

Mentors for **Self Determination**

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PA TRAINING PARTNERSHIP FOR PEOPLE WITH DISABILITIES AND FAMILIES

1414 Cameron Street

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Harrisburg, PA 17103

January 2007

MENTOR MEMO

Winter Issue

“keeping individuals and families informed”

Pennsylvania’s Consolidated Waiver Renewed!!

The Federal Government, Centers for Medicare and Medicaid Services (CMS), renewed Pennsylvania’s Consolidated Waiver on December 23, 2006!!

Below is a message from Deputy Secretary Kevin Casey. The attached Center for Medicare Medicaid Services (CMS) renewal letter can be viewed at www.mentors4sd.org/links.

Attached please find a copy of the letter from CMS renewing the Consolidated Waiver. Many of you have been involved in the process of getting to this point, and I wanted to thank you very much for your assistance. This is a very nice way to start the long holiday weekend.

It is tempting to want to sit back, relax, and breathe a sigh of relief. Our job is to do the opposite. There is much work to do over the next several years to live up to the commitments we have made to CMS in this process. We will be starting this work immediately, and we will need your help as we go.

Much of the work will involve significant change to the system of supports for people with mental retardation. Change is never easy, but we are obligated to make that change, and continue the work to make this system the best system of supports for self advocates and families in the nation.

You have my personal pledge, and the pledge of OMR that we will work as hard as we can towards that goal. We ask your help and support as we proceed.

Have a great holiday season.

Kevin T. Casey

Deputy Secretary

Office of Mental Retardation

WAIVER RENEWAL UPDATE: Pennsylvania will provide statewide consistency of administering waiver services while allowing the individuals receiving mental retardation services more choice and control.

The Office of Mental Retardation will choose what duties the County/Administrative Entity (AE) will perform; such as, monitoring services and managing the Waiting List at a County level.

As of April 2006 every County/ Administrative Entity (AE) in the Pennsylvania mental retardation system signed the same agreement with the Office of Mental Retardation for waiver administration.

Statewide qualification for providers will be mandatory January 2008, and will be implemented through a rollout strategy. During the pilot year, July 2006 through 2007, counties are responsible to qualify waiver providers and must contract with any qualified provider that has signed the Medicaid Agreement with the Commonwealth of Pennsylvania if a waiver participant chooses the provider, the provider is willing to serve the participant, and the provider costs are consistent with economy, efficiency, and are adequate to provide quality of care.

The Centers for Medicare and Medicaid Services (CMS) requires that:

- Waiver service providers are qualified using consistent statewide standards
- Individuals who receive Waiver services have the opportunity to obtain services from any willing and qualified provider.
- Qualified providers have the opportunity to enroll as Waiver service providers.

Individuals and families will have the ability to make informed decisions in selecting willing and qualified providers.

Two exciting items regarding Service Definitions... The **Consolidated Waiver** now contains a service definition for **Personal Support Services, effective December 23, 2006!** This service definition expands options for people to direct their own supports. Personal Support Services are only available to individuals utilizing self directed services.

* **Personal Support Services** cannot be used in place of a **Supports Coordinator**.

Habilitation Service Definition is the same for people living in the community and people living at home.

The Office of Mental Retardation will be assisting Counties/ Administrative Entity (AE) to fully serve all underserved individuals on the **Consolidated Waiver**. In the **Consolidated waiver**, recipients are entitled to the services they need. In the **PFDS Waiver**, recipients are entitled to services up to the cap \$22,525 to meet their needs. It is a **violation** of Medicaid regulations for a person to be underserved.



Mentor's second Get-Together was held on November 1, 2006 at the Lantern Lodge Motor Inn, Myerstown, (Lebanon County). The day long Get-Together was attended by 84 people. Mentor-Self Advocates served as greeters and were responsible for sign in sheets at each training room. Partnership Trainings were offered on *Self Determination Class 1- for Self Advocates*, and *Understanding the Mental Retardation System in Pa: An Overview or Person Centered Thinking for family members*.

Sheila Stasko spoke on the Pennsylvania Waiting List Campaign and showed a compelling DVD of people and families who are waiting for services and their personal stories.

A discussion was held in the afternoon on living an everyday life and self determination with stories and slide shows. The presentations on Self Determination were given by Steven/Susan McCloskey and Dennis/Mary Ohl. Steven and Dennis' stories are posted on Mentor's web site: www.mentors4sd.org.

The day ended with a discussion and question and answer session with the Deputy Secretary, Kevin Casey and Central Region MR Supervisor, Patty McCool.

Mentors will have our 3rd Mentor Get-Together **March 22, 2007** in the Central Region at the Borough of State College, PA (See enclosed flyer, visit Mentor's web site: www.mentors4sd.org for updates or email: dleasure@mentors4sd.org for registration or additional information).

Our focus for the Get-Together will be "Self Determination" and living an Everyday life". The day begins with a Continental Breakfast and a choice of 3 Partnership Trainings; Person Centered Thinking, Understanding the Mental Retardation System: What is a Waiver and How Do I Apply? A self advocate training by and for self advocates will be offered.

The Family Connection will include a question and answer discussion with Kevin Casey, Deputy Secretary, the Office of Mental Retardation. The Family Connection will also consist of Self Advocate and Family stories on Self Determination. Several slide shows will feature Mentor Self Advocates living an Everyday Life.

The Mentor Get Together will also include snacks, and a deli luncheon.

Who are Mentors for Self Determination (M4SD)?

Mentors for Self Determination is a group of knowledgeable self advocates and family members who build networks of people throughout the Commonwealth, connecting people to organizations, community resources and the county Office of Mental Retardation. We are committed to assisting and empowering people to obtain the life they choose.

Our Mission is to provide current, accurate information to families, self-advocates, and caregivers about the Mental Retardation System in Pennsylvania.

Mentoring is helping people help themselves by listening to questions, problems, and concerns of self advocates and families, brainstorming solutions, connecting people to the appropriate resources, and following through to a resolution.

How did Mentors come about? Self advocates and family members of the Pennsylvania Waiting List Campaign were invited to sit on the PA Office of Mental Retardation, Planning Advisory Committee (PAC) to increase the representation and the voice of people with disabilities and their families.

In 1999 a small group of self advocates and family members met regularly. This group was known as Mentors. The group envisioned a grassroots movement where current, accurate information regarding the Mental Retardation System would be shared with people statewide. If real change in the system was to occur, Mentors needed additional training on the Mental Retardation System. Individual mentors learned accurate information about the Mental Retardation System and, subsequently, shared their knowledge with more self advocates and families across Pennsylvania.

In 2005 Mentors joined the Pennsylvania Training Partnership for People with Disabilities and Families, which was created to provide consistent information through trainings to people with disabilities and families statewide. **Mentors for Self Determination (M4SD)** became responsible for trainings in the Central Region with the PA Training Partnership for People with Disabilities and Families (The Partnership) and mentoring people statewide doing Family Connections.

Mentor's Family Connection is an informal information sharing, question and answer session. Unlike training, a *Family Connection* is a face-to-face session where people share their life experiences concerning the system and encourage people to network with each other. A *Family Connection* may be a community gathering or a one-on-one session.

The individualized support people receive by attending Partnership trainings and Family Connections have inspired people to raise their expectations for creative, community support. People are more effective in maneuvering through the human service system when they know their rights, the proper policies and procedures to follow and ask the right questions. This can lead to improvements in the quality of their life or their family member's everyday life.

We continue looking for additional opportunities to share accurate information with people. With their permission, Mentors will share specific issues and the Office of Mental Retardation's responses in the Mentor Memo. We know people have similar issues statewide. It is our intention that everyone will benefit by sharing this information.

M4SD is providing people with information through our M4SD Listserv. If you are not a member of our Listserv, email dleasure@mentors4sd.org to be added.



Steve, a self advocate, graduated from high school in 1997. He has been employed and paying social security taxes since graduation. In the summer of 2006, Social Security notified Steve, he should have been receiving Social Security Disability not Supplemental Security Income. He received a large check from Social Security for his back earnings since 2001.

After attending a Self Advocate Mentor/Partnership Training, which included discussion on income and savings, Steve became concerned about his personal finances. How much money was Steve allowed to have in the bank and was he in jeopardy of losing his waiver? He contacted Mentors for assistance.

Working with Mentors, Steve learned that the Department of Public Welfare (DPW) recently implemented an additional resource regard of \$6,000 for individuals receiving Waiver funding. Now the resource limit is \$8,000 instead of the previous \$2,000. With Mentor's assistance, Steve was able to decide what he could do with his additional funds.

Al's brother has Cerebral Palsy and lives with Al and his wife. His brother attends bowling classes at the Community College. The bowling is excellent physical therapy for his brother's Cerebral Palsy. We know bowling **is not an activity** covered by either Waiver. "What is the official OMR policy on what is covered by the waiver under transportation? It seems like there are some differences in interpretation about whether people can (1) only use waiver dollars to cover transportation to other paid waiver services or (2) can use waiver paid transportation to activities that are specified on their Individual Support Plan (ISP) even though the cost of those activities may not be paid for under the waiver."

OMR'S response: "*Transportation services are offered in order to enable waiver participants to gain access to waiver and other community services and resources, as long as they relate to an identified need and are included in the participant's approved Individual Support Plan (ISP).*"

Sandy's son died while living in a group home. In an effort to have her son's death recognized and to make the general public aware of the safety concerns surrounding people with disabilities, Sandy wrote

letters to many individuals. She hoped they would listen and assist her in protecting others from dangerous situations. Sandy wrote to First Lady, Laura Bush. She referred Sandy to the Department of Public Welfare, who referred her to Mentors (M4SD).

Mentors informed her of the Aging and Older Adult Services Committee's public hearing on September 12, 2006 in Harrisburg. Sandy testified at the hearing before the House of Representative's Committee, telling her son's story. She brought out points that would help legislators realize how important the Adult Protective Services Act is to people with disabilities. Sandy was able to meet with Mentors and have some closure to her son's untimely death.

Mary's son needs respite services: "How many days of overnight/temporary respite is my family member allowed to use per one fiscal year?"

OMR's response:

- ***Overnight Respite*** – 30 days of 24 hour overnight respite per individual in a period of one fiscal year, except when extended by an OMR Regional Office waiver pursuant to Family Resource Services Regulations, 55 PA code Chapter 6350.16.
- ***Temporary Respite*** – up to a recommended maximum of four times per month, but this limit may be adjusted by the administrative entity (A/E) based on individual needs."
- ***Respite - Day Camp*** – The temporary support/supervision of individuals in the absence/relief of their regular caregivers. Respite in a day camp setting is not contingent upon an emergency situation. The recommended maximum of four (4) sessions per family per month may be adjusted by County MH/MR Offices based on individual need.

The limits on Temporary Respite are stated in MR Bulletin 00-06-04 posted on the Partnership web site: www.thetrainingpartnership.org .

Alice attended the Mentor Celebration on June 14, 2006. She learned valuable information that helped her move her son from a nursing home placement after being injured in a fall at his group home.

In the nursing home her son was losing a significant number of his daily living skills and the ability to walk. Alice learned all her son's needs must be met on the consolidated waiver. Mentors worked with Alice to capture all her son's needs on the new PUNS form. Mentor's, also, assisted Alice with her research on options available to her son other than living in a nursing home. During her research she became aware, after 180 days in a nursing home; her son could lose his waiver dollars.

Alice is pleased to report that he was able to attend the Hershey Medical Center for rehabilitation, and has been discharged into the proper living situation. Alice and her son celebrated his progress by taking a trip to New York City. This was an early Christmas gift from mom.



This fall the Partnership introduced a new training: **Person Centered Thinking**. By spring 2007, the Partnership will offer training on the **Individual Support Plan (ISP)**, updated **Waiver** trainings and a **Self Advocate Training, Life after High School (Transition)**.

We have conducted over 30 trainings since July 1, 2006 for people with disabilities and their families in the Central Region, in addition to several Family Connections statewide.

Mentor Self Advocates have trained in several middle/high schools providing information on Self Determination and Sexual Abuse Awareness to transition age students. They have also trained at Self Advocate Group meetings and providers have invited Mentor Self Advocates to train individuals they support.

Mentors are available statewide to provide information and answer questions you may have. Don't hesitate to contact us. If we do not have the answer to your question or concern, we will refer you to someone who has the correct answer.

We are available to conduct Partnership Trainings in the Central Region. If you are interested in scheduling a Partnership Training in the Central Region, or a Family Connection in any county in PA, or learning more about M4SD contact us at: 814.547.1577 or 724.813.5702. Email: dleasure@mentors4sd.org.

Check our web site: www.mentors4sd.org regularly for updates on trainings offered in your area, and a complete description of all Partnership training.



PLEASE NOTE!! NEW TELEPHONE NUMBERS!!



To contact Mentors directly, please use the following NEW telephone numbers:

Debbie Leasure 814.547.1577

or

Susan McCloskey 724.813.5702.

Remember. Our website is www.mentors4sd.org. Check it regularly for updates.