

new directions

'Nothing About Me Without Me' Learning from One Another at the 'Gathering'

It really cannot be called a 'conference', although there were welcoming remarks by community leaders, displays set up in the hallway, and an inspiring keynote speaker. There was a free tote bag filled for everyone and cool refrigerator magnets to take home. And of course, there were danish and coffee. But still, it was not a 'conference.'

"...You have to have to believe in yourself. If you don't no one else will..."

- Liz Obermayer

advocate, consultant and keynote speaker at the 4th Annual 'Gathering'

It was the *4th Annual Gathering for Self-Directed Services: 'Nothing About Me Without Me,'* sponsored by The Boggs Center on Developmental Disabilities. Even with the powerful keynote address by Liz Obermayer, and a dozen or so great workshops, most of the folks who attended the gathering would tell you that the best part of the day was meeting up with other people in the corridors to talk about living a life of choice and self-direction.

In this issue of New Directions, we feature stories from two of the presentations at the gathering. The article on Medicaid (page 2), comes directly out of one of the most well attended workshops. Medicaid is a confusing but very important federal program that is now at risk. It is vital that advocates understand the role of Medicaid and how proposed changes to the program could affect people with disabilities in significant and harmful ways.

The story on Transition (page 3) comes from one of the displays at the conference, and describes a new initiative funded by the New Jersey Department of Education to help promote self advocacy for students leaving school. The project is unique in that it looks at transition from a holistic perspective, and works to help develop linkages and bridges to community resources.

In coming months, look for more stories like these from the 'gathering.' Many workshop presenters have agreed to write stories for New Directions so that those of you who could not attend the event can have the same great information as those who did.

For more information on the Gathering, call Bill Gaventa at the Boggs Center, (732) 235-9300.

...offering
information &
inspiration
to individuals with
disabilities and
their families
as they direct their
own supports and
services



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Medicaid 101:

Why Does Medicaid Matter to People with Disabilities And Their Families

What is Medicaid?

Medicaid is an often invisible source of funding for many different programs that help millions of people with disabilities and their families.

Medicaid provides government funded health insurance to children and adults who do not have much money and who have a disability. Medicaid's services, including prescription coverage and personal care services, are often more extensive than those provided by other insurers.

Medicaid also provides government funding for something called "long term services and supports." These are the services that people with disabilities often rely on throughout their lives. It used to be that long term services meant only institutional care; now it also refers to community-based care. For example, group homes are paid for, in part, with Medicaid dollars; so are many of the direct support workers who help people with disabilities live and work in the communities in which they live. New Jersey's Division of Developmental Disabilities depends on Medicaid funding to provide many of these services.

Medicaid is an "entitlement." That means if someone is found to be eligible for services, then that person must receive Medicaid services. Eligibility for people with disabilities is based on an assessment of an individual's disability as well as their financial resources. Adults with disabilities age 18 and over, for eligibility purposes, are considered a "family of one," even if they live with their families. Adults with disabilities often meet Medicaid's financial eligibility requirements because although most want to earn enough money to be self-supporting, only a small percentage are actually employed in jobs that make this possible. For those individuals who are competitively employed, however, new Medicaid rules called "work incentives" now make it possible for people with disabilities to work and still be eligible for Medicaid coverage.

Why are Medicaid waivers important?

Medicaid waivers are programs that are designed to meet certain specific needs. They provide different benefits than the traditional Medicaid program. They are called "waivers" because some of the rules that apply to Medicaid are waived, or put aside. Waivers can be good for people with disabilities because they allow states to find creative ways to meet their needs.

Home and Community Based Services (HCBS) Waivers are designed to support people in their communities. In New Jersey, this waiver is called the "Community Care Waiver." New Jersey's Division of Developmental Disabilities (DDD) has a new Community Care Waiver Program, Real Life Choices, that helps people to continue to live at home with their families.

Many states have waivers that provide family support services such as respite care for those families who are caring at home for a family member with a disability. New Jersey is currently deciding how best to include those services in its waiver program.

How is Medicaid paid for?

Medicaid is paid for by matching federal/state government funds. That means the state and the federal government split the cost of providing Medicaid benefits. If the amount of money a state spends on Medicaid goes up because, for example, more people become eligible for Medicaid, then the federal government must continue to meet its obligation of matching what the state spends. Currently, the match in New Jersey is about 50% federal funds and 50% state funds.

Things to be aware of:

The federal government is looking for ways to save money by reducing how much it spends on Medicaid. Some of

continued on back cover

PROMOTING SELF-ADVOCACY DURING THE TRANSITION PROCESS IN NEW JERSEY

by Eric S. Fox M.A.

By means of a SIG (Statewide Improvement Grant), hundreds of transition aged students (14-21) within the state of New Jersey are receiving self-advocacy training during this critical step of their lives. The New Jersey Department of Education Office of Special Programs is working through the twelve Centers for Independent Living across the state of New Jersey in executing this initiative. Independent Living Transition Specialists have been trained to enter the high schools in order to access students with disabilities and provide self-advocacy training. Students with all types of disabilities (cognitive, mental/emotional, physical, hearing, vision, and multiple) who have an IEP [Individualized Educational Plan] will be included in this program.

The aim of this project is to better prepare students with disabilities for transition from school to adult life. The program is holistic and addresses all aspects of adult life, including but are not limited to: self-advocacy, higher education, employment, transportation, assistive technologies, recreation, and residential services.

The development of linkages and bridges to community resources is the ultimate goal of the project. For each county, a comprehensive disability resource directory is being provided to all students, families and school personnel who participate. Students attend a series of modules addressing such topics as: Self-Advocacy and Transition, Accessing Community Resources, Understanding Personal Learning Styles, Establishing Positive Relationships, Achieving Personal Wellness, and Realistic Goal Setting. Students will

work at formulating their own Independent Living Plan which consists of a self-directed goals and will take active measures to carry out the plan.

Schools are being provided with additional self-advocacy and transition curricula to use at their own discretion. School personnel will also become more familiar with the community resources available to students with disabilities. The students will be asked to participate in a regional "Dare to Dream" leadership conference offered at a local college or university during which they can share their experiences and learn from one another. These students are the upcoming leaders who will inevitably become members of steering committees and future boards of directors within self advocacy agencies and organizations.

As a result of this project, the Centers for Independent Living hope to see increased participation within the community on the part of students prior to high school graduation.

This collaborative effort between the New Jersey Department of Education Office of Special Programs, New Jersey Centers for Independent Living, high school personnel, community agencies, families, and students can enhance the lives of young adults with disabilities by helping them learn to speak up for themselves and access their communities to the fullest extents possible.



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New Directions
CCS Communications
P.O. Box 384
Hopewell, NJ 08525

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Editor: Brenda Considine
CCS Communications
P.O. Box 384
Hopewell, NJ 08525

phone/fax: 609-466-0694
consid@comcast.net

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the proposals involve things called “block grants” or “caps.” Basically, what this means is that the federal/state partnership would be fundamentally changed. The federal government would give the states money for Medicaid in one lump sum, and the states would decide how to spend that money. Block grants could affect people with disabilities in some very significant and harmful ways. Once federal/state partnerships are changed, if a state’s Medicaid expenses go up, the federal government would no longer have an obligation to match what the state spends. Additional expenses would either have to be paid for by the state alone, or the state would have to cut back on who is included in its Medicaid program and/or what benefits it provides. In other words, the entitlement of Medicaid that guarantees benefits for people with few financial resources would be eliminated. There is no other program that does what Medicaid does for individuals with disabilities and the families that care for them.

For more information about Medicaid, go to The Arc of the United State’s website <http://the arc.org/>, or call The Arc at 301-565-3842.

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New Jersey Council on Developmental Disabilities
P.O. Box 700
Trenton, NJ 08625

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