

Waiting List Desperation

Taking Matters Into Their Own Hands

by Jonathan Jaffe

Frustration over the state's waiting list has prompted some parents and caregivers to take matters into their own hands.

Among them are Bob and Patty Rizas who bought, renovated and furnished a four-bedroom Oceanport house to create a family-run group home for their daughter, Stacey, and others who would be compatible.

"It takes lots of time, energy and effort to get the state on board," Patty Rizas said. "We worked with state architects and renovated the house to their specifications. We crossed every 'T' and dotted every 'I' and finally got state approval to place Stacey there with a full-time support staff."

Stacey Rizas, 40, spent 13 years in a Somerset County group home—dealing with an abusive housemate—before her parents bought her a home in 2006, her mother explained.

While the Rizas worked for more than a year to open their own group home, they cared for Stacey at home. In December 2007, she moved into the freshly-renovated Oceanport house.

"The house is large enough for three other women. Our only condition is that whoever the state moves in there should be compatible with our daughter," Patty Rizas said.

Stacey Rizas lived alone in the Oceanport house—except for her support staff—for a year before the state placed an older woman into the house from the Vineland Developmental Center.

Bob and Patty Rizas are now working with Lynn Evans to move her daughter, Stacy, into the house, noting the two girls are friends and have

known one another since childhood. They are now waiting for state approval, noting Stacy Evans is on the waiting list.

Lynn Evans participates in the state-approved Real Life Choices program and said she was "encouraged to be creative" in her search for solutions to Stacy's housing situation.

"So, I pieced together funding for Stacy to move into the Rizas' house using her state assistance, Social Security and a federal housing voucher," Lynn Evans said. "And I got shot down. I was told the system doesn't work that way."

Parents Dinah Fox and Nancy Delaney said they understand how discouraged parents can get when confronted with the state's waiting list bureaucracy and its rules. The mothers have become vocal advocates for parents to strike out on their own.

Delaney and Fox propose that small groups of parents—four or five families—who live near one another pool their resources to set up group homes for their loved ones. Then, the pair suggest that parents arrange their children's state and federal entitlements to help pay for the operating costs.

They believe the plan is feasible because Delaney, her late husband Robert and four other sets of parents accomplished it a decade ago when they started the "Five Friends" group home in Whippany for their adult children with disabilities.

Fox, who lives in Randolph, said she wants this option available for her 19-year-old daughter, Robyn, when she is done with school and ready to live independently. Robyn, who has cognitive disabilities, is listed as 3,692nd after being on the priority list for three years.

“My husband and I want Robyn to live in or near the community she knows with the supports it offers,” Fox said. “We want her to be close to us, to her brother and to the doctors, dentist, friends and people from our synagogue who she knows. This is the way it should be.”

Tom Baffuto, executive director of the Arc of New Jersey, said that anytime families can find a way to group together to provide housing and services for their loved ones, a place with compatible people and all of the necessary supports, his organization favors it.

“The Arc believes people with developmental disabilities are entitled to lead as normal a life as possible and to live as independently as possible. The Delaney-Fox model is a good way to do that,” Baffuto said.

But there are concerns, he notes.

Specifically, Baffuto said the issue with the Delaney-Fox initiative is that “people with the resources to buy and set up their own group home should not move ahead of people on the waiting list who don’t have that advantage.

“You shouldn’t be able to buy your way ahead on the list,” he said. “We don’t think it’s fair for people whose families can put up \$50,000 or \$60,000 apiece to move to the front of the line to receive hundreds of thousands of dollars in state services.”

Delaney and Fox continue to press ahead.

“We’ve been told that doing it our way circumvents the waiting list, a waiting list everyone acknowledges is not working,” Fox said, stressing that people without money can still be part of these homes if they put in the “sweat equity” or leverage funding from state and federal housing programs.

Last May, Fox and Delaney made their case to Gov. Jon Corzine and his policy advisers, including state Department of Human Services Assistant Commissioner Ken Ritchey, who oversees

the state Division of Developmental Disabilities, which runs the programs and services people on the waiting list are waiting for.

Delaney and Fox explained the details about family-run group homes, including cost-comparisons to developmental centers and state-run group homes.

“Family-run group homes would be less expensive, relieve some of the state’s burden, reduce the waiting list and be a more humane way to deal with our disabled loved ones,” Fox said.

She described the Governor’s reaction as “receptive” and said Corzine left the meeting with the understanding “that the rules, as they are now, need to be scrubbed to accomplish this.”

Ritchey urges families who want to purchase homes to consider all the options.

For example, he said, the cost of a house is the smaller portion of the funds necessary to support people in residential programs. There are also expenses for personal needs, staffing, transportation, day services and operation of the home that can cost up to \$160,000 per person, per year or even more in some cases.

If people want access to those DDD funds, they need to work with the state to take people from the waiting list to join the home. People can also go their own way, not pulling from the waiting list. But then would not have an agency to operate the home and would need to manage the home themselves, Ritchey said.

“The way the system works now, you must sit on this waiting list to receive any state support. Only 23 people came off the list in 2007-08,” Fox said. “At that rate, it would take 100 years to move half the people off today’s priority list. This is why parents are frustrated, disappointed and worried. It’s an outrageous wait.”

Fox said her hope is families who have young children with disabilities will begin to plan early for their future. “They should find other families in their area with whom they feel comfortable, whose children are about the same age, then save money just like they were putting together a college fund,” she said. “Only this would be a housing fund.” **P&F**

cover STORY



Tricia Gardner

Part of a Team

Working Together for the Best Education

by Maryann B. Hunsberger

Tricia Gardner has eight children, ages 3 to 17. So they are all used to large group living and working together, including Andrew, her 13 year-old who has Down syndrome.

It's the most natural thing in the world.

That's not necessarily a given in schools though. And the Gardners have had to keep pushing for Andrew's school experiences to have that same naturalness.

So that's what Tricia and her husband Pip were looking for when Andrew was 4 and going into preschool.

"We felt it would be more natural for him to be in a school that was not just for kids with disabilities. We wanted him to have classmates who didn't have disabilities, like his brothers and sisters. And we wanted him to be challenged academically," said Tricia.



Andrew Gardner loves playing the drums.

Working with Joanne McKeown, an advocate from the Statewide Parent Advocacy Network (SPAN), Tricia got the district to agree to pay for Andrew to attend a Montessori preschool.

“They have an inclusive philosophy. It was a perfect fit for him.”

As first grade approached, the district recommended a school for children with disabilities for Andrew but the Gardners were determined.

Tricia wrote to the NJ Department of Education’s Office for Special Education Programs. After meeting with a state mediator, the district agreed to work with the Gardners.

Tricia visited districts with inclusive programs she had found through parent support groups and relayed what she discovered to Andrew’s district.

They created a class for children with multiple disabilities where Andrew spent 20 to 30 percent of each day. Initially, he was the only one in the class but eventually other students were able to get extra help there for part of the day.

Andrew spent 70 to 80 percent of his time in the regular classroom with an aide who helped anyone who needed assistance.

“The aide wasn’t just for him,” said Tricia. “His academics took place there, but he received extra help in math and reading in the self-contained class. He also went there for some therapies.”

As Andrew progressed through school, it became more challenging. His parents would revisit their goals and objectives with Andrew’s IEP team.

“Since he was the first student with a significant disability to stay in district, we were putting it all together as we went along,” said Tricia.

Although Andrew was the first, he wasn’t the last. Other children with significant disabilities started attending the program set up for him. And that program thrived.

However, as with most things, Andrew’s situation and needs were evolving. Some of the new students were five years younger. The school believed he was spending too much time with younger children. And they were no longer as confident about modifying the curriculum to suit him. Because of the age disparity and the increasingly challenging curriculum, the district recommended that Andrew attend a disability-specific school for sixth grade.

We couldn’t figure out how to get around this problem, so we agreed and made the switch,” Tricia said. “We sent him to Kingsway, which is a fine school. It just wasn’t a fit for Andrew. The curriculum didn’t challenge Andrew, so he regressed academically. He told us he didn’t fit in with the other children and he missed his neighborhood friends. He was used to being at the public school, but now had limited freedom. He wasn’t used to being confined. He didn’t want to go there anymore.”

“By Thanksgiving we reconvened the IEP team to discuss the possibility of his attending public school half the week. Since we and our advocate stressed that he was unhappy and was regressing, they agreed. From January until June, he attended public school two days each week and resumed choir, working at the school store and playing drums in the school band.”

In seventh grade, Andrew resumed public school full time. His parents had suggested allowing Andrew to alternate between a regular class and a resource room, rather than self-contained class. The school wasn’t receptive at first,

Recommendations for Creating the Right Program for Your Child

Tricia Gardner recommends that parents who are seeking to create or find an appropriate placement or program for their child take the following steps.

- Visit other schools to get ideas. “Nobody offers parents this information, so it’s important to research. When I saw what was possible in various inclusion programs, I learned that nothing is impossible, so I shouldn’t be afraid to ask for things.”
 - Bring an advocate to meetings. “My advocate has been a great sounding board who provides support and knows the law. She has provided a lot of help. She always makes sure she understands my goals before each meeting, informs me of my rights, and gives me advice on how to achieve her goals. She attends all meetings with me.”
 - Use diplomacy. “It takes a lot of convincing and reminding. Diplomacy is the best way to do this, so you don’t burn bridges.
- The child’s welfare is most important, and the people who will be working with your child are the most important people in your life.”
- Remember that parents are as much of a team member as any paid school employee. “I had meetings four times a year with all the teachers, the child study team and my advocate. It was a collaborative effort, so the teachers didn’t feel dumped on.”
 - Use the Department of Education’s tools, such as mediation, when necessary. “The school has to appease those at the state level, so parents do have to be patient. But, there is a limit to that patience when the child’s education or socialization is suffering.”

preferring that she wait another year, so Gardner filed for state mediation.

“We had to fight but we prevailed. After I requested mediation though, the school did a remarkable job of getting a program together. So I dropped the request. Andrew was the first person ever with such a significant disability in their junior high school. The resource room was appropriate for his age and so were the lessons.”

Andrew is in regular classes for homeroom, home economics, science labs, gym, band, art

and lunch. He is the first student with Down syndrome in the district to ever take junior high math and so takes that class in the resource room.

The Gardners are getting ready for the transition to high school. Tricia is talking to parents of older children. She said that staff at Haddon Heights Junior High School have already started working with Andrew to help him get ready for the big move.

“His special ed teacher is fantastic,” Tricia said. **P&F**

WHERE TO GET MORE INFORMATION:

New Jersey Department of Education, Office of Special Education Programs, Roberta Whole, (609)292-0147, <http://www.nj.gov/education/specialed>

SPAN (Statewide Parent Advocacy Network), 1-800-654-SPAN, <http://www.spannj.org>

Questions and answers about mediation:
http://www.directionservice.org/cadre/vet_QAonmediation.cfm

Parental Rights in Special Education (PRISE):
<http://www.state.nj.us/education/specialed/form>

Request for enforcement of a mediation agreement:
http://www.state.nj.us/education/specialed/duel/mediation_enforcement.doc

Susan Coll-Guedes



THE TREASURE HUNT

HOW ONE FAMILY LEARNED
TO NAVIGATE
THE MEDICAL CARE SYSTEM

by Maryann B. Hunsberger

Susan Coll-Guedes and her husband Michael Guedes learned soon after Alex's birth that he had Down syndrome.

Their son spent five days in the hospital and had to be fed around the clock as it took him about 40 minutes to drink two ounces.

Alex's feeding difficulties continued. He never progressed past stage two baby food, and eventually he began refusing foods altogether and was failing to thrive.

The Coll-Guedeses had to learn fast how to navigate the complex health care system. And the lessons have kept coming.

A series of repeat hospitalizations for pneumonia, ear infections and dehydration followed Alex's initial medical problems. A hole in Alex' heart had to be repaired when he was two. He also had to keep returning to the hospital while doctors continued to search for reasons why Alex refused to eat.

"Our insurance company would only pay for the formula if he were tube fed," said Susan. "At that point, he drank from a bottle, so we had to pay for this formula, which cost \$300 each month."

As a new teacher Michael wasn't earning much. His insurance plan didn't cover prescriptions for his wife or son, so Susan worked part time as a teacher to help pay for Alex's healthcare needs.

Healthcare supplies regularly cost the family \$300 to \$800 a month. When infections hit Alex, a single prescription for antibiotics could cost \$1000.

"My whole salary went to pay for Alex's medical expenses," Susan said.

When they asked the advice of professionals it was less than helpful.

"People advised us to quit our jobs to qualify for Medicaid, get divorced to lower our income or move out of state," said Susan. "We seriously discussed these recommendations. We looked into moving to other states, but realized we needed the support of having our family close by. We thought about a divorce, but we knew we'd still be living together and living a lie. We made a decision to not live like that. We wanted to be honest and remain an intact family."

When Alex was two, Susan heard a radio ad about the NJ Catastrophic Illness in Children

Relief Fund. She was relieved to discover that the fund would reimburse them for out-of-pocket prescription expenses for that year. Two years later, she again applied, this time for durable medical equipment, grab bars, ergonomic bathroom faucets, travel expenses to out-of-state doctor visits and a wood laminate floor for Alex's bedroom to reduce dust.

"You must spend 10 percent of your income in twelve consecutive months to apply. You need a good credit card, because you have to put out all the money first. Then you apply for reimbursement at the end of the year."

Medicaid paid for Alex's medical expenses until his father obtained better insurance. Medicaid still covers co-pays, out-of-network expenses and any services that private insurance doesn't cover.

The approval process took six months but it has been a big help.

"These things take time," Susan said. "And it involves a lot of paperwork. All expenses must be verified, including every mile I drove out of state and every prescription. But it's worth it."

Susan heard from another parent that Medicaid waivers are available for children with disabilities, even if both parents work. She called DDD and applied for a community care waiver for Alex.

"We wouldn't have known about this Medicaid waiver. So parents need to get involved with parent groups, even if it's an online group. Professionals may want the best for you, but they assume you know things you don't."

Their mayor, advised Susan and Michael to write to their state senator.

“It worked,” said Susan. “Within a few weeks, things started to fall into place. We had already applied to the Catastrophic Fund and for a Medicaid waiver and were waiting for replies. Once that letter went out, people started to call us to ask how they could help. We didn’t have to quit our jobs, divorce or move, because that one letter from our senator pushed people to help us. We had no awareness that writing to a senator was such a powerful thing to do. People overlook that their legislators have power.”

Medicaid paid for Alex’s medical expenses until his father obtained better insurance. Medicaid still covers co-pays, out-of-network expenses and any services that private insurance doesn’t cover.

When Alex was 4, physicians diagnosed him as having an autistic spectrum disorder. His physicians and therapists believed the

sensory issues of autism were the cause of his food refusal. Alex now receives all his nutrients through the feeding tube.

“It costs \$900 a month for Alex’s feeding supplies,” said Susan. “The private insurance and Medicaid are working together, so it’s getting covered.”

Alex is now 8. He just learned to walk last year. Two months later, he was injured on vacation.

“He fell and broke his femur at a rest stop in Virginia. At the hospital where they did emergency surgery to put his femur back together, we learned he has brittle bone disease. He had to stop walking and go back to a wheelchair, although he uses a walker in school.”

The family took out a \$17,000 loan to purchase a stair lift and make other accessibility improvements to the home.

Alex Coll-Guedes, mom, Susan and dad, Michael, play together in Alex’s room



Susan said she has met families who have lost their homes because they didn't know about the Catastrophic Fund or the Medicaid waiver.

"It's like a treasure hunt to look for help out there."

Through an online support group, Coll-Guedes learned about private duty nursing, which began in October last year.

"Alex now receives seven days a week of nursing care. The nurse comes after school and stays for six hours, and then she comes eight hours each day on the weekend. She gets him off the bus, tube feeds him, provides medication, helps him get to the toilet, brushing his teeth. I don't know how we did it all before." **P&F**



Alex Coll-Guedes holds a baseball trophy that he received at a game.

WHERE TO APPLY FOR SERVICES:

NJ Catastrophic Illness in Children Relief Fund: 1-800-335-FUND (3863)

Division of Developmental Disabilities: 1-800-832-9173

Special Child Health Services: 609-984-0755

NJ Family Care: 1-800-701-0710

Medicaid Call Center: 1-800-356-1561

County Boards of Social Services: <http://www.state.nj.us/humanservices/dfd/dfdcwa39.html>

Make-a-Wish Foundation, (800) 722-WISH (9474), <http://www.wish.org>

To find out who your state legislators are, go to:
<http://www.njleg.state.nj.us/members/legsearch.asp>
 or call (800) 792-8630; TDD: (800) 257-7490

MONDAY MORNING NEWS

The **Monday Morning Project** is a grassroots advocacy activity sponsored by the Council. Networks throughout the state are made up of volunteer advocates with developmental and other disabilities. Each county-based network advocates for issues affecting people with disabilities, such as public access and community planning.

Each group has a facilitator or facilitators that help the Council coordinate the networks activities. People & Families spoke with some of the facilitators around the state for an update.

BERGEN COUNTY

The Bergen County Monday Morning Network has been working to get involved with the Meadowlands Xanadu, a project to develop the largest retail and entertainment complex in the United States, encompassing a new Giants' Stadium, mall and office complexes, and a hotel.

"They have their own architects, but they need input from local people with disabilities," said Network facilitator Tom Bengaff. "I've been doing letter writing to get us involved."

The complex is scheduled to open next November. According to Bengaff, one network member, Richard Pietrzak, has been talking with

the architect to arrange a walk-through before the complex is completed.

"They have to be aware of safety and liability, so everything has to be arranged ahead of time. We are hoping they will let us take pictures," said Bengaff.

The group plans to invite HIP (Heightened Independence and Progress) and DIAL, Inc., two Centers for Independent Living, to come along. They will check for any visual, auditory or mobility-related accessibility problems.

"These are tremendously large projects, so people might end up walking a mile from the parking lot to where they need to go. We have to assess the disabled parking spots and the ramp access. It has previously been quite good, but with them building everything new, we need to check this."

The network also has plans to become more involved in preparing people with disabilities for problems caused by the economic crisis. Bengaff said the network is planning some workshops around this as well.

"People with disabilities have lower incomes. There is less money for food, not to mention housing and transportation. It's going to be tough."

Finally, Bengaff noted the emergency preparedness is another issue the network is concerned about.

“We had CERT (Community Emergency Response Team), the County’s emergency management response organization, come to speak to our members,” Bengaff said.

They also plan to invite FEMA (the Federal Emergency Management Administration) and local fire companies to do workshops for area residents with disabilities.

“The Monday Morning Networks all need to start looking at things locally, because many people with disabilities are in need and we want them to be able to look to the Monday Morning Networks for guidance.”

BURLINGTON COUNTY

The Burlington County Monday Morning network continues to have monthly meetings on the second Tuesday of each month. The new Monday Morning coordinator, Barbara Lee, attended one of their meetings and met their members.

Kerry Walker, the network facilitator, attended a training on emergency relief measures and the network is going to be training EMTs, fire personnel and police on how to deal with people with disabilities in an emergency. They will work closely with the County’s center for independent living, Resources for Independent Living, on this project.

The network is planning to go McGuire Air Force Base and Fort Dix Army Base to evaluate their playgrounds for accessibility.

“They called us and asked that we do this, as they feel they might not be accessible,” Walker said. “They’d like us to evaluate and make recommendations.”

CAMDEN COUNTY

The Camden County Monday Morning Network is facilitated by Todd Emmons, who took over six months ago. Emmons has also recently been appointed as a member to the Council.

“I’m looking for a co-facilitator, as I could use another person to help me run the network. It’s hard to do it alone as I’m still learning and familiarizing myself with everything. Barbara Coppens (the previous facilitator) has been showing me how to do everything. This is my second year being on the network, so I’m still learning. I love the

group. I would do anything for the group. I love fighting for people with disabilities.”

The network has monthly meetings on the first Monday night of each month at 7 PM at the library in Voorhees. The meetings are on the third floor, and the building has an elevator.

The group recently coaxed a local restaurant to add a ramp. This had been an ongoing battle.

“Charlie Brown’s restaurant in Maple Shade finally redid the restaurant to make it accessible,” said Emmons. “We had to talk to the manager about it many times. We wrote letters to the owners, also. We finally won this and it was a big goal to achieve. I’m thrilled.”

The group is working on a project to accomplish the same goals with a local shopping center.

Eagle Plaza in Voorhees had no curb cuts. The owners weren’t cooperating, so Emmons went to the borough hall and State Assembly about it.

“Some of the stores have sliding glass doors, but others are hard to get in,” said Emmons. “They have doors that are too heavy to meet ADA requirements. We have spoken to each business owner to explain that people with disabilities can’t shop if they can’t get in the door. They haven’t been cooperative. We had to go to our State Senator’s office about this and are continuing to pursue it.”

Emmons is enthusiastic about working with the Council’s new coordinator for the Monday Morning Project, Barbara Lee and the rest of the Council’s staff and its members.

“I am very happy to be on board. We’re going to fight very hard for people with disabilities.”

HUNTERDON COUNTY

The meets at the Hunterdon County Library in Flemington on the third Tuesday of each month at 7 PM. They also will start a new lunch schedule, probably on the third Thursday of each month, so people who prefer daytime meetings can attend. At their meetings, they often write letters to legislators about various issues affecting people with disabilities.

Emily Anne Schaefer, the facilitator for Hunterdon County Monday Morning Network, said sometimes people stop in to visit their meetings

at the county library in Flemington because they want to find housing.

“We offer support and direction in that area. We also refer people to the Office of Disability Services,” she said.

At the network’s most recent meetings, which are held the 3rd Thursday of each month at 7 p.m., the group discussed President Barack Obama’s published policy plans for people with disabilities.

“It’s very comprehensive. Obama’s plans talk about advocacy, funding for children with disabilities, employment, community housing options and many exciting things.”

For more information the President’s pre-inauguration materials can be found at: <http://my.barackobama.com/page/content/awdplan>.

In addition to its regular meetings, network members are using internet tools, such as Gregory Wilson’s MySpace website where he interacts through posted blogs with other people with disabilities online.

Schaefer said the group is actively recruiting people with developmental disabilities, which is the primary focus of Council sponsored activities.

“But we also welcome all who are interested in advocacy for people with developmental and other disabilities to join us regularly or on specific advocacy projects.”

Currently the network is focusing outreach efforts at Hunterdon Developmental Center and Hagedorn Psychiatric Hospital.

“We are trying to start groups at these two facilities so we can help people there to advocate for themselves and maybe even leave if they choose to live in the community. We have a small group, but we are looking to expand. Anyone who is interested can call me at 908-996-7217.”

MORRIS COUNTY

Sonya Burroughs, the facilitator of the Morris County Monday Morning Network, was in the hospital at this writing. She called to say that the network’s meetings are held at the Morristown United Methodist Church on the third Monday of each month at 7 PM. Their next meeting will be in March and the topic will be emergency management. In the future, they plan to deal with

accessibility issues and current legislation affecting people with disabilities.

OCEAN COUNTY

Barbara Lee, the project’s statewide coordinator, presented information about two pieces of legislation before the New Jersey Legislature at the network’s January meeting.

The legislation concerns enforcement of regulations for accessible housing in new home developments and new apartment buildings, as well as support personnel who deal with persons with disabilities, such as home health aides and group home workers.

Lee also led a discussion about Assemblyman Louis Greenwald’s proposal to close five of the state’s developmental centers in five years.

Network facilitator Colleen O’dell-Multer suggested the group collaborate with the Tom’s River ADA Compliance Commission on school accessibility evaluations and accessible parking space enforcement. The group also discussed a newly-passed law that keeps parking spaces the same width but increases the access aisle to five feet wide to discourage people from parking in the aisles.

O’dell-Multer said the group will be following up on where the funds went that were raised by the increase in some parking fines three years ago.

“The increased fines were supposed to pay for community education about accessible parking and address accessible parking more extensively in new driver’s manuals. We’ll be looking into how that revenue is being used to make sure that use is appropriate.

“The group has worked for a number of years on voting and this past election those efforts could be seen paying off as there were no reports of discrimination at polling places involving people with disabilities in Ocean County.”

In March, the network will resume voter registration activities. The Ocean Network will also work with the Ocean County Commission for People with Disabilities and the Tom’s River ADA Compliance Commission to do a showcase of services for people with disabilities. They will begin planning this in March.

The group continues to have meetings on the third Monday of each month at 11 AM at St. Andrew United Methodist Church, 1528 Church Road, Tom's River, NJ. Anyone wanting more information can call Colleen O'Dell-Multer at 1-732-477-1414.

PASSAIC COUNTY

The Passaic County Monday Morning Network continues to do what they have been doing. Their monthly meetings take place at the Wayne Library. Ellen Brockmann, the network facilitator, said, "The meetings are free and the building is totally accessible."

The group is interested in working further on transportation and continues to be interested in fairness for people with disabilities. "We want to help people understand their civil rights. Without transportation, people can't go anywhere."

Regarding voting, the network found at least nine inaccessible polling places in Paterson. They were told that the county had no other buildings available for use. "Many people with disabilities had so much trouble going to the polls, even with one they declared accessible, that they vote absentee. Accessible voting is a battle that we need to continue fighting."

Most of the network members now have computers and are contacting each other by email. One member returned to school to obtain a GED and has now started junior college. "He never thought he could do it. With his Monday Morning training he will now be able to help other people with disabilities in school or eventually in an office."

The Passaic County Network plans on joining the other Monday Morning Networks at a training retreat.

SUSSEX COUNTY

The Sussex County Network meets at Capital Care in Stanhope on the third Monday of each

month from 9:45 to 11:30 AM. The network's facilitator, Jackie Engel, said the group writes many letters about issues affecting people with disabilities, such as scattered tax funding for transportation. At their meetings, they also discuss the current situation for disabled people. "We talk about which bills are in the House, what is new with housing and how the transportation situation is."

During voting season, the group focuses on voting. Since this was an election year, the group was busy registering people to vote. They have registered more than 40 people to vote. They also checked polling places for accessibility. Engel is on the Board of Elections Advisory Board for Sussex County, so people contact her whenever a polling inaccessibility situation exists.

The network members also assess accessibility at other places in the county, making note of and reporting any barriers at any public places. They make calls and write letters when they find ADA violations. "One member has had positive responses from his letters. He succeeded in getting a business to replace a mechanical door that a woman in a wheelchair was stuck in. The manager had told him they couldn't replace the door, so he contacted their corporate headquarters, who replaced the door."

The group is also planning to have various people speak to the group. They are waiting to see if their county receives an increase in funding for transportation. Public hearings were held on this matter, so the network wrote letters to be read at the public hearing. "Between slow business at the casinos and the loss of some funding from a state grant, county paratransit is only doing the minimum. The people on the outskirts of the county have had their rides cut down because of this, since it costs too much to send a bus out for one person." They will continue to work on this project in the coming months. **P&F**

FAMILY SUPPORT

STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS

WANTED

NEW JERSEY'S REGIONAL FAMILY SUPPORT PLANNING COUNCILS ARE LOOKING FOR NEW MEMBERS!

Nine regional councils were established in New Jersey by the Family Support Act of 1993(see map). Their general purpose is to assure that people with developmental disabilities and their families participate in the design of, and have access to, the needed community services, individual supports, and other forms of assistance that promote self determination, independence, productivity, and integration and inclusion in all aspects of community life.

The councils work in partnership with the state's Division of Developmental Disabilities to advise on budget and policy decisions that affect people with developmental disabilities living at home with their families. Councils sponsor events where individuals and their families can learn about the services available in the area, as well as host public forums to solicit feedback from the community. In addition, councils regularly distribute literature with important information for people with developmental disabilities and their families.

Family members of people with developmental disabilities or individuals with developmental disabilities can volunteer to serve on their regional planning council. Council members assist and advise the Division of Developmental Disabilities as to how resources can best meet the needs of families and individuals living in their region.

Councils meet regularly—usually once a month; each Council may have up to 11 members. Council members are volunteers but will be reimbursed for reasonable transportation, child care and other costs related to serving on the council.

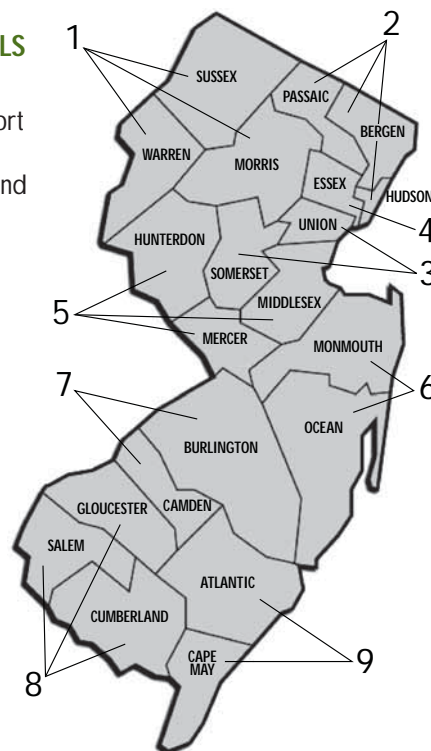
For more information call the New Jersey Council on Developmental Disabilities at 1-800-216-1199 or visit our Web site at www.njdd.org and follow the link to Family Support.

THE FAMILY SUPPORT ACT OF 1993

Establishes in the Division of Developmental Disabilities a system of Family Support designed to strengthen and promote families who provide care within the family home for a family member with a developmental disability.

The system of Family Support shall include, but not be limited to:

- after school care
- cash subsidies
- communication and interpreter services
- counseling services
- crisis intervention
- day care
- equipment and supplies
- estate and transition planning
- home and vehicle modification
- home health services
- homemaker assistance
- housing assistance
- medical and dental care not otherwise covered
- parent education and training
- personal assistance services
- recreation services
- respite care for families
- self advocacy training
- service coordination
- specialized diagnosis and evaluation
- specialized nutrition and clothing
- therapeutic or nursing services
- transportation
- vouchers



Visit the NJ Council on Developmental Disabilities' web site at: www.njccd.org ,
click on the link for Family Support, and the number corresponding to the
Regional Family Support Planning Council in your area.

1 SUSSEX, WARREN, MORRIS

RFSPC #1
PO Box 13
Pompton Plains, NJ 07444
Chair: Margaret Hefferle

Meets the third Tuesday of each month
at Morristown Memorial Hospital
100 Madison Ave.
Level B, Conference Rm. #2
Morristown, NJ 07962
7 p.m.–9 p.m.

2 BERGEN, HUDSON, PASSAIC

RFSPC#2
rfspc_region2_NJ@yahoo.com
Chair: Frank Fiore

Meets the third Monday of the month
Secaucus Public Library
P.O. Box 443
Jersey City, NJ 07302
6:30 p.m.–8:30 p.m.

3 SOMERSET, UNION

RFSPC#3
PO Box 1444
Linden, NJ 07036-1444
e-mail: rfspc3@comcast.net
Co-chairs: Bonnie Brien, Kim Szermeta

Council meets the third Tuesday of each month
Children's Specialized Hospital
The Living Room
New Providence Road
Mountainside, NJ 07092
7 p.m.–9 p.m.

4 ESSEX

RFSPC#4
P.O. Box 56
Bloomfield, NJ 07003
e-mail: rfspc4@yahoo.com
Chair: Rebekah Novemsky

Council 4 meets the first Wednesday of each month
Bloomfield Law Enforcement Building
1 Municipal Plaza
Bloomfield, NJ 07003
7:30 p.m.–9:30 p.m.

5 HUNTERDON, MIDDLESEX, MERCER

RFSPC #5
PO Box 715
Old Bridge, NJ 08857
Chair: Nellie Shoham

Meets Second Saturday of each month
10:00 a.m.–12:00 noon

6 MONMOUTH, OCEAN

RFSPC #6
P.O. Box 76
Lakewood, NJ 08701
e-mail: rfspc_NJ6@yahoo.com
Chair: Mike Brill

Meets the second Thursday of each month
Lakewood Municipal Bldg.
3rd. Street, Rm. 18
Lakewood, NJ 08701
7:30 p.m.–9:30 p.m.

7 BURLINGTON, CAMDEN

RFSPC #7
P.O. Box 641
Mt. Laurel, NJ 08054
(800) 216-1199, OPTION #1
e-mail: rfspc7@comcast.net
Chair: Debra Flagg

Meets the fourth Tuesday of each month
Mt. Laurel Library
100 Walt Whitman Ave.
Mt. Laurel, NJ 08054
7:00 p.m.–9:00 p.m. (September through June)

8 CUMBERLAND, SALEM, GLOUCESTER

RFSPC #8
P.O. Box 5721
Deptford, NJ 08096
Phone: (856) 863-6658
Chair: Nan Ivins
Vice-Chair: John Rubis

Council 8 meetings are held one
evening a month from 7:30 pm.–9:00 p.m.
Call John Rubis at (856) 863-6658 to confirm
meeting date and time.

9 ATLANTIC, CAPE MAY

RFSPC #9
P.O. Box 84
Suite 101
Somers Point, NJ 08244
Chair: Mary Ann Philippi
e-mail: MaryPhilippi119@comcast.net

Meets the third Thursday of the month
Arc of Atlantic County
6550 Delilah Rd.
Egg Harbor Township, NJ 08234
6:30 p.m.–8:00 p.m.