

“keeping individuals and families informed”

June 2007

Mentor Memo

Issue 5

“WE CAN. WE WILL. WE MUST. END THE WAIT!”

The slogan of the PA Waiting List Campaign is being heard throughout Pennsylvania! Mentor families have been very active supporting the PA Waiting List Campaign to reduce the number of people with Mental Retardation waiting for supports and services.

The strategy of the PA Waiting List Campaign this past year has focused on sharing real life scenarios of people waiting for services with those in a position of making changes in the system. Personal visits with legislators and administration within the state continue to be an essential piece of educating people on the impact waiting for supports and services has on people’s everyday lives.

In October, 2006 a group of family members and their sons and daughters held a meeting with Budget Secretary Michael Masch, Department of Public Welfare Secretary Estelle Richman, and Office of Developmental Programs Deputy Secretary Kevin Casey. The reality of their lives was revealed and their struggles, dreams and endless love for family members described. It is believed this meeting turned the tides of understanding with our state officials.

The State Budget proposed by Governor Rendell on February 6, 2007 calls for a significant increase in funding for people with mental retardation. If this budget is supported and passed by members of the House and Senate, it would allow for more than two-thirds of those currently on the emergency category of the waiting list and everyone on the emergency waiting list for non-residential services to be served. This would represent the largest number of people served in nearly a decade.

We understand the proposed budget is in jeopardy and that funds sought may not be approved. We are very concerned about the news that the proposed budget is not being endorsed.

The Proposed Expansion is as follows:

- Group Home Residential service to 204 people
- Non-Group Home Residential services to 759 people
- Non-Residential supports for 1,593 individuals
- Day Activities for 800 graduates of Special Education Programs
- Funding to address the changing needs of people in the waiver
- 3% Cost of Living increase for Community MR Programs

In addition to the Waiting List initiative for Mental Retardation services, 100 adults with Autism would receive services. The budget also includes provisions for the development of quality systems for adults with autism and an additional line of funding for autism intervention and services.

People must continue to be involved to move the system forward. Self advocates, family members, and caregivers, it is critical you contact your Legislators today! Encourage your State Senator and Representative to make the state budget for the MR Emergency List, including the 3 % COLA increase for MR Programs, a priority and ask them to pass the budget for MR services as proposed in February. Visit www.pawaitinglistcampaign.org for up to date information.

How does the Office of Developmental Programs (formerly the Office of Mental Retardation) know the number of people in the emergency category in need of supports/services or waiting for additional supports/services on the PA Waiting List? A form called the Prioritization of Urgency of Need for Services (PUNS) was created in 1999 by Temple University. In April, 2006 your Administrative Entity/County (AE) started using an updated PUNS form. The PUNS form gives the Office of Developmental Programs (ODP) and the PA Waiting List a means of tracking needs.

The PUNS form is the gateway to supports and services in the MR System. The PUNS form is used as a planning tool for you and the system, to gather information about your needs. It is also a county reporting form to gather an accurate number of who is waiting for services, what kinds of services are needed, and when they are needed.

It is very important your Administrative Entity/ County (AE) is made aware of all your needs. The AE/County uses the information from the PUNS form to develop the County Plan and Annual Budget Request, which is sent to the Office of Developmental Programs (ODP). Keep in mind, the County Plan and Annual Budget Request is done 2 years in advance of the current year. PUNS data is the supporting information for the Office of Developmental Programs' (ODP) Budget Request which goes to the Governor and then to the General Assembly for passage.

Information from the completed PUNS form is entered into the statewide computerized data system called HCSIS (Home Community Service Information System) by your Supports Coordinator. It is your responsibility to let your Supports Coordinator know when changes in your needs occur. Remember, if you need support/services the PUNS form is necessary.

Based on your response to questions on the form, there are 3 levels of urgency of need identified in PUNS: **EMERGENCY**: you need support immediately (within the next 6 months), **CRITICAL**: you will need support within the next 2 years and **PLANNING**: you need support more than 2 but less than 5 years from now.

The Waiting List is not like a deli line where people receive a number. The AE/County matches available resources with individual needs to determine who gets supports/services and when. People in the Emergency Category will have priority, but, you may still have to wait for supports/services.

If you have questions pertaining to your PUNS form, you can contact your AE/County PUNS Point Person, Regional PUNS Point Person, ODP toll free Customer service number **888.565.9435**, or Mentors for Self Determination **814.547.1577** or **724.813.5702**.

~~~~~ Lessons for *Everyday Lives* ~~~~~

Since our January issue of the Mentor Memo, families have contacted Mentors with issues they are experiencing regarding the Mental Retardation System. We are aware people throughout the Commonwealth have similar issues. In an effort to fulfill Mentor's mission of providing current and accurate information to people about the Mental Retardation System in PA, we will share a few of their stories with you:

☞ *Cindy* received the winter issue of the Mentor Memo. After reading the individual stories in the Mentor Memo, Cindy decided to contact Mentors regarding her concerns. Cindy's son has significant disabilities and has been waiting several years for supports and services. He receives a small amount of Base Funds. How many years would Cindy's son have to wait for supports and services? Cindy was under the impression her son was on the Waiting List for supports/services. After a discussion with Mentors, she requested a current copy of her son's PUNS form, a copy of the signed Service Preference Form and the Waiver Application from the Supports Coordinator. A signed Waiver Application or a signed Service Preference Form was not in her son's file.

Her son is in dire need of support and services. He was in the Planning Category on the PUNS form. The Planning category means he will not need support for at least 2 years, but less than 5 years. Cindy requested a change of PUNS to reflect her son's emergency need for supports/services immediately, signed a Service Preference Form and Waiver Application. (The Service Preference Form simply means you are choosing supports and services in your home or community instead of an ICFMR or institution. A signed Waiver Application is necessary in order to be placed on the AE/County Waiting List for Waiver support/services.)

Cindy's son is still waiting for services; however, the county now has the proper paperwork in place. When funds become available, he could be placed on a Waiver.

By telephoning her Regional Office, Cindy was able to clarify another issue; you can receive support and services through your Medical Assistance Card, such as Early Periodic Screening and Diagnostic Treatment (EPSDT), and still be a priority to receive Waiver supports and services.

It is vital that you contact your Supports Coordinator, request a copy of your current PUNS form, Individual Support Plan (ISP), Waiver Application, etc. to determine if all the paperwork in your file is current and accurate.

☞ *Leslie's* son lives in a group home. Leslie has concerns that her son's placement may no longer be appropriate for his needs. Leslie may have to bring her son home to live with her until another residential provider is located. The AE/County informed Leslie "since she is guardian of her son, the AE/County is not required to provide in home support and services in the interim of selecting a different provider and is terminating her son's Consolidated Waiver services as of July 1st".

After speaking with Mentors, Leslie telephoned the Office of Developmental Program's Customer Service Number 888.565.9435 and the Regional Office. Leslie was informed by the Regional Office, "guardianship is not a factor in an individual's eligibility for Waiver services". Once you are on the waiver, you have the right to appeal if services are denied, reduced, suspended or terminated after the county has authorized them. Upon receipt of the 10 day

advance notice of termination, suspension or reduction of waiver services you have 10 days to file an appeal with the Bureau of Hearings and Appeals. Unless appealed, the changes in the 10 day advance notice will take effect. You have 30 days to file an appeal with the Bureau of Hearings and Appeals. If you do give notice within 10 days, your services may not be altered in any way. This does not apply to services that have not yet started.

✶ Amy had a very inclusive life and Transition Plan while attending high school. She enjoyed time with friends and participating in community activities. Amy attended an Adult Training Facility during the school year and the summer months.

Amy is in the Consolidated Waiver. The Consolidated waiver pays for her supports and services. However, after graduating from high school she was told by her AE/County there were no funds available to continue at the Adult Training Facility she attended while in high school and during the summer breaks. Amy sat at home with her parents for over a year with no supports or service. Amy's mom attended a PUNS training Mentors for Self Determination held in a neighboring county. At the training Amy's mother learned Amy's Individual Support Plan (ISP) Outcome Statement stated she was to be employed and the ISP was approved by the county.

It is clearly stated in the Medicare/Medicaid Regulations that all of an individual's needs have to be met on a Consolidated Waiver. On the Person Family Directed Support Waiver (PFDS) an individual's needs have to be met up to the cap of \$22,525.

After several telephone calls to Amy's AE/County MH/MR office and several appointments with her Supports Coordinator, Amy's life is starting to get on track.

Amy and her family are pleased they made the time to attend the Partnership training.

MENTOR'S GET TOGETHER SUMMARY MARCH 22, 2007

Mentors for Self Determination 3rd Get Together was held March 22, 2007, 9 am to 4 pm at the State College Borough Building, State College (Centre County). Fifty-one self advocates and family members attended the Get Together. The morning started with a continental breakfast and time for families and self advocates to network.

Sheila Stasko presented a thought provoking CD on people waiting for supports and services across Pennsylvania. Sheila gave a brief summary of the Governor's Budget Proposal for this year. She asked everyone to contact their local legislators encouraging them to vote for the passage of this year's budget. This budget contains substantial funding for the Mental Retardation System.

During lunch a Family Connection, "Living an Everyday Life" was presented. The history of the "Everyday Lives" booklet was discussed. The core values of an everyday life are important to everyone. Choice, Control, Relationships, Community Inclusion along with the remaining core values were discussed. Another very important aspect to people with disabilities living an everyday life is adaptations... "You can do anything with the proper adapted equipment". A slide show with a question and answer discussion followed.

After lunch, three Partnership Trainings were presented by self advocates and family members: *Introduction to Person Centered Thinking*, a training for and by self advocates, *What is a Waiver and how do I apply* and *Person Centered Thinking* were offered to families.

The day ended with a Question and Answer Discussion with Patty McCool, Central Region Office of Developmental Programs' Manager. Patty updated attendees on the name change from

the Office of Mental Retardation to the Office of Developmental Programs. She answered questions from attendees and ended the Get Together with a song from the Rolling Stones... "You can't always get what you want". This was very appropriate since the Office of Developmental Programs, reminds self advocates and families frequently "the funding is based on your needs, not your wants". Everyone had a great time! Thanks, Patty! ☺

This spring the Partnership introduced a new training for families: the *Individual Supports Plan (ISP)*, in addition to updating and separating the Partnership *Waiver* Training into two presentations: "*What is a Waiver and how do I apply*" and "*What do I do once I have a Waiver?*"

Mentors are scheduling Partnership trainings for next fiscal year. We conduct trainings for small or large groups of people. If you are aware of a group of parents, caregivers, or self advocates who are interested in learning more about the Mental Retardation System, we have several training topics available. (Visit www.mentors4sd.org for a complete list and description of self advocate and family trainings.)

Families, self advocates, caregivers and advocates...we need to help one another! Mentor's mission is to provide current and accurate information to people. We have very limited access to people outside our immediate circle of acquaintances. Unfortunately, confidentiality laws are prohibiting Mentor's access to the names of *self advocates, families, caregivers, and advocates* attempting to navigate the complex Mental Retardation System in Pennsylvania. You can make a difference.....if you are a member of an existing group, or are aware of people in your area who would like to learn more about navigating the system, contact Mentors for Self Determination. You can be the one person to make a difference in your area.

We have a wonderful story to share...

Last spring Mentors were having difficulty connecting with families in a particular area. One mother from this particular area made the 2-hour plus drive to the Mentor's Get Together in State College. She did not understand why trainings had not been offered to families in her area.

We explained our dilemma connecting with families. She assisted Mentors in connecting with approximately *eight family members* in August 2006. The family members attended an *Understanding the Mental Retardation System in PA: An Overview*. Family members attending the training requested additional trainings in the fall. In September 2006 Mentors provided training to approximately *12 family members* in the same area on... *Waivers*.

Something very powerful happened; new family members attended the four subsequent trainings, in addition to the original family members who attended our first training in August. During one Family Connection Session, *26 family members* were present and another session *18 family members* were present.

A family group has formed in this area to support one another. Many new friendships have been established.

Mentors offer Family Connections in all Counties in Pennsylvania. Perhaps you need additional information regarding a "Family Connection". We have a detailed explanation on our web site: www.mentors4sd.org/

Mentors are also available to assist people one on one with concerns, questions or issues you may be experiencing with the Mental Retardation System. If we do not have the answer, we will assist you in locating the correct information.

Again, you can make a difference for the families in your area. Call or email Mentors (dleasure@mentors4sd.org). We will help you organize Partnership Trainings in the Central Region or a Family Connection in your area. If you do not live in the Central Region, Mentors will assist you in connecting with the Partnership Training Partner in your region.

All trainings and Family Connections are free of charge and funded by the Office of Developmental Programs. Additional information regarding “*The PA Training Partnership for People with Disabilities and Families*” is located at www.thetrainingpartnership.org.

***☞ Call Debbie (814.547.1577) or Susan (724.813.5702) ☞
Please Note Mentor’s phone numbers have changed.***