

## Linda Rolfe to Receive NASDDDS Censoni Award

The National Association of State Directors of Developmental Disabilities Services' Board of Directors will present Linda Rolfe with the Ben Censoni Award during the Association's annual conference November 18, 2010 at the Hotel Monaco in Old Town Alexandria. Ms. Rolfe is Director of the Division of Developmental Disabilities (DDD) in Washington state and has worked in the field of developmental disabilities for more than 40 years.



Linda Rolfe

NASDDDS' Ben Censoni Award for Excellence in Public Services is the only award that recognizes public officials who strive to improve the lives of people with developmental disabilities. The award is named after the late Ben Censoni, former developmental disabilities director for Michigan and Chair of the Association's Governmental Affairs Committee. Ben's motto was "People are what really matter."

"Linda Rolfe's exemplary leadership as a state director is what the Censoni Award is all about," said Ken Ritchey, President of the NASDDDS Board of Directors. "It's

excellence in public leadership demonstrated throughout her career. She has, in particular, taken a progressive role in promoting community employment in the state of Washington. This has enabled many individuals to become more independent and self-sufficient. She is a role model for the country."

As a result of Ms. Rolfe's leadership, 5,800 DDD adult participants in fiscal year 2008 earned \$41 million in wages. Ms. Rolfe's "unwavering belief that every person – no matter the complexity and multiplicity of disabilities – can and will be employed and earn a living wage, led to the ground-breaking 'Working Age Adult Policy'" for the state of Washington, her award nominators said. "Her refusal to give up, her willingness...her insistence that we try another way and yet another way until we figure out how to get everyone employed – has literally moved thousands of professionals, families, employers, school teachers, bus drivers, apartment owners, and countless others to support and include thousands of individuals with developmental disabilities on the path out of poverty and segregation and into the joys, risks, financial and emotional rewards of an integrated working life in the community."

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# Rhode Island Removes 'R' Word from Agency Name

Rhode Island Governor Donald L. Carcieri signed into law June 22 a measure that changes the name of the Department of Mental Health, Retardation, and Hospitals to the [Department of Behavioral Healthcare, Developmental Disabilities, and Hospitals](#) (BHDDH). [House Bill 7378/Senate Bill 2783](#) took effect at the end of July and signals that ALL state agencies in the United States that had used the pejorative 'R' word in their names, have now removed it.



Donald L. Carcieri

The department celebrated the removal of the 'R' word from its name with a ceremony on September 15.

"The name change reflects our commitment to assuring access to quality services and supports for Rhode Islanders with developmental disabilities, mental health and substance abuse issues, and chronic long term medical and psychiatric conditions," said BHDDH Director Craig Stenning, "And our mission to address and erase the stigma attached to these disabilities as well as planning for the development of new services and prevention activities."

(Censoni Award continued from page 1)

Ms. Rolfe has consulted with several states on employment issues for people with disabilities and authored an article, "Employment in Washington State," published in the Alliance for Full Participation's newsletter and in NASDDDS' *Community Services Reporter* this past year.

For those interested in attending the NASDDDS 2010 Annual Conference, "THE FUTURE," click [here](#).

## NASDDDS

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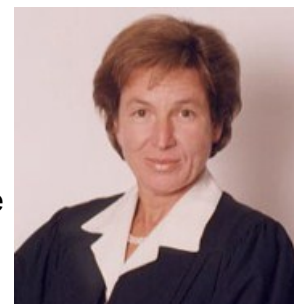
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## Judge Approves Revised Plan for District of Columbia Evans Case

U.S. District Court Judge Ellen Segal Huvelle approved the 2010 Revision of the 2001 Plan for Compliance and Conclusion August 10 in the 30-year-old class action lawsuit, *Evans v. Fenty*, effectively putting an end to the litigation (see CSR July 2006).




*Judge Ellen Segal  
Huvelle*

The 2010 Revision substantially streamlines the goals and targets set forth in the 2001 Plan. The court recognized that the parties had worked collaboratively in the summer to revise the original exit plan in an effort to address areas most critical to ensuring that the district's Department on Disability Services Developmental Disabilities Administration (DDS/DDA) provides to Evans class members the services and supports that were the subject of the lawsuit. The court was complimentary of the efforts of the plaintiffs, the Office of the Attorney General (OAG), and the Special Masters in reaching this important milestone, a department announcement said.

Judge Huvelle also entered a separate order appointing Kathy E. Sawyer to serve as the Independent Compliance Administrator (ICA) for a two-year term. Sawyer is the former commissioner of the Alabama Department of Mental Health and returns to the district fully familiar with the issues and challenges of achieving compliance with the court's orders in Evans. Beginning in 2006, she served in various capacities, including interim administrator of DDS/DDA. Sawyer's prior position with the district played a major role in the parties consenting to her appointment. Judge Huvelle noted specifically that Ms. Sawyer's role was not to supplant the leadership of the agency, Director Laura Nuss and new DDA Deputy Director Cathy Anderson.

"I applaud the work of all parties involved for their efforts to resolve this litigation," said Mayor Adrian M. Fenty. "Furthermore, I am confident in Kathy Sawyer's familiarity with the Evans case and welcome her back to the district."

The parties, the Special Masters, the Court Monitor, Sawyer, and the Quality Trust for Individuals with Disabilities will meet periodically to discuss issues and strategies aimed at implementing the outstanding court orders and the revised plan for compliance.

"Today's orders by Judge Huvelle mark a significant milestone in the history of this case," said Director Laura Nuss. "This begins a new, and we believe, final chapter in which the district, working in partnership with plaintiffs, the court monitor, and the court, will complete transformation of its developmental disability service system into one of the best in the country." 


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## National Leadership Institute Winter Applications Due November 12



The [University of Delaware's National Leadership Institute on Developmental Disabilities](http://www.nlcdd.org) is accepting applications for its January 23 - 28, 2011 Leadership Training Institute. The week-long, intensive leadership development program is designed for current executive-level leaders and emerging leaders.

Participants may work in areas of management or program leadership in organizations that provide, advocate for, or fund supports for people with developmental disabilities and their families.

To submit an application, complete the online form at <http://www.nlcdd.org/leadership-app.php>. Applications will be accepted through November 12. 

## Report Says North Carolina Project A Success

The Center on Human Policy at Syracuse University released a report in August on a North Carolina project for organizational change that aims to facilitate greater independence for individuals with intellectual/developmental disabilities and integration into the community.

[\*The Seeing Is Believing Project: A "Lifeline" for Organizational Change in North Carolina\*](#) report is based on data, interviews, and observations made during a site visit to North Carolina in January 2010

The [North Carolina Council on Developmental Disabilities \(NCCDD\)](#) sponsored the Seeing is Believing (SIB) project, a three-year initiative, running from 2008-2010. The purpose of the initiative is to promote organizational change toward individualized supports within provider agencies in North Carolina. There is a special focus on helping people move from congregate care settings to their own homes, which can include shared living arrangements.




Accomplishments associated with the initiative, according to the report, include:

- ◆ "Organizations have increased their capacity to plan and develop individualized supports;
- ◆ "Organizations have begun to make foundational changes in culture, policy, and procedures that will support and enhance the development of individualized supports;
- ◆ "Organizations have begun to develop the capacity to think in new and different ways about housing, employment, and community relationships and participation for people and to design strategies and initiatives based on this through multiple cross-system collaborations;
- ◆ "A forum has been created for organizations to work together on organizational change, with the assistance of state and national consultants; this collective work has created significant positive energy and commitment among the participating organizations and has attracted the interest of additional organizations in the state, which helps to assure that it will become a new expectation for how services are delivered and that it will also become self-sustaining;
- ◆ "Critical systems issues have been identified and dialogue has begun with state agencies in order to try to address barriers; and
- ◆ "At the time of this writing SIB participating agencies have assisted approximately 35 people to move from a wide variety of settings, including ICFs and other group homes, to their own homes and apartments."

The Seeing Is Believing project grew out of an international conference in Asheville, North Carolina, sponsored by the NCCDD. The conference focused on ways to direct organizational change toward supported living for all people "without exception," meaning without regard to the intensity of supports needed.

Following the Asheville conference, the NCCDD issued a Request for Proposals for a project to spearhead a three-year initiative to build provider capacity in relation to supported living. The grant was awarded to Community Resource Alliance (CRA); CRA then formed a team of consultants to provide training, technical assistance, and other resources. The intent of the project is to build provider capacity through redesigning organizational structures and functioning to enable organizations to shift toward supported living and inclusion of persons with special needs, rather than just creating smaller group homes.

"The North Carolina Council on Developmental Disabilities' investment in this organizational change initiative is a model for other states," the report said. "Increasingly, across the country, individuals with disabilities and family members are expressing the desire for an alternative to traditional facility-based services, and states are eager to espouse the values of individualized, person-centered supports and community inclusion. At the same time, cultural, structural, and regulatory shifts need to be made, at both the organizational and systems level, in order to most effectively offer genuine individualized, person-centered supports." 

## From the Desk of a Former Director...

# Thoughts of a Former State Director on Closing Institutions

*Ed Skarnulis, Ph.D. served as the state director of developmental disabilities services in Kentucky, Texas, and Minnesota before returning to Texas to teach at Texas A&M-Commerce where he headed the Department of Social Work, and has since retired.*



I'm retired now, but have a long history in the field of developmental disabilities. I was Deputy Commissioner of Mental Retardation in Texas in the early eighties, and State Director of Developmental Disabilities in Kentucky and Minnesota. But more importantly, I was stepfather to Michael, who had multiple severe disabilities and lived with my wife and me in Minnesota. He died at age 24, but the years that he and I lived together gave me insight into the challenges faced by him and others.

As I read different newspaper articles on the problems in state-operated institutions I am struck by a sense of déjà vu, that we are still discussing the need to close institutions in this day and age. I was particularly interested in recent statements made by Thomas Perez, Assistant Attorney General for Civil Rights in the U.S. Justice Department who was highly critical of continued reliance on archaic service delivery systems.

This is a complex subject that can't be synopsized easily. In fact, that's been one of the problems over the years. Legislators and public officials used their "common sense" (the least common of the senses) to create the systems we now have. While the motivation for such an approach was undoubtedly well intentioned, it turns out that the assumptions that underpin the institutions for this population aren't supported by either science or experience. Almost inevitably the argument for closure of institutions is dismissed as just an ideological issue, with two equally valid sides being promulgated by well-intentioned advocates. But sometimes there aren't two sides to an issue. The arguments for closure of institutions are not simply philosophical, or legal, or even moral positions. They are based on a body of knowledge that has evolved... on what works in the real world. As Daniel Moynihan so famously observed: "You have a right to your own opinions, but not to your own facts."

**Here are the facts.** We have struggled for decades with the question of how best to serve children and adults with developmental disabilities. Parents and professionals sincerely wanted to do the right thing for their sons and daughters...they wanted public systems to demonstrate compassion and provide what was considered "state of the art care." In the seventies and eighties, with help from legislators, state officials, and a healthy economy, we built beautiful new buildings to provide a protective environment that would let parents rest easy, knowing that their sons and daughters would be cared for in a sheltered community, served by caring professionals and direct care staff. Experts in different architectural styles of institutions were hired to oversee the construction of these buildings. Now, after years of debate, federal intervention, lawsuits alleging abuse and neglect, and watching most states move away from congregate care to smaller, dispersed community services, those in states still invested in institutions have to ask themselves: "Why are we continuing to operate them?"

In the early days, new service systems were developed under departments of mental health and mental retardation often led by commissioners whose professional training was typically medical, usually in psychiatry, i.e., mental health. Community centers serving people with mental health and developmental

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disability needs were also growing, but the lion's share of state resources was centered in the institutional systems.

The community centers were also often headed up by people whose background was in mental health rather than developmental disabilities. Those from the field of mental health who were charged with implementing policies on behalf of people with developmental disabilities were sincere, dedicated people who did their best to carry out the mandates from the Executive, Legislative, and Judicial Branches of Government. This is not a criticism of their intentions or their deeds. In the sixties and seventies the field of mental health (and developmental disabilities as well) was plagued with exposés of horrible conditions, warehousing of people with little or no meaningful treatment or training and violations of basic rights. The field of mental health began moving toward de-institutionalization of residents...which sometimes had unintended, negative consequences for the field of developmental disabilities.

In the field of mental health, there existed a bedrock assumption, held by some professionals and policy makers, that all mental illness could be cured. The introduction of medications to reduce or eliminate symptoms was hailed by mental health professionals and their patients. The success of psychopharmacology aided the belief that moving people out of institutions was the most humane thing that could be done. Unfortunately, the mental health model with its belief in the ability to cure people, to make them normal again, resulted in a failure to develop a comprehensive array of community supports. That failure to assume some people would have lifelong dependency and therefore would need continued support resulted in what came to be known as "dumping," and that, in turn, became the argument used by institution supporters against closure of congregate facilities for people with developmental disabilities.

The assumption in the field of developmental disabilities was the exact opposite, that the needs of the people we served were lifelong. While parents and professionals knew that kids and adults who had developmental disabilities, epilepsy, autism, cerebral palsy, and other problems were capable of much more independence than had been previously assumed there nevertheless was a recognition that these conditions could not be "cured." People would need varying levels of support, depending on the severity of their disability...in most cases, for their lifetime. Thus, when community service systems for this population were developed, they spanned the life cycle, with programs that mirrored stages of development from birth to old age. The specter of homeless, vulnerable or fragile people with severe disabilities almost never occurred in the field of developmental disabilities.

**Assumptions That Drive Public Policy.** Why did professionals in most states abandon the institution or medical model for people with developmental disabilities? The answer to that question requires an analysis of the assumptions that drive public policy in this field:

**Assumption: Congregation is necessary for people with complex needs.** The theory was that we can cluster specialized professionals together to focus on the "special" needs of people who have disabilities. This is the medical model of service delivery. But the reality is that the needs of this population are not usually acute and intense. They are more often chronic or episodic. They are less in need of a hospital crash cart than they are of consistent responses to the person's needs.

Talk with parents who have children with multiple, severe disabilities, especially when their child can't communicate their needs with words. What you learn is that if you live with someone you eventually learn to observe cues that can help you recognize moods, comfort level, happiness, or sadness...even if the child can't talk, can't control muscle movement, or has no self help skills. Anyone who has done the "rumor" experiment in a communication class knows how difficult it is to control information when it passes through large numbers of people. And, mistakes in the case of people who are medically fragile can be deadly. So the

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rule of thumb is that the more involved the person's needs are, the fewer the number of people interacting with them, consistent with respect for the needs of caregivers as well.

Conversely, shift patterns of staffing such as those that exist in institutions almost guarantee that there won't be consistency over a 24-hour day. With staff vacations or sick time, holidays, and covering three shifts for each living unit, getting to an intense, personal relationship with each person is almost impossible. The same principle applies with people who have severe destructive behaviors...changing those requires that there be absolute consistency in programming.

**Assumption: Families will have a major role in the lives of their loved ones.** Even with regularly scheduled team meetings, with family involvement mandated, experience has shown that with few exceptions it's difficult for families to stay in contact when someone doesn't live in the same community. This is true for all of us. "Absence (doesn't necessarily) make the heart grow fonder." At first, despite the best of intentions, our contacts are frequent but life intrudes and over time they become less and less frequent. This is especially true when family members have to travel long distances to visit. It's more accurate to say "out of sight, out of mind."

Conversely, when people live in the same community, it's easier to stay in touch, to know what's going on in each others' lives. Institution supporters argue that this estrangement is the exception....it isn't the norm...but most facility employees know it is.

**Assumption: Institutions serve people community programs can't serve,** i.e., people with severe disabilities, who are medically fragile, who have severe mental illness/behavioral problems. A corollary assumption is that there is something so remarkably different about this population that they require the services of uniquely qualified "mental retardation" professionals.

The reality is that community programs throughout the country have been serving people who are virtual twins of institution residents since the early 1970's. Oklahoma, for instance, has some of the most successful programs in the country, and the residents in those programs were all moved out of the Sand Springs Hissom Memorial Center which was subsequently closed.

Oklahoma's programs for people with medical/behavioral issues are among the best in the nation. Professional schools of medicine, psychology, social work, etc. rarely offer any training in this field. And, why would they? The needs of this population are no different than those of the rest of us. What happens when a person becomes seriously ill in our institutions? They are transferred to tertiary care hospitals in the community. It isn't surprising, given the location of many of our facilities, that recruitment and retention of competent, skilled professionals has always been a major problem.

**Assumption: People are safer and more protected in institutions.** Let me be clear. This letter is in no way a criticism of institution employees. I worked in an institution (Glenwood, Iowa) for five years. The people who work in institutional settings are no different than people who work in community programs. They're just people doing the best that they can, given the cards they are dealt. By and large, we get a lot more heart and soul from direct care staff than we deserve given their level of pay. Having said that, there are at least two reasons institutions are not as safe as community residences.

First, institutions are often located in rural areas or relatively small towns. The community depends on the facility for much of its revenue. The people who work in them are often related. When abuse or neglect occurs there is a higher likelihood that it will be hidden or ignored. Reporting one's brother-in-law or neighbor for abuse is more difficult than reporting a stranger.

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Second, dispersed, integrated, community homes/programs are mistakenly assumed to be more anonymous, hidden away, and therefore less likely to be subject to scrutiny. The reverse is true. Strangers have no problem blowing the whistle when they see a child or adult with disabilities being abused. Neighbors, people in grocery stores, medical personnel, fellow workers, church members, and involved family members are much more likely to see and report suspected abuse or neglect than the closed community of congregate care personnel. During the past two decades the public have become much more aware and sympathetic to the needs of people with disabilities. Thanks to films like *Rain Man*, *My Left Foot*, and countless others, as well as television shows that use people with disabilities in their casts (e.g., Corky, in *Life Goes On*) along with high-profile programs like Special Olympics and celebrity involvement, there has been an outpouring of support from the general public. We've gone from a "there but for the grace of God go I," to seeing people as people, first and foremost. In the field, advocates try to use "People First" language which reflects this view. There's less concern with what makes someone "different" or "special," and more concern with our shared humanity.

**Assumption: Institutions are tried and true**, and have been around forever, but community programs are new and untested. Actually, the reverse is true. Institutions are a relatively new experiment. They didn't exist in the U.S. until the mid to late 1800s. At that time they were small schools, however they grew in size and number, becoming less concerned with education and more custodial in nature, until the exposes in the mid-twentieth century. Even at their peak they never served more than about 2 or 3% of all people with developmental disabilities.

Families have always been the main support for this population. Community programs started in the 1950s because parents couldn't bring themselves to place their children in institutions and, unlike the institutions, they were unable to access state or federal funds, so they started their own schools and vocational programs. Longitudinal studies like the Pennhurst Study (following people who left the Pennhurst institution in Pennsylvania), have shown virtually incredible improvement, using any measure, when people move into community programs. Family satisfaction, weight gain, self-help skill development, etc. all demonstrate the power of moving people into the community.

States like Oklahoma (Hissom Memorial Center), Nebraska (ENCOR), Connecticut (Southbury), and others have done similar studies which yield the same positive results. The University of Minnesota has tracked trends and produced numerous research reports describing the past 40 years of growth in community programs. The Minnesota Governor's Council on Developmental Disabilities website ([www.mnddc.org](http://www.mnddc.org)) has links to most of the significant research done during that time.

**Assumption: "They need to be with their own kind."** It's impossible to generalize about kids and adults with disabilities. In fact, it's the very uniqueness of their special needs that makes them even more diverse, if that's possible, than the population at large. But perhaps the most important reason for not subscribing to this common misconception is understanding how people learn, especially children and adults with cognitive problems.

It's been said that people with disabilities have difficulty understanding abstract concepts, that they're more receptive to concrete, functional ways of learning. We know that it's easier to learn in a real environment than a fabricated one. We know that the most powerful way for any child to learn is through imitating others. As parents we might not always like what our children learn from imitating us (or their friends, or brothers, or sisters), but there can be little doubt that that is the way they learn much of what they come to practice as adults. So, if our goal is to teach someone to talk, to walk, to be toilet trained, or any of the other skills humans need to exist, why would we surround them with people who can't talk, who don't walk, who aren't toilet trained, and on and on? But that's exactly what we do in congregate environments. We put people with the most severe disabilities together and expect a good outcome. Why? If it can be said that what we want in

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terms of training/education is for this group to be “more normal” then it makes sense to surround them with “normal” role models, not people who share their disabilities. This underlies the current practice in special education of “inclusion” (presence and participation) of children with disabilities side-by-side with non-disabled children.

**Assumption: By congregating people together, we can serve them more cheaply.** While the principle of economies of scale and assembly line production might work with Henry Ford, it doesn't work with people who have special needs. The reality is that “per diem (per day)” costs for congregate environments are much more, often two to three times as much, as community alternatives. The average cost per person per day for institutions is more than \$400 (about \$146,000 per year). This difference in cost between community and institutions was always true, even when the institutions had residents with less severe disabilities.

Supporting people in normal housing in typical neighborhoods has always been far less expensive than institution construction and maintenance, even with adaptations made for people who have severe physical disabilities. It means we don't have to replicate resources. We don't have to build gyms, swimming pools, parks, schools, and the like because they're already there. If a son or daughter lives with his/her parents there is no need to provide any of the elements that make up a home....in-home support is the least expensive way to serve. From a taxpayer's point of view, it always makes sense to support, not supplant, the natural home, whenever possible.

**Assumption: We can train or educate people better in a congregate environment.** If there's one organizing theme in this letter it is that institutions don't work for this population because they are fundamentally flawed service delivery models. They are structurally not set up to educate or train because they don't provide opportunities for imitation of “normal” behavior, non-disabled role models. They aren't set up to educate or train because, by definition, people with intellectual disabilities have trouble transferring from artificial settings to real ones....they need concrete experiences in real life situations. You learn to work on an assembly line in a factory on the actual assembly line. You learn to order at McDonald's by actually going to McDonald's.

Government leaders often say “we support choice.” But the choice too often refers to parental/familial choice not necessarily what is in the best interests of those institutionalized. And, no, parents don't always know what's best for their children. Sometimes public policy pits the rights and needs of people who may be adversely affected by those policies against what is considered the inviolate rights of parents. Whether it's Child Protective Services or developmental disabilities [services], when that happens policy makers become the Solomon's. 

## NASDDDS 2010 ANNUAL Conference

(Directors Forum November 17 and Attorneys Meeting November 16-17)

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## New Jersey Launches Participation in College of Direct Support

New Jersey's Department of Human Services Commissioner Jennifer Velez, Esq. announced September 14 the launch of statewide participation in the College of Direct Support. Direct support professionals who provide direct care to people receiving services through the Division of Developmental Disabilities (DDD) will participate in the advanced internet-based educational program.



*Jennifer Velez, Esq.*

Commissioner Velez also presented a proclamation from Governor Chris Christie, designating the week of September 12-18 as Direct Support Professional Recognition Week. The governor's proclamation notes that more than 30,000 people in New Jersey serve as direct support professionals. Most are employees of private agencies under contract with DDD; while almost 3,400 are direct support professionals working in DDD's seven developmental centers.

"Today, we honor the service of direct support professionals and in concert, we recognize the work of the New Jersey Direct Support Professional Workforce Development Coalition, the professional and personal stakeholders in the disabilities community who are dedicating their time to improving the human services workforce," Commissioner Velez said.

Deborah M. Spitalnik, Ph.D., Professor of Pediatrics and Executive Director of The Boggs Center, serves as the chair of the coalition. "In supporting statewide training through what is now known as the New Jersey Partnership for Direct Support Professional Workforce Development, the Department of Human Services is recognizing the dedication of direct support professionals and the value that trained staff brings to the lives of individuals with developmental disabilities and their families," Dr. Spitalnik said.

This coalition formed in 2006 with the goal of reducing the turnover of the direct support professionals. Through a pilot program, the coalition demonstrated a 33% reduction in professional turnover.

Agencies that receive funding through DDD's home and community-based services Medicaid waiver will be able to access the College of Direct Support free of charge to take courses about autism, brain injury, communicating with individuals who are non-verbal, depression, community inclusion, employment and at least 20 others.

### Related Developments:

Kentucky and Maine recently established statewide contracts for the CDS and New Hampshire's initiative hopes to spread the CDS around the state as part of a new program called "DirectConnect."

The following [newsletter](#) excerpt is reprinted with permission from the [College of Direct Support](#),

**KENTUCKY:** In 2009, Bill Tapp (CDS Founder and National Director) was invited by stakeholders to speak to providers and advocates on two occasions. Kentucky's new Commissioner for the Department of Behavioral Health, Developmental and Intellectual Disabilities, Stephen Hall, advocated for CDS based upon his positive experience in Georgia when he was commissioner there. All of this coincided with the need to update elements of the state-mandated training curriculum for Medicaid waiver providers.

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“Our decision to use the College of Direct Support (CDS) as the state-mandated curriculum was based first on our need to offer state-of-the-art training based on best practices. We also wanted providers to have the flexibility of completing training in a variety of locations,” said Linda McAuliffe, Training Manager for Kentucky’s Division of Developmental and Intellectual Disabilities. “The CDS addresses the need for portability of training, which has long been an issue in Kentucky. We also plan to use CDS in the development of a credentialing process for Direct Support Professionals.”

Kentucky’s first step towards implementation was to communicate with the state’s provider network for its Supports for Community Living waiver. Here are the steps McAuliffe says they took:

- Conducted a provider readiness survey using Survey Monkey.
  - Presented at statewide quarterly provider workshops.
  - Spoke at provider organizations and answered questions from individual providers.
- As they neared the roll-out date of September 1, 2010, informational sessions were held throughout the state.

“Most of these sessions also featured Donna Kosak from the College of Direct Support and Donna focused on how providers can use the Learning Management System to track training and generate reports,” Linda added. “Since September 1st, approximately 40% of our provider network has enrolled in the system and begun utilization. We believe that implementing the College of Direct Support in Kentucky honors, promotes, and enhances the work of all who provide services and supports to people with developmental disabilities.”

**MAINE:** Maine’s Developmental Services system adopted CDS to develop and train its Direct Support workforce of approximately 7,000. Some 125 agencies across the state serve and support a population of approximately 5,000 persons, said Paul Tabor, Maine’s Developmental Services Training Coordinator. Tabor also serves as the CDS statewide administrator.

Maine has had a statewide curriculum of 45 hours of classroom training since 2002. That curriculum has been required for Medicaid waiver services since 2008. Maine has used the “train the trainer” model for its classroom training. “We had been using the same curriculum statewide since 2002 and it was good and consistent, but it needed a major updating and we knew it would be expensive and in another five years it would have to be updated again,” Tabor said.

So in late 2008 Maine Developmental Services began looking at CDS. “We were aware of CDS (Tabor is on the CDS National Board of Editors) and Office Director Jane Gallivan asked me to call around the country asking state directors about the CDS. All I heard was that it’s great, so I told our folks here that maybe it’s time we seriously examine it.”

Once the decision was made to go with CDS, a curriculum committee composed of agency trainers began meeting to identify the CDS lessons that would be required in Maine. “This is the dawn of a new era in Maine,” Tabor said. “The folks in the pilot sites are really excited about starting with the CDS.”

He then explained why the state selected CDS. “CDS contains such a wealth of information, and its 24/7 availability is a big advantage for us. When budgets are tight and you have staff shortages, it’s hard to pull everyone together to meet for training. Plus, CDS is a nationally and internationally recognized curriculum and it’s portable statewide, so we decided that by investing in CDS we’ll be getting a lot more bang for our dollars.”

(New Jersey continued on page 12)

(New Jersey continued from page 11)


Tabor says that since the pilot ended in June, Maine has 36 Learning Administrators serving about 65 agencies, with a number of smaller agencies that are not enrolled yet. Maine is requiring 35 online lessons and approximately 11 classroom hours.

**NEW HAMPSHIRE:** With a population that is aging faster than the national average, New Hampshire is facing an increased demand for healthcare and support services and a heavier reliance on home- and community-based services for long-term care. It is projected that the need for community-based direct care workers will increase in the near future and that the demand will rapidly outpace the supply, says Scott Trudo, one of two Project Directors for the state's new DirectConnect program.

A \$2.9 million grant from the U.S. Department of Labor was awarded to the University of New Hampshire that will create an infrastructure to recruit, train and retain high-quality, community-based direct care workers to meet the current need and prepare for a projected job growth in the field of direct support work.

Part of this program will use the College of Direct Support to address the growing direct care workforce shortage and train and retain this workforce. This program is the result of work done by the New Hampshire Coalition for Direct Care Workforce, which began meeting in 2007 to address this statewide issue.

"The state has no broad-based training mandate and minimal training requirements," Trudo says. "This model using the CDS is part of a professional direct care lattice incorporating agency-based orientation and training, national best-practice curricula, professional credentialing and college degree programs to prepare workers for placement and advancement. We have established a tuition scholarship fund that will provide funding for agency trainings, CDS certificates and community college certificates and degrees."

Trudo is hoping this project will transform the workforce across disabilities and change the landscape in New Hampshire." 

## ***Caring Families... Families Giving Care: Using Medicaid to Pay Relatives Providing Support to Family Members with Disabilities***

by Robin Cooper  
NASDDDS Director of Technical Assistance

This study of the practice of paying family members to provide support in state Developmental Disabilities (DD) Systems provides an over view of federal policy on paying relatives, includes the results of a national survey of state DD agency policies and practices, summarizes and analyzes key issues and offers guidance on quality assurance practices. Available in print only.

[Order Form Available Online at the NASDDDS Website](#)

## LITIGATION UPDATES

### ALABAMA

The [U.S. Justice Department announced September 17](#) that it settled a lawsuit against the city of Satsuma, Alabama and the city's Board of Adjustment concerning alleged housing discrimination against individuals with disabilities. Under the consent decree, the city agreed to pay \$59,000 in damages to the operator of a group home for three women with intellectual disabilities and the trustees of the three residents, as well as a \$5,500 civil penalty to the government. As part of the settlement, the city also adopted amendments to its zoning laws.

[United States v. City of Satsuma, Alabama Summary Consent Decree](#)



### CALIFORNIA

Prisons in California still have not complied with a December 2001 order to protect inmates with developmental disabilities. U.S. District Judge Charles R. Breyer issued an [Order](#) September 16 in the case, [Clark v. California](#):

"In total the evidence demonstrates that mentally retarded prisoners and those with autism spectrum disorders are verbally, physically, and sexually assaulted, exploited, and discriminated against in California prisons. Illiterate prisoners are not given the help they need to understand or fill out important prison documents, leaving them with no way to use sick call slips or grievance forms, unless they can pay other prisoners or beg them for help. Developmentally disabled prisoners are punished for violating prison rules that they do not understand, and are punished at hearings which they do not comprehend. These conditions violate those prisoners' rights to be free of unlawful discrimination based on their disabilities."

The judge ordered the state of California to prepare a plan to address deficiencies in staff training, identification and classification of prisoners with developmental disabilities and their needs, and self-monitoring, and submit the plan to Court experts and to the [Prison Law Office](#) by December 15, 2010.

The Prison Law Office, [a team of Bay Area lawyers](#), who work to protect the civil rights of inmates in California, originally filed the lawsuit in 1996.



### HAWAI'I

A federal appeals court reinstated a lawsuit August 26 by parents of two daughters with autism seeking compensation for alleged failure by the Department of Education to provide special education services, the [Honolulu Star Advertiser](#) reported.



### ILLINOIS

A [settlement agreement](#) between the state of Illinois and thousands of individuals with mental health disabilities was signed July 27. The settlement of [Williams v. Quinn](#) "will begin a systemic process of giving approximately 4,500 persons with mental illnesses the choice to move out of large nursing homes known as 'Institutions for Mentally Diseases' (IMDs) and into community-based settings with the supports they need to be successful," Illinois' protection and advocacy organization, [Equip for Equality](#), said. To learn more about the case, click [here](#) and [here](#).



### KENTUCKY

Kentucky's [Council on Developmental Disabilities filed a lawsuit](#) against the Cabinet for Health and Family Services August 19 for denying access to records for an individual with developmental disabilities who died after being transitioned to a community placement.



### MASSACHUSETTS

The family of a teenager who resided at the Judge Rotenberg Center in Canton settled a lawsuit concerning "electric skin shock" therapy used against the boy. They complained the shock therapy was inhumane and violated the student's civil rights, the [Boston Herald](#) reported.

## LITIGATION UPDATES continued from page 13...

### MICHIGAN

[The Grand Rapids Press](#) Editorial Board urged federal judges to rule in favor of child care providers who filed a lawsuit against the state of Michigan for forcing them to pay dues to such unions as United Auto Workers. Last February, a group of Michigan home-care providers [filed a class-action federal lawsuit](#) against government union officials and Governor Jennifer Granholm's Administration allegedly for illegally forcing them to pay union dues. This issue also pertains to parents who provide services to their children with disabilities at home.



### MINNESOTA

A restraints lawsuit against the Minnesota Department of Human Services reached settlement, pending court approval, with the state agreeing to pay \$3 million to the families of individuals with developmental disabilities and phase out the use of restraints, the [Star Tribune](#) reported September 14. The suit was filed by families of three youths with developmental disabilities who resided in the Minnesota Extended Treatment Options in Cambridge, Minnesota and suffered inappropriate use of handcuffs and other restraints. A 200-page [Office of the Ombudsman for Mental Health and Developmental Disabilities](#) report, [Just Plain Wrong](#), found that the Cambridge, Minnesota center had restrained 63 percent of its patients "most of them multiple times." One resident had been restrained 299 times in 2006 and 230 times in 2007. Residents

would be restrained, the report said, for such violations as "touching the pizza box." See August 2009 CSR.



### NEBRASKA

A lawsuit filed by a resident of Beatrice State Developmental Center who suffered two broken legs because she was dropped came to settlement with the state agreeing to pay her \$190,000 and an additional \$10,000 to her guardian, [The Beatrice Daily Sun](#) reported September 4.



### PENNSYLVANIA

The Pennsylvania Department of Public Welfare and [Disability Rights Network of Pennsylvania](#) (DRNP) settlement agreement and intellectual disability and mental health treatment protocol are now available – click [here](#). DRNP filed the lawsuit against the state on behalf of over 60 individuals with intellectual disabilities who were being inappropriately housed in state psychiatric hospitals (see September CSR).



### U.S.

A class-action lawsuit filed against the Social Security Administration by employees with disabilities is moving forward, [The Baltimore Sun](#) reported August 30. The suit alleges that the SSA discriminates against employees with disabilities by denying or limiting promotions.



Save the Date  
for the  
NASDDDS  
2011 Mid-Year Conference  
May 25-27  
Philadelphia, Pennsylvania