

South Dakota

Department Of Human Services

CHOICES

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Renewing the CHOICES Medicaid Waiver: *Public/Tribal Forum & Questionnaire Results*



Division of Developmental Disabilities

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Gathering Public Input for the CHOICES Waiver Renewal

Why is Input Needed?

States that implement a Medicaid waiver program authorized by §1915(c) of the Social Security Act are required by the federal government to secure public and Native American Tribal input in the development of the waiver program. The State can use public input to measure overall satisfaction of the provision of waiver services and make appropriate modifications to the program. Public input is important in order to raise awareness, to promote the use of safeguards, to invite suggestions for program improvement, and to incorporate suggestions into strategic plans.

The current CHOICES waiver program, which funds services for approximately 2,500 participants and certifies 19 Community Support Providers across South Dakota, will expire on May 31, 2013. A renewal of the CHOICES waiver program is due to the federal government before March 1, 2013. Once renewed, the waiver program is in effect for a period of five years.

CHOICES Questionnaire Data Collection

How was the Waiver Participant Questionnaire Administered?

Information from the Waiver Participant Questionnaire was collected via the person receiving CHOICES services or from a direct conversation with the person. Nearly 2,500 questionnaires were mailed directly to all CHOICES waiver participant homes. At the State's request, assistance was provided to participants who asked or could not complete the questionnaire. Assistance was provided by people who best know the participant (such as provider staff, a family member, or friend). The questionnaire had four sections related to preferences, services and supports, satisfaction, and general topics. Each section of the questionnaire included questions that can only be answered by the individual since they incorporated questions that required subjective judgments and personal experiences. Completed questionnaires were mailed back to the Division of Developmental Disabilities (DDD) via postage paid envelope or were submitted in person at any one of the six public and Native American tribal input forums.

How were the Family/Friend and Guardian Questionnaires Administered?

The names and addresses of close family, friends and guardians of CHOICES waiver participants were furnished by Community Support Providers. Questionnaires were mailed to approximately 3,300 homes. This questionnaire had three sections related to services and supports, preferences, and satisfaction. Completed questionnaires were mailed back to the DDD via postage paid envelope or submitted in person at any one of the six public and Native American tribal input forums.

How were the Stakeholder Questionnaires Administered?

Over 100 questionnaires were distributed to CHOICES stakeholders including provider agencies, advocacy groups, disability awareness networks, sponsors, and Native American Tribal governments. The Questionnaire contained three open-ended questions and three multiple choice questions. Completed questionnaires were sent back to the DDD or submitted in person at any one of the six public and Native American tribal input forums.

Questionnaire Results

How many completed Questionnaires were included in the final results?

Overall, more than 1,300 questionnaires were completed and submitted to the DDD which equates to an approximate return rate of 22 percent of the total questionnaires disseminated.

Participant Response

Preferences:

75% choose who helps them and how they spend their day



41%* want to manage their own staff and their CHOICES waiver funding, while **22%** are not sure if they want to manage their own staff and their CHOICES waiver funding

**This percentage is perhaps the result of the difficulty to conceptualize self-directed services. Without full explanation of corresponding responsibilities, the employer and financial requirements may be difficult to understand without the use of more examples and further education.*

Services and Supports:

91% are getting services/supports they need

“...services are better when you live onsite (provider-owned)...but if you choose to live on your own, services are 100 times worse...”

— CHOICES Waiver Participant



88% receive help to plan their own life and supports

73% would not change how their Service Coordinator helps them

“...allow (service coordinator) more time to deal with individual needs...they seem very overworked...” — CHOICES Waiver Participant

Satisfaction:

84% are satisfied with the help they get from staff

57% talk to staff when they don't like something

38% talk to friends/family when they don't like something

General:



78% would know if someone is abusing, neglecting or exploiting them and would know how to report it to someone who can help

52% know what to do if they report abuse, neglect or exploitation and nothing happens

39% need more help to be able to work

*“I need transportation to be taken out into community to apply/look for jobs.”
— CHOICES Waiver Participant*

65% feel they have enough options for work

81% feel they have opportunities to be involved in their community



Family/Friend and Guardian Response

Services and Supports:



90% are satisfied with their involvement in the process of developing their family member's plan

91% believe their family member is getting the services and supports he/she needs

“We feel very fortunate to have our family member in this program. She is happy and well cared for in her current location. Thank you for your good work.” — Family Member of CHOICES Waiver Participant

90% are happy with their current Service Coordinator

68% would not hire their own Service Coordinator

Preferences:

64% do not want to manage their own staff and their CHOICES waiver program funding, while 24% are not sure if they want to manage their own staff and their CHOICES waiver program funding



Satisfaction:



94% are satisfied with the help their family member gets from the CHOICES waiver program

“I am very happy with the whole staff and employees...It makes me feel so good that he will ask to go ‘home’ because he feels safe and secure there.” — Mother of CHOICES Waiver Participant

Stakeholder Responses

- Having more providers is a great option for participants; there are questions about how the State would address quality assurance issues.
- The services not currently part of the CHOICES waiver program that are being requested the most frequently: technology, monitoring equipment, respite services, and self-directed options.
- An Individual Service Plan (ISP) template containing criteria specified by the Division of Developmental Disabilities (DDD) is good for consistency purposes; there are questions about minimum guidelines and concerns of the ISP becoming more burdensome.
- The ways the DDD can better assist those who support people with ID/DD include more funding, less process and forms, DDD staff spending more time with providers, and better understanding and communication.

- The biggest challenge encountered when supporting a CHOICES waiver participant is the co-pay that some people have to pay for services due to their earned income.

How are the findings from the questionnaires disseminated?

Results obtained from each of the three questionnaires are made available to interested stakeholders and to the public at large. The results are posted in a consumer-friendly format on the Division of Developmental Disabilities' website (dhs.sd.gov/dd) and shared with stakeholder groups.

Public and Tribal Forums

Why did the State host Forums?

The purpose of the forums was to gather public and Native American Tribal input about the CHOICES waiver program services in a town hall meeting format. The Division of Developmental Disabilities (DDD) solicited input to determine what services are working and changes that should be considered to support people receiving CHOICES waiver program services. The DDD will use input obtained during the forums in developing ongoing and future services offered by the CHOICES waiver program. Public and Native American Tribal input will be considered as the DDD seeks to renew the CHOICES waiver program.

Who was invited to the Forums and how does it work?

The forums were open to the entire public while the tribal forum was devoted to obtaining input from the state's Native American population. All three versions of the Questionnaire contained an invitation detailing the dates, locations and purpose of the Public and Tribal Forums. Nearly 6,000 invitations were mailed. The forum dates and locations were posted on the Division of Developmental Disabilities' website and also released to the public via media press releases.



During each forum, the Division of Developmental Disabilities provided a brief overview of Medicaid waivers and the services currently offered by the CHOICES waiver program as well as information about the renewal process. After the overview, attendees were asked to break into small groups to gather input about changes or improvements that should be considered in the CHOICES waiver program.

Hundreds of attendees participated at six forums in different regions of the state including Sioux Falls, Aberdeen, Yankton, Chamberlain, Rapid City, and Pierre (Native American/Tribal Forum).

What type of input is commonly mentioned by the public?

The forums focused on six topics that are vital for consideration when renewing the CHOICES waiver program. The topics included qualified providers, service coordination/case management, self-direction (employer and budget authority), alternative residential options, technology, and other input. While some of the input that was provided by the public is very specific to individual situations, the bulk of the input obtained is found to be universal across the state.

Qualified Providers

Scope: the CHOICES waiver program currently provides funding and certification to 19 Community Support Providers (CSP) in South Dakota.

Input to seek: How do we increase the choices of who can provide services and supports?

Universal input obtained:

- The majority of the public is satisfied with their current staff from the CSP and believes they have enough choice in deciding who provides their supports.
- Transportation is a large need across the state and is a struggle to provide in most communities, especially for job needs and community activities. The public presumes additional qualified providers might fulfill these needs.
- Some participants would like to choose their family/friend or another caregiver to provide limited supports while maintaining some of the supports provided by the CSP.
- Participants and their families might be satisfied with the current amount of qualified providers in the State if staff turnover was not so widespread.
- There needs to be more options for rural areas.



Service Coordination/Case Management

Scope: assists participants in gaining access to needed services and development of the support plan.

Traditional vs. Independent: the current CHOICES waiver program provides service coordination through a CSP. This is referred to as Traditional Service Coordination. Independent Service Coordination would allow a CHOICES waiver participant to choose a Service Coordinator that is not employed by the CSP.

Input to seek: What type of Service Coordination would you prefer? What changes do you suggest?

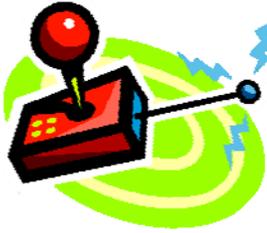
Universal input obtained:

- The majority of the public is satisfied with Traditional Service Coordination.
- Participants expressed satisfaction in the ability to choose the person who provides their service coordination and their involvement in the process of interviewing candidates to provide this support.
- Although only a very small population expressed interest in independent service coordination, the common input was traditional service coordination can be improved by better defining the roles of the Service Coordinator and enhancing the lines of communication amongst the CSP staff.
- Very few indicate they want to be their own service coordinator.



Self-Direction

Scope: a model that expands a participant's choice/control of their services and budgets for those services.



Employer Authority: enables participant's ability to hire, direct, and dismiss the staff who helps them.

Budget Authority: provides participants the opportunity to manage a budget and to authorize the payment of CHOICES waiver services.

Input to seek: What control would you like over your services and a budget?

Universal input obtained:

- Self-Direction is a complex idea for the public to comprehend as an option for participants and a lot of education would be required if this is considered an option in the CHOICES waiver program.
- Much of the public becomes apprehensive of the topic, believing that it might jeopardize services provided by the Community Support Provider (CSP).
- Employer Authority is viewed as the more practical type of self-directing over Budget Authority.
- Those who are interested in self-directing services would like further instruction and guidance during the self-directing process.

Alternative Residential Options

Scope: alternatives to traditional group homes and supervised apartments such as shared-living, living with family, or other semi-independent settings.

Input to seek: What alternative residential options should be considered for community living?

Universal input obtained:

- The term most frequently used by the public when discussing residential options was "*smaller is better*".
- Shared-living or living in own place is the optimal option for participants.
- Home sizes should be maxed at a low number in order to assure privacy and dignity.
- Matching similar interests among roommates is important.
- The participant should have choice in residence rather than based on CSP staffing levels.
- Less staff is better.



Technology

Scope: technology that affords the participant the ability to live as independently as possible.

Input to seek: What types of technology could reduce staff supports?

Universal input obtained:

- Cameras, iPads, and Skype™ are common suggestions from the public to provide opportunities to connect with family and community resources without staff supports.
- Video and other monitoring devices might be useful; concerns of privacy and rights become an issue.
- Smart houses, smart technology and computers.



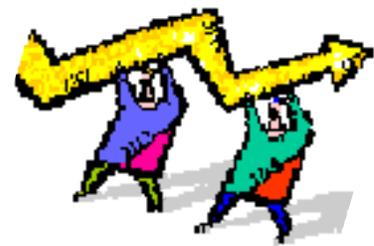
- Participant and staff training in the use of technology will need to occur.
- Few do not want technology and are content with current staff supports.

Other Input

Scope: other input to ensure that people with developmental disabilities can continue to successfully live and work in South Dakota communities.

Universal input obtained:

- The public would like the Division of Developmental Disabilities (DDD) to explore reducing or eliminating the co-pay within the CHOICES waiver program to allow for more money in participant’s pockets and to do away with a potential disincentive to work.
- The public believes more funding is needed in the CHOICES waiver program.
- Available transportation is lacking and is an important need.
- More job options, job coaches and “fitting” the participant to the job.
- Staff turnover is always a concern. The public believes that higher wages may help.
- Public education and awareness is essential.
- The system is in need of crisis supports in the community.



Renewing the CHOICES Waiver Program

What else needs to be done to renew the CHOICES Waiver Program?

The DDD will consider all input obtained from the questionnaires and the forums in developing the new CHOICES Waiver Program. The DDD will continue to seek input from stakeholders, providers, advocacy groups, and disability awareness networks while formulating new and existing components of the program. Final considerations in the new waiver program will be a collaborative process involving the program’s operational authority (the Department of Human Services, Division of Developmental Disabilities), the program’s administrative authority (the Department of Social Services, Division of Medical Services), and the US federal agency which authorizes Medicaid, including waiver programs (the Centers for Medicare and Medicaid Services).

Who can I contact if I have more questions about renewing the program?

Any questions related to the CHOICES waiver program renewal can be directed to Darryl Millner, CHOICES Waiver Manager, at 1-800-265-9684 or Darryl.Millner@state.sd.us.

The Division of Developmental Disabilities would like to thank the self-advocates, families, guardians, stakeholders, provider staff, and everyone who participated in the forums and completed a questionnaire. The input and participation is extremely valuable to ensure that people with developmental disabilities have equal opportunities and receive the services and supports they need to live and work in South Dakota communities.