

## **FINDS Survey Facts to Support “Don’t Cut Our Lifeline” Campaign**

In 2010 The Arc of the United States conducted a national internet survey to capture the perspectives of people with intellectual and or developmental disabilities (I/DD) and their family caregivers. The Family and Individual Needs for Disability Supports (FINDS) survey focused on issues including educational, housing, employment and support needs of people with ID/DD and their families. More than 5,287 family respondents participated in the survey; of these, three-quarters shared their home with a person with ID/DD. Overall, 95% of respondents were parents, siblings, children, grandparents or other relatives of a person with ID/DD.

Family caregivers in 2010 reported substantial ongoing challenges to providing lifelong supports to family members with intellectual or developmental disabilities. People with ID/DD and their families face very real challenges to achieving their aspirations for the future, and decreasing benefits from Medicaid will only continue to hamper such aspirations and millions of lives.

### **Supports provided by Family Caregivers**

- Most family caregivers (58%) provide more than 40 hours of unpaid care per week and 40% provide more than 80 hours of unpaid care per week. This interferes with their work (71%) and causes physical (88%) and financial strain (81%).
- Nearly two-thirds of family caregivers (62%) are paying for some care out of pocket. Family caregivers struggle to find afterschool care (80%), reliable home care providers (84%) and community-based care (82%).
- They report paying for more services out of pocket (47%) and providing more support than they used to (41%).
- Fifty-two percent (52%) of families use Medicaid funds to pay for long term care services and supports, primarily through the Medicaid HCBS Waiver program;
- People with severe ID/DD were more likely to have reported getting supports from a family member paid through the HCBS Waiver program (59%), while people with mild ID/DD were more likely to have received supports from a family member paid out of personal or family sources (56%), most often the personal income of a parent, family member or other caregiver.

### **Challenges**

- Family caregivers report that 25% of the people with ID/DD had no source of income. Only 15% of the people reported being employed.
- Overall, 62% report experiencing decreases in services and 32% were waiting for government funded services, most for more than 5 years.

### **Medicaid Advocacy Toolkit**

- 20% of family caregivers reported that someone in the family had to quit their job to support the person with ID/DD.
- More than 40% of family caregivers reported the person with ID/DD had unmet support needs during the last year for running errands or seeing a doctor (48%), managing finances (46%), transportation (45%) and household management (41%).
- 43% report that schools have cut back on services such as physical, occupational or speech therapies;
- Nearly two-thirds of all family caregivers worry that the person they care for might have to go somewhere they don't want to live.