

# **Home and Community Based Services for Individuals with Intellectual and Developmental Disabilities:**

## **Stakeholder Input Summary**



## **Home and Community Based Services for Individuals with Intellectual and Developmental Disabilities Executive Summary**

TennCare (the State Medicaid Agency) and the Department of Intellectual and Developmental Disabilities (DIDD—contracted by TennCare to operate the State’s three Section 1915(c) home and community based services waivers for individuals with intellectual disabilities) jointly hosted various stakeholder processes to provide opportunities for input regarding the renewal of the Arlington and Statewide Waivers and potential new program designs for people with intellectual and developmental disabilities,

These processes included:

- Meetings with advocacy groups representing individuals with intellectual and developmental disabilities and their families, as well as HCBS provider groups serving individuals with intellectual disabilities;
- A series of statewide Community Meetings with consumers, family members, and providers;
- An online survey; and
- Written comments and other follow-up recommendations.

We recognize that the number of respondents in each of the consumer and family groups is small in comparison to the total number of waiver participants and the total number of individuals waiting for services. We further acknowledge that those who opted to participate in the stakeholder processes are not necessarily representative of the perspectives of the group as a whole. However, the input they provided is incredibly valuable and yields significant insights regarding future program design for the delivery of services to individuals with intellectual and developmental disabilities.

The current comprehensive benefit structure with its heavy emphasis on 24-hour residential care is not, from the perspective of either those receiving services or those waiting for services, among the most critical needs of individuals with intellectual and developmental disabilities and their families. In fact, there were multiple recommendations from individuals waiting for services and their families and conservators, as well as from providers, to move away from 24-hour supports as the default expectation.

Further, for both consumer/family groups, Employment and Day Services are a key priority, with Employment outranking Day Services among the needs identified by providers as well as individuals receiving waiver services.

Also for both consumer groups, there are aspects of service delivery that are among the most pressing service needs. For individuals receiving waiver services and their families, consistent, well trained, quality staff is key—both in terms of services for the individual and supports for the family. They, along with providers, strongly recommended targeted investments in direct care staff pay in order to recruit and retain high quality staff. For individuals waiting for services and their families, opportunities for integrated community activities is important. For both consumer/family groups, Family Education, Navigation

and Support is a high priority. And for all three groups (including HCBS providers), the importance of an integrated and coordinated approach to services and supports, focusing on the whole person and all of their physical and behavioral (i.e., mental) health and functional support needs is among the most critical needs. In fact, continuing throughout responses to many of the questions was a continuing thread of holistic, person-centered service planning and coordination, as well as needs based assessment and utilization of services based on the individualized needs of program participants.

There is widespread support among individuals receiving services and their families, and especially among providers to modify program and service rules and definitions. Likewise, providers and consumers and families in the group waiting for services want to streamline regulations, paperwork and processes, with the latter being focused primarily on intake. Providers made recommendations both with respect to the Independent Support Coordination system and with respect to State program administration, believing there are opportunities to reduce staff as well as cost.

Also worth noting were multiple recommendations to modify the program design and waiting list approach, providing smaller capped waivers that would allow resources to be spread across more of the people who need support, offering services prior to crisis in an effort to delay or prevent more intensive service needs, targeting services to young adults transitioning from high school to assist them in pursuing employment and independent living, and addressing the needs of aging individuals with intellectual and developmental disabilities, as well as aging caregivers. These recommendations were similar to those heard from multiple advocacy groups during discussions held prior to the Community Meetings.

These recommendations highlight important opportunities to ensure that programs and policies are aligned with the needs and preferences of individuals who need services and their families, and that they are cost-effective, allowing more of the people on the waiting list as well as individuals with developmental disabilities to be served.

It will be critical that the State takes all of these perspectives and recommendations into account, with some applicable to renewal of the Arlington and Statewide Waivers, but with most providing key guidance with respect to future program designs that can better and more cost-effectively serve individuals with intellectual and developmental disabilities in the future.

With valuable stakeholder input gathered, TennCare and DIDD will next develop a concept paper regarding how these insights will be used to inform the renewal of the Arlington and Statewide Waivers, as well as how they might inform future new program models for individuals with intellectual and developmental disabilities.

The public release of the concept paper will allow continuation of stakeholder engagement in the process, and the opportunity for the State to begin a dialogue with the Centers for Medicare and Medicaid Services that will help lay the groundwork for future waiver renewal applications and amendments later this year.

## **Home and Community Based Services for Individuals with Intellectual and Developmental Disabilities Stakeholder Input Summary**

### **Introduction**

The State of Tennessee has three Section 1915(c) Home and Community Based Services (HCBS) waiver programs:

- The Arlington Waiver (CMS Control # TN.0357);
- The Statewide Waiver (CMS Control # TN.0128); and
- The Self-Determination Waiver (CMS Control # TN.0427).

With limited exception (i.e., children under age six with a developmental disability who do not yet have a formal diagnosis of intellectual disability), the target population served in each of these waivers is individuals with an intellectual disability who qualify for the level of services provided in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID).

Once a waiver is approved by the federal Centers for Medicare and Medicaid Services (CMS), the waivers must be renewed every five years. The Arlington and Statewide Waivers will expire on December 31, 2014 unless they are renewed. The state intends to renew these waivers in order to ensure continuity of services for current waiver participants.

TennCare (the State Medicaid Agency) and the Department of Intellectual and Developmental Disabilities (DIDD—contracted by TennCare to operate these waivers) also want to explore potential new program designs for serving new program participants that would allow HCBS and other Medicaid services to be provided more cost-effectively so that more people who need HCBS can receive them. This includes people with intellectual disabilities on the waiting list and people with other developmental disabilities.

In order to provide opportunities for input regarding the renewal of the Arlington and Statewide Waivers and potential new program designs for people with intellectual and developmental disabilities, TennCare and DIDD jointly hosted various stakeholder processes. These processes commenced in December 2013 with meetings including advocacy groups representing individuals with intellectual and developmental disabilities and their families, as well as HCBS provider groups serving individuals with intellectual disabilities. Beginning in January 2014, self-report data was gathered from consumers, family members, and providers via a series of statewide Community Meetings. An online survey afforded consumers and family members who were unable to participate in Community Meetings with an alternative mechanism to provide input. Finally, additional written comments and other follow-up recommendations were received by TennCare after the conclusion of the Community Meetings and online survey processes.

## Meetings with Stakeholder Groups

In December 2013, TennCare extended meeting invitations to each of the key advocacy groups representing individuals with intellectual and developmental disabilities in Tennessee, including:

- Tennessee Council on Developmental Disabilities – Wanda Willis, Executive Director
- Tennessee Disability Coalition – Carol Westlake, Executive Director
- The Arc of Tennessee – Carrie Guiden, Executive Director
- Tennessee Network of Community Organizations (TNCO) – Robin Atwood, Executive Director
- Tennessee Provider Coalition – Steve Norris, Treasurer

With the exception of the Tennessee Provider Coalition, each of these groups participates in a broader TennCare Long-Term Services and Supports (LTSS) Stakeholder Group that meets periodically with TennCare LTSS leadership to hear program updates and provide input on key program and policy decisions. (The Tennessee Provider Coalition, a newer organization, will be invited to participate in the LTSS Stakeholder Group going forward.) In some cases, board and/or organization members also participated in the meetings.

Each of the groups was asked to come prepared to share ideas and recommendations regarding the renewal of the Arlington and Statewide Waivers, including potential program reforms, and if possible, to share their thoughts in writing in advance of the meeting. Written suggestions were received in advance from the Tennessee Council on Developmental Disabilities and the Arc of Tennessee. The Arc of Tennessee supplemented their recommendations after the face-to-face discussion. A written document, identified as a “Discussion Draft” that had been developed by an LTSS taskforce (external to state government) was shared by the Tennessee Disability Coalition during their meeting. The document described issues with the current delivery system as well as possible solutions. TNCO submitted written recommendations after the meeting which formed the basis for further discussion during a regularly scheduled quarterly meeting with the group in January 2014. While written comments were not received from the Tennessee Provider Coalition, notes were taken during discussions with the group regarding their ideas and recommendations.

For the advocacy groups, there was remarkable alignment in the initial recommendations received. Two groups recommended HCBS programs offering a tier of capped services beginning at \$12,000-\$15,000, with varying additional service packages and higher expenditure caps, depending on the needs of the target population served. Both strongly recommended self-direction options, including management of an individual budget. One of the clear priorities for both groups was serving young adults transitioning out of school (as well as those who may have already aged out of school), with a primary focus on Employment services and Personal Assistance. Two of the advocacy groups focused on efforts to reduce reliance on 24-hour residential services, moving toward Semi-Independent Living, Personal Assistance, or other less intensive and less expensive support

options. One group drew an analogy around efforts to “rebalance” institutional and HCBS to the need in these waivers to “rebalance” residential and non-residential supports.

There were strong recommendations to modify waiting list management approaches to offer support to families of children and adolescents as well as adults continuing to live at home, building on and directing specific efforts and resources toward developing and strengthening natural and community support systems and capacities. These recommendations included assisting young adults in transitioning from school to employment—in short, investing *before* the crisis occurs rather than responding after it has happened.

There were also recommendations regarding potential finance and delivery models—from Community First Choice<sup>1</sup> to Managed Long-Term Services and Supports<sup>2</sup>, with important considerations around preserving important individual and program goals, including quality of life, member choice and control, community integration, participant rights, and employment, and in ensuring ongoing stakeholder participation in program design and implementation.

In addition to recommendations regarding opportunities for more effective coordination of services, including needs based assessment and planning, provider recommendations focused primarily on ways to redefine or restructure waiver services (e.g., Employment and Day Services, Personal Assistance, Behavior Supports, Assistive Technology, and Residential Services—in particular, Medical Residential and Family Model Residential) to better achieve quality and cost effectiveness goals. Providers also recommended efforts to limit expansion of the provider network to only the highest quality new providers.

Like advocacy groups, Providers also recommended a capped employment waiver with a moderate package of employment-specific services and supports capped at \$12,000-\$18,000 per member per year, targeting young adults with intellectual and developmental disabilities transitioning from school, as well as targeted services to aging members. All groups stressed the importance of ongoing stakeholder engagement in program design and implementation.

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<sup>1</sup> Passed as part of the Affordable Care Act of 2010, the “Community First Choice Option,” authorized under Section 1915(k) of the Social Security Act, allows states to provide home and community-based attendant services to Medicaid enrollees with disabilities under the State Medicaid Plan. It offers a 6% increase in Federal matching payments to States for expenditures related to this option. However, it precludes states from placing any restrictions on the numbers of people who can receive the benefits, and therefore, poses a challenge to states in managing program and expenditure growth.

<sup>2</sup> Medicaid Managed Long Term Services and Supports (MLTSS) programs deliver long term services and supports through capitated managed care arrangements. Tennessee’s MLTSS program for seniors and adults with physical disabilities, called “CHOICES,” integrates physical and behavioral health services, and LTSS, offering seamless coordination across the full continuum of care needed by each member. Through CHOICES, the number of individuals receiving HCBS has grown from the number of people receiving home care has grown from 4,861 to more than 13,000 since 2010, eliminating all waiting lists for this population. Tennessee’s MLTSS program operates under the authority of an 1115 demonstration waiver.

## Community Meetings

In an effort to broaden opportunities for input and to specifically gather ideas directly from consumers and family members, TennCare and DIDD jointly hosted regional Community Meetings. Six Community Meetings were held across Tennessee during the time period of January 31 through February 10, 2014. Two sessions were held in each of the three regions served by the DIDD Regional Offices. In each location, one session was held for consumers and family members (including conservators, etc.) and one for HCBS providers. Advocates could participate in either meeting.

Separate invitations were developed for consumers and family members and for providers, and included the dates, times, and locations of meetings for that target group.<sup>3</sup> Consumers and family members were encouraged to attend the consumer/family group sessions and providers were directed to attend the provider sessions, although responses were gathered and sorted by group regardless of the meeting attended. The availability of the online survey (described below) was highlighted in the consumer/family member invitations as an alternative way of providing input.

TennCare disseminated the Community Meeting invitations to each of the advocacy and provider groups identified above, and requested their assistance in distributing the invitations to consumers, family members, conservators and providers. In addition to announcing the meetings in “Open Line” (a weekly electronic newsletter sent out from DIDD Commissioner Payne), DIDD disseminated the invitations directly to all HCBS providers via email, and asked them to share the consumer/family meeting invitation with the consumers they serve and their families or conservators. Finally, DIDD asked Independent Support Coordinators (contracted to provide Independent Support Coordination services in these waivers) to disseminate the consumer/family invitations to the individuals they serve.

During registration, attendees were asked to sign in according to the group they best represent: consumers receiving waiver services or their family members, consumers waiting for services or their family members<sup>4</sup>, advocates and HCBS providers. Each participant was given a name tag. Name tags for advocates and providers were pre-numbered for purposes of a forced randomization process (described below). Fifty-eight consumers, family members and conservators (including 33 individuals receiving waiver services and their family members or conservators, and 25 individuals waiting for services and their family members or conservators), 23 advocates and 133 provider representatives attended the meetings statewide, for a total of 214 participants.

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<sup>3</sup> Copies of the invitations are available in Appendix X.

<sup>4</sup> Throughout this document, including analysis of input received from the Community Meetings, individuals or consumers “waiting for services” and their family members and conservators includes individuals with intellectual disabilities currently on a waiting list for existing 1915(c) HCBS waivers, as well as individuals with intellectual or other developmental disabilities who need HCBS, but are not on a formal waiting list for such programs or services.

Community meetings began with a twenty-minute PowerPoint presentation describing HCBS waiver programs, services and expenditures in Tennessee.<sup>5</sup> This presentation allowed attendees to better understand the context of the questions to be addressed later in the forum, providing a starting point in their thinking. At the conclusion of the presentation, participants moved to discussion circles, described below.

## **Discussion Circles**

A discussion circle methodology was used to generate recommendations from Community Meeting participants. The facilitator for the large group guided the process across all of the discussion circles, kept time, and provided frequent reminders. Facilitators in each discussion circle kept participants on task and recorded the group's input.

The composition of these circles was structured to create conversations between participants with similar roles and responsibilities:

- consumers receiving waiver services and their families (or conservators);
- consumers waiting for services and their families (or conservators); and
- providers and advocates.

For advocates and providers, a forced randomization process was achieved by assigning group membership based on the pre-numbered name tag received at registration. This helped to minimize the likelihood that those who work together or were acquainted were in the same group, and ensure that a variety of different provider types and perspectives were represented in each group.

The discussion circles contained 5-11 participants. Each team had a flip chart pad and note pads to record individual group member responses.

Discussion circles were comprised of four rounds. Each round focused on gathering, prioritizing, and ranking responses to one of four questions that had been crafted to gather input on key program aspects. The questions were:

1. *What are the kinds of HCBS that people with intellectual and developmental disabilities need most?*
2. *If a person with intellectual or developmental disabilities lives at home with their family, what are the kinds of supports that family caregivers need?*
3. *What are the ways that HCBS for people with intellectual and developmental disabilities can be improved?*

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<sup>5</sup> Copies of the Community Meeting presentations are available in Appendix XX.

4. *What are ways to provide HCBS to people with intellectual and developmental disabilities more cost effectively so that more people who need services and supports can receive them?*

In round one of the discussion group, the large group facilitator instructed the discussion circles to reflect on the first question, and asked each attendee to write down three responses to that question. Then in round-robin fashion, each participant's ideas were listed on the flip chart pad by the discussion circle facilitator. Duplicate ideas were acknowledged but listed only once. After recording each participant's ideas, the large group facilitator asked each attendee to review all of the responses recorded for their discussion circle and to identify their top three responses (which did not have to include any of the responses they had submitted).

The discussion circle facilitator then recorded each participant's top three responses, assigning a point value to each response as follows: the most important response was assigned three points; the second most important response received two points; and the third most important response was given one point. The discussion circle facilitator then totaled the point values for each response and assigned a ranking of "one" to the response with the highest total point value, a ranking of "two" to the response with the second highest point value, and a ranking of "three" to the response with the third highest point value. If two or more top ranked responses had the same value, the same ranking was assigned to each response such that there could be two or more "one," "two," or "three" ranked responses for each discussion circle. This process was repeated for each of the four questions.

To complete the process, the large group facilitator led a round-robin report out across all of the discussion circles, with each group reporting out their top three ranked responses for each question to all Community Meeting participants.

After each Community Meeting, all the flip charts were collected, identified by date, type of meeting (consumer/family or provider) and subgroup (receiving waiver services or waiting for services, as applicable) for data collection purposes. All of the data was then transcribed and became the basis of the data analysis, described below.

### **Data Analysis of Stakeholder Input from Community Meetings and Surveys**

The community meetings yielded data from 58 consumers, family members and conservators (33 receiving waiver services and 25 waiting to receive waiver services) who provided a total of 332 responses, and 133 HCBS providers and 23 advocates who contributed 964 responses, including rankings of the most preferred responses to each question. Combining these, a total of 1,296 responses from 214 respondents were collected at the meetings and subsequently analyzed. Responses at the meetings were captured as described in the Discussion Circles section.

We recognize that the number of respondents in each of the consumer and family groups is small in comparison to the total number of waiver participants and the total number of individuals waiting for services. We further acknowledge that those who opted to participate in the stakeholder processes are not necessarily representative of the perspectives of the group as a whole. However, the input they provided is incredibly valuable in terms of helping to elucidate the needs of individuals with intellectual and developmental disabilities and their families and guide future program design.

The data was first aggregated by question and by respondent group across all of the Community Meetings (i.e., all responses received and point values assigned for each question from individuals receiving waiver services and family members, all responses received and point values assigned for each question from individuals waiting for services and their families, and all responses and point values received from providers and advocates). Responses from each respondent group were categorized first by identifying “exact” and “close” matching terms and concepts, and then further by aggregating similar categories of recommendations (i.e., combinations of close matching terms and concepts). For example, in questions 1 and 2, different types of residential services (e.g., Supported Living, Semi-Independent Living) were grouped together under the heading “Residential”; various types of Employment and Day Services/Programs were grouped together under the heading “Employment/Day Services;” and different types of clinical services (e.g., physical healthcare, mental healthcare, nursing, therapies, and dental services) were grouped under the heading, “Physical/Mental/Dental/Healthcare.”

Although efforts were made to use consistent categorizations across questions where possible, the categorizations varied by question when appropriate. For example, nursing services were categorized among other types of clinical services in responses to questions 1 and 2. Nursing services were categorized differently in question 4 because it was clear that their inclusion pertained to potential cost-effective practices (e.g., opportunities for delegation, and opportunities to avoid duplication of services when both a nurse and a direct support professional are being paid to provide services at the same time and not simply access to nursing care).

Once categorized, point values previously assigned by each of the discussion circles were summed by participant group (i.e., individuals waiting for services, individuals receiving services, and providers). This yielded a total point value for each category by participant group. The categories were then rank ordered by the total point value to identify categories in the top quartile. The following tables reflect the top quartile of responses received from Community Meeting participants for each of the four questions. Spaces marked with “---” indicate that the foregoing categories comprised the entire top quartile.

Table 1

*Top Quartile Community Meeting Respondent Rankings and Percentages for Question 1:*

	Consumer/Family Member Waiting for Services*	Consumer/Family Member Receiving Services	HCBS Provider
Ranking			
1	Employment/Day Services (25%)	Physical/Mental/Dental/ Healthcare (25%)	Residential (29%)
2	Community Inclusion (15.3%)	Consistent, Well-Trained, Quality Staff (13%)	Employment/Day Services (23%)
3	Respite (14.5%)	Employment/Day Services (11%)	Physical/Mental/Dental/Healthcare (14%)
4	---	Residential (10%) and Service Planning/Coordination (10%)	Personal Assistance and other In-Home Supports (7%)
5	---	---	Service Planning/Coordination (4%) and Behavior Support (4%)
6	---	---	Respite (3%)

\*Footnote – With only 11 total categories of responses to this question received from respondents in the Consumer/Family Member Waiting for Services group, three responses were ranked in the top quartile. The fourth ranked response in this group, with only one point less than the third ranked Respite and 13.7% of the total points, was Personal Assistance and other In-Home Supports. The fifth ranked response in this group (also in the second quartile with 10% of the total points) was Improve Waiting List Management and Movement.

Table 2

*Top Quartile Community Meeting Respondent Rankings and Percentages for Question 2:*

	Consumer/Family Member Waiting for Services*	Consumer/Family Member Receiving Services	HCBS Provider
Ranking			
1	Personal Assistance (In-Home Supports) (21.4%)	Consistent, Well-Trained, Quality Staff (21%)	Respite (25%)
2	Family Education/Navigation/Support (20.5%) and Employment/Day Services (20.5%)	Family Education/Navigation/Support (19%) and Respite (19%)	Personal Assistance (In-Home Supports) (15%)
3	---	Improved Communication (17%)	Family Education/Navigation/Support (14%)
4	---	Employment/Day Services (4%) and Service Planning/Coordination (4%)	Employment/Day Services (11%)
5	---	---	Service Planning/Coordination (8%)
6	---	---	Home and Vehicle Modifications (6%)

\*Footnote - With only 11 total categories of responses to this question received from respondents in the Consumer/Family Member Waiting for Services group, only three responses were ranked in the top quartile, two of which received the same point value and were tied for second. The third ranked response in this group, with only two points less than Family Education/Navigation/Support and Employment/Day Services, was Respite with 19%.

Table 3

*Top Quartile Community Meeting Respondent Rankings and Percentages for Question 3:*

	Consumer/Family Member Waiting for Services	Consumer/Family Member Receiving Services	HCBS Provider
Ranking			
1	Add DD Services/Improve Waiting List Management and Movement (45%)	Staffing (26%)	Service Rules & Definitions (12%)
2	Streamline Regulations/ Paperwork/Processes (11%) and Family Education/ Navigation/ Support (11%)	Employment/Day Services (9%) and Provider Oversight (9%)	Staffing (11%)
3	---	Service Rules & Definitions (8%), Physical/Mental/Dental/ Healthcare (8%), and Service Planning/ Coordination (8%)	Employment/Day Services (10%)
4	---	---	Streamline Regulations/ Paperwork/Processes (9%)
5	---	---	Add DD Services/Improve Waiting List Management and Movement (6%), Physical/Mental/Dental/Healthcare (6%) and Service Planning/ Coordination (6%)*
6	---	---	Stakeholder Engagement (4%) and Provider Rates (4%)*
7	---	---	Family Education/Navigation/Support (3%)

\* These percentages are within 0.5% of each other and are therefore considered as a tie.

Table 4

*Top Quartile Community Meeting Respondent Rankings and Percentages for Question 4:*

	Consumer/Family Member Waiting for Services	Consumer/Family Member Receiving Services	HCBS Provider
Ranking			
1	Funding (18%)	Staffing (14%)	Utilization Management (11%) and Service Rules & Definitions (11%)
2	Best Practices (13%)	Quality & Accountability (13%)	Staffing (9%) and Streamline Regulations/Paperwork/ Processes (9%)*
3	Less than 24-hour supports (12%)	Stakeholder Engagement (10%)	Service Planning/Coordination (6%), Less than 24-hour Supports (6%) and Waiting List (6%)*
4	Service Rules & Definitions (10%)	Utilization Management (8%)	Cost Controls (i.e., Capped Waiver and Service Limits) (5%)
5	---	Physical/Mental/Dental/ Healthcare (8%)	Streamline Program Administration (4%)

\* These percentages are within 0.5% of each other and are therefore considered as a tie

## Key Findings and Conclusions

For each of the four questions, there were significant variations in the highest ranked categories of responses received from each of the respondent groups participating in the Community Meetings.

### **Question 1: *What are the kinds of HCBS that people with intellectual and developmental disabilities need most?***

For question 1, **providers** largely identified existing waiver services as those needed most by these populations: **Residential services first** (29%); **Employment and Day Services second** (23%); **Personal Assistance and other In-Home Supports fourth** (7%); **Behavior Support tied for fifth** (4%); and **Respite sixth** (3%).

These services were ranked by providers in an order similar to current program expenditures in the Arlington and Statewide Waivers. In program year 2011 (January 1 – December 31), Residential services accounted for nearly \$36 million (more than 74%) of the \$48.4 million total Arlington Waiver expenditures and \$339 million (65%) of the \$521 million total Statewide Waiver expenditures. Employment and Day Services were a distant second with \$6 million (nearly 13%) and \$81.4 million (15.6%) of 2011 expenditures in the Arlington and Statewide Waiver expenditures, respectively. While Personal Assistance is barely utilized in the Arlington waiver (nearly all participants receive Residential Services), it was the third highest utilized service in the Statewide Waiver during 2011 at nearly \$44 million (8.4% of total program expenditures).

It is worth noting that 54 of the 271 points (nearly 20%) awarded by providers for Residential services specifically recommended a model of Residential services providing less than 24-hour supports, i.e., Semi-Independent Living—either exclusively or as part of a more comprehensive residential array.

Even more noteworthy, providers identified clinical services including **Physical and Mental Health and Dental** services as the **third** ranked service needed most by individuals with intellectual and developmental disabilities at 14%, highlighting the need for a more integrated and coordinated approach to service delivery. Nursing services garnered 42 of the 132 points (32%) awarded for the clinical services category; therapies (OT/PT/ST), 31 points (23.5%); and, physical healthcare and mental healthcare, 25 points (19%) each.

Providers also ranked **Service Planning/Coordination** in the top quartile, **tied for fifth** with 4% of the assigned points.

For **people receiving waiver services** and their family members and conservators, the need for high quality, coordinated clinical services, including **Physical and Mental Health and Dental** services was the **most important need** with 25% of the total points awarded by this group for responses to this question, nearly twice as many points as any other response in the top quartile. Topping the list of clinical needs were dental services with 26

of the 54 total points awarded (48%) for the clinical services category, followed by physical healthcare at 17 points (31.4%).

**Consistent, well trained, quality staff** was the **second** highest ranked response by **people receiving services** for this question at 13%. **Employment and Day Services** ranked **third** at 11%, with nearly all (20) of the 23 total points specifically focused on Employment (rather than other Day) services. **Residential** and **Service Planning and Coordination** rounded out the top quartile of responses for this question, tying for **fourth** with 10% of the total points each. Of note, 9 of the 21 total points for Residential services specifically identified “more secure” residential options for individuals with significant behavior support needs.

For **people waiting for waiver services** and their family members and conservators, the top ranked responses differed significantly from either of the other two respondent groups. The need for **Employment and Day Services** was clearly the **top priority** with 25% of the total points awarded by this group for responses to this question. Opportunities for **Community Inclusion** ranked **second** at 15.3%. Just a point below and ranked **third** was **Respite**, with 14.5%. Another point below (just below the top quartile) and ranked **fourth** (with 13.7% of the total points) was **Personal Assistance and other In-Home Supports**, followed by **Improve Waiting List Management and Movement** at 10%.

**Question 2: *If a person with intellectual or developmental disabilities lives at home with their family, what are the kinds of supports that family caregivers need?***

Responses to question 2 yielded somewhat greater alignment among respondent groups, but also significant differences. **Respite** was the **top ranked** response for **HCBS providers** at 25% of the total points awarded for this question, tied for **second** among **individuals receiving waiver services** and their family members and was a close third (but slightly below the top quartile) for **consumers** and family members in the group **waiting to receive services** at 19% each.

More important than Respite and ranked **first** for **individuals receiving waiver services** and their families was having **Consistent, well trained quality staff** (21%), with **Family Education, Navigation and Support** tying Respite for second (also at 19%), and **Improved Communication** among all parties **third** at 17%.

**Family Education, Navigation and Support** was also a priority among **individuals waiting for services** and their families. It **tied for second** with **Employment and Day Services**, each with 20.5% of the points awarded by this group for responses to this question, and was only a point below the **first ranked Personal Assistance (In-Home Supports)**, at **21.4%**. Thus, for this group, basic waiver services were among the most important family caregiver needs. **Individuals receiving waiver services** and their family members ranked **Employment and Day Services** and **Service Planning/Coordination** **fourth** (with 4% of the points each).

**Providers** identified **Personal Assistance** as their **second** ranked response at 15%, followed closely by **Family Education, Navigation and Support** at 14% (ranked **third**), and **Employment and Day Services** at 11% (ranked **fourth**), aligning well with many of the same priorities identified by the consumer groups. Providers also recommended **Service Planning and Coordination** at 8% (ranked **fifth**). **Home and Vehicle Modifications** rounded out the top quartile for **Providers** at 6% (ranked **sixth**).

**Question 3: *What are the ways that HCBS for people with intellectual and developmental disabilities can be improved?***

As with responses to question 2, responses to question 3 yielded some alignment among respondent groups, but also important differences.

For **individuals receiving waiver services** and their family members and conservators, **Staffing** was identified as presenting the **greatest opportunity for improvement** in the program with more than a quarter (26%) of the total points awarded by this group for responses to this question. This included strong recommendations (59% of the points awarded for the Staffing category) to increase the pay of direct support staff in order to recruit and retain higher quality staff, as well as improved training and tracking of “problematic” workers to prevent their movement among agencies. **Staffing** was also important to HCBS **providers** and ranked **second** with 11% of the points. Providers also recommended investments in direct support staff (56% of the points in the Staffing category), and identified better training as a key improvement opportunity (the remaining 44% of points in the Staffing category).

Slightly more important than staffing and ranked **first** for HCBS **providers** were opportunities to refine program and **Service Rules and Definitions**, with 12% of the total points awarded by providers for responses to this question. The overwhelming majority of recommendations in the Service Rules and Definitions category (82.5%) related to increased flexibility with respect to service definitions in order to allow benefits to be better tailored to the unique needs of waiver participants. This was one of three categories that **tied for third** place among **individuals receiving waiver services** and their families, with 8% of the total points awarded by this group for responses to this question.

Tied for **second** among **individuals receiving waiver services** and their families, and ranked **third** among HCBS **providers** with 9% and 10% of the total points, respectively, were opportunities to improve **Employment and Day Services**. For **individuals receiving waiver services and their families**, the other **second** ranked recommendation was **Provider Oversight**, including stricter standards and monitoring, also with 9% of the points.

With 9% of the points, opportunities to **Streamline Regulations, Paperwork and Processes** ranked **fourth** among responses from HCBS **providers**, a priority that **tied for second** among **individuals waiting to receive services** and their family members with 11% of the total points awarded by that group for responses to this question. For

individuals waiting for services and their families, all of the points were specifically focused on improvements in the intake and application process for waiver services. The other **second** ranked response for **individuals waiting** for services and their families was **Family Education, Navigation and Support**, also with 11%, which was ranked **seventh** by **Providers** (3%).

Overwhelmingly, however, for the group of **consumers** and family members **waiting for services**, the **key opportunity for improvement**, with 45% of the points awarded by the group for responses to this question, is in the design of programs to **serve people with** all kinds of **developmental disabilities** (not just intellectual disabilities) and to **Improve Waiting List Management and Movement**. This concern was also noted in the top quartile of responses for HCBS **providers** with 6% of points (ranked **fifth**).

Rounding out the top quartile for **individuals receiving services** and their families and ranking **fifth** for HCBS **providers** were additional recommendations around integration and coordination of clinical services needs, including Physical and Mental Health and Dental services and opportunities for better **Service Planning and Coordination**, with 8% of the total points in each category for individuals receiving waiver services and their families, and 6% of the total points in each category for **providers**. For both groups, the most important clinical service need (with roughly half of the points for each group in the clinical services category) was mental health.

Providers additionally included **Stakeholder Engagement** and increasing **Provider Rates** in the top quartile. These were tied for **sixth** with 4% of points assigned.

**Question 4: *What are ways to provide HCBS to people with intellectual and developmental disabilities more cost effectively so that more people who need services and supports can receive them?***

As with previous questions, responses varied among groups, but similar to question 3, the greatest alignment was between individuals already receiving waiver services and HCBS providers. Ranked **first** among **individuals receiving services** (14%) and **second** with **providers** (9%), was opportunities to deliver care more cost-effectively through **Staffing** improvements—almost exclusively targeted increases in direct support staff wages in order to reduce turnover and associated administrative costs (e.g., training, etc.).

Ranked **second** for **individuals receiving services** and their families was **Quality and Accountability** with 13% of the total points awarded by the group for responses to this question. Stricter standards and closer monitoring were the specific recommendations from the waiver participant group.

At the top of list of recommendations for **individuals waiting for services** and their families with 18% was additional **Funding** to provide services to people on the waiting list and individuals with developmental disabilities.

**Individuals waiting for services** and their families also recommended and ranked **second**, with 13% of responses to this question, examining other state program models (i.e., **Best Practices**) in order to identify more cost-effective program designs and create public awareness regarding how expenditures for these services in Tennessee compare to other states. **Less than 24-Hour Supports** was the **third** highest ranked recommendation, with 12% of the points assigned by the group, reflecting a suggestion to move away from the current program model centered around the provision of 24-hour supports toward less intensive support options, including Semi-Independent Living.

Continued opportunities for **Stakeholder Engagement**, improved **Utilization Management** strategies to match services with assessed need, and **Physical/Mental/Dental Healthcare** rounded out the top quartile for **individuals receiving waiver services** and their families and conservators, with 10%, 8.3%, and 7.7% of the total points, respectively.

**Utilization Management** was also prioritized by HCBS **providers**, tied for **first** with changes to **Service Rules and Definitions** with 11% of the points each. Provider Utilization Management recommendations specifically noted PA, nursing, and therapies as potential areas for targeted review, and noted areas of duplication in services—where a nurse is being paid to provide services at the same time as direct support staff (either in the residential, home, or other community setting). **Service Rules and Definitions** was the **fourth** highest ranked item for **individuals waiting for services** and their families, with 10% of the points.

Tied for **second** at 9% of the total points assigned by HCBS **providers** for this question was **Streamline Regulations, Paperwork and Processes**, including regulatory relief, and reduced paperwork and monitoring. Three recommendations ranked were tied for **third** for HCBS **providers**, with 6% of the points each: **Service Planning and Coordination** improvements, with 46 of the 55 points (84%) assigned to the Service Planning and Coordination category recommending the elimination of Independent Support Coordination services and the return of case management functions to providers; **Less than 24-hour supports**; and **Waiting List Management and Movement**, with an emphasis on preventative services to help delay or prevent crisis. Ranked **fourth** with 5% of the assigned points for **providers**, were recommendations to implement capped waivers and service limits (categorized broadly as **Cost Controls**). **Providers** rounded out the top quartile with **Streamline Program Administration** as the **fifth** ranked item (4%).

## Online Survey

An online survey was developed via Survey Monkey in order to provide a means for input for consumers, family members and conservators who could not attend the Community Meetings.<sup>6</sup> The availability of the online survey was highlighted in the invitations. The survey was composed of questions used to gather input similar to that collected in

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<sup>5</sup> A copy of the survey is available in Appendix X.

Community Meeting discussions, along with questions intended to gather basic demographic information about their relationship to LTSS (categories such as person with IDD, parent, family member or legal representative, etc.). Individuals needing assistance completing the survey were directed to call staff in the LTSS Division customer service center. Survey responses were received from January 21 through February 10, 2014, with assistance provided by TennCare LTSS staff, as needed.

Seventeen respondents completed the online survey, including 2 consumers receiving waiver services, 7 family members of a person receiving waiver services, 7 family members of persons not yet receiving (i.e., waiting for) services, and 1 provider.

All but one of the respondents to the question, “Do you think the State should try to provide waiver services more cost-effectively so that more people can be served?” responded, “Yes.” The provider was the only one to respond “No” to this question.

Similar to questions 1, 2, and 3 used to guide Discussion Circles in the Community Forums, survey respondents were asked to identify either the 3 most important waiver services they currently receive or if waiting for services, the 3 most important services that would help them live in the community. For individuals receiving services and their families, the top ranked responses were various types of Residential Services, followed by Personal Assistance. Transportation and Behavior Services tied at the next tier of importance, followed by Employment and Day Services and Service Planning and Coordination. For individuals waiting for services and their families, responses varied based on the age of the person with intellectual or developmental disabilities. Among the 3 families with young children (ages 6-12), primary needs were more focused around community and recreational opportunities, as well as therapies and respite; while the 4 families with an adult with disabilities identified such services as Employment and Day Services, supervised Personal Assistance, and Transportation.

Similar to many of the top ranked recommendations received from participants in the Community Meetings, common themes among survey respondents receiving waiver services and their families included increased Program Monitoring and Accountability; more flexible program and Service Rules and Definitions; Staff pay, training and quality; improved Employment and Day Services and Transportation; and recommendations to improve or allow families to opt out of Independent Support Coordination.

Likewise, survey responses from families of individuals waiting for services tracked responses received from Community Meeting participants, including a key focus on Employment and Day Services to allow family caregivers to work and to allow the person to pursue post-secondary employment and community living goals; Family Education, Navigation and Support; and services for people with developmental disabilities.

## **Additional Written Comments and Other Follow-up Recommendations**

At the conclusion of the Community Meetings and online survey, written comments continued to be received from interested stakeholder groups, including:

- An interested stakeholder whose comments did not specify her relationship to program participants;
- The Disability Law & Advocacy Center of Tennessee; and
- The Tennessee Department of Education.

Comments received from an interested stakeholder focused primarily on system-wide accountability—for staff, supervisors, providers, and DIDD, with particular attention to investigations and complaints to ensure that quality of care concerns and compliance issues are promptly and appropriately addressed.

Echoing the previous recommendations of numerous groups, the Disability Law & Advocacy Center (DLAC) recommended a new capped “Employment First” waiver, encompassing a range of flexible employment services such as follow-along once Vocational Rehabilitation funding has been exhausted, benefits counseling, and time limits on pre-vocational training. DLAC recommended comparable “Employment First” initiatives within the renewed Arlington and Statewide waiver programs.

Also aligned with recommendations from numerous other groups, DLAC suggested that in addition to meeting the needs of individuals determined to be “in crisis,” that the State revamp its waiting list management approach to provide services to those on the waiting list *before* they are in crisis, allowing the State to save money, and more importantly, providing the services and supports needed for people with disabilities to participate fully in employment and community life. The recommended program design also echoed suggestions received from numerous other stakeholder groups, including cost cap tiers within which participants can direct their own services, and as noted above, a capped “support services” or “supporting families” waiver.

The Tennessee Department of Education’s recommendations focused exclusively on young adults with disabilities leaving secondary education, once again reinforcing the need for moderate support services such as follow-along and transportation that will allow them to maximize the benefits of the significant resources invested in their education and transition planning, and assist them in meeting their post-secondary education and employment goals.

One provider who delivers HCBS in multiple states requested a face-to-face discussion with TennCare after the conclusion of the Community Meetings. During a meeting on March 10, 2014, this provider, contracted to deliver an array of residential, day, and other support services in the current waivers, expressed concern that focus would be shifted away from core services that people with intellectual and developmental disabilities need most to “ancillary services” that, while important, are not as essential—particularly to individuals not currently receiving HCBS.

The provider also shared concerns that reimbursement methodologies, established in 2005, do not necessarily take into account regulatory and programmatic changes which have occurred since that time. There were also discussions regarding Family Model Residential as a more cost-effective residential service model that has been more widely used in other states. In addition, there were brief discussions regarding how nursing services could be better integrated and more cost-effectively provided within the residential services benefits and reimbursed as an add-on to the residential rate, rather than as a separate hourly service.

Another provider, operating in 42 states as well as Canada and U.S. territories, submitted extensive written recommendations. There were 5 key recommendations, with additional explanation regarding each:

- 1) **Integrated HCBS Programs Focused on Persons with ID/DD**, with “all HCBS/LTSS, medical needs, behavioral supports, employment-related services and other supports...coordinated by a single source that is (a) focused on the unique needs of people with ID/DD and (b) responsible for ensuring that each person receives needed aspects of service within the level of funding available for such services. There should be a single point of entry into this system for all individuals with ID/DD, including coordinated case management of all HCBS and other services. This new service model should reside under one state agency/department managed as a separate program to reduce administrative burdens and improve communication to all stakeholders.”
- 2) **Objective Needs Assessments to Determine Levels of Service**
- 3) **Flexibility in the Service Model to Align Service Levels with Needs**, “allow for the movement of people from more restrictive congregate living settings into HCBS options through strategies and program changes that support institutional diversion, conversion of current ICF-DD homes, and development of therapeutic respite centers to prevent costly hospitalizations and utilize periodic out-of-home placements for people who experience challenging behaviors.”
- 4) **All HCBS, Medical and Behavioral Services for People with ID/DD Need to Be Coordinated and Managed in a Comprehensive Program.** “The program should fiscally incentivize a reduction in institutionalization (ideally by including both institutions and HCBS/LTSS in the same program) and incentivize coordination by including medical (acute and sub-acute), behavioral and HCBS/LTSS services... By approaching physical and behavioral health needs in conjunction with long term services and supports as an integrated continuum of care process, we believe improved outcomes for individuals and cost savings for the State can be achieved... Precisely how this integration of services and coordination of care can best be achieved will obviously be one of the questions that TennCare and DIDD seek to answer in this process. Whether that is done through a combined 1915(b)/1915(c) waiver, or through an 1115 waiver, or other mechanisms can be determined once the appropriate system/program design is established.”

## **5) The System Should Focus on Quality, Data, Outcomes and Metrics.**

“The system for funding these services should be designed to provide the following:

- Appropriate service utilization metrics, resulting in system-wide efficiency and cost avoidance that can be used to expand the number of consumers served.
- Incentives for providers who achieve performance targets established by the program, including improved outcomes, improved consumer satisfaction, cost savings, and other metrics.
- Focus on family and community supports to reduce over-reliance on paid supports and achieve better outcomes.

We recommend a program that initially is based on a fee-for-service structure combined with a model that provides for performance incentives based on achievement of established metrics. As experience is gained with a new service delivery model, the reimbursement structure would migrate over a defined timeframe to a fully-capitated structure.

In addition, to ensure transparency and accountability, TennCare and DIDD should promote implementation of measuring and monitoring systems with metrics for health outcomes and quality of life, which can make a meaningful difference in the support received by individuals with ID/DD...

Fee-for-service reimbursement schemes should be phased out in favor of a system that pays for improved outcomes and higher levels of quality. Quality standards, including the ability to provide data, should be established based on best practices and required for providers to participate in the network.

Shared savings, quality and performance incentives, and other innovative contracting methods should be structured to incentivize new, flexible service delivery models that link services to need and tie reimbursement to outcomes. By doing this, the State can realize a significant reduction in the per person cost of providing services, thus expanding the number of individuals that can be served with the same level of resources.”

## **Summary**

Input received from the Community Meetings yields significant insights regarding future program design. The current comprehensive benefit structure with its heavy emphasis on 24-hour residential care is not, from the perspective of either those receiving services or those waiting for services, among the most critical needs of individuals with intellectual and developmental disabilities and their families. In fact, there were multiple recommendations from individuals waiting for services and their families and conservators, as well as from providers, to move away from 24-hour supports as the default expectation, with the recommendation being ranked in the top quartile of responses among both groups’ cost-effectiveness recommendations.

Further, for both consumer/family groups, Employment and Day Services are a key priority, with Employment outranking Day Services among the needs identified by providers as well as individuals receiving waiver services.

Also for both consumer groups, there are aspects of service delivery that are among the most pressing service needs. For individuals receiving waiver services and their families, consistent, well trained, quality staff is key—both in terms of services for the individual and supports for the family. They, along with providers, strongly recommended targeted investments in direct care staff pay in order to recruit and retain high quality staff. For individuals waiting for services and their families, opportunities for integrated community activities is important. For both consumer/family groups, family education, navigation and family support is a high priority. And for all three groups (including HCBS providers), the importance of an integrated and coordinated approach to services and supports, focusing on the whole person and all of their physical and behavioral (i.e., mental) health and functional support needs is among the most critical needs. In fact, continuing throughout responses to many of the questions was a continuing thread of holistic, person-centered service planning and coordination, as well as needs based assessment and utilization of services based on the individualized needs of program participants.

In some cases, recommendations were directly opposed. There were recommendations to increase provider monitoring from consumer/family groups, and recommendations to decrease them from providers. There were recommendations to expand service arrays and to reduce them, while providing greater flexibility among a smaller number of services. There were recommendations to use service limits as well as expenditure caps, and recommendations to remove certain service limits already in place. Nonetheless, areas of consistency and priority emerged.

Clearly, there is widespread support among individuals receiving services and their families, and especially among providers to modify program and service rules and definitions. Likewise, providers and consumers and families in the group waiting for services want to streamline regulations, paperwork and processes, with the latter being focused primarily on intake. Providers made recommendations both with respect to the Independent Support Coordination system and with respect to State program administration, believing there are opportunities to reduce staff as well as cost.

Also worth noting across multiple questions were responses to modify the program design and waiting list approach, providing smaller capped waivers that would allow resources to be spread across more of the people who need support, offering services prior to crisis in an effort to delay or prevent more intensive service needs, targeting services to young adults transitioning from high school to assist them in pursuing employment and independent living, and addressing the needs of aging individuals with intellectual and developmental disabilities, as well as aging caregivers. These recommendations were similar to those heard from multiple advocacy groups during discussions held prior to the Community Meetings.

Placing this feedback, along with feedback received from the online surveys within the context of the written recommendations received—from stakeholder groups at the start of the process and after the Community Meetings had been completed, highlights important opportunities to ensure that programs and policies are aligned with the needs and preferences of individuals who need services and their families, and that they are cost-effective, allowing more of the people on the waiting list as well as individuals with developmental disabilities to be served.

It will be critical that the State takes all of these perspectives and recommendations into account, with some applicable to renewal of the Arlington and Statewide Waivers, but with most providing key guidance with respect to future program designs that can better and more cost-effectively serve individuals with intellectual and developmental disabilities in the future.

### **Next Steps**

With valuable stakeholder input gathered, TennCare and DIDD will next develop a concept paper regarding how these insights will be used to inform the renewal of the Arlington and Statewide Waivers, as well as how they might inform future new program models for individuals with intellectual and developmental disabilities.

The public release of the concept paper will allow continuation of stakeholder engagement in the process, and the opportunity for the State to begin a dialogue with the Centers for Medicare and Medicaid Services that will help lay the groundwork for future waiver renewal applications and amendments later this year.