A Passing Problem: Evaluating Harm and Benefit in Autism Research

Abstract: Autism research frequently seeks to evaluate interventions or inform their development. Unfortunately, researchers often assume that autism intervention should reduce autistic traits, effectively setting as a goal of treatment that autistic persons attempt to "pass" as non-autistic. A growing body of evidence highlights serious potential harms from passing demands. We discuss the importance of institutional review boards scrutinizing autism research for clinical passing demands, document their existence in outcome measures commonly employed in autism research and propose an ethical framework for IRBs and others to make use of in evaluating the ethical appropriateness of particular treatment goals in autism intervention or intervention-adjacent research, emphasizing that treatment goals should be in pursuit of a beneficial non-passing purpose and be the least burdensome means of accomplishing such a purpose. We also highlight potential promising practices for IRBs, investigators and other stakeholders seeking to address these issues in autism research.

SECTION 1: INTRODUCTION:

There are longstanding concerns regarding research ethics in autism.[1] This paper is intended to explore several issues relevant to the development and approval process for autism research regarding or relevant to interventions. We argue that autism researchers and IRBs reviewing proposed autism research must recognize the potential harms associated with interventions that demand that autistic persons attempt to pass as non-autistic. In doing so, we contend that many existing measures of benefit relied upon in autism research and intervention are not appropriate tools for this purpose, as they define progress in terms of the reduction of autistic traits that pose no harm to the autistic person rather than the mitigation of intrinsic harm or promotion of more meaningful goals. Finally, we propose that autism interventions must demonstrate that they are the least burdensome (to the autistic person) means of achieving a beneficial non-passing purpose in order to be considered ethically permissible.

The structure of the paper is as follows. In Section 2, we review the literature linking passing demands to harm to autistic people and discuss potential mechanisms through which such harm may take place. In Section 3, we document the frequency of clinical passing demands in autism research and interventions. In Section 4, we articulate an ethical framework for IRBs' use in evaluating benefit in research and the ensuing suitability of treatment goals. Section 5 makes recommendations for IRBs to take into account in overseeing autism research.

SECTION 2: AUTISM AND PASSING

Autistic activists associated with the neurodiversity movement have long contended that passing demands impose harms in many contexts[2]. In recent years, a growing body of research has affirmed these concerns.[3] Passing is associated with greater risk of suicidality, burnout, psychological distress and other mental health challenges for autistic people.[4] While for some autistic people passing may help to mitigate stigma, even under these circumstances it comes with substantial personal costs due to ongoing and taxing efforts to "mask" or "camouflage" autistic traits.[5]

These challenges are consistent with a longstanding recognition of the harms that passing imposes on persons from a wide range of stigmatized identities.[6] These harms emerge not only when individuals actively seek to hide their stigmatized identity but also materialize when that identity is nominally acknowledged while any outward traits of it are actively suppressed (a phenomenon known as covering[7]). For simplicity's sake, we refer to pressure to pass and pressure to cover simply as "passing demands" throughout this article.

The literature on passing in non-disability contexts generally focuses on broader societal pressures to pass. These pressures certainly exist with respect to autism and other similar disabilities. However, in the context of intervention they are coupled with *clinical passing demands* – those imposed by service-providers and researchers.[8] Clinical passing demands are frequently operationalized through outcome measures and intervention strategies that seek to promote typical appearance and the complete elimination of autistic traits, regardless of whether a given trait is harmful to the autistic person or others. While they have roots in general societal stigma, they are imposed and enforced by service-providers and researchers and are thus highly relevant to the IRB process.

Unfortunately, autism research has generally taken it as a given that the objective of intervention should be the reduction of autistic traits, defining progress as the suppression of that which led to a diagnosis.[9] Some researchers have defined the complete elimination of diagnostic traits as the "optimal outcome" for autistic persons, suggesting that intervention should prioritize the loss of a diagnosis.[10] This has helped to support a sizable industry of service-providers promising "recovery" from autism for parents who purchase their interventions.[11] It has also prompted objections from autistic-run advocacy groups, who note that autistic persons deemed to have been "recovered" as non-autistic still display challenges consistent with an autistic person struggling to pass.[12]

We discuss several mechanisms through which passing demands can harm autistic persons.

Interventions that Stress Passing Impose an Opportunity Cost

Both autistic children and adults often require services to support the development of important skills, ranging from communication to independent living to the avoidance of self-injury. Interventions that focus on the reduction of diagnostic traits, such as by promoting increased eye contact or reduced handflapping, prioritize typical appearance over more meaningful goals. In addition to crowding out other intervention priorities, clinical passing demands may displace other important life experiences. For example, proponents of Applied Behavioral Analysis (ABA) therapy for autism, a field that has been the source of particularly intense concerns regarding clinical passing demands[13], urge parents to have their children receive therapy for 25-40 hours a week.[14] However, such aggressive treatment intensity is not supported by the existing literature[15] and may impose harms on the children who receive it. In the words of Sandbank, Bottema-Beutel & Woynaroski (2021), "highly intensive interventions that separate children from their siblings, peers, and family members for extended periods may have unintended adverse developmental and social consequences."[16] As another researcher put it, "receiving 40 hours of weekly therapy is essentially a full-time job for a 3-year-old."[17] The ongoing intensive intervention often practiced in passing-oriented interventions can deprive autistic children of much of the non-clinical experiences that define childhood. As such, such interventions impose additional burdens, presenting a risk of harm as well as a denial of more meaningful benefit.

Passing Imposes Cognitive Demands

Passing as non-autistic imposes serious and ongoing cognitive demands on autistic people. A recent literature has documented the phenomenon of "autistic burnout", described as a loss of function and increase in mental health challenges "driven by the stress of masking and living in an unaccommodating neurotypical world".[18] The cognitive demands associated with constant self-policing of behavior, vocal prosody, movement, interests and other autistic characteristics are stressful and for many persons contribute to greater challenges in other areas of life. The feelings of relief many autistic people report upon spending time with other autistic people (implicitly reducing the need to mask) are also consistent with this understanding of passing's cognitive load.

Passing Demands Internalize Stigma

Milton (2012[19]; 2022[20]) argues that the social communication challenges faced by autistic people are best understood as a "double empathy problem". In short, owing to the reciprocal nature of social communication, communication challenges must be understood as reflecting "a breakdown in mutual understanding…and hence a problem for both parties to contend with."[21] The demand to pass places the need for correction entirely on the autistic party. In locating the responsibility for change entirely in the autistic person, passing demands reinforce autism-related stigma in both the broader culture and in autistic persons themselves. Such internalized stigma may play a considerable role in the well documented relationship between passing and mental health challenges among autistic people.

Passing Demands May Teach Ineffective or Maladaptive Skills

Finally, passing demands may also be ineffective or actively counterproductive at facilitating social success. In many contexts attempts at passing may leave autistic people with the same set of challenges and stigmatized presentation without access to the tools necessary to mitigate stigma through contextualizing stigmatized traits as being part of autism. What's more, an emphasis on the imitation of neurotypical standards of behavior may lead to a style of social interaction that is less likely to be effective than more authentic approaches. Recent work examining social skills training programs for autistic people found that such programs may in fact harm autistic peoples' ability to form and maintain meaningful social relationships, teaching skills that come across as inauthentic in real-world social interactions. Since autism social skills training arguably serves to "reinforce social arrangements that require autistic individuals to attempt to learn, memorize, and deploy social rules in order to pass as non-autistic", it can "displace the natural interactional proclivities" of autistic persons, resulting in a stifling of "psychological, relational, and interactional authenticity while increasing stigma."[22]

Unique Harms of Clinical Passing Demands

The harm emerging from many of these pathways are relevant regardless of where a passing demand originates. Given this, investigators and IRBs might question if passing demands embedded in clinical interventions or other aspects of a study design should be considered greater than minimal risk by an IRB (particularly if the IRB uses the everyday experiences of autistic people as a baseline rather than those of the general public, a topic of ongoing controversy in research ethics circles[23]). However, there is good reason to believe that clinical passing demands are particularly harmful and thus that their presence in a proposed study should invoke a greater-than-minimal-risk standard for IRB scrutiny.

The context of intervention entails an inherent power imbalance between those receiving services and those providing them. While the ubiquity of stigma can make it difficult for autistic people to avoid pressure to pass in everyday life, clinical contexts entail a much greater degree of loss of control (especially, though not exclusively, for children). Such passing demands target specific individuals and are likely to be more immediately demanding than those emerging from diffuse cultural norms and expectations. Even when working with adults, clinical passing demands are most likely to be imposed on persons who have not consented to receive them, as researchers frequently rely on substituted rather than supported decision-making processes.[24] Assent is also frequently waived or inadequately documented in autism research, including research on ABA interventions.[25]

Clinical passing demands are also more totalizing than those found in everyday life. As we discuss in Section 3, autism interventions frequently seek to suppress specific traits or behaviors that would be seen as unobjectionable in non-autistic people and/or in non-clinical contexts. Outcome measures define progress based on the elimination of such autistic traits and the promotion of very specific forms of neurotypical behavior. Vivian (2012) refers to this as "passing-as-ethics", described in part as the belief that "any habit, style of movement, facial expression, interest, feeling, word choice, way of pronouncing words, way of sitting, way of communicating…that is commonly associated with disabled people is…the opposite of success, and must be destroyed to improve someone's functioning".[26] The presentation of passing as an imperative that *must* be complied with – immediately and precisely in the fashion demanded by those administering an intervention - is unique to the clinical context.

The evidence that clinical passing demands impose harm on autistic persons should raise serious concerns for institutional review boards (IRBs) evaluating autism research. We raise this issue with some reluctance, knowing that research on people with intellectual and developmental disabilities is often subject to overly cautious ethics review that deprives people with such disabilities of the opportunity to benefit from research.[27] It is not our intent to suggest that research involving autistic people inherently poses greater than minimal risk or that no enhanced risk can be justified. However, we believe that autism research and interventions are presently disregarding a sizable dimension of potential risk in clinical passing demands and the harms they impose.

Evaluating such risks is difficult for IRBs, in part because they often lack familiarity with autism. As such, a degree of deference is typically provided to principal investigators (PIs) to characterize the potential risks. After all, PIs are generally the experts in their areas of research within a given institution. However, this approach may be particularly problematic in autism research. Underlying disputes as to what constitutes appropriate goals for intervention complicate assessments of both risks and benefits. What some autism researchers define as a benefit – the elimination of the diagnostic traits of autism – is precisely what many autistic stakeholders argue imposes risks. In addition, recent research suggests that autism researchers often do not monitor or seek to identify adverse events in human subjects research and fail to classify adverse events as such when they do occur.[28]

These challenges, while not unique, are very different from most other areas of human subjects research, such as cancer, where there is generally greater consensus regarding the objectives of intervention (prevention, symptom reduction and remission/cure) and a greater recognition of the need to monitor for iatrogenic harm.[29] Compounding these problems, recent work has documented widespread under-reporting of COIs in autism early intervention research, often involving researcher commercial interests with autism interventions or measures, a concern that appears particularly acute in ABA.[30]

IRBs should seek to make use of external resources when evaluating risk in autism human subjects research and should scrutinize autism research more carefully than even other areas of developmental disability research, given the presence of factors that may reduce the ability of the autism research community to police its own behavior.

In the next section, we document the history and ongoing presence of clinical passing demands in common autism interventions often made use of in autism human subjects research.

SECTION 3: DOCUMENTING CLINICAL PASSING DEMANDS IN AUTISM INTERVENTION RESEARCH

Owing to the multi-dimensional nature of autism, it has been difficult for autism researchers to determine precisely what to measure when assessing intervention outcomes. Some studies have made use of tools designed for diagnosing autism (such as the Autism Diagnostic Observation Schedule), thereby implicitly defining treatment success as the reduction or elimination of autistic traits.[31] Pushback against the use of diagnostic tools to assess outcomes has largely focused on their psychometric properties and methodological concerns rather than ethical problems.[32]

However, outcome measurement decisions have serious ethical implications. Because they are the primary yardstick through which an intervention is deemed a success or failure, outcome measures define progress in autism intervention research and, by extension, in autism interventions in clinical contexts. Outcome measures that embed clinical passing demands in their definition of success encourage researchers and providers to structure interventions to pursue passing as a goal. Outcome measures that focus on intrinsic benefits, such as communication or the reduction of self-injury, encourage interventions to focus on these goals.

Over the last two decades, researchers have developed many measures specifically designed to assess outcomes in autism research and intervention more generally. Unfortunately, these measures have replicated the same problems by including harmless diagnostic traits of autism, effectively defining these traits as targets for intervention. In Table 1, we provide a set of example items from commonly used outcome measures in autism research studies. These examples are intended to be illustrative only and do not provide a complete list of measure items that reflect clinical passing demands or the data instruments more generally.

For example, the Pervasive Developmental Disorder Behavior Inventory (PDDBI) includes items for whether a child “flaps hands up and down” or “spins objects in a repetitive manner”. Each of these items is perfectly appropriate for purposes of *diagnosing autism* but serves no clear purpose as a target for intervention. Indeed, many of the items reflected below are themselves defined primarily in terms of the social expectations of others rather than any intrinsic harm or benefit they pose for autistic people and those around them. Within the PDDBI, the targeting of “odd or unusual finger movements” or whether an autistic person “puts an unusual stress on words when speaking (not due to regional accent)” represent two such examples. Tricare, the US military’s healthcare program for armed services personnel and dependents, requires providers of ABA to submit the PDDBI, a rating scale used to measure the effectiveness of interventions, with each service authorization request every six months, effectively defining intervention goals and progress via the PDDBI’s items.

In the Social Reciprocity Scale-2, one of the most commonly used outcome measures in autism clinical trials,[33] items that reference “unusual eye contact”, “repetitive behaviors that others consider odd” and using “less inflection of voice than most people demonstrate” further illustrate the tendency of autism outcome measures to target for interventions behaviors that are defined primarily in terms of their perception by others.

[Insert Table 1 Here]

This approach to outcome measurement appears to assume that traits associated with a diagnosis are inherently distressing or harmful. To further illustrate this point, consider the Children's Yale-Brown Obsessive Compulsive Scale in Autism Spectrum Disorder (CYBOCS-ASD). The CYBOCS-ASD is adapted from the Children's Yale-Brown Obsessive Compulsive Scale (CYBOCS), a similar measure intended to assess the severity of Obsessive Compulsive Disorder. In adapting the CYBOCS, the authors condensed the measure and replaced many of the specific items used with examples of repetitive behaviors commonly found in autism. However, they largely retained the same basic structure of the CYBOCS, which presumes that it measures not only "interference due to repetitive behaviors" but also codes greater severity if children report distress from being prevented from engaging in a given behavior or fail to "resist" such repetitive behaviors. As reflected in Table 1, the CYBOCS-ASD includes many such behaviors that are both not harmful and in many instances actively enjoyable to autistic people, including “hand or arm flapping”, “repetitive play with certain objects: trucks, trains, dinosaurs”, and “repetitive behavior involving sensation (rocking, spinning, jumping, pacing)”.

The CYBOCS-ASD replicates wholesale the normative framework of the CYBOCS, despite tremendously ethically relevant differences between autism and OCD. Whereas repetitive behaviors in OCD represent sources of distress, in autism they are generally sources of enjoyment, means of self-regulation or sensory seeking. Though there are some similarities between the outward manifestation of these behaviors, their inner experiences are quite distinct.[34]

The root cause of this problem appears to be the conflation of diagnostic traits with more meaningful measures of outcomes. For example, autism service-provision and research has long emphasized the importance of eye contact, in part under the argument that correcting autistic people’s lack of eye contact can ameliorate social communication challenges. But, as others have noted, autistic people do not garner the same information from eye contact[35] that non-autistic persons do, find it distressing,[36] and can use other means to signal attention and engage in reciprocal social interactions.[37]

Efforts to promote eye contact prioritize form at the possible expense of function. Emphasizing typical behavior may in fact distract from the resolution of legitimate autistic challenges with social communication. Indeed, if the most appropriate solution is itself in some way unique or unusual to autistic people, solutions to autistic social communication problems may ultimately involve greater departure from typical behavior. Recent work on autistic patterns of eye gaze highlights the possibility that differences in autistic eye gaze are an appropriate diagnostic measure of autism but may not play a causal role in subsequent challenges, as autistic people can engage in joint attention (coordinated focus of attention with another person) through non-gaze related mechanisms.[38]

Thus autistic traits are judged as inherently in need of intervention simply because they are associated with autism. This approach reflects a strange, almost cargo-cult-esque fallacy – because: a) autistic persons experience greater challenges, and b) autistic patterns do not match neurotypical patterns of development, then c) the way of correcting autistic persons' challenges is to modify their patterns of development to match those of neurotypical persons. While it is certainly the case that autistic people have many challenges for which service-provision, education or potentially even appropriate medical intervention may be useful and well justified, researchers and IRBs must do a better job linking autistic traits to autistic challenges prior to conducting or approving intervention research that aims to modify or "correct" those traits.

These challenges are not present within every item within most autism outcome measures. For example, the SRS-2 includes a number of items that would likely be broadly recognized as worthwhile and ethically appropriate goals for intervention, including whether a child "is able to communicate his or her feelings to others" or if they have "difficulty making friends, even when trying his or her best". However, they are sufficiently widespread as to merit serious concern and IRB scrutiny of outcome measures proposed by investigators. In a comprehensive review of measures used to assess outcomes in young autistic children, McConachie et al (2015) note the existence of this problem, writing that:

> "The dissonance between attention to the behaviours considered in the diagnostic process in autism, and the lack of focus on valued outcomes, was very evident…tools that were developed primarily to aid assessment and diagnosis have influenced…what we have called 'global measures of outcome', i.e. they include lists of symptoms that may or may not be amenable to change, and which may or may not be related to the focus of intervention. "[39]

IRBs should be aware of these tensions and evaluate outcome measures used in autism intervention research through this lens. Measures that appear to emphasize the reduction of autistic traits that are neither harmful nor distressing should raise ethical concerns, prompting both revision of the study protocol and closer review of the intervention itself for potential clinical passing demands.

While our focus in this article is predominantly on autism intervention research, we note that there are other kinds of "intervention-adjacent" research in which these concerns may still be relevant. Non-interventional research that nonetheless poses risk to autistic subjects may be justified based on potential to reveal knowledge that may be relevant to future interventions. For example, Macari et al (2021) sought to study differences in emotional reactivity between autistic and neurotypical toddlers by presenting both with “fear-inducing probes” (i.e: frightening masks, objects and strangers).[40] The study prompted substantial outcry among autistic people online, prompting the authors to reply to defend the ethics of their work, in part by arguing that it may inform “clinical care of these children”.[41] Similarly, in their paper, the authors indicate that their study will help with “identifying the precursors of atypical emotional reactivity in infancy and its links with later psychopathology [which] will inform about novel treatment targets and mechanisms of change in the early stages of ASD.”

Later, the authors note that autistic toddlers used emotional regulation strategies for managing fear response that were different from those of neurotypical toddlers, as the autistic children’s strategies “were less likely to involve seeking proximity of parents, *making eye contact* [emphasis added], or otherwise communicating their distress to others…This may put already emotionally vulnerable toddlers at further risk for developing affective and behavioral problems later on. Thus, therapeutic efforts at this age may need to be directed specifically at fostering a more frequent utilization of social ER strategies in distressing contexts.”[42]

The potential for Macari et al’s study to inform future interventions that seek to impose neurotypical strategies (such as eye contact) on autistic children is a key component of the study’s overall justification. While research is not rendered unethical by virtue of its potential use in future unethical applications, such potential uses are not appropriate justification for potential risks to study participants. Insofar as the potential harms posed to study participants are justified by the development of interventions that entail clinical passing demands, IRBs should be skeptical of such claims and demand evidence that any treatment goal implicitly identified for future intervention by this research justification is appropriate.

In the next section, we discuss criteria for assessing the appropriateness of potential treatment goals in autism intervention and intervention-adjacent research.

SECTION 4: ASSESSING BENEFIT

Research that poses risk to human subjects may nonetheless be worthwhile and worthy of IRB approval, particularly where there is the possibility of either direct benefit to the subjects or benefit in the form of the production of useful knowledge for science and society at large. In this section, we discuss how IRBs should assess whether benefits justify research on interventions that target traits associated with autism for reduction or elimination.

In the context of research to assess autism interventions or intended to inform the development of such interventions (the two contexts in which clinical passing demands are most likely to be relevant in research), we believe benefit must be justified solely on the basis of benefit to autistic persons themselves, rather than for science or society at large. Though research on causation and the underlying mechanisms of action in autism has the potential for broader societal relevance by identifying useful knowledge about neurology that may have implications across a wide range of other contexts, research on autism interventions is by its nature more limited in the population it may plausibly stand to benefit.

Many outcome measures and interventions used to assess autism interventions presently in use in autism research and clinical practice assume benefit is derived solely from the reduction of autistic traits. Given the harms associated with passing demands articulated in Section 2, studies that define benefit in such a fashion may impose serious harm on study participants and, where they produce interventions predicated on such assumptions, on autistic people more generally. However, there are nonetheless circumstances where traits associated with autism may be appropriately and ethically targeted for intervention (and, by extension, research that supports the development or validation of such interventions may be ethically pursued). For example, few would dispute the appropriateness of interventions designed to reduce the use of self-injurious behavior or to provide access to word-based communication. These treatment goals also entail the reduction of traits associated with autism - on what basis should IRBs distinguish between these treatment goals and efforts to extinguish hand-flapping or promote eye contact? When is it legitimate for research and associated interventions to target the modification of a trait associated with autism as the goal of an intervention?

We argue for a two-part test for assessing the appropriateness of treatment goals. First, we contend that to be appropriate (to count as potentially carrying benefit), interventions must have a beneficial non-passing purpose (i.e: treatment goals must be primarily designed to accomplish a purpose other than the promotion of typical appearance). Beneficial non-passing goals would include preventing harm or acquiring useful skills. Under this first requirement, treatment goals such as the enforcement of eye contact, reduction of stimming, or promotion of typical prosody or vocal intonations would be found illegitimate. At the same time, such a requirement would permit treatment goals oriented towards reducing self-injury, improving communication skills, or developing other important adaptive skills.

Second, we contend that even if a treatment goal is primarily in pursuit of a “beneficial non-passing purpose”, it must be *the least burdensome means of achieving that purpose*, where burden is defined in terms of the autistic person themselves rather than to a provider or family member. This requirement serves as both a backstop to the first requirement (particularly where there are disputes as to what constitutes a non-passing purpose) and a useful operationalizing of the ethical obligation of nonmaleficence in its own right.

We recognize that there are substantial gray areas in this standard. Because relationships by their nature involve other people, promoting typical appearance might be said to advance a non-passing goal, in that it could increase the likelihood of a positive response and subsequent relationship-formation with non-autistic persons (though, as discussed earlier, the research literature suggests this claim is dubious). However, such a line of thinking validates the stigma that the avoidance of clinical passing demands was designed to reject - indeed, it renders our first requirement a dead letter, as *any* effort to promote typical appearance could be justified as having the non-passing purpose of encouraging a more friendly response from non-autistic persons. As discussed, contextual passing to avoid stigma is a legitimate choice for an individual to make, but when passing is embedded into an intervention as a clinical demand, no such space exists for freely informed choice that may vary across contexts.

We contend that the desires of others are legitimate justification for treatment goals only where they have a rationale that emerges from something other than social stigma. For example, the ability to engage in turn-taking represents an intrinsically useful skill that is often important for the formation of reciprocal social relationships. Turn-taking is useful not simply because it is something that non-autistic persons generally do better than autistic ones. It is useful because it enables a type of reciprocity and subsequent relationship-formation that is valuable for reasons other than an arbitrary behavioral norm. Alternatively, the reduction of hand-flapping and similar non-harmful stims does not meet this standard. A social relationship lost due to hand-flapping is lost due to arbitrary stigma and prejudice against a characteristically autistic behavior that harms no one. A social relationship lost due to a lack of conversational turn-taking cannot be said to be rooted in an arbitrary stigma, but instead in the desire of a conversation partner for a reciprocal interaction.

Similarly, we would argue that a non-passing goal cannot simply be satisfying parents' or family members' desires for more typical appearing children. Benefits must be grounded in a legitimate interest for the autistic person, not merely a validation of societal stigma. Family desires for a child who appears more 'normal' do not constitute such a need. Such clinical passing demands are not appropriate goals of intervention, even when desired by family members, given the harm they are likely to cause to autistic people themselves.[43] In short, it is our belief that, when rooted in stigma, meeting the desires of others cannot be sufficient to meet the requirement of a beneficial non-passing purpose. Even were one to disagree with this conclusion, seeking to address those desires via intervention designed to reduce a person's autistic traits is exceedingly unlikely to be the least burdensome means of accomplishing that purpose.

Much like evaluating (for example) an ADA accommodation request, we believe that assessing the appropriateness of an intervention or associated research will involve highly contextual lines of inquiry, balancing the legitimate goals of service-provision against the reality that illegitimate clinical passing demands are often embedded alongside it, all filtered through the (often very broad) contexts in which an intervention is applied to autistic people's lives. It is the responsibility of the researcher and the IRB, working in partnership with autistic community representatives, to weigh these competing considerations.

Intervention goals focused on communication are likely to be particularly ethically complex. As communication is necessarily two-way, it may be difficult to establish when an aspect of social communication is merely a matter of taste as opposed to an intrinsically beneficial skill. We believe that some (though perhaps not definitive) guidance can be found in asking whether a trait is likely to present a barrier to communication across a broad range of contexts. For example, the refusal to respect a peer's desire for personal space or their right to assert their own interests in a reciprocal social relationship is likely to present a problem across contexts. In contrast, lack of eye contact, monotonous prosody, unusual movements, intense special interests, and other traits commonly targeted for intervention would not interfere with communication in a more accepting context. If a reasonable person can envision a circumstance under which a trait would not interfere with communication, attempting to modify the autistic person is likely not the least burdensome target for intervention (defining burden exclusively in terms of the autistic person). Further research should investigate this grey area in more detail.

Caution is necessary to ensure that stigma-based rationales for intervention are not hidden behind overly general descriptions of the purpose of intervention. For example, in a recent response to the neurodiversity critique of ABA, Graber & Graber (2023) raise the example of an autistic teenager in a general education classroom whose "hand-flapping is incompatible with engaging in various tasks at school".[44] But the failure to provide information as to how this incompatibility arises makes it difficult to evaluate it as an intervention justification. If such perceived incompatibility is the result of a stigmatized response to hand-flapping on the part of peers or educators, this would be insufficient to meet our test. IRB personnel must be prepared to look behind such justifications, interrogating the specific mechanism of action for both ethical suitability and proportionality.

Others have noted the importance of articulating a theory for assessing the ethical appropriateness of interventions that extends beyond neurodiversity's origins in autism.[45] We believe our approach has the further advantage of potential applicability across a broad range of potential disability types, including physical, sensory and other non-brain-based diagnoses. Prior work notes that a "trait-oriented approach to operationalizing neurodiversity…has the potential to open up doors for expanding neurodiversity's critique of service-provision practices beyond the realm of mental disability, as many other disability categories experience harm from clinical passing demands imposed by providers."[46]

This would present the possibility of "a common front to transform research and service-provision in all areas of disability, not just those relating to the brain."[47] While we leave to further work the demonstration of our approaches' applicability to other diagnoses, we note that achieving a universal or at least substantially broad standard for how to deal with clinical passing demands would be a major benefit to IRBs, permitting consistency across diagnostic categories and limiting (though not eliminating) the need for specialized condition-specific expertise.

Against Splitting the Autism Spectrum

This approach stands in contrast to another common attempt to reconcile conflicting values in autism interventions: attempts to split the autism spectrum into distinct groups, some of whom should receive treatment consistent with the medical model (prioritizing the reduction of diagnostic traits) while others should receive more neurodiversity-friendly services. For example, Baron-Cohen (2019) argues for "taking a fine-grained look at the heterogeneity within autism" in order to determine which kinds of autistic persons fit into each approach, claiming that doing so is necessary in order to address the needs of autistic people with severe intellectual disability or limited capability to communicate through speech.[48] Similarly, a recent commentary from Camarata (2022) responds to critiques regarding an intervention designed to promote typical social behavior in autistic teenagers by arguing that such criticisms should only apply to autistic people whose "whose social and communication skills are sufficient to generate social pressure to mask autism characteristics and/or who would otherwise be harmed by forcing conformity."[49] Camarata roots this argument in the need to permit interventions oriented towards "initiating social communication and speech and language acquisition" in autistic persons who lack functional communication capable of making complex thought understood to others.

Such responses to neurodiversity critiques of passing interventions are not uncommon. They each focus on the presence of severe impairment, arguing that opposition to passing demands ill-serves the needs of severely impaired autistic people and thus should be limited only to interventions targeting autistic people with less severe forms of impairment. We agree that it is important to ensure that opposition to passing demands does not remove the ability to provide interventions designed to promote necessary and important skills, such as communication, or mitigate intrinsic harms, such as self-injury. However, we argue that a division of the autistic population into those for whom neurodiversity and those for whom the medical model applies would be counterproductive and harmful. We also contend that the critique of clinical passing demands does not necessitate an abandonment of efforts to mitigate the harms of severe impairment.

After all, there is no reason to believe that efforts to promote eye contact or suppress non-harmful stimming do not impose similar cognitive demands on severely impaired autistic people as they do on others. Indeed, given the more extensive support needs autistic people with severe impairments have, it might reasonably be argued that the opportunity cost of focusing on goals that do not provide them with meaningful benefit is larger than the cost it imposes on other autistic people. The critique of clinical passing demands thus continues to be relevant for the severely impaired population. In the same fashion, there are certainly areas in which the medical model is relevant to autistic people with less severe impairments. For example, difficulties with independent living skills or self-injury can be appropriate targets for intervention even in autistic people with no intellectual disability or difficulties with verbal communication. Consistent with this, neurodiversity proponents generally support measures to improve adaptive skills.[50]

Instead of segmenting autism into distinct populations, IRBs should instead evaluate the appropriateness of intervening with respect to specific traits an autistic person may possess using the framework we lay out above.[51] Traits that impose harm are appropriate targets for intervention. Traits that are merely socially stigmatized are not. Because autism is a multi-dimensional phenomenon (to a far greater degree than many other disabilities, such as mobility impairment) the ethics of intervention must be assessed on the far more granular basis of traits rather than that of particular types of individuals. Whereas proponents of “splitting” the autism spectrum argue for classifying individuals into medical model vs neurodiversity oriented approaches, our approach “splits” only on the basis of individual traits. We thus recognize that neurodiversity and the medical model may have relevance to different attributes of the same person.

Interventions at the Level of Individual or Society?

In discussing various approaches neurodiversity advocates could take to drawing these distinctions, Dwyer (2022) notes that debates regarding disability interventions more generally often focus on the appropriateness of intervening at the level of the individual (i.e. attempting to change behavior, prescribe medication or modify biology) versus intervening at the level of society (i.e. removing accessibility barriers, improving public acceptance, providing additional services and/or civil rights enforcement).[52] While neurodiversity advocacy has often criticized the lack of emphasis given to society-level interventions relative to individual ones, proponents do support many interventions at the level of the individual, such as measures to enhance adaptive skills or medication to address anxiety, epilepsy or other co-occurring conditions.[53] As our model permits interventions to target autistic traits when doing so to advance a beneficial non-passing purpose in the least burdensome fashion, we share this view and also see a role for both individual- and society-level interventions.

Dwyer argues for what he terms an “interactionist neurodiversity framework”, in which interventions “could operate at the individual level (e.g., stimulant medications for ADHD individuals), by changing the environment (e.g., removing environmental distractors), or by changing both the environment and the individual. The decision between these alternatives should not be based on whether the individual or environment is perceived to be the ultimate cause of the disability but based on which intervention would best enhance quality of life.” Such an approach “would allow interventions to attempt to promote well-being by teaching adaptive skills [but]...would not endorse interventions that aim to 'normalize'" those receiving services to look more neurotypical.[54]

This approach is largely consistent with our own. We believe our requirement that interventions be the “least burdensome means” of achieving a non-passing goal to be a more precise formulation of this framework appropriate to the autism context (and likely for many other diagnoses, too, though we leave efforts to articulate its boundaries for future work) as it operationalizes the nebulous concept of “quality of life” in a way that provides IRBs, researchers and clinicians with more concrete information on how to evaluate potential interventions.

One potential distinction between our approach and Dwyer’s is on the question of whether an autistic person’s quality of life might be enhanced by passing, despite the burdens it imposes. By requiring that interventions serve a non-passing purpose, we implicitly preclude the possibility that a clinical passing demand might ever yield a benefit worth imposing a burden for. To justify this position, we note the unique context of passing demands embedded into clinical interventions. While an autistic person might choose to pass in specific contexts on their own, the imposition of such a passing demand from a clinician or researcher as a standardized component of intervention is likely to reflect the “passing-as-ethics” dynamic articulated by Vivian (2012), whereby passing is not a time-limited, contextual activity a person engages in of their own volition but instead a totalizing demand to suppress autistic traits across contexts. We would thus argue that while passing may represent an ethical goal for an autistic person to choose for themselves, the presence of a passing demand embedded as a standard component of a clinical intervention is not appropriate or ethical, and could therefore not count as a benefit that justifies burdens on research participants

To illustrate this point, we refer back to the examples cited in Table 1 earlier in this section. As discussed, the SRS-2’s inclusion of “avoids eye contact or has unusual eye contact” as an item effectively embeds the encouragement of eye contact as a clinical passing demand particularly when the SRS-2 is used as an outcome measure for research testing autism interventions. However, the assertion that the inclusion of this item as a measure of impairment or other outcomes is unethical does not mean that an autistic person may not choose to make typical eye contact a goal in a specific context, such as a job interview or other high-stakes social interaction in which limited passing may garner greater benefit than burden. However, the inclusion of eye contact as an item within a standardized measure of social success/impairment does not permit such passing efforts to be contextual or limited to circumstances sought by the autistic person.

We close with a series of operationalizable recommendations for IRBs to take into account when reviewing autism research with respect to these issues.

SECTION 5: RECOMMENDATIONS

First, we affirm that harms from clinical passing demands are an appropriate arena of concern for IRB review and that IRBs should undertake efforts to identify potential clinical passing demands in the research they review. Given that the harms of clinical passing demands are both a frequent component of autism interventions and have largely been overlooked by most investigators, we believe that IRBs should carefully scrutinize each instance of human subjects research involving autistic persons for such passing demands. In doing so, IRBs should begin with a careful item-by-item review of outcome measures employed by researchers. By making use of the two-part test we articulate in Section 4, it is possible for IRBs (and appropriate external consultants) to assess the ethical appropriateness of items that seem as if they may impose potential clinical passing demands.

Where items are identified within an outcome measure that fail to meet ethical review, IRBs should require investigators to either select a different outcome measure or modify the measure to remove items that impose unjustifiable passing demands. Both options present challenges for investigators. In the former instance, the frequency of clinical passing demands in commonly used autism outcome measures may make it difficult to find viable alternatives. In the latter instance, modifications to an existing measure may call into question prior psychometric work conducted to assess the validity of the unmodified measure. Nonetheless, even with these challenges, it is important for IRBs to protect autistic human subjects from the harms imposed by clinical passing demands. Furthermore, by insisting that investigators either replace or modify existing outcome measures, IRBs can play an important role in encouraging the development and validation of alternative, more ethically acceptable measures.

We have placed our primary emphasis on outcome measures because they are comparably easy for IRB members to obtain and review from study personnel in a timely fashion. In contrast, it may require substantial training and on-site observation to properly evaluate the details of interventions. However, it is also common for clinical passing demands to be embedded into interventions under evaluation even where they do not feature in the outcome measures through which such interventions are assessed. IRBs should be aware of this possibility and plan to raise this concern with investigators when assessing autism intervention research, particularly when that research involves intervention methodologies for which concerns regarding clinical passing demands have been raised by stakeholders or applicable research literature. Where necessary, IRBs should request detailed information regarding intervention content, seek appropriate expertise for evaluating its ethical appropriateness, and seek revisions where necessary to avoid subjecting research subjects to harm or unnecessary risk.

Second, the concerns raised here point to the importance of appropriate engagement of stakeholders in research design and review. The significance of inclusion and diverse membership is not a new insight; expectations of a diverse IRB membership have been part of the Common Rule since its inception,[55] and communities who often find themselves merely as subjects of research with inadequate representation in research design and infrastructure have long been advocates of community-based participatory research.[56] IRBs may benefit from seeking the advice of community stakeholders when assessing outcome measures and interventions themselves for potential clinical passing demands. However, the framework we have proposed in Section 4 illustrates a further specific reason for ensuring direct participation from invested groups: better benefit *assessment* when attempting to determine the ethical appropriateness of the study.

Autistic persons are better positioned to offer insight into whether a treatment goal offers some intrinsic benefit aside from the promotion of typical appearance. They may also be particularly well suited to examining whether such a treatment goal is the least burdensome means of accomplishing that purpose. As such, we believe that the two-part test we articulated in Section 4 is best operationalized with input from autistic stakeholders.

Even neurotypical persons who, in the words of the diversity condition of the Common Rule, exhibit “sensitivity to such issues as community attitudes” (45 CFR 46.107(a)), will have less insight into the issues raised by clinical passing demands than autistic persons, even if they are able to point to reasons to question such assumptions. While it is certainly legitimate and beneficial to consult with family and/or provider stakeholders as well, there is no substitute for the representation of autistic people themselves. In addition, efforts must be made to not only include autistic persons in such deliberations, but to endeavor to equalize the power dynamic between autistic and non-autistic persons as much as is feasible.[57] While some have argued that the inclusion of autistic stakeholders constitutes partial representation (given the diversity of the autism spectrum), we believe that these criticisms do not in any way counter the imperative of autistic representation in the research process.[58] No single stakeholder - be they autistic, parent or provider - can represent through personal experience the entirety of a given community. It is for this reason that it is important to ensure that stakeholder representation is not limited to only a single token individual and comes from stakeholders who have a background in the autistic community that goes beyond their own personal experience. As such, wherever feasible, multiple autistic representatives should be included in discussions of benefit assessment.

Given the importance of adequate representation of autistic persons for good benefit assessment, it would be important to consider the traits necessary for serving as a good representative in discharging this role for particular studies. This is particularly important given both the diversity of the autism spectrum and the challenges with deferring to investigator expertise regarding assessing risks to autistic human subjects discussed in Section 2. To secure appropriate representation in assessing benefits of research for autistic patients, a central valuable trait is the ability to operate and navigate within hostile environments as someone with a non-dominant perspective. While gaining entry to a committee is necessary, the ability to consistently and persuasively express a minority viewpoint as it pertains to ethical considerations, to a group of people that may be unused to hearing or considering such perspectives, is key to securing proper consideration in deliberation about the envisioned benefits of a study.

This naturally suggests that strong consideration should be given to seeking input on benefit assessment from individuals from autistic self-advocacy organizations. Such individuals generally are invested in representing the diversity of experiences among autistic persons and will have been in communication with many autistic persons regarding their experiences, offering insight beyond their own personal point of view. They also are likely to be particularly skilled at effectively communicating on behalf of autistic persons in ways that do not flatten this diversity. Moreover, these persons may have greater experience working within institutional settings that may find counterarguments to common assumptions undergirding the benefits of such research to autistic persons inconvenient or frustrating, and are likely to be more skilled at navigating skepticism or outright hostility.

At the same time, reliance on community leaders may pose challenges for securing a sufficiently diverse body of representatives as well as overly burden a relatively small number of people with challenging and undercompensated roles. In order to improve the representation of autistic people in IRB deliberations, it may be useful for research institutions to consider making targeted investments in building a pipeline of autistic persons trained in both the underlying regulatory and conceptual framework of research ethics and the aforementioned knowledge regarding effective advocacy as a minority voice in such environments. Such efforts should proceed in parallel with engagement with autistic self-advocacy organizations and initiatives designed to recruit and train autistic researchers, recognizing that autistic people can contribute to research as both investigators and non-researcher community representatives.

Third, and finally, we believe that it is not possible to adequately address either the potential harms posed by clinical passing demands or the often complex ethical questions as to what treatment goals may be legitimate in autism research on an ad hoc basis. While in the near term these issues may need to be addressed on a study-by-study basis, there is a need for the development of a sizable literature to assess the suitability of potential treatment goals and inform the revision of existing autism outcome measures and interventions.

We highlight this as an area in need of further work. We foresee an emerging literature evaluating the ethics of particular items within clinical outcome measures, their appropriateness as intervention targets and the broader legitimacy of intervention with respect to specific autistic traits. In some instances, such as self-injury, we believe that an affirmative case for intervention will be easy to make. In others, such as lack of eye contact, we believe it obvious that existing modes of autism intervention represent an illegitimate passing demand. We also anticipate the existence of many instances of autistic traits where the appropriateness of intervention will be more contested, requiring further discussion and debate between both autistic and non-autistic researchers and community stakeholders of all kinds.

Such work will not be limited to autism but will likely be broadly relevant to any diagnosis primarily defined by behavior, where clinical passing demands are likely to represent a serious ethical concern when designing and implementing interventions. However, due to the issues we articulated earlier regarding values conflicts in autism research and a culture of underreporting of risk and conflicts of interest, we believe particular scrutiny and development of an ethics literature in this area is necessary in the autism context.

CONCLUSION

Despite a growing body of evidence linking passing demands with harms experienced by autistic persons, autism research practice has failed to account for these risks. In this article, we have summarized the applicable literature documenting a relationship between passing and various harms to autistic persons, highlighted the frequency with which passing demands are embedded into common autism interventions and the outcome measures used to assess them, and proposed a two-part test for evaluating the ethical appropriateness of treatment goals in light of these risks. IRBs should carefully scrutinize autism research proposals for potential harms emerging out of clinical passing demands, consulting with autistic community stakeholders for expertise when doing so. At the same time, we highlight the necessity of building out a research literature on the ethical appropriateness of particular treatment goals, interventions and outcome measures commonly used in autism research. Such a literature will provide IRBs, investigators and other stakeholders with a broader base of knowledge when assessing whether a particular treatment goal serves a beneficial non-passing purpose and is the least burdensome means of achieving that purpose.

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Table 1: Examples of Clinical Passing Demands in Common Autism Outcome Measures

Measure	Items Used in Measure
Pervasive Developmental Disorder Behavior Inventory	"Flaps hands up and down"
Pervasive Developmental Disorder Behavior Inventory	"Makes odd or unusual finger movements (e.g., flicks fingers)"
Pervasive Developmental Disorder Behavior Inventory	"Puts an unusual stress on words when speaking (not due to regional accent)"
Pervasive Developmental Disorder Behavior Inventory	"Spins objects (e.g., wheels of toy cars, strings) in a repetitive manner"
Social Reciprocity Scale-2 (School-Age)	"Avoids eye contact or has unusual eye contact"
Social Reciprocity Scale-2 (Adult)	"I have repetitive behaviors that others consider odd"
Social Reciprocity Scale-2 (Adult)	"I tend to talk in a monotone voice (in other words, less inflection of voice than most people demonstrate)."
Children's Yale-Brown Obsessive Compulsive Scale in Autism Spectrum Disorder	"Repetitive behavior involving sensation (rocking, spinning, jumping, pacing)"
Children's Yale-Brown Obsessive Compulsive Scale in Autism Spectrum Disorder	"Hand or Arm flapping"
Children's Yale-Brown Obsessive Compulsive Scale in Autism Spectrum Disorder	"Repetitive play with certain objects: trucks, trains, dinosaurs"
Children's Yale-Brown Obsessive Compulsive Scale in Autism Spectrum Disorder	"Ordering, arranging (places toys/objects/furniture in assigned place)"
Autism Treatment Evaluation Checklist	"Dislikes being held/cuddled"
Autism Treatment Evaluation Checklist	"No Eye Contact"
Autism Treatment Evaluation Checklist	"Appropriate facial expression"