Methods to Study Family Consequences of Children’s Disabilities

Table 2.1  Type of Disability in Activities, Children Age Five to Seventeen

<table>
<thead>
<tr>
<th>Activity Limitation</th>
<th>Population with Disability</th>
<th>Rate per 1000</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Total Disability</td>
</tr>
<tr>
<td>Mobility</td>
<td>698,000</td>
<td>13.1</td>
</tr>
<tr>
<td>Self-care</td>
<td>506,000</td>
<td>9.5</td>
</tr>
<tr>
<td>Sensory/communication</td>
<td>2,946,000</td>
<td>55.3</td>
</tr>
<tr>
<td>Learning/behavior</td>
<td>5,823,000</td>
<td>109.3</td>
</tr>
<tr>
<td>Any limitation</td>
<td>6,537,000</td>
<td>122.7</td>
</tr>
</tbody>
</table>

Source: Author’s tabulations of National Health Interview Survey on Disability rates (Centers for Disease Control and Prevention 1995) applied to 2008 U.S. Census population counts (Ruggles et al. 2010b).

Children with disabilities is best done for children ages five and older. The best population estimates of children with disabilities who are ages five to seventeen can be obtained from the NHISD, since that survey has the most comprehensive battery of questions about medical conditions, activity limitations, and participation. Table 2.1 illustrates the rate of disability in activities per 1000 children. About 122.7 children per 1000 (6,537,000 children) have any activity disability. The rates of disabilities in mobility (13.1 per 1000, or 698,000 children) and self-care (9.5 per 1000, or 506,000 children) are relatively low. About 55.3 children per 1000 (2,946,000 children) have disabilities in their ability to see, hear, speak, or communicate; one-half of these sensory and communication disabilities are serious. The most commonly observed disabilities involve learning and learning-disruptive behaviors. The rate of learning and behavior disabilities is 109.3 per 1,000 children (5,823,000 children); about two-thirds of these cases are serious. Many children with disabilities in mobility, self-care, and sensory communication also have learning and behavior disabilities.

Most American children (91 percent) attend regular programs in schools and are able to engage in play activities outside of school (Hogan et al. 1997). Another 5.2 percent of children (2,770,000) attend regular schools but are limited in what they can do (for example, participate in physical education classes) or require some assistance (such as speech or language therapy, reading assistance, or wheelchair use). Other children (1.4 percent, or 746,000 children) attend school but either are enrolled in schools specializing in children with disabilities or attend regular schools that have segregated, separate programs for students with disabilities. A small number of children with disabilities (0.3 percent, or about 160,000 children) are not able to attend school at all because of their disabilities. Another 2 percent of children (1,060,000
view Survey. These data allow me to calculate true cohort rates of a marriage ending as well as estimate the divorce rate of parents who have children with severe disabilities. Compared to the data from the National Survey of Children’s Health, however, the sample size is small and not as current. (Using a discrete-time event history model, rates of divorce were calculated by taking into account mothers’ race and ethnicity, age at marriage, and education; the number and age of children; immigrant status; and rural residence.) Compared to couples whose child does not have a disability, the rate of divorce is more likely for parents of children with mild disabilities (odds ratio [OR] = 1.39, p < .05) and even more likely when the child has a severe disability (OR = 2.29, p < .05).

Figure 3.1 Parents’ Relationships Remaining Intact During the First Ten Years After Birth, by Disability Status of the Child

Source: Author’s calculations of data from the National Survey of Children’s Health (U.S. Department of Health and Human Services 2003).
Note: Parents’ relationships include both marriage and cohabitation. This calculation is an approximation based on the proportion of parents who are still together at each year of the child’s age and cumulating the implied probability that parents remain married from one year to the next, from birth to age ten. This is what demographers refer to as a synthetic cohort method. Using this procedure, it was not possible to control for other factors associated with parents’ divorce.
accommodating. I would leave Sunday night with him [to travel to a medical center three hours away], we’d stay over. We’d get his treatment on Monday and then we drive back Monday night.

Figure 3.3 shows how child disability affects maternal employment for women of different marital statuses and education levels, compared to similar mothers raising children without disabilities through adjusted employment rates. Thus, for example, among unmarried mothers with less than a high school education, child disability is associated with a 20 percent lower rate of employment compared to similarly educated single mothers whose children do not have disabilities. Among unmarried mothers with a high school diploma, child disability is associated with a 24 percent lower rate of employment compared to unmarried mothers with a high school diploma who do not have a child with a disability. Among married mothers with less than a high school diploma who have a child with a disability, the rate of employment is

Source: Author’s calculations of data from Census 2000, 6 percent sample (Ruggles et al. 2010b).

Note: Includes all mothers. “Not working” includes the unemployed and women not in the labor force.
10 percent lower than that of married mothers with a high school education whose child does not have a disability.

However, it is a different story for college-educated mothers: both married and unmarried college-graduate mothers who have a child with a disability are 10 percent more likely to be employed than are college-educated mothers whose children are not disabled.

There are a variety of possible explanations for these work patterns, and the reasons are complex. Less educated mothers earn less, so the potential family income loss is less if they do not work. However, their contributions to family income may be even harder to do without. Mothers with less than a high school education earn relatively little compared to the costs of child care; many of them can best support their families by staying home. More educated mothers often have careers rather than jobs, and these careers may have substantial penalties for frequent exits and re-entries. These college-educated mothers more often can afford special child care, including in-home care for a disabled child. They may also be better positioned to negotiate fathers’ involvement in the care of that child. Thus, by continuing employment,
and for her son Julian, who has a disability: “I notice that since I had the baby, [Julian had] been more open. And since I had the baby, it’s like we opened up like . . . [Julian and I are] more close, how we communicate better. And, see, in fact the way that he treats the baby, I teach him . . . it’s helped . . . it helped a lot.”

These decisions show up in the matched information from the National Survey of Family Growth and the National Health Interview Survey. If their first child has a disability, the rate at which parents have a second child is about 20 percent less than among parents of children without disabilities.

Indeed, parents of a newborn child with a disability more often opt for permanent contraceptive measures to limit family size (figure 3.4). The rate of tubal sterilization in the months following the birth among mothers whose newborn infant has any disability is 65 percent higher than that of mothers whose newborns do not have disabilities (Park, 2003).
ened, are higher. Parents at the Children’s Rehabilitation Center told us about some of the unusual costs that families bear as a direct result of their children’s needs. Teresa said that as Sean has grown older, the family has needed to find the money to renovate their home in order to accommodate a bigger wheelchair:

But now he’s bigger, so they made the chair wider now, and he’s hitting more things than he was before. So I had to take his bedroom door off. . . . Just to . . . make his bedroom bigger, build a bathroom, and bring my kitchen out will be $110,000.

Dan, the father of Scott, who has cerebral palsy, works multiple jobs to make ends meet. Even so, he says the family is chronically short of money due to the specialized care and modified home environment that Scott needs:

Figure 3.5 Economic Experiences of Families by Disability Status of Children Under Eighteen

Source: Author’s calculations of data from the National Survey of Children with Special Health Care Needs (U.S. Department of Health and Human Services 2005/2006). Note: Survey includes children who have special health care needs but who do not have disabilities. All differences are significant at $p < .05$. 
Family Consequences of Children’s Disabilities

Figure 4.1  Hours per Week Spent on Children’s Home Health Care by Children’s Disability Status, Children Age Under Eighteen


Notes: Survey includes children who have special health care needs but who do not have disabilities. An ordered logistic regression controlling for race, poverty level, mother’s education, number of children and adults, size of place of residence, and sex and age of the child shows that the intensity of child medical care is increased dramatically (odds ratio [OR] = 2.89, \( p < .001 \), for parents of a seriously disabled child; and OR = 6.70, \( p < .001 \), for parents of a child with a severe disability).

shows that parents of disabled children often find themselves spending significant time scheduling and coordinating professional care (tabulations not shown). While only one-quarter of parents of children with chronic health conditions but no disabilities spend more than one hour per week managing and coordinating medical care outside of the home, two-thirds of families of children with severe disabilities do so. In fact, the burdens of this activity can be extreme: 8 percent of families of children with severe disabilities report spending more than ten hours per week coordinating their children’s medical care. It is easy to see how parents can be overwhelmed by this task.

Of course, parents who are more economically secure are better able to hire specialists to come into the home to help with their children’s health care needs. Some families with sufficient financial resources arrange specialized daycare that takes care of their children’s medical
Bullying

All parents must balance young people’s need for independence with the need to keep them safe. Young people with disabilities, especially those with serious disabilities, are more likely to be bullied than children without disabilities and may encounter bullying in many situations: between home and school, in school, and in the homes of other children. Figure 5.1 shows the prevalence of bullying by age and disability status (among children sampled in the National Longitudinal Survey of Youth [NLSY] who were able to be interviewed). Only 19 percent of children without disabilities say they were bullied before their twelfth birthday, compared to 23 percent of children with mild disabilities and 34 percent of children with serious disabilities who report being bullied. Between the ages of twelve to eighteen, these patterns of bullying continue—10 percent of children without disabilities...
sensory and communication limitations, and 46 percent of those with cognitive limitations. Moreover, only 2 percent of adults ages twenty-five to thirty-four who did not have disabilities were living in institutional settings (such as long-term-care facilities, group homes, or prisons), compared to 3 percent of adults with mobility limitations, 6 percent of adults with self-care limitations, and 8 percent of adults who had cognitive and behavior limitations.

The transition of young persons with disabilities to adult roles and to participation in the labor force is critical to the children’s abilities to lead adult lives. For all young persons, this can be a time fraught with anxiety, as one learns adult social and behavioral skills and has to demonstrate work competence to find and keep good jobs. For parents of young adults with multiple disabilities, one of the most helpful options may be to enroll the child in a school-to-work program. Many children with disabilities do manage to complete high school and transition successfully to adult roles. However, there are many children who do not, although these children may be partially independent (working at a

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**Figure 5.2** Adult Life Experiences by Disability Status, Persons Age Twenty-five to Thirty-two Years

*Source:* Author’s calculations of data from the 2005 to 2009 American Community Survey (Ruggles et al. 2010a).
Parents’ Struggles for Disability Services

of children with severe disabilities are about equally able to provide their children with a usual source of care (90 percent) and a knowledgeable doctor or nurse (90 percent) as parents of special health care needs children who do not have a disability. Parents of children with severe disabilities, compared to children with moderate disabilities, less often report that their health care providers spend enough time (78 percent versus 88 percent), listen to their concerns (82 percent versus 93 percent), or are sensitive to their cultural values (81 percent versus 92 percent).

The specialized services children receive from different providers are often disparate and uncoordinated; this obliges parents to become care coordinators and advocates for their children. This is illustrated by the interview with the mother of two daughters, Katie and Andrea. She is a special education teacher who can use her specialized knowledge

Figure 7.1 Children Under Age Eighteen with Special Health Care Needs Who Have a Medical Home, by Disability Status

Note: Survey includes children who have special health care needs but who do not have disabilities.