Alliance for the Betterment of Citizens with Disabilities

Empowering People: Providers Shaping Policies

Informal Caregiver Supports

Informal caregiving is an important component to meet the needs of individuals with intellectual and developmental disabilities who live in their own home. Caregiving can affect the caregiver's life in a myriad of ways. It can bring great satisfaction and strengthen relationships, thus enhancing the caregivers' quality of life. It may also be experienced as stressful since it is often done alone, and the caretaker is always "on call" with a resulting loss of privacy, autonomy, work, social interactions, and relationships. If not adequately supported in their role, informal caregivers can face negative impacts on their health and well-being which would undermine their ability to continue to care for the individual.

> *Families are the primary source of support for older adults and people with disabilities in the U.S. Many caregivers work and also provide care, experiencing conflicts between these competing responsibilities. Research indicates that caregiving also exacts a significant emotional, physical, and financial toll. With nearly half of all caregivers older than age 50, many are vulnerable to a decline in their own health. Studies have shown that coordinated support services can reduce caregiver depression, anxiety, and stress, and enable them to provide care longer, which avoids or delays the need for costly institutional care.*[1]

ABCD recommends the creation of a Referral and Counseling Hotline for informal caregivers of IDD members. The hotline would include:

- information to caregivers about available services
- assistance to caregivers in gaining access to the services
- individual counseling, organization of support groups, and caregiver training
- respite care; and
- supplemental services, on a limited basis

Supports are needed to recognize the essential contribution of the informal caregiver and assist their ability to continue to care for the individual in the community.

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[1] Support to Caregivers. Administration for Community Living. 12/8/20 www.acl.gov/programs/support-caregivers

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