Respecting Children with Disabilities—and Their Parents

BY ERIK PARENS

In 2004, the parents of six-year-old Ashley, who has profound cognitive disabilities, asked Seattle Children’s Hospital to provide three unusual procedures that aimed, not at treating an illness, but at improving the child’s and her parents’ quality of life. The parents argued that by attenuating Ashley’s growth with high-dose estrogen, they would keep her easy to lift and move, and thus readily integrated into their loving family life. By removing Ashley’s uterus, they would spare her the distress associated with monthly bleeding that girls with cognitive disabilities can experience especially intensely, as well as remove the possibility of impregnation by a sexual predator. And by removing her breast buds, they would reduce the chances of breast cancer, which runs in the family, and minimize discomfort from the harness needed to lift her in and out of bed.1

The Ashley case prompted heated debate about acceding to parental requests for medical treatment to cope with non-medical problems. The parents argued that by attenuating Ashley’s growth with high-dose estrogen, they would keep her easy to lift and move, and thus readily integrated into their loving family life. By removing Ashley’s uterus, they would spare her the distress associated with monthly bleeding that girls with cognitive disabilities can experience especially intensely, as well as remove the possibility of impregnation by a sexual predator. And by removing her breast buds, they would reduce the chances of breast cancer, which runs in the family, and minimize discomfort from the harness needed to lift her in and out of bed.1

Refusing and Requesting Interventions

Over the years, many of the people I have spoken with have said things much like what therapist and disability rights activist Harilyn Rousso said when she described growing up with multiple physical disabilities:

[My mother] made numerous attempts over the years of my childhood to have me go for physical therapy and to practice walking more “normally” at home. I vehemently refused all her efforts. . . . My disability, with my different walk and talk and my involuntary movements, having been with me all of my life, was part of me, part of my identity. With these disability features, I felt complete and whole. My mother’s attempt to change my walk, strange as it may seem, felt like an assault on myself, an incomplete acceptance of all of me, an attempt to make me over.2 (emphasis added)

Ms. Rousso argued powerfully that her disabling features were part of her identity. She was not going to change her body to reduce anyone else’s discomfort.

I am not proud to confess that when I first heard people with disabilities say such things, I practiced some armchair psychoanalysis: “Yes, yes, that’s very nice. You say that the problem is social responses to your disability, not your disability. But let’s be honest; you’re in denial.” The more I heard people like Ms. Rousso say that the most difficult thing about having a disability was the way temporarily able-bodied people like me treated them, however, the more I began to take them at their word. I became convinced that if, after a process of truly informed decision-making, someone with a disability refuses the use of medical means to improve her social experience, then there is no good alternative to respecting her decision, no matter how surprising I might find it.

Frankly, however, showing respect in this way didn’t turn out to be a stretch. I love the idea of learning to let healthy bodies be. I’m naturally inclined to prefer changing minds with words to changing bodies with scalpels. Using social means like words requires us to engage each other and reminds us that we are the sort of animals whose minds can change with the giving and taking of reasons. As wonderfully efficient as they can be, medical means can emphasize our growing understanding of ourselves as mechanisms to be fixed.

The real challenge was listening to children like an elementary-school-age girl I’ll call Isabelle, deciding whether to have surgery to make her face look more normal:

I want to [have surgery] because I don’t want to look so different that people stare or think that I have a developmental problem. . . . I still want to look like me and I was afraid the surgery would change who I was. . . . My mom told me it didn’t matter if I decided to have the surgery or not. She said what I looked like on the outside could never change the person I am on the inside. That made me feel better. . . . [But the surgery] will make it easier for people to get to know me instead of just looking at my outside.3

Parents’ Truly Informed Decision-Making

Respecting parents does not mean thoughtlessly acceding to their wishes. It means asking them hard questions, engaging them in a process of becoming truly informed.

Before listening to children confronting decisions about appearance-normalizing surgeries, I was tempted to apply a bit of Marxist analysis to interpret decisions like Isabelle’s: “Yes, yes, you say that you want surgery, but you’re suffering from ‘false consciousness.’ You don’t really want a surgery that will reinforce an unjust norm.” I have, to some extent, gotten over this response. As conceptually convenient as it would be to say that we should never use medical means to respond to social difficulties, that approach would hurt some of the very people it is intended to help.

So I have made an uneasy peace with cases where a competent person, after a process of truly informed decision-making, either refuses or requests a medical intervention to cope with a social problem. Clearly, the situation is far more complicated when the person who would be directly affected has a profound cognitive disability that thwarts her ability to form, much less articulate, a view about what would promote her flourishing. In such cases, there is no good alternative to respecting parents’ truly informed decisions. They are better situated than anyone else to grasp what is best for their child and family.

But respecting parents does not mean thoughtlessly acceding to their wishes. It means asking them hard questions, engaging them in a process of becoming truly informed. What are the nonmedical alternatives? What are the costs associated with using medical versus nonmedical means? And one of the hardest questions that parents can be helped to explore: Have you gotten beyond thinking of your child as an extension of yourselves, to thinking of her as an individual?

Most parents from time to time view their children as extensions of themselves. This attitude is not always bad; it can motivate parents to promote their children’s interests. But it can also blind them to the distinction between their children’s interests and their own. The tendency to see our children as extensions of ourselves may be especially common among parents of children with profound disabilities, perhaps because their children are so dependent on them—and because some parents can come to depend on their child’s dependency. Indeed, there is an exceedingly difficult empirical question: How much do we know about what the body of a person with profound cognitive disabilities means to her?

Eva and Jeffrey Kittay offer some insight based on their daughter Sesha, who is now in her thirties, and who, like Ash-ley, has profound cognitive and physical impairments. Writing in Bioethics Forum, the Kittays said that when she was very young, Sesha loved children’s songs; as a teen she took pleasure in Elvis Presley’s “Love Me Tender”; and as an adult she enjoys symphonic music, especially Beethoven. Sesha’s taste in music changed as her body changed from childhood to adolescence, and from adolescence to adulthood. Sesha’s changing embodiment has mattered to her. Parents of a child with profound cognitive disabilities should be helped to understand that phrases like “the mind of a six-month-old” can obscure the possibility that their child’s bodily development will matter to her in subtle and unforeseen ways.

They can learn from the Kittays and from myriad other people with first-hand knowledge of what life with a particular disability really is—and is not—like. Though people are inevitably affected by changes to their bodies, it does not follow that all people care about those changes. If parents believe that their child’s developing body does not matter to her, then it would seem to make little difference if they use medical means to curtail its growth to keep her at home, or if they use lifts and additional caretakers. However, if the evidence shows that the child’s body does matter to her, then there would be reason for the parents not to use the medical procedure. The reason to decline wouldn’t be that the procedure is medical, though, but that it could diminish the child’s experience.

At the beginning of the day, we show respect to persons with disabilities and their parents by asking them questions. Only if the questions challenge parental assumptions can the decision be truly informed. Of course, informed decision-making does not ensure wise decisions. But there is no good alternative to allowing the people who will experience the burdens and benefits of the decision to decide. At the end of the day, respecting people with disabilities and respecting their parents requires us to take them at their word, even if they decide to use medical means to achieve a social purpose.

References

1. This bundle of interventions was described in detail at the University of Washington’s May 16, 2007, Growth Attenuation Symposium.
3. Used with the speaker’s permission. Provided by Cassandra Aspinall, a social worker at Seattle Children’s Hospital, who works with children with craniofacial differences.