

NJCDD

NJ Council on Developmental Disabilities

the Council's

Monday Morning Newsletter

A publication of the New Jersey Council on Developmental Disabilities

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Candlelight Vigil



On Friday, October 26, New Jersey advocates will gather for a Candlelight Vigil in remembrance of people with disabilities who, without choice, lived and died in institutions. The evening will include community speakers, a wall of remembrance, group reflections, prayer, song, and a moment of silence.

The vigil will take place in Princeton from 6:00 to 8:00 pm on the front lawn of Nassau Presbyterian Church. The event is organized by SWATT, Seeking Ways Out Together Teams and is co-sponsored by Catholics with Disabilities Network and the NJCDD.

Please call Jane Dunhamn, 609-984-3379 to register your participation.



Capital Update

Election Offers New Jersey Voters a Chance to Make History



A YES VOTE ON QUESTION #4 WOULD CHANGE THE STATE CONSTITUTION

Since 1844, our state Constitution has used the terms “idiot” and “insane” to describe people with disabilities and mental illness who were thought to be not competent to vote. Advocates have long found this language to be stigmatizing and degrading; judges have said that the the language is so outdated and vague that it is not useful.

Now, the New Jersey legislature is asking voters to consider amending the Constitution. On November 6, 2007, voters in New Jersey will decide if the State’s Constitution should be revised to remove this outdated and offensive language. The new language would focus on whether a court had determined that the person lacks the capacity to understand the act of voting. The amendment - in the form of question #4 on the ballot this November - asks voters whether to remove reference to “idiots” and “insane” people.

Last year, advocates launched a campaign to change the State Constitution to remove these words. In June, the New Jersey General Assembly gave unanimous legislative approval to a resolution to do so; the state Senate also unanimously approved the same measure earlier this year.



*Thank you to
Senator Richard Codey
(D-West Orange)
for championing
this resolution in the
State Senate, and
Assemblymen Joseph
Cryan (D-Union) and
Jim Whelan (D-
Northfield) who
sponsored the
resolution in
the Assembly.*

continues on page 5

council Profile

Elaine Buchsbaum



In many ways, Elaine Buchsbaum of Hunterdon County has been preparing for her role as a member of the New Jersey Council on Developmental Disabilities for the last 32 years. She and her husband, Peter have three adult sons; the youngest, Matthew has an autism spectrum disorder.

Elaine comes to the Council with a long and impressive resume as an advocate, trainer, support coordinator and parent. She has been involved with the state and local Arcs for decades in a wide range of volunteer, leadership and staff positions. She has been active with COSAC and SPAN, where she worked as a trainer in special education.

Elaine's son, Matt was born in 1974 when there was little public awareness of autism. Matt was identified at 2 1/2 with a developmental delay. By time he was in grade school, professionals suggested that he had mental retardation, but the word 'autism' was not mentioned until Matt was 12.

"In some ways, it is unfortunate for Matt that he grew up when he did. No one really understood autism when he was younger," said Elaine. "Today, he would be diagnosed in a nano-second."

"I believe strongly that if the system does not work well for everyone, it won't work for anyone."

It was the lack of a definitive diagnosis, however, that led Elaine to become what she calls a "generalist." Because he was not diagnosed with autism until he was older, the Buchsbaums

relied on many generic services for Matt. "In some ways, that was a benefit," said Elaine. "Matt was part of a larger community and we learned to use a wide range of services."

Matt lives at home, but works and volunteers in his community, where Elaine and Peter take a very active

role in planning and coordinating his services. "Matt is at an age when he should be out on his own," said Elaine. "It is great that we can do this now, but there will come a time when we can't." She and Peter hope the service system will be ready when that time comes.

*"If New Jersey could just get the 'funding piece' of our system worked out so that **all** services for **all** people could be truly person-centered, we would have a great state service system..."*

Elaine is particularly excited to be involved with the Council at this point in time. "The Council has new leadership, new members and an opportunity to do great things," she said. Recognizing Elaine's unique background and perspectives, members appointed Elaine chairperson of the Planning Council, which develops the State Plan.

The State Plan describes the Council's goals in key areas such as employment, education, early intervention, transportation, housing and community supports, and is used to help determine which projects and grants the Council funds.

Elaine has always been interested in systems advocacy and is embracing the challenge. "I believe strongly that if the system does not work well for everyone, it won't work for anyone." She is particularly interested in seeing changes to the adult service system, where she recognizes limitations. "If New Jersey could just get the 'funding piece' of our system worked out so that all services for all people could be truly person-centered, we would have a great state service system. I hope I can be part of helping to make that happen," she said. "And I hope it is in Matt's lifetime."

Perfil del consejo: Elaine Buchsbaum

En la última publicación, el Consejo anunció su intención de comenzar a desarrollar más material para abastecer a los residentes de Nueva Jersey que hablan español. En apoyo a este esfuerzo, podrá encontrar en esta publicación el perfil de Elaine Buchsbaum en inglés y en español.

Elaine Buchsbaum, del condado de Hunterdon, ha estado preparándose de diversas maneras en los últimos 32 años para desempeñar su rol como miembro del Consejo de Nueva Jersey sobre las discapacidades del desarrollo. Ella y su esposo Peter tienen tres hijos adultos. El más joven, Matthew, padece de un trastorno del espectro autista.

Elaine se presenta en el Consejo con un currículum extenso y admirable como defensora, capacitadora, coordinadora de apoyo y madre. Durante décadas ha participado en las Arc (Asociaciones para ciudadanos con retraso mental) locales y estatales en una amplia diversidad de puestos como voluntaria, líder y miembro del personal. Participó activamente con el COSAC (Centro para Alcance y Servicios para la Comunidad de Autismo) y la SPAN (Red de Defensa de Padres), donde se desempeñaba como capacitadora en educación especial.

Su hijo, Matt, nació en 1974 cuando existía escasa concientización pública acerca del autismo. A los 2 años y medio de edad le detectaron un retraso del desarrollo. Cuando estaba en la escuela primaria, los profesionales sugirieron que Matt padecía de retraso mental, aunque no se mencionó la palabra “autismo” hasta que tuvo 12 años.

“De alguna manera, fue desafortunado para Matt crecer cuando tuvo que hacerlo. Nadie entendía realmente qué era el autismo cuando él era niño”, afirmó Elaine. “Hoy en día, lo diagnosticarían en un nanosegundo”.

Sin embargo, fue la falta de un diagnóstico preciso lo que llevó a Elaine a convertirse en lo que ella denomina “generalista”. Dado que a Matt no le diagnosticaron autismo hasta que fue mayor, los Buchsbaum tuvieron que depender de diversos servicios generales para Matt. “De algún modo, eso fue beneficioso”, dijo Elaine. “Él formaba parte de una comunidad más grande, y

aprendimos a utilizar una gran variedad de servicios”.

Matt vive en su casa, aunque trabaja y coopera en la comunidad donde Elaine y Peter tienen una participación muy activa en la planificación y coordinación de sus servicios. “Matt tiene una edad en la que debería valerse por sí mismo”, afirmó Elaine. “Es grandioso que podamos llevar a cabo esto ahora, aunque llegará un momento en el que no podremos hacerlo más”. Tanto Elaine como Peter esperan que el sistema de servicio esté listo para cuando llegue ese momento.

Elaine está particularmente entusiasmada con su participación en el Consejo en este momento. “El Consejo ahora cuenta con nueva conducción, miembros nuevos y una oportunidad para llevar a cabo grandes cosas”, afirmó. Al reconocer la trayectoria y las perspectivas únicas de Elaine, los miembros la designaron presidenta del Comité de planificación estatal del Consejo.

El plan estatal describe los objetivos a desarrollar en áreas fundamentales, tales como empleo, educación, intervención temprana, medios de transporte, vivienda y ayudas comunitarias, y se utiliza para determinar qué proyectos y subsidios financia el Consejo.

Elaine siempre se interesó por la defensa de los sistemas y por ello acepta el desafío. “Creo fervientemente que si el sistema no funciona adecuadamente para todos, no lo hará para nadie”. Le interesa particularmente ver los cambios en el sistema de servicio para adultos donde reconoce que existen limitaciones. “Si Nueva Jersey pudiera tan sólo hacer que la “pieza de financiamiento” de nuestro sistema funcionara de modo que todos los servicios para todas las personas fueran verdaderamente personalizados, tendríamos un muy buen sistema de servicio estatal. Espero ayudar a que eso ocurra”, dijo. “Y espero que suceda mientras Matt viva”.

Federal Grant to Help with Transition from Developmental Centers to the Community

New Jersey has been awarded a grant by the Centers for Medicare & Medicaid Services (CMS) to assist people with developmental disabilities now living in institutions to live and receive services in the community.

The five-year grant, which could total as much as \$30.3M, will help the State Division of Developmental Disabilities implement its Olmstead plan, *Path to Progress*, by covering a larger portion of the cost of services for people who move from developmental centers and nursing homes into the community. Olmstead is a 1999 U. S. Supreme Court decision affirming an individual's right to live outside an institution.

CMS awarded the grants to 13 states to help shift Medicaid's traditional emphasis on institutional care to a system that offers greater choice, including home and community-based long term care services. The increased federal matching funds will help New Jersey rebalance its long-term care system.

As in the regular Medicaid program, New Jersey must spend state funds in order to draw down federal funds. Medicaid traditionally pays up to 50 percent of the cost of care for individuals living in institutions. Under the grant, Medicaid will pay 75 percent of the costs for services for one year after an individual moves out of an institution.

The grant will be used to design programs that:

- Increase the use of home and community-based care.
- Eliminate barriers that prevent Medicaid-eligible individuals from receiving long-term services in the settings of their choice.
- Ensure that the Medicaid program can provide long-term care services to those who move from an institution to the community.
- Ensure that home and community-based long-term care services are monitored for quality, and provide for continuous quality improvement.

Free Training on Autism Offered for Parents and Professionals

Parents of Autistic Children (POAC), a Hazlet-based non-profit, is providing free training for parents and professionals in New Jersey.

POAC is a membership organization that offers science-based autism training programs for parents, teachers, para-professionals, direct services providers, and administrators.

POAC's current series of five workshops, each offered at several locations around the state, includes sessions on Teaching Functional Communication Skills, Structuring The Home Environment for Success, Teaching Cooperation and Reducing Problem Behaviors, Teaching Adaptive Life Skills in the Home, Increasing Social Opportunities for Children with Autism.

Workshops require registration. For more information, call 732-888-1000, or visit www.poac.net.

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.

Early Intervention Regulations Proposed

For years, advocates have been requesting formal rules to guide the delivery of Early Intervention Services for infants and toddlers with disabilities and their families

In response, the New Jersey Department of Health and Senior Services has proposed regulations for public comment. The rules are important because they formalize the Department's procedures and policies. In addition, the new administrative rules will formalize the due process procedures through the Office of Administrative Law, which also handles disputes for special education and adult services.

There are three public hearings. Each begins at 4:00 pm and ends at 7:00 pm:

Tuesday, October 9, 2007

St. Joseph's Children's Hospital • Paterson

Wednesday, October 10, 2007

Holiday Inn • East Windsor

Thursday, October 11, 2007

Clarion Hotel and Conference Center • Cherry Hill

Persons planning to speak should call Ms. Khalifa at (609) 777-7734. The public has until November 3, 2007 to send written comments. For more information, call (609) 984-7160.

The author thanks Mary Ciccone, Esq. and Lowell Arye for guidance with this article.

New Jersey Constitutional Amendment

continued from cover

Question #4 on the ballot will read:

- Shall the amendment of Article II, Section I, paragraph 6 of the Constitution, agreed to by the Legislature, revising the current constitutional language concerning denial of the right to vote by deleting the phrase "idiot or insane person" and providing instead a "person who has been adjudicated by a court of competent jurisdiction to lack the capacity to understand the act of voting" shall not enjoy the right of suffrage, be adopted?*

In addition to the ballot questions, all 40 seats in the State Senate and all 80 seats in the General Assembly are up for grabs.

Are You Ready? Are You Registered?

Citizens have until October 16, 2007 to register to vote in this election. Any U.S. citizen who is 18 by the time of the election, and who has lived in the county for 30 days before the election may register to vote. For more information on how to register to vote, log on www.state.nj.us/oag/elections/vote_doe.html, or call the 24 Hour Assistance Line (toll-free): 1-877-NJVOTER.



Resource Desk: New Directory of Services for People who are Deaf or Hard of Hearing

The New Jersey Department of Human Services' (DHS) Division of the Deaf and Hard of Hearing (DDHH) has issued its thirteenth edition of *Organizations Serving People with Hearing Loss in New Jersey*. The 80-page guide provides important consumer information on clinical, educational,

employment and advocacy services for people who are deaf or hard of hearing.

The directory is available online at: www.state.nj.us/humanservices/publications.html or by calling 609-984-7281 V/TTY or 609-984-7283 Videophone.



Community Calendar

- October 11 "DiscoverAbility" 2007 Governor's Conference on Employment for People with Disabilities; presented by the New Jersey Department of Human Services, Division of Disability Services. New Brunswick, NJ. 609-292-7800
- October 16 Last Day to Register to Vote**
- October 23 6th Annual Transition Conference; sponsored by Allies Inc. Edison, NJ. 609-689-0136, www.alliesnj.org
- October 26 Beyond the Autism Diagnosis: Effective Strategies for Home, School, and Life; sponsored by ASPEN/NJ; Iselin, NJ (732) 321-0880 www.aspennj.org
- November 1&2 National Family Caregiver's Conference/ NJ; sponsored by the Family Support Center of NJ. Manalapan NJ. www.fscnj.org
- November 2 Every Child, Every Day- Annual Statewide Conference; sponsored by ASAH. Atlantic City, NJ. 609-890-1400, www.asah.org
- November 6 Election Day - VOTE**
- November 29 New Jersey Council on Developmental Disabilities Public Meeting; Lafayette Yard Marriott Conference Center • 1 West Lafayette Street, Trenton, NJ. 609-292-3745, www.njcdd.org

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