

Applied Behavior Analysis Community Conversations Findings



HEALTHY SYSTEMS DIVISION
Child and Family Behavioral Health

May 2023

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Executive summary

The purpose of this report is to summarize the findings of six virtual, public community conversations that took place throughout November 2022 and January 2023. Participants spoke about their experiences with Applied Behavior Analysis (ABA) therapy and provided recommendations for an ABA model in Oregon. The findings from these community conversation are organized by perspective – lived experience, family or caregiver, provider, and community member.

Background

The Child and Family Behavioral Health Unit, Office of Recovery and Resilience, and the Behavioral Health Equity and Community Engagement Team hosted community conversations on the topic of Applied Behavior Analysis (ABA) throughout November 2022 and January 2023.

ABA is a therapy-based treatment provided primarily to people diagnosed with autism and is currently an Oregon Health Plan (OHP) benefit. Administrative rules for ABA address Medicaid payment and provider requirements but do not address oversight or management of ABA programs or facilities.

The community conversations took place over the course of six virtual, public meetings. Participants included persons with lived experience of autism and ABA treatment, parents, caregivers, ABA therapy providers, advocates, and community members.

Participants were asked to provide information about their experiences with ABA, especially regarding access, quality, and oversight of services. Participants were also asked to consider what is important for Oregon Health Authority to consider in implementing the ABA model in Oregon.

The findings of these community conversations may be shared with community partners, legislators, and policy analysts to inform current and future work.

Community Conversations

Prompts

Participants were asked to share their experiences with Applied Behavior Analysis (ABA). Participants included persons with lived experience with ABA and autism, family members and caregivers, providers and community members. Prompts included:

What has been you or your family's experience with ABA?

Please tell us about:

- Access
- Quality
- Oversight of programs and facilities
- Anything else you want us to know

What is important for OHA to know about when considering the ABA model in Oregon?

Participants broke into small groups to answer the prompts. Each breakout room was staffed by at least one OHA employee who facilitated and took notes.

Findings

Lived Experience Perspectives

Participants with lived experience with Applied Behavior Analysis (ABA) or autism expressed the following:

- A need for inclusion of people with lived experience in decision-making and program evaluation.
- Concerns about the techniques used in ABA therapies.
- Concerns about access to ABA services.
- A desire for transparent data, metrics, and evaluation of ABA programs.
- A need for parents and community members to be educated about ABA and alternatives to ABA.

A need for inclusion of people with lived experience in decision-making and program evaluation

Participants with lived experience expressed the importance of including people from the autism community at all levels of rule making and program building, including evaluation of existing programs. One participant called for coordination between programs and persons with lived experience in the development of curriculum for ABA providers. Another encouraged agencies to visit autism advocacy communities in person to enhance community engagement.

Concerns about the techniques used in ABA therapies

Participants with lived experience expressed a need to acknowledge the historical harms that ABA has caused while honoring the experiences of those who have found the therapy helpful. Several participants voiced concern that the fundamental principles of ABA may be rooted in ableism. Some participants with lived experience described their interaction with the therapy as manipulative and damaging.

Concerns about access to ABA

Participants with lived experience expressed frustration that people who wish to take advantage of ABA therapy must first obtain a diagnosis, a process that can be time consuming and inequitable. Once connected to services, participants may experience hesitation to complain for fear of losing hard won services altogether. Recommendations included removing the requirement to obtain a diagnosis, assessing eligibility criteria and increasing funding for alternative services.

Desire for transparent data, metrics, and evaluation of ABA programs

Participants called for transparent metrics that provide meaningful measures of the outcomes of ABA therapy. One participant held that “there is no effective avenue to work with providers if we cannot reach agreement on the metrics.” Suggestions included evaluating the current data with a critical eye and re-defining “successful therapy” with the input of persons with lived experience.

Need for parents and community members to be educated about ABA and alternatives

Participants with lived experience expressed a desire to increase education around the history of ABA, including why some may be opposed to the practice. A strong theme emerged around the difficulty of accessing and navigating supports, putting parents in a position of feeling that ABA is the only available option to support their children. Recommendations included educational campaigns, peer support, and increased consultation with primary care providers and school staff. Alternative therapy recommendations included school-based supports and occupational therapy.

Family and Caregiver Perspectives

Family members and caregivers with experience with ABA expressed the following:

- ABA has been responsible for positive changes in the lives of children and families
- ABA has caused harm
- Concern that ABA feels like the only treatment option
- Concern about access and funding
- Recommendations for building ABA programming and regulation

ABA has been responsible for positive changes in the lives of children and families

Family members and caregivers shared stories of the positive difference that ABA therapy has made in their families, some noting their gratitude for the experience. Some participants noted that the therapy is relatively quick and easy to access and that the practice has changed for the better in recent years. One caregiver stated that “participation in ABA has stopped [my child’s] self-injurious behaviors and allowed them to fully participate in school.” Another noted that the therapy helps children “identify emotional states and cope with sensory issues”.

ABA has caused harm

Family members and caregivers shared stories of how ABA therapy has negatively impacted their families. One caregiver shared the experience of being excluded from observing their child’s therapy sessions or participating in planning sessions. Another described their family’s participation in ABA as traumatic. Some family members expressed concern that ABA asks neurodivergent children to be neurotypical, contributing to ableism. Recommendations included acknowledging the reasons a child may be behaving in certain ways, like trauma or other factors. A strong theme emerged around the concern of historical relationship between ABA and conversion therapies.

Concern that ABA feels like the only treatment option

Family members expressed the importance of “the right support at the right time”, noting that the ease of accessing ABA makes it feel like the only realistic treatment option when other treatments or therapies may be more appropriate. Caregivers shared their fears of being expelled from programs if they complain or their children do not progress sufficiently.

Concern about access and funding

Family members and caregivers encouraged increased funding for ABA alternatives like occupational therapy, speech therapy, and parent training. They noted that Medicaid reimbursement rules can edge out valuable alternative options.

Recommendations for building ABA programming and regulation

Family members and caregivers recommended strategies for building out and regulating ABA programming. These included:

- Clarify standards for ABA including who it may be appropriate for and available intensity levels
- Address access and funding for alternative services
- Empower families to understand the consent rules and ethics of ABA
- Create oversight rules that protect parent participation and ensure cultural responsiveness, gender diversity, and racial equity in the delivery of ABA services

Provider Perspectives

Participants with experience providing ABA therapy shared the following:

- Importance of understanding the history of ABA
- Considerations on provider training
- Considerations on eligibility and developmental assessments
- Recommendations for provider compensation and rates

Importance of understanding the history of ABA

Providers noted that research on ABA is available based on its historical uses for diagnoses besides autism. They pointed to insures who cover ABA therapy for attention deficit/hyperactivity disorder, Down syndrome, and Williams syndrome. Some providers recommended looking to Mindful Assertive Community Treatment (Mindful ACT) as an early leader of the model that could provide lessons for building programming.

Considerations on provider training

Providers pointed to training as an important factor when building ABA programming and regulations. One provider noted that training “directly impacts quality of services and satisfaction of clients.” Providers recommended incorporating shadowing into initial training and mandating continuing education. Some providers noted that continuing education should include peer support and conversations with lived experience experts. A strong theme that emerged in the provider conversations was the need for a practice act to accompany the existing title act. Participants noted that without a practice act, anyone can provide a therapy resembling Applied Behavior Analysis with no oversight, potentially putting consumers at risk.

Considerations on eligibility and developmental assessments

Providers noted that developmental assessments are an important tool for informing treatment, but that the current system may not work for families. One provider stated that “families often wait 18-20 months after receiving an initial school-based diagnosis to access a medical diagnosis, during which time the family’s ability to access the community may be impeded by intense behaviors like self-injury and aggression.” Assessments

may not be age appropriate or take into consideration other factors, like history of trauma. Providers recommended looking to the Autism Diagnostic Observation Schedule and consulting ABA accreditation organizations like Council of Autism Service Providers and Behavioral Health Center of Excellence.

Recommendations for provider compensation and rates

Providers expressed that increasing rates could stabilize staffing levels and translate into shorter waitlists. Providers also recommended making training hours billable.

Community Perspectives

Community members who attended the community conversations expressed the following:

- Context around the history of ABA in Oregon
- ABA can be a positive tool for families
- Recommendations for building out programming

Context around the history of ABA in Oregon

Community members acknowledged negative stereotypes about Applied Behavior Analysis and its impact. One community member compared the history of ABA usage in Oregon and California, stating that “ABA was once the standard of care, especially in California and the choices were in-home, clinic, provider and how many hours.” They stated that ABA may have been slow to catch on in Oregon partially due to lack of community support.

ABA can be a positive tool for families

Community members shared stories of seeing ABA make a positive difference for children and families. One community member expressed that ABA “can address critical safety needs like self-injurious behaviors, parking lot safety, and hygiene”, but that formal ABA may not be appropriate for all children. Participants suggested educating parents so they can use elements of ABA therapy informally in home. One participant suggested that “ABA works by breaking down the skills a child needs which speeds up teaching and makes tasks feel achievable. It presents trials to make progress towards tolerance.”

Recommendations for building out programming

Community members expressed the importance of centering families when making decisions about ABA programming in Oregon. Participants highlighted the need to tailor the intensity and frequency of services to the individual person and acknowledge that some people may need more intensive services than others. A strong theme emerged around the need to provide oversight, rigid supervision, transparency, and clear goals. Participants were concerned about the use of aversive treatments or coercion. One community member suggested looking to existing high-quality programs in other states. Another suggested working with schools to create better curriculum at all levels of provider education.

Conclusions and Recommendations

Participants were asked to provide information about their experiences with ABA, especially regarding access, quality, and oversight of services. Participants were also asked to consider what is important for Oregon Health Authority to consider in implementing the ABA model in Oregon.

Recommendations included:

Education of the public, families and providers

Inclusion of persons with lived experience in all aspects of planning and oversight

Assessing eligibility criteria

Ensuring consumer protection through training, curriculum overhaul and rigid oversight

Empowering caregivers to understand the consent rules and ethics of ABA

Encouraging family participation in planning and treatment

Stabilization of staffing

Implementation of funding and access solutions

Implementation of a practice act

Expansion of alternatives like occupational therapy and school-based supports

Assessing data and redefining metrics