

Budget Issues Come to Life

Breanna Garbutt and Samantha Bradley

by Brenda Considine

THE GARBUTTS

Lisa Garbutt is a single mom trying to raise two daughters. She says her entire life has been turned upside down just trying to take care of 9-year-old Breanna, who has a rare chromosomal disorder called Kabuki syndrome, autism, intellectual disabilities, and severe anxiety.

“My whole family is stressed out,” says Garbutt. “I can’t hold a job because I have to be here for Breanna. There is no one to watch her when she is out of school.”

Finding a suitable school program has been a particular challenge. In their small South Jersey town, Garbutt says it can sometimes feel like Breanna is the only child with a disability in the whole school.

“I have been in and out court trying to get her a good education,” says Garbutt. “She has huge meltdowns in school. She cannot ride the bus for any distance because she would try to climb out the window.”

Breanna Garbutt and her sister Stephanie



Garbutt says she wanted Breanna to attend the public school, so she could be included with typical peers. “She needs to have good role models,” says Garbutt. “But the teachers and the aides do not know how to handle her.”

Eventually, Garbutt agreed to place Breanna in a county special services program but says her daughter spent her days there “in timeout and lockdown” because of behavior. “They would even call me to pick her up on the bus route,” she said.

That is when Garbutt says she lost her job. “I could not work because every time Breanna had a problem at school, they would call me to pick her up.”

Eventually, Garbutt pulled Breanna out of school altogether and stayed home with her. “I home schooled her for a year, but I was having a nervous breakdown. I lost my job, lost my condo and moved back in with my mom. Now we live on \$1,000 a month. We cannot afford anything.” Breanna has been on Medicaid and SSI since she was three years old.

“Medicaid is a huge help,” says Garbutt. “Medicaid paid for a special car seat I needed. Without it, I couldn’t take her any place. Breanna would try to open the door and jump out, or she would lean forward and pull my hair while I was driving.”

In addition to medical services from Dupont Hospital and Children’s Specialized Hospital, Garbutt says Medicaid paid for a special stroller, diapers, and the medication needed to treat Breanna’s sometimes aggressive and unpredictable behavior. Most recently, Medicaid funded an assistive communication device that her family and therapists hope will allow Breanna to communicate more easily, thereby reducing her high levels of anxiety and challenging behavior.

“These things are definitely not optional for Breanna,” says Garbutt. “If Medicaid stops paying

for these things, I am in real trouble.” Garbutt is also grateful for the services and supports provided to her and her family through DDD.

Through the Positive Behavioral Support Network, Garbutt gets two hours a week of behavior help, at her home or in the community.

“Breanna has meltdowns in public,” Garbutt says. “She will hit me and throw herself on the ground. I cannot take her out by myself.”

Garbutt says she got family support services in the form of a one-time cash subsidy of \$1200 two years ago. “It helped out. But now it’s gone and the state has not got any more money for it.”

Garbutt says she would like to go back to work, but needs to know that Breanna is stable in school. “I need a school program that can handle her, and someone to watch her after school or at night so I can get a job. I need a respite program so I can have a break, or just some time to spend alone with my other daughter Stephanie.

“And, Breanna could really use sports or a recreation program that can handle her. There are a few, but I cannot afford them. There is a horseback program in Toms River that costs more than \$2000 for the year, but we can’t even afford the gas to get there.”

“Breanna is pretty much with me all the time, and I am her friend,” says Garbutt. “But I worry about the future. What if something happens to me? Who will take care of her?”

THE BRADLEYS

Twenty-year old Samantha Bradley attends school at the Passaic County Elks Cerebral Palsy High School. Every day she rides a bus from her home in Haledon to the special education school in Clifton.

Next May, Samantha will turn 21 and graduate. Samantha’s mother, Stephanie Bradley, does not yet know what her daughter will do, or where she will go. She only recently learned that her daughter’s entitlement to services would come to an end at 21.

“Somebody should have sat me down when she was 16 and told me this was coming. I had no idea,” says Bradley. “To tell you the truth, I never saw this coming.”

Bradley, a single mother of two, says her family does not have many support services. She said DDD paid for a summer program for Samantha a few years ago, but the family has not received any support services since.



Samantha Bradley, her mom Stephanie (left) and sister Keyaria

“She gets help from Medicaid,” Bradley says. “They pay for a home health aide who takes care of her when she gets home from school.”

When the aide does not show up, Samantha’s sister, 15 year-old Keyaria, helps out. “She is a big help. I know she really loves her sister, but it is not fair to rely on her for all that.”

Bradley works as a medical biller at a mental health clinic near her home. “This is a great company—I have been blessed,” she says.

Bradley says she took a big pay cut when she accepted the position, but it has been worth it. “I get to be closer to home, and have a lot of flexibility. Sometimes, I can even bring Samantha to work with me, if the school is closed.”

Recently, Bradley was invited to a seminar where she learned about DDD’s Real Life Choices. “I was impressed. I thought ‘that’s what I want for her.’”

“Samantha has been in a daily routine for years. I still want her to get an education. She still will need therapies and learning. She cannot take care of herself. But I really want her to have more of her own life.”

Bradley says her life will be turned even more upside down if Samantha does not have services when she graduates next spring. And while she likes the idea of Real Life Choices, Bradley says the idea of having to plan and structure everything is daunting. **P&F**

AT THE FEDERAL LEVEL

By Jonathan Jaffe

With a new President moving into the White House and the 111th Congress being sworn in down the road, national advocacy groups and lobbyists are writing their priority lists for millions of Americans with developmental disabilities, focusing on independent living and the need for additional services.

The prospect of a new administration is cause for renewed optimism among many advocacy groups. “The disabilities community is very hopeful. A new presidency means new opportunities for improvement and change,” said Andy Imparato, president and CEO of the American Association of People with Disabilities (AAPD).

Imparato thinks big about potential reforms. The ultimate change he said would be an overhaul of “the four primary ways” government delivers money and services to people with developmental and other disabilities.

“Social Security Disability Insurance, Supplemental Security Income, Medicaid and Medicare were all designed at a time when the two signs of being disabled were that you were poor and couldn’t work,” Imparato said. “And each still has these arcane rules.”

“Times have changed. So the Big Kahuna would be to reform the arcane rules so entitlements are consistent with the goals of the Americans with Disabilities Act,” Imparato said. “People with disabilities should not have to live in poverty and should be able to work without losing benefits.”

While each advocacy group, organization and association for people with developmental and other disabilities has its own “wish-list” of federal legislation, most have united behind a set of proposals to improve the way people live and receive services.

The focus is to help more people with developmental disabilities move from nursing homes and institutions into community-based settings, to live as independently as possible, and to help them receive the long-term care and support they need to do so.

Beyond that, insurance reform and education initiatives are among their primary concerns.

Chief among the 2009 priorities is to have Congress adopt and the new President sign the Community Choice Act.

The Community Choice Act would amend Title XIX of the Social Security Act to give those eligible under Medicaid for nursing home services or other institutional care a choice of equal access to community-based services and supports and to restructure the funding to support those choices.

“Of course, we want Community Choice passed,” said Arkansas-based self-advocate Julie Petty, a long-time proponent of independent living. “Most people with disabilities don’t belong in nursing homes or institutions and they don’t want to be there.”

“If they had a real choice, they would choose not to be there,” said Petty, past-president of the Self Advocates Becoming Empowered (SABE) group. “No matter what our disability, our quality of life is better in our own home or at home with our families.”

Justin Chappell, spokesman for the Washington D.C.-based National Council on Independent Living (NCIL), one of the oldest, largest cross-disability grassroots advocacy groups, agreed. “Getting Community Choice passed goes to the core of our independent living philosophy. And it’s a law that makes financial sense.”

According to NCIL statistics, the average cost of a private nursing home room in the U.S. is \$75,000, yet the cost of a full-time home health aide averages \$39,500 per year.

“So, the savings to states and the federal government by simply allowing people to receive services in their homes would allow for expanded healthcare services,” Chappell said. “And it would eliminate lengthy waiting lists of people seeking services anywhere but in an institution. It’s definitely our top priority.”

Val Bradley, president of the Massachusetts-based Human Services Research Institute, a consulting group that works with state agencies and advocacy groups for people with disabilities, said that whatever can be done in Washington D.C. to give people with developmental and other disabilities more choice and more voice in how federal resources are distributed on their behalf would “be a big step forward.”

“The real prize,” said Bradley, “would be to knit together Community Choice, real choice system change grants, money-follows-the-person grants . . . knitting together all these things into a permanent, cohesive set of options for people with disabilities.”

Charles “Chaz” Mosley, associate executive director of the National Association of State Directors of Developmental Disability Services, said states are now wrestling with a wide range of issues. Among the top priorities for a new administration, he said, has to be an expansion of real-choice system grants and money-follows-the-person grants.

“Through these programs, people who need long-term care and prefer to live in their own homes or in their communities would have a chance do so,” said Mosley. “States get more for their money by offering people with disabilities more control over how and where they receive Medicaid-funded, long-term care.”

KEEP WASHINGTON FOCUSED

Texas attorney Jeff Sell, the Autism Society of America’s new vice president of public policy, said action on these initiatives is long overdue, and keeping Congress and a new president focused on disabilities issues should be a primary goal for advocacy groups.

“Staffers on the Hill have already put in an enormous amount of time, blood, sweat and tears to get things like the Community Choice Act or IDEA (the Individuals with Disabilities Education Act) through the committee process,” Sell said.

“There’s wide bipartisan support for the Community Choice Act,” he said. “Both sides of the aisle agree it’s a whole lot cheaper to provide trained support and services to people with dis-

abilities in their own home rather than in brick-and-mortar institutions. Then, somehow, poof! This legislation never made it onto the floor for a vote. It’s frustrating.

“Most of our politicians have very noble intentions,” he added. “Our congressmen and senators seem to agree that things like the Community Choice Act or IDEA are the right way to go. But, sometimes Congress gets a little goofy.

“They vote in favor of authorizing legislation. Then, they never get around to (voting for) the appropriation bill to pay for it. That’s what happened to IDEA,” Sell said. “They get distracted. A war flares up. The economy tanks. Then, a new election cycle is upon us.

“We end up seeing all these campaign commercials saying they supported autism legislation or this or that legislation. What they don’t say is they never got around to paying for it. That’s what we now need them to do. We need to keep them focused,” Sell said.

THE “CLASS ACT”

Another key piece of federal legislation is the Community Living Assistance Services and Supports Act, or CLASS Act.

The legislation would create a new national insurance program financed by voluntary payroll deductions to provide cash benefits for adults who become severely disabled. The benefits would help pay for services and supports like housing modification, assistive technologies, personal assistance services and transportation.

“Again, the CLASS Act is a priority. It’s at the heart of our core values,” said Chappell of the National Council for Independent Living. “People with disabilities can creatively use the flexible cash benefit to purchase services, supports and technology. Beneficiaries would be able to choose how to best meet their own needs.”

Imparato of AAPD agreed. “The CLASS Act represents a new approach to expanding access to services for people with disabilities without further burdening Medicaid because it uses a new funding stream.

“Too many people are forced to live in poverty just so they can qualify for Medicaid to get the

care they need. The beauty of the CLASS Act is that it does not rely on Medicaid,” he added.

“That’s why it’s absolutely brilliant,” said Liz Savage, director of the Health and Housing Policy Disability Collaboration, the public policy and lobbying arm of The Arc of the United States and United Cerebral Palsy. “It’s financed through voluntary payroll deductions of \$30 per month with opt-out enrollment.”

“We view it as important public policy step to help people overcome barriers to independence they may confront due to physical and cognitive impairments,” Savage said.

MORE IDEA MONEY

Advocacy groups for people with developmental disabilities and their lobbyists say raising federal appropriations for IDEA is another important initiative they hope a new President and Congress act upon.

IDEA is a 1975 federal civil rights law designed to ensure that students with disabilities receive a “free, appropriate public education” in the least restrictive setting and receive supports tailored to their specific needs.

When IDEA was first enacted, Congress made a commitment to pay up to 40 percent of the average per-student cost for every special education student, but advocacy groups and education lobbyists point out that commitment has never been met.

“Congress is currently funding IDEA at less than 18 percent and school districts must come up with the rest,” said Marilyn Golden, policy analyst for the California-based Disability Rights Education and Defense Fund (DREDF).

For fiscal year 2008, the authorized funding level for IDEA was \$19.23 billion, but Congress only appropriated \$10.7 billion. Although that amount was \$200 million above 2006 levels, the federal share dropped from 17.6 percent to 17.2 percent.

Most advocacy groups are lined up behind the Maryland-based American Speech-Language-Hearing Association, which asked Congress for a \$2 billion increase in fiscal year 2009 appropriations for IDEA. If approved, that would bring the federal share of IDEA funding up to 20 percent, the highest level of federal funding support for students with disabilities.

Part of the reason Congress never fully-funded IDEA is because “it competes with federal funding for smaller classes, enrichment programs like art, music, building improvements, after-school tutoring, etc.,” said Julia Epstein, director of development for DREDF.

“IDEA funding gets decided annually,” Epstein said. “To fully fund IDEA in an ongoing way would make it a funding mandate and Congress would lose control.”

Safeguarding the level of Medicaid funding in light of rocky economic times is also on the table.

“Medicaid is financed jointly by the federal and state governments through tax revenue. In our current economic downturn, if states can’t find other revenue sources, they could resort to cutting benefits, terminating enrollment or reducing provider reimbursement. None of which are good options,” explained Savage.

Advocates are also lining up behind a bill to temporarily increase the federal medical assistance percentage (FMAP) to Medicaid. Rep. Frank Pallone (D-NJ) introduced a bill earlier this year to raise the federal share.

“But, the measure came too late to be included in the federal stimulus package. It will be back on the table again next year. It’s critical to maintain Medicaid services,” said Savage.

Golden agreed, but also said “certain insurance reforms are desperately needed,” referring to a pending bill called the Medicare Durable Medical Equipment Access Act.

“We would like improved Medicare coverage for durable medical equipment like wheelchairs and walkers, and for prosthetics and orthotics. There’s some coverage now, but it’s not enough,” said Golden.

Also on the “wish lists” for advocacy groups, particularly those representing people with autism, are separate bills that two New Jersey lawmakers have proposed.

First, is the Helping HANDS for Autism Act of 2008 that Sen. Robert Menendez (D-NJ) introduced last spring to help guide families seeking services and care through the Internet.

The Helping HANDS bill would also pay to train first-responders, including police, fire departments, and emergency medical technicians, to recognize and help people with autism and other cognitive behavioral disabilities.

THE OTHER FEDERAL LEGISLATIVE PRIORITIES CITED BY VARIOUS ADVOCACY GROUPS

- **Expand the federal Real Choice Systems Change (RCSC) Grants for Community Living.** Since fiscal year 2001, the Centers for Medicare & Medicaid Services (CMS) awarded about \$270.3 million in Real Choice grants to enable states and non-profit agencies to help people with disabilities receive long-term medical care and supports in homes and community-settings rather than in institutions and nursing homes.
- **Increase funds to the Money-Follows-the-Person (MFP) Rebalancing Demonstration,** enacted under the Deficit Reduction Act of 2005. The program helps states reduce their reliance on institutional care while developing community-based, long-term care opportunities, enabling the elderly and people with disabilities to fully participate in their communities.
- **Re-authorize and reform the State Children's Health Insurance Program (SCHIP),** enacted in 1997 to insure low-income children who are ineligible for Medicaid but whose families cannot afford private insurance. Advocacy groups want to increase coverage to more children and eliminate limits on mental health care for children that many states have imposed, including caps on inpatient and outpatient care, annual cost-restrictions and limits on diagnostic services. President George W. Bush vetoed two earlier versions of the SCHIP bill saying they represented the first step toward "government-run health care for every American."
- **Amend the Developmental Disabilities Assistance and Bill of Rights Act (DD Act)** to fund self advocates in addition to the money the act already provides for state developmental disabilities councils; University Centers for Excellence in developmental disabilities education and research; and for agencies that provide protection and advocacy services.
- **Enact the 21st Century Communications and Video Accessibility Act of 2008,** a comprehensive disabilities bill to amend the Communications Act to ensure that new Internet-enabled telephone and television services are accessible to and usable by people with disabilities.

Menendez's legislation would also, under the federal Department of Housing and Urban Development, create a task force of autism advocacy groups, community-based organizations and parents to develop a housing demonstration grant program for adults with autism and other cognitive disabilities.

Though she declined to comment on Menendez's specific proposal, Golden agreed that "there is far too little affordable housing available for people with disabilities."

"We would want any HUD initiative to steer clear of segregated subsidized housing," Golden cautioned. "People with disabilities are uneasy with the notion of public housing specifically for people with disabilities. The goal should be to provide more subsidized affordable housing that integrates them into a community, not segregates them from it."

Second is the Teacher Education for Autistic Children Act of 2007, or TEACH Act, that Rep.

Chris Smith (R-NJ) proposed to amend the Internal Revenue Code. The bill would provide refundable tax credits for education related to autism spectrum disorders. The purpose of the legislation is to increase the number of teachers with this expertise.

"Helping HANDS and the TEACH Act are absolutely huge for us," said Sell, of the Autism Society of America. "The TEACH Act would offer real incentives, including loan forgiveness, scholarships and tax breaks for young people on the road to becoming teachers, who focus on autism education.

"And Senator Menendez's bill is a navigator," he added. "The number of available services out there for people with autism or with any developmental or intellectual disability is broad and confusing. This would help simplify it and go a long way toward providing affordable housing for people with autism spectrum disorders." **P&F**

Donna Icovino

She Made Herself Visible

by Maryann B. Hunsberger

Following the struggles her family faced to get the right mental health services for her son Michael, who also has autism, Donna Icovino took action that led to the creation of the (Department of Human Services) Commissioner's Task Force on Dual Diagnosis.

Icovino began evaluating what had gone wrong with Michael's situation. She spoke with provider agencies and attended family group meetings. She found misdiagnosis and mistreatment of individuals with dual diagnosis—those with a developmental disability, and mental health and behavioral issues—to be a pervasive problem.

"The crisis centers were revolving doors where they never remedy problems," said Icovino.

She decided that "everyone needed to work together to create a better system."



Icovino wrote a proposal for the establishment of a dual diagnosis task force to study these issues. She began meeting with public officials, including DDD Assistant Commissioner Kenneth Ritchey and two of the governor's policy advisors.

"From there, things began to take shape."

Department of Human Services (DHS) Commissioner Jennifer Velez approved the Commissioner's Task Force on Dual Diagnosis, which convened in January 2008, almost four years after Icovino's quest began.

"I'm just a mom. I'm not a lawyer or a public speaker. I have no background in professional advocacy. I just made myself visible. I attended as many meetings as I could and made people aware of the issues. I introduced myself to everyone and asked to meet with anyone in charge. I spoke with

legislators. I found many people who knew the system needed reform.”

Icovino, who is now co-chair of the Task Force, said writing her proposal for it was a joint effort.

“This was a real collaboration. Many people made suggestions and changes. And it will take an additional collective effort to implement the recommendations of the Task Force.”

“By putting myself out there, I created the opportunity. I didn’t want what happened to Michael to happen to anyone else. I felt passionately that something needed to change.”

Michael Icovino, now 23, lives in a group home and works in a canine bakery business developed by Bancroft.

“He loves his job,” his mother said. “He participates in arts and crafts and a scrapbooking club. He attends cooking classes, plays Bingo, goes to the mall, sporting events, and movies. He engages in activities that anyone his age would enjoy. He comes home for some weekends and holidays. Michael has a fulfilling and productive life.”

But things were not always so.

Michael Icovino was diagnosed with bipolar disorder when he was 13. Behavior issues that had begun to emerge 4 years earlier but were attributed to the ongoing challenges of the autism became increasingly difficult to manage with behavior management and medications.

Icovino and her husband, also Michael, struggled to put the right combination of personal and professional attention together to help their son.

“We never saw any signs when he was younger. He was very sweet. He didn’t have tantrums or cry a lot or seem anxious. He was happy and he was never aggressive.”

Icovino began seeing changes in Michael’s personality about two years after the family moved to a new house.

For those first two years Michael was an active player in the neighborhood, riding his bike with the other kids and swimming in friends’ pools.

“All the kids gravitated to our house.”

Then, Michael began removing himself from his friends.

“He would stand on the outskirts of things that were happening. He looked sad to me.

“We became isolated. Suddenly, life was becoming extremely limited. As a family, we had always found solutions to the challenges brought by Michael’s autism. This time, we felt so powerless. We felt so guilty. It was heartbreaking.”

The greatest change we witnessed was the onset of anxiety and mild aggressive behaviors.”

Visits to doctors followed, along with trials of various medications. The aggression soon became more intense. His parents tried to modify his behaviors, as they had always done, with behavior strategies.

“Suddenly, this wasn’t working. The quick escalation surprised me and I didn’t know how to deal with it. We couldn’t control the aggression. It became increasingly clear to me that he couldn’t control himself.”

When the doctors, behavior management specialists and medications failed to help, the family began spending more time at home. Icovino could no longer drive with her son in the car, because he would become aggressive.

“We became isolated. Suddenly, life was becoming extremely limited. As a family, we had always found solutions to the challenges brought by Michael’s autism. This time, we felt so powerless. We felt so guilty. It was heartbreaking.”

The family also had a daughter to consider.

“Lauren is two years younger. We didn’t want her to miss out on her important things. My husband and Michael would sleep over at my parents’ house so Lauren could have friends over. Our lives were turned upside down.”

Icovino knew Michael was suffering, though he couldn’t talk about it due to difficulties with expressive language. “That was excruciatingly painful. I just had to observe what was going on and try to find the best treatments for him despite not knowing the cause of these problems.”



Michael Icovino and mom, Donna

Then Michael had a severe aggressive episode at home. His psychiatrist sent him to Children's Hospital in Philadelphia a few days before Christmas. "We were so desperate to help him that he entered the program right before the holidays."

The physicians weaned Michael from his medications and put him through a battery of tests. He remained at the hospital for five months.

That's when Michael was diagnosed with bipolar disorder. He was put on medications and the doctors devised a behavioral management plan.

"Before this, everyone just attributed his behaviors to puberty and autism. His correct diagnosis changed everything. Having him away from us for five months wasn't easy, but it was the best treatment he ever received."

Michael began living in a group home through Bancroft Neuro Health. This was a blow to his parents, who had expected him to move home. They realized, though, that this was the best setting for him, since his aggressive behaviors hadn't completely disappeared.

"I wanted him to have the most out of his life, but I realized being at home might limit him. He didn't have friends in the community anymore. His sister was busy with activities. If he lived at home, we would be back to sitting at home."

In March of 2004, Michael, then 18, had a behavioral crisis. He went to the hospital, but was returned to the group home because hospital staff said they couldn't serve someone with autism.

The next day, Michael had another crisis. Since the law mandates that group home personnel call 911 when an emergency occurs, Michael sped to the emergency room again.

Icovino arrived at the hospital to find Michael sedated and in restraints. After four hours of waiting, the staff said they were unequipped to deal with Michael. Unable to return Michael to his group home due to safety factors, Icovino tried to have her son trans-

ferred to Trinitas Hospital. Their acute care unit, which provides treatment to adults with developmental disabilities and mental illness, had no room.

A hospital clinician told Icovino that they would have to transfer her son to Ancora Psychiatric Hospital.

Icovino wanted to research the hospital to assure that they could treat her son properly, but was told she had no legal rights, despite being Michael's guardian.

"They moved him to Ancora against my will the next morning, instead of allowing me to bring him home. I felt that I had lost total control of his well-being. I followed the ambulance to Ancora where he was committed. It was, without question, the saddest day of my life."

Icovino felt there had to be a better way. Although her son is now stable and making good progress it was a traumatic and uncertain road to get an appropriate diagnosis and an appropriate plan in place.

The Icovinos had learned the hard way that the state's capacity to deal with mental health crises for people with developmental disabilities is sporadic at best. Icovino is hoping that the implementation of the Task Force recommendations will begin the long process of turning that situation around. **P&F**

Task Force Calls for Better Services

For People with Developmental Disabilities and Mental Health Needs

by Maryann B. Hunsberger

The Dual Diagnosis Task Force—looking into gaps in services for people with developmental disabilities, and mental health and behavioral issues—last month released a report calling for:

- county-based teams to oversee individual plans for services and community capacity to provide crisis management and prevention;
- training and incentives for professional development across the various services systems;
- Case management specializing in the needs of people with; and
- An ongoing systems' review process to ensure activities continue to adhere to the values and principals described by the Task Force.

The Task Force was convened by Department of Human Services (DHS) Commissioner Jennifer Velez in January at the urging of co-chair Donna Icovino—the mother of a son with autism and behavioral disorders—and other stakeholders.

T. Missy Balmir, DHS assistant commissioner of operations, serves as the other co-chair.

Balmir said the department is committed to reengineering the coordination of medical services for dually diagnosed individuals.

“Our efforts to serve this part of the dually diagnosed community are ongoing. There is a mutual obligation with the Division of Developmental Disabilities (DDD) and the Division of Mental Health Services to share and relay information internally to enhance responsiveness with services.”

The Task Force, which comprises families, provider agencies, self advocates, and public officials formed subcommittees to work on issues related to adults and children around collaborative services, best practices, and crisis care and prevention. Dr. Alison M. Lozano, executive director of The New Jersey Council on Developmental Disabilities, has served on the Task Force since its inception.

New Jersey Department of Human Services
Dual Diagnosis Task Force Report:



**Collaborating to
Provide Services
and Supports
for Children
and Adults with
Co-Occurring
Developmental Disabilities
and Mental Health/Behavior Disorders**

October 10, 2008

Submitted by:

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The Task Force presented its recommendations to the Commissioner of DHS in October 2008. For a full copy of the report contact the department or visit the state's web site.

"We are now starting to develop an implementation plan and have an executive oversight board at the Department to make sure these things happen," said Balmir. "We've been working closely with the Department of Children and Families for the child piece of the recommendations."

Nadezhda Robinson, director, Division of Child Behavioral Health Services, Department of Children and Families, said the biggest challenges have been developing a complete network of expert providers who can meet the particular needs of children and their families along a continuum of care.

"We are looking to develop in-home supports and in-clinic supports, since some children and families are best served by someone coming into the home, while others are best served by going to an office."

One related recommendation involves the expansion of crisis response capacities. Balmir

said some counties have these things in place, but they aren't statewide. "We are always looking to expand these resources to a level that allows us to serve all those who are in need."

Balmir said providers made the recommendation to use telepsychiatry through video conferencing. "They thought we could expand to serve more people using this technology. It's forward thinking because it's not in the traditional model."

Since it's important to have services available at different levels when someone is in crisis, the group recommends expanding community-based inpatient psychiatric and behavioral services.

"That way, the person can get immediate care and be stabilized and hopefully go back home instead of putting them right into a psychiatric hospital," said Balmir.

The Task Force hopes to create a "step-down" level of residential care following inpatient treatment. This would be one way to expand that community-based care. "This means they would still receive services they need, but not necessarily in a psychiatric hospital."

Julie Caliwan, a mental health liaison for DDD, is part of a team that staffs and coordinates the Task Force. She said, "We hope we could increase our service capacity so people don't have to go into crisis. But, if they do, we want to prevent them from going into state psychiatric hospitals or developmental centers. We want to keep people in the community."

Caliwan said the group explored the services model used by the Kennedy Krieger Institute, in Baltimore, Maryland. "They have a team approach to evaluation where they look at multiple factors that could influence a behavior. They come together and find one integrative approach to planning. It's so different from going from one specialist to another, where you can't guarantee that they will have the same approach. Individuals with more complex behaviors will more likely need such a comprehensive approach. The Task Force hasn't formally incorporated this recommendation yet, but everyone feels that having this in New Jersey would be beneficial."

Caliwan said when New Jersey families send their children to Kennedy Krieger, it's hard to maintain the same level of service when they

return home. “Back in New Jersey, they miss the expertise that was all in one location. The Task Force, as a priority service recommendation, talked about creating a service center that had a comprehensive array of mental health and behavioral management treatment in one place. Comprehensive evaluations to create a service plan should be available for anyone with a dual diagnosis in New Jersey.”

Another recommendation is to train direct care staff working with people with dual diagnoses, Caliwan said, “Many people in the community apparently don’t know what a dual diagnosis is. They have been hesitant because they feel they don’t know how to serve this population. We want to train them so they can feel confident in treating this population to support families when something serious is happening.”

Robinson said specializing and integrating services into the community is an overriding challenge. “We want to be sure that our traditional behavioral health providers feel comfortable serving this population. We additionally want those providers serving those with dual diagnosis to be comfortable serving those who also have mental illness.”

The Task Force is also looking to develop advocates. “Each county currently has an organization helping families to advocate for children with mental illness. Since children with dual diagnosis require specialization in treatment and advocacy, I’d like the existing resources to be prepared to serve children with dual diagnosis. Once we finish training the advocates, they can serve families whose children have dual diagnosis,” said Robinson.

Some training has already started through a grant. Robinson, said, “One Task Force recommendation is that New Jersey develop an integrated strategy for responding to crisis. In the child world, our strategy will be multilayered. We will have six trainings next month toward helping providers learn to treat dually diagnosed children. The grant we awarded is providing these trainings. Our providers want to be able to do this work well and deliver good care. We will do this training every month for at least a year. We hope to integrate this into our routine budget after that.”

The Task Force also hopes to develop clearer guidelines in respect to Danielle’s Law, which mandates that group home staff call 911 when someone is in crisis. “We learned that it is very complicated when a provider is trying to gauge what is a life threatening emergency or what is a behavioral issue. This training would let providers and professionals who come into contact with individuals with a dual diagnosis know what to do,” said Balmir.

The Task Force hopes to create a “step-down” level of residential care following inpatient treatment. This would be one way to expand that community-based care.

Balmir will continue to work with the Executive Oversight Board, assuring that they achieve their goals. “If information is needed from Medicaid or Mental Health, we will help facilitate this, for instance.”

As for Icovino’s continuing role, Balmir said, “Donna will continue to advocate and hold the Department responsible for doing what we said we were going to do. If we could clone Donna, that would be great. She really is a clear advocate who has helped everyone learn that we are trying to get to the same place to serve the community better.”

Deborah Fliller, Liaison for Special Populations, Division of Child Behavioral Health Services, Department of Children and Families, said that perhaps the most important step has already taken place. “The convening of the task force was the most important thing that happened. It elevated this issue to a level of concern and importance.”

Robinson agreed. “Everyone is on that task force from parents to self advocates to providers. This step alone is huge for New Jersey. It’s a quantum leap forward.” **P&F**