

**Background:**

Draft minutes from the May 6, 2010, Public Policy Committee meeting are included for review.

**Public Policy Committee**

**Agenda Item 3.**

**Expected Action:**

The Public Policy Committee will take action to approve the minutes.

**PUBLIC POLICY COMMITTEE MEETING  
DRAFT MINUTES  
May 6, 2010**

**Thursday, May 6, 2010**

**COMMITTEE MEMBERS PRESENT**

Rick Tisch, Chair	Mateo Delgado	Jeff Kaufmann, DADS
Hunter Adkins	Mary Faithfull, AI	Amy Sharp, CDD – TX A&M
Kristine Bissmeyer	Frank Genco, HHSC	Lora Taylor
Brenda Coleman-Beattie	Cindy Johnston	

**COMMITTEE MEMBERS ABSENT**

Marcia Dwyer, Vice-Chair	Penny Seay, CDS – UT
Lynn Blackmore, DARS	

**STAFF MEMBERS PRESENT**

Belinda Carlton	Melissa Loe	Roger Webb
Joanna Cordry	Lucy Walker	

**CALL TO ORDER**

The Public Policy Committee convened on Thursday, May 6, 2010, at the Marriott Austin South, 4415 S. IH-35 Austin TX 78744. Committee Chair Rick Tisch called those present to order at 1:30 PM.

**I. INTRODUCTION**

Committee members, staff and guests were introduced. It was announced that Melissa Rosser has been selected for the TCDD Public Policy Assistant position and will begin on June 1st.

**II. PUBLIC COMMENTS**

No public comments were offered.

**III. APPROVAL OF MINUTES**

Tisch asked for corrections or additions to the minutes of the November meeting. Jeff Kaufmann and Mary Faithfull noted that their names were misspelled in the minutes.

**MOTION:** To approve the February 11, 2010, Committee meeting minutes as revised.

**MADE BY:** Lora Taylor

**SECOND:** Kristine Bissmeyer

The motion **passed** without opposition.

#### IV. **PROCESS TO DEVELOP TCDD FY 2012-2016 STATE PLAN**

Following up on work by the Committee of the Whole, the Public Policy Committee discussed possible approaches the Council could take in developing the TCDD State Plan for fiscal years 2012-2016. Discussion centered on two options: a portfolio approach (as done in the past) or a more data-driven, strategic planning model. Planning Coordinator Joanna Cordry requested that the Committee provide a recommendation on what type of model it prefers.

**MOTION:** To recommend that the Council use a “strategic” approach in preparing TCDD’s 2012-2016 State Plan, while keeping a reserve for addressing emerging issues.

**MADE BY:** Mateo Delgado

**SECOND:** Hunter Adkins

The motion **passed** without opposition.

#### V. **TCDD STATE PLAN AMENDMENTS FOR FY 2011**

The Committee discussed the TCDD State Plan for FY 2011 and agreed by consensus that no changes are needed for the next year, which is the final year of the current five-year plan.

#### VI. **2010 BIENNIAL DISABILITY REPORT UPDATE**

The Committee received an update from Executive Director Roger Webb regarding preparation of the 2010 Biennial Disability Report. TCDD staff are coordinating with the Department of Aging and Disability Services (DADS) to develop a Memorandum of Understanding (MOU) in order to survey a random group of people on the Home and Community-Based Services (HCS) Medicaid waiver interest list. The University of Texas at Austin is also working with TCDD to help design this survey and analyze results. TCDD staff are also soliciting offers for a technical writer to assist with preparing the report.

#### VII. **TCDD POSITION STATEMENTS**

The Committee discussed TCDD’s Position Statements on the Right to Privacy, Service Coordination, Guardianship, and Emergency Preparedness. The Committee approved changes to all four Position Statements and recommended Council approval of the position statements as modified.

**MOTION:** To recommend Council approval of the **Right to Privacy** Position Statement as presented, changing the word “must” to “should” throughout the document.

**MADE BY:** Mateo Delgado

**SECOND:** Hunter Adkins

**ABSTAIN:** Cindy Johnston

The motion **passed**. (Attachment 1 as approved.)

**MOTION:** To recommend Council approval of the **Service Coordination** Position Statement as presented, changing the word “must” to the word “should” in the last paragraph.

**MADE BY:** Cindy Johnston

**SECOND:** Kris Bissmeyer

**ABSTAIN:** Jeff Kaufmann and Frank Genco

The motion **passed**. (Attachment 2 as approved.)

**MOTION:** To recommend Council approval of the **Guardianship** Position Statement as presented, changing “mental retardation” to “intellectual disabilities” in the fifth paragraph and deleting “mental retardation” in the seventh paragraph.

**MADE BY:** Amy Sharp

**SECOND:** Mary Faithfull

**ABSTAIN:** Rick Tisch

The motion **passed**. (Attachment 3 as approved.)

**MOTION:** To recommend Council approval of the **Emergency Preparedness** Position Statement as presented, adding “including service animals.”

**MADE BY:** Amy Sharp

**SECOND:** Lora Taylor

The motion **passed**. (Attachment 4 as approved.)

#### **VIII. PUBLIC POLICY REPORT**

The Committee received a public policy report from Executive Director Webb and Public Policy Specialist Belinda Carlton. Webb discussed a few issue-focused initiatives that TCDD may want to consider in the future including the possibility of focusing more directly on employment issues and issues related to children aging out of state conservatorship. Regarding employment, recent discussions suggest there is the potential to work with a variety of key stakeholders and coordinate across agency lines -- with the Department of Assistive and Rehabilitative Services (DARS) Division of Rehabilitation Services and the Department of Aging and Disability Services (DADS), particularly concerning use of waiver funds to support individuals in employment.

The Committee reviewed a letter asking the Health and Human Services Commission (HHSC) to request funds in its next legislative appropriations request to support travel for public members of advisory committees. The letter explains that TCDD has been providing travel funds for this purpose for nearly a decade.

Carlton provided an update on healthcare reform. The Committee also heard a report on recent public policy testimony and comments made by TCDD staff during the last three months.

#### **IX. PUBLIC INFORMATION REPORT**

The Committee received an update by Communications Coordinator Melissa Loe on recent public information activities. Loe also lead a discussion on future plans for the TCDD annual report and communications plan. Chair Tisch asked staff to decide on the best format for TCDD’s annual report for the public.

**X. OTHER DISCUSSION ITEMS**

Following up on a discussion by the Committee of the Whole about future public policy collaboration activities, the Public Policy Committee expressed a desire for this activity to be placed first on TCDD's funding priority list.

**MOTION:** To recommend that the Council include the TCDD Public Policy Collaboration Activities on the Future Funding Activities Priority List and move it to the top of the list.

**MADE BY:** Kris Bissmeyer

**SECOND:** Lora Taylor

**ABSTAIN:** Amy Sharp

The motion **passed**.

**ADJOURNMENT**

There being no further business, Tisch adjourned the meeting at 4:05 PM.

**MOTION:** To adjourn the meeting.

**MADE BY:** Lora Taylor

**SECOND:** Cindy Johnston

The motion **passed**.

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Roger A. Webb  
Secretary to the Council

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Date



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

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- ❑ Efforts should 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 should be used only as originally allowed by the individual.

Reviewed May 7, 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 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.



## **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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## **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.