

Mentors for Self Determination

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PA TRAINING PARTNERSHIP FOR PEOPLE WITH DISABILITIES AND FAMILIES

“keeping individuals and families informed”

October 2008

Mentor Memo

Issue 7

Summer moved into fall much too quickly! I don't know about you, but I am not ready to think about getting out the wool sweaters for the change of season. Change is the only constant guarantee in our life. Speaking of change... in this Mentor Memo I will update you on important issues and changes regarding the Mental Retardation System that may be of interest to you.

By now most everyone is aware the Office of Developmental Programs (ODP) has chosen Ascend to administer the Supports Intensity Scale (SIS) as the statewide needs assessment for participants, ages 16 -72, in the Person Family Directed Supports (P/FDS) and the Consolidated Waivers. The standardized assessment measures the level of support a person needs to be successful in their everyday life. The SIS assessments are being scheduled in every County. The Supports Coordinator will contact you when your son/daughter's name has been chosen to receive an assessment. Further information on SIS is posted on The Partnership's website: www.thetrainingpartnership.org.

The Partnership is offering a training to families and self-advocates, The Supports Intensity Scale (SIS) and the PA Plus. The SIS and PA Plus training explains the purpose of the assessment, what to expect from the interview, how the information will be used, the assessment's connection to the development of the Individual Support Plan, and more. Mentors have completed ten SIS and PA Plus trainings in the Central Region since the first of April. (A SIS and PA Plus training is scheduled for November 6 at 2 PM in Myerstown, Lebanon County during the Mentor Get-Together. See attached flyers for details.)

The Center for Medicare/Medicaid Services (CMS) approved the Person/Family Directed Support Waiver (P/FDS) Renewal on March 10, 2008 and is retro-active to July 1, 2007. The cap for the P/FDS Waiver has increased to \$23,200.00 with another increase expected in the near future.

The long awaited statewide Vendor Fiscal Agent/Employer Agent Financial Management Service (VF/EA FMS) organization, Acumen Fiscal Agent has been selected by ODP as the vendor. Financial Management Service (FMS) was previously known as Intermediary Service Organizations (ISOs). Acumen provides employer-related services to individuals and their families served by either MR Waiver living in their own home, apartment or with their family. The Fiscal/Employer Agent (FMS) will represent the business agent. The FMS will handle payment of worker(s) salary and Social Security, workman's compensation, and insurance deductions.

Individuals currently using a local (VF/ EA FMS)-(ISO) will start using Acumen's services January 1, 2009. Waiver participants not using the VF/ EA FMS service at the present time who wish to use the Vendor Fiscal FMS model should contact their Administrative Entity and Supports Coordination Organizations to initiate the referral process to Acumen. Under the Vendor Fiscal Agent/Employer Agent FMS model, individuals/representatives will be able to [1] recruit and hire qualified support service worker(s); [2] determine his/her work schedule; [3] what, how and when tasks are to be performed; [4] orient and train their worker(s); [5] manage the day-to-day tasks performed by their worker(s); and [6] dismiss their worker(s) when appropriate. For further information on the statewide Fiscal Management Service, information is available on the Partnership's web site: www.thetrainingpartnership.org.

Families have been anxious to learn how the revisions to the Waiver Service Definitions will affect their family member's Waiver Services. Per Kelly Svalbonas, Policy Director, ODP... "Bulletin 00-08-12, Revised Service Definitions, was recently issued by the Office of Developmental Programs (ODP). This bulletin outlines the service definitions for fiscal year 2008/2009 for Consolidated Waiver, Person/Family Directed Support (P/FDS) Waiver, and Base services. These definitions include a couple of minor changes that resulted from the recent amendment of the Consolidated Waiver and the recent approval of the P/FDS Waiver. Please see the bulletin for additional details.

ODP is also in the process of further revising the service definitions with an effective date of July 1, 2009. ODP is currently working to finalize the bulletin that will distribute these new service definitions, and hopes to distribute the new bulletin in the next couple of months." (**Thank you, Kelly for your update.**)

To view MR Bulletin 00-08-12 and the Narrative, they are posted on the Partnership's web site and DPW's web site: www.dpw.state.pa.us (left column, "Bulletin Search", type in "00-08-12")

Do you or an adult family member need Autism Services? The Centers for Medicare and Medicaid approved PA's request for an Autism Waiver on May 14, 2008. The program will serve individuals age 21 and older, who have a diagnosis of Autism Spectrum Disorder, living in PA, who are not currently receiving ongoing state funded or state and federally funded long-term care services. All requests for applications for the Adult Autism Waiver must be made through the Bureau of Autism Services toll free number: 1.866.539.7689. For more information about Adult Autism Waiver Services, visit www.autisminpa.org or Email: PW-ODPAutismWaiver@state.pa.us.

It is time once again for a Get-Together. M4SD and Self-Advocates United as 1 (SAU1) are holding two fall Get-Togethers November 5th and 6th at The Lantern Lodge, Myerstown, Lebanon County. Each day different trainings will be offered and opportunities for families and self-advocates to network. M4SD and SAU1 are pleased to announce Deputy Secretary Kevin Casey will meet with families and self-advocates during lunch for discussion and a question and answer session on November 6th. Family members and self-advocates are welcome to attend one or both days. (Refer to enclosed Partnership flyers for details or visit www.mentors4sd.org.)

Two Get-Togethers were held in State College, September 3rd & 4th. The first Get-Together was held the afternoon and evening of September 3rd at the Borough Building of State College. Family members attended a Partnership training of their choice, **The Supports Intensity Scale and PA Plus (SIS) or What is a Mental Retardation Waiver and How Do I Get One**. After the trainings attendees had dinner and attended a **Family Connection**. Family members and self-advocates had the opportunity to network and discuss their questions and concerns during the **Family Connection** with Mentors regarding the MR system.

The second Get-Together was held September 4th at the Borough Building of State College. The morning started with a new Partnership family training, **"How Do I Choose a Provider for the Supports I Need?"**.

Self-Advocates United as 1 (SAU1) offered trainings for self-advocates attending the two day event, **Introduction to Leadership Development, The SIS and PA Plus and Introduction to Person-Centered Thinking**. SAU1's trainings ran concurrent with the family trainings. After the trainings, attendees had lunch and met with Kevin Casey, Deputy Secretary of the Office of Developmental Programs (ODP). Deputy Secretary Casey presented an update on the system and answered questions and concerns. Families and self-advocates met with Mentors after the question and answer session with the Deputy Secretary to address individual issues.

It was exciting to see new faces along with families and self-advocates that have attended previous Get-Togethers. With a first time attendee's permission, below is an email received after the Get-Togethers:

“Thank you and your “crew” ...for the great trainings! I learned so much, not only from the presenters, but those in attendance, with the individual stories, and events in their lives. We all have one fact in common. We want the most for our loved one...and that means a lot of different things, to different people. We are all trying to get there, just not sure where, what or when.

I have many new ideas. I begin today... our next journey...school to work transition. It is going to be so nice to speak on a level playing field with those that make some of “our” major decisions for us or have been up to now. I know my backbone has been strengthened and I feel I can stand up for those things that are most important to US.

Continue your good work, and know that without you, there are lots of us that would be floundering around trying to figure out the “system” for ourselves.” M.E.M.

Family members and self-advocates, consider taking time out of your busy schedule to attend one or both days Get-Togethers. People who attended previous Get-Togethers have expressed **“It was very much worthwhile”**.

In each issue of the Mentor Memo, information is provided on specific topics regarding the MR System in PA. During the last several months, there has been plenty of confusion, misinformation and misunderstanding about the changes proposed to the two MR Waivers. I will attempt to explain in a brief overview how the two entities, CMS and DPW/ODP, ultimately work together to provide the MR Waiver services to individuals in PA.

Centers for Medicare and Medicaid Services (CMS) is part of the Department of Health and Human Services within the Federal Government. Medicaid is an enormous, complex program funded by federal tax dollars to **support people with low income, the elderly and people with disabilities**. The Home and Community Based Services Waiver program was established in 1981 to provide long-term care and support to people as an alternative to institutional placement. CMS provides approximately 50% match with PA’s 50% match for funds to support participants in the PA Home and Community Based Service (HCBS) Waiver under the Medicaid Program. The HCBS Waiver program is a state-run program. It is up to PA to decide what is included in the Waiver Application. Limits on how services are worded, what’s included in the Waiver Application, how PA will assure health, welfare and quality is PA Department of Public Welfare’s responsibility. The Key Medicaid Requirements unless otherwise approved is that PA must assure in all Medicaid programs and services: state wideness, comparability (comparable supports and services available no matter what County in PA you reside) and free choice of provider. **CMS’s responsibility is to make sure PA has over site and procedures are being followed properly.**

A signed contract exists between CMS and DPW called the Waiver Renewal Application. CMS allows PA/DPW to set up the HCBS waiver program with written assurances in the HCBS Waiver Application that all Medicaid programs and services will provide **5 Federal Assurances**. PA has to assure the Level of Care (an evaluation for the level of care is provided to applicants for whom there is a reasonable indication that services will be needed in the future and the level of care of enrolled participants is re-evaluated at least annually), making sure people are healthy and safe, a written plan is in place (Individual Support Plan-ISP), qualified providers (PA monitors providers to assure waiver requirements are followed, providers meet required licensure and certification and provider training is conducted according to policies and procedures the state implements in the approved waiver), and administrative authority. The State Medicaid Agency (DPW) retains ultimate administrative authority and responsibility for the operation of the wavier program by exercising oversight of the performance of waiver functions by other State and local/regional non-State agencies (if appropriate) and contracted entities. There is designated one State Medicaid Program with uniform requirements, waiver services must be the same throughout PA, all policies must be developed or approved by the State Medicaid Agency (DPW) and be in writing; the waiver is an agreement between DPW and CMS. Financial Accountability means state financial oversight exists to assure that claims are coded and paid in accordance with the standard rate setting method of reimbursement specified in the approved waiver. In other words ...think about when you are asking for reimbursement from your private insurance company... without the proper insurance

code, the claim is not paid by the insurance company. Basically, it is the same concept when speaking of waiver service definition codes.

So in the end...Assurances are the key to the CMS requirements for quality services and supports. Promises are made in the contract (Waiver Application) by PA Department of Public Welfare to CMS (Federal Government) stating DPW's intent on what services will be provided. CMS does not instruct DPW on what to include in the Waiver Application. PA makes an interpretation of the guidelines CMS gives PA Department of Public Welfare then negotiations take place. PA has wide latitude as to what is covered in the waiver. Additional information is available at:

HCBS Waivers Section 1915 (c):

[http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/05_HCBSWaiversSection1915\(c\).asp](http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/05_HCBSWaiversSection1915(c).asp)

National Quality Website: <http://www.communityzero.com/nqc>

It is still a very complicated process; however the information may be beneficial in understanding both PA's role and the Federal Government's role in administering the two MR Waivers.

A critical up-date on PA Waiting List regarding State Budget Cuts ... *"People are facing a crisis in the Office of Developmental Programs. Deputy Secretary Kevin Casey announced a \$6 million cut from the state Waiting List budget.*

*Although the budget had allocated funding for 1818 people, Office of Developmental Programs reduced this to 1354, denying services to 27% of the people slated to come off the waiting list. **The \$6 million dollar cut represents more than half of the total cut in the Department. This means ODP will also lose \$6 Million in Federal funding.** We questioned how this decrease in ODP funding would impact the High School initiative (those 800 High school graduates that would have eventually ended the wait.) We also shared our concerns about the thousands of elderly parents whose sons and daughters are at home without support. In addition, we must look at students with significant medical needs who are graduating from Early Periodic Screening Diagnosis and Treatment (EPSDT). There are nearly 5000 people on the PUNS Emergency Waiting List who need immediate support. Who will help them?" Thank you, Sheila Stasko, PAWL for the update.*

Another issue where numerous questions have been raised pertains to Transition from High School into the Adult MR System. Many people believe Transition planning should start at a very early age. I agree and a Person Centered Plan, which grows with your son/ daughter, is an excellent document to create. The Person Centered Plan can aid in the development of an IEP (Individualized Education Plan). A Person Centered Plan is beneficial whether supports and services are being provided, you are waiting for services and supports, or if no supports and services are needed at this time. Person Centered Planning was discussed in a previous Mentor Memo (Fall 2006). For further information on Person Centered Planning a link to the Fall 2006 Mentor Memo and the Learning Community link is posted on Mentor's web site: www.mentors4sd.org. Mentors are also available to provide you with specific information on Person Centered Planning.

For approximately 800 graduates from Special Education living with their families, last year the state budget provided funds for an individual day program. The long term goal is eliminating the MR Waiting List by serving individuals as they transition from high school into the MR System. At the present time there is not a guarantee that the budget will support this concept on an annual basis. It is a yearly process that depends on whether our voices are heard in Harrisburg advocating for funds to support the Waiting List Campaign. Until legislation is passed to eliminate the present process described above, there are steps you can take to be pro-active by the time your son/daughter graduates from high school.

Make sure you have answered "yes" to all the following questions by the time your child is 16 years of age, or preferably younger. One thing to always remember, your County may need up to five years or more for Transition Planning from High School to an Adult Program in the MR System. Even answering "yes" to the questions below will not absolutely assure supports and services will in place, but you have made an attempt to have all the proper paperwork in place for a smooth transition. Below is a list of questions you need to ask yourself:

1. Have you contacted the county MR Program/AE to register your child for services? (If you are not registered the county MR Program does not know you exist.)
2. Has your child been assigned a Supports Coordinator? (If so, then he/she is registered with the MR Program in your county.)
3. Has a PUNS Form (Priority of the Urgency of Need for Services) been completed with the Supports Coordinator assistance detailing all the supports your child may need in the next 5 years?
4. Were you able to check all the appropriate situations that apply to your child?
5. Do you know the listed category of need for your child; Emergency, Critical or Planning?
6. Do you have a copy of your child's most recent PUNS form? (If not, contact the Supports Coordinator and ask for one.)
7. Have you reviewed and updated the PUNS form annually?
8. Did you fill out a Waiver application/Service Preference Form?
9. Do you have a copy of the Waiver application? (If not, contact the Supports Coordinator for a copy).
10. If you have applied for Waiver Services for your child, do you have a copy of the letter stating whether or not your child is eligible for Waiver services? (Your child may be eligible for waiver services, but no funding exists. This is when your child is placed on the waiting list for Waiver services.)
11. Does your child have an Individual Support Plan? (ISP)
12. Have you had your annual planning meeting (ISP) with the Supports Coordinator and team to discuss the supports and services your child needs?
13. Do you have a copy of the ISP?
14. Does your child's ISP describe all the supports needed to live an everyday life successfully in the community, both paid and unpaid?
15. Do you have a copy of your child's approved ISP and budget? (Remember if a needed support or service is not part of an outcome statement in the ISP, funds will not be budgeted for the needed support/service.)

It is essential that you answered "yes" to the above questions. If not this will initiate action on your part and discussion with your child's Supports Coordinator so the proper paperwork is in place in the near future. If you have a child graduating from high school this up coming year, it is imperative you contact your County MH/MR office so all the proper paperwork is in place. If you need further information regarding any of the above questions, contact the Supports Coordinator, local County MH/MR office A/E, Office of Developmental Program's Customer Service number toll free 888-565-9435 or Mentors at 814-547-1577 or 724-813-5702. Keep in mind, Special Education is an entitlement which means everyone meeting the eligibility criteria receives Special Education Services; however the Adult MR Program is based on **eligibility criteria** and the **availability of funds** for the supports and services the individual needs along with **planning**.

Our email lists are updated on a consistent basis. At the present time, M4SD has approximately 400 + people on each email mailing list. The listserves act as an immediate resource to distribute up-to-date information regarding the current MR system, which may have an impact on individuals and families. They also provide an opportunity for people to receive accurate information, reply to information posted on the internet for public comment, receive announcements for upcoming trainings and meetings, etc. If you subscribe to the Listserv and decide you do not want to receive further information, the List serves have an "unsubscribe" link to remove your name immediately. To be added to M4SD List serve, email dleasure@mentors4sd.org or telephone Debbie (814-547-1577).

Partnership trainings continue to be scheduled throughout the Central Region and Family Connections statewide. M4SD trainings and Family Connections are posted on ***The Training Partnership Calendar*** at www.thetrainingpartnership.org and ***Mentor's Web Site*** at www.mentors4sd.org and announced via several listserves. If you wish to schedule a training in the Central Region, or would like information when trainings are scheduled in or near your county, contact Debbie (814-547-1577) or Susan (724-813-5702).

Our next series of trainings will be in Dauphin County. All listed trainings will be held at the:

Arc of Dauphin and Lebanon Counties
 2569 Walnut Street
 Harrisburg, PA 17103

Date	Training Title	Time
10/07/2008	What is a Mental Retardation Waiver and How Do I Get One?	10:30 am – 12:30 pm
10/07/2008	What is a Mental Retardation Waiver and How Do I Get One?	6:00 – 8:00 pm
10/28/2008	Developing a Good ISP	10:30 am – 12:30 pm
10/28/2008	Developing a Good ISP	6:00 – 8:00 pm
11/18/2008	How Do I Choose a Provider for the Supports I Need?	10:30 am – 12:30 pm
11/18/2008	How Do I Choose a Provider for the Supports I Need?	6:00 – 8:00 pm

Another series will be held for Columbia, Montour, Snyder and Union Counties. All events will be held at one of two locations:

Boscov's Auditorium
 1 Susquehanna Valley Mall, Suite 2
 Selinsgrove 17870

OR

St. Luke's Lutheran Church
 9 St. Luke's Way (off Lightstreet Road)
 Bloomsburg, PA 17815

Date	Training Title	Time	Location
10/8	What is a Mental Retardation Waiver and How Do I Get One?	11 am – 1 pm	Boscov's
10/8	What is a Mental Retardation Waiver and How Do I Get One?	6:30– 8:30 pm	Boscov's
10/9	What is a Mental Retardation Waiver and How Do I Get One?	11 am – 1 pm	St. Luke's
10/9	What is a Mental Retardation Waiver and How Do I Get One?	6:30– 8:30 pm	St. Luke's
10/20	What I Do Once I Have a Mental Retardation Waiver	11 am – 1 pm	Boscov's
10/20	What I Do Once I Have a Mental Retardation Waiver	6:30– 8:30 pm	Boscov's
10/21	What I Do Once I Have a Mental Retardation Waiver	11 am – 1 pm	St. Luke's
10/21	What I Do Once I Have a Mental Retardation Waiver	6:30– 8:30 pm	St. Luke's
11/19	Developing a Good ISP	11 am – 1 pm	Boscov's
11/19	Developing a Good ISP	6:30– 8:30 pm	Boscov's
11/20	Developing a Good ISP	11 am – 1 pm	St. Luke's
11/20	Developing a Good ISP	6:30– 8:30 pm	St. Luke's

For any questions, concerns, or issues you are experiencing with the MR System in PA, you may contact Mentors for Self Determination:

Debbie Leasure: email: dleasure@mentors4sd.org or telephone 814-547-1577

Susan McCloskey: email: wideopen@zoominternet.net or telephone 724-814-5702.