

A publication of the New Jersey Council on Developmental Disabilities

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New Jersey Groups File Lawsuit to Advance Inclusive Education

In a lawsuit filed on June 27 in U.S. District Court, four groups – The Statewide Parent Advocacy Network (SPAN), the Arc of New Jersey, The Education Law Center and New Jersey Protection & Advocacy – claim leaders in the New Jersey Department of Education (NJDOE) are violating the rights of students with disabilities by failing to enforce IDEA’s “least restrictive environment” (LRE) provision.

For nearly two decades, monitors from the U.S. Department of Education have cited New Jersey on a range of issues related to IDEA’s “LRE” provision. The lawsuit charges the defendants with failure to supervise, train, monitor and ensure that districts implement the LRE provisions of IDEA, and failure to correct widespread

continues on page 5**Capital Update****State Budget Offers Some Hope for People with Disabilities and Their Families**

Early this summer, leaders in Trenton finalized the State’s \$33.3B budget for 2007-2008. Spending increases – the few that passed – are aimed at improving services for people with disabilities, children and veterans.

The state budget includes \$11B in aid for education, an increase of \$580M over the current year. \$948M is earmarked for special education categorical aid. The budget also includes \$4.5M in grants for school districts to develop or enhance their special education programs to help build local capacity for inclusive education.

The Division of Developmental Disabilities (DDD) received a \$10M increase to help build community capacity. Funds will go to expand DDD’s ‘Real Life Choices’ initiative to serve 150 more people; continued expansion of DDD’s ‘Transition from School to Adult Life’ initiative; expansion of adult day programs to serve an additional 150 people; and \$1.1M increase for Family Support Services. Funds are also earmarked for a modest waiting list reduction initiative, which will place 124 people over a 4 year period.

The 2008 budget also included \$5M in funds for autism-specific research and services, including a grant to expand vocational and social services to young adults with Asperger’s syndrome, and statewide project to help adults with autism.

The budget provides funds to help roughly 100 people now living in state Developmental Centers move into community settings. This initiative is in addition to money allocated last year, which called for spending \$50M over a three-year period to implement the state’s Olmstead Plan, which details how New Jersey will support people as they move out of institutions and into the community.

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council Profile

Maria Teresa Abinader will tell you that her 5 year-old son's developmental disability is only part of the challenge that she and her family face every day. As a Latina, she says that family issues, culture and language barriers have added a layer of difficulty to her quest for services and support. "Latino children have a double handicap," she said, "disability *and* the language and cultural barrier."

Maria Teresa brings that unique perspective to the Council on Developmental Disabilities as one of the newest members appointed by the Governor to the Council.

"We discovered that there are friends and professionals who truly care and are culturally competent. They made the biggest difference of all."

A resident of Edison, Maria Teresa has four children. Luli, her youngest, is 5 and has an autism spectrum disorder and other medical conditions. When he was younger, Luli would have long periods of uncontrollable tantrums.

Maria Teresa recalls how

he lived in his own world: "We only knew of him by his inappropriate laugh or gesture, words and phrases without sense that sounded like a foreign language," she said. That was when she called the State Regional Early Intervention Office and began receiving early intervention services.

"Culture played a big role with my son's developmental disability," said Maria Teresa. "Some family members refused to admit that there was anything wrong. I shared my worries with my mom and she advised me to give him fried chicken butt from the live poultry place, not frozen from the supermarket. I reached out to my aunt, and she suggested I rub egg whites on his joints so that he would get stronger. I told my cousin, she said to put him in a full day school. According to her, he spent way too much time with me. That is how we do things in my culture, we reach out to family first and then to others."

Maria Teresa Abinader



"I felt abandoned," said Maria Teresa. "Nobody wanted to admit that my child had a developmental disability and I was left to face and embark on this journey alone." Even Luli's father insisted that the professionals were mistaken.

Once she received the label for Luli's misunderstood behaviors, it became Maria Teresa's a mission to advocate for him. "I wanted to cultivate awareness not only for my son, but for all the families that I met along my journey, especially the Latinos."

Maria Teresa and her family found support groups and professionals to help. "We wouldn't have gotten anywhere alone," she said. "We discovered that there are friends and professionals who truly care *and* are culturally competent. They made the biggest difference of all."

Maria Teresa has channeled her experiences into action as a community leader and views her role on the Council as part of that process. She engages in outreach to families, working to cultivate awareness of the importance of cultural competency. She has taken part in conferences and other information sharing opportunities to help others, and provides technical assistance.

Maria Teresa says that her extended family still does not understand – largely due to the language barriers, cultural beliefs, and degrees of ignorance. "This is very painful and lonely, but at the same time it gives us the opportunity to teach, and hopefully some day we'll generate change," she added.

Maria Teresa recommends that families turn to a website:

www.manitasporautismo.com

NJCDD is beginning the process of developing more materials and resources to better serve, support and involve New Jersey's Spanish-speaking citizens whose lives are affected by a developmental disability. In the coming months, watch for more information about our work in this important area. To initiate this effort, Maria Teresa Abinader's story appears in this issue in both English and Spanish.

NJCDD está comenzando a desarrollar más recursos y materiales para hacer participar, apoyar y servir mejor a los ciudadanos de habla hispana de Nueva Jersey cuyas vidas se encuentran afectadas por la discapacidad de desarrollo. En los próximos meses, podrá obtener más información sobre nuestro trabajo en esta importante área. Como una forma de promover esta iniciativa, se incluye en esta publicación la historia de María Teresa Abinader en inglés y español.

María Teresa Abinader

María Teresa Abinader contará que la discapacidad de desarrollo de su hijo de 5 años es sólo una parte de los desafíos que ella y su familia enfrentan cada día. Ella dice que, por ser latina, los problemas familiares, las diferencias culturales y la barrera lingüística hacen que encontrar apoyo y servicios sea aún más difícil. “Los niños latinos tienen una desventaja doble”, afirmó, “la discapacidad y las diferencias culturales y lingüísticas”.

Como uno de los miembros más nuevos designados por el Gobernador del Consejo, María Teresa acerca esta perspectiva única al Consejo de Discapacidades del Desarrollo.

Ella tiene cuatro hijos. Luli, el menor, tiene 5 años y padece de un trastorno del espectro autista y otras enfermedades. Cuando era más pequeño, Luli tenía largos períodos de berrinches incontrolables. María Teresa recuerda cómo su hijo vivía en su propio mundo: “Sus únicas expresiones eran risas o gestos inadecuados, palabras o frases sin sentido que parecían de una lengua extranjera”, afirmó. Fue entonces cuando ella llamó a la Oficina de Intervención Temprana regional del estado y comenzó a recibir servicios de intervención temprana.

“La cultura desempeñó un papel importante en la discapacidad del desarrollo de mi hijo”, dijo María Teresa. “Algunos miembros de la familia se negaban a admitir que algo estaba mal. Comenté mis preocupaciones a mi madre y ella me aconsejó que le diera trasero frito de pollo de criadero, no de pollo congelado de supermercado. Hablé con mi tía y me dijo que frotara clara de huevo en las articulaciones de mi hijo para que se fortaleciera. Le comenté a mi prima y me dijo que lo mandara a una escuela de jornada completa. Según ella, mi hijo pasaba demasiado tiempo conmigo. Así es como actuamos en nuestra cultura, primero consultamos con nuestra familia y después con los demás”.

“Me sentía abandonada”, contó María Teresa. “Nadie quería admitir que mi hijo tenía una discapacidad de desarrollo y me dejaron sola en el camino de enfrentar y sobrellevar esta situación”. Incluso el papá de Luli insistió que los profesionales estaban equivocados.

Una vez que se identificó lo que producía el comportamiento incomprendido de Luli, María Teresa comenzó a defender a su hijo. “Quería generar una concientización no sólo por mi hijo sino también por todas las familias que encontré a lo largo del camino, especialmente de latinos”.

María Teresa dijo que ella y su familia encontraron profesionales y grupos de apoyo que los ayudaron. “Creo que no hubiéramos podido solucionar nada solos”, afirmó. “Descubrimos que existen amigos y profesionales que realmente se preocupan y que son culturalmente competentes. Ellos marcaron la diferencia”.

María Teresa ha volcado su experiencia desempeñando un rol activo en la comunidad y considera que su rol en el Consejo forma parte de ese proceso. Se dedica a ayudar a las familias y trabaja para generar conciencia sobre la importancia de la competencia cultural. Brinda asistencia técnica y ha participado en conferencias y en otros eventos en los que se comparte información para ayudar a los demás.

María Teresa dice que sus familiares aún no comprenden la situación debido a la barrera lingüística, las creencias culturales y los niveles de ignorancia. “Esta es una tarea muy dolorosa y solitaria pero, al mismo tiempo, nos permite brindar conocimiento y esperamos generar un cambio en el futuro”, agregó.

Recomienda que las familias ingresen al siguiente sitio web: www.manitasporautismo.com

Remembering Gregory G. Mizanin, 1955 - 2007

by Norman Reim

Greg Mizanin, communications specialist and graphic designer for the Council for 21 years, passed away over the July 4th holiday of natural causes.

Greg was a professional and emotional anchor for the staff at the office. He often crossed over from his regular duties-which included creating everything related to the “look” of the Council and all its projects-helping everyone with just about anything else they needed. We use to joke about it, quoting a well-known section of state upper-management employment guidelines - “...and other duties as required.” Required or not, Greg would always step in with unassuming grace and goodwill.

Greg came to work at the Council in April of 1986. He began the Council’s long record of quality publications with the launching of Interface. In 1989, he received a Communications Award from the National Easter Seal Society and the American Association of Disability Communicators and was honored during a ceremony at “Tavern on the Green” in Central Park. He then spearheaded the Council’s own awards to news organizations for the coverage of disability issues, enlisting the help of CBS newscaster, Bree Walker, as emcee of the event.

Throughout a transition, Greg picked up the mantle of the Council’s resources and referral efforts, publishing an essential guide to disability agencies and services, which became the Resources Guide now published by the state Division of Disability Services.

From the mid-1990’s, Greg was the “go to” guy here at the Council for layout & design of conference brochures, signs, programs, events, newsletters, the Council table display, annual reports, certificates, convention banners, etc. We would give him basic text and ideas of what was needed and ask Greg to “work his magic.” The end products would always surpass our vision. Greg edited the Council’s newsletter, was our back-up photographer and our web master. And, of course, he designed the magazines “People with Disabilities” and “Families,”

and created the new look when those were combined into one publication – “People & Families.”

Greg will be missed by all who knew him. While he can never be replaced, we will do our best to carry on here at the Council, doing the worked he loved and supported so well.



“Greg was a professional and emotional anchor for the office.

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The Council’s Monday Morning Newsletter is a publication of the New Jersey Council on Developmental Disabilities.

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The Council is a compilation of news from various sources, organized to inform people with disabilities about policies, programs, laws, trainings and events. This publication and others published by NJCDD are available in alternate accessible formats. Please call the Council for more information.

New Jersey Groups File Lawsuit to Advance Inclusive Education

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practices that violate the rights of students with disabilities. The suit contends that the NJDOE facilitates the continued placement of students with disabilities in self-contained classes by approving such classes and by approving the construction of new self-contained buildings.

The complaint describes six different students with disabilities whose districts failed to provide appropriate supports and services in general education classrooms. It claims that “merely placing children with disabilities in general education classes without effective services and support can lead to great harm,” including retention due to poor grades or conversely, promotion to the next grade without obtaining educational benefit.

The attorneys for the plaintiffs are asking the court to require NJDOE to take a wide range of actions to better educate children with disabilities in the least restrictive environment, in areas such as licensing, funding, training, technical assistance, facilities issues, monitoring and timely correction of non-compliance. In addition, they are asking that the court appoint a special master to monitor inclusion by local districts.

State Budget Offers Some Hope for People with Disabilities and Their Families

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Community-based providers were successful in securing a 3% increase in contracts, which will take in January 2008. Agencies that provide early intervention services to children under the age of three and their families will also receive a 3% increase.

The Division of Disability Services saw a \$3.5M increase for the Personal Assistance Services Program (PASP), which will eliminate 150 people from its waiting list. The Medicaid budget saw an increase of \$5M for Medicaid pediatric ‘fee-for service’ rates. The impact of this increase remains unclear because Medicaid has not yet determined which rates will increase in 2008, or by how much. Part of the disability community’s advocacy effort this year was aimed at avoiding Medicaid “co-pays.” Such co-pays would have forced consumers with disabilities to pay up to \$80 a month for prescription drugs, outpatient hospital services, some emergency room visits and medical day care.

The author wishes to thank Lowell Arye at the Alliance for the Betterment of Citizens with Disabilities for his assistance with this article.



Resource Desk: People with Disabilities Find a Ride Online

People with disabilities have a new resource to help them find transportation to work, school and other activities.

Through a federal grant from the Centers for Medicare & Medicaid Services (CMS), the Department’s Division of Disability Services now offers “NJ Find A Ride” at www.njfindaride.org.

NJ Find A Ride contains information about a variety of public and private transportation options,

availability and costs. If a user needs a ride, they may submit information about their destination and when the ride is needed. Transportation providers can also register on the NJ Find A Ride website to become a part of the available resources for users.

The website provides links and phone numbers to transportation resources in New Jersey and helps users better understand the range of accessible transportation services.



Community Calendar

- September 15 "Stand Up, Stand Tall and Be Brave" Annual Statewide Conference. Sponsored by the NJ Self-Advocacy Project and NJ/USA. 9 a.m. to 4 p.m. The Doubletree Hotel, Somerset, NJ. 732-926-8010, http://www.arcnj.org/summer_2007.pdf
- September 27 NJCDD Public Meeting; 10 a.m. to 3 p.m.; Lafayette Yard Marriott Conference Center, 1 West Lafayette Street, Trenton. 609-292-3745, <http://njddc@njddc.org>
- October 12 "Behavioral Challenges: Integrated Behavioral and Medication Interventions." Sponsored by The Boggs Center on DD, 9:30 a.m. to 12:30 p.m., Woodbridge Hilton, Iselin, NJ. 732-235-9325, http://rwjms.umdnj.edu/boggscenter/training/dd_lecture_series.htm
- October 19 "Your Place or Mine?" - Exploring Affordable Housing Options That Work!" Sponsored by The Boggs Center on DD, 9:30 a.m to 12:30 p.m. Woodbridge Hilton, Iselin, NJ. See above contact information.
- October 23 6th Annual Transition Conference; Sponsored by Allies Inc. 8 a.m. to 3:30 p.m. The Pines Manor, Edison, NJ. 609-689-0136, <http://www.alliesnj.org>
- October 30 "Effective Services for Individuals with Intellectual Disabilities and Mental Health Needs." Sponsored by The Boggs Center on DD, 9:30 a.m. to 12:30 p.m. , DoubleTree Guest Suites, Mt. Laurel, NJ. See above contact information.

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