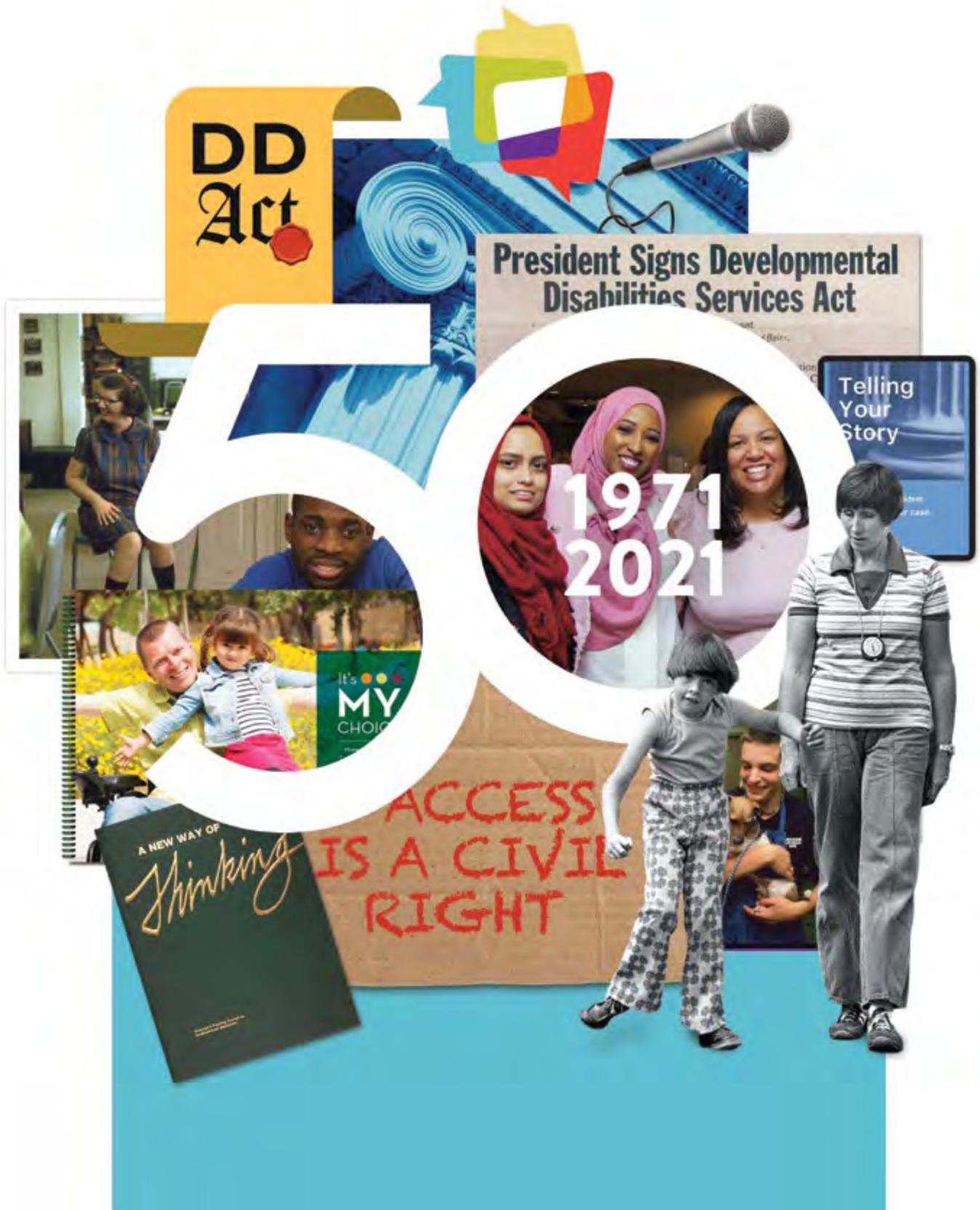


## Minnesota Governor's Council on Developmental Disabilities

# 50 years

of Empowering Advocacy, Expanding Capacity,  
and Envisioning Systems Change



**This document can be made available in alternative formats upon request.**

**The Minnesota Governor's Council on Developmental Disabilities**

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## Dear Colleague

On behalf of the Minnesota Governor's Council on Developmental Disabilities (the Council), we are pleased to present this monograph in celebration of the Council's 50th Anniversary. Over the past five decades, the Council's work has ensured that neighborhoods and communities include all of their members, recognize and promote the uniqueness and worth of each individual, and create an environment that depends on the capacity of individuals rather than needs.

This monograph highlights the work of the Council over these 50 years and the results the Council has helped achieve. In all instances, the Council has been true to the thrust of the federal law, the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), working on advocacy, capacity building, and systems change. To this end, emphasis and direction for our investments have been shaped by what individuals with developmental disabilities and families have told us they need to make informed choices about where and how they live, learn, work, and actively participate in the community.

There is no doubt that dramatic and positive shifts in attitudes, perceptions, and the capabilities of individuals with developmental disabilities have offered opportunities to be innovative and creative about the information, education, and training we provide. Great strides have been made. The Council will continue to make more in the years ahead.

We thank you for your support and commitment to our work and appreciate your role and contributions in helping us to arrive at our 50th Anniversary.

Cordially,



Lee Shervheim  
Council Chair



Colleen Wieck, PhD  
Executive Director

“ By age 6, my son was labeled by medical and educational experts as someone who would never live independently or able to financially provide for himself. Through the training I received at Partners In Policymaking, I was able to procure the proper skills to formulate a plan of self-directed independence for him to bring to fruition. My desire for both my children to receive quality educations, college, graduate school, employment, home ownership and family were never elusive for my daughter. My son was discouraged from dreams at a wee age. He had encephalitis at 2 months of age. He had uncontrolled epilepsy secondary to status encephalopathy. His auditory processing is in the 5th percentile. His visual processing is at the 99th percentile. His 36 years have been high advocacy, but he’s been a participant for 36 years.

**My proof of success would be teaching him to self-advocate, knowing I may not always be here. Along the way, the teacher became the student.** Knowing I have a deadly cancer gene, I faced high risk of early death. Eric had to be independent. Fortunately, I’ve survived four major cancers and he has actively advocated for specialized care for me. I’ve learned it’s much easier to advocate for someone else, than yourself. He is now a college graduate, a published writer, a homeowner ... and has a life of his own determination as any typical adult, if there is such a thing. ”

– *Parent advocate, 2020*

**Contents**  
***50 years of***

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Empowering Advocacy	7
Expanding Capacity	27
Envisioning Systems Change	45
Creating a Foundation for Possibilities	77
Council Investments & Members	81

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# Minnesota Governor's Council on Developmental Disabilities

**“ As far as the Minnesota Governor’s Council on Developmental Disabilities over the years, certainly it has been my experience that it is one of the most effective and impactful DD Councils in the nation.**

I think the factors that have contributed to the success of the Governor’s Council in Minnesota are continuity in leadership; the early decision to situate the Council in a neutral state agency, rather than the agency with major DD service functions; the willingness of the Council to forge strategic partnerships with other state agencies and outside organizations; and the use of discretionary dollars to leverage broader change. ”

– Robert “Bob” Gettings, Former Executive Director, National Association of State Directors of Developmental Disabilities Services



# President Signs Developmental Disabilities Services Act



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*50 years of*

# Empowering Advocacy



“ Right from the beginning, I was told the council that put out the finest work was the Minnesota Council. Minnesota produced the country’s best advocacy materials for improving the lives of people with developmental disabilities. ”

— Jim Shorter, former director of three of California’s community-based regional centers

***The Council advocacy work focuses on training people with developmental disabilities and their family members to influence the policies that affect their lives and communities.***

When Congress considered Medicaid reforms in 1986, the Council saw how people with developmental disabilities and their families were once again missing from the debate. When they did engage with policymakers, people with developmental disabilities and their families did not know much about how policies were developed or how to make a difference in the process.

Driven to make sure that people with developmental disabilities and their families have a voice in policymaking, the Council started the Partners in Policymaking program in 1987 with 35 participants. Since then, Partners in Policymaking has grown into a trademarked, internationally recognized program that’s trained more than 1,100 self-advocates and family members in Minnesota and over 29,000 people nationally and internationally.

# Partners in Policymaking®

Partners is an innovative national model of leadership training focused on disability issues, training participants on how to advocate and influence policy at all levels of government, from school boards to state agencies to Congress. The program is specifically designed for adults with disabilities and the parents of young children with developmental disabilities. For its in-person format, the program consists of three primary components:

1

128 hours of leadership training offered during weekend sessions held monthly for eight months.

2

Readings and homework assignments that supplement and reinforce each weekend session.

3

A public policy project that demonstrates successful application of leadership skills.

Through Partners, participants develop twenty-five competencies, including how to be effective in meetings, conduct meetings, meet and discuss issues with public officials, testify at legislative hearings and public meetings, and serve on boards. The program covers how bills become law at the state and federal levels, the principles of self-directed choice and control, and techniques to effectively advocate for services that meet people's needs.

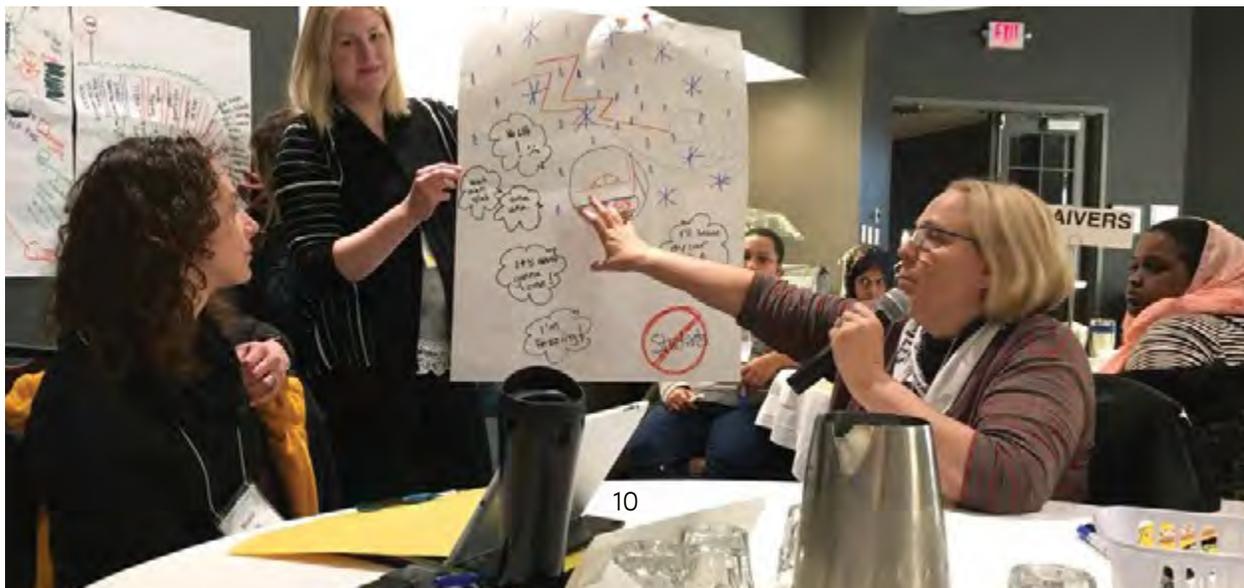


**Many of the competencies emphasized in Partners in Policymaking relate to the following core topics covered in the training sessions:**

1. History of disabilities
2. Histories of the Parent Movement, Independent Living Movement, and Self-Advocacy Movement
3. Inclusive and quality education, early intervention, post-secondary education, and lifelong learning
4. Effective team meetings
5. Service coordination
6. Flexible, responsive system of community supports for individuals and families
7. Home ownership and supported living
8. Supported, competitive, and customized employment
9. State-of-the-art technologies and assistive technology
10. Meetings and effective communication with local, state, and federal public officials
11. Vision for 2030 (and beyond)
12. State and federal legislative processes
13. Drafting and delivering testimony to public officials
14. Critical federal issues
15. Community organizing and advocacy techniques
16. Media and social media to promote issues
17. Parliamentary procedures and serving on boards

Participants learn about best practices in the field of developmental disabilities, engage in skill-building activities, join in small-group discussions, and work on a shared vision of the future. Presenters include national and state experts. Partners enlarges the base of effective advocates for disability rights who can influence system-wide, long-term public policy changes.

*Linda Brant-Malm, right; Jaclyn Landon, center; and Nicole Plan used visuals to talk about services they need from county government at a Partners in Policymaking class in 2017.*



“ Partners in Policymaking changed my life! For the first time, I finally felt as though it was OK to be myself. I was treated just like everyone else, welcomed and included. Peers genuinely looked forward to seeing me again each month, and I had something to offer that was of value to others. Everyone was handed a microphone when sharing as though what we had to say was so important they wanted to be sure we were heard. **I had been told before Partners in Policymaking that all human beings are the same, no one is less than another. Yet, I had not actually felt that until my experience in Partners in Policymaking course.** ”

— Self-advocate, 2020

Each Partners class includes self-advocates, parents of children with developmental disabilities, and people who identify as both. They are carefully selected and generally have not been involved in the disability rights movement before. Partners charges no participation fee and provides funds to help pay for childcare, personal assistance, transportation, and overnight accommodations.

“ The experiences I had during my time with Partners taught me to look beyond what I thought I couldn't do, and gave me the education and resources to succeed in life, pursue ultimate and meaningful goals, and gave me the network of people in my life today. ”

– Kurt Greniger, Self-Advocate, from *Changing Lives, Changing Policies*, 2015

“ This past year has been difficult to be as actively involved as I would have liked because of COVID. I did what I could to help my local candidates for State House and State Senate, including lit drops, participating in Zoom calls, and writing blog posts. I also write in my blog about issues that matter to me such as healthcare, disability rights, disability services, and accessibility. ”

– Self-advocate, 2020

*Below: Justin Smith, disability activist, and U. S. Senator Dave Durenberger, co-sponsor of the 1990 Americans with Disabilities Act, share a fist bump after speaking at the Reopening of the Minnesota State Capitol, August 13, 2017. Opposite: from A Major Minnesota Problem by Earl Seubert, Minneapolis Tribune.*





Partners in Policymaking grew from advocacy movements aimed at improving the quality of life for people with disabilities.

Before those movements began in the United States, many children and adults with developmental disabilities lived in public institutions, hidden from view. Residents lived in filthy, dangerously overcrowded conditions under the care of overworked, sometimes abusive caregivers. They typically received inadequate medical care and few, if any, educational opportunities. Other people generally viewed individuals with developmental disabilities with pity or fear.

## Historical Highlights

### SETTING THE STAGE

## 1950s and 1960s

“ Thinking you have a child who is never going to be able to do anything, you’re always going to have this quote-unquote ‘burden,’ I mean, that’s kind of what you got. I know doctors don’t say these things anymore, but during those years that’s what parents left with and struggled with. ” – Fran Smith, parent advocate

In 1950, 90 parents of children with disabilities from across the United States traveled to Minneapolis to participate in the first national conference for parents of children with developmental disabilities. They formed The Arc as a national organization for parents, which continues to be a leading advocate for the rights of people with developmental disabilities.

Throughout the 1950s and 1960s, participants in a broader Parent Movement collectively advocated for people with disabilities. They fought for legislative changes, initiated critical court challenges, worked with the media on exposés about poor living conditions for people with disabilities, pressed for their children’s educational rights, and sought access to vocational training for them.

# 1970s

In addition to the Parent Movement, several other movements emerged in the United States in the 1970s to improve the lives of people with disabilities, advance civil rights, and change society's expectations. The Partners in Policymaking program is rooted in the tradition of these powerful movements.

One was the Independent Living Movement, which started early in the decade with the founding of the Berkeley Center for Independent Living in California. Another was the Self-Advocacy Movement, which started in Sweden in the late 1960s and spread to the United States in the early 1970s. A third was the emerging Disability Rights Movement, with its focus on civil rights and federal action.

“ [The Berkeley Center for Independent Living or CIL] was a revolutionary concept at the time. **Most people never thought of independence as a possibility when they thought of us.** But we knew what we wanted, and we set up the CIL to provide the vision and resources to get people out into the community. The Berkeley CIL was also revolutionary as a model for advocacy-based organizations; no longer would we tolerate being spoken for. Our laws said that at least 51% of the staff and Board had to be people with disabilities, or it would be the same old oppression. We also saw the CIL as a model for joining all the splintered factions of different disability organizations. All types of people used and worked in our Center. This was the vision we had for the future of the movement. ”

— Ed Roberts, World Institute on Disability

In 1970, Congress passed the Developmental Disabilities Act. Other important developments at the federal level included legislation for the education of children with disabilities and Section 504 of the Rehabilitation Act, which prohibits discrimination against people with disabilities. Under Section 504 the civil rights of people with disabilities were protected by law for the first time.

Along with their allies, people with developmental disabilities were organizing and exerting political power and influence. They were gaining more control over their lives, futures, finances, and services. Legislators, other policymakers, and service providers were questioning the long-held belief that people with developmental disabilities were unable to contribute to society in meaningful ways.

During this period, community services expanded, educational and employment opportunities emerged, and conditions improved in institutions. But most people with developmental disabilities still lived in segregated group settings, and those with complex, severe disabilities remained isolated in institutional care.

*George Roberts, left, and Les Hubbard bludgeon a curb in protest with other members of the Atlantis community surrounding them in a demonstration against obstacles to their mobility. Photo by John Sunderland/The Denver Post via Getty Images, July 1980*



## STARTING UP AND SPREADING OUT

# 1980s

During the 1980s, the Disability Rights Movement pushed long and hard for federal legislation to ensure:

Equal access to education, housing, and living in the most integrated setting with community supports.

Access to equal employment opportunities.

Access to public transportation, public buildings, and information.

Equal opportunities to participate in community activities and events.

Those efforts succeeded when, on July 26, 1990, President George H.W. Bush signed the federal Americans with Disabilities Act (ADA). President Bush said that under the ADA, “every man, woman and child with a disability can now pass through once-closed doors into a bright new era of equality, independence, and freedom.”

*President George H. W. Bush signs the Americans with Disabilities Act on July 26, 1990. Sitting beside him from left to right are Evan Kemp, Chairman of the Equal Employment Opportunity Commission, and Justin Dart, Chairman of the President’s Committee on Employment of People with Disabilities. Standing behind him from left to right are Reverend Harold Wilke and Sandy Swift Parrino, Chairperson, National Council on Disability. Photo courtesy of the George H.W. Bush Presidential Library and Museum.*



It was during this period of attention to federal action that the Council created Partners in Policymaking in 1987 to address issues relevant to people with disabilities and to train program participants in advocacy at the local, state, and federal levels. The program recognized that progress would flow from a shared vision of the future among people with disabilities and their families.

**Partners presented:**

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A structured program to train people with developmental disabilities or the parents of children with developmental disabilities on how to influence public officials.

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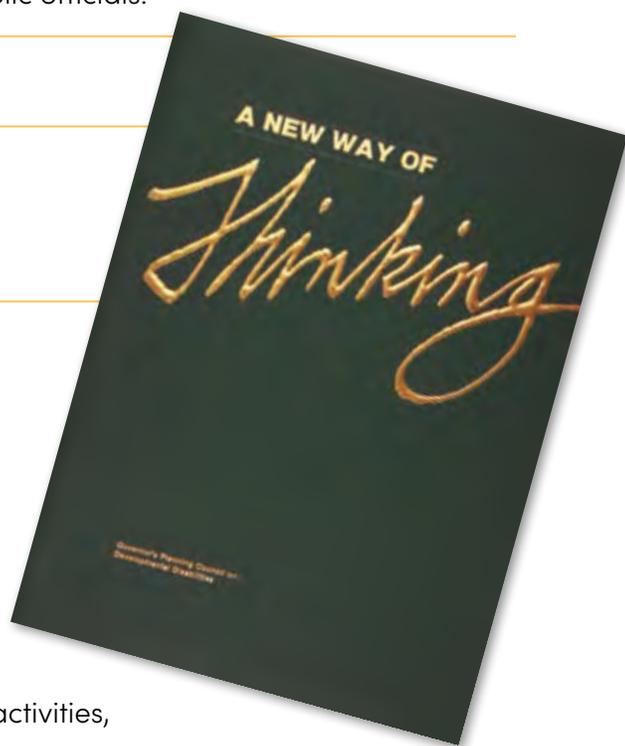
A formalized way to share best practices.

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An opportunity for state and national experts in the disabilities field to meet and discuss issues directly with people with disabilities and their families.

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From its very start, the Council emphasized evaluation and continuous improvement for Partners. Program participants evaluate each training session and then complete a comprehensive evaluation at the end of the year. In addition, the Council uses follow-up surveys of participants after their graduation to learn about how the program has improved their personal advocacy skills, expanded specific advocacy activities, and led to communication with public officials.



The same year it offered the first Partners class, the Council published *A New Way of Thinking*, which aligned closely with its new advocacy training program. This publication reviewed the history of services for people with developmental disabilities and looked at disability policies from a different perspective than the old ways of thinking. For people with developmental disabilities, *A New Way of Thinking* emphasized dignity and respect, family, friendship, a real home, chances to learn and grow, and opportunities to contribute to society. More than 6,000 copies were distributed in the first three months. Over the next two decades, the Council distributed more than 100,000 copies.

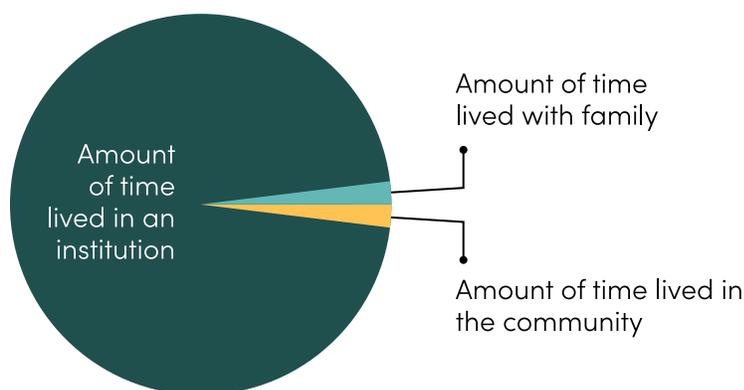
“ The Minnesota Council designed Partners in Policymaking. That was unique in lots of ways. The design was such and the effort was such that it was extremely successful. And it spread to most states. It did something that in retrospect seems logical but nobody had envisioned it before... **[I]f you look longitudinally the people who've been through this process, the series of 8-9 weekends where they get together and learn to support people who need supports... [that m]akes for strong, strong advocates when you're done, advocates who, across the test of time, keep at it.** That program has been replicated in most states. [It has been] powerful in the field in terms of change, in establishing people who will be leaders, who will push for what's right and what's best, and not settle for better. ” – Dohn Hoyle, The Arc Michigan

# 1990s

The Partners program expanded dramatically in the 1990s, beyond Minnesota to other states and other countries.

Already by the end of the 1980s, a few other states had adopted Partners and the program was attracting attention from independent living activist Ed Roberts and his California-based World Institute on Disability (WID). The Council partnered with WID to manage the 1990 program in Minnesota. Together the Council and WID conducted a National Academy for the first time to share learning among representatives from different states. The next year, Partners expanded to 12 states. Driven in part by additional National Academies from the Council and WID, the number of states adopting or adapting the program grew to 24 by 1994 and 41 by 1997.

**In Arkansas, there were people still living in institutions when Fran Smith worked with the Partners in Policymaking program in the state. The Director of the Arkansas DD Council was able to bring some people living in institutions to participate in the program. Fran remembers one very quiet young woman who, following what Ross Perot was doing during the presidential campaign at the time, created her own pie chart. One thin slice of her pie showed the part of her life she lived with her family. The rest of the pie, almost the whole chart, was how much of her life she'd lived in an institution. Another very small slice was the time she was able to be in her community. She said she wanted the largest slice to be living in the community. She did not want to be in an institution.**

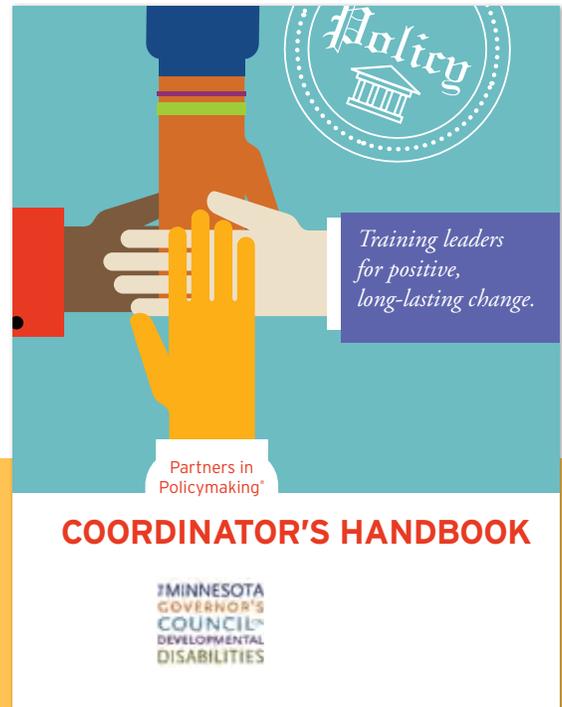


At the same time, the Council initiated its formal Cultural Outreach Program of parent education and training. The first such program, On Eagles Wings based in North Minneapolis, was developed based on the results of a targeted survey of African American parents of children with disabilities.

In 1994, the executive director of the Council participated in workshops at a conference in the United Kingdom (UK). This led to the development of several leadership trainings across the UK. All of the trainings were based on the Partners program but designed and modified for specific audiences, including adults with disabilities, parents and caregivers of children with disabilities, and professionals and other service providers working in education, health, and other sectors. Over time, Partners was adopted and adapted for use in eight countries.

The Council received official trademark status for Partners in 1999 to protect the program and the name, Partners in Policymaking, and help ensure its integrity.

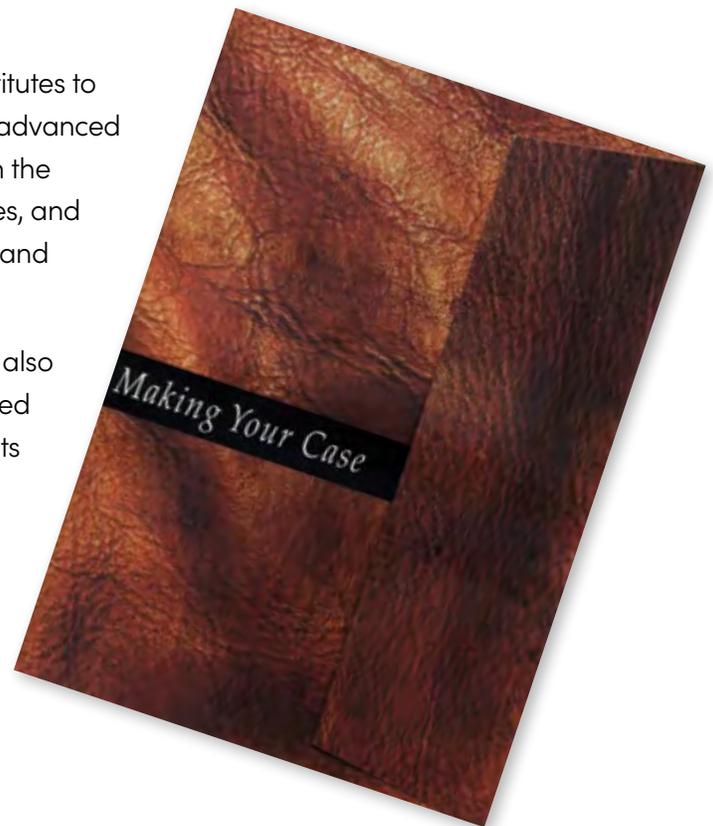
The Council developed a detailed *Coordinator's Handbook for Partners* in 1990 to help new coordinators get started and ensure that experienced coordinators maintained and improved the quality of their programs. The *Handbook* offers step-by-step guidance on topics such as recruitment, the application process, participant selection, speaker selection, interpreters and translators, skill-building activities, homework, session topics, graduation ceremonies, session evaluation, budgets and funding, costs, and post-graduate support. The Council continues to update the *Handbook*, adding new topics as needed, such as tips for integrating online learning.



“What Minnesota has done with Partners in Policymaking, I think, has been replicated by every or almost every council in the country. This has changed lives. **Partners in Policymaking has changed so many lives.**” – Dr. Ann Turnbull

Also in the 1990s, the Council offered two Summer Institutes to Partners graduates from across the country. With this advanced training, the Council looked to strengthen and build on the Partners program, foster networking among graduates, and provide them with opportunities to share experiences and perspectives.

As an outgrowth of the Partners program, the Council also published a detailed advocacy guidebook in 1994 called *Making Your Case*, which offers techniques and insights for effectively communicating with policymakers at all levels of government. It has been reprinted more than a dozen times.



## EXPANDING THE REACH

### 2000s

Recognizing the potential for online outreach and learning, the Council launched online courses both to supplement in-person Partners training and provide accessible, stand-alone modules for anyone to access. In a four-year period starting in 2003, the Council released five free, self-directed, online courses focusing on the same key concepts, tools, practices, and competencies emphasized in the in-person Partners sessions. The online courses have been incorporated into curriculum across the country for pre-service special education teachers and social workers at the college and university levels. In 2007, the online courses won a “Best of the Web Digital Government Achievement Award” from the National Center for Digital Government.

The Council took steps in the 2000s to ensure the quality and integrity of Partners programs offered outside of Minnesota. The Council began offering technical assistance to other state programs and advice to any Partners program in the United States and internationally. The Council fields questions from program coordinators, encourages coordinators to visit and learn from other state programs, updates and shares the *Coordinator’s Handbook*, and provides access to a collection of helpful documents and resources.

During this period, the Council also expanded its Cultural Outreach Programs, funding ten classes in the African American community, eight classes in the Latino community, two classes in the Indigenous community, and two classes in the Asian community.



# Stories

**OF LEADERSHIP**

*Partners taught Rijuta Pathre to recognize her daughter Minu's capabilities and changed their lives. From Stories of Leadership.*

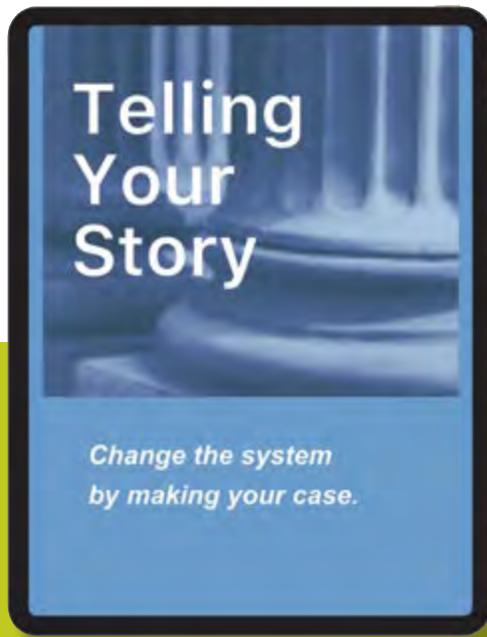
## **2010s to the present**

During the 2010s, the Council tapped new and innovative formats and technology for Partners and its related offerings.

In the early 2010s, three of the Council's online courses were translated into Spanish, and the Council released *Making Your Case* in Spanish. The Minnesota Commission of the Deaf, DeafBlind, and Hard of Hearing also created a customized version of *Making Your Case* in American Sign Language.

In 2011, the Council released an "EZ Read" version of its online Partners in Employment course using simpler language and icons to convey basic concepts and facilitate the learning process.

The Council also created a free mobile app called “Telling Your Story,” which is available at the Apple App Store and at Google Play. People with disabilities, their family members, and other advocates use the app as they compose and practice the personal stories they present to policymakers. Compelling, personal stories are a crucial element of the Partners approach to increasing awareness of disability issues and advocating for systems change. The free app guides users through the process for constructing, rehearsing, and presenting their compelling personal stories. So far, the “Telling Your Story” app has been downloaded over 10,000 times.



In 2020, the Council revised and updated the Partners online training courses to reflect current best practices. That same year, the Council conducted a national survey of programs and updated its list of program faculty and coordinators.

“ I knew that I wanted to be an advocate, but before I did Partners in Policymaking,

I didn't know how to go about doing it, and I didn't have the confidence to take action. I would be nervous to talk on the phone, and now I've testified in Senate hearings, interacted with media, and consulted with state agencies, disability service organizations, and legislators about policy. ”

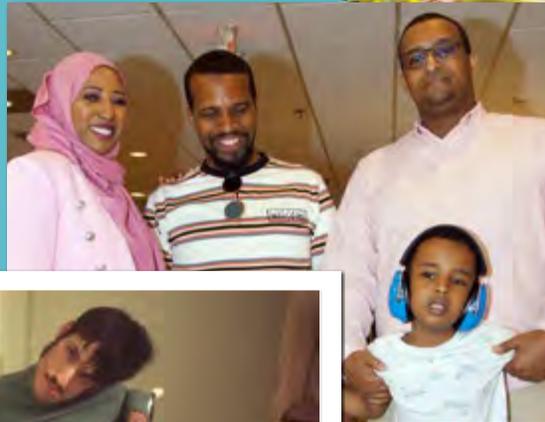
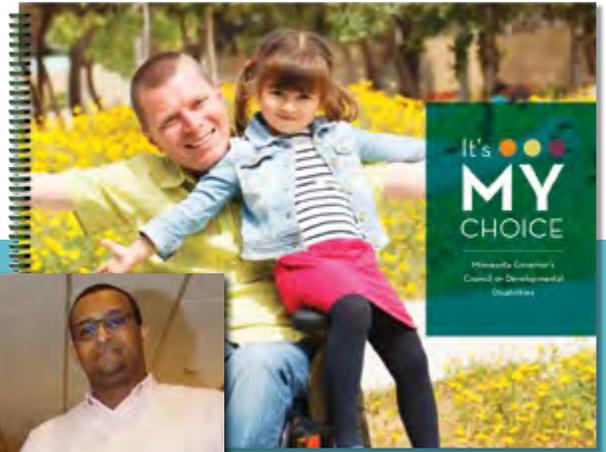
– Self-advocate, 2020



Also in 2020, as a supplement to Partners, the Council released the documentary *Hadamar: The Forgotten Holocaust*, which details the often-overlooked extermination of an estimated 200,000 people with disabilities before the start of the Nazi Holocaust that killed six million Jews.

Finally, the Council continued with its Cultural Outreach Programs by working with partner organizations to offer 30 hours of practical information and training on access to services, developing leadership skills, and the Partners program. During this period, they supported programs in African American, Latino, Indigenous, and Asian communities. Over the years, hundreds of parents and self-advocates have graduated from the Cultural Outreach Program, and many have gone on to participate in Partners.







*50 years of*

# Expanding Capacity

“ All of our concepts come from the words we use. And to the extent that we can purge our language of judgmental, devaluing language, we change the way people are seen, and the way people are dealt with, and the way we think about what is our job—what’s the job that we’re doing? **The Minnesota Governor’s Council on Developmental Disabilities has generated so much language, so much material, in order to break down, and to penetrate, and to develop a new vocabulary to describe differentness that’s not devaluing.** Part of that change of vocabulary comes from a devotion to the great scholarship of people like Wolf Wolfensberger, Burton Blatt, Gunnar Dybwad, and Ed Roberts. ”

— Dr. William “Bill” Bronston, a national leader in the fight to close institutions and to integrate people with disabilities fully into our society

Capacity building is the work an organization does to develop the abilities of individuals, communities, other organizations, and systems to effectively carry out its mission and ensure long-term sustainability. In addition to its work training people with developmental disabilities and family members to become effective advocates, the Council has successfully strengthened the knowledge and skill of allies, policymakers, and providers, building their capacity to integrate and meaningfully include people with developmental disabilities in all aspects of community life.

The Council has done this through its funding of substantial efforts to research, document, and amplify the voices, experiences, and histories of people with developmental disabilities in Minnesota. For 50 years, these efforts have developed the abilities of advocates, service providers, lawmakers, and the judicial system to understand, empathize, and fight for systems change.

The Council has always been firmly committed to learning from people with developmental disabilities and their families, and to sharing those stories with policymakers, state agencies, service providers, and the broader community. Whether collected through a formal survey or a taped interview, the Council's website is a wealth of information about the history, lives, and opinions of people with developmental disabilities.

**“ In my opinion the Minnesota Council has more resources on their website than anybody.** There have been a few efforts from other organizations to have online disability history museums. The Minnesota Council has gathered so many resources of a historical nature. The material they offer is beyond the scope of anything anyone else is doing. ” – Kathie Snow, speaker, trainer, author, and consultant

*A girl using a wheelchair at the Dowling School in Minneapolis, 1925. Photo courtesy of the Minnesota Historical Society*



By looking at the past and leading the way toward a vision for the future, the Council has been able to adapt its capacity building work and remain instrumental in changing perspectives, policies, and practices over time. Even before Minnesota’s state hospitals were closed, the Council was promoting person-centered planning practices, and shifting toward building understanding and recommending improvements in community supports. While the methods may have changed over time, the Council’s commitment to listening to and sharing the voices of people with developmental disabilities has not.

## Historical Highlights

### THE BEGINNINGS

## 1970s

In 1975, the Council published the results of the Community Alternatives and Institutional Reform (CAIR) Task Force. The Task Force created a comprehensive plan for establishing community alternatives for people with developmental disabilities. This plan focused on developing an individual-centered process to determine the needs of residents in state-operated facilities and to provide service planning based on those needs during their transition from state institutions to community settings.

## 1980s

In the 1980s, the Council published two separate sets of Policy Analysis Series papers: a thirty-paper series on *Issues Related to Welsch* and an eight-paper series on *Issues Relating to State Hospitals*. The first set addressed implementation issues related to the *Welsch* Consent Decree. The Decree resulted from a 1970s class action lawsuit based on the inhumane treatment of people with developmental disabilities in state hospitals and required the state to move people with disabilities out of state hospitals and into the community.

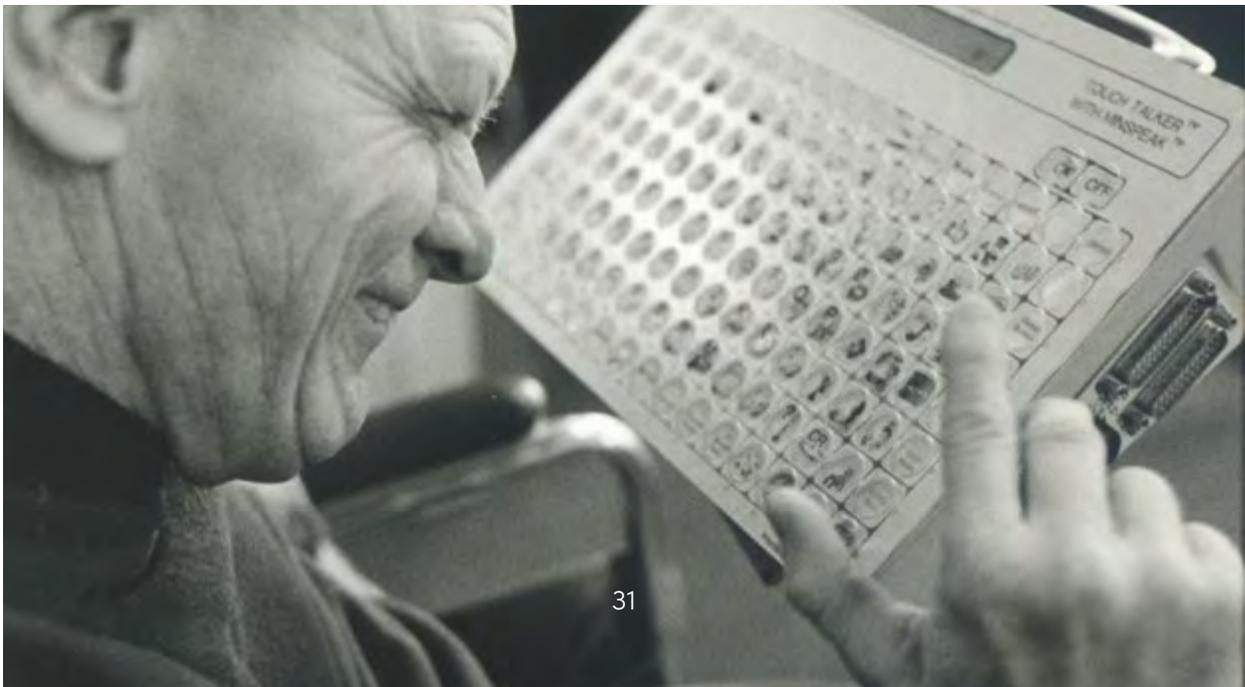


The Policy Analysis papers updated the disability community, service providers, and people with developmental disabilities and their families about the progress of deinstitutionalization and the process of community integration. The papers discussed deinstitutionalization, respite care and employment, and the use of technology. They also showed the impact of grants and research studies, highlighted successful activities and programs, and discussed where policy changes were needed. One paper, published in 1984, focusing on the potential uses of technology for improving the quality of life for people with disabilities, was a foundational first step that later led to legislation on assistive technology.

“ Access to computers is crucial for the disabled because the machines can greatly expand their job opportunities. That access would make many offices and some factory jobs possible as well as let some disabled people join the growing number of people who work by ‘telecommuting,’ or transferring their work product electronically from their homes to an office across town or across the country. ”

— J. Saddler, *Wall Street Journal*, February 7, 1984, cited in

*Policy Analysis Paper #22 (1984)*





One of the Council’s other publications during this period, released in 1983, *Developmental Disabilities and Public Policy: A Review for Policy Makers*, was delivered to state legislators by constituents involved in developmental disability issues. The report provided information about persons with developmental disabilities, trends in community services, and policy issues and alternatives for the 1980s.

In 1987, the Council published *A New Way of Thinking*, a document that discussed new ways of thinking about how, when, and with whom people with developmental disabilities learn, live, and work. It offered new service and funding strategies and gave examples of alternatives to traditional approaches. The publication

centered around the idea that quality services are responsive to basic and individual needs, and recognize that, first and foremost, people with developmental disabilities are people with abilities.

On October 16, 1987, Gunnar Dybwad gave a speech at the 25th anniversary dinner for the Olmsted Developmental Achievement Center in Rochester, Minnesota. He specifically praised *A New Way of Thinking*, saying “To me, it is without a doubt the most striking, the most demanding challenge for change, for real meaningful change that I have ever encountered in our field of work.”

“Funding, policies and services often have been focused only on the special needs of people with developmental disabilities. **The result has been that their basic needs have gone unmet.**” — *A New Way of Thinking*, 1987



*Participants in On Eagles Wings, the Cultural Outreach and Leadership Training Program in the African American community, learned about services and how to access them, and beginning skills to help them develop positive partnerships with elected officials and other policymakers*



## 1990s

The Council began providing grant funding to On Eagles Wings, a cultural outreach and leadership training program for the African American community. The program prepared parents with children with developmental disabilities for the Partners program. Parents received outreach services and personal support. They also attended a training program that gave them information about programs and services, taught them beginning leadership and communication skills to work effectively with their elected public officials, and introduced them to the concepts of the Partners program. Since that time, the Council has expanded its Cultural Outreach Programs to more communities. On Eagles Wings continued through 2017 and trained hundreds of people.

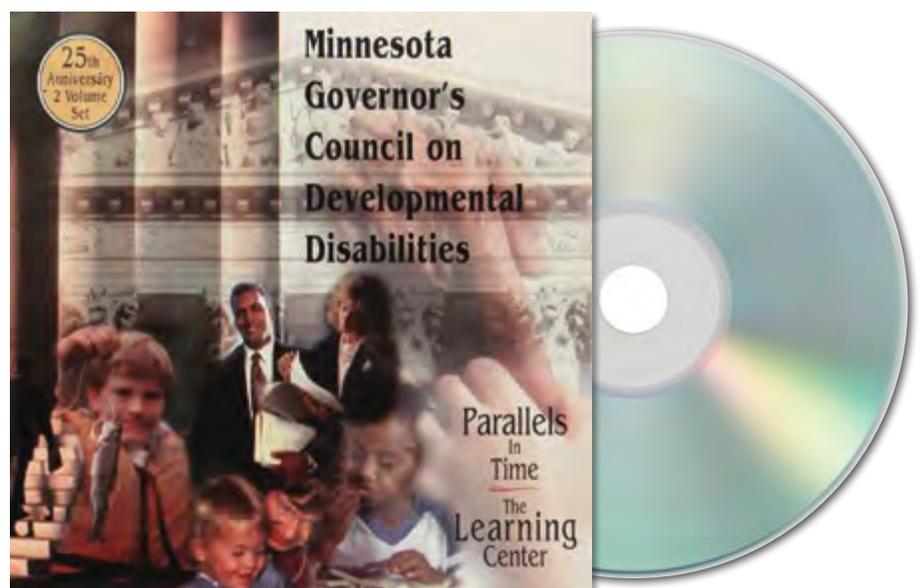
Also in 1992, the Minnesota Department of Human Services created a group to review how developmental disabilities services are provided and how much they cost. The group held town meetings to hear what Minnesotans thought. In the end, the group identified six themes about the strengths and issues of Minnesota's service delivery system. Members turned their work into a document published by the Council called *Minnesotans Speak Out!* In 1997, the group asked people if these themes were still important and correct, what had changed, and what they thought about the themes. Members created a new version of *Minnesotans Speak Out!*, which the Council released in 1998, that highlighted what they found.

“ All the people I interviewed said the themes are still relevant. Self advocates think, for the most part, that nothing has changed in the last five years, and nothing will change in the next five. Parents seemed a little more optimistic, and thought there would be more control and choice offered to individuals and families in an effort to reduce costs and allow people to have the services they need.” – *Minnesotans Speak Out!* 1997 Edition

In 1996, for its 25th anniversary, the Council first released *Parallels in Time*, a feature summarizing the history of the Parent Movement, the Independent Living Movement, and the Self-Advocacy Movement. The feature shared images, photos, and stories that reflected and represented several historical periods. While *Parallels in Time* was originally only available on CD-ROM, the Council moved it online in 2000, making it widely available.

Over time, the Council has made many updates and additions to *Parallels in Time*. It now has hundreds of videos, 1,905 text files, and 2,669 images. In 2015, it won the Hervey B. Wilbur Historic Preservation

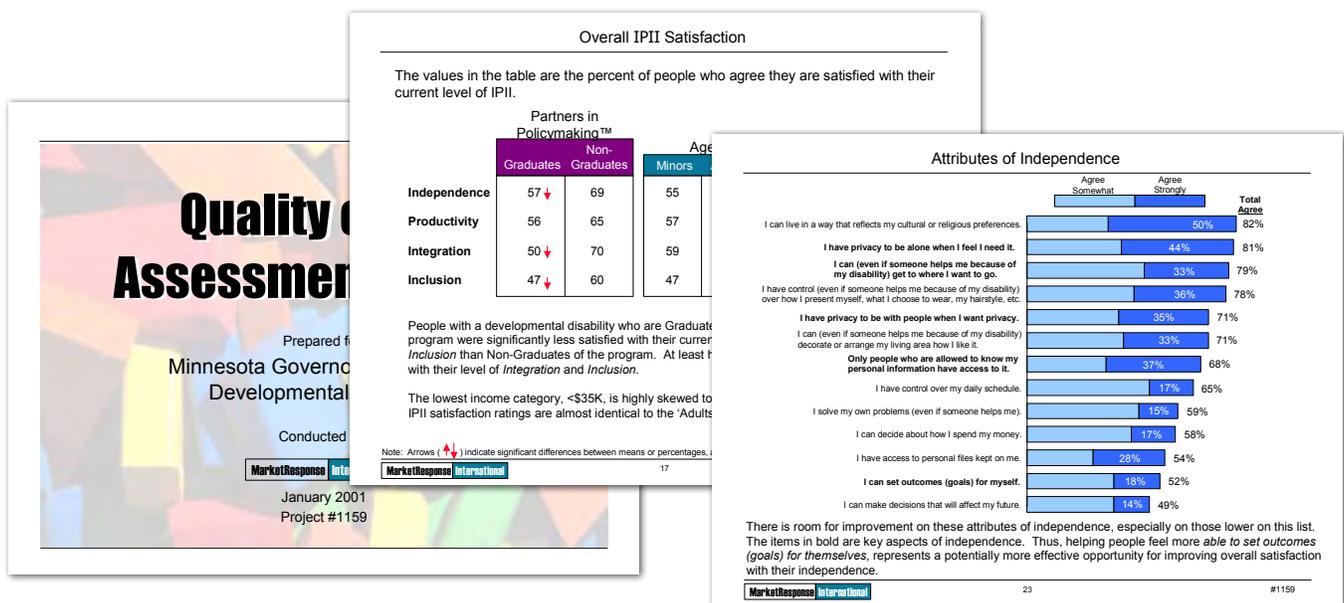
Award from the American Association on Intellectual and Developmental Disabilities for its outstanding contributions to the field of intellectual and developmental disabilities.



## EXPANSION AND ARCHIVING

# 2000s

The Council completed the first Quality of Life survey in 2000, a survey tool that continues to be administered every five years to support development of the Council's five-year plan. The survey asks people with developmental disabilities what they think about their independence, productivity, integration, and inclusion. It also asks them about the quality of services they receive and what obstacles they face in their day-to-day lives. Over 20 years, the surveys have found evidence of improvement in independence, self-determination, and integration. However, the surveys have also found that there has not been as much improvement in inclusion or employment.



On February 7, 2001, the Council and the Citizens League presided over a recognition lunch celebrating the start of the first year in which no Minnesotans with developmental disabilities were in institutions. The presentation celebrated the contributions that have been made to improving the care and quality of life of thousands of Minnesotans. The Council gave out "Let Freedom Ring" awards to attendees and every Minnesota governor dating back to 1948. Families attended for those governors who had died. Former Governor Elmer L. Andersen attended and gave a speech celebrating the last resident out of the state institution system. The following day, the Honorable Roger Moe, former Senate Majority Leader, addressed the Minnesota Legislature. He spoke about the profound and moving speech made by Governor Andersen and invited the Senators to view the Council's presentation.

“ There are times when the progress is discouraging. There are times when the mental states of people seem to be beyond belief in their lack of understanding and lack of vision, lack of humanitarian concern for other people. And yet, every effort is a part of continuing progress.

You never lose because every effort contributes to an ultimate final good result. And this is a glorious day to know that visions that have existed now for over sixty years. It took the federal government until 1975 to get anything like a special education program going, where Minnesota was in the vanguard of the states in 1957.

So, it's been a wonderful progress. Minnesota continues to be a wonderful state, and it will only so continue as there's eternal vigilance and a caring heart for people, not out of the goodness of heart but out of the value to society of utilizing the potential of every blessed human being on Earth. ”

– The Honorable Elmer L. Andersen, Former Governor of Minnesota, February 7, 2001 luncheon

The lunch and presentation led to a new Council website section called *With an Eye to the Past*. This website feature tackled the enormous task of commemorating and acknowledging the 50-year effort to deinstitutionalize Minnesota’s state hospital system and integrate people with developmental disabilities into the community.

In March 2002, the Council published *It’s My Choice*, an updated version of the 1987 resource book *Read My Lips*. The book was designed to help family members, friends, social workers, service coordinators, service providers, and advocates help people with developmental disabilities get the services and supports they need to lead the lifestyles they prefer, be more independent, and be active members of the community. Supporting people in their freedom of choice was central to the resource guide. In 2005, the Autism Society of Minnesota featured *It’s My Choice* as a primary training tool. The State of Indiana also adopted it as a person-centered planning tool and provided a copy to every person in the state with a developmental disability. The Council updated *It’s My Choice* to an interactive format in 2017. Each of the guides and checklists can be downloaded, completed and printed out to help individuals prepare for planning meetings and be actively involved in the conversation.



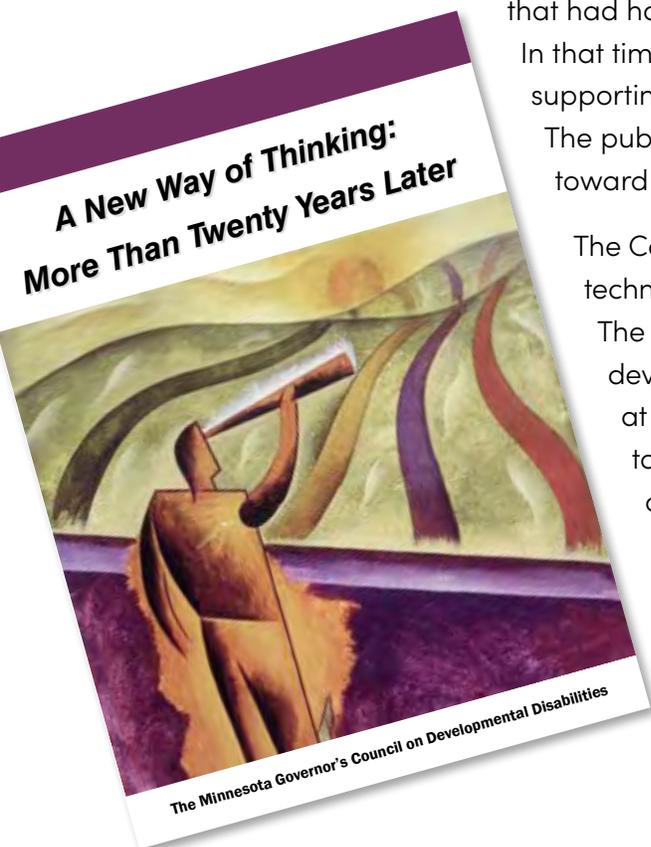
In 2002, the Council also released the results of a survey of individuals participating in the Consumer Directed Community Supports (CDCS) program. The survey included questions on whether the program was meeting customer needs, requirements, and expectations. In general, people were happy with the program. They said it was the best option yet for individuals with developmental disabilities. However, the survey also showed that some counties were doing better at leading the program than others.

In 2003, the Council funded a study of the current state of electronic government services. Researchers interviewed people with developmental disabilities to understand their needs, requirements, expectations, and desires of electronic government services. The interviewees reviewed different websites and shared their thoughts on what they liked and didn't like, including the Council's own website. Based on people's comments, the Council updated its website to better meet people's needs.

Advocating Change Together, a grantee of the Council, started a new networking group in 2007 for Minnesotans with developmental and other disabilities called Self-Advocates Minnesota (SAM). Self-advocates and allies had been trying for years to start a group but were frustrated that there was little funding available and no structure. SAM was created to be a networking and communication hub for the self-advocacy movement in Minnesota. SAM does not tell any local, community-based self-advocacy group what to do. Instead, SAM supports self-advocacy groups' efforts by giving them money and technical assistance, and by building a communication system so groups can learn from each other. SAM's mission is to promote the human and civil rights of people with developmental disabilities and help support people with all disabilities to be active participants in the larger disability and human rights movement. SAM is located in six regions, and each region works on personal empowerment, disability awareness, and systems change. The Council currently provides grant support to the Northwest and Central SAM regions.

In 2009, the Council published *A New Way of Thinking, More Than Twenty Years Later*, which traced the progress that had been made since the original *A New Way of Thinking* was published in 1987. The new report highlighted the significant changes that had happened over more than two decades of advocacy work. In that time, state institutions were closed and the state began supporting person-centered planning and community supports. The publication also described how society could move forward toward a better, more inclusive future.

The Council also funded a survey in 2009 to measure information technology use among people with developmental disabilities. The study found that households that had people with developmental disabilities had computer and internet access at the same rates as the general population. Compared to the general population, households with people with developmental disabilities were also more interested in keeping up with the latest technologies, and in learning more about how technology could help them live better.



“ The last 25 years, in particular, have been marked by significant progress, thanks to the dedication and creativity of self-advocates, family members, teachers, researchers, policy makers and professionals in the field of disability services. Several critical milestones achieved over the last quarter century have resulted in significant improvements that furthered the lives, livelihoods, and inclusion of people with developmental disabilities. ”

– *A New Way of Thinking, More Than Twenty Years Later*

## THE MODERN ERA

### **2010s to the present**

The Minnesota Governor’s Council on Developmental Disabilities started giving grant money to The Discovery Process in 2013, which is a tool to help people with developmental disabilities find a job that matches their interests, talents, and skills. The tool involves seven stages of learning about an individual, including interviews with the person and their family. The tool also explores people’s relevant school and work experiences. The process builds on personal strengths and abilities and offers people the chance to learn about a specific job before deciding if it would be a good match. This program has helped dozens of people with disabilities find a job that is a good fit and pays at least minimum wage. People participating in the program have also done informational interviews with hundreds of businesses. Some students have gone on to complete schooling in the areas they’re interested in, like culinary arts or architectural drafting.

Also in 2013, the Council funded a study about K-12 education for students with developmental disabilities. The study tried to understand the issues, challenges, and opportunities facing students and their families in Minnesota. The study collected more than 200 stories from 110 individuals, including students with developmental disabilities, parents, teachers, case managers, special education administrators, self-advocates, and others. A follow-up study was conducted in 2014 to take a baseline of overall quality and satisfaction levels of the special education experience from parents and the students themselves.

“ Learning leads to transformation; it’s the goal of education. The ultimate goal of public education is transformation to productive and fulfilling adulthood. But for students with developmental disabilities, transformation of this type is far from guaranteed.”

— K-12 Education Study for Students with Developmental Disabilities, 2013, designed and implemented by MarketResponse International.

In 2013, the Council also began funding *Ambassadors for Respect*, an anti-bullying campaign targeted at 4th grade students. The campaign uses the *Ambassadors for Respect Handbook* to train self-advocates to become Ambassadors for Respect. These self-advocates are trainers and teachers in the classroom, sharing personal stories about bullying that they’ve experienced, modeling respect for all, and fostering self-advocacy skills among 4th grade students to address and respond to bullying incidents. Teachers and paraprofessionals are also involved in the training sessions so they can reinforce the tips and tools that students learn. Thousands of students and hundreds of teachers have participated in training sessions at elementary schools. In the 2019-2020 school year alone, the program trained 477 students



*Ambassadors for Respect present to fourth-graders at Otter Lake Elementary School*

and 21 teachers. The program began in a few Twin Cities school districts, but it’s grown over time to more metro-area school districts and hopefully soon to districts in Greater Minnesota. In 2014, the program won the Arc Minnesota Community Innovator Award, and in 2019 won the State Government Innovation Award.

In addition to the many Cultural Outreach Programs the Council has supported since the 1990s, the Council began funding a new program in 2017 focused on the Somali-American community. The Horn of Africa Aid and Rehabilitation Action Network (HAARAN) coordinated and carried out training for participants in Nicollet and Blue Earth Counties. Like On Eagles

“ I was happy to learn about person-centered support plans. I feel more of a person than my disability. Now I know more resources in the county and now my disability will not scare me anymore. ”

– Somali Cultural Outreach Program participant



*Abdi Matan, founder of HAARAN, with his family*

Wings, the program prepares parents with children with developmental disabilities for the Partners in Policymaking program. This grant is now administered by the Somali Community Resettlement Services agency and serves both Somali and Latinx individuals with disabilities and families.

The Council received Legacy funding in 2018 to add documents and video interviews about the future of disability rights in a new website feature called *With an Eye to the Future*. The website documents key moments in the Council's history, beginning in the year 2000. As well as honoring disability history, the website celebrates modern progress and looks toward more disability rights and activism achievements in the future. The Legacy funding allowed the Council to initially add more than 750 documents and 20 videos to the website. After the page was made public on June 6, 2018, it received more than 5,000 views



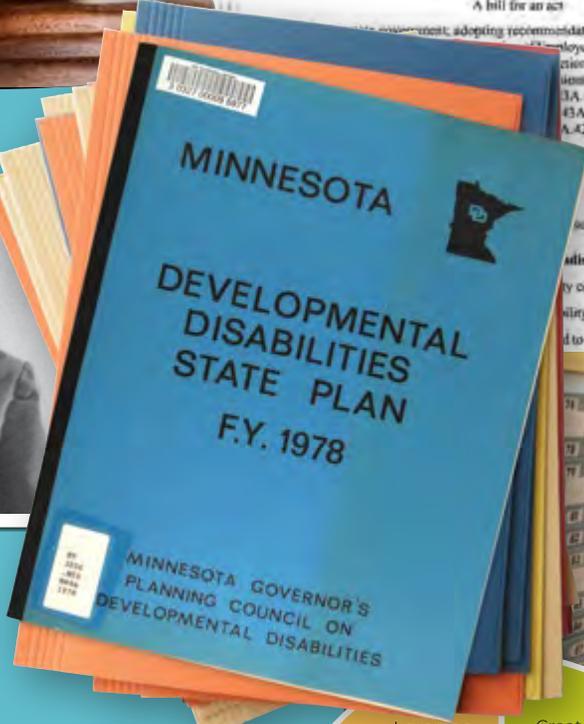
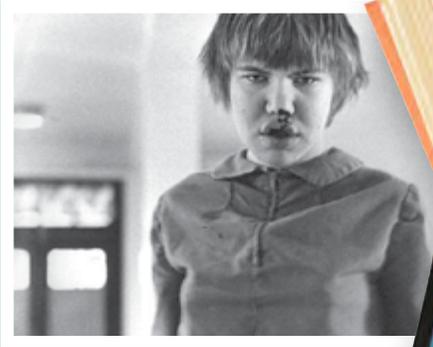
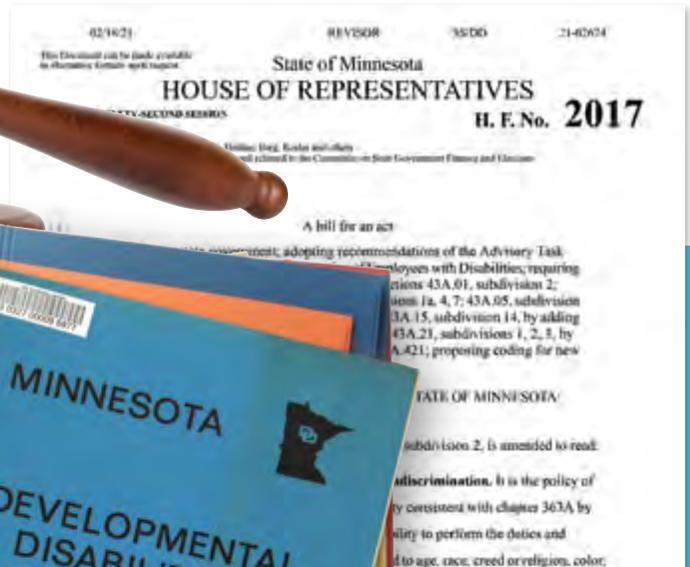
“Empowering people to contribute, in the ways that they can, fosters much more motivation and happiness. The important thing is having people integrated into their communities in a way that is respectful and empowering for them, not a bullet list of requirements they have to make themselves fit into. This is hard, it requires understanding each person and what they need to be successful.”

— *Becoming ONE MINNESOTA* study participant

and likes within the first 20 days. Since the website’s release, the Council has added more than 50 new stories.

In 2019, the Council funded a study called *Becoming ONE MINNESOTA*. Governor Tim Walz’s administration has centered around the message of One Minnesota, and the Council wanted to understand what must happen for all state agencies to really embody One Minnesota in a way that is inclusive of people with developmental disabilities. Through interviews and online bulletin board focus groups, 43 individuals shared their thoughts. Participants said state agencies must stop seeing people with developmental disabilities as a cost to society. Among other things, they told the state to do better at helping them find fulfilling jobs that earn a livable wage, and to include people with developmental disabilities, their families, and advocates in policy processes and decisions.





*50 years of*

# Envisioning Systems Change

Two black binoculars with orange lenses, lying horizontally on a yellow background. The binoculars are positioned in the lower half of the frame, with the text 'Envisioning Systems Change' overlaid on top of them.

“ The Minnesota Council was a leader in matching the language of the DD Act to what they were doing. As my friend Allan Bergman put it, we should stumble as little as possible over better to get to best. That, in many ways, is what in my mind characterizes the Minnesota Council. It has always been concerned with how we get to best. ”

– Dohn Hoyle, The Arc Michigan

***Systems change is all about working on a big problem from a lot of different directions, knowing that changing things and making them better will be a long and complex process. Systems change is also about fixing the way that society and the government works so that people get what they need, instead of trying to “fix” people so that they’ll take what they’re given.***

When it comes to the complex issues that people with developmental disabilities have faced, there have not been easy solutions. It has taken hard work and many years to get closer to the goals of the Developmental Disabilities Assistance and Bill of Right Act, and there is still work to do.

The Minnesota Governor's Council on Developmental Disabilities has helped create systems change in partnership with people with developmental disabilities and their families for the past 50 years, in Minnesota, nationally, and around the world.

Since its start in 1971, the Council has fought for changes at the systems level to:

- 1 Move people with developmental disabilities out of state institutions and to integrate them meaningfully into our communities;
- 2 Prevent abuse and neglect of people with developmental disabilities both in facilities and in our communities;
- 3 Change the way that society sees and thinks about people with developmental disabilities;
- 4 Create opportunities for people with developmental disabilities to gain meaningful employment;
- 5 Implement and expand the use of person-centered planning practices; and
- 6 Increase equity and reduce disparities in outcomes for people with developmental disabilities who are also marginalized because of their race, ethnicity, gender identity, or identification as LGBTQ+.

*Supported employment greatly expanded in the 1990s.*



## Historical highlights

### DEINSTITUTIONALIZATION AND COMMUNITY INTEGRATION

## 1970s

Patty Welsch, who lived at the Cambridge State Hospital, became the lead plaintiff in a federal lawsuit against the Minnesota Department of Public Welfare in 1972. Patty's dad, Richard, had reached out the Legal Aid Society of Minneapolis after seeing how Patty and other residents were being treated. They filed a lawsuit on Patty's behalf. Eventually other families got involved, and the suit became a class action that challenged the conditions at six state hospitals.

In 1974, United States District Court Judge Earl Larson agreed with the family and said that anyone, no matter their disability, could grow and develop if they had the right care and treatment. However, this wasn't the end of the *Welsch* case.

“As time went on, we could tell that [Patty] was being heavily medicated, and she would come home or we would see her with bruises or she had fallen... At one time we did notice that she was in bed with a top on top. She could not get out of the bed. They had her confined right to the bed.”

— Eleanor Welsch, mother of Patty Welsch, on whose behalf a lawsuit was filed against the Cambridge State Hospital



*Exhibits from the 1973 Welsch trial used to show the conditions of people with developmental disabilities at the Cambridge State Hospital.*

In January 1975, the Council published *CAIR: Planning alternatives for the developmentally disabled individual*, a systematic plan for the deinstitutionalization of people with developmental disabilities. The report recommended how the state should develop, license, fund, and evaluate residential programs. More than that, the report laid out how the state should use individualized planning by first understanding the specific needs of individuals in each part of the state, before developing community-based residences or services.

## **1980s**

Despite the court's ruling in 1974 on the *Welsch* case, the Minnesota Legislature did not do anything in 1975 to fix what was happening at the Cambridge State Hospital or other state institutions. So, the plaintiffs went back to the court, and Judge Larson made additional orders – but the state of Minnesota appealed all of the decisions. Although one state hospital was closed and some changes were made at Cambridge, overall things in the state did not get better for people with developmental disabilities who lived at state hospitals. A Consent Decree in 1980 required more staff and improvements to the state hospitals and set limits on using medicine or physical actions to control residents or keep them away from others. It also required the state to reduce the number of people living in state institutions from 2,650 people to 1,850 by 1987. The people who left were supposed to be placed in community programs that met their individual needs. Patty Welsch was one of the people who moved from an institution into a group home. At the time, the court did not say what should happen to the 1,850 people who still lived in state institutions after 1987. Between 1987 and 1989 there was a separate agreement. The case ended on August 25, 1989.

“Those group homes are wonderful. She’s well taken care of there, and Patty likes it there... We have her come home about twice a month. She’s happy to come home... but in a little bit... she is ready to go back. She likes it over there. She misses her friends.” – Eleanor Welsch

In 1984, the Minnesota legislature required a study and plan for Minnesota State Hospitals, because it was unclear what the impact would be if state hospitals were closed or the number of residents substantially reduced, as required by the *Welsch* settlement and the waiver. The Legislature stated that it is “the policy of the state that deinstitutionalization policies shall be carried out in a manner that ensures fair and equitable arrangements to protect the interests of employees and communities affected.” The responsibility for the study was given to the Governor’s Council on Developmental Disabilities.

In January 1985, through the Institutional Care and Economic Impact Planning Board, the Council produced *Policy Analysis Series: Issues Relating to State Hospitals*, eight groundbreaking, technical policy papers on the following topics:

1. Minnesota State Hospital Facilities and Alternative Use
2. Minnesota State Hospital Energy Use and Cost
3. A Profile of Minnesota State Hospital Employees
4. The Economic Impact of Minnesota State Hospitals
5. Public Opinions About State Hospitals
6. Residents/Patients in Minnesota State Hospitals
7. The Cost of Minnesota State Hospitals
8. Opinions and Recommendations for the Minnesota State Hospital System

Also in 1985, Governor Rudy Perpich formed the Governor's Commission on Mental Health to make recommendations about a number of issues related to mental health and barriers experienced by people with mental illness. The Council published a report that included the Commission's recommendations for the immediate and near future. The report found that less than one percent of expenditures on mental health services went to community mental health services, while almost half went to nursing homes.



“The absence of a vigorous case management and individual service planning approach, and of uniform placement criteria, increase the risk that services will be offered based on ‘the costs to the unit of government making the placement’ rather than the needs of people. A full array of service is neither in place nor funded.”

— *Mandate for Action*, written and published by the Minnesota Governor's Council on Developmental Disabilities for the Governor's Mental Health Commission in 1985.

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## 2000s

On February 7, 2001, the Council joined the Citizens League to celebrate the start of the first year in which no Minnesotans were in institutions because of developmental disabilities. It had been over 50 years since Governor Luther Youngdahl had burned physical restraints outside of the Anoka State Hospital, proclaiming the “end” of using such restraints on people at state institutions, and it had been almost 30 years since the Welsch family brought their lawsuit against the state because of the conditions at Cambridge State Hospital.

The campus of the Cambridge State Hospital became Minnesota Extended Treatment Options (METO) in 1997 and was supposed to be a temporary place for people with disabilities to live who had been removed from where they lived, or who were coming out of incarceration or at risk of being incarcerated, because they could not be safely served in their communities.

After receiving complaints about handcuffs and other restraints being used on people with developmental disabilities at METO, the Office of the Ombudsman for Mental Health and Developmental Disabilities conducted a review of how METO residents were being treated. In September 2008, the Ombudsman Office released the report, *Just Plain Wrong*. It said that residents were physically and mechanically restrained on a routine basis at METO, in violation of best practices, state statute, and the facility's own guidelines.

“ Staff immediately began to use metal handcuffs and leg hobbles to restrain him/her when he/she displayed behaviors that were deemed to be antecedent to more severe self-injurious behaviors. There did not appear to be other methods of programming discussed or considered. Typical behaviors displayed by this person that resulted in restraints include: spitting, becoming agitated (there was not a clear definition of this behavior) and other behaviors that are not unusual for this person to display when their environment is over stimulating or stressful for him/her. ”

— *Just Plain Wrong*, 2008



*Just Plain Wrong* showed that the issues at the heart of the *Welsch* case had not been resolved and set the stage for the *Jensen* lawsuit.

Three former METO residents filed a lawsuit against the State of Minnesota in July 2009. The lawsuit said that the residents had been treated inhumanely and that their civil rights had been violated. The men's stories were like those that were reported in *Just Plain Wrong*. The case was called *Jensen* after the last name of the lead plaintiff. Although it started with three people, *Jensen* became a class action lawsuit that represented more than 300 families.

## **2010s to the present**

The *Jensen* case ended in the *Jensen* Settlement Agreement adopted by the court in December 2011. In addition to providing money to the people who had been harmed, the State of Minnesota was required to appoint a committee to review Minnesota's Rule 40 and for another committee to create an Olmstead Plan. The Minnesota Governor's Council on Developmental Disabilities was involved closely in both of those efforts, as the Council had been appointed as a consultant to the Court on the *Jensen* case.

“ The State Ombudsman for Mental Health and Developmental Disabilities did us all a great service by shedding light on what occurred out there [at METO]. So with that backdrop, the state and our office on behalf of the settlement class and the individuals that were sued in the lawsuit all came together, and we said, ‘Look, we can agree that the use of metal handcuffs and leg irons and these mechanical means to restrain are out and are prohibited.’ And that’s what the settlement agreement does.”

– Shamus O’Meara, partner at Johnson and Condon, Edina, Minnesota, and lead counsel for the *Jensen* settlement class.

In 2012, the Olmstead Planning Committee was created, as required by the *Jensen* Settlement Agreement. The committee included people with disabilities, family members, providers, advocates, and staff from the Department of Human Services. The committee presented recommendations in a report to the Commissioner of the Department of Human Services in October 2012. One of the recommendations was for the Governor to create an Olmstead Subcabinet to include all of the agencies that would be involved in making sure that Minnesotans with disabilities have choices about where to live and have the opportunity to live in the most integrated setting possible.

It was a federal lawsuit from 1999, *Olmstead v. L.C.*, that required states to have an Olmstead Plan, but it wasn't until January 2013 that Governor Mark Dayton created the Olmstead Subcabinet through an Executive Order and tasked the Subcabinet with developing an Olmstead Plan for Minnesota. The Executive Director of the Governor's Council on Developmental Disabilities was named as a member of the Olmstead Subcabinet. Throughout 2013, several drafts of the Minnesota Olmstead Plan were written, presented for public comment, and reviewed by the Court.

In January 2014, the Court temporarily approved the Minnesota Olmstead Plan but required some revisions. Revisions to the plan continued in 2014, with the Court deciding again not to approve it and requiring more revisions. In May 2015, the Court reviewed the draft at that time and said that it still did not meet the requirements. The state submitted a new version of the Minnesota Olmstead Plan again in August 2015, and it was approved by the Court in September.

“ People with disabilities are living, learning, working, and enjoying life in the most integrated setting. ”

– Vision statement of the Minnesota Olmstead Subcabinet



The Council continues to be involved in the monitoring and evaluation of the Minnesota Olmstead Plan through representation on the Subcabinet and by engaging self-advocates, advocates, and others in the yearly process of reviewing and amending the plan. The Council has also documented the history of the METO lawsuit and *Jensen* Settlement Agreement, the history of the Minnesota Olmstead Plan and its implementation, and has funded efforts to graph and publicize progress toward the Olmstead Plan goals.

On October 24, 2020, the Court's jurisdiction over the *Jensen* Settlement Agreement ended—including the Olmstead Plan. The Commissioner of the Department of Human Services said that the Department remains committed to the Olmstead Plan, and that the Department will keep tracking the plan's goals and milestones.

## Preventing abuse and neglect

### **Before 1950**

On October 31, 1949, Minnesota Governor Luther Youngdahl celebrated the end of the use of physical restraints in Minnesota's institutions, where many people with mental illness lived at the time, by burning straitjackets, hand cuffs, straps, and mittens outside the Anoka State Hospital. But the use of these aversives continued into the latter half of the 20th century and into the 21st.

*Governor Luther Youngdahl setting fire to restraints at Anoka State Hospital, October 31, 1949. Photograph by Hi Paul. Published in the St. Paul Pioneer Press on November 1, 1949.*



“ All I can tell you is if my kid is running across the street in front of traffic and he doesn't see the danger, might I grab him and hold him and keep him from doing that? Absolutely. Am I then going to take him into my house and tie him to his bed and tell him he has to stay there for two days because he created an unreasonable risk? What parent would do that? **And if we can't legitimize it for anyone else, how can we possibly legitimize it for people who have intellectual disabilities who understand the world even less than everybody else in those kinds of scenarios.**”

— Michael “Mike” Mayer, former senior partner of Community Resource Alliance and clinical director of the ACT Process in Illinois. The Governor's Council on Developmental Disabilities recorded an interview with him on Positive Behavior Supports in 2013 where this quote was captured in response to a question on whether seclusion and restraint are helpful to changing people's behavior. Mike Mayer passed away in 2015.

# 2010s to the present

Rule 40 is the term used to describe the Minnesota state rule, first created in 1987, that said what type of actions a licensed facility could use to physically control and punish people with developmental disabilities, including when those actions were allowed. In the *Jensen Settlement Agreement*, the Court said that the Department of Human Services had to immediately stop METO from doing things like putting handcuffs on residents, giving residents medicine against their will to control them, holding residents down, putting them in time out, or otherwise hurting and abusing residents for punishment or to change their behavior.

The *Jensen Settlement Agreement* also required the creation of the Rule 40 Advisory Committee, to make recommendations on how to update the state statutes to focus on positive behavior supports and best practices. The Governor's Council on Developmental Disabilities was part of the Rule 40 Advisory Committee, which started meeting in 2012. The Council hired Michael Mayer and Derrick Dufresne to look at how other states handled similar rules, and they gave their report to the committee in May 2012.

Minnesota's Positive Support Rule was published in August 2015. The Positive Support Rule came from the work of the Rule 40 Advisory Committee.

The Council also supported a small work group that wrote the *Abuse and Neglect Prevention Plan for People with Disabilities*. The recommendations in the Plan were approved by the Minnesota Olmstead Subcabinet in September 2016. Based on the plan, the Olmstead Subcabinet asked that yearly measurable goals about preventing abuse and neglect be added to the Minnesota Olmstead Plan.

A special committee presented the *Comprehensive Plan for Prevention of Abuse and Neglect of People with Disabilities* to the Minnesota Olmstead Subcabinet in January 2018. This Plan outlined promising actions that could be taken before abuse and neglect of people with disabilities happens.

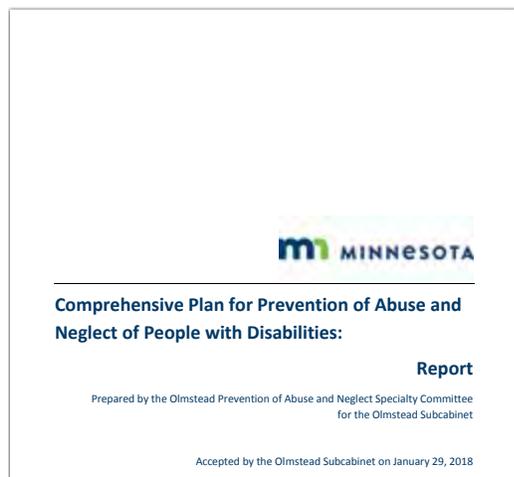


Table 1: 'Who', 'When' and 'How' of Comprehensive Prevention of Abuse and Neglect of People with Disabilities: Descriptions and Goals<sup>14</sup>

Primary Prevention (All people)	Risk Reduction Education and Outreach (People with Disabilities)	Risk Reduction Awareness Education and Outreach (Family members, informal supporters and the general public)	Risk Reduction Awareness Education and Outreach for Service Providers (People working in Service and Response Systems)	Secondary Prevention: Early Recognition and Response (People who have experienced abuse and neglect and Offender)	Tertiary Prevention: Long-Term Response, Intervention and Evaluation (Person who experienced abuse and neglect, Offender, Supportive and System)	
Area 1	Area 2	Area 3	Area 4	Area 5	Area 6	Area 7
Change behaviors, attitudes, cultural norms, and policies that contribute to abuse and neglect by promoting relationships based on equality and respect, and include nonviolent communities.	Provide knowledge, skills, opportunities, and experiences that lessen one's own risk of engaging in abusive, harmful, and disrespectful behaviors in relationships based on equality, dignity, and respect.	Provide knowledge and skills that lessen one's own risk of engaging in abusive, harmful, and disrespectful behaviors in relationships based on equality, dignity, and respect.	Educate public about the problem of abuse and neglect of people with disabilities, and ways to best support people who have experienced abuse and neglect.	Provide knowledge and skills that lessen one's own risk of engaging in abusive, harmful, and disrespectful behaviors in relationships based on equality and respect.	Educate providers about the problem of abuse and neglect of people with disabilities, options for reporting, where to access services, and ways to best support the needs and wishes of people who have experienced abuse and neglect.	Promote healing of people who have experienced abuse and neglect and hold perpetrators accountable. Provide education and supports for practicing nonviolent, non-harmful behaviors in relationships based on equality, respect, choice, and self-determination. Create measures and strategies for systems accountability. Change policies and practices that contribute to abuse, neglect and disempowerment.
<b>Desired Outcome:</b> People with disabilities are better able to protect their dignity, and respect, and included as valued leaders and community members.	<b>Desired Outcome:</b> People with disabilities are better able to protect themselves, know their options and rights, know where to go for help, and are better able to advocate for themselves.	<b>Desired Outcome:</b> People take active steps to prevent abuse and neglect. Treat people using alternatives to violence. Build relationships based on equality, respect, choice and self-determination.	<b>Desired Outcome:</b> People know and care about the problem. Take steps to prevent abuse and neglect. Recognize early warning signs. Have skills for speaking up.	<b>Desired Outcome:</b> Providers take active steps to prevent abuse and neglect. Recognize early warning signs. Have skills for speaking up. Report and where to get services. Provide supports to people who have experienced abuse and neglect based upon their needs.	<b>Desired Outcome:</b> Harm is minimized by early recognition. Providers take active steps to prevent abuse and neglect. People get trauma-informed and victim-centered help and safety planning. Offenders are quickly identified and prevented from causing further harm. All responsible systems work collaboratively to investigate and hold offenders and agencies accountable. Initial changes to prevention, supports for people who have experienced abuse and neglect, education, and response are quickly made.	<b>Desired Outcome:</b> Ensure long-term trauma-informed, victim-oriented supports for people who have experienced abuse and neglect. Hold individuals accountable and have responses set up to change behaviors and promote respectful interpersonal relationships with systems of accountability. Ensure ongoing organization and system analysis and improvement.

In February 2018, the Olmstead Subcabinet approved adding annual goals to the Olmstead Plan to reduce abuse and neglect of people with disabilities. These goals have been updated and continue to be monitored as part of the Minnesota Olmstead Plan today.

In November 2019, the *Treat People Like People* public awareness campaign was launched. The campaign was made possible by a partnership between the Office of the Ombudsman for Mental Health and Developmental Disabilities and the Council. The website, toolkit, and published materials raise awareness of abuse and neglect of people with disabilities and educate people with disabilities, their families, guardians, and the public on identifying, reporting, and responding to abuse and neglect of people with disabilities. The messaging and materials were co-created with people with disabilities, their family members, and advocates.

“ [‘Treat People Like People’] marks the first time that Minnesotans with disabilities have played a central role in the messaging of a statewide campaign to prevent abuse and neglect. And unlike many anti-abuse campaigns, which reduce victims to impassive caricatures, **‘Treat People Like People’ features people with disabilities as fully actualized humans, with voices and dreams of their own.** ”

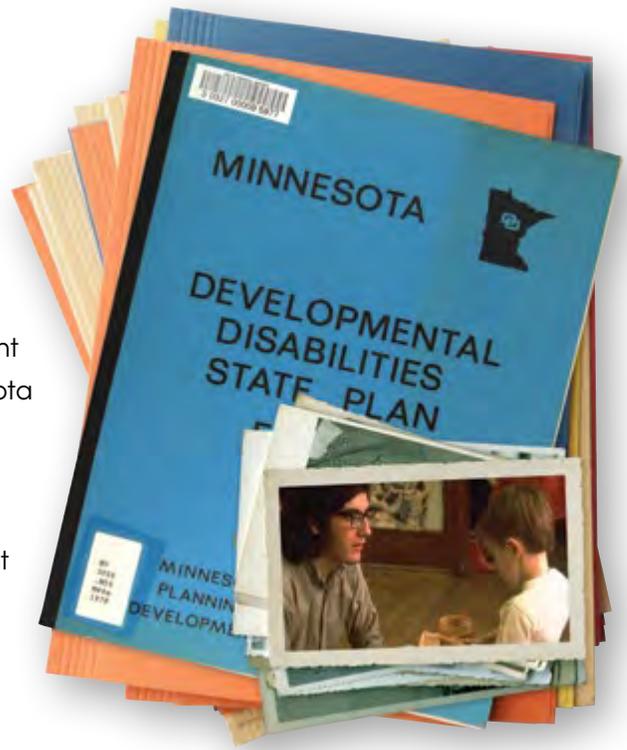
— Chris Serres, *Star Tribune/TNS*, 2019, from the article “Campaign highlights power of people with disabilities” published December 13, 2019, about the Treat People Like People awareness campaign



## Changing attitudes

### 1960s and 1970s

In 1962, the Arc Minnesota and the state's Department of Public Welfare sponsored a survey of 900 Minnesota households, the first such public poll of attitudes toward people with developmental disabilities. Most Minnesotans said that people with developmental disabilities should be allowed to lead typical lives, but also said they shouldn't be allowed to vote or drink alcohol. At the time, most Minnesotans also said that people with developmental disabilities should not be cared for at home.



In 1976, the Minnesota Governor's Council on Developmental Disabilities undertook a research study about public information and public attitudes about people with developmental disabilities. The study found that while public attitudes had become more positive toward people with epilepsy and cerebral palsy, it wasn't as positive toward people with other types of developmental disabilities. The survey also found that doctors did not know about services for people with developmental disabilities, and families had a hard time finding support because doctors, teachers, and even the family members themselves had negative or hopeless attitudes about children with developmental disabilities.

**One of the recommendations from the study was to create a lending library to spread information and awareness, which the Council created and implemented for decades, until materials could be put online for easier access. Website features, including detailed historical records, continue to be an important and popular part of the Council's website.**

### 1980s and 1990s

When the Partners in Policymaking program was created in 1987, it included a competency about working with the media. That competency still exists, and training people with developmental disabilities and their family members on how to work with the media, including social media, and tell their stories to impact public opinion continues to be an important part of the Partners curriculum.

“One way to recognize that there is something in the air, a major shift in the works, is to see the emergence of a new crop of buzz words. The words “empowerment,” “self-determination,” “self-transformation,” and “autonomy” are not new. What is new is the frequency with which they are used in today’s discussions about people with developmental disabilities. What is really new is the shifting patterns that such concepts represent.”

– *Shifting Patterns*



## 1992

In October 1992, the Governor’s Council on Developmental Disabilities published *Shifting Patterns*, a publication and video that presented best practices for empowerment and self-advocacy from around the United States and the world, which had been collected by the Council through a national survey of other state councils, university affiliated programs, and a major provider organization. *Shifting Patterns* brought attention to programs and concepts that were helping shift beliefs and attitudes about people with developmental disabilities. Many of these programs continue including the Partners in Policymaking program, Personal Futures Planning, People First, Career Vision, Parents as Case Managers, vouchers, and youth leadership.

## **2000s to the present**

Throughout the 2000s and continuing today, the Council has effectively helped shift public opinion about people with developmental disabilities, especially through media coverage. The Council has either directly funded journalistic efforts, helped find speakers or interviewees, or had its own work publicized in such outlets as Twin Cities Public Television, *US News & World Report*, National Public Radio, the *Star Tribune*, the *Pioneer Press*, WCCO, *Mouth Magazine*, *The Federal Lawyer* magazine, and *Access Press*, among others.

Starting in 2007 and continuing in 2012, 2017, and 2020, the Council repeated the 1962 public opinion survey to see how attitudes toward people with developmental disabilities have changed over time. In 2012, 50 years after the original survey, the results showed that attitudes had changed a lot. In 1962, 71 percent of Minnesotans thought that people with developmental disabilities should not be cared for at home, but in 2012, 83 percent of Minnesotans thought that they should be cared for by their immediate family as much as possible. By 2012, Minnesotans were more likely to say that people with developmental disabilities can live typical lives, should be able to obtain a driver's license, and should be able to vote.

*Suzanne, left, and Pam now live in an apartment together. They previously lived in institutional settings, 1987*





Prior to the 1960s, people with developmental disabilities may have had the opportunity to work in a sheltered workshop or do unpaid work while living in an institution. It wasn't until the 1970s that federal Courts ruled that making people living in institutions do unpaid work was unconstitutional.

## Employment

### 1960s

The 1965 Vocational Rehabilitation Act Amendments required that people with severe disabilities have access to vocational rehabilitation services, which led to the expansion of day programs and sheltered workshops. By 1972, Minnesota had the most day activity centers of any state and was recognized by a presidential committee as a leader in establishing standards for those programs.

“ This is a bicycle brake. Since 1967 when we began this research, it has had a major impact on the development of my philosophy and on the techniques that have generated from our research... The hundreds of people that we’ve trained on this task, almost 100% of the time, have learned quickly and efficiently to do this. If they can learn to do this task, this task which in and of itself means nothing at all, certainly many of the things that we have kept from them, complicated things to learn we think. **Many of those things are things that they could learn, things that would allow them to join us as thoroughly participating members of society.**”

– Dr. Marc Gold demonstrates the “Try Another Way” method in a documentary film by training people with developmental disabilities to assemble bicycle brakes.

Dr. Marc Gold started his career as a special education teacher in Los Angeles. It was then that he began formulating “Try Another Way,” a value-based approach for training people

with developmental disabilities. In 1967, Dr. Gold and his staff began training hundreds of people with developmental disabilities to be able to do a variety of tasks, including those that they could use in a job. In 2014, the Council added Dr. Gold videos to its website.

## 1970s

The “Try Another Way” framework was a precursor to supported employment. This concept emerged in the 1970s and recognized that people with disabilities, including people with developmental disabilities, can have meaningful jobs with the right training and support.

The Rehabilitation Act of 1973, which is called the first civil rights act for people with disabilities, created funding for training and placement of people with disabilities into employment. It also focused on rehabilitation services for people with severe disabilities. While Section 504 of the Rehab Act was written to prohibit discrimination against people with disabilities by any agency or organization that received federal funding, enforcement of Section 504 was delayed until the late 1970s, following protests by advocates with disabilities, which were chronicled in the documentary *We Won't Go Away*.

## 1980s

The Developmental Disabilities Act of 1984 included the first definition of supported employment. In the 1980s, more funding was available to offer supported employment to more people. Minnesota was one of ten states to receive a five-year grant in 1985 from the federal Office of Special Education and Rehabilitative Services to expand supported employment. Several Council members also served on the leadership team for the federal grant project.

**In 1983, President Ronald Reagan signed Proclamation 5131, declaring a National Decade of Disabled Persons. In his remarks on signing the proclamation, President Reagan said, “Today I’m establishing a clear national goal. Let us increase the economic independence of every disabled American and let us begin today.” His remarks also announced an initiative to strengthen private sector job opportunities.**



*Still from one of Dr. Gold's videos*

**In 1987, President Reagan declared March to be National Developmental Disabilities Awareness Month. In the proclamation, President Reagan said, “One important new milestone is the fruitful partnership between government and the private sector in finding productive employment for people with developmental disabilities who might otherwise have been destined to a lifetime of dependency. In the past two years, the Administration’s Employment Initiative has resulted in finding job opportunities for more than 87,000 people with developmental disabilities.”**

In 1986, the Council funded the Legislative Task Force on Supported Employment, which led to a state statute requiring at least 50 people with developmental disabilities to be employed within state government. When the Partners in Policymaking program was created in 1987, employment was included as a key competency. A focus on employment has always been maintained as an essential part of the Partners curriculum.

## **1990s**

Throughout the 1990s, the Council went out into the community and advocated for employment of people with disabilities.

The Council was also part of the effort to reauthorize the federal Rehabilitation Act, which was profoundly changed in 1992. Previously, in order to receive vocational rehabilitation services, a person had to be considered “employable,” which prevented many people with developmental disabilities from getting services based on the assumptions made by other people of what they could and could not do. The 1992 reauthorization of the Rehab Act said that agencies had to assume that anyone with a disability can work, which opened up vocational rehabilitation services to many more people.



## 2000s

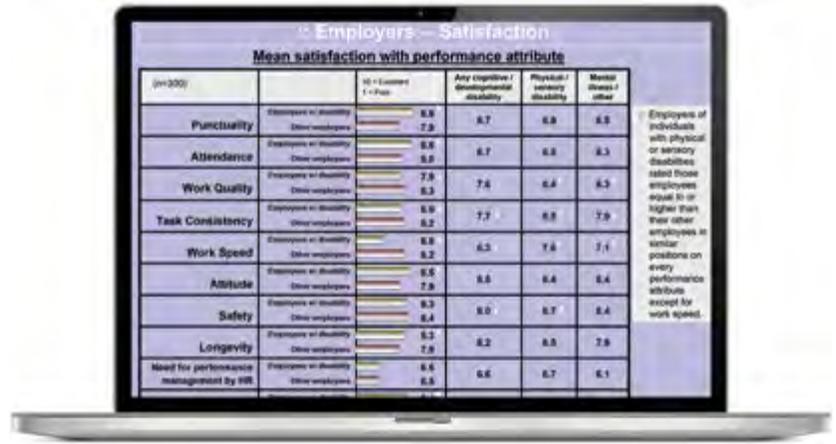
The Quality of Life survey conducted by the Council every five years from 2000 to 2020 found that employment is the top priority of people with developmental disabilities and their family members. Throughout the 2000s, the Council continued to raise awareness and advocate for employment for people with developmental disabilities.

In 2003, the Council added a course to the Partners in Policymaking online curriculum called Partners in Employment to help people with developmental disabilities and their family members explore employment options, understand what services and supports exist to help them, and successfully enter the workforce.

“ Employers were asked to compare their employees with disabilities to their other employees in similar positions on a set of performance attributes. Employees with physical or sensory disabilities rated equal to or higher than their coworkers in similar positions on every performance attribute except for work speed. **However, employees with disabilities appear to be judged differently, in terms of overall satisfaction, than other employees in similar positions.** For employees with disabilities, ‘attitude’ was the biggest driver of overall satisfaction; while for the other employees the biggest driver was ‘work quality.’ ”

– Findings from the Employer Focus Research survey conducted in 2005 by MarketResponse International for the Minnesota Governor’s Council on Developmental Disabilities

The Council conducted a survey of 600 employers in Minnesota in 2005, which asked about their experiences with employees with disabilities. The survey found that employers had higher satisfaction with employees with developmental disabilities, compared to other employees in similar positions, when it came to punctuality, attendance, attitude, longevity, and overall satisfaction. And in 2008, the Council recognized eleven businesses as Innovative Employers who were using innovative employment practices in hiring people with developmental disabilities and promoting an inclusive work environment.



The Council hired people with developmental disabilities through the Metro Work Center and the Minnesota State Operated Community Services network to digitize thousands of pages of documents, which inspired the Department of Human Services to do the same. In 2006, the Department of Human Services won an award from the international Computerworld Honors Program for that effort.

*Parallels in Time, Part 2*, added an online historical record of the fight for competitive integrated employment for people with developmental disabilities and was released by the Council in 2006.

In 2009, the Council supported bringing Project SEARCH to Minnesota. Project SEARCH is a school-to-work program. Minnesota Project SEARCH sites include Medtronic, Children’s Minnesota, Mayo Clinic, Avera Marshall Regional Medical Center, Fairview Lakes Medical Center, Gillette Children’s Specialty HealthCare, Hennepin County Medical Center, and the State of Minnesota. In 2015, three Minnesota sites received employment outcomes awards at the Project SEARCH International Conference.

“Project SEARCH is more fun than school! Project SEARCH is like family—it makes you feel like you are treated fairly.” — Project SEARCH participant

## 2010s to the present

2010 was the 20th anniversary of the Americans with Disabilities Act (ADA). The Council funded a research study on the awareness, attitudes, and impact of the ADA among Minnesota businesses. The study found that while awareness of the ADA is high, actual familiarity with what the law says is low. Over half of businesses said that the ADA had a positive impact on their business.

As part of an employment initiative of the Council and the Department of Employment and Economic Development's Vocational Rehabilitation Services, the Autism Society of Minnesota, along with 3M, Cargill, and Best Buy, hosted an "Autism and Employment" event in 2011 that was attended by over 1,500 people and featured a keynote address by author Temple Grandin.

The Council engaged in substantial efforts throughout the 2010s to increase employment of people with disabilities within state government. The Council worked with the Minnesota Commission of the Deaf, DeafBlind, and Hard of Hearing to advocate for Executive Order 14-14, which was signed by Governor Mark Dayton in 2014, and reaffirmed by Governor Tim Walz with the signing of Executive Order 19-15 in 2019, to increase state employment of people with disabilities.

In 2016, the Council was involved in updating and relaunching the Connect 700 program, which gives eligible people with disabilities another path to employment with the state.

“ It is not enough to merely change state statute in order to improve the hiring and retention of employees with disabilities. Policy change must be implemented effectively and with necessary resources. **Agencies must be held accountable for implementation that leads to real results for people with disabilities.** ”

— “Strategies for Attracting and Retaining State Employees with Disabilities” from the Advisory Task Force on State Employment and Retention of Employees with Disabilities



Finally, starting in 2019, the Council served on the Advisory Task Force on State Employment and Retention of Employees with Disabilities. The Task Force worked for 15 months developing recommendations on how to attract and retain more state employees with disabilities by modernizing outdated state statutes. They presented their recommendations to members of the Legislature and the Commissioner of Minnesota Management and Budget on January 15, 2021. Companion bills in the Minnesota House and Senate were introduced by the 92nd Legislature to implement the Task Force’s recommendations.

## Person-centered Planning

### 1970s and 1980s

Since the Minnesota Governor’s Council on Developmental Disabilities published *CAIR: Planning alternatives for the developmentally disabled individual* in 1975, it has advocated for person-centered approaches to providing supports and services for people with developmental disabilities.

Several different ways to engage in person-centered planning developed in the 1980s, including Personal Futures Planning. In the 1980s, the Council provided grant funding for several projects that were either directly or indirectly focused on core elements of person-centered planning and practices, including training facilitators in Personal Futures Planning.

As a result of the Council’s grant funding in the 1980s, two manuals written by Beth Mount and Kay Zwernik on Personal Futures Planning were published, one for people with developmental disabilities and their families, *It’s Never Too Early, It’s Never Too Late*, and one for facilitators,



*Making Futures Happen*. Variations on Personal Futures Planning, MAPS and Whole Life Planning, were also developed. As the concept and principles expanded, other models of person-centered planning have also been used in Minnesota, including Essential Lifestyle Planning and Planning Alternative Tomorrows with Hope (PATH).

“ We face a turning point in human services that is challenging us to let go of many past assumptions and practices. We must replace these old assumptions with new ways of thinking and new tools to help focus our attention and activities on accomplishing positive, desirable outcomes in the lives of people with disabilities. We must learn new ways to bring out the best in people and their communities. One way to discover these new directions is by listening to and building more positive futures for one person at a time. **As we learn to build more desirable futures for some people, we will learn to change systems and build a stronger community for all of us.** ”

– *It's Never Too Early, It's Never Too Late*, by Beth Mount and Kay Zwernik, published in 1988

The Council's 1987 publication, *A New Way of Thinking* advocated for new ways of thinking and approaching policy development. This new way of thinking included a shift that was grounded in the values of person-centered planning. The vision was of Minnesota moving:



In 1989, the Council was involved in the National Conference on Self Determination, which was supported by the University of Minnesota Research and Training Center on Community Living. For the conference, the Office of Special Education and Rehabilitative Services invited sixty people to meet and make recommendations. Over half of the people involved had disabilities. The Council helped design and paid for the writing and production of a report including the 29 recommendations from the conference participants. Many of the recommendations reflected the values of person-centered planning, including the first: The enabling of people with disabilities to determine their own futures must be the top priority in all government policymaking functions.

## 1990s

In 1990 and 1991, the Council funded the creation and publication of a book of stories about Personal Futures Planning in Minnesota called "*Listen, Lady, This Is My Life.*" The book collected stories from people who facilitated Personal Futures Planning groups and celebrated the use of Personal Futures Planning to help people find and have their visions.

In 1992, the Council published *Shifting Patterns*, which featured Personal Futures Planning as a promising practice. And in the early 2000s, the Council purchased thousands of copies of Personal Futures Planning guides and workbooks written by Beth Mount and distributed them to people with disabilities and their families.

In 1995, the Council funded a study called Person-centered Planning and Community Action Approaches for Transition to Employment, which included proposals for possible pilot projects to use Community Action to promote employment of people with disabilities.

## 2000s to the present

Person-centered practices are now an expected part of Minnesota's service delivery system, and the use of person-centered planning is required in state law and by the federal government. The Minnesota Olmstead Plan, which was developed starting in 2012 and approved by the Court as part of the *Jensen* Settlement Agreement in 2015, is centered around person-centered planning and has specific goals related to its use.

The University of Minnesota's Institute on Community Integration, a designated University Center for Excellence in Developmental Disabilities and key partner of the Council, offers training on person-centered thinking and planning, in partnership with the Minnesota Department of Human Services.

“Terms like ‘person-centered planning’ and ‘person-driven planning’ are distinct, but they share the fundamental principle that government and service providers begin by listening to individuals about what is important to them in creating or maintaining a personally valued, community life. **Planning of supports and services is not driven or limited by professional opinion or available service options but focused on the person's preferences and whole life context.**”

– The Minnesota Olmstead Plan

## Diversity, equity, and inclusion

### 1990s

The 1994 reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) included a definition of what it means for supports to be culturally competent. The definition stated that culturally competent services, supports, and assistance are “responsive to the beliefs, interpersonal styles, attitudes, language, and behaviors of individuals” and provided in a way that “has the greatest likelihood of ensuring their maximum participation” in the program. The Minnesota Governor’s Council on Developmental Disabilities hired Vivian Jenkins Nelsen, co-founder for a diversity think tank at Augsburg College, to help the Council become more culturally competent itself and to advocate for culturally competent services, supports, and programs.

By the 1990s, the Council initiated its formal Cultural Outreach Program of parent education and training with On Eagles Wings. Over time, the Council has supported the expansion of Cultural Outreach Programs to reach parents of children with developmental disabilities from the African American, Indigenous/Native American, Somali, Latino, and Hmong communities. Many participants in these programs have gone on to participate in Partners in Policymaking.

“Our challenge is to reach all cultures to understand how each culture views an individual or child with a disability. Not until we gain such understanding and sensitivity will anyone really effectively communicate and work together as a team.”

— Vivian Jenkins Nelsen on the definition of “culturally competent” from *Futurity*, the Minnesota Governor’s Council on Developmental Disabilities newsletter, September 1994



## 2000s

The Governor's Council on Developmental Disabilities received a Project of National Significance: Family Support 360 Centers grant in 2003, which provided five years of funding to develop a 360 Center in the Jordan neighborhood of Minneapolis. A 360 Center is a family-driven, one-stop family support center that targets unserved and underserved communities.

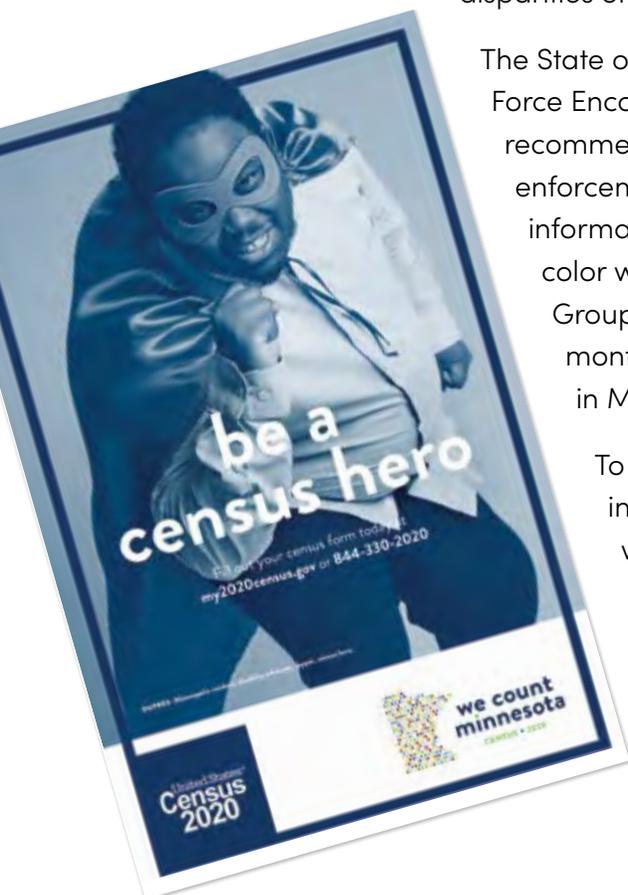
## 2010s to the present

In 2011, Twin Cities Public Television began airing *Honoring Choices*, a documentary series focused on advance care planning, as part of a public health initiative of the Twin Cities Medical Society. The Governor's Council on Developmental Disabilities invited panel members from diverse backgrounds to participate in the series, helping to ensure that all voices and perspectives were represented in the messaging.

Starting in 2017, the Council provided funding to ensure that more people of color participate in surveys about health care and about attitudes toward people with developmental disabilities. This oversampling was also done on surveys in 2020. By getting additional survey participants from six different racial and ethnic groups in Minnesota, the Council and state agencies can compare the results across the groups to identify where disparities or inequities exist.

The State of Minnesota Working Group on Police-Involved Deadly Force Encounters was created in 2019 to listen, learn, and develop recommendations to reduce deadly force encounters with law enforcement. The Council provided a significant amount of information to the Working Group on the experiences of people of color with developmental disabilities with the police. The Working Group released their recommendations in February 2020, just months before George Floyd was murdered by a police officer in Minneapolis.

To make sure that people of color with disabilities participated in the 2020 Census, the Council had a staff member who worked exclusively on racial and disability outreach. Dupree Edwards, a Council member and Partners in Policymaking graduate, was recognized as a Census Hero. His image was featured on a poster encouraging people to participate in the 2020 Census.



“ [The DD Council is] one place where you don’t have to put on a mask or pretend. It is just 100% truth and down to the core of what it means to have an integrated and inclusive life. In other places in the State, you know you have to speak in a certain way, and it is like, ‘We’re all going to sit here and pretend.’ I’ve sat on committee after committee, at stakeholder group after stakeholder group, where everybody sits in a room, and there are 20 adults pretending that something is true. I feel like the DD Council is a place where all of that is melted off, and we all can just speak to each other with truth and understanding of what is actually going on without pretending... You just can talk to each other about what’s really going on in the real world, and not this pretty picture of what we say it can look like, but rather what’s really going on and now how do we fix that. **I don’t think there’s any other place that does it like the DD Council.**”

– Katheryn Ware, former Council member





**50 years of**

# Creating a Foundation for Possibilities

The Council asked self-advocates and families to provide their vision of the future. Here are a few excerpts.

**Funding is individualized which accelerates social progress.**



**INCLUSION SURPASSES EXPECTATIONS**

Special interests and talents are used as a springboard for searching for a job in order to increase the chances of success and to ensure rewarding, meaningful and enjoyable employment.

All programs (TV and movies) are closed captioned.

All higher education is inclusive, teaches quality 21st century skills to everyone, and has person centered disability transition programs.



*The world will have eliminated degrading, inhumane, and violent ways of dealing with behavioral, challenging issues in schools and we have found a system that works to help kids with challenges to help them grow.*



Mass transit covers the entire nation and is 100% accessible.

Jetson cars are available to all.

Funding is based on what the person needs and requests rather than a number spit out by a computer. It is discovered that budget savings occur simply by asking people because people focus on what is important.

All people are seen as belonging to one human race without regard to physical abilities, race, or economic status.

Disabilities are social constructs **NOT** elements of a diagnosis.

**Once you receive services, you never have to reapply**

Community living allows you to live with dignity, safety, and hope where and with whom you wish in housing that is available, accessible and affordable.

*Individuals and families receive accurate and up to date information.*

***Disabilities are accepted as differences to be celebrated.***





**50 years of**

# Council Investments & Members

***As it has since its inception, the Council continues to make strategic investments with its federal and other grant funding that dramatically improve the lives of people with developmental disabilities and their families.***

**After 50 years, the Council has provided approximately \$40 million in grant funding.**  
*This list does not include all the recipients of training conference funding during the past 30 years.*

## 1970s

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### Planning and Service Grant Recipients

Association of Residential Resources Minnesota (ARRM)  
 Assisi Residences  
 Augsburg College  
 Camp Confidence  
 Clearwater Day Activity Center  
 Consumer Coalition  
 Dakota County Mental Health Center  
 Dakota's Children  
 Department of Public Welfare, Faribault State Hospital  
 Division of Vocational Rehabilitation  
 Duluth Arc  
 Duluth Sheltered Workshop  
 East Range DAC  
 Glacial Ridge Training Center (Willmar)  
 Hammer School

Home Services – St. Paul  
 Independence for Impaired Individuals  
 Independent School District #625  
 Lakeland Mental Health  
 Meeker-Wright Community Action Project  
 Miller Dwan  
 Minneapolis Arc  
 Minneapolis Legal Aid Society  
 Minneapolis Public Schools  
 Minnesota Arc  
 Minnesota Department of Public Welfare  
 Minnesota Epilepsy League  
 Minnesota Health  
 Minnesota Learning Center  
 Minnesota State Planning Agency  
 Minnesota United Cerebral Palsy  
 MnDACA  
 Moose Lake State Hospital  
 Multi-Resource Centers  
 Murray County Day Activity Center

Northeast Residence  
 Northwest Sheltered Workshop  
 Phoenix Residence  
 Polk County Group Homes  
 Redwood Falls Community School  
 Regional Development Commissions (all)  
 Rochester State Hospital  
 St. Paul Arc  
 St. Paul Ramsey Hospital  
 United Day Activity Center  
 University of Minnesota  
 West Central ECSU  
 Windom Educational Service Area

## 1980s

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### Respite Care Grant Recipients

Alternatives for Autistic People, Inc.  
 Arc Duluth  
 Chisago County Welfare Department

Cook County Social Services  
Courage Center  
Developmental Learning  
Center, Inc.  
Developmental Services  
Organization, Inc.  
Isanti County Family Services  
Lakes Homes and Program  
Development  
Northeast Residence, Inc.  
Olmsted County Department  
of Social Services  
PLS, Inc.  
Ramsey County Human  
Services Department  
Region 9 Development  
Commission  
Respite Care Program -  
Northwest Minnesota  
St. David's School for  
Exceptional Children

Volunteers of America -  
Bar None

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### Employment Grant Recipients

Clay County Developmental  
Services, Inc.  
CWDC Industries, Inc.  
Freeborn County Alpha DAC,  
Inc., Careers Training Center  
DAC, and Dodge County  
DAC  
Interstate Rehabilitation  
Center, Inc.  
Kaposia Developmental  
Learning Center, Inc.  
Mankato Rehabilitation  
Center, Inc.  
Metropolitan Council  
Occupational Development  
Center

ORC Industries, Inc.  
Region 5 Regional  
Development Commission  
Region 9 Regional  
Development Commission  
RISE, Inc.  
Southwest Regional  
Development Commission  
Stevens County DAC

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### Case Management Grant Recipients

Dakota County Human  
Services  
Itasca County Social Services  
Metropolitan Council  
The Arc Minnesota  
The Arc Suburban  
University of Minnesota

“What always resonates and stays with me is when we bring some of the grant recipients into the meetings. I love that. That is my favorite meeting of the year. You can connect the dots. **It's a lot of work to review the grants and make the decisions, and you can hear through those presentations how this really affects people, how it has changed lives in some way.** It brings everything full circle.” — Mary Martin, appointed to the Council in 2017

“ I spent a lot of time on the grant committee, and it’s not always the most glamorous work—it’s a lot of reading through proposals, evaluating, having discussions, and providing recommendations. But at the end of it all, we end up being a really important channel to guide funding to what we thought were the most important ideas.”

— Derek Nord, former Council member

### McKnight Grant Recipients

#### Day Programs Accessibility Grants

*Alpha School*  
*Big Stone County*  
*Brown-Nicollet County*  
*Cedar Branch*  
*Clay County*  
*Developmental Learning Center*  
*East Range*  
*Fillmore County*  
*Grant County*  
*Lake County*  
*Le Sueur County*  
*Mankato Rehabilitation Center*  
*Martin County*  
*Merrick*  
*Otter Tail County*  
*Sibley County*  
*Wadena County*

Arrowhead Regional Development Commission

Comprehensive Epilepsy Program, University of Minnesota

Comprehensive Services for Disabled Citizens and Accessible Space, Inc.

Greater Minneapolis Day Care Association

Jewish Community Center

Lake County DAC

Lakeland Mental Health Center

Mankato Rehabilitation Center

Minnesota Epilepsy Foundation

People to People

Pine River DAC

Polk County DAC

Region 9 Development Commission

Reuben Lindh Learning Center

Rural Enterprises for Acceptable Living, Inc.

Traverse Des Sioux Chapter, Council for Exceptional Children

Twin Cities Society for Children and Adults with Autism

United Cerebral Palsy of Minnesota, Inc.

West Central Industries, Inc.

Winona County DAC

## 1990s

### Grant Recipients

Advocating Change Together

Brainerd Staples Technical College

Concordia Leadership Center  
 Dakota County Community Services Planning  
 Destiny 2  
 Educational Cooperative Service Unit  
 Government Training Service  
 Habilitative Associates  
 Human Services Research and Development Center  
 Institute for Minority Development  
 Institute on Community Integration, University of Minnesota  
 Kappel Consulting  
 KDWB Variety Family Center  
 Legal Aid Society of Minnesota  
 Master Communications Group  
 Metro Work Center, Inc.  
 Minnesota Council for Quality  
 Minnesota Disability Law Center  
 Minnesota Institute for Public Health  
 MnDACA and Minnesota Association of Rehabilitation Facilities (MARF)  
 MnSCU  
 Murray County Extension Services  
 North Central Service Cooperative  
 Opportunity Services, Inc.  
 Partners in Quality  
 Quality Culture Institute  
 Ridgedale YMCA  
 State Board of Technical Colleges

The Arc Anoka County  
 The Arc Minnesota  
 The Arc St Paul/Ramsey County  
 Third Age, Inc.  
 Twin Cities Autism Society  
 YMCA of Metropolitan Minneapolis  
 World Institute on Disability  
 Tom Zirpoli, Ph.D. and Sharon Patten, Ph.D. (evaluators)

WISE  
 Zenmation  
 Tom Zirpoli, Ph.D., Nancy Miller, Ph.D., and John Johnson, Ph.D. (evaluators)

## 2011-2021

### Grant Recipients

Advocating Change Together, Inc.  
 CLUES  
 Government Training Services  
 Horn of Africa Aid and Rehabilitation Network (HAARAN)  
 Kaposia, inc.  
 IPSII, Inc.  
 Leer Communications & Consultants  
 MarketResponse International  
 Mastcom (formerly Master Communications Group)  
 Merrick, Inc.  
 MH Consulting  
 Midwest Special Services, Inc.  
 Odyssey Group  
 PeaceMaker Minnesota, Inc.  
 Quality Culture Institute  
 Russell Herder  
 Somali Community Resettlement Services  
 Third Age, Inc.  
 The Wallace Group  
 Zenmation  
 Nancy Miller, Ph.D. (evaluator)

## 2000-2010

### Grant Recipients

Advocating Change Together  
 Advantage Business Center  
 CLUES  
 Government Training Service  
 Institute for Minority Development  
 IPSII, Inc.  
 MarketResponse International  
 Master Communications Group  
 Metro Work Center, Inc.  
 Minnesota Council for Quality  
 North Central Service Cooperative  
 Olmsted County  
 People First Minnesota  
 Quality Culture Institute  
 Ridgedale YMCA  
 Terry Swanson  
 The Wallace Group

## Council Members

**This list of past and present Council members was compiled from fifty years of Council archives. We honor and thank all members for their time, talents, and contributions to the Council.**

Sandy Adams	Bourgeault	Lee Engen	Andre Hanson
Maribeth Ahrens	Emilie Breit	Stephen England	Sharron Hardy
Michelle Albeck	Ben Bryant	Eric Errickson	Stephen Harner
Jeffrey L. Alexander	Patricia Burns	William Everett	Mary Hauff
Richard A. Amado	Douglas H. Butler	Jaclyn Ferrier	Thomas "Jerry" Hayes
Dawn C.A. Anderson	Harvey Caldwell	Ellen Z. Fifer	Shirley Held
Sandra Anderson	Claudia Carlisle	Sandra J. Fink	Lowell E. Hendrickson
Will Antell	Dona Caswell	Margaret Fletcher-Booth	Kay Hendrikson
Jenny Arndt	Steven K. Chough	Bonnie Ford	Anne Hennessey
Catherine Atneosen	Terry Cikanek	Lois Fort	Anne Henry
Krista Lynn Bahnsen	Jayne Clairmont	Barbara Foster	Brittanie Hernandez-Wilson
Ashley Bailey	Edward Constantine	Mary Fox Sinclair	Sharon Heuring
Bruce Balow	Eunice Davis	Mary Rae Freeberg	Amy Hewitt
Anne Barnwell	Barbara H. Dawson	Jo Gascoigne	Mary Hinze
Hanna Barr	Kevin Dawson	August W. Gehrke	John Hoffman
Alex Bartolic	Robert DeBoer	Jennifer E. Giesen	Lois Holleman
Cathryn Baudeck	Agnes DeFoe	Mary Golike	Darlene Holm
Jane Belau	Janice Den Hartog	Barbara Goman	Shawn Holmes
Wendy Berghorst	Roger Deneen	Karen Gorr	Tom Holtgrewe
Kathleen Berland	Evelyn Deno	George Gottfried	Andrew Hommerding
Laurie Berner	Suzanne M. Dotson	Judy Graves	Shirley Hood
Jason Blomquist	Sharyl Downwind	Florence Gray	Pamela Hoopes
Roberta Blomster	David Dunn	Marian F. Greiner	Linda Horkheimer
Laura Bloomberg	John DuRand	John Groos	Elizabeth "Betty" Hubbard
Dawn Bly	Barbare Eaton	Ella Gross	Kathryn Jacobson
Jo Ann Bokovoy	Dupree Edwards	Brian Gustafson	
Peg Booth	Carolyn Elliott	Bonita Hammel	
Marrie Bottelson	Tom Emery	Virginia Hanel	
Marcel A.	Lisa Emmert		

“ I joined the council out of frustration, looking for resources and groups of people with like minds. I didn't know a whole lot about the Council. But I am a mother of twins who were born early and have disabilities. I think I joined the council when they were maybe seven-ish. And at the time, I didn't have support. I didn't have resources. And, oh my goodness. Being on the Council helped a lot in so many different aspects. **I would say the biggest takeaway—and I get emotional now even talking about it—was to see the respect that the Council gives to the population that is disabled and the voice they have on the Council.** I got to see young adults with disabilities and see their brilliance and see their example. To be in the presence of a mixture of these individuals was tremendous.

” – Hanna Barr, former Council member

Loraine Jensen	Barbara Lundeen	Cynthia G. Obinger
Mary Ann Jensen	Raymond F. Lundgren	Linda Obright
Steven A. Jensen	Kathleen Lynch	Chet Oden
Robert Jirik	Doris Makela	Paul M. Odland
Bruce Johnson	Sarah Mapellentz	Mary O'Hara-Anderson
Byron Johnson	Virginia Marolt	Nancy A. Okinow
David R. Johnson	Irving Martin	Marijo Olson
Karol Johnson	Mary Martin	Shamus O'Meara
Paula H. Johnson	Web Martin	Richard B. Oni
Robert A. Johnson	Abdi Matan	Kate Onyeneho
Michal Jorgens	Nancy McCarthy	Sue Parriot
Mick Joyce	Noah McCourt	Shirley J. Patterson
Paul R. Kenworthy	Katie McDermott	Jeffrey Pearson
Lesli Kerkhoff	Carolyn McKay	Ella Perpich
Jeannette Kester	Chris McVey	Carolyn Perron
Benjamin F. Kilgore	Lynne Megan	Dorothy M. Peters
Bernice Klein	William F. Messinger	Donna Petersen
Eric Kloos	Randean Miller	Irving Peterson
Emily Knight	Paralee Milligan	Garrett Petrie
Creighton Koski	Jackie Mlynarczyk	Red Pierce
Matt Kramer	Alexandra Morrissey	Barbara Pihlgren
Susan Kratzke	Rollie Morud	John Poor
Avis Kruger	Nina Mae Moss	Jerry Pouliot
Steven D. Kuntz	Gerald Nelson	Scott Price
Helmi Lammi	Jillian Nelson	Robert Provost
Daro Larson	Richard Nelson	Harold Prust
James Larson	Stacey Nelson	Kate Quale
Sheryl Larson	Stevie K. Nelson	David Quilleash
Steve Larson	Bill Niederloh	Mary Raasch
Ron Leif	Debra Niedfeldt	Connie Rabideaux
Louis Lenzmeier	Catherine Nolan Baudeck	Ruth M. Rafteseth
Margaret C. Lindstrom	Bernadine Nolte	Richard Ramberg
Antoinette "Toni" Lippert	Derek Nord	Felipe Z. Ramirez
James Lovold	Mildred Norval	Dan Reed
Gayle Lund	Marisa Novak	Robbie Reedy

Sophie Reuben  
Jacqueline Rightler  
Ordean Rosaasen  
A.B. Rosenfield  
Linda Rother  
Janet M. Rubenstein  
Elaine Saline  
Glenn Samuelson  
Margaret Sandberg  
Ronald Sandness  
Jennifer “Jenny” Santema  
Terry Sarazin  
Lee Schacht  
Mary Beth Schafer  
Reid Scheller

Bryan Schmidt  
Lorie Schulstad-Werk  
Barbara Schultz  
Henry J. Schut  
Thomas Schwartz  
David Schwartzkopf  
Steve Serkland  
Sharon Shapiro  
Lee Shervheim  
Cindy Shevlin-Woodcock  
Duane R. Shimpach  
Mary Shortall  
Ernest J. Silbernagel  
Linda Simenstad  
Edward Skarnulis

Jeffrey Skwarek  
Bonnie Jean Smith  
Susan Smith  
Dottie Spencer  
Beverly St. John  
Michael Stern  
Dan Stewart  
Kathryn Stiemert  
Virginia Strand  
Kurt E. Strom  
Kathleen E. Sturre  
Sue Swenson  
Dean F. Thomas  
Sarah Thorson  
Heather Tidd

“ When supported employment was being enacted in the late-80s, the Council created a ‘grand experiment’ to see if ten Minnesotans with significant disabilities would be able to find their way, with support, to full employment. The project results proved these people could be successful. **It was a moment that broke boundaries and led to integrated competitive employment.** ” – David R. Johnson, former Council member

Patricia Tietz  
Joe Timmons  
Karen Titrud  
Marvin Tritz  
Charles Turnbull  
Maxine Tykwinski  
Lorrie Ufkin  
F. Van Konynenburg  
Nancy Vanderburg

James Varpness  
Wendy Velzke Wangen  
Stacey A. Vogeles  
Teri Wallace  
Katheryn Ware  
Bob Wedl  
Larry R. Wefring  
Susan Wehrenberg  
Carol Louise Werdin

Marge A. Wett  
Alan Wilensky  
Kirk Williams  
Melissa Winger  
Jerry Wood  
Ardo Wrobel  
Cynthia Yongvang  
Levi Young  
Ann Zick

“ **When you’re feeling like you don’t have the strength to do things you need to do, the DD Council provides you with that backbone.** When you’re unsure if this is something you should even pursue, they give you the knowledge, tools, strength and energy to say, ‘If this is important to you, it’s worth pursuing and doing. We hear you and you’re right, and this is something that you should be able to advocate for.’ I can’t say enough about it—and neither my son nor I would be in the position we are today, if we hadn’t been involved in the DD Council. ”

— Kate Onyeneho, former Council member

## Council Members

Michelle Albeck  
Jenny Arndt  
Wendy Berghorst  
Jason Blomquist  
Dupree Edwards  
Lisa Emmert  
Jaclyn Ferrier  
Kay Hendrikson  
Brittanie Hernandez-Wilson  
Amy Hewitt  
Lesli Kerkhoff  
Mary Martin  
Abdi Matan  
Katie McDermott  
Chris McVey  
Jillian Nelson  
Garrett Petrie  
Kate Quale  
Connie Rabideaux  
Dan Reed, Vice-Chair  
Jennifer (Jenny) Santema  
Reid Scheller  
Lee Shervheim, Chair  
Dan Stewart

## Council Staff 2020–2021

Stephanie Boucher  
Ross Dugas  
Stephanie Nelson  
Paul Nevin  
Mary Jo Nichols  
Colleen Wieck

## Special thanks to:

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