

WV Waiver Families' MR/DD Waiver Renewal Input

November 2004

WV Waiver Families (WVWF) was founded in May, 2000 as an online support group for those involved with the MR/DD waiver program in West Virginia. At this writing, it has over 350 members, with approximately 90% being program participants and/or their family members. Other members include advocates, attorneys, DHHR employees, provider agency employees, direct care staff, QMRPs, service coordinators, CMS representatives, and a handful of newspaper reporters.

WVWF can be found online at http://groups.yahoo.com/group/WV_waiver_families

Through feedback from members and other stakeholders, WVWF has developed the following input for consideration as West Virginia prepares to renew the MR/DD waiver program. Questions, comments, concerns, or other follow-up should be directed via e-mail to WVWF's founder and moderator, Debi Lewis (DLewis0991@aol.com).

I. GENERAL

A. SCOPE

The program **MUST** remain state wide. Anything less becomes an *Olmstead* issue because DHHR has failed to respond to wide spread consumer interest in additional options such as the Independence Plus waiver. The MR/DD waiver program is the “only game in town” for almost all West Virginians with developmental disabilities.

B. REVIEW

Prior to submission, the waiver renewal application should be reviewed by the Olmstead coordinator to ensure compatibility with the Supreme Court's *Olmstead* decision. When the state's *Olmstead* plan is finally signed by the governor, the waiver renewal application should also be reviewed in light of this plan. The Olmstead coordinator's review should be included with the waiver renewal application when it is submitted to CMS.

C. TIMING

DHHR has recently instituted a practice of holding new waiver slots for 90 days after “awarding” the slot before billing can begin. This effectively screws the service provider agencies out of back billing for the preparation of application packets. As a result, some agencies are now discouraging applications and making informal eligibility determinations without due process for the applicants.

If DHHR persists in this practice, local DHHR offices must be ready, willing, and

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able to complete and submit application packets without the involvement of a service coordination agency. (Actually, it would probably be a good idea for consumers to have the option to have a local DHHR office prepare application packets – since many service coordination agencies are choosing their clientele rather than vice versa.)

D. ACCESSIBILITY

Currently, the Bureau for Medical Services (BMS) requires a password to access program regulations online. This is completely unnecessary and creates ridiculous barriers for both consumers and providers in addition to expending limited resources on the maintenance of mere red tape. WVWF recommends that such password “*protection*” be eliminated immediately.

E. STAKEHOLDER INPUT

DHHR has a long history of making changes to its programs without considering the input of stakeholders, most especially the consumers. This was recognized and documented in the *Benjamin H.* agreement, but it has not resulted in a change in the way DHHR does business. Public comment periods are brief (if they exist at all) and are poorly advertised.

WVWF recommends that all program and policy changes be announced both online and via service coordination agencies at least 90 days in advance of proposed implementation dates. WVWF also recommends that public comment be solicited on all such changes and accepted via phone, fax, e-mail, and U.S.Mail.

II. CHOICE

As part of the 2000 waiver renewal, DHHR was required to develop and encourage expansion of the service provider network. This has indeed been accomplished. However, while there are now many more agencies providing services, consumers still have no real choice. It is currently the agencies that have the real choice.

A. HOSTAGE SERVICES

1. Some service provider agencies tell consumers that they will only accept clientele who live in their group homes, even if the consumer already has a home and wishes to remain in it. This is an *Olmstead* violation.

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When an agency contracts with DHHR to provide a service, that service is NOT contingent upon other factors. There is absolutely no valid reason a one-to-one service cannot be delivered in the location desired by the consumer.

2. Some service provider agencies tell consumers that they will only provide service A if the consumer also uses the agency for services B, C, and D. In some instances, the consumers are being required to use one agency for ALL services. Many consumers prefer to have service coordination provided by a separate agency in order to preserve and/or enhance the role of the service coordinator as an advocate for services. (See also SERVICE COORDINATION under the QUALITY OF SERVICES section.)

B. PICKY AND CHOOSY

1. **SCREENING CLIENTELE**

Many agencies have instituted “packet review” committees to evaluate potential waiver clientele. While the only legitimate reason to turn a waiver client away is capacity, agencies are actually basing such decisions on other factors including billable hours, living arrangements, and involvement in advocacy. Consumers with challenging behaviors find it extremely difficult to find service providers, effectively preventing there being real choice.

2. **CAPACITY**

When an agency turns a client away, a plan is supposed to be developed to ameliorate the capacity issue. These plans are not being completed – probably because *capacity* is not the real reason clients are being denied services.

During the workgroup meetings hosted by WVWF, one parent recommended that waiver utilize a system similar to that employed by the West Virginia Birth-to-Three program to enhance consumer choice.

WVWF recommends the immediate development of a pilot program under which consumers can direct program services as needed per their Individual Program Plans (IPPs). This could be approached as a voucher program or via the use of an impartial fiscal intermediary. (See also the SELF-DIRECTION section.)

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III. ACCOUNTABILITY

Currently, service provider agencies are not being held accountable for program implementation at any level.

A. SERVICE COORDINATION

If the waiver services documented as needed on the IPP are not provided, the service coordination service has been ineffective. As such, service coordination should not be billed – or should only be billed at a reduced rate. This would provide incentive for service coordination agencies to get IPPs implemented.

B. QMRP

If the participant is not making progress toward Individual Habilitation Plan (IHP) goals and objectives, then the plan is either poorly developed or poorly implemented (or both). Thus, the QMRP service has been ineffective. Data collected over the years will readily demonstrate that a program developed by a QMRP is no guarantee of an appropriate or effective program. If this is TRULY to be a training program (and one promoting independence), then a system needs to be developed to hold QMRPs accountable for the development of appropriate programs and the effective training of staff who are tasked with the implementation of those programs. (See also QMRP under the QUALITY OF SERVICES section.)

C. OVERALL PROGRAM IMPLEMENTATION

DHHR should make available quarterly statistical data comparing DD-6s (cost estimates) with actual billing by agency, by catchment area, and state wide. Such data should also be made readily available by individual client for purposes of appeals and Medicaid fair hearings.

Failure to implement IPPs should result in agency penalties per contract terms and program regulations. (See also SERVICE COORDINATION under the QUALITY OF SERVICES section.)

D. FRAUD, WASTE, and ABUSE

DHHR should make available itemized Medicaid statements. Consumers and their families are best equipped to know when fraud, waste, and/or abuse are occurring.

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DHHR should implement a consumer-friendly system for reporting fraud, waste, abuse, and neglect.

IV. DIRECT CARE STAFFING

Recruitment and retention are huge issues for the MR/DD waiver program. This, we believe, is predominantly due to the low wage. The Medicaid reimbursement for most direct care services is such that decent wage could be paid of agencies weren't withholding up to 50% of the Medicaid reimbursement rather than passing it on to the direct care staff.

A. WVWF proposes a percentage cap not to exceed 25% be placed on the Medicaid reimbursements for services provided by all agency-employed direct care staff. At current rates, that would enable most 1:1 direct care staff to earn \$9.38 per hour in gross pay. This would go a long way toward easing the high costs of turnover as well as improving the quality of services.

B. WVWF encourages DHHR to adopt a system similar to that employed by the public school system for the delegation of certain nursing duties such as the administration of medications and the use of feeding tubes. RN oversight should be required, as it is in the schools, and documented on the IPP. Direct care staff performing such duties should receive a pay incentive. This would still save the program a great deal of money and resolve many staffing issues. (Prior authorization for RN oversight should not be required.)

C. There is a wide spread misconception that community residential habilitation (CRH) is some sort of boon to families of waiver participants. This mind set needs to END. Providing CRH is hard work for dismal pay. Data collection burdens that exceed those required of other habilitation providers are unnecessarily onerous and only serve to make a tough job even tougher. DHHR and service coordination agencies need to recognize that families are doing them a huge favor by providing CRH and stop treating families as if they're only trying to milk the system. Given the amount that CRH saves the program (\$6.50 per hour over other habilitation services!), a raise in the reimbursement rate – including a requirement to pass that raise on to those actually providing the service – is LONG overdue.

CRH is often the only service standing between a waiver participant and some sort of more expensive residential placement. It is the BACKBONE of the MR/DD waiver program and deserves to be respected as such.

D. TRAINING COMPONENT

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1. STAFFING VACANCIES

If agency is unable to recruit habilitation staff (residential or day), and if CRH is not available, respite or adult companion care providers should be permitted to implement the participant's IHP in the short term while recruiting takes place – even if contracted – in order to meet the program's requirement for a habilitation component.

Too many program participants are being told they're going to lose their waiver slots because habilitation services are not being provided. **THIS IS NOT THE FAULT OF THE PARTICIPANT!** It is the service coordination agency that should be penalized for this failure, not the client.

2. RETIREMENT

In 2001, the Adult Companion care service was added to the MR/DD waiver program's menu of services. It was touted as a way for program participants to have supported "leisure" time and for older participants to be relieved of the requirement for near constant habilitation efforts.

WVWF strongly recommends that the requirement for **day** habilitation be eliminated for program participants over the age of 55.

E. INDEPENDENT CONTRACTING OF DIRECT CARE SERVICES

Rather than strive to resolve the issues surrounding independent contracting, DHHR instead elected to make contracted (Level I) respite care and adult companion care "optional" for service provider agencies. Naturally, since the agencies can skim from the Level II reimbursement without any checks and balances whatsoever, most have "opted" to not provide the Level I services at all. This has had a profound effect on both the consistency and the quality of care provided. Even when an agency is demonstrably UNABLE to fill long-standing vacancies with Level II staff, it is not required to make the Level I service available.

1. WVWF proposes that a 25% cap be imposed on agency withholding of direct caregiver pay for Level II services. If DHHR is unable or unwilling to impose such a cap, then it should consider doing away with the Level II services altogether. (See Endnote A). Relying solely on Level I services will save millions annually in Medicaid expenditures.

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2. WVWF encourages DHHR to make standard contracting guidelines available online and in print for all services that can be contracted. If an independent contractor meets those guidelines, agencies should not be allowed to refuse a contract for service delivery – especially when that agency has been unable to arrange for service delivery otherwise!
3. WVWF urges DHHR to expand the menu of services that may be contracted to include residential habilitation, day habilitation, pre-vocational services, and supported employment.
4. The “optional” label for Level I services should be immediately removed, and the decision of whether to use Level I or Level II services should rest entirely with the IDT. Level I services, because the agencies currently cannot skim more than 8% from the Medicaid reimbursement, result in greater gross pay for the staff which, in turn, result in improved quality, consistency, and effectiveness of the services.

V. QUALITY OF SERVICES

Agency “report cards” should be made available to consumers based upon the collection of raw consumer satisfaction data and IPP implementation statistics.

A. QMRP

1. Current program requirements fail to ensure that QMRPs are adequately trained in the areas specific to the clients served. This is especially notable in terms of behavior issues. WVWF recommends a requirement be imposed that QMRPs complete regular disability-specific training with periodic “*recertification*” in order to stay abreast of effective evidence-based practices.
2. WVWF recommends a program requirement that IHPs be reviewed to ensure appropriateness.

Behavior plans, in particular, need to be reviewed to see that they meet the criteria of a positive behavior support plan. This review needs to be done in addition to any human rights committee evaluation. Currently, there is nothing that triggers a requirement for a human rights committee evaluation. ALL behavior plans should be reviewed by a positive behavior support committee as well as a human rights committee. (See also SELF-

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DIRECTION section re Olmstead committee review.)

3. As it stands, the waiver program does not provide a means for QMRPs to spend (and bill for) time with the client in order to develop a true understanding of current abilities and training needs. This typically results in a “cookie cutter” program which fails to meet the individual needs of the client. Subsequent training of direct care staff is thus often ineffective and program implementation inconsistent.
4. In order to ensure consistency of program implementation across all direct care staff (especially given the high turnover of staff at all levels), the IHP must not only document WHAT the goals & objectives are, but also HOW each will be addressed (method).
5. WVWF recommends that QMRPs tasked with the development of IHPs have a case load limit.

B. SERVICE COORDINATION

1. CONFLICT OF INTEREST

The potential for a conflict of interest exists when service coordination is being provided by the agency “*chosen*” to provide QMRP and direct care services. Service coordinators are often hampered in their advocacy efforts due to arbitrary agency policies regarding service delivery. Such policies, often informal and unwritten, include a push to have the service coordination agency provide all other services (keeping all the billing under one roof). As mentioned earlier, this effectively limits consumer choice.

A current directive from DHHR requires the service coordination agency provide services when the direct care agency can/does not. This potentiates terrible conflicts of interest. One way to obviate this conflict would be to disallow the comprehensives from providing service coordination and mandate that the comprehensives provide the any services that other agencies can/will not.

2. INCENTIVE

As mentioned in the ACCOUNTABILITY section, there must be an effective

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way to “encourage” agencies to implement program plans. WVWF recommends a two-tiered service coordination reimbursement. If all waiver services are delivered per the IPP, then service coordination may be billed at “Level A.” If the service coordination agency fails to arrange the delivery of all waiver services (again, per the IPP), then service coordination may only be billed at “Level B” (at a substantially lower rate). The program participant or his/her legal representative would have to sign off on service coordination billing as verification.

VI. SELF-DETERMINATION

A. SELF-DIRECTED SUPPORT CORPORATIONS

There exists a CMS-supported consumer-directed service delivery system that DHHR has completely failed to embrace: the self-directed support corporation (SDSC).

A SDSC is a very small corporation, like most of the 5 million corporations in America. It is set up to provide Medicaid-funded supports to one person with disabilities – to be a provider agency for that individual. It is governed by a board of directors consisting of trusted friends and family of the person with the disability.

With CMS’ support, SDSCs are up and running effectively in several states, improving the lives of those they’re intended to serve, removing barriers to service delivery, and eliminating much of the waste inherent in a multi-tiered service delivery system. (See www.self-determined.org for more information.)

There are two major barriers to this approach in West Virginia: (1) the arbitrary requirement for a waiver service provider to maintain behavioral health licensure; and (2) the requirement, per the Summary Review or Certificate of Need process, for an agency to serve all eligible consumers per its “capacity.”

WVWF strongly encourages DHHR to waive these requirements (as other states have done) in order to make this option accessible.

With so many consumers lacking services for which a need has been documented, and with DHHR apparently unwilling to hold agencies accountable for program implementation, failure to explore this option is nothing short of an *Olmstead* violation.

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B. INDEPENDENCE

One of the MR/DD waiver program’s primary objectives is to provide habilitative training that will enable participants to achieve greater levels of independence.

Currently program policies and practices run counter to that objective as agencies insist upon billing for services 24/7. Agencies either: (a) view the waiver program as an entitlement to bill all day, every day; or (b) mistakenly believe that their clients will be dropped from the program if services are not billed around-the-clock. Both assumptions are inaccurate.

The Office of Behavioral Health Services (OBHS), which currently administers the program, clarified that while IPPs must document the need for around-the-clock supports (as would be needed by someone requiring an ICF/MR level of care), those supports DO NOT have to consist entirely of waiver-billable services.

“Informal” supports (such a family and friends) and electronic supports (such as alarm systems) are allowable and are consistent with stated program objectives.

Insisting that program participants accept services that could be provided informally or less invasively is not only unnecessarily restrictive (from a human rights perspective), but it is also a gross misuse of public monies.

WVWF recommends that this be made abundantly clear to all agencies and all program participants.

C. *OLMSTEAD* ISSUES

The *Olmstead v. L.C.* decision challenges federal, state, and local governments to develop more opportunities for individuals with disabilities through accessible systems of cost-effective community-based services. The *Olmstead* decision interpreted Title II of the Americans with Disabilities Act (ADA) and its implementing regulation, requiring states to administer their services, programs, and activities “**in the most integrated setting appropriate to the needs of qualified individuals with disabilities.**” (emphasis added)

WVWF recommends that all IPPs that are contested by any member of the Interdisciplinary Team (IDT) be reviewed by an independent Olmstead committee to ensure that the documented service needs reflect this “most integrated setting”

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standard. If the standard is not met, then the IDT must reconvene to bring the IPP into compliance.

VII. FAIR HEARINGS

The system of due process as currently implemented is seriously flawed in several ways:

- DHHR is not following established time lines for hearings
- DHHR is not following established time lines for issuance of decisions
- DHHR *employs* the hearing officers, creating a conflict of interest
- DHHR is not enforcing the decisions, even going so far as to claim that the hearing officers do not have the authority to make certain rulings. (If hearing officers don't have the authority to rule, what is the purpose of having a fair hearing?)
- There is no standardized training for hearing officers

WVWF recommends that:

- An INDEPENDENT system of fair hearings be created, perhaps similar to that used by the public school system for special education due process hearings
- Hearing officers be attorneys with standardized training on disability law and policy
- Hearing officers be free of conflict of interest
- Rulings be enforceable in any State court of competent jurisdiction or an district court of the United States

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ENDNOTE A

There are presently over 3,500 individuals on the MR/DD waiver program. Each of those individuals is eligible to receive up to 144 hours of respite care or up to 654 hours of adult companion care (and in some instances, both) per month – if the IDT determines the need.

Under current guidelines, respite care and adult companion care are each divided into two service levels: I (contracted) and II (employed). One option would be to completely eliminate the level II services. Here's why:

First, Level II costs Medicaid \$2.50/hour more than Level I. If every waiver recipient had a documented need (per the program plan) for the full 144 hours of respite care, that's a difference of \$15,120,000 annually in Medicaid dollars at current program numbers.

Similarly, if every waiver recipient had a documented need (per the program plan) for the full 654 hours of adult companion care, that's a difference of \$68,670,000 annually in Medicaid dollars.

Of course, every waiver recipient does not need the maximum amounts of each of these services, but if even HALF of the recipients use HALF of the available adult companion care (and that's a conservative estimate), we're still talking about \$17,167,500 in annual Medicaid savings – simply by eliminating Level II adult companion care in favor of the Level I service.

Factor in respite care, and that figure jumps even higher. These figures will only increase as the number of waiver program participants grows.

Second, Level I is the service that waiver recipients CHOOSE because staff receives a better wage (given the current 8% cap on agency withholding) which leads to lower turnover, higher quality, greater flexibility, and better continuity. These things are critical to "*improving the lives of West Virginians with disabilities*" (per BHHF's mission statement). Can you even begin to imagine the indignity of having a different staff person giving you the most intimate of personal care day in and day out -- all because agencies insist upon employing care providers and keeping up to 50% of the Medicaid reimbursement? We treat our pets better than that.

Third, it would totally negate the agencies' argument that "Wage & Hour" regulations prevent them from having employed and contracted staff doing the same job (for there would no longer BE any employed respite or adult companion care providers). Those staff who are working for benefits (with those agencies that graciously "allow" them to work enough hours to be eligible for benefits – and most don't) can become res.hab. or day hab. providers without any loss in wages or benefits.

Fourth, it would attract applicants to direct care staff positions because of the better pay.

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Fifth, it would cut costs for the agencies because their turnover rates would drop dramatically.

There are, admittedly, a few hurdles:

There's still the IRS independent contracting issue. That can easily be overcome by changing the way contracts are executed and by having DHHR provide a recommended template to agencies. There are currently a few agencies who still do provide contracted services. How do they manage the IRS ruling?

All contracts should specify that services are to be provided in accordance with: (a) waiver regulations; and (b) the client's most recent program plan. That simple change would provide the requisite specificity without compromising the independence of the contractor. Then, teams can get as specific as necessary in the program plans as to the days and times and locations that services are needed.

Of course, all contracted staff would be responsible for their own taxes, and the contracts must also make that clear. If a business license is required, then so be it. That's not an insurmountable obstacle.

Some agencies may wish to require that contracted staff obtain liability insurance, but that should be an informed choice on the part of the contracted staff and the client, as the agency would have no stake. A disclosure would suffice.

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