



# West Virginia Developmental Disabilities Council

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## WV DD Council I/DD Waiver Application Comments March 27, 2015

The WV Developmental Disabilities Council appreciates the opportunity to submit these comments on the application to the Centers for Medicare and Medicaid Services (CMS) for the next five years of services in the I/DD Waiver program. 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 in 2013. Staff has also participated regularly in meetings of the I/DD Waiver Quality Improvement Advisory (QIA) Council and numerous phone conference calls between BMS and QIA Council Members held in preparation for writing this application. Additionally, Council staff hears regularly from families when they have questions or concerns, or are experiencing difficulty in accessing services. It is with all of this in mind that the following comments were developed. These comments are written in the order they appear in the application.

### **2. Brief Waiver Description**

The Council does not agree with the statement that the purpose of the waiver is to avoid or delay institutionalization. We would agree that the purpose is to avoid institutionalization. Further, the waiver provides a means to support eligible people to leave institutional settings and programs.

Home and community-based services (HCBS) provide opportunities for individuals to receive services in their own homes and communities, rather than in more restrictive institutional settings. In fact, a person “waives” receiving services in an institution in order to receive them in their own home and community. HCBS services are offered by CMS as an option through states so that people can avoid going to institutions, but they were not designed as a stop-gap to delay institutionalization.

The Council believes if the stated objective “to increase enrollment capacity in a systematic manner on order to reduce waiting lists for these services” was true, the unduplicated numbers listed in Appendix B, B-3 (1 of 4), would not be

stagnated at 4,634 for each of the next five years. 4,634 is the current number of participants in this program. This number has been the same since July 31, 2014.

1,025 individuals were on the wait list as of February 28, 2015. 265 individuals have been added to the wait list during the current fiscal year to date (July 1, 2014 – February 28, 2015), an average of 33 people per month.

As of February 28<sup>th</sup>, some people have been on the wait list as long as two and one half years. Since the last 100 slots required under the *Benjamin H.* lawsuit were released on July 1, 2014, there are no additional slots for people in need of the program. People will only be able to access services as those on the program die, leave the State, or become ineligible to continue for some other reason. It is unfortunate that the DHHR has chosen not to inform the legislature of the need for additional funding for this program, and instead has kept the current number of 4,634 in place for the next five years. Only 12 people have been enrolled in the program in the past six months. If an average of 24 people per year are added to the program, it will take more than 42 years to accommodate the current wait list numbers alone.

#### **Attachment #1: Transition Plan**

**1.** The Council does not agree with the addition of a minimum age of three as a qualification for this program. Although it is stated that no under the age of three receives services at this time, that does not mean that there are not, or will not be, younger children who meet the other qualifications and need services. It is likely that children currently under the age of three are not served by the program because, although they apply, they are placed on the wait list. Not allowing them to apply until the age of three will cause them to wait even longer for needed services. Some children are born meeting the qualifications, but are not children of otherwise Medicaid eligible families and therefore may not be eligible for Medicaid State Plan services.

**2. and 3.** It is encouraging to see the addition of two new employment related services to the Waiver – Pre-vocational and Supported Employment Job Development services. The Council is very interested to see what training will be provided to currently licensed Facility-Based Day Habilitation providers to ensure that a true transition to pre-vocational training, rather than in name only, occurs to meet the new HCBS rules for integrated settings. No intent to provide such education is mentioned.

**5.** The Council does not agree with the reduction in the units of Respite service being proposed. To date, no information has been provided to show that Respite causes a financial hardship to this program. Families still regularly report the inability to find Respite providers.

The Council strongly opposes the restriction of the use of any other services on days Respite is accessed. The purpose of Respite is to provide a needed break to families who are caring for a family member with needs significant enough to qualify for this program. For families who are fortunate enough to find someone to provide Respite services, the needs of the individual do not go away simply because the family provider is able to go out to dinner, to church functions, a gathering with friends, etc. As proposed, an individual would have to forego other needed services (such as LPN, PCS, or Supported Employment) in order for their family member to use Respite.

**6.** The Council has some concern about the restriction of LPN services to two hours per day for adults without further explanation. If nurses are no longer able to bill for travel time, will agencies provide nursing services to individuals on the program? Also, the Bureau knows that, while AMAP services are allowable, many agencies choose not to use them. What, if any, efforts will be made to remedy this situation?

It remains unclear to us how someone whose needs for nursing do not change is expected to transition from State Plan Services to a maximum of two hours of nursing services per day simply because they reach the age of 21.

**7. and 8.** No explanation is provided as to what the anticipated result of the proposed combining of Therapeutic Consultant and Behavior Support Professional services will be, or the reason for the change.

**11.** Children who are medically fragile and unable to attend school do not necessarily need supports that would be provided by Private Duty Nursing. In fact, it would be less expensive to the system as a whole to increase the hours of Person-Centered Supports (in recognition of the extra care and supports needed) than to pay the Private Duty Nursing rate through State Plan services.

**18.** The re-insertion of numerous, costly psychological evaluations back into the program does not appear to be warranted. If the concern truly is that children may improve to the point they no longer qualify for the program, it seems likely



that this would be determined during their annual assessment by APS Healthcare, at which time a psychological evaluation could be requested if needed.

The Council maintains that WV already has one of the most (if not the most) stringent criteria for eligibility in the country. It seems highly unlikely that children who meet the criteria would have been misdiagnosed to such an extent that a psychological evaluation every three years would be necessary. The Council would like to see the data showing the problem that has led to this proposed change.

Overall, many of these proposed changes end with the statement, “People will be able to ask for Medicaid Fair Hearings if they feel this reduction adversely affects them.” In order to determine if individuals can expect to be granted any leeway, the Council would like to see the data showing how often individuals are granted the change they request through a Medicaid Fair Hearing.

#### **Appendix B: Participant Access and Eligibility, B-3: Number of Individuals Served (1 of 4)**

1,025 individuals were on the wait list as of February 28, 2015. 265 individuals have been added to the wait list during the current fiscal year to date (July 1, 2014 – February 28, 2015), an average of 33 people per month.

As of February 28<sup>th</sup>, some people have been on the wait list as long as two and one half years. Since the release of the last 100 slots required under the *Benjamin H. v. Bowling* lawsuit were on July 1, 2014, there are no additional slots for the program. People will only be able to access services as those on the program die, leave the State, or become ineligible to continue for some other reason. It is unfortunate that the DHHR has chosen not to inform the legislature of the need for additional funding for this program. The Department plans to only maintain the current number of 4,634 in place for the next five years. Only 12 people have been enrolled in the program in the past six months. If averages of 24 people per year are added to the program, it will take more than 42 years to accommodate the people who are currently on the wait list.

#### **Appendix B: Participant Access and Eligibility, B-6: Evaluation/Reevaluation of Level of Care, b.**

The re-insertion of numerous, expensive psychological evaluations back into the program does not appear to be warranted. Each person on the program, including children, is already reevaluated during their annual functional assessment

by APS Healthcare. According to this application, the assessment includes “an annual diagnosis and standardized measures of adaptive behavior in the six major life areas completed by the UMC and the results provided to the MECA.” (Appendix B, B-6, d.) If the concern truly is that children may improve to the point they no longer qualify for the program, it seems likely that this would be determined during their annual assessment by APS Healthcare, at which time a psychological evaluation could be requested if needed.

The Council maintains that WV already has one of the most (if not the most) stringent criteria for eligibility in the country. It seems highly unlikely that children who meet the criteria would have been misdiagnosed to such an extent that a psychological evaluation every three years, on top of the annual reassessment, would be necessary. The Council would like to see the data that indicate the need for this proposed change.

### **Appendix C: Participant Services, C-1/C-3, Day Habilitation**

The Council understands that Facility-Based Day Habilitation services must be transitioned to more inclusive services and settings in order to comply with recent changes to the Home and Community Based Services ruling from the Federal government. However, we are concerned about what will happen to people in the midst of this transition.

If facility-based day habilitation programs are being given two years to transition to pre-vocational services, and people will not be able to access facility-based day habilitation as a new service prior to the transition to pre-vocational services, what plans have the DHHR made for them?

### **Appendix C: Participant Services, C-1/C-3, Residential Habilitation**

The Council strongly disagrees with the limits on Family PCS services for children under the age of 18, or those over the age of 18 who are still attending public school. A maximum of six hours for all PCS services on non-school days does not allow family members to work outside the home!

In today’s society, generally, both parents in two parent households work, and many families are made up of single parent households. Typically, a work day consists of eight hours. Having a family member who qualifies for the waiver program does not change the fact that most people have to work. Typically even two-parent families do not have the power to adjust their work schedules in order to accommodate this restriction. Children should be allowed up to nine hours per

day on non-school days in order to allow family members to work a typical eight hour day.

For those who have already given up work outside the home in order to care for a family member on the program, this constitutes a cut in the income that has helped them to support their families.

If enacted, these cuts will have negative impacts throughout the systems in the state that are designed to support those with low incomes – Medicaid, TANF, SNAP, and other services.

Families who have a member who qualifies for this program typically already have other extraordinary expenses associated with the person's disability. These proposed reductions will cause some family members to lose employment.

#### **Appendix C: Participant Services, C-1/C-3: Service Specification, Home-Based Agency Person-Centered Support**

Please see above comments under **Appendix C: Participant Services, C-1/C-3, Residential Habilitation**

#### **Appendix C: Participant Services, C-1/C-3: Service Specification, Respite**

The Council does not agree with the reduction in the units of Respite being proposed. This is a 58% cut. 730 hours per year equates to two hours per day. To date, no information has been provided to show that Respite causes a financial hardship to this program. Families still regularly report the inability to find Respite providers.

The Council strongly opposes the restriction of the use of any other services on days Respite is accessed. The purpose of Respite is to provide a needed break to families who are caring for a family member with needs significant enough to qualify for this program. For families who are fortunate enough to find someone to provide Respite services, the needs of the individual do not go away simply because the family provider is able to go out to dinner, a church function, a gathering with friends, etc. As proposed, an individual would have to forego other needed services (such as LPN, PCS, or Supported Employment) in order for their family member to use Respite.

### **Appendix C: Participant Services, C-1/C-3: Service Specification, Supported Employment, Job Development, Provider Qualifications**

The Council firmly believes more than the current minimum qualifications for all direct care staff are necessary for staff who will be performing job development functions. The functions listed for this service include: planned visits and meetings with prospective employers to facilitate job acquisition; negotiating job duties and employer expectations; analyzing work duties expected by the employer; creating, modifying, or customizing a community-based job so that it may be successfully performed by the person who receives services; assessment in integrated employment settings to evaluate task management and job skill requirements; assessment of personal interactions with co-workers and the public; and supports to assist a person who receives services in developing a business plan and obtaining funding to start his/her own business.

The wide scope of job development services listed (to support people with complex support needs) will require that staff have demonstrated knowledge and skills in community employment planning and supports. The Council recommends the development and/or adoption of a supported employment training and certification process that ensures that personnel are capable of developing customized employment plans and supports for people with intellectual and other developmental disabilities. These are specific skill sets that cannot be performed by direct care staff who have received no training in job development. In order for people with developmental disabilities to be appropriately supported and have a reasonable expectation of obtaining employment, this service must be provided by individuals who have knowledge and training related to job development. This service requires a separate set of qualifications and a separate billing code from that of typical direct care staff.

The Council also recommends that it be clearly stated that employment in the general workforce is the first and preferred outcome for working age people supported by the I/DD Waiver. Additionally, it needs to be clearly stated that people with even severe levels of developmental disabilities can work in integrated workplaces when provided the opportunity, training, and support.

### **Appendix C: Participant Services, C-1/C-3: Service Specification, Residential Habilitation, Licensed Group Home Person-Centered Support**

The Council understands the plan to transition people into settings that serve less than four people within a two year period in order to meet the new HCBS requirements, but suggests the statement should say, "Any person residing in a site

serving 4 or more people must have an individualized transition plan created to move to a site that serves less than 4 people within a two year period.”

### **Appendix C: Participant Services, C-1/C-3: Service Specification, Respite, Out-of-Home Respite**

Please see comments under **Appendix C: Participant Services, C-1/C-3: Service Specification, Respite**

### **Appendix C: Participant Services, C-1/C-3: Service Specification, Prevocational Services**

The services listed under this service definition are many of the same services listed under the current definition of facility-based day habilitation. The Council is very interested to see what training will be provided to currently licensed facility-based day habilitation providers to ensure a true transition to pre-vocational training, rather than a change in name only, to meet the new HCBS rules for integrated settings. Other than information on how to get a new license, no education is mentioned.

The Council appreciates and supports the new requirement that employment goals will be included in each individual’s IPP. We suggest expanding prevocational services to better align with the idea of “creating a path” to employment described in the service definition. Services should not only work to strengthen skills and behaviors at program sites, but also facilitate each individual’s experiences in the greater community. Those community experiences should be employment focused (e.g. Discovery) and lead to a person-centered job choice. The Council recommends this service allow for off-site job experiences as a prevocational service. Community experiences should be individualized and not accomplished in groups.

The Council also recommends core competency training on customized employment principles and practices for agency staff who are responsible for developing transition plans leading to competitive employment.

### **Appendix C: Participant Services, C-1/C-3: Service Specification, Case Management, Service Coordination**

Listed among the activities is a requirement for Service Coordinators to act as an advocate for the person who receives services, including advocating for appropriate services in the school system. Service Coordinators are not typically



trained in education law and generally do not have the ability to advocate on behalf of students in the school system.

The Council is pleased to see that Service Coordinators should not visit day services such as job development and supported employment settings unless absolutely necessary to remedy a problem identified at the site. It is not typical for people to visit work settings.

Caseloads have been increased from 20 to 30 per service coordinator. During discussions on this issue, there was to be a division between numbers of people who receive traditional and self-directed services. Will this be further delineated in the Waiver Policy Manual?

### **Appendix C: Participant Services, C-1/C-3: Service Specification, Supports for Participant Direction, Participant-Directed Goods and Services**

The Council continues to believe that the combined cap for PDGS and Environmental Accessibility of \$1,000 is too low for these services. Environmental accessibility modifications are generally expensive. Combining the two services makes very little money available for either.

The Council is concerned about the requirement for the UMC to issue payment directly to the vendor. We have heard from families regarding complications with this process. While the need for oversight of the process is understood, the problems with this method should be addressed.

Also, the reason for not allowing the purchase of car seats and strollers that do not require modifications under this service is unclear. Individuals who have outgrown standard size car seats, but still need a car seat for safety reasons, must buy seats specifically made larger than those for children. They do not require modifications, and they are quite expensive. We are unaware of car seats that can be modified. Is this a mistake?

### **Appendix C: Participant Services, C-1/C-3: Service Specification, Other Service, Electronic Monitoring**

The Council remains opposed to the use of electronic monitoring of individuals receiving I/DD Waiver services.

The DD Council has expressed its disagreement with electronic monitoring and surveillance systems continuously since a vendor first came to WV to pitch

such products. It is disturbing to see that many of the ‘safeguards’ that were mentioned previously are not in this draft Manual, i.e., no surveillance equipment in bedrooms and bathrooms.

Breakdowns in the staff response are likely to occur. The time frames listed (within 20 minutes from the time an incident is identified by the remote staff and the stand-by staff acknowledges receipt of the notification by the remote staff) are unacceptable in an emergency situation. The qualifiers listed mean a response time could be an hour or longer.

Combining this service with all other types of direct care services could mean that an individual using electronic monitoring services eight hours per day would receive no other service at all, since the hard cap for adults is eight hours.

**NOTE:** This opposition does not mean the DD Council believes all Waiver recipients need 24 hour staff supports. The Council does believe that some Waiver recipients are quite capable of maintaining their own health and safety for periods of the day and should be afforded the opportunity for independence and privacy when they have that capability without jeopardizing their eligibility for this program.

### **Appendix C: Participant Services, C-1/C-3: Service Specification, Other Service, Environmental Accessibility Adaptations**

The DD Council has repeatedly commented over the years that the \$1,000 cap on this service is quite low when considering the cost of many adaptations. By combining an already low cap on this service with Environmental Accessibility Adaptations for the Vehicle and with Participant-Directed Goods and Services, many individuals will not be able to purchase either accessibility adaptations or goods and services they may need.

The exclusion of car seats unless specifically adapted/modified raises the same concern as that mentioned in comments for participant directed goods and services. This may be a misunderstanding of the wording used. Specialized car seats are not typically adapted or modified, they are purchased because regular car seats do not meet the unique needs of an individual and cannot be adapted or modified. They are often car seats designed to safely support individuals who have outgrown traditional car seats. Will such car seats be allowed?

**Appendix C: Participant Services, C-1/C-3: Service Specification, Other Service, Transportation, Non-Medical Transportation**

Transportation trips for agency vans have been reduced by 50%, from four one-way trips per day to two one-way trips per day. This reduction will limit the choices individuals are able to make about how to spend their day. For instance, if an individual works, two one-way trips will be used by transporting him/her to and from work. No trips will then be available to take part in any other planned activities.

Also, this reduction in services appears to make it nearly impossible for people to receive critical community-based training, given the current policy that requires people to travel to a day program site before going to other community settings.

The DD Council does not endorse the use of vans or other human service vehicles to transport multiple Waiver service recipients. However, this is the practice in many situations and does need to be addressed.