

**Statewide Planning and Policy
Council
Annual Report to the Governor**

Calendar Year 2015

In 2011, when the Department of Intellectual and Developmental Disabilities (DIDD) became a new State department, the Tennessee Code Annotated (TCA) was updated to reflect that change and also to create the Statewide, Regional, and Developmental Disabilities Planning and Policy Councils to allow for public collaboration on issues affecting the department and the individuals interested in DIDD services.

TCA 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 TCA 33-5-602(c), the council, in conjunction with the commissioner, shall present a report annually to the governor. The following constitutes the fourth annual report, covering calendar year 2015, of the SPPC.

The SPPC wishes to commend the DIDD on the recent achievement of becoming the first State service delivery system to obtain the Council on Quality and Leadership (CQL) accreditation in Person Centered Excellence. This is a remarkable and worthy accomplishment. Also the SPPC recognizes the DIDD accomplishment of the final closing of the Clover Bottom Developmental Center. After many years of work toward that end, this year the realization has finally succeeded. And in similar manner, the SPPC commends the DIDD as it moves forward to transition the remaining residents of Greene Valley Developmental Center into community homes. A lot of DIDD personnel have spent many hours over the past years to meet the expectations of the court orders and settlement agreements. Commissioner Payne is commended for having been a constant force for constructive change throughout. Through tireless efforts, finally the systems have evolved and are in the finale changes to deliver the supports and services to people where they are best utilized, in their communities.

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The SPPC met in Nashville four times during 2015: February 25, May 20, August 19, and November 18. A quorum was present for each meeting, and official minutes were recorded and posted on the State website. An ad hoc meeting of the SPPC also took place on October 21, 2015, to further develop the recommendations from the August meeting in preparation for the November meeting where these recommendations were finalized. Official minutes from the October meeting were also made available to the public on the State website.

The Department supports the East, Middle, and West Regional Planning and Policy Councils (EPPC, MPPC, and WPPC), as well as the Developmental Disabilities Planning and Policy Council (DDPPC). Each of these councils consists of a chairperson, plus eight additional members. Each of these councils met four times during 2015, approximately three to five weeks prior to the SPPC quarterly meetings. The chairpersons (or designees) of each council attended all quarterly SPPC meetings and provided reports, highlighting recommendations and/or other significant issues that arose from their meetings.

Agendas for SPPC meetings include a section devoted to updates provided by the Commissioner of DIDD and/or members of the executive management team upon the council's request. Previously, much of the council's time during meetings surrounded departmental updates; therefore the department now presents updates upon the request of the council to allow more working time during meetings. The department provides management resources to help in the development of each meeting's agendas, follow-up on topics, arrangement for departmental updates, and overall support. Additionally, the department devotes administrative support to assist with securing meeting accommodations and preparation/distribution/publication of meeting minutes.

The membership of each council, by design, is diverse, representing all stakeholders in the system including: self-advocates, family members, service providers, and advocates. This diversity not only allows for enriched discussions, but also necessitates establishing some common points of reference as DIDD moves forward as a person-centered State service delivery system.

The SPPC recommendations to DIDD for 2015, which are provided in this report, incorporate the recommendations of the EPPC, MPPC, WPPC, and DDPPC. Some of the recommendations made by the councils throughout the year were either adopted by DIDD and/or were already in development.

2015 Statewide Planning and Policy Council Recommendations

LEGACY RECOMMENDATIONS FROM 2014

1. **The SPPC recommends** that DIDD continue to execute its role as outlined in the Memorandum of Understanding (MOU) between Vocational Rehabilitation, TennCare, DIDD, et al. The SPPC is very interested in what is discussed during the meetings. The SPPC requests an update from DIDD on the Employment First initiative.
2. **The SPPC recommends** that DIDD request that HB0106/SB0117 “Protection of Volunteer-Insured Drivers of the Elderly (PROVIDE) Act be amended to include protection of volunteer-insured drives of people with disabilities.
(Background: Limited transportation options are cited by families as the number one barrier to employment for individuals with disabilities. Expanding this legislation to cover drivers for individuals with disabilities could alleviate this barrier.)
3. **The SPPC recommends** that TennCare amend the definition of “transportation” in the proposed ECF CHOICES Waiver to be written to include a wide variety of transportation options, including but not limited to: public buses, taxis, Uber, and/or paying friends/neighbors a stipend to provide transportation.
(Background: Transportation is typically mentioned as one of the top challenges in getting jobs for individuals with intellectual disabilities (ID). Creating flexibility in the definition of transportation service in the new ECF CHOICES Waiver to include transportation options beyond DIDD contracted transportation providers to pay for options such as public buses, taxis, etc., thereby allowing waiver services to pay for a variety of transportation options, allows individuals and families more flexibility and could also save money in the long run by utilizing options that already exist in the community.)
4. **The SPPC recommends** that DIDD, in collaboration with TennCare, improve the rates structure to address the current staffing crisis, which can be a barrier to individuals receiving approved services. The SPPC recommend that TennCare and DIDD develop a rate methodology that will support paying direct support professionals a competitive wage to address the staffing crisis and to improve staff recruitment and retention for the present waivers and the 1115 waiver.
(Background: The staffing crisis is a statewide issue for providers employing direct support professionals.)

5. **The SPPC recommends** that DIDD facilitate a state roundtable discussion on the topic of the staffing crisis among direct support professionals, not only in DIDD provider agencies, but other similar caregiving industries. The purpose will be to articulate possible solutions, and initiate a process of moving this to a level where meaningful action can occur.

(Background: The Bureau of Labor Statistics states that the direct-care workforce is expected to grow from 4.2 million in 2014 to more than 5.2 million by 2024, making it the largest single workforce in the country. Also, direct-care jobs represent three of the top six occupations that will create the most jobs in the decade spanning 2014 to 2024. From <http://www.phinational.org/>)

6. **The SPPC recommends** that the DIDD Family Support Program continue in the provision of flexible, family-friendly, cost-effective supports for individuals with disabilities who may have no other options for support services through current or future programs operated through DIDD or TennCare.

(Background: Traditionally, the Family Support Program provided funding for many individuals with DD other than ID who could not access waiver services. There is concern that, with the creation of the ECF CHOICES Waiver, that people will wrongly assume that the Family Support Program will no longer be needed. However, there will still be a population of individuals with IDD who will not qualify for waiver services because of income or other issues but will still need the assistance that the Family Support Program provides. The Family Support Program is a successful example of how a small amount of funds can support a large number of people and make a huge difference in their lives.)

7. **The SPPC recommends** that DIDD move forward with hiring a specialist in services and supports for individuals with DD other than ID, as approved in the current budget.

(Background: Prior to the creation of the ECF CHOICES Waiver, DIDD had approval to create two (2) new positions that would focus specifically on service provision to individuals with DD other than ID. One position was subsequently eliminated. Even with the creation of the new waivers that will provide services and supports to individuals with DD other than ID, it is critical that there be a staff within DIDD who has expertise in DD other than ID to ensure that ECF CHOICES meets the needs of this population.)

8. **The SPPC recommends** that DIDD explore providing technical assistance to providers of Facility Based Day Services to facilitate compliance with the CMS Final Rule on Home and Community Based Services. Even though there may be limited funds from the federal government, there may be other contributors available over time.

(Background: This recommendation is an effort to leverage funds which are currently allocated, but may be an option in the future.)

9. **The SPPC recommends** that DIDD strengthen the Protection from Harm (PFH) system by implementing qualitative data analysis of abuse, neglect, mistreatment and exploitation (A/N/M/E) incidents; improving training for people receiving services and supports (e.g., recognizing and self-reporting A/N/M/E); and improving training for direct support professionals (e.g., prevention of A/N/M/E, stress management, systems approach to preventing A/N/M/E).

It is recommended that DIDD continue the Prevention of Harm Workgroup that is now meeting. It would be beneficial to expand the committee to include a family member and an active self-advocate or two. This committee should continue to be progressive in its vision and seek to find ways to eliminate all acts of abuse, neglect and mistreatment throughout the service delivery system and to as much as possible, finally eradicate it from the lives of people.

It is recommended that DIDD, TennCare and the provider community can work together to plan and execute an anti-abuse, anti- neglect and anti-mistreatment strategy that can thwart people from being harmed or placed at risk. In the same way there are campaigns against smoking, drinking and driving, a campaign should be initiated to stop abuse, neglect and mistreatment before it ever happens.

10. **The SPPC recommends** that DIDD in collaboration with TennCare pursue amendments to the Nurse Practice Act to allow Direct Support Professionals (DSPs) to perform certain physician-ordered tasks, which are currently only allowed to be performed by a licensed nurse. Tasks under consideration for review may include, but not be limited to: oxygen administration, blood sugar level checks, insulin pens, nebulizers, and C-Pap machines.

11. **The SPPC recommends** re-evaluation and clarification of the role, membership, training, responsibilities, and procedures of the Human Rights Committee (HRC) in reviewing psychotropic medications.

(Background: This recommendation comes from the observation that guidelines are needed that specify which medications require review, how often medications need to be reviewed, which dosage changes require review (increases/decreases), and whether the committee can approve the use of a medication within a range of doses.

2015 RECOMMENDATIONS

1. **The SPPC recommends** that DIDD in collaboration with TennCare establish adequate access to and provision of mental health services for people with intellectual disabilities. There is potential to address the concerns of the lack of mental health services for people in crisis with other State and private agencies, such as the Department of Mental Health and Substance Abuse Services, in a collaborative effort to define the problem statewide and to seek viable solutions. The SPPC suggests that the DIDD approach the Governor's office to request a task force to place emphasis on this growing problem urgently.

(Background: The lack of mental health services for individuals with ID is a statewide problem that requires collaboration between the hospital organizations, the Department of Mental Health and Substance Abuse (DMHSA), and DIDD.)
2. **The SPPC recommends** that the DIDD review and reexamine the Title 33-5-601 authority for the SPPC to ensure stakeholder involvement as systems shift wherever services are provided, whether through managed care organizations (MCO) or DIDD.

(Background: As systems change, the mechanism of the SPPC may evolve. There must always be a mechanism for stakeholder input.)
3. **The SPCC recommends** the appointment of a special committee charged to examine and determine whether supported decision-making can be implemented as an alternative to conservatorship for people with intellectual disabilities.

(Background: The SPCC recognizes that the issue of conservatorship is a legal concept used in the United States which appoints or elects someone to take care of an individual with a disability. Although the spirit of this concept is care, conservatorship may take away an individual's personal rights and rights to make decisions. With that said, there are complex issues given intellectual and developmental disabilities. We recognize that there are no easy answers because on any given day and at any time of the day, one's ability to make decisions may be significantly impacted. For the most part, this is a quagmire (e.g., financial, social, emotional, health, and access) for individuals with disabilities. Ultimately, the SPCC purports the best interest, least intrusive, and highest quality of respect with rights. It is recognized that a blanket "one size fits all" option for everyone should not be the typical solution. A person centered philosophy must be incorporated into conservatorship dilemmas. At times family conservatorship or corporate conservatorship may be appropriate. At other times, there may be less robust solutions to help the person. This recommendation comports with person-centered service provision, whereby efforts are made to assist with ascertaining what decisions individuals with ID can make, what help

they need with making decisions, and getting them the support that they need to make those decisions, as opposed to conservatorship, which in essence takes away a person's personal rights.)

4. **The SPPC recommends** that DIDD play an active role in instilling the values of person-centeredness in service provision to individuals with ID who are supported in both private and public Intermediate Care Facilities (ICFs/ID).
(Background: Traditionally, DIDD did not have oversight over private ICFs/ID in TN. AS DIDD has taken on this oversight, it is important that its values be instilled in the services and supports provided at these facilities.)

5. **The SPPC recommends** that DIDD play an active role in establishing eligibility criteria and the intake process for people enrolling in the ECF CHOICES Waiver that addresses people on the DIDD Waiver Waiting List for current waivers and people with DD other than ID who have not previously been eligible for the DIDD Waiver Waiting List.
(Background: Tennessee proposes to implement within its existing managed care demonstration an integrated managed long-term services and supports (MLTSS) program that is specifically geared toward promoting and supporting integrated, competitive employment and independent, integrated community living as the first and preferred option for individuals with intellectual and developmental disabilities (I/DD).)

6. **The SPPC recommends** that DIDD in collaboration with TennCare develop a model for Day Services that is independent of the setting in which the service is delivered and implement a single rate for Day Services which would include transportation. Thus, there would be one Day Service instead of separating each service by type, e.g., community based, facility based, in home (CB/FB/IH). Supported employment would be a separate service. The option for 7 days per week for Day Services to be provided would continue.
(Background: The concerns for the way things are separated now, means that some people are expected (and will be more so in the future) to be doing either community based for 6 hours a day or doing in home based for the full 6 hours a day. Facility Based is still offered to the current people who have it. In the new waiver, it will not be an option. As Mr. Robert Vaughn (SPPC member and Self Advocate) informed SPPC in the last meeting it does take much effort and he does not enjoy being in the community for 6 hours a day. This option if it were to become a reality would allow some flexibility in how Robert's day is structured. And Mr. Vaughn like others would be in control of his supports.)

7. **The SPPC recommends** that the DIDD complete activities of planning and calculation that will lead to the outcome of a 3 to 5 year strategic plan for the Department of Intellectual and Developmental Disabilities. It is recommended that the activities begin with the inclusion of the CQL plan for continued accreditation and work from there. To be clear, the SPPC would suggest a set of outcomes and objectives that go beyond the Customer Focused Government goals. The SPPC requests regular updates on the Department's strategic plan.

(Background: The SPPC recognizes that the DIDD has and will be affected greatly as the services and supports for people with disabilities in Tennessee continue to modify toward managed care. The extent of how much the DIDD can direct the flow of this transition is uncertain to the SPPC. The mission of DIDD is to support all Tennesseans with intellectual and developmental disabilities in living fulfilling and rewarding lives. The vision is to become the nation's most person-centered and cost effective state support system for people with intellectual and developmental disabilities.)

8. **The SPPC recommends** DIDD collaborate with the SPPC in developing a position statement on Cultural Recognition and Quality Improvement.

(Background: As the nation's population grows more diverse, it's increasingly important to be aware of the influence of culture on everything from a patient's diet to attitudes about death and dying to a patient-centered model" (Betancourt, 2015). Of course this includes, with significance and relevance, individuals with intellectual and developmental disabilities." As the SPPC recommends policy, the SPPC is reminded that four key cultural recognition drive quality improvement: 1) cultural knowledge (i.e., familiarization of history, values, beliefs systems, and behaviors of one's ethnic group), 2) cultural awareness (e.g., developing sensitivity and understanding of another ethnic group with openness and flexibility); 3) cultural sensitivity (i.e., recognizing that differences exist); and cultural competency (i.e., attitudes, behaviors and policies that enable the system to effectively improve communication in cross cultural situations). Essential elements as proposed by the Quality Improvement System

Essential elements as proposed by the Quality Improvement System for Managed Care

*for Managed Care (QISM) for policy recommendations for all persons include: **Availability** (needs assessments to understand community needs and ethnic makeup); **Outreach** strategies tailored to communities based on needs assessments; **Access** (reaching individuals from diverse cultures, meeting language needs, breaking down geographic barriers; and **Cultural competence** (in diagnosis, treatment, regimes, patient compliance, satisfaction, and clinical outcomes) (Jean Lau Chin, Ed D, 2015). Tennessee's rapidly changing demographics suggest that vigilance is needed to eliminate any and all*

disparities, particularly a vulnerable population, individuals with intellectual and developmental disabilities. (References: Joseph Betancourt, MD, Director of the Disparities Solution Center, Massachusetts General Hospital, Boston, 1/19/2015), Jean Lau Chin, Ed D. "Cultural Competence and Health Care" 2015))

Respectfully Submitted December 29, 2015