

NJCDD

NJ Council on Developmental Disabilities

the **Council**

A publication of the New Jersey Council on Developmental Disabilities

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**Comments Invited on Rehabilitation Plan**

The U.S. Rehabilitation Services Administration (RSA) has developed a Strategic Performance Plan for the vocational rehabilitation (VR) program. The plan will ensure a long-term strategic focus on program performance, performance improvement, and outcomes for individuals with significant disabilities. RSA will use the plan to guide its administration of the VR program, and to address its basic challenges. By identifying goals and objectives linked to specific populations and high priority outcomes, the plan will assist RSA in monitoring progress of the VR program and provide targeted support to state agencies to help them achieve the desired outcomes.

These goals, objectives and related performance measures will provide

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**Effort Highlights Needs of Youth Transitioning from School to Adult Life**

During the course of budget hearings held earlier this spring, advocates for students with developmental disabilities and their families worked to raise awareness of the need to provide state funding for students making the transition to adult life after their secondary school education.

As part of that effort, the New Jersey Council on Developmental Disabilities provided a statement of the issues to members of the state legislature for hearings on the budget proposal for the Department of Human Services. The materials, collectively entitled *Transition from School to Adult Life: The Missing Link is Fiscal Commitment*, include stories of New Jersey families with students ready to exit the school system, and describe how these and other graduates with developmental disabilities currently have no promise of day supports or services. Although these students have transition plans, the adult services they need are contingent on state funding, which may or may not be available on July 1, 2008.

In 2004, the New Jersey state budget included a \$5 million line item for students with developmental disabilities exiting school. Since then, however, the state budget has not included a specific fiscal commitment to address the needs of these young adults. According to testimony and materials provided to the legislature, that situation could be addressed though a modest, on-going line item in the state budget for those transitioning from special education to the Division of Developmental Disabilities' (DDD) adult day services.

For more on Transition to Adult Life, see page 4

Graduates with developmental disabilities continue to exit the school system with no promise of supports or services.

council Profile

If you ask her enough questions, Ellie Byra can give you a first-person account of nearly every major disability-related systems-change effort in New Jersey in the last two decades. From inclusive education, to family support, transition, to self-directed adult services – Byra was there, both among the ‘grass roots,’ and as a leader.

Byra, who was appointed to the New Jersey Council on Developmental Disabilities (NCDD) last year, is modest about her role in shaping the state’s service system. In fact, she says she never intended to become an agent of systems change. “I just wanted services for my Matthew.” Matthew, now 32, has medical and developmental disabilities.

Byra’s work in systems advocacy began shortly after Matthew began attending school. In the late 1980s, he attended a Day Training Center, then the only placement option available to him by law. In an effort to improve the quality and scope of services for students who were educated in these state-run centers, Byra and a handful of other mothers launched the Day Training Coalition. She was quickly appointed to a number of work groups and steering committees, and found herself providing turnkey training programs for other parents, working alongside leaders in the Departments’ of Human Services and Education.

It was then that she met the late Diana Cuthbertson, founder and first director of SPAN. She says her work with Cuthbertson affected her deeply and continues to inspire her to this day. “I became passionate about inclusion and making sure people with disabilities and their families had the supports they needed to make real choices.”

Byra’s advocacy resume is long and impressive. She has served in leadership roles and on decision-making committees at two local chapters of the Arc, as well as the Arc of New Jersey. She was a founding member of the NJCDD’s Education Task Force, where she helped

Ellie Byra



“I have always understood and appreciated the important and challenging role of families. Before the first family support grants from the Council, there was nothing for families in New Jersey. That grant from the Council got families – and the system - thinking about the possibilities. It grew into a movement!”

guide initial efforts to engage the Council in education issues. She has served on workgroups, task forces and advisory groups dealing with housing, education, waiting lists and transition from school to adult life. She currently serves in a leadership and advisory role for both of the Council’s ‘sister organizations’ - New Jersey Protection and Advocacy, and the Elizabeth M. Boggs Center on Developmental Disabilities.

Byra’s experience with developmental disabilities actually began years before Matthew was born. She has a younger sister with significant developmental disabilities, and has served as her advocate, working to get her into a community-based program.

“I have always understood and appreciated the important and challenging role of families,” said Byra. She described how the Council’s early grants helped to spur on the family support movement in New Jersey. “Before the first family support grants from the Council, there was nothing for families in New Jersey,” Byra said. She shared the story of one single mother who had not left her daughter’s side in 13 years because she had no one trained to stay with the girl. “That grant from the Council got families – and the system - thinking about the possibilities,” she added. “It grew into a movement!”

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Perfil del Concejo: Ellie Byra

Si usted le hace suficientes preguntas, Ellie Byra puede proporcionarle información de primera mano sobre casi cualquier intento importante realizado para cambiar los sistemas relacionados con las discapacidades en Nueva Jersey durante las dos últimas décadas. Desde educación inclusiva, hasta mantenimiento familiar, transición, hasta servicios autodirigidos para adultos—Byra estuvo allí, tanto con los participantes de la comunidad, como en su carácter de líder.

Byra, quien fue asignada al Consejo de Discapacidades de Desarrollo de Nueva Jersey, se muestra modesta sobre el papel que ha desarrollado para darle forma al sistema de servicio del estado. En realidad, dice que ella nunca tuvo la intención de convertirse en agente de cambios del sistema. “Yo sólo deseaba contar con servicios para mi Matthew”. Matthew, que ahora tiene 32 años, tiene discapacidades médicas y de desarrollo.

El trabajo de Byra en la defensa de los sistemas, se inició poco después que Matthew comenzó a ir al colegio. A finales de la década de los 80, él asistía a un Centro de Capacitación Diurno, que entonces era la única opción disponible de colocación para él de acuerdo a la ley. En un esfuerzo por mejorar la calidad y alcance de los servicios para los estudiantes que estaban siendo educados en estos centros administrados por el estado, Byra y otras madres que deseaban ayudarla, lanzaron la Coalición de Capacitación Diurna. Se le asignó rápidamente a una serie de trabajos de grupo y comités directivos, y se encontró a sí misma proporcionando programas de capacitación estratégicos para otros padres, trabajando lado a lado con los líderes de los Departamentos de Servicios Humanos y Educación.

Fue entonces cuando conoció a la difunta Diana Cuthbertson, fundadora y primera directora de Statewide Parent Advocacy Network, Inc. (SPAN). Dice que su trabajo con Cuthbertson la afectó profundamente y continúa inspirándola hasta el momento. “Me convertí en una apasionada de la inclusión y de garantizar que las personas con discapacidades y sus familias tuvieran el apoyo que necesitaban para elegir opciones realistas”.

“Siempre he comprendido y apreciado el importante y desafiante papel de las familias. Antes de las primeras subvenciones de apoyo familiar otorgadas por el Ayuntamiento, no había nada para las familias en Nueva Jersey. Esa subvención del Ayuntamiento hizo que las familias –y el sistema– pensaran sobre las posibilidades. ¡Creció hasta convertirse en un movimiento!”

El currículo de defensoría de Byra es largo e impresionante. Ha desarrollado papeles de liderazgo y participado en comités de toma de decisiones en dos capítulos locales del programa Arc, así como también en el programa Arc de Nueva Jersey. Fue miembro fundador del Grupo de Trabajo de Educación para Discapacidades de Desarrollo, donde ayudó a dirigir los esfuerzos iniciales para comprometer al Ayuntamiento en temas de educación. También desarrolla un papel de liderazgo y defensoría para ambas “organizaciones afiliadas” del Ayuntamiento – New Jersey Protection and Advocacy (Protección y Defensoría de Nueva Jersey) y Elizabeth M. Boggs Center on Developmental Disabilities (Centro de Discapacidades de Desarrollo de Elizabeth M. Boggs). Ha participado en grupos de trabajo, grupos de estudio y grupos de asesoría que tratan sobre problemas de vivienda, educación, listas de espera y transición de la escuela a la vida de adulto.

La experiencia de Byra en el campo de las discapacidades de desarrollo años antes que naciera Matthew. Byra tiene una hermana menor con discapacidades de desarrollo significativas, y ella trabajó como su defensora, tratando de colocarla en un programa basado en la comunidad.

“Siempre he comprendido y apreciado el importante y desafiante papel de las familias”, sostiene Byra. Describió cómo las primeras subvenciones del ayuntamiento ayudaron a impulsar el movimiento

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Transitioning from School to Adult Life

Real Lives – On Hold...

The following students' are among more than 500 who will age out of the school system in June, and for whom there is no fiscal commitment for day services from DDD:

Colleen

Colleen is a 21 year-old Morris County woman with severe multiple disabilities transitioning from a special education program operated by the Morris-Union Jointure Commission. She uses a wheelchair, is non-verbal, wears diapers and has a seizure disorder.

Colleen's mother has worked closely with her school district and DDD on transition planning, a process that began when Colleen was still in elementary school. Colleen's school is a provider for DDD's Real Life Choices, and offers a unique program called 'Cornerstone College' for its graduates. Colleen's school district is willing to continue to provide specialized transportation services on a fee-for-service basis.

Colleen's future, and that of her family, is on hold waiting to learn if the Legislature will commit funds for day services for special education graduates. Colleen's mother fears that her daughter's gains will be lost if she is not in a program. Her mother also fears that if Colleen does not have a day program, she will have to quit her job and lose health care insurance for her family of 6.

Colleen has been known to DDD since she was 2 years old. On June 20th, Colleen will graduate, but DDD cannot yet commit to providing day services for her.

Number of Special Education Graduates Likely to Need On-going State-Funded Services

Year	Number of Graduates
2004	474
2005	497
2006	489
2006	510
2008	545
2009	563*
2010	636*

* estimate

Source: New Jersey Division of Developmental Disabilities

Anthony

Anthony is a 21 year-old man with Down syndrome, who is transitioning from a public high school in Monmouth County. Anthony's mother and his school team have been working together with DDD for seven years to plan his transition to adult life. As part of his transition plan, Anthony works part time at the local Wal-Mart, with on-site job support services from his school. In spite of all the planning, Anthony's family has been told that his services cannot be guaranteed when he graduates because they depend on adequate funding for DDD's Real Life Choices transition services. Absent support services, Anthony will lose his job and be stuck at home.

Anthony's mother, a two-time breast cancer survivor, now fears she will lose her job and her family's health care insurance so she can stay home to care for her son.

Anthony has been known to DDD for many years. He is on the priority waiting list for residential services. On June 23, Anthony will graduate from school, but DDD cannot yet commit to providing day services for him.



Graduation Bill On Governor's Desk

A bill that clears the way for students with disabilities to participate in graduation ceremonies, even if they still require additional instruction, has passed the Senate and Assembly.

The bill (S442) directs New Jersey school districts to allow special education students whose individualized education programs (IEP) call for continued special education services beyond the fourth year of high school to participate in commencement ceremonies with the graduating class, and receive a certificate of attendance. The bill does not preclude a classified student from receiving a high school diploma when he/she has completed his individualized education program, and has met graduation requirements.

The bill, known as "Alicia's Law," is named for East Hanover high school senior Alicia Vitiello. Vitiello was initially told that she could not walk with peers at the school's graduation ceremony because her IEP called for additional instruction and services before she would graduate. Vitiello was ultimately allowed to participate in her class's graduation ceremony. This bill will ensure that students in similar situations will be able to join friends and classmates in celebrating this rite of passage.

Introduced in January, the bill moved quickly through both houses of the State legislature, where it has enjoyed bipartisan support. As *The Council* goes to press, the bill is awaiting the Governor's signature.

Bill to Expand Rights of People in Self-Directed Services Awaits Senate Action

A measure that concerns the rights of adults with developmental disabilities who participate in self-directed services has cleared the Assembly and is awaiting action in the Senate.

"The Self-Directed Support Services for Persons with Developmental Disabilities Rights Act," (A2259/S1650), requires the Department of Human Services to offer participants in self-directed services, such as

Real Life Choices, rights and protections offered under the "Developmentally Disabled Rights Act," which now covers the civil rights of adults with disabilities in traditional residential services, such as group homes and supervised apartments. The Act prohibits discrimination, deprivation of certain rights, or a presumption of incompetence by reason of a person with developmental disabilities receiving services from the division.

Under the measure, the Department must ensure that each person in a self-directed service has a written, individual habilitation plan, and services designed to maximize developmental potential, with full recognition and respect for their dignity, individuality and legal rights. The bill further directs the Department to expand the use of self-directed support services, and make them available without regard to the severity of a person's disability, except to the extent that a person's disability would prevent him/her from being safely served through self-directed support services.

Bill to Establish Autism Advocate Clears the Assembly

A bipartisan measure to establish an Autism Advocate within the New Jersey Department of the Public Advocate passed the state Assembly unanimously in mid-May, along with a package of other autism-specific legislation.

The bill, A2257 requires the Public Advocate to designate a staff person with expertise in issues relating to the needs and concerns of people with autism and their families, to serve as the primary advocate for those seeking to obtain services, information or assistance. The autism advocate would provide leadership within the autism community in New Jersey; communicate with and provide guidance to the departments of State government that provide services to those with autism; and work with the business community to facilitate the accommodation of individuals with autism and their families in public places. The bill awaits action in the Senate.

Youth Leadership Project Gets New Coordinator

Frank Latham has joined the Council on Developmental Disabilities to launch the Youth Leadership Project. The project helps prepare young people with developmental disabilities to become leaders in self-advocacy.

Latham brings direct experience, both as a social worker and as a field coordinator working with advocacy groups across the state.

Latham says he is looking forward to working with young advocates who were involved in the Council's early efforts in this area, as well as recruiting new participants the Project.

"Youth development is the cornerstone of any movement," said Latham. "The Council's Youth Leadership Project is a key resource for young advocates who want to get involved and help move that mission forward."

Latham believes membership should reflect a wide range of backgrounds and experiences, with a focus on young people with developmental and intellectual disabilities, as mandated by the federal law governing the Council.

Latham will be working with young advocates to recruit new members, set goals, and develop short and long range plans. For more information about the Council's Youth Leadership Project, contact Frank Latham at 609-292-3453, or e-mail frank.latham@njcdd.org.

Comments Invited on VR Plan

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RSA with the foundation to begin documenting practices that lead to successful outcomes for individuals with significant disabilities and transitioning youths, identify factors that may inhibit success, and identify effective practices that help accomplish the program's mission. RSA will use the plan to help state VR agencies focus their planning activities on practices that will assure progress in providing high quality services for individuals with significant disabilities.

The 16 page report is available online at http://www.ed.gov/programs/rsabvrs/performance.html#draft_perf_plan.

RSA is inviting comments on the draft measures corresponding to the Plan's goals and objectives. Individuals and organizations should submit comments to: OSERS.RSAStrategicPerformPlanComments@ed.gov. For more information, call 202-245-7313.



Resource Desk: Information on Scholarships Available

Scholarship information for students with disabilities has recently been added to the HEATH Resource Center's News pages. News items, updates and announcements of special interest relating to postsecondary education, career and technical education, and young adults with disabilities will be found on this page.

The page is updated frequently. Visit <http://www.heath.gwu.edu/taxonomy/term/3> for more information.

Council Profile: Ellie Byra

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Despite years of advocacy, Byra says she remains energized by the opportunities ahead, particularly those provided through the grants process the Council oversees. “I am hoping to see some creative grants get funded,” she said. “I would love to see something grow and follow in the footsteps of the Family Support Act - something that captures the energy of our community. We have some very creative, visionary, people ready to respond to these grants and show us that things can work in new ways. I am glad to be part of it!”

Perfil del Concejo: Ellie Byra

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de apoyo familiar en Nueva Jersey. “Antes de las primeras subvenciones de apoyo familiar otorgadas por el Ayuntamiento, no había nada para las familias en Nueva Jersey”, dijo Byra. Ella compartió la historia de una madre soltera que no se había separado del lado de su hija en 13 años porque no tenía a ninguna persona capacitada para quedarse con ella. “Esa subvención del Ayuntamiento hizo que las familias –y el sistema– pensarán sobre las posibilidades”, agrega. “¡Creció hasta convertirse en un movimiento!”

A pesar de los años de defensoría, Byra señala que mantiene su energía debido a las oportunidades –y posibilidades– que hay más adelante, en particular aquellas que provienen del proceso de subvenciones que supervisa el Ayuntamiento. “Espero ver que se obtengan fondos para algunas subvenciones creativas”, dice. “Me encantaría ver que algo se desarrolle y siga los pasos de la Ley de Apoyo Familiar, algo que capture la energía de nuestra comunidad. Contamos con algunas personas muy creativas, visionarias, listas para responder a estas subvenciones y demostrar que las cosas pueden funcionar por nuevos caminos. ¡Me siento feliz de ser parte de esto!”

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Funding Available for National Self Advocacy Conference

The New Jersey Council on Developmental Disabilities has funding available to help five New Jersey self advocates attend the national conference of SABLE (Self Advocates Becoming Empowered), September 4 – 7, in Indianapolis, Indiana.

Because of the number of advocates expected to apply, the Council will select scholarship winners by lottery. From the applicants who apply, five will be selected in a random drawing.

Funding will cover registration and hotel costs, as well as a portion of travel costs (depending on what those are at the time). Winning advocates may need to secure additional funds to cover some costs.

The Council staff will work with those selected on the arrangements and details of their trip. If any winners are not able or eligible to go, an alternate will be randomly selected from the remaining pool.

If you or someone you know would like to be considered for funding for the national SABLE Conference, contact Norman Reim at norman.reim@njcdd.org or call the Council office at 609-292-3745. Sign up sheets will also be circulated through the Council’s outreach process and posted its web site www.njcdd.org.

The New Jersey Council on Developmental Disabilities is not connected with SABLE, nor is it a sponsor of the conference. For more information about the conference visit SABLE’s web site at www.sabeusa.org



Community Calendar

- June 6 Developmental Disabilities and The Family System: Current Objectives and Research. 10:00 AM- 1:00 PM. Mount Holly, NJ. Sponsored by Trinitas Hospitals' Statewide Clinical Consultation and Training Program (SCCAT). For more information or to register, call Fatu Bangura at 908-497-9636 x 201, or e-mail fbangura@trinitas.org.
- June 13 Positive Behavior Support Conference: Enhancing Quality of Life for Individuals with Developmental Disabilities and Their Families, featuring Mark Durand, Ph.D., and Ann Poindexter, M.D. 8:00 AM – 4:00 PM, Somerset, NJ. Sponsored by the Boggs Center UAP, with NJ Department of Human Services, Division of Developmental Disabilities. Go to: <http://rwjms.umdnj.edu/boggscenter/conferences/index.htm> or call 732-235-9314.
- June 14 Men's Health Conference, sponsored by the NJCDD Men with Disabilities Health Care Task Force, Trenton Marriott at Lafayette Yard, Trenton, NJ. For more information visit: <http://www.njddc.org/calendar.htm>.
- June 14 Health Care Advocacy in the Managed Care Environment Teleconference. 12:00 NOON – 1:30 PM. Sponsored by SPAN. Register on line at www.spannj.org or by calling 973-642-8100 .
- June 16 Understanding Autism: Signs, Symptoms, Strategies. 10 AM – 1:00 PM, Newark, NJ. Sponsored by Trinitas Hospitals' Statewide Clinical Consultation and Training Program (SCCAT). For more information or to register, call Fatu Bangura at 908-497-9636 x 201, or e-mail fbangura@trinitas.org.
- July 21-25 Time for Change - Use Your Power. Sponsored by The National Council on Independent Living. Washington, D.C. For more information, go to www.ncil.org.

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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.

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