The Neurodiversity Paradigm as a Foundational Ethical Framework for Medical Standard of Care in Pediatrics

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I. Introduction

Despite the growth of bioethics scholarship and evolution of pediatric standards of care, neurodiversity-affirmation in clinical settings continues to be treated as exploratory (Dwyer, 2022), with best practices framed as optional rather than foundational. Much of the existing conversation has focused on neurodiversity-affirming language, conceptual frameworks, and the consequences of their absence, specifically the perpetuation of ableist mindset amongst practitioners, and the resulting risk of reduced quality of care or harm (Shear, 2025).

Pediatric medicine, meanwhile, occupies a formative role in the lives of neurodivergent children. Early clinical encounters and the prescribed models of care that drive them, shape everything from developmental trajectory and identity to long-term familial bonds. Neurodiversity-affirming care demands that we consider neurodivergence not as a disorder to cure, or a condition to treat, but as a natural, valuable part of human diversity (Flower, 2025). Thus, the lack of established framework within pediatric medicine recognizing neurodiversity-affirmation as an ethical imperative risks fostering clinical practices that perpetuate significant unintended harm.

Both the lived experience testimony of neurodivergent individuals and leading research suggests that neurodiversity-affirmation reduces masking (Sedgewick, 2022), improves mental health outcomes, and reduces suicidality (Sedgewick, 2022; Conner et al, 2023). Beyond improved health outcomes, this raises treatment questions that challenge the status quo for children with neurodevelopmental disabilities to ask not necessarily if proposed interventions

"work", though this concern has also been raised (Department of Defense, 2024; Sandbank et al, 2024; Devita-Raeburn, 2017; Anderson, 2023; Reichow et al 2018), but if they *should* be pursued in the first place. For example, numerous ethical concerns have been raised amongst Autistic self-advocates, parents, and clinicians regarding Applied Behavior Analysis, the most highly utilized and longstanding "best practice" intervention for neurodivergent children (Wilkenfield 2020; Dallman 2022, Roberts, 2024). Some researchers question both its underlying assumptions and the evidence used to support its role in addressing Autistic needs and challenges (Anderson, 2023; Aguirre Mtanous 2025; Roberts, 2024). This firmly positions the conversation around adoption of neurodiversity-affirmation in clinical practice as one of ethical concern.

The purpose of this review is to examine existing scholarship that discusses neurodiversity-affirmation as an ethical imperative in pediatric clinical care and suggest an applied ethical framework for neurodiversity-affirming care for neurodivergent children. It will discuss prevailing ethical standards in pediatric medicine for children with neurodevelopmental disabilities, including universal principles of care. In doing so, it will identify points of philosophical convergence and discuss the resulting implications, including the application of the neurodiversity principle to clinical care settings. Finally, this review will identify gaps in the literature on neurodiversity-affirmation as an ethical consideration in pediatric standards of care and propose novel directions for future research.

II. Historical Context: Emergence of the Neurodiversity Paradigm

Neurodiversity entered mainstream academic scholarship in the 1990s, though the neurodiversity movement itself predates the term's arrival in scholarship. Its origins lie in the wider disability rights movement and in Autistic self-advocacy communities that were already transforming understandings of disability (Sinclair, 2005). Judy Singer's 1999 thesis *Odd People*

In: The Birth of Community Amongst People on the Autism Spectrum is often credited with introducing the term, though a pivotal piece written by Harvey Blume (Blume, 1998) suggests it may have emerged through a collective process shaped by the interplay of disability activism, media, and public discourse.

Despite having significant implications for the healthcare of neurodivergent people, the neurodiversity principle developed outside of traditional academic or clinical institutions and their scholarship. Instead, it emerged through grassroots self-advocacy networks, scholar-activist theory from adjacent fields, and external, often informal channels of thought leadership within the Autistic community rooted in lived experience (Bascom, 2012). The Autistic community largely regards the philosophy as a collective production of critical analysis on the caregiver-savior model (Sinclair, 1993) dominant at the time. The model depicted Autistic individuals as subjects of intervention and constant management instead of human beings with agency and authority over their own needs, identities, relationships, and daily lives (Sinclair, 1993). In a manner similar to the clinical and research uptake of subjects like Black maternal health (Owens & Fett, 2019) and HIV/AIDS treatment (Ayala & Spieldenner, 2021), neurodiversity first entered public and scholarly discourse from the margins.

The Autism Network International was among the first Autistic-led, community-driven organizing models (Sinclair, 2005). Founder Jim Sinclair's 1993 presentation at the International Conference on Autism in Toronto titled *Don't Mourn for Us*, was one of the earliest contributions to emphasize Autism as an intrinsic identity, inseparable from the Autistic individual. This concept would later become a conceptual cornerstone of neurodiversity and its applied theory and would begin the push away from a pathologizing model of support.

This framing was further institutionalized with the founding of the Autistic Self Advocacy Network (ASAN) in 2006 which championed the slogan "Nothing About Us Without Us." In 2012, then founder Julia Bascom published *Loud Hands: Autistic People, Speaking*, and the concept gained broader mainstream recognition with the release of Steve Silberman's *Neurotribes* in 2015. Finally in 2021, a seminal text on the neurodiversity movement, Nick Walker's *Neuroqueer Heresies: Notes on the Neurodiversity Paradigm, Autistic Empowerment, and Postnormal Possibilities* introduced readers to the Neurodiversity Principle and its application (neurodiversity-affirmation) with clarity. The work became both a scholarly touchstone, a philosophical grounding, and a mainstream reference point for understanding neurodiversity, and henceforth its applied ethical principle (neurodiversity-affirmation).

As these works brought neurodiversity into broader public awareness, they also began to shape conversations beyond advocacy and theory, especially within clinical care and medical research. Increasingly, clinicians, researchers, and caregivers have engaged with neurodiversity with curiosity and concern for ethical implications in care (Anderson 2023; Dallman et al, 2022; Devita-Raeburn, 2016; Roberts, 2024). In pediatric settings especially, this shift in discourse has raised reconsideration of standard practices around diagnosis and intervention and raised questions about both quality of life and ultimately patient autonomy.

III. Existing Ethical Standards in Pediatric Clinical Care: The Emergence of Informed Assent

Pediatrics has long relied on ethical principles which are standard to all of medicine. Attard-Montaldo (2001) establishes the guiding points of ethical standard in pediatrics to include "Respect of the Individual's Autonomy", "Respect of the individual's competence", "Respect of beneficence", "Respect of the truth", "Respect of patience confidentiality", "Avoidance of

paternalism and bias", "Avoidance of all conflicts of interest", and "Respects the limitations of medical care", many of which reflect the themes addressed in the research on neurodiversity-affirming care. While many explorations in this field are targeted specifically toward critical care decision-making (Orioles, 2013), ethics is also used to develop treatment protocols per diagnosis and what is known as "standard of care", or for those more highly touted or utilized treatments, the "gold standard of care."(Roberts, 2024)

The existing proposed ethical frameworks for pediatric research also rely upon similar guidelines to generalized medicine to include child assent, and risk-benefit tradeoffs (Roth-Cline 2011). Recently, emphasis has been placed on child autonomy regarding consent in treatment decision-making (Kurtoglu, 2025), specifically understanding treatment to a developmentally appropriate degree and voluntarily agreeing to the proposed intervention (Kurtoglu, 2025). Assent differs from consent in that informed consent for minors may only be granted by parents of minors as their legal guardians and is legally required to participate in research or to commence treatment, while assent is a minor's own active expression of voluntary participation in that research or treatment. As such, assent is not just a passive compliance to what a parent has agreed to on their behalf but is an important aspect of a child's expression of their will and autonomy. Assent in pediatrics is a relatively recent contribution in the field of ethics (Giesbertz, 2014), and questions arise regarding how this has been conceptually integrated into the treatment and care of children deemed intellectually or developmentally different, especially those who communicate assent through less conventional means.

Being that the neurodiversity principle is a value-neutral philosophy that approaches all types of neurological ways of being as valid, valuable, and naturally occurring, assent is fundamentally compatible with neurodiversity-affirming care approaches. If the neurodiversity principle

compels us to honor the child as they are, this puts the decision-making, goal setting and definitions of their strengths and challenges in the hands of the individual, versus the hands of the perceived caregiving authority, whether parent or practitioner. Thus, this also puts the purpose of care on honoring the individual, their self-determination, and autonomy. Importantly, receiving assent from children, is considered equally important in IRB considerations as informed consent, meaning both must be received to initiate research. A recent publication from Physicians for Human Rights states that "children must have the opportunity to dissent…and such decisions should be respected", and that "informed assent is a continuous process. Assent can be withdrawn at any time." (Physicians for Human Rights, 2024). This implies that a child's own expression of consent should be sought, not just initially, but ongoingly in the process of administering research or care.

There is a small but emerging field of research regarding the intersection of assent with children with neurodevelopmental disabilities, specifically those who are Autistic, have intellectual disabilities, or are non-speaking, and the ways assent applies to interventions that impact their lives (Morris et al, 2021). This field of study is an important pivot from the ways interdisciplinary care teams organize themselves around neurodevelopmental disability both presently and historically (Bannerman et al, 1990). Overwhelmingly, until very recently, those administering interventions on neurodivergent youth rarely pursued or engaged with the topic of informed assent for their patients (Morris et al, 2021; Bannerman et al, 1990). To the contrary, many modalities integrated an intentional bypassing of neurodivergent distress with numerous tactics such as planned ignoring and extinction, pathologizing the distressed behavior as "non-compliance". These practices have been a focal point of critical feedback provided by those in the neurodiversity movement (Bascom, 2012). A recent article by Breaux and Smith exploring

assent in Applied Behavioral Analysis suggests that the withdrawal of assent should not only be honored, but that both vocal and "non-vocal expression" should be accepted as assent (Breaux & Smith, 2023).

When considered in the evolution of models of care for neurodivergent children, these developments suggest that traditional models of pediatric care, particularly those that prioritize compliance over autonomy, have been ethically lacking. As such, assent emerges as a critical point of convergence between a neurodiversity-affirming ethical framework and standardized pediatric ethics. Thus, the comprehensive integration of assent into models of care is not just ethically urgent but further necessitated by the neurodiversity principle.

IV. Implications for Standard of Care

The strong alignment between neurodiversity and pre-existing ethical standards mandates a much closer evaluation by clinical ethicists, pediatric ethics committees, and clinical governing and licensing entities. As neurodiversity-affirmation is a human right, it should be moved into the realm of other uniform, bioethics standards within pediatric standard of care. HIPAA for example, provides a uniform basis for clinician self-conduct when accessing records by the way of ethical imperative for reasonable privacy. Neurodiversity-affirmation demands that standards be integrated into medical standard of care in pediatric medicine for those with neurodevelopmental disabilities.

Mandating neurodiversity-affirmation into code for practitioners is already underway in several places, most notably Australia. In 2025, neurodiversity-affirming practice, or NAP, became a core competency for becoming a psychologist per the Psychology Board of Australia (Australian Psychological Society, 2025). Elsewhere in 2023, the American Medical Association (AMA) Medical Student Section introduced to the AMA Draft Resolution 706, which sought to

revoke the AMA's support of ABA through a compelling body of evidence (American Medical Association, 2023). While the American Medical Association did not respond by fully banning the use of ABA, they did remove an explicit endorsement of ABA and adopted a broader endorsement of interventions to include other evidence-based, and neurodiversity-affirming, modalities.

Similar shifts are becoming evident across countries and disciplines. Recently, in the United Kingdom, the National Institute for Health and Care Excellence (NICE) guidelines removed explicit mention of ABA, and instead focused on language emphasizing diverse supports toward improved quality of life for neurodivergent people. Also apparent are ethical shifts in public education. In 2024, the Boulder Valley School District in Colorado passed the nation's first Neurodiversity Philosophy, providing a foundational ethos and basic commitment "to proactively support students through equitable and accessible instructional design and practices that incorporate educational research, including current and neuro-affirming research, and strategies to affirm a student's identity, rather than trying to "fix" or "cure" them" (Boulder Valley School District, n.d.).

However, as the neurodiversity principle breaks into public spheres such as public education and individual disciplines of healthcare, an overarching approach or ethical mandate that compels and informs neurodiversity-affirming pediatric care is still lacking. Many individual clinicians possess the will to become a neurodiversity-affirming practitioner, and while waiting for an organized ethical mandate, an applied ethics framework could support this endeavor. Using one of the most common bioethical guideposts for standards in all medical care, the following applied ethics framework maps a line of ethical reasoning toward neurodiversity-affirming care along the four pillars of medical ethics. These pillars include nonmaleficence, beneficence, autonomy, and justice. This applied ethics framework for neurodiversity-affirmation was developed utilizing the long-established and emerging

evidence for how a lack of neurodiversity-affirming care produces harm, as well as how current approaches do or do not align with the ethical principle of neurodiversity, leveraging findings in best practice toward neurodiversity-affirming care.

1. **Nonmaleficence "First, do no harm."**
    - Is this promoting masking of neurodivergent traits (Scheeren et al., 2025)?
    - Is this rooted in behavioral compliance?
    - Does this respect neurodivergent social styles? Is this rooted in the Double Empathy Problem (Milton, 2025)?
    - Have I adopted an intersectional lens (Mallipeddi & VanDaalen, 2022; Eilenberg et al., 2019; Diemer et al., 2022)?
    - Is this rooted in self-determination?
    - Am I working collaboratively with my patient?
    - Am I encouraging independence on their own terms?
    - Am I honoring their challenges?
    - Are my choices driven by preservation of self-regulation?
    - Have I presumed competence (Biklen & Burke, 2006)?
    - Is my presumption of competence matched to the patient's zone of proximal development, sensory profile, and motor profile?
    - Do I hold bias against this patient's way of being, mindset, approach, needs, or nervous system state? Do I understand and honor the scope of their strengths and challenges?
    - Do I seek to understand their way of being, mindset, approach, needs or nervous system state?
    - Am I using anti-ableist language? *(place link to language list)*
    - Am I assigning intent or willfulness to their behavior?
    - Am I treating my neurodivergent patient as though they are not in the room with us? Am I speaking about them in front of them without including them in the conversation?
    - Am I speaking over my neurodivergent patient, making assumptions about them, or assigning intent to their behavior without firm evidence or personal testimony to the purpose of their behavior?
    - Do I use infantilizing or condescending tones when I speak to my neurodivergent patient? Is the tone respectful and age appropriate?
    - Is there evidence of substantial harm in the ways (tools, methods, underlying research, etc.) I've diagnosed, discussed, made recommendations for, advised, prescribed a medication to, or administered an intervention with my patient?
        I'm 100% certain that yes, there is. → Then stop.
        I'm 100% certain that no, there isn't. → Then proceed.
        Harm is suspected, but research is pending. → Then wait.
        I am not 100% sure what the research says. → Comprehensive self-education and exploration before proceeding using updated review of

literature, trusted self-advocacy resources with collective lived experience, and a reliance on neurodivergent accountability partners.

Beneficence

- What is the scale of challenge and who has defined the challenge?
- Is it physically endangering?

  No. → No intervention.
  Yes.
  If yes, is this due to the environment?
  Yes. → Adapt the environment.
  No.
  If no, is it situational?
  Yes. → Accommodate the situation.
  The environment is impossible to adapt, the situation is impossible to accommodate. → Understand and design around the WHY.

- Have you truly exhausted all tools and resources? Have you sought neuroaffirming practitioners in all possible fields?

Concerns of Medical Neglect/Negligence

- Does it meet ALL three criteria for medical neglect (Zate, n.d.)?
  1.) "The child is harmed or at risk for harm because of a lack of healthcare."(Zate, n.d.)
  → If the child is at risk of harm because you won't offer a non-affirming form of care, your solution cannot introduce new risk of serious harm. (See nonmaleficence.)
  2.) "The recommended healthcare offers a significant net benefit to the child." (Zate,n.d.)
  → Risk versus benefit scenarios should be considered in extreme cases, but "net" benefit must consider harm (please see nonmaleficence). Research metrics are constantly evolving on some non-affirming practices, making calculations challenging. "Benefit" considerations must still be neurodiversity-affirming.
  3.) "The anticipated benefit of the treatment is significantly greater than its morbidity." (Zate, n.d.)
  → Again, benefit must be weighed against harm. (Please see nonmaleficence.) Morbidity suggests the degree of how disabling the characteristic is, which is subjective to the individual, not the clinician.

Autonomy

Autonomy and Drive

- What is the presenting concern, condition, challenge or need as it was described to you today? Who is the primary source of information about the patient?
- Is the patient themselves able to describe their own needs and challenges independently?

Yes, they are.→ Honor their voice. Do not override.
No, they are not.→ Am I honoring all forms of communication?
Do I have robust education in all forms of communication?

Is their behavior or nervous system reaction communicating something to me?

Yes, but I disagree with them. → Honor their voice. Pursue connection and collaborative problem-solving. Find the WHY.

- What are the patient's goals?
- What are the patient's interests, strengths, and preferences?
- Have you incorporated the patient's interests, strengths, and preferences into their care plan?
- What are the patient's values?
- What non-affirming or ableist influences has this patient already been exposed to? How might it influence their thinking about their own needs, goals, and sense of self?
- Does my approach center the caregiver needs, convenience, and concerns over the patient's autonomous goals, drive, and preferences?
- Does my approach center the needs, convenience, and concerns of an educational or group setting over the patient's autonomous goals, drive, and preferences?
- Does my approach put the onus of external sources of distress, including discrimination, social ostracization, bullying, and abuse (physical, mental, or sexual) on the patient? Does it conceptualize that patient as having agency or control in these types of abuse?

Issues of Consent and Bodily Autonomy

- Have I asked for their consent before touching them and examining them? Have I asked for their consent to be there with them today?
- Am I placing my hands on them in ways that are essential to their self-determined learning?
- Am I taking video or pictures of them without their consent? If relying on older video or pictures, have I made every possible effort to contact the now adult subjects and obtain consent?
- Am I displaying video or pictures of neurodivergent distress, crisis, or any moment that is private or potentially humiliating?
- Are my video or pictures essential? Can descriptions suffice? Are depictions and descriptions truly necessary?
- If necessary, are my video or pictures duplicating other available video or pictures?
- Are my videos and pictures creating an emotional distancing from patients and an orientation of them as subjects where a connection-based orientation is essential?
- If I was unable to determine consent from a patient in previous encounters, am I continually attempting to ascertain consent in consecutive encounters as they age and develop?
- Am I recommending supports that encourage bodily autonomy and self-advocacy in ways that do not cause harm? *(See nonmaleficence.)*

Justice

- What are the implications of my choices, actions, and language for neurodivergent people more widely in society? Will what I have described/recommended/prescribed have negative repercussions for the way

neurodivergent people are viewed by society? The family members who support them? Their peers? Their workplace?

- Would I describe/recommend/prescribe in this exact way with this exact language if I were discussing the goals, needs, and health of a person from a different socio-politically marginalized identity (queer, trans, poor, indigenous, Black, immigrant)? Am I subjecting my neurodivergent patients to standards, scrutiny, or expectations that I do not have for those in the neuromajority?
- Have I listened to the collective concerns and priorities of the community I serve and tailored my methods, goals, research, etc. towards these concerns? Am I spending the valuable resources and authority I have been given towards the priorities of the community I serve?
- Is my lens intersectional? Am I understanding neurodivergent needs across the lifespan? Across gender, sexual orientation, race, religion, language, culture?
- Am I using my position of "expert" and authority in the clinical, research, or educational realm to knowingly speak over neurodivergent voices, their collective concerns, and their public testimony to their lived experiences?
- Am I using my position of "expert" and authority to gatekeep diagnoses and labels, diagnostic criteria, resources, research, funding, supports and services for neurodivergent people?
- If I am hesitant to adopt neuroaffirming practices, am I checking myself on why? What am I fearful of?
- How am I actively working to redistribute power back to neurodivergent people in clinical, research, and educational spaces?
- Who are my sources of information and continual learning?
- What communal mindsets does my work cultivate?
- Am I imagining myself as an authority with superior knowledge or a collaborative partner and ally to my patients?
- What am I doing to support a society, a culture, and public systems that make space and understanding for behavior outside the norms? (*gun control example)*
- Are my choices cultivating unconditional inclusion and belonging *as is* for neurodivergent children? Or am I building systems and a society that accepts neurodivergent people only conditionally? Am I fostering true connection with and understanding of neurodivergent children?
- Am I cherry picking the neurodivergent voices that I listen to? Am I listening to voices that make me uncomfortable, challenge my ways of thinking, and represent the larger neurodivergent community?

V. Further Research

Pediatric standard of care for those with neurodevelopmental disabilities is at a pivotal moment. Clinical decision-making and its long-standing norms around evidence-based practice are being thoroughly reevaluated within the scholarship. However, a review of the literature

indicates pediatric medicine has seemingly disorganized itself in orientation to the issue. The research approach surrounding this topic has taken a fundamental ethical principle—a philosophical premise from which critical medical ethics questions are derived including not if an intervention "works" but if it *should* be pursued in the first place—and turned it into a question of an optional "approach"(Dwyer, 2022) akin to a trend or patient religious preference (CITE), or a suggestion for potentially improved care outcomes (CITE). The lack of serious inquiry by bioethicists into the ethical imperatives stemming from the neurodiversity principle warrants significant further research. Potential scholarship on this subject would build the logical foundation for all other inquiry into the appropriate clinical approaches and standard of care for neurodivergent children, which is also needed to fill the gaps in understanding.

In a field which is struggling to orient to neurodiversity accurately and appropriately, and as pediatric clinicians and researchers seek to understand how to select neurodiversity-affirming models of care for their patients, the pursuit of more robust investigation into the mental health, physical health, and quality of life outcomes of neurodiversity-affirming clinical approaches is especially useful. As previous practices are called into question and inevitably the research paves the way for neurodiversity-affirming progress, further research in health outcomes would provide reassurance in clinical decision-making.

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