

Partners in Advocating, Partners in Life

by Maryann B. Hunsberger



Eric Smith and Safiyyah Muhammad of East Orange are not only partners in marriage, but also partners in advocacy. Muhammad attended Partners in Policymaking (PIP) in 2007, followed by Smith, who attended the leadership training program in 2008. The couple has five children between the ages of 6 and 21, including their son Sufyaan Muhammad, 10, who has autism.

Muhammad has been active with the State-wide Parent Advocacy Network and Autism NJ. She has developed a large network of parents, including a number of online connections.

The best source of networking that she found, however, has been PIP. “PIP taught me the importance of the power of networking. And it helped me understand policies and legislation.



Sufyaan, their son, loves the computer.

I've been doing a lot of networking; learning from others and passing that information on. Everywhere I go, I say "autism" and "disability" like the words are my first and middle name. I want people to learn more."

Smith attended PIP in 2008. He saw what his wife had gotten out of the experience and decided it was something he needed to do as well.

Smith had always concentrated more on working while his wife raised the children. A growing feeling of wanting to be more active in working with his son, Sufyaan, made him realize he needed to learn more.

"I found out that few men are involved in dealing with children with disabilities. This compelled me to take on the challenge. When I attended my wife's graduation from PIP, I knew I needed to do this. Other people needed to know about all the struggles that my son and other children with disabilities go through.

"At first, my son's issues drew me. But as I got more into it, I knew I needed to be involved for all people with disabilities." Before Partners, Smith knew very little about advocacy.

"I really didn't know how to advocate. But, at PIP's mock hearings, I learned that my voice can count. We often feel that we are just this small person nobody will listen to. But voting is very

powerful. It's important to know who your legislators are and tell them your stories.

"Even if legislators know that people with disabilities exist, they probably know very little about the issues. I learned it's powerful to take your personal case to them. To open the door. Everyone has a story to tell, and your story is just as important as the next. Maybe more."

Partners enhanced the depth of Muhammad's passion for change.

"I have always been the type of parent who has a concern for other people's children. Partners gave me more tools, more insight and more information."

Although Muhammad was never shy about reaching out to legislators, PIP taught her how to reach out in more effective ways.

"I now know how to meet and greet legislators, how to find them at the Statehouse, how to approach a legislator in Trenton when he or she is having a slice of pizza and how to follow up. PIP also taught me about the power of the media and letter writing campaigns."

Smith agreed that a key part of the training was learning how to approach legislators.

"I learned that my first contact isn't about getting an end result, but to make myself known. That's the first goal—to make my legislators aware of me and my family.

After making those initial connections, Smith said, you can get to some more specific issues.

“My specific issue was with transition out of school. Although Sufyaan’s private school prepares kids, this isn’t really happening in the public school system. Parents don’t know that there are transition services available, so children don’t get them.

“Parents may want their children to eventually be able to live without them. And I know that’s possible. But transition help is necessary for success. I wanted my legislators to recognize this, because I know they can apply pressure to the Board of Education.”

Muhammad spends a good deal of time writing letters to legislators now.

“I’m working on convincing East Orange legislators about the need for better housing. I’ve also been working on promoting employment for people with disabilities. This will benefit the city and businesses.”

Smith and Muhammad know you can’t assume that other people know about developmental disabilities. And their PIP experiences reinforced that.

“We need more understanding of disabilities in our communities,” Muhammad said. “More organizations around here need to follow the lead of the Essex County College police department’s training about developmental disabilities.”

Since attending PIP, Muhammad began working with Rhonda Singleton at the East Orange YMCA with the NJ After 3 program. She and Singleton are working to find funding sources to create an inclusive after school program that children with disabilities can attend. She is also working with an East Orange music school on developing a music program that children with disabilities can attend.

“This area does not have enough inclusive extracurricular activities for children with disabilities. I hope to see a lot happening in the next couple years. It’s just a matter of getting started, and that means funding.”

Smith recommends that parents of children with disabilities keep the channels open with their legislators. “Know their names and phone numbers. Drop by their offices. Write and call.”

Since his son is only 10, his father isn’t sure what Sufyaan will want to do with his life. Right now, he is enjoying the New Beginnings School, learning social skills, playing video games, learning to type, playing soccer and baseball—the usual.

However, Smith knows that adulthood is just around the corner. He wants to see his son have a job and his own apartment someday.

“I know it’s possible, because I’ve seen other people do it.” **P&F**

FOR FURTHER INFORMATION

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

**TO CONTACT NJ AFTER 3,
call (732) 246-7933, or Email info@njafter3.org
or go to www.njafter3.org/index.php**

**FOR MORE INFORMATION ON PARTNERS IN POLICYMAKING,
contact Advocacy Training Coordinator Dennie Todd, 609.984.4516
or email dennie.todd@njcdd.org
or go to: www.njcdd.org/PartnersInPolicymaking/advocacy.htm**

**TO CONTACT THE STATEWIDE PARENT ADVOCACY NETWORK (SPAN),
call 1-800-654-SPAN or email span@spannj.org or go to: www.spannj.org**

**TO CONTACT AUTISM NJ, call 1-800-4-AUTISM
or email information@autismnj.org or go to www.njcosac.org**

A Growing Movement



Advocating for One's Self and Others

by Kathi Wolfe

NJ Council on Developmental Disabilities Spearheads Campaign to Change Attitudes by Changing Language

The kindest word in all the world is the unkind word, unsaid—Anonymous

In October of last year, the New Jersey Council on Developmental Disabilities launched a campaign to stop the use of the word “retarded” in all its forms. The campaign was in direct response to the movie *Tropic Thunder* and the way that satire exploited the word “retard” for comic effect.

Advocates with developmental disabilities and their colleagues were outraged by the advertising campaign for the movie, which is a satire on Hollywood that focuses on a character who had previously played the part of a man with an intellectual disability in order to give himself a better chance to win acting awards. Although the movie took swipes at everyone featured, the thoughtless way it handled its references to people with developmental disabilities took the unconsulted advocacy community by surprise and ignited a nationwide backlash.

Members and staff of the Council understood that the reaction tapped into a long standing and understandable frustration about the way the old-time clinical term “mental retardation” had lost its meaning in describing people with intellectual disabili-

ties and had taken on troubling new life as slur against them.

In recent years, movies and other outlets of popular culture had turned the word “retarded”—and the even more offensive “retard”—into a widely-used “joking” putdown.

It had to stop. Words hurt, even when they are not directed at the individuals who are hurt by them.

Advocates in New Jersey and across the country have taken the momentum from the *Tropic Thunder* protests to get rid of the “R-word.” In doing so, the campaigns are also aiming to better educate the public about language, respect, good citizenship and building communities that are welcoming of all the members.

The Council’s campaign produced the popular No R-Word button and a brochure about hate speech, bullying, and the importance of language in shaping our perceptions and behaviors.

In the fall, Council staff will be available for half-hour presentations for schools and organizations. For more information check the Council’s Web site at www.njcdd.org or contact the office at NJ Council on Developmental Disabilities, (609) 292-3745, PO Box 700, Trenton, NJ 08625.

Last fall, Kelley Schreiner of Indianapolis, a 20-year-old Special Olympics athlete, went to a high school football game. As Kelley watched the home team lose, a “guy” caught her attention, she said in a telephone interview.

“He was calling the team a bunch of losers,” added Pat Schreiner, Kelley’s mother. But the man expressed his frustration with the team’s poor performance by calling them “a bunch of ‘retards,’” Kelley said. The use of this epithet

angered Kelley, but she’d come prepared.

Reaching into her pocket, she pulled out a business card and handed it to the frustrated sports fan. On the front of the card there was a logo with a fist and the phrase “Words hit like a fist.” On the back, the card said, “When you use words like “retard” or “retarded” it hurts people. I heard you and it hurts me.” (The “Words hit like a fist” logo and cards were created by disability advocate, author and blogger Dave Hingsburger.)

After reading the card, “the boy didn’t say a word” for the rest of the game, Kelley said.

Later, Kelley gave one of the “Words hit like a fist” cards to the daughter of a family friend, Pat Schreiner said.

“She gave it to her boyfriend who worked at Burger King with an intellectually challenged man whose co-worker bullied him,” Pat explained. After being given the card, he “backed off” and apologized.

Handing out the cards and “speaking out against the ‘R word’ made a big difference,” added Kelley, who is involved with Project Unify, a Special Olympics program to promote inclusion in schools.

Kelley Schreiner is one of an increasing number of people with developmental disabilities nationwide who are speaking out on issues impacting their lives—from ending the use of the “R” word to where they want to live. More than ever before, more people with intellectual disabilities are coming to see themselves not as clients whose decisions are made for them by service providers, but as self advocates who make their own choices—sometimes with the support of their families and professionals.

“I’ve been in the business of working with people with intellectual disabilities for over 40 years,” said Fred Robinson, executive director of the Arc of Ventura County in California. “There was a time when we never asked people we supported to speak for themselves. But, that’s come a long way.”

The early seeds of self-advocacy were planted during the 1970’s and 1980’s as institutions for people with developmental disabilities began to be closed across the country, Robinson said.

“Self-advocacy really began to take off during the 1990’s after the Americans with Disabilities Act (ADA) passed.”

Now there’s growing recognition that people with intellectual disabilities are their own best advocates, Robinson said,

“I can collate numbers that demonstrate the budget problems we face to legislators. But I can’t tell a personal story. Hearing a person with an intellectual disability relate a personal anecdote will

have far more impact on public opinion or policy makers than listening to a “professional.”

Self-advocacy is vitally important because “people with disabilities are the last great civil rights movement,” Robinson said. “They’re sometimes still kept in segregated settings, and they’re discriminated against simply because they’re disabled.”

Still, through laws, changing public attitudes and self advocates, “barriers are being broken down. I would like for us (professionals) to stay in the background, to not take the lead but to offer support.”

More and more people understand that the whole point of the disability rights movement has to be “people with disabilities speaking for themselves—with professionals working with them,” said Michael J. Brogioli, CEO of the National Association of Councils on Developmental Disabilities. “Most people I know get it and try to make it real.”

“You don’t need an IQ of 140 to go up to Capitol Hill,” Brogioli said. “People with intellectual disabilities are among the most powerful self advocates that I’ve ever seen.”

The Administration on Developmental Disabilities, the federal agency that oversees the country’s councils on developmental disabilities, would not comment on self-advocacy for this article. An ADD spokesperson said the Administration does not have “a permanent commissioner at this time,” and so is not able to comment on issues for publication. At press time, Faith McCormick was the agency’s acting commissioner.

“For too long policy makers and the social service system have taken a paternalistic attitude towards self advocates, leaving them out of the most fundamental decisions about how programs and projects are developed that are intended to serve them,” Dr. Alison Lozano, executive director of the New Jersey Council on Developmental Disabilities, wrote in an e-mail. “Self advocates must be equal partners in the decision making process. The role of self advocates is increasing as we all see how effective they are in their efforts.”

People with intellectual and developmental disabilities are engaging in self-advocacy on an

individual and organizational level. Nationwide, there are numerous local, state and regional self-advocacy groups.

One well-regarded self-advocacy group People First operates on the state and local level in the U.S. and Canada. Self Advocates Becoming Empowered (SABE) is an umbrella group for a number of the self-advocacy organizations in the United States. SABE divides the country into nine regions and two representatives from each region are on its board of directors.

“Self-advocacy organizations across the country have increased their numbers and participation,” SABE president Chester Finn, wrote in an e-mail, “On a national level self advocates are asking to participate by giving advice to the President and Congress on issues such as Medicaid, health care, employment, education, et cetera.”

SABE was formed in 1991. The group usually has a national conference every two years. But, “SABE doesn’t know when we’ll have our next conference due to state budgets and restrictions,” Finn wrote. “However, we’re going to have some type of celebration for our 20th year anniversary.”

There is much to celebrate in the success of their movement. Yet, self-advocacy is hard work, said the advocates and supporters of their efforts, who were interviewed by this reporter.

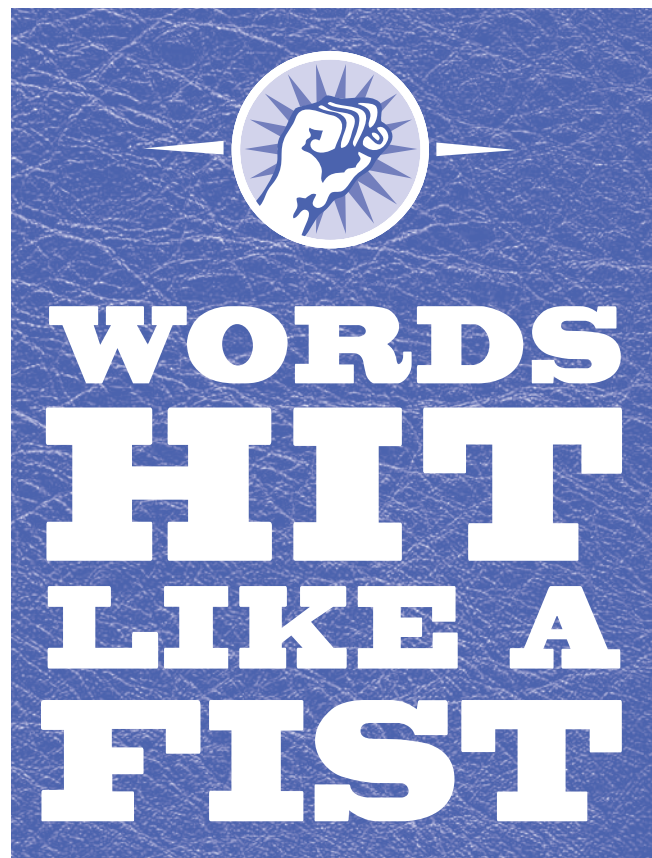
For more than three years, Nancy Mercer and Jill Egle have been co-executive directors of the Arc of Northern Virginia. Mercer has a social work background and Egle, 32, who has an intellectual disability, began her work with the Arc as an intern.

To be a good self advocate you need to be “strategic in your planning,” Mercer said. In the beginning, some self-advocacy was “a little bit angry. This put people off.”

Now, it’s moved somewhat away from angry confrontation (such as civil disobedience) toward other means of communication, she said.

Sometimes if you protest, “you can get arrested,” Egle said. “And that doesn’t look good to the community or if you try to get a job.”

Like many with intellectual disabilities, Egle was angered by the use of the word “retard” in the movie “Tropic Thunder.”



Rather than protesting in front of a movie theater though, Egle registered her anger by making a video “Can We Talk Ben Stiller.” The video—of Egle reading her letter to Stiller—has received more than 10,000 hits (on YouTube).

“Jill was eloquent,” Mercer said.

It’s important that people be paid a good wage for their work (including work in self-advocacy), Egle said. “But, let me be honest with you, you have to work up to that. When I was first hired by the Arc, I was willing to intern.”

“It’s been tough on Egle sometimes,” Mercer said. “She’s had to earn her stripes to be seen as co-executive director. There are other kinds of smart other than book smart. And Jill is very smart at reading people

Egle and Mercer work as a team. While Mercer helps Egle remain focused, Egle has taught Mercer to be more direct and more outgoing.

Both say that self-advocacy empowers people with intellectual disabilities to make decisions. “It moves us from doing to and for to doing with.”

You don't have to engage in self-advocacy on the state or national level, you can be a self-advocate any way you choose, said Julie Petty, a SABE past president and founder of People First in Arkansas.

Petty, 38, has cerebral palsy. She has been married for seven years, has two young sons and works with the Youth Training and Information Center in Springdale, Ark. The Center, one of 21 such centers across the country, provides training in self-advocacy to youth with developmental disabilities.

"I wish I'd had that when I was growing up," Petty said. "I didn't grow up with people with disabilities."

Growing up her family told Petty that she wouldn't be able to drive. "But after I got involved in self-advocacy, I wanted to try. I had a friend who said he'd help me—I had people who believed in me," she said. With their support and her own tenacity, Petty got her driver's license. "I learned a new type of independence," she said, "now I can give other self-advocates a ride."

"I've been labeled before as intellectually disabled," Petty said. "But it's just a label. Labels don't mean anything in terms of what people can do. Some people with that label go to college. We can do things other people can do." (Petty earned her B.A. in journalism from the University of Arkansas in 2004.)

SELF-ADVOCACY IN NEW JERSEY

Self-advocates are heard, said David Tag, a member of the New Jersey Council on Developmental Disabilities.

"I have mild cerebral palsy, attention deficit disorder, obsessive compulsive disorder," Tag said, "I'm neurologically impaired and I'm kind of slow."

Tag is community liaison for the New Jersey Self-Advocacy Project, a program of the Arc of New Jersey. "Legislators listen to us when we show up at hearings," Tag said, "They pay attention when people like myself speak."

He tells his "personal story" to law makers, Tag said.

"I live with a roommate. But I had to wait almost ten years for my supervised apartment."

While Tag was on the waiting list, he lived with his parents. But if he hadn't been able to live with his folks, Tag's not sure what he would have done.

"It wouldn't have been very nice," he said.

Hearing his story makes policy makers pay attention to the housing problems of people with developmental disabilities, Tag said.

"Every time I'm up at the state house, legislators come to me for information and with questions. I love it!" he added.

It's important to have a choice about where you live and where you work. But making sure that you have a choice is hard work, said Barb Coppens, an advocate assistant with Disability Rights New Jersey.

Coppens knows from personal experience.

"I used to live in an institution (Vineland Developmental Center)," she said. "After I graduated from high school, I got myself out."

First Coppens lived in a group home; then a supervised apartment.

"I now have my own apartment and work full time," Coppens said.

"I'm my own guardian. It keeps me busy," Coppens said. "I know the legislator in my district. That means a lot."

Coppens uses her own experience to encourage people with intellectual disabilities to be advocates for themselves, adding "they're happy to see me."

VOICES FROM NEW HAMPSHIRE

Janet Hunt, executive coordinator of People First of New Hampshire used to work at Laconia (N.H.) State School and Training Center, an institution for people with developmental disabilities that has since been closed.

"I wanted to help people with intellectual disabilities," said Hunt, who does not have a disability.

Wanting to give people with intellectual disabilities a larger voice, Hunt started People First of New Hampshire in 1992. The group has about 17 chapters across the state.

"Last year, we had a law passed to get rid of the word 'retardation' in all of the language in all of our (state) laws," Hunt said. [P&F](#)

Praying with Lior



Real and Compelling

by Kathi Wolfe

Until recently, if you wanted to see a movie that showed someone with an intellectual disability as a three-dimensional human being rather than a one-dimensional stereotype, you were out of luck.

As the furor over the film *Tropic Thunder*'s miss-fired satire of the Simple Jack caricature demonstrated, much change still needs to take place.

Documentaries, too, have too often tended to sentimentalize people with developmental disabilities or depict them as victims, with virtually no capabilities.

Yet, during the last few years, things have been changing. Increasingly, people with intellectual disabilities are appearing as vibrant, complex characters in the media—from the Farrelly Brothers' movie *The Ringer* to the Lifetime

movie *The Memory Keeper's Daughter* to the MTV documentary *How's Your News?* (All previously reviewed in these pages.)

"Praying with Lior," a documentary about native Philadelphia Lior Liebling, a boy with Down syndrome, preparing for his bar mitzvah, is an example of how far media depictions of people with developmental disabilities have evolved. Directed by Ilana Trachtman, the 2008 film (now available on DVD), offers a compelling, well-rounded portrait of a family.

Every family, in its own way, experiences happiness, sadness, times of exhilaration and moments of intense emotional pain. This is sometimes particularly true if a family member has a disability.

Praying with Lior, which was filmed over a three year period, draws you into the unique, complex life of the Liebling family. You don't have to be familiar with the religious, cultural traditions of a Jewish Reconstructionist rabbinical family to find this film absorbing, as they plan this coming-of-age bar mitzvah ceremony for Lior.

His father Mordecai is a rabbi. Lior's mother Devorah Bartnoff Liebling, who died from breast cancer when Lior was six, was also a rabbi.

Lior has four siblings: Ben, who doesn't appear in the film, his older sister Reena, his older brother Yoni and his younger sister Anna. After Devorah died, Morecai married Lynne Iser, the children's step-mother.

As is quickly apparent from the family's home movies and Devorah's journals and newspaper articles, even as a small child Lior loved to pray with his mother. And he continued to enthusiastically engage in traditional Jewish forms of prayer.

Many in his community call him a "spiritual genius." A few wonder whether Lior is spiritually gifted or whether his enthusiasm for prayer partly derives from the "beaming faces" that surround him when he prays.

"Lior would ecstatically sing Christmas carols if that were the norm," one person suggests.

Despite this the fact that the focal event of the documentary is his bar mitzvah and Lior is often shown praying the documentary never preaches or proselytizes.

Though Lior seems exceptionally spiritual and quite loving, he's also a "just-becoming-a-teen" kid. What we see is a real boy, with developmental disabilities, surrounded by a loving but not doting family as he enters the first stages of growing up.

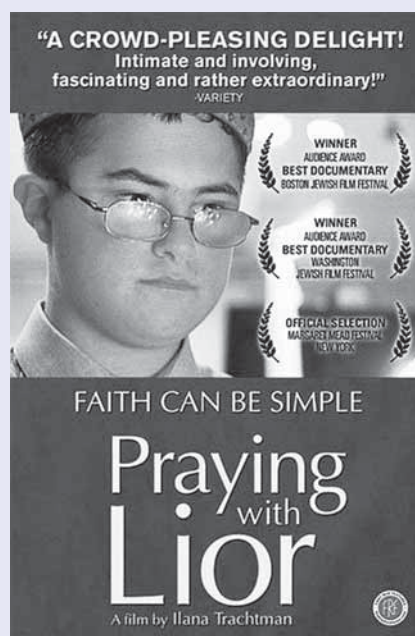
When Trachtman asks him what he'll do when he grows up, Lior says, "I'll drink beer." And he tells his father he'll "watch more TV."

Lior wrestles and plays video games with his brother, and helps his brother get dressed before he goes on a date. He loves to tell jokes and to tease people. "Every day is April Fool's Day this year," he tells his older sister, because it's his bar mitzvah year.

Like any kid, Lior doesn't always like talking to people he

doesn't know or speaking about himself at his parent's request. A scene where Mordecai takes Lior shopping hit home with me.

When Mordecai prompts him to tell the shoe salesman that they're buying the shoe for his bar mitzvah, the usually talkative Lior clams up. He turns quiet and won't explain what being bar mitzvah-ed means—a trait typical of most kids that age.



Preparing for one's bar mitzvah is hard work for any 12-year-old. "Praying with Lior," without lapsing into sentimentality, shows how this is particularly true for someone with Down syndrome.

As we have already seen, Lior loves to sing Hebrew songs and prayers. During his bar mitzvah prep, we see and hear Lior singing and chanting prayers—sitting in his living room or outside in a tree house as well as with his classmates in Hebrew school.

But despite this spiritual devotion, studying for his bar mitzvah is tiring and frustrating. It's particularly tough for him as he works on the speech that he will make at the bar mitzvah ceremony, even his father's help.

"I want to think about it for a couple of days," he says during one particularly preparation stretch.

Lior tells his father that the heart of the Torah (part of the Hebrew Bible) for him is "community." He can't say why this is, but says that in his Bar Mitzvah speech, he'll talk about "community."

Morecai jokingly says to him, "you've heard too many sermons about 'community.'"

For me, the most telling moment of Lior's bar mitzvah came when a member of the congregation, reflecting on the meaning of the ceremony, says the event isn't just for Lior, but that "it's for us."

Praying with Lior isn't a razzle-dazzle, fast-paced, in-your-face documentary like Murderball (the 2006 Oscar nominated film about wheelchair rugby athletes)—which I loved.

Yet, "Praying with Lior," resonated with me precisely because it is so understated.

Though it sometimes is too slow-paced, it is a quiet, beautifully told story—a moving narrative of a boy and his family.

Praying with Lior is captivating, even though it doesn't have much plot, conflict or special effects. Because no story is as dramatic as a well-told family story, and most all of us, no matter what our taste in movies, have those family connections. **P&F**

FAMILY SUPPORT

STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS

WANTED

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

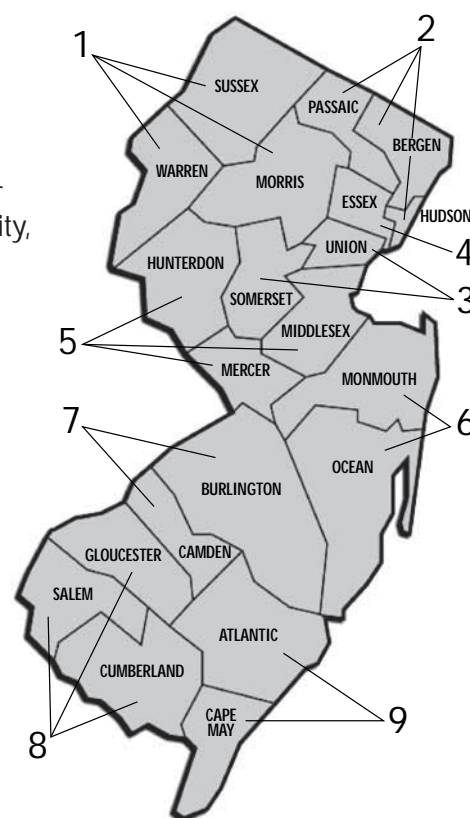
Nine regional councils were established in New Jersey by the Family Support Act of 1993(see map). Their general purpose is to assure that people with developmental disabilities and their families participate in the design of, and have access to, the needed community services, individual supports, and 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.njccd.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



Julie Blackman - Photo by Rebecca Shavulsky