

== Chapter 1 ==

Families' Experiences with Children's Disabilities

MORE THAN one-eighth of all families with children in the United States include at least one child under age eighteen who has been diagnosed as having a disability. Nearly all of those children live with their families. Their disabilities range from mild (for example, asthma that limits participation in sports) to severe (such as cerebral palsy with extensive neurological complications). All told, 6.5 million American school-age children have a disability, and for 4.3 million of them, the disability is seriously limiting. This book is about how American families respond to the challenges of raising children with disabilities, and how these challenges affect those families.

Four Families

The following four families' experiences illustrate what can happen when a child has a disability.

Jake's Family

Thomas and Sandra are the parents of Jake, age ten, and Katie, age seven. They are a white, middle-class family, and Thomas works at a professional job. They have sufficient income to meet all basic family needs. It was clear early on that Jake was different from other children. As a baby and young toddler, Jake would not meet his parents' eyes, was seldom interested in others unless they were giving something he wanted, and ignored children his age. By his second birthday, Jake still did not say words. After months of telling themselves he was just developing late, Thomas and Sandra took Jake to a major medical center for tests. They were stunned when the doctors told them Jake had autism. They knew little about autism—its symptoms, its progression, or its treatment. They went home and consulted library materials and the

Internet. They looked into medical sites, material by educators, and advocacy groups, and they had conversations with other parents. And they looked to themselves to consider what they could and would do to best help Jake.

After much discussion, Sandra agreed to a strategy that Thomas had been advocating. Rather than undertaking medical treatments, intensive expert behavioral interventions, unproven special diets, and the like, they decided to work with Jake at home to help him participate in family, social, and educational roles. Based on what they had learned, they realized that they would need to provide an exceptionally calm home environment, patiently encouraging slow step-by-step progress in self-care, play, speaking, and using skills as an integral part of functioning, rather than simply repeating these skills again and again until they were mastered for practical use.

Above all, they wanted to emphasize overwhelming family love in Jake's life. Sandra quit her job to become the primary caregiver for Jake. However, although her commitment to Jake is strong, her time at home has been far from easy. Thomas sometimes comes home from work to discover Sandra at wits' end—frustrated, angry, and far from calm. When this happens, Thomas is able to take a fresh approach with Jake in order to help settle the entire family. To take part in the day-to-day challenges of raising Jake, Thomas sometimes works at home, and he stays home evenings and weekends so that he can provide some relief for Sandra as Jake's primary caregiver.

Within a few years of the initial diagnosis, Jake began to interact with family and then with age-mates. He was able to enter kindergarten on schedule. However, the central city public schools were unable to provide the support Jake needed. Because Sandra had stopped working in order to be with Jake at home, the family could not afford to pay for a special school for children with disabilities. Moreover, they were committed to mainstreaming Jake in a regular school. The costs of private schools for Jake were prohibitive, and these schools typically do not have mainstream programs. Thomas and Sandra ended up moving to an affluent suburb that they do not like, but where the public school can give Jake the educational supports he needs. He is now doing grade-level academic work and has made some friends, including friends without disabilities. But Thomas worries that as he becomes a teenager, Jake will lose friends who begin to consider him "different" or even "weird." Thomas has no sense of how Jake might function in the adult world; for the moment, he's focused on getting Jake through school, keeping him involved with peers, and enabling him with the range of skills needed for participation in adult life.

Brandon's Family

Brandon, age five, is the son of Karen and Gregory. They are a working-class family who live in a rural town. Brandon has had multiple severely disabling medical conditions since birth. He has pressure on the brain caused by the premature closing of the growth plates in the head. This condition can be corrected by surgery, but Brandon did not get the surgery until age three, after some of the worst damage to his verbal and motor functions had occurred, because, in the words of his parents, his previous neurologist was "an idiot" who has since lost his medical license. Since birth, Brandon has had a digestive condition that causes projectile vomiting. He has failed to thrive; at five years of age, he is only 40 inches tall and weighs only 33 pounds—both measurements are lower than 99 percent of all children of the same age. Brandon also suffers from epilepsy, asthma, and severe anger and aggression.

Karen says she is the only one who can take care of Brandon. This is her full-time job, and having to fight for him is central to her identity. Brandon receives physical and occupational therapy at a medical center four days per week and does therapeutic horseback riding one day a week. Karen coordinates his medical appointments with his part-time special education program and makes sure he gets to the right place at the right time. He is mainstreamed in a preschool program with an individual education plan that provides additional physical and occupational therapies. To attend school, Brandon needs personal aides to help with his diet, eating, and digestion; to work buttons and zippers; and to assist with toileting and frequent incontinence. Karen reports that she is constantly tired and often lacks sufficient sleep. The only free time she has is after Brandon goes to sleep, when she does crafts and watches movies on television.

Karen says that alternative at-home care arrangements cannot provide the same kind of care that she gives Brandon; as a result, she and Gregory have no social life outside their home. Karen has a brother and sister who live next door but are of no help. If she gets too sick to care for Brandon, her mother will help. Karen also says she cannot rely on Gregory for Brandon's care—he loses patience and becomes very angry, especially at Brandon's violent outbursts. Karen is afraid that, if left alone with Brandon, Gregory would physically abuse him. She does not let Gregory provide care, even if it is just for a short trip to the store—she says it is just too dangerous.

Karen became unemployed the day after she learned she was pregnant with Brandon. She was sterilized after Brandon was born so that she could devote herself entirely to his needs. Gregory, however, wants

to have another child. Though they were married just six months before Brandon was born, Karen and Gregory are no longer intimate; their marriage is in danger. Karen thinks it is possible Gregory will abandon them.

Karen and Gregory have been financially ruined by their reduced income and the special costs of Brandon's disabilities. Gregory works at night for minimum wage. Karen tries to supplement their income with Tupperware sales at home. Karen is diabetic and believes that her own health has been harmed by Brandon's needs and lack of attention to herself. Gregory and Karen declared bankruptcy because of unpaid medical bills and credit card debts. They are chronically unable to pay their monthly bills. They do not always know if they will have food to eat, so they have reduced their consumption of meats and fresh fruits. On some days, they eat only two meals.

Christina's Family

In August of 1992, Christina, the second of three daughters, was born to Todd and Michele. Christina's sisters did not have disabilities. After seeming to develop normally for the first few months, Christina began to show deficits in her development. As Christina got older, she was unable to crawl or walk. She did not speak words, although she used her verbal abilities to communicate. Physicians diagnosed her as having a global developmental delay or a form of cerebral palsy. Over time, Christina's parents became convinced this diagnosis was incorrect: Christina was bright-eyed and could understand, but she could not speak; she enjoyed the world around her and liked to participate; she wanted to walk but was unable to do so. She was not able to eat, bathe, or dress by herself and could not be toilet trained. She had difficulty digesting food and was diagnosed with gastroesophageal reflux disease. Christina also had scoliosis, or curvature of the spine, and a significant seizure disorder.

Michele and her husband kept pushing the doctors for a more comprehensive diagnosis, with no success. Finally, as a result of their online investigation of medical conditions, they began to suspect Christina had Rett syndrome, a neurological disorder affecting only females. Rett syndrome is characterized by deterioration in function over time, and survival rates decline after age ten. Pneumonia is often followed by death. Because the condition is very rare (fewer than one in ten thousand girls have it) and the United States did not have its first diagnosed case of Rett syndrome until 1983, their physicians doubted their suspicions. Still, Michele and Todd insisted that their neurologist order the

diagnostic test, and at age ten, Christina was finally diagnosed with Rett syndrome.

Christina was able to go to a public school for special-needs children. Her father and mother both continued to work to support Christina and her sisters; Michele's job provided better health insurance. But one of the parents also had to see Christina off to school (on a special bus) and meet her when she came back home; the state did not allow her sisters to do this. Michele, who holds an important administrative position, was able to negotiate flexible hours with her employer so that she could handle arrangements for Christina's schooling, doctor appointments, and special care needs.

Both parents and children were actively involved in Christina's care and enjoyed involving her in family activities. Todd and Michele retrofitted their house to handle Christina's needs with wheelchairs, an electric lift to bring her up and down the stairs, a wheel-in shower, and a ramp to get her into the house. Many of these accommodations would only work as long as her parents could lift and carry her. In anticipation of not being able to do this, the family installed a pulley and lift system to move Christina between rooms.

Michele's insurance covered Christina's medical care. The family received financial assistance from the state-administered Katie Beckett Program (which helps middle-income families afford the substantial expenses of keeping a child with severe disabilities at home). This included financial help for the purchase of a succession of wheelchairs as Christina grew larger, the pulley and lift system, special foods, and diapers. The schools mobilized resources so that Christina could continue her schooling. Michele says that the family feels good about what they did—they not only coped, but also thrived, creating a loving and supportive home centered on Christina's needs. Because of these supports, there was adequate income for all family needs.

After her twelfth birthday, Christina began to have recurring respiratory problems and spent many weeks repeatedly hospitalized. Finally, after she turned thirteen, Christina developed severe pneumonia and succumbed to a cascade of medical problems. While Christina's situation had been dire, her death was not expected. Her father had just left on an international business trip, and after arriving at his destination airport caught the next flight home. As her husband was still en route to the hospital, Michele was left to face the situation alone. The hospital's neurologist was blunt with Michele, pronouncing Christina brain dead after only a brief neurological assessment, and recommended that they take her off life support. He was not well known to Michele and her family and made no attempt to sit and speak with

Michele, offer any kind words, or even offer his condolence. Michele felt the neurologist lacked sympathy, as well as any sort of understanding as to what Christina meant to the family. This lack of compassion made Michele feel very angry. More than a year later, Michele still feels that way.

Today, the family has begun to adjust and to do some things that were impossible when Christina was with them. Michele has returned to her job during regular business hours, and the family is very involved with the Rett Foundation, working to increase awareness of Rett syndrome as a way to honor Christina's life. They've taken a vacation, and their oldest daughter is beginning to look at colleges, both parents visiting campuses with her. Michele carries a small book of prayers and poems with Christina's picture and holy card. But the hole in their family life is gaping. It continues to be unsettling, sad, and difficult to adjust to the loss of such a focal family member.

Derek's Family

Derek, an African American four-year-old, was playing with his cousin on the sidewalk in front of his public housing apartment; there were no parks or playgrounds in the neighborhood. A person riding a dirt bike rounded the corner at high speed and swerved onto the sidewalk to avoid a speed bump, hitting Derek and a telephone pole. The bike bounced off the pole and landed on Derek's head. Derek's mother panicked and needed neighbors to help call for an ambulance. Derek spent one month in a local pediatric hospital, two weeks of which were in critical care. At first, his chance of survival was touch and go. After Derek's situation stabilized, it became clear that Derek's brain injury had paralyzed his left side. Medicaid covered the cost of Derek's initial care and rehabilitation therapy. Now he is covered by state medical insurance for persons on Social Security Disability Insurance.

Derek was sent to a university rehabilitation hospital that was a seventy-minute drive away from home. The doctors were not optimistic about even a partial recovery. But Derek's mother, Alicia, saw him as a fighter determined to overcome his disability. In fact, Derek made a remarkable physical recovery, and one year later he is able to walk with leg braces (although he tends to fall over) and to use his arm. He needs help with bathing and dressing but otherwise can care for himself. However, Derek's physical recovery has not been matched by cognitive and mental health recovery. While his disability is not severe, it is likely Derek will require special education in a regular school. The biggest problem for Alicia is that Derek's personality has changed—he now angers easily and turns violent; Alicia says “he is mean.” She will not

leave him alone with his younger brothers (ages two and four) out of fear that he will hurt them. He cannot be taken out to the homes of others or to play with his cousins. His mother keeps him inside where he is "safe" and where his anger cannot result in him hurting another child.

Alicia did not complete high school after giving birth to Derek when she was age seventeen. Alicia has never worked for pay and has not been married. Derek's father has never supported Alicia and her family financially, even after Derek's injury, but he is "around." He stayed with Derek for the first week when he was in the rehabilitation hospital. He sometimes takes care of the younger children while Alicia brings Derek to therapy. Alicia seems satisfied with the level of his involvement in their lives.

However, Alicia mainly relies on her own family for help with child care and for sharing the costs of basic family necessities such as heat, food, and clothing. Even with their help, Alicia and her children live in poverty in shabby and cramped public housing. An aunt who lives next door typically takes care of the younger children when Alicia needs to take Derek to tests and treatments and watches all of the children when Alicia needs to go out.

Alicia deals with Derek's needs and is a good mother to her other children. But she remains angry about one thing—the driver of the dirt bike was initially charged with reckless driving resulting in serious injury, but the charges were dropped when he told the police about another dirt bike driver who illegally possessed a gun, thus getting off the hook by providing information about another, unrelated crime.

Family-Centered Care

The United States depends on families like those of Jake, Brandon, Christina, and Derek to assume the extraordinary responsibilities of raising children with disabilities, although as a nation, we have made an unprecedented commitment to emancipate persons with disabilities. The Individuals with Disabilities Education Acts (IDEA) of 1975 and 1997 guarantee children with disabilities an education that maximizes their full potential and that is provided in a school setting most closely approximating that of other children. The Americans with Disabilities Act (ADA) of 1990 emphasizes the potential for all persons with disabilities to participate fully in American life, with appropriate medical care, rehabilitation, and helpful social and physical environments. But these national policies expect that children with disabilities will reside at home and that parents will provide them with medical care, provide them with access to an education that maximizes their potential, and equip them for adult life.

This national strategy of family-centered responsibility works, to a large extent. When a child with a disability is born into a family, most parents do everything they can to promote that child's well-being and life chances. This book focuses on what parents do when they have a child with a disability and how this affects them and other children in the family. Specialists who care for children with disabilities know there are costs and consequences for many families raising children with disabilities, and the families of children with disabilities are all too familiar with many of those. As the literature makes clear, a family's experience of a child's disability depends on that child's medical conditions, the severity of those conditions, and how those conditions affect the child's abilities and everyday activities.

The Population Approach

This book uses case studies like those of Jake, Brandon, Christina, and Derek. My approach is unique in that I also use information representative of American families raising children with disabilities to portray commonalities and variety among families, describe the added responsibilities and parenting challenges they undertake, and investigate the consequences for family life and family members.

The population approach involves the use of representative survey data that refer to all American families raising children with disabilities. This approach means that I can study families whose children have what appear to be relatively mild disabilities, rather than paying attention to just families of children with more serious or severe disabilities. By using information from the Census and seven national surveys, I can provide a comprehensive picture of the disability status of children and the wide variety of family situations and impacts on the family. In this way, I present a portrait of all American children with disabilities and their families, and it is possible to examine how they compare to families whose children do not have disabilities. The population approach also permits me to examine how children's disabilities affect the situations of all types of families—those that are poor and those that are economically secure, households with one parent or two, families with health insurance and families that lack insurance, and minority families, as well as families who are in the American majority.

A population approach is useful in other ways, as well. For example, there are children with disabilities who may never obtain necessary specialized medical or rehabilitation care and thus do not appear in published clinical studies. A population approach can identify children with unmet needs for specialized care and the problems their parents encounter in getting this care. In contrast, some children may have re-

ceived appropriate specialized care and modifications to their environments so that they are able to do all daily activities and can participate fully in all age-appropriate roles. These success stories may have been missed in prior studies focused exclusively on children who have ongoing disabilities.

Using information from representative national data on families and more detailed interviews with parents of children with disabilities, this book shows that there are numerous consequences for families raising children with disabilities, many of which are not favorable. Parents of children with disabilities divorce more often than parents of children without disabilities and sometimes change their plans about how many children they will have. Family life is almost always reorganized so that disabled children can receive all the care they need. Against the trend for women to be in the workforce, mothers of disabled children are more likely to be full-time homemakers with primary caregiving responsibilities, and fathers are more likely to work longer hours, work at two jobs, or continue working beyond retirement age to support the family. This return to traditional family roles reduces income at a time when families face unparalleled expenses. Brothers and sisters of children with disabilities thus grow up in families with more expenses and fewer resources. To cover the needs of a disabled child, parents sometimes allocate a smaller share of those resources to their non-disabled children than they would if they did not have a disabled child.

The population approach helps to assess whether media accounts of extreme actions of parents of children with disabilities reflect the reality of how these families function. Most people have seen or heard media coverage of parents who avoid taking care of their disabled child. For example, in one New England town, news sources reported on a woman who had a prenatal test to determine if her fetus had Down syndrome and was told the baby would be healthy. However, there was a mix-up in the lab work, and she gave birth to a child with Down syndrome. Immediately at birth, she placed her child in a permanent residential facility and supposedly used some of the money gained in her lawsuit against the laboratory to remodel her kitchen.

Such stories are outrageous and get considerable public attention. But the fact is that such instances are extremely rare and do not even show up in population data. Overblown media attention to such stories does a public disservice by distracting from the real sacrifices made by nearly all parents of children with disabilities. The purpose of this book is to demonstrate to Americans and our policymakers that the actual situations of most families of children with disabilities are quite different.

I have given many professional and public lectures on these findings. Many members of the audiences are often astonished. This book will likely stun readers unfamiliar with these families' challenges, but it is essential for a broader public understanding of the struggles and needs of families with children with disabilities. While the findings of this study may not surprise parents of children with disabilities, such parents may be surprised by the extent to which my findings apply to parents of children with all types of disabilities, not just children who have the same medical conditions as their own child. This book should reassure parents of children with disabilities that they are not alone.

The Constantly Changing Lives of Parents and Children

While disability associated with old age tends to be a progressive process, this is not the case for many children with disabilities: their disabilities can diminish, disappear, or worsen as they grow to adult ages. They may be able to participate in schools, but in other contexts, such as work, they may not have as many opportunities.

This means that over time, changes occur in their capabilities and needs, affecting their ability to perform daily tasks in life (for example, feeding, dressing, and bathing themselves) and to participate in social life (going to school, making friends, and working at a job). The age of children with disabilities is implicated in this process, especially in regard to age-appropriate activities. This is best thought of as a dynamic process in which the life of the child with a disability, and changes in the disability, are linked to the lives of others in the family, and the lives of all family members are linked to each other. The lives of children with disabilities are, in turn, affected by what their families do.

I use life course theory to study children with disabilities and the consequences of disability for parents, brothers and sisters, and the family (Elder, Johnson, and Crosnoe 2003). Life course theory regards the lives of individuals from birth to death (or some portion thereof) as being structured by the unique historical times in which they live, the social institutions they encounter, and family and community environments. Life course theory also directs attention to how experiences at one age influence options and experiences at later ages; when individuals follow an established life course pattern they are said to follow a life course pathway. A key element of the life course is individual choice—that is, based on prior experiences, their interpretation of those experiences, and what they see as their (constrained) options, individuals exercise agency and can affect their own life courses.

Life course theory helps situate the families of children with disabili-

ities and directs attention to specific aspects of the life courses of family members. The families studied here are historically unique—they are the first families raising children under new government policies that promote the inclusion of persons with disability in all aspects of life. For these families, the option of placing their young children in an institutional setting is largely absent. No matter how seriously disabled a child may be, national policy expects that families will provide comprehensive care.

There have been some institutional changes intended to help parents in this regard. Medical services are supposed to be available to meet the needs of children with disabilities. Yet, as this study shows, the organization of medical practice, diagnoses, and care delivery is often unsatisfactory. This situation is further exacerbated by private and public insurance options and limitations in coverage. Schools are mandated to provide medical and rehabilitation assistance free of charge to enable a child with a disability to participate in regular schooling to the extent possible. However, school access to such support only occurs when funding allows, and parents often need to fight with schools for correct diagnoses and necessary services.

Parents of older children with disabilities face significant challenges finding suitable employment for adult children and preparing them for work. Workplaces with the necessary physical and organizational accommodations for persons with disabilities exist more in theory than in practice. Even as they age and develop infirmities themselves, many of these parents continue to provide care for their adult child. There are few community supports for these families.

Life course theory is therefore a particularly useful framework for understanding the family dynamics of medical conditions, rehabilitation, enablement, and participation in the lives of children with disabilities. It recognizes that children with disabilities interact with their parents and siblings to structure ongoing family relations (often called family functioning). Their life courses are linked; as the life of a child with a disability in the family affects the members of that family, so too the family affects the life of the child with a disability. This process is ongoing, since as the life of one person changes, other family members may have changed responsibilities or new opportunities that can have long-term impacts on the course of their lives.

Thus, for example, when a child's disability requires a mother to quit work and provide round-the-clock home care, fathers typically try to increase their earnings by working longer hours, securing better paying jobs, or undertaking multiple jobs. As the child gets older and is able to attend school, the mother may be able to return to work, at least on a part-time basis, and the father may return to holding only one job.

These changes depend on the income the mothers could earn by returning to work, the help and assistance they receive from other family members, and the parents' ability to access satisfactory medical and school care and enablements. The changing needs and abilities of children with disabilities thus alter the situations of others in their families.

As a result of these linked life course experiences, these family members are stressed, more often depressed, and less happy in their day-to-day lives. Yet at the same time, parents take satisfaction in their commitment to enabling their children with disabilities. They see themselves and their families meeting the challenges they face and coping well with the complexities of raising a child with a disability.

The Study

It is my belief that information from informal and semi-structured interviews, unstructured observation, and representative population data together allows me to draw an original, realistic, and comprehensive picture of families raising children with disabilities. Here, I briefly describe how I approached the study of children's disabilities and the information and methods I used. Chapter 2 gives a complete description of the study methodology.

The World Health Organization's (WHO) International Classification of Functioning, Disability, and Health, and its 2007 adaptation to children, provide the rubric for conceptualizing children's disabilities. The most relevant elements of the WHO framework for this study include medical impairments (medical conditions that are potentially disabling), limitations in the ability to do everyday activities (walk, dress, eat, understand, communicate, learn, concentrate), and limitations in the ability to participate in social life and age-appropriate roles (play with peers, attend school, work, live independently). An important innovation in the WHO framework is its attention to the ways in which physical and social environments limit the ability to participate when a child, adolescent, or young adult has limitations in his or her ability to do daily tasks. While the term "rehabilitation" suggests that a person with a disability needs to be "fixed" to participate in life, "enablement" refers to helping persons overcome limitations in daily activities to allow full participation in daily life. Enablement includes rehabilitation (surgeries and drugs, therapies, prosthetics, and education supports), but it also goes beyond this to include improvements in the physical and social environment that remove barriers to participation.

I use twenty-four interviews with parents of children who receive occupational and vocational therapy at the Children's Rehabilitation Center. These interviews were organized in a conversational format to

reduce the stress parents experience in discussing the positive and negative aspects of raising a child with a disability and to permit me to uncover new insights into causal connections. After studying this information there were still important unanswered questions. I then conducted my own interviews with six families of children with disabilities to fill in these gaps. I was also privileged to stay with one family whose son had severe cerebral palsy to supplement my own experiences with families raising children with disabilities.

Complementing this qualitative information, I use data that is representative of the entire population to measure how many families are raising children with disabilities, to investigate the extent to which some unfavorable family outcomes (such as divorce, required changes in patterns of work, income loss, and stress) are likely, and to estimate the extent to which families are able to adapt to and cope with the special challenges of raising children with disabilities. For this, I use the 2000 U.S. Census and seven surveys of the American population. Census 2000 included 157,000 children, age six and older, with disabilities, and the seven surveys in combination include 55,142 children with disabilities, including children of all ages. Together, the Census and surveys include information about children from birth to adolescence and from adolescence to the early years of adult life. They also include information about the lives of parents, brothers, sisters, and the family.

An American Issue

The family costs of meeting the national mandate for the enablement of children with disabilities are seldom appreciated. Families of children with disabilities see family strengths and some advantages in their situations. This book shows that mothers, fathers, brothers, and sisters make many sacrifices when their family includes a child with a disability. By identifying the most difficult challenges they face, this study will show the compelling national need to support these families. Greater social and public supports for parents raising children with disabilities are essential to family well-being.

I hope that families of children with disabilities will find this book helpful. I aim to show that many of the costs, adaptations, and perplexities associated with having a child with a disability happen to parents whose children have mild and serious disabilities, and not just to families whose children have severe disabilities. Families also will see that the challenges and struggles of raising children with disabilities are due in large part to the huge societal expectations placed on the parents and the poor institutional arrangements that are available to help them. I also hope that professionals working with children with

disabilities and their families will bring to their work a better understanding of the overall challenges that families—particularly parents—face. Finally, I trust that readers of this book will be better able to recognize the contributions to American life made by families of children with disabilities and will be inspired to help reduce the family consequences of raising children with disabilities in the United States.