

# People & Families

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

WINTER 2015

**Professionals Guiding Families  
Through the Transition to Preschool**

**GIVING THEM  
THE SUPPORT  
THEY NEED**

Anna and  
Fabian Santos



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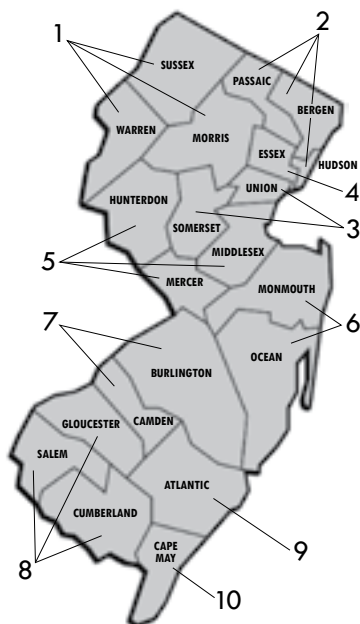
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## A Final Note and Then on to Albania

This is my final note from the Executive Director in the *People and Families* magazine. I have reached, and passed, that noble age when most Americans retire. Incidentally, my husband Ron, who is a vocational rehabilitation counselor with the New Jersey Division of Vocational Rehabilitation Services (NJ DVRS), has also reached that age. Ron and I will be retiring from our respective positions on February 1, 2015.

However, a couple of years ago we realized that despite approaching that milestone in our lives, we were not ready to take to our rocking chairs and watch game shows and soap operas on television.

So, faced with this dilemma we did what any other reasonable couple would do. We applied to become Peace Corps volunteers.

We plowed through all the paperwork and then were delighted to be accepted as volunteers. We leave for Albania on March 13, 2015. The volunteer assignment is for 27 months and we will find out what city we will be living in once we are in country. Ron will be doing community development and I will be teaching.

Later in this issue of the magazine I have written about my 40 years working as a social worker with people with developmental disabilities. I have come to the end of this 'career' hoping that I have made a small difference in the lives of the people with whom I have worked. Personally, it has been a challenging but enormously rewarding 40 years. As I look back, I cannot imagine having done anything else with my life.

I have a feeling that when I get to Albania I will be drawn to people with disabilities like a moth to the light. It will be interesting to see how this plays out. If you would like to follow Ron's and my Peace Corps experience, please feel free to call the NJ DD Council offices. I have been told I should write a blog, and most probably will! The Council staff will know how to access my blog.

So, as I end this most rewarding position as the Executive Director of the NJ DD Council, I wish the Council membership, Council staff and magazine readers well. I am sure the person who is hired as the new Executive Director will find this position equally personally fulfilling as I have for this past almost nine years.

For those of you who know my baseball-fanatic husband you will understand that it would be most appropriate for me to let Nolan Ryan express my final thoughts; "I am going to spend my time today just thanking the people that played a role in my career, because I truly do believe that I was blessed by a lot of people whose paths crossed mine as I went down the road in my career."



—Alison Lozano, Ph.D., M.P.A.  
Executive Director

## Jaymes Brill Joins the Council Staff to Coordinate People First Efforts



Jaymes Brill has joined the staff at the New Jersey Council on Developmental Disabilities to coordinate its exciting new People First Project.

People First is an internationally recognized, locally sponsored and coordinated self-advocacy movement. According to the web site PeopleFirst.org ( <http://www.peoplefirst.org/> ), the movement got its start in Oregon during the planning for a self-advocacy conference in 1974, and

carried over throughout the conference itself. It took the name from efforts to end the labeling of people with developmental and other disabilities as “handicapped” or by use of the “R” word and other derogatory language.

The goal was to promote people as people first. Self-advocacy groups in the U.S. and throughout the world have now formed under the name People First and many existing groups have chosen to be known as

People First and to be part of a movement that puts the individual members in charge.

Brill is joining the Council to help coordinate those efforts here in New Jersey.

Brill, who lives in Howell, with his wife, graduated from Rutgers and has extensive experience working with people with developmental disabilities and coordinating Long-Term recovery work for victims of Hurricane Sandy with the American Red Cross. He also worked for many years as a government contractor at the now-closed Fort Monmouth in Eatontown.

He knows the Council and its work as both of his parents are graduates of the Partners in Policymaking program and are active with the Regional Family Support Planning Council in Monmouth and Ocean counties.

In addition, his older brother Marc is a person with Down syndrome.

“I’ve learned a lot from Marc,” Brill says. “I wanted to help to give people with disabilities the chance to become advocates and champions of their own causes. To have more opportunities to further contribute to their communities.”

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## For Many with Disabilities, Special Education Leads to Jail

(See related article on page 22)

By: Jackie Mader and Sarah Butrymowicz, The Hechinger Report

October 29, 2014

(From Disability Scoop <http://www.disabilityscoop.com/2014/10/29/for-sped-leads-jail/19800/>

edited by People & Families for length and local relevance)

GRENADA, MISS. — Cody Beck was 12 years old when he was handcuffed in front of several classmates and put in the back of a police car outside of Grenada Middle School. Cody had lost his temper in an argument with another student, and hit several teachers when they tried to intervene. He was taken to the local youth court, and then sent to a mental health facility two hours away from his home. Twelve days later, the sixth-grader was released from the facility and charged with three counts of assault.

Officials at his school determined the incident was a result of Cody’s disability. As a child, Cody was diagnosed with bipolar disorder. He had been given an individualized education program, or IEP, a legal

document that details the resources, accommodations and classes that a special education student should receive to help manage his or her disability. But despite there being a medical reason for his behavior, Cody was not allowed to return to school. He was called to youth court three times in the four months after the incident happened, and was out of school for nearly half that time as he waited to start at a special private school.

Cody is one of thousands of children caught up in the juvenile justice system each year. At least one in three of those arrested has a disability, ranging from emotional disability like bipolar disorder to learning disabilities like dyslexia, and some researchers estimate the figure may be as high as 70 percent. Across



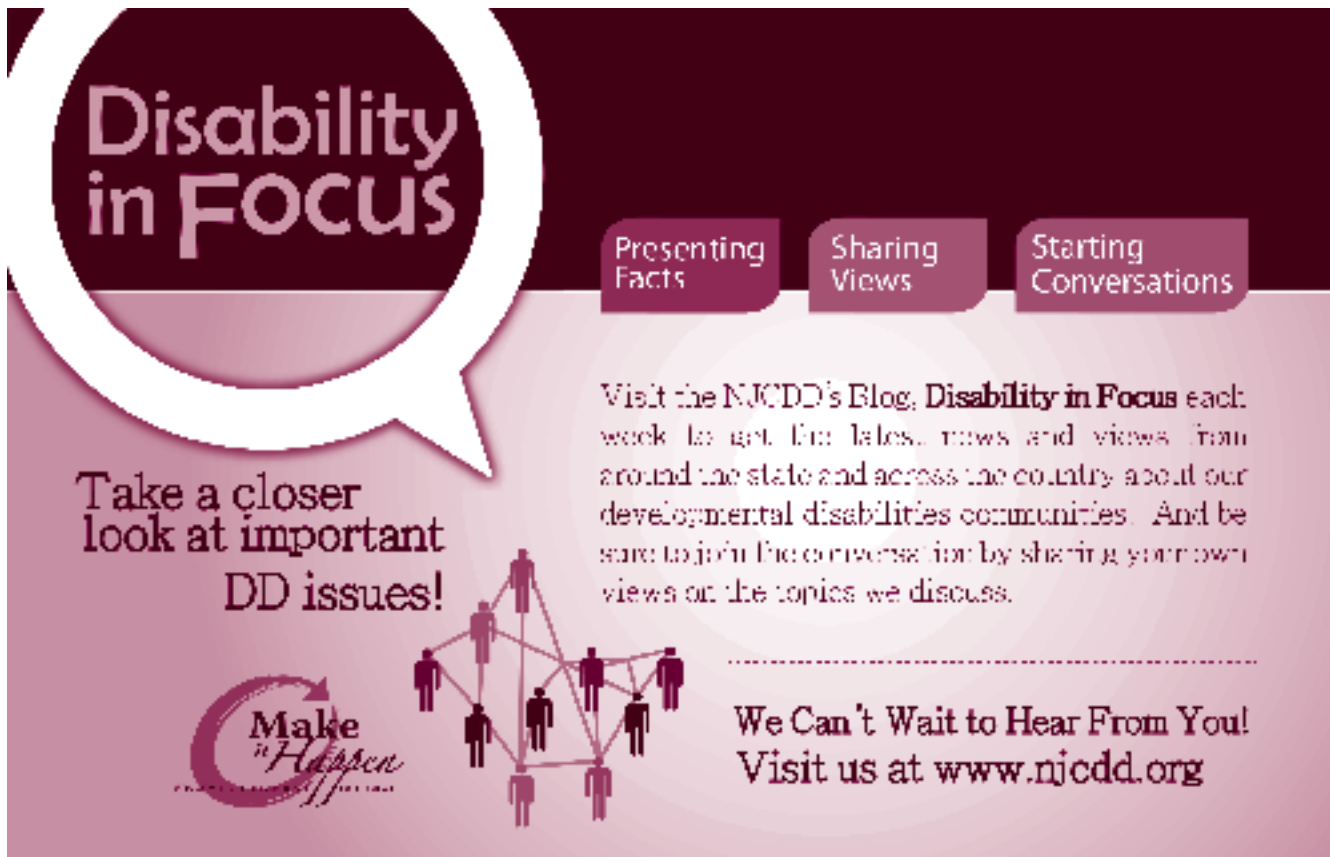
the country, students with emotional disabilities are three times more likely to be arrested before leaving high school than the general population.

When the special education system fails youth and they end up in jail, many stay there for years or decades. The vast majority of adults in American prisons have a disability, according to a 1997 Bureau of Justice Statistics survey. Data hasn't been updated since, but experts attribute the high percentage of individuals with disabilities in the nation's bloated prison population — which has grown 700 percent since 1970 — in part to deep problems in the education of children with special needs.

In Mississippi and across the country, the path to prison often starts very early for kids who struggle to manage behavioral or emotional disabilities in low-performing schools that lack mental health

care, highly qualified special education teachers and appropriately trained staff. Federal law requires schools to provide an education for kids with disabilities in an environment as close to a regular classroom as possible. But often, students with special needs receive an inferior education, fall behind and end up with few options for college or career. For youth with disabilities who end up in jail, education can be minimal, and at times, non-existent, even though federal law requires that they receive an education until age 21.

"A lot of times, it's a major setback," said Elissa Johnson, a staff attorney for the Southern Poverty Law Center. She added that some transgressions are serious, and it's behavior that needs to be addressed. "But when you're dealing with students with disabilities, youth court referrals are harmful."



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A 2013 report by the Minneapolis-based PACER Center, a parent training center, warned that one of the biggest reasons students end up in the corrections system is “school failure.”

Another factor is a lack of quality early educational options.

“Early education and nurturing is absolutely critical,” said Oleta Garrett Fitzgerald, director of the Children’s Defense Fund’s Southern Regional Office.

## Suspension

For many students with disabilities, suspensions are often the entry point in the pipeline to the criminal justice system. School discipline policies often do not take into account students with disabilities. They may, for example, include zero tolerance policies not only for serious behavior, but also for disrespect or noncompliance. Experts say this can lead schools to disproportionately suspend special education

students, whose actions may be manifestations of their disability.

## Teachers and Counseling

One of the main reasons children with special needs are jailed more often than their peers is because teachers aren’t trained in how to manage kids who are insubordinate or disruptive, according to the 2013 report by the PACER Center. Reece Peterson, a professor of special education at the University of Nebraska-Lincoln, says discipline needs to move to a more “teaching-based” approach so that students explicitly learn correct behavior.

“If [a student] has a disability that has characteristics of being aggressive and acting out, we can’t simply punish him for that,” Peterson said. “We would want to provide some sort of service or intervention for it.”

After an arrest, school districts are often reluctant to let those children return to school and are often still ill-equipped to handle them if they do.

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## Report: Changes Fail To Curb Restraint, Seclusion

By: Shaun Heasley

November 3, 2014

From Disability Scoop

<http://www.disabilityscoop.com/2014/11/03/report-changes-restraint/19809/>

A new report suggests that local decisions may have a greater impact on the use of restraint and seclusion in schools than changes at the state level. (Thinkstock)

Despite many states making policy updates in recent years, a new analysis suggests that students with disabilities continue to experience high rates of restraint and seclusion at school.

The practices were employed at similar levels during both the 2011-2012 School Year and the 2009-2010 year, according to a review of federal education data conducted by researchers at the University of New Hampshire.

Between those time periods, the report indicates that about half of states revised their policies on restraint and seclusion.

The analysis found that 69 percent of school districts reported no use of restraint and 87 percent did not use seclusion, but a small percentage of districts had “exceedingly high rates.” School districts at both the high and low ends were found in nearly every state.

“Although restraint and seclusion rates across states continue to range considerably, between-state variation is overshadowed by the tremendous within-state variation,” the researchers said. “These findings suggest that local policy decisions and other factors related to school culture, rather than state policy, seem

to be the greatest determinants of restraint and seclusion rates.”

During the 2011-2012 School Year, the U.S. Department of Education found that kids with disabilities accounted for three-quarters of those who were physically restrained and 58 percent of students who were placed in seclusion or some other form of involuntary confinement at schools across the country.

Efforts to enact federal legislation to regulate restraint and seclusion in schools have been unsuccessful, leaving a patchwork of state and local policies.

The New Jersey Council on Developmental Disabilities

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To recommend yourself or someone else to be a member of the Council, follow the steps below:

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- On the top, red tab, choose —————> Administration
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Follow the instructions for submitting the required information, and be sure to include that you are interested in becoming a member of the New Jersey Council on Developmental Disabilities.

**Or contact the Governor's Appointments Office:**  
 Phone: 609-777-0251 Fax: 609-777-0331

**Council Members are appointed by the Governor. Membership is open to New Jersey residents who have a developmental disability or are immediate family members of someone with a developmental disability.**

**Council members review the state's service systems for people with developmental disabilities, advise policy makers on the best ways to change those systems to better serve the population, and promote the goals of the federal Developmental Disabilities Assistance and Bill of Rights Act. Members review and award grants to spark innovative projects throughout New Jersey. The Council and its individual members also advocate for people with developmental disabilities and their families on an on-going basis.**

**For more information about the Council visit our web site: [www.njcdd.org](http://www.njcdd.org)**

## Community Players Holding Auditions for Next Production



CAU Community Players put on a production of *Beauty and The Beast* at Jonathan Dayton High School, in Springfield, NJ. This was the dress rehearsal.

The Community Access Unlimited's theater group, Community Players, is holding auditions in January for a future production. The group is a New Jersey Council on Developmental Disabilities grantee and will be mounting a production of *Shrek, Jr.*

### **The auditions will be held on:**

Monday, January 12th from 6:30 – 8pm;  
Wednesday, January 14th from 6:30 – 8pm; and,  
Saturday, January 17th from 11am until 2pm.  
They will take place at 45-51 Cherry Street in Elizabeth.

For further information visit the Community Access Unlimited's web site at:

[www.caunj.org](http://www.caunj.org)

or contact Community Access Unlimited at their main offices:

80 West Grand St. Elizabeth, NJ 07202; (908) 354-30340; TTY/TDD (908) 354-2665.

### **According to the web page for the group:**

"The CAU Community Players was established in 2011 by Community Access Unlimited (CAU) as an exciting new opportunity for its members to collaborate with the community to create an incredibly unique and inspiring theatre experience. In 2012 we teamed up with talent from three surrounding counties to present *Seussical Jr.* as the first production in Union

County to showcase performers with developmental disabilities. The concept of the CAU Community Players is to give everyone the opportunity to audition on an even playing field and to be given the part they deserve according to their talent, ability and interest. Together we are changing the perception of theatre and its accessibility to the entire community."



# UPCOMING EVENTS

## NJCDD UPCOMING PUBLIC MEETINGS

**THURSDAY, JANUARY 15, 2015**

**10:45 a.m. to 1:30 p.m.**

### **Special Olympics New Jersey Sports Complex**

1 Eunice Shriver Way  
Lawrenceville, NJ 08648

**AND**

**THURSDAY, MAY 21, 2015**

**10:45 a.m. to 1:30 p.m.**

### **Special Olympics New Jersey Sports Complex**

1 Eunice Shriver Way  
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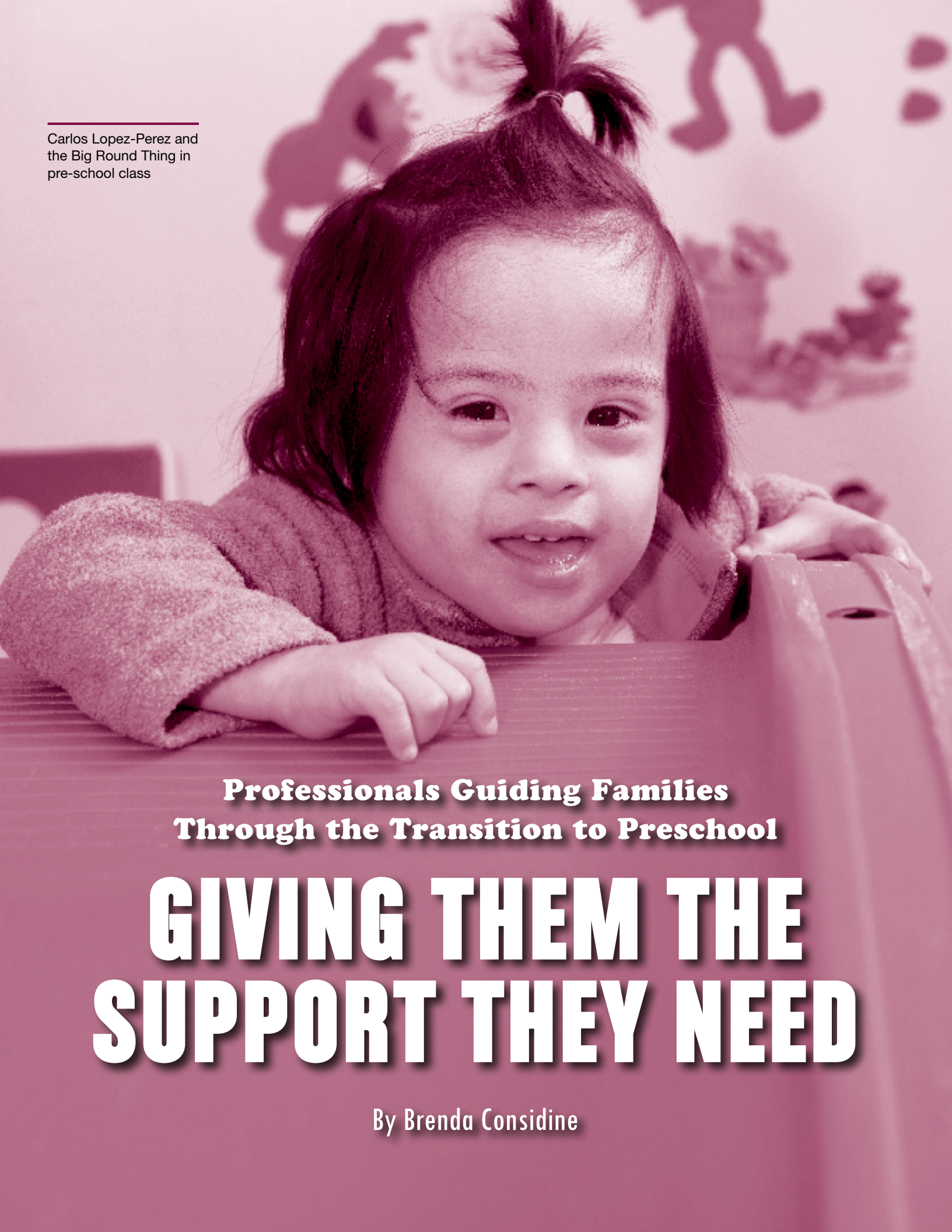
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Carlos Lopez-Perez and  
the Big Round Thing in  
pre-school class

**Professionals Guiding Families  
Through the Transition to Preschool**

# **GIVING THEM THE SUPPORT THEY NEED**

By Brenda Considine



Parents chat and laugh as they make their way down a hallway framed with metal braces, walkers, special strollers, and other adaptive equipment at North Jersey Elks Developmental Disabilities Agency (NJEDDA). With a toddler by the hand or a baby perched on a hip, mothers pour into a sunlit room and take a seat on the carpeted floor among brightly colored mats, balls, and toys.

They have arrived for the Special Toddler Playgroup, a program launched two years ago to provide support services for children ages one through three, who have physical and developmental delays. They take part in activities such as language stimulation, socialization, educational games, and therapeutic movement, while moms share smiles, tears, and tips with each other.

“The playgroup is a return to our roots, when families brought their children in for groups, and early intervention services were offered in our agency,” says Dr. William Weiss, executive director of the Clifton-based NJEDDA. The agency offers the group twice a week at no charge to families. “Our goals are to help these children reach their maximum potential, and to offer support for their parents,” adds Weiss.

For more than 10,000 infants and toddlers with developmental delays, New Jersey’s Early Intervention System (NJEIS) can be a lifeline of hope. The system, funded through Part C of the Individuals with Disabilities Education Act (IDEA), offers free evaluation for children birth through age three. If determined eligible for Early Intervention Services, the family receives an Individualized Family Service Plan (IFSP) mapping out needed services, such as speech therapy, physical therapy, occupational therapy and developmental therapy. The evaluation and IFSP are free, but the services and therapies themselves are provided on a sliding-fee basis. In some cases, private insurance is used.

While NJEDDA no longer provides services as part of the Early Intervention System, they

offer the toddler group because the agency is committed to providing outreach and support to underserved families, particularly as they transition from the early intervention system to the special education system.

## **Transition to Preschool**

All toddlers who receive early intervention services are considered “potentially eligible” for special education, but not all will receive special education when they leave the NJEIS at the age of three. Some children are found eligible for special education preschool services by the local school district, but others are not. Some families simply ‘opt out’ of the system.

The transition process, managed by regional service coordinators, is designed to put families in the ‘driver’s seat,’ empowering them to make decisions. But according to many of the professionals who provide direct services and therapies day-in-and-day out to children and their families, not enough is being done to ensure that parents are ready for this role.

“Most families need a lot more hand holding in order to get through the transition process,” says Joyce Salzburg, a licensed clinical social worker who has been in the field of Early Intervention for more than 25 years. Salzburg, co-founder and CEO of Sunny Days Early Childhood Developmental Services, which serves more than 1,700 New Jersey families each week, sees many parents of toddlers who lack the information and skills they need to make informed decisions.

“It is like giving a four-year-old the keys to the car and telling them to drive. These parents are told they are in a role of decision-maker, but they do not know the rules of the road. We just do not offer enough direct support and training for families,” she concludes.

## **The Role of Therapists and Providers**

One of the difficulties is the lack of a formal, ongoing role for the therapists and providers in the transition process.





Fabian Santos with Anne Foster

According to Patti Carlesimo, chair of the board of trustees for the Alliance for the Betterment of Citizens with Disabilities (ABCD) and chair of ABCD's Early Intervention Providers Association, the mandatory 'transition planning meeting' that occurs when a child is two years old is the only formal opportunity for service providers to support the child's transition. Transition support is provided through a regional service coordinator who may not know the child, the local community or the therapists who provide direct services.

Anne Foster, a physical therapist who consults with parents in NJEDDA's Special Toddler Playgroup, sees a need for better parent support, and a more direct connection between early intervention service providers and the local school district.

"I have been providing in-home early intervention services for 15 years and have never been asked by a Child Study Team (CST) member for information about a child, or for recommendations about what a child needs," Foster says.

"The professionals who work directly with these children have a lot of information and

insight, but it gets lost. After the initial transition meeting, children are evaluated by the district therapists. There is no venue for the EI therapists and the district therapists to collaborate about recommendations or placement for a child," she adds.

## Advocacy and Support

Early intervention providers claim that many families want the therapists to stay involved and come to meetings with the school district, but that is not allowed—at least not in an official capacity. Providers believe that their absence at the table is a problem for families of young children, especially when local school districts deny eligibility for special education, limit service options, or, in some cases, fail to follow the law.

Foster shares the story of one Essex county family who was told by the Child Study Team at the first individual planning meeting that it is the district's policy not to send children out-of-district under any circumstance. After trying the in-district program for several months, the family felt their child's needs were not being met, so they moved to a different district, which placed the child in an out-of-district, specialized program.

Early intervention providers stressed that while families have the right to appeal, those who do not speak English or know their rights may simply give up.

That was not the case for Ana Pérez. Her 4-year-old son, Fabian Santos now attends a specialized preschool program at NJEDDA. Through an interpreter, Pérez described her dreams for Fabian, and her tireless work advocating for him as he moved through the early intervention system to preschool.

"I feel like I have been blessed by God that Fabian got the help he needed and he got into this preschool," says Pérez. "I hear horror stories from other parents. They face obstacle after obstacle and in the end, the district just tells them 'no, your child cannot have these services and will be going to the local program.' Other parents ask me how I did it. They want me to help them."

Pérez adds that while her study team did suggest in-district options, ultimately, they agreed



that the private program she found for Fabian represented the most appropriate placement for preschool.

Pérez had done all of her homework. She had video of Fabian, tracking the progress he made at the toddler playgroup where he learned to talk, walk and run. She also had medical reports, evaluations, and documentation showing that her son needed intensive therapies, adaptive equipment and other specialized supports, in order to benefit from special education.

“If Fabian’s mom was not such a good advocate, I am pretty sure he would have been placed in a less intensive program,” says Foster.

## **The Intersection of Two Complex Systems**

One of the biggest challenges families face as they transition from Early Intervention to preschool services is the structure of the system itself. Early Intervention (Part C of IDEA) is housed in the New Jersey Department of Health. It is a multi-

tiered system that includes four Regional Early Intervention Collaboratives (REIC) that plan and coordinate services, and provide a point of entry into the system. Direct services and therapies to children and families are not provided by the REIC, rather, they are delivered by local provider agencies. Special education services (Part B of IDEA) are housed in the New Jersey Department of Education (NJDOE). It uses a highly local system, in which direct special education services are planned, administered, and delivered by one of New Jersey’s 611 local school districts.

Terry Harrison, Part C Coordinator for the Early Intervention System in the NJDOH acknowledges that there are some “expected challenges” during the transition from early intervention to preschool, especially considering the number of school districts in New Jersey, and the shift from Early Intervention’s focus on “developmental services,” to special education’s focus on “free and appropriate” public education. She adds that late referrals to the early intervention system,

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Mateo Ruiz intent on the hands and Jenneve Inocenrio on the many colored balls around the classroom, with staff members at an Elk’s pre-school session.





Fabian Santos coming out at the Elks DD agency's pre-school in Clifton

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as well as complex, and irregular residency and registration requirements that vary from school district to school district can delay the eligibility determination for preschool services and hinder smooth transition.

## **Bringing All The Players Together**

In 2012, the Health and Education departments signed a 5-page interagency agreement delineating the responsibilities of each for the transition of toddlers leaving early intervention. The agreement addresses notification and referral of children potentially eligible for preschool services for students with disabilities, parent opportunity to 'opt-out' of the notification/referral process, and transition planning.

Harrison believes that the interagency agreement is strong evidence that the two departments are working closely together at both the administrative and service delivery level. She adds that interdepartmental staff meet at least monthly, and that leaders in the system jointly develop and present regional workshops on transition from the early intervention system to preschool.

According to Harrison, the challenges around transition are being addressed through joint training and local networking opportunities for personnel and families. She adds that, as part of best practice, joint transition training is provided for Part C Service Coordinators and school district Child Study Team members in order to build relationships and common understanding of transition requirements and effective practices that support families through the transition process.

Salzburg and other providers agree that these steps are part of the solution, but she sees a much larger role for those who work directly with children and families. She believes that greater collaboration between local early intervention providers and local school districts is critical.

"CST members need more training about early intervention," Salzburg explains. "Effective transition to preschool is an entitlement, and we have to take that more seriously. If all the players in the two systems worked together more, and supported families throughout the process, I think we would do a better job here in New Jersey."

# one Family, Two children

## A Story of Successful Transition

**G**loucester County resident, Andrea Targonski is a mother of two young children, Sean and Elizabeth, both of whom went through New Jersey's Early Intervention System. (For the privacy of her children, Targonski asked that their real names not be used.)

Sean, now 4, received speech and developmental intervention. His progress was so dramatic that there was no need for transition to special education preschool, but for his sister, Elizabeth, things were different. Following a transition process that began last spring, Elizabeth started attending the preschool disabled program in Glassboro public schools, only days after her third birthday.

"I cannot say enough good things about the therapists from St. John of God who worked with Elizabeth and helped us through the transition. When she was two, we had the initial transition planning meeting, with the service coordinator, one of Elizabeth's therapists from St. John of God, and the psychologist from our school district. They answered all of my questions and gave me a great overview of the system and how it works," said Targonski.

When it came time to develop the IEP and determine placement this fall, Targonski said she felt ready.



Sean and Elizabeth on the couch with Mickey.  
—photo from the family

"We looked at the classrooms the district offered. They assured us that we, as parents, would be making the final decisions about Elizabeth's services and placement," she said.

"I feel fortunate to live in a district that offers a top notch preschool program. I feel like they want to help her as much as we do and they will get her the services she needs. I hear horror stories about children who are sent out, but we live in a town where the services are all right here."

While Targonski's experience was positive, she admits that there was a "certain level of bureaucracy and red tape."

"The service coordinator's doors were always open to us," she said.

"No one wants their child to need Early Intervention, but I thank God that the services were here," said Targonski. "I would tell other parents this: Don't hesitate to call. The evaluation is free and the worst thing that can happen is you learn your child does not need services. But if they do, you get what you need."

## EARLY INTERVENTION AT A GLANCE

- New Jersey serves more than 10,000 infants and toddlers through its Early Intervention System, representing 3.22% of all New Jersey infants and toddlers.
- Infants and toddlers from birth to age three are eligible if they have developmental delay (cognition, communication, social-emotional, motor or adaptive delays) or are diagnosed with a physical or mental condition that has a high probability of resulting in developmental delay.
- Services may include assistive technology services/devices; audiology services; developmental intervention; family training, counseling and home visits; health services; nursing services; nutrition services; occupational therapy; psychological services; social work services; speech and language therapy; vision services; and other early intervention services.
- The system is required under the Individuals with Disabilities Education Act (IDEA, Part C) and is funded by state and federal dollars.
- The cost to families is a progressive monthly fee based on family size and income along the federal poverty guidelines. For more information go to [nj.gov/health/fhs/eis/cost\\_participation.shtml](http://nj.gov/health/fhs/eis/cost_participation.shtml)

## RESOURCES

### ***When I Am 3, Where Will I Be***

and other information on transition at:

<http://www.thefamilymatterswebsite.org/PDF/FamilyTransitionHandbook2013.pdf>

### ***Getting Ready for Pre School: What Parents of Toddlers with Disabilities Need to Know*** (English & Spanish)

Call **609-890-1400** or go to:

<http://www.asah.org/pdf/ASAH-preschool-guide.pdf> (English)

[http://www.asah.org/pdf/asah\\_preschool\\_guide\\_spanish.pdf](http://www.asah.org/pdf/asah_preschool_guide_spanish.pdf) (Spanish)

Family transition workshops provided by NJEIS Family Support Coordinators  
and the Statewide Parent Advocacy Network (SPAN)

[www.spannj.org](http://www.spannj.org)





# FAMILY SUPPORT

## STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS

### WANTED

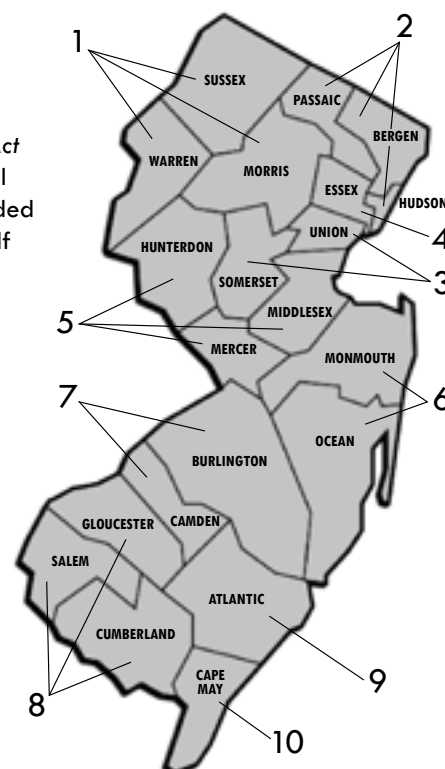
#### NEW JERSEY'S REGIONAL FAMILY SUPPORT PLANNING COUNCILS ARE LOOKING FOR NEW MEMBERS!

A number of 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 Statewide Family Support Coordinator Kyoko Coco at 609-341-3112 or email her at [kyoko.coco@njcdd.org](mailto:kyoko.coco@njcdd.org) Or visit our website at [www.njcdd.org](http://www.njcdd.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



# First to Respond: Sometimes the Last to Know How

By Jonathan Jaffe

A motorist with **CEREBRAL PALSY** is mistaken for a drunk driver.

A non-verbal woman with **AUTISM** baffles an EMT trying to assess her injuries after an accident.

A teenager with **INTELLECTUAL DISABILITIES** is disregarded as an unreliable witness.

A man with **INVOLUNTARY SEIZURES** is arrested for pushing a police officer.

**These incidents—  
and others like them or worse—are real.  
And they happen routinely.**

Disabilities advocates say they illustrate the growing need for greater training for first responders—police and sheriff's officers, firefighters, EMTs, judges, court bailiffs and corrections officers—in New Jersey and nationwide.

In New Jersey—a state of nearly 900,000 people with developmental and intellectual disabilities, and more persons with mental health issues and learning disabilities—there is a constant likelihood of an encounter with police and emergency first-responders.

"This is also a state with more than 38,000 sworn officers working in more than 600 law enforcement agencies. The training they receive concerning people with disabilities is rather minimal," said attorney Jessica Oppenheim, director of the Criminal Justice Advocacy Program (CJAP) at The Arc of New Jersey.

The NJ Police Training Commission operates 15 police academies, 12 of which now offer the 24-week basic training for police and special law enforcement officers.

Since 2008, developmental disabilities awareness training is provided through NJLearn, an online system created by the state Department of Health and Senior Services (DHSS), the state Department of Human Services (DHS) and representatives of police, fire and EMS services, according to Training Commission spokesman Paul Loriquet.

Advocates like Oppenheim and Shirla Simpson, deputy director of the New Jersey Council on Developmental Disabilities (NJCDD), insist this is insufficient. "There is a lack of training among



*"There is a lack of training among police officers to understand people with disabilities. We are not doing a good job to fix the problem, at least in New Jersey."*

—Shirla Simpson

police officers to understand people with disabilities. We are not doing a good job to fix the problem, at least in New Jersey," Simpson said.

"To increase basic training at police academies would take a legislative mandate or a directive from the Police Training Commission. The hurdle is always cost," Oppenheim added. "Change must come from the top down ... from the state Police Chiefs Association and from county prosecutors who recognize a need for better training in this area."

Meanwhile there are several initiatives to help bridge the training gap.

Besides providing technical assistance to lawyers who represent people with disabilities and providing direct advocacy, The Arc's Criminal Justice Advocacy Program also offers training for people who work within the state's criminal justice system.

Oppenheim said CJAP recently partnered with the Middlesex County Prosecutor's Office to host a two-day law enforcement training to help police better understand people with developmental and intellectual disabilities.

"The goal is to teach people in law enforcement and other first-responders that people with disabilities are part of their community. They should be accepted; their needs understood and they should be treated with respect," said Oppenheim.

Since 2006, the New Jersey Crisis Intervention Training (CIT) Center of Excellence holds several week-long classes each year to provide law enforcement officers, other first-responders and

mental health professionals with intensive training to identify and assist people with mental health issues and developmental disabilities who are in crisis.

And, in the spring, Simpson said the NJCDD will fund two training seminars for first responders—including police, firefighters, first aiders, corrections and probation officers—conducted by the First Responder Disability Awareness Training Center at Niagara University in upstate New York.

David Whelan, project director for the First Responder center, explained that people with developmental and intellectual disabilities “pose a whole set of new and different challenges for police, firefighters, EMS workers, 911 operators and corrections or probation officers.”

“I met David (Whelan) in Washington D.C. and was impressed by his breadth of knowledge on these issues,” Simpson noted. “He had a strong understanding of what is happening across America and, sadly, he knows of many cases in which people with Autism, Down syndrome or

other disabilities have been harmed because of a lack of training among first responders.”

## New and Different Challenges

“People with intellectual disabilities may exhibit physical behaviors and speech that can be difficult to interpret or easily misunderstood,” explained Whelan, who travels the nation to help connect first responders and people with development disabilities.

“It’s imperative for first-responders to understand that people with disabilities may communicate differently and that their disability does not mean incompetence,” said Whelan. “Properly educated and trained, emergency personnel are better equipped to treat these people with dignity and respect. The end result will be more positive.”

Many first-responders do not realize “that on any given workday they may encounter a person (with disabilities) who poses these types of challenges,” Whelan said. During training sessions “you can see the light bulb go on.”

For example, Whelan often asks: “How would a corrections officer search someone in a wheelchair

From The Arc: (from left) Detective Lisa Frattali, Washington Twp Police Dept; Self-Advocate Brian Van deVaarst; Captain Michael Randall, Wilingboro Twp Police Dept; Self-Advocate Kenny Swartz; Jessica Oppenheim, Director, Criminal Justice Advocacy Program; Self-Advocate Joey Mietz; and kneeling: Self-Advocate Justin Stewart. All Self-Advocates were directed by Denise Dennin (not pictured) Theatrical Director of the Possibility Players, a repertory theatre group for people with I/DD.





who arrives at the courthouse for a trial? What does an EMS worker do when trying to treat someone with Autism who may have aggressive outbursts if they are touched?”

“Police officers tend to adopt a certain demeanor at work. But their standard, stern approach on the street may not be the best approach for a person with Autism or another type of disability,” Whelan said.

“Once officers recognize they are dealing with a person with an intellectual disability or a mental health issue, they can adapt their approach. They will be less likely to unnecessarily ignite a tense situation,” he explained.

Oppenheim echoed this sentiment. “People in law enforcement often need to take control of a emergency situation, but it may not be best for them to touch or invade the space of a person with certain intellectual disabilities.”

Whelan said a routine practice such as handcuffing a person could unintentionally trigger a life-threatening medical reaction for a person with certain types of disabilities. “Rather than provoke an uncomfortable or unsafe response, better training can teach officers how to de-escalate a crisis that involves a person with disabilities.”

The challenges often go beyond initial interaction with police officers or other first-responders. People with disabilities, particularly intellectual disabilities, face a variety of disadvantages in the criminal justice system. “For many people with intellectual disabilities, from the time of their arrest, there is an inability to understand the process,” Simpson said.

“People with intellectual disabilities may not understand their Miranda Rights or they may confess (to a crime) because they say what they think an officer wants to hear,” Oppenheim noted.

***“It’s imperative for first-responders to understand that people with disabilities may communicate differently and that their disability does not mean incompetence.”***

—David Whelan

“Those who end up in jail may have a hard time understanding the rules and unintentionally commit infractions.”

In fact, inmates with an intellectual disability are denied parole more frequently and serve an average of two to three years longer than non-disabled inmates convicted of the same crime, according to data from CJAP. “It’s essential for training to reach all segments of law enforcement including the courts and corrections,” Oppenheim said.

### **Training-the-Trainers**

The First Responder Disability Awareness Training Center is a comprehensive program, funded by the New York State Council on Developmental Disabilities. It recently received full funding to begin training throughout Arkansas. Whelan said he is eager to conduct introductory training sessions in New Jersey in the spring.

The program is designed to “train-the-trainer,” enabling police officers to return to their respective departments armed with knowledge and understanding—along with a 280-page training manual and a resource guide—to instruct their fellow officers, Whelan said.

“The first thing we do is demonstrate to first-responders how crucial this training can be to their job performance. We dispel the myths and misconceptions about people with disabilities,” Whelan said.

As the First Responder Training program evolves, Whelan said it is gradually being customized for the variety of first-responder audiences.

“We are adapting our main template to focus on what court personnel, corrections or probation officers may need to know. Firefighter or EMS workers need a different understanding and

skill-set than a police officer or a corrections officer,” Whelan said. “One size does not fit all.”

## Ongoing Training in NJ through CIT

Whelan’s First Responder Training program is similar, but more comprehensive than the existing Crisis Intervention Training (CIT), available in New Jersey since 2006.

The CIT Center of Excellence provides police officers and other first-responders with 40 hours of rigorous training in the signs and symptoms of mental illness, Attention Deficit Hyperactivity Disorder (ADHD), dementia, Alzheimer’s, Autism and other cognitive and intellectual disabilities.

With an allocation from the New Jersey Division of Mental Health and Addiction Services, the CIT Center of Excellence was started by the Mental Health Association of Southwestern New Jersey in Haddon Heights.

Today CIT hosts several week-long classes in 11 New Jersey counties. “We don’t have to sell CIT training. More and more people in law enforcement now recognize there’s a real need in their local communities,” said Edward C. Dobleman, director of the CIT program.

Working with volunteer county coordinators and instructors, the CIT goal is to provide law enforcement officers, other first-responders and mental health professionals with intensive training to identify and assist people with mental health issues and developmental disabilities who are in crisis.

“CIT teaches police officers to better identify a person’s needs and to communicate better,” said Dobleman. “Identifying the symptoms of people with mental illnesses or a disability and teaching officers to use a calmer approach enables them to

*“CIT teaches police officers to better identify a person’s needs and to communicate better,” said Dobleman. “Identifying the symptoms of people with mental illnesses or a disability and teaching officers to use a calmer approach enables them to better assist people.”*

—Edward C. Dobleman

better assist these people.”

The week-long CIT training seminars are based on a model first implemented by the Memphis Police Department in 1988 to teach police officers safe, calm and humane approaches to help people with mental illness in crisis.

CIT training was initially designed to put police officers in the same room as mental health professional from their community to “get them talking and forming solid working relationships,” Dobleman said. Over the years, CIT’s 40-hour classes have attracted EMS workers, firefighters, court

personnel and postal inspectors who want to learn more.

CIT also shows first responders the variety of services available in their area. “The program teaches officers what resources are available and where mental health or intervention services are offered,” he said. “CIT brings everyone to the table. It encourages them to work together.”

Participants are taken on site tours of facilities in their area that provide services for people with mental illness and with developmental disabilities. In addition, participants meet with local mental health professionals and disabilities advocates, they learn about legal rights for people with special needs and receive instruction in cultural, gender and ethnic diversity issues, Dobleman explained.

NJDDC’s Simpson—who is also a first responder and a volunteer CIT—noted that only 90 minutes of a 40-hour training program actually concentrates on people with developmental and intellectual disabilities, and the remainder focuses on people with mental illness. “That needs to improve,” she said. **P&F**





# DISABILITY PRIDE

By Maryann B. Hunsberger

The fourth annual New Jersey Disability Pride Parade took place in Trenton on Friday, October 3, 2014. The Alliance Center for Independence (ACI) in Edison has organized each year's parade. Carole Tonks, ACI's executive director, caught a video of Chicago's annual disability pride parade and thought it would be a good idea for New Jersey.



Proud sister and companion just past West State Street.



Anomie in performance.

The Chicago parade began in 2004. Since then, disability pride parades have since taken place throughout the US—in New Jersey, Philadelphia, Houston, Atlanta, Detroit and San Francisco. The movement has also spread to Norway, the United Kingdom and South Korea.

The disability pride movement promotes the belief that disability is a natural part of human diversity, in which people living with disabilities can take pride. One way to celebrate this diversity, while also creating awareness of disability culture, is to have disability pride parades.

And the theme for the day was that simple. The paraders weren't asking for anything, or complaining about anything, they were just showing their pride in being people; people with disabilities.

The statewide event drew a crowd of 500. A lineup of dancers, musicians, singers, drama troupes and comedians—encompassing people with disabilities and their families—entertained.

Disc Jockey DJ Wale provided music for folks to groove to on the dance floor. A clown painted children's faces and the Drakes Cakes "team mascot" duck mingled with the crowd and offered free snacks.

Twenty-five vendors—including the Division of Vocational Rehabilitation Services (DVRs), the Council on Developmental Disabilities, Community Access Unlimited, Advancing Opportunities and Easter Seals—lined the sidewalks. The Division of Disability Services (DDS) raffled off bags filled with emergency preparedness supplies.

DVRS director Alice Hunnicut was there to show the division's support and to talk about National Disability Employment Awareness Month.

Joe Amoroso, DDS director and a member of the NJ Council on DD, told people about how important it is for them and the people they live and work with to be well prepared for emergencies before they happen.

Both directors received appreciation awards





Thomas, Patty Calbrese's grandson, dances in the parade with Ashley of Joy's Dance House.



Joe Amoroso, Executive Director of the Division of Disability Services and Council member, speaking to parade goers.

for their support and involvement with ACI and the parade.

"The parade joins us into society," Amoroso said. "People come out from their offices to get lunch or ice cream from the trucks and they get involved. They see the performances and appreciate the opportunity to have some fun in the middle of their work day. This is a source of pride. This is absolutely why the Division has been a supporter all these years."

Frank Latham, the Council's youth leadership coordinator, spoke about the knowledge and enthusiasm of our state's disability advocates and the role self-advocates play in New Jersey.

"Advocates get discouraged when they don't see something big happening. But that's the way change is. There's good advocacy work going on here and although it may sometimes appear as if we aren't moving at the speed we think we should, compared to other parts of the country, we are really making progress. It takes time to effect change in the right way and that's

from the grassroots up. From a solid base of self-advocacy."

Latham said the parade is one example of something that started small and continues to grow.

"ACI's consistent willingness to assure that advocates are the focal point of the parade in terms of presenters, advocates and speakers is a really important component. Advocates see people like themselves in positions of prominence and this inspires them to reach for leadership roles moving forward. I think that is a really good thing."

Patrice Jetter, grand marshal of the 2014 New Jersey parade, danced to the drum line of the Mercer County Special Services School District's Dolphins Drum Corps and performed onstage with the Arc of Mercer where she volunteers in their art, music and drama programs.

"I love it because it's a parade that celebrates people," she said. "I was always a proud person with a disability, and being parade marshal made me feel even prouder!"

# Patty Calabrese

*Raising Her Grandchildren with Determination and Joy*



Patty Calabrese with her granddaughter Lucia.

For the past six years, Patty Calabrese, 59, has been raising her four grandchildren.

Her oldest, Anthony, was 6 when he came to live with her. “He has the most severe autism. He had no communication skills.”

Calabrese first taught Anthony to sign and created a Velcro picture book to help Anthony communicate. She laminated pictures and put Velcro on the backs to attach them to the book. Anthony used the pictures to show what he wanted.

Eventually she bought a tablet and taught Anthony how to type. He now types out sentences.

“I change the password so when he wants to play with the tablet, he has to type the new password to get in,” Calabrese said. “That’s how he has learned to type things such as his address and his name.”

And he comes up with his own methods of communication now, like playing a YouTube video about pizza to let Calabrese know its time for that favorite treat.

“He communicates every way he can.”

Thomas, 7, talks but has some significant challenges with his autism spectrum disorder.

Calabrese works with his school to see he gets the right supports, such as speech therapy and ABA (Applied Behavioral Analysis) therapy, applying simple specific instruction to promote positive behaviors and reduce negative ones.

“Sometimes his speech is repetitive, but he can communicate what he needs.”

Jimmy, 10, has Asperger syndrome.

“He does well on his own but he has a harder time with other children,” Calabrese said. “He has a lot of fears, which cause anxiety attacks.”

Lucia, 12, is the boys’ sister. She likes to dance as well, and she and Jimmy both started taking classes at the Joy Dance House in Edison.

“One of the teachers is a special ed teacher whose sister has Down syndrome,” said Calabrese. “Jimmy loves her class. Lucia signed up for

another class and goes five days a week.”

Three years ago, Anthony also began taking dance. Last year, Thomas joined his siblings. The three boys attend class every Thursday evening, starting out with some gymnastic exercises to loosen up.

The Joy Dane House’s Exceptional Dance Troupe has a yearly dance recital and performs for various statewide autism nonprofits. They dance in competitions and perform on floats at parades.

“The response has been unbelievable. They get standing ovations and have won trophies.”

The troupe performed at the annual New Jersey Disability Pride Parade in October.

“They loved it and were jumping for joy.”

After the performance, Jimmy summed things up quite neatly.

“We really liked dancing today,” he said. “The end.”



Patty Calabrese’s grandchildren — from left, Thomas, Jimmy and Anthony — with other dancers from Joy’s Dance House, Ashley, Celine, and Brianna.



# Charles Dodge

*Accessibility Advocate and That's a Fact*



Charles Dodge remembers the two worst accessibility violations he ever saw.

One restaurant had an outside lift that led to a locked door.

“There was no buzzer or phone to let them know I was outside waiting.”

The second was at a local theater. His friends had told him that the bathroom was fully accessible. There were stalls big enough for wheelchairs

like the one Dodge uses. There were grab bars and a low height urinal. What his friends didn’t realize, which is easy to do if you don’t have mobility issues yourself, and the owners and management of the theater didn’t provide for—a much more serious oversight—is that the men’s room was down a flight of stairs and there was no elevator.

“People just don’t think sometimes,” says Dodge, 37, of Westfield.



Dodge was born with spina bifida. His parents taught him to be proud of who he is. In addition to encouraging him to be independent and believe in his abilities, they instilled in him a deep sense of the importance of advocating, for himself and for others, to improve the world around him.

"I try to be cordial at first, because you can catch more flies with honey. I ask how I can help them fix the situation. I have a lot of success with that. Most of the time, people aren't acting maliciously. They just haven't thought it through. They lack knowledge. I'm trying to give them some."

He participated in wheelchair sports—track and basketball.

"Wheelchair sports opened my eyes to see how large the disability community is. It gave me opportunities to travel, meet people and see that people with disabilities participate in all sorts of activities. It gave me self-confidence."

Dodge, who was the only wheelchair user in his local public school, went on to attend Kean University, earning degrees in English and secondary education. He worked as a classroom aide for a child with Asperger syndrome while in college. Since graduation, he has worked for a national tutoring center, where he tutors high school students in English and college entrance exam (ACT and SAT) readiness.

He has been involved with ACI and disability pride for several years. He took ACI's ADA course to learn to more accurately assess buildings for accessibility.

"I learned a lot from growing up using a wheelchair, but it's good to know the law and to really have your facts right when advocating for better accessibility."

He volunteers at the yearly parade, setting up chairs, manning a table and disseminating materials to visitors.

"The New Jersey Disability Pride Parade is a fantastic event. It provides an opportunity for community awareness, it furthers the message of disability pride and it allows a platform for



individuals to have their voices heard.

"Disability pride is being proud of who you are, all of it. In my case, that includes a developmental disability. That's part of who I am, and I am proud of all of me. The parade reinforces that. It shows that people with disabilities should be proud of who they are. Each organization and vendor present supports that idea."

Dodge loves teaching but he also wants to branch out into more diverse ways of working for and with people with disabilities.

"I believe I can use my teaching abilities to help so I am hoping to change careers to the disability services field. When things are being built, planned or implemented, I'd like to provide the knowledge they need to be sure everyone can access whatever building or service they want to use.

"My hope is that one day we won't even need to have a separate disability community, but that we will all be part of one community with people with disabilities included in everything." **P&F**

# Dr. Alison Lozano

## Some Reflections on 40 Years of Service

By Alison Lozano, Ph.D., M.P.A.



It is with very mixed emotions that I write my final piece in the New Jersey Council on Developmental Disabilities *'People & Families'* magazine. For the last almost nine years I have penned at least a Letter from the Executive Director in this magazine, but this final time I will do a longer piece. I am going to use this opportunity to reflect on the last 40 years of my career and to discuss some of the changes that have occurred and some of the people I have met, both good and bad.

In 1974 I began my career right out of undergraduate school as an Intake Worker for the newly built Fort Worth State School (FWSS) in Texas. It was the beginning of the 'deinstitutionalization' movement in the United States and the FWSS was built as a short-term residential facility to teach people who lived there the skills they would need to live successfully in the community. My job was to find resources in the community so that people with developmental disabilities would not have to be institutionalized in the first place.

Although we were very successful for the first few years, when the original far-sighted administration of the school left it became a long-term residential facility. The FWSS closed in the mid 1990's after multiple scandals involving abuse of individuals who lived there. Unfortunately, the thinkers of the time had not yet convinced the public at large that people with developmental disabilities had the right to live lives that paralleled their peers without disabilities.

My time at the FWSS and the year that I spent at Richmond State School in southern Texas gave me a strong foundation for working for the rights of individuals with developmental disabilities and their families.

I travelled around rural Texas visiting in homes of families who had never sought assistance from any source outside their families. I sat on flea ridden couches, dodged massive dogs, drove miles on unpaved roads, played pantomime with families who did not speak English and ate way too many hamburgers from Dairy Queen.

Most importantly though, I was often able to connect the families with resources in their

communities and thereby avoid institutionalization. I also got to know some wonderful advocates who were at the forefront of closing the institutions.

I have previously written about Bonnie who was considered to have profound intellectual disabilities who clearly spoke to me one Christmastime. I met another young lady who was being abused by family members who had to return to her abusive situation because the adult protective services at that time were so weak. These, and many others, shaped my advocacy work.

After obtaining a Masters in Social Work I was hired as a Genetics Social Worker in both Texas and Tennessee. Not only was I able to gain knowledge about genetic disorders that has been very helpful in my subsequent career, but I got to know and counsel individuals and families at risk for birth defects.

The mid 1980's was

when genetics knowledge was exploding and the medical profession and families at risk were beginning to see the potential value of genetics information. It was also a time when the ethical issues of genetics were becoming evident.

Questions like, how to handle situations where a woman who abuses alcohol gives birth to a child every year with more significant disabilities associated with Fetal Alcohol Syndrome than the child born the year before? How to counsel a young lady who was newly pregnant whose father had Huntingdon's Chorea? What about the woman who wants amniocentesis or chorionic villus sampling for sex selection? These were the issues of that decade.

Over the years there have been more and more complex ethical questions to answer and I

***“My time at the FWSS and the year that I spent at Richmond State School in southern Texas gave me a strong foundation for working for the rights of individuals with developmental disabilities and their families.”***

—Alison Lozano



Hall Institute Executive Director Michael Riccards sits down with Alison M. Lozano, PhD, MPA. They discuss policy on closing centers for citizens with developmental disabilities, and the impact on these citizens as they're moved to community-based care models.

am sure that will continue a genetics knowledge increases.

My next position was as the Chief of Social Work at the Boling Center for Developmental Disabilities, the Tennessee University Center for Excellence on Developmental Disabilities.

During that time my sister-in-law passed away and my husband and I became the parents to her children. Her daughter had (and has) developmental disabilities so I was now thrust into the life of a family member as well as a professional.

Living the life for 24-hours a day, seven days a week, changes one's perspective. I had to wrangle with school systems, physicians who did not understand her special needs and making sure care-taking was in place around the clock.

I found myself representing families on many committees and boards, which I found both rewarding and frustrating. Rewarding because I had knowledge about family life that includes an individual with a developmental disability and challenging because so often the voices of the families are drowned out by 'the system.'

Too often professionals sit in offices and make decisions about lives they know nothing about. It seems decisions too often are made for the convenience of those who work with people with

disabilities or calculated by the costs associated with that care. Furthermore, the 'system' pitted programs for people with disabilities against each other because they were all competing for the same tiny bit of funding. In the 1980's the Department of Defense was spending \$500 on toilet seats while our programs were laying off direct care staff because funding was cut.

I have a learning disability, which I described in the *People & Families*, Summer 2012 issue. Once I learned how to manage my learning disability I wanted to challenge myself academically. For no other reason than I wanted to prove to myself that I could do it I applied to two doctoral programs and was accepted by both!

In 1996, I dragged my family across country and began work on combined degrees at the University of Utah, a Doctorate in Social Work and a Masters in Public Administration. I chose as the focus of my studies and as the topic of my dissertation, parents who have developmental disabilities themselves. I had begun a parenting class for parents with developmental disabilities in Memphis after the court system referred several parents who did not benefit from other parenting classes. The topic piqued my interest and concern.





Dr. Lozano with Iowa Senator Tom Harkin.

I quickly realized there was very little information on the subject of parents with developmental disabilities. I think as a society we are so scared of the thought of people with disabilities having sexual relationships that we react punitively, most often taking the child away from the parents at birth. But one of the more significant outcomes from my research is that with the proper supports parents with disabilities can be very successful at parenting.

After receiving my PhD and MPA I was hired as the Executive Director of the Utah Council on Developmental Disabilities. Five years later I came to New Jersey as the executive director of the Council here.

In both of these positions I have been able to fulfill a couple of my passions, to organize and advocate.

In my professional and personal life I have met some wonderful advocates, families and professionals. But I have also met some terrible advocates, parents and professionals.

I don't know why it is we are more tolerant of bad behavior in an advocate than we are in a person without a disability. Having a disability does not give a person the right to be rude and disrespectful.

Likewise, having a child with a disability does not mean you can be demanding and overbearing in your treatment of professionals who may be attempting to assist you.

The worst kind of professional is one who is working with people with disabilities because it is 'a job.' You have to have some sort of passion for this type of work because you are certainly not going to get rich and the work itself is oftentimes very frustrating. Some of the frustration is in having to deal with the individuals described above. But, working with an unresponsive system with limited funds is equally difficult.

Several times during my career I have been accused of being an ideologue, particularly by parents of individuals who reside in institutions. I am not sure being an ideologue is a bad thing, but it must not get in the way of practicality.

To hold to the ideal that all persons have the right to live in the community with lives similar to everyone else in our society is an absolute given. We cannot under any circumstances justify segregating individuals with intellectual disabilities based solely on the fact they have a disability.

However, there are many grey areas where people with the best intentions must just agree to disagree.

For example, my niece was in special education in our neighborhood school during her school years and it was the right place for her. She was 'mainstreamed' for non-academic activities but was in a classroom with additional assistance for math, English, etc. She had behavior challenges that would have made a regular classroom setting difficult for the teacher, the other students and for my niece herself.

Also, when she moved out of our home and into services in the community she did not do well when she lived alone. She is much happier with room-mates, although that setting is labeled a 'small group home.'

One of the dangerous trends we face at the moment is the movement towards 'specialized housing' or 'gated communities' for people with disabilities. Many have fought hard and long and here in New Jersey continue to fight so that people do not have to be housed in institutions. Yet, we see apartment complexes and campuses springing up that specialize in housing for people with disabilities, often for residents with a specific diagnoses.

Some would argue it is no different than 'over 55 only' communities. But the difference is the 'over 55' group live in that setting for convenience and it does not segregate them from the community as a whole. When an apartment complex for people with disabilities has its own workshop, congregate dining room, wire fences, locked or guarded gates and health clinic then it is not community living, it is a fancy institution. We must remember that for every person living in an institution there is someone with the exact same medical diagnosis or behavioral issues living successfully in the community with appropriate supports.

However, 'one size does not fit all.' Our social service system must customize services appropriate for the individual and their family.

Unfortunately, as I mentioned previously, our social service system is critically underfunded and it costs more in terms of time and effort to individualize supports.

As a community we have not done well at 'selling' our issues to the individuals who make decisions about appropriations. The most effective way to sell our issues is to have the people who are affected most lead the charge. Individuals and families must be given the supports in terms of training and organization to get their message to policymakers.

First the advocates and their families must teach the policymakers and legislators about disabilities.

And, make sure this is done with clarity so that the message does not get simply a sentimental knee-jerk response to a current situation. Second, legislation should not be made as a temporary fix to a long-term problem. Thoughtful consideration of the issues of life with a disability must be the foundation of legislation and funding decisions. Third, the most effective method of carrying our message to the

policy-makers is by well informed and supported advocates and their families.

I have seen a lot of fads come and go over the past 40 years. We have even had fads in diagnosis and treatments. In fact, we have one diagnosis at the moment that is getting more attention and funding than others. But instead of bemoaning that fact we must find common ground and not become territorial. We must ensure that all services for people with disabilities are adequate and ultimately respect the people who are most affected by funding and programmatic decisions.

So, I would end with this one piece of advice—leave the bickering to the non-disability community. Keep as the only focus of future efforts lives for people with disabilities that parallel the lives of their friends and relatives without disabilities. **P&F**

*We must ensure that all services for people with disabilities are adequate and ultimately respect the people who are most affected by funding and programmatic decisions.*

# THE R-WORD CAMPAIGN

## What You Can Do:

1. Stop and Think
2. Stop saying "retard" and "retarded"
3. Ask others not to use "retard" and "retarded"
4. Promote tolerance
5. Become part of a community to promote inclusion
6. Take an Action Pledge

*The kindest word in all the world is the unkind word, unsaid.*

— Anonymous

GO TO [www.njcdd.org](http://www.njcdd.org)

If you would like a presentation on the campaign, or if you would like to get materials—buttons, bumper stickers, T-shirts—contact us.

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**T-SHIRTS**  
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**BUTTONS**

## DON'T USE IT

The word **RETARD** is Hurtful to  
People with Developmental Disabilities

TAKE THE PLEDGE at [WWW.NJCDD.ORG](http://WWW.NJCDD.ORG)



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**BUMPER STICKERS**





Patrice Jetter, Parade Grand Marshal  
—Photo by Rebecca Shavulsky