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).

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\(^1\). 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)\(^2\). 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.

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