



Understanding Caregiver Burden of Children with Intellectual and Developmental Disabilities (IDD)

A key part of providing holistic support to SWTCIE participants is understanding their caregivers and families. Research suggests that caring for a child, or managing the affairs of an adult with an intellectual or developmental disability (IDD) can be tough and stressful for parents and caregivers (Lahaije et al., 2024). They may need extra help with everyday tasks like eating, bathing, dressing, using the bathroom, and personal hygiene compared to other children/adults with IDD (Oliveira Barros et al., 2016). People with IDD often rely heavily on their caregivers to assist them with managing their daily lives. These factors contribute to parents of people with IDD reporting higher rates of stress, anxiety, and depression. If these feelings persist, they can lead to marital issues, family dysfunction, various physical and mental health problems, and caregiver burden (McConnell & Savage, 2015). Here are some key findings about the health and well-being of caregivers/parents of children with IDD that are important to consider when serving SWTCIE participants:

- Over half (52%) of caregivers of children with both IDD and autism (ASD) report financial difficulties.
- Similarly, 51% have had to stop working to care for their child (Saunders et al., 2015).
- About 25% of caregivers of people with ID experience major depressive disorder (MDD).
- Regarding the level of burden experienced by caring for a child with IDD:
 - Around 23% report severe burden
 - About 45% report moderate to severe burden
 - Approximately 27% report mild to moderate burden
 - Only 3.6% report little or no burden (Maldebha Odedra et al., 2022).

Importance of Supporting Caregivers and Families

Research demonstrates significant challenges reported by caregivers and families. So, what can be done to support them better? Greater social support, both to and within the family, has been shown to help. Social

support is linked to better long-term care planning for a child/adult with IDD, but fewer than 40% of caregivers report having the social support they need (Santos et al., 2022). In many cases, mothers tend to take on more caregiving responsibilities than their spouses or partners, especially in lower-income households (Holloway & Dominguez-Pareto, 2024). Mothers are more satisfied with their lives and rate their families as having a better quality of life when caregiving activities are more evenly distributed, particularly when less-involved spouses become more knowledgeable about their child's disability (Dominguez-Pareto, 2024). It is important to be aware of the limited social support that some families and caregivers have which contribute to caregiver burden and may impact not only the SWTCIE participant but also the entire family dynamic.

Family and Caregiver Support Strategies

The well-being of a family caring for a child/adult with IDD is influenced by social support, the availability of appropriate supports for families, communication and relationships with services and professionals, the availability of information, attitudes toward disability, and governmental support (Chadwick et al., 2013). Several strategies have been suggested in the literature to better support family caregivers in their role. These include:

- providing flexible and timely support,
- offering services and support,
- supplying helpful information,
- showing respect to families and caregivers by listening and involving them in decisions,
- and ensuring that their family member with IDD is supported, listened to, and given opportunities to develop skills and be part of the community (Chadwick et al., 2013).

Consequently, being responsive, communicating clearly and often, and involving families and caregivers when appropriate are recommended practices for SWTCIE practitioners.

Parents Value Competitive Integrated Employment

A person with IDD being part of the community includes being competitively and integratively employed (CIE). Research findings show that parents of children with IDD prioritize CIE over sheltered options (Gilson et al., 2018). Helping people with IDD transition to CIE is the primary goal of our SWTCIE project, and research supports that it is a goal for parents as well, even though it can take a lot of time and effort. Providing SWTCIE practitioners with research information to better understand parents or caregivers' perspectives about their children (youth and adults) with IDD may enhance SWTCIE practices. When someone asks you what makes a job "good," you might mention pay, good hours, and benefits. These are common employment metrics. There are also qualitative metrics like job satisfaction and social interaction opportunities. Interestingly, parents of children with IDD tend to value these qualitative metrics the most when considering employment for their youth or adult with an intellectual and/or developmental disability (Gilson et al., 2018).

Conclusion

In summary, families and caregivers of children, including youth and adults, with ID face many unique challenges, and if left unchecked and unaddressed, these can lead to personal and familial dysfunction. Families face financial and emotional stressors, often having to quit their jobs to care for their child with IDD, because of worrying about the child's health and well-being, along with their own. Helping a youth or adult with IDD work in a CIE setting can help alleviate both financial and emotional burdens families may face by providing good pay and personal well-being through job satisfaction and opportunities that offer positive social engagement with coworkers and colleagues.

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