly, humans have a variety of different brains, and secondly, that that variation is actually beneficial to our flourishing as species (1998). Currently, while neurodiversity can mean slightly different things to different people, most conceptualizations of neurodiversity contain these or similar core tenets: 1) neurodiversity is valuable to society; 2) there are no "normal" brains (see Chapman, 2020a for a discussion on how even statistical "normality" is defined differently depending on the definition of the population); and 3) differences in neurology are subject to the same social issues as other forms of diversity such as gender or race (Walker, 2014). Some steer clear of providing a definitive definition of neurodiversity, calling it a "moving target" (Chapman, 2020b, p. 291).

The neurodiversity model thus retains and rejects aspects of both the medical and social model. For example, most neurodiversity advocates are vehemently against "cures" for things like autism or ADHD, as they view them not as diseases but simply different neurotypes, akin to different genders. Neurodiversity proponents often thus promote acceptance of differences and environmental/societal accommodations as opposed to interventions targeted at changing individuals. This rejection of the medical model does not, however, imply that neurological differences themselves are *never* disabilities (see again Ballou, 2018). In fact, it sometimes might be worthwhile to intervene at the individual level (Dwyer, 2022).

Why Are Attitudes Toward Neurodiversity Important?

The neurodiversity approach is not simply a theoretical lens through which to view people whose brains work differently than the majority. It is also a practical concept that can drastically shift the way neurodivergent people interact with the world. In the words of Robert Chapman (2020b), an autistic researcher:

> A core function of the concept regards how it helps us imagine the world differently to how it currently is. For instance, it helps us to both reimagine pathologised and dehumanised kinds in a more humane and compassionate way and reimagine the world in a way that is less hostile to such kinds. In turn, by adopting a neurodiversity perspective, we can alter actual relations; the way from how we empathise with neurological others on a personal level, to how we design scientific experiments or public spaces. Similarly, within and between neurominorities, it helps us foster not just solidary and resistance, but also grounds the development of shared vocabularies for making sense of our experiences and increasing our understanding of both each other and ourselves. So what starts out first as something epistemically useful, translates into the generation of different social facts, and finally into real world change. (pp. 219-220)

This real-world change can take place at all levels of interactions: with friends and family, coworkers and acquaintances, strangers at a store or on social media, service providers, et cetera. These interactions can be greatly affected by one's attitude toward neurodiversity. For example, Kim & Gillespie-Lynch (2022) found that participants' endorsement of the neurodiversity movement was associated with less reported stigma toward autism. While all levels of interaction are important, service providers in particular have an ethical duty to treat their clients/patients humanely and with compassion. In fact, this is a core tenet of the ethical guidelines for many service providers (such as medical doctors [Orr et al., 1997], behavioral interventionists [Behavior Analyst Certification Board, 2020], and teachers [California Teachers Association, n.d.]). Adopting the neurodiversity perspective is a step toward ensuring helping professionals provide services that are truly supportive and accepting of their clients, as opposed to inadvertently contributing to stigma and prejudice. For example, by introducing families to neurodiversity immediately upon providing a diagnosis to a child, diagnosticians can ensure that families are aware of both the challenges *and* strengths that their child will experience (Brown et al., 2022). This approach, coupled with positivity and warmth (Anderberg & South, 2021) can reduce stress amongst parents and also increase the chance that their child feels accepted, which is what many autistic people call for (e.g., Sinclair, 1993; the authors in the *Sincerely, Your Autistic Child* anthology [Ballou et al., 2021]). Additionally, this early exposure to neurodiversity might open up avenues of identity for children that they otherwise might take a while to discover on their own (Dwyer, 2022).

With regard to education, embracing the neurodiversity perspective may lead educators to utilize a strengths-based approach. Armstrong (2012) details how educators can support neurodivergent students by figuring out what they are good at and what interests them and providing appropriate accommodations to flourish in those areas of interest. For example, if a student with ADHD fails to turn in homework, instead of giving detention, find out what their interests are and assign work that is more motivating. Learning about neurodiversity can also lead teachers to reduce deficit-thinking when it comes to their own students (Lambert et al., 2021), which can lead to richer educational experiences for disabled students. Viewing the neurodiversity approach positively can also lead to interventionists (such as behavioral, speech, or occupational therapists) creating more socially valid (i.e., acceptable, Wolf, 1978) programs (Fletcher-Watson, 2019; Schuck et al., 2021).

Measuring Attitudes Toward Neurodiversity

One's overarching attitude toward neurodiversity can be conceptualized as a latent variable (Borsboom, 2008)—that is, everybody has such an attitude (it's a *variable* part of everyone's world view), but it is *latent* because it is not something that can be readily observed (one cannot pull out a yardstick and measure one's attitude toward neurodiversity). Assessing one's attitude toward neurodiversity can be important insofar as one who is more favorable toward and understanding of the approach may be more likely to engage with neurodivergent individuals from this standpoint. Measuring such attitudes could also come in handy when identifying the need for or assessing the effectiveness of anti-stigma programs or professional development workshops on neurodiversity. Though multiple instruments have been designed regarding attitudes toward autism and other disabilities (for example, the Multidimensional Attitudes Scale Toward Persons with Disabilities [Findler et al., 2007]; the Autism Attitude Acceptance Scale [Kim, 2020]; the Scale for ADHD-specific attitudes [Mulholland, 2016]), measuring attitudes toward neurodiversity in general is still in its infancy. Even the recently developed *Neurodiversity Attitudes Scale* (VanDaalen, 2021) was designed such that all of the survey items are specifically about autism. This decision was justified in that much of the neurodiversity movement has been fueled by autism rights activists, but it nevertheless means that the survey is more about autism than it is about neurodiversity in general. A valid instrument to assess attitudes toward neurodiversity is thus needed.

Validity Theory

Tests—or surveys/questionnaires—will always generate results. However, results are not always meaningful. Therefore, it is necessary to ensure the test's validity—that is, "determine whether the instrument does in fact accomplish what it is supposed to accomplish" (Wilson, 2004, p. 155). Not long ago, the concept of validity was seen as multidimensional, with different *types* of validity including content validity (i.e. are the test items representative of the domain they are trying to assess?), criterion validity (i.e. are test scores predictive of a criterion variable, such as college success?), and convergent/divergent validity (i.e. the degree to which test scores correlate with other measures that are supposed to measure similar or different constructs; Markus & Borsboom, 2013). These were each seen as distinct "validities" and viewed as separate entities, each to be assessed individually. However, many now see these *types* of validity as subsumed under one overarching *validity*, and it is therefore now usually seen as a unitary concept (American Educational Research Association [AERA], American Psychological Association [APA], & National Council on Measurement in Education [NCME], 2014; Markus & Borsboom, 2013).

Accordingly, instead of assessing individual, distinct validities, one should gather different kinds of *evidence* for the validity of a given test (AERA, APA, & NCME, 2014; Wilson, 2004). Such evidence might include assessing the response process of those who take the test to ensure they are following the same logic as the test developer (e.g., Wolf et al., 2021), ensuring that the internal structure of the test is aligned with theory, looking at the relationships between test results and other variables, and assessing the consequences of instrument use (AERA, APA, & NCME, 2014; Wilson, 2004).

This evidence should be used to ensure that the test assesses as much of what it is supposed to assess as possible and as little of what it is not intended to assess, thus maximizing both construct representation (which happens when the test items are representative of the construct) and minimizing construct irrelevant variance (which happens when the test results are affected by an extraneous factor, such as socioeconomic status or race, when it is not supposed to) (Markus & Borsboom, 2013). Importantly, this kind of assessment of validity should be done for each context in which a test is going to be given. Different uses, interpretations, and theories can result in a different validity claim or argument (AERA, APA, & NCME, 2014; Markus & Borsboom, 2013). This is why the AERA, APA, and NCME define validity as "the degree to which evidence and theory support the interpretations of test scores for *proposed uses* of test" (p. 11; emphasis added).

Designing Measures

Wilson (2004) suggests four steps to designing measures: 1) definition and mapping of a construct (i.e. what is being measured and what is the expected spectrum of participant abilities/attitudes?); 2) designing items (i.e. what is the instrument actually asking participants?); 3) designing the outcome space (i.e. how are participant responses turned into a score?); and 4) choosing a measurement model (i.e. which statistical model will best allow us to learn about the utility of our instrument?). He suggests that engaging iteratively in this process will enable researchers to develop valid instruments.

Wilson's (2004) first step—defining and modeling a construct—is crucial. If the construct is not clearly defined, it will be impossible to create items that adequately assess it. This is also the case if you are unidimensionally modeling a construct that in reality is multidimensional (for example, an instrument to assess reading ability is simultaneously trying to assess comprehension, speed, and fluency). We know that neurodiversity itself is a complex topic; furthermore, *attitudes* themselves are complex. For example, should questionnaire items tap into individuals' *feelings toward* neurodivergent individuals? Or perhaps the items should ask about individuals' *knowledge of* neurodiversity from a biological standpoint? Or how they *act* when there are neurodivergent people around? All of these contribute to attitudes according to the Tripartite Model of Attitudes (Rosenberg & Hovland, 1960).

Measures of Attitudes Toward Disability Using the Tripartite Model of Attitudes

One way to address a broad, complex construct is to break the construct up into multiple dimensions. This is precisely what Findler and colleagues (2007) called for when they designed the Multidimensional Attitudes Scale Toward Persons with Disabilities (MAS), highlighting that prior research in this area generally conceptualized attitudes as unidimensional. To create their instrument, they designed items according to the tripartite model of attitudes. This model was originally put forth by Rosenberg & Hovland (1960) and elucidates three distinct dimensions of attitudes: affect, cognition, and behavior. The affective domain is concerned with how people *feel* toward something; the cognitive domain is concerned with what people *believe* about something (though it could also refer to *knowledge* of something; Eagly & Chaiken, 1993); and the behavioral domain is concerned with how people *act* in response to something. Rosenberg and Hovland (1960) argue that it is important to attend to all three dimensions if one wants to understand how attitude change happens. Furthermore, if one is to look at how emotions, beliefs, and behaviors are related to one another, then it is necessary to measure them separately. This model seems highly applicable to the study of attitudes toward neurodiversity, as individuals' feelings, thoughts, and behaviors about disabled persons may not always be aligned. For example, one may abstractly *believe* that disabled individuals have a right to accommodations, but then get *upset* when they see a person receiving such accommodations since they view it as a form of cheating.

Multiple multidimensional instruments regarding attitudes toward disability have been developed. For example, when developing the MAS, Findler and colleagues (2007) presented 132 non-disabled individuals with a vignette about a non-disabled person encountering a wheelchair user and asked participants questions about how they think the non-disabled person would *feel* in the situation (affective component), what they might *think* (cognitive component), and what they might *do* (behavioral component). The degree of likelihood of each feeling, thought, and action was rated on a scale from 1-5. Principal component analysis (PCA) confirmed the presence of three distinct factors corresponding to affect, cognition, and behavior. Similarly, recognizing that prior instruments regarding attitudes toward intellectual disability were mostly unidimensional, Morin and colleagues (2013) designed an instrument to multidimensionally assess such attitudes. Exploratory factor analysis of data from 1605 participants revealed a five-factor structure after removing misfitting items. These five factors were labeled discomfort, knowledge of capacity and rights, interaction, sensitivity and tenderness, and knowledge of causes. Though this questionnaire was designed with the tripartite model of attitudes in mind, the authors argue that the five factors still map onto the cognitive, affective, and behavioral components of attitudes, in that the cognitive dimension is represented by the two knowledge factors and the affective dimension is represented by the discomfort and sensitivity factors.

Several autism-specific instruments have been developed as well. For example, the Children's Attitudes Toward Autism Questionnaire (CATAQ; Derguy et al., 2021) was designed specifically for use in school-age children, as most measures looking at attitudes toward disability/autism were geared toward adults. The CATAQ has 24 items (three in each attitudinal domain); each item has five answer choices ranging from *No, strongly disagree* to *Yes, strongly agree* (schematic faces were also used [e.g., a large frown for "strongly disagree"]). After giving the instrument to 204 6-11-year-olds, the three-factor structure was confirmed using confirmatory factor analysis. Kim (2020) also used the tripartite model of attitudes to develop the Autism Attitude Acceptance Scale (AAAS). After piloting with 129 adults, PCA did not confirm the three-factor structure; after removing items that did not meet statistical criteria (and were potentially worded poorly), a two-factor structure emerged. These factors were named General Acceptance and Attitudes Toward Treating Autistic Behaviors. Only three items loaded onto the latter factor, and the author notes that more items to assess this factor are likely needed.

While the tridimensional model of attitudes was not necessarily confirmed in all studies, all of these instruments show how the tripartite model can be a starting point to developing a multidimensional instrument to measure attitudes. It is also possible that the three factors were not confirmed in some of the aforementioned studies because of the tools used to validate the measures (e.g., factor analysis or PCA). While these can be useful tools, they should not necessarily be taken as evidence of validation of a particular factor structure, at least not by themselves (see Maul, 2017 for a discussion of how factor analysis can be used to “validate” a measure full of meaningless items). In the current investigation, the Rasch model (1960/1980) will be used instead of factor analysis or PCA. One reason the Rasch model can be seen as preferable to factor analysis or PCA is that it takes into account differences in item difficulties, as opposed to assuming each item is equally likely to be endorsed by participants. Additionally, the Rasch model also estimates person abilities on the same scale (i.e., logits) as item difficulties, such that person ability and item difficulty can be directly compared. Another strength of the Rasch model is that it uses ordinal-level data. Though most questionnaires do indeed collect data that is ordinal (e.g., Likert-type scale answer choices such as “slightly agree” or “slightly disagree” or answers such as “sometimes” or “always” indicating frequency), such ordinal-level variables must be converted to an interval scale in order to use factor analysis or PCA (for example, assigning a “1” to strongly disagree, “2” to disagree, and so on). With the Rasch model, this assumption that ordinal-level variables can be treated as interval-level is not necessary. This is because it is not the instrument answer choices that are treated as an interval scale, but the probabilities of successfully answering a question given the item difficulty and person ability (Bond & Fox, 2015).

Current Study

The current study attempted to develop and validate an instrument to assess attitudes toward neurodiversity: the Neurodiversity Attitudes Questionnaire (NDAQ). The following goals relate to the validity argument of the NDAQ:

1. The content of the instrument will contain items that are representative of individuals’ attitudes toward neurodiversity.
2. Participants will understand the instrument items and answer items using

similar logic.

3. The NDAQ items will be well targeted toward helping professionals.
4. The internal structure of the instrument will be multidimensional, with items fitting a multidimensional Rasch model with minimal misfit.
5. Participants' scores on the NDAQ will correlate with scores on instruments designed to assess knowledge and attitudes toward neurodivergent diagnoses such as autism, ADHD, and dyslexia.

Method

This study was approved by the UCSB IRB. Participants in all phases of the study provided informed consent before completing any study activities.

Measure Development

All steps of this study are based on Wilson's (2004) four-step approach to designing and validating measures. These steps include: 1) definition and mapping of a construct; 2) designing items; 3) designing the outcome space; and 4) choosing a measurement model. In terms of step 1 (defining the construct), attitudes toward neurodiversity were conceptualized as a *multidimensional* construct as opposed to a unidimensional one. Such multidimensionality was suggested by several researchers who have designed instruments to measure disability-specific attitudes in the past (e.g., Derguy et al., 2021; Findler et al., 2007). Therefore, the tripartite model of attitudes (Rosenberg & Hovland, 1960) was used to conceptualize the construct and develop items. Initial items in each of the three domains (affective, cognitive, and behavioral) were brainstormed by the author and three graduate student colleagues based on prior review of both academic literature and first-person accounts of neurodiversity (e.g., blogs and social media posts, and in the case of two colleagues, lived experience of being autistic or having an autistic child). Items consisted of statements that could then be answered using agree-disagree Likert-type answer choices. Once an initial set of items was completed, three methods of refining items were employed iteratively: 1) expert review; 2) cognitive interviews; and 3) systematic evaluation of participants' written response process. An overview of this process can be found in Table 1.

Table 1

Outline of Feedback Sought During Measure Development

	Expert Review	**RPE**	**Cognitive Interviews**
Pre-RPE	Professor of Education (Disability Studies Expertise) Professor of Education (Measurement Expertise)		
RPE Phase 1 Feedback	Research Fellow in Education (Inclusion Expertise)	103 undergraduates each saw 12 of the 31 items and provided feedback.	1 autistic individual and 2 individuals with ADHD provided feedback on all items
RPE Phase 2 Feedback		51 undergraduates each saw 12 of 15 revised/new items and provided feedback.	
RPE Phase 3 Feedback		38 undergraduates each saw 7 of 7 revised/new items and provided feedback.	
RPE Phase 4 Feedback		50 undergraduates each saw 8 of 8 revised/new items and provided feedback.	

Expert Review

Prior to implementation of the RPE method, three expert reviewers reviewed our initial items. Experts included a professor of education with expertise in neurodiversity, a professor of education with expertise in measurement, and a research fellow in education with expertise in inclusive education. Experts were either shown the items during a Zoom meeting or emailed the items. Feedback included potential wording changes and potential new items.

Cognitive Interviews

Cognitive interviews (Wills, 2004) were conducted with three neurodivergent individuals (two with ADHD, one autistic) to ensure items were understandable and accurately capturing issues related to neurodiversity. Cognitive interviews took place via Zoom or via email and were conducted by the author. During Zoom interviews, the author shared her screen to show each item. The participant was asked to describe what they thought about the item, whether it made sense, and how they would answer it. Participants were also asked at the end of the interview whether they felt anything related to neurodiversity was missing. Participants who preferred to participate via email were sent the items in a word document and asked to provide the same feedback.

Response Process Evaluation

In order to more systematically understand how potential participants were interpreting the questionnaire items, a process inspired by Wolf et al.’s (2021) response process evaluation (RPE) technique was used. This process essentially moves the cognitive interview process into a questionnaire so that a large number of participants can provide feedback in a less time- and resource-demanding way. It consists of participants answering survey items, answering meta-questions about the items, and review of responses by the research team in order to assess understanding. Items that are not understood are revised and more feedback is sought until the items are judged as being adequately understood and answerable.

Participants. Participants in the RPE portion of the study were all undergraduate students who were part of a research participant pool through the Communication department at a large university. Participants took the survey via Qualtrics for course credit. Though this undergraduate population does not exactly fit the population of interest for the NDAQ (i.e., helping professionals), we felt that these students would be representative of individuals going into a wide range of helping professions. Of the 190 students whose responses were reviewed, 11 indicated they identified as disabled; however, it is likely that the number of RPE participants with a diagnosis that falls under the umbrella of neurodiversity is higher, as at least 11 other participants mentioned having ADHD in open-ended responses but did not check "yes" to identifying as disabled.

Procedure. The RPE took place in four rounds. During each round, participants were randomly assigned no more than 12 items to respond to. Participants were asked to respond to the item and the following two meta-questions to assess their response process: 1) What do you think [insert item] means? 2) Why did you choose the answer you did? After roughly 25-40 participants responded to each question, responses were assessed. Each response was rated as *definitely* understanding, *likely* understanding, or *not* understanding the item. All ratings were made by the author, and judgements were made based on the following criteria: 1) do participants explain the item in the way we intended? 2) do their answer choices align with their explanation? Usually, if at least 90% of participants were rated as definitely understanding an item, the item was determined to be "final" and was not included in the next round of RPE. Items that were rated as being definitely understood by 80-90% of participants were considered finalized if at least 90% of participants completely and/or likely understood the item. A few items met criteria for being definitely understood but participants' responses indicated that the item still needed revision (e.g., everyone chose "strongly disagree" and provided feedback that item wording was offensive or silly). After each round of rating the items, the research team met to discuss the feedback and brainstorm revisions and/or new items. Revised items would then be entered into Qualtrics for the next round of RPE. When we started RPE, our initial set of items used a 5-point Likert scale (strongly disagree, disagree, neutral, agree, strongly agree), but after data was reviewed, it was decided to use a 6-point scale (with slightly disagree and slightly agree instead of neutral), as some participants were choosing "neutral" for various different, non-systematic reasons. After the fourth and final round of RPE, the NDAQ consisted of 29 items, which can be found in Figure 1.

Figure 1

Neurodiversity Attitudes Questionnaire Pilot Items

<u>All items have the following answer choices:</u>

strongly disagree -- disagree -- slightly disagree -- slightly agree -- agree -- strongly agree

<u>Cognitive Domain</u>

1. Neurodivergent people should learn social skills in order to fit in with their peers*
2. It is important for non-neurodivergent people ("neurotypical" people) to learn to better interact with neurodivergent people.
3. There is no such thing as a "normal" brain
4. Neurodivergence (brain differences such as autism, ADHD, intellectual disability, etc.) contributes to diversity just as do race and gender
5. I believe people should have access to any accommodations that they need to be successful at work (such as getting an extension on a deadline, allowing for sensory-friendly workspaces, etc.)
6. I believe that neurodivergent people's brains work differently because they have inherent defects in their brains*
7. Terms like 'low-functioning', 'high-functioning', 'severe', 'mild' can be a useful way of describing neurodivergent people*

8. Neurodivergent people shouldn't work in jobs that could require them to make life-or-death decisions (e.g., medical doctor, airplane pilot)*
9. If a neurodivergent person becomes aggressive towards others at school, physically restraining them is a good option*
10. Some neurodivergent people have such serious challenges that they should live in institutions*
11. Neurodivergent students have a right to be included in general education classrooms along with their neurotypical peers
12. If people with ADHD work really hard, I think a lot of their difficulty focusing will go away*
13. Neurodivergent children should take medication to help them focus at school*
14. Many of the challenges neurodivergent people face are due to society not being accommodating to them
15. Spoken language should be prioritized over other forms of communication when teaching neurodivergent children to communicate*

Affective Domain

1. I would feel uneasy if someone stopped a person from flapping their hands
2. I would like to have the opportunity to work with neurodivergent people so that I can learn from them
3. I feel angry when people talk about finding a cure for autism
4. I feel frustrated when I think about the ways in which neurodivergent people are discriminated against
5. I would be embarrassed to admit if I had a learning disability, such as dyslexia*
6. I'm concerned that neurodivergent adults with guardians or conservators (i.e., people who make legal and/or financial decisions on their behalf) might get taken advantage of.

Behavioral Domain

1. I would be friends with a neurodivergent person
2. If someone uses a different kind of speech than I do (such as typing on a keyboard, using a speech-generating device, picture cards etc.), I would be less likely to try to communicate with them*
3. I seek out opportunities to learn more about neurodivergent people through first-person accounts (e.g., social media, books, blogs, podcasts, etc. by neurodivergent people)
4. At work, I would be willing to take direction from or be supervised by a neurodivergent person
5. I can see myself dating a neurodivergent person
6. I support organizations that want to find a cure for autism*
7. I prefer to listen to neurodivergent people's perspectives on their brain differences, as opposed to other stakeholders', such as parents or researchers
8. I spend time thinking about how to make things more sensory-friendly for neurodivergent people

Note. Items with an asterisk (*) indicate that this item was reverse-scored, such that *not* agreeing is consistent with a positive attitude toward neurodiversity.

The results of the RPE supported goal #2 of the study: Participants will understand the instrument items and answer items using similar logic.

Pilot Testing

Pilot testing was completed with a sample of helping professionals or individuals who planned to go into a helping profession. Data was then compared to the Rasch model to assess the NDAQ's fit as a unidimensional or multidimensional measure of attitudes toward neurodiversity.

Participants

All participants met the following inclusion criteria: 1) at least 18 years of age; 2) currently working or planning to work as a helping professional; and 3) able to read and type in English. "Helping professionals" was defined broadly as anyone involved in the fields of Education (e.g., professor, teacher, class aide, paraprofessional), Medicine (e.g., physician, nurse, medical assistant, physician assistant, physical therapist), or other therapy (e.g., psychologist, therapist/counselor, BCBA, occupational therapist, speech therapist, social worker).

Participants were recruited via one of two routes: 1) through a university undergraduate research participant pool hosted in the Communication department, or 2) online via listservs or social media outlets (e.g., Facebook, Twitter, Reddit, etc.). Undergraduate participants received course credit for participating. All other participants who were recruited online were given the opportunity to enter into a drawing to win one of 20 $15 e-gift cards for participating.

The total sample included 191 undergraduate participants and 92 online participants. Online participants were significantly older than undergraduate participants (31.97 years old on average versus 19.81, *t*(91.86) = -11.91, *p* < .001). The two groups also endorsed significantly different familiarities with neurodiversity: χ2(3) = 98.74, *p* < .001, with the online group endorsing more familiarity (only 5.4% of online participants endorsed being "not at all familiar" with neurodiversity, as opposed to 35% of undergraduates; 40% of online participants endorsed being "extremely familiar" as opposed to 3% of undergraduates). Though the two groups differed on these variables, the two groups were conceptualized as simply a more and a less experienced portion of the same population (helping professionals). Even if their age or familiarity with neurodiversity impacted their attitudes, this could be explained by the construct itself (i.e., more experience working in the field can affect attitudes) and was not necessarily seen as problematic. Undergraduates and online participants were thus combined into one large sample. The total sample thus included 283 participants; see Table 2 for full demographic information. Of note, the sample was predominantly female (81.3%). Non-White participants made up just over half of the sample, and almost a quarter identified as neurodivergent and 11.7% identified as disabled. Anxiety and depression were the most common diagnoses reported (51.6% and 33.9% of the sample, respectively). The three most common developmental/learning disabilities were ADHD (25.1%), autism (3.9%), and sensory processing disorder (3.2%).

Online participants (n=92) were asked what their current occupation was, or if they were still in school, what their future occupation would be. Answers were coded into medicine/mental health, education, professor, and other. Most (n = 66, 71.7%) were in the medical/mental health field (e.g., physicians, nurses, speech or occupational therapists, psychologists, BCBAs, etc.); 22 (23.9%) were in the education field. Eight individuals indicated they were currently professors and did not indicate any other clinical occupations (one participant indicated they were still in school but planned to be a professor). An additional four participants were involved in other fields (e.g., as a research coordinator, neurology graduate student). Five participants who were coded as being in medicine or education also indicated they were professors. One person did not answer the occupation question.

The undergraduate participants (n=191) were asked a similar question, but since they were all still in college, they were asked what occupation they thought they might want to do in the future. Most (n=132, 69.1%) indicated they wanted to be in the medical/mental health field and 56 (29.3%) wanted to go into the education field (note that some participants wanted to go into both/either fields and are thus counted twice). Eight undergraduate participants indicated they wanted to be professors without indicating any additional clinical focus; another 15 indicated they wanted to be a professor in addition to the clinical/educational field.

Table 2

Demographic Information

Demographic Group	N (%)
Gender	
Male	47 (16.6%)
Female	230 (81.3%)
Non-binary	6 (2.1%)
Ethnicity	
Asian/Pacific Islander	72 (25.4%)
White	132 (46.6%)
Hispanic	41 (14.5%)
Black	5 (1.8%)
Middle Eastern	6 (2.1%)
Mixed	21 (7.4%)
Not Stated	4 (1.4%)
Identify as Neurodivergent	
Yes	69 (24.4%)
No	105 (37.1%)
Not sure	109 (38.5%)
Identify as Disabled	
Yes	33 (11.7%)
No	232 (82.0%)
Not sure	18 (6.4%)
Diagnosis/Self-Identification	
Autism	11 (3.9%)
ADHD	71 (25.1%)
Sensory Processing Disorder	9 (3.2%)
Tourette's	2 (0.7%)
Intellectual Disability	0 (0.0%)
Dyslexia	6 (2.1%)
Dyscalculia	5 (1.8%)
Dysgraphia	0 (0.0%)
Anxiety	146 (51.6%)
Depression	96 (33.9%)
OCD	27 (9.5%)
Schizophrenia	0 (0.0%)
Bipolar Disorder	13 (4.6%)
Personality Disorder	2 (0.7%)
Epilepsy	1 (0.4%)
Other Psychiatric	5 (1.8%)

Other Learning Disability	3 (1.1%)

Note. Individuals who identified as mixed race were only counted in the “mixed” category; they were not added to all of the categories they endorsed.

Measures

Participants first answered demographic questions (i.e., gender, ethnicity, location, occupation) and then were presented with questions about neurodiversity. Participants were asked about their familiarity with neurodiversity (not at all, slightly, moderately, or extremely; see Burkhart, 2019 for a similar question), whether they identify as neurodivergent/neurodiverse and/or disabled and any diagnoses they have, whether any other contacts in their life have any diagnoses that might be considered under the umbrella of neurodiversity, and whether they have experience working with disabled individuals, and if so, in what capacity. Participants were also asked the open-ended question, “What do you think ‘neurodiversity’ means?” Participants were then presented with the Neurodiversity Attitudes Questionnaire (NDAQ) as well as other questionnaires designed to assess attitudes and knowledge about neurodiverse diagnoses.

Neurodiversity Attitudes Questionnaire (NDAQ). The pilot post-RPE version of the NDAQ consisted of 29 items (see Figure 1). All questions were in the form of a statement, and participants were asked the degree to which they agreed with the statement using a 6-point Likert scale. See above for details about the NDAQ development.

Social Distance Scale (SDS). Gillespie-Lynch et al.’s (2021) adaptation of Bogardus’ (1933) SDS was used to assess participants’ willingness to interact and engage with populations who might be stigmatized. Three SDSs were used: one about autistic people, one about people with ADHD, and one about dyslexic people. Each SDS included 10 items. Items were rated on a scale of -2 to 2, with higher scores indicating more stigma.

Participatory Autism Knowledge Measure (PAK-M). The PAK-M (Gillespie-Lynch et al., 2021) is a 29-item instrument designed to assess autism knowledge. Its recent updates include questions about masking/camouflaging and updated diagnostic criteria. Items were rated on a scale of -2 to 2, with higher scores indicating more knowledge.

Scale of ADHD-specific Knowledge (SASK). The SASK (Mulholland, 2016) is a 20-item instrument designed to assess knowledge of ADHD. Though the original SASK items were designed as true/false questions, it was decided to use the SDS' and PAK-M's answer choices (5-point Likert scale including strongly disagree, somewhat disagree, neither agree/disagree, somewhat agree, strongly agree) and scoring system (-2 to 2).

Dyslexia Knowledge Scale. Gonzalez's (2020) 10-item instrument is designed to assess understanding of dyslexia. Though the original instrument's answer choices included Definitely True, Probably True, Probably False, and Definitely False, it was decided to use the SDS' and PAK-M's answer choices (5-point Likert scale including strongly disagree, somewhat disagree, neither agree/disagree, somewhat agree, strongly agree) and scoring system (-2 to 2).

Though the SDS, PAK-M, SASK, and dyslexia knowledge scale all use summation scores, average scores are used in this study to account for the possibility of missing data (e.g., if someone skipped a PAK-M question, their summed score would be artificially lower than their average score). While an instruments' validity comes into question when answer choices and scoring is changed, it was thus decided that the impact in this study would be negligible, given that these instruments were only being used as evidence of convergence of similar measures.

Data Integrity

As with any study conducted entirely online—especially one with even a modest monetary incentive—there is a risk that some data may not be accurate. This could stem from actual humans who participate without reading the questions or from computer generated bots. Several procedures were used to ensure data integrity (Yarrish et al., 2019; Teitcher et al., 2015): 1) questions were embedded within the survey designed to be too hard for bots to answer (e.g., a question that included a long paragraph of text, in the middle of which participants were told to choose a particular answer choice; a question asking participants to spell the researcher's name backwards after being provided with the correct spelling); 2) inclusion of survey answer choices that were nonsensical (e.g., the options "intentionally blank" and "all of the above" as diagnosis options to the question about whether personal contacts were neurodivergent); 3) reviewing open-ended responses in order to identify identical (and sometimes nonsensical) phrases likely generated by bots (e.g., "Everyone is equal and helps us accept them better"; "To understand what people think and know about neurotransmitters"); 4) open-ended responses that indicate lack of attention (e.g., "afds"); and 5) suspicious answer choice patterns (e.g., "strongly agree" to all questionnaire items). The first three criteria applied only to online data susceptible to bots. The last two applied to all data. The author reviewed all survey responses using the first four criteria and coded responses as *authentic*, *inauthentic,* and *unsure*. Responses that were coded as *unsure* were reviewed using the fifth criterion (suspicious answer choices). An undergraduate research assistant double coded responses for data integrity; discrepancies were resolved by the author.

Data Analysis

The Rasch model (Rasch, 1960/1980) was used to evaluate certain properties of the

NDAQ. A rating scale model was used, as the answer choices are polytomous with the same number of categories and the same six response options, and there is no reason to believe that the answer choice difficulty thresholds should vary for different items (Andrich, 1978). The typical unidimensional Rasch model assumes that 1) items measure a unidimensional construct, 2) observations are independent from one another, and 3) the relationship between individuals' "abilities" (or, in this case, the intensity of an individual's attitude) and the difficulty of the items (in this case, how hard it is for individuals to endorse the item) do not change for different subsets of individuals or items. Because the NDAQ was designed with three components of attitudes (affective, behavioral, and cognitive) in mind, the data was first fit to a multidimensional Rasch model (using the Multidimensional Random Coefficient Multinomial Logit (MRCML) model; Briggs & Wilson, 2003), which allows for a relaxation of the unidimensionality rule. The fit statistics from the multidimensional model were compared to the data fit to a unidimensional Rasch model, as it is possible that the affective-cognitive-behavioral model of attitudes is useful for item creation, but the underlying construct is still best understood as unidimensional. These two models were compared using the $\chi 2$ difference test as well as comparison of the parsimony-adjusted Akaike Information Criterion (AIC) and the Bayesian Information Criterion (BIC). Generally, the model with the smaller AIC/BIC is preferable. These fit indices, along with consideration of theoretical and practical implications, were assessed to determine which model (unidimensional or multidimensional) was best.

Next, model and item- and person-level fit was assessed with the following tools:

1. Infit and outfit mean square statistics (MNSQs) for individual items. MNSQs help identify any persons or items that seem to be behaving unusually (e.g., if an

item's pattern of endorsement does not fit with the rest of the items such that items perform too "erratically" or too "perfectly" according to the model). For rating scales, according to Bond and Fox (2015), reasonable MNSQs range from 0.75-1.3 (the acceptable range is slightly larger for Likert-type surveys: 0.6-1.4), though the guidelines differ depending on sample size (Wu & Adams, 2013).

2. The frequencies of each answer choice for each item were reviewed if an item appeared to misfit. This could reveal whether some answer choices were especially not likely to be chosen for certain items.

3. A Wright map (a figure that displays the relationships between item difficulties and person abilities–or again, in the current context, difficulty to endorse the item and the intensity of a person's attitude) and item difficulties were used to evaluate whether the NDAQ items provided an adequate range of potential attitudes. The Wright Map was also assessed to determine whether the data was in line with the theoretical underpinnings of the items (e.g., were some items unexpectedly easier or harder to endorse than anticipated?).

4. Standard error of measurement (SEM) and person separation reliability (using Weighted Likelihood Estimation [WLE]) were reviewed for each dimension. The SEM is a plot used to look at the amount of standard error in ability estimates for each person ability. WLE is used to gauge the degree to which persons can be differentiated by the instrument and is analogous to Cronbach's alpha. The SEM and WLE can help assess whether an instrument is well targeted to the sample.

Spearman correlation coefficients between NDAQ person abilities and the other measures were also used to help build the validity argument. Specifically, it was hypothesized that those with less stigma and more knowledge of autism, ADHD, and dyslexia would score higher on the NDAQ. It was also hypothesized that those who had more familiarity with neurodiversity (e.g., indicated greater familiarity on the item "How familiar are you with neurodiversity?" would also score higher on the NDAQ.

All data analysis was done in R (R Core Team, 2022). Rasch analysis was conducted using the Test Analysis Module package (TAM; Robitzsch et al., 2017).

Results

Dimensionality

The first analytical step was to assess whether the NDAQ data better fit a unidimensional or multidimensional Rasch model. The $\chi2$ difference test, AIC, and BIC for both models were assessed and compared. According to the $\chi2$ difference test, the multidimensional model fit significantly better than the unidimensional model ($\chi2(5) = 51.71$, $p < .001$). The AIC, BIC, and AIC corrected for small sample size (AICc) were all lower for the multidimensional model compared to the unidimensional model, indicative of better fit for the former (see Table 3). It should be noted that, in general, multidimensional models tend to fit better than unidimensional models, as they have more parameters to work with. However, this also means there is a risk of the model overfitting the data, meaning that the model gets closer to simply replicating the data (and is no longer really a "model"). Therefore, determination of dimensionality should be made on the basis of both fit statistics and theoretical/practical considerations.

It was thus decided to treat the NDAQ as multidimensional. Because it is theorized that people may have different domains of attitudes (i.e., affective, behavioral, cognitive) toward neurodiversity, it is possible that an individual is high in one but low in another. If the purpose of the NDAQ is to highlight potential training needs, it is important to know whether someone is particularly low in a specific attitudinal dimension. For example, someone who exhibits high affective and behavioral yet low cognitive attitudes might benefit from a different training than someone who exhibits high affective and cognitive yet low behavioral attitudes. Similarly, only looking at overall attitude scores may miss certain individual variations (see Jones, 2022 for a discussion of how an overall score indicating a "positive attitude" does not mean that the person has a positive attitude across the board). Therefore, because both the fit statistics and the theoretical/practical justification pointed toward the NDAQ being multidimensional, it was therefore decided to treat it as such for the rest of the analyses.

Table 3

Comparison of NDAQ Data Fit to Unidimensional and Multidimensional Rasch Models

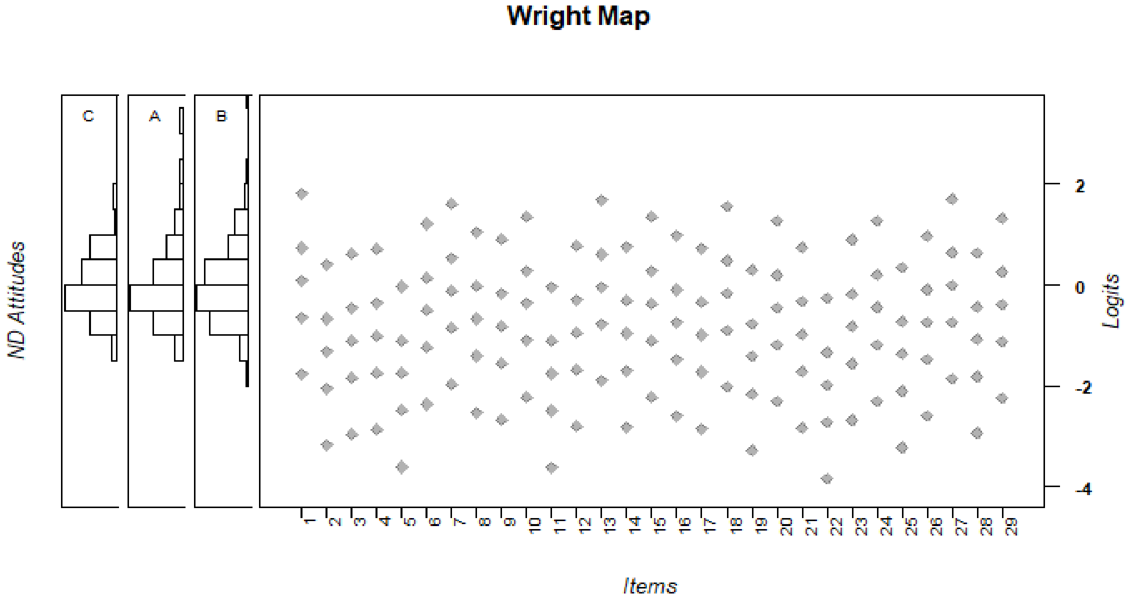
Model	deviance	AIC	BIC	AICc
Unidimensional	22594.17	22662.17	22786.11	22671.77
Multidimensional	22542.46	22620.46	22762.63	22633.30

Are Participants Well Targeted by the NDAQ?

Analysis of the Wright Map (Figure 2) indicates that the NDAQ items are on the easy side for this sample. That is, most participants' abilities are higher than the difficulty level of the questions. This can be seen by the fact that the distribution of participants across all three dimensions (affective, behavioral, and cognitive) is skewed toward positive logits, meaning that participants of average ability found it easier to endorse positive as opposed to negative attitudes.

Figure 2

Wright Map of the NDAQ Fit to a Multidimensional Rasch Model



The item difficulties (Table 4) also show that the items are fairly easy, given that all except one are negative logits (meaning that a participant of average "attitude toward neurodiversity"—i.e., ability at the mean of 0 logits–has a greater than 50% chance of endorsing a positive attitude in response to all but the first item).

Table 4

NDAQ Item Means & Difficulties

Item	M	Item Difficulty (Logits)	Item	M	Item Difficulty (Logits)
1	2.418	0.047	**16**	3.417	-0.786
2	3.986	-1.36	**17**	3.676	-1.033

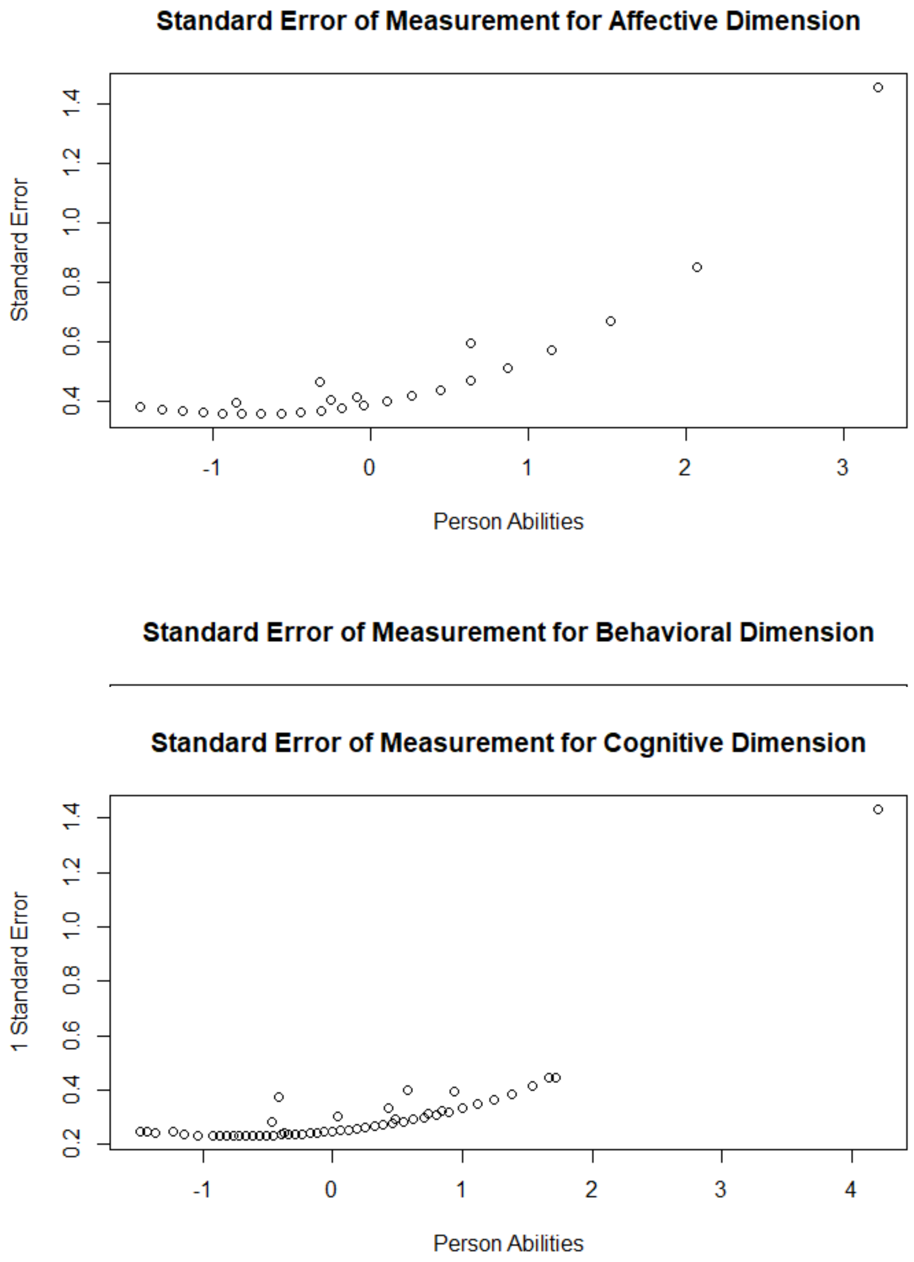
3	3.807	-1.149	**18**	2.745	-0.211
4	3.701	-1.055	**19**	4.057	-1.464
5	4.298	-1.793	**20**	3.09	-0.5
6	3.157	-0.549	**21**	3.671	-1.023
7	2.676	-0.158	**22**	4.414	-2.028
8	3.351	-0.714	**23**	3.507	-0.869
9	3.514	-0.862	**24**	3.086	-0.493
10	2.989	-0.407	**25**	4.011	-1.414
11	4.301	-1.801	**26**	3.42	-0.788
12	3.645	-0.991	**27**	2.56	-0.054
13	2.574	-0.081	**28**	3.763	-1.127
14	3.659	-1.005	**29**	3.022	-0.438
15	2.996	-0.416			

Note. Item means are out of 5, as the six answer choices were coded from 0-5.

The standard error of measurement (SEM) for each dimension was also used to assess whether the items were adequately targeting the sample (Figure 3). The standard error was relatively low for most participants, with the smallest standard error (and thus greatest certainty) for participants with attitudes below average. There was increasingly more uncertainty in measurement for those with greater ability (i.e., more positive attitudes toward neurodiversity), likely reflecting that there need to be more items that are more difficult to endorse for those with higher ability. As it stands, the NDAQ is better at measuring attitudes amongst those with more negative as opposed to more positive attitudes across all dimensions.

Figure 3

Standard Error of Measurement for NDAQ Dimensions



The estimated person separation reliability (WLE) for the three domains was as follows: affective: 0.67; behavioral: 0.76; cognitive: 0.81.

Item Fit Statistics

Infit and outfit mean square statistics (MNSQs) are presented in Table 5. For the sake of identifying potentially misfitting items, infit was primarily assessed, as it is information-weighted and thus less sensitive to outliers. The infit MNSQ for 8 items indicated statistically significant misfit (Table 6 includes these eight items). Three items were overfitting, suggesting that the response pattern was perhaps "too regular" for these items. The remaining five items underfit, suggesting that the response pattern for these items was highly irregular. Though statistically significant, the MNSQ for two items was still within the generally accepted guidelines of .75-1.30 (i.e., item 7 MNSQ = 1.21 (*t* = 2.60, *p* = .01); item 20 MNSQ = 1.28 (*t* = 3.28, *p* = .001)). Nonetheless, all eight of these items were further assessed to understand whether they should be revised, removed, or kept as is.

Table 5

Item Fit Statistics

Item	Outfit	Outfit *t*	Outfit *p*	Infit	Infit *t*	Infit *p*
1	0.99	-0.16	0.87	0.99	-0.13	0.90
2	**1.48**	**4.65**	**<.001**	**1.31**	**3.16**	**.002**
3	1.14	1.55	0.12	1.08	0.95	0.34
4	1.08	1.01	0.31	1.05	0.66	0.51
5	1.12	1.15	0.25	1.07	0.76	0.45
6	1.06	0.75	0.45	1.04	0.58	0.56
7	**1.20**	**2.53**	**0.01**	**1.21**	**2.60**	**0.01**
8	0.92	-0.97	0.33	0.94	-0.79	0.43
9	0.97	-0.36	0.72	0.95	-0.66	0.51
10	1.19	2.32	0.02	1.14	1.79	0.07
11	0.88	-1.20	0.23	0.91	-0.90	0.37
12	**1.30**	**3.38**	**<.001**	**1.31**	**3.47**	**<.001**
13	0.92	-1.11	0.27	0.89	-1.51	0.13
14	**0.73**	**-3.56**	**<.001**	**0.71**	**-3.90**	**<.001**
15	0.94	-0.76	0.45	0.95	-0.69	0.49
16	0.94	-0.79	0.43	0.90	-1.33	0.18
17	**0.83**	**-2.08**	**0.04**	**0.72**	**-3.67**	**<.001**
18	1.09	1.15	0.25	1.09	1.22	0.22
19	0.78	-2.52	0.01	0.83	-1.92	0.05
20	**1.30**	**3.59**	**<.001**	**1.28**	**3.28**	**.001**
21	1.15	1.68	0.09	1.06	0.68	0.50

22	0.97	-0.30	0.77	0.89	-0.98	0.33
23	0.92	-1.00	0.32	0.90	-1.19	0.23
24	0.96	-0.50	0.62	0.96	-0.56	0.58
25	**0.63**	**-4.64**	**<.001**	**0.66**	**-4.21**	**<.001**
26	0.91	-1.11	0.27	0.93	-0.88	0.38
27	**1.33**	**3.86**	**<.001**	**1.33**	**3.90**	**<.001**
28	0.95	-0.54	0.59	0.91	-1.01	0.31
29	1.14	1.74	0.08	1.13	1.63	0.10

Note. Bolded rows indicate items with statistically significant misfit according to infit MNSQ.

Table 6

NDAQ Items with Statistically Significant Misfit

Item	Misfit Type (Overfit/Underfit)	Decision
2. It is important for non-neurodivergent people (“neurotypical” people) to learn to better interact with neurodivergent people.	Underfit	Remove
7. Terms like 'low-functioning', 'high-functioning', 'severe', 'mild' can be a useful way of describing neurodivergent people*	Underfit	Keep
12. If people with ADHD work really hard, I think a lot of their difficulty focusing will go away*	Underfit	Remove
14. Many of the challenges neurodivergent people face are due to society not being accommodating to them	Overfit	Keep
17. I would like to have the opportunity to work with neurodivergent people so that I can learn from them	Overfit	Remove
20. I would be embarrassed to admit if I had a learning disability, such as dyslexia*	Underfit	Remove
25. At work, I would be willing to take direction from or be supervised by a neurodivergent person	Overfit	Keep
27. I support organizations that want to find a cure for autism*	Underfit	Keep

Note. Misfit determined by infit MNSQ. *Item was reverse scored such that a higher score indicated a more positive attitude.

Misfitting Items

The frequency of each answer choice (see Table 7) was reviewed for the above eight misfitting items. Two of the items (#7, #27) that were underfitting (i.e., their response pattern was more erratic than the other items) seemed to have more participants endorsing a strongly negative attitude than other items. Because these two items tap into important concepts within the neurodiversity paradigm (i.e., for item #7, that functioning labels are ableist and do not respectfully or accurately reflect autistic individuals' strengths and weaknesses [den Houting, 2018]; for item #27, that autism is not something that should be cured because it is a brain difference not a disease or defect [Walker, 2016]), it was decided that these two items should not be removed or revised, even if they had significant misfit.

Table 7

Frequency of Answer Choices for Misfitting Items

Item	Answer Choice						Misfit Type
	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	
2	2	8	17	48	96	110	Underfit
7*	31	58	51	81	50	10	Underfit
12*	90	82	54	30	17	6	Underfit
14	1	9	19	84	108	58	Overfit
17	1	10	16	83	109	59	Overfit
20*	49	67	61	66	28	6	Underfit
25	0	3	18	45	118	93	Overfit
27*	41	41	52	68	48	27	Underfit

Note. *For scoring and statistical purposes, item was reverse scored such that a higher score indicated a more positive attitude. The frequencies here represent actual answer choices *before* reversal.

Another one of the underfitting items (#20) was phrased such that participants were asked to judge how they would feel about *themselves* if they were neurodivergent (specifically, if they would be embarrassed to admit they had a learning disability such as dyslexia). This is different from most of the other items, where the participant is asked to make some kind of judgment about neurodiversity as it pertains to *other* people. Answer choices were fairly spread out in response to this question (Table 7). Given its misfit and its dissimilarity to the rest of the items, this item was highlighted as one that should be reviewed by the research team. It was decided that this item would be removed, since personal identity and attitudes toward oneself are not necessarily the same as attitudes toward others (see Chan and Mak [2015], where self-stigma amongst individuals with psychiatric conditions was not related to implicit stigma of mental illness).

Of the remaining two underfitting items, one was quite easy in terms of difficulty (#2, -1.36 logits) and one was a bit more difficult (#12, -.991 logits). While the researcher deemed that these two items were highly relevant to the construct of attitudes toward neurodiversity, qualitative data from prior participants' response process evaluation was reviewed to help determine why the items might be misfitting. Eighty-two percent of the 28 RPE participants were rated as understanding item #2 and answering the item using the same logic as other participants. All of these participants either strongly agreed or agreed with the item (*It is important for non-neurodivergent people ("neurotypical" people) to learn to better interact with neurodivergent people;* note that the answer choices at this point in the RPE were strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, strongly disagree). However, two of the participants (7%) were rated as definitely not understanding the item, as they seemed to think the item was about getting neurodivergent (not neurotypical) people to change, either by learning to better interact with neurotypicals or other neurodivergent people. The remaining three (11%) individuals were rated as potentially understanding the item, but their responses indicated a different line of reasoning for choosing their answer choices than most other participants:

> Participant 1: *I chose neither agree nor disagree because unfortunately people do not owe other people the active practice of trying to relate to one another. It sounds harsh but everyone has their own matrix of thoughts going on so in passing conversation or upon meeting a neurodivergent person of course I will take that into the highest consideration when interacting with them BUT others may not care.*
>
> Participant 2: *I chose this answer* [neither agree nor disagree] *because I feel like both non-neurodivergent people and neurodivergent people should make an effort to understand one another.*
>
> Participant 3: *I believe this kind of accommodation may also be seen as condescending towards neurodivergent people* [chose somewhat disagree].

These responses indicate that some pilot participants who choose an answer that falls in one of the disagree categories may be using different reasoning to answer the item than the people who choose one of the agree choices. For example, like participant 2, a person might feel that it *is* important for neurotypical people to learn to interact with neurodivergent people, but because they also think the reverse is true (neurodivergent people should learn to interact with neurotypical people), they may not agree with the statement. Others, like participant 1, may *personally* feel that it is important to learn to interact with neurodivergent people, but do not agree with the statement because they think others might not. These potential comprehension issues combined with the significant misfit suggest this item should be removed.

The final underfitting item (#12; *If people with ADHD work really hard, I think a lot of their difficulty focusing will go away*) was rated as definitely understood by 95% of RPE participants. When asked what the question meant, the only two participants who were rated as possibly understanding the item stated, “ADHD patients are hard to explain their action” and “Means nothing, because I don’t believe that is true.” The first person did not answer why they chose their answer choice (Disagree), and the second participant said “I have ADHD” in response to why they chose Strongly Disagree. While not rated as definitely understood, these participants’ responses do not suggest any serious misunderstanding or significant deviations in reasoning compared to the rest of the participants. None of the pilot participants wrote anything about the ADHD question in their open-ended feedback about the survey. However, *all* of the 37 RPE participants indicated that they somewhat to strongly disagreed with item #12, whereas 53 (19.0%) of the 279 pilot participants who answered the item indicated that they somewhat to strongly agreed with it. This discrepancy suggests we do not have enough information about participants’ response process to truly understand what is happening with this item. Although this item does tap into something that is mentioned in pro-neurodiversity circles (e.g., ADDitude Editors, 2020; Rayburn, 2020), it is perhaps referencing something that is highly specific to ADHD and is less relevant to neurodiversity in general. For this reason, it was decided this item would be removed.

The remaining three items were overfitting, meaning that their answer patterns fit the model *too* well—they performed even *better* than expected. In the case of these three items (#14, #17, #25), almost no participants displayed the most negative attitude, while most endorsed the answer choice corresponding to the second-most positive attitude. Practically speaking, overfit often has little importance, as it will not degrade the quality of an instrument; in fact, it may make it appear better than it is (Bond & Fox, 2015). Nonetheless, these three items were reviewed for potential lack of local independence. Lack of local independence occurs when one item ends up answering another item or when items are redundant. Item #14 (*Many of the challenges neurodivergent people face are due to society not being accommodating to them*) was reviewed in conjunction with other items to see if there was any overlap or redundancy. Though there was an overlap in the notion of "accommodations" from item #5 (*I believe people should have access to any accommodations that they need to be successful at work (such as getting an extension on a deadline, allowing for sensory-friendly workspaces, etc.*), the meaning of the items did not appear to be overlapping. For example, a person could believe that disabled people should have access to accommodations (agreeing with #5) yet also think that most challenges associated with neurodiversity are *not* due to society (disagree with #14). Item #10 also used the word "challenges" (*Some neurodivergent people have such serious challenges that they should live in institutions*), though this overlap was also determined to not violate local independence, as the two items were again focusing on different topics. The author concluded that there was not substantial overlap with any of the other items; thus, item #14 was kept in the NDAQ.

Upon reviewing the last two misfitting items (#17: *I would like to have the opportunity to work with neurodivergent people so that I can learn from them,* and #25: *At work, I would be willing to take direction from or be supervised by a neurodivergent person*), it was clear that both mentioned the word "*work*." Though the former was designed to target people's openness to learning about neurodiversity, it is possible that participants were interpreting these two items similarly, perhaps along the lines of "*I would accept working with neurodivergent people*." RPE responses for #17 were reviewed specifically for participants' use of the word "work" in their answers. With this in mind, it was clear that some participants were viewing this item specifically in a professional context (e.g., an RPE participant said, “Having the opportunity working with neurodivergent people and having hands-on experience with how they would view projects, how they would approach and execute these projects would allow me to work differently too”). Others, however, seemed to interpret “work with” in a sense more aligned with intervention/assistance (e.g., “I would like to be able to assist with neurodivergent people so that I can learn from them”). Though these responses were initially rated as understanding the item, with this renewed focus on “work,” it became clear that participants may be understanding the item differently. Because of the overlap in the word “work,” the potential misunderstanding of whether the item referred to working as professional colleagues or support professionals/clinicians, and the fact that #17 was designed to be in the affective domain but is perhaps getting more at a *behavior* (i.e. working alongside and learning from someone), it was decided to remove #17. On the other hand, RPE responses to item #25 indicated that participants understood the item was about being supervised by someone while working at a job. Because this item was more uniformly understood and seemed to align better with its domain (behavioral), item #25 was retained.

Updated 25-Item NDAQ Fit Statistics

After deciding to remove four of the eight misfitting items, another multidimensional Rasch model was run to determine how well the new 25-item NDAQ fit the Rasch model. The remaining four items that misfit in the original model again displayed statistically significant misfit in the revised model. An additional item (#10, *Some neurodivergent people have such serious challenges that they should live in institutions*) also now misfit. However, despite having t-values indicative of statistical significance, the infit values for items #7 and #10 were both within the acceptable range of .75-1.30 (#7: 1.19; #10: 1.16); the misfit for these items was therefore minimal. Items #14 and #25 still displayed significant overfit and item #27 still displayed significant underfit. However, as these items were already determined to be relevant to the construct and/or locally independent, these items were still retained in the revised instrument. The WLE for each updated dimension remained similar to the 29-item NDAQ (affective: 0.60; behavioral: 0.76; cognitive: 0.80).

Convergent Evidence

The association between participants' ability estimates on the updated 25-item NDAQ and other neurodiversity-related measures was assessed. Estimates from all three dimensions were correlated with the three social distance scales—which measure stigma toward autism, ADHD, dyslexia—and instruments designed to measure knowledge of the three diagnoses. The correlation matrix can be seen in Table 8. For the stigma questionnaires, where lower scores indicate less stigma, correlations ranged from -0.68 to -0.39. In general, the strongest correlations were with the behavioral domain. For the knowledge questionnaires, where higher scores indicate greater knowledge, correlations ranged from 0.327 to 0.584. These correlations represent what would generally be considered moderate correlations (Akoglu, 2018). Correlations were lowest for the ADHD knowledge instrument across all domains. Ability estimates were not correlated with participants' reported familiarity with neurodiversity (cognitive: ρ = 0.048, affective: ρ = -0.014, behavioral: -0.069).

Table 8

Correlations Between NDAQ Ability & Stigma/Knowledge Instruments

		Autism Stigma	ADHD Stigma	Dyslexia Stigma	Autism Knowledge	ADHD Knowledge	Dyslexia Knowledge
Cognitive	ρ	-0.556	-0.422	-0.472	0.525	0.327	0.408

Domain	N	269	270	270	267	265	262
Affective Domain	ρ	-0.546	-0.39	-0.445	0.506	0.386	0.398
	N	269	270	270	267	265	262
Behavioral Domain	ρ	-0.683	-0.544	-0.599	0.584	0.39	0.446
	N	269	270	270	267	265	262

Note. All correlation coefficients are Spearman's ρ. All correlations were significant at the $p < .01$ level.

Discussion

This study was an initial effort to create and validate an instrument to measure attitudes toward neurodiversity. Such a measure could help identify helping professionals who would benefit from education/training to improve their attitudes toward neurodiversity. Improvements in attitudes toward neurodiversity could lead to decreased stigma and prejudice toward neurodivergent people and ultimately improve their quality of life. The instrument, the Neurodiversity Attitudes Questionnaire (NDAQ), was developed by a team of researchers using the tripartite model of attitudes (Rosenberg & Hovland, 1960) and subsequently subjected to both qualitative and quantitative investigation in order address the following goals in order to build a validity argument:

1. The content of the instrument will contain items that are representative of individuals' attitudes toward neurodiversity.
2. Participants will understand the instrument items and answer items using similar logic.
3. The sample will be well targeted by NDAQ items.

4. The internal structure of the instrument will be multidimensional, with items fitting a multidimensional Rasch model with minimal misfit.
5. Participants' scores on the NDAQ will correlate with scores on instruments designed to assess knowledge and attitudes toward neurodivergent diagnoses such as autism, ADHD, and dyslexia.

Below, each goal is addressed and suggestions for future research are discussed.

Goal 1: NDAQ Content Relevance

The first piece of evidence pointing to the relevance of the NDAQ items to the construct of attitudes toward neurodiversity is the researchers themselves. The entire research team endorses the neurodiversity approach and recognizes the importance of attitudes toward neurodiversity in education, medicine, and other helping professions. Though the researchers share an orientation toward neurodiversity and have all published academic articles/chapters on the topic, individuals' varied backgrounds and identities (e.g., clinician, parent of an autistic child, autistic researcher) helped ensure that different aspects of neurodiversity were being captured. Item development was further informed by review of relevant literature including academic papers and first-person accounts via blog posts and books. The team incorporated feedback from disability/inclusive education and measurement experts and neurodivergent cognitive interview participants in order to create an initial set of items. The feedback, coupled with the researchers' background knowledge, helped ensure the NDAQ items were valid insofar as they captured content relevant to the construct.

Goal 2: Participant Response Process Evaluation

Items were iteratively revised based on the response process evaluation of 190 undergraduates' survey responses. RPE included both reviewing what participants thought the item meant and making sure their answer choices were justified by similar logic across participants (Wolf et al., 2021). Items were only considered finalized after at least 90% of participants were rated as definitely or likely understanding the item. The depth of this qualitative analysis lends considerable evidence to the NDAQ’s validity, as we can be fairly sure that participants were interpreting the items as intended and answering them according to our construct map. We did, however, end up removing certain items that were not performing well during RPE that may be highly relevant to the construct. For example, despite participants understanding the item, an item about how neurodivergent people see neurodivergence as part of their identity was removed due to participants consistently pointing out that the item was hard to answer due to its nuance (i.e., it might be true for some people, it might not for others). Future investigations may benefit from further qualitative work to determine whether items that tap into highly nuanced aspects of the construct should be included in the NDAQ, and if so, how those items should be worded.

Goal 3: The Sample Will be Well Targeted by the NDAQ

Analysis of the Wright Map (Figure 2) shows that participants were on average more likely to show more positive attitudes than negative attitudes. Specifically, participants with an average attitude toward neurodiversity were over 50% likely to endorse positive attitudes in response to all but one item. While the NDAQ still appears to target the sample fairly well, it is possible that harder items need to be added in order to better discriminate amongst those with more positive attitudes. On the other hand, it is possible that the pilot sample was simply composed of individuals who happen to have more positive attitudes toward neurodiversity. This is likely given that the sample was composed of undergraduate students, who may be more likely to be progressive, and individuals who saw advertisements for the study online (who are likely to have an interest in the topic of disability and neurological differences). The NDAQ thus needs to be administered to a wider range of individuals in order to fully understand how well it is targeted to *all* helping professionals.

Furthermore, NDAQ ability estimates displayed greater error for those with higher ability, again suggesting perhaps that there were not enough items to adequately distinguish between highly positive attitudes. However, it is also possible that the construct of attitudes toward neurodiversity has a ceiling and that those who display very positive attitudes will agree with all items that are in favor of the neurodiversity approach.

Goal 4: Internal Structure of the NDAQ

Data from the NDAQ piloting fit a multidimensional Rasch model (Briggs & Wilson, 2003) better than a unidimensional model. This helped to confirm that our conceptualization of attitudes toward neurodiversity as being composed of affective, behavioral, and cognitive components was valid. Theoretically, this also made sense, as we intended the NDAQ to be able to distinguish between individuals who had positive attitudes toward neurodiversity overall versus those who might be positive in one area but not another (see Jones, 2022). Further validity evidence was provided via item fit. Most items (21/29) had acceptable infit statistics. Items that misfit were reviewed to determine next steps. It was decided based upon fit statistics, frequency of answer choice, and evaluation of local independence to remove four items. Though the resulting 25-item NDAQ still had five misfitting items, two were within the acceptable MNSQ range (.75-1.30) and the remaining three were determined to be theoretically important to the construct and thus retained. While the NDAQ's fit to the Rasch model was not perfect, these results still support the instrument's validity given that most items fit well. Nonetheless, future investigations will need to reassess the item fit, particularly with regard to the misfitting items.

Goal 5: Convergent Evidence

NDAQ ability estimates across all three dimensions were moderately correlated with participants' scores on instruments designed to measure stigma toward and knowledge of common neurodivergences (i.e., autism, ADHD, and dyslexia). Some of the strongest relationships (ρ = -0.683, -0.599, -0.544) are between the NDAQ behavioral domain and the stigma scales. This provides especially strong evidence of the validity of the behavioral dimension items, given that the stigma scale (Gillespie-Lynch et al.'s [2021] version of the Social Distance Scale) items all tap into behaviors (e.g., "I would be willing to have lunch with an autistic person"; "I would NOT be willing to work with an autistic co-worker").

Overall, the degree of association between NDAQ dimension abilities and the other measures (ranging from |0.327| to |0.68|) suggests the NDAQ is related to these instruments but is not measuring the same thing. This makes theoretical sense and provides further validity evidence, as attitudes toward neurodiversity may be influenced by stigma and/or knowledge, but they are not exactly the same. For example, a clinician may have thorough knowledge of autism traits, prevalence, and intervention techniques but approach autism from a purely medical model perspective, thus having somewhat negative attitudes toward neurodiversity.

Interestingly, reported familiarity with neurodiversity was not related to any of the three NDAQ dimensions. It is of course possible that, amongst participants who were very familiar with neurodiversity, some rejected its premise and some accepted it, thus contributing to a lack of linear relationship. However, it is also possible that some participants were familiar with the *term "*neurodiversity" (for example because they have seen posts about it on social media) but were not actually familiar with the underlying ideas. Den Houting (2018) points out multiple misconceptions regarding neurodiversity, so it is likely that some participants who felt they were “extremely familiar” with neurodiversity were actually familiar with some of its misconceptions. While this finding should not be given much weight with regard to the NDAQ validity argument considering the neurodiversity familiarity item was just *one* non-validated item, future research may want to investigate what it really means to be familiar with neurodiversity.

Limitations & Future Directions

This study provides initial evidence of the NDAQ’s validity as an instrument to measure attitudes toward neurodiversity. However, these results are preliminary and should be evaluated with several limitations in mind. First, though the pilot sample was somewhat ethnically/racially diverse with over half of the participants identifying as a non-White minority, there was little representation of Black individuals. The sample was also overwhelmingly female. Further validation efforts thus need to target a wider sample with particular care to recruit Black and male participants. The current study’s participants were also recruited using convenience sampling. It is likely that both undergraduate and online participants were drawn to participate due to an existing interest in disability/neurological differences. This is especially evident by the fact that roughly a quarter of the sample identified as neurodivergent. While one would expect helping professionals to be interested in this topic, it is possible that some professionals see working with neurodivergent people as just part of their work and are not interested in thinking much about it outside of their job. It is important that future NDAQ validation work capture these views. Partnering with community organizations that employ helping professionals may help ensure a more representative sample who displays a wider range of attitudes toward neurodiversity is recruited.

Though this study explored the NDAQ's validity from both qualitative and quantitative angles and presents strong validity evidence, there are some areas that need further investigation. For instance, this study did not assess invariance across groups (i.e., differential item functioning [DIF]). DIF happens when an item behaves differently in different demographic groups and can be evidence of bias. Future work on the NDAQ must include a large enough sample such that different demographic groups can be compared. For example, it is possible that certain professions interpret and answer items completely differently. Alternatively, identifying as neurodivergent or having neurodivergent friends or family members may cause individuals to answer items differently than those with less direct experience.

Lastly, this version of the NDAQ was designed to specifically gauge helping professionals' attitudes toward neurodiversity in the hopes of identifying individuals who would benefit from education/training. Though it would be ideal to have an instrument that could assess the impact of such a training, it should be made clear that the NDAQ has not yet been validated for that purpose (see the AERA, APA, & NCME [2014] standards regarding validating instruments for specific uses). The NDAQ therefore needs to go through the entire validation process again (including cognitive interviewing, RPE, piloting, etc.) before it can be deemed suitable as a pre-post outcome measure.

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Dissertation Conclusion

The three papers in this dissertation highlight areas where interventions for autistic people can be improved, particularly with regards to listening to and valuing autistic people's opinions. First, even though it is often claimed that naturalistic developmental behavioral interventions are socially valid (e.g., Gengoux et al, 2020), it is apparent that social validity needs to be assessed more frequently in Pivotal Response Treatment (Koegel et al., 2016) research. This is especially the case with regard to including the autistic intervention recipient in the social validity assessment, as very few studies did this, either by asking them for their opinions directly or by assessing child affect. Without knowing how autistic people feel about the programs developed for them (which are often delivered without explicit buy-in from the autistic child, especially when they are young and unable to provide verbal consent), it is impossible to know whether they are truly socially valid. As a field, we need to move away from simply assuming an intervention is acceptable just because, anecdotally, children and their families seem to be enjoying it, or because it is "effective" at producing an outcome deemed beneficial by non-autistic providers or parents.

While it is absolutely necessary to assess social validity from the intervention recipient's perspective, it can also be tremendously useful to get feedback from other autistic people who are not directly involved in an intervention. The second paper herein asked autistic adults to comment on intervention goals commonly used with autistic children. Their feedback provided many suggestions for professionals in terms of how interventions can be improved such that they are autism- and neurodiversity-affirming. The three overarching themes generated by qualitative analysis focused on the importance of 1) understanding autistic identity and the need for neurotypical providers to recognize that neurotypical behavior is not superior to autistic behavior; 2) goals that support autonomy and self-advocacy skills should be prioritized, and providers should emphasize *inter*dependence over always pushing for complete independence; and 3) that the implementation of a goal matters, particularly with regards to monitoring side effects and looking beyond observable behavior to addressing the underlying causes of behavior.

The last paper of this dissertation presented the development of a tool that could ultimately aid in increasing social validity of service programs for autistic people: the Neurodiversity Attitudes Questionnaire (NDAQ). The NDAQ was developed by a team of autistic and non-autistic researchers with the aim of creating an instrument to assess helping professionals' attitudes toward neurodiversity. Understanding where attitudes might be less favorable toward neurodiversity can come in handy when training new employees or attempting to improve existing programs, as adopting a neurodiversity approach is likely to increase social validity. The NDAQ was subjected to extensive qualitative examination before finalized items were piloted with a sample of current or future helping professionals. Results from fitting the data to a multidimensional Rasch model suggested the instrument fit the model fairly well, though minor changes were made to the items based on analysis of item misfit and theoretical considerations. This qualitative and quantitative analysis provided preliminary evidence of the NDAQ's validity.

Where Do We Go From Here?: Connecting Social Validity & Neurodiversity

The concepts of social validity and neurodiversity are not usually seen as intimately related. The first was borne out of applied behavior analysis (ABA). The second blossomed out of the autism rights movement. And we know that, both historically and currently, ABA is not something generally lauded by the neurodiversity community (Des Roches Rosa, 2020;

Michael, 2018; Therapist Neurodiversity Collective, n.d.). However, the papers in this dissertation should hopefully make it clear that assessing the social validity of interventions is *imperative*, and though it began in ABA, social validity can be applied to any intervention or service (such as speech, occupational, or physical therapy or special education). Additionally, this dissertation also hopefully shows that in order to ensure intervention social validity, we must listen to autistic people. That means viewing them as valued members of society who, while perhaps needing certain support services, should be accepted regardless of whether their behavior aligns with neurotypical standards. And therein lies the connection between social validity and neurodiversity: researchers and clinicians are unlikely to fully incorporate autistic people's views into interventions unless they are taking a neurodiversity approach. Thus, true social validity is not possible without embracing neurodiversity.

This then is a call for all researchers, clinicians, teachers, and other providers to take up the neurodiversity approach in their work. We all have an ethical imperative to do the best we can for autistic and otherwise neurodivergent people, and there is no excuse to not treat them with respect and dignity and appreciate them for their differences. It should be noted that this does *not* mean erasing disability or depriving people of support -- instead, it means assessing an autistic person’s needs from *their perspective* and providing whatever service will best serve that person’s personal goals. And while social validation is an important component of this, we must also critically evaluate our social validity practices in order to make sure we are not just going through the motions, perpetuating the same issues. For example, are there some forms of social validity assessment that actually perpetuate stigma and prejudice? Normative comparison, where autistic children are compared to neurotypical children on intervention outcomes may be something that the field needs to move away from now that we understand more about neurodiversity and autistic identity.

Obviously, as stated above, we must also prioritize social validity judgments from the autistic perspective. However, that does not mean other interested parties' opinions are not important; in fact, parents and clinicians can provide valuable input on all dimensions of social validity. However, we have to ask them the *right* questions. We need to ask them about potential side effects, how they think the child is feeling, and whether they feel any ethical objections to implementing the intervention. When presenting social validity results in papers, it must be clear exactly how it was assessed; presenting questionnaire average scores without mentioning specific questions is inadequate. Additionally, in order for parents' and clinicians' social validity ratings to be meaningful, parents and professionals must be empowered to understand neurodiversity. If parents have never even heard of neurodiversity, and they trust professionals to always know best, how are they supposed to critically evaluate interventions? If professionals tell parents that it is normal for their child to cry throughout intervention sessions, how can they feel empowered to call this out? There therefore needs to be a concerted effort to teach the general public about neurodiversity—both in terms of what it is and what it is not, in order to quell misinterpretations (e.g., Bailin, 2019; den Houting, 2018) —so that social validity does not just become another check box for researchers and clinicians to fill out without enacting any meaningful changes.

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