

Department of Intellectual and Developmental Disabilities
Statewide Planning and Policy Council
Annual Report to the Governor
For Calendar Year 2013

In 2011, when the Department of Intellectual and Developmental Disabilities (DIDD) became a new state department, the Tennessee Code was updated to reflect that change and also to create the State, Regional, and Developmental Disabilities Statewide Planning and Policy Councils to allow for public collaboration on issues affecting the department and the people interested in DIDD services. Tennessee Code 33-5-601 created the Statewide Planning and Policy Council (SPPC) for DIDD to assist in planning a comprehensive array of high quality prevention, early intervention, treatment, and habilitation services and supports and to advise the department on policy, budget requests, and developing and evaluating services and supports. As stated in the Tennessee Code, section 33-5-602 (c), the council, in conjunction with the commissioner, shall present a report annually to the Governor. The following constitutes the second annual report, covering calendar year 2013, of the council.

The Statewide Planning and Policy Council met in Nashville four times during 2013: February 20, May 15, August 21, and November 13. A quorum was present for each meeting and official minutes were recorded, posted on the state website, and distributed.

The Department also created East, Middle, and West Regional Planning and Policy Councils (EPPC, MPPC and WPPC), as well as the Developmental Disabilities Statewide Planning and Policy Council (DDPPC). Each of these councils consists of a chairperson, plus eight additional members. They have each met four times during 2013, approximately three to five weeks prior to when the Statewide Planning and Policy Council has held its quarterly meeting. The chairpersons of each council have attended the SPPC meetings and provided reports, highlighting recommendations and/or other significant issues that arose in their meetings.

The agenda for all meetings typically included a section devoted to updates provided the Commissioner of DIDD and/or members of the executive management team. These updates were extremely helpful to all the council members and the members want to express appreciation to Commissioner Payne and her staff for the time devoted to preparing and delivering them.

The department also provided excellent management resources to help in the development of each meeting's agendas, conduct research and follow-up on topics, arrangement for department updates, and overall support. Additionally, the department devoted administrative support to assist with meeting set up and minutes. Once again, all members of the various councils want to acknowledge and give thanks for this vital support.

A great deal of time was spent during the meetings of all five councils during the year on providing education for the members about the very complex system of service delivery for people with intellectual and developmental disabilities within the State of Tennessee. The membership of each council, by design, is diverse, representing all stakeholders in the system including people supported, family members, service providers, and advocates. This diversity not only allowed for enriched discussions, but also necessitated establishing some common points of reference and education.

2013 Planning and Policy Councils Recommendations

The council recommends that community meetings are organized for the purpose of discussing waiver rewrites to include provider agencies, individuals with disabilities, families, and other organizations, who advocate and work with larger populations in order to gain as much quality input for consensus as possible.

The Family Resource Guide should include a statement directing families to, "Refer to the website for additional information".

Consideration of converting electronic information into apps available to providers and staff to access information needed on specific topics is recommended. As tools and resources (e.g. apps) are created they should be accessible on the DIDD website.

DIDD considers developing a standardized information sheet that can be used when mobile crisis is involved. This will improve communication between all parties involved. (e.g. provider, law enforcement, hospital, etc.)

DIDD should develop a bullet-type protocol for families that explains what to expect when you are placed on the waiting list. This information sheet can be given to families during the intake process and placed on the DIDD website to provide ongoing education about the waiting list process.

Council recommends that greater inter-agency collaborations take place when reviewing families on the waiting list (Department of Education-DOE, Department of Labor-DOL, DRS, and AAA) and direct importance granted to the following:

- Be a presence when waiting list reviews take place (CHOICES, et al).
- Be involved with DIDD case management at Point of Entry.
- DIDD sends letters to families listing full menu of waiver and non-waiver options.
- Market available services to pediatricians as an effort to increase public relations/outreach that includes all available services (Waiver, CHOICES, et al).

The department develops an enhanced process for the waiting list to include obtaining more detailed information on specific needs of each individual on the list, assessing various needs, and obtaining projected costs for those services needed. This would provide a better consensus of exact service needs represented by individuals and families presently on the waiting list. The benefits of developing and implementing this task could include:

1. To obtain more detailed information/data on specific needs of each individual/family on the waiting list as intake application is completed.
2. To categorize or break down information received on specific needs of each individual/family on the waiting list.
3. To have the ability to retrieve or pull data provided for specific service needed by persons on the waiting list when funding may become available (i.e. in the form of grants) to enable more people to receive services.
4. To seek ways to serve more people on the waiting list.
5. To seek ways to redistribute current resources to serve more people with the same amount of funding.

DIDD should categorize waiting list by services needed rather than by level of need (i.e. crisis, urgent, active, and deferred).

Require that individuals on the waiting list prioritize their service needs versus them saying, "We need it all."

Extend the waiver to people on the waiting list and people with developmental disabilities, even if only for one service. Intent of this recommendation is to give the one service people need most. There are many people currently receiving multiple services and many whose lives could be dramatically changed for the better with only one service. The idea being that need should be evidence based. The extension would involve a rewrite of waiver criteria, but would also create a more balanced approach of services provided.

The department should prepare inventory of all waiver service options available for children and families. DIDD should investigate the type of service families in the urgent and active categories need, so they can meet those needs earlier and possibly deter them from needing to move into the crisis category. This could possibly lead to a cost reduction for the department.

Supports are desperately needed for youth and young adults exiting the school system. Many of these Tennesseans are on the waiting list with little hope of receiving waiver services anytime soon. With much more minimal supports than is offered by most of the current waivers, many of these youth and young adults could be successful in finding employment and thrive in community living. The council recommends that DIDD consider replicating the successful strategies used by other states and approved by CMS as DIDD waivers are revised and new ones are developed.

The Enrollment Committee meets monthly with eight to ten new waiver members enrolled for services each month. If someone leaves the waiver (moves out of state or dies), by federal law, DIDD cannot fill the space until the next calendar year. Cynthia Galbreath, formerly the Director of Intellectual and Developmental Disabilities Services of TennCare, commented that she observes inactive cost plans, approximately 20 being used every month. Currently, the process now takes 12 to 18 months. The councils and she would like to see a speedier process for disenrollment.

More flexibility in waiver services to reflect person centered schedules (monitoring requirements, utilization, and rules) is needed. More flexibility in appropriation of funds to address use of waiver regarding unneeded services is needed; due in part to participant's fear of losing service. There is inflation or over utilization of needs by some just to keep services they fear they will lose. Education may be necessary for those who believe they will lose services for no reason. The difference between abuse of service and the proper use of services should be clearly explained. If they are maxing out on service units regularly each month, waiver services need to be revised. The recommendation intends to ensure funds are used properly.

The councils have discussed at length the importance of preventative care for people who are served on the waiver. The emphasis being that investing in preventative care will save DIDD money in the long run (i.e. costly dental expenses). The use of an annual cap for certain health benefits can serve to contain costs while allowing the service recipient the flexibility to choose how those dollars are used. The councils recommend that DIDD explore ways to include preventative care as a part of waiver services. The council suggests incorporating this into the new waiver.

Council members revisited their previous recommendation for a 5% rate increase for community provider agencies. The discussion touched on issues justifying such a request based on the following:

1. No rate increases since 2006.
2. The rising cost of gas to provide community-based services.
3. The rising cost of healthcare premiums.
4. The impending costs associated with the implementation of the Affordable Care Act.

The councils acknowledged and expressed appreciation for the recent rate increase of nearly 1%, but they are concerned this will not keep pace with the other financial issues facing community providers. It is recommended that DIDD include a 5% rate increase for waiver services in the DIDD Budget for FY 2014-15.

The Family Support Program was fully restored with recurring funding for fiscal year 2013-2014. It is recommended that the department continue to fully fund the Family Support Program. This is an invaluable service provided to families. For many families, it is the only assistance they receive.

DIDD provide continuous updates on each of the department's priorities through *Open Line*.

The department should provide written information about the SMART 911 program for distribution to all Middle Tennessee providers and their staff.

DIDD should strengthen the Protection From Harm system by emphasizing prevention and encouraging greater collaboration among providers and with the mental health system.

Vocational rehabilitation should be an option in the Employment First Initiative, specifically for those individuals with an intellectual and/or developmental disability that are under the age of 18 years or still in school be established.

DIDD has developed two models of residential services that may lead to significant improvements for persons with behavioral and mental health challenges. These models are Intensive Behavior Residential Services (IBRS) that requires provision of interdisciplinary/holistic services to individuals with severe or challenging behavior; and the other is Semi-Independent Living (SIL) that provides an alternative to IBRS for individuals whose behavioral challenges are exacerbated by intense staff supervision. The SPPC recommends that DIDD provide direct and consultation behavioral health and crisis supports for individuals with an intellectual and/or developmental disability at each regional office and that the department add additional funding for individuals transitioning from IBRS into level 4 homes in order to provide supports for an effortless transition. Funding for an individual's transition is meant to be a temporary increase as to fund for extra expenses for transitioning only.

As advised by the Governor's office, DIDD has revised the mission statement. The new mission statement is: *To become the nation's most person-centered and cost effective state support system for people with intellectual and developmental disabilities*. Prior to making any substantial changes in the mission, values, or major initiatives, DIDD should consult with the Statewide, Regional, and Developmental Disabilities Planning and Policy Councils.

People transitioning from nursing homes to community-based services need to have a level of service that will keep them safe and that need for safety should not force them to stay in an institutional setting. DIDD should look at the population of young adults transitioning out of state custody and how they would fit into the department's services for those with a developmental disability.

Workers hired to complete personal assistance for individuals who self-direct should have the flexibility to work for more than one individual without becoming licensed. Because this has been a problem in the past, the councils recommend that the department revises this policy.

DIDD should work with advocacy organizations to facilitate data collection including a needs assessment for people with developmental disabilities.

Develop resources to serve people with developmental disabilities and physical impairments other than nursing homes which can cause social isolation for many.

Develop a family consultation or a family therapy model designed to assist the families of individuals with a developmental disability.

Create a training model to train medical professionals on how to communicate with people who have a developmental disability. Dr. Tom Cheetham, DIDD's Director of Health Services, and Dr. Bruce Davis, DIDD's State Director of Behavioral and Psychological Services, are currently working with Vanderbilt University. They were awarded a special foundation grant which may provide resources that assist to primary care physicians in overcoming barriers to communication with person with disabilities and appropriate care. Communication can prevent individuals with intellectual and developmental disabilities from receiving high-quality healthcare.

Open up the mobile crisis teams to respond to families who do not receive waiver services, but are either on the waiting list or caring for a loved one with a developmental disability. During a council meeting, Dr. Davis discussed the barriers to producing a mobile crisis system for individuals with developmental disabilities. Some of these barriers are, but not limited to a very large population of individuals with developmental disabilities and the only interface is a managed care organization (MCO). He has also talked about considering other resources. A resource that many states utilize is The Center for START, which provides services for Systematic Therapeutic, Assessment, Respite, and Treatment. It is a national initiative that strengthens efficiencies and service outcomes for individuals with an intellectual and/or developmental disability and the behavioral health needs in the community. Dr. Joan Beasley, director of The Center for START, provided consultation and training for the TN-START program in Chattanooga (which is funded by DIDD). Dr. Beasley is a licensed mental health counselor and the co-founder of the START program that was first developed in 1989.

The council is aware that DIDD does not have monetary resources available for individuals with disabilities other than intellectual disabilities, but they strongly suggest that the department should begin an immediate collection of data of people with disabilities statewide, so that the department can accurately assess the volume of resources that are required to provide service to them. The council recommends that DIDD assign at least one full-time staff committed to collecting data that consist of the number of individuals in Tennessee that have a development disability, the type of disability, their age, and any other information that will be needed to create a waiver.

The council also recommends that facility based services should not be included in a developmental disabilities waiver and suggests that the following criteria will determine who needs service(s) offered by a Developmental Disabilities Waiver:

1. Overarching eligibility criteria to include persons at risk of institutionalization either in a nursing home or ICF/DD.

2. Priorities within the population of people who meet the above criteria:
 - a. Persons with a developmental disability currently residing in nursing home; who can and should be served in community settings.
 - b. Young adults transitioning from high school.

The DDPPC has made the following recommendations regarding capital to fund services for people with developmental disabilities:

1. Diverted funds – Use dollars that can be diverted from nursing homes when individuals with a developmental disability currently residing in them move out (money follows the person concept). The amount is unknown at this time.
2. “New” money – No less than \$5 million of the savings that DIDD will realize from the settling of the Arlington Exit lawsuit be used to fund services for people with developmental disabilities. The diverted funds plus the \$5 million (or more) will be used to draw down the federal match resulting in a minimum of \$15 million in total funding available.
3. Waiver services should be person-centered, flexible and have a self-directed option
4. Once the waiver is established, funds should not be pulled from the Family Support Program to fund the Developmental Disabilities Waiver.

The DDPPC believes that setting rates is the role of DIDD and that they have sufficient information to do so. However, this council makes the following recommendations related to rates and/or waiver cost in general:

1. Review recommendations from other states, particularly Washington State, which is the mentor state for the ODEP grant.
2. Make certain that the rate for personal assistance is high enough that providers will actually be able to offer the service and hire quality staff. (Of all the current rates in the DIDD intellectual disabilities waivers, we hear the most complaints about the personal assistance rate.)
3. Cap the total amount of waiver dollars that can be spent on each individual enrolled (similar to the DIDD Self-Determination Waiver).
4. Offer up to three different levels of funding based on level of need (or some other measure) similar to how the CHOICES Waiver is set up. Unlike the CHOICES Waiver, eliminate the impossible standards set that actually qualify for the higher levels if someone truly needs the service, for example: level I: \$15,000, level II: \$30,000, and level III \$45,000.

DIDD should put in place a reference to developmental disabilities that will be included in the mission statement of the Provider Manual.

It is the request of the DDPPC that when establishing services for individuals with developmental disabilities that the following recommendations are considered by DIDD. These are in order of priority and based upon the *Fulfill the Promise* report from 2007 that continue to be relevant even today.

1. Employment services (job development, job coaching, customized employment, supported employment, follow-along)
2. Therapies (OT, PT, Speech and Language)
3. Respite
4. Assistive Technology (and repair/maintenance)
5. Transportation
6. Home modifications
7. Personal Assistance
8. Personal Emergency Response Systems

The council deems that the following tactics are a means to reduce the DIDD Waiting List and recommends that the department:

1. Investigate all feasible options for obtaining additional resources that can be used to provide services to more individuals on the waiting list.
2. Write the waiver, so that it may allow more flexibility for allowing services to more individuals on the waiting list.
3. Cap the dollar amount that is available to families (similar to how the self-determination waiver is capped at \$30,000) for managed care.
4. Consider moving the waiver services into a managed care model with DIDD as the MCO. Although this would require a great deal of research and thoughtful planning, it is working in some states.

We are looking forward to continuing our work next year. Clearly, a solid foundation has been laid. Members have a basic understanding of the department's mission, organizational structure, budget, constraints, and the strategic planning initiatives.

Sincerely,

Mike McElhinney, Chairperson
Statewide Planning and Policy Council