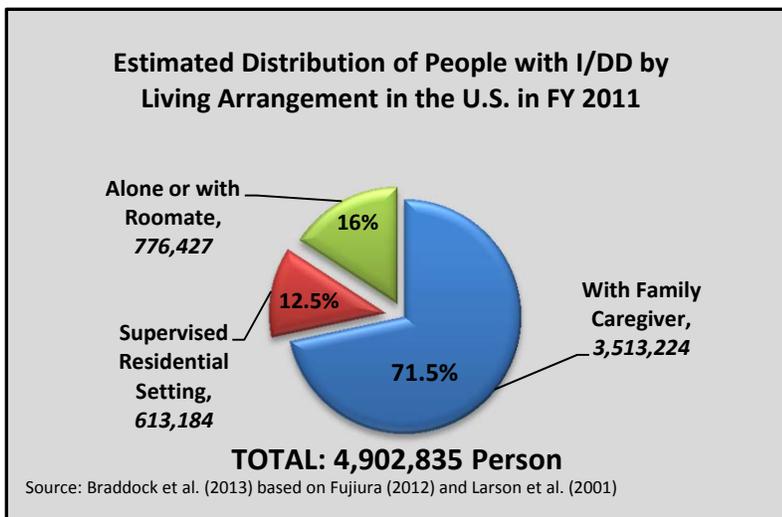


The State of the States in Developmental Disabilities Research and Policy Brief: National Youth Leadership Network (NYLN)



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

In 2011, an estimated 71.5% of children and adults with intellectual and developmental disabilities (I/DD) were living with family caregivers (**Figure below**).



Support for Families...

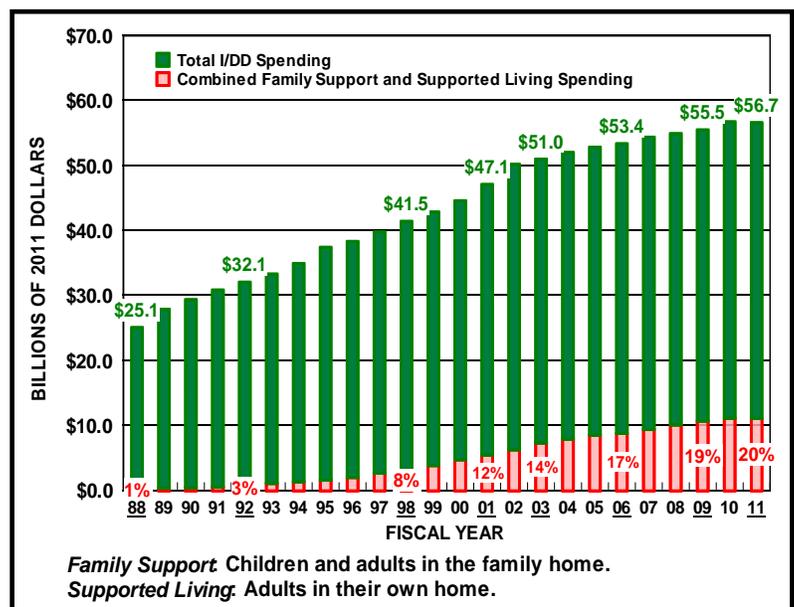
- Includes community-based services supporting families with relatives with I/DD living in the family home. Supports may include financial subsidy/cash payments to families, respite care, family counseling, equipment, home adaptations, parent education, and other supports.

Supported Living...

- Housing for adults with I/DD owned by other than the support provider (the individual, family, landlord, housing cooperative); individuals choose where and with whom they live; and the individual has a personalized support plan that changes as her or his needs change.

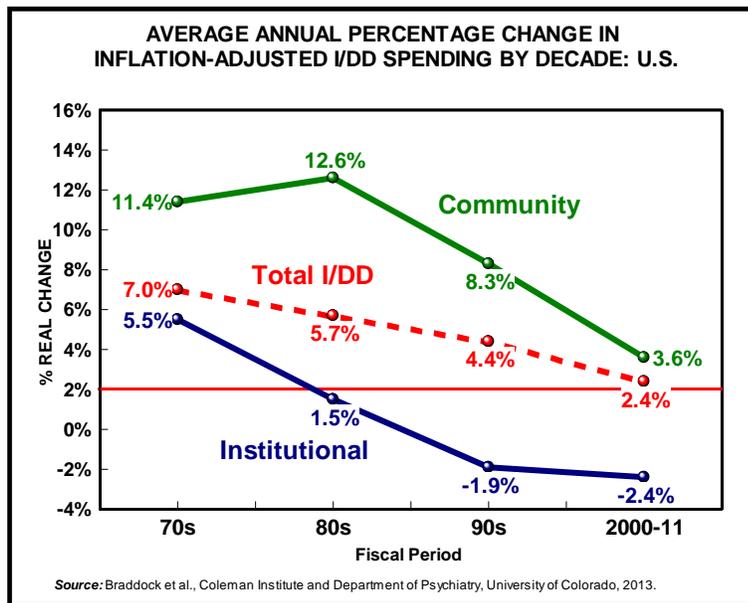
...yet individuals with I/DD living with families and in their own home receive only a fraction of total I/DD spending.

While 72% of individuals with I/DD live with family caregivers, only 20% of total I/DD spending goes to support individuals in supported living or living in the family home. There has been progress but far to go (**Figure on right**).



- 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+
 - The role of youth in families will become more important as parents age beyond their caregiving capacity.
- Youth in families often have the longest relationship of their lives with each other.
- Young family members take on multiple caregiving roles for their aging parents, siblings with I/DD, and their children.

Planning must recognize the reality of contracting resources.... Not only has institutional spending declined by decade, so has the rate of growth of community services spending (*see Figure below*). The efficiencies that come with a shift from expensive, segregated residential setting to community and family services are more critical in meeting the need for supports for individuals in the future.



Youth need to be at the table...

- As potential future caregivers, youth and siblings of individuals with intellectual disabilities 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!

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