The preceding chapters in Part II focus on an organizational level. In this chapter and the next, we move to focus more on the experiences and perspectives of parents. Whereas Chapter 6 examines the ways in which organizations frame disability activism, in this chapter we examine how parent activists frame their activism and in particular how they understand the idea of “disability rights.” We first look at some of the broadest and most common uses of the term “rights” and then consider more controversial uses of the idea.

Parents may frame disability as a tragedy, a medical condition, a moral dilemma, or an issue of discrimination and rights, but what parent activists tend to agree on is the host of unmet needs they face. Need, rather than rights, is the common denominator across parent narratives. According to the Arc, “There are currently over 500,000 people with disabilities on waiting lists for home and community-based long term services and supports. The wait can be as long as 8–10 years in some states. This crisis results in unnecessary, unwanted, and costly institutional care; the desires of people with I/DD [intellectual and developmental disabilities] to live in and be a part of the community being denied; family members being forced to quit jobs or take on second jobs to help care for their loved one; and having to leave their loved ones unattended.” According to Mental Health America, in 2014 “56.5 percent of adults with a mental health illness received no treatment.” And according to a National Alliance on Mental Illness (NAMI) report, when they do receive treatment, they are faced with a system that is
“currently regulated and funded in ways that often pressure front line staff to adhere to procedures, time frames and reporting requirements. Many staff have unrealistically high caseloads that do not leave room for the discretion and time needed to employ the art and science of healing.”3 An impersonal and demeaning system pushes people away from the support they need. As explained by a NAMI parent:

My son’s first [mental] break was when he was most open to the idea of engagement. He was scared and didn’t know what was going on. He voluntarily went to see a psychiatrist, but the manner in which he was treated really closed the door at that opportune moment. The psychiatrist was proud of being the kind of doctor who tells it like it is. He told my son, “you have a mental illness and are going to be on medications for the rest of your life. They’ll probably cause you to gain significant weight, and you probably won’t be able to work in a regular job. If you don’t take the medications, you are going to end up homeless, in jail or dead.” My son’s reaction was to reject that and to close the door on treatment.4

While the quality of care and supports in the community today is undoubtedly better than that available in the community or institutional settings in the 1970s, grave concerns remain. Direct care staff who work with people with disabilities in the community too often live in poverty. Service providers typically only require direct care staff to have a high school degree and perhaps a driver’s license; many positions are part-time without benefits; and training is minimal and largely on-the-job. Not surprisingly, staff turnover is high. Trained social workers find that they can make more money working within the criminal justice or nursing home industry or doing administrative work rather than offering direct care to people with disabilities in the community. Trained medical professionals in the community may refuse to treat people with disabilities or people on Medicaid because it is time consuming, poses risks, and reimburses poorly.

Thus, many people with disabilities and their families do not have the level or quality of supports and services that they need to thrive in the community. Across disability groups, it should not be surprising that parent activism is centered on addressing the extensive unmet needs. Some of the most common areas are education, lifelong residential supports, work, and access to medical care and appropriate treatment. While the needs are clear, parents disagree on the appropriate way to address these unmet needs.

Education offers a vivid example, both of unmet needs and varied responses. In one example, the parents of a seven-year-old with Down syndrome sought an inclusive education for their son and eventually sued their
school district to attain it. They described the following treatment: “In court, my heart broke as Liam’s aide testified that he was once forced to stand outside in the rain because he wasn’t welcome in class. She said that he was ultimately put in a trailer behind the school, away from credentialed teachers and isolated from his peers for the majority of the day.” Although they won their case, months later they still were in battle with the school district. According to Liam’s parents, the school had not yet implemented accommodations or provided Liam with an aide. They wrote, “His rights are completely being ignored. This tactic is referred to as ‘delay and deny.’ It is a way to not give the child what they need and drain the family’s financial resources so they eventually have to give up. . . . It’s incredibly abusive.” The family resorted to an online petition and social media to raise awareness of their plight.

In a second example, an interviewee, Yvonne, uses the idea of rights to fight to maintain her son’s enrollment at a large, disability-specific school that was slated to be closed in order to integrate children with disabilities into the public school. Yvonne described her son as a child with profound intellectual disabilities, frequent seizures, and medical complications, who is difficult to feed, throws up several times per day, and cries frequently. As a result of this combination of conditions and behaviors, she states, “he was like this time-bomb, going off all the time, and it was really difficult.” Public school programs did not want to serve him, and even a school for orthopedically disabled children “didn’t want him because he cried all the time and he obviously wasn’t learning his ABCs.” Yvonne found a center-based educational program with two hundred or more children in special education. Her son was placed in a classroom with children with multiple disabilities. “It was great because everything was there that they [students with disabilities] needed. They didn’t need a nurse for instance to be constantly hovering over them, but there was always a nurse there, and occasionally something would happen where they really—they needed a nurse!” The state and disability activists wanted to close the center to increase educational integration, which from Yvonne’s perspective would only move them back into the unwelcoming and ineffective settings they had left.

Both of these parents faced a system that utterly failed to meet their child’s needs despite the Individuals with Disabilities Education Act (IDEA). One fought for inclusion, and the other fought to maintain a specialized setting. Both used the language of rights to describe their activism. Parents tend to stress their child’s needs and the ability to make choices, often among sadly unsatisfactory options, rather than an allegiance to a pure philosophical approach with regard to integration versus segregation or public versus private venue. As an interviewee, Erica, put it, “I feel that the services for people should supersede anybody’s philosophy that people
should be in a certain kind of place.” 8 Another parent, Donna, stated, “You know, we should be talking about what people need and then be determining what’s the best way for them to receive the services that they need, and that will also protect their rights.” 9

How do “rights” fit into the advocacy of parents, then? The rights frame offers several key benefits that are well recognized and used across parents: it focuses attention on issues of equity, recognizes people with disabilities as valued members of society, and provides legal mechanisms for creating and implementing change. Less commonly and in tension with some other uses, the language of rights is a tool to recognize the rights of the family and the right to family. Some families, though, criticize the way rights have been politically used, in their opinion, to subvert services and choices and to remove authority from the family. At times this criticism is used to advocate for greater integration and empowerment, while at other times it is used to advocate for disability-specific settings, protections, and family control and “choice.”

The Power of Rights

Addressing Discrimination and Creating Equity and Access

Rather than positioning rights as a personal trouble, the rights frame calls attention to the disadvantages created by an unequal and prejudiced society that creates an inferior class of citizens. This use of “rights” is common and has been useful, both personally and politically, for families across various disability groups. Mental illness, for example, is highly stigmatized in our society, and parents have found it politically powerful to reorient discussion around issues of discrimination and stigma rather than personal tragedy or failed morality. Rick Warren began speaking out about discrimination against people with mental illness after his twenty-seven-year-old son committed suicide. “If I have diabetes, there is no stigma to that,” explains Warren. He continues, “But if my brain doesn’t work, why am I supposed to be ashamed of that? It’s just another organ. People will readily admit to taking medicine for high blood pressure, but if I am taking medication for some kind of mental problem I’m having, I’m supposed to hide that.” 10 This quotation from 2014 strongly echoes parents who stated back in 1951, “You would not deny schooling and playmates to a crippled child—should they be denied to my child because it is his brain rather than his limbs that is crippled?” 11 Thus, as articulated by the rights frame, the central problem is not the disability per se but rather the stigma and structures of exclusion that prevent children from accessing the supports they need.
The rights frame focuses attention on correcting society to ensure equity. For example, parents of children with ADHD described barriers to the right to education, such as punishment in response to disability-related behaviors: “It’s discrimination when a teacher knows that your child has an IEP [individualized educational plan], has signed the IEP, and still requests that your child complete the work of his/her neurotypical peers—commenting about the lack of ability to get the work done. When a teacher knows that your child has a modification but chooses not to apply or enforce it, that’s discrimination. . . . If your child is punished for having a disability, or for not being able to keep up when they are unable to do so, they are being discriminated against.”

Parents similarly look to rights to address inequities in work, such as pay below the minimum wage. Mississippi Representative Greg Harper (R), whose son has an intellectual disability, introduced legislation to end subminimum wages and require transition plans to move people with disabilities into jobs in the community at competitive wages alongside workers without disabilities. Harper stated, “Segregated, subminimum wage work is just an expression of low expectations that instills a false sense of incapacity in individuals who could become competitively employed with proper training and support.” For that reason, he supported a law to remove the exemption that allowed employers to pay people with disabilities less than minimum wage and thereby establish a right to fair pay.

**Rights as a Broad Vision of Respect and Value**

More than addressing discrimination specifically, rights provide a broad, empowering vision, in which people with disabilities are valued and respected as full members of a community. Parents across disability groups use rights as a language to communicate the value of their children. For example, Jaclyn Barney, coordinator of Parents for Inclusive Education, stated in court testimony, “In many respects, inclusive education is a civil rights issue as it allows students to be full members of their communities and, in turn, prepares them for real world experiences.” Specific academic outcomes are important of course, but the bigger issue may be the opportunity to be a part of society. Blogging on the Department of Education website, a parent wrote, “Inclusion is not about the grades or closing the gap, it’s about belonging in society, it’s about being part of a whole, it’s about non segregation, it’s about Brown vs. Board of Education. It’s about civil rights. I find it crazy that someone would even try to take this right away from my child who has worked so hard to get what he’s getting. It can be done, I don’t care who argues with me on this subject, because I have proof that it can be
done. And he’s the first child to ever be included in our school district, so all of his teachers are green.”15

People with disabilities have a broad right to be in the community and to be disabled in the community, because they are a part of the community. Describing an expansive view of her sibling’s rights, an interviewee, Cindy, states, “My brother has the right to have a safe environment. He has the right to be out of his house and go places. He has the right to, if he chooses, to, well, throw a temper tantrum, too. He has the right to safety, he has a right to food, he has a right to housing, he has a right to proper care.”16 It’s unclear if legally all of these rights are really enforceable, yet the claim itself asserts a broad view of what it might mean to build a world that recognizes and supports her brother as a valued member of society. In contrast with this view of broad inclusion, people with disabilities are too commonly excluded and even victimized in the community. Criticizing the justification of police brutality against people with disabilities on the basis of their “strange” behavior or disability-related noncompliance (e.g., not responding to a police order because of one’s deafness or autism), parent David Perry explains that “being autistic in public isn’t a crime.”17 For Perry, people with disabilities need to know that they can be who they are—including stimming, drooling, and making noises, for example—in the community without threat of lethal force used against them.18

**Asserting Competence**

Although parents vary considerably in their assessment of their family member’s competence and the degree to which they advocate self-determination, rights are commonly used to assert competence, maximize independence, and challenge systems that deny liberty and self-determination—a necessary counterbalance to a system that long presumed the incompetence of people with disabilities. When Ryan King’s parents were told by the Washington, D.C., social service system that King had to have a guardian for him to receive services, they were shocked. The need for services, they thought, should not a priori require that the recipient be declared incompetent. King and his parents decided to fight this archaic rule. King stated, “Everyone needs a little help sometimes. . . . But just because people need a little bit of help doesn’t mean they can’t be independent.” His father agreed: “Everyone makes decisions—they make their own decisions—and Ryan is a whole person, and we want Ryan to be a whole person. If I force Ryan to do something or try to force him, I destroy his selfness.”19 His parents argued that their fight is not just about the availability of services in the present, but also about King’s future; since King is under guardianship, when his parents die the state would step in, possibly appoint a stranger as guardian, and he would
have no say over his life. This possible future was unacceptable to King and his parents.

Building self-advocacy is a crucial component to ensuring rights. Parents and parent organizations have individually and collectively supported self-advocacy in many ways. For example, one interviewee, Mark, attributed his success as a self-advocate in part to the important role played by his mother, who fostered his development as a self-advocate, traveled with him, assisted him in preparing speeches, and sometimes participated in events, especially when they were addressing families.20 Younger parents, in particular, are encouraged to consider developing self-determination skills in their children. A parent of a teenager explained, “It is important the team hear from [my daughter] and respect her opinion. It also keeps them on better behavior when she is there, but most important I want her to learn to be her own advocate and recognize when school [is] not in compliance and how in her adult life she will need to use her advocacy skills on her own.”21 On an organizational level, the Arc, United Cerebral Palsy (UCP), and NAMI serve as examples of the varied ways to support self-advocacy groups through providing office space for meetings, funding events, offering leadership training opportunities, and creating organizational avenues to hold leadership.

However, as discussed later in the chapter, parents also subvert and qualify their support for self-determination by asserting parents’ rights. Similarly, formal parent-led organizations undercut the power of self-advocacy even as they promote it (see Chapter 6).

**Rights as a Path to Implementation**

For some parents, the main appeal of rights is the effectiveness of rights as a path to implementing mandates that are defined in laws, especially for parents who are savvy about the law and how to use it. Thus, parent advocates stress the value of educating parents about their rights. Donna explains that schools and service providers will often try to avoid providing costly services, so prepared parents are a school’s “worst nightmare.”22 In a lengthy story, Yvonne remembers her introduction to activism, when she called a friend to help her prepare for her first IEP meeting:

> What she said was, “You are not getting together for a little chat. There will probably be fifteen people in the room, and they all want you to do something, and you need to be aware of that,” and she told me about getting records and reading the law and doing all of those things. And we went to that meeting, and there were at least a dozen people there, all around a table, and they had put kind of a stool at
the corner for—little stools for my husband and I to sit on, and they were going to tell us what they were planning to do with our kid. What they wanted to do was get rid of him. And it was just, you know, they read reports we had never seen before, and there were doctor’s reports that we had never talked to the doctor about. All kinds of surprises. And so at that point, I decided the person I was going to listen to was [her friend], because she really knows what’s going on. . . . She had two children with severe learning disabilities.23

Learning about the IDEA provided Yvonne and Donna a legal tool to protect their children and to demand participation in the educational process.

The establishment of laws and legal contestation regarding these laws potentially affects a broad group. Speaking about his family’s recent court victory to ensure appropriate education for their son who has autism, the father stated, “We didn’t want to pull him out of the school. We didn’t want to take them to court. We didn’t want to do any of this. But we were pushed into a corner and had to—to get what he was entitled to by law and what he needed.”24 Reacting to this court decision on a parent website, Amanda Morin, a parent of two children with IEPs, stated, “I’m thrilled, because I think it really empowers parents to feel confident when they go in the door [of an IEP meeting].”25 Not everyone has the capital required to use the court system, but a single court decision potentially creates a ripple effect for many kids with disabilities; thus, the activism related to one child can potentially affect implementation for a large number of children.

Even without formal action, laws serve as an informal threat to compel action. When his daughter was denied services and treated poorly in a public business, Harold said he threatened the establishment with a lawsuit. “The ADA is great, because everyone’s afraid of it. I wrote a letter threatening to sue, and the next week they treated [my daughter] like gold.”26 As discussed later in the chapter, though, both the use and threat of lawsuits are reliant on economic and social capital and therefore the power of the law often favors white, wealthy parents like Harold.

Rights for, of, and to Family

Although rights are typically conceived of as individual in nature, families have a long history of fighting for the rights of families. In doing so, they reflect the relational nature of rights—that one’s rights are shaped by the access, opportunities, and rights of those around you. This position, though,
can be complicated by internal, and often unrecognized, power dynamics within families.

Rights for Family
First, regarding rights for families, parents have long called attention to the need for services as a means to enhance both the well-being of the individual with a disability and the family more holistically. As stated by advocates for people with intellectual disabilities back in the 1950s, the state must recognize “that no child stands alone; that a child is part of a family and a community; that what happens to the family affects the child and certainly affects the family.”

Disability has a tremendous impact on the family, as does the provision of services, or lack thereof, and this impact on the family has long been used to justify services for the individual with a disability as well as for family members. A 2015 study of those providing care to a family member with a mental health issue identified significant negative consequences in terms of finances, health, and social participation. A daughter caring for her mother with mental illness explained that she needs to earn an income sufficient to support her and her mother, attend college, and provide intensive care—an impossible set of demands. Without services for her mother, she would have to either quit school (reducing her chances of a well-paying career) or abandon her mother. She said, “I shouldn’t be expected to quit school. It’s my future.” The pursuit of the right to services is justified as a right of people with disabilities to enhance their well-being as well as a right of family members to be free of or assisted in meeting caregiving demands.

Similarly, a 2017 survey of thousands of caregivers of people with intellectual and developmental disabilities found that 35 percent had provided care for more than ten years. Ninety-five percent reported a negative impact on their work (e.g., 55 percent reported cutting hours, 32 percent giving up work, 17 percent retiring early, 33 percent turning down promotions), and 90 percent reported stress, including 48 percent who reported feeling extremely stressed. Twenty percent had a family member who had been waitlisted for the receipt of public services for over ten years. Here again, this report on the negative impact on family is used to justify services and supports for people with disabilities. As Erica, a single mother of a daughter with medical and intellectual disabilities, explained, she could not find stable, suitable care for her daughter on the days off from school. “That got to be very, very frustrating because I just thought I couldn’t survive like that. . . . It seemed like I eventually was going to have to not work and just be at home with her. And you can’t—to me that would limit me.” Sue Swenson, executive director of the Arc from 2005 to 2007, argued that a
model of individual rights is insufficient to ensure the rights of disabled individuals; it must be complemented with the assurance “that all families that include persons with disabilities can enjoy the support they need” to take care of their disabled family members and themselves.32

Rights of Family (i.e., Parents)
Second, regarding rights of family, families have fought not only for services and supports but also for the right of authority over decision-making in their families. Indeed, one of the core principles of parent activism is the idea that parents are the experts when it comes to their families, and their authority must be recognized (or at least their participation accepted and valued). One parent, Yvonne, explained that parents need input into the IEP process “because they’re the experts on their child.”33 Jack stated, “Parents and guardians, their views should prevail, and usually they do know what’s best for their child. I think by and large parents are capable, they are loving, and they are interested in what happens to their disabled child.”34

Because they believe in their own authority, parents resist threats to it. They perceive these threats as coming from several sources, including the state (conceived of as laws, service systems paid for via public funds, schools), medical professionals, and disability advocacy organizations.

The state exerts a significant influence in the lives of families. Parent activism encouraged an expanded role of the state in families’ lives; however, the expansion of the social service system and its infiltration into the family threatened parental authority.35 Disability history shows that there are good reasons to be wary of state intervention in the family when disability is concerned. Eugenic and punitive state policies justified institutionalization, sterilization, and segregated education, harming many families, especially those characterized as single-parent, poor, nonwhite, and with disabled family members who were labeled “unfit.” Institutions explicitly removed parental authority and transformed people with disabilities into wards of the state. In response, parents argued that families were “disabled” by the system and unable to effectively advocate for their child. In contemporary politics, parents still feel heavily and unfairly constrained by the state. Sara stated, “It’s because someone else [the state] is paying for it; they’ve decided they can tell you what is best for you.”36 Yvonne explained, “Families . . . don’t have a lot of power. The only power is when they can use the things that are in the rules and laws that give them a fighting chance to make sure that their kid is getting what they need. So the idea that parents are dictating what happens with their kid, I think, is really funny, because that rarely happens. You are always dealing with an agency; you’re always dealing with people who may not like your kid or who don’t want to spend the money or any of that.”37
The state also is perceived by some parents as prioritizing the disabled person’s right to self-determination, even when parents are the primary caregivers or will feel the consequences. This issue is discussed frequently among parents of adult offspring with mental illness. Laws that protect self-determination and privacy (e.g., the Health Insurance Portability and Accountability Act, HIPAA) are seen by many parents as major roadblocks to their effective advocacy for their children. For example, Chip Angell’s son committed suicide after struggling with mental health issues, and Chip felt shut out of his son’s health care, unable to inform the doctor of key information or to learn of his treatment plan. “Whenever we tried to get Chris into the hospital, we always ran into the fact that doctors wouldn’t talk to us. Some doctors think they’re protecting the privacy rights of the patient. Others simply use privacy as an excuse because they don’t want to talk to someone with an idea contrary to their own, or because they can’t be bothered to call someone back.” He continued, “If we had been able to talk to the doctor, we could have told him that no matter how much this drug cost, we’d have paid for it.”

Deeply connected to and reinforced by the state, medical authority also represents a consistent threat to parents. As noted previously, parents of offspring with mental illness rely heavily on a medical system that often excludes them and devalues their expertise. Parents in other disability communities also feel their authority threatened by medical authority. For example, despite evidence of the positive effects of exposure to American Sign Language (ASL), many medical professionals advise against teaching it to deaf children, instead endorsing cochlear implants and oralism only. And, despite efforts by parents to improve doctors’ negative views of Down syndrome, medical professionals define Down syndrome as a “defect,” identify it prenatally, and offer prospective parents very little—and mostly negative—information, in effect if not overtly encouraging high abortion rates of fetuses identified with Down syndrome. Thus, as documented in Chapter 6, several parent organizations explicitly work with the medical profession to deepen their appreciation of the value of their children.

The dominance of the medical mind-set in general can be deeply problematic for parents of children with significant disabilities. In her blog, parent Heather Kirnlanier spoke of how doctors too often metaphorically situate her daughter (who is diagnosed with Wolf-Hirschhorn syndrome) in a race that she is losing, and therapists push a therapeutic regime in which mothers are expected to act as full-time, in-home therapists. Challenging the medical perspective, Kirnlanier suggests “radical acceptance.” She writes:

Somewhere after our first year with Fiona, the desire to change my kid died and got buried in that imaginary sand dune along with her nonexistent tip of chromosome four. The desire to catch her up in
weight, the desire to keep her development as close as possible to her peers, the desire to make her into the standard-issue human, with its bipedal mobility and buh-buh B sounds. . . . It just . . . died. And I was freed into a deep acceptance for my daughter that felt bottomless. This did not mean that we didn’t continue therapy. We did. Of course we did. But I no longer held onto desired outcomes with the same nervous, rigid tension of a clenched jaw. I gave my daughter opportunities to grow, yes, but I also trusted that her body would proceed in a manner we could always call, deeply and truly, good.40

After thinking deeply about the pursuit of normality, she came to realize that “living with a person who wants you to be fundamentally different than you are . . . is toxic. No matter the scenario.”41 The medical demand to intervene, at any cost—personally, financially, and physically—essentially overshadows the person’s right to be who they are and the family’s right to just be a family. Reclaiming these rights may entail rejection of the medical model.

A third set of external constraints on parental authority is activists with disabilities and the parents and professional advocacy groups promoting self-determination and inclusion. In other words, parents are divided, some siding with activists with disabilities and others opposing them, and opposing activists can be experienced as a threat to one’s authority. Activists with disabilities demand that parents accept that inclusive situations are preferable to disability-specific settings, a belief that not all parents share. They also demand that the expertise of people with disabilities be acknowledged and their voice in policy prioritized. In both of the following quotations, family members speak of a coercive “they,” a reference to the alliance between disability advocates and state policy makers who pursue inclusive policies. Sara explained:

They’re [disability advocates] saying . . . that Jason should be working around the non-handicapped. I don’t think anybody is going to hire Jason, first of all, because he does hand-over-hand with envelopes and only when the person who is doing the other part is forceful and really pushes it, and for him to be paid ten dollars an hour, there’s no company out there who would do it, other than for a token thing.42

Similarly, Cindy stated:

They [disability advocates] wanna close the day habilitation services because we’re making it too easy for the developmentally disabled to
not go find a job. Ooookaaayyy. So, you want my brother, who’s not potty trained and has temper tantrums, to not have his day services and go get a job? Nobody’s going to hire him; he’s not going to have any place to go every day. His caregivers are gonna have to figure out what to do with him every day, to prevent him from having temper tantrums, because he won’t stay in the house.43

To these family members, outsiders are removing valued choices, putting their view of the world ahead of parental decision-making. Yvonne clearly referenced advocacy organizations when she stated, “I have always believed in self-advocacy. I also think there are people like my sons who can’t do that for themselves. . . . I don’t like the anti-guardian push by advocacy organizations, which is just a way of pushing parents out of the way.”44 And Liz stated that, while she appreciates self-advocacy, activists with disabilities “should speak for themselves but not for all people with disabilities.”45 For these parents, parents’ views should be prioritized over the views of other activists, at least for their own children.

To resist external threats to autonomy, the word “choice” plays a central role, especially in the narrative of parents who support disability-specific and congregate placements. When Yvonne described efforts to close the large, disability-specific school her son attended, she felt that external activists swooped in to remove options rather than provide them: “The emphasis shifted from everybody having an appropriate education or appropriate services as they got older to meet their unique needs, and it shifted to non-discrimination, and we can’t have these kids in these [segregated] settings, and everybody should have a right to be in a regular classroom, and everybody should have a right to live in a certain way.”46 For her, the integration agenda pushed one way of doing things, in effect removing, rather than granting, the right to choose. Sara concurred: “There’s this craziness approach, that it can’t be congregate care. We do congregate for everything, from seniors with Alzheimer’s to people in camp, college, you name it. Why not have economies of scale . . . rather than saying only four people in a group home, and you can’t have an overnight nurse, you can’t have a lot of things? . . . If you want to go to college, I’m not going to tell you you have to pick a school that’s below a certain number in a small city, or a big. You pick it based on your needs and your wants and what works for you and your family.”47

Furthermore, some parents argued that so-called inclusive choices are actually more restrictive. Cindy described her brother, Billy, who loves to walk and prefers to be outside in constant motion. At a large facility with grounds, he was allowed to move freely within the grounds: “You know, the fact that he could walk out of his cottage, go out on the back patio, or leave
the back patio and wander the grounds.” At his community-based group home, however, he is not allowed to leave the house unsupervised. “Now it’s called ‘wandering.’ When he cannot go outside and walk, he throws temper tantrums and smears feces, which also get listed as ‘behaviors.’”

Thus, in the congregate facility, where Billy had relative freedom of movement, he was considered to need only minimal supports (rated a 2 on the Supports Intensity Scale, SIS), but in the community his SIS rating increased to a 4. In other words, the inadequate staffing and lack of safe grounds produced a greater perception of disability and the imposition of surveillance and behavior modification to control his “wandering behavior.” These family members are saying that rights as implemented through inclusion policies actually further restrict their loved ones and deny them opportunities that are more important to their happiness, such as freedom of movement and easy access to diverse activities.

What some parents frame as a reasonable “choice,” though, other parents and disability activists frame as a denial of human rights. Family autonomy allows parents the freedom to resist external influences and make choices, but who protects the person with the disability from the family, especially given parents’ penchant for advancing their own interests and promoting paternalism and normalization? Increasingly, parental authority and parents’ claim to choice have been challenged, especially in relation to guardianship and choosing institutional settings for their offspring. Parents of deaf children, for example, have the legal authority to decide the communication strategy and treatment plan for their children. Some Deaf activists, though, argue that giving the parent an open choice of communication method for the child actually denies the basic human rights of that child. One’s communication strategy “should be a child’s choice, not a parent’s. Is there really such a choice for the child? Because, typically a choice among parents and hearing professionals is metaphorically 99% oral. Is this truly a choice? The child is given virtually no choice. To give a child a true choice with the maximized language acquisition in both languages (ASL and English) is to give him/her bilingualism. It’s not only a child’s choice, but also, more importantly, a child’s human right to language regardless of the modality.”

Thus, in this view, a child’s right to full language should trump a parent’s right to select language modality.

Other parent “choices,” such as the use of applied behavior analysis (ABA), large-scale disability-specific settings, institutionalization, the denial of sexuality, and support of euthanasia, are similarly controversial and contested by disability activists as denying human and civil rights. As a few examples, parent-led Autism Speaks and the National Autism Association (but not the Autistic Self Advocacy Network, which is led by people with autism) fought for Kevin and Avonte’s Law, which allows “voluntary” track-
ing of persons with diminished capacity, so that families and systems can better respond when people “wander” away from caregivers. Supporters, including some parents, argue that they have a right to track people with disabilities to ensure their safety and well-being and enhance the effective caregiving of parents. Autistic activists, however, argue that tracking and surveillance invalidates their right to privacy and criminalizes autism.

Parents may even include institutionalization of their offspring as within their set of legitimate choices. In her memoir, Fern Kupfer argued for expanded access to institutional placement for her son, who was still a minor and who had significant developmental delays and medical conditions: “It is their [advocates’] belief that the best place for every child is at home with his family. Even if that is true, it’s not always the best place for the family. . . . In order for him to be in a less restrictive environment, everyone else has to be restricted.” Kupfer fought against the system’s insistence that children reside with their family, and she eventually secured a residential placement for him. Psychiatric survivors and self-advocates with intellectual disabilities decry extended use of institutionalization as dehumanizing and ineffective, and they instead fight to enhance community-based treatment and services. They argue that the liberty of people with disabilities should not be sacrificed to meet the needs of people without disabilities.

A number of cases document that parents and their offspring do not necessarily share the same views or interests. In 2013 Jenny Hatch made the news. Hatch, a woman with Down syndrome, lived with friends, had a romantic relationship, and volunteered in her community. After she was hit by a car, her parents decided to pursue guardianship because they felt she needed greater supervision for her own protection. They were awarded it and placed her, against her wishes, in a group home. Hatch, supported by the Arc of Virginia, took her parents to court. According to the Arc of Virginia’s brief, “Extensive research has found that the vast majority of people with intellectual disabilities, including Down syndrome, can live successfully in their own homes and make their own choices.” The brief argued that guardianship in this instance did not support her in independence but rather led to her placement in a “segregated group home, isolated from her job, her friends and her community.” The court agreed and removed her from guardianship. Given the paternalism common among parents, a reliance on parental authority can be worrisome indeed.

Rights to Family
The preceding sections speak about the rights for and of families, but a third area, the right to family, should also be noted. The right to family was a centerpiece of the deinstitutionalization movement, demanding that all
children have a right to live with their natural families and that all families have a right to receive the supports necessary to accomplish this. The United Nations Convention on the Rights of Children declared that all children, including disabled children, have a human right to live with their parents unless doing so is not in their best interests. Institutionalization, mass orphanages, and “Indian schools,” which removed indigenous children from families to assimilate them into “American” culture, all posed a direct threat to this human right.

While the right to family may seem secure in the twenty-first century, the recent crackdown on immigration and the related policy separating children from their parents at the U.S. border has brought this issue back into the news. For example, in June 2018 headlines reported the removal of a child with Down syndrome from her mother, as well as the removal of a sixteen-year-old, Matheus da Silva Bastos, who has autism and severe epilepsy, from his grandmother upon their arrival at the border. All children need to be with their families; however, children with disabilities particularly need specific care and accommodations. In fact, many families immigrate specifically to secure medical care and social rights denied or unavailable to them in their home countries. The Hassan family was broken apart when father and son, both American citizens, traveled to California to seek treatment for the two-year-old’s terminal degenerative brain condition, but his mother, a Yemeni national, was denied a visa. For undocumented residents already in America, family life is also insecure. Irma and Oscar Sanchez were deported after following the advice of medical professionals in Texas that their infant, diagnosed with the rare condition pyloric stenosis, needed lifesaving care at a more specialized hospital in Corpus Christi. After their arrival at the Corpus Christi hospital, while they were waiting for their child’s surgery, the couple was arrested.

Although framed as a right of children, the right to family is vital for many adults with disabilities who continue to rely on their family throughout their lifetime. Dolores Gaspar Garcia, an American citizen, had few recourses to protect her older brother, who has Down syndrome and is not an American citizen, from deportation after a U.S. Immigration and Customs Enforcement (ICE) raid led to his arrest. Although he was thirty at the time of his arrest and detention, his forced removal from his family threatened his well-being both in the short term in the detention center and in the long term if deported to a country where he has no immediate family, no support system, and few skills to adapt to a new culture and language. Dolores started a petition to draw attention to his plight.

America’s extensive use of prisons and punitive child welfare system also threaten family integrity. People with disabilities are disproportion-
ately represented in prison, and thereby removed from family and community supports. Because people who are poor and African American are also overrepresented among prisoners and because poor children and African American children disproportionately have disabilities, a disproportionate number of poor minority children with disabilities likely grow up without access to their parents as a result of unequal criminal justice policies. As discussed by Sylvia Ann Hewlett and Cornel West in their book *The War against Parents*, stingy and punitive social welfare policies also still rely heavily on family separation and dissolution. 57 Thus, while many white middle-class families feel their right to family is secure, punitive and racialized policies related to immigration, criminal justice, and social welfare pose considerable threats to nonwhite and poor families.

**The Perceived Failures of Rights**

Parents use rights to resist discrimination, demand respect, showcase the competence of their family member, enforce laws, support their own authority, and access choices. But parents also speak of the ways in which “rights” are used against them, as mentioned previously regarding the perceived threats of the inclusion ideology, antiguardianship and self-determination policies, and the growing power of activists with disabilities in shaping disability policy and options. Parents’ concerns related to the rhetoric and implementation of rights also include the ways in which rights rhetoric demands compulsory productivity, masks neoliberalism and a disinvestment in disability services, and exposes people to unnecessary dangers.

**Compulsory Productivity and the Fear of Disinvestment in Disability**

Politicians have too often justified the cost of rights to services, education, accessibility, and community for people with disabilities by promising to decrease their dependency and increase their productivity. 58 Iconic disability rights activist Marta Russell argued, “When George Bush signed the ADA in 1990, a bargain was struck. Disabled people’s civil rights would be tolerated by the anti-government GOP, the party of business, as long as the ADA cost the federal government next to nothing and promised to get people off entitlements.” 59 However, this utilitarian calculation does not add up for all people. For some people, providing a meaningful education and accessibility will cost more than their eventual productivity yields. The economic calculus behind the provision of rights may lead to divestment in...
On the one hand, disability activists have maintained a steady commitment to those with the most significant disabilities. For example, as the commissioner of rehabilitation for California, Ed Roberts reprioritized funding to ensure that those with the most significant disabilities received services, rather than focusing attention only on those for whom a minor investment would ensure success. Roberts’s vision was that all people, even those with the most significant disabilities, could work and exercise independent decision-making in their lives. On the other hand, politicians easily distort this vision into a rhetoric of compulsory productivity that sees value in people only insofar as they are able to eventually become productive, forcing people to be productive in a traditional capitalist economy or else abandoned to segregated services, social isolation, or family care.

We see this tension in modern debates regarding employment. Sheltered workshops are criticized for fostering segregation and poverty and denying people with disabilities the training and opportunities actually needed to enter the workforce. Activists with disabilities strive for a world in which all people have the accommodations and supports to contribute productively in a competitive, inclusive job placement, and therefore urge the closure of sheltered workshops and the creation of competitive employment at living wages. But some parents question the idea that all people can or should have to be productive and participate in capitalist competition. They fear that the idea that all people may become productive actually justifies the denial of any care for those who cannot be adequately productive for a competitive job. As we close segregated, congregate care, they ask: Are all people receiving a right to community or are the least able being left behind, abandoned now in isolated family homes, nursing homes, and prisons rather than institutions? Sociologist and parent Barbara Altman worries about the future of her son: “Sheltered workshops, which provided stimulating activities for Andy for years, are now being closed. This closing is best for most clients, but for some, like Andy, it means being relegated to day programs mostly populated by the elderly or, if there is no day program available, being placed in a nursing home. While I live, I won’t let that happen.”

Thus the choice some parents perceive as actually being made is not between a world of segregation versus community integration but rather between segregation that is at least attentive to particular needs versus complete abandonment. Meaningful inclusion is not perceived as a likely option because it costs too much and requires too much support, and the state is unlikely to intensively invest in someone unlikely to yield returns. Disability activists counter that the solution is not to fall back on and legitimate segregation but rather to demand social investment in inclusion. Radical
inclusion, for example, puts the participation of people with disabilities at the center and builds the inclusion of people without disabilities from that starting point.61

Rights as a Mask for Neoliberalism

Concerns regarding compulsory productivity and the abandonment of those with the most need directly relates to the connection between rights and neoliberalism. American rights tend to be “negative rights,” which guarantee the freedom to be left unimpeded. The rights to free speech, to assemble, and to opportunity free of discrimination are all examples of negative rights. Negative rights come at little cost to the state other than ensuring people’s freedom. “Positive rights,” on the other hand, require that the state or others actively provide something or invest to ensure an outcome. The right to an education is a positive right; it requires the state to create, maintain, and implement a publicly funded system of education for all children. Disability activism has always demanded both kinds of rights, because the freedoms accorded via negative rights alone are not sufficient for the disability community to participate in society. Freedom and opportunity must be paired with investment in supports, services, accessibility, and accommodations to ensure the meaningful participation of people with disabilities.

Although people with disabilities require both negative and positive rights, neoliberalism promotes a view of freedom based on a laissez-faire economic system with little government regulation or public provision of services in favor of an open, private, capitalist marketplace. Thus, neoliberals tend to agree with disability rights activists that state-funded institutions, sheltered workshops, and public specialized schools for children with disabilities should all close, but they resist funding other community-based public services.62 Rights become a political tool to mask fiscal conservatism, with little commitment to creating the material conditions necessary to practice freedom, make choices, and participate in society.

Christopher clearly articulates this economic calculation and how it affects his son, who requires twenty-four-hour care for complex medical conditions. His son resides in a large-scale center for people with disabilities. When asked if his son could be cared for in the community, Christopher said, “Oh, it’s not impossible. The problem is, to do it properly, it’s costly. . . . It’s going to be enormously expensive. . . . They’re [the state] not prepared to do so because they are trying to save money.”63

Another parent, Erica, discusses the problem of rights when paired with a lack of investment in community services. Erica’s daughter has frequent seizures and uses a feeding tube, and Erica argues that staff tend to be
unreliable in attendance, have high turnover, and lack qualifications to administer medication and handle seizures, or to even recognize seizures. She states, “The staff aren’t nurses, and they aren’t trained appropriately. . . . What about at night if there’s only one person on staff and three or four consumers. Somebody can have a seizure, and you can’t wait for another staff member to get there [to handle the other consumers].” For Erica, there is not a sufficient number of knowledgeable staff, or even just a sufficient number of staff, to deal with crisis situations that are bound to occur when you have individuals who routinely need significant medical intervention. Moreover, the system becomes privatized, putting the consumer or their family in charge of identifying and managing staff and services. Erica explains that although she is a single working mother, not only must she provide extensive care, but she must locate, manage, and monitor services. This would not be so daunting if she knew quality services and staff existed and that she could afford them, but no such assurances exist. She cannot afford services that meet her daughter’s needs, so she must take time off from work to provide the services, which then makes paying for services all the more problematic. She feels trapped in an inadequate system that gives her the “right” to manage her daughter’s care but does not provide the funding, time, resources, or services to actually do this successfully. Thus, the political wish that the delivery of rights will save money creates a dangerous demand for productivity and is related to a path toward divestment rather than investment.