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Missouri Division of Developmental Disabilities

Stakeholders Meetings

on

Home and Community-Based Waiver Programs

**Facilitated by Robin Cooper,
National Association of State
Directors of Developmental
Disability Services**

Summary Notes August 3 & 4, 2010

Report Prepared For:

Missouri Department of Mental Health
Division of Developmental Disabilities

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Executive Summary

The Missouri Comprehensive and Community-Support Waivers for people with developmental disabilities are approved through June, 2011. New waiver applications will be submitted to the Centers for Medicare and Medicaid Services (CMS) during the winter of 2011. To aid in the development of the applications, input was requested from self-advocates, providers, family members and advocates on the current waiver program. Meetings were held in early August in St. Louis and Kansas City.

In the course of discussions, several themes emerged regarding the waiver programs administered by the Division of Developmental Disabilities. Participants were asked to identify the things they thought were working properly in the current waiver program and issues and areas where they had problems and concerns. Five broad themes in the discussions were: a) consumer choice, b) employment, c) transportation, d) communication regarding services and definitions, and e) level of need and how budgets are created.

Self advocates (SA), providers and family members felt that the current waiver program offered an array of services and supports that were much improved upon earlier programs. Both providers and SA felt that the new waiver program should be more flexible in its ability to better customize supports for consumers for the same amount of money. The waiver should also have a written plan on working toward independence. The new waiver should also allow for respite services in the home of the consumer, not make them transfer to a different setting to receive respite care. Another issue that was strongly mentioned was that the new waiver should have some process for a trial living period to see if potential roommates are compatible. It was felt that many new placements were made to meet funding needs at the expense of the consumer. Forced housing was reported to have lead to serious long lasting behavior problems. New models for housing such as Shared Living should be explored to provide more opportunities for community living.

Self advocates who used self directed services (SDS) reported that this was working for them and that it should be continued in the new waiver. SA stated that they felt that providers often lacked information on SDS and that the new waiver should have provisions to provide more information and training on SDS for both families and providers. They also felt that there should be a better process to guide the transfer from an Individualized Supported Living (ISL) or group home to SDS.

The revised waiver program should have provisions for better access to medical specialists such as dentists and dermatologists. Dental treatment and training of professionals in how best to administer dental care should be a priority.

Transportation costs to both social and work settings should be included in the new waiver. Transportation should be flexible and affordable.

All participating groups, especially SA reported that employment needed to be a high priority for the new waiver. The new waiver should include support and job training for jobs outside the

workshop setting. Included in this should be training on how to handle and resolve conflicts on the job. Workshops should be used for individuals who were unable to work in the community, not as a destination. Procedures might need to be developed to allay fears of employers over hiring individuals with ID/DD.

Another cited area was the lack of transparency and communication regarding waiver services and supports that were available. It appeared that support decisions were made but the information not shared across the state. SA indicated that they would like more information on what support services and equipment charges that would no longer be allowed...what is funded and what is not?

Participants in these meetings felt that there should be better definitions of supported services and supports in the new waiver program. These definitions should be clear, transparent and easily accessed across the state. Included in these definitions should be a clear definition of what is an ISL in the state of Missouri. Staffing issues should be addressed in the new waiver including staff ratios and supervision. SA indicated that they needed more and better trained staff. Perhaps have a continuing education requirement? Providers would like the new waiver to have an exception clause that would allow them to hire experienced staff with a proven employment record in the field, but did not meet the current education requirements of a GED or HS diploma. Another issue that should be addressed in the new waiver is the role the Qualified Developmental Disability Professional (QDDP, or "Q") for example, who qualifies and can professionals with other qualifications provide the same type of oversight.

All participants recognized that budgets for the state are tight and would like the new waiver to have more flexibility that would allow providers to be creative and have the opportunity to develop more customized supports that might save monies. Budgeting procedures should be less difficult to complete under the new waiver and there should be more information on hearing rights and processes when services are denied. Some provisions that require professional contact (for example, nursing services) should be reviewed and allowed to be omitted from the service plan if not necessary.

Regarding the overall state budget, SA strongly reported that they felt state monies should not be spent to develop segregated living communities for persons with developmental disabilities and call them community living facilities, call them something else but not community living. In addition, these monies should be spent on programs and supports to facilitate actual community living.

There were also questions on how budgets would be determined under the new waiver program using the Supports Intensity Scale (SIS). The new waiver should identify how this scale will be administered and by whom? Its use in budgeting should be transparent and flexible to accommodate support needs with a clear process to appeal service denials. In addition, there should be clarification on how this will interact with the Priority of Need utilization review. This assessment process should not replace Person Centered Planning.

Compilation of Responses by Participants

Consumer Choice Issues

Providers, Self Advocates (SA) and Families reported that Missouri offers some programs that promote and offer consumers choices in support services. The Money Follows the Person Project was also mentioned as a positive in this area. Overall, providers felt that Missouri offered an array of services that allowed them to provide support to persons in the community that they were unable to do earlier.

ISL's were reported to be working but there was confusion as to what exactly is an "ISL" in Missouri. Providers felt it was one thing (3-4 person homes operated by a provider) and some consumers stated that it should be their own home.

Choice of roommates was a concern expressed consistently in the discussion with self-advocates. Many have experienced, or have friends who have experienced, ISL services in settings where they did not get to choose their roommates. Several have personally experienced, or know people who have been "kicked out" of the ISL, ostensibly their own home, due to difficulties with a provider. While Missouri waiver policy permits free choice of provider within the ISL, in fact and practice, services are so strongly linked to housing that it is almost impossible for a person to change providers without having to move from the home.

Both providers and SA felt that more flexibility was needed in being able to provide services tailored to the individual. Waiver requirements were too rigid. Providers felt that they needed more room to be creative in how to provide services for the same amount of money. The budget rules were flexible as written, but not as they are implemented or interpreted.

Problems were reported on roommate issues by both SA and providers. Funding appears to drive roommate choices and assignments...what or who is available...not the best fit for the person! Need a trial period for potential roommates to see if they are compatible. When people are forced to live with housemates they did not choose, this can lead to serious behavioral problems.

Waiting lists are a problem along with criteria issues. State regulation sets forth the process for movement from the waiting list. Prioritization of need takes priority over time on waiting list.

Respite care was listed as a problem. Respite care should be provided in SA's own home when possible, SA should not have to go to another location to receive services when their primary support person is unable to provide services.

Self Directed Services (SDS)

SA reported that SDS was working great for them. The ability to hire and fire staff was a definite positive.

There should be better and more organized transfer procedures between living in an ISL and transitioning over to SDS.

Many reported that they thought providers needed more information and communication on self directed services. There appears to be some conflict between providers and SDS as providers feel threatened. Perhaps could lead to new business models for providers. Many family members indicated that they could use assistance from someone in guiding them through the maze of rules on Self Direction (SD). They could also use help in budgeting and making payrolls comply with tax regulation. Need more trained SDS support brokers.

Better education to families, SA and guardians on how budgets are created, allotted, and spent. Need a better explanation in the concept of individual budgets.

Families felt that there should be more support for families assisting with SDS and covered respite care.

Need a better definition of self-determination in the new waiver.

Employment

All groups and especially the self-advocates reported that employment needed to be a high priority and more of a state focus. "Good jobs are important!" Need more help in finding jobs for people in integrated work settings in the community, not workshops. There needs to be more support and training for jobs outside the workshop setting.

People need training on how to resolve conflicts and problems on the job.

People who become employed should not lose their MO HealthNet and other benefits due to earnings.

Persons who are working in a workshop setting need to be treated better by staff.

Day habilitation should lead to workshop experience and then to a job with competitive wages in integrated settings. In actual practice, this rarely occurs.

Staffing and Staff Training

There should be an exception clause in the hiring requirements that would allow an agency to hire someone with a proven record and experience that does not have a GED/HS diploma.

Should there be requirements in the new waiver for continuing education credit requirements?

The current staffing ratios and supervision numbers should be defined to allow for more flexibility were appropriate. More staff hours at times would be a positive. As practiced now, they are too restrictive.

SA reported that they needed more and better trained staff. More money to pay them would also be nice. Hard to find good staff.

Medical Concerns

There should be dental services covered in the new waiver and monies for the Elks Mobile Dental program.

The process to request and obtain needed medical equipment should be more open. Few participants in the discussions have a clear understanding of how this works. In addition, the appeal process for denied services is not clear to many people.

The new waiver should make allowances for access to medical specialists e.g. dermatologists.

The new waivers should include training of medical staff.

The state should keep people better informed when changes will be made in coverage of services, supports and medical equipment.

QDDP Issues

The Qualified Developmental Disability Professional qualifications should be expanded or modified. Missouri follows what is allowed by federal regulation, however, participants feel there are differing interpretations at the local level.

More efficient policies of developing budgets for required QDDP time are needed. Perhaps not all participants need the same amount of QDDP time, and some may not need this level of service at all. The new waiver should allow for “program manager,” time instead, and define program manager qualifications differently than QDDP.

Transportation

Transportation is limited by day of week and time of day. Geographic region also plays a large role in availability. Even when available, it is expensive.

Housing

There is a need to better define services and support in the comprehensive waiver. Examples include rehabilitation versus training and skill development. Is there a difference between state and federal definitions?

SA and providers would like to be more creative in the development of more housing options. The state should research other best practice models for shared housing in other states as examples.

Some people have experienced problems when applying for public housing, leases, or utility connections due to earlier issues in not being able to pay bills. Bad credit scores have impeded some individuals from qualifying for loans.

ISLs

Need a better definition of an ISL in the new waiver.

There is some confusion on how an ISL is defined in Missouri. Everywhere in the United States, 3-4 persons sharing a home when those people did not choose their housemates is considered a “group home.” Also, when the house is owned or controlled in some manner by a provider, this is usually considered a group home rather than an ISL. The state should develop a more clear definition for ISL; one that truly promotes independence. Also need to explore the “Shared Living” model.

Communication on Services and Definitions

There is confusion on what is allowed for employment support. Some places may use personal assistance services instead of supported employment. Regardless of what services are used to support employment, this should be driven by the individual via the person-centered planning process.

Some participants recommended that day programs and employment support to go together.

Providers would like to see easier and better access to information on what has been tried and is working in other states for supporting competitive employment.

Level of Need, Budgets and Budget Creation

Providers felt that budgets are difficult to complete, especially for people receiving ISL services.

Some participants were confused over waiver caps, whether or not there are individual spending caps in the waiver, and there was much discussion over the pros and cons of a cap.

The Community Support waiver does have an individual cap of \$22,000, and participants recommend this be adjusted annually via a cost of living increase. As service rates increase, some people may actually experience a reduction in services if they are required to be under the cap.

Create sensible levels for caps on support limits with more flexibility and creativity. Need a better protocol and review steps for this to happen. Need a mechanism to raise the cap with a COLA or to accommodate cases that are high cost.

How are support units established and maintained? Need to allow for local flexibility. The current ranges are too rigid. Budget should be based on an ISL type plan, not on a level plan i.e. if level 2 then this is the budget. In general, participants have differing understandings of Missouri's system of levels of need, and whether this has any direct relationship with the amount approved in a person's budget.

Need more information on appeal rights and processes when services are denied.

Workshop and day habilitation programs need some flexibility in billing rates to allow for absenteeism by consumers or if transportation is late. A recommendation was made that day habilitation be changed to a daily unit, rather than requiring billing in 15 minute increments.

Transportation costs need to be included in service rates.

Support Intensity Scale and other assessments

SA reported that they thought that the SIS did not capture enough of their life and support needs. Will this affect their support services they already receive? Some people were unable to fully answer some questions on the SIS. Generally, participants agree the SIS should NOT replace person centered planning (PCP).

If the SIS is to be used to drive individual budgets, the process will need to be transparent...who will administer it, how will it relate to PON, how will it be used to affect funding and budgets, whether the SIS will it take priority over PCP, should be clearly addressed in policy.

Misc. Concerns / Issues

SA with older parents and siblings had concerns on future planning for their family members.

SA felt a need for more support at a statewide level to resolve housing and job issues.

It was reported that the Lopez Waiver was working great. It reduced stress and alienation in the families served by it and allowed them to a part of society. More slots are needed and a more transparent process on who is eligible and how one can qualify for the waiver program. There should be a better way to share information on the program with potential family participants.

It was thought that there could be an increase in available waiver slots if the county based waiver program was approved. There were questions on how this would interact and affect those persons already on the waiting list.

The new waiver should have a written plan to work toward independence.

Providers would like the new waiver to allow for electronic signatures by direct support staff, supervisors, etc. Also, providers should be allowed to store records electronically, rather than being required to have hard copies. This may reduce provider costs, which will help in an era when reimbursements are actually being cut, rather than increased due to state budget issues.

There are assistance programs for consumers for clothing and housing furniture.

SA were quite vocal that state money should not be spent to create segregated communities for persons with ID/DD. They were referring to the Nevada proposal to spend state funds to build cottages on site of old center and call it a community placement. This money should be spent on real community services and supports.

Need more and better monitoring of medications for their effectiveness and need.

Next Steps

The Division of Developmental Disabilities will establish small “ad hoc” workgroups to focus on specific parts of the waiver reapplication. Draft material developed by the work groups will be shared widely with all stakeholders to ensure input from all groups.

Robin Cooper, of NASDDDS will be providing technical assistance throughout the waiver development.

The Department of Social Services MO HealthNet Division, (the single state Medicaid agency) will be at the table throughout waiver development. The waiver applications will need to be submitted to MO HealthNet for final review in late fall, and will then be submitted to CMS by winter. By federal statute, CMS has 90 days to approve a waiver or ask questions. Once the state has formally submitted answers to questions, CMS has another 90 day period for review. Ideally, the goal is to submit the waivers at least 6-7 months before they will expire to enable sufficient time for CMS questions and state responses.

Stakeholders are encouraged to become educated about national best practices and to understand the technical aspects of waiver development. Resources are located at these websites:

The Clearing House for Home and Community-based Services: A comprehensive resource repository including best practices: <http://www.hcbs.org>

General information about Medicaid home and community-based waivers; federal requirements, general information, state by state information:

[http://www.cms.gov/medicaidstwai/progdemopgi/05_hcbswaivers-section1915\(c\).asp](http://www.cms.gov/medicaidstwai/progdemopgi/05_hcbswaivers-section1915(c).asp)

1915(c) Waiver application, frequently asked questions, other information:

<https://www.hcbswaivers.net/CMS/faces/portal.jsp>

The National Association of Directors of Developmental Disability Services’ website has a wide range of tools and resources. Some are available at no cost, and some may be purchased. For a complete listing of NASDDDS publications, go to this website:

http://www.nasdds.org/Publications/special_pubs.shtml

Agenda
Stakeholder Meetings
Facilitated by Robin Cooper
National Association of Directors of Developmental Disability Services

August 3, 2010 – St. Louis Missouri

Residence Inn-Marriott
101 Progress Point Court
O’Fallon, MO 63368
636-300-3535

August 4, 2010 – Kansas City Missouri

Developmental Disability Services of Jackson County - EITAS
8508 Hillcrest Road
Kansas City, MO 64138
Phone: (816) 363-2000

9:00-10:30 Provider representatives

11:-00-12:30 Self Advocates

1:00 – 2:30 Family members and advocates

- I. Welcome and Introductions
- II. Overview of Project
- III. Focus group questions and discussion
 - What is currently working well in the system of supports and services for people with developmental disabilities?
 - What is not currently working well?
 - What suggestions do you have for positive change?
- IV. Wrap up and next steps