

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
- Transportation
- Children and Families
- Emergency Preparedness

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

Position Statements Last Reviewed

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

Public Policy Committee

Agenda Item 9.

Expected Action:

The Committee will review provide recommendations to the Council for revisions to those Position Statements reviewed, and may provide guidance to staff as appropriate for a schedule to review remaining Statements.

Council

Agenda Item 10.

Expected Action:

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



Public Transportation Systems Position Statement

Within our society, freedom of movement is a fundamental right; however, it remains a largely unfulfilled promise for citizens with disabilities. Transportation is essential to any effort to enable all citizens to live as independently as they choose, to engage in productive self-sustaining activity, to participate in all facets of community life, and to be fully integrated in their communities. A transportation system should be a seamlessly connected network with a pedestrian infrastructure linked to all modes of public transportation including taxi services, bus, light rail, trains and airplanes as well as cars and bicycles. A public transportation system must meet the needs of citizens in an accessible and affordable manner.

The Texas Council for Developmental Disabilities believes that all publicly funded and/or regulated transportation service systems must be:

- seamlessly coordinated at state, federal and local levels among all modes of transportation;
- expanded in suburban, urban, rural and unincorporated areas to connect places people live with places they work, shop, socialize, worship, attend school, access health care, etc.; and
- be fully accessible to all people with disabilities

[The Council advocates that people with disabilities actively be actively represented on boards and advisory groups for both public and private entities that oversee or provide transportation services.](#)

The Council will continue to work collaboratively with partners such as agencies representing seniors, [people with disabilities](#) and low income families, who share transportation concerns, to continue to seek solutions now and in the future.

Reviewed ~~November 13, 2009~~ February 09, 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 believes 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 ~~can are~~ not ~~be~~ actively involved in their ~~child's life~~ children's lives, permanency planning must occur to allow ~~the~~ each child to live in a family.
- ❑ School districts and health and human services agencies are ~~an~~ 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 believes 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 believes that the State of Texas should adopt a public policy statement recognizing the value of families in children's lives and develop programs, policies and funding mechanisms that allow all children to live and grow up in a family.

Comment [c1]: Kathy Griffith Bailey comment:
Since the state includes the executive, legislative and judiciary branches, "State of Texas" may be too broad and not specify where responsibility for adopting the policy really is.

Reviewed ~~February 12, 2010~~ February 09, 2012



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, reducing costs and ensuring 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 should be applied to all information data collection systems.

- ❑ Individuals, government entities, profit and nonprofit organizations, and businesses have a shared responsibility for the secure use of personal information.
- ❑ Prior to the collection and dissemination of personal and identifiable information, each individual should 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

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- the degree of risk that personal information may be inadvertently collected by other entities through the electronic transmission processes.

- ❑ Those who obtain, possess or retain personal information should make efforts ~~should be made~~ to ensure that such 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 should be used only as originally allowed by the individual.

| Reviewed ~~May 7, 2010~~ February 9, 2012



Emergency Preparedness Position Statement

People with disabilities deserve respectful, prompt and efficient assistance during [“shelter in place,”](#) evacuation, and relocation resulting from a natural disaster or emergency event. Individuals must have access to appropriate and accessible transportation, shelter, medical and mental health care, and information on temporary support services. The Texas Council for Developmental Disabilities 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, [to include “shelter in place” plans](#), with support from long-term care and support programs when appropriate;
- Confidentiality of personal and medical information included in an individual’s emergency preparedness plan or provided to any [voluntary](#) 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](#).