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*).
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>Category</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregivers Aged &lt;41</td>
<td>1,389,642</td>
<td>40%</td>
</tr>
<tr>
<td>Caregivers Aged 41-59</td>
<td>1,232,785</td>
<td>35%</td>
</tr>
<tr>
<td>Caregivers Aged 60+</td>
<td>891,783</td>
<td>25%</td>
</tr>
<tr>
<td>Total</td>
<td>3,514,210</td>
<td>35%</td>
</tr>
</tbody>
</table>

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:**


This brief was prepared for the Sibling Leadership Network (SLN) by the *State of the States in Developmental Disabilities Project* with partial support from grant no. 90DN0296 from the Administration on Intellectual and Developmental Disabilities. For more information or to create a custom chart for any of the 50 states or the US visit [www.stateofthestates.org](http://www.stateofthestates.org)