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Introduction: Childhood and Disability

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Abstract From growth attenuation therapy for severely developmentally disabled children to the post-natal management of infants with trisomy 13 and 18, pediatric treatment decisions regularly involve assessments of the probability and severity of a child's disability. Because these decisions are almost always made by surrogate decision-makers (parents and caregivers) and because these decision-makers must often make decisions based on both prognostic guesses and potentially biased quality of life judgments, they are among the most ethically complex in pediatric care. As the introduction to *HEC Forum's* special thematic issue on Childhood and Disability, this article orients the reader to the history of bioethics' relationship to both pediatric ethics and disability studies and introduces the issue's five manuscripts. As clinicians, disability scholars, philosophers and clinical ethicists writing on various aspects of pediatric disability, the articles' authors all invite readers to dig beneath an overly-simplified version of what disability might mean to children and families and instead embrace a posture of genuine humility, recognizing both the limits and harms of traditional medical and bioethical responses (or indifferences) to the disabled child.

Keywords Childhood · Pediatrics · Disability · Quality of life · Disability paradox

While questions concerning medical care for individuals with disabilities have never been far from the pediatric clinic, several critical events within the past few decades have invited increasing discussion about the nature and role of disability within the context of pediatric care. First came the widely-publicized cases of two handicapped infants in the early-mid 1980s—Baby Doe and Baby Jane Doe—for whom

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treatment was withheld based on judgments about the infants' quality of life. These cases catalyzed a public debate which eventually resulted in two sets of federal regulations: the first set, based on civil rights claims, was rejected by the Supreme Court in *Bowen v. AHA* and ultimately replaced by a second set, which ties federal funding to state regulation of a set of provisions outlining the circumstances under which withholding or withdrawing medical treatment for a disabled newborn is allowable. Although the Baby Doe Regulations are still officially on the books, they have been cited in only *one* court decision (*Montalvo v. Borkavec*) and no state has lost federal funding due to violations of the regulations. Similarly divisive was the 2007 case of Ashley X, a severely developmentally disabled girl whose parents requested growth attenuation therapy with the goal of caring more effectively for her at home. The "Ashley Treatment", as it was dubbed, is still hotly debated even a decade later with some arguing that it was an appropriate option considering the benefit offered by being cared for at home by her family and others arguing that it was an egregious violation of her dignity and rights (Gunther and Diekema 2006; Brosco and Feudtner 2006; Wilfond et al. 2010).

Meanwhile, these were the same decades (1980–2000s) that birthed a new, and distinctly non-clinical, academic field of interdisciplinary scholarship called, broadly, disability studies. Of notable significance, the field offered the academy a radically new starting point for conversations about disability, one which shifted the emphasis away from the individual impaired body and instead called attention to the social forces—the disabling environmental, economic and attitudinal barriers—that restrict the life choices of those with disabilities. This "social model" of disability served as a platform for increasing political and social activism that ultimately resulted in the passage of the Americans with Disabilities Act of 1990, the first piece of comprehensive civil rights legislation addressing the needs of individuals with disabilities.

Despite all this, however, the disabled child remains, in important ways, two steps removed from mainstream *bioethics*. First, because bioethics evolved centrally out of concerns about the *rights* of *adult* patients, the *child* patient has only recently garnered critical attention by bioethicists. Second, because the field was initially charged with solving problems related to end-of-life decision-making and technology, for many decades bioethics has been preoccupied with issues of the *acutely-ill* adult patient and has left the needs and concerns of the chronically-ill and disabled patient unattended. Let's explore each of these clefts below.

Inheriting the physician-patient relationship of earlier centuries, which Jay Katz argues was primarily characterized by a beneficent silence in which physicians were encouraged to shoulder the entire "burden" of decision-making, early work in bioethics concentrated on correcting this paternalism through a focus on patient autonomy. Most of the field's early work was, thus, consolidated around the enterprise of defining, regulating and championing the patient's right to "self-determination". A major victory to this end was the creation and justification (both legally and clinically) of the practice of informed consent. "Good" patients were no longer passive, they were informed and active, and "good" doctors no longer made decisions unilaterally, but instead involved their patients in a dynamic process of shared decision-making. However, the result is that, even today, much of the work

done in pediatric ethics still relies on frameworks imported from the bioethics of adult patients, even when these frameworks are ill-suited to the unique tasks of caring for ill children (Salter 2014; AAP Committee on Bioethics 2016). For instance, because informed consent has been imported as the model for how to involve children in medical decision-making (via the concept of child assent), we often experience a clash of goals. Children aren't usually capacitated decision-makers, nor are they often afforded legal decision-making authority, which means their "assent" or "dissent" to medical treatment must mean something different than it means for adults.

The second cleft between the disabled child and bioethics is a result of the academic disengagement of bioethics with issues of disability, identified as such. The life and death conversations in the field's early years, conversations like how to allocate scarce life-saving resources like organs and dialysis and how dead must someone be to harvest their organs or unilaterally to withdraw ventilator support, necessarily centered around urgent, acute-care decisions (Rothman 2003).[1] Often left in the wake of these decisions, and in the rear-view mirror of bioethicists charging on to the next urgent life-and-death decision, are the chronically-ill and the disabled. No longer bound to the hospital bed, and therefore all but forgotten by mainstream medical ethics, the disabled individual is returned to society without the support and resources necessary to live a full and satisfying life. Mark Kuczewski (2001) argues that this inattention to disability is at least in part due to the fact that bioethics emerged as a "guest in the house of medicine", and its survival was dependent on an alignment with the structures and practices of the medical enterprise (p. 36). As a result, bioethics has been criticized for unreflectively adopting the medical understanding of disability: that disability is primarily about an individual "defective" body that must "repaired", primarily through medical intervention. Only recently has the social model of disability gained any traction in bioethics circles (Garland-Thomson 2012).

Not only has the disabled child been distanced *academically* from the field of bioethics, perhaps more centrally problematic is the *epistemic* distance between bioethics and disabled children. First, we haven't been great at listening to people with disabilities. In her (2008) book *Disability Bioethics*, Jackie Leach Scully draws attention to the lack of extended phenomenological research into the lived, embodied experience of those with disabilities, emphasizing how critical it is for medical professionals and bioethicists to better grasp how it might *feel* to live with a disability. The conviction to begin with the experience of the individual is furthered bolstered by a recently discovered phenomenon known as the "disability paradox", which suggests that we are bad at imagining what life would be like with a given impairment, both for others and for ourselves. Many (if not most) individuals with disabilities report much higher qualities of life than accorded to them by outside observers. This under-estimation of quality of life is exhibited by not only strangers,

[1] Many would argue that these "life and death" issues were, in fact, issues of disability, but at the time they were not identified as such, nor were they discussed or analyzed with attention to the types of concerns typically engaged by disability studies.

but by clinicians, caregivers and even parents of the disabled individual (Albrecht and Devlieger 1999; Ubel et al. 2005; Shelly et al. 2008).

Even when disability is attended to within the field, scholars are rarely, themselves, disabled. There are notable exceptions to this generalization, including two authors included in this special issue (Anita Silvers and Adam Cureton), but even when scholars are themselves disabled, the nature of academic scholarship necessarily excludes whole groups of disabled individuals, notably those with moderate to severe intellectual disabilities.

The goal of this issue is to start bridging these gulfs by acquainting bioethics, and clinical ethics specifically, with the disabled child. Tal Levin-Decanini opens the issue with "The Evolution of Spina Bifida Treatment Through a Biomedical Ethics Lens" (2017), offering readers a particular historical example of the evolving relationship between disability and medicine. Decanini begins by discussing the selective treatment protocols championed in the 1970s, in which physicians offered treatment for infants based on potential survival and levels of cognitive or physical disability. Couched in terms of beneficence and non-maleficence, physicians were making purportedly objective "quality of life" judgments about these infants, effectively stating that because of particular functional deficits, their lives would not be worth living. Even with advances in diagnosis and treatment of spina bifida, physicians still make treatment recommendations based on a medical model of disability, which does not consider the social factors that may contribute to adverse experiences of disability. In order for families to be truly informed about their options, Decanini ultimately concludes that providers must approach families with uncertainty, honesty and humility as they strive to provide unbiased guidance concerning treatment decisions for infants with spina bifida.

Similarly, Isabella Pallotto and John Lantos, in their article "Treatment Decisions for Babies with Trisomy 13 and 18" (2017), call our attention to the power that clinical bias can exert on parental decision-making. Because trisomy 13 and 18 disorders typically present with severe and life-threatening defects across most organ systems, they have historically been considered lethal diagnoses and infants are rarely offered life-sustaining treatments. However, the high mortality rate may be the result of a self-fulfilling prophecy. If babies are expected to die, they will not be treated. And if not treated, they will certainly die, thus fulfilling the prophecy. Recent studies have shown that the lethality of these conditions may be lower than is commonly thought, and others studies have suggested that these infants have an acceptable quality of life. By exploring the ways in which trisomy 13 and 18 are portrayed in pediatric textbooks and social media sites, Pallotto and Lantos demonstrate the wide variation that characterizes treatment decisions for babies with these conditions. Given this variation, and the continuing evolution of practice standards for infants with trisomy 13 and 18, providers and clinical ethicists must treat each infant as an individual, exhibiting a similar humility and tolerance as advocated by Decanini.

While Pallotto and Lantos argue for individualized decision-making when treating infants with trisomy 13 and 18, parents and providers are often unable to imagine what life will be like for these infants and thus often find it difficult to make treatment decisions. In an effort to improve the ability of medical teams to counsel

families on what they might expect when caring for a child with trisomy 13 or 18, Joshua Arthur conducted a qualitative study with parents of infants with trisomy 13 or 18 in order to better understand their experiences. In "'You Can Carry the Torch Now': A Qualitative Analysis of Parents' Experiences Caring for a Child with Trisomy 13 or 18" (2017), Arthur discusses four themes that characterized parents' experiences. First, parents saw their children as significant, having special importance within their families and communities. Second, they saw their child as having a transformative effect on those around them. Third, many parents expressed feelings of powerlessness in the medical setting that alienated them from their child. Finally, parents felt motivated to tell their child's story, believing that storytelling could be therapeutic for them and others. Arthur suggests that storytelling may foster shared decision-making between parents and providers as they seek to develop a mutual understanding of each unique child's meaning and significance.

The next contribution, my article "Reimagining Childhood: Responding to the Challenge Presented by Severe Developmental Disability" (2017), takes a step back from the particularities of treatment decisions for a specific diagnosis and instead uses severe developmental disability as a lens through which we might uncover and critique the implicit medical and philosophical understandings of "childhood", broadly understood. By examining the relevant work of three prominent western thinkers—Aristotle, Immanuel Kant, and Jean Piaget—I reveal that we do, in fact, possess a rich, although unacknowledged, anthropology of childhood: the child is primarily a future rational, independent adult. Then, I turn to the experiences of parents and children with severe developmental disabilities to show how this anthropology is deficient and argue that an expanded notion of childhood ought to be embraced, not only to re-infuse dignity into the lives of children (and adults) with severe developmental disabilities, but to better represent childhood generally.

Finally, in their article "Respecting the Dignity of Children with Disabilities in Clinical Practice," Adam Cureton and Anita Silvers (2017) extend my call to uphold the dignity of disabled children by critiquing the protectionist approach to parenting disabled children. Cureton and Silvers argue that children with disabilities deserve at least as much—if not more—respect for self-governance as non-disabled children. While parents often try to protect their disabled child from risks, they must weigh those risks in terms of the child's well-being and must try to take up the point of view of their disabled child, engaging with them as individuals who deserve full respect. Even children with severe cognitive disabilities who cannot actively participate in shaping their future deserve to be respected as individuals in their own right. Cureton and Silvers conclude that healthcare providers may be most aptly situated to untangle the child's interests from the parent's interests in order to determine what is best for the child.

While much of the debate about what constitutes the nature of and a proper response to disability, including pediatric disability, has taken place on the political or academic stage, this special issue returns us to the clinic and the real conversations taking place not about "disabled children" generally, but instead about (and with) the particular, embodied child and his or her particular family. This context invites readers to dig beneath an overly-simplified version of what disability

might mean to children and families. Instead, the authors encourage us to embrace a posture of genuine humility, recognizing both the limits and harms of traditional medical and bioethical responses (or indifferences) to the disabled child. In this way, they reintroduce us to the disabled child, in all her complexity, and invite us to expand our understanding of who she is and what we owe her.

References

AAP Committee on Bioethics. (2016). Informed consent in decision-making in pediatric practice. *Pediatrics, 138*(2). doi:10.1542/peds.2016-1485.

Albrecht, G. L., & Devlieger, P. J. (1999). The disability paradox: High quality of life against all odds. *Social Science and Medicine, 48*(8), 977–988.

Arthur, J. (2017). You can carry the torch now: A qualitative analysis of parents' experiences caring for a child with trisomy 13 or 18. *HEC Forum, 29*(3). doi:10.1007/s10730-017-9324-5.

Brosco, J., & Feudtner, C. (2006). Growth attenuation: A diminutive solution to a daunting problem. *Archives of Pediatric and Adolescent Medicine, 160*(10), 1077–1078.

Cureton, A., & Silvers, A. (2017). Respecting the dignity of children with disabilities in clinical practice. *HEC Forum, 29*(3). doi:10.1007/s10730-017-9326-3.

Garland-Thomson, R. (2012). The case for conserving disability. *Journal of Bioethical Inquiry, 9*(3), 339–355.

Gunther, D. F., & Diekema, D. (2006). Attenuating growth in children with profound developmental disability: A new approach to an old dilemma. *Archives of Pediatric and Adolescent Medicine, 160*(10), 1013–1017.

Kuczewski, M. (2001). Disability: An agenda for bioethics. *American Journal of Bioethics, 1*(3), 36–44.

Levin-Decanini, T. (2017). The evolution of spina bifida treatment through a biomedical ethics lens. *HEC Forum, 29*(3). doi:10.1007/s10730-017-9327-2.

Pallotto, I., & Lantos, J. (2017). Treatment decisions for babies with trisomy 13 and 18. *HEC Forum, 29*(3). doi:10.1007/s10730-017-9319-2.

Rothman, D. (2003). *Strangers at the bedside: A history of how law and bioethics transformed medical decision making*. New York: Aldine de Gruyter.

Salter, E. (2014). Resisting the siren call of individualism in pediatric decision-making and the role of relational interests. *Journal of Medicine and Philosophy, 39*(1), 26–40.

Salter, E. (2017). Reimagining childhood: Responding to the challenge presented by severe developmental disability. *HEC Forum, 29*(3). doi:10.1007/s10730-017-9331-6.

Scully, J. L. (2008). *Disability bioethics: Moral bodies, moral difference*. Lanham: Rowman and Littlefield.

Shelly, A., Davis, E., Waters, E., Mackinnon, A., et al. (2008). The relationship between quality of life and functioning for children with cerebral palsy. *Developmental Medicine and Child Neurology, 50*(3), 199–203.

Ubel, P., Loewenstein, G., Schwarz, N., & Smith, D. (2005). Misimagining the unimaginable: The disability paradox and health care decision making. *Health Psychology, 24*(4), S57–S62.

Wilfond, B., Miller, P., Korfiatis, C., Diekema, D., Dudzinski, D., & Goering, S. (2010). Navigating growth attenuation in children with profound disabilities: Children's interests, family decision-making and community concerns. *Hastings Center Report, 40*(6), 27–40.