

**WV Developmental Disabilities Council**  
**Comments Re:**  
***MR/DD Waiver Manual Working Draft***

**May 4, 2006**

**A. General**

The WV Developmental Disabilities Council submitted comments regarding the 2004 version of the MR/DD Waiver Manual, as well as the previous drafts to the current policy manual on December 15, 2005 and January 11, 2006. The following comments focus on the most critical areas of the current draft. They serve to supplement and amplify concerns that have been raised previously and have not been satisfied.

Additionally, the Council made numerous comments in reaction to the (then proposed) MR/DD Waiver Renewal Application submitted by the Department of Health and Human Resources (DHHR) to the Federal Centers on Medicaid and Medicare Services (CMS) in 2005. Some of the problems identified by the DD Council in that document remain as well.

The DHHR did make some changes requested by the DD Council and others from the most previous draft document. It is appreciated that the provision which would have eliminated guardians from providing essential habilitation services to their family member was eliminated. Some changes were made to the "Extraordinary Care" instrument to bring the age criteria for what constitute *extraordinary* developmental problems more in line with typical developmental milestones.

The Council continues to have numerous concerns with specific proposed changes to the MR/DD Waiver. We believe the stability of people's families could be undermined and can lead to the movement of persons on the program into less integrated, more restrictive settings if the draft policies are enacted as proposed. We also believe the program is not progressing adequately to increase the choice and personal control people on the program experience. The draft policy manual continues to take on more of a medical/facility based philosophy and model than a supports based approach that is the nature of a home and community based program.

## B. Specific Issues

- **Definitions:** (Page Two) “The MR/DD Waiver Program is a health care coverage program....” The Waiver program has been a program designed to provide community based services and supports to individuals with MR/DD who preferred not to live in facilities (group homes). These services (Res hab, Day hab, Adult Companion, Respite, Supported Employment, etc.) are not “health care” services.
- The characterization that this is a “health care program” indicates that the participants are sick, which reinforces the use of an outdated, deficit driven, medical model.
- **Initial Application Packet:** (Page Nine) “An eligible applicant will be enrolled into the Waiver program once the allocation (slot) is available.” The Council continues to disagree with this statement as it appears to ignore the *Benjamin H. v. Ohl.* court order and because the DHHR did not request any additional slots in its renewal application for the next five years of the program. As of March 20, 2006, there were 160 people on the wait list for services.
- **Medical Eligibility Criteria: Diagnosis:** (Page Ten) The newly proposed requirements “Individuals diagnosed with mental illness must provide clinical verification through the appropriate eligibility documentation that their mental illness is not the primary cause of their substantial deficits.” is a medically and psychologically invalid requirement. The Council agrees the purpose of this Waiver program is to serve individuals who have mental retardation or other related conditions (developmental disabilities). However, individuals who have co-occurring conditions of mental retardation and mental illness should not be required to “provide clinical verification.” National authorities, such as the National Association for the Dually Diagnosed (mental retardation and mental illness) state this is not clinically possible to obtain. The new requirement is unrealistic and discriminatory towards such individuals.
- **Functionality:** (Page 11) The Council disagrees with the more restrictive requirements identified in this section, which appear to mean many individuals currently eligible for Waiver services would

no longer be eligible. Recent research on this issue indicates that if enacted in policy, West Virginia's eligibility in this regard would be more restrictive than all other states. What will be the impact on people who have been on the program and continue to require the "level of care", support, and training that only the MR/DD Waiver offers?

- **Active Treatment:** (Page 11) The draft states, "Requires and would benefit from continuous active treatment." The Council disagrees with the inclusion of this institutional language into the Manual. Active treatment is not required for Waiver eligibility as the program, by design, is a "waiver" of ICF/MR requirements. The MEDICAID LETTER NUMBER: 97-10, (from HCFA dated March 6, 1997) states, "...there is no requirement in §1915(c) or implementing regulations that an individual in need of ICF/MR services receive active treatment under the §1915(c) waiver. The active treatment concept is based on the assumption that an individual is a resident in an institution (which is required to provide all necessary care and services for that individual). The applicability of active treatment, therefore, is limited to the institutional setting. Federal law requires that individuals served under the waiver would be eligible, in the absence of the waiver, to receive active treatment in an institution (in this case, an ICF/MR.)"
- **Appeal of a Denial of Service by the State MR/DD Waiver Program Office:** (Page 17) "If the individual is eligible financially for Medicaid services without the MR/DD Waiver program, other services may be available for the individual." Please clarify what these services might be.
- **Reporting Alleged Abuse and Neglect:** (Page 17) "Anyone providing services to an MR/DD Waiver member who suspects an incidence of abuse or neglect is mandated by State Law (Title 64 Series 11) and State Code (Chapter 9, Article 6) to report the incident to:" is not accurate. Title 64 Series 11 does not make mention of this requirement at all. Chapter 9, Article 6 only applies to adults. NEITHER document mandates "anyone providing services." There are certain mandatory reporters, they are not "anyone." Proper citation of any code concerning reporting of abuse and neglect of children also needs to be included.

- **Dual Processes for Transition to Individual Waiver Budget:** (Page 18) “ASO recommends the Individualized Waiver Budget to the Service Coordinator.” Will the ASO only “recommend” a budget? Or is that contractor the actual controller of the Members’ budgets?
- The Council must also comment that recommending the budget to the Service Coordinator, rather than to the Member, does not fit with the DHHR’s stated commitment to a person-centered planning and person-driven service philosophy.
- **Prior Authorization:** (Page 19) This entire section is confusing. Section 509.1 states that BMS “in its sole discretion” determines what information is necessary in order to approve a prior authorization request. Section 509.2 states that “prior authorization must be received from the ASO...”
- Section 509.2 then states “Staffing in excess of 1:1 ratio cannot be considered” although later in the Chapter, Crisis Services will be staffed at a ratio of 2:1.
- Timelines are listed for submitting requests for prior authorization, but there is no indication of any timeline for a response from the BMS, ASO, or whichever entity will actually be responsible for approving such requests.
- **Payment Limitations:** (Page 20) “...the member may receive respite services when the member require a support staff...” (when hospitalized). The Council once again states this is an inappropriate service for many Members on the program. Respite, by definition, is not a service for adults living in their own or in group settings. This exception should include both Respite and Adult Companion services, which is the appropriate service for adult Members living in settings outside their family home. Since both codes are billed at the same rate, there does not appear to be a sound rationale for this policy.
- **Payment Limitations:** (Page 21) “Ongoing services such as residential habilitation or day habilitation may be billed when the following criteria is in place: “...Medically necessary assessments

have been completed and indicate a medical necessity for the service.” The Council is not aware of any medical entity that considers Residential habilitation or Day habilitation to be medically necessary, nor does the Council acknowledge these services as medical services. Members may require such services, because of the nature of their needs, in order to live, work, and otherwise be a part of their communities, however, they are not medical issues.

- **Interdisciplinary Team (IDT) Composition:** (Page 21) Once again, the Council objects to the statement that “the IDT must be based on person centered philosophy,” when the minimum composition of the team is mandated. This requirement is not compatible with a person-centered philosophy.
- **Interdisciplinary Team (IDT) Composition:** (Page 22) “In extenuating circumstances, family members or guardians may participate by teleconferencing or video conferencing if the family member or guardian does not bill for the time spent in the IDT.” What is the justification for this limitation?
- Family members who have long histories with this program know that such meetings are regularly scheduled for/at the convenience of the “professional” members of the team, and their own convenience is seldom considered. Presuming they could attend by teleconference or videoconference (which the Council questioned previously and still questions), and presuming they would be a team member with the ability to bill if attending in person, why would they be denied that right when participating as a member of the team from another location?
- **Individual Program Plan Development (IPP):** (Page 27) The definition refers to a person center plan and a “Circle of Support.” The definition of a “Circle of Support” as presented does not match the nationally established concept as developed and used by people such as John and Connie Lyle O’Brien, Beth Mount, and organizations in Canada where the concept was first developed. Furthermore, the inclusion of places such as clinic or physician offices as sites where program planning can take place is incompatible with a person-centered approach or the personal dignity of the individuals.

- **Respite Care:** (Page 36) Sites of service include a general medical hospital and a licensed Day Habilitation program. The Council commented earlier about the inappropriateness of the use of “Respite Care” in hospital settings for adults. We recognize that this setting was included in the renewal application without reference to age, but would again suggest that a change be submitted that would refer to “Adult Companion Services” in this instance for adults.
- The Council has spoken numerous times against the restriction on family members’ ability to access Respite Care when they work outside the home. Thus far these comments have had no impact on the proposed policy. The current draft states: “When the primary care-giver works outside the home, the every day scheduled day care of the member is the responsibility of the primary care-giver and is not an eligible service activity for respite care.” The DHHR has made a point of this in more than one place in this draft Manual. Therefore, the Council requests that the DHHR provide us with the following: (1) the data which indicate that “every day scheduled day care” is available across the State (or in any area) that accepts children who, by the nature of their disability, qualify for the MR/DD Waiver program; (2) how it was determined “that working outside the home” is not, in fact, a form of respite for the primary care-giver; and (3) evidence that providers around the State can regularly support a family member with staff for services included in the IPP without relying on respite care providers to fill in, at least occasionally.
- After a review of the WV Child Care Centers database on the DHHR’s website, the Council was able to locate only one provider in the entire State that serves children up to age 14. A child care study, conducted by the Easter Seals Rehabilitation Center of Ohio County and funded by the Council in 2003, indicated that most respondents do not employ any specially trained staff. While some programs responded that they currently had children with special needs enrolled, special needs was defined as “individualized services provided by specifically trained staff to assist child with skills in one or more areas of development.” During random phone interviews conducted recently, day care providers indicated a varied concept of what constitutes “special needs.” When questioned about accepting children who might require some particular procedure, as could be expected to

be the case for a child served on this Waiver program, the typical answers were: “I don’t know if we could accommodate that;” “We’ve never had a child like that;” and “I don’t know who would pay for the extra staff needed.” Surprisingly, none of the programs indicated they would turn children down because they continued to wear diapers past the age typical for their programs, and some programs contacted had actually served a child who wore diapers after age three. Before and after school programs are offered by some elementary schools in the State for children in an elementary school program. What does the DHHR intend to tell families who will be unable to access Respite Care to fill in the gaps?

- The documentation required for the provision of Respite Care, including “the content of the activity” and “the relationship of that activity to an objective on the IPP” would seem to indicate that Respite care is not really “respite” at all. It is our belief that the intent of Respite care should be as much a break for the member as it is for the primary care provider.
- The Council has commented previously concerning the DHHR determination that Level I Respite Care and Adult Companion Level I are optional services. These are the only two services in the Manual that offer choice and control by the Member or their family of the actual individual to provide the service. Yet, they are termed “optional.” Agency providers are typically not allowing these services to be provided.
- We have also commented on the overly burdensome requirement placed on Level I providers to already have training that Level II providers will receive after being hired. DHHR has a responsibility to provide Members with the justification for making the only two services (Level I Respite Care and Adult Companion) families and members advocated strongly for in years past, due to the inability of providers to secure staff, optional services with pre-employment requirements that no other service has.
- **Residential Habilitation:** (pp. 39-41) The Council recognizes that Community (provided by family) Residential Habilitation hours have been cut to four hours per day (including any Agency Residential Habilitation) while Agency Residential Habilitation hours remain at

24 hours per day (including Adult Companion services). How has the DHHR determined that members residing with their families require less habilitation than those who live in other settings?

- Agency Residential Habilitation service also has an additional specific restriction against Members living at home vs. Members not living at home... “A member living in a natural family home who has a legally responsible adult (guardian or parent) may only receive habilitation services that have been identified as necessary in the Extraordinary Care Assessment.” Members of similar ages and needs may live in different types of settings, yet some groups of Members will be restricted in the types and amounts of services they are able to access. Is this allowable in a 1915(c) Waiver?
- While Members receiving Community Residential Habilitation services can only receive them in their home settings, Members receiving Agency Residential Habilitation services “may also be carried over in the necessary local public community environments as specified in the IPP.” The restriction for Community Residential Habilitation is contrary to the concept that people with mental retardation learn best in the natural environment (e.g. ordering and paying for food at a restaurant or learning to check out tapes at the public library). What is the justification for this restriction?
- Page 33. “Residential Habilitation providers must maintain detailed documentation (e.g., progress notes, daily activity logs) for residential sites in the center’s chosen format....” **AND**
- Page 40. “Community Residential Habilitation providers must complete the Community Residential Habilitation Documentation Form (DD-12). **THE DD-12 IS A FORM THE DEPARTMENT ALREADY HAS KNOWLEDGE OF BEING UNDULY BURDENSOME, AS SOME FAMILIES HAVE REPORTED HAVING TO COMPLETE UP TO 80 PAGES PER MONTH ON THE FAMILY MEMBER FOR WHOM THEY PROVIDE SERVICES. What could possibly be the purpose of “detailed documentation in the center’s chosen format” AND the DD-12?**

- **Day Habilitation Program:** (pp. 48-49) Service restrictions include “Individuals who have aged out of school must participate in day habilitation/prevocational training or supported employment programs.” This does not appear to support the DHHR’s stated intent of allowing person centered planning, including allowing Members to choose which services they want and need. This is particularly problematic for Members who are older or otherwise not able or willing to tolerate this level of continuous training.
- “Day Habilitation services may not be delivered in a residential site except in rare circumstances where the individual cannot receive Day Habilitation services outside his/her home.” This statement is more supportive. It should be combined with the restrictive sentence above as a caveat.
- “Children who do not receive extended school year services may be eligible to receive day habilitation in the summer months. However, during the remainder of the year, school is considered the day habilitation and the child is not eligible for day activities under Waiver both during the week and on weekends (day activities include day habilitation, prevocational services and supported employment).” The Council has expressed its concerns about this during previous comment periods. They are as follows:
  - Extended school year services do not amount to a full day, full week, or full summer in any County that the Council is aware of.
  - School aged children, especially at the high school level, often hold part time jobs or do volunteer work after school. Why would this program not allow Members who are school age to access prevocational and/or supported employment services? The Council disagrees that this would be providing mandated education services to Members. The educational system is neither Federally or State mandated to provide such services to students after school or on week-ends. These stated restrictions are more stringent than the language in the Waiver Renewal Application (page 13).
- **Prevocational Training Services:** (Page 50) The only sites listed to receive this service are segregated sites such as day activity centers or adult day service programs. Since people with mental retardation

learn and retain skills in natural settings (such as real places of employment) this restriction is counter-productive to the intent of the service. Members should be able to receive such training in the community.

- **Supported Employment:** (pp. 51-52) If supported employment services are to be provided in an integrated community work setting, which is where they should be provided, why would there be such a thing as “group services” and staff/member ratios up to 1:4? This appears to be neither individualized nor integrated.
- **Therapeutic Consultative Services:** (Page 55) Why is a CIB check not required for the Skills Specialist?
- The Council understands that requiring a bachelor’s degree in a human service field is intended to insure well qualified individuals will fill these positions. The sudden policy change requiring a Skills Specialist to have a four year degree in a human services field will eliminate good, hard to recruit and hard to retain staff persons across the state. This will leave agencies, and thus Members, around the State without qualified staff to provide these services. An appropriate approach would be to treat this type professional similar to the Service Coordinator position. On Page 29 of the document, there is a provision for a Service Coordinator to have a four year degree in a non-human service field if they have one year of experience in the MR/DD field and work under appropriate supervision.
- **Skilled Nursing Services:** (Page 59) The assurances (for the safety of the Member) would appear to make it possible for the DHHR to determine that a Member’s family home or other unlicensed home (e.g. small apartment) would not be an appropriate place for the Member to live. Requirements such as a back-up power system, space requirements, fire safety and exits, and telephone, while appropriate requirements for a “facility,” are not appropriate to be “required” in a person’s home or family setting in order to receive needed services. These institutional/facility base regulations should not be imposed across the board.

- A dilemma is presented by the proposed change to the Manual that “nursing service must be ordered and implemented under the supervision of a physician” in light of the current interpretation of nursing and AMAP guidelines by DHHR and agency staff. The DHHR is well aware that, while physicians have not necessarily ordered nursing services, the department itself has deemed them to be mandatory for certain Members served by the Waiver program. How will these Members access services they need if the DHHR does not address this discrepancy? For example, many physicians would not feel an individual needed a nurse to administer medication or give g-tube feedings but the DHHR maintains this to be the case. What happens to such a Member?
- **Crisis Services:** (Page 63) The Council still strongly disagrees with the DHHR’s decision to not allow natural families or specialized care providers access to this service for their Member who receives Waiver services. How, under the 1915(c) Waiver program, is the DHHR able to discriminate against Members because they live with their families?
- By the nature of “crisis,” how does a Member and his/her team go about planning to need such service as seems to be required? “Effective July 1, 2006, the service must be based upon the assessed need of the member, identified by the IDT, and included on the individualized Waiver budget. The ASO will register the service(s) with the claims agent. Services not registered with the claims agent will not be reimbursed.”
- PP. 65-66 – If no other services, such as residential or day habilitation, adult companion, nursing, etc. can be provided while receiving crisis services, why is it that “crisis services may also be carried over into the necessary local public community environments, as specified in the IPP.”?
- If a Member requires nursing services typically, why would they not also require them during the provision of crisis services?
- **Environmental Accessibility Adaptations:** (pp. 68-69) One of the restrictions to this service includes requiring the benefit to be paid to the provider of the adaptation. This appears to be in conflict with a

person-centered, self directed approach. What data does the DHHR have to show that providing the benefit to the Member, who can then pay the provider, has resulted in problems that necessitate this new restriction?

- “This benefit is not to be utilized by combining the benefit allocated to the member for more than one calendar year for any Environmental Accessibility Adaptations.” Adaptations are sometimes quite expensive. If a Member could receive a needed adaptation by purchasing it at the end of one calendar year and the beginning of the next (December and January), why would this be of concern to the DHHR? The total expense for both years would not be exceeded, so the restriction apparently is not about financial concerns. Why is this restriction being made?
- **Extended Physician Services (Annual Medical Evaluation)**: (pp. 69-70) Included in the definition is the following statement: “Information should also be gathered from the individual or legal guardian on what he/she wants from services with relation to his/her goals for home life, day services, social life and/or other life areas.” The Council responded previously that this is inappropriately included in the medical evaluation section as it is clearly not a medical issue, but one more appropriately addressed by a social worker. This is not something that is typically addressed with physicians, nor do physicians typically include this as a part of a medical examination. The Council again requests that this requirement be removed from this section.
- Please explain what “other applicable community location” might be an appropriate site of service for an annual medical evaluation. The Council strongly encourages this be limited to physicians’ offices and clinics as is typical. If a Member has a relationship with a physician who actually does make house calls due to the Member’s medical fragility, this could be granted a prior authorization. However, the Council does not condone the practice of agencies contracting with physicians to make visits to group homes and other group settings for the convenience of the physician or provider as this limits the Member’s ability to participate in typical community activities, services and settings and it can be degrading to the individual.

- **Assessment to Determine Extraordinary Care**
- It is well recognized that early intervention and follow-through on training objectives are important for young children with developmental delays and disabilities. The nature and severity of these delays and disabilities can require training, assistance, and supervision that is extraordinary compared to that of a normally developing child. For a child with severe disabilities such as autism, mental retardation, and/or significant sensory-motor impairments, it would be deleterious to withhold habilitation skill training until they reach some upper, arbitrary limit of an age range on the proposed “Assessment to Determine Extraordinary Care” form.
- The draft policy Manual states in Section 513.5.1, “A member living in a natural family home who has a legally responsible adult (guardian or parent) may only receive habilitation services that have been identified as necessary in the Extraordinary Care Assessment.” This indicates that neither a parent nor an agency provider can be reimbursed to provide this service if the child is, ‘too young to be considered.’ Using the new assessment tool, a child with severe and pervasive physical and mental impairments would not be eligible to receive habilitation intervention through the MR/DD Waiver when they may need those services the most. It is not reasonable to say that the care needs of a child who qualifies for the MR/DD Waiver cannot be considered before some arbitrary age is attained. A child with significant impairments requires care and training that is extraordinary, and is likely to be needed from birth. This proposed approach and tool need to be modified further and not be used in a way that ignores the need for intervention at a critical period in a child’s growth.
- **Person Centered Planning & Self Determination**
- It is appreciated that the DHHR is talking about including in the Waiver both person centered planning and self determination. Providers of service will be required to be trained in person centered planning. Since true person centered planning has not occurred in WV through the MR/DD Waiver, it will be critical that this training be carried out by knowledgeable individuals using uniform information that meets national standards.

- The DD Council is highly committed to seeing people with developmental disabilities have more control over their lives and services/supports; have more choice in who helps plan and provide those supports; and have more authority over the use of the MR/DD Waiver and other public funds. It is well established in other states that when waivers make this shift, people's lives improve while the budget remains cost neutral. Cost savings have been realized when the concepts are properly implemented.
- In the draft policy manual the words "person centered" have been added, and a new form has been added. However, several aspects of the policies continue or have added new ways in which the overall approach is neither person centered nor self directed. Key aspects of a properly formed Waiver would at the minimum include (at least an option of) independent supports brokerage, personal/global budgeting, true person centered planning, unrestricted choice of providers, and the use of fiscal intermediaries. While it may be important to phase in some of the features, the proposed policies need to enhance the development of this concept. The following are some examples of draft policies that do not move the concepts forward.
- The same services, essentially, are available as before. Some services will be required on a person's plan whether the individual or the people he/she considers to be a circle of support feel are needed. The costs for those will be deducted from an individual's budget. If any funds remain available, a person may be able to choose and receive the services they want and need.
- Some services such as Respite Care I, Adult Companion I, and independent QMRP services have the important aspect of permitting the participant choose the individuals who will provide the service. The current policies and practices have all but eliminated those services.
- The Council has made available and has provided to both the program staff and the Quality Council members training on self determination, person centered approaches, and the application of both in the MR/DD Waiver. The Council will continue to make training and consultation from experts in these areas available to the State staff,

Quality Council members, and others in hopes that the program will be refashioned into one that supports people to have real, meaningful choice and authority over the their lives.

- **Other**
- Council staff and Members attended several of the public meetings conducted by the Lewin Group, and the later meetings conducted by the DHHR on the Waiver renewal application. Family members have complained repeatedly about the numerous assessments that are required for their family member to stay on the Waiver program.
- DHHR has removed the requirement for the annual psychological update (for individuals 18 years of age or older) and the annual social history update. However, additional assessments include the Inventory for Client and Agency Planning and/or the Supports Intensity Scale; and an extraordinary level of care assessment.
- Families (and providers) have complained about the burden of the overly bureaucratic procedures and the requirement to take services they find no value in. Yet another level of bureaucracy – the Administrative Services Organization was added. It remains unclear as to how this agency’s involvement will affect participants.