

## Autism, Ethics, and Public Policy Development



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Friday @ 12:45pm ET

## Desmond P. Kelly, MD Nurturing Developing Minds Conference & Research and Implementation Symposium:



## Restoration, Resilience and Rebuilding

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# Autism, Ethics and Public Policy Considerations

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# Why We Are Presenting Today

- New challenges have arisen that may impact evaluation, treatment and professional interactions related to Applied Behavior Analysis therapy for individuals with Autism Spectrum Disorder.
- Our hope is to identify the challenges, their sources and considerations for professionals to aid in successful navigation of potentially challenging situations.
- We are saving time after the 3 presentations for discussion.

Listening to consumers

# Overview

- Currently there are very different views on ASD and ABA therapy that may pose ethical, clinical practice and policy challenges. These views come from a variety of national organizations.
- We will focus on views expressed by:
  - Autistic Self-Advocacy Network (ASAN)
  - National Council on Severe Autism (NCAS)
  - National Councils on Independent Living (NCIL)
  - Autism Science Foundation
  - And excerpts from "Disability Scoop" overview discussion

# Autistic Self-Advocacy Network (ASAN)

- This is a well respected national organization that has done a great deal of good for the ASD community.
  - Combating Autism Act → Autism CARES Act (federal legislation)
  - Advocacy on autism issues with multiple agencies
- Autism cannot and should not be cured”  
“Instead of wasting time on and money on something that isn’t possible and that autistic people don’t want, we should focus on supporting autistic people to live good lives.”

## ASAN continued:

“... But there are some therapies that focus on making autistic people seem “normal” or appear “less autistic”. The most common type of this therapy is Applied Behavioral Analysis (ABA). ABA uses rewards and punishments to train autistic people to act non-autistic. ABA and other therapies with the same goals can hurt autistic people, and they don’t teach us the skills we actually need to navigate the world with our disabilities (emphasis added). Sometimes people say they use ABA to work on other skills, like communication. There are better ways to teach those skills. We work to make those better ways available to everyone.”

- From ASAN Website on “What We Believe”.

- We see areas of agreement and disagreement with ASAN views, but the opposition to ABA is what is often the key area of focus (in internet information, social media) that results in challenges to effective practices and difficult conversations.
- The ASAN point about good lives and individual dignity is something we can agree on, *especially for individuals with the ability to make decisions in their own best interests and for those who are not exhibiting severely challenging behavior.*
- This leads us to the NCAS view:

# National Council on Severe Autism (NCAS)

- The National Council on Severe Autism (NCSA) advocates for the burgeoning population of Americans who are significantly disabled by Autism Spectrum Disorder (ASD).
- “We advocate for actions that are effective, efficient, and fair, and rooted in reality, not fantasy”.
- “Over the past decade we have witnessed the ascent of a feel-good narrative about autism – that autism is a ‘strength’, a mere ‘difference’ or ‘neurodiversity’. *Continues . . .*

## NCAS continued:

- “But for the majority with ASD, the disorder can be debilitating and even ruinous, as it can compromise higher-order cognitive processes, including language, social comprehension abstract thought and learning. In addition . . . Many in this population have challenging behaviors, including aggression, self-injury, property destruction, and elopement, as well as medical conditions on such as seizures . . . .”
- Recently an expert panel recommended the term “profound autism” to encompass those with ASD who require access to 24/7 care and supervision and who have an inability to manage activities of daily living . . . .”

# National Council on Independent Living (NCIL)

## *Resolution Opposing applied behavioral analysis – 7/2021*

- “. . . the practice of ABA seeks to erase characteristics associated with autism”
- “Whereas, ABA is a practice that follows a long history of culturally, socially, and psychologically abusive practices, all subjugating individual choice, dignity and freedom in the interest of promoting normative conduct, including practices such as: the separation of native

## NCIL continued:

American children from their families and their assimilation in boarding schools, the of “conversion” therapy to promote hetero and gender normativity, over-policing and excessive incarceration of the Black community, and the present-day use of electric skin shocks at the Judge Rottenberg Center...”

- “Be it resolved that ABA is a harmful and abusive practice that the NCIL opposes in all its forms . . . .”
  - JRC skin shock has been deemed unethical and never to be used per Association for Behavior Analysis International (ABAI).
  - JRC founder & director (DVABA) and avoided prison by retiring.

# Notes on National Organization Stances

- While recalling that there are several key factual errors in NCIL view:
- ABAI was very late in deeming electric shock as unethical and that “fringe” treatment center regularly presented and or exhibited at the annual conference
- National Association of State Directors of Disabilities Services strongly endorses positive behavior support (based on ABA) and condemns the use of aversive interventions.
- American Association on Intellectual & Developmental Disabilities explicitly condemns the use of aversive interventions and also electric skin shock.

## Disability Scoop article (2/4/22)

# “Debate over applied behavior analysis at a crossroads”

- *Advocates for ABA say some of the controversy stems from outdated practices like the use of restraints or withholding food that are now considered unethical. Newer methods are more focused on promoting a child’s self-direction and choice while supporting neurodiversity.*

# Autism Science Foundation

chief science officer (A. Halliday)

- “The goal of ABA is to improve communication, improve the way people with autism are able to interact with other people. The goal is absolutely not to make them appear normal or less autistic. The goals of all these behavioral therapies is to improve their quality of life, to promote learning.”

# Autism Speaks

New resource on treating severe behaviors in autism (2023)

- Disseminated in article by Disability Scoop (2/14/23)
- “Despite the prevalence of these behaviors, the majority of families lack access to appropriate and effective treatments,” said Jacqueline Perlmeter, program manager of clinical programs at Autism Speaks. “This lack of access to quality care can lead to poor treatment outcomes, limitations on skill development, poorer quality of life and inability to participate in the community that they live in. In addition, these behaviors can lead to substantial physical and emotional harm to themselves and others.”

# Autism Speaks continued:

- Evidence-based practices in treatment of challenging behavior
  - Are some of the primary ABA practices
    - Functional behavior assessment
    - Functional analysis
    - Antecedent based interventions
    - Extinction
    - Functional communication training
    - Parent training
    - Reinforcement
    - Response interruption and redirection

# Policy Considerations

- May not have policy influenced yet
- But, some of the groups are very influential
- What could be affected???
  - Insurance coverage for ABA??
  - Licensing standards??
  - Practice guidelines??
- Not to be alarmist, but also wise to be focused on issues

# “Nothing About Us Without Us”

Listening to autistic voices

# Listening to consumers

- Diversity of all types improves group performance
  - Autistic people, family members, clinical providers, researchers, etc.
- Autistic people should be involved in anything that impacts them (“nothing about us without us”)
- Like other marginalized groups, autistic voices need to be amplified by those in privileged positions
- Multiple voices: one voice cannot speak for a community (especially in a community as diverse as autism)

# Acknowledging the history of ABA

- ABA principles used in conversion therapy
- Use of aversives (yelling, slapping, shock, bad tastes) to decrease undesired behaviors
- Selection of goals that do not directly benefit the autistic person or that try to make the person appear “normal”
  - Hugging
    - Eye contact
    - Decreased stims\*\*

# Acknowledging the history of ABA (2)

- Poor generalization
- Discrete trial training – long repetitive teaching sessions
- Unclear accuracy
  - Withholding of food/affection (??)
  - Decreasing behaviors without providing replacement behaviors (??)

# Current concerns of autistic self-advocates

- Lack of consent by nonspeaking autistic people
  - Who has the right to make decisions for nonspeaking people?
- Treating challenging behaviors without understanding root causes
  - E.g. Rewarding a child for staying seated in a crowded cafeteria without addressing possible sensory issues
- Treatment is at odds with autistic pride/identity
  - diversity vs. disability vs. disorder
- Functional lack of choice in treatment

# Profound autism

- Lancet Commission report, 2021
  - At least 8 years old
  - Requires 24-hour access to an adult who can care for them
  - Has a cognitive ability measured by IQ of less than 50 and/or non-speaking or minimal verbal ability
- What is the role of autistic voices in discussions of profound autism?

Talking to Families

# Shared decision making

- Patients, families, providers working together to develop care plan
- Balance of:
  - Patient and family's priorities and preferences
  - Clinical evidence: risks, benefits, expected outcomes
- Benefits of shared decision making
  - Increased knowledge
  - Improved follow-through/adherence
  - Improved patient/family-provider relationship

# Evidence Based Interventions and Autism

- Evidence based defined
- Evidence based interventions in Autism
  - National Autism Center's National Standards Project (NSP)
  - National Clearinghouse on Autism Evidence and Practice (NCAEP)

# Discussing ABA

- Common myths (and a response)
  - Limited evidence in support/experimental
    - Scientific evidence: independent reviews and meta-analyses

# Discussing ABA

- Common myths (and a response)
  - Designed to “cure” or change personality
  - Only for autism
  - Not applicable to daily activities/disruptive to daily life
  - All ABA programs are the same
  - No consideration of emotion
  - Bribery