new directions

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

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Real Life Choices:
"Just What We Were Waiting For"

Regina Tegeler will tell you that she and her husband, John, did 'ok' for many years: "Somehow, we got by."

Like a lot of families, we put Matt on the waiting list, but to be honest, we were not really sure what we were waiting for...."

Their 23 year old son, Matt, who has mental retardation and other disabilities, has been in the Division of Developmental Disabilities' (DDD) system 'almost since he was born.' Very early on, Matt's pediatrician advised Regina to call DDD, which she did, and from the time Matt was six, the family received family support services in the form of 20 hours of respite care a month. With no extended family in the area, the Tegelers also used friends and neighbors to help out. As Matt got older, his twin sister, Katie, would help by caring for Matt while Regina and John worked.

But in 2002 when Matt graduated from the Midland School, a private school for students with disabilities in Somerset County, things changed. Katie left for college and without support from family or the school, the responsibilities for caring for Matt became much greater. "Things got very complicated," recalls Regina. "Matt needed more supervision and support, but when young people come of school and enter the adult system, there is non available." Matt spent more and more time at home. John helped when he could, but was often away on work-related travel. Regina, who was experiencing health problems, left her job. " Suddenly, I was doing everything," said Regina. "We had no back up; no cushion."

At that time, Matt had been on DDD's residential waiting list for years. "Like a lot of families, we put our son on the waiting list, but to be honest, we weren't really sure what we were waiting *for*," admits Regina. "We had considered a group home, but that wasn't right for us. *This* is his home. He wanted to stay here and we wanted him here."

Regina heard about Real Life Choices (RLC) while participating on her Regional Family Support Council. "When I heard that DDD was providing funding for people to live at home and choose their own supports, I knew that *this* was what I had been waiting for."

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Just What They Were Waiting For

(continued from the cover)

Through RLC, Matt has supports for independent social activities. He participates in a local therapeutic recreation program where he takes cooking and exercise classes. Using RLC funds, the Tegelers were able to hire staff through Alternatives, Inc., who have become a consistent part of Matt's life. Twice a week, either Ruth or Angela takes Matt shopping, to the mall or to the movies. Every Saturday, Matt goes to the bowling alley where he is part of a Special Olympics team. "I like to bowl strikes," Matt says. "On Saturday, Ruth will take me bowling."

Funded through his RLC plan, Matt also spends time away from home at United Cerebral Palsy Association's hotel respite program, and the Midland School's Alumni Getaway weekends. "It amazes me how he always learns something new when he is away," says Regina. She recalls how Matt came home from one respite weekend and surprised her. "He walked over to the phone and said, 'I'm calling my friend to tell him about my vacation, mom…' He had never used the phone before, but there he was, calling his buddy about his weekend."

Regina continues, "You think you are doing the best job you can with your kids, but when he came from his weekend and picked up the phone, I realized how much he learns from other people. He learns so much by having others come into his life. This program has given Matt an active, busy life."

The Tegelers are not doing this alone. They are supported by the Boggs Center where they attend regular networking meetings with other RLC families to share ideas and strategies. "This is not a problem-free process," Regina admits. "Along the way there have been paperwork difficulties, but so far, we have been able to work things out."

Matt also attends the Midland School's 'Job Shop,' where he works in both center-based and community-based jobs. Several times a week, Matt goes into the community, where he performs different jobs, depending on what is needed. For example, at Shoprite, he bags groceries and works in the floral department; at MetLife, he works in the employees' cafeteria; and, at Somerfield Suites, a hotel chain, he works in the laundry. According to Regina, Matt like working in different places every day, and needs the high level of supervision provided on-site by the Midland's job coaches.

The biggest change that RLC has brought for Matt is the ability to speak his own mind… He now takes great pride in doing things on his own.

But Matt's day program at Midland is not part of his RLC plan. "Right now, we pay for that ourselves," says Regina. "Next year, we are looking to make it part of his plan. He needs it."

The Tegelers want Matt to live in his own home as long as possible, but like any parent looking ahead, they worry. "As long as our health is good, this works," explains Regina. "The other key is staff. Right now, we have great people working with Matt, but if that changes, we'll need to find new staff." Regina is even considering ways to enable Matt to remain in the family home indefinitely, after she and John are gone.

For Matt, RLC has meant the ability to speak his own mind. "He is taking initiative now," says Regina. "He'll direct his own day and have a routine in mind. If suggest another way, he'll say 'no.' He now takes great pride in doing things on his own."

For Regina and John, RLC has meant knowing that Matt *can* go out without them. "He has *his* time and we have *our* time."

On most Saturdays, John likes to take Matt bowling. It's their special time together. However, this Saturday, John and Regina are going to New York to see a play. Matt will go bowling with Ruth. "Before, we had the support of RLC, we would have had to choose between what Matt wanted and what we wanted. Now, **we** all can have a life."

Q: What is DDD Doing to help youth with disabilities and their families make the transition from school to adult life ?

A: Historically, DDD placed a major emphasis on adult residential services, and did not focus on the needs of young adults leaving the special education system. Although special education laws have required transition planning and services since 1997, little has been done. For most graduates with developmental disabilities, employment supports or day programming were not in place or funded, leaving young adults at home with little or no support. DDD recognized that this lack of transition planning created crisis, and advanced the need for residential services.

Recently, DDD initiated a major systems change. Responding to the preferences of families and people with disabilities, the Division began shifting away from traditional services (e.g. group homes, sheltered day programs) and toward the development of a wider array of self-directed, community-based supports and services. In a self-directed system, individual budgets are determined, based on the person's level of need. The person and their families can then select and direct the services they need, based on their own preferences and priorities.

Self-direction is central to the system change. Self-direction refers to a combination of skills, knowledge and beliefs that allow a person to be more autonomous, goal-oriented and self-regulated. The skills leading to self-direction (e.g. goal-setting, problem-solving and decision-making) enable people with developmental disabilities to assume greater responsibility and take control of their own lives. Research has shown that self-direction in high school is related to positive outcomes in adult life, regardless of the person's disability or the severity of that disability.

As part of this systems change effort, DDD has begun to focus on the transition needs of students, working more closely with schools, families and young adults to develop an individualized transition planning process.
DDD established a new position, Director of Transition Services, to oversee this important area.

A key component of this effort is to survey DDD-eligible students *before* they leave school to determine what they need and offer opportunities to help them explore options. In addition, DDD offers a series of education outreach seminars to help families and youth make informed decisions.

For more information, or to schedule an outreach event for your parents' group, contact Lorraine D'Sylva-Lee, Director of Transition at 1-800-372-6510 or e-mail her at ldsylvaless@family supportnj.com

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Family Support and Self-Direction: How to Make the Mix Work

Most people with significant disabilities live at home with their families. At times, this can lead to tensions between the needs and preferences of the individual and those of the person with the disability.

Dr. John Agosta, Vice President of Human Services Research Institute in Portland Oregon will be in New Jersey later this spring discussing the emerging issues surrounding family support and self-directed supports, and ways in which family support, self-determination family empowerment and self- advocacy and co-exist. Dr. Agosta will explore ways of assuring a sustainable future for developmental disability systems and to empower families and individuals with developmental disabilities.

The lecture is sponsored by The Boggs Center of Developmental Disabilities, Robert Wood Johnson Medical School and is part of the Spring 2005 Developmental Disabilities Lecture Series. The event is free of charge, however, pre-registration is required.

Friday, April 22, 2005
9:00 - 12:30
Woodbridge Hilton, Iselin NJ

For more information on this event or any of the other lectures in the series, please contact Wendy Kuziemski at 732--235-9325, or visit the Boggs Center web site at www.rwjms.umdnj.edu/boggscenter.

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