ABA, Autism Interventions and Ethics

About us

Gregory Robinson,
Deputy Director of Public Policy
Autistic Self Advocacy Network

The Autistic Self Advocacy Network is a 501(c)(3) nonprofit organization run by and for autistic people. ASAN is a national grassroots disability rights organization for the autistic community. We fight for disability rights. We work to make sure autistic people are included in policy-making, so that laws and policies meet our community's needs. We work to support all forms of self-advocacy and to change the way people think about autism. Our members and supporters include autistic adults and youth, cross-disability advocates, and non-autistic family members, professionals, educators, and friends.

History of Autism Interventions

Applied Behavior Analysis is not the only autism intervention, but it is one of the most common and prevalent

Developed by O Ivar Lovaas at UCLA -1960s and 70s

Based on behaviorist models of therapy, operant conditioning

Early ABA practice relied heavily on aversives

- Shouting
- Slaps
- Electric Shocks

Links between early ABA and conversion therapies

Later Developments

ABA as a field has moved away from the use of physically violent aversives, but while retains many other core elements of Lovaas's approach

- Numerical data collection and documentation of defined behaviors
- Focus on changing external behaviors of autistic children, based on a goal of making an autistic child look and act non-autistic

Significant focus on early childhood intervention

Early Intensive Behavioral Intervention

Many non-ABA interventions use behaviorist elements and tools

Later Developments

New ABA interventions: PECS, pivotal response therapy

Other new Approaches, both as complements and alternatives to ABA

Sandbank (2020)identified seven categories of autism therapies and services:

- Behavioral approaches,
- Developmental approaches,
- Naturalistic developmental behavioral interventions (NDBIs),
- Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH),
- Sensory-based interventions,
- Animal-assisted interventions, and
- Technology-based interventions.

Evaluating the Evidence Base: Evidence of What?

Medical and social models of disability

Intervention outcomes oriented around goal of reducing or eliminating disability

- Evidence in autism research presumes an outcome of making intervention subjects less autistic
- Downplays iatrogenic harms of intervention

Alternative goal is to focus on accommodating individual needs

- More difficult to operationalize

Strength of Evidence

While ABA is frequently considered the "gold standard" of autism interventions, the evidence base is weak

Challenges

- Most evidence from small-sample or single-subject studies
- Nonspeaking and ID individuals frequently excluded
- Weak evidence of persistence between settings and following intervention
- Limited evidence of dose response
- Conflicts of interest (Bottema-Buetel, 2021)

The Tricare Autism Services pilot itself represents one of the largest-sample reporting on ABA delivery and outcomes

What does TRICARE say?

2019- "approximately 76 percent of beneficiaries made little to no change in their symptom presentation after 1 year of ABA services"

2020- "no correlation in any category for the impact of rendered ABA services nor any significant changes from the previous results regarding beneficiary categories. In all categories, approximately the same number of beneficiaries demonstrated improvement as demonstrated worsening of scores"

2021- "57 percent of the beneficiaries saw improvement while 43 percent saw no improvement or worsening of symptoms… There is still the question of whether the changes are clinically significant. In addition, there is no comparison group (no treatment or another type of treatment) to determine whether the change score is associated with ABA services or other treatments received… there is no way to know if the relatively small change observed is the result of ABA services or another variable.

General Ethical Concerns

Lack of Autonomy

- Informed consent/assent seldom sought

Pathologizing Unremarkable Behaviors

- Noncompliant behaviors not limited to aggressive or self-injurious
- Targeted behaviors serve self-regulatory or communicative roles
- Connects to consent issues

Iatrogenic risks

- Adverse effects underidentified and underreported

Broader Consequences

Limited Access to Other Services:

- Exclusion and underfunding of non-behaviorist approaches to autism
- Limited support for mental health services and supports, including reduced provider competence and confidence in providing non-autism-specific-services to autistic individuals

Reduced Evidence Development Beyond ABA

Developing Ethical Approaches

- What are the goals of the intervention, both stated and unstated?
- Who is involved in developing goals?
- What beliefs about autism are implied by the intervention? Why does it target a specific skill or behavior?
- Who benefits most from the intervention? How do various people involved in the intervention (the autistic person, their parents/family, their support people, etc.) benefit?
- Would an intervention be considered ethical if performed on a non-autistic person?
- What are the possible (or known) long-term effects of the intervention on the person? What are the possible (or known) long-term effects of not having the intervention on the person?

For More Information:

- For Whose Benefit?: Evidence, Ethics, and Effectiveness of Autism Interventions
  https://autisticadvocacy.org/policy/briefs/intervention-ethics/
- First-Hand Perspectives on Behavioral Interventions for Autistic People and People with other Developmental Disabilities
  https://autisticadvocacy.org/policy/briefs/interventions/