

Realizing the Intent of the DD Act:

How the DD Network Advances the Independence, Productivity, and Integration of People with Intellectual and Developmental Disabilities

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July 2011

EXECUTIVE SUMMARY

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act, P.L. 106-402) established a set of programs to improve the lives of people with developmental disabilities through capacity building, systems change, advocacy, and the enforcement and protection of civil rights. These programs are the **Developmental Disabilities Councils (DDC)**, the **Protection and Advocacy (P&A)** agencies (now known as the **Disability Rights Centers**), and the **University Centers for Excellence in Developmental Disabilities (UCEDD)**; collectively, they are known as the "**DD Network**." Funds for the DD Network programs are administered by the Administration on Developmental Disabilities (ADD), a federal agency presently located in the Department of Health and Human Services, Administration on Children and Families.¹

The DD Network partners have been integral to the growth and development of service systems across the nation; they

- **Provide resources to test out new service models.**
- **Conduct research and evaluation of outcomes and effectiveness.**
- **Conduct extensive interdisciplinary training on cutting edge service strategies and evidenced-based practices.**
- **Provide advocacy to project legal rights.**

The efforts of the DD Network partners are essential in helping states' Medicaid agencies, developmental disabilities agencies, schools, and other providers to meet the mandates of the Americans with Disabilities Act, the Individuals with Disabilities Education Act, and the Olmstead decision through advocacy, research, and training that assures individuals with significant disabilities are served in the community, rather than in institutional settings.

The DD Network partners engage in critical functions that would otherwise result in critical gaps in the development of services systems for children, youth, and adults with disabilities. They fulfill a critical role in moving the entire field of intellectual and developmental disabilities forward through research, program development, education, and training that enhance the lives of individuals with developmental disabilities, their families, and communities.

State Medicaid and developmental disabilities systems do not have the capacity to try out new approaches or pilot programs, conduct research, train personnel and certainly cannot engage in the type of legal advocacy provided by the P&A arm of the DD Network. The DD Network partners provide essential resources that have had a profound effect on the lives of individuals with developmental disabilities. The collaborative efforts of the DD network partners have resulted in sustained changes in the landscape of supports and services to individuals with developmental disabilities. DD Network efforts have been and remain

¹ ADD is located in the ACF although the populations ADD mainly relates to are within the Department of Education (children) and CMS. See, "*Rising Expectations: The Developmental Disabilities Act Revisited*," NCD, February 15, 2011, pp. 38-40 for an analysis of ADD's position within the federal structure.

essential to the deinstitutionalization of individuals with developmental disabilities and the growth of home and community-based services and the improvement in the quality of lives of people with developmental disabilities and their families.

For the purposes of this report, examples of DD Network initiatives in just six states (Maine, Oregon, Pennsylvania, Tennessee, Washington, and Wisconsin) are cited to illustrate the broader array of programs and projects that the DD Network engages in around the country. These examples and topics are in no way exhaustive of the types of activities that the DD Network is engaged in across the states and territories. These examples merely provide a snapshot of the scope of DD Network initiatives on key state and national trends in the development of policies, supports, and services for individuals with developmental disabilities.

DD Councils have set the standard that assures the voices of consumers and families are always included as essential stakeholders in determining policy. The UCEDDs provide a laboratory for demonstrating emerging and promising positive practices such as working with schools and provider agencies on using positive behavioral supports or providing interdisciplinary training to professionals on cutting-edge approaches to serving children and adults with autism and other developmental disabilities. The P&A programs play a pivotal role in assuring that the civil rights of individuals with developmental disabilities are upheld through both advocacy and litigation.

In short, this report, using six states as examples, clearly illustrates how the DD Network partners, working with each other and in collaboration with state developmental disability agencies and others, have positively affected the lives of hundreds of thousands of individuals with intellectual and developmental disabilities — assuring their rightful place as full community members through advocacy, research, training, and programs that directly support individuals and families. The DD Network continues to move the entire field of intellectual and developmental disabilities to advance independence, productivity, and integration of people with developmental disabilities.

BACKGROUND

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act, P.L. 106-402) established a set of programs focused on individuals with intellectual and developmental disabilities (ID/DD).² ³ The intent of the DD Act is to improve the lives of individuals with intellectual and developmental disabilities through planning and building system capacity and competence; providing for protections of their individual and civil rights; and establishing centers focused on research, training, and knowledge dissemination. These activities are carried out by three types of organizations, collectively known as the Developmental Disabilities (DD) Network: **Councils on Developmental Disabilities Councils (DD Councils)**, the **Protection and Advocacy (P&A)** agencies (also known as the **Disability Rights Centers**), and the **University Centers for Excellence in Developmental Disabilities (UCEDD)**. Although their work is interrelated and complementary and they frequently collaborate, each entity comes with specific charges in terms of purpose and activities. The DD Act was first authorized in 1963, was last reauthorized in 2000. The DD Act funds these organizations for each state and U.S. territory, at a total of \$155 million in fiscal year 2010.⁴ These funds are administered by the **Administration on Developmental Disabilities (ADD)**, a federal agency presently located in the Department of Health and Human Services, Administration on Children and Families.⁵

According to the stipulations of the Act, DD Councils, "engage in advocacy, capacity building, and systemic change activities...; and, (2) contribute to a coordinated, consumer- and family-centered, consumer- and family-directed, comprehensive system of community services." The DD Councils' members are appointed by their respective governors and include a wide array of stakeholders who determine the priorities of each council. The P&A organizations are established to protect the legal and human rights of individuals with ID/DD (as well as other disability groups) through advocacy and legal actions. The UCEDDs are charged to provide training to students and clinicians, across a range of disciplines provide technical assistance to community services providers, develop demonstrations and model exemplary projects, and carry out basic and applied research in the field of developmental disabilities.

In particular, the Developmental Disabilities Act recognizes the competencies, capabilities and personal goals of individuals with developmental disabilities in contributing to a system where individuals with developmental disabilities have the ability and opportunity

² The DD Act can be found at www.acf.hhs.gov/programs/add/ddact/DDACT2.html.

³ According to the federal Developmental Disabilities Act, Section 102(8), a developmental disability is: a severe, lifelong disability attributable to mental and/or physical impairments which manifest themselves before age 22 and are likely to continue indefinitely and result in substantial limitations in three or more of the following areas: self-care, comprehension and language skills (receptive and expressive language), learning, mobility, self-direction, capacity for independent living, economic self-sufficiency, and ability to function independently without coordinated services.

⁴ DD Councils received \$75 million; P&As received \$41 million; UCEDDs received \$39 million. Projects of National Significance and Help America Vote Act were funded at 14 and 17 million respectively.

⁵ ADD is located in the ACF although the populations ADD mainly relates to are within the Department of Education (children) and CMS. See, "*Rising Expectations: The Developmental Disabilities Act Revisited*", NCD, February 15, 2011, pp. 38-40 for an analysis of ADD's position within the federal structure.

to make personal decisions, exert control over their lives, and participate in the same community activities that are available to individuals without disabilities. Inclusion and integration of individuals with developmental disabilities in the communities of our society, as well as individual choice and control of life decisions and daily living activities are core intents of the DD Act. Furthermore, the Americans with Disabilities Act (ADA) expressly states that, "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by such entity." (42 U.S.C. § 12132) The guiding principle of the U.S. Supreme Court's landmark 1999 decision in *Olmstead v L.C.* is the inherent right of an individual to be free from unnecessary segregation from the general public. Both the ADA and *Olmstead* reinforce the principles stated in the DD Act.

THE DD NETWORK'S CENTRAL ROLE IN ADVANCING THE FIELD OF ID/DD

The past four decades have seen the DD Network lead transformative changes away from the old model of people with developmental disabilities living in institutions towards systems that support the independence and integration of people with developmental disabilities in communities. The DD Network has been integral to the development and change of service systems across the country, providing resources, research, and training on cutting edge service strategies, and providing legal advocacy for people with developmental disabilities. As described later in this document, the efforts of the DD Network partners are essential in helping states meet the mandates of the Americans with Disabilities Act and the *Olmstead* decision.

The DD Network partners engage in critical functions that would otherwise be a gap in the development of service systems, as they are not within the scope, capabilities, or responsibility of the publically funded state services system whose main goal is to provide funding for, and oversight of, services to individuals. The DD Network partners fulfill a critical role in moving the entire field of intellectual and developmental disabilities forward through conducting research, developing new programs, testing of new ideas, and education and training that enhances the lives of individuals with disabilities and improves the capacity of those providing supports.

DD Councils:

- DD Councils have been trailblazers in establishing the now nationally adopted practice that assures that the voices of people with developmental disabilities and their families are included as essential stakeholders in determining policy. Through their policy training programs, inclusion of people with developmental disabilities and their families in planning efforts as council members, and support of self-advocacy, councils serve as a model for the inclusion of individuals with developmental disabilities in decisions affecting their lives.

- The DD Councils provide training in policymaking to family members through the Partners in Policymaking efforts in 30 states, bringing the voices of families and individuals with disabilities into the policymaking arena.⁶
- All DD Councils support goals establishing and strengthening self-advocacy groups, offering training and support to help develop and promote self-advocacy which allows individuals with ID/DD to speak for themselves in every state and territory.
- The councils provide seed grants to fund 'best practice' projects and initiatives, demonstrating their effectiveness and working with stakeholder and partners to have practices adopted by service systems. For example, 24 DD Councils have invested in the training of direct support professionals, enhancing the quality of services to people with developmental disabilities and leading to the adoption of these training programs as part of the state's qualifications for all providers.

UCEDDs:

- The UCEDDs provide a laboratory for demonstrating emerging and promising positive practices such as working with provider agencies on using positive behavioral supports and providing training to professionals on cutting-edge approaches to serving children with autism.
- The UCEDDs develop and provide services demonstrating promising new and emerging practices that serve as models for the greater provider community.
- The UCEDDs engage in research that advances the field of intellectual disabilities including such diverse areas as genetics to helping individuals with ID/DD develop relationships to assessing the efficacy of technology in assisting individuals with ID/DD.
- The UCEDDs train the next generation of professionals working in a wide range of disciplines that impact people with disabilities by providing additional research and educational opportunities to approximately 2000 undergraduate, graduate, and post-graduate students each year.

P&As:

- The P&A agencies play a pivotal role in assuring that the civil rights of individuals with ID/DD are upheld through both advocacy and litigation.
- The P&A agencies are engaged in numerous litigation activities, many of which relate to individuals with ID/DD.
- The P&A agencies successfully litigate cases that have resulted in the expansion of community services for people with ID/DD including litigation around waiting lists, access to services and upholding the provisions of the Americans with Disabilities Act.

⁶ Information found at the Partners in Policymaking website: www.partnersinpolicymaking.com.

INDIVIDUAL AND COLLABORATIVE EFFORTS OF THE DD NETWORK TO FULFILL CRITICAL NEEDS THAT OTHERWISE ARE NOT ADDRESSED

As noted, state service systems do not typically have the capacity to explore new approaches or pilot programs and cannot engage in the type of legal advocacy provided by the protection and advocacy arm of the DD Network. The DD Network provides essential resources that have had a profound effect on the lives of individuals with ID/DD through individual and systems advocacy.

For the purposes of this paper, we selected examples from six states (Maine, Oregon, Pennsylvania, Tennessee, Washington, and Wisconsin) to illustrate the broad array of programs and projects that state DD Networks engage in around the country. The examples and topics selected are in no way exhaustive of the types of activities the DD Networks are engaged in, neither in the selected states, nor around the country. The examples provide just a snapshot to illustrate the scope and far-reaching impact of DD Networks' initiatives on state and national trends in the development of supports and services to individuals with intellectual disabilities.

DEINSTITUTIONALIZATION AND THE GROWTH OF HOME AND COMMUNITY-BASED SERVICES

The past four decades have seen an enormous social and cultural transformation in how individuals with ID/DD and their families are supported. The **University of Minnesota Institute on Community Integration** (a UCEDD affiliate that receives funding from ADD) annually tracks national data substantiating this transformation. States, lawmakers, providers, researchers, and citizens all rely on this data to track the progress of their state services systems in reducing reliance on large congregate settings while expanding community services. These are invaluable publications and are recognized as the most reliable and informative data sets in the field of ID/DD in assessing state progress and understanding expenditures.

The two most striking trends documented through these publications are the reductions in institutional populations and the parallel expansion of the community-based services system. The 1981 regulatory change permitting states to use Medicaid funds for home and community-based services (HCBS) under the 1915(c) waiver program provided the financing mechanism to undergird the move from institutional-based to community-based services — as well as the financing to deter institutionalization *and* provide services to individuals already living in the community.⁷ If we take just three points in time (table on following page), we can see the steady downward trend in the use of large state institutions and the concomitant rise in the home and community-based services.⁸ As a base

⁷ In 1981 federal Medicaid regulations under 1915(c) of the Social Security Act were changed to allow states to apply for a waiver that permits states to spend funds on community services for individuals who are otherwise eligible for institutional care.

⁸ Institutions for individuals with ID are facilities licensed as Intermediate Care facilities for the Mentally Retarded (ICFs/MR) having 16 beds or greater. All data taken from, K. Charlie Lakin, et al., "*Residential Services for Persons with*

comparison, in 1982, just as the HCBS waiver program came into existence, 122,750 individuals lived in large (greater than 16 beds) state operated facilities.⁹

Year	Large State ICF/MR Census ¹⁰	Average ICF/MR Annual Cost/Person (in 2009 dollars) ¹¹	HCBS Services Utilization June 30 ¹²	Average HCBS Annual Cost/Person (in 2009 dollars)	States with HCBS Waiver Programs
1987	95,022	\$ 102,000	22,689	\$ 25,262	35
1997	54,666	\$ 133,190	221,109	\$ 36,558	50
2009	32, 909	\$ 196,710	562,067	\$ 45,463	51

This downward trend in institutional census resulted in the closure of 192 large, state operated facilities between 1960 and 2010 — and more closures are in progress.¹³ At present eleven states have no state operated facilities and seven states have less than 100 individuals in state facilities larger than 16 beds. Another eight states have less than 200 individuals in large state-operated facilities. During this same period, large privately operated ICFs/MR also reduced their bed capacity nationally from 42,081 in 1987 to 26,695 in 2009. And, in terms of rebalancing long-term support systems, the DD system has been the most successful in deinstitutionalizing individuals, with 65.8 percent of all individuals with ID/DD living in the community as compared to 33.8 percent of seniors and individuals with physical disabilities.¹⁴ The DD Network, through program support and development, influencing policy, training, litigation, and technical assistance, has been essential to this expansion of HCBS services.

Oregon, a state that as of 2011 became the first state to have *no licensed public or private institutional beds for individuals with ID/DD* serves as stellar example of how the collaborative efforts of the state DD Network partners have transformed the services system. The **Oregon DD Network** is composed of the Oregon Council on Developmental Disabilities, Disability Rights Oregon (P&A), the Center for Excellence in Developmental Disabilities at the University of Oregon, and the Oregon Institute on Disability and Development at Oregon State Health and Sciences University. The system transformation efforts began in the mid-1980s when Disability Rights Oregon filed litigation seeking the closure of the state institution and continued to represent plaintiffs in negotiations with the state and the U.S. Department of Justice until final closure of Fairview, the state-operated ICF/MR, in 2000. The Specialized Training Program (STP) at University Center on Excellence in Developmental Disabilities, and the DD Council in conjunction with their state developmental disabilities agency, worked together to develop the resources needed to

Developmental Disabilities: Status and Trends Through 2009, University of Minnesota, Institute on Community Integration/UCEDD, 2010.

⁹ Lakin, 2010, p. 48.

¹⁰ Lakin, 2010, p. 48.

¹¹ Lakin, 2010, p. 15.

¹² Lakin, 2010, pp. 66-72.

¹³ Alabama and Georgia recently announced they are fully committed to closing all their state-operated facilities.

¹⁴ Steve Eiken, et al., "Medicaid Long Term Care Expenditures in FY 2009", Table: FY 2009 InstitutionCommunityRankings.xls, Thompson Reuters, August 2010.

assure the quality and competency of the supports and services afforded to the individuals moved out of Fairview, as well as those already served in the community. These collaborative efforts have had a sustained and profound impact on the services system which is still evident today.

Impact of the Initiative:

- Demonstrated that any individual with ID/DD can successfully live in the community when provided the appropriate supports through the types of training and technical assistance provided by the Specialized Training Program.
- Rebalanced the Oregon system from costly institution-based services to community and individually focused services in large part through the Oregon Council on Developmental Disabilities' efforts to mobilize political and community support for the closure of the institution and facilitating passage of legislation that established the final "Long Range Plan" for *all* institutional closures while assuring that people would receive community-based services.
- Eliminated the largest institution in the state and set the stage for the closure of all ICFs/MR in Oregon which was accomplished in 2009, while assuring that former residents received the services they need in the community.
- Established backup system of community-based, state-operated group homes for individuals with complex combinations of behaviors and conditions.
- Secured the money from the sale of the institutional property for a trust to be used for home modifications to allow individuals to live safely and independently in the community and created a strategy for funding housing and established nonprofit housing organizations to own the houses.
- Created a nonprofit entity to provide ongoing technical assistance and training that continues to respond to systemic issues (Oregon Technical Assistance Corporation).
- Created the Oregon Intervention System to provide an individualized approach to addressing behavior issues while keeping both the individual and the staff safe.
- Set the pattern for state, DD Network, and advocate collaboration on systemic change issues.

And, most important of all, Oregon serves as an example to the nation that all individuals can live in community settings — without the need for any institutional services.

Wisconsin is another great example of the critical role played by DD Networks. During the period 2002-2004, **Disability Rights Wisconsin** (DRW, the state's Protection and Advocacy program) and the **Wisconsin Board for Persons with Developmental Disabilities** (BPDD, Wisconsin's DD Council) were instrumental in the closing of a state institution, Northern Wisconsin Center for the Developmentally Disabled (NWC). Beginning in 1990, DRW and BPDD called for the closing of NWC, one of three state institutions for people with developmental disabilities built around 1900. Prior to this, no Wisconsin governor or legislature had ever closed a residential setting of this nature. Working with the governor's transition team, DRW presented a combined value-based, legal, and economic proposal to close NWC, an idea the governor had not considered before these meetings. The governor included closing NWC in his first budget proposal submitted to the

legislature in February 2002. There was immediate backlash from some state legislators, parents who supported institutional settings, and some unions resulting in a lawsuit that was filed against the governor seeking an injunction to stop the closing. DRW made an unprecedented decision to petition the court to join the governor as a co-defendant in the lawsuit. The judge agreed and DRW attorneys joined the defense team with the outcome that the judge denied the motion for injunction, the closing preceded, and all the residents moved out over the subsequent 2½ years. DRW staff attended all the closing meetings and assisted a number of residents and guardians in the individual planning process.

Impact of the Initiative:

- The first closing of a major state institution in Wisconsin and a major reduction in Wisconsin's institutional population.
- Proving that a state institution can be closed by bipartisan consensus of the governor and legislature, without an ADA/Olmstead lawsuit.
- Significant changes to guardian perceptions about community placements as evidenced by survey responses whereby, after the closing, more than 80 percent of guardians reported they were satisfied with the community placements and some added comments indicating a realization that their wards were much better off in the community.

ASSURING AND EXPANDING ACCESS TO HOME AND COMMUNITY-BASED SERVICES

Through political action, advocacy, and legal actions, the DD Network can secure new resources and assure access to those resources — roles that state officials cannot fulfill (and in fact are prohibited from doing so, in some instances.) Nationally, many protection and advocacy agencies are engaged in active cases for assisting individuals with ID/DD waiting for HCBS services to gain access to needed supports. DD Councils assist through educating and informing policymakers and advocates about effective and efficient practices, and convening public and private partners to develop strategies for change. The UCEDDs provide training and technical assistance to direct care workers and community providers. These critical functions cannot be accomplished by state agencies. Securing new resources and assuring access to those resources requires the funding, political pressure, and legal advocacy that only the DD Network can provide.

Disability Rights Center-Maine through litigation gained access to **in-home supports** for children who had either been sent out-of-state for services or had received nothing. In partnership with Maine Equal Justice Partners, the **Maine DD Council**, the state of Maine Children's Behavioral Health Services, and a private law firm reached an agreement.

Impact of the Initiative:

- The settlement agreement resulted in the adoption of a state rule that no child would wait more than 6 months for in-home supports.
- The state created a children's behavioral health program, promulgated rules, and began serving children with developmental disabilities in state. At the outset, it was estimated that the class consisted of at least 600 children.
- Since the suit, thousands of children have been served resulting in the state applying for and receiving federal approval for a home and community-based services waiver for children with developmental disabilities.

During the period 2003–2009, the efforts of the **Tennessee Disability Law & Advocacy Center of Tennessee (DLAC)**, the **Tennessee Council on Developmental Disabilities**, the two UCEDDs in Tennessee: **Boling Center on Developmental Disabilities**, and **Vanderbilt's Kennedy Center for Excellence in Developmental Disabilities**, in collaboration with the Tennessee Department of Education, Dr. Ed O'Leary (Transition Specialist with the Mountain Plains Regional Resource Center), The Arc Tennessee, and other advocacy organizations, have opened up community options for youth in transition from the public school system into community services.

Impact of the Initiative:

- The Division of Special Education hired Dr. Ed O'Leary as a consultant to develop a statewide transition program focused on the student's goals for life after secondary school.
- During the first year of the pilot program, the Tennessee Department of Education selected 10 school districts to participate in trainings and data driven analysis of the outcomes in changes made to improve the transition process of students leaving the public schools and moving to post-secondary education or work.
- By 2010, **all 138 school districts** in Tennessee had incorporated the TOPS program for facilitating the post-secondary transition process.

WAITING LISTS

Waiting lists for services continue to grow as states face budget woes. Although state officials may request funding, they are constrained by the levels of appropriations awarded by state legislatures — and are expressly prohibited from lobbying the legislature for additional resources. The DD Network plays a critical role in garnering new resources for those on waiting lists through public education, community organizing, political and legal action. Waiting list actions have been taken by the DD Networks in the states including litigation and political advocacy through "unlock the waiting list campaigns," educating legislators and working with families to make their voices heard.

Disability Rights Wisconsin and the **Waisman Center (UCEDD affiliate)** joined efforts to reduce the waiting lists for children's services. In 2007, with the support of the state's major disability coalition (the Survival Coalition of Wisconsin Disability organizations including the state DD Network members), DRW, and Wisconsin Family Voices initiated a

campaign to secure a major funding increase in the 2007–2009 biennial budget. Despite a state announced goal of ending waiting lists for adults with disabilities and frail elders, the governor proposed no funding increase in his budget for children and families. Through concerted advocacy, the waiting list message resonated with legislators in both parties, and ultimately the legislature decided to add \$9 million (\$4 million state and \$5 million federal) to the program's budget for the biennium.

Impact of the Initiative:

- Reduced waiting lists for children with disabilities by half.
- Established the Children's Medicaid Waivers as a viable program with sufficient capacity to impact a significant number of children and families in every one of Wisconsin's 72 counties.
- Created momentum for the program in the legislature, which contributed to the governor's decision to propose a second major increase in the 2009–2011 biennium.
- Greatly reduced the risk of children with disabilities having to move into out-of-home placements as a result of having no in-home services available.

Oregon's Staley Settlement Agreement is the product of the joint efforts of the state's DD Network partners: **Oregon Council on Developmental Disabilities; Disability Rights Oregon (P&A)** ; and the **Oregon Institute on Disability and Development** working in concert with each other and multiple other partners including families and self-advocates; The Arc of Oregon; Department of Human Services, Seniors and People with Disabilities, Office of Developmental Disability Services; County Developmental Disability Programs; Oregon DD Coalition (26 organizations); and provider organizations. Staff from Disability Rights Oregon and the Oregon Council on Developmental Disabilities negotiated settlement of the lawsuit resulting in a new system of self-directed services based on a model for the service delivery developed through a Robert Wood Johnson self-directed supports grant operated by the Center for Self Determination at the Oregon Institute on Disability and Development.

Impact of the Initiative:

- The waitlist of adults with no access to services was eliminated.
- More than 7,000 adults with developmental disabilities receive self-directed services under a capped support services waiver living in the family home or living independently in the community.
- More than 300 individuals received access to 24-hour comprehensive services;
- Thirteen support brokerages were created to provide access to a person centered planning process and support to implement the plan.
- Self-advocates and families have embraced the philosophy of self-determination and self-directed services based on person centered thinking.
- Adult support services have delayed or prevented the need for more costly out of home placements.
- Close to 10,000 independent contractors and personal support workers are

employed by individuals with ID/DD in the adult support services program, greatly expanding the pool of qualified workers.

- The advisory group has become the model for stakeholder involvement.

The **Disability Law & Advocacy Center of Tennessee (DLAC)** filed a waiting list suit in 2000, called *Brown, et al. v. Tennessee Department of Finance, et al.*, Case No. 3:00-0665 in U.S. District Court. DD Network partners and other disability organizations helped DLAC identify potential class representatives during the lawsuit. The Tennessee Council on Developmental Disabilities, Boling Center on Developmental Disabilities, Vanderbilt Kennedy Center for Excellence in Developmental Disabilities, and other disability organizations also testified at the fairness hearing regarding the settlement agreement and provided helpful input during DLAC's monitoring of that agreement. In addition, they provided input into the development of two new programs: consumer directed support services and the self-determination waiver. The suit was settled in 2009.

Impact of the Initiative:

- 3,000 people on the waiting list were enrolled into a Medicaid waiver program and remained in their communities rather than in institutional care.
- The number of providers of home and community-based waiver services grew to more than 400.
- People on the waiting list received more than \$15 million in consumer directed support funds.

Disability Rights Network of Pennsylvania in partnership with the **Pennsylvania Developmental Disabilities Council** and the **Institute on Disabilities UCEDD at Temple University** implemented a Waiting List Campaign that resulted in increased resources and the development of a Prioritization of Urgency of Needs (PUNS) evaluation that establishes the need for services and helps prioritize individuals with the most urgent needs.

Impact of the Initiative:

- The state has the tools to anticipate and plan for level of need on an ongoing basis.
- From 2003 to 2011, **\$317 million** new dollars were appropriated for persons on the waiting list.
- Due to unmet needs identified by PUNS, the 2011 proposed budget includes an additional \$228 million to meet the needs of individuals currently underserved through the state's Medicaid waiver program.
- The PUNS methodology is now seen as a successful model for assessing service needs and priorities and with support from the Institute on Disabilities has been adapted for use in five states with an additional three states using an approach modeled on PUNS.

SELF-ADVOCACY

DD Networks have played a critical and often pivotal role in the development of the self-advocacy movement, both at the state and national level. The self-advocacy movement

supports and encourages people with developmental disabilities to be their own self-advocates — in determining their life goals, directing their own services and supports, and living and working in the community. Consistent and persistent education of decision makers by the individuals served is essential if legislators and administrators are to understand the perspectives of people with disabilities. State agencies solicit and value the input of individuals with disabilities, with every state agency actively including individuals with disabilities on stakeholder groups and planning committees. These individuals benefit from support and training on how to become effective leaders and work with decision-makers. Self-advocates have local, statewide, and national organizations that receive substantial support from the DD Councils and UCEDDs. This support has contributed to the inclusion of self-advocates in high level policy decision-making around the country and has undergirded the national development of the self-advocacy movement. Inclusion of self-advocates in policy decisions has become a priority with the Centers for Medicaid and Medicare Services (CMS) which ask states to assure public input into decision-making about states' development of home and community-based services under their waiver programs, listing self-advocates *as the first group* states should include for giving public input. This input will likely become a requirement with the passage of new proposed regulations from CMS.¹⁵

Self-Advocates as Change Agents:

The efforts of self-advocates organized by **DisAbility Rights Washington** and other DD Network members and advocacy organizations resulted in the legislature requiring that all public schools include disability history as part of the public school curriculum.

Impact of the Initiative:

- All schools in Washington state are required to promote the historical contributions of people with disabilities which means more than 1,000,000 public school students are made aware of this information.

Every year since 1999, the **Wisconsin Board for People with Developmental Disabilities** has provided core funding and technical assistance to establish and expand a statewide network of self-advocates comprised of local chapters and a statewide umbrella People First organization. During the past 12 years, People First Wisconsin has grown to include 20 local self-advocacy chapters with 500 self-advocates involved in local chapter efforts and an overall membership of 1,450 (925 self-advocates; 445 friends/allies; and 80 organizations) including an internet presence with a website and Facebook page.

Impact of the Initiative:

- Efforts in conjunction with Disability Rights Wisconsin resulted in the formation of the governor's task force on sub-minimum wage and successfully petitioned APSE to take a national position regarding sub-minimum wage.

¹⁵ NPRM CFR 441.304 indicates when applying for a HCBS waiver, the state agency, "must establish and use a public input process...[and] ensure meaningful opportunities for input for individuals served."

- Developed 'Care for the Person' training which trained more than 300 medical students at the Medical College of Wisconsin and more than 125 nursing students across the state.
- Worked with local groups to: increase transportation funds for people with disabilities to five north central counties; extend community sidewalks and lengthening cross walk times in multiple cities; train local city bus drivers on accessibility, accommodation and safely securing mobility devices; create an integrated recreation program in their community.
- Supported a self-advocate to publish a book on her experiences who has since gone on to present her story to 3000 students in Wisconsin.
- Since 1999, the DD Network has supported three statewide self-advocacy conferences with more than 1,000 participants; more than 100 trainings to local self-advocacy groups — with 2,000 total participants; and self-determination training to more than 750 transition students.

Other self-advocacy efforts include the **Washington State Developmental Disabilities Council (DDC)** support of Self-Advocates in Leadership (SAIL) since 1990. This coalition of more than 200 people with intellectual and developmental disabilities (ID/DD) is influential in shaping public policy in Washington state. This coalition has been successful in impacting bills in every legislative session since 2004 from accessibility of voting machines to making sure all legislation uses respectful language, including removing the use of the word "retarded" from all statutes.

EMPLOYMENT

The DD Network is focusing attention on full community integration of people with developmental disabilities, including employment and the over usage of sheltered and sub minimum wage facilities for hundreds of thousands of people with ID/DD. Through data collection sponsored by the UCEDD network, recent exposes by the national association of P&As (NDRN), and program development and policy advocacy by DD Councils, this remaining significant frontier of discrimination and segregation is being addressed. Integrated non-facility based employment of adults individuals with intellectual disabilities is at only 14.1 percent of working age adults.¹⁶ The network is poised to use its collective expertise, experience, and resources to develop viable alternatives to segregated and sheltered employment and bring people with developmental disabilities into full community participation.

A critical resource in the development of employment supports is the **University of Massachusetts Institute on Community Integration** (a UCEDD), which is a national source of research and technical assistance to states as they focus on employment. This effort was initiated by the Administration on Developmental Disabilities with a national data collection projected award to the Institute for Community Inclusion (ICI), the UCEDD based at the University of Massachusetts Boston and Children's Hospital of Boston. In 1997,

¹⁶ University of Massachusetts ICI, www.Statedata.info.

ADD funded the ICI to create the National Report on Employment Services and Outcomes, annually documenting on a state by state basis changes in employment outcomes for persons with intellectual and developmental disabilities. The development of the StateData website has served as an ongoing resource for administrators, policymakers, providers, families and consumer in measuring change over time as the movement to competitive, integrated employment has advanced.

In response to the low rate of workforce participation among people with ID/DD, a number of states have joined the State Employment Leadership Network (SELN), a collaborative project of the ICI and the National Association of State Directors of Developmental Disability Services (NASDDDS). DD Councils have been actively involved in supporting the efforts of the SELN in more than 20 states.

Increasingly, states are focusing on employment, adopting "employment first" policies with the intent of moving services away from congregate day programs towards employment options that create jobs, and income, for individuals with intellectual and developmental disabilities in employment settings in which they are integrated with non-disabled employees. The efforts of the DD Network have helped states create new options for employment, and as of 2011, 17 DD Councils were actively managing projects to enhance integrated employment for individuals with ID/DD.

The **Tennessee Council on Developmental Disabilities** offered a 'challenge grant' to the state of Tennessee Department of Intellectual and Developmental Disabilities to increase the percentage of individuals with intellectual disabilities served in home and community-based programs who were employed to 25 percent over a 3-year period.

Impact of the Initiative:

- Set new rates to incentivize employment services.
- Increased the employment of service recipients from 7 percent to a high of almost 24 percent.
- Adopted an 'Employment First' policy that makes employment a priority.
- Developed job coach training that was adopted by the state DD agency.
- The DD Council, the state Department of Vocational Rehabilitation and the state developmental disabilities agency became equal funding partners for the Employment Consortium.
- The **Tennessee Employment Consortium** (TEC) received national recognition in 2007 when the Institute for Community Inclusion named TEC an innovative practice in the employment of people with disabilities.

The **Washington State Developmental Disabilities Council (DDC)** in partnership with AmeriCorps, Central Washington University, Division of Vocational Rehabilitation, Service Corps of Retired Executives, University of Washington Community Education Services, Yakima Legends Casino, and Yakima Valley Transition sponsored a self-employment initiative to assure that individuals with intellectual and/or developmental disabilities and their families have opportunities to save money to maintain or improve their basic economic and social status including employment, housing, and retirement. Activities

under the Project include establishing collaborative community partnerships, providing resources to initiate self-employment, conducting training for the individual entrepreneur and their direct support professionals.

Impact of the Initiative:

- Forty people became self-employed.
- \$333,312 was leveraged for employment supports.
- 482 individuals with ID/DD were exposed to entrepreneurial concepts and trained in self-employment.

The P&As have also played a significant role in increasing employment opportunities for individuals with ID. As an example, **DisAbility Rights Washington (DRW)** filed Boyle, a class action lawsuit and settlement covering nearly 10,000 people with developmental disabilities, beginning in 1999 and ending in 2012. Many problems with the quantity and quality of services authorized to assist people with disabilities attain and retain employment were discovered during the course of the investigation. DRW, along with co-counsel Columbia Legal Services, conducted an investigation into employment and day services provided through the Division of Developmental Disabilities' HCBS waivers. The investigation revealed problems with freedom of choice, adequate assessment of need, quality assurance, and procedural due process.

Impact of the Initiative:

- After negotiations, the state agreed to address these concerns and the court approved the parties' joint motion to modify the existing class action settlement order to allow for the parties to implement and monitor the changes to employment and day services.
- As a result, 10,000 people with disabilities benefited from four positive changes in policy, law, regulation, or practice as a result of the pursuit by DRW of one or more of the desired outcomes assigned to this goal/priority.

Another suit filed by the **Maine Disability Rights Network (MDRN)** initially focused on individuals waiting for day services. As the suit unfolded, MDRN started working with the state on efforts to increase employment opportunities for people with disabilities. MDRN was involved with drafting successful legislation encouraging individuals with disabilities graduating from high school or aging out of the special education system to use existing funds that were available for facility-based day services for employment purposes. This legislation is modeled on efforts established by other states.

Impact of the Initiative:

- Eventually, the state eliminated day habilitation service and applied for and was granted a Medicaid HCBS waiver that allowed funds to be used for employment services, which funds for day habilitation had specifically excluded.

These DD Network efforts have clearly shown that individuals with significant disabilities can become employed — and self-employed. These projects serve as a model for states and

a beacon of encouragement to individuals with disabilities that they can participate in the workforce, earn real wages, and be productive members of society.

AUTISM

Today, 1 in 110 children is diagnosed with **autism**. The UCEDDs are leaders in the field of autism research, developing clinical intervention, training and educational and prevention programs throughout the country.¹⁷ Many DD Network partners across the country are actively engaged in programs and projects relating to autism, with 20 DD Councils and 61 UCEDDs identifying current projects and programs on this topic. As one example, the **Center on Human Development and Disability**, at the **University of Washington**, has conducted a comprehensive initiative involving research, training, outreach, and advocacy on behalf of individuals with autism in Washington state. A major emphasis was placed on early identification and early intervention as well as the addition of new community services.

Impact of the Initiative:

- Created extensive new resources and clinics across the state, especially Tacoma, through funding by the state legislature.
- Worked to establish Senate Bill 5311 to create a state-wide autism task force.
- Carried out research demonstrating the effectiveness of a combined treatment approach for toddlers with autism.
- Within the last 5 years, this initiative has successfully provided training and technical assistance to more than 2,500 professionals from more than 100 school districts and early childhood programs.
- Medical services have improved by establishing medical home teams in 18 of the 39 Washington state counties and a new autism-specific genetics clinic at our UCEDD.

ASSISTIVE TECHNOLOGY

Assistive technology (AT) is a rapidly changing and immensely promising area. While technology is an essential element in our society, it remains an allusive resource for most individuals with developmental disabilities. Substituting technology for human assistance can be enormously beneficial in terms of independence — and can positively impact the costs of supporting individuals as well. AT has been a major focus of training, outreach, and research within the **Center on Human Development and Disability**, (the University of Washington UCEDD) since 1993. Working with partners including colleges and universities, foundations, private industry, state agencies, and legal advocacy organizations, the program serves all Washington state residents with disabilities, their families, employers and employment service providers, educators, health care and social service providers and others seeking information about assistive technology.

¹⁷ Centers for Disease Control statistics found at <http://www.cdc.gov/ncbddd/autism/data.html>.

Impact of the Initiative:

- Formal presentations to approximately 100,000 individuals across the state.
- Technical assistance and training provided to approximately 20,000 individuals, and received approximately 800,000 hits on the website.
- On-going technical assistance and consultation to numerous private and public entities on accessible information technology as well as assistive technology.
- Legal advocacy activities have resulted in passage of a Washington state law on resale of school district technology to consumers, adoption of Washington state Department of Information Services web-accessibility guidelines, changes to Medicaid coverage for assistive devices, accessibility improvements to the WorkSource Centers, and training of law students and lawyers on the rights of individuals to assistive technology.
- Permanent changes to the curricula at several post-secondary institutions across the state to include courses related to funding, acquisition, and use of assistive technology.

OTHER PROGRAMS AND PRACTICES THAT ASSURE THE RIGHTS AND ENHANCE THE LIVES OF INDIVIDUALS WITH ID/DD

The scope and impact of the DD Networks' many initiatives far exceeds the capacity of this brief paper — but below we offer a variety of examples of the other types of investments that have positively affected the lives of individuals with ID/DD. Issues as varied as transportation to reducing reliance on restraints to family financial planning for individuals with ID/DD benefit from the efforts of the DD Network. Many of the issues and barriers that individuals with developmental disabilities face fall outside the scope and capabilities of state services systems; therefore, the efforts of the state DD Networks to bring essential resources to bear on these critical needs is paramount.

Individuals with disabilities report that **transportation** is a severe barrier to a full life in the community, including obtaining and maintaining integrated employment. The **Pennsylvania DD Network** partners and others including the independent living centers, Department of Transportation, legislative supporters, engineering consultants, ADAPT, and local transportation authorities joined together to improve rural transportation.

Impact of the Initiative:

- 68 of Pennsylvania's 71 counties, with more than 12,000 registered riders participated in the project.
- Legislation authorizing the system was passed and funded, eventually leveraging more than \$7 million per year.
- More than 44 percent of riders utilized the service for the purpose of going to and from work;
- In 2008, Pennsylvania celebrated the provision of the millionth ride made available through this project.
- The system now sustains itself with no further funding from the DD Council.

Financial planning for individuals with ID/DD is often a neglected area — and far outside the responsibilities or capabilities of state services systems. But families who wish to invest in their family member's future often have limited access to the specialized approaches that allow for the establishment of trusts that do not jeopardize critical benefits such as Medicaid or Supplemental Security Income. The **Washington State Developmental Disabilities Council** advocated for the establishment of the, Developmental Disabilities Life Opportunities Trust (DDLOT) a private-public partnership.

Impact of the Initiative:

- Individual contributions are combined with an original appropriation of \$5 million in an endowment that is invested by the Washington state investment board in the same way as the state's other retirement programs.
- Since 1999, the DDLOT has grown to more than 1,518 beneficiaries with accounts in an endowment of more than \$27 million.
- During 2010, more than \$1 million dollars was disbursed from the trust accounts which beneficiaries used to purchase goods and services in their local communities, all across Washington state.

Sustainable housing is a continual problem for individuals with disabilities. Cost and accessibility of housing are cited as the top barriers to moving individuals into the community from institutional settings. Individuals living in provider-controlled group settings are not truly living in their own home, as evidenced by the need for the person to move if he/she doesn't care for roommates, or if the supports in the home do not meet the person's needs. Beginning in 2003, the **Wisconsin Board for Persons with Developmental Disabilities** implemented Movin' Out, a program focused on stable rental homes and/or home ownership for individuals with ID/DD.

Impact of the Initiative:

- Successful, sustainable home ownership for 1,100 households in 67 of 72 Wisconsin's counties.
- Subsidies totaling more than \$18 million in gap financing to Movin' Out home owners.
- Movin' Out homeowners leveraged more than \$60 million in mortgage loans, virtually all with 30-year, fixed rate mortgages, assuring stability over the long haul.
- Movin' Out housing counselors fielded housing inquiries from 2,500 people a year.
- Movin' Out develops and operates small-scale, unlicensed rental housing that provides affordable, safe, and community-integrated housing to tenants who rely on long-term support systems.
- For families desiring to preserve the family home as a housing asset available to family members with disabilities, Movin' Out administers a charitable housing trust and welcomes direct transfers of property to Movin' Out with the promise that Movin' Out will manage the properties so that they are safe and affordable to the family members throughout their lives.

CONCLUSION

For several decades, the DD Network has positively affected the lives of hundreds of thousands of individuals with intellectual and developmental disabilities — assuring their rightful place as full community members through advocacy, research, training, and programs that directly support individuals, families, and communities across the country. The DD Network fills critical gaps in state services systems. State systems are complex and do not have the resources to fund research and pilot projects, to test new ideas or provide extensive training to teachers or medical practitioners — and they are prohibited from engaging in the types of advocacy that the DD Councils are in fact chartered to do.

The DD Network is central to moving the entire field of intellectual and developmental disabilities toward improved effectiveness and efficiency, and is essential in securing positive outcomes in the lives of individuals with intellectual and developmental disabilities, their families and communities. This vital network continues to advance state and national policies and practices in the disabilities field in ways that enhance the quality of our communities and the lives of all U.S. citizens.

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