



NACDD

National Association of Councils
on Developmental Disabilities

State Developmental Disabilities Councils

2012–2016

INVESTMENTS TOWARD IMPACT



This report was developed through AIDD's Technical Assistance contract (#HHSP233201600068C) administered by the National Association of Councils on Developmental Disabilities to provide technical assistance to the national network of DD Councils.





TABLE OF CONTENTS

EXECUTIVE SUMMARY	1
INTRODUCTION.....	3
TABLE I Performance Measures and Data Reported by Councils FY12–FY16	4
TABLE 2 Funding Leveraged by Councils FY12–FY16	4
TRANSITION AND POSTSECONDARY EDUCATION	5
EMPLOYMENT	7
HEALTH AND WELLNESS	10
COMMUNITY LIVING.....	12
SELF-ADVOCACY AND LEADERSHIP	15
CONCLUSION	20

EXECUTIVE SUMMARY

Developmental Disabilities Councils (DD Councils) are part of the Developmental Disabilities Network as outlined by the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 2000 (DD Act). Councils exist in every state and US territory. They consist of volunteer members appointed by the Governor. The majority of members must be individuals with Developmental Disabilities (DD) or family members of individuals with DD. Councils receive federal funding through a grant formula and are charged with addressing the most pressing needs of people with developmental disabilities (DD)¹ and their families in their state or territory.

Approximately 5 million individuals in the US have developmental disabilities. As defined in the DD Act, a developmental disability is a severe, chronic disability, which originated at birth or during the developmental period (prior to age 22), is expected to continue indefinitely, and substantially restricts the individual's functioning in several major life activities. Examples of developmental disabilities include autism spectrum disorder, cerebral palsy, Down syndrome, Fetal alcohol syndrome, Spina Bifida, and intellectual disabilities.

The 56 Councils across US states and territories work to address identified needs by conducting advocacy, systems change, and capacity building efforts that promote self-determination, integration, and inclusion. Key activities include conducting outreach, providing training and technical assistance, removing barriers, developing coalitions, encouraging citizen participation, and keeping policymakers informed about developmental disability issues.

Councils play a unique role in making investments towards impact at the local and state levels. Councils have direct contact with individuals with DD, families, and providers. They provide a venue for policymakers and agencies to listen to people with DD and their families. They perform comprehensive reviews and analyses of needs, services and supports. They develop and implement state plans every five years to respond to needs and leverage funding to make investments towards greater impact.

This report highlights the work of Councils during the most recent five-year cycle, FY 2012 to FY 2016 based on a review of annual reports submitted by Councils. It provides themes and investments made in five key areas:

1 TRANSITION AND POSTSECONDARY EDUCATION

• *Information for Transitioning Students and Families*

Councils fostered interagency partnerships to develop and disseminate resources for students and families during the transition process.

• *Training of Teachers and Professionals*

Councils enhanced training of teachers and professionals to improve transition outcomes for youth with disabilities.

• *Skill-Building of Transitioning Youth*

Councils enhanced the capacity of transitioning youth through self-determination trainings and partnerships with universities and businesses to provide opportunities to gain experience and skills.

• *Development of Postsecondary Educational Opportunities*

Councils played a significant role in forming partnerships and providing funding to develop new postsecondary educational opportunities for individuals with DD.

2 EMPLOYMENT

• *Initiatives to Support Employment*

Councils advanced policies within their states to improve employment outcomes for individuals with DD, particularly advancement and passage of Employment First legislation and implementation of the *Achieving a Better Life Experience (ABLE)* program.

• *Implementation of Statewide Employment First Policies*

Councils played leadership roles in implementation of Statewide Employment First policies. Councils led interagency committees, participated in collaborative workgroups, assisted with monitoring class-action settlement agreements, and promoted participation in learning cross-state learning collaboratives.

• *Improving Provider Capacity and Customized Employment Practices*

Councils improved capacity of vocational rehabilitation and employment service providers, particularly in customized employment practices. This included training, technical assistance, and development of partnerships with the business community.

• *Opportunities for Self-Employment and Entrepreneurship*

Councils promoted greater opportunities for individuals with developmental disabilities to gain business skills and pursue self-employment and entrepreneurship.

3 HEALTH AND WELLNESS

- ***Improved Access to Health Care***

Councils engaged in a variety of advocacy and systems change activities to reduce barriers and improve access to health care for people with DD.

- ***Improved Access to Dental Care***

Councils improved access to dental services through awareness campaigns, worked with managed care organizations, and helped establish donated dental programs.

- ***Education and Training of Health Care Professionals***

Councils played significant roles in improving training of medical and dental professionals in working with individuals with DD.

- ***Health Promotion and Empowerment of Individuals with DD***

Councils developed and implemented health promotion programs that empowered individuals and their families in a variety of health-related areas, including nutrition, physical activity and recreation, sexual health, and improving physical and programmatic accessibility of medical facilities.



4 COMMUNITY LIVING

- ***Home and Community Based Services***

Councils actively provided guidance into state Medicaid reforms and other initiatives to enhance access to Home and Community-Based Services and Supports.

- ***Access to Affordable and Accessible Transportation***

Councils played leadership roles in bringing partners together to find innovative solutions to address transportation barriers faced by people with developmental disabilities. Work included reports, formation of coalitions and workgroups, development of partnerships with transportation agencies, and targeted efforts in local, regional, and rural areas with significant transportation barriers.

- ***Access to Affordable and Accessible Housing***

Councils expanded access to affordable and accessible housing options. Councils formed collaborations and workgroups to expand housing options. They partnered to promote universal design/accessible housing development, shared living, and home ownership opportunities for individuals with developmental disabilities.

5 Self-Advocacy and Leadership

- ***Self-Determination and Self-Advocacy Capacity Building***

Councils supported a variety of trainings and programs for peer-to-peer support to build self-advocacy and self-determination skills. Councils also supported programs for individuals to access opportunities to gain public speaking experience.

- ***Statewide Self-Advocacy Organizations and Cross-Disability Coalitions***

Councils supported statewide self-advocacy organizations and networks to provide training to people with developmental disabilities in leadership, self-advocacy, and self-determination. Councils supported the development of statewide self-advocacy organizations and networks in states where structures do not yet exist. Councils also supported development of cross-disability coalitions.

- ***Leadership and Advocacy Training***

Councils supported a wide range of leadership and advocacy training for individuals with developmental disabilities and families.

The report highlights these five areas due to the significant amount of activity across the network on these issues during the last cycle. These are critical areas of importance to people with developmental disabilities and their families. The work of Councils extends far beyond the areas and examples highlighted in this report. However, the report helps demonstrate the valuable role of Councils in working towards increasing independence, productivity, inclusion and integration of individuals with developmental disabilities and their families.

INTRODUCTION

Developmental Disabilities Councils (DD Councils) are part of the Developmental Disabilities Network as outlined by the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 2000 (The DD Act). The DD Network also consists of University Centers for Excellence in Developmental Disabilities (UCEDDs) and Protection and Advocacy Systems (P&As).

Approximately 5 million individuals in the US have developmental disabilities (DD).¹ As defined in the DD Act, a developmental disability is a severe, chronic disability which originated at birth or during the developmental period (prior to age 22), is expected to continue indefinitely, and substantially restricts the individual's functioning in several major life activities. Examples of developmental disabilities include autism spectrum disorder, cerebral palsy, Down syndrome, Fetal Alcohol Syndrome Disorder, spina bifida, and intellectual disabilities.

The 56 DD Councils across the US and its territories work to address identified needs by conducting advocacy, systems change, and capacity building efforts that promote self-determination, integration, and inclusion. Key activities include conducting outreach, providing training and technical assistance, removing barriers, developing coalitions, encouraging citizen participation, and keeping policymakers informed about developmental disability issues.

In each state or territory, the governor appoints a Council made up of voluntary members. By law, the majority of members must have a developmental disability or be a family member of a person with a developmental disability. DD Councils receive federal funding through a grant formula process. Every five years, they are required to develop and implement a five-year statewide plan to address identified priorities important to individuals with DD and their families. This report highlights the collective work of Councils during the most recent five-year cycle, FY 2012 to FY 2016.

DD Councils have the unique role of being able to bring a variety of groups, organizations, and agencies together to address the needs of people with DD and their families. To illustrate the significant reach of Councils, Table I highlights selected performance measures and data reported by Councils in the areas of self-advocacy/advocacy and systems change. On average, Councils trained over 166,000 individuals per year in a variety of areas related to goals and objectives in their state plans. They trained 55,902 individuals with DD and families in leadership, self-advocacy, and self-determination and 46,751 per year in systems advocacy. On average, Councils reported engaging 67,020 people per year in system advocacy and 3,700 individuals per year attaining membership on public/private bodies and leadership coalitions.

Also highlighted in Table I, Councils reported having significant impacts on systems change at the local and state levels. On average, Councils reported creating or improving 3,026 programs and policies per year. They brought together 14,447 organizations per year to work in collaborations, networks, and partnerships and engaged 9,886 organizations in systems change efforts. Finally, Councils educated an average of 31,401 public policymakers per year and reached 160,321,520 members of the general public.

As Councils implement their state plans to address unmet and under met needs of people with DD, they are able to build on investments with additional funding from the public and private sectors to support meeting the needs of people with DD. The additional dollars gained as a result of an investment of federal grant dollars is called "leveraged funds." As highlighted in Table II, during the 2012-2016 reporting period, Councils leveraged a total of \$505,202,747 - which is just over \$100 million dollars per year. Examples of leveraged funds include increases in state dollars to serve people with DD waiting for services and supports in the community, funds for accessible housing with universal design features, state funding to fulfill family support services and increases in state general funds for DD services and supports. Through the work of DD Councils, resources are gained to support citizens with DD and their families to work, learn, play, and participate in their communities.

Councils report annually on activities and progress towards the goals and objectives of their five-year state plan. Annual reports were reviewed for all Councils in the following key areas:

1 TRANSITION AND POSTSECONDARY EDUCATION

2 EMPLOYMENT

3 HEALTH AND WELLNESS

4 COMMUNITY LIVING

5 SELF-ADVOCACY AND LEADERSHIP

Examples of Council investments towards impact are highlighted in this report. The work of Councils extends far beyond these areas and examples. However, there was considerable activity across the network in these areas during the last cycle due to the critical importance of these issues for people with DD and their families. The following sections highlight examples of Council work in these areas to help demonstrate the valuable work of Councils in improving the lives and opportunities for individuals with DD and their families.

TABLE I
Performance Measures and Data Reported by Councils FY12 – FY16

	FY12	FY13	FY14	FY15	FY16	Average
SELF-ADVOCACY / ADVOCACY						
People trained in area related to goal/objective	162,531	148,028	186,755	192,405	192,405	166,880
People trained in leadership, self-advocacy, and self-determination	45,243	49,666	60,806	69,087	54,707	55,902
People trained in systems advocacy	49,091	39,260	42,694	53,948	48,761	46,751
People active in systems advocacy	65,477	60,690	69,267	74,317	65,349	67,020
People attained membership on public/private bodies and leadership coalitions	3,093	3,597	2,593	4,391	4,828	3,700
SYSTEMS CHANGE						
Programs / policies created or improved	3,656	2,018	2,540	3,542	3,372	3,026
Number of organizations involved in coalitions / networks / partnerships	17,459	9,420	11,406	15,723	18,228	14,447
Organizations engaged in systems change efforts	13,385	5,414	9,379	9,439	11,814	9,886
Number of public policymakers educated	28,853	30,076	33,151	51,255	40,672	36,801
Members of general public reached	25,072,688	25,798,454	22,321,599	22,268,638	33,530,890	25,798,454

TABLE 2
Funding Leveraged by Councils FY12 – FY16

FY12	\$147,639,080
FY13	\$92,378,660
FY14	\$84,515,087
FY15	\$62,702,101
FY16	\$117,967,819
Total FY 12 – FY16	\$505,202,747
AVERAGE	\$101,040,549



TRANSITION AND POSTSECONDARY EDUCATION



BACKGROUND

Transition from secondary education (high school) to adult life is a major challenge for students with developmental disabilities and their families. The Individuals with Disabilities Education Act (IDEA) requires schools to provide transition services for students so that they will be prepared to enter the adult world, including continuing their education and employment. However, transition planning and services for students with developmental disabilities are often poor, leaving many youth with disabilities isolated at home and posing caregiving challenges for family members who work outside the home.

Many students with DD graduate without self-determination skills to be successful. Students with DD and their families often do not receive adequate information or person-centered planning. Connections are not made to relevant services and supports, such as vocational rehabilitation,

postsecondary education options, benefits counseling, and the adult DD service system.

While higher education is a primary pathway for personal growth and economic security, until very recently, postsecondary education options for students with developmental disabilities did not exist. The Higher Education Act of 2008 opened the door by providing federal funding to develop model postsecondary programs. Evidence suggests that participation leads to greater employment outcomes.²

DD COUNCIL INVESTMENTS TOWARD IMPACT

Themes in Council investments included: 1) Information for Transitioning Students and Families; 2) Training of Teachers and Professionals; 3) Skill-Building of Transitioning Youth; and 4) Development of Postsecondary Educational Opportunities.

Information for Transitioning Students and Families

The following examples of investments by DD Councils are leading toward greater impact by bringing entities together in a coordinated effort and by providing up-to-date, relevant resources to students with DD and their families during the transition process:

- **California** State DD Council and **Hawaii** State Council on DD formed interagency partnerships between education, vocational rehabilitation, and DD services agencies. They assembled “roadmaps” of linked resources, supports and services. In Hawaii, the map provided a visual aid that would assist students with DD and their families to plan for a successful transition from high school to employment, and to facilitate discussion at meetings.
- **Florida** DD Council developed and sustained a statewide employment and transition website (*called the FYI Transition*) to provide resources to transitioning students with DD and families about post-secondary education and/or employment. It also included modules to assist in the development of independent living skills needed by these students as they approach adulthood. During FY16, the website experienced 1,507 visits by students, families and professionals. Users of website reported an increase in knowledge and understanding of transition from secondary to post-secondary in Florida.
- **New York** State DD Planning Council partnered to establish a statewide database of existing postsecondary education programs within New York.
- **Virginia** Board for People with Disabilities partners with the Virginia Department of education on development of a face-to-face and web-based training to improve the knowledge of transitioning students and assist them with making informed decisions in order to improve access to general curriculum, education and employment outcomes.
- **Wisconsin** Board for People with DD received a grant from the National Resource Center on Supported Decision-Making to decrease incidents of unnecessary guardianships and promote autonomy of people with developmental disabilities.

Training of Teachers and Professionals

The following examples of investments by DD Councils are leading toward greater impact by improving training of teachers and professionals to improve transition outcomes:

- **Alabama** Council for DD developed a training and certification program for service providers to support effective life transitions for people with DD, including access to employment, increased independent living skills, and community integration.

- **Delaware** DD Council conducted a needs assessment with school personnel from all the state's middle and high schools that was used to improve training and dissemination of transition information to students with DD and their families.
- **Massachusetts** DD Council partnered to establish a voluntary transition specialist qualification endorsement program for licensed special education teachers, guidance counselors, school social workers, and rehabilitation counselors.
- **North Dakota** State Council on DD launched a community of practice to build, support, and sustain community partnerships to foster successful transitions and independence for students with DD.

Skill-Building of Transitioning Youth

The following examples of investments by DD Councils are leading toward greater impact in preparing youth with DD to make decisions, speak up for themselves, and gain skills to prepare for jobs and college experiences:

- **Georgia** Council on DD implemented a project called Partnerships for Success to improve self-determination of transitioning youth. This included: student-led individual education plans, inclusive social and service clubs, self-determination training, and futures planning.
- **Massachusetts** DD Council developed a training program called *Youth in Transition Self-Advocacy Leadership Series (SALS)* to prepare students with knowledge about self-determination, systems advocacy, employment, independent living, and the disability rights movement. The Council partnered with nine area colleges and universities to offer this series in school districts across the state.
- **Missouri** DD Council supported a project called Show-Me-Careers, which scaled up evidence-based practices in eight pilot communities. Projects adopted a variety of approaches, including skill-building of youth, career planning, and development of partnerships with the local business community.
- **Nevada** Governor's Council on DD supported the *Community Based Career Exploration Camp*. Participating students gained real world experiences through partnerships with local businesses and employers. Students also gained skills in such areas as resume writing/job applications, interviewing, and mobility/transportation.
- **South Carolina** DD Council initiated a series of pilot programs that included academic training, interpersonal skill-building, and work experience for high school and postsecondary students with DD.
- **Tennessee** Council on DD developed a youth readiness training to better prepare youth with disabilities for life after high school and put youth on a positive trajectory toward employment, postsecondary education and living more independently.

Development of Postsecondary Educational Opportunities

The following examples of investments by DD Councils led toward greater impact in expanding inclusive, postsecondary educational opportunities for students with DD:

- **Florida** DD Council partnered with Florida State College and local school districts to develop a model postsecondary program for students ages 18-22. The program allows students to work towards technical certification in fields of their choice, including cosmetology, child care, welding, carpentry, auto body repair, hazardous waste disposal and warehouse management.
- **Pennsylvania** DD Council worked with community colleges in the state to develop model inclusive postsecondary education programs. Harrisburg Area Community College approved courses for two career pathways: Culinary Specialist Certificate and Nurse Aide Training Certificate. Lehigh Carbon Community College developed a model program to include students with DD across a range of programs.
- **Tennessee** Council on DD provided startup funding that resulted in the establishment of four new postsecondary programs in the state, located at Vanderbilt University, Lipscomb University, University of Memphis, and Union University.
- **Texas** Council for DD worked with South Texas College and El Paso Community College to create inclusive postsecondary programs for students with DD. They also worked with Texas A&M University to develop an inclusive postsecondary program that provides a certificate in human services professions.





Inclusive Postsecondary Education Programs in Georgia

Georgia Council on Developmental Disabilities

The Georgia Council on Developmental Disabilities worked with a network of colleges and universities to offer students with intellectual disabilities an opportunity to receive a postsecondary experience. What began with one university and a \$25,000 grant from the Council has grown to 6 universities/colleges with another 4 coming on in 2017-2018 and a budget of over \$1.5 million including state and federal funds.

Currently, there are 80 students enrolled in two and four-year programs across the state.

A major focus of the programs is preparing students for employment. Data collected between 2011 and 2015 on students who attended these programs indicated that:

57%
gained
employment



22%
were
continuing
their
education



7%
were seeking
employment



EMPLOYMENT

BACKGROUND

Historically, the majority of people with developmental disabilities have been either unemployed or underemployed despite their ability, desire, and willingness to work in the community.³ Many individuals continue to be placed in segregated “prevocational” programs and sheltered workshops where they are paid below minimum wage. While there have been many advances in employment supports for people with developmental disabilities, currently only about 15% of people receiving services from state DD agencies work in integrated employment.⁴

Many factors contribute to the poor employment status of people with developmental disabilities. Low societal expectations persist, as well as many systemic barriers. Students often transition with few opportunities to gain community-based vocational experience. Vocational rehabilitation professionals and providers often lack training and technical assistance on effective practices, such as customized employment. Customized employment is a flexible process designed to personalize the employment relationship between a job candidate and an employer in a way that meets the needs of both.

A promising development is state adoption of Employment First initiatives. “Employment First” is a framework for systems change that is centered on the premise that all citizens, including individuals with significant disabilities, are capable of full participation in integrated employment and community life. Another promising development is passage of the Workforce Innovation and Opportunity Act (WIOA) in 2014 which among other things increases services to youth with disabilities, supports employer engagement, and places greater emphasis on competitive integrated employment outcomes.

DD COUNCIL INVESTMENTS TOWARD IMPACT

Themes in Council investments included: 1) Legislative Initiatives to Support Employment; 2) Implementation of Statewide Employment First Policies; 3) Improving Provider Capacity and Customized Employment Practices; and 4) Opportunities for Self-Employment and Entrepreneurship.

Legislative Initiatives to Support Employment

The following examples of investments by DD Councils are leading toward greater impact in advancing public policies at the state and local levels to improve employment outcomes for individuals with DD, particularly advancement and passage of Employment First legislation and implementation of the Achieving a Better Life Experience (ABLE) program:

- **Alabama** Council for DD, **Georgia** Council on DD, **Oklahoma** DD Council, **Tennessee** Council on DD, and **Washington** State DD Council impacted the passage of legislation within their states to implement (or plan for implementation) of the *Achieving a Better Life Experience (ABLE) program*. The ABLE program allows individuals with DD to establish tax preferred savings accounts for disability-related expenses without jeopardizing access to disability programs such as Medicaid and SSI.

- **Colorado** DD Council, **Florida** DD Council, **Mississippi** Council on DD, **Texas** Council for DD and **Virginia** Board for People with Disabilities played key roles in the passage of Employment First legislation in their states.
- **Georgia** Council on DD established an Employment First Coalition to educate advocates, lawmakers, providers, and the public. Actions led to formation of a legislative study committee and a report recommending creation of an advisory council regarding future steps Georgia might take.
- **Kansas** Council on DD sponsored biannual Employment First Summits and commissioned a report which provided policy recommendations for the state movement away from sheltered workshops towards more cost-effective individualized employment and community-living supports.
- **Maryland** DD Council contributed to passage of legislation to phase out subminimum wage in Maryland by 2020. Approximately 40 Maryland providers used certificates that allow payment below the prevailing wage to an estimated 4,000 people. The Council is playing a key role in phasing out these subminimum wage certificates.
- **Nevada** Governor's Council on DD contributed to the establishment of an executive order and strategic plan on integrated employment. Several pieces of legislation have been approved from this strategic plan, including legislation that requires provision of long-term, competitive employment supports to persons with DD, use of government as a model employer, and establishment of a committee to evaluate provider rates.
- **Tennessee** Council on DD drafted and contributed to the passage of legislation adding "business owned by person with a disability" to existing state procurement preferences.

Implementation of Statewide Employment First Policies

The following examples of investments by DD Councils are leading toward greater impact in implementation of statewide policies to ensure people with DD are provided equal opportunities for work:

- **Alaska** Governor's Council on Disabilities & Special Education, **California** State Council on DD, **Idaho** Council on DD, **Maine** DD Council, **Tennessee** Council on DD, and **Wyoming** Governor's Council on DD played leadership roles in implementation of Employment First policies in their state. This included leading interagency workgroups, committees, and summits.
- **Oregon** Council on DD, **Rhode Island** DD Council, and **Virginia** Board for People with Disabilities played leadership roles in monitoring and implementing class-action settlement agreements within their states to decrease placements in sheltered workshops and increase supported employment services and employment outcomes.
- **Arizona** DD Planning Council, **Colorado** DD Council, **Nevada** Governor's Council on DD, **Oklahoma** DD Council, **South Dakota** Council on DD, and **Virginia** Board for People with Disabilities influenced involvement of their states in the *State Employment Leadership Network (SELN)*. SELN is a partnership between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Institute of Community Inclusion at the University of Massachusetts Boston to assist states with developing more effective employment systems and partnerships that achieve integrated, competitive employment outcomes.

Improving Provider Capacity and Customized Employment Practices

The following examples of investments by DD Councils are leading toward greater impact for service providers to receive and increase their knowledge of best and promising practices, particularly customized employment practices, to improve employment outcomes:

- **Alabama** Council for DD, **Hawaii** State Council on DD, **Iowa** DD Council, and **Michigan** DD Council influenced state involvement in the US Department of Labor, Office of Disability Employment Policy (ODEP) *Employment First State Leadership Mentoring Program*. This program provides mentoring, intensive technical assistance (TA) and training from a national pool of subject matter experts to increased integrated employment outcomes for individuals with disabilities.
- **Alaska** Governor's Council on Disabilities & Special Education, **Connecticut** Council on DD, **Idaho** Council on DD, **New Jersey** DD Council, and **Utah** DD Council supported training and certification initiatives in customized employment.
- **Maryland** DD Council partnered on an initiative to provide technical assistance from subject matter experts, and ongoing peer-to-peer mentoring for service providers to improve employment and community-based outcomes for people with DD.
- **Nebraska** Planning Council on DD, **Puerto Rico** DD Council, and **Kentucky** Commonwealth Council on DD forged partnerships with the business community and employers to enhance employment outcomes.
- **Virginia** Board for People with Disabilities awarded a grant to Virginia Commonwealth University to assist adults with disabilities to transition from sheltered (center-based) employment to integrated, competitive employment. As of the end of 2016, 25 individuals gained a job of their choice.

Opportunities for Self-Employment and Entrepreneurship

The following examples of investments by DD Councils are leading toward greater impact by expanding opportunities for self-employment and entrepreneurship for people with DD through development of business skills:

- **Alaska** Governor's Council on Disabilities & Special Education leveraged funding for microenterprise grants and professional business coaching for people with disabilities. Individuals that received grants reported an improvement in all aspects of quality-of-life with the item reported as most improved by self-employment being "personal sense of self-worth," followed by "enjoyment of daily life." Recipients noted that they would not have been able to achieve their business goals without the funds allotted via this grant opportunity.
- **Delaware** DD Council funded a program called *LaunchSpace* to provide entrepreneurship training, one-on-one coaching, and information sessions with area business professionals. A highlight of the program was the "Dolphin Tank" event, modeled after the popular television show "Shark Tank," where participants presented business plans in front of a panel of judges. One participant stated, "The *LaunchSpace* program has opened several doors for me in the last couple of months. The staff at Independent Resources has used what I already have inside. But with their helping hand, they help me realize my full potential. And with programs like this, for people with developmental disabilities, the sky is truly the limit".
- **Mississippi** Council on DD funded the *Farm Entrepreneurship and Independence Initiative* in the Mississippi Delta to train and employ young farmers. Students with disabilities and their peers learned farming skills, food safety standards, and how cooperatives work.

Project SEARCH

Project SEARCH is a unique, business led, one-year school-to-work program that takes place entirely at the workplace. Total workplace immersion facilitates a seamless combination of classroom instruction, career exploration, and hands-on training through worksite rotations. Throughout the school year, students work on employability and functional skills. Through a series of targeted internships the students acquire competitive, marketable and transferable skills to enable them to apply for a related position. Potential student worksites are identified through a continuous collaborative process involving the teacher, job coaches and business liaison. During the last few months of the program, the emphasis is on refining skills, achieving the career goal, and carrying out individualized job placement based on the student's experiences, strengths, and skills.

Project SEARCH was developed at Cincinnati Children's Hospital Medical Center in 1996. It has grown from a single program site at Cincinnati Children's to over 300 sites across the United States and internationally. Over the years, many DD Councils have contributed to implementing the model within their states. During the last five-year cycle, Councils supporting Project SEARCH programs included: **Alabama, Alaska, Arkansas, Colorado, Florida, Iowa, Kansas, Minnesota, Mississippi, New Hampshire, New Mexico, New York, North Carolina, Oklahoma, South Carolina, Tennessee, and Texas.** There were 145 individual Project SEARCH sites in these 17 states.

Through implementation of Project SEARCH, these Councils successfully built relationships with the business community and achieved integrated, competitive employment outcomes for youth with disabilities.

“

Project SEARCH, for me, has been a real chance to enter the adult world. Learning responsibility, credibility and how to earn employers trust were invaluable to me. I've built many great professional relationships and gained firsthand experience of the workplace environment.

”

—Project SEARCH
Participant

HEALTH AND WELLNESS

BACKGROUND

Individuals with DD experience a wide range of health disparities.⁵ People with DD experience lower life expectancies and greater rates of preventable secondary conditions than the general population. Individuals with DD experience high rates of obesity related to poor nutrition and lack of physical activity, as well as high rates of multiple chronic conditions, including high cholesterol, hypertension, and cardiovascular disease.

Individuals with DD and their families frequently report significant barriers in access to health care, particularly dental care. People with DD also frequently do not receive routine preventative care, such as cancer screenings. There is evidence that health disparities are even greater for rural, racial/ethnic, and other underserved populations. Also, as individuals with DD reach older ages, they face a number of specific age-related issues and health conditions.

Health disparities for people with DD are due to many factors, including high rates of poverty and factors related to social determinants of health. One longstanding issue for people with DD is the lack of adequate training of health care providers to effectively meet their needs. Many physical and programmatic barriers exist at health care facilities which make care inaccessible. People with DD are also often not involved in decision-making and health promotion activities that empower them to better manage their health.

DD COUNCIL INVESTMENTS TOWARD IMPACT

Themes in Council investments included: 1) Improved Access to Health Care; 2) Improved Access to Dental Care; 3) Education and Training of Health Care Professionals; and 4) Health Promotion and Empowerment of Individuals with DD.

Improved Access to Health Care

Councils engaged in a variety of efforts to improve health care access in areas such as:

- Improved transitions from pediatric to adult health care
- Increased access to mental and behavioral health services for people with developmental disabilities
- Increased access to services and supports for adults with developmental disabilities and dementia-related conditions

Additional examples of investments to improve health care access included:

- **Alaska** Governor's Council on Disabilities & Special Education developed partnerships to increase use of technology and telepractices in rural areas, particularly to expand access to early intervention services.
- **Massachusetts** DD Council partnered with the Autism Insurance Resource Center to assist families with information and referral via phone and email on issues related to insurance coverage for autism-related treatments and services.
- **Maine** DD Council collaborated to expand a "medical home" model for individuals with DD to ensure people with DD have a primary care physician or regular health care provider to better coordinate their overall care.
- **Texas** Council for DD supported projects in 10 targeted regions to increase capacity to provide culturally appropriate health care services, community services, behavior supports, and respite to support people with DD and their families.

Improved Access to Dental Care

The following examples of investments by DD Councils are leading toward greater impact for dental care services for people with DD through such activities as awareness campaigns, work with managed care organizations, and establishment of donated dental programs:

- **California** State DD Council partnered with coalitions to assist individuals with DD and families in understanding managed care and assisted health plans to improve access to dental care, particularly anesthesia-based dental care.
- **Delaware** DD Council conducted an awareness campaign about the importance of adequate dental care for adults with DD that reached Delaware health care systems, all Delaware dental practices in the state, and state policymakers.
- **Hawaii** State Council on DD worked with the state legislature to establish a donated dental services program that has assisted hundreds of individuals with developmental disabilities.



- **Montana** Council on DD worked with community health centers, dental associations, and donated dental program to increase dental care options and training for dental professionals, including procedures that might involve sedation.
- **Tennessee** Council on DD, through Project OPEN Wide, established the first dental clinic in East Tennessee with a developmental dentist, designed to serve people with and without I/DD. In total, the dental clinic saw 3,438 patients during the project. Tennessee also trained 1,299 para professionals, service providers, and families in oral health care for people with DD.
- **Virginia** Board for People with Disabilities awarded a grant to the Virginia Oral Health Coalition that resulted in the training for 37 hygienists and dentists that improved access to 104 individuals with DD.

Education and Training of Health Care Professionals

The following examples of investments by DD Councils are leading toward greater impact by increasing education, training, and knowledge of health care professionals working with people with DD:

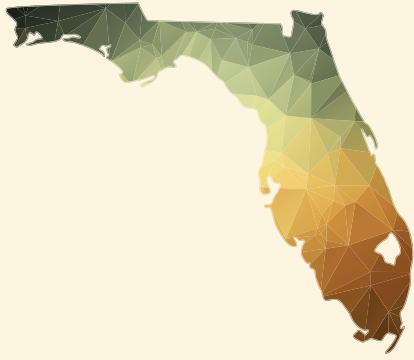
- **Alabama** Council for DD, in collaboration with their Department of Public Health, developed courses and online modules to educate health care providers on serving individuals with DD.
- **Mississippi** Council on DD supported a project to train professionals at the University of Mississippi Medical Center in Parent-Child Interaction Therapy and CARE training. In addition, training was provided to Mississippi State University students on best practices in applied behavior analytic services for people with DD.
- **Nebraska** Planning Council on Developmental Disabilities created a curriculum to increase the knowledge and understanding of healthcare practitioners when treating individuals with DD.
- **New York** State Developmental Disabilities Planning provided training to over 500 health-related personnel and over 350 oral health-related personnel on the needs of children and adults with DD and their families.
- **Oklahoma** DD Council trained nursing students on family-centered care principles and children with DD through staff outreach and Partners in Policymaking graduates.
- **Virginia** Board for People with Disabilities supported a collaborative of 22 hospitals to improve NICU outcomes for infants and children.

Health Promotion and Empowerment of Individuals with Developmental Disabilities

The following examples of investments by DD Councils are leading toward greater impact for people with DD in health promotion by increasing the ability of people with DD to make informed decisions about their health and healthcare options:

- **Alabama** Council for DD partnered with community-based organizations to develop a training curriculum on sexually transmitted infections for healthcare providers to increase their capacity to serve people with DD.
- **Arkansas** Governor's Council on DD developed a curriculum to promote and teach healthy nutrition for people with DD.
- **Delaware** DD Council provided information and advocacy training to people with DD and their families on rights concerning accessibility in medical facilities.
- **New Jersey** DD Council established active partnerships to provide an inclusive health promotion program called Get Fit to over 2,000 individuals with DD.
- **Nevada** Governor's Council on DD partnered with the University of Nevada Reno Behavior Analysis Program to improve access to local recreation and healthy living services for individuals with behavioral issues.
- **Oklahoma** DD Council supported the *Oklahoma Self-Advocacy Network* to develop and deliver peer training on building leadership skills, improving personal health outcomes, and writing personal emergency plans.
- **South Carolina** DD Council supported implementation of a range of evidence-based programs to promote health and prevent secondary conditions for people with DD.





Training Individuals with DD and Health Professionals

Florida Developmental Disabilities Council

The Florida Developmental Disabilities Council led successful training initiatives for both individuals with DD and health professionals to achieve better health outcomes.

My Health Care

The Council developed a training program called My Health Care to educate individuals with intellectual and developmental disabilities on how to communicate with health care professionals and to identify and advocate for their own health care needs. Since 2012, over 480 adults with intellectual and developmental disabilities have completed the program across the state of Florida. An evaluation found the program contributed to an increase in health-related knowledge and self-efficacy. In order to make it more widely available, the Council worked with the Florida Department of Education to make the curriculum available to all high school teachers, adding it to an online toolbox of official, vetted resources.

Training for Health Professionals

The Council also supported development of a training program for primary care physicians that was accredited by American Academy of Family Physicians. Through establishing relationships with medical schools and universities the Council extended the training to also reach medical residents and nurse practitioners.

“

I was able to take the information learned and directly apply it to the patients I was seeing in my clinical rotation site. Many of the patients there had developmental disabilities and were challenging to assess and gain their trust. After using some of the communication skills I learned in the modules, I was able to gather better histories and physical exams.

”

—Medical Student

COMMUNITY LIVING

BACKGROUND

Individuals with developmental disabilities often rely on long-term services and supports (LTSS) to assist with activities of daily living, daytime activities, and community participation. Medicaid is the primary payer of formal LTSS. Great progress has been made over the past decades within the DD service system to move away from institutional care towards home and community-based services (HCBS). Thirteen states and the District of Columbia have closed all of their state-operated facilities for 16 or more people; and over 82% of funding for residential supports is allocated to settings for 6 or less people.⁶

The vast majority of individuals with DD, however, reside at home with and rely on unpaid supports from family caregivers. Waiting lists for Medicaid HCBS have more than doubled over the past decade. States are increasingly looking for ways to better support families within and outside of Medicaid.

In addition to access to Medicaid HCBS, accessible transportation and housing are major barriers to community living for people with disabilities. Barriers to transportation and housing pose significant challenges to living in the community, employment, and full participation in society.

DD COUNCIL INVESTMENTS TOWARD IMPACT

Themes in Council investments included: 1) Home and Community-Based Services; 2) Access to Affordable and Accessible Transportation; and 3) Access to Affordable and Accessible Housing.

Home and Community Based Services

Councils worked to enhance Home and Community-Based Services in areas such as:

- Guidance into Medicaid HCBS waiver and HCBS state plan amendment applications and renewals.
- State adoption of federal programs to expand access to HCBS (e.g. Money Follows the Person, Balancing Incentive Program, Community First Choice option)
- Medicaid expansion
- Implementation of the HCBS settings rule
- Consideration and implementation of Managed Long-Term Services and Supports (MLTSS) programs within states

Additional examples of investments towards impact on improving access to HCBS included:

- **Delaware** DD Council advocated for deinstitutionalization of individuals from long-term residential state institutions to HCBS settings through testimony, guidance, and input into policy and regulations.
- **North Carolina** Council on DD partnered with the P&A on a model demonstration to transition individuals out of Adult Care Homes (ACHs) and into HCBS settings.
- **Oklahoma** DD Council played a leadership role in innovative planning for how to serve individuals on the waiting list for HCBS services and reprioritize those on the waiting list.
- **Tennessee** Council on DD collaborated to establish an association to provide technical assistance and training to assist people with developmental disabilities to create individual microboards and cooperatives for their paid and natural supports and services. The Council also contributed to the passage of legislation that requires waiver services be provided to persons with I/DD if their family or caregiver is 75 years or age or older.
- **Virginia** Board for People with Disabilities partnered to develop a peer-to-peer education project, a required part of the state's Settlement Agreement with the Department of Justice. Peers were paired with people exiting a state training center or living in the community to improve understanding of consumer direction, inclusion, person-centered planning, and informed decision-making.
- **Washington** State DD Council conducted independent quality of life surveys with individuals with disabilities transitioning from institutional to HCBS as part of the State's Roads to Community (Money Follows the Person) program.
- **Wisconsin** Board for People with DD advocated for maintaining and expanding self-direction for people with DD. The Council also impacted the full state adoption of the National Core Indicators to assess quality of life outcomes for all individuals with DD participating in long term services and supports programs.

Access to Affordable and Accessible Transportation

The following examples of investments by DD Councils are leading toward greater impact on transportation systems to improve access to affordable, accessible transportation:

- **Alaska** Governor's Council on Disabilities & Special Education advocated for accessible taxi options through a report that led to the purchase of wheelchair accessible vehicles in two communities.
- **Alabama** Council for DD contracted with the Regional Planning Commission of Greater Birmingham to conduct a needs assessment and prepare a comprehensive report with viable transportation solutions for people with DD.
- **American Samoa** DD Council, **Guam** DD Council, and **Hawaii** State Council on DD improved disability awareness, accommodations, and access to paratransit. Activities included advocacy to increase number of accessible vans, working with drivers and owners to make accommodations for people with DD, and educating the public through billboards.
- **Colorado** DD Council supported grassroots projects in rural areas which led to community action at the local level that increased transportation, livable communities, and meaningful participation of people with DD in their communities.

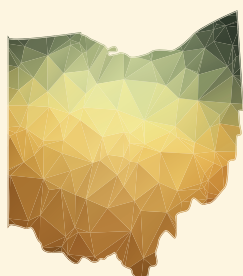


- **Florida** DD Council partnered with the Florida Department of Transportation to implement a transportation voucher pilot project in two Florida sites. The project contributed to voucher users gaining access to increased employment opportunities, training and higher wages. For example, prior to implementation of the program one participant had turned down a job at Walmart the year before due to not having available transportation. Through the program, she resubmitted her application, was rehired and is getting to work at Walmart on time every day.
- **Indiana** Governor's Council for People with Disabilities, **Michigan** DD Council, **Texas** Council for DD supported advocacy coalitions, workgroups, and summits to improve regional and local transportation options for people with DD.
- **Missouri** DD Council partnered with three Regional Planning Commissions and leveraged funding with the Missouri Department of Transportation (MODOT) to launch *MO-RIDES*, a referral service that connects riders to transportation providers. MO-RIDES works with existing transportation providers to find affordable, accessible and flexible transportation for people with DD who need a ride to work, appointments or shopping, thus improving their quality of life, by giving them greater access to their community.
- **Nevada** Governor's Council on DD supported the development of a policy report that led to the establishment of a workgroup to explore transportation barriers faced by nonprofits that serve individuals with DD.
- **New York** State DD Planning Council awarded competitive regional demonstration grants and provided TA to increase access to transportation for individuals with DD.
- **Virginia** Board for People with Disabilities awarded a grant to its Department of Aging and Rehabilitative Services (DARS) to grow affordable transportation services in rural and underserved areas through three projects.

Access to Affordable and Accessible Housing

The following examples of investments by DD Councils is leading toward greater impact through public and private partnerships to enhance access to affordable, accessible housing:

- **Alabama** Council for DD partnered with Accessible Alabama to promote universal design and accessible housing education through trainings and materials for builders, realtors, and agency representatives.
- **Connecticut** Council on DD supported the *Community Connector Program* which developed a website to facilitate roommate matching for individuals with DD seeking housing with a roommate.



Athens On Demand Transit Pilot

Ohio Developmental Disabilities Council

The Ohio Developmental Disabilities Council collaborated with the Hocking-Athens-Perry Community Action Program to develop a pilot to provide accessible and affordable door-to-door transportation.

Accessible, affordable transportation options in the rural county of Athens, Ohio were extremely limited:

- While the city of Athens has a transportation system, it did not operate outside the city limits.
- Athens is an impoverished county, with more than 30% of the population living in poverty.
- Even when transportation was available, it was extremely limited. One existing program provided rides, but only between 8 AM and 2:30 PM, making it impossible for some individuals to maintain employment in the community.
- Residents in rural Athens County also found it difficult to get to medical appointments, the grocery store or the bank.

Council funding was leveraged with additional funding and support from the Osteopathic Heritage Foundation, Athens County Board of Developmental Disabilities, and Ohio Department of Transportation to use, purchase, and lease accessible vehicles to get the program off the ground.

The Athens On Demand Transit Pilot has successfully provided rides to hundreds of individuals with disabilities, significantly improving quality of life, community participation, and employment.



Back Home in Indiana Alliance

Indiana Governor's Council for People with Disabilities

The Back Home in Indiana Alliance is a statewide collaborative effort that comprises representatives from federal, state and local housing, advocacy and disability-related organizations. Back Home is working to increase the availability of individual and dispersed, affordable and accessible housing for people with disabilities. Back Home is working in 6 Indiana communities to train teams of people with disabilities and others to advocate increasing Indiana's supply of affordable, accessible, and integrated housing.

Accomplishments include:

- Worked with Indiana Housing and Community Development Authority (IHCDA) to secure federal funding for its Ramp Up project which provides financial assistance for residents seeking to install ramps at their home.
- Collaborated with Habitat for Humanity of Indiana to create a new policy that requires future Habitat homes that receiving state Habitat funding to be "visitable" (have basic access features).
- Provided presentations on visitability and access to fair housing.
- Increased Indiana's stock of accessible rental property due to advocacy that resulted in incentives to builders to increase the number of accessible units constructed using rental housing tax credits and Section 504 funds
- City of Indianapolis considering adoption of a visitability policy.

- **Florida** DD Council supported development of a new nonprofit dedicated to address housing advocacy, policy, and resources for individuals with DD. The Florida *Inclusive Housing Corporation, known as Residential Options of Florida, Inc. (ROOF)*, achieved independent nonprofit status with a governing board; established a statewide housing network with nearly 150 members and almost 40 volunteers, educated thousands of individuals through community presentations, and provided housing information and referrals to people with DD and their families.
- **Illinois** Council on DD developed a partnership with the Corporation for Supportive Housing to include individuals with DD in their work on supportive housing.
- **Michigan** DD Council, **Missouri** DD Council, and **Ohio** DD Council engaged in collaborative efforts and workgroups to expand affordable, accessible housing for individuals with developmental disabilities.
- **Mississippi** Council on DD partnered with the UCEDD on a *Home of Your Own* program. Since this project began (as a Council grant) over 15 years ago, more than 500 people with DD have obtained home ownership.
- **Tennessee** Council on DD supported the *Tennessee EasyLiving Program* that resulted in 503 visitable homes certified, 17 builders joining the program, and 717 people trained about visitability.
- **Virginia** Board for People with Disabilities awarded a grant to the Virginia Association of Centers for Independent Living to train 277 building and planning officials in 138 localities on accessibility and develop an interactive computerized training.

SELF-ADVOCACY AND LEADERSHIP

BACKGROUND

The self-advocacy movement is a human and civil rights movement led by individuals with DD. The movement has transformed the lives of individuals with DD. It has empowered individuals to make choices in their lives, provided opportunities to speak up and have a voice, and opened pathways for leadership development. For many, it has provided access to a disability community and contributed to development of a positive self-identity and sense of disability pride. The movement has challenged negative attitudes about disability and achieved major advances in rights, full participation, and social justice.⁷

The movement exists in many forms. States have engaged in a wide range of initiatives to build self-determination and self-advocacy capacity. Advocates have formed informal and formal local, regional, and statewide self-advocacy organizations. Some states have formed broader cross-disability coalitions.

The DD Act requires Councils to support self-advocacy, specifically including a goal in their state plans to:

- 1) Establish or strengthen a program for the direct funding of a state self-advocacy organization led by individuals with DD;
- 2) Support opportunities for individuals with DD who are considered leaders to provide leadership training to individuals with DD who may become leaders; and
- 3) Support and expand participation of individuals with DD in cross-disability and culturally diverse leadership coalitions.

In addition to supporting self-advocacy, leadership development of individuals with DD and family members is needed to enhance their capacity to assume leadership positions, become peer mentors, and affect systems change within their communities.

DD COUNCIL INVESTMENTS TOWARD IMPACT

Themes in Council investments included: 1) Self-Determination and Self-Advocacy Capacity Building; 2) Statewide Self-Advocacy Organizations and Cross-Disability Coalitions; and 3) Leadership and Advocacy Training.

Self-Determination and Self-Advocacy Capacity Building

The following examples of investments by DD Councils are leading toward greater impact to build self-determination and self-advocacy:

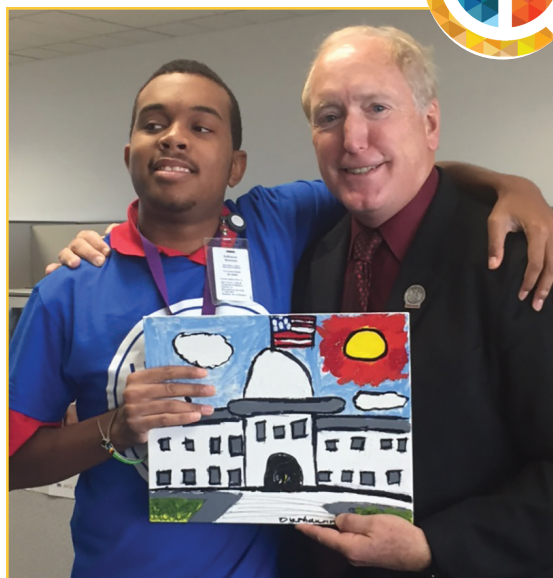
- **Connecticut** Council on DD revitalized the Connecticut chapter of Kids As Self Advocates (KASA). KASA is a national grassroots program of Family Voices for leadership development of youth with disabilities.
- **Hawaii** State Council on DD supported the *Self-Advocacy Advisory Council (SAAC)* to deliver a broad range of training in areas including speaking up for yourself and telling your personal story, running your own meetings, transition, employment, housing, and emergency preparedness.
- **Pennsylvania** DD Council partnered with Lehigh Valley Center for Independent Living to strengthen self-advocacy and leadership skills of students and youth with developmental disabilities.
- **Tennessee** Council on DD supported People Planning Together, a training that uses certified trainers with DD to train peers who want to learn how to speak out at meetings about the services and supports they receive.
- **Texas** Council for DD, **Utah** DD Council, and **Virgin Islands** DD Council, Inc. supported projects to train and support self-advocates in public speaking.

Statewide Self-Advocacy Organizations and Cross-Disability Coalitions

The following examples of investments by DD Councils are leading toward greater impact on establishment and support for statewide self-advocacy organizations and cross-disability coalitions:

Examples of support for statewide self-advocacy organizations

- **Alabama** Council for DD supported *People First of Alabama*.
- **Illinois** Council on DD established a new statewide self-advocacy organization, *Illinois Self-Advocates In the Lead (I-SAIL)*.
- **Indiana** Governor's Council for People with Disabilities supported *Self-Advocates of Indiana (SAI)*.
- **Maryland** DD Council supported *People on the Go*.
- **Massachusetts** DD Council supported *Massachusetts Advocates Standing Strong (MASS)*.
- **Michigan** DD Council supported a statewide self-advocacy network known as *Regional Inclusive Community Coalition (RICC)*. RICCs are local coalitions that help people with disabilities become leaders in advocacy in their communities, while emphasizing self-determination and community inclusion. The Council provides funding for RICCs based on acceptance of a work plan and budget.



- **Missouri** DD Council supported *People First of Missouri*.
- **Nevada** Governor's Council on DD supported *People First of Nevada*.
- **New York** State DD Planning Council supported *Self-Advocacy Association of NYS (SANYS)*.
- **Rhode Island** DD Council supported *Advocates in Action Rhode Island*.
- **Tennessee** Council on DD supported *People First of Tennessee*.
- **Vermont** DD Council supported *Green Mountain Self-Advocates*.
- **Washington** State DD Council supported *Self-Advocates In Leadership (SAIL)*.
- **Wisconsin** Board for People with Developmental Disabilities supported *People First of Wisconsin*.
- **Wyoming** Governor's Council on DD supported *People First of Wyoming*.

Examples of support for development of statewide self-advocacy organizations in states where such structures do not yet exist

- **Idaho** Council on DD worked with people with DD and other partners to host a statewide self-advocacy conference, which included sessions on speaking up for yourself, relationships and dating, employment, supported living, and voting.
- **Commonwealth of the Northern Mariana Islands** Council on DD supported development of a new self-advocacy organization, *Voices of the CNMI*.
- **North Dakota** State Council on DD supported efforts to develop and maintain an ongoing statewide self-advocacy network.

Examples of support for development of cross-disability coalitions

- **Guam** DD Council established a cross-disability organization, *Self-Advocates in Action (SiñA)*, which means "We Can" in Chamorro language.
- **Rhode Island** DD Council established the *Rhode Island Cross Disability Coalition*.
- **Kansas** Council on DD developed a leadership training curriculum in partnership with the *Self-Advocate Coalition of Kansas*.
- **Washington** State DD Council supported the Equal Partners Interstate Congress (EPIC) which is a collaboration of regional disability civil rights organizations in Idaho, Alaska, Wyoming, and Nevada.

Leadership and Advocacy Training

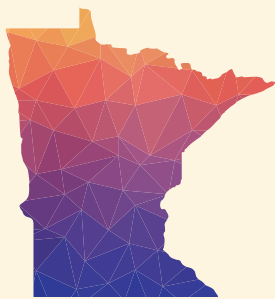
The following examples of investments by DD Councils are leading toward greater impact on leadership and advocacy skills through training opportunities for individuals with DD and their families:

- **Alabama** Council for DD, **Oklahoma** DD Council, **South Dakota** Council on DD, and **Virginia** Board for People with Disabilities hosted Youth Leadership Forums which provided intensive leadership development for youth with developmental disabilities. The Virginia forum was held at Virginia State University; the Alabama forum was held at Troy University, both centralized, accessible campuses. A highlight of the Virginia program was the mock legislative panel during which youth testify before legislators, legislative aides, and agency officials regarding topics of importance to them. A highlight of the Alabama forum is the mentor luncheon which youth have the opportunity to learn from leaders and policymakers in the state who have developmental disabilities.





- **Arizona** DD Planning Council supported *Partners in Leadership*, a leadership training program for individuals with developmental disabilities and parents to be community leaders and affect systems and policy change at the local, state, and national levels.
- **Colorado** DD Council supported participation of the first self-advocate with disabilities in the Colorado *Leadership Education in Neurodevelopmental and Related Disabilities (LEND)* program. LEND programs are funded by the Maternal and Child Health Bureau to provide graduate-level interdisciplinary training to professionals working with infants, children, and adolescents with disabilities.
- **Florida** DD Council supported the *Self-Advocates Leadership Training (SALT)* project, which developed a train-the-trainer curriculum for peers to provide self-advocacy and leadership skills.
- **Michigan** DD Council supported Connections for Community Leadership (CCL) which provided a range of statewide leadership development opportunities for self-advocates and parents. The Council also supported training for self-advocates to become Medicaid-Certified Peer Mentors.



Partners in Policymaking Minnesota Governor's Council on Developmental Disabilities

In 1987, the Minnesota Governor's Council on Developmental Disabilities created Partners in Policymaking®. Partners is an innovative, competency-based leadership training program for adults with disabilities and parents of young children with developmental disabilities. The purpose of the program is two-fold: to teach best practices and to teach the competencies needed to influence public policy.

The program's curriculum includes 128 hours of instruction that are taught over 8 weekends. It is delivered by organizations or individual coordinators who are responsible for recruiting participants, class organization, communication with expert trainers, and organizing financial aspects.

Partners programs have been implemented throughout the United States and internationally. More than 27,000 Partners graduates are part of a growing worldwide network of community leaders serving on policymaking committees, commissions, and boards at local, state, and national levels.

DD Councils have been instrumental in implementing Partners. Over the last five-year cycle, this included: **Alaska, Connecticut, Delaware, District of Columbia, Idaho, Louisiana, New Jersey, New York, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, West Virginia, and Wisconsin.**

DD Councils reported significant outcomes including graduates assuming leadership roles on boards, committees and influencing policy.



Speaking Up for US

Maine Developmental Disabilities Council

The Council prioritized support for its partnership with the statewide self-advocacy organization Speaking Up for US (SUFU) through direct funding, in-kind support, and increased capacity build skills.

Leadership training was provided to board members to improve understanding of 501(c) functions, intensive problem-solving and team-building. Capacity building activities contributed to the organization obtaining additional funding through a private grant and direct appeal.

SUFU revised their mission, vision, and goals. Their mission is “To create new opportunities for adults living with developmental disabilities to discover their abilities, exercise freedom and contribute to their communities. SUFU members engaged in systems advocacy at the regional and community levels through chapters. SUFU also reached out to youth with disabilities under the age of 25 through use of social media.

“

We have begun to think of advocacy as more than just “speaking up for yourself” but more of a problem solving process to identify what you want to change in your life, the resources needed for this change and creating the plan to make the necessary change. Board members themselves are taking the initiative and asking questions about the issues facing the board and people with disabilities.

”

—Self-advocate



CONCLUSION

This report highlights the work and impact of Councils in five key areas: 1) Transition and Postsecondary Education; 2) Employment; 3) Health and Wellness; 4) Community Living; and 5) Self-Advocacy and Leadership. These areas were selected based on considerable focus in these areas across the network during the last five year cycle.

The work of Councils extends far beyond the selected areas and examples contained in this report. For example, other areas of Council work include areas such as early intervention, secondary education, family support, assistive technology, and supported decision-making. However, the report helps to highlight the collective work of Councils.

Councils undergo extensive planning within their state or territory to develop state plans to meet the particular needs of people with DD and families in their communities. Councils are now in the first year of the next five-year cycle (FY17 – FY21). Much of the work of Councils builds upon previous work and investments continue towards impacts on independence, productivity, inclusion and integration of individuals with DD across the US and territories.

AUTHOR

This report was prepared by Joe Caldwell, Ph.D.

ENDNOTES

¹ The last estimated prevalence rate was approximately 1.49% of the US population based on the 1994/1995 NHIS-D; however, there is evidence that the rate has increased for children in recent decades. Larson, S.A., Lakin, K.C., Anderson, L., Kwak Lee, N., Lee, J.H., & Anderson, D. (2001). Prevalence of mental retardation and developmental disabilities: estimates from the 1994/1995 National Health Interview Survey Disability Supplements. *American Journal on Mental Retardation*, 106, 231-252. Boyle C.A., Boulet S., Schieve L., Cohen R.A., Blumberg S.J., Yeargin-Allsopp M., Visser S., Kogan M.D. (2011). Trends in the Prevalence of Developmental Disabilities in US Children, 1997–2008. *Pediatrics*, 108(5), 1155-61.

² Grigal, M., Hart, D., Smith, F., Domin, D., Sulewski, J., & Weir, C. (2015). Think College National Coordinating Center: Annual report on transition and postsecondary programs for students with intellectual disabilities (2013–2014). Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.

³ American Association on Intellectual and Developmental Disabilities and The Arc of the US (2012). Joint position statement on employment.

⁴ Butterworth, J., Winsor, J., Smith, F. A., Migliore, A., Domin, D, Ciulla Timmons, J. & Hall, A.C. (2015). StateData: The national report on employment services and outcomes. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.

⁵ Anderson, L.L., Humphries, K., McDermott, S., Marks, B., Sisirak, J., & Larson, S. (2013). The state of science of health and wellness for adults with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 51(5), 385-398.

⁶ Owen, R., Bonardi, A., Bradley, V., Butterworth, J., Caldwell, J., Cooper, R., Eisenberg, Y., Ford, M., Hewitt, A., Larson, S.A., Rizzolo, M.K., Rotholz, D., Stewart, C., Terrill, B. & Terrill, C.F. (2015) Long-term services and supports. *Inclusion*, 3(4), 233-241.

⁷ Caldwell, J., Keiling Arnold, K., & Rizzolo, M.K. (2012). *Envisioning the future: Allies in self-advocacy final report*. Silver Spring, MD: Association of University Centers on Disabilities and University of Illinois at Chicago.



NACDD

National Association of Councils
on Developmental Disabilities

