

**REVISITING ASHLEY X: AN ESSAY ON
DISABLED BODILY INTEGRITY, SEXUALITY,
DIGNITY, AND FAMILY CAREGIVING**

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***Abstract:** This Essay looks back on controversial medical procedures performed on a young girl in Seattle over a period of several years. Ashley X, deemed by her family one of the “Pillow Angels,” has significant intellectual and mobility disabilities. She was given high dose estrogen treatment to attenuate her growth, a mastectomy to protect her from sexual assault and from the discomfort and sexualization of large breasts, and a hysterectomy to prevent menstruation and pregnancy: these interventions were also intended to make her more easily manageable by family members and caregivers so that she would be more able to be included in family life. Since the case became public, more children, both girls and boys, in the United States and around the world have undergone similar protocols. The passage of time, intervening changes in the legal landscape, and Ashley’s transition to adulthood prompt us to ask questions about how parents and healthcare providers can make better decisions for children with disabilities without altering their bodies or their sexuality or reproductive capacity. Without castigating Ashley’s family for their decision or rehashing the ethical and other arguments that have been made, we explore, from a family support and human rights perspective, alternatives to invasive procedures that maintain personal integrity and preserve dignity while also offering day-to-day assistance.*

***Key words:** Bodily Integrity, Cognitive Disability, Community Support, Developmental Disability, Dignity, Growth Attenuation, Legal Capacity, Sexual Capability, Sexual Liberty Interest, Supported Decision-Making*

I. INTRODUCTION

A little over a decade ago, in 2006, CNN publicized a clinical report in the *Archives of Pediatric and Adolescent Medicine* detailing the case of a child with significant developmental disabilities.¹ Identified only as Ashley X, her parents had requested, and received approval for, a then unknown treatment protocol intended to keep their daughter small and to remove her sexual and reproductive organs.² Doctors at Seattle Children's Hospital removed Ashley's uterus and breast buds, and administered high doses of estrogen to slow and ultimately stop her growth. Other mainstream media outlets soon picked up the story, sparking a brief public controversy that blossomed into a full-fledged debate in disability and bioethics communities regarding the ethical, ableist,³ and legal issues underlying these interventions.

Despite a subsequent ban on growth attenuation treatment (hereinafter "GAT") at Seattle Children's Hospital,⁴ this controversial

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¹ We use the term "significant disabilities" interchangeably with "profound" or "severe" disabilities, although these words may have slightly different medical or diagnostic meanings, depending on the user. On the politics of disability linguistics, see *infra* note 6.

² Daniel F. Gunther & Douglas S. Diekema, *Attenuating Growth in Children with Profound Developmental Disability: A New Approach to an Old Dilemma*, 160 ARCHIVES PEDIATRIC & ADOLESCENT MED. 1013 (2006).

³ On the meaning of "ableist" and "ableism," see, e.g., DAN GOODLEY, DIS/ABILITY STUDIES: THEORISING DISABLISM AND ABLEISM 21 (2014) (explaining that ableism "privileges able-bodiedness; promotes smooth forms of personhood and smooth health; creates space fit for normative citizens; encourages an institutional bias towards autonomous, independent bodies; and lends support to economic and material dependence on neoliberal and hyper-capitalist forms of production").

⁴ DAVID R. CARLSON & DEBORAH A. DORFMAN, INVESTIGATIVE REPORT REGARDING THE "ASHLEY TREATMENT" (2007), https://www.disabilityrightswa.org/wp-content/uploads/2017/12/InvestigativeReportRegardingtheAshleyTreatment_May2007.pdf. The Washington State Protection & Advocacy System ("WPAS") is now known as Disability Rights Washington. Since 1977, the federally funded Protection and Advocacy System has been working at the

protocol⁵ continues to be an option elected by parents and other caregivers of intellectually and developmentally disabled⁶ children.⁷ It

state and territorial level to protect the legal and service rights of individuals with disabilities “by empowering them and advocating on their behalf.” See *State Protection & Advocacy Systems*, ADMIN. FOR COMMUNITY LIVING, <https://acl.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems> (last modified June 25, 2018). See also 45 C.F.R. pts. 51 & 1326 (2018).

⁵ One commentator wrote that while growth attenuation dominated the pediatricians’ account in defense of the surgery, and perhaps dominated the public narrative as well, a more accurate description of the medical protocol would have been “[a]ttenuating growth, involuntary sterilization, and prophylactic mastectomy in children with profound disability.” John Lantos, *It’s Not the Growth Attenuation, It’s the Sterilization!*, 10 AM. J. BIOETHICS 45, 45 (2010). It strikes us that “treatment” is not the appropriate term for interventions whose goal is to alter a body, absent medical necessity.

⁶ Disability nomenclature is a minefield. As is the case with ethnic, sexual, or other affiliations, identity labels change over time. Reasonable—and even *unreasonable*—people disagree whether “disabled person” is acceptable in lieu of a “people first” term such as “person(s) with (a) disability” that accentuates the humanity, rather than the impairment or disabling condition. Some crimp activists and academics actually choose “disability first” language as an act of defiance or pride. See, e.g., PAUL K. LONGMORE, *WHY I BURNED MY BOOK AND OTHER ESSAYS ON DISABILITY* 1, 14, 19, 32 (2003); Stephen A. Rosenbaum, *Hammerin’ Hank: The Right to Be Raunchy or FM Freak Show?*, 23 DISABILITY STUD. Q. _ nn. 51-57 (2003) (discussing naming and reclaiming of outmoded identity terms and epithets), <http://www.dsqsds.org/article/view/432/609>. On the art and politics of identification, see Stephen A. Rosenbaum, *The Alien Cloak of Confidentiality: Look Who’s Wearing It Now*, 4 JOHN F. KENNEDY L. REV. 23, 24 (1991-92) (choosing commonly used terms or those that reflect society’s prejudice). But see Richard Fung, *Looking for My Penis: The Eroticized Asian in Gay Porn*, in *HOW DO I LOOK? QUEER FILM AND VIDEO* 145, 168 (Seattle: Bay Press 1991) (“[T]oo much time spent on the politics of ‘naming’ can in the end be diversionary.”).

⁷ A recent survey by the Pediatric Endocrine Society revealed that 99% of respondents (mainly U.S. pediatricians) had been asked to prescribe, or had prescribed, growth attenuation therapy for children with severe physical and cognitive disabilities. Allison J. Pollock, Norman Fost & David B. Allen, *Growth Attenuation Therapy: Practice and Perspectives of Paediatric Endocrinologists*, 100 ARCHIVES DISEASE CHILDHOOD 1185 (2015). Results of another survey (New Zealand pediatricians) suggest that family requests for this treatment do occur and that the majority of pediatricians are not opposed to it. Rebekah Wrigley, Nikki Kerrush, Paul L. Hofman, Craig Jeffries, Allison J. Pollock & Benjamin J. Wheeler, *Growth Attenuation Therapy for Children With Severe Physical and Cognitive Disability: Practice and Perspectives of New Zealand Paediatricians*, 53 J. PAEDIATRICS & CHILD HEALTH 1180 (2017). For mainstream media accounts, see Ed Pilkington & Karen McVeigh, *Ashley treatment’ on the Rise Amid Concerns From Disability Rights Groups*, GUARDIAN (Mar. 15, 2012), <http://www.theguardian.com/society/2012/mar/15/ashley-treatment-rise-amid-concerns>, and for a response to this article, see Peter Singer, *The ‘unnatural’ Ashley Treatment can be Right for Profoundly Disabled Children*, GUARDIAN (Mar. 16, 2012), <https://www.theguardian.com/commentisfree/2012/mar/16/ashley-treatment-profoundly-disabled-children>. For a response to Singer, see S.E. Smith, *Is the Ashley Treatment Right? Ask Yourself if Disabled People are Human*, GUARDIAN (Mar. 16, 2012), <https://www.theguardian.com/commentisfree/2012/mar/16/ashley-treatment-disabled-people>; Genevieve Field, *Should Parents of Children With Severe Disabilities be Allowed to Stop Their Growth?*, N.Y. TIMES MAG. (Mar. 22, 2016), <https://www.nytimes.com/2016/03/27/magazine/should-parents-of-severely-disabled-children-be-allowed-to-stop-their-growth.html>.

is a procedure that continues to generate public debate.⁸ Two other intervening factors are worth noting: (1) the Presidential signing of the United Nations Convention on the Rights of Persons with Disabilities in 2009⁹ and attendant questions about legal capacity;¹⁰ and (2) an increased preference for supported decision-making over substitute decision-making¹¹ on behalf of persons with cognitive disabilities.

Ashley is now a young adult and should enjoy a full spectrum of adult rights and privileges. The passage of time, intervening changes in the legal landscape, and Ashley's transition to adulthood prompt us to ask questions about how parents and healthcare providers can make better decisions for children with disabilities, which at once respect their dignity and allow for a future where options remain open

⁸ See, e.g., Field, *supra* note 7; Julia Harris-Parker, *Georgia Parents Debate Medically Stunting Growth of Disabled Children*, AJC (Mar. 31, 2016), <https://www.ajc.com/lifestyles/parenting/georgia-parents-debate-medically-stunting-growth-disabled-children/RE99wfmomfrZ0eFZ04jr5L/>; Jennifer Baker, *The Ashley Treatment: The Philosophy and Ethics of Growth Attenuation*, PSYCHOL. TODAY (June 29, 2012), <https://www.psychologytoday.com/us/blog/the-love-wisdom/201206/the-ashley-treatment> (guest column by college nursing instructor and lawyer Robert Newsome III in defense of the treatment); Jennifer Baker, *The Case for Not Mutilating Your Child*, PSYCHOL. TODAY (Aug. 31, 2012), <https://www.psychologytoday.com/us/blog/the-love-wisdom/201208/the-case-not-mutilating-your-child> (guest column in opposition by parent dubbed “One Father’s Voracious Opinion.”).

⁹ The United Nations Convention on the Rights of Persons with Disabilities (hereinafter “Convention” or “CRPD”) was enacted on December 13, 2006, 2515 U.N.T.S. 3, and entered into force on May 3, 2008. This treaty has been ratified or acceded to by 177 countries. See UNITED NATIONS–DISABILITY, DEP’T OF ECON. & SOC. AFF., <https://www.un.org/development/desa/disabilities/> (last visited Feb. 20, 2019). U.S. President Barack Obama signed it a year later on the 23rd anniversary of the Americans with Disabilities Act and presented it to the Senate for ratification. The Heritage Foundation and Family Research Council were among the organizations that mounted successful opposition in 2012, arguing that the CRPD challenges U.S. sovereignty and strips parents of children with disabilities of their decisional authority. Jasmine Harris, *The Role of Support in Sexual Decision-Making for People with Intellectual and Developmental Disabilities*, 77 OHIO ST. L.J. FURTHERMORE 83, 90 n.35 (2016) [hereinafter Harris, FURTHERMORE]. Whether eventually ratified or not, the Convention and authoritative interpretation of its articles can be used to inform U.S. legislation and jurisprudence under a theory of customary international law. See, e.g., *Abdullah v. Pfizer, Inc.*, 562 F.3d 163, 181 n.11 (2d. Cir. 2009) (“*Khulumani* makes clear that treaties that the United States has neither signed nor ratified—let alone treaties like the ICCPR that the United States has signed but not ratified—may evidence a customary international law norm for [Alien Tort Statute] purposes where the treaty has been ratified widely and it is clear that the reason for the United States’s failure to subscribe to the treaty was unrelated to the particular norm in question.” See *Khulumani*, 504 F.3d at 276, 276 n.9 (Katzmann, J., concurring.”); *In re Mark C.H.*, 906 N.Y.S.2d 419, 433 (Sur. Ct. 2010) (ruling under the Vienna Convention on the Law of Treaties that the U.S. is obligated to “refrain from acts which would defeat [the Disability Convention’s] object and purpose” (alteration in original)).

¹⁰ See *infra* Part IV.

¹¹ See *infra* text accompanying notes 48-53.

and their life paths have not been pre-determined for them by irreversible interventions.

In this Essay, we situate the GAT or “Ashley Treatment,” a term devised by Ashley’s parents and physicians,¹² in its legal and social context. Our aim is not to reexamine this particular case, which has been amply dissected and analyzed.¹³ Rather, we want to examine how similarly situated families manage to raise children with significant disabilities and what questions must be raised about consent, autonomy, sexuality, and bodily integrity.

In order to think through the issues raised by Ashley’s case, we draw from interviews with families that we conducted shortly after the firestorm of responses triggered by Ashley’s surgery and that we have since updated.¹⁴ These families have followed different paths for rearing children with significant disabilities. Two of the six children are now teenagers, three are adults, and one has died. By way of their stories, interspersed throughout this Essay, we see how families have managed and what they need. By exploring these experiences, we ask how, as a society, we should support families like Ashley’s in ways that respect their children’s dignity and autonomy and do not require reconfiguring their children’s bodies or predetermining their physical, social or sexual capabilities.

¹² *The “Ashley Treatment”: Towards a Better Quality of Life for “Pillow Angels”*, PILLLOWANGEL.ORG (Mar. 17, 2012), <http://pillowangel.org/Ashley%20Treatment.pdf> [hereinafter Ashley’s Parents’ Blog]. According to her parents, the “[a]ffectionate nickname for Ashley X [Pillow Angel] now generally refers to people with a physical and cognitive developmental level that will never exceed that of an infant’s. Pillow Angels are entirely dependent on their caregivers.” *Id.* at 14.

¹³ See, e.g., Alicia R. Ouellette, *Growth Attenuation, Parental Choice, and the Rights of Disabled Children: Lessons from The Ashley X Case*, 8 HOUS. J. HEALTH L. & POL’Y 207 (2008); David B. Allen, Michael Kappy, Douglas Diekema & Norman Fost, *Growth Attenuation Therapy: Principles for Practice*, 123 PEDIATRICS 1556, 1559 (2009); Benjamin S. Wilfond, Paul Steven Miller, Carolyn Korfiatis, Douglas S. Diekema, Denise M. Dudzinski, Sara Goering & The Seattle Growth Attenuation and Ethics Working Group, *Navigating Growth Attenuation in Children with Profound Disabilities: Children’s Interests, Family Decision-Making, and Community Concerns*, 40 HASTINGS CTR. REP. 27 (2010); Adrienne Asch & Anna Stubblefield, *Growth Attenuation: Good Intentions, Bad Decision*, 10 AM. J. BIOETHICS 46 (2010); Merle Spriggs, *Ashley’s Interests Were Not Violated Because She Does Not Have Necessary Interests*, 10 AM. J. BIOETHICS 52 (2010); Timothy Lillie, *What Took So Long? Disability Critique Recognized*, 10 AM. J. BIOETHICS 57 (2010); Peter Singer, *A Convenient Truth*, N.Y. TIMES (Jan. 26, 2007), <https://www.nytimes.com/2007/01/26/opinion/26singer.html>; DAVID CARLSON, CINDY SMITH, NACHAMA WILKER, *DISABILITY RIGHTS WASHINGTON & NAT’L DISABILITY RIGHTS NETWORK, DEVALUING PEOPLE WITH DISABILITIES: MEDICAL PROCEDURES THAT VIOLATE CIVIL RIGHTS* (2012).

¹⁴ We use pseudonyms to protect the privacy of family members and their children.

II. THE REMAKING OF ASHLEY X

Ashley has static encephalopathy, a brain disorder of unknown origin that is a form of cerebral palsy. She does not walk, talk, or care for herself. When she was six-and-a-half years old, her family brought her to the Children's Hospital and Regional Medical Center of Seattle with concerns about her precocious puberty. They worried that as she grew, they would no longer be able to care for her at home and to include her in family outings. They also believed that menstruation and breasts would be detrimental to Ashley, causing her confusion and discomfort she would be unable to understand and sexualizing her body in a way that could make her vulnerable to sexual assault.¹⁵

Ashley's parents asked that Children's Hospital physicians perform an experimental therapy on their daughter. Working with the late pediatric endocrinologist Daniel Gunther, MD, who was Ashley's attending physician at Children's and an associate professor at the University of Washington School of Medicine, the hospital convened an ethics panel to consider this unprecedented request. Ashley's parents presented their reasoning before this panel, and Ashley's physicians and the panel accepted the parents' argument and began the protocol.

In 2004, surgeons removed Ashley's uterus and breast buds. Endocrinologists then administered high doses of estrogen to slow and ultimately stop her growth. She subsequently attained her full adult size of 4 feet, 5 inches and 75 pounds, with no reproductive capacity or visible secondary sex characteristics. Following the outpouring of media attention, the family posted a detailed blog to respond to the public controversy, and to justify what they had done. For example, in the blog, her father reported:

Ashley's smaller and lighter size makes it more possible to include her in the typical family life and activities that provide her with needed comfort, closeness, security and love: meal time, car trips, touch, snuggles, etc.¹⁶

¹⁵ Her breast buds were surgically removed so that "large breasts would not become a source of discomfort, particularly from the straps that held Ashley in her chair and applied pressure to her chest." Douglas S. Diekema & Norman Fost, *Ashley Revisited: A Response to the Critics*, 10 AM. J. BIOETHICS 30, 31 (2010).

¹⁶ Ashley's Parents' Blog, *supra* note 12, at 4. In their scathing scrutiny of the Ashley X affair, one scholar-blogger team wrote:

Later, her parents reiterated:

[G]iven Ashley's developmental state and prognosis . . . voluntary procreation was not applicable to her case and will never be.¹⁷

Her physicians' published report also asserted that Ashley "will never be capable of holding a job, establishing a romantic relationship, or interacting as an adult," and concluded therefore that "it is hard to imagine how being smaller would be socially disadvantageous."¹⁸

Further, they stated that certain constitutional (reproductive) rights and privacy interests

are clearly intended for those with the capacity to make decisions for themselves now or at some future point, and it is unclear how, for example, a right to make personal procreation choices or refuse life-sustaining care have any meaning in the context of someone who

Ill prepared for the spotlight and intense media interest, Ashley X's parents complicated matters in January of 2007 by posting a blog about their daughter and children like her [whom they] deemed "pillow angels." It is our belief that [Dr.] Diekema, Ashley X's parents, and proponents of the Ashley Treatment, now referred to as growth attenuation, are disingenuous. On the one hand they collectively argue the Ashley Treatment was about one profoundly cognitively and physically disabled child and yet simultaneously promote the treatment for other "pillow angels."

William J. Peace & Claire Roy, *Scrutinizing Ashley X: Presumed Medical "Solutions" vs. Real Social Adaptation*, 14 J. PHIL., SCI. & L.: DISABILITY SPECIAL ISSUE 33, 33 (2014).

¹⁷ Ashley's Parents' Blog, *supra* note 12. Since it was first launched, this website has been reduced to a few links with the family's focus on supporting other families seeking growth attenuation for their children. Many entries are no longer available for viewing.

¹⁸ Gunther & Diekema, *supra* note 2, at 1016. Much skepticism remains about the certainty of the medical prognosis. One disability advocate and scholar claimed that "Diekema and Gunther recognized little potential for the growth and development of this child. . . . There is abundant evidence that all children are able to learn, that the cognitive capabilities of children with severe motor impairments can be grossly underestimated." Henry A. Bersani, Jr., *Growth Attenuation: Unjustifiable Non-Therapy*, 161 ARCHIVES OF PEDIATRICS & ADOLESCENT MED. 520 (2007) (alteration in original). Philosophy professor, ethicist, and disability studies scholar Sara Goering commented that "even children with profound impairments develop over time," that there are "stories of how [children just like Ashley have] matured in multiple ways . . . despite the official medical prognosis that they would remain at the cognitive level of a 6-month-old." Sara Goering, *Revisiting the Relevance of the Social Model of Disability*, 10 AM. J. BIOETHICS 54, 55 (2010) (citing Eva Feder Kittay & Jeffrey Kittay, *Whose Convenience? Whose Truth?*, HASTINGS CTR. (Feb. 28, 2007), <https://www.thehastingscenter.org/whose-convenience-whose-truth/>).

will never have the capacity to make any of these choices.¹⁹

As noted previously, much has already been written about the bioethical and legal issues that Ashley's case raises, and we will not re-examine those issues here. Instead, we want to look beyond the particularities of Ashley's case and identify how to change social support systems so that no family has to consider medically and surgically altering their child's body.

III. DIGNITY: PROTECTING BODILY INTEGRITY AND SEXUALITY

We start from a basic premise that sets us in disagreement with the family, doctors, and healthcare systems that permitted the Ashley Treatment—and have permitted similar interventions for children in the United States, Europe, and elsewhere.²⁰ Admittedly, the intent of deciding to perform a series of body-altering procedures—despite the absence of medical necessity—is to benefit these children and their families. However, such a decision rests on the principle that individuals with severe cognitive impairments differ from other people, that their inability to make decisions for themselves—their inability to communicate that in turn erodes the effective possibility of self-determination—renders them powerless over the fate of their own bodies. As a result, family members and healthcare providers, even if unwittingly, strip these individuals of their autonomous right to bodily integrity and sexuality, the loss of which leaves them less valuable as human beings—whether such an outcome is explicitly intended or not.

The importance of the body has taken on new meaning since the dawn of the disability rights and independent living movements. Amongst disability studies scholars, “the body was initially perceived as irrelevant to an emancipatory politics.”²¹ Beginning with the new millennium, a divide developed between those who “maintained allegiance to more strictly sociopolitical models” of disability and those for whom “[b]ringing back the body into the study of disability was beneficial to the theorization of the dilemma of disabled

¹⁹ Diekema & Fost, *supra* note 15, at 34 (responding to criticisms leveled in CARLSON & DORFMAN, *supra* note 4).

²⁰ *See supra* notes 7-8.

²¹ Russell Shuttleworth, Nikki Wedgwood & Nathan J. Wilson, *The Dilemma of Disabled Masculinity*, 15 MEN & MASCULINITIES 174, 181 (2012).

masculinity in several important ways.”²² The body is likewise arguably also key to a theoretical understanding of disabled femininity or disabled sexuality.

In response to the Ashley X controversy, a prominent bioethicist and a philosopher wrote:

When [Doctors] Diekema and Fost argue that growth attenuation is morally acceptable only if it is performed on a child who will never know what was done, they are arguing, in effect, that the intervention was morally acceptable because Ashley’s presumed cognitive impairment makes her different from most people. We argue, in contrast, that it is unacceptable because Ashley is the same as most people. She is the same in deserving to be accepted by and respected by and loved by her family for who she is and what she will become, with no modification required.²³

Individuals with disabilities, including those with cognitive, intellectual, and developmental disabilities, have the same fundamental right to bodily integrity as does every person. We believe that our bodies are a part of who we are, and if we choose to change a body part in any way, that changes who we are. Permanently altering a person’s body and body chemistry, without a rationale based on medical necessity, represents a disrespect for who that person is and constitutes a violation of their human rights and dignity.

The saga of Ashley X demands that we question whether it is possible to judge a person’s ultimate potential from their situation at a very young age, and to consider the legal and pragmatic status of individuals who have profound disabilities. Her case calls on all of us

²² *Id.* The “right to be left alone” is how one commentator describes “[t]he fundamental right to bodily integrity.” Mary Koll, *Growth, Interrupted: Nontherapeutic Growth Attenuation, Parental Medical Decision Making, and the Profoundly Developmentally Disabled Child’s Right to Bodily Integrity*, 2010 U. ILL. L. REV 225, 262 (2010). It is a right that “fully attaches” to children with significant developmental disabilities. *Id.*

²³ Asch & Stubblefield, *supra* note 13, at 48. Professor Stubblefield herself became mired in controversy. She lost her faculty position at Rutgers and was imprisoned for two years, while appealing her conviction for sexual assault against a man with significant developmental disabilities. Disability and Human Sexuality scholar Kevin Mintz referenced the Stubblefield case in his commentary on “society’s discomfort with the notion that people with disabilities are sexual beings who might be appealing romantic partners to those without disabilities.” See Kevin Mintz, *Ableism, Ambiguity and the Anna Stubblefield Case*, 32 DISABILITY & SOC’Y 1666, 1668 (2017).

to examine our own assumptions and social strategies when we consider significant disabilities that include cognitive impairment and the interconnections—and failures to connect—between healthcare, community services, and family systems.

Getting beyond “ableist normativity” is a difficult but fundamental leap for parents, family members, and society at large. Disability is a natural human condition, and how we confront it in our personal lives needn’t be about “fixing it” or making it conform to a certain aesthetic or lifestyle.²⁴ In the words of an ethicist and Catholic priest:

The Ashley case is an alarming example of parents presuming to hold absolute determination over their disabled child. The deliberation on the part of the parents, physicians and the ethics committee rose out of a conviction . . . that for Ashley’s good and the good of her parents, family, and future caregivers, the treatment was justified because Ashley was disabled.²⁵

It is well established that parents are legally entitled to make medical decisions on behalf of minor children, but it is not a right without limitations.²⁶ The rationale is that a minor cannot legally or practically provide informed consent and, as a society, we should guard against foreclosing future options in the day-to-day activities, lifestyle, or identity for all children—no matter how “severe” their disability. If there is no life-threatening circumstance, or other medical

²⁴ See, e.g., 42 U.S.C. § 15001 (2018) (U.S. congressional finding that “*disability is a natural part of the human experience* that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full *integration* and inclusion in the economic, political, social, cultural, and educational mainstream of United States society.” (emphasis added)). In Ashley’s case, it seems that “[n]o one discussed the ways in which human difference is valuable.” Ouellette, *supra* note 13, at 236-37 (citations omitted).

²⁵ Rev. Gerald D. Coleman, *The Irreversible Disabling of a Child: The “Ashley Treatment”*, 7 NAT’L CATHOLIC BIOETHICS Q. 711, 723-24. (2007).

²⁶ Barry Lyons, *The Limits of Parental Authority*, 10 AM. J. BIOETHICS 50 (2010). While a parent’s authority over their child should only be “subject to state interference when the harm done is great,” Professor Lyons argues that “we should not unquestioningly accede to parental decisions in the mistaken belief that parents will always do what is best for their child. This is particularly so where those decisions impose a burden upon a child.” *Id.* at 51. Moreover, there is evidence “demonstrating the inability of parents and others without disabilities to comprehend the value of life with disability, or the inability of able-bodied parents to make truly informed decisions for their children without adequate education.” Ouellette, *supra* note 13, at 236-37 (citations omitted).

necessity, and if the medical procedure poses a serious risk to or impact on the bodily integrity of the child, the state has an interest in overseeing these decisions, generally in the form of medical professional judgment.

Thus, amputation, organ removal, or chemotherapy are among the invasive and body altering procedures that are generally left to parental discretion, usually with medical advice. The issue of parental convenience—harm to the child as a benefit to the parents—should not be the rationale for these decisions.²⁷ As one bioethicist and jurist has written:

[B]y allowing parents to subordinate their children's interests to their own, the current paradigm distorts the parent-child relationship and objectifies children in violation of the moral principle, deeply embedded in American legal tradition, that no person, even a parent, may subordinate the life, liberty, or body of another for his or her own purposes.²⁸

²⁷ An end-of-life determination for a critically ill child or severely disabled infant would also presumably fall into the category of decisions that are entrusted to parents with minimal intervention. *But see* Craig A. Conway, *Baby Doe and Beyond: Examining the Practical and Philosophical Influences Impacting Medical Decision-Making on Behalf of Marginally-Viable Newborns*, 25 GA. ST. U. L. REV. 1097, 1134-35 (2009) (strong consensus in medical, legal, and ethical literature that best interests of the infant standard must prevail, *i.e.*, if the burden on the infant is overwhelming or prospects of survival are extremely bleak, as is the case with lethal abnormality, there is no obligation to subject the infant to further procedures).

²⁸ Alicia Ouellette, *Shaping Parental Authority Over Children's Bodies*, 85 IND. L.J. 955, 955-56 (2010). In an earlier article, Professor Ouellette argued persuasively that "[a]n advocate could . . . have pointed out that the interventions would expose Ashley to what disability activists view as dehumanizing manipulation." Ouellette, *supra* note 13, at 238. "[T]o the extent the interventions impaired Ashley's healthy bodily functions to serve third parties, Ashley suffered the moral harm that results when a person is denied full human respect." *Id.*

There is a subset of invasive medical procedures that have an impact on sexual liberty²⁹ or capability,³⁰ *i.e.*, the sexual expression, activities, practices and identities that may potentially be experienced by disabled bodies.³¹ Whether to undergo these medical procedures should be left to the discretion of the patient, provided she has the legal capacity to provide informed consent. Again, in the case of a minor, the surrogate decision-maker is the parent or other adult caregiver, subject to the same limitations noted above.³² Sexual reassignment

²⁹ The term “sexual liberty,” as used in *Lawrence v. Texas*, 539 U.S. 558 (2003) concerning consensual sexual conduct between same-sex adults, has not really been well-defined, much less addressed in U.S. jurisprudence as a liberty interest held by adults with cognitive disabilities. There is, however, case law that addresses the ambiguous and evolving notions of legal and clinical “capacity” and “competency” for disabled individuals, often in the context of criminal justice or civil tort litigation. *See, e.g.*, *McManus v. Neal*, 779 F.3d 634 (7th Cir. 2015) (holding that retrospective competency hearing was not appropriate remedy for court’s determination that petitioner was not intellectually disabled); *United States v. Christian*, 749 F.3d 806 (9th Cir. 2014) (holding that district court abused its discretion in refusing to allow defendant to introduce expert testimony in support of diminished capacity defense). In those instances, the judicial inquiry is usually on the safety of a disabled victim. Disability scholars Tom Shakespeare, Kevin Mintz, and others refer to “sexual ableism” as the manifestation of lowered societal expectations for those with intellectual and other disabilities in the realm of sexuality and intimate relationships and suggest that it is at the root of a disproportionate incidence of sexual assault upon people with intellectual disability. K.T. Mintz, “*My Blessed Child Does Not Need to Know About That!*”: *How Should Sexual Health Educators Confront the Challenge of Religious Pluralism in Working With Individuals Who Have Intellectual Disabilities?*, 5 ETHICS, MED. & PUB. HEALTH 8, 9-10 (2018), <https://doi.org/10.1016/j.jemep.2018.03.003>. However, sexual liberty and capability constitute more than protection against exploitation and assault.

³⁰ Professor Alexander Boni-Saenz explores the broad concept of “sexual capability” for persons with “persistent cognitive impairments,” *i.e.*, “the opportunity to achieve certain states of being or perform certain activities associated with sexuality, such as experiencing sexual pleasure or forming a sexual identity.” Alexander A. Boni-Saenz, *Sexuality and Incapacity*, 76 OHIO ST. L.J. 1201, 1205, 1224-30 (2015). In her response to Boni-Saenz, Professor Jasmine Harris leans more directly on the CRPD model of supported decision-making and a recognition of universal legal capacity in the exercise of sexual capability, irrespective of the severity of disability. *See Harris, FURTHERMORE, supra* note 9, at 83, 88-95.

³¹ *See, e.g.*, Michael L. Perlin, “*All His Sexless Patients*”: *Persons with Mental Health Disabilities and the Competence to Have Sex*, 89 WASH. L. REV. 257, 265-70 (2014) (defining sex as an array of practices and activities). Professor Perlin writes: “Defining ‘sex’ is made more complex because, on many levels, sexuality is ‘an identity rather than [simply] an act,’” and “[a] person’s sexuality is often entwined with his or her gender identity.” *Id.* at 265, 269 (first alteration in original).

³² Commentator Andrew Behrns writes: “At its constitutional core, informed consent is based on the rights to privacy, bodily integrity, and medical decision making.” Andrew E. Behrns, *To Cut Or Not To Cut?: Addressing Proposals to Ban Circumcision Under Both a Parental Rights Theory and Child-Centered Perspective in the Specific Context of Jewish and Muslim Infants*, 21 WM. & MARY BILL RTS. J. 925, 939 (2013). When exercised by proxy—*i.e.*, by a parent or guardian on behalf of an infant or minor—consent has been held to be tantamount to a child’s best interests test. *Id.* at 940-41.

surgery,³³ estrogen or testosterone therapy, sterilization and vasectomy, for example, all affect sexual behavior, gender expression, reproductive capacity, and bodily integrity—usually irreversibly.³⁴ But, society has little interest in regulating these decisions, if made by an informed adult, emancipated minor, or a “competent” youth.³⁵

Even if sexual activity may not be dependent on an intimate partner, it is important to preserve a basic human anatomical condition that permits sexual expression by a more mature child or young adult. “Some scholars argue that sexual release is as much a basic need as the need for sleep or food.”³⁶ To date, the research on disability and

³³ To the extent that transsexuality, transgendered identity, gender fluidity, and gender nonconformity are accompanied by gender reassignment procedures or other significant alteration of the body and socio-psychological and sexual functioning, it is distinct from the case of Ashley X, who was below the legal age of consent to provide, with or without supported decision-making, reproductive or sexual alterations to her body. The thorny issue of whether intersex/indeterminately-sexed infants, or infants with androgen insensitivity syndrome, should be raised as one gender or another, with or without surgery, in ways that cannot easily be turned back in adulthood, is beyond the scope of this Essay. In Hazel Glenn Beh & Milton Diamond, *An Emerging Ethical and Medical Dilemma: Should Physicians Perform Sex Assignment Surgery on Infants with Ambiguous Genitalia?*, 7 MICH. J. GENDER & L. 1, 56-59 (2000), Professors Beh and Diamond note that “[t]he literature documenting the tragic aftermath of genital normalizing surgery on the intersexed identifies frank and unintended dangers of using irrevocable elective surgery for social reasons.” For historical context, see JULIA EPSTEIN, *ALTERED CONDITIONS: DISEASE, MEDICINE, AND STORYTELLING*, ch. 4 (“Ambiguous Sexes”), 79 (1995).

³⁴ Female genital cutting and male circumcision also fall under the category of medical procedures that alter bodily integrity and sexual behavior. Notwithstanding—and not discounting—cultural or religious rationales, it may be argued that these interventions should not be performed without consent, including proxy consent by a parent, where the alteration is permanent, not medically necessary, and may result in harm, including interference with potential sexual capability. That debate is also beyond the scope of this Essay. See, e.g., Maree Parry, Juliet Rogers & Nan Seuffert, *Perversion and Perpetration in Female Genital Mutilation Law: The Unmaking of Women as Bearers of Law* (2019) (unpublished manuscript on file with authors); and Ouellette, *supra* note 13, at 231. Young women with intellectual disabilities have also been subject to an unsavory history of non-consensual sterilization, based on theories tinged with eugenics, paternalism, and/or pseudo-science. See Jasmine E. Harris, *Sexual Consent and Disability*, 93 N.Y.U. L. REV. 480, 510-13 (2018). See also *id.* at 511 n.125 (noting current parental argument that (voluntary) sterilization “affords greater sexual agency” to minors (and adults) with cognitive disabilities “who are freed from the burdens of reproduction and parenthood and [can still] receive the intimate connections desired”).

³⁵ On the authority of minors to consent to or refuse medical procedures, see, e.g., Kathryn Hickey, *Minors’ Rights in Medical Decision Making*, 9 JONA’S HEALTHCARE, L., ETHICS, & REGULATION 100 (2007), https://journals.lww.com/jonalaw/Abstract/2007/07000/Minors__Rights_in_Medical_Decision_Making.13.aspx.

³⁶ Perlin, *supra* note 31, at 269 n.52 (citing Julia Bahner, *Legal Rights or Simply Wishes? The Struggle for Sexual Recognition of People with Physical Disabilities Using Personal Assistance in Sweden*, 30 SEXUALITY & DISABILITY 337, 340 (2012)). For a thoughtful exploration of what constitutes non-procreational sexual health and intimacy for disabled

sexuality or sexual or gender identity has tended to focus on persons with acquired disabilities or, more generally, those with mobility or psycho-social impairment, whereas the sexual needs and yearnings of individuals with significant intellectual disabilities has received scant attention.³⁷

In examining this question, it is important to look beyond the case of Ashley. Our concern is with the *potential* growth and development of any young person with a significant cognitive disability at the time that parents or other caregivers are entrusted with decisions that may have an impact on physical or sexual development. If these decisions are not scrutinized for the interests of the person, we “fall[] far short of protecting or empowering people with profound cognitive and physical disabilities . . . [and a] genuine commitment to viewing the rights of . . . all people with disabilities, regardless of severity—as inalienable civil rights.”³⁸

Despite the benefits her family believes she received, Ashley’s treatment left her sterilized and her body permanently altered—a decision reflecting an appropriation by others of Ashley’s inherent rights to her own bodily integrity and sexuality, thereby diminishing her dignity as a full human being. In essence, our concern for preserving bodily integrity, sexuality, and legal personhood is about

persons, see Kevin Todd Mintz, *Sexual Intimacy, Social Justice, and Severe Disabilities: Should Fair Equality of Opportunity in Health Extend to Surrogate Partner Therapy*, 14 J. PHIL., SCI. & L.: DISABILITY SPECIAL ISSUE 4 (2014), <http://jpsl.org/files/6114/0555/6558/IntimacySocialJustice.pdf>.

³⁷ Shuttleworth et al., *supra* note 21, at 182-84. Based on rare and “richly contextualized ethnographic research in group homes for young men with significant cognitive impairments” conducted a few years ago, the degree to which these youths “experience a contradiction of expectations between being masculine and being disabled is unknown.” *Id.* (citing Nathan J. Wilson, “Conditionally Sexual”: Constructing the Sexual Health Needs of Men and Teenage Boys with a Moderate to Profound Intellectual Disability (unpublished doctoral thesis, Faculty of Medicine, University of Sydney (2009)). Because these men were unable to participate in interviews, “the dilemma can only be gleaned from interviews with their caregivers. . . . It may well be that men with cognitive and intellectual impairments experience such a dilemma only minimally if at all.” *Id.*

³⁸ Peace & Roy, *supra* note 16, at 40. Co-author Claire Roy, a parent and blogger, described her then 20-year-old daughter Sophie as someone who shared many of Ashley’s physical and intellectual disabilities: “As with Ashley, how [Sophie] perceives herself, as a young woman, is not fully known, because she does not have the ability to express it.” *Id.* Sessa, the daughter of philosopher and disability studies scholar Eva Feder Kittay, “is non-verbal and cannot express any form of critical thought, but is able to communicate her desires to family members, friends, and caregivers. She is also able to express joy and affection in a way that reciprocates the love and care that she receives from those around her.” K.T. Mintz, *supra* note 29, at 4 (citation omitted).

preserving dignity.³⁹ “The fact that an infant cannot articulate her dignity is irrelevant. The intrinsic value and the rights of a human being are not qualified by a person’s intelligence or physical capabilities.”⁴⁰

IV. LEGAL CAPACITY: ADDED DIMENSIONS FROM UNITED NATIONS CONVENTION

The debate over the capacity of persons with profound intellectual or developmental disabilities to control their bodies and their lives has become more complicated since the adoption of the Convention on the Rights of Persons with Disabilities, with its controversial article on legal capacity.⁴¹ Simply put, under Article 12, people with disabilities enjoy legal capacity—capacity for rights and capacity to act—on an equal basis with others in all aspects of life.⁴²

³⁹ For an extensive discussion of dignity in the mental disability context, see Jonathan Simon & Stephen A. Rosenbaum, *Dignifying Madness: Rethinking Commitment Law in an Age of Mass Incarceration*, 70 U. MIAMI L. REV. 1, 21-25 (2015) (reviewing ancient and post-Holocaust emergence of pragmatic doctrine of dignity, based on five core meanings and informed by human rights practice). There is no reason to restrict the analysis to individuals with *mental health* disabilities. Other discussions of dignity and human rights with respect to growth attenuation can be found in Peace & Roy, *supra* note 16; Caroline Harnacke, *The Ashley Treatment: Improving Quality of Life or Infringing Dignity and Rights?*, 30 BIOETHICS 3 (2015); and Adam Cureton & Anita Silvers, *Respecting the Dignity of Children with Disabilities in Clinical Practice*, 29 HEC F. 257 (2017).

⁴⁰ Coleman, *supra* note 25, at 724.

⁴¹ The controversy is manifested in part by the high number of treaty reservations, understandings, and declarations that have been lodged by states-parties. See UNITED NATIONS-DISABILITY, *supra* note 9. Much ink has been spilled—and keyboard text manipulated—over Article 12 since the CRPD entered into force. See, e.g., Amita Dhanda, *Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar of the Future?*, 34 SYR. J. INT’L L. & COM. 429 (2007); Gerard Quinn, *A Short Guide to the United Nations Convention on the Rights of Persons with Disabilities*, in 1 EUROPEAN YEARBOOK OF DISABILITY LAW (Gerard Quinn & Lisa Waddington eds., 2009); Shirli Werner, *Individuals with Intellectual Disabilities: A Review of the Literature on Decision-Making Since the Convention on the Rights of Persons with Disabilities (CRPD)*, 34 PUB. HEALTH REV. 1, 16 (2012); Lucy Series, *Relationships, Autonomy and Legal Capacity: Mental Capacity and Support Mechanisms*, 40 INT’L J.L. PSYCHIATRY 80 (2015); Piers Gooding, *Navigating the ‘Flashing Amber Lights’ of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns*, 15 HUM. RTS. L. REV. 45 (2015).

⁴² Article 12 states, in pertinent part:

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

States have a duty to provide persons with disabilities access to the supports they may require to exercise their legal capacity and ensure that these measures provide for safeguards to prevent abuse that are both proportional and tailored to the individual's circumstances. These safeguards:

shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body.⁴³

In a meticulously researched text on legal capacity, disability scholar Anna Arstein-Kerslake discusses at length the importance of decision-making and the ways in which it is still denied to people with cognitive disability.⁴⁴ The academician and advocate, who was influential in the U.N. convention monitoring the committee's adoption of a General Comment,⁴⁵ is primarily concerned with

3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

For access to the CRPD Articles, see CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES—ARTICLES, [https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html) (last visited Feb. 20, 2019).

⁴³ CRPD, *supra* note 42, at art. 12(4). An additional subsection requires that state parties ensure equality in disabled persons' ownership, inheritance, and disposition of property, control of their financial affairs, and access to credit. *Id.* at art. 12(5).

⁴⁴ See ANNA ARSTEIN-KERSLAKE, RESTORING VOICE TO PEOPLE WITH COGNITIVE DISABILITIES: REALIZING THE RIGHT TO EQUAL RECOGNITION BEFORE THE LAW (2017). Dr. Arstein-Kerslake is a senior lecturer at Melbourne University's law school and Convenor of the University's Disability Research Initiative. While debate remains amongst CRPD signatories about their interpretation of Article 12, there is general consensus on these core elements: recognition of legal capacity for everyone on an equal basis; primacy of an individual's will and preferences, establishment of adequate safeguards, and replacement of substitute decision-making systems with *supported* decision-making systems. *Id.* at 73.

⁴⁵ Anna Arstein-Kerslake & Eilionóir Flynn, *The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: A Roadmap for Equality Before the Law*, 20 INT'L J. HUM. RTS. 471 (2016). Human rights monitoring bodies, such as the CRPD Committee, adopt General Comments when there is concern about States Parties misinterpreting, or giving insufficient attention to, certain areas of human rights law. The comments are not legally binding, but are considered an authoritative interpretation. ARSTEIN-KERSLAKE, *supra* note 44, at 27. Dr. Flynn is Director of the Centre for Disability Law and Policy at the National University of Ireland-Galway.

determining what decisions constitute “legal agency,” as this is central to the definition of legal capacity. While all human beings have the potential to exercise legal agency, irrespective of the significance or complexity of their disability,⁴⁶ it does require “an element of intention.”⁴⁷

One such measure for exercising legal capacity is Supported Decision-Making (hereinafter “SDM”). Cherished in the disability community as the antidote to guardianship and other antiquated frameworks for governing the lives of people with mental health, psycho-social, and intellectual disabilities, SDM “reflects a significant normative shift in the structure of Anglo-American conceptions of legal rights and responsibilities, yet, in the spirit of legal realism, better reflects the everyday decision-making of people with and without disabilities.”⁴⁸ This shift from making *substituted* to *supported* decisions means that legally recognized decisions move from the individual to a family member or designated others.

There are four recognized principles for safeguarding supported decision-making: Both parties are respected as legal agents with full personhood; the power or dependency imbalance does not result in domination by the support person; the product of the relationship is an expression of the will and preferences of the person with cognitive disability; and the SDM system does not overregulate the lives of persons with disability.⁴⁹

A well-known disability rights scholar and advocate offers this succinct definition:

[A] series of relationships, practices, arrangements, and agreements, of more or less formality and intensity, designed to assist an individual with a disability to make and communicate to others decisions about the individual’s life.⁵⁰

⁴⁶ See Eilionóir Flynn & Anna Arstein-Kerslake, *Legislating Personhood: Realizing the Right to Support in Exercising Legal Capacity*, 10 INT’L J.L. CONTEXT 81 (2014).

⁴⁷ Intention may be broadly and presumptively manifested by any indication of *purpose* and *deliberation* behind an action, decision or omission. ARSTEIN-KERSLAKE, *supra* note 44, at 149-50. For purposes of Article 12, Arstein-Kerslake and Flynn make “an assumption . . . in favour of finding intention—and therefore ascribing legal agency,” *id.* at 150 (emphasis added), or “universal legal capacity.” *Id.* at 29.

⁴⁸ Harris, FURTHERMORE, *supra* note 9, at 94.

⁴⁹ ARSTEIN-KERSLAKE, *supra* note 44, at 190.

⁵⁰ Robert D. Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship*

There is a particularly fine line between *substituted* and *supported* decision-making for persons, like Ashley, who are non-verbal, minimally communicative, and/or have complex disability.⁵¹ Moreover, “a preference for autonomy above all other rights and needs of the individual” is not the solution to attaining recognition of legal capacity, but must be reconciled with a panoply of other human rights.⁵² In the end, the recognition of legal capacity and equal treatment for all people with cognitive disabilities, with the requisite decision-making support, may be more about human dignity than any other right or consideration.⁵³

V. CHILD-REARING AND THE SOCIAL MODEL OF DISABILITY

Almost two decades into the 21st century, it should be acknowledged that the social model of disability has supplanted the medical model, although much education remains to be done on this fundamental concept—for policy makers and the public at large. Unlike its antecedent, the social model views disability as caused by society and an environment that creates disabling barriers, rather than by a physical or mental impairment that needs to be treated, cured, or rehabilitated. Its focus is on society rather than the individual.⁵⁴ It

to Supported Decision-Making, 19 HUM. RTS. BRIEF 8, 10 (2012). Professor Dinerstein notes that “[t]he use of the word ‘support,’ and the related concept of supported decision-making, represents nothing less than a ‘paradigm shift’ away from well-established but increasingly discredited notions of substituted decision making.” *Id.* at 8. For an overview of SDM, see Harris, FURTHERMORE, *supra* note 9, at 86-93; and Piers Gooding, *Supported Decision-Making: A Rights-Based Disability Concept and Its Implementation for Mental Health Law*, 20 PSYCHIATRY, PSYCHOL. & L. 431 (2013).

⁵¹ One group opposes the position of the CRPD Committee, which takes a dim view of any form of proxy or surrogate decision-making. This camp asserts that there must always be a legal option for substituted decision-making, with a regulated standard, although unclear what that standard is. The “abolitionist” camp, on the other hand, “argues equally adamantly” that to permit any substituted decision-making is an Article 12 violation. ARSTEIN-KERSLAKE, *supra* note 44, at 75. In fact, the Committee’s position may not be absolutist, given the guidance provided in the General Comment on replacing substituted decision-making “regimes” with SDM. *Id.* at 64-75.

⁵² ARSTEIN-KERSLAKE, *supra* note 44, at 181.

⁵³ See, e.g., Simon & Rosenbaum, *supra* note 39, at 38 (discussing how individual autonomy and respect for inherent dignity are as essential to people with mental disabilities as enjoyment of internationally recognized human rights).

⁵⁴ See ARSTEIN-KERSLAKE, *supra* note 44, at 71; THERESIA DEGENER, A HUMAN RIGHTS MODEL OF DISABILITY 3-5 (2014), <https://www.researchgate.net/publication/283713863>. The social model “does not disavow medical treatment or interaction with medical professionals,” a position on professional judgment that many of our peers might not share. Prominent disability civil rights attorney Arlene Mayerson, our former DREDF colleague, reminded one

asks that professionals not provide treatment or care “through the lens of a diagnosis or disability,” but based on what individuals want for themselves, in order to overcome “a potentially unbending social or physical environment.” CRPD Committee Chair Theresia Degener, however, posits that a human rights model⁵⁵ is now the favored framework for addressing disability.⁵⁶

The fact that families like Ashley’s feel the need to consider resorting to radical alteration of their children’s bodies in order to care for them at home or to provide them with a safe and fulfilling life in their community speaks loudly to the inadequacies of our social care system. The Ashley X case raises several complex questions: how does our society view people with severe disabilities? What methods have individual families found to cope with their caregiving responsibilities and challenges? What social supports are necessary for people with intellectual and developmental disabilities and their families to thrive without invasive body alterations?

Beyond the law, philosophy, and ethics lie the practical questions of how we manage the hard work—physical, cognitive, and

of us a few years ago that “the Independent Living Movement was fueled in large part by a rejection of professional control over disabled lives.” Stephen A. Rosenbaum, *Une Procédure en Difficulté: A Blueprint for Resolving “Special” Education Disputes through a Quasi-Inquisitorial Process*, 32 WINDSOR Y.B. ACCESS TO JUSTICE/RECUEIL ANNUEL DE WINDSOR D’ACCÈS À LA JUSTICE 115, 130 n.72 (2015). Similarly, Professor Harris calls attention to the “privileging of medical expertise” in the assessment (and identification) of disability. See Harris, *Sexual Consent*, *supra* note 34, at 518 & 519 n.161 (reflecting “deeply-rooted history of pathologizing non-normative differences that cut across race, class, gender, and sexual identity”). See also Susan Stefan, *Leaving Civil Rights to the “Experts”: From Deference to Abdication under the Professional Judgment Standard*, 102 YALE L.J. 639, 680, 691 (1992) (disabled person’s “voice is so completely silenced” vis-à-vis the professional’s).

⁵⁵ For an introduction to the human rights model of disability, see Gerard Quinn and Theresia Degener, *A Survey of International, Comparative and Regional Disability Law Reform*, in *DISABILITY RIGHTS LAW AND POLICY* 13 (Mary Lou Breslin and Silvia Yee eds., 2002). In *A Human Rights Model of Disability*, *supra* note 54, Degener, who is also outgoing chair of the CRPD Committee, lists distinctions between the human rights and social models. The latter’s “sociological explanation of disability may lay the foundation for a social theory of disability,” according to Professor Degener, but it does not provide foundational moral principles or values, such as the human rights and fundamental freedoms that are articulated in the disability rights convention. *Id.* at 7.

⁵⁶ Degener notes that one of the social model’s founding fathers, Michael Oliver, has called for a halt to the strong criticism of this model by disability studies scholars “unless someone can come up with an alternative.” DEGENER, *supra* note 54, at 3. She asserts that the human rights model as embodied in the disability convention is just such an alternative. *Id.* “[W]hereas the social model merely explains disability, the human rights model encompasses the values for disability policy that acknowledge[] the human dignity of disabled persons. Only the human rights model can explain why human rights do not require absence of impairment.” *Id.* at 6.

emotional—of raising children. That reconstructing their bodies even surfaces as a solution testifies to the shortcomings of our social care system.

Aaron's Story

Aaron was Ellen and Michael Zafrani's first child, and endless days in the intensive care neo-natal nursery followed his birth in California. The treating neonatologist at the Kaiser HMO Medical Center gave a prognosis early on that rings in his parents' ears to this day: The developmental delay "could range from being a B+ student in school to profound physical disability and mental retardation." Michael later recounted that, "we didn't fully realize that 'delay' can also mean 'never catching up.'" The hospital social worker referred the Zafranis to the local Regional Center,⁵⁷ while Michael and Ellen's parents overwhelmed the couple with outdated notions of how to care for a child with "birth defects" and brought up the topic of "placement" options.

Aaron's challenges tested the Zafranis' resolve as parents and as a couple. Michael recalls his anger and frustration rising to the point that after countless visits to the HMO, he shouted "Fuck Kaiser!" on one occasion to anyone within earshot of the waiting room receptionist. Interactions with Aaron were never just about play; there was always a therapeutic component. A Parent Infant Program at Children's Hospital, however, was a safe space to play with Aaron without pitying glances or curious gazes from other parents. They took refuge among Aaron's developmentally disabled peers and their parents.

Things got a bit easier once Aaron began school, by which time it was clear he was not going to be a B+ student. Ellen and Michael were surprised at the school district's decision to place Aaron in

⁵⁷ The 21 California regional centers are quasi-public clearinghouse agencies that "provide fixed points of contact in the community" for developmentally disabled persons and their families, so that they have access to "the services and supports best suited to them throughout their lifetime." CAL. WELF. & INST. CODE § 4620(a) (2018). Reflecting a skepticism of government and/or privileging of the non-governmental sector, the California Legislature issued a finding that "the service provided to individuals and their families by regional centers is of such a special and unique nature that it cannot be satisfactorily provided by state agencies. Therefore, private nonprofit community agencies shall be utilized by the state for the purpose of operating regional centers." *Id.* § 4620(b). *See also infra* Parts VI-VIII.

“inclusive” classrooms for his preschool and elementary years.⁵⁸ They knew that inclusion was an option for “higher functioning” children with more moderate disabilities. Nonetheless, they eagerly embraced the recommendation. Two younger siblings had now joined the household. The Zafranis qualified for Regional Center vendor-provided respite care, a service for which the eligibility guidelines were not transparent.⁵⁹ It also entailed scheduling difficulties, training each new caregiver, and worrying if the caregiver would show up.

Wanting to make sure their younger children also got adequate attention and feeling that they did not have the patience or physical endurance to meet all of Aaron’s needs, Ellen and Michael began to look for alternatives. First, Aaron spent weekends in a family care home. Then Ellen and Michael founded a non-profit corporation to establish a small licensed home in their community where Aaron could have the company of peers and round-the-clock caregivers. The Zafranis monitored the quality of care and did fundraising to supplement the inadequate Medicaid⁶⁰ allocations for each resident; this solution was also labor-intensive. With ardent advocacy⁶¹ by his parents, Aaron continued to receive 1:1 support for community-based

⁵⁸ The word “inclusion” never actually appears in the text of the Individuals with Disabilities Education Act (IDEA). The statutory term of art, “least restrictive environment” (LRE), is shorthand for the federal mandate that “[t]o the maximum extent appropriate, children with disabilities . . . are [to be] educated with children who are not disabled.” 20 U.S.C. § 1412(a)(5)(A) (2018); 34 C.F.R. § 300.550 (2018). *But see* CPRD, *supra* note 42, at art. 24(1)-(2) (“States Parties shall ensure an inclusive education system at all levels and lifelong learning [and] that . . . [p]ersons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live.”).

⁵⁹ In-home respite services or “intermittent or regularly scheduled temporary non-medical care and supervision” are designed to help keep at home a disabled child with high needs and to relieve family members from “the constantly demanding responsibility” of attending to the individual’s “basic self-help needs and other activities of daily living.” CAL. CODE REGS. tit. 17, § 54302(a)(38) (2018). The stresses faced by parents, siblings, or other family members who engage in care or support may indeed be substantial and are not easily alleviated by extra hours of respite care. Stephen A. Rosenbaum, *Representing David: When Best Practices Aren’t and Natural Supports Really Are*, 11 U.C. DAVIS J. JUV. L. & POL’Y 161, 169 (2007).

⁶⁰ “Medicaid provides health coverage to millions of Americans, including eligible low-income children and people with disabilities. The program is funded jointly by the states and federal government.” *Medicaid*, CTRS. FOR MEDICARE & MEDICAID SERVS., <https://www.medicaid.gov/medicaid/index.html> (last visited Feb. 20, 2019).

⁶¹ The expectation that “parents and guardians will not lack ardor” in making sure their disabled children receive all the benefits to which they are entitled under law was articulated by the U.S. Supreme Court in its initial review of the IDEA, the nation’s decades-old special education law. *Bd. of Educ. of Hendrick Hudson Cent. Sch. Dist. v. Rowley*, 458 U.S. 176, 209 (1982).

activities from East Bay Innovations (EBI), a non-profit agency that provides independent living, supported living, and employment services.⁶² There was never serious consideration by Aaron's parents of how he might attain any degree of intimacy or sexual pleasure after reaching adulthood. It simply was not on the menu of options, although Michael was familiar with the literature and controversy about facilitating sexual activity in adult institutional settings for persons with cognitive disabilities.

Even with this elaborate support system, challenges persisted in attending to Aaron's physical care and enjoyment. His non-motorized wheelchair became difficult to maneuver after he developed scoliosis, and his health required special skills to manage. Aaron died suddenly in 2012, at age 25, from health complications not directly related to his disability.

VI. MANDATE FOR COMMUNITY-BASED LIVING AND SUPPORT

Rectifying the lack of meaningful resources and care for families with disabled children is no easy task. However, some states have successfully enacted ambitious and comprehensive legislation to address these problems. California's landmark Lanterman Act provides a model for how states can use public policy initiatives to establish supports and services that permit families to raise children with disabilities so that they achieve their maximum potential. California is the only state that provides entitlement-based services for people with at least some types of developmental disability. On its face, the statute explicitly recognizes that "the mere existence or the delivery of services and supports is, in itself, insufficient evidence of program effectiveness."⁶³ And, like all bureaucracies, California's

⁶² EAST BAY INNOVATIONS, [HTTPS://WWW.EASTBAYINNOVATIONS.ORG](https://www.eastbayinnovations.org) (LAST VISITED Feb. 20, 2019). EBI's mission is "[t]o arrange and provide personalized support that enables individuals with disabilities to live in their own homes, work in jobs of their choosing, and feel a sense of membership in their community." *About*, EAST BAY INNOVATIONS, <https://www.eastbayinnovations.org/about/> (last visited Feb. 20, 2019).

⁶³ CAL. WELF. & INST. CODE § 4501. The legislative intent further states that "agencies serving persons with developmental disabilities shall produce evidence that their services have resulted in consumer or family empowerment and in more independent, productive, and normal lives for the persons served." *Id.*

developmental disability infrastructure demands concerted and indefatigable advocacy.⁶⁴

The California Legislature adopted the Developmental Disabilities Act or “Lanterman Act” in 1977.⁶⁵ This nationally renowned legislation affords Californians with developmental disabilities the right “to make choices in their own lives.”⁶⁶ The statute accomplishes this with the aid of a network of service centers that contract with the state to implement an Individual Program Plan (“IPP”) for each “consumer.”⁶⁷ A team of family members, therapists, other caregivers, service providers, and agency representatives join a team that, together with the consumer, determines the necessary services and supports, based on the latter’s “needs and preferences” or, “when appropriate,” those of her family.⁶⁸ Services and supports—not cash benefits—are directed toward social, personal, physical, or economic habilitation or rehabilitation or “the achievement and maintenance of independent, productive, normal lives.”⁶⁹

⁶⁴ On the theory behind the Lanterman Act and particularized implementation by the Department of Developmental Services (DDS) and the network of regional centers, vendors, and offices of Client Rights Advocates, see generally Rosenbaum, *supra* note 59.

⁶⁵ Assemb. 846, Stats. 1977, c. 1252, p. 4521, § 550 (1977); CAL. WELF. & INST. CODE § 4500 *et seq.* (2018). The precursor statute adopted in 1969 was dubbed the Lanterman Mental Retardation Services Act, named for visionary Republican Assembly Member Frank D. Lanterman. Developmental disability is defined as “a disability that originates before an individual attains 18 years of age; continues, or can be expected to continue, indefinitely; and . . . shall include intellectual disability, cerebral palsy, epilepsy, and autism.” *Id.* § 4512(a). The term also includes disabling conditions closely related to intellectual disability or requiring treatment similar to that required for intellectually disabled persons. *Id.*

⁶⁶ CAL. WELF. & INST. CODE § 4501 reads in relevant part: “Services and supports should be available to enable persons with developmental disabilities to approximate the pattern of everyday living available to people without disabilities of the same age.” These individuals “and where appropriate, their parents, legal guardian, or conservator, should be empowered to make choices in all life areas. . . . The contributions made by parents and family members . . . are important and those relationships should also be respected and fostered, to the maximum extent feasible” allowing disabled persons and their families to “build circles of support within the community.” *Id.*

⁶⁷ CAL. WELF. & INST. CODE § 4512(b). “Consumer” is the current statutory term of art for individuals with developmental disabilities who qualify for regional center services and supports in this “cradle to grave” system. Sometimes they are referred to as regional center “clients” who are assigned to service providers or case managers. Several years ago, a badge surfaced among advocates and activists who did battle with the DDS bureaucracy. It read: “I am not a ‘case’ and I don’t need to be ‘managed.’”

⁶⁸ CAL. WELF. & INST. CODE § 4646. *See also* DISABILITY RIGHTS CAL., INDIVIDUALIZED PROGRAM PLAN (IPP) PLANNING GUIDE (2016), <https://www.disabilityrightsca.org/system/file/s/file-attachments/503801.pdf>.

⁶⁹ CAL. WELF. & INST. CODE § 4512(b). It is beyond the scope of this Essay to examine other national “womb to tomb” support schemes for persons with intellectual or other complex

In ways that reflect the spirit of Article 12, the Lanterman Act is filled with mandates for services and parental and consumer rights: all agencies receiving state funds shall respect consumer choice and provide “opportunities to exercise decision making skills in any aspect of day-to-day living.”⁷⁰ In explicit terms, the Lanterman Act aims to achieve several positive outcomes: for example, children should live at home with their parents, and adults with disabilities should have “supported living” arrangement options “with support available as often and for as long as it is needed.”⁷¹ State-provided services also help regional center adult consumers choose “where and with whom to live; and control[] the character and appearance of the environment within their home” and enable them to “[m]ake fundamental life decisions.”⁷²

This entitlement legislation resulted from many years of parental activism and lobbying. The text is well crafted, and the courts have interpreted its language favorably. In an instrumental decision, the California Supreme Court held that the Legislature has enacted:

a comprehensive statutory scheme . . . to provide a “pattern of facilities and services . . . sufficiently complete to meet the needs of each person with developmental disabilities . . . [and] to enable them to

disability and their families. It is worth noting, however, that there are deeper policy roots in other countries. For example, Sweden’s Committee for the Partially Able-Bodied articulated in 1946 an expectation that organizing services for disabled persons should bring about “a ‘normalization’ of conditions of life.” EUROPEAN INTELLECTUAL DISABILITY RESEARCH NETWORK, INTELLECTUAL DISABILITY IN EUROPE: WORKING PAPERS 54 (2003), <http://www.enil.eu/wp-content/uploads/2012/07/Intellectual-Disability-in-Europe.pdf>. This policy, the product of a postwar social welfare state, burgeoning human rights doctrine, deinstitutionalization movement, and economic incentives, was eventually extended to persons with more significant disabilities and “oriented towards giving the family support, in order to be able to live with its child at home during infancy and school years. When it becomes an adult, the family has become older and no longer able to give its support, the person gets the possibility to establish his own adult life.” *Id.* at 57. Shortly thereafter, in 1958, a parents’ association *Lebenshilfe* was founded in (West) Germany, maintaining that “services for intellectually disabled people should be family-oriented until adulthood when they should take into account the separation of the living areas of home, work and recreation.” *Id.* at 15. This right to early support “anchored in law” rose from the ashes of the genocidal regime of the Third Reich and eventually culminated in family-support services on a broad basis by the 1970s. *Id.* at 16.

⁷⁰ *Id.* § 4512.1. These are the quotidian decisions that may not rise to the level of legal agency under Article 12, but are nonetheless “intricately tied to our personhood and the construction of our individual personalities.” ARSTEIN-KERSLAKE, *supra* note 44, at 148.

⁷¹ CAL. CODE REGS. tit. 17 § 58614(a)(1) (2018).

⁷² *Id.* § 58614(a)(2).

approximate the pattern of everyday living of nondisabled persons of the same age and to lead more independent and productive lives in the community.⁷³

Carol's Story

After a bout with pneumonia before her first birthday, Carol Larsen was diagnosed with cystic fibrosis, and with cerebral palsy six months later. Her father, Max, built a special frame for changing Carol's diapers while she was in a full body cast. Max also constructed an adaptive walker, because Carol didn't begin to walk until she was nearly 5 years old, and he renovated their house so she could get around.

In the meantime, Carol's mother, Diana, built a support system for the family. She put Carol in a county-run early intervention nursery program designated for children with severe disabilities. This was before the passage of Section 504⁷⁴ and IDEA⁷⁵ and was forward-looking for the era. Despite having few financial resources, Diana became one of her region's most knowledgeable and effective advocates for children with disabilities, and the Larsens received the full range of services available because Diana learned to use Regional

⁷³ Ass'n for Retarded Citizens (ARC) v. Dep't of Developmental Servs., 696 P.2d 150 (Cal. 1985). The statute's lofty language, however, does not necessarily translate into legal enforcement, as the mandate for supports and services is subject to the Legislature's appropriation of funds. In recent years, the Lanterman Act was amended, presumably due to the augmenting cost and number of potentially qualifying beneficiaries, to require that the disability be deemed as *substantial*, i.e., "a major impairment of cognitive and/or social functioning." *Id.* § 4512(a); CAL. CODE REGS. tit. § 54001 (2018). On the Act's fiscal and other limitations, see Rosenbaum, *supra* note 59, at 173-74 (observing how state reimbursement rates to service providers do not keep pace with real world wages and operational costs). On unfunded mandates generally, see, e.g., Sch. Dist. of City of Pontiac v. Sec. of U.S. Dep't of Educ., 512 F.3d 252 (6th Cir. 2008) (discussing unfunded mandates for No Child Left Behind Act); Connecticut v. Duncan, 612 F.3d 107 (2d Cir. 2010) (same); and Breitenfeld v. Sch. Dist. of Clayton, 399 S.W.3d 816 (Mo. 2013) (discussing Missouri's Unaccredited District Tuition Statute).

⁷⁴ Under Rehabilitation Act of 1973, as amended, § 504. Pub. L. No. 93-112, 87 Stat. 355 (1973), 29 U.S.C. §§ 701-796l:

No otherwise qualified individual with a disability in the United States . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.

29 U.S.C. § 794 (2018).

⁷⁵ See *supra* note 58.

*Center and In Home Supportive Services (IHSS)*⁷⁶ to obtain respite care and financial help. The family had medical insurance, and Carol now has financial support from Supplemental Security Income (SSI)⁷⁷ and State Supplemental Security Disability Income (SSDI)⁷⁸ as well as Medicare and Medicaid.

By late elementary school, Carol's older sister Stephanie routinely met Carol at the bus stop after school and watched her until their parents got home from work. This was not easy, and Stephanie admits to having felt some resentment while growing up. She avoided having friends over because it was embarrassing to have to explain her sister to them. Stephanie herself, tellingly, became an attorney specializing in disability law and is active in the disability rights community.

Now in her late 40s, Carol lives with a disabled roommate in a 24/7 supported living apartment, supervised by East Bay Innovations. For many years, Carol attended a non-profit adult day program and volunteered in the community, with support from an agency service provider. Her health has begun to decline over the past several years. She now uses supplemental oxygen and, having developed diabetes, she is insulin-dependent and her diet is monitored closely. Despite these health challenges, Carol continues to live an active and happy life with a loving family and a supportive community.

VII. COLLECTIVE RESPONSIBILITY

The significance of the Lanterman Act's community-centric approach cannot be overstated. In nearly all the personal narratives we include in this Essay, parents talk about the importance of having a

⁷⁶ California's IHSS Program pays for services to allow persons, including disabled children, to "remain safely in [their] own home . . ." Services include: housecleaning, meal preparation, laundry, grocery shopping, personal hygienic care, and paramedical services, and protective supervision for persons with mental disabilities. *In-Home Supportive Services (IHSS) Program*, CAL. DEP'T SOC. SERVICES, <http://www.cdss.ca.gov/In-Home-Supportive-Services> (last visited Feb. 20, 2019).

⁷⁷ SSI (Title XVI) is a federal cash assistance program funded by general tax revenues to help low-income aged, blind, and disabled people meet basic needs for food, clothing, and shelter. *Supplemental Security Income Home Page—2018 Edition*, SOC. SECURITY ADMIN., <https://www.ssa.gov/ssi/> (last visited Feb. 20, 2019).

⁷⁸ To qualify, SSDI recipients must first have worked in jobs covered by Social Security (Title II) and have a medical or disabling condition and are therefore unable to work, in general, for a year or more. *SSDI: The Details*, DISABILITY BENEFITS 101, https://ca.db101.org/ca/programs/income_support/ssdi/program2.htm (last updated Feb. 11, 2019).

community of support—not only for their children, but also for their own personal and emotional well-being. From the Zafran's parent-infant play group to Carol's supported living residence for adults, the lives of disabled people and their families quickly come to depend on the communities of support created by the Lanterman Act and other related programs and organizations.

Moreover, these communities provide a safe and inclusive environment for individuals with disabilities to develop physically, cognitively, and emotionally. Respecting the dignity of others means taking them seriously as who they are. A child is going to grow into adolescence and then adulthood. Teenagers with developmental disabilities are still teenagers, and adults with developmental anomalies are still adults.

Family members provide the most obvious form of “natural support,” and where family is not an option, friends and the community can fulfill that role.⁷⁹ The statute characterizes natural supports as those “personal associations and relationships typically developed in the community that enhance the quality and security of life” for disabled individuals.⁸⁰ This includes family, as well as friends, fellow students, co-workers, and relationships developed through organizational or civic participation.⁸¹ The Lanterman Act advances the support concept even further in what may be construed as California's version of Supported Decision-Making. The so-called “circle of support” is “a committed group” of mostly volunteers, including family and/or community members, who meet regularly “to share experiences, promote autonomy and community involvement, and assist the individual in establishing and maintaining natural supports.”⁸²

The circle of support model is consistent with CRPD Article 12 insofar as it rejects liberal political theory's notion of the individual as a “rational man, walking alone through the world” in favor of a rights

⁷⁹ CAL. WELF. & INST. CODE § 4512(e).

⁸⁰ *Id.* Interestingly, the definition under state regulations is slightly different: “relationships typically developed *in the family* and community.” CAL. CODE REGS. tit. 17 § 54302(a)(48) (emphasis added). “No doubt someone somewhere is defending a dissertation in which these nuanced forms of support are discussed and deconstructed.” Rosenbaum, *supra* note 59, at 177 n.48.

⁸¹ CAL. WELF. & INST. CODE § 4512(e).

⁸² *Id.* § 4512(f). The regulations further provide that this “informal but identifiable and reliable group of people . . . meet and communicate regularly to offer support, at a frequency and in a manner consistent with and appropriate to the need, to the consumer for whose benefit it exists.” CAL. CODE REGS. tit. 17 § 58601(a)(1).

holder legal scheme in which the individual “exercises her liberty through her social connections.”⁸³ This change in thinking may be attributed to feminist scholars who have “pointed out the fallacy of the isolated autonomous man . . . instead highlight[ing] the interdependence of every individual.”⁸⁴ Notably, “[s]ome individuals use social support more than others, but no one is free from the web of familial and social structures that make up our communities.”⁸⁵ Recognition of interpersonal relationships and mutual dependencies should not detract from the notion of individual autonomy, but these relationships and dependencies form part of the assistance in decision-making and taking autonomous actions utilized by many people with cognitive disability.

Connor’s Story

When Connor Benoit was born, the bleeding wouldn’t stop after a blood draw from his heel. His platelets were dangerously low and his spinal fluid wasn’t circulating properly. The obstetrician told Martha and George Benoit they shouldn’t get too close to their son, as

⁸³ ARSTEIN-KERSLAKE, *supra* note 44, at 62.

⁸⁴ *Id.* at 63. The late San Francisco State University historian Paul Longmore insisted that interdependence is more critical to people with disabilities than independence. In some cultures, the role of (extended) family in decision-making is legally embraced. For example, New Zealand’s determination of eligibility for funded disability support services may involve consultation with *whānau* (Māori) or *aiga* (Pasifikan) family members to identify support needs and available resources, supports, and services. *Disability Support Services*, SUPPORT OPTIONS, <http://www.supportoptions.co.nz/support/services.aspx> (last visited Feb. 20, 2019). The Hawai’i Family Court and Child Protective Services has adopted an “*ohana* conferencing” model which “empowers the extended family and uses often-untapped resources and community supports” in its child welfare system. Paul Adams & Susan M. Chandler, *Building Partnerships to Protect Children*, 40 FAM. CT. REV. 503 (2002). See also Rosenbaum, *supra* note 59, at 176-77 (emphasis on person-centered planning can obscure benefits of family input). Almost two decades after passage of the Lanterman Act, the California Legislature adopted a legislative intent amendment “recogniz[ing] the ongoing contributions many parents and family members make to the support and well-being of their children and relatives with developmental disabilities” and directing “that the important nature of these relationships be respected and fostered by regional centers and providers of direct services and supports.” CAL. WELF. & INST. CODE § 4620.1.

⁸⁵ ARSTEIN-KERSLAKE, *supra* note 44, at 62-63. The family-centered approach “modifies the view of family members as people who only cause problems and are obstacles to the improvement of clients, and it is consistent with the notion of collaboration as a preferred style of family-professional interaction.” Reva I. Allen & Christopher G. Petr, *Toward Developing Standards and Measurements for Family-Centered Practice in Family Support Programs*, in REDEFINING FAMILY SUPPORT: INNOVATIONS IN PUBLIC-PRIVATE PARTNERSHIP 65 (G.H. Singer, L.E. Powers & A.L. Olsen eds., 1996).

“he might not last that long.” A nurse in the neonatal intensive care unit had assured them: “We’re going to see what we can do to salvage your baby.” As if the memory were still fresh, George later remarked: “Salvage—she actually used that word.”

When he was 3, Connor began to have seizures that caused his speech and cognition to deteriorate. As he grew less articulate, his inability to communicate discomfort or distress exacerbated his challenging behaviors, which included a chair-throwing episode in a restaurant the family frequented. Teachers felt put upon to have him in class, and his middle school administration balked at painting a yellow safety stripe, to accommodate his vision impairment, on a set of stairs where Connor had fallen.

The Regional Center eventually provided George and Martha with some respite time, and they applied for some IHSS hours, including a part-time nurse. Additionally, the Blind Babies Foundation (BBF)⁸⁶ offered the Benoits vision specialists, connections to community services, and a community of other families of children with visual impairments. The family maintains close relationships with their BBF counselor and behaviorist, and for several years Martha served on the BBF Board.

Still, George Benoit compares having a child who needs 24-hour supervision to looking down a dark tunnel that sucks in everything you’ve got. “Whatever you put in, it’s never enough. But you get used to it,” George says. “Really, there isn’t any other option.”

When he was 22, Connor developed renal failure unrelated to his disabilities and started dialysis, for six years at a dialysis center and thereafter with a home dialysis program that continues. In his mid-30s, Connor’s condition stabilized and he has not required hospitalization for several years. He walks with the assistance of a walker and someone by his side. While he can sometimes be difficult to understand, he communicates reasonably well. For years, Connor accompanied his family every Saturday to a local ranch that offers equine therapy for children and adults with disabilities. He remains a

⁸⁶ The Blind Babies Foundation provides early intervention and education services to young children who are blind or visually impaired and may have additional disabilities. Its vision impairment specialists “collaborate with family members, medical professionals, caregivers and teachers” to help “[f]amilies learn to become successful advocates for their children’s education and care.” *Blind Babies Foundation*, WAYFINDER FAMILY SERVICES, <https://www.wayfinderfamily.org/program/blind-babies-foundation> (last visited Feb. 20, 2019).

Regional Center consumer, continues to IHSS, and SSI, with nursing care for 60 hours a week in the family's home. Connor lives with his parents, and his younger sister recently enrolled in college.

In-home respite care, a classic Lanterman Act family service, is not merely glorified babysitting. It requires extraordinary skills on the part of the caregiver, especially in the case of older youths, who need, and want, to be as independent as possible. Under the legislation, parents have a right to a provider who will attend to their child's basic self-help needs, safety, and other activities of daily living usually performed by a family member. By law—and presumably by best practice and the natural order of things—respite care is intended to avoid out-of-home placement and to preserve family unity as well as offer parents time with each other or with their other children.⁸⁷

Paul's Story

When Paul was born to Victor and Liz Delgado, he was having seizures. The morning after Paul's birth, the obstetrician repeated ominously to Liz: "Everyone did everything they could do." Paul was diagnosed with static encephalopathy, the same diagnosis given to Ashley X. Liz's mother spent that first month helping the family, but soon they were on their own. Feeling that she could do nothing to help her son compounded Liz's distress at his prognosis. She often sat in her parked car, crying to herself so as not to alarm her husband.

No one could tell the family what to expect for the future. Victor and Liz heard everything from "He might not ride a bike" to "He might be profoundly mentally retarded." One doctor told them, "Some people call these kids motor morons." Paul received physical therapy, occupational therapy, and speech/language therapy to work on his difficulties with feeding and to provide him with a means of alternative augmentative communication (AAC). He became a Regional Center client and the family received respite services.

The Delgados joined a parent support group facilitated by Through the Looking Glass (TLG), a non-profit agency that "encourage[s] respectful and empowering services—guided by personal disability experience and disability culture—for families that have children, parents, or grandparents with disability or medical issues."⁸⁸ Liz says this group "saved my life and gave me the emotional

⁸⁷ CAL. CODE REGS. tit. 17 § 54302(a)(38)(A).

⁸⁸ *Mission*, THROUGH THE LOOKING GLASS, <http://www.lookingglass.org/who-we-are/mission>

tools I needed to cope.” United Cerebral Palsy matched Liz with a parent mentor who provided additional peer-to-peer education and gave the Delgados a vision forward.

Doing battle with schools when Paul was younger, and with insurance companies and social services later, consumed an inordinate amount of the Delgados’ time. They had to advocate unrelentingly to get their school district to provide adequately for Paul’s learning and safety needs. For example, Paul had an instructional aide, but she could not feed him, nor was there any private place for his brief to be changed. Paul’s assistive technology required expertise that the school lacked.

In his early 30s, Paul continues to live with his parents. Victor has been his primary caregiver since Paul was 4 years old, and Liz works at a disability rights advocacy organization to support the family. Paul began to receive IHSS and SSI when he turned 18. The Delgados prioritize family time, and while the family stayed close to home when Paul was younger, as his extreme spasticity and high tone made sitting in a stroller or car seat painful, they now enjoy taking long hikes together, made possible once Paul got a properly fit motorized chair and they acquired an AAC system and accessible van. Paul experienced some serious health setbacks in his late 20s that entailed surgery and several hospitalizations. He has regained health and strength over time.

While American political rhetoric regularly invokes “family values,” the reality is that caregiving is a devalued profession, and families are on their own to devise ways to manage daily life. Moreover, child care and home care are among the poorest paid professions, and many older adults and people with disabilities live in institutions with only custodial care because they have no family to care for them, or their families are unable to provide their care.⁸⁹ As to the status of non-familial carers, support persons, and service providers, we acknowledge the universality of support: “None of us

ion (last visited Feb. 20, 2019). TLG proclaims on its Facebook page: “Services are not pathologizing, are strength based, and sensitive to the needs of those served.” These include mental health and developmental services, assistance with adaptive equipment, services for transitional age youth, and Head Start program consultations. The staff, many of whom themselves have disabilities, also provide information and referrals.” Through The Looking Glass, FACEBOOK, <https://www.facebook.com/lookingglass.org/> (last visited Feb. 20, 2019).

⁸⁹ See *Special Needs Care for Adult Children: Your Care Options*, CARE.COM (Jan. 24, 2018), <https://www.care.com/c/stories/10265/special-needs-care-for-adult-children-your-care-options/>.

exercise legal capacity alone or in a vacuum. We take support from those around us—our friends, families, *experts, and professionals*.”⁹⁰

Keeping a family member with disability at home should not mean filing for bankruptcy, giving up one’s own life aspirations, deciding not to have other children, or otherwise reorganizing priorities and expectations around caregiving as the family’s central activity.⁹¹ To make that goal a reality, we need a carefully designed and fully funded system of physical and financial supports for families. If we maintain that such a system is too expensive or too cumbersome, then we need to ask ourselves a simple question: What kind of society casts out or reshapes its most vulnerable members? And, if we believe that we don’t want to inhabit such a society, how can we build a world in which families do not need to consider the desperate measures necessary to alter their children’s anatomy, appearance, and body chemistry in order to care for them? Surely, there is a way to handle the dilemma of raising children with complex medical and social needs that does not require this invasive last resort.

VIII. SOCIAL CAREGIVING RECOMMENDATIONS

Societies bear a collective responsibility to care for those who cannot care for themselves, and to assist people with disabilities, from birth to beyond the death of their parents. What should this responsibility entail? What are the optimal ways for making caregiving a shared obligation of family and society? How can we support families so that people with care needs can remain in their homes and communities?

Isabella’s Story

Kayla Jefferson looks out for her family. When her methamphetamine and alcohol-addicted niece gave birth to 4 lb. Isabella and couldn’t care for her, Kayla volunteered to take Isabella

⁹⁰ ARSTEIN-KERSLAKE, *supra* note 44, at 181 (emphasis added).

⁹¹ See Stephen A. Rosenbaum, *When It’s Not Apparent: Some Modest Advice to Parent Advocates for Students with Disabilities*, 5 U.C. DAVIS J. JUV. L. & POL’Y 159 186 n.86 (2001) (author took pleasure in construction of Allen Ginsberg Memorial Poetry Garden on vacant plot at elementary school where son received special education services). “Quite apart from the intrinsic satisfaction, I was not oblivious to the fact that this allowed me to be seen by the principal, teachers and other parents not merely as the (demanding) father of a disabled child, but as someone who contributes to the greater good of the school community.” *Id.*

in, despite the fact that she was already raising her own teenage son, who has Asperger's Syndrome, as well as Isabella's teenage sister. Isabella had a brain malformation, a tethered spinal cord, cysts on her spinal cord, scoliosis, torticollis, difficulty swallowing, visual-perceptual and balance impairments, and global developmental delays. She required a pump to provide her with continuous feeding.

Through California's Regional Center system, Isabella received physical and occupational therapy, and she had an early intervention specialist, a speech/language therapist who worked on her swallowing and feeding issues, and a case manager. But no child care center, even those advertised as "inclusive," would accept Isabella. She had pulled out her feeding tube multiple times, each time requiring a return to the hospital. Kayla resorted to driving Isabella 90 minutes each way to a day care center run by a relative. Kayla had to take many weeks off work to handle Isabella's medical care. She didn't own a home, drove a car on its last legs, and lived from paycheck to paycheck.

By the time she was 5 years old, Isabella had made enormous progress. Nevertheless, some medical issues remained, and she continues to have significant cognitive impairments. Kayla knows how precarious Isabella's health and her family's stability are. "I feel like, at any point, my life—and Isabella's!—could completely go off the rails."

After successful neurosurgery, Isabella was able to be weaned off her feeding tube, but she still struggles with intermittent back pain, and with trauma—both medical and emotional. Today, thanks to all the services and the specialized instruction she received, Isabella is a thriving 12-year-old, attending her local public middle school and fully included in 90% of the general education program. She continues to receive mental health support for her PTSD, special education through her IEP, and Medicaid benefits.

Isabella's birth mother died homeless, with a diagnosis of mental illness, on the streets. Isabella remains very close to her sister, a college freshman, and has grown to become a valued member of her school and local community, standing up for every underdog with empathy and persistence. She is the poster child for early intervention—a funny, resilient and witty young person who refuses to accept binary definitions and identifies as gender queer.

The stories we share here of California families that have raised children with significant disabilities represent many different

approaches to the challenges such households face, and these families have differing beliefs and varying access to resources, both in money and in community support. They have all “made do.” Some have financial resources, others use settlement funds from their child’s birth complications. All navigate the public service labyrinths and obstacle courses. All of them also deploy vast amounts of creativity, perseverance, problem solving, patience, and physical and mental stamina. Families whose primary language is not English and those with fewer resources have a particularly hard time. Access hurdles become especially high in periods of austerity and belt-tightening.

Andres’ Story

For Jorge and Silvia Gomez, the road to parenthood was rocky: Silvia experienced five miscarriages before successfully delivering Andres. Ecstatic to have a son after so much heartbreak, the new parents didn’t make much of a few early difficulties, such as having to feed Andres with a syringe because he had a hard time nursing. Then their pediatrician noticed that Andres’ head wasn’t growing proportional to his height and weight.

The diagnosis was complicated: cortical visual impairment and a small visual cortex; microcephaly; a seizure disorder; and severe developmental delays. Jorge and Silvia were terrified they were going to lose their little boy. The doctors predicted that Andres would never walk or talk, but assured Jorge and Silva that none of Andres’ disabilities were incompatible with life. As a deeply religious family, that was all that the Gomez’ needed to hear.

At 17 months, Andres started to walk. Now in his early 20s, Andres is playing the guitar and the ukulele, and he is happiest when he receives music therapy, provided by the Regional Center. He wears a brief for incontinence and receives medications through a gastrostomy tube. He comes to the kitchen table to communicate he’s hungry or thirsty, and Silvia, or someone else, sits in the back seat with him in the car when the family travels. He recently received a diagnosis of Lennox-Gastaut Syndrome, a severe form of epilepsy, and he is entering a study for a new anti-convulsant.

The Gomez’ have worked hard to ensure Andres is supported. When he was very young, they moved so he could attend a school with a well-known special education inclusion program. Silvia devoted herself to learning how to advocate for Andres, and she worked closely

with his school. The Regional Center provides 30 hours of respite and nursing care each month, and Medicaid covers his medical co-payments.

The Gomez family does most things together. But, when their church said Andres could not take communion, Silvia asked the priest how he wanted her to explain to her young boys that Russell could learn about Jesus and his message of love, but Andres would be excluded. The family found another church.

At 22 and out of the public school system, the family had a tough time finding a program that could serve Andres' medical and intellectual disabilities. However, he has transitioned to a 10-person community-based adult day program with a 1:1 staffing ratio. Andres's younger brother Russell is a college junior majoring in cellular and molecular biology with an emphasis in genetics. The whole family recently took a hiking trip through western state national parks; Andres loves to be outdoors.

We return to the question with which we began: Is it necessary to alter the body of a child with disabilities in order to raise her in a way that fulfills her greatest human potential? For these recommendations, we posit a human rights model of disability that assumes the full rights and dignity of all people to be free from stigma and from being viewed through a medical-only lens.⁹²

If we were to follow our core values to their logical conclusion, we would base our social policy on several key tenets:

- **Dignity and Integrity:** Every human being has value and deserves dignity and bodily integrity.
- **Interdependence:** When self-determination and autonomy are unavailable due to disability and an individual cannot make informed choices alone, we should advocate for an ethic of interdependence, including family-centered decision-making, where appropriate.⁹³
- **Universal Design:** A growing area of architectural design works on the premise that everything we make or adapt should be able to be used by all people, whether or not they have impairments. Social attitudes must change to accept that people come with different levels of ability, and that people with

⁹² See *supra* notes 55-56.

⁹³ See *supra* Part VII.

disabilities have much to offer their communities. The concept of universal design also provides a model for other fields, such as education.⁹⁴

- **Societal Systems of Care:** The costs to support individuals and families who require more support than others must be borne as a shared societal obligation. Under the current scheme, disability-related costs are spread rather arbitrarily, between private health insurance underwriters, underfunded public school districts, and a hodgepodge of local, regional, and state agencies providing other services. The system does not need to be siloed in this way. In the United States, antipathy to paying taxes is practically a national character trait. It will take a huge cultural and fiscal shift to reorganize and retool our systems of care.
- **Legislative Systems of Care:** Laws enacted to protect the rights of the most vulnerable must be fully funded. As a society, we espouse the value that we have collective as well as individual and family responsibility for those among us who are most vulnerable.⁹⁵ We say we believe in ensuring the safety and well-being of children, youth and older adults as well as of people with disabilities. In practice, we have never quite measured up.

IX. CONCLUSION

“It’s a bitch, having a disabled kid,” George Benoit told us, with his characteristic bluntness, and only half joking. He doesn’t

⁹⁴ See, e.g., Stephen A. Rosenbaum, *Full Sp[re]ed Ahead: Expanding the IDEA Idea to Let All Students Ride the Same Bus*, 4 STAN. J. C.R. & C.L. 373 (2008). “There is no reason why the entitlement to a free appropriate public education should be limited to students in need of specialized instruction. . . . Doesn’t every child deserve an individualized learning plan that charts a course for obtaining an appropriate education and measuring her progress?” *Id.* at 385.

⁹⁵ Here, again, the Swedish model is relevant: The community tradition sees persons with an intellectual disability as citizens of society, with a right to welfare and participation in community life. The services to be used by them are the services of other citizens, that is, the welfare services used by the general public. Persons with a disability, their life and support, are seen from a citizen perspective in the community tradition. EUROPEAN INTELLECTUAL DISABILITY RESEARCH NETWORK, *supra* note 69, at 55. See also COUNCIL OF AUSTRALIAN GOVERNMENTS, 2010-2020 NATIONAL DISABILITY STRATEGY 47-52 (2011), https://www.dss.gov.au/sites/default/files/documents/05_2012/national_disability_strategy_2010_2020.pdf (implementing policy that “[p]eople with disability, their families and carers have access to a range of supports to assist them to live independently and actively engage in their communities”).

exaggerate. Ellen Zafrani confessed, “No offense to those who see life differently, but, no, we were *not* blessed.” The early years can be utterly devastating, when parents spend their days juggling medical appointments, therapies, the needs of their other children, jobs, insurance, and financial worries—and often grieving.⁹⁶ Baffled family members and friends don’t know what to do or say or how to help—and many just disappear. The dream of parenthood morphs into a reality of unexpected diagnoses—or mystery causes—for impairments and limitations whose final form may remain unknown for years.

But what is right might differ from family to family. It may mean bucking pressure from family members or doctors to “put away” your child (*i.e.*, placement, or the dreaded “P word” as Michael Zafrani dubbed it) and move on. For some families, like the Zafranis, a small community-based group care home may be a good answer. For others, supported living in the community can work well, as it does for Carol. For still others, it makes the most sense to keep their disabled son or daughter at home as adults, as the Benois and the Delgados are doing. Parents who have the means need to consider setting up a special needs trust or other system for when they are no longer able to provide for or oversee their child’s care. Families without resources must try to identify and recruit younger people who will be able to care for their adult child when they are no longer able to do so themselves.

The distinctively American ideal of rugged individuality has historically meant that unless a family decided to place their child, they were on their own to provide full financial and caregiving support, for their lifetimes and beyond. Given deinstitutionalization trends of the last several decades, placement is no longer a preferred, or even available, option. Yet, even friends, family members, and neighbors and acquaintances may remain unaware of—if not indifferent to—the attendant financial, physical, and emotional struggles.

Congenital illness, birth mishaps, injuries, or disease: all can produce disability, and these events can happen to families from any socio-economic stratum. Surely, those who win this random and ecumenical lottery should receive assistance. People with disabilities deserve—and have the legal right to—a life as part of a community, without having to bankrupt themselves or their families or relocate

⁹⁶ The duration and typical stages of grief are not necessarily predictable when a parent is dealing with a child’s loss of developmental skills or medical needs. *See generally* Ken Moses, *The Impact of Childhood Disability: The Parent’s Struggle*, CAL. DEP’T EDUC. (2004), http://www.pent.ca.gov/beh/dis/parentstruggle_DK.pdf.

somewhere that offers a better educational or social services system. We *all* deserve this.

Finally, no family should have to take extreme measures to alter their child's body to make it conform to a society that fails to recognize the value of the many varieties in which human beings enter, live, and socialize in the world.