

WV DEVELOPMENTAL DISABILITIES COUNCIL

Comments on 2015 I/DD Waiver Renewal
December 20, 2013

WV DD Council staff traveled the state to attend the open forums conducted with Waiver members, families, and providers by the WV Bureau for Medical Services (BMS) and APS Healthcare. Having heard the comments of families and providers in these settings, along with other information the Council receives, we now offer the following comments to be considered for the 2015 I/DD Waiver application. Other comments may be shared later as issues emerge prior to the writing of the renewal application.

General Comments:

Training on abuse/neglect

The Council's Workgroup on Abuse and Neglect has determined that gaps and inconsistencies exist in behavioral health personnel education and training related to reducing the risk of abuse and neglect of people with developmental disabilities. Recent nationally published reports and studies have found that people with developmental disabilities, and in particular those with significant intellectual disabilities, are at the highest risk of any group for abuse and neglect, as well as financial and sexual exploitation.

It is the position of the Council that the Home and Community Based I/DD Waiver should institute new training standards for all personnel levels focused on reducing the risk of sexual abuse. The discussion at the October 23, 2013 I/DD Waiver Quality Improvement Advisory (QIA) Council on strengthening and standardizing the curriculum is appreciated. The DDC has some expertise in this regard and welcomes the opportunity to contribute to that effort. The Council believes the I/DD Waiver Program is well positioned to create and carry out uniform, competency based personnel training related to the protection against all forms of abuse and neglect of people with developmental disabilities.

Allied to this issue of training is the need for more pro-active measures by service providers. Perhaps there should be a requirement that, in order to be certified, each provider agency or company must have an approved, viable, provider-wide plan to reduce the risk of sexual and other abuse and neglect without jeopardizing each service recipient's loss of autonomy and human rights.

Employment Options for Waiver Members

It is estimated that there are 20,000 West Virginia citizens with developmental disabilities who are between 16-64 years of age. People with developmental disabilities are an untapped pool of workers for employers. Competitive, supported, customized, and self-employment approaches enable people with developmental disabilities to work, pay taxes, and contribute to society. It is also estimated that less than 15% of adults with developmental disabilities in WV are working in regular, inclusive employment settings with co-workers without disabilities.

As we are all aware, real work for real pay is important to everyone. It means having choices and making decisions, getting paid, living independently, contributing to our communities, and connecting with other people. The work we do is an important part of defining who we are.

The Council's Employment Workgroup has developed several suggestions for improving employment outcomes for people with developmental disabilities which should be considered for inclusion in the I/DD Waiver. They include:

- Development of a policy that makes competitive employment in integrated settings the first and preferred option for those supported by the Waiver;
- Allowing employment services to be a funded service in the Self-Direction Option rather than only in the Traditional Option;
- The provision of basic guidelines for innovative employment planning, such as the Discovery Process, the necessity for trained job coaches, and linkage/collaboration with stakeholders such as the DRS, BHHF, and the WVDE;
- A service name change from "supported employment" to "customized employment" to allow for more current forms of assisting people to obtain valued work;
- An increase in the supported employment services rate to make it more attractive than the facility based day habilitation rate (the current rate for supported employment is just twelve cents higher);
- The addition of a requirement for a knowledgeable discussion of work and benefits to be included in the IPP development for each Member of working age, to include federal work incentive programs such as the Medicaid Buy-In (M-WIN), Plan for Achieving Self-Support (PASS), and the Impairment-Related Work Expenses (IRWE) along with the variety of employment planning options that can be pursued.

[The federal incentives mentioned above allow people with disabilities to earn a living wage and not lose benefits.]

The Council is willing to assist in developing an employment section for this Waiver.

Single person 24 hour staffed settings

Council staff heard at many of the forums that new single person settings that are staffed 24 hours/day may no longer be allowed with the renewal (current settings would be grandfathered in). While the Council agrees that providing staff 24 hours/day for one Member is expensive it is also sometimes necessary. The Council cautions against a blanket policy that does not allow for any Member who may require it to be served in a single person home, or to aspire to it. The expenses for these living arrangements do not cause the overall average of the Waiver to exceed the average cost of ICF/IID services.

Participant Directed Goods and Services

The Council has heard from families that the system designed to access the funds for purchasing anything through Participant Directed Goods and Services is cumbersome, and in some instances can cause a Member to spend more for an item than necessary. Methods should be explored that could alleviate the problems with turn-around time and third party checks, along with a method of purchasing goods on-line.

Comments specific to the forum questionnaire:

1. Change in the eligibility redetermination process

In general, dropping the requirement for an annual psychological and medical evaluation for eligibility redetermination has been a positive change. The Council has advocated for many years that developmental disabilities do not disappear or change in ways that substantially alter individuals' eligibility for this program. By reducing the frequency, cost savings are achieved while also simplifying life for Members and/or their families. We encourage the BMS to continue the current requirements for eligibility redetermination.

We believe that Members should continue to visit their doctors on an annual basis for a comprehensive examination. Is there any data to indicate whether or not this is occurring since it is no longer a requirement for redetermination?

A concern was raised related to the numbers and locations of psychologists in the Independent Psychologists Network for individuals requiring a psychological evaluation for initial eligibility determination. More rural areas of the state may not have easy access to this service. We suggest the BMS review the numbers and locations of eligible psychologists for this program to ensure fair and convenient access for all areas of the state.

2. ASO Completion of Freedom of Choice form

The change requiring the ASO evaluator to complete the Freedom of Choice form at the annual functional assessment is a positive change and should be continued in the 2015 renewal application.

3. Participant-Directed Services Option: Fiscal Employer Agent Model

The Council would like to see the Participant Directed Service Delivery Model expanded to include services currently available only in the Traditional Option, such as Supported Employment. While Members can use Participant Directed Supports for Supported Employment, the reimbursement rate is lower.

Many complaints have been heard about the money being paid to parents no matter which option they choose. Families using the Participant-Directed Services Option don't have the same ability to hire other staff due to the lower reimbursement rate, and are at a distinct disadvantage for having non-family staff in their homes because of the inability to provide Worker's Compensation coverage or benefits. The Council recognizes rates are higher for agencies because of "overhead" expenses. We are also aware that the rate adjustment for the Traditional Option included a calculated amount for benefits such as vacation and health insurance. Are they actually being provided? The Participant-Directed Services rates do not allow for these benefits. The Council would like to see more fairness in the reimbursement fees for the Participant-Directed Model.

4. Criminal Background Checks

Although the new process has not always run smoothly, the Council believes the new requirement for staff to have a Criminal Background Check every three years is important and should continue. Obviously, this needs to be accomplished efficiently and, if possible, more frequently.

5. Protective Service Record Check

The Council endorses the idea of increasing the Protective Service Record Check for all staff to an annual requirement rather than only upon hire. This appears to be

the only means available to determine if an individual has a substantiated incidence of causing abuse and/or neglect that didn't result in a criminal prosecution. It is important that such checks be done annually in order to reduce the risk of abuse/neglect by the individuals being hired to work with this very vulnerable population.

6. Annual Training Requirements

Many of the previous training requirements were dropped in the current five year renewal, but current trainings are now required to be completed annually. The Council agrees that a yearly refresher on important issues such as confidentiality and abuse and neglect is a positive change that should continue. The Council also suggests additional mandatory training in the area of abuse/neglect, employment, and related benefits options which are further clarified earlier in this document, as well as an overview of Positive Behavior Support.

7. New DD Forms

The Council is pleased to hear reports from families that the excessive documentation requirements have decreased dramatically. Although some agencies continue to require additional documentation beyond the program requirements we are no longer hearing from families who must complete 80-120 pages of documentation monthly. This is a very positive change that should be continued.

8. Direct Care Service Limits

The Council continues to oppose the age imposed limits to services and believes the logic used to justify such limits is faulty. For at least two decades, families and advocacy systems have worked to encourage the inclusion of students with developmental disabilities into regular classrooms in neighborhood schools with their peers. When this is successful most students will also graduate with their peers, whether with a regular or a modified diploma. The majority of students graduate high school at age 18, and many at age 17.

To use the rationale that the Waiver cannot pay for services that should be provided by the education system is not valid in this instance since the education system is not responsible for providing any sort of service to a student following graduation.

This rationale also does not apply to students of any age who are placed on out-of-school environment (or homebound) status, as educational services provided to

these students are not equivalent to the hours provided in school, nor are they required to be. Therefore, more hours of waiver services would not be replacing services mandated by the education system. Families of children who are fragile to the extent they are not able to attend school with their peers have more demands placed on them for care and are likely in need of more hours of service provision than families whose children are able to spend their days in school. They (or another responsible adult) are also required to be present when school personnel are providing educational services in the home. School personnel are not there to meet other needs the student may have so there is not a duplication of services and/or payment by two entities. If this is the real reason for prohibiting additional hours, the number of hours, up to 12, could be derived by subtracting the (required) actual number of hours per week provided by the education system.

The Council agrees that students should not be removed from school prior to graduation in order to receive more hours of Waiver funded services. However, for those students who have graduated, the full 12 hours of services should be made available. The Council also looks favorably upon additional hours being made available for supported employment services but does not agree with making this the sole requirement for the increase in hours for the reasons cited earlier – the education system’s obligation ends upon graduation. To treat recent graduates differently than Waiver recipients age 21 and over is discriminatory.

9. Respite Care

The Council was pleased to see the return of Respite Care being allowed while the primary caregiver works in the last approved application and highly recommends that it continue to be allowed. As is commonly heard, for some caregivers work is a period of respite. Other forms of child care or adult care which would allow the caregiver to work outside the home are often not available for Waiver recipients. Respite care is also not readily available for many caregivers, so it has never been a service in which most of the allowable hours are accessed.

10. Person-Centered Support Service

The Council is neutral on the replacement of individual services such as Adult Companion, Community Residential Habilitation and Community Based Day Habilitation with one service labeled Person-Centered Support service. We have not heard comments on this particular change from families or provider agencies.

11. Elimination of Active Treatment Requirement

The Council strongly believes it is important for people with intellectual disabilities to be challenged and motivated and to have access to stimulating environments. Receiving the right amount of training by qualified trainers at the right time is essential for developing competencies, which then can lead to the achievement of valued social roles.

The Council is overall neutral on the elimination of “active treatment” as a required component of the program. This elimination was the result of a CMS directive, so no change is anticipated in the next application, and active treatment does not always include those components listed above (right training, right time, right teacher). The Council believes that most caregivers have a vested interest in seeing their family member develop to their fullest potential, and assist in providing or arranging for the training, support, and other services needed without having a mandate to do so. The Council has long believed that while everyone needs challenge in their lives, not all Waiver recipients should be required to receive “active treatment.” For instance, elderly members who have been working on attaining goals their entire lives which they have been unable to attain, either due to the inappropriateness of those goals, or due to the Members’ limited capacities or limited physical abilities.

Closing Comments

While the State has not operated state institutions for people with I/DD since 1998, there remain “institutional biases” in WV. There are examples of such bias in the I/DD Waiver program, one being the eligibility process. This program has a 90 day eligibility process, and for those individuals determined eligible, a waiting list that exceeds two years at the present time. If these same individuals applied for services through an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) they could be admitted to an ICF/IID and begin receiving services prior to being determined eligible through a policy of presumptive eligibility.

Data from the WV Bureau for Medical Services (BMS) for calendar year 2009 shows that, while 58% of the eligibility reviews for I/DD Waiver services resulted in denials, only 2% (one person) of the reviews for ICF/IID services resulted in a denial.

Individuals with developmental disabilities who live in ICF/IID settings receive Medicaid funded dental and vision services while those on the Waiver do not.

Another example of the institutional bias that continues in WV is related to the Medicaid long-term care budget. CMS data for 2012 shows that, while improvements have been made in this regard, WV spent 55.2% of its Medicaid long-term care budget on institutional care vs. 44.8% on community-based supports. The Council encourages the state to continue to move in the direction of reversing those percentages by allotting more of its funding to true community-based services while reducing the number of ICF/IDD facilities.

WV also continues to fund the placement of hundreds of people with developmental disabilities in long-term-care nursing facilities, as well as 517 ICF/IDD beds across the state.

The Council sees the need for the state to add at least 1500 new I/DD Waiver slots over the next five years to accommodate those on the wait list and those who will be added. The DHHR needs to decertify the ICF/IDD facilities and support the residents in homes and the community using an HCBS Waiver option.

A troubling trend is developing as a result of the push several years back to have the Internal Revenue Service (IRS) declare parents who provide services to their family member to be classified as employees. We do not believe the intent was to go further than making compensation be counted as taxable income, and yet it has. Recent surveys conducted by the Office of Health Facility Licensure and Certification (OHFLAC) show agencies being cited for failing to train parents to care for their own children. We have also heard of AMAP related issues due to the uncertainty of the role of parent vs. employee. The idea that a “health facility licensure program” can cite a provider agency for issues related to a parent providing a service to a family member in their family home is an untenable one. Family’s homes are not facilities, are not licensed, and must not be treated as such.

Approximately 75% of Waiver recipients are supported in their homes by their families. The state could not find, or fund, the staff necessary to provide 24/7 services to these members. The eligibility criterion for this program is one of, if not the, strictest in the country, which indicates that Members on the program truly need supports. Family members are only reimbursed for providing supports above and beyond what is required for a typically developing son or daughter, for a limited number of hours, and often are not able to work outside the home due to the level of support that is required. Yet, they are often eyed with suspicion by the state agencies that have determined that their family member requires support as well as by the provider agencies that would be unable to provide it. The Council

encourages the valuing and support of families who are caring for and providing training to a family member with developmental disabilities.

The Council appreciates the opportunity to provide comments to be considered for the 2015 renewal of the I/DD Waiver, and looks forward to the opportunity to discuss many of these issues further.