

People & Families

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

SUMMER, 2009

THE PISACRETA TWINS,
RACHEL (RIGHT) AND
ALYSON (LEFT)

PHOTO BY
REBECCA SHAVULSKY



CHOOSING THE RIGHT ADULT SERVICES

The Brien/Pisacreta Family



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The purpose of the Developmental Disabilities Councils, according to the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402), is to engage in advocacy, capacity building and systemic change that contribute to a coordinated, consumer and family-centered, consumer- and family-directed comprehensive system that includes needed community services, individualized supports, and other forms of assistance that promote self determination for individuals with developmental disabilities and their families.

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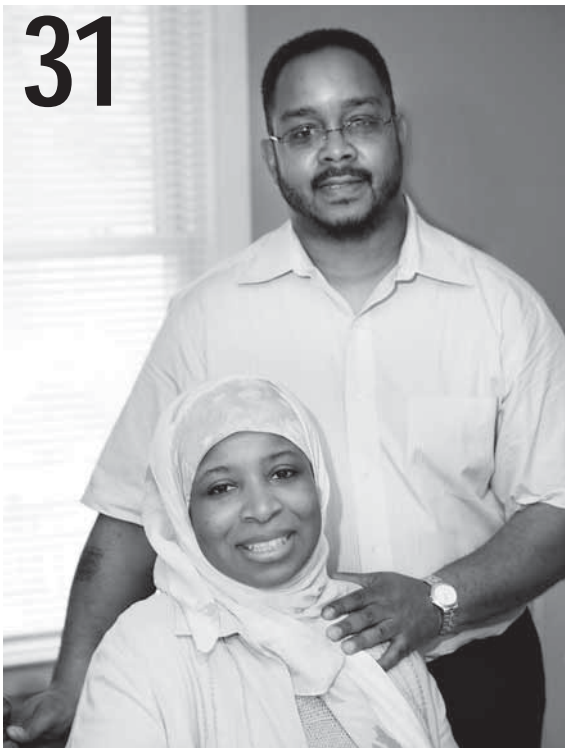
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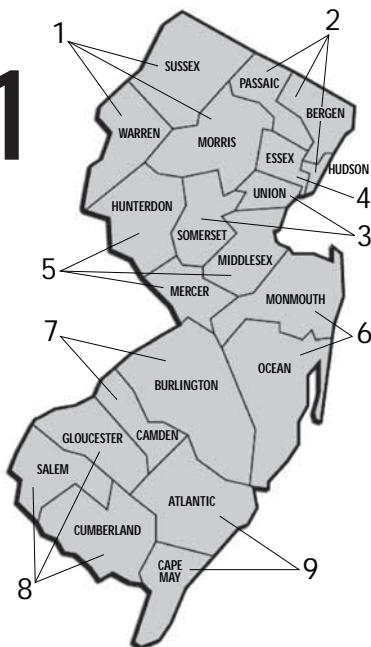
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We Need to Support Our Family Caregivers

In this magazine there is an article about self advocates. Much of the work and focus of Councils on Developmental Disabilities over the past few years has been on supporting and preparing self advocates to advocate for themselves. However, I would like to take the opportunity to address the concerns of another group. These are the family caregivers of the roughly 90,000 New Jerseyans with developmental disabilities who are living at home.

In recent years there has been a definite shift in how services are provided to individuals with developmental disabilities and their families. The emphasis has been on keeping the family intact and offering assistance to help them provide long-term supports in the home. Unfortunately, in many cases the shift has been motivated by a need to manage dwindling financial resources. The results have been less advocacy and support services for families.

Social work services, which used to be provided through the case management model, are a thing of the past. When I was a young community social worker in south Texas I had a caseload of between 40 and 60 individuals with developmental disabilities. I interviewed each family in their home and had close contact with them until their situ-

ation was settled or moved beyond my jurisdiction. Now the caseloads are between 300 and 400 individuals, depending on their level of care. It is impossible for caseworkers to give adequate attention to this number of people. The result is that families have to find resources and supports themselves, which is an almost impossible task.

Funding for respite for caregivers to have time to rest and regroup has come under scrutiny because of the perception the money is being used extravagantly. Other support services that enabled parents to manage the multiple needs of their children with developmental disabilities are no longer available or have limited availability because of lack of funding. Families simply do not have the supports available to them to adequately care for their members with developmental disabilities in their homes and provide themselves with the relief necessary for their own mental health.

There are many families who state they could manage if only they had respite available to them—or behavior management services, or after school programs—to name a few.

This is not just an issue with our state social service system; it is a much larger problem. The



issue is that services for people with developmental disabilities are not high priority with many who make policy and funding decisions. We must all take it upon ourselves to be willing to repeatedly bring before our local, state and national leaders the importance of adequately funding community services for people with developmental disabilities. This is the only way families who wish to keep their members with developmental disabilities in their homes will be able to do so without enormous financial, physical and emotional cost to themselves and other family members.

—Alison Lozano, *Ph.D., MPA*
Executive Director

First Youth Leadership Group Tours State Capitol

FIRST YOUTH LEADERSHIP GROUP TOURS STATE CAPITOL

The New Jersey Council on Developmental Disabilities' Youth Leadership Project is alive and well—very well.

Just ask the tour guide at the State Capitol Building in Trenton.

A tour of the seat of New Jersey's government in June sparked a number of spirited exchanges between the guide and the members of the group of students and young adults that had participated in the Council's first Youth Leadership training sessions in February and March.

Project coordinator Frank Latham first met with the group at the end of last year, working with the West Windsor Department of Recreation. Based on those discussions and discussions with other young people, parents and professionals—and drawing on his own experiences working with advocates with developmental disabilities—Latham has crafted a training curriculum he is taking throughout the state.

The Mercer County group was the first. And the fruits of some of that training were evident on the recent State House tour as the group members responded to questions from the guide and



West Windsor group with Mercer County flag

The youth leadership project is a training designed to help young advocates gain an understanding of the skills that are required to be a good advocate.



State House tour guide explains images in stain glass window.

peppered him with a few of their own—not all softballs either.

In fact there were a couple of questions to which he had to sheepishly admit he didn't have the answer.

“Now I have homework to do,” he grouched, jokingly.

More seriously, the trainings and tour are part of a broad effort by the Council to identify young people with developmental disabilities who want to become better advocates for themselves and others, and help them gain the skills to do so.

The youth leadership project is a training designed to help young advocates gain an understanding of the skills that are required to be a good advocate. Over the course of eight sessions, advocates work on building advocacy skills they can use in day-to-day life and in advocating for improvements for all people with developmental disabilities should they choose to do those kinds of activities.

Each session covers one set of leadership skills and can be held in any number of settings—such as public libraries, schools, community centers and other community-based locations.

Topics include understanding how government works at the state, county, and local level; public speaking; different leadership styles; what advocacy is and how to be a good advocate; developing better communication skills and styles; and topics that may be of special interest to the group.

The project is designed to encourage current and former participants to recruit others who may be interested and to evolve into something local communities can continue and expand upon. Key partners will be schools and local community groups and resources.

For more information about the project or to schedule trainings for your area contact Frank Latham at 609.292.3745 and visit the Council's Web site at www.njcdd.org (link to Youth Leadership Project).

On the State House steps



The NJ Council on Developmental Disabilities Awards 2009 Fellowships in Inclusive Education

Each year the Council, through its Education Subcommittee, identifies and honors teachers, administrators, schools and districts who have demonstrated innovative and successful ways to include students with developmental and other disabilities in classrooms with their non-disabled peers.

This year's winners ranged from an inclusive kindergarten to a plan for long-term systemic change; and from socialization to conceptual physics.

Brick Community Primary Learning Center

No one would ever know from looking at the outside that within this modest looking converted strip mall is an exemplary inclusive kindergarten program. Over the last 12 years, 210 children with a range of disabilities have been included within general education kindergarten classrooms. Currently, the program has four inclusive classrooms with six children with IEPs (Individualized Education Plans) for students with disabilities in each.

At the Learning Center, kindergarten teachers use research-based and best educational kindergarten practices consistently and wisely within their classrooms. This has resulted in an enriched environment, which nurtures all children.

Lisa Capone-Steiger, Supervisor of Student Services, Livingston Public Schools

Long term, systemic change requires that both general and special educators are taught research based strategies and best practices for inclusion of students with disabilities into general education

classes. The Livingston Public School district has adopted a strategic plan that recognizes the need for ongoing professional development.

As the Supervisor of Student Services, Lisa Capone-Steiger has provided thoughtful, energetic, and creative leadership in implementing this vision. She holds a strong belief that all students must feel comfortable and a part of every aspect of life in this learning community. She speaks with passion about the expectation that all teachers should be prepared to teach all students, and that teachers need to learn to recognize the unique strengths in each of their students. She works with everyone in the district, including coaches and teachers of after school clubs and activities, to help ensure that staff has the supports they need to make inclusion successful.

Keyport District Linda Gaital and Megan Hendershot

More often than not, pre-schoolers with and without disabilities can co-exist in a classroom and make noticeable academic gains. Through repetition, these students are taught the days of the week, colors, the alphabet, how to use scissors, and how to write their name.

However, a main ingredient that is often missing is peer acceptance and sensitivity, a key component to an inclusive classroom. Linda Gaital and Megan Hendershot have recognized this missing piece and are successfully addressing this topic in their class. These teachers place a heavy emphasis on diversity, social skills and social awareness. Due to their progressive philosophy,

commitment, and exceptional curriculum, Ms. Gaital and Ms. Hendershot are viewed as models in their district, which has prompted others to follow in their footsteps.

George Needham (Special Education teacher) and David Wilson (General Education teacher) Hopewell Valley Central High School, Hopewell Valley Regional School District

Most students with disabilities in high school take a general Life or Earth Science class. However Mr. Needham and Mr. Wilson have been teaching a Conceptual Physics course and advocate for all students with disabilities in the school to take their class, alongside their non-disabled peers.

They co-wrote the curriculum and have been co-teaching the course for seven years. The building administrators support the strength these two teachers bring to the course and are committed to keeping them together by providing collaborative planning time, professional development and workshops. The benefits of their long-term partnership is clearly visible by their seamless collaboration of skills.

They emphasize that with proper instructional strategies, a focus on strengths and individualized assessments, all students can learn. Mr. Needham and Mr. Wilson provide many excellent examples of the benefits of sustained team teaching and ongoing reflection and improvement of their practices, so that indeed, all students benefit.

Fellowship Award Winners





Governor photos/Tim Larsen

Running on Empty

The 2010 State Budget

by Brenda Considine

“...Even as we cut the cost of government in unprecedented and historic amounts, we are doing so in the right way—the way that sustains our abiding commitment to those core values... nurturing our children, honoring our seniors, and protecting the most vulnerable.”

—New Jersey Governor Jon Corzine
in his budget address, March 2009

In budget testimony submitted by the Council on Developmental Disabilities, Chairwoman Elaine Buchsbaum, wrote:

“The time has long past where it is possible to wait yet another year for a genuine Legislative and Executive commitment to meet the needs of the thousands of people and families who each year are denied services despite being eligible and in dire need of assistance. Although we are cognizant of the state’s current fiscal restraints, families and self advocates cannot remember a year when our calls for change were not met with concerns about other budgetary demands and limits.”

Buchsbaum, whose adult son with autism was on the waiting list for community services, adds that the state has a “legal and social imperative” to develop the supports and services needed to allow people with developmental disabilities live in the community.

“In 1945, our state became the first in the country to outlaw racial discrimination. In 2009, we should not be among the last to address disability discrimination by failing to design and fund a system that allows people with developmental disabilities to be valued and welcomed into our communities.”

“Economic crisis ... belt tightening... tough times... global recession... financial emergency...”

No matter what he called it in his 2010 budget address last March, Governor Jon Corzine was, and still is, faced with the fact that New Jersey has far less money than it needs. As a result, he recommended uncomfortable—and unprecedented—cuts.

The Legislature grappled with that proposal as it struggled to put together a budget in the midst of the worst economic crisis in decades.

The \$29.8 billion budget Corzine proposed was a billion dollars less than his first budget three years earlier. This year his initial proposal reflected over \$2.5 billion in cuts to the base budget, including \$85.5 million in Medicaid and pharmaceutical programs, \$20.8 million in hospital cuts, \$156 million in furloughs and other state employee actions.

In addition, it called for reductions in vocational services and early intervention for infants and toddlers with disabilities.

Millions of dollars in anticipated revenue from the Medicaid Community Care Waiver program were re-directed in 2009 from services for people with developmental disabilities to other areas in the state budget. Most programs and services for people with disabilities in dire need

of increases were flat funded. Still, many disability advocates breathed a private sigh of relief, knowing that it could have been much worse.

The 102-page Budget in Brief, released in conjunction with the Governor’s address, included several initiatives aimed at helping people with developmental disabilities: \$20.7 million for the state’s Olmstead Plan to help people with developmental disabilities and those with mental illness move out of institutions; limited funding to address the urgent residential waiting list; and funds to carry over earlier initiatives on an annual basis. Special education funding, in the form of “extraordinary aid” funding, received a \$78 million boost.

The proposal did not include funds for day programs to serve students leaving special education in June 2009. However, Human Services Commissioner Jennifer Velez announced that the department would make funds available so these students may participate in either traditional or self-directed day programs.

Within days of the release of the Governor’s budget proposals, disability advocates testified at three public hearings, urging not to cut the few disability initiatives he had included. And they pleaded for funding for community-based programs at levels needed to meet the growing demand for care and services.

The June 30 deadline for final passage neared and even small victories appeared to be in jeopardy. Proposed cuts and reductions seemed to be “done deals,” and traditional budget advocacy was having little effect.

Tom Baffuto, executive director of the Arc of New Jersey, and in the field of developmental disabilities for more than 30 years, said he had never seen a budget season so challenging. As hearings progressed, Baffuto said he heard rumors suggesting “across the board cuts” to existing programs and services.

“Cuts like that would be devastating,” said Baffuto. “And they could come at any time.”

Lowell Arye, executive director of the Alliance for the Betterment of Citizens with Disabilities (ABCD), expressed a similar sentiment: “I think we are going to take several steps back this year. No matter what we do, there just isn’t any money.”

Both Arye and Baffuto said the gloomy fiscal situation did not stop them from mobilizing constituents to take action. Baffuto’s organization encouraged families to call and write letters to lawmakers and arrange face-to-face meetings. Arye’s group did the same.

“We’re knocking on doors, writing letters,” said Arye. “But at this point, we don’t know what to do because we don’t know what else is coming. We’re just trying to keep what we have.”

Arye admitted that most consumers and families did not really understand the problems, because there are so few direct and visible cuts to the budget. “The cuts seem to be in small places, but they will have big impact,” he said.

HEALTH CARE, MEDICAID CO-PAYS, AND FAMILYCARE

One of those places is health care. In mid-May, health care advocates were joined by Senator Joe Vitale (D-19) at the State House for a press conference to oppose proposed cuts to public health care programs.

Arye said one cut likely to affect people with disabilities is a new Medicaid co-pay for prescription drugs. Under the current budget proposal, consumers will be charged \$2 for drugs with a cap of \$10 a month.

The move will save the state \$4.6 million, but Arye said it is a false savings.

“Imposing co-payments on Medicaid beneficiaries will harm the most vulnerable citizens and will not result in actual savings,” said Arye, who also chairs the Coalition for a Moral Budget. He said that other states were re-thinking co-pays because research has shown that co-pays caused low-income people to forgo health care services.

“This leads to higher costs because of increased use of emergency rooms and hospitalizations,” he said.

Another health care cut is a proposed reduction to medical day care rates. According to Arye, cuts to medical day care providers will hurt people with multiple physical and developmental disabilities. The budget cuts reimbursement rates for smaller community medical day care providers from the current daily average of \$83 to \$70.

“People with developmental disabilities, particularly those with physical limitations, require a different level of care and support than does the general geriatric population,” said Arye. “They need more staff, more professional specialties on a regular basis, and individualized approaches to transportation.”

Arye said the cuts were coming at a time when more funds were needed.

“People with developmental disabilities are aging and need services provided at medical day care facilities. These programs help families stay together and prevent institutionalization.”

Arye added that many agencies have been running deficits and are considering stopping some necessary services—a loss that will deeply affect the more than 300 adults with developmental disabilities now served by medical day care facilities.

The state’s FamilyCare health insurance program was also marked for cut back, a move that will have a negative effect on children with disabilities, according to Lauren Agoratus, director of FamilyVoices/NJ, a national health care advocacy network.

“A freeze on the FamilyCare program is a big problem for the disability community,” said Agoratus. “When kids with disabilities don’t have health care coverage, they don’t go to the doctor. They are diagnosed later and don’t get services they need when they are young.”

Agoratus said uncovered health care will put pressure on the special education system, which will cost more money.

Agoratus also noted cuts to Maternal Child Health Services would force county case management units to eliminate staff, making it harder for families to find and coordinate services.

SHELTERED WORKSHOPS & FOLLOW-ALONG SERVICES

Another big cut to a small program is the plan to take \$3.81 million from a program funded through the state Division of Vocational Rehabilitation Services (DVRS) that helps people with disabilities get jobs. Advocates at ACCESS New Jersey, a nonprofit association that helps people get employed and supports them on the job, said the cuts could lead to unemployment for 1,000 workers with disabilities.

The Arc of Camden County operates a sheltered workshop program and is being affected by

budget cuts. Leaders there said the organization has already had to cut services to nearly 50 people with disabilities.

“Many workers moved to day programs—programs without wages—but now those are at risk, too,” said Dan Ravasio the Camden Arc’s assistant executive director.

In addition to cuts to sheltered workshops, there were also cuts to DVRS’s ongoing, long-term follow-along supports to help people keep established jobs and do well there.

Jessica Short is the director of LifeWorks, a transition and job support program in Monmouth County. About 20 of the workers with disabilities they now serve will see cuts in these follow-along services.

“Some of our adults have been in jobs for a long time, others, only for a few months,” said Short. “But they all need support of some sort, whether for one hour or six hours a month. If any of these folks lose their jobs, they have to go back and start over.” **P&F**

At Press Time: Final Update On a Long and Painful Process

In spite of seemingly insurmountable odds, disabilities advocates fought back, urging that cuts be restored.

Eventually, lawmakers responded to pressure to eliminate proposed Medicaid co-payments and make some adjustments to cuts to medical day care rates.

“I was both pleased and dismayed,” said Arye, one of the chief opponents of Medicaid co-pays. “This is the seventh consecutive year that we have had to fight to hold back these co-pays.”

With less than six weeks to go before the June 30th deadline, the Governor had returned to the Legislature with more bad news; the non-partisan Office of Legislative Services (OLS) had reviewed the revenue estimates and informed the Governor of a \$2 billion hole in his spending plan. In addition to proposing to eliminate property tax rebates for everyone except seniors and residents with disabilities; raise taxes on wealthy residents; and delay expansion of the

state’s preschool program, Corzine also announced more cuts. Those included cuts to school-based youth programs (restored as part of the employee furlough agreement still pending a union vote), early childhood programs and family support. There were also cuts proposed to the Early Intervention program for infants and toddlers with disabilities, the Office on Prevention of Disabilities, special education, and millions in community provider contract recoveries.

Hours before the legislature was poised to vote, Governor Corzine announced that the state’s tax amnesty program has netted more than had been projected—enough to restore the property tax rebate for most homeowners. With that in mind, the budget was redesigned, and within days the Senate passed a \$29 billion state budget, restoring nearly half a billion dollars in direct property tax relief. Even with the last minute windfall, no more money was restored to cuts in disability services.