

# The State of the States in Intellectual and Developmental Disabilities

Data Brief 2020 (3)



## FAMILY SUPPORT IN ILLINOIS

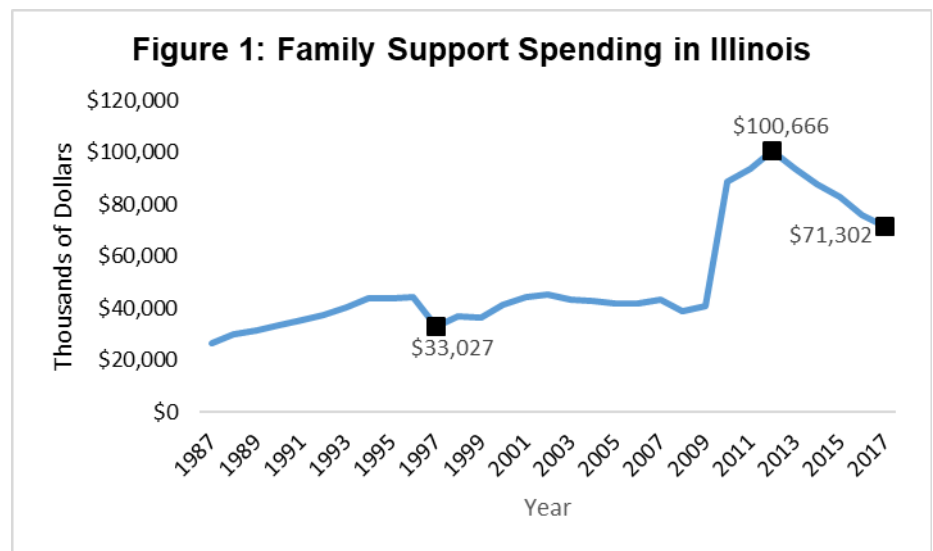
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### SPENDING FOR FAMILY SUPPORT IN THE UNITED STATES

Total spending for Intellectual and Developmental Disabilities (IDD) services and supports in the United States reached \$71.6 billion dollars in adjusted spending in FY 2017. This represents a 20% increase in total spending in the last decade. However, despite the growth in overall spending for IDD services and supports, family support as a service category represents a mere 9.5% of total IDD spending. With this limited investment, greater burden is placed upon families to not only provide caregiving supports but pay out-of-pocket for caregiving needs. Based upon the 2017 FINDS Survey produced by The Arc of the United States, 92% of families reported some out-of-pocket expenses related to family caregiving<sup>1</sup>.

### ILLINOIS FAMILY SUPPORT

In Illinois, family support spending decreased nearly 30% between FY 2013 and FY 2017 as well as the number of families supported (Figure 1)<sup>2</sup>. In FY 2013, 8,801 families were receiving family support through Illinois Home and Community-Based Services Waivers (HCBS) while only 5,949 families were receiving support in FY 2017. Despite this decrease in family support spending, Illinois ranks 18<sup>th</sup> in family support spending in the United States.

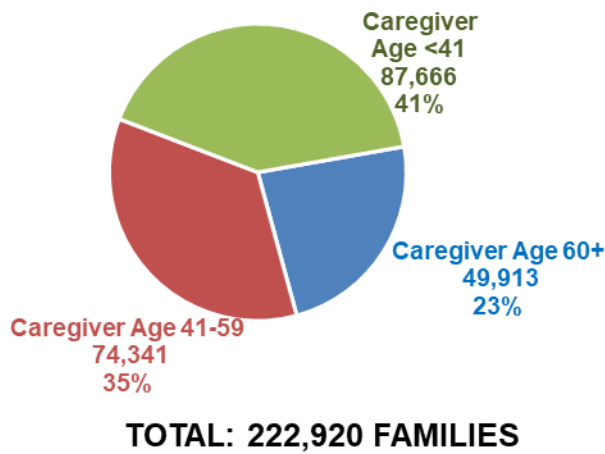


**Family Support** includes community-based services provided to families for people with IDD living in the family home such as financial subsidy/cash payments to families and supports such as respite care, family counseling, equipment, home adaptations, parent education and training, behavior management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

<sup>1</sup> Anderson, L., Hewitt, A., Pettingell, S., Lulinski, A., Taylor, M., & Reagan, J. (2018) Family and Individual Needs for Disability Supports (v.2) Community Report 2017. Minnesota: Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota.

<sup>2</sup> Tanis, et al., (2020). State of the States in Intellectual and Developmental Disabilities Project, University of Colorado.

**FIGURE 2: AGE OF FAMILY CAREGIVERS FOR PEOPLE WITH IDD IN ILLINOIS 2017**



**FAMILY LIVING AND CAREGIVING IN ILLINOIS**

In FY 2017, over 72% of people with IDD lived with family caregivers, including siblings in the U.S. Illinois replicated the national percentage of people with IDD living with family caregivers at 72%. Also similar was the percent of aging caregivers providing supports to people with IDD. Twenty-three percent of family caregivers of people with IDD in Illinois were 60 years of age or older (Figure 2)<sup>3</sup>. Considering most people with IDD in Illinois are living in the family home and aging caregiver numbers are increasing, policy, practice and public funding will need to align with the evolving landscape of family-centered supports and services.

**ILLINOIS STATISTICS FAMILIES NEED TO KNOW...**

- Total public spending for IDD services was \$1.92 billion in FY 2017. This was a slight decrease from total public IDD spending in FY 2016 (\$1.95 billion).
- *Fiscal Effort* is a measure of how much a state spends on IDD long-term supports and services per \$1,000 of statewide personal income. In other words, how much does your state spend after you control for state wealth. In FY 2017, Illinois ranked 43<sup>rd</sup> in the nation in total fiscal effort for IDD services and supports at \$2.86 (national average \$4.41).
- 72% of people with IDD live with family caregivers in Illinois.
- Only 3% of the total number of families providing care for people with IDD receive state IDD agency family support in Illinois.
- 23% of family caregivers in Illinois are age 60 or older.

This brief was prepared for the Sibling Leadership Network (SLN) by the **State of the States in Intellectual and Developmental Disabilities Project** with support from the U.S. Office of Intellectual and Developmental Disabilities, Administration of Community Living.

For more information or to create a custom chart for any of the 50states or the US visit [www.stateofthestates.org](http://www.stateofthestates.org)



<sup>3</sup> Tanis, et al., (2020). State of the States in Intellectual and Developmental Disabilities Project, University of Colorado.