



## Direct Care Support Workforce Survey *Summer 2023*

The National Association of Councils on Developmental Disabilities (NACDD) recognizes the complex issue of recruiting, retaining, and mobilizing direct support professionals (DSPs) and Direct Care Workers (DCWs) throughout the United States and territories. While the lack of a robust DSP/DCW workforce has been a concern for many years, the recent shortages have become unsustainable. This crisis has significant impacts on the daily lives of individuals with disabilities, their families, allies, and communities. To address these issues, it is necessary for NACDD to explore the goals and legislative efforts of the DD Council network.



### Systemic Challenges to Meeting the Need for Direct Care Workers

A high-quality professional workforce that earns a living wage is essential to providing the necessary support and services to our constituents where they live, work and play. Medicaid is the primary source of funding for the programs employing these workers. The current Medicaid reimbursement system and cost-cutting actions by state legislatures and Medicaid officials have exacerbated the workforce crisis already hampered by low wages, a lack of affordable health insurance, high turnover, and a shortage of staff. Demand for these workers from private industry and other human services sectors is also high, leading to competition among industries for workers. Low wages, high demand, and poor reimbursement systems have been compounded over three decades, leading to a systemic failure that has left many people in crisis. Indeed, a grave threat to the lives of our constituents and their families has resulted from a lack of solutions to this problem.

Millions of people receive help from family and unpaid caregivers for health and functioning reasons. These supports are critical and yet we do not have sufficient data for strategic planning conversations. We need more exploration of community-supported living options and employment goals when family caregivers can no longer provide adequate care.

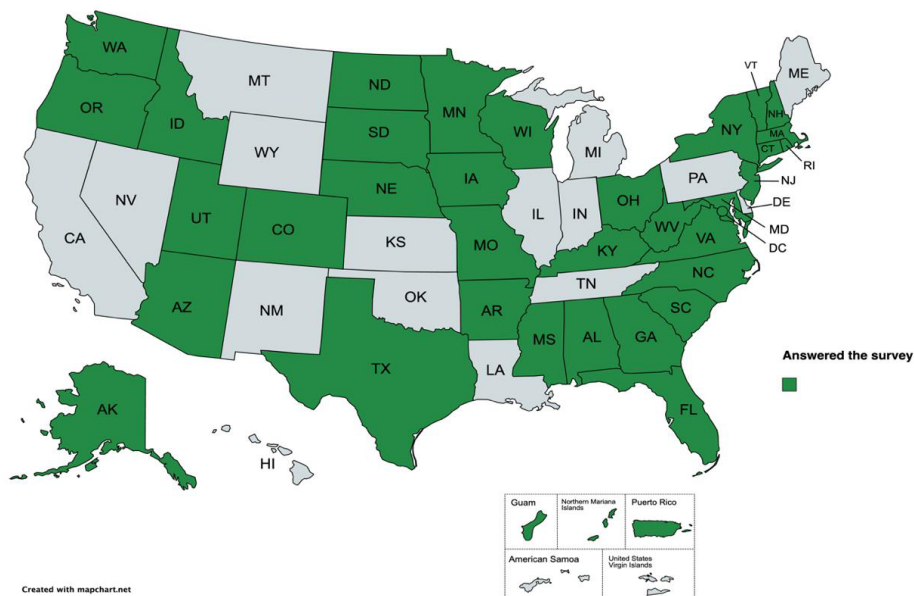


## History of the DD Council Survey of Activities to Address the DCW Crisis

The Direct Care Workforce/Direct Support Professional (DCW/DSP) Survey was created by NACDD staff and sent to the State Councils on Developmental Disabilities (SCDD), also known as the Councils, on June 20, 2023. Each Council received a reminder email three weeks after the survey was opened, with follow-up phone calls, discussion on bi-weekly Zoom calls and emails. After one month, the survey received 39 responses out of 56 DD Councils, with a 68% response rate. The following DD Councils contributed information to this survey.

Northeast:	Midwest:	South:	West:	Territories and Other:
Connecticut	Ohio	Florida	Arizona	CNMI
Massachusetts	Wisconsin	Georgia	Colorado	Guam
New Hampshire	Iowa	Maryland	Idaho	Puerto Rico
Rhode Island	Minnesota	North Carolina	Utah	
Vermont	Missouri	South Carolina	Alaska	
New Jersey	Nebraska	Virginia	Oregon	
New York	North Dakota	DC	Washington	
	South Dakota	West Virginia		
		Alabama		
		Kentucky		
		Mississippi		
		Arkansas		
		Texas		

No response: American Samoa, California, Delaware, Hawaii, Illinois, Indiana, Louisiana, Maine, Michigan, Montana, Nevada, New Mexico, Oklahoma, Pennsylvania, Tennessee, Virgin Islands, Wyoming, Kansas

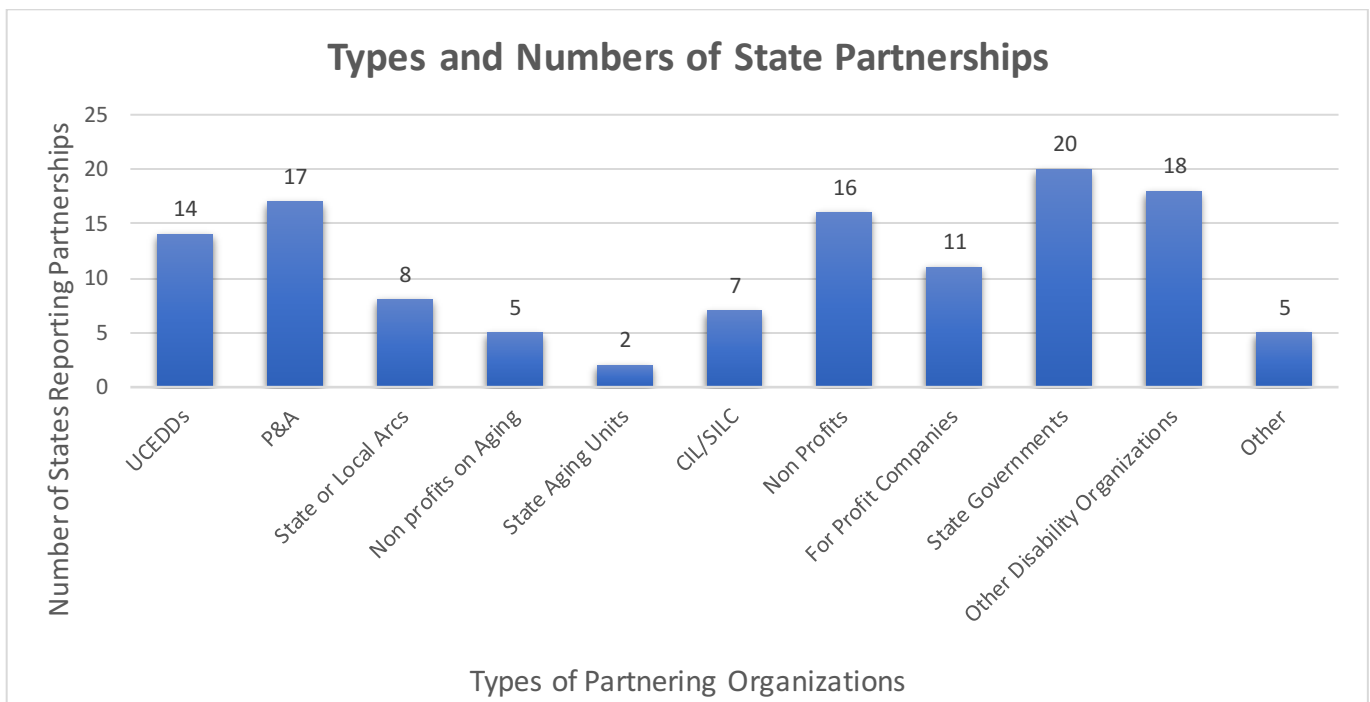




## Overwhelming Majority of Councils are Addressing the DCW Crisis

Of the 39 responding Councils, 18 reported that they are addressing the crisis this year, and 26 reported currently working with partners. Eight Councils reported that the DCW/DSP crisis is an explicit goal in their five-year state plan while other Councils are addressing the crisis in other ways. **72% of Councils that responded (26) are actively working on the DSP crisis and partnering on policy solutions.**

The following graph shows the variety of partnerships which Councils report working with this year. Twenty councils noted partnering with their state governments. Additionally, 18 Councils identified other disability organizations as current partners. Many Councils worked with multiple organizations. For example, partnerships in the “other” category include Parent Training and Information Centers, University programs other than the University Centers for Excellence in DD (UCEDDs), Leadership Education in Neurodevelopmental Disabilities (LEND programs), private research firms, self-advocacy organizations, and provider organizations.

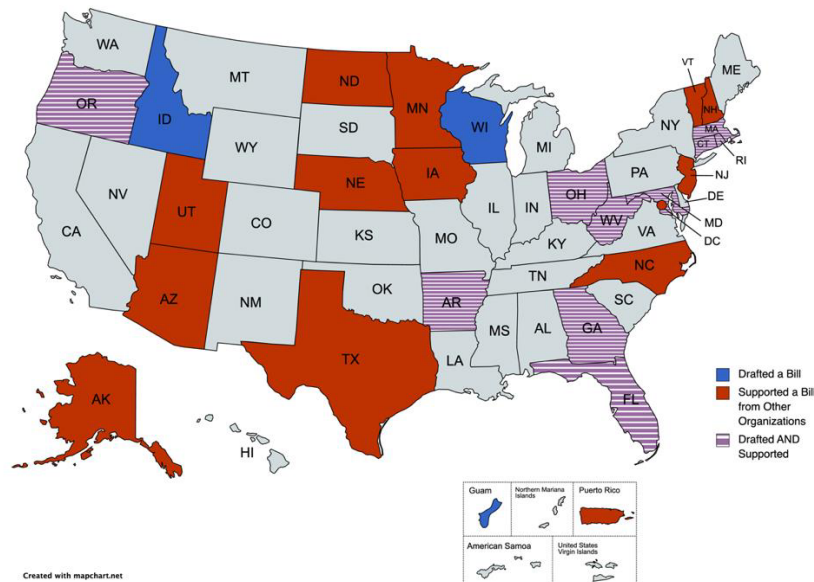




## Councils are Working on Legislative Action for Systems Change

NACDD is proud to report that legislative advocacy has been a key area of advocacy efforts across the Councils. **33% of Councils that responded to the survey (13/39) have drafted their own state legislation. In addition, 62% have supported bills from other organizations (24/39).** Ten states have both addressed the crisis with their own bills and by supporting bills from other organizations. This type of legislative advocacy is a clear demonstration of the unique role of Councils in relationship to their legislatures and governors' offices.

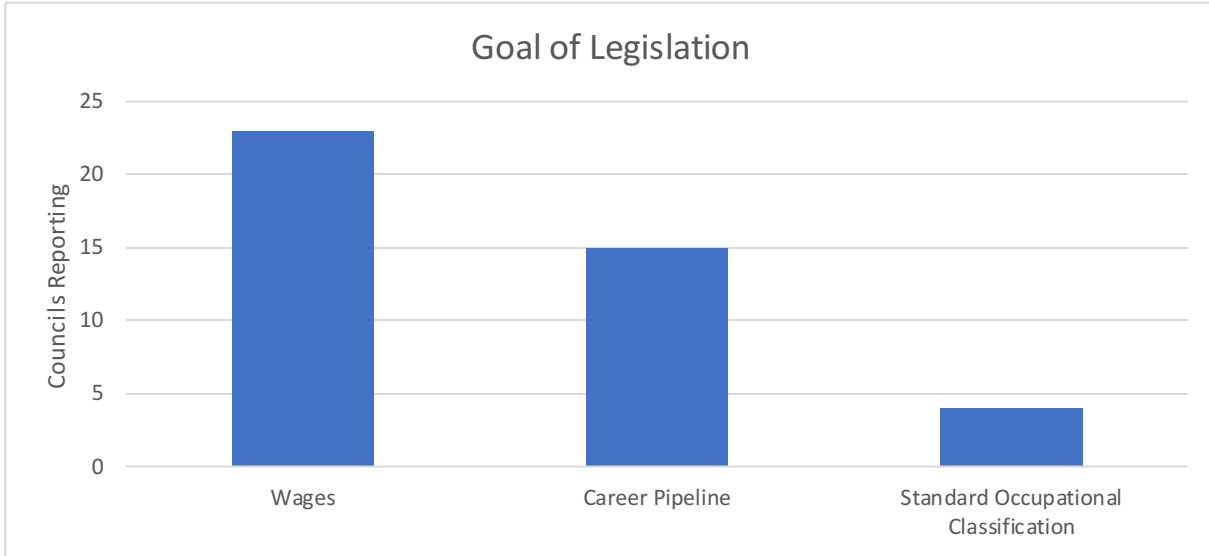
States drafting their own bill	States supporting bills from other organizations:	States drafting their own bill AND supporting bills from other organizations
<ol style="list-style-type: none"> <li>Arkansas</li> <li>Georgia</li> <li>Oregon</li> <li>Rhode Island</li> <li>Guam</li> <li>Ohio</li> <li>Connecticut</li> <li>Florida</li> <li>Idaho</li> <li>West Virginia</li> <li>Wisconsin</li> <li>Maryland</li> <li>Massachusetts</li> </ol>	<ol style="list-style-type: none"> <li>New Hampshire</li> <li>Arkansas</li> <li>North Carolina</li> <li>Nebraska</li> <li>Texas</li> <li>Georgia</li> <li>Oregon</li> <li>New Jersey</li> <li>Arizona</li> <li>Alaska</li> <li>Rhode Island</li> <li>Puerto Rico</li> <li>Minnesota</li> <li>District of Columbia</li> <li>Utah</li> <li>Ohio</li> <li>Connecticut</li> <li>North Dakota</li> <li>Iowa</li> <li>Florida</li> <li>West Virginia</li> <li>Vermont</li> <li>Maryland</li> <li>Massachusetts</li> </ol>	<ol style="list-style-type: none"> <li>Arkansas</li> <li>Georgia</li> <li>Oregon</li> <li>Rhode Island</li> <li>Ohio</li> <li>Connecticut</li> <li>Florida</li> <li>West Virginia</li> <li>Maryland</li> <li>Massachusetts</li> </ol>





## DCW Wages is the Most Common Legislation

Most Councils are focused on increasing wages for DCWs/DSPs, with 59% of Councils (23) identifying this as their main legislative goal. The second most common goal of legislation is about career pipeline and training, which is identified as a legislative goal by 38% of Councils (15). Standard occupational classification is identified as a goal by 3% of Councils (4).



NACDD is proud to recognize that 31% of Councils (12/39) report passing legislation in at least one legislative chamber that addresses the DCW/DSP crisis. This momentum is a strong indication of future success. Successful legislation that passed at least one legislative chamber addresses related needs such as wages, rate setting for providers and Managed Care Organizations, Home and Community Based Settings and Early and Periodic Screening and Diagnostic Treatments (EPSDT).

Ohio, Virginia, and Wisconsin reported that in their states, they have approached this issue in the budget processes, not separate legislation. Oregon and Arizona councils stated that while they did have bills in committees, their bills were not approved. Future studies or research could include a deeper analysis of these bills.



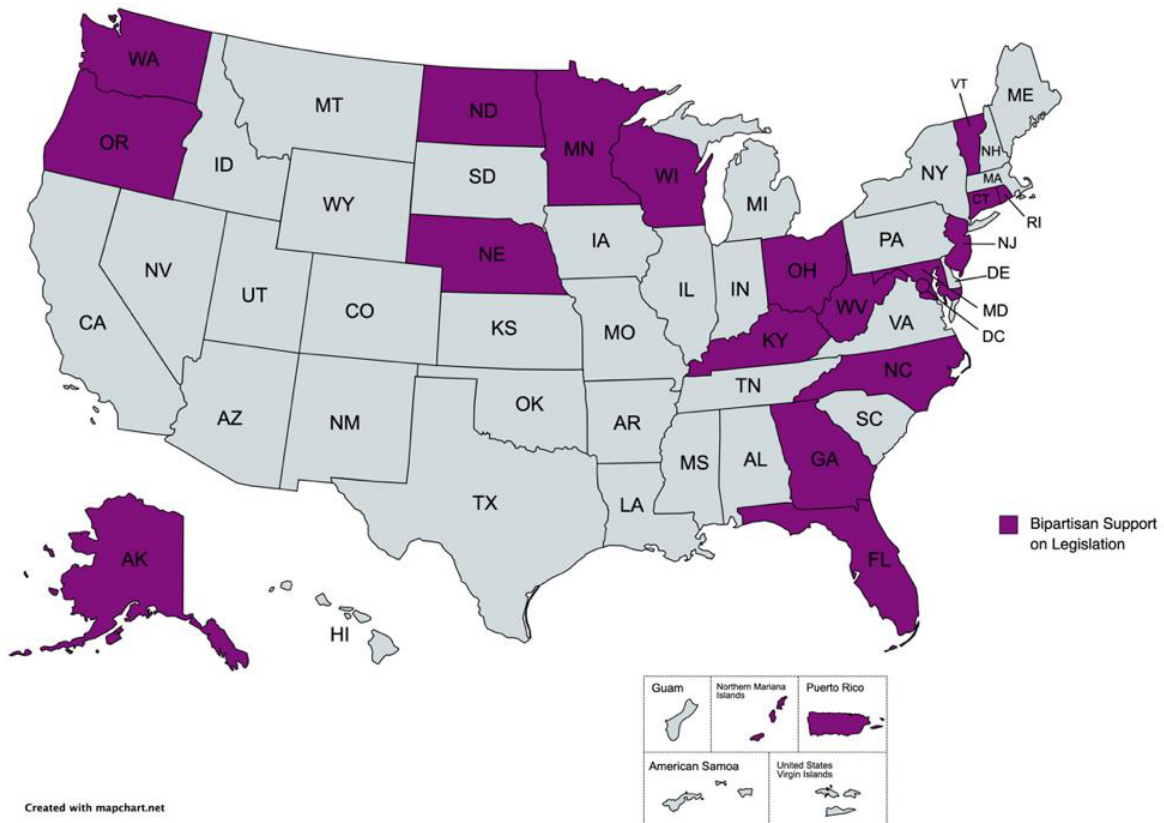
Six Councils reported to NACDD that they worked on laws that passed in the last year that include support for DCWs.

<b>New Hampshire</b>	Wages and training	Language included in the state budget requiring reviewing rates for HCBS with intent to increase wages and support training for DCWs in 2023. See HB 2-FN-A-LOCAL at <a href="https://www.gencourt.state.nh.us/bill_status/billinfo.aspx?id=1081&amp;inflect=2">https://www.gencourt.state.nh.us/bill_status/billinfo.aspx?id=1081&amp;inflect=2</a>
<b>Rhode Island</b>	Wages	Following a consent decree which was highly critical of the reimbursement rates for Medicaid HCBS, the legislature included increase in wages for direct support professionals through the state budget process.
<b>Connecticut</b>	Standard Occupational Code; Wages	Created new state statutory definitions for IDD and definitions for services based on state and study national best practices and evaluate how funding levels for services and programs are determined for each individual within the state and in other states. See Substitute HB 5001 at <a href="https://www.cga.ct.gov/2023/ACT/PA/PDF/2023PA-00137-R00HB-05001-PA.PDF">https://www.cga.ct.gov/2023/ACT/PA/PDF/2023PA-00137-R00HB-05001-PA.PDF</a>
<b>Florida</b>	Wages	The work of the Pay Fair for My Care campaign alongside the voices of thousands of individuals and families, influenced lawmakers to raise the level of pay to \$15 per hour for DCWs. This is the largest increase Florida has committed to in over 10 years. See HB 5001 <a href="https://laws.flrules.org/2022/156">https://laws.flrules.org/2022/156</a>
<b>West Virginia</b>	Wages and Career Pipeline	Required a workforce study pertaining to HCBS waiver services to include recommendations as to the appropriateness of the current mean hourly pay rate for DCW, as well as any potential pay rate increases necessary to ensure that the programs can successfully recruit and retain qualified personnel. See SB 617 at <a href="https://www.wvlegislature.gov/Bill_Status/bills_text.cfm?billdoc=sb617%20sub1%20enr.htm&amp;yr=2023&amp;sesstype=RS&amp;i=617">https://www.wvlegislature.gov/Bill_Status/bills_text.cfm?billdoc=sb617%20sub1%20enr.htm&amp;yr=2023&amp;sesstype=RS&amp;i=617</a>
<b>Nebraska</b>	Wages	Council efforts during the past legislative session included testifying at an appropriations committee legislative hearing and providing educational talking points on the DSP shortage to advocate for increased provider rates (LB526 & LB601). Rates were increased in an appropriation state budget bill. See <a href="https://nebraskalegislature.gov/bills/view_bill.php?DocumentID=50699">https://nebraskalegislature.gov/bills/view_bill.php?DocumentID=50699</a>



## DCW Legislation has Bipartisan Support

When asked about partisan support of legislation, 14 Councils noted that this question was not applicable. **Twenty-one (21) Councils responded that they have bipartisan support for their legislation. This means that of 24 Councils that had support on legislation, 21 Councils (88%) had bipartisan support.** The following map shows the Councils with bipartisan support on legislation. Only Arkansas, New York, and Iowa indicated that their legislation received Democratic support only.





## Other Advocacy Efforts

Councils have advocated for policy changes in a variety of ways. 74% of Councils (29/39) reported advocating in meetings with lawmakers to educate and inform them about the DSP crisis, for example providing testimony or personal stories to the legislators. Other councils worked in the administrative branch by providing comments to proposed state regulations on the DCW crisis.

Personal storytelling continues to be a useful strategy to encourage dialogue among lawmakers, Councils, community members, and families. Councils were able to check specific strategies that they use. **The most consistent advocacy strategies used by Councils was to collect and share stories using social media.** In addition, 17 Councils have created publications or reports based on the personal stories gathered. Several councils used more than one strategy. The table below shows a few of the ways councils advocated in their states and the different media used to educate lawmakers and the public about the DCW crisis.





## Messaging Strategies



### Additional Comments and Insight

The final questions in the DSP survey asked for additional comments from the Councils. These comments show how the use of media, sharing stories, developing or supporting legislation, and solving problems is accomplished in local communities. **Some Councils have been working on the crisis for years, noting that it is no longer a crisis but a systemic failure, while others have just begun focusing on this issue.** NACDD encourages all Councils to share their successes, strategies, and barriers. Here are a few examples of comments (lightly edited for clarity).

We have funded a large service provider organization to utilize the Charting the Life Course framework to improve the organization itself.... utilizing our Public Health Workforce funding in partnership with our UCED D to find solutions to the DSP workforce crisis. The project is a) identifying promising practices both within the state and across the country to gain buy-in from DSPs and their managers through active participation, b) product development and testing a tool kit, c) finalize and share the toolkit.

- Arkansas Governor's Council on Developmental Disabilities

We have "Meet the Need NC," which is an initiative focused on raising awareness, policy, collective impact. We have our film, "Unmet," showing at NACDD's 2023 annual conference. We have worked to bring together multiple groups across the state to engage on the DCW issue.

- North Carolina Council on Developmental Disabilities

"Making Work Work for People with IDD" is a 30-minute educational program produced in partnership with Nebraska Public Media ([www.nebraskapublicmedia.org](http://www.nebraskapublicmedia.org)). The program was developed in partnership with, and funding from, the Nebraska Association of Service Providers (NASP), People First of Nebraska, and the Nebraska Council on Developmental Disabilities. The film encourages neurotypical Nebraskans to consider a lifelong career in I/DD supported employment service provision.

- Nebraska Council on Developmental Disabilities

We are part of a group that meets with our state DD agency working on 3 training pathways that seek to create career paths for DCWs.

- Georgia Council on Developmental Disabilities

We are advocating with the Governor's office for a workforce campaign focused on this population... We participated in the initial designs of a state-run website that connects job seekers with careers in developmental disabilities services in Oregon. See <https://impactoregon.careers/browse-careers/>  
- Oregon Council on Developmental Disabilities

We successfully advocated to a state Medicaid agency request of CMS for a permanent change to a waiver allowing parents to be paid for attendant care/habilitation services for their minor children (previously a temporary flexibility supported during pandemic and with ARPA funds).  
- Arizona Development Disabilities Planning Council

Missouri has a strong provider network that has worked almost exclusively on the DSP crisis for many years. They have succeeded in having the wages for DSPs raised. The Council has shared information about the workforce crisis online, as well as information about opportunities to testify at hearings... The Council formed an Olmstead Sub-committee that is working to address [threats to community living], that will also include addressing the workforce crisis as this is being used as leverage to develop institution-like settings.  
- Missouri Developmental Disabilities Council

We are working with colleges to provide credit on courses for DSPs, working with High School Career Programs to include DSP as a possible career choice, and working to change the image of DSPs to align their duties with other professions.  
- Ohio Developmental Disabilities Council

We are now partnering with our Protection and Advocacy (P&A), ND Assistive (technology devices and service solutions), Money Follows the Person (MFP) project, and aging services to explore assistive technology to help people live in lesser restrictive environments and to cut down on staff needs.  
- North Dakota State Council on Developmental Disabilities

We are currently working with Mathematica, Inc. which is completing an environmental scan and conducting a survey and interview research project to hear from individuals with I/DD and families on how they solve the problem of finding supports through innovative and creative means. In future years, we will be implementing recommendations from the Mathematica study and an evaluation to assess impact.  
- Florida Developmental Disabilities Council

The HCBS Quality Committee is sponsored by the Council and is comprised of self-advocates, family members, providers and department representatives. The committee meets four times a year, with provision for more frequent sub-committee meetings on select topics as needed. It provides a forum for active, open and continuous dialogue between stakeholders and the DDA for implementing, monitoring and improving the delivery of waiver services to best meet the needs of people with intellectual and developmental disabilities.  
- Washington Developmental Disabilities Council

We were on a Governor's Task Force on Caregiving that developed 16 proposals including credentialing and free certification; rate band study; paid leave legislation; etc.  
- Wisconsin Board for People with Developmental Disabilities



## Possible Opportunities for Future Action

NACDD continues its commitment in supporting network-wide activities to help guide the Councils. Currently, NACDD maintains a working group within the Public Policy Committee (made up of council members, council staff and self-advocates from 12 different states) which is focused on state policy matters including the DCW crisis. Meeting monthly, this committee provides a forum for councils to share their expertise and success stories from their states.

With additional resources, future NACDD activity could include additional data and analysis of annual council activities and story collection around DCW policy initiatives, the development of a shared story database, member and staff led trainings to provide a roadmap for systems change and dedicated technical assistance to councils looking to improve state policy concerning DCWs.

## Conclusion

Councils are key stakeholders in creating systems change because of their expertise in state legislative and administrative systems and close relationships with their governors, state legislators and administrators of state programs involving DCWs. The State Developmental Disabilities Councils network continues to leverage its unique relationship with federal and state stakeholders to find innovative solutions to the DCW crisis through the development of state public policy. Many of these innovations are replicable and scalable and should be considered by other states and Centers for Medicaid and Medicare when developing policy.

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NACDD extends a sincere message of gratitude to Lily Gullion, MS, OTR/L, for her contribution to this report and to all the DD Council executive directors and staff who took part in this survey and continue to advance community living for all through their hard work and dedication.

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