

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



Volume 3, Number 5
May 2005

Looking at Quality of Services New Standards for a New System

Until now, measuring the quality of services for people with developmental disabilities has had more to do with programs than it has had to do with people.

But with the expansion of self-directed services, and a grant from the Center for Medicaid and Medicare Services (CMS) in Washington D.C., the New Jersey Division of Developmental Disabilities (DDD) is developing a new way to measure and assess the quality of services - at the core of that new assessment system are people with disabilities and their families.

“Like many states, New Jersey’s quality assessment system was driven largely by paper and pencil measures,” says

Jeanne Wurmser, Ph.D., a consultant who will help direct DDD’s new quality assurance efforts. “We looked at licensed providers, and checked charts. We inspected buildings, looked at water temperature and checked fire extinguishers. These things are important, but there is so much more. We never talked to consumers about how the services they were getting affected their lives.”

But what constitutes “quality”?

Researchers found that in states with more self-directed services, people with disabilities experience better outcomes: they are happier, meet more of their goals, maintain more connections to people in the community and, as a result, experience a higher level of health and safety. CMS, which provides federal funding for most of the nation’s services to people with developmental disabilities, wants to see States help more people create a self-directed life in community, and reduce the number of people in group care situations. To make this happen, CMS is providing grants to states - New Jersey among them - to help build an infrastructure to support system change.

*“...quality measures
must move beyond
things like the wattage of
light bulbs and the
temperature of food.*

*We need to look at
what improves quality
of life from the
perspective of the
people who use
the services...”*

continues on page 3

In Real Life

How do participants use their budgets to get the supports they need?

Just as no two fingerprints are identical, the plans created by participants in Real Life Choices reflect the uniqueness of the person. Even with identical levels of funding, the ways in which people choose to use resources vary according to their needs and preferences.

But as different as the people and their plans are, they all share a few things in common: a desire to direct their own services and supports; the ability to allow personal preferences and their own unique lifestyle determine the supports they choose, and freedom and responsibility that comes with choosing the people or agencies they want to help them.

What follows is a description of what eight different people and their families are doing with the freedom and flexibility of self-directed services through Real Life Choices

- With a budget of \$63,500 **Joan** purchases services from a DDD-funded day program. She also purchases individual supports from an agency to assist her two nights a week in personal care (bathing, hair washing, getting ready for bed.) Additionally, she purchases supports from an agency to provide a companion to eat dinner with her one night a week, either in a restaurant or in her home. One day a week she has a full day of support from an agency to do ‘fun things’ like go shopping, go to the movies or get her nails done.

- With the same level of funding, **Sean** hires a person to support him in volunteer work at the local zoo and community “Meals on Wheels” program. He hires a support person to assist him in learning personal grooming skills and basic house keeping, and another companion to take him out to movies, the gym and other ‘guy’ activities. One night a week, he uses his funds to hire a person for an overnight so his mom can go out.

- **Seth**, with \$36,500 uses his budget to create an alternative day program with the assistance of an agency where he participates in volunteer activities, physical fitness classes and art classes. He purchases 6 hours of in home respite care every Saturday night from a neighbor. He also hires a companion through an agency to teach him meal

preparation skills. Finally, he hires an agency support person to join him and drive him to dances at the local YMCA.

- With the same level of funding, **Tiffany** chooses to attend her DDD-funded day program and purchase services from an agency to attend their Saturday program. She also pays for hotel respite care services from a DDD contracted agency and hires a companion from an agency to take her to free concerts once a month at a local community center.

- With a budget of 23,500, **Suzanne** hires a companion to assist her in learning new skills by providing transportation. She has also arranged to have support for attending adult enrichment classes, such as basic computer skills, arts and crafts and social skills. She hires a companion to assist her when she volunteers at a local animal shelter, and purchases services from the Community Center in her town to provide supports and assistance when she goes swimming.

- **John**, also with a budget of \$23,500 chooses to have an agency support him once a week at work. He lives with his sister and spends the night at a neighbors house when she is out of town. He hires a companion to join him on Friday nights, when he goes out to dinner at an Italian restaurant and a movie.

- With a budget of \$14,300, **Danny** uses his funds to hire a companion to go overnight deep sea fishing, to the movies, watch sports games and simply ‘hang out’ with guys his own age. He also hires a companion to help him learn how to cook dinner for others, do laundry and shop on a budget.

- With the same level of funding, **Tracy** purchases services from an agency to assist her in learning to shop on a budget and balance her check book. She purchases other services from an agency to provide transportation to two classes at a local community college and has hired a person from a local greenhouse to teach her basic horticulture skills.



“What the individual and family set as a goal is what is important,” said Dr. Wurmser. “We know that people with disabilities do better and like it more when they have more choices. Our quality assessment system will increase the role of consumer and families. We will be looking at the opportunities people have to make choices in their own lives.”

To get started, DDD established a Quality Management Steering Committee, comprised of stakeholders in the system (consumers, families, providers, state groups.) The group will guide DDD and provide feedback. “We are involving families, consumers and the self-advocacy community at every step,” said Wurmser.

According to Wurmser, the new system will look at many aspects of a person’s life and ask the person and his/her family to evaluate satisfaction, using objective measures of health and well being, as well as subjective components. “We want to measure quality as it relates to the *person*, not a program,” said Wurmser.

DDD will be building quality assessment into all parts of the system, making it easier for families and consumers to participate. According to Dr. Wurmser, the new system will make better use of technology, with tools such as an on-line quality assessment system, a ‘consumer-friendly’ website, and a cost-efficient training program available on CD.

The new quality assessment system will be used across the DDD system, in traditional programs as well as self-directed services. “Regardless of where a person lives, they can have more choices,” says Wurmser. “It isn’t written in stone that people who live in a group home or a developmental center have to eat breakfast at the same time or get into the van together to set out for the same place. Quality assurance is not just a one time thing, it is every day.”

The First 100: A Look at the People in Real Life Choices

	Real Life Choices	DDD Waiting List
Average Age:	35.2	34
Average Age of Parent:	61	60
Support Needed		
Level 1	16%	30%
Level 2	18%	32%
Level 3	33%	26%
Level 4	33%	12%

Plans By County

County Process	Approved	Planning
Atlantic	15 plans	0
Bergen	2 plans	17 plans
Burlington	4 plans	12 plans
Camden	24 plans	3 plans
Cape May	7 plans	0
Mercer	11 plans	3 plans
Middlesex	0	11 plans
Passaic	6 plans	0
Somerset	9 plans	1 plan

PLEASE ADD ME TO THE MAILING LIST:

Name _____

Address _____

City _____

State/Zip _____

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

new directions

is produced by CCS Communications under a contract for the New Jersey Council on Developmental Disabilities.

The views and opinions do not necessarily reflect those of the editor, the Division of Developmental Disabilities or the Council, its staff or its volunteer members.

Your letters and stories are welcome. Authors of published stories will be paid \$100.

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

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

The Alliance for Full Participation *Many Voices, One Vision*

Two years ago, ten leading organizations in the field of developmental disabilities formed the **Alliance for Full Participation (AFP)**. They seek full realization of the vision of people with developmental disabilities living meaningful, productive and personally satisfying lives in the community of their choice. They are committed to the successful inclusion of people with developmental disabilities into the mainstream of American life.

The Alliance's mission is to mobilize and organize people with developmental disabilities, their families, communities, and organizations to make the promise of integration, productivity, independence and quality of life a reality in policy and practice.

This fall, AFP is sponsoring a national summit in Washington D.C. called *Summit 2005: Many Voices, One Vision*, which will be held in September. This is an opportunity for advocates to come together to dream, plan and organize around the common vision of establishing national strategic social and policy goals, and create a proactive and responsive action plan for the future.

Over twelve hundred individuals are expected to attend the Summit where they will help craft a new strategic policy and social agenda in support of full participation, and make plans to carry that agenda forward in their communities.

new directions

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

FIRST CLASS U.S.
POSTAGE
PAID
Trenton, N.J. 086
PERMIT #21