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).

...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**

- 6 person or fewer Residential & Related Community Services: 59%
- Family Support: 7%
- Supported Living/Personal Assistance: 13%
- Supported Employment (1.5%)
- Public Institutions (16+): 3%
- Private Institutions (16+): 3%
- 7-15 Person Settings (5%)

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**

<table>
<thead>
<tr>
<th>Caregivers Aged &lt;41</th>
<th>Caregivers Aged 41-59</th>
<th>Caregivers Aged 60+</th>
</tr>
</thead>
<tbody>
<tr>
<td>1,389,642</td>
<td>1,232,785</td>
<td>891,783</td>
</tr>
</tbody>
</table>

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

**References:**


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