University of Pittsburgh

Ethical Issues in Applied Behavior Analysis

Daniel A. Wilkenfeld, PhD, University of Pittsburgh School of Nursing
Allison M. McCarthy, PhD

PittNursing

Disclosures

- Neither author has any material conflicts of interest or necessary disclosures.

Overall Claims

- Applied Behavior Analysis (ABA) as traditionally defined is an inappropriate treatment for autists, as it is based on both ethically and scientifically dubious foundations.
  - ABA as practiced can be either better or worse, but our fundamental concerns remain for virtually all forms.
  - Our concerns do not generalize to all treatments for autists, or to all parenting strategies involving incentives/disincentives.

Outline of Paper/Part 1

- Background
  - Characterizing Autism
  - What is Applied Behavior Analysis (ABA)?
- Children and Autonomy Interests
- ABA as Violation of Tenets of Bioethics
  - Autonomy interests in children
  - Justice
  - Nonmaleficence
- Objections and Replies
  - Is ABA beneficent?
  - Does our argument prove too much?
  - Exceptions
- Conclusion

Outline of Part 2: Current Issues

- Responses to our paper
  - From autists
  - From educators
  - From parents
- Judge Rotenberg Center

Outline of Part 3: Extensions of Our Paper

- Parental decision-making in the non-ideal world
- Is autism really a disability in the first place?

Outline of Paper/Part 1

- Background
  - Characterization of Autism
  - Characterization of Applied Behavior Analysis (ABA)
- Children and Autonomy Interests
- ABA as Violation of Tenets of Bioethics
  - Discussion of autonomy interests in children
  - Discussion of justice
  - Discussion of nonmaleficence
- Objections and Replies
  - ABA Works
  - Our argument proves too much
- Exceptions and Conclusion

Background on Autism Spectrum "Disorder"

- As of 2018 autism is found in 1 in 59 children, up from 1 in 150 in 2000.
  - How many adults are autistic? Good question! There are no generally accepted valid criteria for diagnosing autism in adults.
- Is autism really a disability and/or disorder? Should we be treating "autism" at all?
  - Good question! See Part 3.
- Important heuristic:
  - "If you know one person with autism, you know one person with autism"

Examples of Typical Autistic Behaviors/Symptoms

- Consider autistic Patient X.
- X has trouble with language, obsesses over the outcome of every professional wrestling match, and eventually stops going to school because it regularly causes sensory overload.
- As an example of sensory overload, group meals are terrifying, because he cannot filter different threads of conversation or overlook the sound of people chewing.
- Patient X also self-stimulates (“stims”) by shaking his arms at many times throughout the day.

Kinds of Symptoms (Probably Not Mutually Exclusive—Definitely Not Exhaustive)

- Stimming—X's arm shaking.
  - Might want treatment because: Distracting in class and other environments.
- Special Interests—Professional wrestling.
  - Might want treatment because: ??? Maybe detracts from more important pursuits?
- Weaknesses in Social Skills—Difficulty to be in group environment and attend school.
  - Might treatment because: Social interaction part of the good life, potentially interferes with other goals.
- Weaknesses in General Skills—Language use
  - Might want treatment because: Extremely likely to interfere with other goals, difficulty bonding.

- Obvious Point: We sympathize with wanting to treat some of these symptoms.
- Equally obvious (we think) point: Not every possible treatment would be ethically appropriate (e.g., extreme corporeal punishment)

Different Kind of Symptom

- Immediately Dangerous Conditions Comorbid with Autism:
  - Pica Syndrome: The child attempts to eat anything they see.
    - Not usually a component of autism per se.

Temporary Concession (To Be Revisited)

- In our paper we grant that autism is a disability.
- If it is instead just a difference, then treating it medically would be even more ethically problematic.
- We'll actually explore that later in Part 3.

What is Applied Behavior Analysis (ABA)

- “The applied branch of [behavior analysis] (applied behavior analysis; ABA) involves using scientific principles and procedures discovered through basic and applied research to improve socially significant behavior to a meaningful degree” (Association of Behavior Analysts)
  - Fairly vague, but already contains root features we find objectionable: focusing only on behavior, and defining problematic behaviors socially.
- Generally based on the psychology of operant conditioning:
  - You can use small incentives and disincentives to radically alter behavior over time.
  - If you trace back the web of citations, they positively incorporate elements from Lovaas (1987), back through Baer, Wolf, & Risley (1968), and all the way back to BF Skinner (1950s, especially 1953 and 1957).

Skinner and Operant Conditions

Science of Behaviorism:

- Dominant in 20th century American psychology
  - Largely (but not entirely) discarded now because (among other reasons):
    - Cannot account for language learning (Chomsky 1959).
      - (Not explicitly trained, poverty of stimulus, systematicity, generativity)
    - Behaviorist descriptions under-determine behavior
      - (Did he go out without his umbrella because he believed it wasn't raining or because he wanted to get wet? They might look the same.)
- Important takeaway: Clinical practice in this one field is based on theoretical science that failed us 60 years ago.

Dominant Model of ABA

- "UCLA Model"
  - 40 hours per week of therapy for 2 years
  - Express use of incentives and disincentives.
- Other models are less costly, but generally share the same conceptual foundations.

Baer, Wolf, and Risley (1968) Defining "Applied", "Behavior", and "Analysis"

- Analysis = The best scientific study of behavior.
- Applied = Defined in terms of efficaciousness and usefulness.
- Behavioral = What "subjects can be brought to do, rather than what they can be brought to say; unless, of course, a verbal response is the behavior of interest" (p. 93)

More on “Analysis”—Probably Okay

- Initially defined in terms of our ability to control a phenomenon.
- This is potentially problematic if it involves controlling other people, but there are ways to render this inoffensive.

More on "Applied"—Could be Okay, But Usually Done Badly

- Defining goals as "usefulness" and "efficaciousness" can be either good or bad depending on what something is supposed to useful for or efficacious in doing.
  - Baer et al were explicit that they defined usefulness in terms of benefit to society, which explicitly neglects bioethics' emphasis on individual well-being (especially in context of therapeutic relationship).
  - One could coopt the goal of usefulness and say that a behavior is useful in improving people's lives, though studies proving the usefulness of ABA usually don't make this apparently obvious step.
    - We saw few studies that measured individual well-being of the child, e.g., by looking at anxiety. Those that did almost always incorporated another therapy in addition to ABA, such as Cognitive Behavior Therapy.
    - We imagine most individual therapists *are* focused on client rather than societal well-being, but if their methods are tailored to achieving the latter that might not be enough.
      - Our issue is with the practice, not necessarily individual clinicians.

More on "Behavior"—Inherently Problematic

- Recap: What "subjects can be brought to do, rather than what they can be brought to say; unless, of course, a verbal response is the behavior of interest"
  - Glaring fact: They were usually ignoring what clients might be *saying*.
  - More subtle but even more disturbing fact: They didn't even consider what a client might be *thinking* or *feeling* as worthy of comment.
- Our main dilemma (preview):
  - What ABA seems to do is change behavior without adjusting underlying thoughts, leading to a harmful mismatch, requiring "masking" or "camouflaging".
  - If instead it somehow actually alters people's minds, it violates autonomy by changing who someone is.

Two Major Issues in ABA

- Success defined in terms of behavior rather than holistic well-being of child.
- Overrides children's interests in ways that are coercive.
  - Theoretically possible that someone could practice something we could call ABA just by praising the child for doing things we like, but:
    - A) Parents do that anyway—if that were all ABA meant it wouldn't be a specific therapeutic program.
    - B) That's not how ABA actually works (Kupferstein 2018).

Outline of Paper/Part 1

- Background
  - Characterization of Autism
  - Characterization of Applied Behavior Analysis (ABA)
- Children and Autonomy Interests
- ABA as Violation of Tenets of Bioethics
  - Discussion of autonomy interests in children
  - Discussion of justice
  - Discussion of nonmaleficence
- Objections and Replies
  - ABA Works
  - Our argument proves too much
  - Exceptions
- Conclusion

Autonomy and Children

- In general, autonomy is concerned with control over important matters pertaining to oneself for oneself.
  - (There are lots of variants and nuances here—we'll get back to some of them.)
- Traditional bioethics struggles with the autonomy interests of children
- One might be skeptical about there being meaningful autonomy interests to protect for children at all
- Threats posed by ABA to children's autonomy provide lessons for thinking about children's autonomy interests in bioethics

Autonomy vs. Decisional Authority

- Claim that respect for autonomy applies to children ≠ children should have control over medical decisions
- Decisional authority: who is entitled to make a decision
  - Almost always the parents.
    - This is already a somewhat significant historical advance from older views that frequently left decisional authority in the hands of doctors.
  - Further question of *on what basis* deciders should decide.
    - In contexts pertaining to adults, one *reason* cited for shifting decisional authorities from doctors to patients is respect for the patient's autonomy.
    - Possible for autonomy interests of children to figure into considerations for decision-making on their behalf
- Bottom Line: Autonomy interests are independent of and go beyond who is making the decision.
  - We will argue that children have at least two autonomy interests that are relevant to ABA and to treatment decision-making in general

Autonomy-Based Interests in Freedom Pt. I

- An interest in freedom from interference with their ability to act on their desires
  - Children as young as two have a sense of themselves and what they want.
    - (Otherwise the “Terrible 2s” would be much easier.)
  - Too much interference with children’s desires can be detrimental to long-term development.
- Not saying that children should always get what they want
- Simply to point out that there are autonomy-centered reasons to give their preferences some moral weight

Autonomy-Based Interests in Freedom Pt. II

- An interest in freedom to develop preferences that could be foundation for more substantive passions or pursuits.
  - Frequently supported as a goal by developmental psychologists with respect to typically developing children.
- Pro tanto interest in allowing not just breadth but also depth where it appears
- Not only focused on non-interference interest
- Also part of shaping the fully operative moral agent they will become

Outline of Paper/Part 1

- Background
  - Characterization of Autism
  - Characterization of Applied Behavior Analysis (ABA)
- Children and Autonomy Interests
- ABA as Violation of Tenets of Bioethics
  - Discussion of autonomy
  - Discussion of justice
  - Discussion of nonmaleficence
- Objections and Replies
  - ABA Works
  - Our argument proves too much
- Exceptions and Conclusion

Violation of Autonomy

- Core claim: even granting these may be weak considerations in face of promoting child's welfare, children have significant autonomy-based interests to be afforded certain freedoms
- These freedoms are those necessary to grow into autonomous individuals
- But if ABA works, it either effects:
  - "Deep change": changing underlying thought structures and values
    - In that case, it violates children's interest in freedom to develop preferences central to identity formation.

OR

  - "Superficial change": changing behavior to be discordant with underlying thought structures and values
    - In that case, it violates children's interest in being uninterfered with in acting on their preferences

Analogy: ABA and Gay Conversion Therapy

- Gay Conversion Therapy—a process by which someone tries to change a person's sexual orientation.
  - These have shown no efficacy at changing people's sexual orientations, but do leave signs of trauma.
  - Generally agreed to be ethically impermissible
    - "All leading professional medical and mental health associations reject "conversion therapy" as a legitimate medical treatment. In addition to the clinical risks associated with the practice, the means through which providers or counselors administer change efforts violate many important ethical principles, the foremost of which: 'First, do no harm.'"
    - "It is clinically and ethically inappropriate for health care providers to direct mental or behavioral health interventions, including SOCE and GICE, with a prescriptive goal aimed at achieving a fixed developmental outcome of a child's or adolescent's sexual orientation, gender identity or gender expression."

  --AMA Issue Brief, "LGBTQ Change Efforts (So-Called "Conversion Therapy")" 2019.
  - Illegal for minors in 20 states + D.C.

Gay Conversion Therapy and Deep Change

- Suppose gay conversion therapy worked (which it doesn't) and did so without harming the patient (which it does)—we argue it would *still* be an autonomy violation.
  - Such a mythical treatment would eradicate many of the patient's dispositions, emotional attachments, and desires that are partially constitutive of their identity.
- Similarly, even if ABA worked (which, depending on one's definition, it might), and did so without harming the patient, it would still violate their autonomy interests
  - Coercively closes off certain paths for identity formation
  - Example: targeting patient X's intense interest in wrestling
- Two possibilities:
  - Closes off identity formation that incorporates embrace of autism and autistic behaviors
    - While there is not consensus on the issue, what studies have been done indicate that autists think of autism as part of their identity, usually (but not always) preferring "autist" or "autistic person" to "person with autism".
    - Even if some autists don't identify with their condition, the fact that many/most do indicates we probably should not alter it when they are not in a position to consent.
  - Closes off paths of identity formation that may be uniquely shaped by being autistic
    - Disregard for the interest in cultivation of one's individual dispositions and traits—finding one's talents and inclinations and crafting an identity that expresses and aligns with that
    - All of this is independent of whether or not we consider autism a "disability,."

Objections to "Deep Change" Gay Conversion Analogy

- 1) Gay conversion is done on adolescents, who have stronger identity claims.
  - Reply: Younger children still have identities, and are in a more formative stage—alterations made earlier can impact one's right to freely create one's identity even more than interventions later.
- 2) If ABA opponents really are behaviorists, they wouldn't accept all this "identity" talk in the first place. We saw earlier that Skinner rejected free will.
  - Reply 1: "Identity" can be defined in compatibilist terms without resorting to any inner will independent of the environment.
  - Reply 2: Behaviorism is wrong. Defending an unethical practice by appeal to its defendants' bad scientific views doesn't really help matters any.
  - Reply 3: We're somewhat at a loss regarding how radical behaviorists could make any sense of the bioethics of autonomy in the first place. This paper operates in the space of modern bioethics (even if we suggest some tweaks to perception of children's autonomy in Part 3)—simply rejecting that a person can have autonomy interests defined in terms of anything other than what we observe would be best for them would be inconsistent with our whole approach.
  - Reply 4: See reply 2 again.

Gay Conversion and "Superficial Change"

- Suppose gay conversion worked by simply making gay people act heterosexual (note: it can't) without changing their underlying preferences, desires, etc.—*that would be even worse.*
- This is the more important horn of the dilemma, because:
  - 1) From the accounts of autists who have been through ABA, we think this is what's actually happening when ABA "works" at making children behave in the "correct" ways.
  - 2) We can't really imagine any ethicist saying that this is remotely okay. It is entirely contrary to respect for autonomy to condition them to behave in ways contrary to their genuine preferences and desires and interests
    - This is true even if it would be convenient from a societal perspective to have people act differently—say because having "out" gay people could be used as a cudgel to push other regressive policies.
  - 3) On this horn, the effects have to be evaluated against not only the rights of the child, but of the adult they will become.

Objection: Unlike being Autistic, There's No Harm in Being Gay

- Objection: Having people act heterosexual is wrong because being true to their preferences isn't inherently harmful to them—it's only societally harmful, and so we should be fixing society. Having social and language impairments is inherently harmful, so it's okay to fix those.
- Reply: This at most shows that some goals of ABA overlap with some legitimate goals—that does not imply that achieving these ends in a way that misaligns behavior and preferences is an ethically acceptable way to pursue those ends.

Reasons to Think ABA Effects "Superficial Change"

- It's what most communicative autists who have undergone ABA seem to say (this is admittedly not conclusive).
- Those who have undergone ABA seem to exhibit the traits of psychological harm (Kupferstein 2018, including suicidality per Cassidy et al 2019) that would be more difficult to explain on a "deep change" picture.

Violation of Justice

- Argument:
  - Sufficient Condition: An institution is unjust if it places a disproportionate burden on a sub-population on the basis of morally irrelevant attributes.
  - Being autistic is not a morally relevant attribute.
  - Expecting autists to mold themselves to existing social structures places a disproportionate burden on them.
  - ABA does (among other things) expect autists to mold themselves to existing social structures.
  - ➔ ABA is unjust.
- Does this overgeneralize?
  - Not really. Other approaches don't define their success based on conformity (more on that later) and can be less costly in other regards.
- Also—just treating autism as something that always needs to be "cured" creates stigma.

Violation of Non-Maleficence

- A 40-hour/week regimen has huge psychological and opportunity costs.
- Aversives (i.e., punishments) are fairly clear violations of non-maleficence.
  - Even withholding positive things can be (somewhat reasonably) perceived by the child as a harm.
- Empirical evidence on the harmfulness of ABA:
  - Kupferstein (2018) finds those treated with ABA have more PTSD symptoms. (Though his sample wasn't random.)
  - Trying to "mask"/"camouflage"/"fit in" can lead to increased suicidality (Cassidy et al 2019)

Outline of Paper/Part 1

- Background
  - Characterization of Autism
  - Characterization of Applied Behavior Analysis (ABA)
- Children and Autonomy Interests
- ABA as Violation of Tenets of Bioethics
  - Discussion of autonomy interests in children
  - Discussion of justice
  - Discussion of nonmaleficence
- Objections and Replies
  - ABA Works
  - Our argument proves too much
  - Exceptions
- Conclusion

But it Works! (Surgeon General Edition)

- To this day, people cite a 1999(!) Surgeon General's Report that ABA works. BUT…what does it work at doing?
  - Evidence cited is from Lovaas that children fit in at school.
    - Why would that be the measure of success?
    - See earlier notes about challenges to autonomy and justice.

But It Works! (Beneficence Edition)

- ASD is burdensome, and ABA makes it less so. Beneficence says that our goal is to help individual patients. BUT…are we really helping individuals?
  - We don't really help someone by changing them into someone else ("deep change"), and we don't really help someone by making them behave like someone else ("superficial change").
- Maybe beneficence isn't just about helping people as they are, but about creating better people (Savulescu 2001)?
  - For this to work, autism would need to be unequivocally a bad thing to be selected against.
- But surely helping developmental skills is always good!
  - In a vacuum maybe, but it could just paper over deeper issues that then remain unaddressed.
    - For example, potty training a reluctant autistic child might well leave a source of initial bathroom anxiety unaddressed. Addressing the child's anxiety directly is less likely to leave lasting wounds.

But Helping Developmental Skills is Necessary and Good!

- This is only necessary if the only intervention is on the child rather than social structure. But what seem like clear developmental shortcomings can in fact be societal issues.
  - Example: “Non-communicative” autists can frequently communicate if we know how to listen:
    - “Though every person with autism can learn to communicate, it’s not always through spoken language. Nonverbal individuals with autism have much to contribute to society and can live fulfilling lives with the help of visual supports and assistive technologies.” (Dawson and Elder 2013)
    - “And one of the best things that I’ve achieved, that I consider to have achieved, is I’ve found ways of communicating with my little brother and sister, who as I’ve said are nonverbal. They can’t speak. And people would often write off someone who’s nonverbal, but that’s silly, because my little brother and sister are the best siblings that you could ever hope for. They’re just the best, and I love them so much and I care about them more than anything else.” (Autistic self-advocate Rosie King, TED Talk)
- Whether it may be good, in view of slow social progress, is something we will address in Part 3

Overgeneralization: By This Logic Parents Can Never Try to Reduce Character Traits

- Response 1: It's probably still be okay to try to reduce morally problematic character traits.
- Response 2: There are specific features of ABA (cost, stigma, etc.) that make it particularly pernicious.
- Response 3: Everything we know suggest that you can't really "cure" autism anyway, unlike (for example) laziness.

Overgeneralization: Do We Have a Better Idea How to Help?

- Therapy should be driven by the patient's goals, not caregiver goals
  - It is typically/frequently possible to ascertain goals from all but the youngest children and almost always possible with older autists even in the face of communication difficulties.
  - Resource: Therapist Neurodiversity Collective (https://therapistndc.org/)
    - Has a great list of considerations when seeking therapy
- Also critical: not everything needs helped because not everything is really a “problem” (e.g., most stims).
- Other possibilities:
  - Speech Language Therapy
  - Occupational Therapy
  - Cognitive Behavioral Therapy
  - Mindfulness

What Does Good Speech and Language Therapy Look Like?

- Focuses on communication as goal rather than verbal speech
- Client/patient should be the one to choose communication method to learn to allow for functional communication
- Alternative Augmentative Communication (AAC) should be an option for all, including those with verbal speech
- Helps client/patient develop self-advocacy skills to have communication needs met in different environments

What Does Good Occupational Therapy Look Like?

- Evaluates and assesses sensory profile to provide tools to alleviate sensory distress and discomfort
- Provides supports and tools for accomplishing motor tasks as the client/patient desires
- Motivates through intrinsic rewards, as the client/patient should be in charge of the goals
- Allows and accepts a variety of independence related goals, and helps develop plans for creating accommodations in the home and work environment to allow for the desired level of independence
- Respects bodily autonomy (for example, asks before guiding client/patient's hands)

What Does Good Cognitive Behavioral Therapy Look Like?

- Addresses thoughts and anxieties that patient finds problematic.
- Teaches coping skills and way to challenge thoughts.
- Note: This will be most helpful when autism is accompanied by distressing thoughts, as when it comes with an anxiety disorder.

Mindfulness

- Mindfulness and mindful meditation is a well-validated method for virtually anyone who needs coping skills.

What if it's an Emergency?

- *If* a child has pica syndrome and *if* ABA is the only way to treat it and *if* it's done with as little cost as possible and *if* it doesn't affect the child's other traits…okay, you win, maybe ABA is okay then. BUT that doesn't imply that it's a generally acceptable method.
- Analogy: If a child is about to walk into a busy street it's probably okay to tackle them if nothing else would work. That doesn't make tackling children generally acceptable.

Outline of Part 2: Current Issues

- Responses to our paper
- Judge Rotenberg Center

Responses from Autists

- Generally we weren't saying anything autistic self-advocates didn't already know.
  - Advances:
    - 1) Located concerns in more systematic bioethical framework
      - Explored subtleties (e.g., autonomy vs. decisional authority) that if ignored could be used to defend continuation of practice.
    - 2) Brought concerns to new audiences
- We have encountered very little pushback from autists ourselves.
- Obvious selection worries:
  - Maybe our conclusions ring true to more communicative autists but not less communicative autists.
  - Maybe people are just being nice.

Responses from Education

- Unsolicited endorsement via email from Alfie Kohn, perhaps America's best proponent of progressive education strategies.
- Pushback from ABA practitioners.
  - That isn't really a surprise.
  - They frequently argued that we overstated the costs of ABA.
    - That is probably true for some ABA programs, but misses other logically independent aspects of the argument.

Responses from Parents:

- Parent 1: ABA helped her son learn to communicate.
  - The fact that ABA succeeded at something good does not mean it was ethically justified all-things-considered.
  - Interestingly, she mentioned that when she asked her son if ABA had been a good thing he said he didn't want to talk about it.
  - Suggested that maybe our ideas would work in a more ideal world but ABA is best as society transitions to become more inclusive.
    - This is an interesting move, but we think ABA is still doing considerable harm even in this hopefully transitional period.
    - Other suggestions above are more narrowly targeted to targets worth pursuing (more on that later).
  - General Note: We don't mean to judge individual parents, but rather a clinical practice.
- Parent 2: ABA was somewhat successful, but perhaps made her son too compliant.
  - We didn't even think of this worry!
  - It might suggest that there's some sort of compromise position that does weaker ABA.
    - We do not think there have been any such programs developed.
    - What we have seen seem to just make things ethically worse—e.g., by having the parents practice the therapy ("Parent Training"). That just does ABA while depriving the child of an external support!

Outline of Part 2: Current Issues

- Responses to our paper
- Judge Rotenberg Center

Judge Rotenberg Center

- Things that merit angry exclamation marks:
  - Uses electric shocks to punish patients for autistic behavior!
  - Condemned as torture by the UN Special Rapporteur on Torture!
  - Uses other aversive techniques: withholding food, long-term constraints, and sensory deprivation!
  - Still in operation today!
    - They were sued to shut down in 1985, but they countersued, won, and renamed the center after the judge that sided with them.
    - The FDA tried to ban the electric shocks in 2020, but there were bureaucratic hurdles and in July 2021 a court ruled that they could still be in use.
    - Literally every year autistic advocates try to get it shut down legislatively, but it never works.
  - Parents keep defending it!
- There are videos…but we definitely won't show them
- BL: We hope to educate clinicians (and maybe parents) to end this sort of thing and hopefully avoid future manifestations. If you see something, speak out!
- "If this same treatment were allowed on terrorists in Guantanamo Bay, there would be worldwide outrage." Former State Senator Brian Joyce.

Outline of Part 3: Extensions of Our Paper

- Parental decision-making in the non-ideal world
- Is autism really a disability in the first place?

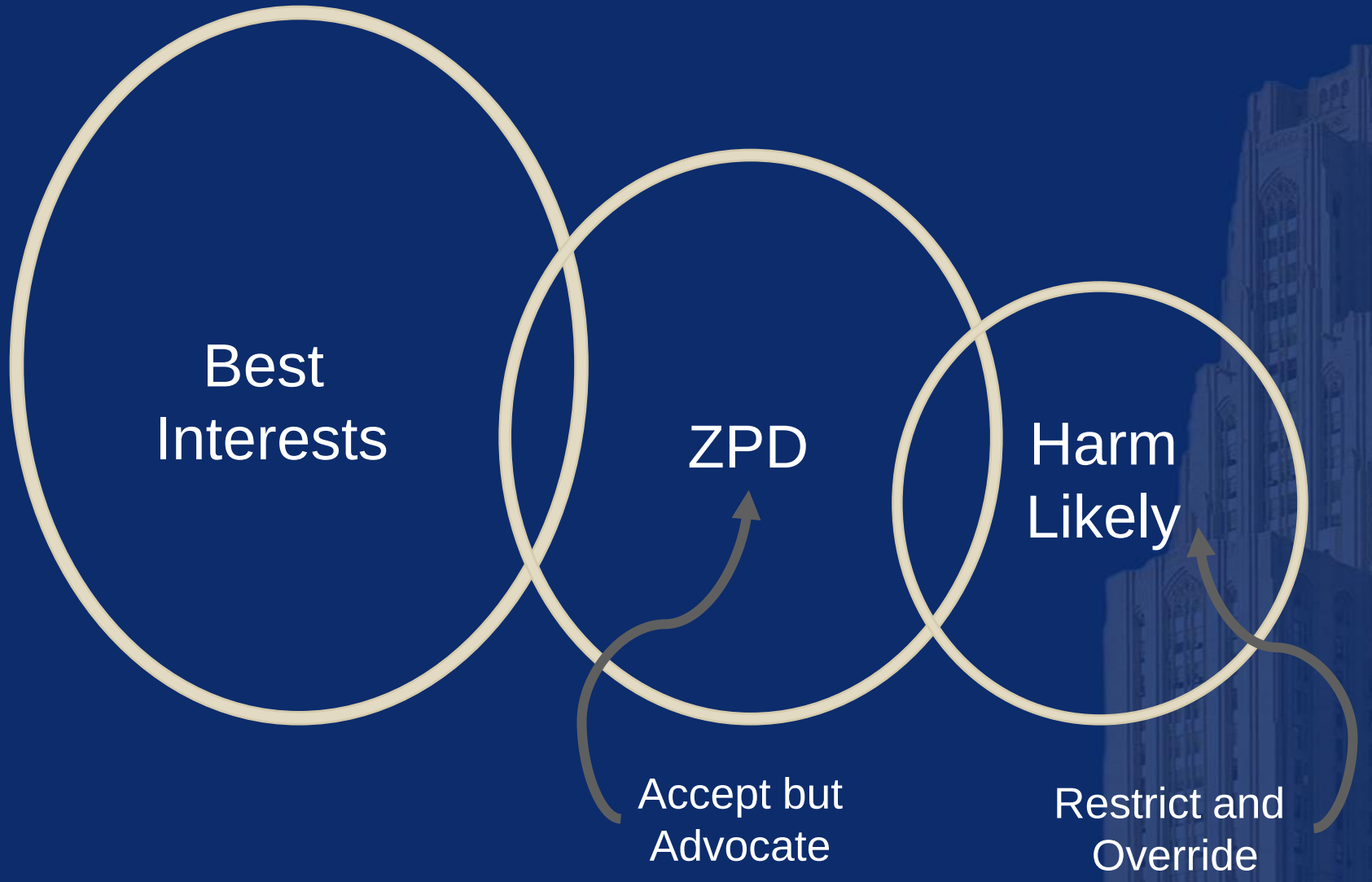
Pediatric Decision-Making

- Default decision-makers = parents
- Best interest standard
  - Caregivers choose the one best thing
  - Not *exclusively* best medical interest, but best overall interest
- Best interest as *guidance* principle, not intervention principle
- Grounds for intervention = harm principle
  - Providers intervene when parents' decisions put patients at the immediate risk of preventable harm
  - Least-restrictive possible intervention known to prevent identified harm(s)

Zone of Parental Discretion

- Zone of Parental Discretion (‘ZPD) = the set of options that are sub-optimal from perspective of patient’s best interest, but that do not fall outside of parental jurisdiction
  - Balance children's well being and parental rights to make decisions.
  - Acknowledges a range of ethically acceptable options
  - Acknowledges that overriding parents may create harms
  - Congruent with principles of family centered care

Gillam, “Zone of Parental Discretion”, 2016

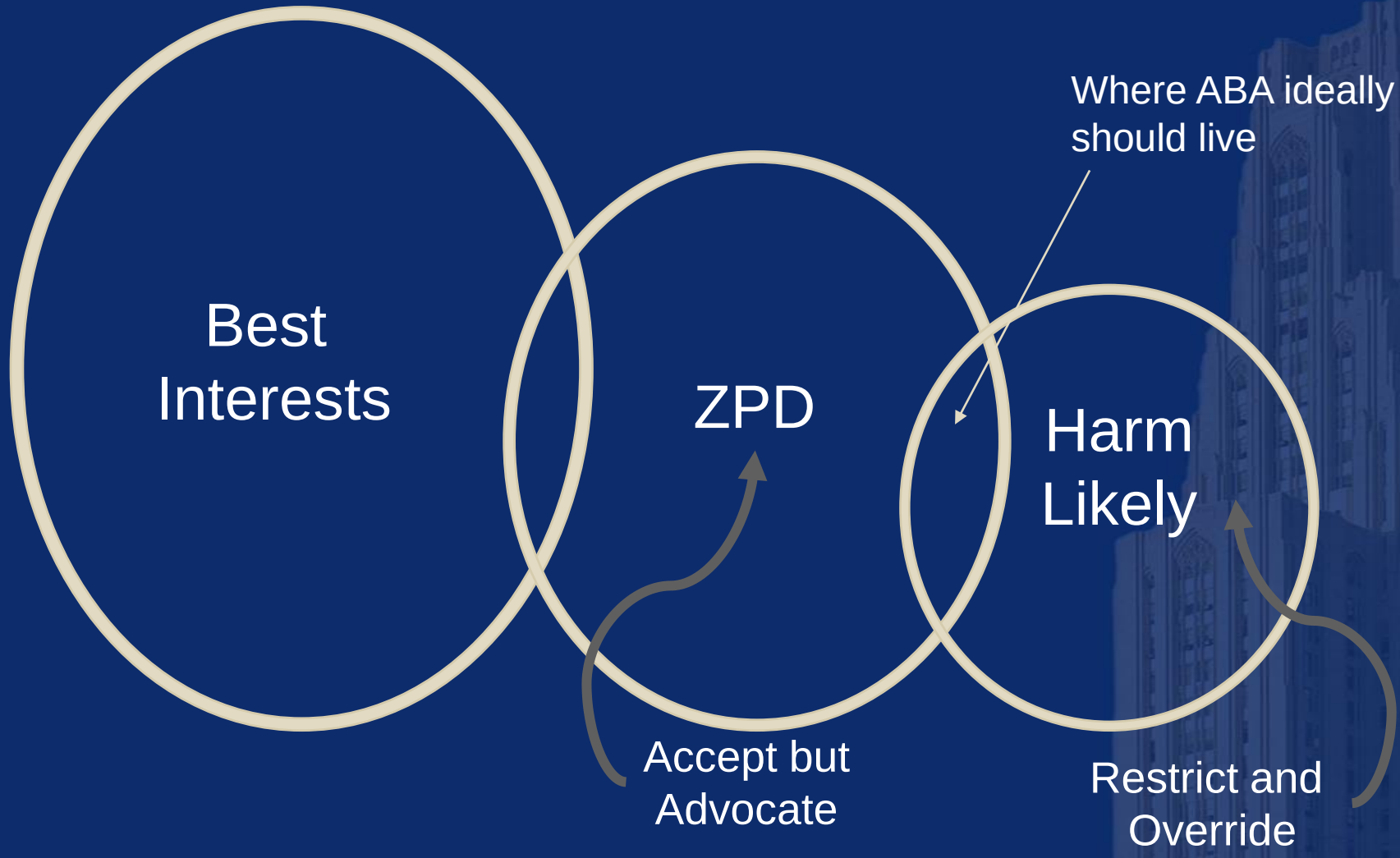


PittNursing

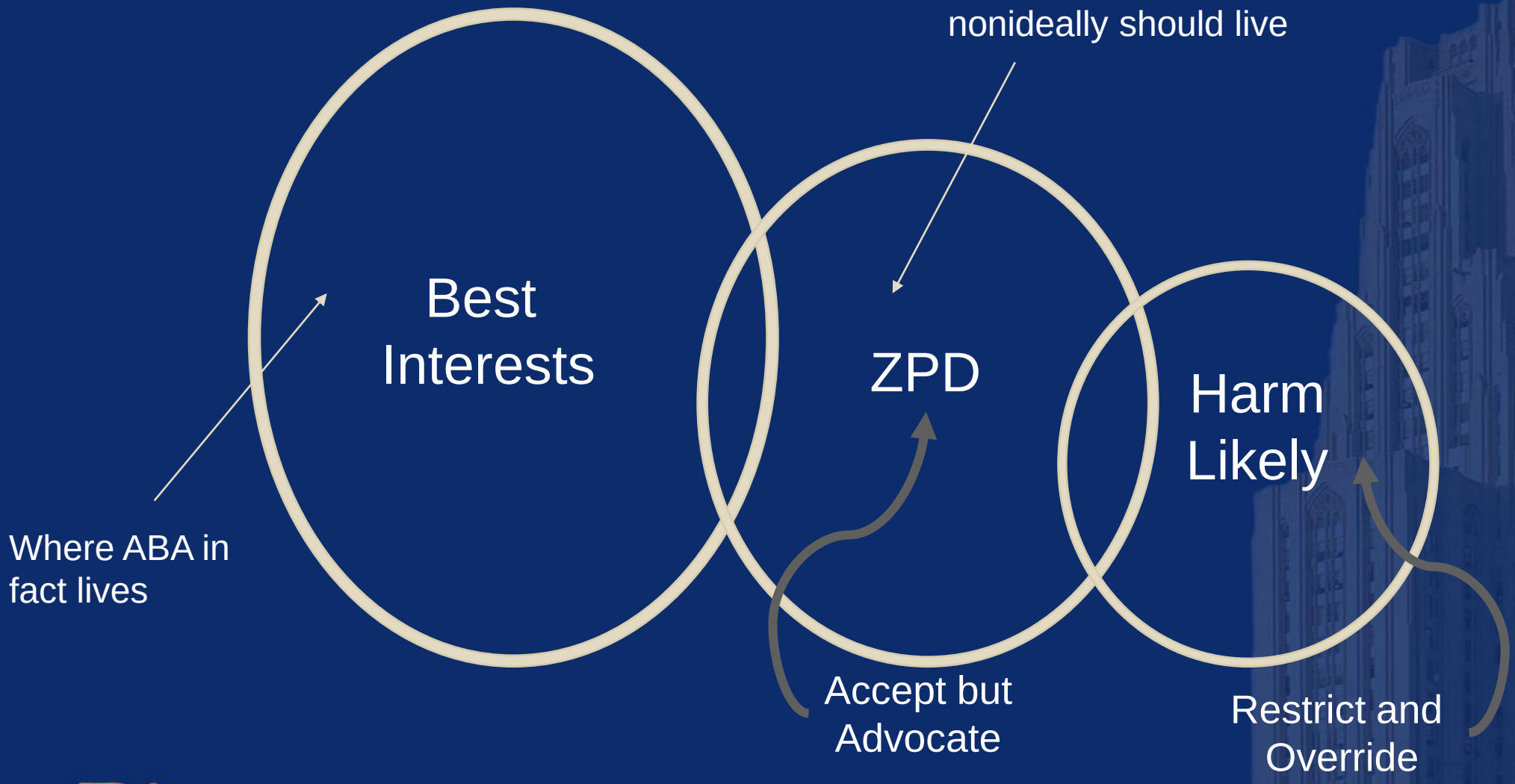
Institutional Support for ABA

- Our main concern is with how ABA affects children's autonomy, but the institutional support of ABA limits parental decision-making as well.
- In many states it is the only covered intervention, despite the existence of other possibilities such as occupational therapy, cognitive behavior therapists, and mindfulness.
- Schools also sometimes put autistic students on tracks that involve ABA, with the National Association of School Psychologists suggesting 25 hours of ABA per week.
- Individualized Education Plans are often funded through Medicaid, and the federal government supports ABA as the only approved intervention.
- Caveats:
  - Some localities offer no help for parents with autistic children. We think this is probably still a better alternative than pushing ABA, but in any event is an artificial dilemma given the availability of other therapies.
  - We are not saying that it's always impermissible to pressure parents into certain health decisions (*CoughVaccinesCough*), but that there should be a generally strong presumption against doing so.

ABA in the Ideal World



ABA in the Nonideal World



Achieving the Nonideal

- Improved discussion about what are appropriate targets
  - This is on ethicists, health policy experts, and clinicians
- Education on the reported harms of ABA
  - Possible ban of aversive ABA
- Advocacy for institutional support of alternative methods of intervention
- Continued education of public and institutions about modes of supporting flourishing for autists without forcing conformity to majority modes

Outline of Part 3: Extensions of Our Paper

- Parental decision-making in the non-ideal world
- Is autism really a disability in the first place?

What is a Disability?

- 2 Main Models:
  - Medical Model: Disabilities are biological deviations that are inherently problematic.
  - Social Model: Disabilities are deviations that are problematic due to societal oppression.
- Both models agree that disabilities are problematic, even if they locate the cause of the problem in very different places.

Is Autism Always a Problem?

- This might not be a well-defined question, but to our experience the answer is “no”.
  - (Experience: working with parent groups, working with autistic students, parenting autistic children, being autistic (Daniel)…)
- Many autists consider autism part of their identity, rather than something that is a problem to be fixed.
- This explains the data that suggest that autists show a tendency to prefer identity-first language (“autistic person”) over person-first language (“person with autism”). (Kenny et al 2016)
- Difficult to overlook the success of autistic individuals in certain areas, especially tech (Silberman 2015)

If Autism Isn't Always a Problem, Where Does That Leave Us?

- 2 options:
  - Our "Disability" talk makes sense, but autism isn't a disability.
  - There's something fundamentally wrong with how we talk about disabilities.
- Not the point of this presentation, but we think you could make similar cases about other "disabilities", which would lead to Option 2:
  - Being deaf vs. Deaf culture (Cooper 2019)
  - Having a wheelchair for long lines (Silvers 2003)

Aside on Philosophy of Language: How Concepts (Maybe) Work

- Concepts provide us with rules for when we can apply them and what we can conclude from them.
- We can see that something has feathers, apply the concept of **bird**, and conclude that it has wings. That works! (I think.)
- On main models of disability, we can apply **disability** on the basis of a particular condition (e.g., autism, deafness) and conclude that the person is disadvantaged.
  - We argue that that doesn't always work, and so the concept is "broken".
- Possible fixes:
  - 1) Block the inference from particular conditions to the application of the concept **disability**.
  - 2) Block the inference from our concept of **disability** to the conclusion that someone is necessarily disadvantaged.
- Given the importance of making accommodations available to people who claim a disability, we would go with route (1).

Proposal:

- Personal Criterion of Disability (PCD): What counts as a disability will vary from person to person, based on whether it's actually a disadvantage to them and/or whether or not they would want to be rid of it if they could.
- Upshots:
  - Some autistic people are disabled and some are not.
  - People should be allowed to self-identify whether they are disabled (as we allow for other disadvantaged groups).
    - (Some restrictions might be necessary for some accommodations, t.b.d.)