

Background:

The Council periodically reviews TCDD’s Position Statements. This quarter, TCDD staff asked Council members to review and recommend updates for the following Position Statements: Children & Families, Emergency Preparedness, Family Support, and Guardianship Reform & Supported Decision-Making.

The following Position Statement documents are included for your review:

- A. Emergency Preparedness - Current Position Statement with Markups*
- B. Family Support - Current Position Statement with Markups*
- C. Guardianship Reform & Supported Decision-Making
 - 1. Current Position Statement with Markups*
 - 2. Position Statement with Recommendations Accepted
- D. Children & Families
 - 1. Current Position Statement with Markups*
 - 2. Position Statement with Recommendations Accepted

* **PURPLE** Council Member input; **RED** Staff input.

<p><u>Public Policy Committee</u></p> <p><u>Agenda Item 6.</u></p>	<p><u>Expected Action:</u></p> <p>The Committee will consider suggested changes to four position statements and may recommend revisions to the Council.</p>
<p><u>Council</u></p> <p><u>Agenda Item 10.</u></p>	<p><u>Expected Action:</u></p> <p>The Council will consider any recommendations offered from the Committee.</p>



Emergency Preparedness Position Statement

The Texas Council for Developmental Disabilities supports the position that 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. 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 following principles as 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 services](#) 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 [in plain language in a format that meets established accessibility standards for people with disabilities](#).



Family Support 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. Emotional, social and economic challenges accompany a family's commitment to their family member with a developmental disability.

Throughout an individual's lifespan, family support services are ~~sometimes necessary 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/or specialized clothing;
- assistive technology devices and services;
- counseling services;
- financial assistance with the extra expenses of providing support;
- home modifications;
- ~~leisure time planning; meaningful day activities;~~
- person-centered ~~comprehensive~~ planning for transition from early childhood to school, from school to adult life, and from adult life to retirement;
- personal assistance ~~and habilitative 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 ~~that is accessible and affordable~~; and
- vehic~~ular~~ ~~accessibility~~ 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 to maximize each individual's ~~potential self-determination~~ and ~~full community~~ 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.

Approved ~~August 8, 2014~~



Guardianship and Supported Decision-Making Position Statement

The Texas Council for Developmental Disabilities supports increasing opportunities for, and protecting the civil rights and well-being of, people with developmental disabilities. The vast majority of people with disabilities, including those with intellectual and developmental disabilities are able to make important decisions, independently or with support, without the need for a guardian. ~~With the provision of supports and services, most persons with disabilities are capable of making important decisions such as where they want to live without the need for a full or limited guardian.~~

Guardianship is a legal tool proceeding which ~~allows a person to make decisions for another person. It also~~ removes the civil rights and privileges of a person by assigning control of their-his or her life to someone else. ~~Although state law in Texas directs a court to encourage the development or maintenance of maximum self-reliance and independence, it is not uncommon for courts to create full guardianships that deprive individuals with disabilities of the right to make fundamental decisions about their lives.~~ The broad definition of incapacity in Texas Estates Code has a discriminatory impact by enabling a court to appoint a guardian if an adult has a physical or mental condition and is substantially unable to provide food, clothing, or shelter, to care for their physical health, or manage their own financial affairs. Even though individuals with a disability may need supports and services or assistance from others to provide for such needs, they should still be afforded able to maintain the right to make choices about these aspects of their lives.

Recent legislative changes promoting alternatives to guardianship, including supported decision-making and a bill of rights for individuals under guardianship, provide the opportunity to significantly advance the rights and protections for individuals with disabilities. To achieve the goals of guardianship reform there must be statewide monitoring and accessible and useable information, training and technical assistance provided to individuals with disabilities, families, courts, attorneys, guardians, educators, medical providers and state and local providers of services and supports.

The Texas Council for Developmental Disabilities supports the following changes to the guardianship system in Texas that would promote the self-determination, well-being and protect the rights of people individuals with disabilities:

- A person should not be presumed to need a guardian because of advanced age or the presence of a physical or mental disability.
- ~~Courts should consider alternatives to guardianship before creating a guardianship. People with disabilities should be given the opportunity to avoid or limit guardianship through a variety of alternatives including supported decision-making. Supported decision-making would allow a person with a disability to select a person or persons to help the person with disability to understand and make decisions about their own lives.~~
 - The definition of incapacity in state law should be revised to consider the person's everyday functioning, values, preferences and cognition rather than their medical diagnosis. ~~The definition of incapacity should also require the consideration of the various proactive measures that have been taken or could be taken, including the use of available supports and services, to~~

~~maximize the ability of that individual to function, and to make and communicate informed decisions.~~

- ~~o The physical examination and documentation for incapacity should be based on functional abilities with or without services and supports.~~
- ~~o Guardianship based solely on the diagnosis of intellectual disability should be prohibited.~~

- ~~□ Attorneys ad litem should be knowledgeable of alternatives to guardianship and supports and services that assist or could assist individuals to make their own decisions and minimize the need for guardianships.~~
- ~~□ A person under a guardianship should receive a copy of their guardianship orders and be informed in a manner accessible to the individual about how they may raise complaints or concerns about their guardian or guardianship to the court, including resources for further assistance.~~
- ~~□ A The court should be required to explain the bill of rights for persons under guardianship ~~that delineates all rights, responsibilities and privileges granted under state and federal laws should be adopted in state law~~ in a manner accessible to the individual.~~
- ~~□ People who have guardians should, when possible, be able to make decisions about where they live.~~
- ~~□ The term “ward” should be revised changed to “person individual under guardianship” in state law and supporting materials.~~
- ~~□ A guardian should be required to meet with the person under guardianship and the person’s and their physician before consenting to the administration of psychoactive medication for that individual except in a medication-related emergency ~~as defined by the Section 574.101(2), Texas Health and Safety Code.~~~~

Approved ~~May 9, 2014~~



Guardianship and Supported Decision-Making Position Statement

The Texas Council for Developmental Disabilities supports increasing opportunities for, and protecting the civil rights and well-being of, people with developmental disabilities. The vast majority of people with disabilities, including those with intellectual and developmental disabilities are able to make important decisions, independently or with support, without the need for a guardian.

Guardianship is a legal proceeding which removes the civil rights and privileges of a person by assigning control of his or her life to someone else. The broad definition of incapacity in Texas Estates Code has a discriminatory impact by enabling a court to appoint a guardian if an adult has a physical or mental condition and is substantially unable to provide food, clothing, or shelter, to care for their physical health, or manage their own financial affairs. Even though individuals with a disability may need supports and services or assistance from others to provide for such needs, they should still be able to maintain the right to make choices about these aspects of their lives.

Recent legislative changes promoting alternatives to guardianship, including supported decision-making and a bill of rights for individuals under guardianship, provide the opportunity to significantly advance the rights and protections for individuals with disabilities. To achieve the goals of guardianship reform there must be statewide monitoring and accessible and useable information, training and technical assistance provided to individuals with disabilities, families, courts, attorneys, guardians, educators, medical providers and state and local providers of services and supports.

The Texas Council for Developmental Disabilities supports changes to the guardianship system in Texas that would promote the self-determination, well-being and rights of individuals with disabilities:

- A person should not be presumed to need a guardian because of advanced age or the presence of a physical or mental disability.
 - The definition of incapacity in state law should be revised to consider the person's everyday functioning, values, preferences and cognition rather than their medical diagnosis.
 - The physical examination and documentation for incapacity should be based on functional abilities with or without services and supports.
 - Guardianship based solely on the diagnosis of intellectual disability should be prohibited.
- The court should be required to explain the bill of rights for persons under guardianship in a manner accessible to the individual.
- The term "ward" should be changed to "individual under guardianship."
- A guardian should be required to meet with the person and their physician before consenting to the administration of psychoactive medication for that individual except in a medication-related emergency as defined by the Texas Health and Safety Code.

Approved



Children and Families Position Statement

The Texas Council for Developmental Disabilities supports the position that all children belong in families ~~where they feel loved and cared for and have the supports and opportunity to that provide love, caring, nurturing, bonding and a sense of belonging and permanency that best enables them to learn to be independent and successful, 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 ~~loving~~ permanent family ~~relationship~~. All children ~~benefit and~~ are enriched by being part of ~~an inclusive environment a family and community~~ that promotes ~~their~~ 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 meant to strengthen support~~ the ~~family's role as family to continue as~~ primary caregiver, ~~maintain family unity and~~ prevent expensive ~~and isolating~~ 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 makeup~~ or cultural background, a family ~~is the best chance for a~~ offers a child to have a home ~~and a lifelong commitment to~~ love, belonging and permanency. Parents with disabilities ~~are capable of can~~ and do provide loving ~~families and~~ homes to children.
- ~~All Families, including parents with disabilities, families~~ 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, ~~habilitation~~ and assistive technologies, personal assistant services, parent training and counseling, ~~vehicular vehicle~~ and home modifications, and assistance with ~~extraordinary~~ expenses associated with disabilities. ~~In addition, s~~
- ~~Since the vast majority (over 85%) of individuals with disabilities reside live with families in their own households, families of children with disabilities need they need access to appropriate~~ child care and ~~to before- and after-school programs with the necessary accommodations to their disability provided in the same settings as other children. 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-appropriate and based on functional needs rather than categorical labels.
- ❑ When children with disabilities cannot remain in their own families, for whatever reason, the first priority should be to reunite the family ~~through the infusion of~~ by offering the necessary services and supports they need to continue to be a family. When ~~that reunification~~ is not possible ~~and the family can remain actively involved in the child's life,~~ the ~~natural~~ family should be an active participant in the child's care plan and 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-necessary to provide parents with accurate, timely information regarding-about services and eligibility-requirements-supports to help their child stay in the home and transition to independent adult life.
- ❑ 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.

~~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-that recognizes 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.

Approved August 8, 2014



Children and Families Position Statement

The Texas Council for Developmental Disabilities supports the position that all children belong in families where they feel loved and cared for and have the supports and opportunity to learn to be independent and successful. Children with disabilities are no different from other children in their need for the benefits that come only from growing up in a loving permanent family. All children are enriched by being part of a family and community that promotes their physical, social, and intellectual well-being and leads to independence and self-determination.

Families of children with disabilities often need supports and services to keep their children at home and included in the community. Family support services are meant to support the family to continue as primary caregiver, maintain family unity and prevent expensive and isolating out-of-home placement of individuals with disabilities.

The Texas Council for Developmental Disabilities supports the position that:

- To best develop and thrive, children can and should grow up in families.
- No matter its makeup or cultural background, a family is the best chance for a child to have a home, love, belonging and permanency. Parents with disabilities can and do provide loving homes to children.
- All families should have the 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, rehabilitation, habilitation and assistive technologies, personal assistant services, parent training and counseling, vehicle and home modifications, and assistance with expenses associated with disabilities.
- Since the vast majority (over 85%) of individuals with disabilities live with families they need child care and before- and after-school programs with the necessary accommodations to their disability provided in the same settings as other children.
- 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.
- Supports and services must be easy to access, family-driven, individualized, flexible to changing needs and circumstances, culturally appropriate and based on functional needs rather than categorical labels.
- When children with disabilities cannot remain in their own families, for whatever reason, the first priority should be to reunite the family by offering the necessary services and supports they need to continue to be a family. When reunification is not possible the family should be an active participant in the child's care plan and 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 necessary to provide parents with accurate, timely information about services and supports to help their child stay in the home and transition to independent adult life.
- ❑ 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 supports the public policy statement adopted by the State of Texas that recognizes 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.

Approved