

**Background:**

The Council has developed “position statements” on various issue areas to express the Council’s views and beliefs on each of those issues. The Public Policy Committee periodically reviews and recommends revisions to existing Position Statements. Staff solicited input this quarter regarding proposed revisions from Council members on the following position statements:

- Access to Health Care
- Service Coordination
- Guardianship
- Family Support Services

Revisions suggested by Council members and/or staff are included in the draft materials. Comments in **RED** represent Council member input whereas comments in **BLUE** were suggested by TCDD staff.

The Council adopted revisions to the Children and Families Position Statement during the May meetings. That Statement indicate the “Council believes that the state of Texas should adopt a public policy statement recognizing the value of families in children’s lives.” During a final review following the meeting, staff realized that state law already includes a priority for children to be raised in families. Government Code as a result of SB 368 (2001).

*Sec. 531.152. POLICY STATEMENT. It is the policy of the state to strive to ensure that the basic needs for safety, security, and stability are met for each child in Texas. A successful family is the most efficient and effective way to meet those needs. The state and local communities must work together to provide encouragement and support for well-functioning families and ensure that each child receives the benefits of being a part of a successful permanent family as soon as possible.*

Staff therefore propose a final technical revision to the Statement in this manner:

The Council supports the ~~position that public policy statement adopted by~~ the State of Texas ~~should adopt a public policy statement~~ 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.

The table below reflects the most recent dates that position statements were reviewed (statements in **bold** are currently under review). The Public Policy Committee will review a schedule to update TCDD’s Position Statements prior to the 83<sup>rd</sup> Session of the Texas Legislature, which begins in January 2013.

**Position Statements Last Reviewed**

Employment	Aug '09	Education	Feb '10	Emergency	Feb '12
		Criminal Competency	Feb '10	Preparedness	
Transition	Aug '09	<b>Children &amp; Families</b>	<b>Feb '12</b>	<b>Services Coordination</b>	<b>May '10</b>
Aging & DD	Nov '09	<b>Family Support</b>	<b>Feb '10</b>	<b>Guardianship</b>	<b>May '10</b>
Transportation	Feb '12	Right to Privacy	Feb '12	<b>Access to Health Care</b>	<b>Aug '10</b>
				Community Living	Aug '10

**Public Policy Committee**

**Agenda Item 12.**

**Expected Action:**

The Committee will review provide recommendations to the Council for revisions to those Position Statements reviewed.

**Council**

**Agenda Item 9.**

**Expected Action:**

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



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## 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 efforts to increase the access and affordability of health ~~care insurance~~ for employer groups and its employees and for those not eligible for employer coverage. The Council supports the position that full access to health care must be based on the following critical principles:

**Comprehensiveness** - All people, regardless of their disability, age of onset, or age, must have access to a comprehensive, integrated array of health, behavioral health and rehabilitation personal, and support services across all service categories and sites of service delivery services. ~~To be comprehensive, these services should be provided 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. A medical home is defined as primary care that is comprehensive, accessible, continuous, consumer-centered, coordinated, compassionate, and culturally effective. Through this partnership, the clinician helps the individual and/or family coordinate and access specialty care, educational services, out of home care, family supports, and other public and private community services that are important to the overall health of the individual and/or family. In addition to the traditional acute care hospital and physician services, comprehensive health related services include, but are not limited to the following: Which includes:~~

- traditional acute care hospital and physician services;
- wellness and preventive services, including services to prevent secondary conditions or a loss of functional ability;
- health promotion/education services;
- (something re: medical home)
- diagnostic services;
- long and short term in-home health-related services;
- prescription drugs, biologicals and medical foods;
- mental health and counseling services;
- rehabilitation services and specialty care, including audiology, occupational, physical and respiratory therapy, speech-language pathology services, cognitive therapy, vision and hearing care, behavioral therapies, and therapeutic recreation;
- personal assistance and habilitative services and independent living services and;
- durable medical equipment and other assistive technology devices, equipment and related services.

**Choice** - All people, regardless of their disability or age, must be assured that comprehensive health, rehabilitation, personal and support services are provided on the basis of individual need, preference and choice which:

- ensure a level of consumer choice in relation to services and providers;
- ensure a range of service community-based settings through an integrated delivery system;
- ensure an appropriate amount, scope and duration of services; and
- ensure the availability of trained personnel.

(Continued)

**Equity** - All people, regardless of their disability or age, must be ensured equitable participation in all available health care systems and not be burdened with disproportionate costs. An equitable system:

- limits out-of-pocket expenses and cost sharing requirements;
- provides access to services based on health care need, ~~not income level or employment status~~ rather than ability to pay and/or insurance coverage;
- ensures adequate reimbursement for service; ~~and~~
- promotes health and related services in the most integrated setting; and
- ensures equity in coverage between mental health and physical health benefits.

**Efficiency** - All people, regardless of their disability or age, must have access to a comprehensive health care system - including wellness, prevention and treatment services - that provides appropriate, effective, quality services and which minimizes administrative waste. An efficient system:

- reduces administrative complexity and minimizes administrative costs;
- ~~allocates resources in a more balanced way between~~ invests in preventive services to minimize utilization of more costly services such as emergency room, hospital and physician acute care;
- promotes rehabilitation and chronic care management; and
- maintains effective, ~~cost controls~~ comprehensive service delivery systems so that ~~all~~ people can get the health care services which they need in a timely manner.

**Non-Discrimination** - All people, regardless of their disability or age, must be able to fully participate in all health care systems and have access to health care services:

- provided in locations and facilities that fully comply with the Americans with Disabilities Act and other applicable accessibility requirements;
- that embrace research that recognizes and includes people with disabilities, ethnic minorities, people living in rural areas, the elderly, women and children as a disparity populations; and
- that are affiliated with health care training programs which include developmental and mental health disease and best practices.

**Transition and Coordination** – All people, regardless of their disability or age, must have access to and receive services needed to enable and facilitate sensitive and planned transition and coordination from one health service provider or setting to another, including at least the following situations:

- among primary care and specialty care providers;
- upon discharge from one setting to another, such as from acute inpatient care to less intensive care settings, including to care provided in the home;
- when moving from a pediatric to an adult ~~servicing~~ medical home; and
- when considering and upon entering palliative or hospice care ~~settings~~.

~~Reviewed August 6, 2010~~ May 3, 2012



## Access to Health Care Position Statement

The Texas Council for Developmental Disabilities believes 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 believes 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 TCDD 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 TCDD believes that as policymakers consider health care reforms they should:

- Make certain that 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.
- Ensure that people with mental health conditions have access to the full array of services necessary for recovery from these conditions and are not subject to arbitrary limits on days, visits, and other conditions of coverage;
- Ensure that people with disabilities of all ages and their families must 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 must be assured that comprehensive health, rehabilitation, and long term support services are provided on the basis of individual need, preference, and choice.
- Ensure that people with disabilities and their families must have equitable access to health coverage programs and not be burdened with disproportionate costs

*(continued)*

TCDD are 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 (e.g., evidence-based practices, payment structure that attracts providers, etc.).



## 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 advocate 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 **or financial status**. 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.

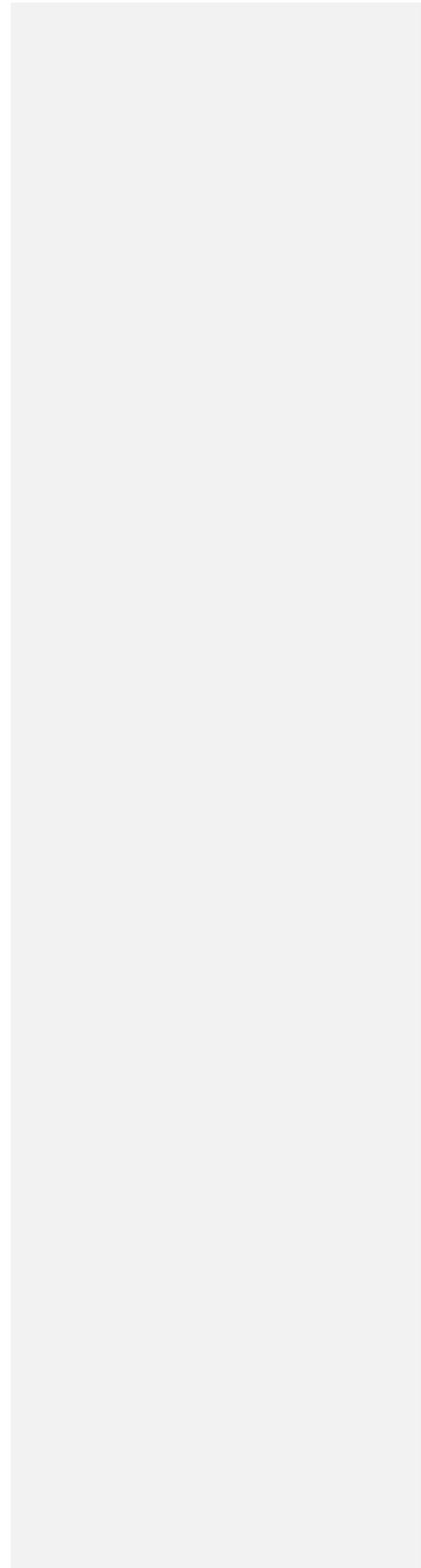
It is the responsibility of the service coordinator to: (1) advocate on behalf of the individual; (2) help the individual become empowered to act on his or her own behalf; and (3) support the right of that individual to make decisions and to take risks based on informed choice and individual goals and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

**Comment [c1]:** This sentence is a staff suggestion to be included in the position statement since reference is made below to the "advocacy role" of the service coordinator but it is not defined what the role should be.

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.

Reviewed May 7, 2010





## Guardianship Position Statement

The appointment of a guardian is a legal proceeding designed to protect individuals from abuse, neglect (including self-neglect) and exploitation and to provide for their care and the appropriate management of their property. The appointment of a guardian is a legal proceeding designed to promote and protect the well-being of the person.<sup>1</sup> 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.

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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 that some limitations may be reduced with education, training, and/or assistance support. 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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<sup>1</sup> 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 support 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.

[Reviewed May 7, 2010 May 3, 2012](#)



## Family Support Services 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. ~~Families that care for individuals with disabilities range from young parents learning to care for children with physical and mental disabilities, to parents caring for teenagers and young adults with disabilities, to frail and elderly parents of aging, dependent adults with disabilities.~~ 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 [c1]:** Staff comment: Lengthy sentence...suggestions to keep to it the way it is, alter to shorten or cut all together?

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 ~~settings~~ [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.

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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 ~~sensitive~~ [appropriate](#).

Reviewed ~~February 12, 2010~~ [May 3, 2012](#)



## 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](#) ~~position that~~ the State of Texas [should adopt a public policy statement](#) 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 February 09, 2012