

***Concept Paper on
Renewal and Redesign of
Tennessee's Long-Term Services and
Supports Delivery System for
Individuals with Intellectual and
Developmental Disabilities:***

Stakeholder Input Summary



On May 30, 2014, TennCare and the Department of Intellectual and Developmental Disabilities (DIDD) posted for public review and input a *Concept Paper*¹ summarizing proposed changes to the State of Tennessee’s Section 1915(c) Home and Community Based Services (HCBS) waiver programs and a proposed new program that will provide HCBS to individuals with intellectual and other kinds of developmental disabilities. The new program will help to ensure more cost-effective delivery of HCBS so that more people will be able to receive needed services and supports.

The changes proposed in the *Concept Paper* were based on extensive input received from stakeholders through in-person meetings with advocacy and provider groups, statewide community meetings with consumers receiving or waiting for services, their family members, providers and advocates, an online survey, and other written comments.²

As part of the ongoing public input process, TennCare and DIDD again jointly hosted regional community meetings in order to present the *Concept Paper* to stakeholders, respond to questions, and gather stakeholder feedback. These meetings were announced in the *Concept Paper*, including a link to meeting invitations and details.

Separate invitations were developed for consumers and family members and for providers and advocates, and included the dates, times, and locations of meetings for that target group.³ In addition to announcement in the *Concept Paper*, community meeting invitations were posted on the TennCare and DIDD websites and disseminated to HCBS provider groups and advocacy organizations representing individuals with intellectual and developmental disabilities.⁴ In addition, the meetings (including a link to meeting invitations) were detailed in the May 30, 2014 edition of *Open Line*, a weekly electronic newsletter disseminated by DIDD to all contracted providers, including Independent Support Coordination agencies, advocacy groups, and state staff.⁵ Each provider/advocacy group was asked to disseminate meeting invitations to individuals with I/DD and their families.

¹ The *Concept Paper* is posted on the TennCare and DIDD websites (see below):
<http://tn.gov/tenncare/forms/ConceptPaper.pdf> and
<http://tn.gov/didd/newsroom/announcements/Concept%20Paper-5.30.14.pdf>.

² The *Stakeholder Input Summary* is available at:
http://tn.gov/tenncare/forms/ID_DDStakeholderInputSummary.pdf.

³ Copies of the consumer/family and provider invitations are available at:
<http://www.tn.gov/tenncare/forms/ConceptPaperConsumerCommunityMeetingInvite.pdf> and
<http://www.tn.gov/tenncare/forms/ConceptPaperProviderCommunityMeetingInvite.pdf>.

⁴ HCBS provider groups include the Tennessee Network of Community Organizations, Tennessee Provider Coalition, and Tennessee Alliance of Support Coordinators. Advocacy organizations include the Arc of Tennessee, Tennessee Council on Developmental Disabilities, and the Tennessee Disability Coalition.

⁵ A copy of the May 30, 2014 version of *Open Line* is available at:
<http://www.tn.gov/didd/newsroom/OpenLine/2014/Open%20Line%205-30-2014.pdf>.

Consumers and family members were encouraged to attend the consumer/family group sessions and providers and advocates were asked to attend the provider/advocate sessions, although registrants and responses were recorded and sorted by group regardless of the meeting attended. The availability of the online survey (described below) was highlighted in the invitations and during the meetings as an alternative way of providing input.

Community meetings were held across Tennessee beginning on June 4, 2014 and concluding on June 11, 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 and advocates.

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, advocates and HCBS providers. Registrants included 74 consumers, family members and conservators (including 48 individuals receiving waiver services and their family members or conservators, and 26 individuals waiting for services and their family members or conservators); 23 advocates; and 193 provider representatives who attended the meetings statewide, for a total of 290 participants (excluding state staff).

Community meetings began with a 60-75 minute PowerPoint presentation describing key elements of the *Concept Paper*.⁶ The presentation was followed by a 30-45 minute period for questions and answers. The purpose of the presentation and question and answer session was to aid attendees' understanding in order to facilitate their provision of informed stakeholder input.

At the conclusion of the presentation and question and answer session, participants were strongly encouraged to take the remaining time (generally 10-15 minutes) to craft written comments regarding the *Concept Paper* which they could submit prior to leaving. An input form was made available to each attendee, including the following questions:

- Please tell us the top three things you like best about the proposed plan.
- Please tell us the top three ways you think the proposed plan can be improved.
- Please tell us your top three concerns with the proposed plan.

The use of structured questions to help guide input helps to facilitate the aggregation and analysis of information received. The form also included a section to list questions not addressed during the community meeting they attended.

Attendees were also advised of the online survey as an alternative way to submit comments. TennCare and DIDD committed to accept comments on the *Concept Paper* through Monday, June 30, 2014. Attendees electing not to submit comments prior to

⁵ Copies of the community meeting presentations are available at:
<http://tn.gov/tenncare/forms/DIDDConceptPaperCommunityMeetingsConsumers.pdf> and
<http://tn.gov/tenncare/forms/DIDDConceptPaperCommunityMeetingsProviders.pdf>.

leaving the meeting were strongly encouraged to submit comments via the alternative online option, in order to help inform future program changes.

Immediately following the community meetings and based on additional feedback, TennCare worked with the Tennessee Council on Developmental Disabilities to develop easier-to-understand summaries of the *Concept Paper* for two target groups: individuals receiving waiver services and their families/conservators, and individuals needing and waiting to receive services and their families/conservators.⁷ As with the community meeting presentations and question and answer sessions, the purpose of these documents was to minimize potential concerns and aid understanding of individuals in each of the target groups in order to facilitate their provision of informed stakeholder input. As with previous materials, TennCare disseminated these summaries to each of the advocacy and provider groups identified above, and requested their assistance in distributing the materials to consumers, family members, and conservators.

Input Received from Community Meetings and Online Survey

Of the total 290 community meeting attendees, a very small number (only 19) elected to submit written comments at the conclusion of the meeting, encompassing a total of 199 individual comments and questions. This included 33 comments from consumers waiting to receive services or a family member, 63 responses from consumers receiving services or a family member, and 103 comments from providers. The vast majority of individuals submitting input (47) elected to submit written comments via the online survey tool, encompassing a total of 345 individual comments and questions. This included 42 comments from respondents self-identified as family members, 103 comments from respondents self-identified as advocates, and 200 comments from respondents self-identified as providers.

Responses to each question received were categorized whenever possible to help identify those ideas or recommendations offered more frequently by respondent groups. Response categories representing at least 5 percent of the total response to a particular question are highlighted below.

“Please tell us the top three things you like best about the proposed plan.”

A total of 180 responses were received to this question,⁸ including 17 responses from consumers waiting to receive services or a family member; 28 responses from consumers receiving services or a family member; 33 responses self-identified as advocates (including

⁷ Copies of the “plain language” summaries of the Concept Paper for each of the target populations are available at:

<http://tn.gov/tenncare/forms/ConceptPaperSummaryCurrentWaiver.pdf> and
<http://tn.gov/tenncare/forms/ConceptPaperSummaryWaitingList.pdf>.

⁸ Please note that, for each question, the total number of responses represents the number of unique comments received on that question across all respondents. Both the comment form and the online survey requested 3 responses to each of the 3 questions, or a total of 9 responses. Individual respondents may have provided fewer or more than 9 responses.

16 responses from ISC providers who self-identified as advocates, 6 responses from DIDD employees who self-identified as advocates, and a total of 11 responses from The Arc of Tennessee, Disability Law & Advocacy Center of Tennessee, Tennessee Disability Coalition, and Tennessee Works Partnership); and 102 responses from providers (including 31 from self-identified ISC providers, 36 from non-ISC providers, and 35 from unspecified providers). Responses to this question represent the greatest alignment of recommendations across the 3 questions.

- Of the 180 responses, nearly one-third, (or 57) liked that the proposed changes would expand access to HCBS—including individuals with intellectual disabilities currently on the waiting list, individuals with developmental disabilities, and children under age 21. (In fact, no category of responses to *any* of the 3 questions was more frequently offered.)
- Twenty-three (23) responses indicated that one of the best things about the proposed changes is the focus on employment and independent living. This is consistent with input received through previous public input processes, and which was used to inform the development of the *Concept Paper*.
- Twenty (20) respondents also liked person-centered aspects of the plan, including opportunities for increased choice and self-determination.
- Fifteen (15) respondents—including individuals receiving services, a single response from a coalition of parents, and several responses from other advocates and providers—liked that that the proposed changes to the system will be implemented in a manner which ensures continuity of waiver services for individuals already enrolled in a waiver program.
- Twelve (12) responses were supportive that the proposed changes will help to ensure a more cost-effective use of available funding.
- Eleven (11) respondents liked specific aspects of proposed “essential amendments” to the Arlington and Statewide waivers, including flexibility in shared living arrangements, shared nursing and personal assistance services, and in the provision of unskilled assistance needed during the course of skilled care, as well as the move toward an objective approach to setting levels of reimbursement for certain services.
- Nine (9) responses expressed general support for the State’s plan, without identifying particular elements of the plan that were preferred.

“Please tell us the top three ways you think the proposed plan can be improved.”

A total of 155 responses to this question were received, including 13 responses from consumers waiting to receive services or a family member; 25 responses from consumers receiving services or a family member; 33 responses self-identified as advocates (including 17 responses from ISC providers who self-identified as advocates, 5 responses from DIDD employees who self-identified as advocates, and a total of 11 responses from The Arc of Tennessee, Disability Law & Advocacy Center of Tennessee, Tennessee Disability Coalition, and Tennessee Works Partnership); and 84 responses from providers (including 28 from self-identified ISC providers, 32 from non-ISC providers, and 24 from unspecified providers) There was less alignment of recommendations as to how the proposed plan can

be improved, although several categories of responses were clearly identified more frequently than others.

- The largest category of responses—19 in total—reflect a desire for greater specificity and detail regarding the proposed changes and how they will be implemented. Several of these responses encompassed a number of individual questions or requests for additional information.
- Eighteen (18) responses recommended that there continue to be a system of independent support coordination. Fifteen (15) of those comments were submitted by individuals affiliated with independent support coordination agencies (whether self-identified as an advocate or provider) contracted to provide this service in the Arlington and Statewide waiver programs, with the remaining recommendations coming from two individuals receiving services or a family member, and one individual needing services or a family member. Regardless of source, these comments reflect important considerations around the importance of person-centered aspects of service planning, and the need for someone to function as an advocate on behalf of individuals receiving support.
- Ten (10) respondents recommended that the cost cap amounts (whether the individual cost neutrality cap in the Statewide waiver or expenditure caps in the proposed new program) be higher, or that there be a method for requesting exceptions to these caps when needed by an individual. Several of those comments related specifically to concerns regarding individuals with significant behavior support needs who may be a danger to self or others.
- Eight (8) respondents (6 of which were providers) recommended against using the Supports Intensity Scale as a tool for determining reimbursement rates.
- Eight (8) respondents also indicated that the plan would be improved by strengthening person-centered aspects of service planning and delivery.

“Please tell us your top three concerns with the proposed plan.”

A total of 189 responses to this question were received, including 16 responses from consumers waiting to receive services or a family member; 28 responses from consumers receiving services or a family member; 37 responses self-identified as advocates (including 17 responses from ISC providers who self-identified as advocates, 6 responses from DIDD employees who self-identified as advocates, and a total of 14 responses from The Arc of Tennessee, Disability Law & Advocacy Center of Tennessee, Tennessee Disability Coalition, and Tennessee Works Partnership); and 108 responses from providers (including 35 from self-identified ISC providers, 38 from non-ISC providers, and 35 from unspecified providers). The most common responses in the “concerns” question track closely to those in the “improvements” question, suggesting that these are important areas for further consideration, dialogue, understanding and development.

- The most frequent concern by far (received from 29 respondents) was the provision of Support Coordination for people who will be enrolled in the new program. At least 14 (nearly half) were expressed by self-identified providers of Independent Support Coordination services in the Arlington and Statewide waivers. Concerns

were also expressed by individuals receiving services, their family members, and other providers not self-identified as ISC agencies.

- The next most common category of concern pertained to cost caps (again including both the individual cost neutrality cap in the Statewide waiver and expenditure caps in the proposed new program), again with mention of individuals who exhibit behaviors that may endanger others.
- Twelve (12) respondents expressed concerns with understanding the plan or how it will be implemented.
- Twelve (12) respondents (including 6 advocates and 6 providers) also expressed concern regarding whether person-centeredness and individual choice will be protected and preserved.
- Eleven (11) responses (10 from providers) reflected concerns about MCOs contracting with current waiver providers and preserving individual choice of providers in the new program.
- Eleven (11) respondents expressed concerns specifically about the proposed managed care delivery system model for the new *Employment and Community First CHOICES* program, including administration of the new program, as well as more person-centered aspects of support delivery.

In addition to input received from community meetings and the online survey, TennCare received a number of more extensive sets of written comments—primarily from advocacy and provider groups, including:

- The Arc of Tennessee
- Disability Law & Advocacy Center of Tennessee
- Mid-TN Supported Living, Inc.
- Tennessee Council on Developmental Disabilities
- Tennessee Parent Coalition
- Tennessee Provider Coalition
- Tennessee Works

DIDD also made available, including to DIDD staff, an opportunity to submit open-ended written comments on the DIDD website.

Both TennCare and DIDD further received and accommodated requests from individual providers, provider groups, and advocacy groups to discuss the proposed *Concept Paper* in face-to-face meetings.

While the nature of the more extensive and open-ended comments make the aggregation of responses more challenging (and accordingly they are not represented in the quantified data set above), each set of comments (whether written or verbal) have been carefully reviewed and will be thoughtfully considered to help inform future program design as appropriate. Input received through these processes generally mirrored recommendations and concerns received from the community meetings and online survey, but with additional context or detail that is invaluable in the planning process.

Summary

As with previous stakeholder processes, public comment received on the *Concept Paper* yields significant insights for TennCare and DIDD.

It appears we were able to appropriately identify and capture many of the key objectives and concerns expressed during previous public input processes, and that people are thus pleased with many aspects of Tennessee's proposed renewal and redesign of the I/DD service delivery system.

In particular, stakeholders like the ability to serve more people, including people on the waiting list and people with developmental disabilities. They also supported the more cost-effective approach to using program funding in order to accomplish this important goal.

Stakeholders expressed support for the focus on employment and independent living, although there is some level of misunderstanding that everyone will be required to get a job, regardless of individual needs, abilities, and preferences.

People—in particular those currently receiving services and their families, as well as advocates and providers are also pleased that the State plans to renew the Arlington and Statewide waivers in a manner that ensures continuity for current program participants.

Clearly, person-centered support, including choice and self-determination is an important system priority which the State recognizes and will continue to work with stakeholders to firmly embed in both current and future program designs, regardless of delivery model. This includes the provision of Support Coordination (i.e., assistance in assessing needs, and planning and implementing supports) in a manner that is directed by the person and that reflects individual preferences and goals, as is required under the new federal person-centered planning rule.

One of the most important takeaways is that significant investments will be needed in education and outreach efforts. In fact, many of the concerns reflect misunderstandings that the State has attempted to address through a question and answer document, posted on the TennCare and DIDD websites.⁹ Other concerns will need to be carefully considered and addressed as appropriate in the implementation of the new program, including clearly defined member safeguards in all aspects of services/supports planning and delivery. Additional questions/answers will be posted moving forward, and we will continue to share information and address concerns as we move forward with waiver renewal applications and amendments.

Likewise, there is an ongoing need for dialogue with stakeholders—as we strengthen person-centered planning, evaluate program components such as expenditure caps, and

⁹ A copy of the Q and A document is available at:
<http://www.tn.gov/tenncare/forms/ConcpetPaperForumQandA.pdf>.

with providers, as we plan and transition to a more objective needs-based approach to reimbursement. Specifically in response to concerns on this issue, we intend to undertake a careful study of the Supports Intensity Scale and supplementary questions and conduct extensive data analysis that will be used to inform member needs and the cost of services and supports. This will include in-depth engagement of providers and other stakeholders before the new reimbursement model is implemented.

In addition, we recognize that the *Concept Paper* did not address certain aspects of stakeholder concerns. Stakeholders identified important opportunities to ensure that staff are consistently assigned, well trained and provide high quality supports. We agree that there are opportunities to review and revise training programs and requirements and to better align financial incentives in order to help achieve these important objectives. However, these kinds of quality improvement efforts are not necessarily part of the waiver renewal process, and thus, not included in the *Concept Paper*. We will continue to work with stakeholders on these aspects of program improvement, and are already pursuing opportunities through a more comprehensive State Innovations Model Testing Grant application to be filed next week.¹⁰

Next Steps

With valuable stakeholder input continuing to be provided and thoughtfully considered, TennCare and DIDD will soon post for a 30-day public input process draft renewal applications for the Arlington and Statewide Waivers, an amendment for the Self-Determination Waiver, and a proposed amendment request to the State's 1115 demonstration in order to implement the *Employment and Community First CHOICES* program.

The public release of these documents will allow continuation of stakeholder engagement in the process, and the opportunity for further refinement of proposed changes, as appropriate.

¹⁰ When filed, the SIM grant application will be posted at: <http://www.tn.gov/HCFA/strategic.shtml>.