



## For Whose Benefit? Evidence, Ethics, and Effectiveness of Autism Interventions

Executive Summary and Ethical Guidance Brief

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#### **Executive Summary**

As recognition and diagnosis of autism continues to increase, a variety of medical and social-behavioral therapies and services have emerged. However, little attention has been paid as to whether or not these services truly benefit autistic people. Autistic people are rarely involved in the creation or implementation of autism-related services, which creates questions around who is deciding what these services should address.

One of the main interventions for autism is Applied Behavioral Analysis (ABA). ABA is a model of intervention focused on changing the external behaviors of autistic children, with the goal of making an autistic child look and act nonautistic. Ethical concerns have been raised within the autistic community as to how ABA and similar practices serve to "normalize" autistic children, via teaching children to hide their autistic traits. Hiding autistic traits has been linked to worse mental health outcomes and increased suicidality in autistic adults. Furthermore, these practices often "normalize" autistic children at the expense of promoting key life skills, self-determination, and self-esteem. However, the autistic community's concerns around therapies and services for autism go far beyond the issue of "normalization" or even ABA specifically.

In order to learn what specific concerns autistic people have with autism therapies and services, ASAN conducted a thorough literature search and review, focusing on what autistic people have said and written about autism services. We also conducted a literature search to explore the strength and quality of the evidence supporting different autism services.

In our report, we identify several main topics as critical to the evidence and ethics of autism therapies and services. First, we explore the strength of the evidence for different autism services, finding that it is often quite poor or that it does not support the grandiose claims that services often advertise themselves with. We also find that, even when there is evidence to support the efficacy of different interventions, it is rarely evidence of outcomes that are ethically sound and meaningful to autistic people ourselves. Next, we categorize the ethical concerns autistic people have with autism therapies and services broadly. In addition to the concerns around "normalization" raised earlier, we find significant concerns around violations of consent and bodily autonomy; the pathologization of unremarkable behavior; and the amount of risks interventions often subject autistic people to for little reward. We also find specific concerns around ABA, namely, the brutal practices that ABA historically and currently uses; ABA's connections to LGBTQ+ conversion therapy; and the way ABA dehumanizes autistic people through its view of our behaviors.

We also address two common arguments around autism interventions: first, that "new ABA" is ethical because of its gentler approaches to "normalizing" autistic people when compared with "old ABA"; and second, that our concerns are solely with ABA and similar interventions. We argue that "new ABA" is no more acceptable or ethical than old ABA, even if it is less brutal. We then argue that our concerns are not with any single autism intervention or type of intervention. Rather, we argue that all autism services can have unethical components and that people developing, administering, or considering a therapy or service must analyze the ethics of said therapy or service closely.

Finally, we derive a core set of underlying ethical principles for autism-related services, and propose an ethics framework based upon these principles for the development and delivery of autism-related services for children, adolescents, and adults. We construct this framework broadly to address a wide range of current and future approaches, including applied behavioral analysis, developmental approaches, naturalistic developmental behavioral interventions, psychiatric medication, speech and language therapy, occupational therapy, and others.

The Autistic Self Advocacy Network seeks to advance the principles of the disability rights movement with regard to autism. ASAN believes that the goal of autism advocacy should be a world in which autistic people enjoy equal access, rights, and opportunities. We work to empower autistic people across the world to take control of our own lives and the future of our common community, and seek to organize the autistic community to ensure our voices are heard in the national conversation about us. Nothing About Us, Without Us!

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#### **Ethical Standards and Guidance**

After thoroughly exploring the literature and summarizing some of the ethical questions inherent in different autism therapies and services, we derived the following set of ethical principles for autism services. We have divided these into four categories: first principles and core ethical statements, "always acceptables" and practices to promote in autism supports, "never acceptables" and red flag practices that are abusive, and ethical guidelines for research into autism therapies and services. We emphasize that these guidelines and principles apply to *all* therapies and services autistic people go through, regardless of whether those therapies and services are autism-specific or what the therapies and services call themselves. These principles are not intended to be exhaustive, but to provide a starting point for service providers, researchers, and educators to examine their practices and identify initial areas for change.

#### First Principles and Core Ethical Statements

Autistic people are people. We are human beings with thoughts, feelings, wants, needs, and dreams. We experience pain and joy, just like non-autistic people do. Our internal experiences and inner lives are important, even if they are different from those of non-autistic people. We have the same human rights as non-autistic people. We may struggle with things that non-autistic people do not but this *does not make us less human*. Autism is not a justification to abuse us or subject us to harmful therapies against our will.

This statement is true of all autistic people. It is true of autistic children. It is true of autistic adults. It is true of autistic people of color. It is true of autistic women and non-binary people. It is true of non-speaking autistic people. It is true of autistic people with intellectual disabilities. It is true of physically disabled autistic people. It is true of autistic people with mental health disabilities. It is true of autistic survivors of seclusion, restraint, institutionalization, and forced/ coerced/involuntary treatment. It is true of any and all multiply marginalized autistic people. It is true of all autistic people. There is no group of autistic people that is okay to abuse or harm because they are autistic or because of other parts of their identity.

Autistic traits in and of themselves are not acceptable targets for intervention. Therapies and services must have a more concrete and substantial rationale for targeting a particular trait than "it is an autistic trait" or "it makes this person look different." Autistic people have full, rich selves. We do not exist to be made "less autistic" or "more typical."

**Autism and autistic people do not exist in a vacuum.** We are affected by our environments and the actions of others around us. It is not solely the autistic person's duty to "fix" communication breakdowns and differences in experiences between us and non-autistic people. It is also the duty of non-autistic people around us to help fix these breakdowns – and also realize when something is less a problem to be solved and more a matter of different communication styles.

Autistic people have the same right to give, and refuse, informed consent and assent as our non-autistic peers. We have the same right to information about the services we receive. If we cannot give informed consent to a given service (for example, an autistic child who cannot legally consent), we still must be given the chance to give or refuse assent.

Therapies and services must focus on improving the autistic person's quality of life by increasing opportunities for and access to self-determination, communication, self-advocacy, and other goals that are important to the autistic person in question. The autistic person must be involved in setting those goals. If an autistic person cannot make their goals clear (e.g., because of age or communication barriers), their goals should be set based on their team's most reasonable guess of what will best allow them to lead a self-determined life and what needs and wants they are currently demonstrating. If a goal must be set against a person's wishes (e.g., teaching someone not to run into traffic so they can safely cross the street), it must be explained to them why it is so important and implemented in such a way that the person maintains as much control over the intervention as possible.

Autistic children thrive when they have the supports they need to succeed, just like any other child. Autistic children often respond well to structured, accessible interaction with an adult who is focused on them, supporting their communication and engagement, sharing learning and enjoyment, and providing a warm, positive relationship – as would any child. Providing these kinds of supports is crucial, and should not be conflated with "treating" autism. An autistic child who does well or appears more visibly engaged with these kinds of supports in place isn't becoming less autistic – they're simply showing what they are capable of with the right support.

**Therapies and services should use knowledge that we have about humans in general to best support autistic people.** Therapies and services should treat autistic people as capable of learning, growing, and developing, just like all people do when well-supported. Therapies and services must not portray autistic people as a nebulous "other" type of human who cannot learn at all from the same techniques as non-autistic people.

**Supports don't need to be autism-specific to help autistic people**. For example, an autistic child who has trouble with handwriting might benefit from the same type of occupational therapy and assistive technology (such as typing assignments rather than handwriting them) that a non-autistic child would. Supports also don't need to be specifically for disabled people to help. For example, while some autistic adults who want to drive will require specialized instruction, many autistic adults just need the same kinds of driving lessons that non-disabled people have.

Autistic people have a wide variety of interests, hobbies, and activities we enjoy, just like non-autistic people. **We have the right to engage in these activities without it being a "therapy" or "intervention."** Our hobbies do not exist to be tools to make us more "normal." Even if we need support or accommodations to engage in an activity (e.g., an autistic person who needs a support person to accompany them to a weekly board games night), that should not make the activity a therapy.

What the intervention calls itself is not as important as what it actually is. There are therapies and services that are largely ethical but call themselves ABA because that is the only way insurance will cover them. There are interventions that insist they are not ABA or they are "safe" alternatives to ABA, despite being rooted in ABA or having significant unethical elements.

#### "Always Acceptables" and Practices to Promote

**Trauma-informed approaches** and making sure practitioners are trained in trauma-informed care.

**Cultural competency and cultural humility** among practitioners<sup>1</sup> and making sure practitioners provide care and services that are sensitive and relevant to the autistic person's culture, community, and social background.

Ensuring that the autistic person always has **an effective and robust method of communication as the first priority**. An "effective and robust" method of communication means a method that allows the person to communicate whatever they have to say, does not limit them to simple requests, allows them to create grammatically correct sentences if they choose to, and is relatively easily understood by those around them. If speech is not a reliably effective and robust method of communication for the autistic person, they should be provided with an augmentative and alternative communication (AAC) system. Effective communication also means working in the language the person is most fluent in and most comfortable using, even if this is not the dominant language of the area. Ensuring effective and robust communication for AAC users also means supporting them in learning how to use, program, and care for their systems and devices. For some autistic people, this process may take a lifetime. Support should be provided for as long as the person needs or desires it.

**Giving the person space and time** to move around (including stimming), take breaks, and feel comfortable. Explicitly **encouraging the autistic person to communicate** (in whatever ways they need to) if something is wrong or if they don't like something, or, conversely, what they *do* like or want during the intervention

Explicitly encouraging the autistic person to **communicate their goals for the intervention**. **Including the autistic person as a core member** of all goal-setting/planning the course of the intervention and any associated meetings, such as IEP meetings or support planning meetings.

**Presuming competence**: presuming that, with the right supports, the autistic person is capable of learning, thinking, communicating, and gaining new skills. A practitioner who presumes competence focuses on identifying the supports an autistic person needs in order to meet their goals, rather than making assumptions about what they can and cannot do.

Cultural humility is "a lifelong process of self-reflection and self-critique whereby the individual not only learns about another's culture, but one starts with an examination of her/his own beliefs and cultural identities" (Yeager & Bauer-Wu, 2013, p. 2). It is contrasted from cultural competency, or the "attitudes, knowledge, and skills necessary for providing quality care to diverse populations" (Calvillo et al., 2009, p. 138).

**Minimizing physical contact** to what is absolutely necessary for the intervention to work. **Asking for consent every time** physical contact is necessary and informing the person of exactly what the physical contact will be. For example, in some kinds of physical therapy, contact between the therapist and the client will be inevitable. But asking for consent ("is it okay for me to touch your shoulder now?") and telling the person what the contact will be ("I'm going to put my hands on your upper arm and slowly rotate your shoulder.") is important!

**Distinguishing when an issue is less something for the autistic person to do differently and more something to change in their environment or address in the behavior of others around them.** For example, if an autistic person has meltdowns at school everyday because they find the lighting too harsh, changing the lighting in their classroom instead of trying to get them to tolerate it. If they have a meltdown every time their neighbors mow the lawn, working with the neighbors to find a time when the person won't be around and mow the lawn then.

**Figuring out when the issue is something that could be resolved with assistive technology** and equipment. (This does not need to be disability specific equipment.) For example, if someone is sun-sensitive to the point it causes meltdowns, make sure they always have a hat and dark glasses with them. If someone chews holes in their shirts when they stim, buy them stim toys specifically designed for chewing.

**Targeting services and supports towards specific skills and problems** (for example, learning how to drive, finding a job, reducing frequency of self-harm) rather than "autism" or broad diagnoses in general. Similarly, when providing support to gain specific skills or address specific problems, examine if the supports truly need to be autism-specific, or if there are generic supports used by a range of people with disabilities that might meet this person's needs.

Working with other healthcare providers to **ensure an issue is truly behavioral, not medical, in nature**. For example, someone who has severe migraines that manifest as meltdowns where they curl into a ball, holding their head, needs to be assessed by a neurologist, not put into an intervention to change how they behave during a meltdown. If there is a sudden change in someone's behavior and they cannot explain why, the first course of action should be a medical evaluation to rule out or identify medical causes.<sup>2</sup>

**Provide support in inclusive settings (those where disabled and non-disabled people are together) whenever possible.** Therapies and services (especially school-based therapies and services) should be offered in the least restrictive environment possible. Whenever possible, **offer services in a setting of the autistic person's choice** (for example, home, clinic, school or day program). If an intervention is being offered for autistic people in a mixed setting (e.g., autistic students in a mainstream classroom), it should be offered without removing or pulling out the autistic people as much as possible.

**Rejecting functioning labels** and other unclear, undefinable ways of labeling a person rather than identifying their specific needs. Avoiding pejorative labels like "low-functioning" for autistic people who have high support needs, intellectual disabilities, who are non-speaking or engage in self-injury. Similarly, avoiding labels like "high-functioning" for people with lower support needs, as these labels are often used to deny people services they would benefit from.

Acknowledging, celebrating, and encouraging what a person can do and is good at. Finding ways to connect a person's strengths to their goals. This should also include finding ways to integrate the autistic person's interests into the intervention – not as a way to modify their behavior, but to engage with that person and increase the chances they will find the intervention meaningful.

**Embracing the idea that all people (autistic and non-autistic alike) grow up and change on different developmental tracks**. An autistic child may develop some skills later than non-autistic children, or in an unusual order. While knowledge of developmental stages can be useful in assessing and diagnosing developmental disabilities, including autism, they are not a roadmap that must be forcibly followed. Therapies and services should be helping autistic children develop skills because they are relevant to their personal goals – not because they are next on the typical timetable.

<sup>2</sup> Clarissa Kripke, the director of the Office of Developmental Primary Care at UCSF, has written extensively on the need for medical evaluation of behavior changes in autistic people and other people with intellectual and developmental disabilities (2016a, 2016b, 2016c, 2018).

#### "Never Acceptables" and Red Flag Practices to Avoid

**Targeting "undesirable" traits or behaviors that are common in all people of a certain age**, autistic or not. In other words, therapies and services should not pathologize normal/typical behavior for the age group of the client. An autistic 5-year-old being unable to sit still for long periods of time or an autistic 15-year-old wanting to play video games all day aren't "autistic behaviors," they're just things that most 5- or 15-year-olds go through. Holding autistic people to higher standards than their non-autistic peers merely because they are autistic is unacceptable.

**Deeming a trait or behavior "desirable" or "undesirable" based on whether it is typical of people of a certain age**. Therapies and services should not force autistic people to engage in a behavior simply because most people their age do it or discourage a behavior because most people their age do not do it. For example, discouraging a 15-year-old from talking about Dora the Explorer because "that's not what teenagers talk about." We realize that there are some activities that most people learn at a certain age (e.g., toilet training toddlers or teaching elementary school children to read). We do

not object to autistic children learning these skills because their similar-age peers are learning them, so long as there is a

more substantial reason for them learning the skills than "it's just what people their age do."

**Stating or implying that there is only one possible or "correct" way for all people to learn a skill** (e.g., learning to speak, learning to solve math problems). For example, insisting that visual joint attention is an inherent requirement for developing speech or that nonverbal communication is a prerequisite for symbolic thought in all humans. Even among non-autistic and non-disabled people, there is a tremendous diversity of how people learn any given skill. There are as many developmental paths as there are humans. Just because one way of learning or developmental path is more common does not make it the "correct" one or the only possible one.

**Conflating impairments in areas like speech or motor skills with the absence of internal processes and feelings**. For example, many autistic people have speech disabilities. A difficulty in producing oral speech is distinct from an impairment in language processing, which the autistic person may or may not struggle with as well. But often, nonspeaking people are automatically assumed to have language disabilities. Similarly, autistic people are known to experience varying degrees of difficulty with motor planning and other motor skills, which can impact our speech, facial expressions, and how we appear to relate to other people or our environment. This means that it is dangerous to make assumptions about what an autistic person understands or how they think or feel based on these things.

**Teaching autistic children to assume that their viewpoint or way of being in social situations is wrong,** and that they must defer to their neurotypical peers, whose way of being is "correct." This can be done by explicitly telling autistic children repeatedly that their way of social interaction is wrong. For example, it is obviously harmful to tell an autistic child that they are approaching social situations incorrectly because they have an inflexible mind, so they should default to copying their peers. But it is also harmful to more implicitly show an autistic child that, if there is a discrepancy between what they are doing and their neurotypical peers, their neurotypical peers will be held up as an exemplar.

**Punishing autistic people differently than non-autistic people for the same behavior** solely on the basis of autism/ related diagnoses. For example, if a non-autistic speaking child swears, their teacher might tell them "we don't use words like that in class, it's not appropriate right now." But if a non-speaking autistic child who uses an AAC device swears, the teacher might take their device away from them so they can't talk at all.

**Focusing on non-specific "social skills," to the detriment of all other skills.** Autistic people, like all people, need and deserve support on a wide range of skills and activities, not just those related to socialization or interpersonal interaction. Moreover, while most daily activities have *some* social component, knowing how to navigate a general social situation is not enough to navigate many activities. For example, an autistic person who cannot navigate a bus system on their own due to sensory or executive functioning barriers would probably be poorly served by social skills instruction to learn this particular skill. Or, an autistic person applying for jobs might benefit somewhat from generalized social skills support, but would also probably need help with application-specific skills. When the balance of time spent shifts too far in favor of social skills, other crucial skills suffer.

**Social skills training that encourages autistic people to merely "act neurotypical" rather than presenting neutral information for navigating social interactions**. Autistic people may need support in interpreting social situations or thinking through how to respond. There are ways to provide helpful information, but the goal should be to provide

that information in a neutral way so we can decide what we want to do with it. Too many social skills interventions simply promote masking or camouflaging autistic traits, or inflexibly presume there is one correct way to handle a given situation. Support in thinking through social scenarios should not be seen as *training*, but should aim to empower autistic people to self-advocate and give us tools to make the social decisions that we decide make the most sense for us. We realize that there are examples of social skill-type supports that focus on a specific scenario or subset of skills (e.g., a sexual education class or training on job interview skills). We do not object to these types of supports, especially if they are offered to the autistic person's non-autistic peers as well.

A goal of indistinguishability, or making the autistic person appear "normal" or exactly like their non-autistic peers.

A **goal of reducing stimming.** In some rare cases, a person might express they want to reduce a stim for a practical purpose; for example, someone who communicates using an AAC device and stims by hitting their device at random, to the point where they are distressed that they cannot use their device to communicate. As we addressed above, there are some stims that a person may want or need to redirect as a matter of safety. But even when there is a very good reason to stop or modify a particular stim, the **goal should never be to eliminate stimming entirely**. The goal should be to help them find a stim that does not have the same negative effects (for example, someone who is distressed by hitting their AAC device might get calming input by squeezing a stim toy instead).

Using restraints or seclusion of any kind.

Using aversives of any kind.

Abuse or neglect of any kind, including, but not limited to, physical, verbal, emotional, sexual abuse.

**Using basic needs** (for example, food, drink, toys, favored objects, breaks, change of activity, attention, special interests) as rewards.

Withholding basic needs (for example, food, drink, toys, favored objects, breaks, change of activity, attention, special interests) as a punishment

Hassling, harassing, coercing, or annoying an autistic person who has communicated "no" until they say "yes." Coerced consent is not consent.

**Knowingly or intentionally overriding someone's "no."** We recognize that sometimes caring for children requires compelling a person to do something they do not want to do (e.g., a child who needs to get a vaccine but is scared of needles). We are not referring to such instances here, but rather when interventions portray the mere *act* of saying no as "non-compliance" and teach the autistic person that their right to say "no" does not exist.

**Using "exposure therapy,"** or teaching autistic people to "tolerate discomfort" in and of itself, as opposed to giving us tools to self-regulate, helping us reduce and control exposure to painful stimuli, or changing our environment to reduce exposure to triggers.

**Patronizing/infantilizing language and actions**, such as treating an autistic person as younger than they are. For example, speaking to an autistic teenager in a "baby voice." We stress here that this does not mean autistic people should be kept from engaging with interests atypical for their age group (e.g., preventing a teenager from watching Sesame Street because "they're too old for that"). We also stress that this does not mean autistic people should be denied accommodations such as information in Easy-Read or plain language or simplified instructions merely because these things use simpler language, if this is an accommodation a person needs.

**Using "mental age,"** e.g., saying "this person has the mental age of a 5-year-old" of someone who is not actually five years old. Using mental age is offensive and demeaning to autistic people, and especially autistic people with co-occurring intellectual disabilities (Smith, 2017). Autistic people, regardless of our support needs, are the same "mental age" that our bodies biologically are. An autistic adult with an intellectual disability is not a 5-year-old in an adult's body; they are an adult with a lifetime of experiences, knowledge, and relationships, who also is autistic and has an intellectual disability.

Using deficit-based thinking, or focusing mainly on what an autistic person cannot do or has trouble with.

Touching autistic people unnecessarily (for example, using hand-over-hand tactics).

**Portraying an intervention as "the only way [the autistic person] can learn."** While autistic people may share certain general cognitive styles and differences in ways we learn, think, and communicate, we have as many learning styles as non-autistic people do. There is no one ultimate autism intervention that will work for every autistic person. While some autistic people do need heavily individualized services and one-on-one support to learn, this does not mean that they cannot learn using a variety of methods if given the proper supports. We urge people to be wary of practitioners who claim that their interventions are the "only way autistic people will learn" or that they are the only people who can save us.

**Portraying autistic people as some kind of nebulous "other"** to whom general knowledge about humanity does not apply. The fields of child development, educational psychology, and many others offer plenty of useful information applicable to autistic people, who are first and foremost human beings. We can acknowledge common differences in how an autistic person might process or express something without treating autistic people as inhuman aliens who are incapable of human emotions or relationships, unable to share any common human experiences, and who cannot ever learn, develop or change.

Asserting that an autistic person will never "improve" without multiple hours of a specific therapy/intervention per day.

**Subjecting an autistic person to multiple hours of intervention per day**, to the point where the person is prevented from other important life activities (including rest and relaxation), the person is obviously in distress, or there is no observable purpose or benefit for the excess hours of intervention. This does not need to be multiple hours of *one* intervention per day; it can be the sum total of multiple interventions or interventions on top of other necessary events in the person's day, such as school.

**Predicating certain types of services or supports (and funding for those services and supports) on the autistic person/ their family/supporters accepting a different type of intervention**. For example, an autistic person on Medicaid who wants to have their waiver pay for environmental modifications to replace harsh fluorescent lighting in their apartment should not be required to undergo ABA to help them "tolerate" fluorescent lighting before Medicaid pays for the modification.

**Predicating services and supports on an autistic person already possessing certain skills or demonstrating certain behaviors**, unless those skills and behaviors are absolutely necessary for the intervention to proceed safely. For example, autistic children can learn academics without being "table ready." Similarly, autistic people should be provided access to robust AAC from the start, instead of having to prove they can use more limited artificial systems first.

**Requiring autistic people to give up or not use their assistive technology**, unless there is a clear and unavoidable reason why the intervention could harm the assistive tech and a suitable alternative is offered. For example, telling someone they can't use their AAC device in a class about developing relationships is wrong; telling someone they can't use their AAC device in the pool during swim therapy might be understandable if getting the device wet would cause it to stop working. In that instance, the person should be offered an alternative that can get wet, like a laminated letterboard or a whiteboard to write on.

#### Principles for Research into Autism Therapies and Services

Therapies and services must be developed and researched with autistic people as part of the core research and development team. Autistic feedback needs to be considered and respected at all points of the research, formulation, development, and administration of the therapy or service. There should be multiple autistic people on the research and development team, representing a diversity of opinions, experiences, and support needs. Token inclusion of a single autistic person is not acceptable. Autistic people on the research team should be considered experts on the social acceptability of the research – whether autistic people would consider the research and its aims and potential outcomes acceptable – and non-autistic researchers should defer to them on such matters.

Intervention research should address the autistic person's *experience* of the intervention, including their internal experiences and well-being alongside external/visible behaviors and reactions.

**Therapies and research on therapies should prioritize outcomes that matter to autistic people**, such as selfdetermination, communication, sensory processing and self-regulation, self-advocacy, independent living skills, executive functioning, mental health, and overall well-being, **rather than the reduction of visibly autistic traits.** 

The creators, practitioners, and professional associations of developmental therapies and other alternatives to ABA should prioritize rigorous, high-quality research of their services. We have shown that the evidence base for ABA is quite weak – but so is the evidence base for many other approaches. The lack of solid research prevents good services from being widely adopted, and limits the willingness of public and private insurers to pay for them. Autistic people deserve access to evidence-based options, and we have the right to know which approaches are shown to help us reach our goals most effectively.

**Researchers should make sure that their research on autism includes all kinds of autistic people** – including autistic people of color, non-speaking autistic people, autistic people with intellectual disabilities, autistic people with mental health disabilities, autistic people with co-occurring medical conditions, and autistic people with higher support needs. These groups should be represented as partners in participatory research, not just as research subjects.

**Research into autism services should prioritize developing best practices for working with autistic people who are currently the most poorly served by existing services**: non-speaking autistic people and autistic people with intellectual disabilities, especially people in those groups who have co-occurring mental health disabilities or who may struggle with self-injury or aggression. Too often, autistic people in these groups are not offered any services other than ABA. This is unacceptable. There must be a significant investment in research to develop best practices for delivering ethical, comprehensive services to autistic people with the highest support needs, including mental health services and communication supports.

Qualitative research and non-scholarly writing about autism services can be just as, if not more, important as quantitative research. Autistic people (especially autistic people of color, autistic women and non-binary people, autistic young people, autistic people from the Global South, nonspeaking autistic people, and autistic people with intellectual disabilities) have been systematically excluded from academia. Interventions must not discount criticism solely on the fact that it is qualitative and/or non-scholarly.

Intervention research must use the same human subjects research protocols that research on non-autistic participants use. Autistic services research has long exploited autistic people and subjected us to unethical and unsafe research practices with little to no oversight. We stress that autistic people, with the proper supports, are still eminently capable of taking part in research studies, but that our autism is not a reason to lower ethical standards or research participant protections for us.

**Autistic people must be given the accommodations we need** in order to give informed consent/assent and to take part in the study. These accommodation can include, but are not limited to, plain language and Easy-Read versions of materials, extra breaks during sessions, use of an augmented/alternative communication (AAC) device, having a support person with them if possible, and being able to familiarize themselves with the study team and materials before they participate in the study.

There must be protocols in place to ensure that autistic people are able to give continuous informed consent/ assent during the study, not just once at the beginning of the study or at designated points within the study. Researchers should develop language for asking for continued consent/assent (e.g., "this is voluntary and there will be no bad consequences if you don't wish to continue – do you want to stop?") during the study. Researchers must honor any and all requests to stop from the autistic person immediately and without protest.

**Research on autism services should be held to the same quality standards as research outside of the realm of autism.** Autistic people deserve access to services and supports that are truly evidence-based, with rigorous research backing and high ethical standards.

**Practitioners and researchers should be upfront about their conflicts of interest and how these affect their practice, research, and publication**. Journals, conferences, and professional organizations that publish and promote research, education, and professional regulation of therapies and services should adopt a standardized code for disclosing conflicts of interest.

**Practitioners of an intervention should take criticism of that intervention seriously**, especially when that criticism comes from autistic people who have gone through the intervention.

Practitioners should encourage the autistic person, as well as their parents, guardians, caregivers, and/or support staff, to **report any possible adverse health events.**