



**NORTH DAKOTA STATE COUNCIL
ON DEVELOPMENTAL DISABILITIES**

ANNUAL REPORT - 2013





TO THE CITIZENS OF THE GREAT STATE OF NORTH DAKOTA:

The 2013 North Dakota State Council on Developmental Disabilities (NDSCDD) Annual Report highlights its 2013 projects and priorities. NDSCDD remains steadfast in its commitment to improving the lives of North Dakotans with intellectual and developmental disabilities and their families.

NDSCDD focuses on diverse projects that improve opportunities for people with intellectual and developmental disabilities, including education, employment, transportation, community living, and health care projects. Just as importantly, NDSCDD works to build the capabilities of individuals, families, and communities, enabling each to become more self-sufficient through the Developmental Disabilities Assistance and Bill of Rights Act (the DD Act).

NDSCDD projects are developed in direct response to the concerns and ideas voiced by consumers, families, service providers, policy-makers, and other professionals. By listening to these collective voices, NDSCDD advances the dialogue for change.

Members of NDSCDD work together in a dedicated spirit of progressiveness, always mindful of North Dakota's plan, mission, and goals. NDSCDD members continue to embrace the challenge of shaping a brighter future for North Dakotans with intellectual and developmental disabilities and their families.

Best regards,

A handwritten signature in white ink that reads "Cheryl Hess". The signature is fluid and cursive, with the first name "Cheryl" being more prominent than the last name "Hess".

Cheryl Hess
Executive Director
North Dakota State Council on Developmental Disabilities

THE NORTH DAKOTA STATE COUNCIL ON DEVELOPMENTAL DISABILITIES (NDSCDD)

The North Dakota State Council on Developmental Disabilities (NDSCDD) is a federally funded, self-governing organization charged with identifying the most pressing needs of people with intellectual and developmental disabilities in North Dakota. The Council was established in 1979, under Chapter 25-01-01.1 of the North Dakota Century Code in accordance with the federal Developmental Disabilities Assistance and Bill of Rights Act.

The Council engages in advocacy, capacity-building, and system change activities. Comprised of 20 governor-appointed members, the NDSCDD is dedicated to ensuring that the estimated 13,000 North Dakotans with intellectual and developmental disabilities have the opportunity to be independent, productive, and valued members of their communities. At least 60 percent of the members must be persons with developmental disabilities, or parents, guardians, or other immediate relatives of persons with developmental disabilities.

NDSCDD receives approximately \$451,000 a year to carry out activities in its federally approved Five-Year State Plan.

MISSION STATEMENT

- The Council advocates for policy changes that promote choice, independence, productivity, and inclusion for all North Dakotans with intellectual and developmental disabilities.
- The Council supports and provides funding for projects and activities that maximize opportunities for consumers and family members.
- The Council serves in a planning and advisory capacity for state policymakers and agencies relative to services for persons with intellectual and developmental disabilities.



State-Level Planning and Goal Implementation

The NDSCDD submits a five-year State Plan to the U.S. Administration on Intellectual and Developmental Disabilities. The 2012–2016 State Plan includes targeted goals and objectives related to all or some of these priority areas:

- Community living
- Employment
- Transition
- Health care
- Self-advocacy
- Leadership

Activities in the plan include:

- Outreach
- Training
- Technical assistance
- Community education and support
- Interagency collaboration and coordination
- Barrier elimination
- Systems design and re-design
- Coalition development and citizen participation
- Policy-making
- Grant funding that focuses on demonstration of new and innovative approaches to services and supports.



FEDERAL AREAS OF EMPHASIS

Transportation
Recreation
Employment
Quality Assurance
Education & Early Intervention
Child Care
Health Care
Housing

GOALS AND OBJECTIVES

GOAL 1	Individuals with developmental disabilities, their families, and stakeholders will benefit from advocacy and capacity-building activities ensuring that individuals with developmental disabilities will have the services and supports they need in order to live in the communities of their choice. COMMUNITY LIVING
GOAL 2	Individuals with developmental disabilities, their families, and stakeholders will benefit from advocacy and capacity-building activities that will result in desirable employment options for people with developmental disabilities. EMPLOYMENT
GOAL 3	Youth and young adults with developmental disabilities are involved in transitional activities to support their independence so they are prepared for life outside of their educational settings. TRANSITION
GOAL 4	People with developmental disabilities, their families, and stakeholders will be provided necessary knowledge and skills in order to access comprehensive health care. HEALTH CARE
GOAL 5	Individuals with developmental disabilities will be provided leadership skills development and opportunities to exercise self-advocacy skills in their communities. SELF-ADVOCACY
GOAL 6	Families and stakeholders of individuals with developmental disabilities will be provided leadership skills development and opportunities to exercise advocacy skills in their communities. LEADERSHIP

Council Projects and Activities

The NDSCDD uses its information about the service system, disability issues, and people's needs to:

- Develop projects and activities that are focused on the gaps and barriers in the current array of services and supports
- Help North Dakotans with disabilities and their families live in, work in and contribute to their communities

These activities are designed to impact the entire state and are developed in close collaboration with consumers, parents, advocate groups, state agencies, service providers, and state and local policymakers.

The NDSCDD:

- Analyzes state and federal policies, including agency state plans
- Informs policymakers about disability issues and their impact on people with disabilities and their families
- Makes recommendations regarding policy

Historically, nearly 70 percent of NDSCDD funds, \$300,000 - \$350,000, is awarded annually to 9-15 grants. These include direct service demonstration projects that:

- Invest funds in local communities
- Test new ideas
- Help state agencies develop more effective ways to provide services

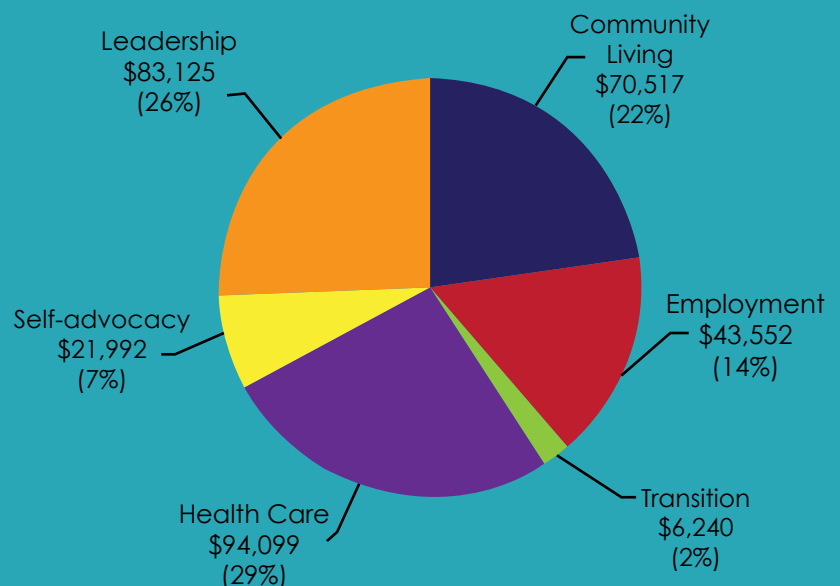
Grants also provide technical assistance and training to individuals, service providers and agencies, as well as other activities.

2013 Funded Organizations:

- March of Dimes
- North Dakota Center for Persons with Disabilities
- Family Voices of North Dakota
- Arc of Bismarck
- Pathfinders Parent Center
- North Dakota Association of Community Providers



North Dakota SCDD Fiscal Year 2013 by Goal Area



2013 Disabilities Awareness Day

The North Dakota Disabilities Advocacy Consortium (NDDAC) sponsored the 2013 Disabilities Awareness Day on Feb. 21. The event was held at the North Dakota Legislature in the Great Hall of the State Capitol in Bismarck. Staff from the North Dakota State Council on Developmental Disabilities set up a booth and talked to legislators, self-advocates, and the general public about the Council's mission, focus, and current state plan activities.



"I Am a Person" – Documentary

"I Am a Person," a documentary that showcased the lives of individuals with disabilities residing in North Dakota communities, debuted on Prairie Public Television in February. It was nominated for an Upper Midwest Emmy in September, and several North Dakota cinemas screened the documentary.

The North Dakota State Council on Developmental Disabilities supported a grant for the North Dakota Association of Community Providers to work with Prairie Public Broadcasting to develop the documentary. The documentary aimed to challenge the stigmas and negative attitudes held by some in the general public.

The video highlights what is possible when people with developmental disabilities get the care they need to live full and happy lives. It also portrays how individuals with disabilities contribute to their communities through both their work and the developmental of social capital.



New Employment First Policy

The North Dakota Disabilities Advocacy Consortium awarded a grant to Minot State University to support the Employment First movement in North Dakota. North Dakota Employment First's mission endorses "integrated and competitive employment as the first and preferred employment option for all people with disabilities." Its mission promotes a shared vision that those of working age in America work, and that competitive employment be assumed for everyone, regardless of severity of disability.

Through the grant, the project successfully secured legislative sponsors to help pass Senate Bill 2271. On Aug. 1, the bill officially established an Employment First policy called the Governor's Committee on Employment of People with Disabilities.

The Employment First project also planned and organized a successful summit on Sept. 19. More than 75 individuals attended the summit. The summit focused on educating individuals on the new Employment First policy.



Success Story – March of Dimes NICU Family Support Program

Sara was admitted to Essentia Health in June, 22 weeks pregnant with twin boys. She was at high risk to deliver early. A March of Dimes Neonatal Intensive Care Unit (NICU) Family Support Specialist visited Sara and her husband Joe daily. She encouraged them and talked about how Sara can be an advocate for her and her babies' health.

Because Sara knew how to be her own best advocate, she decided to go to the hospital of her choice. So at 23 weeks, Sara and Joe were transferred to an out-of-state hospital. They were disappointed to leave an environment where they felt so supported, but they knew it was the best option for their babies. Sara was eventually discharged, and a few weeks later she returned to Essentia Health to deliver her boys. Jase and Jackson were born at 28 weeks on Aug. 8.

Through the March of Dimes NICU Family Support Program, Sara and Joe received the support, encouragement, and education to make it through one of the most difficult experiences a couple can have. Sara and Joe thanked program members often. Sara expressed on numerous occasions how she received emotional support, encouragement, and the confidence to be an advocate for herself and her babies. As Joe simply stated, "Support was always there when we needed it."



Success Story – Partners in Policymaking Program

The Partners in Policymaking Program helped reinforce my perseverance and the need to stand up for yourself. It was helpful to learn the laws about when it is appropriate to disclose a disability in the workplace if accommodations are needed. I have since been able to assist a family member in advocating for their needs. That experience has resulted in a positive outcome in their employment situation.

– Rhonda Boehm

Family Voices – Parent to Parent Program

"I would like to express my sincere gratitude for the continued support from Family Voices' Parent to Parent Program. Their compassionate assistance has been awesome. The challenges faced by families of children with special needs can be overwhelming. A helpful program like Family Voices is highly appreciated." – Viola

Viola contacted Family Voices Executive Director Donene Feist on a cold wintery weekend in December 2012. Viola's son was born with Down Syndrome. "Viola shared her life experiences, and it melted my heart," Donene stated.

Donene contacted Melissa (Moe) Schroeder to set in place the Parent to Parent match for Viola. As a mom of a newly diagnosed child, Viola was experiencing many emotions. Families and staff supported Viola with the new diagnosis. And as she was transitioning from Minot to Fargo, she and her son received support at every phase.



COUNCIL MEMBERS

Darcy Andahl

Consumer

Maggie Anderson

Department of Human Services

Dr. Brent Askvig

University Center of Excellence

Missi Baranko

Parent

Perry Boudlin

Consumer

Wendy Conica

Consumer

Tammy DeSautel

Job Service North Dakota

Tamara Gallup-Millner

Department of Health

Leann Haug

Parent

Tim Huseh

Service Provider

Marcia Kilzer

Protection and Advocacy

Pam Kolling

Parent

Holly Major

Parent

Mitchell Neumiller

Consumer

Marietta Rasmussen

Guardian

Brenda Schmidt

Parent

Alex Schweitzer

State Developmental Center

Sheryl Stradinger

Parent

Gerry Teevens

Department of Public Instruction

Heather Wittliff

Parent



The NDSCDD is represented on:

- The ND State Community of Practice on Transition
- The North Dakota Employment Learning Community
- The A-Step Committee
- The ND State Rehabilitation Council
- The Region 7 Human Rights Committee
- The Employment First Task Force
- The Seclusion and Restraint Task Force
- The North Dakota Olmstead Commission
- The North Dakota Transition Task Force
- The ND Money Follows the Person Stakeholders Committee
- The North Dakota Legislative Partnership Committee

2013 Council Activities

- 2013 Disability Day at the Capitol
- Three Effective Grant Writing Trainings
- Nine Self-Advocacy Town Hall Meetings
- Launch of website www.LaunchMyLifeND.com

For More Information:

North Dakota State Council
on Developmental Disabilities

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