

# The State of the States in Intellectual and Developmental Disabilities

Data Brief 2020 (2)



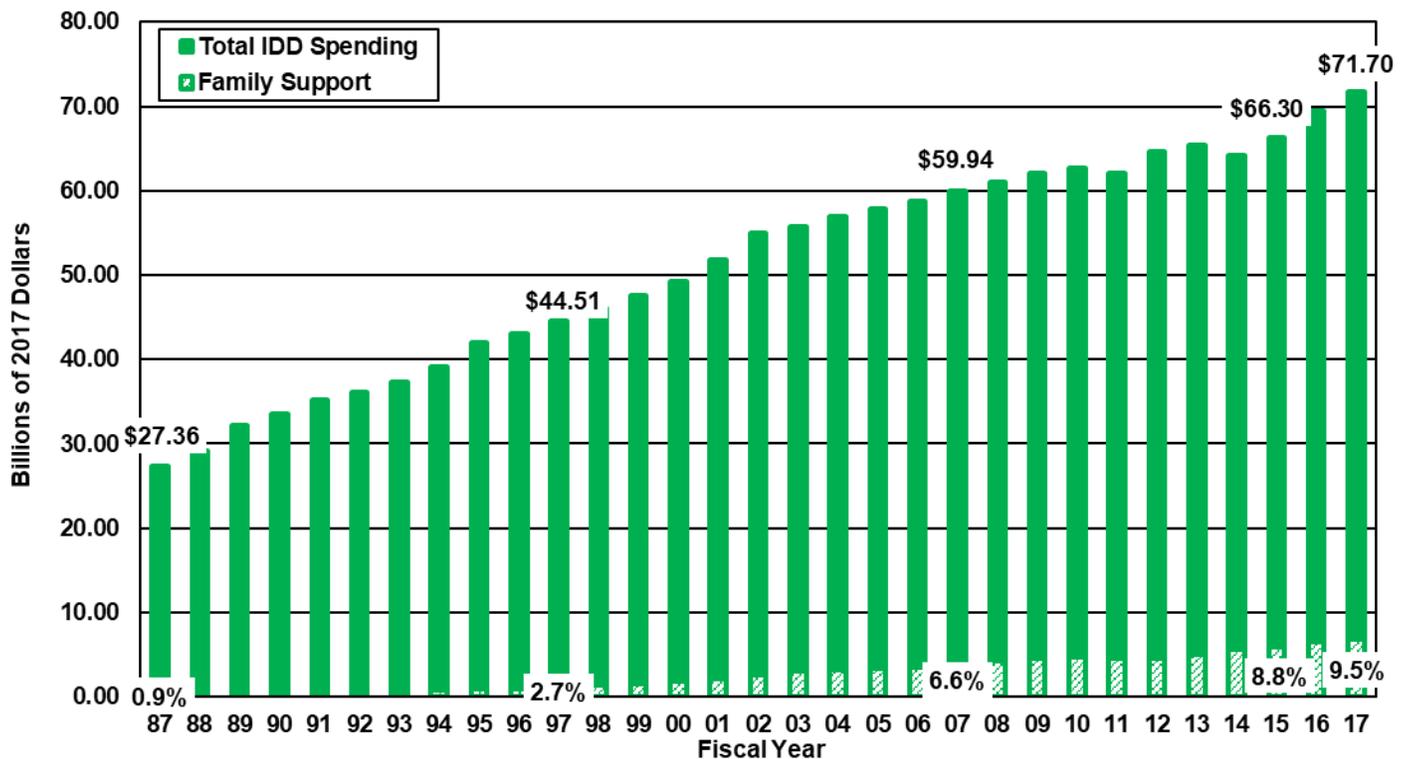
## FAMILY SUPPORT IN THE UNITED STATES

Emily Shea Tanis, PhD, University of Colorado

### Spending for Family Support

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 spending (Figure 1).

FIGURE 1: FAMILY SUPPORT AS PERCENTAGE OF TOTAL IDD SPENDING



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.

States vary in waiver definitions and service categories, as such, family support spending ranges across the states as well from \$278,362 in Iowa to \$973,832,000 in California.

## Family Living and Caregiving

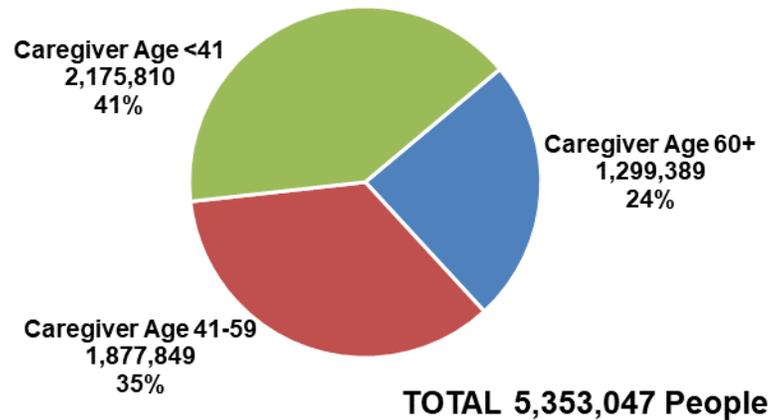
Trends in the United States have revealed more young adults are choosing to reside in the family. In 2019, over 50% of young adults ages 18-24 resided in the family home and over 20% of men and 13% of women ages 25-34 resided in the family home<sup>1</sup>. There are similar trends for families that include adults with IDD. In FY 2017, over 72% of people with IDD lived with family caregivers, including siblings. Other living situations include 10% of people with IDD living in supervised residential

settings and 18% of people with IDD living alone or with a roommate. Additionally, over 24% of caregivers to people with IDD were 60 years of age or older (Figure 2)<sup>2</sup>. With the life span of people with disabilities nearing the national average and increases in aging caregivers, there is a need to reevaluation the service structure and support growing demands of family caregivers.

## Siblings and Family Support

Siblings represent the longest lasting relationship in a person's life. As the nation faces direct support workforce shortages, aging caregivers, and greater demands on natural supports, siblings will begin to play ever increasing roles as advocates and caregivers. Thus, siblings need to be included in systems and person-centered planning activities, representing a unique perspective to establish promising practices and progressive policies.

**FIGURE 2: AGE OF FAMILY CAREGIVERS FOR PEOPLE WITH IDD IN THE U.S. IN 2017**



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



<sup>1</sup> Source: U.S. Census Bureau, Current Population Survey, March and Annual Social and Economic Supplements. Source of 1980, 1970, and 1960 data: U. S. Bureau of the Census, 1980 Census of Population, PC80-2-4B, "Persons by Family Characteristics," Table 4. 1970 Census of Population, PC(2)-4B, Table 2. 1960 Census of Population, PC(2)-4B, Table 2.

<sup>2</sup> Tanis, et al., State of the States in Intellectual and Developmental Disabilities Project, University of Colorado, 2020, based on Fujiura (2012).

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.