

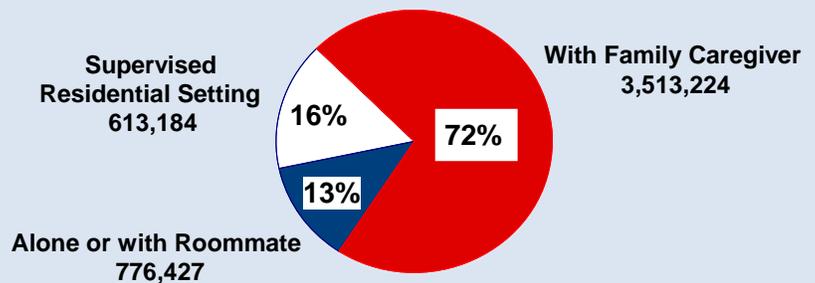
The State of the States in Developmental Disabilities Research and Policy Brief: Siblings of Individuals with Intellectual/Developmental Disabilities



Families provide the majority of support for persons with I/DD...

Between fiscal years (FYs) 2010 and 2011, the total amount of spending for intellectual and developmental disabilities (I/DD) services and supports fell by \$140 million to \$56.65 billion (inflation-adjusted). This decline is cause for concern for the estimated 3.5 million family caregivers (including siblings) who are providing care for their loved ones across the US (**Figure on right**).

Estimated Distribution of People with I/DD in the US in FY 2011

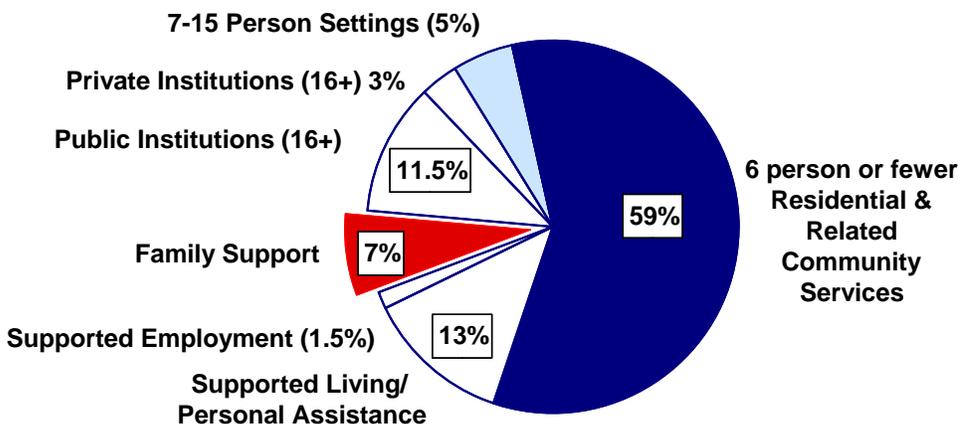


Source: Braddock et al. (2013) based on Fujiura (2012) and *Larson et al. (2001)

...yet receive only a fraction of I/DD funding.

While most individuals with I/DD live with family caregivers, only a fraction of I/DD spending goes to support individuals living in the family home. Family support spending in the US is only 7% of total I/DD spending (**Figure below**).

Spending for I/DD Supports in the US in FY 2011



\$56.65 Billion in Total I/DD Funding in the US in FY 2011

Source: Braddock et al. (2013)

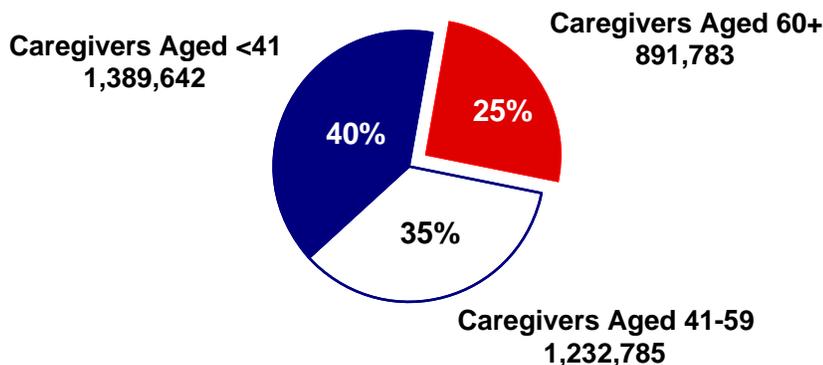
Family support

includes community-based services provided to families for people with I/DD living in the family home such as financial subsidy/cash payments to families, and supports such as respite care, family counseling, equipment, home adaptations, parent education and training, behavior management training, or other state-designated categories of family support.

Siblings are playing an increasing role...

- An estimated 3.5 million people with I/DD are living with family caregivers in the US.
 - Roughly 25% of these individuals are living with caregivers aged 60+ (**Figure below**).
 - The role of siblings is going to become even more important as parents age beyond their caregiving capacity, and siblings shift into the primary caregiving role.
- Siblings often have the longest relationship of their lives with each other.
- Siblings may ultimately take on multiple caregiving roles for their aging parents, siblings with I/DD, and their children.

Estimated Number of People with I/DD Living with Family Caregivers in the US in FY 2011



Total: 3,514,210 Persons with I/DD

Source: Braddock et al. (2013) based on Fujiura (2012) and Larson et al. (2001)

Siblings need to be at the table...

- As future caregivers, siblings need access to information and supports to prepare them for future caregiving roles. This includes information from parents and other caregivers to ensure a smooth transition.

...it's time to start planning for the future!

References:

- Braddock, Hemp, Rizzolo, Tanis, Haffer, Lulinski, & Wu. (2013). State of the States in Developmental Disabilities 2013: The Great Recession and Its Aftermath. Boulder/Chicago: Universities of Colorado and Illinois-Chicago.
- Fujiura, G.T. (2012, June). Structure of Intellectual and Developmental Disabilities Households in the United States: Demographics of the Family in 2010. Presented at AAIDD 136th Annual Meeting, Charlotte, NC.
- Larson, S.A., Lakin, K.C., Anderson, L., Kwak, N., Lee, J., & Anderson, D. (2001). Prevalence of mental retardation and developmental disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements (NHIS-D). *AJMR*, 106(3), 231-252.

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