

WV Medicaid Recipients' Union  
 Comments on the *MR/DD Waiver Manual Working Draft*  
 16 December 2005

First of all, for DHHR to release a 126-page document and hold four public “hearings” on very short notice during the holiday season is just another indication of the regard in which “members” and their families are held. It signals, loudly and clearly, that DHHR is not really interested in listening to stakeholder concerns but is instead simply going through the motions of soliciting input in order to comply with CMS directives and avoid media scrutiny.

Once again, MRU WV commends the DD Council for its dedication and diligence in providing families with vital information about this process.

**501 : DEFINITIONS**

One wonders why DHHR feels it necessary to redefine terms which are already defined in federal statute or code. In some instances, the definitions are contradictory; in others, merely redundant; and in still others, BOTH within the same definition! For example:

Draft Waiver Manual Definition	Definition in Federal Code
<p><b>Active Treatment</b> [is] a comprehensive training program which necessitates the availability of trained staff to aggressively and systematically address the acquisition of skills to improve, maintain or prevent the regression of basic activities of daily living as they relate to self-care, mobility, communication, learning, self-direction, and the capacity for independent living. Active treatment does not include services to maintain generally independent members who are able to function with little supervision or in the absence of a continuous active treatment program.</p>	<p><b>Active Treatment (42 CFR 483.440(a))</b></p> <p>Refers to aggressive, consistent implementation of a program of specialized and generic training, treatment and health services. Active treatment does not include services to maintain generally independent clients who are able to function with little supervision or in the absence of a continuous active treatment program.</p> <p><b>Components of Active Treatment:</b></p> <p>A. <b>Comprehensive Functional Assessment</b> (42 CFR 483.440(c)(3)). The individual's interdisciplinary team must produce accurate, comprehensive functional assessment data, within 30 days after admission, that identify all of the individual's:</p> <ul style="list-style-type: none"> <li>• Specific developmental strengths, including individual preferences;</li> </ul>

	<ul style="list-style-type: none"> <li>• Specific functional and adaptive social skills the individual needs to acquire;</li> <li>• Presenting disabilities and when possible their causes; and</li> <li>• Need for services without regard to their availability.</li> </ul> <p><b>B. Individual Program Plan (IPP)</b> (42 CFR 483.440(c)). The interdisciplinary team must prepare an IPP which includes opportunities for individual choice and self management and identifies: the discrete, measurable, criteria based objectives the individual is to achieve; and the specific individualized program of specialized and generic strategies, supports and techniques to be employed. The IPP must be directed toward the acquisition of the behaviors necessary for the individual to function with as much self-determination and independence as possible and the prevention or deceleration of regression or loss of current optimal functional status.</p> <p><b>C. Program Implementation</b> (42 CFR 483.440(d)). Each individual must receive a continuous active treatment program consisting of needed interventions and services in sufficient intensity and frequency to support the achievement of IPP objectives.</p> <p><b>D. Program Documentation</b> (42 CFR 483.440(e)). Accurate, systematic, behaviorally stated data about the individual's performance toward meeting the criteria stated in IPP objectives serves as the basis for necessary change and revision to the program.</p> <p><b>E. Program Monitoring and Change</b> (42 CFR 483.440(f)). At least annually, the comprehensive functional assessment of each individual is reviewed by the interdisciplinary team for its relevancy and updated, as needed. The IPP is revised as appropriate.</p>
Draft Waiver Manual Definition	Definition in Federal Code

<p><b>Individual Program Plan (IPP)</b> is an outline of proposed activities that primarily focus on establishment of a potentially life-long, person-centered, goal-oriented process for coordinating the range of services, instruction and assistance needed by persons with developmental disabilities and their families. It is designed to ensure accessibility, accountability, and continuity of support and services. This service also ensures that persons with developmental disabilities have opportunities to make meaningful choices with regard to their life, and inclusion in the community. The IPP (DD-5 – version 04-01-2006) is the critical document that combines all information from the evaluations to guide the service delivery process. The completion of the IPP must be a joint effort among all parties involved in the member's life.</p>	<p><b>The definition of "Individual Program Plan" is a part of the federal definition of "Active Treatment" (above), but copied here for comparison:</b></p> <p><b>B. Individual Program Plan (IPP)</b> (42 CFR 483.440(c)). The interdisciplinary team must prepare an IPP which includes opportunities for individual choice and self management and identifies: the discrete, measurable, criteria based objectives the individual is to achieve; and the specific individualized program of specialized and generic strategies, supports and techniques to be employed. The IPP must be directed toward the acquisition of the behaviors necessary for the individual to function with as much self-determination and independence as possible and the prevention or deceleration of regression or loss of current optimal functional status.</p>
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Well, "one" doesn't really "wonder." It's quite obvious that the inclusion of DHHR's definition is geared toward avoiding accountability for implementation of the IPP.

Let's look at the proposed definition for "**Waiver Program for Mentally Retarded and Developmentally Disabled Persons (MR/DD Waiver Program)**" to which the following was added:

The MR/DD Waiver Program provides services in natural settings (such as the local neighborhood shopping entities, banks, libraries, etc), homes and local communities where the member resides instead of Intermediate Care Facility/Mental Retardation (ICF/MRs).

Exactly what is gained (or, rather, lost) by adding these words? It seems that much of it could be stricken without compromising the meaning – and without leaving the door open for the denial of services based on nit picky minutiae. Take another look without the added verbiage:

The MR/DD Waiver Program provides services in natural settings (~~such as the local neighborhood shopping entities, banks, libraries, etc~~), homes and local communities ~~where the member resides~~ instead of Intermediate Care Facility/Mental Retardation (ICF/MRs).

If DHHR is truly looking at a person-centered model, then "natural settings" are wherever the PERSON wants to live/work/play. We don't need a list of *acceptable* natural settings defined for us. This is yet another indication that DHHR doesn't have the

first clue what “person-centered” really means. (We’re only on page 8 of 126, folks! Get comfy. This is going to take a while.)

## **502 : PROVIDER PARTICIPATION**

The administrative divide between BMS and BHHF has long been a source of inefficiency and ineffectiveness for the MR/DD waiver program. Historically, BHHF has employed folks who truly want to improve the program and its services; whereas BMS’ focus has seemed to be totally impersonal and geared solely toward cutting costs. (There is, we now note, some blending of these traits across the Bureaus as personnel shift. Rather than ameliorating the problem, however, it seems that callous, near-sighted management is just better situated to silence the voices of the enlightened.) Adding an ASO to this mix, even if tied with a shiny red ribbon and presented to the “members” as the greatest thing since sliced bread, is only going to make things worse. (“We cannot solve our problems with the same thinking we used when we created them.” ~Einstein)

MRU WV points out – once again – that the addition of this layer of bureaucracy is one that neither the “members” nor the providers support, and yet DHHR persists with its misguided endeavor and ignores all requests for copies the data used to reach its decisions. (It must’ve been some slick sales pitch, though, to convince DHHR to ignore APS’ failures in other states. Well, that’s assuming DHHR bothered to look at APS’ track record.)

### **502.1 : PROVIDER PARTICIPATION – GENERAL**

The arbitrary requirement for behavioral health licensure is a barrier to self-determination and person-centered services.

### **502.3 : PROVIDER PARTICIPATION – REPORTING REQUIREMENTS**

It’s all well and good to require providers to report when service coordination case loads are exceeded, but what is DHHR going to DO if the providers fail to fix the problem? This speaks, yet again, to the accountability issue. Rather than regulate providers to within an inch of their lives and drown them in meaningless paperwork which serves no purpose but to kill trees and increase overhead expenses, DHHR needs to implement and enforce REAL penalties for failure to deliver services as outlined in regulations and treatment plans.

### **502.5 : PROVIDER PARTICIPATION – SERVICE LIMITATIONS**

Rather than place the onus on the “member,” would it not be MUCH simpler to insist that the provider meet stated participation requirements? Providers are not going to go to the trouble of obtaining licensure and certification in West Virginia if they don’t have the business to support it. If a provider in, for example, Philadelphia has enough West Virginia business to justify the red tape, then why not give the “member” the freedom to

decide – *especially* if the services aren't available in state? THAT, in case you didn't recognize it, is person-centered.

## **502.6 : PROVIDER PARTICIPATION – SERVICE EXCLUSIONS**

“MR/DD Waiver services may not be provided concurrently unless otherwise indicated in the service definition. For example Residential Habilitation services may not be provided concurrently with the individual's Day Habilitation Program, school services or Respite Care services.”

The above requires clarification, because some providers interpret “concurrently” to mean that the services cannot co-exist on the same IPP (regardless of WHEN each is provided).

“Court Appointed Guardian cannot be reimbursed for service pursuant to West Virginia Code §44A1-8(a) (under research)”

Keep researching! The damage that will be done with the implementation of this one change is “extra-ordinary” and will significantly increase the risk of institutionalization for many “members.” We all know that institutionalization costs MORE, right? We're clear on that much, are we not? Sure, sure – the providers don't get to siphon off 50% of the Medicaid reimbursement for Community Residential Habilitation – BUT the service is a very cost-effective use of Medicaid dollars. The same service delivered by agency staff would cost Medicaid MORE THAN TWICE as much. That's nothing to sneeze at!

Hmmm ... let's say, for the sake of argument, that 25% of the “members” (961) use 25% of the available 186 hours/month (46.5 hours) of Community Residential Habilitation. That's a program expense of \$268,119 monthly. If the SAME residential habilitation services were provided by agency staff, it would cost \$558,581 monthly. To the Medicaid bottom line, that's a difference of roughly \$3.5 MILLION annually (which is over \$870,000 in state matching funds). [As an aside: If BMS would release program billing figures – as has been repeatedly requested via FOIA – we wouldn't have to use such hypothetical examples.]

“Legally Responsible Adult cannot be reimbursed for services except for Community Residential Habilitation Services that are considered “extra-ordinary”.”

Why single out the “legally responsible adult” ??? Would it not be more accurate (and more consistent with other provisions of this draft) to simply state:

“Providers can only be reimbursed for Residential Habilitation Services that are considered “extra-ordinary”.”

We can haggle about the definition of “extra-ordinary” later.

## **503 : MEMBER ELIGIBILITY**

Enrollment (i.e., the availability of a waiver program “slot”) has absolutely NOTHING to do with “eligibility.” It has to do with DHHR covering its big, hairy ass to avoid censure under *Benjamin H.* Actual “eligibility” for this program has only TWO legitimate components: medical and financial. Once those are met, the individual is “eligible” – regardless of whether or not DHHR has the resources to “enroll” the individual. Let’s keep our terminology straight, shall we? Perhaps definitions of ELIGIBLE and ENROLLED should be added to Section 501. Just a thought.

To illustrate the inconsistency, look at these statements:

“The member may be enrolled in the waiver program upon the availability of an allocation (slot).”

“An eligible applicant will be enrolled into the Waiver program once the allocation is available.”

Um ... how can the individual even BE a “member” or BE “eligible” if not (per DHHR’s draft) already *enrolled*? (Let’s all say it together, now: IN-CON-SIS-TENT! Harsh? Hardly! It’s so much softer than: HYP-O-CRITE!)

In terms of the “steps” themselves:

The member eligibility and enrollment process consists of four steps:

FIRST STEP: Medical Eligibility

SECOND STEP: Notification of Available Allocation

THIRD STEP: Financial Eligibility

FOURTH STEP: Member Enrollment (Waiver allocation)

What is the difference between the 2<sup>nd</sup> and the 4<sup>th</sup> steps? MRU WV recommends that once medical and financial eligibility are determined, applicants be immediately provided a Medical Card so they can access necessary Medicaid services. (In other words, put the 3<sup>rd</sup> step immediately after the 1<sup>st</sup> step so that folks can get a Medical Card in a more timely manner.) The program-specific services (such as residential habilitation, day habilitation, etc.) would only be accessible when allocations (“slots”) became available. This would alleviate much of the stress on families and individuals biding their time on a waiting list as well as decrease their risk of institutionalization.

### Medical Eligibility Criteria

BMS has no need for copies of the IEP for school-aged individuals or ANY other documents beyond the medical, psychological, and social assessments conducted as part of the application process. It should be ENTIRELY up to the individual how much (if any) additional information to provide when making an application (or an appeal). In most cases, such additional documentation would be totally extraneous and only drive overhead costs higher. There is no VALID reason to require such additional information when eligibility can clearly be determined without it.

## Medical Eligibility Criteria : Diagnosis

If it weren't so damned frightening, this would be laughable. A "developmental disability" is, by its very nature "chronic." To further add to the redundancy, one can state with a fair amount of certainty that "chronic" conditions are "likely to continue indefinitely."

Now, let's talk about the word "severe." How is it defined, exactly? Sure, "substantial deficits" is defined in federal code, but DHHR then goes on to use the term "substantially limited functioning" instead. What gives? Are we now talking about "severely substantial deficits" or "substantially severe limited functioning" or some other arbitrary language? Why not just add a little disclaimer: DHHR reserves the right to restrict program access to anyone it doesn't want to serve for whatever reason it deems fit. That's what it boils down to, after all.

"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."

Could DHHR be any more blatant in its attempts to exclude one specific individual?

## **505 : RIGHTS OF MEMBERS**

Wow. Members have rights! What happens when those rights are violated? The regulations are silent.

"All applicants must be given a choice between services either in an ICF/MR or by means of a home and community-based service under the MR/DD Waiver Program when Waiver services are determined to be a feasible alternative to institutional care."

Determined by whom to be a *feasible alternative*? And what kind of "feasible" are we talking about, here? Fiscally feasible? Administratively convenient? Seems to be quite a bit of wriggle room here for some penny-pinching bureaucrat (in addition to flying in the face of *Olmstead*). Oh, but these "rights" have no penalties associated with their violation – so they have no teeth. Thanks for nothing!

"Members have the right to choose a provider agency or agencies. Member choice must be verified on the DD-7A."

Oh, goody. Members can "choose." How magnanimous! However, if DHHR isn't willing to make the agency (or agencies) accept the "member" as a "client," that choice is absolutely, positively 100% meaningless.

## **506 : MEMBER DISCHARGE**

Um ... this sounds like an STD. Can you come up with a better heading?

### **507 : RIGHT TO APPEAL**

Oh, more rights! But, alas, no consequences for their violation. What happens if DHHR fails to provide due process per timelines? What happens to a member's appeal of the individual budget as determined by the ASO? Are there timelines associated with that appeal?

All those rights look just peachy, but ... WHERE'S THE BEEF?

“Based upon clinical need, the member may contact the ASO to re-negotiate the Individual Waiver Budget.”

Huh? Who determines “clinical need,” here? The Interdisciplinary Team (IDT) is the entity designated by federal law for identifying service needs and developing treatment plans ... yet members must “negotiate” with the ASO? Negotiate WHAT, exactly? “Oh, excuse us, dear member, we didn't realize your disability was quite as functionally substantially severe and chronic as your IPP thoroughly documents. Here, we'll add another twenty dollars to your individual budget. Don't spend it all in one place, now! Y'hear?”

### **508 : REPORTING ALLEGED ABUSE AND NEGLECT**

Such a tiny little section for such a big, big problem. An investigation “may” take place ... or not. Guess it all depends on how functionally substantially severe and chronic a pain in the ass you make of yourself.

### **509 : DUAL PROCESSES FOR TRANSITION TO INDIVIDUAL WAIVER BUDGET**

“The assessment and budgeting process must be completed prior the IPP.”

So much for person-centered. So much for TEAM-centered, even. The IDT should be doing ALL of this work. Take the team-developed IPP – from it, complete the DD-6 (cost estimation worksheet) and then make that figure the budget. Could it be any simpler? But, no! DHHR had to award a multi-million dollar contract to an ASO to come up with an administratively-intensive system of costly assessments ... and we're supposed to buy that bridge they're trying to sell us! (Don't forget to thank DHHR, y'all.)

Oh, and take it one step further: Deposit the budget with a fiscal intermediary (i.e., BANK) and let the “member” pay for his/her services as needed. What a concept!

### **509. 2 : SERVICES REQUIRING PRIOR AUTHORIZATION (BHFF)**

“The following services must be prior authorized at the state level before a member may receive the service or a provider may bill:

- Exceeding the monthly ICF/MR cost of \$6,400
- Waiver Nursing services (all)
- Exceeding of service limits or exceptions to service.
- Community Residential Habilitation in excess of four (4) hours per day with a maximum of six (6) hours per day.”

Wait just a second! As long as the member’s individual budget is not exceeded, why does DHHR even care? Oh, wait – it’s that “H” word again, huh? (Pssst! HYPOCRISY.) Uh huh. Person-centered, right? Yuppers.

### **510 : INTERDISCIPLINARY TEAM (IDT) COMPOSITION**

Ha! A medical professional must be on the team if the member has a “medical need,” yet all members are required to have annual nursing assessments (per a DHHR audit) in addition to the annual medical evaluation – regardless of their need. There’s “quality” for ya. (Don’t step in it!)

Come to think of it, don’t ALL “members” have a “medical need” ??? Would individuals be eligible for the program WITHOUT one?

Drop the useless mandatory nursing assessment, DHHR. It adds NO value and just drives up costs. Let the IDT identify needs – as federal law intended. Let the physician identify medical issues on the DD-2A. And, for heaven’s sake, STOP meddling where it’s not necessary.

### **511 : MISSING ???**

#### **512.1 : BILLING PROCEDURES – PAYMENT & LIMITATIONS**

“As an exception, while a member is inpatient in a non-state operated hospital, the member may receive respite services when the member requires a support staff who are familiar with the member’s individualized needs, provided the service is not duplicated by the hospital. This service requires state approval.”

First of all, if the service need is identified by the IDT on the IPP, then WHY require state approval if not to simply be a bureaucratic pain in the posterior?

Secondly, the service should be either respite or adult companion care – as appropriate.

### **513 : DESCRIPTION OF COVERED SERVICES**

#### **513.1 : SERVICE COORDINATION**

Nothing in the renewal application or these draft regulations effectively addresses the conflict of interest which exists when an agency providing service coordination is also providing direct care services to that same “member.”

“Promote a valuable and meaningful social role for the member in the community while recognizing the member’s unique cultural and personal value system.”

Awww ... doesn’t that sound nice? Warm fuzzy words ... with ZERO meaning in this hollow context.

## **513.2 : RESIDENTIAL HABILITATION**

“Residential Habilitation cannot replace the routine care and supervision which would be expected to be provided by a legally responsible care taker, or for activities or supervision for which payment is made by a source other than Medicaid.”

Gee, what part of caring for someone with a substantially limiting functionally deficient severe and chronic disability is *routine*? Inquiring minds wanna know!

And, please make sure that agencies KNOW that NO additional paperwork is required. The DD-8 and DD-12 are ample documentation. Anything more is adding no value and is detracting from the provision of services to the “member.”

There needs to be a billing mechanism in place for new staff to shadow existing staff for training purposes. QMRP training is completely inadequate for the really nuts ‘n bolts hands-on care. QMRPs typically don’t have the necessary in-depth knowledge of and experience with the “member,” and there aren’t enough service hours available on the program for them to acquire this knowledge & experience.

### **513.2.1 : COMMUNITY RESIDENTIAL HABILITATION**

“A legally responsible adult may only be reimbursed for services that have been identified as necessary in the Extraordinary Care Assessment.”

Again, what part of caring for someone with a substantially limiting functionally deficient severe and chronic disability is not *extraordinary*? Is giving up a job outside the home in order to be available because agency staffing is completely unreliable (and DHHR refuses to hold agencies accountable) considered *extraordinary*? Damned straight, it is!

What, pray tell, happens if the criminal investigation background check turns up something? Will the “legally responsible adult” be prevented from providing community residential habilitation? Will DHHR seek guardianship? What? If no ACTION is going

to be taken based on the results, then WHY DO IT? It adds no value and just drives costs higher.

### **513.3 : ADULT COMPANION SERVICES**

Get over the contracting issue, already! It's fixable with a wee bit of thought, y'know? We're all aware that the agencies don't want to deal with it, but it happens to be the service the "members" and their families most often want. Wait a minute! Is the "person" in person-centered someone other than the member? That would explain a LOT, actually!

### **513.5 : PSYCHIATRIC DIAGNOSTIC INTERVIEW EXAMINATION**

WHY?

#### **513.15 : RESPITE CARE**

See ADULT COMPANION CARE (*above*) re contracting issue.

"Respite is not intended for routine day care."

Oh, so if the legally responsible adult isn't around, no one is thus responsible for feeding or bathing or clothing the "member." Good to know. Thanks. (Of course, you realize that would result in many reports of "alleged abuse and neglect" – which *may* be investigated ... or not.)

#### **513.16 : SKILLED NURSING SERVICES**

"Members requiring ongoing nursing care due to the intense medical need of the member and nursing activities that cannot be performed by a non-medical, non-licensed nursing staff will be not be eligible for respite services. Nursing care will be considered "respite" care for the family."

You've got to be kidding! What in the WORLD does one have to do with another? How incredibly short-sighted.

There are 24 hours in a day. What happens when the "member" requires 8 hours of nursing through the night? Does the family then forego employment during the day because it can't access respite services? Or, rather, does the family forego sleep at night in order to be able to access respite services during the day? This makes NO sense whatsoever.

Let the IDT determine service needs – as the law intended – and stop making these sweeping proclamations which are just not feasible for many families.

#### **513.17 : ENVIRONMENTAL ACCESSIBILITY ADAPTATIONS**

“Routine durable medical equipment or routine communication devices are not considered environmental accessibility services through Waiver. These services may be otherwise available through Medicaid state plan services.”

Define “routine” – especially as it pertains to durable medical equipment.

\* \* \*

That concludes our comments on the text of the proposed regulations. Now, on to the forms ...

### **DD-2A : ICF/MR LEVEL OF CARE DETERMINATION**

Renamed the form, eh? Interesting. It seems to now include a whole bunch of information which would be more appropriately included on a social history as opposed to a form completed by a doctor. Clarification would be nice, if it’s not asking too much, on precisely which information from this form is actually used to determine the need for an ICF/MR level of care. Perhaps it’d be wise to separate it into sections: (a) to be completed by service coordinator; (b) to be completed by “legally responsible adult;” and (c) to be completed by doctor. Then, perhaps an explanation should be provided as to why most of it is even NEEDED.

Thank you, DHHR, for removing the dental assessment portion of the form. How the condition of the applicant’s teeth influenced the need for an ICF/MR level of care has always been a mystery.

### **ASSESSMENT TO DETERMINE EXTRAORDINARY CARE**

Every shred of information sought on this lengthy form SHOULD be available on the report generated by the triennial psychological evaluation. The conduct of yet another assessment is: (a) unnecessary; (b) costly; (c) invasive; or (d) all of the above.

(HINT: The answer is “d.”)

### **WAIVER NURSING ACUITY CARD & WAIVER NURSING PSYCHOSOCIAL CARD**

Well, it’s quite obvious from the added red tape that nursing services are under heavy attack. These score cards are certainly handy-dandy tools for limiting services. Who can argue with numbers, after all? By the way, where’s the grade sheet (or is that arbitrary)?

### **MY PLAN**

Oh, it’s a retitled IPP with cute little graphics! We’re supposed to be impressed, right?

\* \* \*

And so, in closing, we (once again) thank DHHR for the opportunity to provide public comment which will (once again) be totally ignored. We (the stakeholders) are damned if we do (provide comment) and damned if we don't. Having this ASO shoved down our throats is yet another indication that our input is not really HEARD.

DHHR has apparently learned to parrot all the current buzz words with respect to self-direction, but it is painfully obvious that it does not understand their meaning. If it did, we wouldn't be fighting to preserve the IDT's autonomy; we wouldn't be scrapping to save Community Residential Habilitation; we wouldn't have to repeat ourselves *ad nauseum* about contracted services; and we sure as hell wouldn't have to get prior authorization of every damned service the IDT has already identified as a legitimate need.

If DHHR truly understood the meaning of person-centered, we'd instead be talking about fiscal intermediaries, REAL choice of providers, accountability for the implementation of team-developed program plans, and consumer rights with teeth that bite instead of just gumming the system to death.

With all due respect,

The West Virginia Medicaid Recipients' Union  
<http://www.MRUWV.org>