Addressing the Direct Care Crisis: Creating an Advocacy Campaign around Direct Care

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Outline of this session

- Who are we?
- What is the direct care crisis and how has that manifested in Ohio?
- What actions have we taken to combat the direct care crisis?
    - Research and education
    - Budget advocacy
    - Wage Study
    - HB 530: Establish a long- term Care Workforce Study Committee
- Discussion – what is going on in your state?

Who are we?

The Ability Center is a Center for Independent Living Serving thirteen counties in NW Ohio. The major city within our service area is Toledo, Ohio.

Together, we work to make our community the most disability-friendly in the nation by increasing independence for people with disabilities, discovering true passions, and changing the community's perception of disability.

What is the direct care crisis and how has that manifested in Ohio?

- The Issue: There are not enough direct care workers to serve everyone in the community who needs one. Without enough direct care workers, people may be forced into institutional settings.
- This is an issue across the country.

Detailed overview of the issue

- People with disabilities and aging Ohioans need direct care workers to live independently in their homes.
- Many people use direct care workers to complete their activities of daily living – getting out of bed, bathing, toileting, eating, re-adjusting their position, etc.
- Some people use direct care workers for incidental activities of daily living – for example, transportation and socialization
- Either way, direct care workers are key to independent living

A note on language

- In Ohio, different Medicaid HCBS Waivers call direct care workers by different terminology
    - Home Health Aide (HHA)
    - Direct Service Provider (DSP)
    - Personal Care Aid
    - Home Care Aide
- Advocating for one of these roles often means only one system, so we settled on Direct Care Worker to encompass all systems

Ohio, and other states, fail to create a robust system of direct care

- Direct care workers are a reimbursable service through Medicaid, but there are not enough workers to fill the need
- In Ohio, nearly 70% of direct care workers leave their position within a year – DODD survey, 2022
- In our survey, 54.43% of Respondents stated that there is a high turn- over of direct care providers and that their staff changed often
- 39.11% stated that they are sometimes left for hours at a time without an in-home provider

The problem is national

- Nationwide, the direct care workforce consists of approximately 5.4 million workers including home care workers, residential care aids, and nursing assistants
- Nationally, turn- over of direct care workers is 60-80% annually
- Over the next decade, the sector needs to create 772,000 new direct care jobs to meet the need

Personal stories

- Around 2020, especially, we began to hear from people with disabilities who couldn't find direct care workers. Our I & R line was also receiving increased calls.
- One person who relied on direct care workers to get her out of bed described being left without care for weeks. Her issue was how long it took for new direct care workers to be approved by the department of Medicaid. In order to sign up to be her worker, they needed to provide care without pay for nearly six weeks.
- One person's family member required complete care, and she often had new direct care workers leave before the end of their first shift because they didn't want to provide the level of care required.

Personal stories, continued

- One person's aging parents needed direct care workers to remain independent in their home. Even though they were on Medicaid, the caller had to hire college students using private pay in order to get people to help her.
- One young person who was blind and deaf was hit by a car crossing the street because he could not find someone to act as his direct care worker.
- We received multiple calls from people whose direct care worker just never showed up for their shift, leaving them in the lurch, and who could not find another one.

A lack of direct care workers is a health and safety issue and a threat to people's independence

- Across the board, many people would rather live at home with no support than go into an institutional setting like a nursing home or ICF
- If someone relies on direct care for all activities of daily living, this is a safety issue
- A lack of direct care workers makes it impossible for people to work and engage in normal day- to- day activities
- Places people at risk of institutionalization

Why is there a shortage of direct care workers?

- Low wages: Medicaid provides reimbursement for direct care as a service but does not control how much workers receive.
- No benefits: Many direct care providers do not receive health insurance, sick leave, travel reimbursement, or retirement benefits.
- No career path: Most direct care workers have no chance of promotion. If they continue to work their jobs, there is no opportunity for them to move up.
- Difficult work: The qualifications and level of pay for direct care workers equal that of a fast food or retail job. Many people who enter the field aren't called to be health care workers and can get jobs with steadier hours, comparable pay, benefits, and easier tasks.

Our campaign

- In 2020, we found ourselves to be in a particular crisis. Community members kept contacting us out of desperation because a direct care worker hadn't shown up for the day or because they could not find anyone.
- One of our long-term policy goals is to ensure that health care services are provided in the community, rather than in institutional settings, so we decided to take action.

Forming a coalition

- The Ability Center is part of a statewide coalition called the Ohio Olmstead Taskforce
- Once we had identified this as an issue, we formed a committee on that taskforce called the Direct Care Taskforce
- While we further researched the issue, we began to take action as part of that taskforce to begin drawing attention to the issue
- We drafted a sign on letter for the state Department of Medicaid, organized statewide editorials/ letters to the editors, and organized regional public forums to discuss the issue

Forming a coalition, continued

- For each of these, we sent out press releases to get the issue into the news
- We also drafted common talking points that each member of the taskforce could use to share with their own regional legislators to begin talking about this issue

Researching solutions

- Our advocacy team drafted an issue brief using research from around the country to name the problem and identify solutions
- While we knew the problem was multi-faceted, we kept hearing about low wages, which at the time, averaged $12/ hour
- We found a legislative model in the State of Maine, which raised wages for direct care workers

Researching solutions, continued

- Maine had established a legislative commission to study long term care workforce issues to form solutions to the crisis
    - Direct care workers are legally entitled to a minimum wage floor equal to 125% of the state's minimum wage
    - Also established a long- term care workforce oversight advisory committee to provide advice and oversight to HHS committee

2023 Budget advocacy

- In 2023, we formed a specific budget advocacy work group around setting a minimum wage for direct care workers and also advocated for a long-term care study commission
- That workgroup crossed the aisle to encompass any groups affected by the direct care shortage: aging, disability-specific groups, CILs, our P & A
- Each of these groups met on a monthly basis to coordinate advocacy, and each activated their own advocacy network
- We also held a day at the statehouse to meet with legislators and drop off our issue briefs and talking points
- All groups came together to give testimony and recruit testimony

2023 Budget advocacy, continued

- We worked directly with interested legislators to get a base wage for direct care workers and long- term care workforce study commission into the budget bill
- The final budget bill increased funding for direct care workers and established a wage floor for workers of $15 for the first year and $16/ hour for the second year – the long- term care study commission was taken out
- The budget bill also required the state to track this issue, to collect data on direct care wages
- But when it got to our Governor's desk, he vetoed the wage floor – though he left the increased funding for direct care

What came next?

- We began preparing for the next budget cycle. We wanted to be able to argue that the increased funding without a set base wage did not do enough to solve the crisis
- We began a regional study of direct care givers and care agencies to gauge the impact of the reimbursement increase
- We also introduced the long- term care study commission as a stand-alone bill

The Ability Center Wage Study

- 95% of home care agencies believe there is a worker shortage
- Almost 50% of caregivers receive no benefits from their agency. No caregivers reported that their agency began to offer benefits as a result of the reimbursement increase
- More than 90% of home care agencies believe that higher wages for workers would result in higher quality care for individuals
- The average turnover for our participants was only 3.16 years as a caregiver, which is especially low for a skills-based profession
- Over 15% of participants had not received a wage increase in the last year, meaning the reimbursement increase did not affect their wage

The Ability Center Wage Study Continued

- 50% of caregiver participants learned about the reimbursement increase during the focus group, showing that Medicaid and their agency were not communicating the increase well. It also means the increase didn't have a noticeable impact for those caregivers
- 1 in 6 caregivers noted that caregivers are not given enough respect for the work they provide
- 73% of caregivers had only received a single wage increase during their tenure as a caregiver. This includes those who would have received an increase due to the reimbursement increase
- The findings of our regional survey were that the average wage among participants in 2023 was $17.38 an hour, with 2024 average wages being $18.96 an hour

Working Towards a Long- Term Care Study Commission

- Set up a monthly coalition on the Long Term Care Study Commission
- Organized a sign on letter
- Organized testimony
- Passed out of House Committee unanimously

HB530, Long- Term Care Study Commission

- Since 2024, we have been working with two legislative sponsors to introduce a Long- Term Care workforce Study Commission
- The bill would establish a legislative commission to study the long-term care workforce in Ohio
- Sets out goals for the commission
- Sets out members of the commission
- Sets out a term for creating a report

Other actions that have had an impact

- Medicaid reimbursement for family caregivers
- Increased self-direction in Ohio

Results

- We are still working on this issue, but the discussion and increased reimbursement have had an impact
- We have heard especially from organizations that manage waivers that it is easier to find direct care workers than it was
- Coalitions have been easier to organize because other groups have already taken action on this issue

Lessons

- Persistence is Key: the more you talk about an issue, the less you have to convince others that it is an issue
- A disability coalition is very powerful:
    - Often, we find ourselves in silos but when we come together, it is hard to ignore us
    - Every group that was involved in the 2023 budget advocacy takes credit for coordinating the advocacy and the resulting increase in funding; the reality is that while we worked together on this, each group took leadership of their own network and that was powerful advocacy

Lessons, continued

- Change is often incremental. Each piece of this project was a huge project of its own, but each moved the needle a tiny bit and that is how change is taking place
- We are on the verge of having to change strategies because the political climate has changed, and likely will change, in Ohio, but we keep moving forward and can make more of a difference at a state level than you would think

Discussion questions

What has your organization done?

What strategies have been successful?

What strategies have not been successful

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