

# Addressing Disability Bias in Neuroprognostication

Grant L. Lin, MD, PhD,<sup>1</sup> Sarah Jean Barton, ThD, MS, OTR/L, BCP,<sup>2</sup> Tyler Tate, MD, MA<sup>3</sup>

“Has anyone spoken to family? Do they understand the terrible prognosis?”

Diego, a three-year-old with trisomy 21, was admitted to the pediatric intensive care unit (ICU) after a near-drowning event requiring prolonged resuscitation. Concerns about cerebral edema were growing.

“Will they want extreme measures? I sure hope they don’t. His brain injury is devastating...I mean, even if he survives, he’ll just be suffering.”

The medical teams were discussing prognosis. Four days after his injury, Diego had not demonstrated any purposeful movements. Imaging showed widespread changes consistent with hypoxic-ischemic brain injury, and his electroencephalogram showed diffuse slowing.

“What are his chances? He’ll never walk and probably never talk. At best, even if he survives, he’ll be trapped in there, dependent on others for everything. He was already significantly disabled—and now this—some fates are worse than death.”

In a conference room, the medical teams sat down with Diego’s parents to discuss his prognosis. Yet, after the neurologist spoke, the parents offered a radical reorientation: “Will he know when his family is around? Will he be able to hear us sing to him? Can he still be happy?”

This vignette (which is an anonymized composite of cases) captures a common phenomenon where parents and medical teams have different and, at times, conflicting perspectives about prognosis. While these differences highlight challenges in pediatric neuroprognostication—for example, uncertainty of recovery potential in a developing brain, differences in family preferences for receiving prognostic information after a neurologic injury or diagnosis, and difficulty of effectively conveying medical information<sup>1</sup>—we believe that Diego’s case reveals a fundamental flaw in neuroprognostication: the reliance on ableist heuristics that frame disability as loss and deficiency. To enhance care delivery and equity of care, we propose a challenge to ableist assumptions and offer an alternative, capabilities-based framework for neuroprognostication.

## ABLEISM IN NEUROPROGNOSTICATION

Clinical approaches to neuroprognostication often focus on how an injury or disease deviates from a well-child norm. We argue that this approach represents an implicit form of *ableism*, defined as “a network of beliefs, processes and practices that produce a particular kind of self and body” such that disability “is cast as a diminished state of being human.”<sup>2</sup> In Diego’s case, this approach generates multiple deficit-focused statements regarding ambulation (“he’ll never walk”), communication (“never talk”), and other capacities (“dependent on others”). This insistence on normalcy has been criticized by disability scholars:<sup>3</sup> by framing prognostication around how a child differs from a well-child norm, a sense of deficiency and loss is implied. This perspective is rooted in the medical model of disability, which views disability as a problem residing within an individual

<sup>1</sup>Department of Neurology and Neurological Sciences, Division of Child Neurology, Stanford University School of Medicine, Stanford, California; <sup>2</sup>Department of Orthopaedic Surgery, Occupational Therapy Doctorate Division, Duke University School of Medicine, and Duke Divinity School, Durham, North Carolina; and <sup>3</sup>Department of Pediatrics, Division of Palliative Care, Stanford University School of Medicine, Stanford, California

Address correspondence to: Tyler Tate, MD, MA, Stanford University School of Medicine, 291 Campus Dr, Stanford, CA 94305. [ttate@stanford.edu](mailto:ttate@stanford.edu)

Dr Lin conceptualized and designed the study, drafted the initial manuscript, and critically reviewed and revised the manuscript. Dr Barton critically reviewed and revised the manuscript. Dr Tate conceptualized and designed the study, and critical reviewed and revised the manuscript. All authors approved the final manuscript as submitted and agreed to be accountable for all aspects of the work.

**CONFLICT OF INTEREST DISCLOSURES:** The authors have no conflicts of interest to disclose.

**FUNDING:** Dr Tate receives funding from the Greenwall Foundation Faculty Scholars Program. This funding supported his time to work on this project. This funder had no role in the design, conduct, manuscript drafting, or approval of this research.

Accepted for Publication Date: January 9, 2026

<https://doi.org/10.1542/peds.2025-074710>

This is an open access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License, which permits noncommercial distribution and reproduction in any medium, provided the original author and source are credited.

**To cite:** Lin GL, Barton S, and Tate T. Addressing Disability Bias in Neuroprognostication. *Pediatrics*. 2026; 157(4):e2025074710

that medicine aims to minimize or eradicate.<sup>4</sup> The medical model is commonly accompanied by language that both reflects implicit ableist attitudes<sup>5,6</sup> and inserts negatively-valenced value judgements into prognostic communication<sup>7</sup> (eg, “devastating injury,” “terrible prognosis,” or the extreme “fate worse than death”). Although these linguistic qualifiers can represent a clinician’s (or at times, parents’) reflexive emotional response to difficult circumstances, centering them in prognostic communication perpetuates negative disability bias. The bias introduced by a clinician’s choice of words is further complicated by clinician bias toward pessimistic prognostication, especially early in the disease course.<sup>8,9</sup>

Compounding the challenges for neuroprognostication is the absence of relevant outcome data. Much of the longitudinal data guiding neuroprognostication uses clinician- or researcher-defined outcomes lacking family perspectives.<sup>10,11</sup> The frequent use of composite outcomes, which often conflate neurodevelopmental impairments with death, has been justifiably criticized.<sup>12</sup> These limitations make the terminology used in medical prognostication difficult to relate to caregiver questions.<sup>13</sup> Even if clinicians want to predict how Diego’s injury will impact his capacity to delight in play or love his family, empirical data are lacking, and relevant examples often only reflect personal anecdotes.

Social and cultural factors can heighten the challenge of discussing disability during neuroprognostication. For example, parental perspectives on disability often differ from clinical definitions: in one study, only 12% of parents of formerly preterm children clinically classified to have severe neurodevelopmental impairment agreed with the classification.<sup>14</sup> This propensity toward divergent conceptions of the capacities of children with neurologic impairment is captured in a qualitative study of pediatric ICU providers: “Oh. Holy smokes. I’m completely off base here’... [the] kid is capable of x, y, and z, and [I] didn’t think they could get past a, b, and c.”<sup>15</sup>

Additionally, clinicians and parents frequently have different values and perceptions about quality of life in neurological injury,<sup>16–18</sup> reflecting different baselines of conceptualizing disability. This discrepancy, which is closely related to the well-described “disability paradox” (where people with disabilities report significant limitations alongside good quality of life, whereas health care workers and/or society at large perceive worse quality of life than what people with disabilities report<sup>19</sup>), may exacerbate implicit ableism in prognostication. Moreover, people living with disability can demonstrate a “response shift” in their self-rated quality of life, where personal and social adaptation leads to higher reported quality of life over time.<sup>20</sup> Taken together, these social and culture dimensions ensure that the concept of disability is never set in stone (and that talking about disability is rarely straightforward). Instead, the meaning of disability can change over

time, and is often be shaped by culturally constructed definitions of health, well-being, beauty, suffering, and quality of life.<sup>21–24</sup>

As a final related point, it is important to note that pediatric neuroprognostication has been criticized for discriminating against intellectual disability. Pediatric bioethics arose in part because of the “Baby Doe” cases, where treatment was withheld from infants with trisomy 21 on claims about poor quality of life.<sup>25–27</sup> Recently, the accuracy of other diagnoses historically referred to as “lethal” has been challenged, with calls to liberalize medical and surgical interventions for children with genetic conditions like trisomy 13 and 18.<sup>28–30</sup> These shifts in medicine reflect larger cultural trajectories toward disability justice which is *a movement and accompanying set of principles that focus on societal transformation beyond disability rights to full societal access and inclusion*.<sup>31</sup> The framework of disability justice reminds the field of pediatrics that the category “disabled” is just as much a product of [1] inadequate social and cultural supports and [2] negatively biased practices of clinical care, as it is from impairments in a child’s body.<sup>32</sup>

Together, the reliance on a well-child norm, limitations of existing outcome data, and bias around quality of life in neurologic injury combine to form an ableist baseline in prognostication. An ableist baseline assumes that what needs to be predicted and communicated after neurologic injury is the degree of deviation from a neurotypical or “ideal” child. As medicine’s ability to care for critically ill children improves, there is an urgent need for a disability-inclusive approach to neuroprognostication.

## TOWARD A CAPABILITIES APPROACH IN NEUROPROGNOSTICATION

In contrast to a medical model focused on losses compared with “normal” children, we propose an approach centered on capabilities. A capabilities-based approach (CBA) focuses on describing and cultivating fundamental human capacities.<sup>33</sup> A CBA spotlights what people can do, rather than what they cannot. A CBA views children with neurological injuries in light of central capabilities that all humans share: for example, maintaining bodily integrity and homeostasis, relating and connecting to others, delight in movement, and perceiving the world through multiple senses.<sup>33</sup>

A CBA offers a novel way to conceptualize and practice pediatric neuroprognostication. We hypothesize that integrating a capabilities lens into neuroprognostication will result in (1) active debiasing of neuroprognostication, (2) adjustment of language used in prognostic communication, and (3) reworking of assumptions commonly used in the collection of prognostic outcome data.

First, clinicians should use prognostication frameworks to actively debias (eg, ouR-HOPE<sup>13,34</sup>) and reorient prognostication to family values (eg, ALIGN<sup>35</sup>). Use of functional assessments designed for children with disabilities

**TABLE 1.** From Won't to Will: Capabilities-Based Language Choices in Prognostication

Topic Area	Considerations	Deficit-Oriented Language	Capabilities-Based Language	Associated Capabilities
Distinguishing injury, impairment, and disability	Injury: Organic change to the nervous system (structural, chemical) Impairment: Impact of an injury on a person (hemiplegia, vision loss) Disability: How the interaction between a person's impairments and their social and build environment impact function	Diego will be profoundly disabled because of this stroke Because of this stroke, he may not be able to interact meaningfully with his environment and will be completely dependent on others for his care	Diego's stroke has injured parts of his brain involved in bodily movement and control of speech production This will lead to impairments in his motor and communication function, meaning he will probably move and communicate quite differently than you or I He will have high support needs from others and technology to reach his full potential	Bodily integrity
Motor function	Use of technology and environmental adaptations to support mobility	Diego's mobility will be severely limited—he won't be able to walk	Diego's capability to explore his environment and engage in play will be supported by assistive technology and adaptive equipment, such as a wheelchair	Bodily integrity Play Control over one's environment
Communication	Importance of nonverbal communication Importance of AAC strategies to support meaningful interaction	Diego won't be able to talk	While Diego's ability to produce speech may be impacted, he should be capable of developing alternative means of communication especially with the support of speech and language therapy and AAC	Senses, imagination, and thought Demonstrate love Affiliation with others Emotions
Cognition	Integration with early intervention services Early engagement with school districts for 504 or Individualized Education Plan (IEP) support	Diego will be severely cognitively disabled and won't be able to participate in mainstream classes	Diego will need tailored educational strategies, supports, and assistive technologies to maximize his capability for learning and reasoning. Participation in special education and/or supported classroom structure will be likely	Practical reason Senses, imagination, and thought Control over one's environment
Vision, hearing	Timely audiology and ophthalmology evaluations	Diego won't see or hear as well because of his stroke	Diego may require additional assistive technologies like glasses or hearing aids to support his perception of and interaction with his environment	Senses, imagination, and thought Affiliation

Abbreviation: AAC, augmentative and alternative communication.

(eg, Pediatric Evaluation of Disability Inventory [PEDI]) can provide a natural strengths-based foundation for discussing baseline function and skills.<sup>36</sup> Clinicians should also develop disability humility<sup>37</sup> and strive for disability cultural competence<sup>38</sup>—an understanding of the behaviors, knowledge, attitudes, and policies that contribute to lived experiences of people with disabilities.

Second, a CBA uses language to reframe prognosis. It weaves into the idea of prognosis a conversation about what supports a particular child needs to meaningfully engage with their environment. Table 1 illustrates examples of how clinicians may shift from deficit-oriented to capabilities-based language across multiple domains of neuroprognostication.

Third, the assumptions used in data collection around prognostic outcomes must evolve. The mismatch between clinician- and researcher-derived outcomes and the reported experiences of families represents a form of epistemic injustice<sup>39</sup>—by omitting the testimony of patients and caregivers, disability bias in medicine is reinforced.<sup>5,6</sup> For example, a hyperfocus on speech ignores expansive forms of nonverbal communication.<sup>40</sup> To enable a CBA in

prognostication, research on outcomes of neurologic impairment must both critically examine the types of data studied and collected, as well as incorporate qualitative data from families and patients with disabilities.<sup>41,42</sup>

Integrating a CBA in prognostication offers a holistic avenue for clinicians to share knowledge with patients and families. Similar to calls for use of strengths-based approaches<sup>43,44</sup> and appreciative inquiry<sup>45</sup> in health care, this broader perspective focuses on children's capabilities—alongside necessary conversations about medical and functional impairments—to promote a more supportive approach to their care. This integration requires systems-level changes in our training, research agendas, and clinical conversations.

#### ACKNOWLEDGMENTS

We are grateful to have had critical review from Lindsey Topping-Schuetz, mother of Owen, who has years of lived experience as a parent of a child with a complex diagnosis and accompanying disability. We would also like to thank Dr David Magnus and Dr Talia Shear for their critical reviews of the manuscript.

## ABBREVIATIONS

CBA: capabilities-based approach

PEDI: Pediatric Evaluation of Disability Inventory

## REFERENCES

1. Kirschen MP, Walter JK. Ethical issues in neuroprognostication after severe pediatric brain injury. *Semin Pediatr Neurol*. 2015; 22(3):187–195. PubMed doi: 10.1016/j.spen.2015.05.004
2. Campbell FA. “Disability’s” date with ontology and the ableist body of the law. *Griffith Law Rev*. 2001;10(42).
3. Davis LJ. *Enforcing Normalcy: Disability, Deafness, and the Body*. Verso; 1995. <https://hdl.handle.net/2027/heb02823.0001.001>
4. Iezzoni LI, Freedman VA. Turning the disability tide: the importance of definitions. *JAMA*. 2008;299(3):332–334. PubMed doi: 10.1001/jama.299.3.332
5. VanPuymbrouck L, Friedman C, Feldner H. Explicit and implicit disability attitudes of healthcare providers. *Rehabil Psychol*. 2020; 65(2):101–112. PubMed doi: 10.1037/rep0000317
6. Iezzoni LI, Rao SR, Ressleram J, et al. Physicians’ perceptions of people with disability and their health care. *Health Aff (Millwood)*. 2021;40(2):297–306. PubMed doi: 10.1377/hlthaff.2020.01452
7. Bogetz J, Wilfond BS, Wightman A. Moving beyond using the term *poor prognosis* in children with severe neurological impairment: a linguistic shortcut better avoided. *JAMA Pediatr*. 2020;174(1): 11–12. PubMed doi: 10.1001/jamapediatrics.2019.4503
8. Ferrand A, Poleksic J, Racine E. Factors influencing physician prognosis: a scoping review. *MDM Policy Pract*. 2022;7(2): 23814683221145158. PubMed doi: 10.1177/23814683221145158
9. Sampat V, Whiting J IV, Flynn-O’Brien K, et al. Accuracy of early neuroprognostication in pediatric severe traumatic brain injury. *Pediatr Neurol*. 2024;155:36–43. PubMed doi: 10.1016/j.pediatrneurol.2024.03.010
10. Peralta D, Bogetz J, Lemmon ME. Neurological conditions: prognostic communication, shared decision making, and symptom management. *Semin Fetal Neonatal Med*. 2023;28(3):101457. PubMed doi: 10.1016/j.siny.2023.101457
11. Janvier A, Farlow B, Baardsnes J, Pearce R, Barrington KJ. Measuring and communicating meaningful outcomes in neonatology: a family perspective. *Semin Perinatol*. 2016;40(8):571–577. PubMed doi: 10.1053/j.semperi.2016.09.009
12. Lemmon ME, Ubel PA, Janvier A. Estimating neurologic prognosis in children: high stakes, poor data. *JAMA Neurol*. 2019;76(8):879–880. PubMed doi: 10.1001/jamaneurol.2019.1157
13. Racine E, Bell E, Farlow B, et al. The ‘ouR-HOPE’ approach for ethics and communication about neonatal neurological injury. *Dev Med Child Neurol*. 2017;59(2):125–135. PubMed doi: 10.1111/dmcn.13343
14. Richter LL, Janvier A, Pearce R, et al. Parental and medical classification of neurodevelopment in children born preterm. *Pediatrics*. 2025;155(2):e2024066148. PubMed doi: 10.1542/peds.2024-066148
15. Oslin E, Montenegro RE, Kraft SA, Van Cleave A, Bogetz J. “I’m completely off base here on what this child is capable of”: a qualitative analysis of how medical ableism manifests in PICU clinicians’ care of children with severe neurological impairment. *Disabil Health J*. 2025;18(1):101691. PubMed doi: 10.1016/j.dhjo.2024.101691
16. Stahl D. Misuses of “Quality of Life” Judgments in end-of-life care. *Chest*. 2023;163(5):1228–1231. PubMed doi: 10.1016/j.chest.2022.11.030
17. Ubel PA, Loewenstein G, Jepson C. Whose quality of life? A commentary exploring discrepancies between health state evaluations of patients and the general public. Published online September 2003. doi: 10.1023/A:1025119931010
18. Kukora SK, Boss RD. Values-based shared decision-making in the antenatal period. *Semin Fetal Neonatal Med*. 2018;23(1):17–24. PubMed doi: 10.1016/j.siny.2017.09.003
19. Albrecht GL, Devlieger PJ. The disability paradox: high quality of life against all odds. *Soc Sci Med*. 1999;48(8):977–988. PubMed doi: 10.1016/S0277-9536(98)00411-0
20. Schwartz CE, Andresen EM, Nosek MA, Krahn GL; RRTC Expert Panel on Health Status Measurement. Response shift theory: important implications for measuring quality of life in people with disability. *Arch Phys Med Rehabil*. 2007;88(4):529–536. PubMed doi: 10.1016/j.apmr.2006.12.032
21. Garland-Thomson R. The case for conserving disability. *J Bioeth Inq*. 2012;9(3):339–355. PubMed doi: 10.1007/s11673-012-9380-0
22. Garland-Thomson R. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. Columbia Univ. Press; 2007.
23. Tate T. Pediatric suffering and the burden of proof. *Pediatrics*. 2020;146(Suppl 1):S70–S74. PubMed doi: 10.1542/peds.2020-0818N
24. Leduc A. *Disfigured: On Fairy Tales, Disability, and Making Space*. Coach House Books; 2020.
25. Mercurio MR. The aftermath of Baby Doe and the evolution of newborn intensive care. *Ga State Univ Law Rev*. 2012;25(4). Available at: <https://readingroom.law.gsu.edu/gsulr/vol25/iss4/9>
26. Fost N. “The Hopkins Mongol Case”: the dawn of the bioethics movement. *Pediatrics*. 2020;146(Suppl 1):S3–S8. PubMed doi: 10.1542/peds.2020-0818C
27. Antommaria AM. “Who should survive?: one of the choices on our conscience”: mental retardation and the history of contemporary bioethics. *Kennedy Inst Ethics J*. 2006;16(3):205–224. PubMed doi: 10.1353/ken.2006.0016
28. Kett JC. Who Is the Next “Baby Doe?” From trisomy 21 to trisomy 13 and 18 and beyond. *Pediatrics*. 2020;146(suppl 1):S9–S12. PubMed doi: 10.1542/peds.2020-0818D
29. Janvier A, Watkins A. Medical interventions for children with trisomy 13 and trisomy 18: what is the value of a short disabled life? *Acta Paediatr*. 2013;102(12):1112–1117. PubMed doi: 10.1111/apa.12424

30. Koogler TK, Wilfond BS, Ross LF. Lethal language, lethal decisions. *Hastings Cent Rep.* 2003;33(2):37–41. PubMed doi: 10.2307/3528153
31. Berne P, Morales AL, Langstaff D, Invalid S. Ten principles of disability justice. *Women's Stud Q.* 2018;46(1):227–230. doi: 10.1353/wsq.2018.0003
32. Kittay EF. At the margins of moral personhood. *Ethics.* 2005;116(1):100–131. PubMed doi: 10.1086/454366
33. Nussbaum MC. *Creating Capabilities: The Human Development Approach.* Belknap Press; 2011. <https://search.ebscohost.com/login.aspx?direct=true&db=nlebk&AN=386066&site=ehost-live&authtype=ip,sso&custid=s4392798>
34. Bracken-Roche D, Shevell M, Racine E. Understanding and addressing barriers to communication in the context of neonatal neurologic injury: exploring the ouR-HOPE approach. In: de Vries LS, Glass HC, eds. *Handbook of Clinical Neurology.* Vol 162. Neonatal Neurology. Elsevier; 2019:511–528. doi: 10.1016/B978-0-444-64029-1.00024-2
35. Lemmon ME, Barks MC, Bansal S, et al. The ALIGN Framework. *Neurology.* 2023;100(8):e800–e807. PubMed doi: 10.1212/WNL.0000000000201600
36. Feldman AB, Haley SM, Coryell J. Concurrent and construct validity of the Pediatric Evaluation of Disability Inventory. *Phys Ther.* 1990;70(10):602–610. PubMed doi: 10.1093/ptj/70.10.602
37. Reynolds JM. Three things clinicians should know about disability. *AMA J Ethics.* 2018;20(12):E1181–E1187. PubMed doi: 10.1001/amajethics.2018.1181
38. Garland-Thomson R, Iezzoni LI. Disability cultural competence for all as a model. *Am J Bioeth.* 2021;21(9):26–28. PubMed doi: 10.1080/15265161.2021.1958652
39. McKinnon R. Epistemic Injustice. *Philos Compass.* 2016;11(8):437–446. doi: 10.1111/phc3.12336
40. Schrooten AF. *Shared Struggles: Stories from Parents and Pediatricians Caring for Children with Serious Illnesses.* Springer International Publishing AG; 2021.
41. Zurn P, Stramondo J, Reynolds JM, Bassett DS. Expanding diversity, equity, and inclusion to disability: opportunities for biological psychiatry. *Biol Psychiatry Cogn Neurosci Neuroimaging.* 2022;7(12):1280–1288. PubMed doi: 10.1016/j.bpsc.2022.08.008
42. Sunderland N, Catalano T, Kendall E. Missing discourses: concepts of joy and happiness in disability. *Disabil Soc.* 2009;24(6):703–714. doi: 10.1080/09687590903160175
43. Gokoolparsadh A, Bourne M, McEwen A, Amor DJ, Turbitt E. Parents' perspectives on conversations about prognosis and an assessment of prognostic information available online: A mixed-methods study. *Disabil Health J.* 2025;18(2):101718. PubMed doi: 10.1016/j.dhjo.2024.101718
44. Dunn W. Strengths-based approaches: what if even the 'bad' things are good things? *Br J Occup Ther.* 2017;80(7):395–396. doi: 10.1177/0308022617702660
45. Naaldenberg J, Banks R, Lennox N, Ouellette-Kunz H, Meijer M, van Schrojenstein Lantman-de Valk H. Health inequity in people with intellectual disabilities: from evidence to action applying an appreciative inquiry approach. *J Appl Res Intellect Disabil.* 2015;28(1):3–11. PubMed doi: 10.1111/jar.12130