

**Background:**

The Council reviews TCDD’s Position Statements during even number years. Staff solicited input this quarter regarding proposed revisions from Council members on the following position statements:

- A. Family Support *draft*
- B. Children and Families *draft*
- C. Emergency Preparedness *draft*
- D. Community Living *draft*

Revisions suggested by Council members and/or staff are included in the draft materials. Comments in **PURPLE** represent input from Council members; comments in **RED** represent suggestions from TCDD staff.

**Public Policy Committee**

**Agenda Item 7.**

**Expected Action:**

The Committee will consider suggested changes to TCDD Position Statements and recommend revisions to the Council.

**Council**

**Agenda Item 6.**

**Expected Action:**

The Council will consider revisions to TCDD Position Statements recommended by the Public Policy Committee and determine final action.

## Family Support

### Draft Position Statement

~~The Texas Council for Developmental Disabilities supports the position that families should have access to supports and services needed to provide sustained care throughout the lifespan of a child, a sibling, or an adult with disabilities. Family caregiving is the backbone of long term services and supports for Texans with disabilities. 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.~~

**Comment [STA1]:** The first half of this paragraph is redundant to the second half, which is best stated.

~~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:

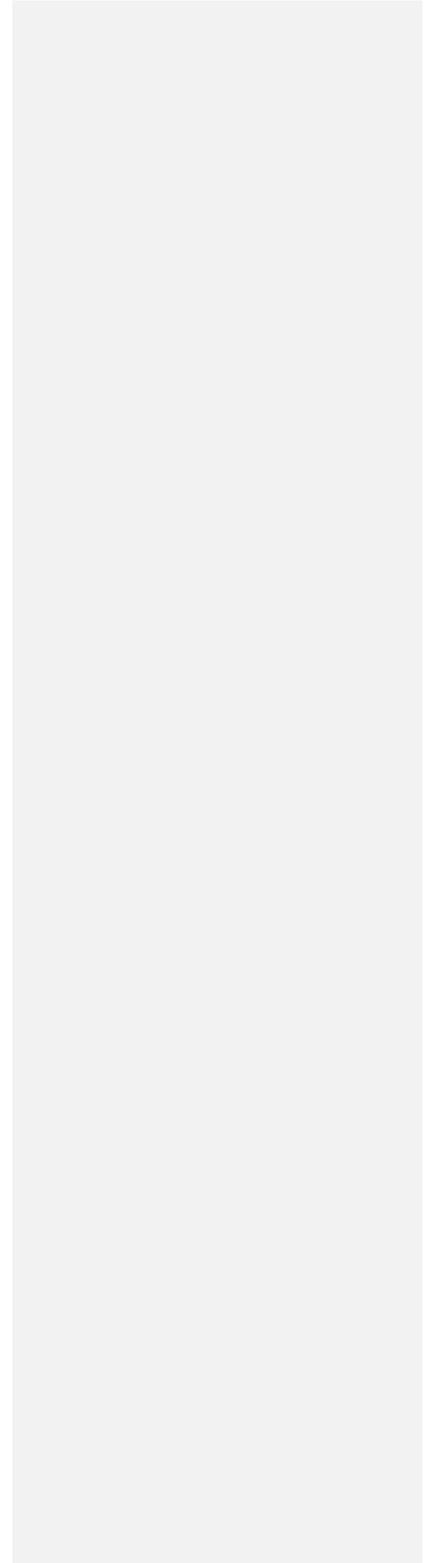
- adaptive equipment and specialized clothing;
- assistive technology devices and services;
- counseling services;
- financial assistance with the extra expenses of providing support;
- home modifications;
- leisure-time planning;
- person-centered comprehensive planning for transition from early childhood 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.

*(Continued)*

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.

Reviewed ~~May 3, 2012~~





## Children and Families

### Draft Position Statement

The Texas Council for Developmental Disabilities supports the position that aAll children belong in families that provide love, caring, nurturing, bonding and a sense of belonging and permanence that best enables them to grow, develop and thrive. Children with disabilities are no different from other children in their need for the unique benefits that come only from growing up in a permanent family relationship. All children benefit and are enriched by being part of an inclusive environment that promotes physical, social, and intellectual well-being and leads to independence and self-determination.

Families of children with disabilities often need supports and services to sustain family life and keep their children at home and included in the community. Family support services are intended to strengthen the family's role as primary caregiver, prevent expensive out-of-home placement of individuals with disabilities, maintain family unity and foster self-determination.

The Texas Council for Developmental Disabilities supports the position that:

- ❑ All children can and should live in a family. All children need a family to best grow, develop and thrive. All children deserve the love, nurturing and permanency that are unique to family life.
- ❑ Families come from many cultures and are multidimensional. No matter its composition or cultural background, a family offers a child a home and a lifelong commitment to love, belonging and permanency. Parents with disabilities are capable of and do provide loving families and homes to children.
- ❑ Families, including parents with disabilities, should have available the level of supports and services needed to keep their children with and without disabilities in their own homes. Family support services should include, but are not limited to, respite care, provision of rehabilitation and assistive technologies, personal assistant services, parent training and counseling, vehicular and home modifications, and assistance with extraordinary expenses associated with disabilities. In addition, since the vast majority (over 85%) of individuals with disabilities reside with families in their own households, families of children with disabilities need access to appropriate child care and to before- and after-school programs. Child care for children with disabilities should be affordable, safe, appropriate and in the most integrated setting.
- ❑ Providers of family support services must have education and training that will prepare them to work with people with disabilities in inclusive settings to achieve this goal.
- ❑ To be effective and beneficial, supports and services must be easy to access, family-driven, individualized, flexible to changing needs and circumstances, culturally sensitive and based on functional needs rather than categorical labels.

*(Continued)*

- ❑ When children cannot remain in their own families, for whatever reason, ~~they still deserve to live and grow up in a family.~~ The first priority should be to reunite the family through the infusion of services and supports. When that is not possible and the family can remain actively involved in the child's life, the natural family should be a key participant in selecting an alternate family situation for their child, including foster families, co-parenting and adoption.
- ❑ When families cannot be actively involved in their children's lives, permanency planning must occur to allow each child to live in a family.
- ❑ School districts and health and human services agencies are integral sources of information and training for parents. Coordination among school districts and outside agencies is critical to provide parents with accurate, timely information regarding services and eligibility requirements.
- ❑ ~~The state Child Protective Services system~~ It is essential to guarantee that all children are safe from abuse and neglect. Support of the families of children with disabilities from this system is critical to make sure children remain in a safe, family environment and are not unnecessarily removed from families due to the absence of necessary services and supports.

~~The Council also supports the position that~~ When children with disabilities grow up in families, the community at large accepts the value of providing supports to children and families at home so that children become and remain participants and contributors to their communities.

The Council supports the public policy statement adopted by the State of Texas recognizing the value of families in children's lives and supports the development of programs, policies and funding mechanisms that allow all children to live and grow up in a family.

Reviewed ~~May 3, 2012~~

# Emergency Preparedness

## Draft Position Statement

~~The Texas Council for Developmental Disabilities supports the position that p~~People with disabilities deserve respectful, prompt and efficient assistance during “shelter in place,”\_evacuation, and relocation resulting from a natural disaster or emergency event. Individuals must have access to appropriate and accessible transportation, shelter, medical and mental health care, and information on temporary support services. ~~The Texas Council for Developmental Disabilities supports the position that T~~to achieve this, people with disabilities and their families, state agencies, first responders, relief workers, and local and state government must work together to create emergency preparedness systems and plans that are responsive to people with disabilities’ needs and stated preferences. There also must be a priority on people with disabilities and their families creating individual emergency preparedness plans.

The Texas Council for Developmental Disabilities supports the position that people with disabilities and their families must be involved in planning and implementing first responder and relief worker trainings that address the needs of people with disabilities in an emergency event, including accessible transportation, adherence to an individual’s existing emergency preparedness plan, and the importance of keeping families and other support networks, including service animals, together throughout the evacuation and relocation processes.

The Texas Council for Developmental Disabilities supports ~~the position that~~ the following principles ~~as are~~ integral to the health and safety of people with developmental disabilities during an emergency event:

- Individuals and families create, review and revise as necessary (at least annually) individual emergency preparedness plans, to include “shelter in place” plans, with support from long-term care and support programs when appropriate;
- Confidentiality of personal and medical information included in an individual’s emergency preparedness plan or provided to any registry system or service provider;
- Participation of people with disabilities and families in developing local, regional, and state emergency preparedness plans, to include “shelter in place” plans, that are responsive to the needs and preferences of people with disabilities;
- Participation of people with disabilities and their families in developing trainings for first responders and relief workers on the needs of people with all disabilities during and after an emergency event, including information on invisible disabilities, self-determination, and preserving support networks; and
- Information on emergency preparedness and preparedness planning activities and resources must be available to everyone.



## Community Living

### Draft Position Statement

The Texas Council for Developmental Disabilities supports the position that individuals with disabilities should have access to opportunities and the supports needed to be included in community life, have interdependent relationships, live in homes and communities, and make contributions to their families, communities, the state, and the nation.

Individuals with disabilities must have access to the full range of accommodations necessary to ensure that living in their community is possible. These accommodations may take various forms such as personal attendant services, medication monitoring, [nursing, behavior supports](#), respite, durable medical equipment, employment services, transportation, and/or minor home modifications. Accommodations may be sustained for either longer or shorter duration or may be of greater or lesser intensity depending on the need of the individual.

Services to children should be provided in their family setting. When children cannot remain with their families, they must be cared for using principles, policies and processes akin to those of permanency planning and have access to family-based alternatives that ensure enduring and nurturing relationships.

Adults with disabilities shall have choice and control about where ~~they live among available options, how, and with whom they live~~. They must be provided with assistance that may be needed to make ~~these~~ [informed](#) choices ~~about how and with whom they live~~ and to sustain choices regarding community living. All people with disabilities should have access to the services and supports they need to live in the community. The state of Texas must allocate the requisite resources to support community living for people with disabilities ~~including community based services and supports and affordable, integrated housing~~. In addition, the state must rapidly expand the availability of individualized community options, transition all individuals in state institutions to community living ~~who choose to do so~~, commit to a ~~thoughtful, measured~~ transition plan to ~~downsize the I/DD institutional capacity in line with anticipated future needs, consolidate and close state-supported living centers~~ and transfer any cost savings ~~resulting from consolidations or closures~~ to quality community programs. Communities must also be cultivated to ensure local systems foster accessibility within and across all facets of community life, so that [living as independently as desired and](#) maintaining [quality](#) community ~~placement living~~ is a feasible outcome for individuals with disabilities.

Approved ~~May 9, 2014~~