

First-Hand Perspectives on Behavioral Interventions for Autistic People and People with other Developmental Disabilities





Office of
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Improving outcomes for people with developmental disabilities



Office of Developmental Primary Care
Department of Family and Community Medicine
University of California, San Francisco
500 Parnassus Avenue, MUE318
San Francisco, CA 94143
Tel: 415-476-4641 Fax: 415-476-6051
Email: odpc@ucsf.edu
Web: <http://odpc.ucsf.edu/>

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Author: Finn Gardner

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Introduction

The Autistic Self Advocacy Network of Greater Boston prepared this report to provide personal perspectives on behavioral interventions for people with developmental disabilities. These interventions include Applied Behavioral Analysis (ABA), Floortime, and cognitive-behavioral therapy (CBT). We believe strongly that people with lived experience can provide well-needed perspective on what works and doesn't work for them, and that service providers working with people with disabilities can benefit from first-hand accounts. As a disability rights organization rooted in the principles of self-determination, we also believe that autistic people and other people with developmental disabilities deserve culturally competent, trauma-sensitive, empathetic care.

In order to find people who were interested in sharing their perspectives, we reached out to people through personal networks, professional networks and social media websites like Facebook and Twitter.

After reviewing potential participants' applications, we found ten people on the autism spectrum or with related disabilities who were ready to talk to us about their experiences. We talked to some people by phone, in person, and online chat, and we also heard from some participants through an online questionnaire.

In the interviews and questionnaire responses, participants identified values they considered important in behavioral treatment: promoting positive outcomes, preventing harm to people with disabilities, protecting people's autonomy, advocating for inclusion, being sensitive to people's past trauma, and supporting cultural competency.

Promoting Positive Outcomes and Preventing Harm

"The therapeutic goal was presented as learning social behavior - in retrospect, this was learning to mimic NT [neurotypical, or non-autistic] social behavior. It resulted in corrosive damage to self-esteem and deep shame about who I really am. No effort was made to explain autism to me or to explain the role of sensory overload in issues like meltdowns, shutdowns, etc."

Participants preferred treatments to focus on skills that would help them understand their own disabilities and coping with sensory overload, as opposed to therapies that made people look less autistic on the surface. Therapies that participants considered helpful included occupational therapy to help with sensory integration, play therapy, social skills groups for children, job coaching, mentoring, and mindfulness to help with anxiety. All the therapies suggested were

aimed at encouraging self-determination and self-care, rather than indistinguishability from their peers.

On the other hand, participants thought that therapies designed to make them appear superficially non-autistic did more harm than good. For example, “stimming,” or repetitive movements that many autistic people use to calm down or focus, should not be suppressed if there is no physical harm to others. Thea was particularly critical of “therapists and teachers who saw just ‘behaviors’ to extinguish without considering the feelings and thoughts that might be motivating them.”

Rachel described her training as judgmental and punitive; it was focused on changing her outward mannerisms instead of helping her cope with overload and stress. Alex grew up with teachers who would force him to keep his hands still and stop rocking and pacing. As a replacement stim, he started biting the inside of his cheek at school to the point that it would start bleeding. He also developed tremors in his hands because he knew that if he flapped his hands, he would be punished and other students would make fun of him. Multiple participants stated that behavior was communication, and that someone who appeared to be misbehaving might have underlying sensory or emotional difficulties. For example, someone may be exhibiting signs of a meltdown because of an overstimulating environment, and punishing the meltdown with restraint, seclusion, or other forms of hostile methods do nothing to address the underlying stressor and can lead to additional trauma. When somebody appears to be “acting up,” there is probably a reason behind it, and it is important to identify that reason instead of just punishing the outward behavior.

Protecting Autonomy

“It all goes back to consent. The power differential between the patient and the therapist needs to be taken into consideration. The patient needs to have a say-so in their treatment plan and if they say no to something the therapist needs to try something else.”

Participants placed a high value on consent and respecting the autonomy of autistic people and other people with disabilities. Some of them, like Barbara and Rachel, had undergone treatments in childhood in which they were taught to be compliant without question or were physically restrained in order to “correct” them. These treatments ultimately made it more difficult for them to say “no” as adults, even when that “no” would protect them in a potentially dangerous situation. Barbara said that coercive treatments “teach you to anticipate that when you say ‘no,’ they’ll bulldoze through that because you don’t own your own body.” Alex added that consent for therapies should be mandatory in order to prevent coercion and avoid inducing trauma. Matthew’s views were similar to Alex; he said, “our culture doesn’t respect children. Children don’t have their own agency and we’re going to consent for them.”

Though respecting autonomy may seem clearer for adults, the same principles can also be applied to children and adolescents. For example, a child or teenager can be offered a series of choices chosen by the parent for them to decide from to help model informed decision-making. Parents and professionals should teach young people life skills that are meaningful and useful, and should guide them before they can make decisions.

Being Inclusive

“I think the most important part is to value all types of brains. In school, that could mean explaining things in different ways, allowing more movement, and explaining and accepting things like stimming rather than discouraging it.”

Participants thought it was important to try to include autistic people within the rest of society. They had a number of ideas they thought would be helpful: self-advocacy skills, increasing accessibility, and fostering social inclusion.

Self-advocacy skills. It is important to teach self-advocacy skills to young people with developmental disabilities from an early age. Examples of self-advocacy skills mean learning how to say “no,” setting appropriate interpersonal boundaries, and stating personal preferences. Saying “no” in situations where someone may be put into danger by saying “yes” is a valuable and potentially life-saving skill, and training people to say “yes” to everyone perceived as an authority will ultimately prove risky. Understanding others’ boundaries and creating one’s own will help people navigate complex social situations and help prevent them from being assaulted or from committing assault. Learning how to state personal preferences will be useful in determining the course of one’s life.

Accessibility. Accessibility tools, like text-to-speech applications for people who struggle with oral speech or easy-to-read documents about medical conditions, can help people make their own informed decisions. Creating accessible environments for people with sensory sensitivities can help foster inclusion. For example, some people are sensitive to fluorescent lights, rough clothing textures, artificial scents, loud noises, or cigarette smoke. Other people may benefit from having space to decompress before after overwhelming days at school or work.

Social inclusion. There are a number of ways that autistic people and other people with developmental disabilities can be part of their community: they can join integrated playgroups as young children, they can be included in mainstream classrooms, and they can work integrated jobs with non-disabled people. It is important not to segregate people with disabilities from the rest of the community. It is also important to remember that treatments that help autistic people

adhere to social norms, like maintaining good eye contact in a job interview, should be placed within an understandable context. Contextualizing training will help people understand social norms, instead of just viewing them as arbitrary niceties. “Because I said so” isn’t an explanation that gives context. “Because people will feel bad if you don’t do this” can give context.

Being Trauma-Sensitive

“When you have everybody there saying they have flashbacks [...] and PTSD from being forced into situations beyond what they can handle, I think that’s a concern and they need to hear it. They’re not listening to us and not getting all the input.”

People with disabilities can encounter many traumas throughout their lifespan. Living in a world that feels hostile or frustrating can cause psychological responses that are difficult to contend with. People with developmental disabilities are also more likely to be emotionally, sexually, or physically abused. These realities caused participants to feel strongly about trauma-sensitivity when working with autistic people and other people with developmental disabilities. Jennifer noted that “not retraumatizing would be a key thing,” especially since autistic people can be more sensitive to their environments than neurotypical people might be. “Nobody is walking in without baggage without already having been, from the womb practically, put into a world that’s not made for them,” she continued. Sarah added, “Correction feels like censure and criticism. Trust is challenging both to autistics and people who have experienced trauma, so the approach needs to be gentle and accepting. I do not support any interventions such as physical restraint for stimming.”

When people navigate through a world that is not designed to accommodate their needs, there is a high chance that they will experience stress from that environment. Any intervention intended to help people adapt to their environment must be conscious of that stress. Barbara was especially emphatic, saying that disability professionals should take into account the voices of adults on the autism spectrum who describe growing up with trauma: “When you have everybody there saying they have flashbacks [...] and PTSD from being forced into situations beyond what they can handle, I think that’s a concern and they need to hear it.”

Alex reiterated the importance of consent in trauma-sensitive therapies, stating that “[it] all goes back to consent. The power differential needs to be taken into consideration. The patient needs to have a say-so in their treatment plan.” Matthew had a similar view to Alex; he stressed his preference for an advisory role for therapists, in contrast to methods that treat them as authority figures. Even for children and adolescents, placing the emphasis on guidance rather than punishment and restraint will prove beneficial.

Promoting Cultural Competency

“There is so much loaded in our generic cultural image of what an autistic person is to begin with, or what a disabled person is, but the image in people’s mind is a white male, fairly affluent, at least middle-class.”

“It’s so easy for these people to be missed in diagnosis.”

Autistic people and other people with developmental disabilities are not a monolithic community. They can come from all racial, ethnic, socioeconomic, and cultural backgrounds, though middle-, upper-middle, and upper-class white men and boys are more likely to receive diagnoses than are women, racial and ethnic minorities, or low-income people because of differential access to healthcare and comprehensive disability services. Jennifer weighed in: “It’s so much easier for those people to be missed in diagnosis and have behavioral issues attributed to a moral view rather than a view of disability.” For example, a black child who is having a meltdown in class might be considered a “bad kid,” while a white child would be more likely to receive services that reflect their needs. She stressed the need for disability professionals to identify youth from disadvantaged backgrounds early on in order to provide them with the best services available to combat inequity in service provision. Barbara agreed: “Get out of your minds that autism is an eight-year-old non-verbal white boy.” Barbara saw this failure of popular representation first-hand: she was previously homeless and had noticed multiple people with developmental disabilities of several races and ethnicities who were also experiencing housing insecurity. Systemic discrimination that allows some people with disabilities to have comprehensive supports while others fell through the cracks contributes to a number of social ills, including homelessness, chronic illness, depression, and self-medication through substance abuse. Ensuring cultural competency when working with vulnerable populations is one way to mitigate the effects of entrenched social inequality.

Concluding Remarks

Through protecting autonomy, promoting cultural competency, being sensitive to patients’ trauma, and fostering social inclusion, professionals can help work toward treatment and training plans that affirm the right of autistic people and other people with developmental disabilities to learn, work, and thrive within their community.

Choosing Your Service Providers

Interview Questions – The following questions may be helpful to you when interviewing a new therapist for yourself or your child. You are an important part of the team that decides what type of services you get. You help decide the goals. You help choose the methods that work for you. You also have choices about who provides your services.

1. Promoting Positive Outcomes and Preventing Harm

How will you help me function better?

How will you help me do the things I want to do?

How will you help me learn the skills I want to learn?

How will you help me learn about the things that interest me?

How will you help me learn about my disability?

How will you help me be accepted?

2. Protecting Autonomy

How will you make sure I agree to the goals of therapy?

How will you make sure I agree to the methods you will use?

If I tell you that I don't want to do something during therapy, will you listen to me?

3. Being Inclusive

How will you help me be included?

How will you help address physical barriers I face?

How will you help address problem attitudes about disability?

Will you help me set healthy boundaries?

How will you support my communication and decisions?

4. Being Trauma-Sensitive

I have had some bad experiences in the past.

How will you help me with any therapy-related fears I have?

5. Promoting Cultural Competency

How will you respect my culture?

How will you help me participate in my family and community?