



# Choosing the Right Adult Life Services for Your Child

by Maryann B. Hunsberger

**B**onnie Brien began researching schools soon after the birth of her twin daughters—Rachel and Alyson Pisacreta.

Rachel had gone into respiratory and cardiac arrest immediately after the premature birth. She was left with significant developmental disabilities, including cerebral palsy and severe seizures.

Brien knew then that she would have to be a strong advocate throughout her daughter's life. That advocacy began with school and is now centered on what comes next.

Three weeks short of Rachel's third birthday, Brien enrolled Rachel at the Lakeview School in Edison, an out-of-district school for children with disabilities at that time.

---

**The Brien/Pisacreta Family—Bonnie Brien with Dan, Rachel and twin sister, Alyson Pisacreta**

“I had to fight for that. They didn’t want to enroll her in preschool for that year because she hadn’t yet hit her third birthday. I knew that the earlier a child begins therapies, the more they get out of it. So, I pursued it and they enrolled her. That’s when my role as her advocate began in earnest.”

The Lakeview School came highly recommended and Brien feels it has been the best option for Rachel, now 22.

Brien and her husband, Dan Pisacreta, did not feel that interaction with children without disabilities was a real need for Rachel as she and Alyson frequently had friends over to the house.

“We felt it was more important to place her in a school that is on the cutting edge of new techniques for therapies.”

When Rachel reached her mid-teens, Brien took proactive steps in planning her future. She spoke with parents of older children with disabilities, stayed in contact with her daughter’s DDD caseworker, attended DDD transition meetings, researched online and visited programs.

“Transition is a scary, stress-provoking time for families, so you have to learn how to handle it. Families need to discuss many things with the school social worker, such as guardianship, SSI, and which programs are available in the community.”

If the social worker doesn’t approach a family concerning transition by age 14, Brien advises that the family reach out. “They should ask for guidance.”

---

### Rachel and her mother



Three years before Rachel was due to graduate, Brien found an option that seemed to fit Rachel’s needs, and the requirements her and her husband, Dan Pisacreta, thought were necessary.

Midland Adult Services in North Branch offered a low ratio of participants to staff, close proximity to an on-duty nurse and a policy of actively engaging clients in the community.

Brien sent a letter to Rachel’s case manager and the transition team at DDD when Rachel was 18 making the case for Midland. She also attended DDD’s transition meetings.

“It’s important to let the adult day services director at DDD know who you are. Do this in letters and in person if possible. It’s important to attend the meetings to learn about the routes you can take—traditional or self-directed.

“It’s even more important to let them know exactly who your child is. It’s about finding the best program for the individual.

Brien said that Rachel visited the Midland program three times, twice with her school social worker and once with Brien and Pisacreta.

“We wanted to be sure that Rachel liked the program, and we wanted her to feel comfortable there. She has limited verbal abilities, but when we would ask her she would get excited, smile and say yes.”

Brien explained that Real Life Choices—the state’s more self-directed option for adult services—was not the best fit for the family’s situation.

“I didn’t choose Real Life Choices for a couple reasons. I worried about the possibility of the personal care assistant becoming sick or having an emergency. The Midland program is there every day, so I know when she will leave and be home each day, and it allows me to work and go to doctors’ appointments.

“Also, the Real Life Choices budget wasn’t big enough to do what we needed to do for Rachel, and the program required a lot of management on the part of the parent. It’s almost a full-time job to be the administrator of a program for your child. It’s up to the parent to orchestrate finding the personal care assistant, contacting programs where the individual will go on various days, working with a fiscal intermediary and more. Since I work and already oversee much of Rachel’s life, I couldn’t take on any more.”

Although Midland brings contract jobs to the center, even their most involved clients sample many types of jobs in various community settings on a 13-week job cycle. Rachel is now working with Meals on Wheels one day a week. One day a week, she bags and stocks shelves at a local ShopRite.

“The director, Jane Wilkie, is very devoted,” said Brien. “Her focus is to get them out into the community, and if possible, working independently or with a job coach.”

Finally, Brien had to tackle the thorny issue facing so many people with developmental disabilities and their families—transportation.

“I had heard nightmares about people not being able to get reliable transportation. I made calls to paratransit companies in ours and surrounding counties. I found out it was impossible to get her out-of-county. Even our own county paratransit said they had no room for someone in a wheelchair.

“I finally wrote to one of the Somerset County freeholders and the director of Somerset County Transportation. I told them I was a 27-year resident of the county and I needed someone who could tell me what families like mine are supposed to do. The



**Rachel and her job coach Edith, work together at ShopRite.**

director called the next day and said they had a ‘found’ a spot on the bus.”

Brien and her husband hope to see Rachel transition into a group home or supervised apartment in the near future. Again, Brien is researching and planning her advocacy strategy.

“We want to handle this before we get too old and a crisis situation occurs. Advocacy for children with disabilities never stops.” **P&F**

## RESOURCES FOR TRANSITION

**Great Expectations: Preparing Your Child with Developmental Disabilities for Employment Success**  
[www.heldrich.rutgers.edu/uploadedFiles/publications](http://www.heldrich.rutgers.edu/uploadedFiles/publications)

**Adult Day Services at DDD:** [www.state.nj.us/humanservices/ddd/dayprogram.htm](http://www.state.nj.us/humanservices/ddd/dayprogram.htm)

**Regional Family Support Planning Councils:** [www.njcdd.org/familysupport/familysupporthome.htm](http://www.njcdd.org/familysupport/familysupporthome.htm)

**DDD Transition to Adult Life:** [www.state.nj.us/humanservices/ddd/transition.htm](http://www.state.nj.us/humanservices/ddd/transition.htm)

**DDD Life After 21:** [www.nj.gov/humanservices/ddd/la21.htm](http://www.nj.gov/humanservices/ddd/la21.htm)

**New Jersey Paratransit:** [www.njtransit.com/as\\_paratransit.shtml](http://www.njtransit.com/as_paratransit.shtml)

**Transition to Adult Life Resources:** [www.spannj.org/transition](http://www.spannj.org/transition)

# using public transportation



## Advice from Self Advocates

by Maryann B. Hunsberger

**T**wenty-two years ago, when Dave Tag was 17 and still living at home with his family, he started using public transportation.

“My mother taught me how to flag down a bus, how to explain to the driver where I needed to go, and where to get off. She followed me in the car when I was learning, rather than getting on the bus with me. She showed me how to stand on the sidewalk to get their attention.”

Tag lives in a supervised apartment in Lindenwold, and works for both the New Jersey Self-Advocacy Project in Trenton and for the Occupational Training Center in Berlin, and is a member of the New Jersey Council on Developmental Disabilities. He said that bus drivers were helpful to him, for the most part, in learning to use public transportation.

“I have had rare occasions where bus drivers didn’t know how to direct me to where I was going, but they are normally very helpful.”

The first thing Tag said he would tell people with disabilities who are learning to use public transportation is to get a schedule and study it.

“On the first day of using the bus, get there 20 minutes early. Make sure to have the money. If exact change is needed, have the right amount. To find out if exact change is needed, check the bus schedule.”

Barbara Coppens of Cherry Hill, who works for Disability Rights NJ in Trenton, uses public transportation to get to her job, and to the many meetings and conferences she goes to as one of the state’s most active self advocates.

(Coppens was recently selected by the NJ Council on Developmental Disabilities for its Colleen Fraser Self-Advocacy Award—see story page 15)

Coppens has used public transportation since she was 20.

Coppens echoed Dave Tag’s advice about the importance of having a schedule and said they can be found in different places.

“People can pick up a schedule when they get on their transportation, as they keep the schedules right on the buses and trains. In Trenton, the schedules are also right at the ticket counter. They can check out schedules online by Googling NJ Transit or the name of any other bus, train or airplane company. Once a person gets a schedule, they need to learn how to read the schedule, how to research online, and where they need to get off the bus or train.”

Coppens takes an express bus to Trenton each day. She picks up the bus several blocks from her apartment at 7. The bus ride takes 30 minutes. She works from 8 to 4. In the evening, she arrives home about 5.

When I work in the field it’s different. Today, for instance, I worked at Vineland Developmental Center. Sometimes, a coworker will take me on these assignments, and other times, I take public transportation. To get to the office, I always take public transportation.”

Besides taking buses, Coppens frequently uses a bicycle to go to parks, to friends’ houses and to medical appointments. She also enjoys walking, which she does when she goes shopping. She has no interest in driving and never uses Access Link.

Tag also takes public transportation to get to both of his jobs. It takes him an hour to get to Trenton and 20 minutes to get to Berlin.

Although most of his experiences have been positive, he has encountered buses that don’t show up. On those rare occasions, he calls his support staff to take him home from work. He recommends that other people with disabilities carry a cell phone in case they need to make other arrangements on the spot.

If someone is uncomfortable traveling alone, Coppens said they should start by taking a friend or relative as a companion. “It’s a good idea to bring someone along at first.”

The first thing Tag said he would tell people with disabilities who are learning to use public transportation is to get a schedule and study it.

Gary Rubin of Plainfield said that when people want to learn to use public transportation, they should ask friends to train them.

“Other people with disabilities who have experience traveling make good travel trainers. Travel training involves learning how to read bus and train schedules to figure out how to get from

point A to point B, then learning how to actually use the public transport.

“It also involves learning how to pinpoint landmarks to know where to get off. A travel trainer can also explain to a person whether any transfers to other forms of transit are necessary. Once a person learns this, they need to alert the driver to remind them of when it’s time to get off.”

Rubin too said that most of the drivers he has dealt with have been helpful, although he has encountered the rare driver who isn’t willing to help.

“Drivers are mostly helpful. Sometimes, other passengers are helpful, too. Another passenger might offer to walk with me from the bus stop to the building where they might be going if they know how to get to a building and I don’t.”

In Rubin’s opinion, public transportation has improved over the years. However, he has seen drivers pass by people in wheelchairs. “Sometimes, buses don’t come on time, or they pass by despite not being full. The buses now have lifts, but some drivers don’t seem to know how to use the lift or don’t seem to care to use it. There are some drivers who are slackers. However, I see many more good drivers than bad ones. Generally, there is more good than bad with using public transportation.”

Rubin uses public transportation to get to various advocacy group meetings throughout the state. These meetings often take place in Trenton and New Brunswick. He uses both buses and trains to get to these meetings, sometimes transferring from one method of transportation to

another on the same trip. He said that an average trip to one of these meetings takes an hour. Depending on where each meeting is, he first learns how to get there by public transportation.

Tag also uses public transportation to attend advocacy meetings, such as the Camden County Monday Morning Network meetings in Voorhees. He frequently takes the PATCO High Speed Line to go to Camden and Philadelphia and then transfers to the River LINE to go to Trenton for other advocacy meetings.

Another mode of travel Tag has used is Amtrak. He rode Amtrak trains from Philadelphia’s 30<sup>th</sup> Street Station to Washington, DC and back. He recommends purchasing tickets in advance when using Amtrak.

He said it’s a good idea for people in wheelchairs to ask for a Red Cap at customer service to help them. “They are attendants who help people carry their bags.”

Looking back to what it was like when learning how to use public transportation, Rubin makes a point that people might get frustrated, but they shouldn’t give up on public transportation. “Sometimes, people feel they don’t have the patience for it, but they need to keep going. If they give up mid-trip, they can be stranded somewhere. Some people can give up altogether and just sit home all the time, which isn’t good. People won’t depend on you to be on committees and to advocate if you aren’t responsible for going places on your own. We can’t let our disability control us. We have to take control.” **P&F**

## RESOURCES

To find information about any of the resources mentioned in this article, see below:

**RIVER LINE:** 1-973-275-5555, [www.riverline.com](http://www.riverline.com)

**NJ TRANSIT:** (973) 762-5100, [www.njtransit.com](http://www.njtransit.com)

**AMTRAK:** (800) 872-7245 or TDD/TTY (800) 523-6590, [www.amtrak.com](http://www.amtrak.com)

**PATCO:** 856-772-6900, [www.ridepatco.org](http://www.ridepatco.org)

**NEW JERSEY PARATRANSIT:** [www.njtransit.com/as\\_paratransit.shtml](http://www.njtransit.com/as_paratransit.shtml)

# Real Life Choices

## SELF-DIRECTED PROGRAMS TO UNDERGO CHANGES

In a Q&A with Assistant Commissioner Kenneth Ritchey, 'People & Families' asks about changes to 'Real Life Choices' and 'The Community Care Waiver'

### **People & Families:**

*The New Jersey Legislature expanded the rights of people receiving self-directed support services, of which RLC is one version. What does this mean for families?*

### **Department of Human Services Assistant Commissioner Ken Ritchey:**

The Medicaid waiver program that was amended and approved by the federal government has self-directed as a cornerstone for choice of services so that our families if they so desire, can choose a more self-directed option. The level of involvement depends on the interest and choices of the individual family or guardian.

### **People & Families:**

*Since the Division can no longer set a predetermined ceiling on the level of funding, how will the funding level be decided, when, and by whom?*

### **Ritchey:**

We use an assessment tool that is a version of the developmental disabilities resource tool known as a DDRT. We use that to determine the funding levels for an individual. For the time being, we will keep using this same method. We have a

subcommittee under the Olmstead work groups that has been looking at various assessment tools, and they will be making some recommendations for the future.

### **People & Families:**

*Does this change affect other self-directed programs other than Real Life Choices? If so, what types of services?*

### **Ritchey:**

Not in particular. We have three specific programs that are self-directed—Real Life Choices, Self-Determination and Self-Directed Day Services. Self-Determination started a number of years ago, is closed to admissions, and the philosophy evolved as a different program into Real Life Choices. The division closed admissions, but didn't kick anyone out. They then developed Real Life Choices.

When we amended the Medicaid community-based waiver, we included Real Life Choices as a Medicaid approved program. The federal government agreed with us. Self-Determination and Self-Directed Day Services, used to be called Real Life Choices Transitions. People had no idea what the difference was between that and Real Life Choices.

They thought if they were in Transition, they were in Real Life Choices, but they weren't.

So, we re-titled the program to Self-Determination and Self-Directed Day Services, and that is only for day services, not for residential. That program is available to any family in the state that wants to access it. This is for anyone graduating from school or needing day services. There is no waiting list for this as long as a family finds a provider. Self-directed means they incur the choice to find the provider. Otherwise, they find traditional day services. Self-Determination and Self-Directed Day Services will not be affected. Self-Determination has been a Medicaid approved program for years. Real Life Choices will have changes, as it's now an approved Medicaid program. The state cannot get reimbursed for the program. We're still working on what it will look like. It won't fundamentally change Real Life Choices, but like anything, when you bring in federal dollars, you have to follow federal guidelines. The states have to create the regulations, and the federal government must approve it. You must have consistent regs so all families are affected equally, for example.

**People & Families:**

Real Life Choices is a cash option in lieu of residential services for clients on the priority waiting list. Will this change at all?

**Ritchey:**

Not necessarily, but it will be contingent upon the movement of individuals on or off the waiting list. It's not currently that way.

**People & Families:**

Will there no longer be a separate pot of money for Real Life Choices?

**Ritchey:**

We included it as a waiver amendment, so it's officially part of the Medicaid community care

waiver. It means that if your name comes up on the waiting list, you can exercise the option to choose this program to direct your own services. When kids get out of high school, the program Self-Determination and Self-Directed Day Services is available to all. Part of the confusion is that people getting out of high school have never been able to choose Real Life Choices unless they were at the top of the waiting list. That will not change. What has been changed is that we are encouraging anyone who wants it to choose the self-directed option for day services. It could be a daytime, weekend, or evening program. They get the resources to direct what meets their needs. They can get approximately 35 hours in a week's time. It is an either/or program, self-directed or traditional. You can't take both. The idea would be that all of our citizens need to access what is appropriate. College courses could be part of their day, but DDD won't pay. They look at other funding sources first. Jobs and job coaches can be part of it, coordinated between DVR and DDD. It's for all levels of DDD-eligible clients, which is why it's called self-directed.

**People & Families:**

What will now happen when a client's turn comes up on the priority waiting list? Will they be offered Real Life Choices, will they be offered cash to set up a program, or will they be offered a choice of placement with an organization?

**Ritchey:**

They will be offered a choice. You aren't giving them cash, but the ability to direct their services to meet their needs, and the state pays for it. We don't care if you want to change your choice later. It's not a lifetime choice. You can go from self-directed to traditional or the opposite. You just can't do both simultaneously.

**People & Families:**

Will people who are lower on the priority waiting list be negatively affected by the changes?

**Ritchey:**

Because many people declined Real Life Choices to hold out for an actual placement, people further down on the list were being offered Real Life Choices. Now DDD will have a single pot of Community Care Waiver money. The same number of placements will be made in a given year, but only from the top of the list.

**People & Families:**

Will individuals in day programs be affected in any way?

**Ritchey:**

We have no waiting list at this time for day services. We've been pleased that so far, the resources have kept up with the demand. We only have so many resources and can only serve so many people under any scenario. The state can now get reimbursement from their services from the federal government. In times aplenty, the hope would have been that more money would be available, but with current budget cutting, some of those funds have been directed toward the state budget in general.

**People & Families:**

What date did changes to Real Life Choices go into effect?

**Ritchey:**

Real Life Choices being in the waiver was effective October 2008. The philosophy about opening up self-directed day services was available to last year's graduates, so around June or July of 2008.

The title change to SDDS was in 2009. We announced in our publication DD Today that the 2009 grads would receive money for day services in April 2009.

**People & Families:**

Will Real Life Choices have a new name? If so, what will it be?

**Ritchey:**

No, I don't think so at this point.

**People & Families:**

Is the priority waiting list still for people with at least one parent over age 55?

**Ritchey:**

It's still the same. Both parents.

**People & Families:**

Is it now more critical to get on the priority waiting list for services?

**Ritchey:**

If you need services, you need to ask to be put on the appropriate waiting list. It allows us to document the need even if we can't meet it initially.

**People & Families:**

What more can you tell me about the future of Real Life Choices and/or self-directed services?

**Ritchey:**

It's a challenging time for NJ because of the recession, and we are trying to move the DD system forward to try to be as responsive as we can to meet the needs of our families in the communities while not harming those already in services. The needs aren't diminishing. They are increasing. More people are eligible every month. **P&F**



## Do Educational Accommodations Work?

# Ask Michelle Ehart

by Maryann B. Hunsberger

**I**n ninth grade, because of some visual and auditory issues as a result of her disabilities—which include cerebral palsy, seizure disorder, visual tracking problems and fibromyalgia—Ehart’s school district finally began providing a quiet location for study hall and allowed for extra time to take tests in this quieter environment. It helped Ehart gain an A average.

“I can’t concentrate with background noises, so it’s hard for me to study or take notes. I was determined, though, because I realized that I didn’t have a chance athletically or musically. I knew that the only chance I had at doing well was to put all my energies into working hard.”

Ehart made the National Dean's List at Georgian Court College in Lakewood. And with some help from Congressman Rush Holt's office—which brokered a deal with the college for the non-driving Ehart to live on campus as she worked on her graduate's degree—the Hamilton resident earned her Master's in counseling psychology in 2003.

Next came the challenge facing all graduates—finding a job.

As Ehart knew, most beginning counseling jobs involve traveling from one client's house to another. Since she doesn't drive, this wasn't possible.

Ehart contacted the Division of Vocational Rehabilitation Services (DVRS), but her situation was outside their sphere of usual job placement.

“They set me up with a job coach, but I had more education than they did and they ended up asking me for advice on how to get a Master's degree.”

Finally, a different job coach put her in touch with the Division of Disability Services.

“It seemed like a place I'd enjoy working at, so I began volunteering for them, mostly doing paperwork, such as filing.”

In 2004, the Division asked her to volunteer with their Traumatic Brain Injury Fund. The fund helps individuals in New Jersey who have sustained a brain injury after birth.

As the program grew, she became a paid part-time employee. In January 2008, the Division hired her to work full time as a program assistant. In that capacity, she works with case managers, vendors and clients.

“I am a jack of all trades. I handle a little of everything. I do administrative tasks—writing letters, paying vendors, dealing with people on the phone. I like it a lot. Everyone is really nice and it is a great place to work.”

In addition to not driving, Ehart hasn't had much practice with the general public transportation systems, and so finds it difficult and intimidating. So she uses Access Link (New Jersey Transit's paratransit service) for her work

commute each day. And, so far, it's working out okay for her situation.

“In the morning, they usually pick me up early, so I arrive early. I get there at 8 and work until 4:40. It takes about 20 minutes in the morning. But I can arrive home as late as 5:30.

“It takes longer in the afternoon, because other people have to be dropped off. It's my only way to get to work and back. The 40-minute window can be problematic, as they can come 20 minutes early or 20 minutes late. Overall, though, it's a good deal.”

Ehart moved out of her family home, where she had been perfectly content, in order to get in to the Access Link coverage area.

“They live in an area where there are only fields and farms. There are not even any sidewalks. If you didn't have a car, you're stuck.”

She now lives at Project Freedom, an apartment complex designed for people with disabilities, which she heard about through work.

“All the units at Project Freedom are on the first floor. I have a living room, kitchen, walk-in closet, utility closet, bedroom and a bathroom with a walk-in shower. The rooms are a nice size.”

As with most people, living on her own has been an adjustment.

“I feel a sense of accomplishment at having an apartment, but I'm still adjusting. I also had an adjustment period when I moved to college, but I went home on weekends, which made it easier to get used to. Although having an apartment is an accomplishment, I miss my family, especially in the evenings.

“During the week, I mostly just get up, go to work and come home, so it would be nice to have them around in the evenings. I still talk to my mom on the phone every day. My dad says that she and I finish each other's sentences. My twin sister, Jennifer, and I have become a lot closer now. She moved out of the house first, when she got married. When I was growing up, I wanted to do everything my sister could do.

“I was surprised to learn how much sway people can have on legislators. I didn’t realize how large and influential the disability community is until I went to Partners. I learned good advocacy tips and that gave me more confidence and helped me on the job.”

And now we both have our own places.” Ehart still sees her parents on the weekends, which is when she does most of her shopping.

“You really do need a car to shop. I could use Access Link, but going in the car is so convenient. With Access Link, you can go to one place, but not several stores in one day. It is very time consuming, especially when you work all day and don’t have the time. I only get one day, Saturday or Sunday, where I can go do all the errands.”

When she was working part time at the Division, Ehart signed up for the New Jersey Council on Developmental Disabilities’ Partners in Policymaking (PIP) advocacy training sessions.

“I was surprised to learn how much sway people can have on legislators. I didn’t realize how large and influential the disability community is until I went to Partners. I learned good advocacy tips and that gave me more confidence and helped me on the job.

“Many times I must advocate for clients when their health insurance might be terminated. It requires doing conference calls with the client and the health insurance company to make sure their health insurance benefits don’t get cut off.”

Currently, Ehart is so busy with work that she doesn’t have the time to join an advocacy group. However, it is something she might like to do in the future. She recently attended a forum to discuss how disability influences different areas of life. She would have felt uncomfortable at the prospect before attending PIP.

“I was apprehensive about talking in front of a group of people, but I did speak, both at PIP and at the forum. We discussed education, inclusion

and employment at the forum. I enjoyed it, as it was something new and different. We discussed possible ways that people with disabilities can be hired by employers. I suggested that apprenticeships can help people with disabilities to build their resumes. If you are higher functioning, yet have no experience, you can’t get a job. I’d like to see this change.”

Having a job has increased Ehart’s confidence, which she lacked just after graduation, despite her academic achievements.

“I graduated magna cum laude as an undergraduate and with honors with my Master’s, but my biggest accomplishment is having a full-time paying job. When I began volunteering, I felt it was a foot in the door as a way to build a resume. I knew I would gain a lot, but I wasn’t sure it would turn into paying work, even though I hoped it would.

But Ehart would still like to meet more people of her age and interest.

“I don’t really know people my age who I can do fun things with, like going to the movies or nature walks. Things like that. But I’m coming out of my shell. Having a career is helping me gain confidence little by little.”

Joe Amoroso, the administrator of the Division’s Office of Information and Assistance, said it was his suggestion that Michelle start by volunteering. “Michelle has really worked her way up. She has always been a very diligent worker who is on task, but she was initially uncomfortable talking to people on the phone. That’s why we started her off doing paperwork.

Now that she has gained confidence in her abilities, she can easily talk to clients and case managers. She doesn’t need direction on the job now, as she knows which activity to do next. As an administrator, this is what you want from an employee. Between her tremendous intellect and her work ethic, she is unstoppable. We are fortunate to have her.”

Ehart’s goal for the future is to continue being an integral part of the New Jersey Division of Disability Services. “I found my niche in a very unique Division. I’m here to stay, and I want to become more and more involved in working to help people with disabilities.” **P&F**