Navigating Growth Attenuation in Children with Profound Disabilities

Children's Interests, Family Decision-Making, and Community Concerns

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A twenty-person working group convened to discuss the ethical and policy considerations of the controversial intervention called "growth attenuation," and if possible to develop practical guidance for health professionals. A consensus proved elusive, but most of the members did reach a compromise.

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In 2006, the *Archives of Pediatric and Adolescent Medicine* published a case about a six-year-old girl with profound developmental disabilities who was given estrogen patches to reduce her final height.[1] The article also offered an ethical justification for growth attenuation, as this kind of intervention is known: it would let her parents lift and move her more easily, which the parents believed would allow her to participate in more social and recreational activities and would help them with routine activities like dressing and changing her diapers. The authors estimated that the estrogen reduced the child's final adult height from a predicted five feet four inches to approximately four feet six inches. They also recommended that similar parental requests in the future be reviewed by neurobehavioral specialists, endocrinologists, and ethics committees, so that decisions would be based on an accurate neurodevelopmental prognosis and a thorough, case-by-case evaluation of harms and benefits to the child. An accompanying editorial criticized the intervention but praised the publication for offering an opportunity for a public response.[2]

In January 2007, the girl's parents posted a justification of growth attenuation on their blog and suggested that the "Ashley Treatment," as they called it—which also included surgical removal of her uterus and breast buds—should be considered by other families.[3] The blog attracted media attention and strongly critical reactions by many disability rights and family support groups.[4] The parents' blog also received many letters supporting the decision. More than seven thousand people responded to an online MSNBC poll, with 59 percent supporting the parents' decision and 41 percent finding the decision unethical.[5]

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In response to complaints it received regarding the "Ashley Treatment," the Washington Protection and Advocacy System, now known as Disability Rights Washington, conducted an investigation of Seattle Children's Hospital, where the intervention had taken place.[6] Following the negotiations with DRW, the hospital agreed to obtain a court order prior to any future medical interventions to attenuate growth in children with developmental disabilities.[7] Physicians and ethics committees elsewhere, of course, are not bound by this agreement. Given parents' interest in growth attenuation, they are eager for guidance.

In order to engage the underlying ethical and policy considerations of growth attenuation, Benjamin Wilfond and Paul Miller—of Seattle Children's Hospital and the University of Washington Disabilities Studies Program, respectively—held a public symposium about the case in spring 2007. Following this community-engaged discussion, they, along with Carolyn Korfiatis, Douglas S. Diekema, Denise Dudzinski, and Sara Goering, assembled our twenty-person working group—the authors of this article—to discuss the ethics of growth attenuation in greater depth and develop practical guidance for health professionals. Our group included diverse perspectives and experiences—including those of both scholars and activists—on disability issues. A few of us were directly involved in the Ashley case. Nearly half either have family members with significant disabilities or themselves have significant disabilities. We deliberated over the course of a year, both via e-mail exchanges and in two face-to-face meetings.

We began our deliberations with some shared views about profound disabilities. We are concerned that many people and institutions in society do not positively value people with profound developmental disabilities. We agree that investing in improvements in medical and social services (medical equipment, human

assistance, respite care, lift-equipped vans, and the like) is a priority. Equally important is the need to encourage more welcoming societal attitudes toward individuals with developmental disabilities.[8] Further, we agree that parents of children with profound developmental disabilities face a complicated set of challenges and should be afforded respect and considerable deference in making the complex and difficult decisions unique to their child's care.

The differences within our working group relate to attitudes toward our own bodies and toward those of our children. Whereas some emphasize the moral importance of learning to accept our (and our children's) bodies as they are, others emphasize the moral importance of shaping our (and our children's) bodies to advance our (and their) interests.[9] All members appreciate that both approaches are intended to support the child's flourishing within the family.

The working group's objective was to move beyond staking out positions with divisive and polarizing rhetoric about growth attenuation in order to find common ground and better identify and understand the areas of deep disagreement. In this paper, we offer sympathetic accounts of differing views so that those who hold a particular view can better understand others' concerns. We also reach for a middle ground—a moral compromise based on respect for sustained disagreement rather than on consensus.[10] Most of our group agreed to the compromise that growth attenuation can be morally permissible under specific conditions and after thorough consideration.

This is one of many parental decisions for which a decision in either direction may be ethically justified. The working group acknowledges statements criticizing the procedure made by the broader community of people with a wide range of disabilities.[11] Such statements understandably reflect concerns about growth attenuation's adverse impact on profoundly disabled children and the disability community's progress in overcoming societal challenges. However, because the potential impacts of growth attenuation are no more profound than the impacts of other decisions that parents routinely make, parents should be supported in making such decisions based on their assessment of the interests and needs of their children and families. This paper presents recommendations for strategies to assure that parental decisions about growth attenuation are made only after thorough consideration.

The experience of participating in the working group influenced the views of many of the members. In particular, hearing about the diversity of members' family experiences with profound cognitive disabilities was very helpful. Two of the accompanying essays by working group members—those by Sue Swenson and Sandy Walker—describe how their family experiences shape their opposing views about growth attenuation. But we cannot say more than that most of the group agreed to a compromise. Some of us held fast to other positions. Accompanying essays by Norman Fost and Eva Kittay illuminate persistent disagreements about the appropriateness of special oversight of parental decision-making and the significance of offering growth attenuation only to children with the most profound disabilities.

There are several reasons to focus on the issues raised by growth attenuation—administration of short-term, high-dose estrogen to close growth plates, thereby permanently limiting height—rather than to address all three interventions collectively called the "Ashley Treatment."[12] Growth attenuation is particularly interesting because supporting healthy growth is a fundamental aspect of clinical pediatrics and growth attenuation poses a unique potential exception. Addressing breast bud removal would have added a layer of complexity to an already sufficiently challenging issue.[13] And while it is difficult to disentangle hysterectomy from growth attenuation in females, we chose not to discuss hysterectomy because there is an established literature and a general consensus on policy, including the issue of judicial review.[14]

In this paper, we consider the impact of growth attenuation on children, the importance of shared decision-making between parents and doctors, strategies for safeguards and oversight, and community concerns about social implications. We begin with the community concerns because they generated the public debate about growth attenuation. We preface that discussion with a description of the children who might be candidates for growth attenuation.

Children with Profound Disabilities

The children for whom growth attenuation would be considered have persistent, profound developmental and intellectual impairments. As a result, these children require total care by others, including feeding, dressing, toileting, and mobility assistance. These conditions may result from problems during fetal development, perinatal or postnatal brain injury due to infection or trauma, or inherited conditions.

A determination of permanent developmental impairment requires ongoing periodic developmental assessments in which the child shows little progress in motor, communicative, and social and emotional development past an infantile stage. Some children have specific conditions related to a defined genetic, metabolic, or structural brain disorder associated with lifelong, profound developmental deficits. Even when such disorders are identified, there may be variable developmental consequences, so evidence of minimal developmental progress over several years is necessary before one can conclude that further progress is unlikely.

Over the last century, significant intellectual disability has affected two to five of every one thousand children. In the United States, this amounts to as many as twenty thousand children

Offense to Third Parties?

Consensus development over a hotly debated topic such as growth attenuation is difficult at best. In this case, feelings ran deep among many members of the working group, reflecting divisions in the wider public. It is therefore especially remarkable that the working group was able to find a middle ground—a compromise—that attracted such broad support, including mine.

That said, I believe too much deference has been given to the claims of third parties that their interests or preferences should be taken into account when individual families, in consultation with their physicians, are contemplating growth attenuation for children similar to Ashley.

Third-party interests related to medical care can include a range of possible harms. At one end of the spectrum, third parties may suffer physical harms, such as exposure to tuberculosis if an infectious patient refuses standard treatment, or homicide, when a criminal not in detention is treated for a life-threatening illness. More common are financial harms, when treatment of a patient imposes costs on others due to higher taxes or insurance premiums. Harder to define would be social harms, such as loss of a political leader if she does not receive effective medical treatment.

In Ashley's case we have none of these kinds of harms or interests. Rather, we heard about disagreement and distress because a caring set of parents, with consultation from competent physicians and the support of an experienced ethics committee, pursued a treatment plan that offended the personal beliefs of some individuals and groups about the treatment of people with disabilities. The report states that these "concerns and perspectives . . . should be considered during the decision-making process" by providing parents with "information summarizing arguments for and against this controversial intervention, or offering them copies of relevant publications."

With the help of a federally authorized advocacy group with remarkable powers to subpoena hospital records, those who were offended by Ashley's treatment succeeded in pressuring the hospital to prohibit its physicians from offering similar treatment to future patients without court approval.

This remarkable intrusion into private medical decisions lacks any plausible claim of harm to third parties other than emotional distress on becoming aware that one's moral or political views are not shared by everyone. By this criterion, parents seeking cochlear implants for a deaf child, surgical correction of club feet or scoliosis, or a do-not-resuscitate order for a terminally ill child should be reminded that their decisions may be offensive to others and should be given literature on the reasons for the disagreement. Worse, many of those who opposed Ashley's treatment argue that other treatments that involve changing the body should be prohibited without prior court approval.

If those who object to growth attenuation in patients like Ashley claim that their rationale is not simply their own moral distress but a belief that a medical intervention (or withholding of medical intervention in the case of "natural" short stature) is contrary to the child's interests, then they should work through the long-established system of adjudicating questions of abuse or neglect of children—namely, by making a report to the county or state child protection service.

While the working group's paper calls for deference to informed parental decisions in cases like Ashley's, I believe it does not adequately examine the rationale and broad implications of suggesting that disagreement by strangers—absent a finding of abuse or neglect by an established process—should play an important role in private medical decisions.

—Norman Fost

per year.[15] However, consideration of growth attenuation is limited to children with the most profound disabilities, who have an IQ of less than twenty to twenty-five. There are about four thousand such children born each year—roughly one of every one thousand births.[16] Some of these children rely solely on committed caregivers in nonfamilial settings, but many others live in the family home with loving and supportive parents. In trying to understand how people with profound intellectual disabilities experience their world, we sometimes extrapolate from our own lives; however, accounts of the close observation and interaction that routinely occurs in families with such children can aid others in understanding their experience.[17]

In the 1980s, public debate and federal action about withholding treatment from infants with Down syndrome and neural tube defects changed societal views and medical practices about the limits of parental decision-making for children with *moderate* developmental and physical disabilities.[18] A similar public discussion about children with profound disabilities and their treatment is just now occurring.[19] Consideration of the ethical issues surrounding growth attenuation is important, in part, because it directs attention toward a population that is not often a focus of public deliberation.

Community Concerns about Social Implications

Our working group agreed that if growth attenuation is to be considered, the broad concerns and perspectives of people with disabilities should be considered during the decision-making process. Regardless of the kind of impairment or physical difference, people with disabilities face unnecessary social and environmental barriers to full acceptance and participation in their communities. While we believe these social problems should not exclusively determine parent and clinician decisions about growth attenuation, our working group spent considerable time discussing concerns related to the devaluation of people with disabilities, the impact on social resources, and the potential for misuse. Growth attenuation is a prism that refracts these general concerns with vivid intensity.

Devaluing people with disabilities. A common theme throughout much of the disability community's criticisms is that parents and clinicians who support growth attenuation lack respect for and understanding of children with developmental disabilities.[20] This concern ties strongly to the history of horrific treatment (involuntary sterilization, for example) to which people with disabilities have been subjected, ostensibly for both individual and social benefit.[21] Some people with disabilities and their advocates view growth attenuation primarily as a sign that medical professionals and parents without disabilities neither respect people with disabilities *as they are* nor work to accommodate their bodies.[22]

The disability rights movement understands disability as primarily a sociopolitical problem of justice rather than an individual failing of the body.[23] According to this view, society must reexamine its norms and standard practices in order to overcome its disability oppression instead of requiring individuals to change so they conform to the norm. This can be accomplished by making public environments and the workplace more accessible to people with nonstandard modes of functioning and by acknowledging the important contributions to families and society that are made by people who are unable to work. Society could be altered to better accommodate children with profound disabilities, and growth attenuation appears to some to perpetuate the notion that disabled bodies should accommodate a society that does not accept disability.[24]

Despite many shared experiences among those living with disabilities in our group, growth attenuation was not universally seen as a negative expression about disabilities or a representation of injustice. Some appreciate that the kinds of discrimination and stigmatization that most commonly affect people with disabilities are not relevant to children with profound disabilities. Further, the weight given to the potential harms to communities is complicated by the difficulty of determining who speaks for a community, what defines community membership, and how to account for diverse views within a community.[25] Nonetheless, we recognize that the broad community of people with disabilities has some stake in this debate. Despite their heterogeneity, people with disabilities and their advocates may be able to articulate community concerns that others might not fully appreciate.

Impact on social resources. Another plausible worry about growth attenuation is that it could compete with alternative strategies to improve social services for individuals with disabilities and, in particular, for families of children with profound disabilities. If growth attenuation is seen as less expensive and easier to provide than social resources, its very existence may compound the problems of inadequate resources and services. Reducing the need for such resources might lessen the social pressure to provide them for others, including disabled people who are not candidates for growth attenuation but who rely on similar social services.

However, support for growth attenuation and support for improved social service funding are not clearly at odds, nor are the two mutually exclusive. Employing growth attenuation does not eliminate *parents'* need for social resources, especially given their own aging and the possibility of their own future impairment. The policy decisions about social resources are sufficiently complex, and the eligible population for growth attenuation sufficiently small, that its availability alone is unlikely to have any significant impact on funding decisions.

Most in our working group would prefer to limit growth attenuation to the very small group of profoundly developmentally disabled children. This is not intended to be discriminatory. The idea, rather, is that children with vastly different medical and social needs may require different options.

Concerns about misuse. Could growth attenuation's potential benefits also apply to children who have less profound disabilities? For example, growth attenuation might be attractive to families raising children with challenging behavior (autism, for example), or to families of children with significant physical disabilities but no cognitive impairments (such as spinal muscular atrophy) that demand lifelong assistance with tasks of daily living. Such a possibility raises two key concerns.

Discrimination against Children with Cognitive Impairments?

Those who have not raised a severely cognitively disabled and nonambulatory child into adulthood may feel diffident about expressing opposition to growth attenuation because they have not walked in the parent's shoes. I *have* walked in them, or at least in very similar ones. My daughter Sesha is now a woman of forty. She, too, does not toilet herself, speak, turn herself in bed, or manage daily tasks of living, and she has no measurable IQ. Like Ashley, Sesha is so loving and easy to love that her impossible-to-articulate sweetness and emotional openness make it tempting to call her an "angel." Still, we refrain. To love Sesha as she is, we must accept that, unlike an angel, she has a body that grows and ages.

The Seattle Growth Attenuation and Ethics Working Group settled on the compromise that growth attenuation should be limited to severely cognitively disabled and nonambulatory children. I respectfully disagree. I do not believe that growth attenuation is ethically or medically appropriate, even when limited to children with profound developmental and intellectual impairments.

The compromise position rests on the assumption that the constraint will avoid many of its possible abuses. The problem is that the limitation is itself already an abuse. If growth attenuation should not be done on children without these impairments, then it should not be done on any children. To do otherwise amounts to discrimination.

The working group, anticipating this charge, write, "The distinction is not intended to represent a veiled discrimination against such children. The idea, rather, is that children with vastly different medical and social needs may require different options."

It is easy enough to grant the point that medical interventions aim at particular ills and thus "discriminate" by targeting the population who can benefit from the treatment. But consider some procedures that disabled children often face: gastrostomy tubes for feeding, spinal fusions for scoliosis, and tendon releases for spasticity. All may also be carried out on children not otherwise disabled, or they address a specific medical disorder, not a class of persons per se. Some, like gastrostomy tubes, may be more frequently administered to those with impaired cognitive function, but only because the impairment is often coupled with difficulty swallowing and ingesting food. Severe cognitive disability is not an *indicator* for these or for any other procedure. But the majority of the working group believe that profound cognitive disability is a necessary and sufficient justification for growth attenuation.

Growth attenuation, which neither cures nor mitigates the impairment, aims to facilitate the difficulties in care and yet is not to be administered to others with equally challenging care. One putative reason is that these children alone will never be in social situations where its effects will be noticeable to others. However, a potentially six foot tall and sometimes violent autistic boy treated with growth attenuation might lose even a foot in height without the difference being very noticeable to others, and the difference might benefit him by making him less threatening.

Another reason cited is that less severely disabled children treated with growth attenuation might come to resent their parents. Yet we know little of what people with severe cognitive disabilities can comprehend. If a person with these disabilities resented the treatment, we would not know. And the wrong done to her would be multiplied, as she would have no way to make her grievance known.

The real supposition underlying the restriction is that severely cognitively disabled people will never know the difference—even though we cannot be sure this is true. And with that supposition, what else might we be able to do to this population? The long and gruesome history of abuses done to people with severe cognitive disabilities includes a litany of similar claims—that they won't know the difference if a part of their brain is lobotomized, if they are deprived of clothing, if they are showered communally by being hosed down. Yet we have learned that once we stop supposing that they don't know the difference anyway, we learn how often they understood the treatment as mistreatment.

The Pandora's Box of horrors is opened still again when severe cognitive disability is the lone and sole indicator for a certain treatment. The shame of it is made that much worse when some turn out to be cognizant of their mistreatment. The risk that these demons will reemerge is too great for the procedure to be acceptable.

—Eva Feder Kittay

First, permitting growth attenuation for these children opens a door to its incremental expansion to all families who believe the practice would benefit them. Second, applying growth attenuation exclusively to the most profoundly disabled children appears discriminatory, and singling out these children represents a further erosion of the hard-won ground gained in their fight for justice.[26]

At least for now, most in our working group would prefer to limit growth attenuation to the very small group of profoundly developmentally disabled children. Insisting on such limitations may appear

discriminatory, since it means treating children with different kinds or levels of disability differently, but the distinction is not intended to represent a veiled discrimination against such children. The idea, rather, is that children with vastly different medical and social needs may require different options.[27] Their needs may justify interventions that would not be appropriate for others. The benefits associated with growth attenuation may improve their quality of life and promote the family's flourishing. Our group was also concerned that children with more expansive abilities and self-awareness might come to resent their parents' decision. While we were not convinced that children with greater intellectual capacities would in fact resent their parents' choice, we believe the possibility of such resentment warrants a conservative stance in eligibility criteria.

We acknowledge the possibility of "slippery slopes" leading both toward making growth attenuation available to other populations and toward mistreatment of the most profoundly disabled children. However, most in our group believe that appropriate safeguards, such as clear selection criteria and a careful oversight process, can address these concerns. With these caveats, the potential for expansion to other populations is not so great as to override the present benefits sought by parents. We appreciate that further experience, research, scholarship, and advocacy may result in decisions not to provide this at all—or conversely, to offer it somewhat more broadly.

Children's Interests

Impact of short stature on children with profound developmental disabilities. The primary benefits sought by short stature resulting from growth attenuation relate to facilitating increased involvement in a family's social and recreational activities that relate to mobility, such as family trips to the beach, snow sledding, or going down a slide at the park, where lifts are not available. These potentially enhanced social interactions with the family, facilitated by short stature, may be more significant to families than "easing the burden" of daily caregiving (moving, dressing, personal hygiene, and so on). Of course, even large adults with profound developmental disabilities can participate in some of these activities, particularly if caregivers have training in methods of transfer and mechanical assistance (hoists, lifts, braces, and seating systems), or have more people assisting. However, these resources (both in and out of the home) are not uniformly available, and their use can pose financial burdens on families. Thus, while short stature is not necessary to achieve the goals of increased mobility and participation in family activities, it may prove to be a helpful option.

Our group discussed a potential risk relating to stigma, such as looking *very* unusual to the typical observer because of extreme short stature.[28] However, it is not clear that the modest short stature resulting from growth attenuation would add more stigma than would already be present for a child or an adult with profound developmental disabilities. Further, there is little evidence supporting the long-held notion that short stature itself leads to stigma in children without disabilities.[29] Finally, it is not clear that a "standing" height of between four and five feet would be apparent to a casual observer of a person in a wheelchair.

Interventions for growth attenuation: Commissions and omissions. The use of estrogen to attenuate growth has been studied in healthy adolescent females, and few serious adverse effects were reported. However, there are limited clinical data about its efficacy and risks in the population of children with profound disabilities.[30] While there are physical risks, such as blood clots, associated with using high-dose estrogen over one to two years, these are qualitatively not much different from the risks of using hormones over decades for menstrual control.[31]

Growth attenuation might benefit the parents at the child's expense. Parental interests are not necessarily incongruent with the child's well-being, however. More often than not, the interests of parents and children coincide, and in many cases those interests are intertwined.

Is there an ethical difference, for a parent, between *forgoing* an intervention that will result in her child only reaching an ultimate height of four-and-a-half feet and *administering* estrogen to achieve the same height?[32] Many children with profound developmental disabilities have related conditions that limit growth and contribute to short stature. Pituitary dysfunction can result in growth hormone deficiency or early onset of puberty, both of which can lead to short stature. Feeding difficulties can result in growth attenuation when caloric needs are not met. Sleep apnea, either from poor muscle tone that results in airway obstruction or because of poor neurological control of breathing, can also limit growth. Medical interventions exist to ameliorate the negative effects of all of these conditions. Many of these interventions have associated risks that must be balanced against their potential benefits. Parents are usually given significant discretion in forgoing other treatments that may result in growth attenuation, such as allowing precocious puberty to progress, refusing a

Against "Fixing" a Child—A Parent's View

It is difficult to care for a son who is legally blind, quadriplegic, nonverbal, autistic, profoundly intellectually disabled, prone to seizures and sleep disturbances, six feet tall, and 190 pounds. Heck, if you put it that way, it sounds impossible. Just to be clear: he has a good life, friends, and interests. He is loved. At twenty-eight, he is no longer a child. He is a man with a lot of support needs.

We would never allow our son to be placed in an institution. Institutional placement of children or adults with profound disabilities—being shut away from the community, rather than engaged with it—is no longer considered an option in civilized places. Fortunately, family support and home- and community-based supports for adults offer modern alternatives. Family support—services whose aim is to help families nurture and enjoy their disabled child at home—helped us learn to let go and gave us information about raising a severely disabled child: how to position him so he could participate in a broad range of activities, how to transfer him without lifting, how to support his mobility and find useful equipment, how to include him in everything, how to figure out what he wanted, how to think about his rights.

Home- and community-based supports are services offered to adults in places other than a family home, as the person's needs and the family's situation (and age) dictate. Last month, Charlie moved to a house (not a group home) with two roommates and staff. His community support workers are great. They support him; they do not control him. They are well trained, well supervised, and well managed. They are dedicated, friendly, and respectful.

The pressure to "fix" a child with a disability or to "intervene" weighs heavily on some families, especially absent family support. The Internet is full of quackery and the promise of "cure." Expert advisers—even highly skilled professionals and officers of the court—may see our need for hope as a need to pursue radical interventions. Sometimes the interventions are medical or surgical, and sometimes they are all-day programs that have the unintended consequence of using up all the time our child needs for play. We are always at risk of making our child feel we are dissatisfied with him just as he is.

Growth attenuation should be out of bounds unless it treats an underlying disorder. The human rights of the child as a person with disability should limit parental rights. Some good questions for parents to ask themselves are:

What would I do if my child did not have disabilities? Parents (and physicians) of children with disabilities do not always understand disability policy and culture. Interventions such as growth attenuation that are allowed only when a person has profound intellectual disabilities are especially difficult to justify.

Do I know what my child wants or will want? Is there a supported decision-making process that gives me more to go on than my own interpretations? Who is protecting my child's rights? Decisions that are made behind a parental privacy shield can be too easy for our own good.

Does my decision affect my child into her adult years? Can she grow out of or undo my action later, if she chooses? Parents are almost always out of bounds when we base our decisions on the idea that we will *always* be responsible for our disabled child. If we project a false lifelong private "burden," we will likely fail at our basic responsibility of helping our child grow up.

Am I driven by my own pride or ego? We are often put on the defensive about our sons' and daughters' dependence on public support. But support of vulnerable people is almost always recognized as a legitimate activity of government. It is easier to overcome the shame of public dependence when you try to be public-spirited. Disabled people, too, can live simply so that others may simply live.

—*Sue Swenson*

surgically implanted feeding (gastrostomy) tube, and refusing continuous positive airway pressure (CPAP) or a tonsillectomy for sleep apnea.

When short stature occurs because parents choose *not* to use a feeding tube, a CPAP machine, a tonsillectomy, or growth hormone, they may fail to see themselves as a primary cause of the child's short stature. However, though commission and omission may feel somewhat different to parents and providers, their connections with moral responsibility are notoriously difficult to parse.[33] The distinction may actually reflect an incompletely articulated concern of another sort—that medical interventions should not be used to move someone away from a "norm." It is important to note, however, that many medical interventions move someone away from the norm in some respect but are ultimately justified by some benefit that compensates for the potential risks and resulting variation from the norm.

These benefits may be physical, psychosocial, or both, and the balancing can be subjective and variable. For example, feeding tubes are used to facilitate feeding in people for whom feeding by mouth might take more time than the caregiver can spend, or to reduce the risk of recurrent pneumonia even when

sufficient time is spent. Some parents (and competent adults) choose not to use a feeding tube because of how it changes the child's appearance and the symbolism it evokes of not being able to provide nourishment naturally.[34] These parents are willing to risk pneumonia and the inconvenience of outpatient visits or hospitalizations. Adults making decisions about their own care are typically permitted considerable discretion, in recognition of the fact that their decisions depend on subjective preferences about quality of life and their views about appearance and medical technology, and parents making decisions on behalf of their children are given similar leeway. In developmentally typical children, parents are permitted to make decisions for tonsillectomy for sleep apnea even though the benefit of improved cognitive function and school performance has yet to be firmly established.[35]

Identity and bodily integrity. Growth attenuation is problematic for some because it compromises bodily integrity, failing to respect the person "as she is," which should never be permissible.[36] However, the concept of bodily integrity has the same limitations as the distinction between the artificial and the natural.[37] Just as it is not always wrong to use artificial approaches to treat cancer, it is not always wrong to "change" someone. Yet bodily alterations may raise concerns about undermining an individual's identity for those who believe that a person's identity is partly defined by her physical attributes. Of course, determining what qualifies as central to identity proves difficult. For some, growth attenuation will inhibit natural flourishing, and for others, it will enhance personal flourishing within the family. The difficulties of making these determinations are exacerbated when the individuals affected cannot assert their own interpretation of identity.

Labeling an intervention as "identity changing" is not dispositive, in any event. Inserting plastic tubing into surgically created orifices, as is done in a tracheostomy or gastrostomy, is arguably a dramatic change in identity. These interventions are sometimes justified by a quality-of-life benefit, even though they carry greater physical and social risks than growth attenuation. Male circumcision is considered by some as identity changing, or defining, and in the United States, its benefits and risks are primarily psychosocial. Yet parents are given discretion in making this decision for their children, despite others' concerns that parents should not make decisions that could be deferred until the child is older. While some parents might object to growth attenuation, a gastrostomy tube, or circumcision as identity changing, other parents believe the benefits outweigh the potential physical or social risks.

Dignity and respect. In both our working group and in the broader public discourse, there was never a question that profoundly disabled children have dignity and are owed respect and support, despite the difficulty in deciding on one formal definition of dignity.[38] However, it is less clear what respect for dignity requires. Does growth attenuation support or pose an affront to the child's dignity? Some families believe that growth attenuation poses an affront to a child's dignity by treating her as if she is in need of "fixing." Others believe it promotes the child's dignity by helping her to flourish and to foster social connections in her particular familial context. We take seriously the concerns raised about how to best respect the dignity of children with profound disabilities. However, because dignity and respect can be employed in arguments both supporting and opposing growth attenuation, the majority in our working group believes the issue of dignity should not trump other ethical considerations.

Certainty and permanence. Our working group considered the accuracy of the prognosis of permanent profound developmental disability. If an individual may develop greater self-awareness and interactional ability, we would be less confident about proceeding with an irreversible alteration to the person's body, as he might later wish it had not been done. Communication difficulties can make cognitive function difficult to assess accurately.[39] It is therefore important for clinicians to conduct a series of developmental evaluations over several years, to pay particular attention to verbal and nonverbal communication, and to involve skilled speech therapists, early childhood educators, and family members in the evaluations. Certainty about developmental impairment will increase with the passage of time.

A decision of this significance should be made with a realistic view of the likely benefits and risks of the intervention and of the alternatives. Clearing up misconceptions should not be interpreted as disrespect for parental choices.

Neurologic conditions that are unquestionably degenerative—such as Tay-Sachs, Trisomy 13, or Leigh's Encephalopathy—are a different matter; we concluded that growth attenuation would not be problematic for children who have these conditions and therefore have permanent and profound developmental problems. Many parents choose not to treat infections or not to use clinical approaches to managing airway secretions, such as a tracheostomy. In fact, Tay-Sachs is often described as lethal or fatal, but such descriptions are typically related to choices that parents are permitted to make about forgoing interventions.[40] Suppose parents request ongoing clinical interventions,

In Support of the "Ashley Treatment"—A Parent's View

I have a beautiful fifteen-year-old daughter. Jessica is nonverbal, quadriplegic, fed through a gastrostomy tube, and requires assistance with all activities of daily living. She has very discriminating tastes in music (preferring Barney the dinosaur over Kermit the frog), loves dancing and wild rides, in her wheelchair or anywhere else we manage to get her, and has a smile that could end all wars.

Jessica is around five feet and one inch in height, and she weighs about eighty-five pounds. During the past few years, as she has gone through puberty and an incredible growth spurt, life has changed considerably for her and for our family. We are no longer able to take her out to many of her favorite places and activities, and our ability to travel with her—by car or air—has also been limited. Until she was around four feet tall, she used to be able to ride on her father's shoulders. This allowed her passage to many places where it was difficult to carry her or to take the chair: the beach, through the snow for that wild sled ride down the hill, and even up the stairs of our friends' inaccessible homes. At her present size, this is no longer possible. Her height and weight, her parents' aging bodies, and the development of knee-flexion contractures (which have deprived her of the ability to bear weight and limited her comfort time in the wheelchair) have greatly limited her life experiences. She can no longer assist with transfers, stand or dance with Barney in front of the television, jump on the trampoline, zoom down the slide, or be supported in the swing at the local park. Getting her in and out of the pool is also no longer possible for me. We installed a manual lift in our home and Jessica tolerates this quite well, but lifts can be used only where they are available (in our case, at home and school), and they do not provide access to any of the recreational activities she enjoys. Diaper changes and positional changes at night also cannot be managed by a lift, and they, too, have become increasingly difficult with her increased size and spasticity.

These are problems that no amount of resources could solve. And in reality, not only are these "resources" not readily available, but many of them do not work for a child like Jessica. Those who call for "more resources" to solve these problems do not fully understand my daughter's needs or my desire not only to keep Jessica comfortable and healthy, but also to save her from boredom and seclusion. The "Ashley Treatment" was not a last-ditch effort born of desperation and despair. It was a creative solution born of a deep-seated love for a child whose opportunities for familial and social interaction are already limited by size and mobility issues.

When Ashley's story became public, I was surprised by the reaction of those who identify themselves as "advocates" of persons with disabilities and their families. They spoke of the "perspective of the disability community," as though Ashley and her family were not a part of it. I felt disenfranchised by the very organizations and individuals that were put into place to protect Jessica and our family. I also found that many of those speaking out against growth attenuation did not understand the enormous physical implications and limitations of children as involved as Jessica. We also have a twelve-year-old daughter with Down syndrome, and although she has her own set of needs and limitations, the absence of severe physical limitations makes a huge difference with respect to her life experiences and daily living needs.

Raising children is a personal journey we all embark upon from different locations. We begin with different presuppositions, different ideals, different hopes and dreams, different resources, and different destinations in mind. In the bigger picture, I believe the opposition to the Ashley Treatment has taken our society a step backward in what has been a positive attempt in recent years by the medical community to allow parents to make some of the difficult decisions regarding their children's care. Personalized medical care should allow individual families to make informed decisions within the medical and moral boundaries that are found in the hospitals they frequent.

—Sandy Walker

including antibiotics, tracheostomy, and mechanical ventilation, and also request growth attenuation because it will assist them in caring for their child. If withdrawing life-sustaining interventions from a child with Tay-Sachs disease is not problematic, using growth attenuation to promote the same child's quality of life should not be particularly controversial.

Shared Decision-Making

Respect for parental decision-making about medical care. Parents are presumed to be best situated to make good decisions on behalf of their children: they are most familiar with their children's needs and preferences and are intimately affected by medical interventions. Nowhere is this point more salient than in the care of children with chronic medical conditions, and particularly the care of children with profound disabilities. Parents often provide complex care at home, including feeding tube and tracheostomy management, and many providers consider parents integral members of the medical team—close partners providing health care. This partnership sometimes means that providers make decisions out of

respect for parental preferences even when they have concerns about the decision.

One concern relates to parents' and family members' motivations. A request for growth attenuation might actually reflect the parents' desire to ease their own burden rather than support the child's interests. Indeed, growth attenuation might benefit the parents at the child's expense. Parental interests are not necessarily incongruent with the child's well-being, however. More often than not, the interests of parents and children coincide, and in many cases those interests are intertwined.[41] Both parents and children may enjoy the child's increased participation in family activities as a potential result of growth attenuation.

Further, the presumption that parents must always sacrifice their own interests for the sake of the child is, practically speaking, untenable and disrespectful of the parents.[42] Often enough, parents properly make decisions that balance the interests of many family members.[43] For example, a parent's decision to relocate for a new job may benefit the child if the new job offers financial and social benefits for the family, even if the move will burden the child. While accommodating the interests of the child might be preferable, it does not follow that the child's interests must always be paramount.[44]

Clinicians' role. Clinicians have a responsibility to engage parents about their decisions for medical procedures such as growth attenuation. All parents make decisions on behalf of their children, and most appreciate that, as their children mature, these decisions should be informed by the child's preferences. Providers often help parents identify decisions that can be deferred until the child is capable of choosing for herself. This can be particularly important for value-dependent, irreversible health care decisions like growth attenuation. If the evidence indicates that a child will never be able to participate in medical decision-making, there is no good reason to defer decisions to a later date. Decisions must be based on balancing the best available information and opinions.

According to deliberative models of the doctor-patient relationship, clinicians should actively engage the patient in discussion rather than simply disclose information for their independent consideration.[45] If the patient is a child, then it is the parents who ought to be engaged in discussion. But engaging parents as partners may mean a variety of things: it may mean challenging the parents' reasons, sharing the provider's own clinical and ethical opinions, making recommendations, exploring options that the provider might not deem optimal, and sometimes refusing parental requests.[46] Some physicians who believe that growth attenuation is not ethically appropriate might still be willing to provide it after an in-depth conversation with the parents. Those with more skeptical views might choose to refer parents to providers who would be more willing to accommodate such a request—an appropriate appeal to conscientious objection.[47]

Exploring the reasons parents request growth attenuation is important for several reasons. Most obviously, the parents might have an unrealistic view of its clinical impact. Also, the request may represent an attempt to exercise control in a setting otherwise filled with uncertainty and feelings of powerlessness. A decision of this significance should be made with a realistic view of the likely benefits and risks of the intervention and of the alternatives. Clearing up misconceptions should not be interpreted as disrespect for parental choices. Rather, respecting parental decision-making requires a reasonable effort to ensure that parents' choices reflect an adequate understanding of the issues involved and are not based on misperceptions or unreasonable expectations.

Clinicians must give parents information about growth attenuation's anticipated benefits and risks to the child, and about alternative means (through medical technology and human assistance) of including a child in the family's social and recreational activities.[48] Some of the benefits and risks of growth attenuation are either unknown or debatable, making balanced information challenging to provide. An enthusiastic provider might overstate the benefits and minimize the risks, while a skeptical provider might minimize the benefits and overstate the risks. The working group agreed that parents should be given the opportunity to talk with other parents of profoundly disabled children in order to dispel any myths or assumptions about what life with a maturing child with profound developmental disabilities would be like. In particular, parents who have older children with profound disabilities can share how they have adjusted or adapted to life with medical equipment, home health aides, personal assistant services, and the like. Further, while in-home trials of mechanical devices and personal assistance services may not always be feasible, they might be very useful in decision-making. Some parents may find the prospect of lifts or paid staff more unappealing before they have used them than after they have had some experience with them.

Parents should also be made aware of the objections to growth attenuation expressed by organizations and individual members of disability communities. This can be accomplished by providing parents who are considering growth attenuation with information summarizing arguments for and against this controversial intervention, or by offering them copies of relevant publications. Such materials might describe the experiences of people in the disability community, as well as the experiences of parents who have used growth attenuation and found it beneficial.

Safeguards and Oversight

Decisions about growth attenuation are similar to many other

decisions parents make for children with profound disabilities, yet they are less weighty than decisions affecting life and death, such as do-not-resuscitate orders or decisions not to treat pneumonia. Nonetheless, our working group believes safeguards are desirable when growth attenuation is considered, given the intervention's novelty, the limited data about its benefits and risks, the potential for misuse, and the importance of expressing respect for those with disabilities who are opposed to the intervention.

The decision-making process should begin with a competent evaluation of the likely etiology and prognosis of the child's developmental level and prospects for improvement. General pediatricians, specialists in developmental disabilities, pediatric neurologists, and speech-language pathologists play a critical role in these assessments. Consultation with a pediatric endocrinologist is desirable since growth attenuation involves medically complex issues; pediatric endocrinologists can help gauge the prospects for growth with or without intervention, determine the proper dose and duration of hormones, and monitor the child for adverse effects. Finally, it is crucial to assess whether growth attenuation is a suitable option for the *family*, given their reasons for requesting it and their understanding of the procedure and alternatives to it.

More controversial is whether the assessment requires the involvement of ethics consultants or committees, institutional review boards, or the courts. One concern about any of these safeguards is whether they will ensure adequate representation of the child's interests—a point that most concerns individuals for whom growth attenuation is abhorrent. The use of a guardian ad litem and review by a judge has been suggested as one way to accomplish this. This approach is used for decisions about sterilization in many states, but not for most clinical decisions in such children.

Turning to the courts is sometimes appropriate for cases that involve novel and profound issues. The judicial system can set publicly articulated boundaries for family decision-making and is designed to make decisions about complex issues of individual rights. Landmark court cases involving the withdrawal of life-sustaining treatment in developmentally disabled individuals have provided a framework for considering such decisions in the clinical setting.[49] However, courts may also reach idiosyncratic opinions, and they make decisions that do not further public debate but rather confound it.[50] While guardians and judges might seem to offer greater impartiality, they may lack direct, prolonged engagement with the family—a limitation that can reduce the decision's quality. Courts have historically preferred that critical decisions like withdrawing life-sustaining therapies be made by families, providers, and consultants.[51]

Ethics consultation services and committees are accustomed to dealing with ethical dilemmas, and they are practiced in constructively addressing differences between institutions', providers', and patients' (or families') values, preferences, and interests. While ethics committees have traditionally sought a diverse membership with a range of disciplinary perspectives, they do not always include members who have experience with the challenges of raising a child with profound disabilities and including that child in family and community life. This perspective is important because health care professionals' experience with disabilities is sometimes limited to the medical setting. Knowledge about the experience of family life for children with profound cognitive disabilities is particularly important. When ethics committees lack individuals with the pertinent expertise and experience, it is advisable to use ad hoc consultants.[52]

Growth attenuation continues to occur under the radar and outside of a research context, partly because of the intense public reaction to the Ashley case. That case was not reviewed by an IRB because growth attenuation was being provided as an innovative intervention rather than as a research project intended to generate knowledge. Nevertheless, we see at least two reasons to encourage providers to consider offering growth attenuation in a research context. First, a well-defined intervention and a prospective longitudinal assessment of outcomes and adverse effects provide better opportunities for others to learn from the experience. Second, conceiving of this as research offers the opportunity for another source of oversight (from the IRB), which might serve as a useful safeguard (as it can for any innovation). At a minimum, we recommend creating a registry to document the clinical and outcomes data, as well as the social impact on children who have undergone growth attenuation and its effects on family members. Ideally, a prospective study of children from across the country, using a standardized protocol and standardized assessments of physical and psychosocial outcomes, is worthwhile.

Toward Compromise

By examining the impact of growth attenuation on children, families, and community, we navigate a complex terrain of issues and concerns. For those who believe growth attenuation is valuable, we articulate the reasons others find it problematic. For those who believe it is always wrong, we explain why others believe it can be justified. Those who hold either view—at least in our working group—are united in their commitment to improving the lives of children with profound disabilities and the families who raise them.

We reached a moral compromise rather than a consensus. The compromise left some of us dissatisfied, and even distressed, because it was a less-than-desirable position given our convictions. However, it arises out of respect both for those concerned about growth attenuation's negative

effect on children and others living with disabilities, and those who believe that it may benefit children with profound disabilities and their families. The majority of our group reached this compromise position: growth attenuation can be an ethically acceptable decision because the benefits and risks are similar to those associated with other decisions that parents make for their profoundly disabled children and about which reasonable people disagree. But clinicians and institutions should not provide growth attenuation simply because parents request it. It is important to have safeguards in place, such as eligibility criteria, a thorough decision-making process, and the involvement of ethics consultants or committees.

The implications of growth attenuation are unique for children who are nonambulatory and have persistent, profound developmental disabilities. In this context, growth attenuation is one of several means to try to include such children in family life and improve their quality of life. Based on the limited data about the clinical and social benefits and risks, most in our working group believe that requests for growth attenuation in young children who are ambulatory or communicative (children with autism or muscular dystrophy, for example) are not appropriate at this time.

Engaging the issues about growth attenuation sheds light on the experiences of children and adults with profound disabilities and their families. It is clear that these families need greater social support. To date, there has been insufficient public discussion about how to provide that support and improve the lives of people with profound disabilities. Further, the issues facing this population have not been a primary focus for many health care professionals. We hope that engaging in questions and discussions about growth attenuation will, if nothing else, enhance public and professional awareness about children with profound disabilities and garner a greater appreciation for the value of these most dependent members of our society.

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