

# NDSCDD Annual Report

2023

NORTH  
**Dakota**  
Be Legendary.

State Council on Developmental Disabilities

HEALTH & HUMAN SERVICES

# Introduction

Dear Friends,

It has been an exciting year of new projects and work for the North Dakota State Council on Developmental Disabilities!

To start, we have continued to work on expanding self-advocacy initiatives throughout the state. The Advocates Leading their Lives (ALL) statewide self-advocacy group continues to meet quarterly. Other local groups have begun meeting monthly with the support of the Council:

- Together We Stand - Jamestown
- Fargo Friends Moving Forward - Fargo
- Bowman Advocaters - Bowman
- Minot- No group name yet

We have continued to support training individuals and family members through the Partners in Policymaking Program, which has produced some amazing advocates around ND who are sharing their stories and making change!

The Council has engaged in several larger system change efforts this last year; National Core Indicators work, TAC Olmstead Report Creation, and funding Inclusion Specialist Positions with Uspire ND.



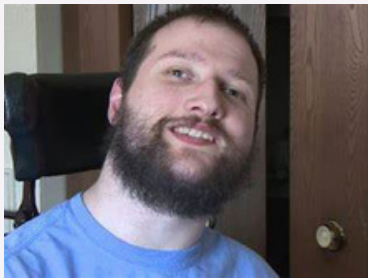
Peer to Peer continues to grow around our state and includes high schools, middle schools, and higher education institutions. To make this a “best practice” the Council funded a peer-to-peer study to showcase how this model in ND is different and is changing the lives of participants in peer to peer, the school system, families, and future education opportunities.

Our Power Up Your Voice: health and advocacy conference was another huge success this year! With over 200 people in attendance, it was an exciting 1.5 days full of information for individuals with disabilities, their families, educators, service providers, and health professionals! We look forward to hosting this event again, in the Spring of 2025!



None of this would have been possible without the help of some very important people, our Council members. A council is only as strong as its membership. Empowering and innovating have been defining words for our organization. Your support and unwavering commitment continue to drive our efforts forward. Meet our Council members here: [www.nd.gov/scdd/council](http://www.nd.gov/scdd/council).

All my best,  
Julie Horntvedt, M.Ed.  
Executive Director, North Dakota State Council on Developmental Disabilities



Hello, my name is Trevor Vannett. I am the DD Council chair for the North Dakota State Council. We accomplished a lot together we've done great working this past year and I'm happy to advocate for people throughout the state of North Dakota and I'm happy to make a difference in peoples lives And I will always strive to make North Dakota a better place for people with disabilities.

# Mission Statement

The council advocates for policy changes that promote choice, independence, productivity, and inclusion for all North Dakotans with developmental disabilities (DD).

The council supports and provides funding for projects and activities that maximize opportunities for consumers and families.

The NDSCDD serves in a planning and advisory capacity to state policymakers and agencies relative to services for persons with developmental disabilities.

# About the Council

## Funding

The Council administers the federal DD Basic State Grant Program and provides funding to: private agencies, non-profits, licensed DD providers, state and local agencies, individuals, families, others

## Areas of Emphasis

- Community Inclusion
- Health
- Employment
- Self-Advocacy
- Education/Training/Outreach
- New Innovative Ideas for people with ID/DD and their families (Small-Innovative Grants)
- Consumer Leadership Development Fund (CLDF Small Grants)

# Partners in Policy-Making

By the end of 5 years, SCDD will have trained 75 individuals with disabilities and or family members (an average of 15 per year) through Partners in Policy-Making or other workshops that support training for individuals with disabilities and their families so they can advocate for themselves, change systems, and create policy improvements; so far, 18 have graduated.

In 2023, we had 11 partners signed up: 6 individuals with I/DD, 5 parents, and 1 staff person who supported a participant. At the end of class, we graduated 7 partners. We lost 3 individuals due to the Special Olympics state competition requirements, and we didn't graduate the staff person who was supporting the individual in class. The participants of this training did homework monthly and reported back, sent thank you cards, provided us feedback in real-time, and overall satisfaction with training. In the future, we will push to have larger classes to reach our overall goal of training 75 individuals at the end of 5 years.

The Partners graduates became friends and supported each other. Two of the graduates (Colin and Jacey) became members of the ALL group and their statewide activities. Colin and Jacey also serve on a transitional leadership self-advocacy group called YESS (Youth Empowering Social Status).

Jacey has also started to serve on the IDEAS board and the State Rehab Council. Terri Cote, another graduate, is serving as Region 1's representative on the Consumer Family Network Council. Jason Kunz, a Partners graduate, is serving as an alternate in Region 7 on the Consumer Family Network Council. Maran Blair, parent and graduate, testified several times this past legislative session on SB2276 to pass a law to provide paid family caregiving services. Teresa Olson, parent, and graduate, lives in Fargo, and has been active in education reform and advocacy for her daughter at her local level. Colin is now using Supported Decision Making to have more control in his own life. He often shares his story at events so people hear about his successes.

Our group was small but mighty, and they will have lasting effects on public policy for families and people with I/DD in our state.

Policy

# Policy / Program Changes

Completed:

- Updated Bylaws
- Updated Policy and Procedure Documents
- Merged code of conduct, conflict of interest, and ground rules document into 1
- Created a spending policy and a finance committee to meet monthly
- Updated the Consumer Leadership Committee name to Advocacy Committee
- Updated Membership to include 3 more citizen/consumer members

Working on:

- Assurances with DHHS
- Updating our MOU with DHHS
- Updating our Grants Manual
- Working with fiscal to create a policy and procedure for match tracking



Policy

# Advocacy

## Advocates Leading their Lives (ALL) Self-Advocacy Statewide Network

ALL is a self-advocacy network run by and for people with disabilities whose mission is: The Purpose of the Advocates Leading their Lives (ALL) Network is to ensure that people with disabilities are treated as equals, and are given the same decisions, choices, rights, responsibilities, and chance to speak up to empower themselves to live, learn, recreate, and work.

During this reporting period, we had 328 people attend our ALL group self-advocacy trainings/meetings to include cities; Bismarck, Fargo, Bowman, Valley City, Jamestown (their number is reported outside of this total), and Minot.

The Valley City, Minot, and Bowman numbers are the newest amount of people to join. One meeting in Fargo had 59 attendees. We have been going monthly to Fargo for about 2 years. Valley City has asked us to come quarterly for training. Currently, Bowman is every few months, but we would like to increase this to monthly; staffing for the Council to get there does create a barrier, but we are working on it.

The Minot group is the newest. They had been getting together at an informal frequency; however, they now have a group that meets monthly at Second Story, which is a non-profit social club that provides social and educational training to people with disabilities. They have donated their facility and some staff time to help these meetings occur monthly.

NDCPD (our state UCEDD) has devoted one of their staff's time on this project to provide support to the group. This group was started by 2 individuals who have been on the ALL-statewide board and wanted local advocacy.



# Disability Awareness Day

Our last legislative session occurring in January-April, 2023, brought a big opportunity for us to assist people with sharing their stories, coming to Bismarck to testify and we expected to have associated costs for those things.

Two activities that occurred during this time that we helped educate people to share their stories were the ALL Meeting on March 6th and the Disability Awareness Day event on March 7th. Participants came in for one or both events and on March 6th, we held a training session on testimony writing and delivery and helped people log into computers to upload their testimony online if they weren't going to share in-person at a session the following day.

We had 125 people attend Disability Awareness Day and 11 exhibitors share information about their program or services they provide. We provided costs to families and individuals to come to Bismarck, have a hotel, and participate in the event through a grant to the North Dakota Disabilities Advocacy Consortium. The Consortium also raised money for the event to contribute to costs.

With our funds, we were able to support 45 individuals/families to participate in Disability Awareness Day and have a presence at our Capitol with legislators. This was an advocacy opportunity many had never had before.



Advocacy

## DD Network Partnerships – Federal Requirement to Work on Activities Together

# Partnerships

- Provide training and support to the ALL group and group activities through staff time and training amongst the 3 entities (P&A, NDCPD, and DD Council)
- NDCPD helped us make advocacy pictures and videos to use at the conference
- FASD and Aging goals are in both NDCPD and our plans
- The 3 network partners are all co-contributors/leaders of the NACDD Aging and disability federal grant application
- P&A and the Council are working on the Public Health workforce project for AT use in homes, independent living, and staffing shortages
- NDCPD Consumer Advisory Council and the ALL group share ideas and work together

# The Peer-to-Peer Project at Bismarck State College

BSC mentors and students have been busy with study sessions, homework sessions, creating weekly homework plans, and participating in social events on and off campus.

- One of our students receives employment support for her on-campus job in Admissions.
- Two of our peers also serve as paid mentors and help with social events and activities.
- BSC's Public Affairs Office posted about our BSC Peers mentoring program on their Facebook page to help raise awareness and reach out to those who are interested in applying to be a mentor.
- One mentor attended Disability Awareness Day at the Capitol with two BSC staff members on March 7th to share what resources and opportunities BSC has to offer.
- BSC's Student Accessibility and Peer Mentor Coordinator went to Century High School on March 10th to observe their Peer-to-Peer program and to network with Century students who are interested in attending BSC.
- Our BSC Peers group has been organizing an "Autism Awareness Event". A mentor and two peers have met multiple times to help plan the event.
  - One of our peers created flyers for the event using the information that he learned in his graphic design classes.

72 students received academic accommodations during the Spring 2023 semester.



Education

## The Peer-to-Peer Best Practice Study at NDSU

Data collection methods include:

- Traveling to Bismarck for data collection
  - 3 schools accepted and completed
  - 3 ongoing collection efforts
- Interviews with special education teachers
  - 2 completed
- Ongoing data analysis process concerning peer-to-peer best practices around the country
  - Interviews
  - Surveys
  - Literature review

Preliminary results:

1. Past mentors are reporting positive attitudes towards peers with disabilities and greater comfort around people with disabilities.
2. Compared to peers who are not mentors, mentors appear to enjoy interacting with peers with disabilities more and view them as more capable.
3. Mentees report very positive experiences in Peer to Peer.

Looking ahead to the next 6 months:

- Analyze data as a whole
- Finalize best practice
- Share full findings
- Project to be completed in May, 2024

# Inclusion Efforts

SCDD will promote strategies that improve meaningful inclusion into general education at school, including preschool and post-secondary education through training and education on universal design.

- Began USpireND Inclusion Support in October 2021 with one staff person
  - Hired a second Inclusion Coach in April 2022 and a third started on July 1, 2022.
- Connected with SEEC and Lakes and Prairies to begin Build Strong Partnership
- Trained and supported 28 childcare providers to implement a developmental screening program using the Ages and Stages Questionnaires and ASQ Online
- Supported 36 providers in applying for Inclusion Grants
- Completed 237 Inclusion Support Instances with 108 providers/facilities
- Over the last 10 months, USpireND provided Inclusion Support in circumstances where five children (males) were at risk.

Before this project, the Council had funded a comprehensive study of daycare/childcare in ND and found that most suspensions and expulsions are for behavioral outbursts that are harmful to other children and providers have little training in how to positively intervene before an outburst occurs, nor do they know how to de-escalate behavioral situations. Providers and parents want positive behavioral specialists, like inclusion specialists, who can provide specific training that is contextualized to the children in their care.



# Power Up Your Voice: Health & Self-Advocacy Conference

This conference was intended for individuals with disabilities, their family members, service providers, and professionals working with them to learn about healthy strategies for both body and mind. The goal of the conference is to equip these individuals with the tools, resources, and knowledge on healthy living to ensure that individuals with disabilities make the best choices possible.

We hosted the Power Up Your Voice: Health and Self-Advocacy Conference in September 2023. By hosting an annual health conference and pairing that with a self-advocacy conference, we felt it was a way to reach a large number of people by providing in-person and recorded sessions that were shared on our YouTube page. This conference has grown year to year and continues to be successful.

This year, we had 210 participants.

Focused sessions concerning behavioral health this year were:

- Dr. Terry Chase; Charting a Wholehearted Life: One Step at a Time and A Wholehearted Approach for Wellbeing, Resilience, and Courage
- Sue Swenson: Advocating for a Whole Life and How to Work with Other Advocates and Have Fun Doing It
- Deb Eslinger: Shaping Your Future with a Resilient Mindset
- Katrina Hayes: The Art of Self Care: Prioritizing Mental Health and Awareness
- David Hoff: Building Relationships to Help People Be Their Best
- Megan Kraft: Navigating Trauma: Understanding Diversity, Building Resilience
- Jennifer Turnbow: Authentic Advocacy: Navigating Trauma and Understanding Diversity

Our speakers were trained in this area of behavioral and mental health and/or advocacy:

- Terry Chase; 3 graduate degrees in Nursing (ND), Exercise Science (MA), and Spiritual Psychology (MA) with additional certifications in education, teaching, and equine-assisted learning. She is also a professional coach.
- Katrina Hayes: certified in Mental Health First Aid and holds 2 BS degrees.
- Megan Kraft has a Master's Degree as a licensed professional clinical counselor specializing in trauma, recovery, and cognitive management of chronic pain.
- Sue Swenson served 2 terms of the Obama Administration as Deputy and Acting Assistant Secretary for Special Education and Rehabilitative Services and was Director of the National Institute for Disability and Rehabilitation Research.
- Jen Turnbow and Deb Eslinger are professional speakers

# Health

# Small Innovative Grants

These grants are for new ideas in the state for individuals with ID/DD and/or their families. I like to think of them as “Kickstarter” funds for something new.

One recipient in 2023 was Dreams in Motion.

Dreams in Motion applied for a Small Innovative Grant to create the first adaptive race at the Bismarck Marathon. The race occurred in September and the funding included registration costs for people with disabilities to participate in the race, adapted race signage, accessible restroom rental, adaptive signage at the race and race markers, and marketing awareness for the event. The first event had 20 registered participants.

This is the first-ever adapted race in the state of ND!



**BISMARCK MARATHON'S FIRST EVER  
ADAPTIVE RACE**

THURSDAY, SEPTEMBER 14  
6:30 PM | ND STATE CAPITOL

The Adaptive Race, presented by Dreams in Motion, allows individuals with physical, emotional, or mental disabilities to be a part of the Bismarck Marathon.

The Bismarck Marathon  
PRESENTED BY MDU RESOURCES

Dreams in Motion

This project is supported by the DD Council, through the Administration for Community Living (ACL), financial assistance awarded with 100% funding by ACL/HHS. The contents do not necessarily represent the official views of, nor an endorsement by ACL/HHS, the US Government or DD Council.



Grants

## Grant Funding

Annually, SCCD will support innovative projects to promote systems change and policy change activities that increase community inclusion, and better access to services, supports, and other assistance for people with DD and their families.

We funded some small initiatives, but we also promoted other larger efforts to create systems change in ND specifically around service delivery and reporting. We accomplished this through funding the National Core Indicators study and the Olmstead Plan Creation for our Olmstead Commission.

- Pathfinders Conference: Family Stipends/Keynote Speaker for Pathways to Partnerships Conference
- Lake Region: Disability Awareness Month Speaker
- ND Autism Center: Safety Jacket
- South Central Cass: ABLE Games
- Triumph: Self Advocacy Group
- YMCA: Adaptive Swimming
- TAC: Olmstead Plan Creation
- National Core Indicators





## Progress Toward State Plan Accomplishments

In 2023, we had work/activities in all State Plan Areas as identified -- YAY!

In 2024, we will need to focus on:

1. Childcare-daytime/afterschool programs for children under 18 with I/DD
2. Increase formal/informal support to people with I/DD who also have a behavioral health diagnosis.
  - a. Right now, we have provided 2 trainings to ALL members concerning BEH health
3. Increase DSP/Disability Workforce-Staffing.
  - a. Our Public Health workforce project working with Protection and Advocacy and the Providers
4. Increase employment opportunities for people with ID/DD
5. Increase housing opportunities

# NDSCDD Council Involvement in Advocacy/Leadership

- The Council Director serves as the Chairperson of the North Dakota Disability Advocacy Consortium with 18 other disability organizations as members

- The Council Director serves as the Secretary of the National Association of Councils on Developmental Disabilities

- The Council Director is appointed to the Olmstead Commission

- The Council serves on the Transition Community of Practice

- The Council Director will sit in on the Cross Disability Council meetings as a public member

- The Council was awarded a federal grant for Aging/Disability technical assistance with 13 identified partners in this work.

- 

- 

# Council Leadership

# Looking Ahead

We will be entering Year 3 of our 5-year state plan for years 2022-2026.

We will continue to fund projects in some old and newly identified goal areas, along with our small grants for individuals/families, and our small innovative grants.

Julie Horntvedt, Executive Director  
North Dakota State Council on  
Developmental Disabilities

600 E Boulevard Ave  
Bismarck ND 58505

701.328.4847

 [www.nd.gov/scdd/council](http://www.nd.gov/scdd/council)

 [jhorntvedt@nd.gov](mailto:jhorntvedt@nd.gov)

 @ndscdd