

Attachment 4



Family Support Position Statement

National caregiver studies estimate that more than 85 percent of individuals with developmental disabilities reside with and rely on their families for care. Family caregivers need support throughout the lifespan of a person with a disability. Emotional, social and economic challenges accompany a family's commitment to their family member with a developmental disability. To provide sustained care for a child, a sibling, or an adult with disabilities, families need access to supports and services.

Services and supports to families with a family member with disabilities have a dual focus. Those services support the health and integrity of family units, and they maximize the strengths and potential of individuals with disabilities to independently participate in and be included in their communities. During childhood, family support services are intended to strengthen the family's role as primary caregiver and prevent institutional placement of individuals with disabilities. Throughout an individual's life span, family support services are intended to strengthen and maintain family connections while fostering self-determination, independence, and participation in school, job, recreational and community activities. Adequate support services must be available to people with disabilities so that they can remain in the community rather than face inappropriate institutional placements.

The Texas Council for Developmental Disabilities supports the provision of a full array of flexible, culturally competent family support services that include but are not limited to:

- adaptive equipment and specialized clothing;
- assistive technology devices and services;
- counseling services;
- financial assistance with the extra expenses of providing support;
- home modifications;
- leisure-time planning;
- person-centered comprehensive planning for transition from early childhood to school, from school to adult life, and from adult life to retirement;
- personal assistance services/direct care services;
- respite care that is affordable, safe, age-appropriate and in the most integrated setting;
- service coordination including information and referral services;
- training to empower people with disabilities and their families to advocate for lifestyles they choose and skills to effectively support their family member at home;
- transportation; and
- vehicular modifications.

Providers of family support services must have education and training that will prepare them to work with families and people with disabilities of all ages in inclusive settings to maximize each individual's potential and inclusion with their peer groups.

To be effective and beneficial, family supports and services must be affordable, easy to access, designed by the individual and their family, individualized based on functional needs rather than diagnosis, flexible to changing needs and circumstances, and culturally appropriate.

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