
Perspectives on the 50th
Anniversary by National Experts,
Minnesota Council Members, and
Partners in Policymaking[®]
Graduates

Governor's Council on Developmental Disabilities
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Introduction

Every year the Minnesota Governor’s Council on Developmental Disabilities engages in customer and market research. These studies help measure and assess the quality outcomes of the federal Developmental Disabilities Act. Federal fiscal year 2021, however, was a year of reflection for the Council as it prepared for its 50th anniversary celebration. Instead of the usual surveys and other research, the Council hired Management Analysis and Development (MAD) to conduct interviews with national subject matter experts and current and former Minnesota Council members to understand its impact. The Council also engaged The Odyssey Group to survey participants from the Council’s long-standing program *Partners in Policymaking*®. The results of these data collection efforts have been incorporated into two publications and a documentary celebrating the 50th anniversary.

This report summarizes the findings from the interviews and the impact study. The report includes statements from interviewees and survey respondents that are formatted in *italics*. The statements reflect the participants’ sentiment and content, but MAD may have lightly edited them for spelling, grammar, and clarity.

National subject matter expert interview summary

MAD consultants interviewed ten subject matter experts in the fall of 2020. Each interviewee received customized questions, including about their own personal histories. This report summarizes the two themes that crossed most interviews: the impact of the Developmental Disabilities Act (DD Act or the Act) and the Minnesota Governor's Council on Developmental Disabilities.

Impact of the DD Act

Interviewees described how the DD Act offered a new paradigm that moved away from the old medical model. They also explained how the Act created person-centered systems that could effect change, enabled other parties to push for more change, and provided an aspirational framework.

Offered a new paradigm

The DD Act not only affected the field of developmental disabilities, but it created a template for all other federal disability laws, according to Allan Bergman, a consultant, keynote speaker, and former administrator of nonprofit organizations. "Every federal law has been amended since the DD Act and the words are identical [on those topics]," Bergman said. "That's the legacy of the DD Act."

Bergman credited the DD Act as the first federal disability legislation that set high expectations for how people with developmental disabilities should achieve a life of independence, productivity, and integration. He said the law's emphasis on these factors made it clear that these outcomes were achievable for people with disabilities and not a fantasy.

"Independence is defined as exerting choice and control," Bergman explained. "Those words now permeate nearly every other piece of disability legislation." This deviated from the previous, more paternalistic model that assumed caretakers and professionals knew what people with disabilities wanted and needed. In that framework, providers were not required to ask people with disabilities what they wanted or what was important to them.

The previous model, often called the medical model, focused on "fixing the broken person," Bergman said. "But we haven't got the fix for autism, Down syndrome, epilepsy, or cerebral palsy. That model really set people up for failure in the service delivery system." Bergman added, "I give the DD Act credit for having eliminated the medical model, and that the job of service is to remove deficits." He said the DD Act helped focus on functionality, not fixing. Rather than spending 20 hours a week on speech therapy, caretakers can instead get someone an iPad or augmented communication device. "It's more important to have communication than to talk," he said. "It's more important to have mobility than to walk."

"The DD Act had a different paradigm," Bergman said. "It was in the business of enhancing and supporting people's capacity and preferences. We may have to help them discover what it means for them to have a

valued, meaningful life in the community. One where they are living where they choose, with whom they choose.”

Created person-centered systems that could effect change

Rud Turnbull explained how the DD Act created systems that have worked together to change state government. Together with his wife, Dr. Ann Turnbull, they have served for decades as professors, researchers, and advocates for individuals with disabilities, their families, and service providers. “[The systems created by the DD Act] made it possible to penetrate previously impenetrable state systems,” he said. “They did it by reason of working by themselves, but most of all by working together.”

The DD Act created a Council on Developmental Disabilities in every state and a protection and advocacy system. “[The DD Act] embedded into those [systems] a cadre of staff, of agency staff in the states, and of families,” Turnbull said. “The Act thereby connected the councils to state government. The councils were federally protected and therefore they were somewhat free from the influence of state policy leaders. [As a result,] they were somewhat freer to suggest the direction and to plan the direction and to fund the direction of state agencies.”

Turnbull described how having multiple systems led to “a bifurcation of political innovation and systems innovation, and of political accountability.” He said innovation lay within the councils, and accountability lay mostly within the protection and advocacy systems. “Together the councils and the protection and advocacy systems became the vanguard of innovation. They were a fresh face, each on its own and the two together. They were a vanguard in this respect: They raised issues. They inquired. They investigated, and they surfaced issues that were sometimes known but not articulated. Having raised those issues, they developed possible and likely answers to some very old problems.”

According to Turnbull, the DD councils and the protection and advocacy system “were as effective as all of the major lawsuits have been effective. Major lawsuits had been resisted by state government, but it was hard to resist one of your own: the protection and advocacy system and the DD Council.” The lawsuits combined with the systems, Turnbull said, “together caused a tremendous change in what people did, for whom they did it, how they did it, and why.”

One of the key impacts of the DD Act, said Dr. Turnbull, was how it centered the voices of people with disabilities. By law, 60 percent of DD Council members had to be people with disabilities or their family members. “Until this time,” Dr. Turnbull explained, “the voices in the field were professionals, and they were primarily physicians and psychiatrists and psychologists. The DD Council and the DD Act put the human face on disability, and by that human face of family members and self-advocates, it empowered them and it enabled stories to be generated that could be shared with state legislatures and that could lead to more positive change.”

Dr. Turnbull said the Act has had a major systems impact in terms of person-centered planning. The Act changed payment streams, so rather than funds going to professionals to provide services, money instead went to families. “Having control of the budget made all the difference in the world in [my son’s] quality of life,” she said. “That was brought about through the triumvirate of DD councils, University Centers of Excellence in Developmental Disabilities (UCEDDs), and the protection and advocacy system.” These three systems all came

into existence as a result of the DD Act, and Dr. Turnbull called them a vanguard in the field that made profound change.

The UCEDDs represented the first time that interdisciplinary services were brought together, explained Dr. Turnbull. “I remember being hired in 1973 at the UCEDD in North Carolina,” she said, “and being shocked that around the table there were not only physicians, who were very important, the pediatricians and psychiatrists and psychologists, but the educators and physical therapists and occupational therapists, nutritionists, nursing, social work, audiology, speech and language, on and on. This was revolutionary.”

Dr. Turnbull also described how the initial creation of UCEDDs led to more and more good work. “The UCEDDs have been incubators of projects because there was a core staff that was provided, and then this core staff wrote all sorts of additional grants. The UCEDD was the seed and these additional grants were the leaves and the branches that kept growing and growing from that UCEDD seed. This was huge.”

Self-advocate Bev Jackson also explained how the DD Act helped effect additional change. In 1973, a group she was involved with—the United Cerebral Palsy Association of Greater Hartford (UCP)—received a grant from the Connecticut Council on Developmental Disabilities, which had been created following the passage in 1970 of the federal DD Act. With that grant, UCP created opportunities for nonvocational social development for people with cerebral palsy and other severe and multiple disabilities, which enabled Jackson to participate on the UCP Board, the Consumer Advisory Council, and the National Advisory Council.

In 1977, when she was 28 years old, Jackson was invited to testify before the Subcommittee on [Disability] of the Senate on Human Resources. The Subcommittee heard from people about the impact of the state DD councils, and Jackson told the Subcommittee that she had changed a lot in the five years since she’d first attended Camp Harkness (a camp for children with disabilities) and gotten involved with UCP. “I have gained confidence in myself by handling responsibilities I have acquired,” she testified. “I like what I have become. I no longer allow people to forbid me to do something simply because the [disabled] can’t or aren’t supposed to do it!”

Enabled other parties to push for more change

Jim Shorter has held several leadership positions, including at an Area Board in California and at the California State DD Council. He explained how the DD Act, with Shorter and his allies’ support, has had a lasting impact in California. “Without the DD Act,” Shorter said, “the California State Council could not have paid for litigation that impacted our system so dramatically. Without the DD Act, the California’s Area Board system would have been left to a planning role rather than the dramatic differences they made as system advocates.”

After the passage of the DD Act, Shorter and Richard “Dick” Jacobs wanted to file a lawsuit against the California State Hospital, which was segregating children with disabilities. The California DD Council was not just a planning board, but an advocacy organization, due to California’s Lanterman Act, so the Council funded their effort. They won the lawsuit.

With additional funding from the state DD Council, Shorter and Jacobs went on to sue for the entitlement of people with developmental disabilities to treatment and habilitation services. At the time, the state was saying they could not afford it. Although legal experts were pessimistic about their chances, The Arc chapter in California filed a parallel lawsuit, and ultimately the state Supreme Court ruled in their favor. Although Shorter

said it is known as “The Arc Decision,” it was really an “outgrowth of the DD Act’s protection and advocacy provisions, and the persistence” of Richard Jacobs, whom Shorter called “the father of entitlement in California.” The Supreme Court, Shorter said, “was quite clear that people had a right to services and so long as the Lanterman Act stays intact, they will get them, and the state had to come up with the money.”

Provided an aspirational framework

The DD Act has always been more aspirational than a reflection of the status quo, according to Dohn Hoyle, Director of Public Policy at The Arc Michigan. Hoyle described the DD Act as a law that has always asked the field to do better. “It didn’t settle for what we thought was best practice,” he said. Instead, the DD Act looked forward, toward what could be instead of what was common practice. “It kept moving ahead of the field, so the field had something to aim for.”

Allan Bergman explained that while the law has high ideals and has evolved over time, it only sets a framework of “what we believe in.” The translation of words on paper to life for an everyday person, he said, can take time.

Still, Rud Turnbull described Elizabeth Boggs and the others who created and implemented the DD Act as stargazers. “They looked into the universe of developmental disabilities, and they said, as Hamlet did about the state of Denmark, something’s rotten in the state, cursed spite that ever I was born to set it right,” Turnbull said. “These stargazers, these individual Hamlets, together created a new universe and that universe is the one that predated Individuals with Disabilities Education Act (IDEA). It predated the Medicaid Home and Community-Based Services programs. It predated Supplemental Security Insurance. It predated all of these important laws. Not necessarily and only the Act itself, but the coming together of all of these stars in this new universe. Whoever was responsible, Elizabeth Boggs, Elsie Helsel, and others, they were the stargazers. And with them the rest of us looked into the stars and said, let the change begin with me—let the change begin with all of us together.”

Impact of the Minnesota Council

Interviewees shared many examples of how the Minnesota Council has been a national leader, and in particular how the *Partners in Policymaking*[®] program has changed lives.

Served as a national leader

When it comes to the impact of Minnesota on advancing the rights of people with developmental disabilities, Bob Gettings noted that Minnesota was a leader that provided a model for the federal government. Gettings served as the former executive director of the National Association of State Directors of Developmental Disabilities Services and explained how Minnesota has been leading the nation for decades. In 1960, the Minnesota Governor’s Council on MR was established, and its comprehensive plan was cited in the report from President Kennedy’s Panel on MR. Gettings also said the Minnesota Council “is one of the most effective and impactful” in the nation. He attributed its success to continuity in leadership, its situation in a “neutral agency” by being part of the Department of Administration, and its ability to forge strategic partnerships within and beyond state government.

Dr. Bill Bronston, a physician and activist, cited the Minnesota Council as an instrumental force in shifting the national conversation about people with developmental disabilities. Dr. Bronston said the Council has generated an immense amount of material that helps “break down, penetrate, and develop a new vocabulary to describe different-ness that is not devaluing.”

While the DD Act affected every state directly, Dr. Turnbull credited the Minnesota Governor’s Council on Developmental Disabilities as a leader in the field. She said, “I want to thank the Minnesota Council for the amazing, transformative, pivotal, catalytic role [it’s played] in keeping the movement not only alive, but growing and with vitality and vision for the future.”

Hoyle also highlighted the Minnesota Council as a national leader. “The Minnesota Council was a leader in matching the language of the act to what they were doing,” he said. “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.”

Among other things, Hoyle described how he worked with the Minnesota Council to guide the developmental disabilities field toward adopting the concept of permanency planning. The idea, originally from the broader child welfare field, generally holds that every child should grow up in a family, not an institution. Before the field embraced this concept, Hoyle said, “even some medical professionals were telling some families, ‘Forget you ever had this child [with disabilities]’—that their family would be better off with no contact.” But the work of the councils created by the DD Act helped the field move away from that mentality, and toward integrating people with disabilities into their families and communities.

Hoyle also praised the Minnesota Council as a national leader in getting Medicaid to pay for services delivered to people with disabilities in community settings. Prior to the change, Medicaid would only pay for “medically necessary” services if the person lived in an institution. But as part of their drive to integrate people with disabilities into their communities, leaders from Minnesota, Michigan, and elsewhere persuaded Medicaid to cover those services for people living outside of institutions. The changes also included expanding what counted as “medically necessary” to include services like job coaching for people with disabilities. As Hoyle put it, “Now we could design services to pay for supporting people in the community instead of the institution. It changed a medical service to a community support.”

Overall, Hoyle stressed the aspirational aims and actions of the DD Act and Minnesota Council. “I think most of us are indebted to the Minnesota Council for their leadership and their perseverance to follow the DD Act,” he said, “to an extent that most councils and others have not. We’ve benefitted from the leadership of the Minnesota Council. The rest of us have benefitted from the Council’s steadfastness to the principles in the Act.”

Shorter explained how Minnesota specifically helped California make progress. When he became the executive director of the California State DD Council, he asked who he should talk to and he was referred to the Minnesota Council. “Right from the beginning,” Shorter said, “I was told the Council that put out the finest work was the Minnesota Council.” According to Shorter, the Minnesota Council produced the “country’s best advocacy materials for improving the lives of people with developmental disabilities.”

Taking a page from the Minnesota Council, one of the influential resources that resulted from the support of the California State DD Council under Shorter leadership was a report called “Surviving in the System: MR and the Retarding Environment.” It was prepared by People First of California. “If you want a perspective of what is actually happening for people out there,” asked Shorter, “who would you ask? And you know, in those days, no

one was asking people with disabilities.” He said the result was totally the product of People First. The California DD Council “sent out a few copies,” according to Shorter, but soon received hundreds of requests for copies from all over the world.

The DD Act, with Shorter and his allies’ support, has had a lasting impact in California. He credited his success, in part, to being able to learn from and use the resources created by the Minnesota Council. And without the DD Act, Shorter said he would not have gotten connected to the Minnesota Council, or been able to take advantage of the “clear, simple, straightforward” and “amazing” work it produced.

Changed lives through *Partners in Policymaking*®

Dr. Turnbull explained that “Probably the biggest impact of the DD councils has been the Minnesota Council and the *Partners in Policymaking*® program. This took that requirement of family and self-advocate participation, and not only said that these representatives are welcome to sit on the council, but to be empowered to shape the council, to lead the council. 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* has changed so many lives.”

Hoyle agreed, saying the Minnesota Council has had a tremendous impact through *Partners*. According to Hoyle, “The program makes for strong, strong advocates when you’re done—advocates who across the test of time keep at it.” Minnesota’s successful program has not only yielded local advocates and change, but has been replicated in most other states. Hoyle added, “It has probably been one of the most powerful tools 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.”

Two interviewees, Kathie Snow and Fran Smith, described how participating in *Partners* changed their lives. “I don’t know where our family would be,” Snow said, “if it hadn’t been for the Minnesota Council supporting and creating and funding *Partners*.”

Snow became aware of the DD Act during a Texas *Partners* session, which she was attending as a parent of a son with cerebral palsy. Hearing a speaker read part of the DD Act preamble completely shifted her views on disability. “I was a parent and thought I knew a lot,” she said. “But that day at that conference, I heard ‘disability is a natural part of the human existence,’ and my way of thinking about my son changed. It was life changing.”

She explained that as a parent, “you get so enmeshed in the medical mode of disability. ‘What’s wrong with your child?’ They say what’s wrong with him is what his legs and arms are not doing. It was not a place I felt comfortable in my mind because I never thought anything was wrong with my son, but that’s the message you get [from professionals].” Hearing the DD Act preamble, though, led Snow to believe that it was as natural for her son to have a disability as to not have it. It made her realize that her son should be able to live the same life with a disability as without one.

The programming of *Partners* taught her that she should expect her son to be included, be integrated, and be a productive member of society. “The DD Act reinforced my dreams for my son,” she explained. “You have dreams for your child, so we thought we’d have the same dreams for my son as my older daughter. But we’re surrounded by people—medical professionals, unfortunately—who say, ‘don’t have dreams for him.’ The DD Act helped me realize that we needed to do what we were doing: keep having big dreams for my son, the same ones we had before the diagnosis.”

Learning from adults with disabilities in her *Partners* class showed Snow that every person in society is born included. Included is the default position, until someone deems you otherwise. Her classmates described how their therapies made them feel like they couldn't do the same things as their peers. They explained that not being able to complete the same physical tasks in therapy as their peers made them feel like failures.

Several years later, when her son was in first grade, Snow realized that putting her son into therapy was making him feel similarly excluded. "He wanted ordinary. He had a meltdown and starts telling me, 'I don't want to go to therapy after school. I want to go to home after school. I've been going to therapy all my life. It doesn't make me feel like a regular person, but I felt like one at school.' I realized he was telling me the same thing adults had told me years ago."

She said that experience "reinforced the whole idea of disability being natural. Why are we making him try to do things he can't do? That's like trying to make me into a ballerina. You could give me ballerina therapy all my life, but I'm never going to be one." After that, she and her husband stopped focusing on what their son couldn't do, and started focusing on what he could do. They took their son out of therapy and found alternate approaches to helping him, ones that made him feel more like his peers. "We'd have never gotten there had I not been to *Partners* under the auspices of the DD Act," Snow said.

Although Snow participated in the Texas *Partners* class, she attributed the model and the messaging to the Minnesota Council that created it. "In my opinion," Snow said, "the Minnesota Council is the best DD Council in the country. Everything the Minnesota Council does oozes the DD Act more than anyone else. The Council staff and members are the change they want to see in the world."

Fran Smith was also effusive in her praise for *Partners in Policymaking*[®]. She said that one of her greatest achievements in life, besides raising four children, two of whom had disabilities, was participating in the program. Smith believed that her daughter, and other people with developmental disabilities, belonged with their families and in their communities. However, this wasn't always an easy message for parents who participated in the *Partners* program to hear. One of the very first women Smith trained in Minnesota ran out of the room when Smith talked about how doctors and teachers aren't always right, and that parents needed to change the way the rest of the world thinks about people with disabilities. At first this mother said that it was too much to expect, on top of taking care of her son. But she came back and said, "I got it, Fran. I don't need to change [my son], I just need to change the world."

Smith also worked to help people with disabilities become self-advocates. In Arkansas, there were people still living in institutions when Smith worked with the program there, and the director of the DD Council was able to bring some of them in to participate in the *Partners* program. Smith remembers one very quiet young woman who, following what Ross Perot was doing during the presidential campaign at the time, created her own pie charts. One thin slice of her pie showed the part of her life that she lived with her family. The rest of the pie, almost the whole thing, 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. "It about knocked me out of my chair," Smith said of the young woman's testimony. Smith said she "got so much joy from supporting people" to have opportunities like that.

She believes *Partners* has had a huge effect on families of kids with disabilities, and said it would not have been possible without the Minnesota DD Council. "They changed the nation," Smith explained. "I know giving parents

their voice and the confidence to use their voice and some practice using it, it was a huge impact. I don't know how to quantify it."

She added, "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. And *Partners* didn't touch every single family in the nation, but enough to make a big difference in the way services are provided and planned and organized."

Minnesota Council member interview

summary

MAD consultants interviewed 36 current and former Council members in the summer of 2021. The interviews consisted of three questions, followed by an opportunity for additional comment.

What made you want to be a member of the Council?

Nearly half of the interviewees explained that they wanted to join the Council to act as advocates. They used words like “wanting to contribute,” “make a difference,” “give back,” and “make their voices heard.” Joining the Council gave them a way to effect change and make the world more like the one they wanted to see.

- *I have three daughters with Down syndrome. As I look at them and the world that they are coming into, I want to know that at the end of my time that I've done everything I could to make it more inclusive, more accepting, and just a better place for them. That's the personal motivation. I look at all the other people with disabilities and all the challenges they have, and everything that we touch is really helping that community toward the goal of more inclusion and a better part of life.*

Nearly one-third of interviewees said they came to the Council after participating in the *Partners in Policymaking*[®] program. They had already learned more about advocacy and the Council and were eager to take an opportunity to continue their activism.

- *I took Partners in Policymaking, which, I think, is a common thread that you'll find as you do these interviews. So many of us were in Partners in Policymaking. So, I really was drawn to be on the Council because I wanted to further my advocacy. I had never been on any council before, and so for me, it was a completely new opportunity to learn and grow in my advocacy. To make connections with other people in the community, and a chance to really have my voice be at that table. As someone who is multiply marginalized—as a queer, brown woman of color with a disability myself—there's so much intersectionality going on there, and I find that on a lot of different boards and councils, that representation like that is really needed. And so that was another really big driving force for me, just wanting to have a voice from my specific community and intersectionalities, to be a part of that conversation.*

One-quarter of interviewees were working in organizations that had a dedicated Council seat. Often their supervisor asked them to take the position for a while, and while some did not know much about the Council prior to their tenure, they all came to appreciate the Council and its work.

When discussing why they joined the Council, more than one-third explained that they were themselves someone with a disability or that they were a family member of one. They had seen how the world treated people with disabilities and wanted to improve things for them.

- *I had a personal connection. My one and only sibling, younger sister has a developmental disability, so I grew up watching my mom be a tireless advocate for her, and I wanted to do something in my own way, I guess. So it was really my sister's growing up—growing up with my sister and wanting to do something that would benefit her and other people with developmental disabilities.*

What are you most proud of accomplishing as a member of the Council?

Interviewees cited many different topics as their proudest accomplishments. One of the most commonly mentioned accomplishments was the *Partners* program, which one-third of interviewees discussed. They explained that *Partners* makes a difference in people's lives. One person called it a necessary "balance of the system," one that helped people with disabilities understand how policy is made and how to effect change.

- *I'm thinking about the Partners in Policymaking efforts as well, but also the Governor's Council provides many other avenues for people to explore different ways to become self-advocates, and for advocates to support the self-advocates. It is really a virtual collection, but it is also an in-person collection, where people can grow and thrive, share experiences, and take the next steps to become independent in the community and to live vibrant lives, like other people can. It's critical to our civil rights, it's critical to our human rights, and the Governor's Council just plays an immensely important role to help people do that.*

Another third of interviewees discussed the Council's advocacy work as one of their proudest accomplishments. They were satisfied with how their position on the Council, and the Council's broader work, helped advocate for positive changes for people with developmental disabilities. A few said they felt like they were participating in something bigger than themselves, and that they were contributing to the disability community.

- *I'm proud to be part of an organization that has been driving a singular point home to any audience that will listen and promoting legislation and working within the government and working within the school system, and working broadly toward the goal of inclusion and a better life for people with disabilities. What I'm most proud of is how far we've come. I look at the striking differences between my daughters' lives and the life of my cousin, who was 10 years older than me and lived in state institutions for many years. I do look at how far we've come.*

About one-third of interviewees also described how they were proud of working with other people. They said they made friends and connections and enjoyed the chance to make a difference with their fellow Council members. One person specified that they are still in contact with people they met through the Council on a regular basis.

- *It was also nice to be part of the council—it's just a great thing. I worked with wonderful colleagues, in an era of either continuously shrinking budgets or inflation, so we worked hard together to try to do more and more with less and less. I also really enjoyed meeting the people, and one fellow Council member even helped to write my sons' CDCS plans every year, and I wouldn't have met him otherwise.*

Several interviewees cited being able to fund important work, and several others mentioned helping with the court settlement and Olmstead Plan as key accomplishments. A few members from the grant committee

explained how they appreciated being able to provide funding to programs and trainings that would help the communities. Those who were involved with key court cases and the beginning of the Olmstead Plan talked about how that work led to critical changes in society.

- *Two words for what I'm most proud of: Jensen settlement. I'm an African American, a Black American. Before the Jensen settlement, they had young African Americans in shackles and handcuffs. They called it behavior modification. We couldn't get the people who were supposed to police this to police it because, once again, of fear of change and rocking the boat. We said hell no. Sometimes when the emperor has no clothes, you have to stand up and say so. I was proud when the Council pursued that and won that.*

When asked about accomplishments, a few interviewees mentioned the Council's archival work, as well as the data and research it funded. In particular, a few interviewees explained that the Council's research into racial disparities was groundbreaking and critical. Other accomplishments brought up by interviewees included supporting employment, the *Telling Your Story* app, and the *Ambassadors for Respect* program.

What is your favorite memory from being part of the Council?

One-half of interviewees described a memory that centered around the other people they worked with during their time on the Council. These interviewees explained how fun the meetings were and how they enjoyed the chance to work with other people on a shared passion. Several appreciated the diversity of perspectives of their fellow Council members and enjoyed hearing their different perspectives, while a few others praised the dedication of Council staff. Because the COVID-19 pandemic caused the meetings to go virtual, a few recent Council members said their favorite memory had yet to come: the moment they eventually meet up with people they have so far only met remotely.

- *The connections I was able to make with family members and self-advocates that served on the Council. My favorite memory was lunchtime and being able to sit with people I would never have been able to meet if I wasn't a Council member. There was always a time during the meeting when the energy in the room was wonderful. I walked out of every meeting with a full heart. I felt like I spent time replenishing my bucket.*

While interviewees most often offered memories around human connection, one-fifth also shared favorite memories that centered around effecting change. These were often not memories of specific instances, but rather the sense that Council work was fulfilling. Participating on the Council meant they were able to help change lives and help other people. They found it fulfilling to improve things for people they knew and the broader community.

- *I always cherish the little moments that can demonstrate that a difference was made. Especially when people come to share and teach us about their personal, professional, or organizational experiences that made a difference. It's those little things that make the generational change happen, so others—people who are joining this world, like my kids—they don't live with the segregation that we've experienced over our lifespan. Behind those updates, it's hard to pick out one, but my favorite memories are each time I*

see or hear someone leading that productive life, centered on the things that are the valued outcomes for us, which are independence and self-determination balanced with integration and inclusion.

Interviewees not only enjoyed hearing about change, but also hearing about specific topics. Several mentioned different speakers who had come to present to the Council as their favorite memory, and a few others were satisfied with how much they had been able to learn overall. Some explained how it inspired them to know other people were out there fighting for their rights and for a better world. Others said their time on the Council exposed them to research and studies they would not have otherwise known about.

- *The speakers who come to the Council are very informative and interesting to listen to because they offer a different angle than what I would experience in my everyday life. It's informative hearing about the Olmstead decision and the lawsuit and seeing how that plays out, the trickle that that creates. I've found the speakers motivating. They inspire me to think differently and follow up on things. Maybe it's just a quote they added to the meeting that stuck with me and I really found motivating, one to have hope.*

Several interviewees also discussed how much they enjoyed learning about the work the Council funded through grants. They liked both being able to support those initiatives and hearing how the grant funds had made a difference.

- *What always resonates and stays with me is when we bring some of the grant recipients in to tell us about how they spend that money. 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 decision, 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.*

Other memories shared by interviewees included celebrating the 25th anniversary of the Americans with Disabilities Act and having policy discussions. A few interviewees praised the Council's overall tone and approach. They described the Council as being run by advocates, as an organization that truly centers people with disabilities, and as an entity dedicated to continuous improvement.

- *Sometimes you get that with political stakeholder groups, where the person with the disability isn't even heard and everybody else just kind of talked for them. This is not a council where that happens. This is an organization where truth is spoken without hesitancy, without apology, without masking, or pretending. It is just 100% truth and to the core of what it means to have an integrated and inclusive life.*

Is there anything else you'd like to share about the Council?

More than one-third of interviewees ended their interviews by praising the Council and its staff. They described the Council environment as inclusive and supportive, and highlighted how much the Council has accomplished in the last 50 years. A few specifically mentioned the importance of the Council's archival work and website. According to interviewees, Council staff are true advocates who helped make Minnesota a national leader. As one of them explained, "Other states look to Minnesota as the shining example."

- *If I were to reflect on what I'm most appreciative of, it's their really strong advocacy and leadership around the Minnesota Olmstead Plan. At the time it was being rolled out, I don't think people*

appreciated how the plan could be used for really robust change in the state. And the Council's leadership put that plan at the center of change within disability services in the state. Without the plan, Minnesota would be in a different place. That was a unique opportunity that our Council took leadership on, and it has had an immense, positive effect. For the Council to have the initiative and foresight and to lead from the sidelines has been remarkable.

Several other interviewees closed their interviews by explaining how much they had enjoyed their time on the Council, with a few calling it an honor and a privilege. A few others praised the *Partners* program and the impact it has had on them and others.

- *I'm just honored to be a council member. It's a pleasure and an honor. It's been a great experience so far, working with the council on rights and issues for people with disabilities. We've come a long way, and we have a long ways to go, still. I'm proud to help with it.*

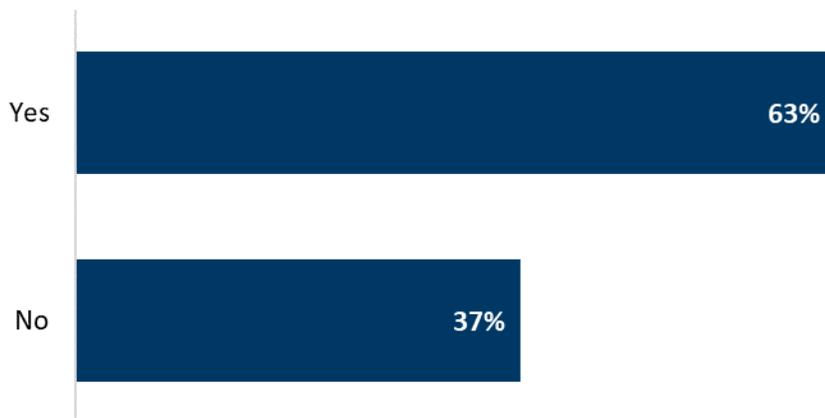
Partners in Policymaking® Impact Study

summary

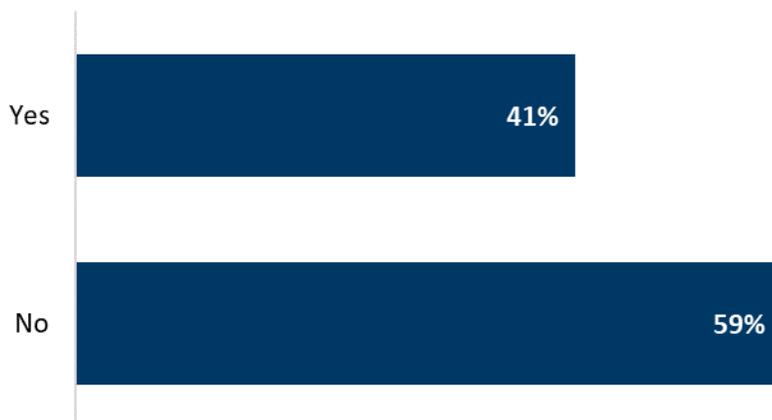
In 2020, The Odyssey Group conducted a study of *Partners in Policymaking*® graduates and received 111 responses. This section summarizes select results from that study.

The survey results show that many *Partners* graduates have gone on to advocate for the broader community. The two charts below demonstrate that 63 percent of respondents are currently employed in or participating in any advocacy activities related to disability issues, and 41 percent have written, helped write, testified at a hearing, or participated in other ways regarding congressional/legislative bills or other legislature.

Are you currently employed in or participating in any advocacy activities related to disability issues? (This could be any employment activities, cross disability coalitions, policy boards, advisory boards, governing bodies and/or leadership positions). (111 total responses)



Have you written, helped write, testified at a hearing, or participated in other ways regarding any congressional/legislative bills or other legislature? (111 total responses)



The survey also asked participants to share a personal story that best illustrates the impact the training had on their life since they graduated. More than four-fifths of them described how *Partners* had helped them become better advocates. More than half of respondents shared stories of how they had advocated for themselves or their families. Some described how they had successfully gotten integrated education for their children, while others explained that they had argued for more services or care. Graduates also gained inclusive employment and other opportunities because they knew how to speak up for themselves more effectively. The training not only taught them how relevant systems work, but it showed them how people with disabilities should be included. Participants learned how they and their loved ones could and should be treated.

- *I worked at a DAC for ten years. Every year I told my team I wanted a real job. They always said no, it couldn't happen. I kept fighting that answer. I have been working for a year and a half in a job in my community because I didn't give up. Partners taught me not to give up.*
- *In our school district, students with special needs were moved from building to building due to the needs of "typical students." This creates hardship for special ed students. Teachers need to make new connections with regular ed teachers, students need to find new friends and get used to a new school; only to have to do it again the next year. Because of Partners in Policymaking®, I had the confidence to stop this practice when my daughter was going to move school for only one year. I organized other parents, talked to local and state resources and even consulted with the Civil Rights Office in Chicago. Ultimately, I won the fight for the special needs students at my daughter's school. They were allowed to stay with their friends in a surrounding they were comfortable being in. Their teachers were also very grateful that they would be staying in the same building.*
- *Taking this course was one of the best things that happened to me. When my daughter was born, according to doctors, there was not much hope for her survival and if she did, she would not amount to anything. We did not give up but it was like we were in fog and Partners showed us a clear path. My whole world changed. I learned so much in those 2 years. I met many people in the same boat and it became like my support group. We learned so much from each other's experiences. We got tools to help our children, we learned how to navigate all different systems like medical system, school system, government system, social services and many more complexities of all the whole world of disability. My whole attitude changed. Despair turned into a can-do outlook. I became a fierce advocate for my child. This shy immigrant submissive girl turned into a confident, assertive mother who fought many fights, making almost 30 appeals and winning every single time. My daughter was non-communicative and severely physical and mentally impaired but last year she turned 40. She still is totally dependent for her daily needs but she is alert and connects to the world around her. She smiles, enjoys swimming and horse carriage driving. Everyone loves her million-dollar smile. I had started doing advocacy from being on different boards, different advisory committees, and task forces. I am still serving on many advisory councils. For the last 30 years, I have helped many new moms, giving them the benefit of my experience. I have no words to express my gratitude to Partners training. It opened a whole new world for me. I urge new mothers like me to take this course. Today my life is so much enriched and fulfilling because of Partners. I had chances to experience going to seminars, going to different classes, went out of town for retreats, etc. I got such a wealth of information and different types of empowering experiences so that today I am happy, ready to help who ever needs it. I enjoy sitting on our deck enjoying our koi pond with my daughter. I love her with all her limitations. Partners taught me the value of her life and in 2018 we*

celebrated her 40 years of journey with our family and friends. She was beaming like a princess. It was possible because of Partners training. It was my guiding light.

- *I was fortunate to be chosen to attend Partners in Policymaking® in the early 90s. Partners gave me the information, tools, resources and skills to make significant changes in my daughter's educational program that met her needs through high school graduation and well into adulthood. At that time she was receiving special education services in a segregated classroom setting. After attending Partners sessions, I learned about inclusion and found ways to advocate for her individual needs. After years of struggling to have her included in the elementary school, she transitioned to the junior high school. A meeting was held with the current staff and the new staff. It was clear this was something they were not prepared for and they were suspiciously cautious about what they would be expected to do for her in their school? Two short years later she was ready to transition to the high school. Once again a meeting was held with the current staff and the new high school staff. Looking at the group of teachers, it was clear they were suspiciously cautious about what they would be expected to do for her in their school. The principal from the junior high stood up and addressed the group. He said two years ago we had a meeting like this. I want to tell you that all the things we were worried about never happened and our school is a better place because [the student] was here. That affirmed the positive benefits of inclusion for [my daughter] and the delightful feeling of acceptance from the staff. That was a win-win!*
- *It has been 20 years since I did Partners. It has been an invaluable resource to me and my son. I remember in the beginning when I told an educator that I was doing Partners and their response was "anytime you have trouble getting [your child] what you need, mention that you've done Partners." While I learned very important skills—from understanding IDEA to learning why laws become screwed up because of legislative process/Roberts Rules of Order/politics, I fully understand the resources and challenges that I have in helping my son. To mention one specific event where Partners would minimize its impact to us, however, understanding the procedural mandate that IDEA puts on schools, allowed my son to FAIRLY get his services determined and delivered. Also, by understanding the challenges that schools face (lack of federal funding etc.), I was more aptly able to navigate the educational system for my son (who is nonverbal and non-ambulatory) to graduate with a full diploma! This is noteworthy because when we learned about inclusion, at first, my response was "OK, maybe for someone mildly delayed, but not MY SON with his severe disabilities." HA! He was FULLY INCLUDED his entire education, from ECSE to his senior year! It was a HUGE fight along the way, but he (and his classmates) benefited at levels I can't describe!*

One-quarter of respondents shared stories about how they had advocated for formal changes, including testifying before the legislature, speaking with local leaders, and talking to the media. They said *Partners* taught them how to share their stories and build relationships with policymakers.

- *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.*
- *I graduated from Partners in June. In September one of my daughter's physicians asked me if I would be willing to testify before the Minnesota MA Drug Formulary Committee about the difficulties we had been*

having getting a prior authorization for a particular type of medication. We (and the physician) believe the committee is unnecessarily preventing access to some important and necessary medications for individuals with my daughter's condition. Because of my Partners training, I did not even hesitate for a second before agreeing to testify. I knew how to do it, I had practiced, and I was confident in my skills. I went back and looked at my Partners notes on how to give public testimony as I was preparing my comments, and found them very helpful. I received positive feedback on my testimony and was told it did have an impact on the committee. I am continuing to work on advocating on this particular issue.

In addition to legislative advocacy work, more than one-tenth of respondents noted that they had taken on a leadership position since participating in *Partners*. Among other organizations, they mentioned joining their local school board, the Governor's Council on Developmental Disabilities, and the State Quality Council. They said *Partners* taught them how to apply for those sorts of positions and gave them the confidence to pursue them.

- *After graduating, I understood the options for getting my voice heard at the policy level. Not being confident in the legislative process, I had not reached out before. Since then I have been a part of many open appointment boards, including Health Care Home Advisory Council and CMS state innovation grant. I have had a story in the Star Tribune regarding COVID and day programs and felt I am fully prepared to make change in our state, in the most effective way possible for my young adult son.*
- *This was a life changing experience. With this knowledge and expertise I have been able to advocate for both of my sons and others with disabilities. I became a support planner and have been helping others since I graduated 7 years ago. I also helped to spread my knowledge and support your program to the Support Group I ran in person and the Facebook Support Group I still help to run. Many of them have gotten help and waivers that have greatly improved their lives. I became part of the school district's parent advisory council (their version of SEAC) and have given my input on how to make things better and how to educate others in the community on a variety of topics. I know my son's rights so I know when to push to advocate for him, plus I have many people that come to me with questions and help direct them to the best location to get the help they need.*

More than one-tenth of respondents described actions they had taken as a result of their *Partners* education. A few highlighted works of art they had created to help people with disabilities feel included, including a children's book and a play. A few others shared that they had developed training or curricula for others, and presented or worked on running conferences or other trainings.

- *After I graduated from Partners in Policymaking in 1988 or so, 3 or 4 of my Partners created a cable TV show called "Diversability" and did 1 show a month on Minneapolis Cable TV out of the Mound, Minnesota, outlet. We ran those shows for 4 years and had Disability Nonprofit(s) groups on our show to make the public more aware of all the programs and services the community of Minnesota had for people with Disabilities. I learned so very much about producing a show for people with disabilities and also was able to learn how to advocate and communicate information to the community about what services people could use in order to better their lives at the time. Also I was able to learn how to be a leader. At present in 2021 I am now the Executive Chair of Midwest Region Wheelchair Sports (MRWS) Group and have led this Nonprofit since February 2000. What I learned from Partners in Policymaking and participating with the Diversability Cable TV show put me on a path to creating the MRWS Nonprofit and gave me the skills to be a leader. Today our MRWS Group Serve the Wheelchair Sports Community in*

Wheelchair Basketball, Softball, and other sports supporting the Minnesota Courage Timberwolves Basketball and Minnesota Rolling Wheelchair Softball Teams and raise funds every year to support competitive activities in the State of Minnesota and beyond.

- *One of my first actions following my time in the program was to write a grant and form a group to survey and publish information about the accessibility of the public buildings and spaces in my city including restaurants, lodgings, etc. according to ADA guidelines. My group began to notice the effect this had on the businesses surveyed and the city government itself. Curb cuts were made to city sidewalks, restaurants and lodgings installed accessible bathrooms and entrances, etc.*
- *When I was in the program, there seemed to me a hole in services to help parents cope with the stress of parenting a kiddo with a disability—lack of sleep, endless paperwork, nonstop advocating for my kiddo or helping other parents in my school advocate for themselves made it clear there was a need that needed to upend the story parents tell themselves that they must be lower on the priority list for self-care—not the spa idea—sleep, nutrition and a practice that can be done anywhere. The venue to start to create something like that for parents was formed in my experience as a LEND fellow in 2019–2020 which I never would have applied for if not for my Partners experience. I worked with Communities Engaging Autism to develop a Mindfulness Based Stress Reduction Program for parents of disabilities. 2-7 week sessions produced profound results (and COVID paused that process) and we are looking to expand into different communities and online offerings. Parents reported that the regular practice made meltdowns easier to cope with and help to avoid them all together. I have also worked with the Walker Art Center and Guthrie Theater on their sensory friendly programs. I started working with Playwrights' Center and TPT to make their programming more accessible to people with disabilities.*

Other participants shared how *Partners* helped them understand others' perspectives more and fostered their connections with others. Several mentioned how learning the history of people with disabilities helped them better understand current situations and inspired them to help change things further.

- *When my son was diagnosed with autism, he became the first person I loved that had a disability. I do not remember going to school with kids with disabilities, working with people with disabilities or otherwise socializing with anyone who had a disability. The Partners program opened my eyes to how widespread of an experience that is—and it's unfortunate for everyone. Sitting in class with adults with disabilities during Partners was my first experience hearing firsthand how hard the system of support is to navigate and rely upon. It gave me a window into what my son's experience will be like if changes are not made. But the relationships I made with other parents and adults with disabilities is something I bring with me to everything I have done since. Maintaining that connection on social media and through Christmas cards is something I will never take for granted.*
- *Partners in Policymaking® helps parents/individuals build confidence to know that what they want or dream of for their child/self is okay. Learning the history of how folks with DD were "supported" in the past instills a drive to not let that type of "support" be repeated and continue the work of the parents and individuals before us until we gain the recognition and respect in society as a whole. I joined many local committees in hopes of impacting how my young son could be included in his community. I found that much of my time was spent advocating for adults with disabilities to be included in activities (recreation, sports, church, community events, voting, volunteering). I was willing to take the "Risk" of*

pushing boundaries for my son. I signed him up for a community event of the day, where kids participated in the activities of track. My son used a chair; however, another participant offered to push him in his chair. So heartwarming for me. As my son's race started, the entire audience cheered him on. A lesson learned for all; participation was more important than winning.

Overall, participants were extremely grateful for *Partners in Policymaking*[®] and everything it taught them.