

Attachment 3



Access to Health Care Position Statement

The Texas Council for Developmental Disabilities supports the position that all people, regardless of their disability, age, or ability to pay, should have access to affordable, comprehensive health care. TCDD supports healthcare initiatives and efforts to increase the access and affordability of health insurance for everyone.

The Texas Council for Developmental Disabilities supports the position that in any consideration of changes to the health care financing and delivery system in the United States, the well-being of the patient must be the highest priority. The Council strongly supports the reform measures and principles set forth in this statement as providing individuals consistent access to patient centered, timely, unencumbered, affordable and appropriate health care and universal coverage while maintaining physicians as an integral component to providing the highest quality treatment.

The Council supports the position that as policymakers considers health care reforms they should:

- Ensure patients are empowered to control and decide how their own health care dollars are spent;
- Eliminate pre-existing condition exclusions;
- Ensure unencumbered access to specialty care;
- Make health care coverage more affordable;
- Improve value and increase quality on our healthcare system;
- Extend both coverage and access for the uninsured and under-insured;
- Avoid establishing new unsustainable programs;
- Provide comprehensive, culturally and linguistically appropriate behavioral health services and supports;
- Provide services in the context of a medical home, where the clinician works in partnership with the individual and/or family to ensure that all of the medical and nonmedical needs of the person are met;
- Ensure that children and adults with behavioral or mental health concerns have access to screening, diagnosis and treatment that is not subject to arbitrary limits on coverage and integrated into the broader health care system;

- Ensure that people with disabilities of all ages and their families have access to health care that responds to their needs over their lifetimes, and provides continuity of care that helps treat and prevent chronic conditions;
- Ensure that people with disabilities and their families receive comprehensive health, rehabilitation, and long term support services provided on the basis of individual need, preference, and choice;

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- Ensure that people with disabilities and their families have equitable access to health coverage programs and not be burdened with disproportionate costs;

The Council is concerned about proposals that call for deep reductions in Medicare and Medicaid payments. Reforms are necessary to strengthen the Medicaid program so that it provides accessible, high-quality health care services to people with disabilities enrolled in the program examples include, but are not limited to, evidence-based practices and payment structures that attract providers.

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Children and Families

Position Statement

All 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 children with 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.

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- ❑ 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 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.

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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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Guardianship Position Statement

The appointment of a guardian is a legal proceeding designed to promote and protect the well-being of the person.¹ Establishing a guardianship removes rights and privileges from the individual and assigns control to someone else. The Council believes guardianship should be granted only if all other alternatives are insufficient, and only to the extent and only for the length of time determined to be necessary, with annual reviews to determine if the guardianship can be terminated or reduced. The Council supports the position that individuals should receive support, education or training to develop their capacity to make decisions for themselves, so that the guardianship may be averted.

The Texas Probate Code requires that all guardianships be as limited as possible. The Council also supports the position that guardianship must be demonstrated to be the most appropriate and least restrictive alternative. When determined to be necessary, a guardianship should be tailored such that it is limited to only those specific areas in which surrogate decision making is likely to be needed. The individual's ability to make decisions should be developed and supported to the maximum extent possible, and guardianship should not decrease an individual's dignity or the right to make choices if there is no undue risk.

According to Texas Probate Code, Chapter XIII, a court may appoint a guardian with full authority over an "incapacitated person" or may grant a limited authority over an "incapacitated person" as indicated by the person's actual physical or mental limitations and only as necessary to promote and protect the well-being of the person. Texas Probate Code further defines "incapacitated person" to mean (A) a minor; (B) an adult who, because of a physical or mental condition, is substantially unable to provide for their own food, clothing or shelter; to care for their own physical health; or to manage their financial affairs; or (C) a person who must have a guardian appointed to receive funds due the person from any government resource.

The Council supports the position that such limitations in abilities must be carefully evaluated, with a presumption that persons with disabilities are competent and individual's decision-making abilities can be supported with education, training and/or assistance. Individuals may require assistance from others or accommodations based on their disability but still be able to make informed decisions based on their own preferences. Most importantly, the presence of a physical or mental disability or the age of an individual does not indicate the need for guardianship. The Council supports the position that the evaluation of a person's mental status must take into consideration and rule out any reversible conditions that can cause confusion and seeming incapacity before certifying the need for a guardian.

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¹ Texas Probate Code, Sec. 602. Purpose of Guardianship.

The vast majority of people with disabilities, including intellectual disabilities, do not need guardians. An in-depth capacity assessment must be conducted prior to any guardianship hearing, focusing on the person's decision-making skills, experience, capacity and support system. The assessment should be conducted by a professional trained to administer and interpret an appropriate instrument related to need for guardianship. Additionally, there must be a mechanism for individuals to provide input during their own capacity assessment and guardianship reviews.

There are a number of alternatives to guardianship that should be explored before proceeding with a guardianship hearing. In the financial area, multi-party contracts, trusts, powers of attorney, representative payees, and money management programs may enable an individual to successfully manage financial issues without the necessity of having a **guardian of the estate** appointed. For health and programmatic concerns, the use of advance directives or surrogate decision-makers (under the Health and Safety Code) might prevent the need to establish a **guardian of the person**. Consideration should be given to providing education and support to develop decision-making skills and opportunities for additional experience.

If the alternatives are not sufficient to protect the interests of the individual, a guardianship hearing may be necessary. It is important that a judge carefully evaluates the qualifications and interests of a proposed guardian and gives special consideration to the nature of the relationship. It is also essential that an appointed **attorney ad litem** adequately represent the interests of the person for whom guardianship is being proposed, and that all attorneys ad litem appointed by judges in guardianship proceedings have been certified in guardianship law by the State Bar of Texas as required by the Texas Probate Code. Further, a professional evaluation of the individual by a physician or psychologist must clearly indicate how the individual's disability affects his or her ability to make and communicate informed decisions and what proactive measures have been taken to maximize the ability of that individual to make and communicate informed decisions.

The Council supports the position that if a **guardianship of the person** is granted, it should be of the limited type in which the specific areas of needed assistance are listed in the order by the judge. The guardianship should encourage the development of maximum self-reliance and independence for the individual. Further, the required annual review of the guardianship must involve a serious consideration of whether it needs to be continued, modified or terminated, and a yearly report of this review must be filed in each guardianship. It is essential that annual reviews are not limited to a financial review, but also consider the individual's capacity and needs. Additionally, the judicial system must have the resources needed to make and review guardianship assessments. The Council further recommends that participants in the annual review should include, but not be limited to, the individual, the guardian, attorney ad litem, and an outside advocate/ombudsman.

It is estimated that many of the Texans with disabilities who do not have the capacity to provide informed consent for services, treatments or legal issues have no one to provide assistance in decision-making or even to serve as a guardian. Financial barriers (bonds and court costs) often prevent family members from serving in this role. The Council supports the position that the state of Texas should remove these barriers. Local guardianship and money management programs (supported in part by the Health and Human Services Commission) plus surrogate consent committees (for ICF-MR residents only) fill part of this gap, as do services provided by the Texas Department of Family and Protective Services. However, more resources are sorely needed in this area. Additionally, the Council believes that the state needs to establish statutory authority to regulate private professional guardians more closely.

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Service Coordination Position Statement

The Texas Council for Developmental Disabilities believes that the full inclusion and participation of people with disabilities in community life requires that individuals be aware of the services and supports available, that they have an array of service and support options from which to choose, and most importantly, that they have the central role in planning and directing their own future. These goals are most readily achieved when individuals and their families receive the benefit of effective, conflict-free service coordination.

Service coordination involves assisting individuals through planning, coordinating, locating, accessing and monitoring services and supports that will result in an optimal quality of life and level of community participation. It is the responsibility of the service coordinators to also serve as advocates for the individuals and their family and provide support for people who are receiving services to advocate for themselves. Service coordination should be viewed as a distinct benefit available to people with disabilities who require assistance, information and advocacy to obtain access to various services and supports to participate fully and be fully included in their communities.

TCDD believes that the service coordination system should be independent from service delivery such that, the service coordinator is free from conflict of interest, and independent or separate from the direct delivery of other services received by the individual and/or family. Service coordinators who are employees of public or private agencies, family members or individual contractors should be independent from conflict of interest. An independent service coordination structure also enables service coordinators to maintain the integrity of their advocacy role. Individuals should be able to choose a qualified service coordinator.

Service coordination must be available on an ongoing basis and support individual(s) rights to:

- access or refuse specific services and supports, as desired;
- develop their own service plan;
- request alternate services and supports, providers or service coordinators; and
- appeal decisions made about the services and supports they receive.

Access to service coordination should be available as necessary and upon request to all persons with disabilities who have functional needs for an array of services and supports. Eligibility should not be based on specific diagnosis. Service coordination must be readily accessible and must have sufficient staff to provide assistance to individuals in a timely and responsive manner. Service coordination should be provided by one person who:

- is committed;
- is well trained;
- is culturally competent;
- serves a reasonable number of individuals; and
- spends most of the time in support and coordination activities.

It is the responsibility of the service coordinator to: (1) advocate on behalf of the individual; (2) help the individual become empowered to act on his or her own behalf; and (3) support the right of that individual to make decisions and to take risks based on informed choice and individual goals and values.

Service coordinators should: (1) be knowledgeable about public and private resources; (2) be creative in their ability to make public and private supports and services work to meet the individuals' needs; and (3) serve a facilitative role in bringing individuals, families and providers together. While service coordinators should be available to assist and consult with providers to ensure services are delivered, they also have a responsibility to monitor the quality of services and supports received.

(j) No organization shall receive more than three (3) direct grants from the Council at any time.

§877.2 Application and Review Process

(a) All requests for proposals will be published in the Texas Register and posted on the Council's website, and a notice will be provided to interested parties.

(b) Proposal information for each request for proposal shall be available upon request from Council offices and will be made available at the Council's website.

(c) Proposals received after the closing date will not be considered unless an exception is approved in a manner consistent with Council policies.

(d) Projects seeking continuation funding may have separate application forms, instructions, and procedures, as determined by Council staff.

(e) Grants shall be awarded based on guidelines that reflect state and federal mandates. Selection criteria shall be designed to select applications that provide best overall value to the state and to the Council and meet the requirements and intent of the Council as provided in the request for proposals.

(f) Final approval of organizations to receive grant funding shall be determined by the Council consistent with Council policies.

(g) Council staff may negotiate with selected applicants to determine the final terms of the award.

§877.3 Suspension or Termination of Funding

(a) If a grantee fails to comply with the terms of the grant, the Council may suspend authority to obligate or receive grant funding pending the result of corrective measures.

(b) The Council, in its complete discretion, may terminate authority to obligate or receive grant funding prior to the end of the funding period if corrective actions are not taken during the suspension period, or if the deficiency is serious enough to warrant immediate termination.

(c) A grant, or portion thereof, may also be terminated at the grantee's request by approval of the Council executive director.

(d) The procedure to request reconsideration of a suspension or termination of funding shall be included in grant award materials.

§877.4 Appeal of Funding Decisions

Appeals may be submitted from applicants for grants who did not receive funding or from grantees whose grants have not been awarded continuation funding. The appeals process adopted by the Council shall be included in grant application materials.

§877.6 Confidentiality of Records

A grantee that provides direct services to individuals under a Council grant must have a system to protect client records from inappropriate disclosure. Disclosure of confidential information must be in accordance with applicable law.