

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 reviews and recommends revisions to existing Position Statements every four years. Staff solicited input this quarter regarding proposed revisions from Council members on the following position statements:

- Right to Privacy
- Service Coordination
- Guardianship
- Emergency Preparedness

Revisions suggested by Council members and/or staff are included in the draft materials.

At the current time, staff does not anticipate “Right to Privacy” as a key policy issue in upcoming public policy discussions and recommends dropping that statement from TCDD’s cluster of Position Statements.

Public Policy Committee

Agenda Item 5.

Expected Action:

The Committee will review and consider any revisions to recommend to the Council on four Position Statements.

Council Meeting

Agenda Item 6.

Expected Action:

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



Right to Privacy Position Statement

The Texas Council for Developmental Disabilities recognizes that people with disabilities have the same right to privacy as all people have in our nation. Confidentiality has historically been a cornerstone in providing services and medical care to people. The level of privacy protected under the Fourth Amendment of the U.S. Constitution is being challenged by the rapidly developing interactive technologies with a quickly emerging global information infrastructure.

In this age of the evolving information and communication technologies, the Council recognizes the positive role that the electronic media brings to the compilation and exchange of information. Our government agencies, businesses and non-profit agencies now have the advantage of quick exchange of information and the ability to gather and analyze massive amounts of information. This new capacity can help in streamlining business, reduce costs and ensure appropriate services for people. However, this new capacity for data collection can also be used intentionally or unintentionally to the detriment of the people the government agencies serve. The Council believes that the following basic principles must be applied to all information data collection systems.

- ❑ Individuals, government entities, profit and nonprofit organizations have a shared responsibility for the secure use of personal information.
- ❑ Prior to the collection and dissemination of personal and identifiable information, each individual must be advised of:
 - the specifics of personal information to be collected and/or released;
 - the entity which is collecting the information and the entity to which the information will be released;
 - the purpose for which the information is to be collected and/or released;
 - the individual's legal rights to privacy and confidentiality of personal information;
 - the administrative procedures to follow to review personal information;
 - the process to remove, correct or add information that has been entered in a data collection system;
 - the avenues of recourse to recover damages in the case of improper use and/or disclosure of personal information; and
 - the degree of risk that personal information may be inadvertently collected by other entities through the electronic transmission processes.

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- ❑ Efforts must be made to ensure that personal information is not inadvertently shared, obtained, or collected by unauthorized parties through the process of electronic data transmission.
- ❑ Directories of an individual's personal information which may include personal identity; social security number; religious, political or organizational affiliations; employment; educational, medical, psychiatric, psychological, financial, and legal history; and family status must be used only as originally allowed by the individual.

Reviewed ~~August 5, 2006~~ May 6, 2010



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 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. Service coordination should be viewed as a distinct benefit available to people with disabilities who require 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.

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 to all persons with disabilities who have functional needs for 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 must: (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.



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. 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 Texas Probate Code requires that all guardianships be as limited as possible. The Council also believes 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 believes that such limitations in abilities must be carefully evaluated, with a presumption that persons with disabilities are competent. 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 also believes 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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The vast majority of people with disabilities, including mental retardation, 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 (for mental retardation) must clearly indicate how the individual's disability affects his or her ability to make and communicate informed decisions.

The Council believes 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 believes 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.



Emergency Preparedness Position Statement

People with disabilities deserve respectful, prompt, and efficient assistance during 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 believes that 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 also believes 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 believes that the following principles 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, 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 voluntary registry system;
- Participation of people with disabilities and families in developing local, regional, and state emergency preparedness 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.