### Children with Disabilities and Other Special Needs: Opportunities to Participate in Quality Programs Must Be Expanded

amilies who have children with disabilities or other special needs face many challenges, particularly when trying to find high quality, appropriate child care, early education, and school-age programs for their children. While research has shown that both children with special needs and other children can benefit from inclusive settings, too few opportunities are available in most communities. Even when care is available, a lack of training and other supports means that these families must often struggle to help providers understand and meet the unique developmental needs of their child.

#### Many children have disabilities and other special needs that make it particularly important for them to receive quality care and early education that responds to their needs. Low-income children are more likely to have special needs.

- Nationwide, approximately 6.2 million children with disabilities receive special education and related services under the Individuals with Disabilities Education Act (IDEA). This includes 200,000 infants and toddlers, 600,000 preschool-age children, 2.8 million children ages six to 11, and 2.6 million children ages 12 to 17.<sup>1</sup>
- Nearly 2 percent of the nation's infants and toddlers, 5 percent of the nation's preschoolers, and 11 percent of children ages six to 17 have disabilities and thus require early intervention or special education preschool services under IDEA.<sup>2</sup>
- A large proportion of children with disabilities and other special needs are in low-income families. In 1997-1998, 41 percent of families with infants and toddlers who received early intervention services earned less than \$25,000 a year and another 29 percent earned \$25,000 to \$50,000 a year.<sup>3</sup>
- Sixteen percent of low-income families (families earning less than 200 percent of poverty) have a child with a disability; 9 percent have a child with a severe disability. This is nearly 50 percent higher than the rate among higher-income families. The percentage is particularly high among welfare families—20 percent of these families have a child with a disability, including 13 percent where a child has a severe disability.<sup>4</sup>
- In more than one-third (36 percent) of single-mother, low-income families (families earning less than 200 percent of poverty), the child, the mother, or both have a disability. Nearly half (46 percent) of single-mother families who are receiving welfare include a child and/or mother with a disability.<sup>5</sup>
- Low-income children are more likely to have learning disabilities than higher-income children. Eleven percent of children with family incomes below \$20,000 a year and 8.6 percent of those with family incomes of \$20,000 to \$35,000 a year have learning disabilities, compared to 5.5 percent of children with family incomes above \$75,000 a year.<sup>6</sup>
- Children in poverty are more likely than other children to have a chronic condition that limits activities. The proportion of poor children under age five with a chronic condition is 3.6 percent, versus 3.2 percent of nonpoor children. Among children ages five to 17, 10.5 percent of those in poverty have a chronic condition while 7.1 percent of those above poverty have a chronic condition.<sup>7</sup>

One study found that mothers who had been on welfare were more likely than those who had not been on welfare to be caring for at least one child with a chronic condition—37 percent versus 21 percent, respectively.<sup>8</sup>

#### Providing children with disabilities and other special needs with opportunities to participate in quality child care and early education in inclusive settings can help all children and parents.

- Research shows that providing supports to children with disabilities and other special needs in their early years reduces their need for special education and other supports later in life.<sup>9</sup> For example, a long-term study of a comprehensive, quality preschool program for low-income children in Chicago found that participants had a 41 percent lower rate of special education placement than a similar group of children who did not participate.<sup>10</sup> A study of the Colorado prekindergarten program found that it resulted in cost savings of \$4.7 million over just three years in reduced special education costs.<sup>11</sup>
- Quality child care and early education benefit the parents of children with disabilities and other special needs by giving parents opportunities to learn how they can best support their children and work effectively with school systems to ensure that they are responsive to their children's needs.
- It is important to all children that child care, prekindergarten, and after-school programs provide access to children with disabilities and other special needs.<sup>12</sup> Inclusive programs can benefit children with disabilities and other special needs by allowing them to learn from their peers. They can also teach children the values of interdependence and acceptance of human differences.

# Despite the importance of child care and early education to children with disabilities and other special needs, many lack access to quality care.

- A major study on early childhood development, *From Neurons to Neighborhoods*, identifies several factors that make it extremely difficult for families to find child care for children with disabilities and other special needs. Barriers include the inability or unwillingness of many child care providers to accept children with disabilities, transportation and other logistical problems, challenges coordinating early intervention and child care services, and the scarcity of appropriately trained providers.<sup>13</sup>
- In a study by the U.S. General Accounting Office, six out of seven states surveyed indicated a shortage of child care for children with disabilities or other special needs.<sup>14</sup>
- Care for infants and toddlers with disabilities or other special needs is in extremely short supply, according to a study that involved focus groups of Early Head Start and child care staff from across the country. In many communities, the demand for infant/toddler care is so great that centers are able to fill all of their slots and can avoid accepting children with disabilities or other special needs. For example, a provider from Colorado stated that parents of children with special needs, especially those with significant disabilities, cannot find any infant/toddler care in her community, even though centers cannot deny access to children simply because they have special needs.<sup>15</sup>

- A study of welfare mothers whose children had disabilities and other special needs found that these mothers had difficulty finding quality child care that would accommodate their children. For example, one mother whose two children (an infant and a three-year-old) had asthma discovered that the child care provider was not giving them their asthma medication. The mother immediately removed her children. Another mother whose son had a shunt in his head expressed fear that the providers would not understand that her son cannot lay down. She also worried that they would not recognize signs of a medical crisis. If her son gets a cold or flu-like symptoms, he must be sent to the doctor immediately.<sup>16</sup>
- A survey found that parents who were using paid care and whose children had emotional or behavioral disabilities had great difficulty making child care arrangements. These parents were 20 times more likely than other parents to report that their caregivers had quit or let their children go because of behavioral problems.<sup>17</sup>
- The few high quality programs that are available for children with special needs cannot come close to meeting the demand. For example, the Kindering Center in Bellevue, Washington is the only facility in the area that provides intensive, comprehensive early intervention services for children with disabilities and other special needs. The center offers home visits, family counseling, intensive speech therapy, a specialized preschool program, and other supports for children under age three and their families. The center serves about 1,000 families each year. Many additional families are turned away because the center does not have the capacity to serve them—166 children were on the waiting list in 2000. In the region, other centers that offer similar services are also full.<sup>18</sup>
- One national organization has made a significant commitment to increasing the supply of quality, inclusive child care. Easter Seals now operates more than 50 inclusive full-day, full-year centers for children with and without disabilities between the ages of six weeks and five years in 27 states. Easter Seals hopes to expand these services to all states. These centers strive to meet the highest standards of quality in the child care industry.<sup>19</sup>

### Parents who have children with disabilities or other special needs struggle to balance work and family.

- In a national survey of families who had children with disabilities, one-fifth of the respondents indicated that someone in their family had to quit working or work fewer hours because of a child's health. In a Florida survey of a similar group of families, 40 percent reported that caring for their children's special needs caused someone in the family to not work, 33 percent reported turning down a job, and 20 percent reported working less. The shortage of child care that can appropriately meet the needs of young children with disabilities or other special needs is one of the major factors that make it difficult for these parents to work.<sup>20</sup>
- Parents who have children with disabilities or other special needs, like all parents, must have flexibility in their jobs so they can take time off to care for their children when necessary. Yet, low-income parents, who are more likely to have children with special needs, are also more likely to lack such flexibility:

A study found that mothers who had received welfare were more likely to lack sick leave, paid leave, and the option of flexible schedules. More than one-third (36 percent) of these mothers lacked sick leave for the entire time they worked, compared to 20 percent of mothers who had not been on welfare.<sup>21</sup>

A study of working mothers who were living in poverty found that 37 percent of those who had a child scoring in the bottom quartile on reading tests lacked paid leave. A similar percentage of poor mothers with a child scoring in the bottom quartile on math tests lacked paid leave. Paid leave was not available to 46 percent of poor mothers who had children with the most serious behavioral problems.<sup>22</sup>

# Federal and state resources are available to help support quality care and early education for children with special needs.

The Individuals with Disabilities Education Act provides federal funding for two early childhood programs:

The Preschool Grants Program, authorized under Section 619 of Part B of IDEA, was established in 1981 to provide grants to states to serve young children with disabilities, ages three through five years. All states and eligible jurisdictions and outlying areas have participated in the program since FY 1992. In the 2000-2001 school year, nearly 600,000 preschool-age children received special education and related services nationwide.<sup>23</sup> Special education and related services for preschool-age children can be provided in child care settings. Funding for the program in FY 2002 was \$390 million, the same level as the previous year.

The Grants to Infants and Families (Early Intervention) Program was created in 1986 and supports states in providing comprehensive early intervention services for infants and toddlers (birth through their third birthday) with disabilities, children at risk of developmental delay, and their families. The program operates in every state and served approximately 231,000 children in 2000-2001.<sup>24</sup> Early intervention services are designed to meet the needs of children in the areas of physical, cognitive, communication, social-emotional, and adaptive development. Services must be appropriate to meet the unique needs of each child and family. Most children receive their early intervention services in "natural environments," typically defined as the child's home or child care setting if their parents work outside the home. In FY 2002, federal funding for the program was \$417 million, an increase of \$33.4 million from the previous year.

- Head Start works with children who have disabilities or other special needs. Programs are required to allocate 10 percent of their spaces for children with special needs. In 2000-2001, 13 percent of the Head Start enrollment consisted of children with special needs, such as developmental delays, health and orthopedic impairments, visual and hearing impairments, emotional disturbances, speech and language impairments, and learning disabilities.<sup>25</sup>
- Several states, recognizing that families who have children with disabilities or other special needs often face particular difficulty finding and affording care, establish child care assistance policies specifically targeted to help these families. (States each develop their own definition of "special needs," which may include children with physical and learning disabilities as well as children with other special circumstances, such as a teen parent.)<sup>26</sup>

A number of states give top priority for child care assistance to children with special needs.

Most states take advantage of the federal Child Care and Development Block Grant provision allowing children with special needs to remain eligible for child care assistance past the usual age limit of 13. California allows children to remain eligible for the state component of its program up to age 22 (the age limit for the federal component is 19). In 25 other states, children with special needs can receive assistance up to age 19, and in 21 states the age cutoff for children with special needs is 18.

Four-fifths of the states offer higher reimbursement rates for providers caring for children with disabilities or other special needs. Several of these states set the special-needs rate at least 30 percent higher than the standard rate.

Several states, including the District of Columbia, California, and Missouri, exempt parents receiving assistance from copayments if their children have special needs. A few additional states exempt parents if their children are receiving Supplemental Security Income (Maryland, Oklahoma, and Texas).

Many state prekindergarten initiatives have eligibility criteria that target children with disabilities and other special needs. Kentucky's initiative requires districts to make prekindergarten available to all children ages three and four with developmental delays or disabilities, regardless of family income. Many states also make efforts to serve these children by coordinating their initiatives with other programs and resources or offering teacher training on working with these children.<sup>27</sup>

#### **Source Notes**

<sup>1</sup> U.S. Department of Education. (2001). To Assure the Free Appropriate Public Education of All Children with Disabilities: Twenty-third Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act. Washington, DC: U.S. Department of Education.

<sup>2</sup> U.S. Department of Education. (2001). To Assure the Free Appropriate Public Education of All Children with Disabilities: Twenty-third Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act. Washington, DC: U.S. Department of Education.

<sup>3</sup> U.S. Department of Education. (2001). To Assure the Free Appropriate Public Education of All Children with Disabilities: Twenty-third Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act. Washington, DC: U.S. Department of Education.

<sup>4</sup> S. Lee, M. Sills, and G. Oh. (June 20, 2002). *Disabilities among Children and Mothers in Low-Income Families* (Research in Brief, IWPR Publication #D449). Washington, DC: Institute for Women's Policy Research. The study analyzed data from the Survey of Income and Program Participation collected in 1997.

<sup>5</sup> S. Lee, M. Sills, and G. Oh. (June 20, 2002). *Disabilities among Children and Mothers in Low-Income Families* (Research in Brief, IWPR Publication #D449). Washington, DC: Institute for Women's Policy Research.

<sup>6</sup> B. Bloom and L. Tonthat. (2002). Summary Health Statistics for U.S. Children: National Health Interview Survey, 1997 (Vital Health Statistics, Series 10, No. 203). Washington, DC: U.S. Government Printing Office.

<sup>7</sup> Data from the Centers for Disease Control and Prevention, National Center for Health Statistics, National Health Interview Survey, as cited in Federal Interagency Forum on Child and Family Statistics. (July 2002). *America's Children: Key National Indicators of Well-Being 2002*. Washington, DC: U.S. Government Printing Office. Table HEALTH2.

<sup>8</sup> S. J. Heymann and A. Earle. (April 1999). "The Impact of Welfare Reform on Parents' Ability to Care for Their Children's Health," *American Journal of Public Health*, Vol. 89, No. 4. pp. 502-505.

<sup>9</sup> C. L. Salisbury and B. J. Smith. (June 1993). *Effective Practices for Preparing Young Children with Disabilities for School* (ERIC Digest #E519). Reston, VA: ERIC Clearinghouse on Disabilities and Gifted Education.

<sup>10</sup> A. J. Reynolds, J. A. Temple, D. L. Robertson, and E. A. Mann. (June 1, 2001). "Age 21 Cost-Benefit Analysis of the Title I Chicago Child-Parent Center Program, Executive Summary, June 2001." Report presented at the Annual Meeting of the Society for Prevention Research in Washington, DC.

<sup>11</sup> Colorado Department of Education. (1993). Colorado Preschool Program Child Progress in Years 1-3: Summer 1989 through Summer 1992. Denver, CO: Colorado Department of Education.

<sup>12</sup> K. E. Diamond. (June 1994). Integrating Children with Disabilities into Preschool (ERIC Digest). Urbana, Illinois: ERIC Clearinghouse on Elementary and Early Childhood Education.

<sup>13</sup> J. P. Shonkoff and D. A. Phillips, Eds. National Research Council and Institute of Medicine. (2000). From Neurons to Neighborhoods: The Science of Early Childhood Development. Washington, DC: National Academy Press.

<sup>14</sup> U.S. General Accounting Office. (September 1995). Welfare to Work: Child Care Assistance Limited; Welfare Reform May Expand Needs (GAO/HEHS-95-220). Washington, DC: U.S. General Accounting Office.

<sup>15</sup> D. Paulsell, J. Cohen, A. Stieglitz, E. Lurie-Hurvitz, E. Fenichel, and E. Kisker. (March 2002). Partnerships for Quality: Improving Infant-Toddler Child Care for Low-Income Families. Washington, DC: Zero to Three and Mathematica Policy Research, Inc.

<sup>16</sup> J. C. Timmons, S. Foley, J. Whitney-Thomas, J. Green, and J. Casey. (March 1999). *Negotiating the Landscape: The Path to Employment for Individuals with Disabilities.* Boston, MA: Institute for Community Inclusion/UAP Research and Training Center on Promoting Employment, Children's Hospital; and email correspondence from Susan Foley, November 3, 1999.

<sup>17</sup> A. C. Emlen. (Spring 1998.) "From a Parent's Point of View: Flexibility, Income, and Quality of Child Care." Paper presented at the Child Care in the New Policy Context Conference in Bethesda, Maryland.

<sup>18</sup> C. Cleary. (January 20, 2002). "Giving Kids a Helping Hand: Little Wonders Spark Sweet Joy," The Seattle Times.

<sup>19</sup> Information provided by Easter Seals, 2002.

<sup>20</sup> U.S. General Accounting Office. (June 28, 1999). SSI Children: Multiple Factors Affect Families' Costs for Disability-Related Services (GAO/HEHS-99-99). Washington, DC: U.S. General Accounting Office.

<sup>21</sup> S. J. Heymann and A. Earle. (April 1999). "The Impact of Welfare Reform on Parents' Ability to Care for Their Children's Health," *American Journal of Public Health*, Vol. 89, No. 4. pp. 502-505.

<sup>22</sup> S. J. Heymann and A. Earle. (Winter 2000). "Low-Income Parents: How Do Working Conditions Affect Their Opportunity to Help School-Age Children At Risk?" *American Educational Research Journal*, Vol. 37, No. 4. pp. 833-848.

<sup>23</sup> U.S. Department of Education. (2001). To Assure the Free Appropriate Public Education of All Children with Disabilities: Twenty-third Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act. Washington, DC: U.S. Department of Education.

<sup>24</sup> U.S. Department of Education. (2001). To Assure the Free Appropriate Public Education of All Children with Disabilities: Twenty-third Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act. Washington, DC: U.S. Department of Education.

<sup>25</sup> U.S. Department of Health and Human Services, Head Start Bureau. (2002). *Head Start Fact Sheet.* Retrieved from the Internet at http://www2.acf.dhhs.gov/programs/hsb/research/02\_hsfs.htm.

26 K. Schulman, H. Blank, and D. Ewen. (2001). A Fragile Foundation: State Child Care Assistance Policies. Washington, DC: Children's Defense Fund.

<sup>27</sup> K. Schulman, H. Blank, and D. Ewen. (September 1999). Seeds of Success: State Prekindergarten Initiatives 1998-1999. Washington, DC: Children's Defense Fund.