

The Service System in New Jersey *Equity, Fairness and Real Life Choices*

In January, 2005, New Directions ran an article about transition planning that worked - the story of Aailya D'Sylva Lee. The story generated a tremendous amount of interest among readers. Some were inspired and wanted to know more about transition planning and self-directed services. Others readers were angry that some people with developmental disabilities get *what* they need *when* they need it, while others do not. New Directions got many phone calls, and questions, but only one letter to the editor, which appears below.

The issue of equity and fairness in the New Jersey service system for people with developmental disabilities has been a major theme of advocacy efforts almost since the Division opened its doors. Recognizing one of the greatest inequities, over 20 years ago, the Division changed from a Division of *Mental Retardation* to a Division of *Developmental Disabilities*, more than tripling the Division's case load in one day. No new money was allocated by state government.

Historically, DDD, provided services to people with disabilities through institutional care in one of our state's Developmental Centers. It was a "take it or leave it" system, with little choice. Responding to national service trends, New Jersey began developing group homes in the 1970's, opening the door to community-based services and more consumer choice. Families began to decline institutional placement in favor of these more 'home like' options.

Respite care, the first and only 'family support services' was offered, and had a waiting list within days of the service being launched. Hours of service were limited and it was available only in certain counties. Some

Dear Editor

We read with great interest the recent article "Transition from School to Self-Directed Services." We would like to offer some comments.

On March 2, 1998, our daughter, Maria, suffered a severe traumatic brain injury in a motor vehicle-pedestrian accident. Instantly, she changed from a vibrant, healthy 12 year old to someone whom doctors said had less than a 25% chance of survival; from a young girl with dreams of law school to someone with a feeding tube and diapers.

Since that awful day, Maria has fortunately

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



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Q&A:

I read in *New Directions* about families who receive up to \$40,000 dollars to direct their own services, yet, there are thousands of families, like mine, in similar situations - some worse - who get nothing. This does not seem fair. What is being done to address this inequity and allow this program to serve all who need it, and not a select few?

'Real Life Choices' is part of an overall systems change toward 'self-directed services' on the part of DDD. It reflects a national trend toward providing supports and services that are controlled by consumers with disabilities and their families. This trend is driven, in large part, by an expressed interest on the part of people with disabilities to be more independent, make more choices about the care they receive, build natural supports around themselves and ultimately, be less dependent on a 'system' to take care of them,

Self-Determination, launched in 1997, was DDD's first effort at consumer-controlled, self-directed supports. Although the initiative was popular, many agreed that it lacked equity and fairness. Funding was based on an individual budget, developed with the help of a support broker. But without an objective way of determining an appropriate level of funding for each participant, people with similar needs and situations ended up with very different levels of funding.

'Real Life Choices' was launched in 2002, reflecting DDD's desire to maintain the self-directed nature of Self-Determination, but improve equity and fairness in the system. RLC is part of an overall 'system change.' In RLC, the abilities and needs of individuals and their families are assessed using a 'tool' designed for that purpose. Based on identified needs, and self-reported limitations, individuals are assigned to one of four different levels of funding,

ranging from \$13,000 to \$63,500. At their assigned level, they may purchase supports they chose. The response to this effort has again been positive with over 100 people now in the program and another 60 people in the planning process. Never the less, some believe that this system of assessing needs is inaccurate, imprecise and therefore, inequitable. Others have suggested that it violates federal Medicaid rules by pre-determining a level of funding. The initiative is still in the early stages of implementation, however, and these issues have not been explored by the courts.

One major difference between Self-Determination and RLC is that RLC does not assume that housing costs will be paid through the individual's budget. RLC funds the supports needed for someone to *remain with their family*, not move out on their own. Some advocates have argued that this amounts to expanded family support.

RLC also allows people to fund self-directed 'day services', which Self-Determination did not, giving participants more flexibility.

Access to Real Life Choices is based on several factors. First, one must live in one of the counties in which the program is being implemented. By June, 2008, DDD plans to offer this option on a statewide basis, but until such time, it is limited to certain counties. There is a 'roll out plan' that describes DDD's plan for statewide implementation. Secondly,

one must be on the DDD waiting list for community residential services and be considered a priority level one.

That is where another issue of equity and fairness is raised. The waiting list for community residential services is in the thousands, with over 3,000 people considered 'priority.' While many are not in a position to accept community services were they to be offered, others are eagerly waiting and in dire situations. Over the years, there have been many initiatives and efforts aimed at reducing the waiting list, but short of a massive commitment by state and federal government, there is little hope that the waiting list will be eliminated. Nearly every other state in the nation is in a similar situation.

Roughly 6 years ago, DDD initiated a plan to eliminate the waiting list by 2010. A major push by the families, consumers and providers who participated in developing this plan was not only to eliminate the waiting list, but also to improve access, fairness and equity in the system. It was recognized that DDD's was still a system of "haves" and "have nots."

The Division has developed rules and regulations to define how the waiting list's priorities are determined. There are a number of factors, including age of parent. Some have suggested that these criteria are arbitrary and not truly indicative of the family situation. In

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Editor's Note: This is one of many questions *New Directions* has received. Other questions will be featured in subsequent issues. Representatives from the Division of Developmental Disabilities were invited to respond directly, but declined the opportunity, instead suggesting readers turn to www.fscnj.org/rlc for answers. Therefore, the responses are those of the editor.

"...society needs to question why only a few are being served..."

- Frank & Alycea Tetto

come a long way. She is now home and attending high school, and has become a vibrant, cheerful young woman—who still needs 24/7 care and will never be independent. However, the final cost of that day is not measured in lost hopes and dreams, but in the failure of our society to provide an equitable quality of life for all its' citizens.

For the past 7 years, Maria has been struggling, along with us, to obtain the necessary services and supports needed to get her out and keep her out of the institution-like settings where she lived for 23 months following the accident. We have been repeatedly ignored, misdirected and lied to, both by commission and omission, by the very governmental agencies and their representatives who are supposed to help us.

While we applaud those who are fortunate enough to have received an entrée into the "Self-Determination" and "Real Life Choices" programs, society needs to question why only those few are being served a gourmet smorgasbord and the rest of DDD's clients get crumbs.

Why, from the onset of Maria's injury, did we have to struggle through a morass of denied services, delayed supports and incompetent case managers who sparingly shared information, who told us services and supports were not available and who lied to us about eligibility criteria, when all the while others were receiving the very services we were told didn't exist.

The article talks about how the D'Sylvas got involved in Self Determination in 1998 when they were "at a breaking point" and "We would have had to place her." At that very same time, Maria WAS in an institution and we couldn't even get respite services to bring her home for weekends.

We find ourselves hurting for all families stuck in the DDD system with little or no hope for making a "Transition from School to Self-Directed Services". And frankly, we find it offensive that there is a newsletter for "offering information and inspiration to individuals with disabilities and their families as they direct their own supports and services" while the rest of us get table scraps.

DDD needs to reevaluate its' priorities. Throwing banquets for a few is not going to feed the remaining 20,000 clients who are starving for services. "Transition Planning" for the less than 1.5% in "Self-Determination" and "Real Life Choices" means having the funding and resources to ensure quality of life. For the rest of us, it means determining at what point our health, our money and our lives are going to run out and our loved ones' quality of life will end.

Sincerely,

Frank & Alycea Tetto

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Equity

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families, such as those with children who had very challenging behavior and autism, had little or no services, while families of children with other disabilities had more access.

In the last two decades, most of the new initiatives and service expansion efforts initiated by the Division have been aimed at expanding service availability, and addressing inequities and unfairness. This means not only creating new services, systems and programs, but also dismantling outdated systems so that limited resources can be reallocated.

This issue of New Directions is dedicated to opening to doors to the discussion about the future of the service delivery system in our state. Readers are invited to respond.

Q&A

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order to be considered a priority one, and therefore be able to take advantage of Real Life Choices and other community residential services, some families have gone to court to change their priority level.

Regardless of how many people need services, or the extent of that need, it is against the law for DDD to spend more money than the legislature allocates. Historically, that level of funding has dictated service expansion and availability.

Spring is the state 'budget season,' and is a good time to get involved in this process to once again bring to the attention of the New Jersey legislature the pressing needs of people with disabilities and their families. For more information on how to get involved in advocacy efforts, contact the NJCDD at 609-292-3745.

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