Expendable Necessities?: Cutting Essential Care for People with Disabilities in Minnesota

written by Rachel Garaghty | May 28, 2012

On October 26, 2011, legislation that would lower the wages of caregivers who provide personal assistance services to their disabled family members was ruled unconstitutional by a Minnesota judge. The decision was made on the grounds that it disproportionately affected women and people of color, who comprise a majority of paid caregivers, and that it arbitrarily creates two classes of workers who perform identical duties.[1] This legislation, part of a large health and human services omnibus bill riddled with cuts to many programs, was an attempt to reduce Minnesota's $5 billion deficit without raising taxes. It would have reduced the wages of family caregivers by 20 percent, saving the state approximately $24 million over three years, but lowering the earnings of many caregivers significantly. This proposed legislation represents a growing assault on personal assistance services in Minnesota and across the United States as state governments scramble to cut spending at the expense of their most vulnerable citizens.

Personal assistance services (also called "direct support") enable people with disabilities to receive assistance from paid caregivers to complete activities of daily living (ADLs), which they would be unable to do themselves. ADLs are grouped into six categories of functions that are essential to a person's health and wellbeing: personal hygiene (bathing, grooming, brushing teeth, etc.), dressing, feeding, toileting, transfers (on and off bed, to and from chairs, etc.), and mobility. Other recognized ADLs include behavioral support; supervision in performing routine activities; managing bills, appointments, or other activities; and a variety of other supports that enable a person with disabilities to complete basic functions of daily life. Without personal assistance services, people with disabilities would be forced to live in restrictive institutional settings such as nursing homes, to rely on help from unpaid family members or friends, or to lose the ability to care for themselves entirely.

Yet, in spite of the benefits of personal assistance services, they have come under increasing scrutiny in Minnesota. Fueled by a handful of stories about fraud and mismanagement, the public's suspicion has been aroused over a service that enables over 25,000[2] Minnesotans with disabilities to live independently. Elected leaders of all political stripes have also jumped on the bandwagon, proposing increased amounts of regulation, restrictions, and cuts to personal assistance programs. Some changes, such as greater oversight and more training for personal care assistants (also called direct support professionals, or DSPs), are appropriately designed to protect both DSPs and people with disabilities. Others, such as the proposed wage cut, represent attempts to shift the burden of care from the state to individuals with disabilities and the people who care for them.

Personal Assistance Services: A History

The ability to choose when, how, and by whom a disabled person receives care is a central tenant of independent living and one that was fought hard for. Historically, people with disabilities have been separated from their homes, families, and communities and placed in institutions where they were cared for en masse by limited staff. Overcrowding and inhuman treatment in these institutions was graphically exposed in the 1970s Willowbrook Hospital investigation, where reporters found people with disabilities living lives of extreme deprivation and abuse. In Minnesota, the legacy of

institutionalization is also grim as state hospitals operated well into the 1980s. Evidence of their disregard for basic human dignity still exists in the thousands of unmarked graves of people with disabilities who died while institutionalized.[3] A Minnesota disabled persons' organization, Advocating Change Together (ACT), has led a powerful campaign to restore these institutions' graveyards by identifying the names, birth and death dates, and families of those anonymously laid to rest. In 2010, after much lobbying from ACT, the State of Minnesota finally issued a formal apology to Minnesotans with disabilities who lived, and died, detained in institutions.

The U.S. Disability Rights Movement sought to end the practice of long-term institutionalization and instead transition to full-fledged independent living. Disability rights activists such as Wade Blank, Judy Heumann, and Ed Roberts led Americans with disabilities in a nationwide fight to receive direct support services on an individual basis in their own communities. Direct support enabled people with disabilities to live and participate in their communities, to seek education and employment, and to live with dignity. Moreover, direct support was a more cost-effective way to ensure that people with disabilities received necessary services and experienced a decent quality of life. Money poured into institutions was expended to feed, clothe, and house hundreds of individuals under the same roof and to pay high administrative costs, yet the level of care people received was shamefully low and neglect was rampant. Direct support services cut administrative overhead by enabling people with disabilities to manage their own care. The ability to choose caregivers was also an important victory for personal rights and dignity: people with disabilities could finally choose caregivers whom they trusted, especially with highly personal care such as bathing and toileting, and who were appropriately qualified to meet their unique needs.

Community-based care in group homes provided an alternative to independent living. Today, group homes located in residential communities—often no different in appearance from the single-family homes around them—enable people with significant disabilities to live and receive care without being institutionalized. Group homes with qualified staff and a commitment to enabling people with disabilities to live lives of dignity have a track record of success. However, verified cases of abuse and neglect comparable to that of bygone institutions have recently come to light. In New York State, widespread abuse of people with disabilities living in group homes, including sexual assault, physical beatings, and psychological torment, was exposed in 2011.[4] Acts of abuse were committed by staff who often received no more than a reprimand or were simply transferred to a different group home. In New York and other states where group home abuse has been uncovered, there are a few common denominators: the homes have little oversight and accountability, staff are often unskilled and poorly paid, and people with disabilities are rendered voiceless for lack of advocacy and reliable reporting mechanisms. People with developmental disabilities and mental illnesses have been among the most victimized in cases of group home abuse, yet, they are also among the least eligible to receive direct support services that would enable them to live independently.

Present Day Inequalities

In Minnesota, direct support professionals are the paid employees of over 700 personal assistance provider agencies. These agencies are reimbursed by the state through Medical Assistance (MA), Minnesota's largest publicly funded health care program. MA is Minnesota's Medicaid program and receives both state and federal funding. The reimbursement rate, which is the amount that provider agencies are funded to pay DSPs, determines wage levels. When agencies seek to raise the wages of DSPs above the reimbursement rate, they absorb those costs themselves. Wages for DSPs rarely exceed $11 or $12 per hour and, as result of overall cuts to the personal assistance program in Minnesota since 2009, their average real median wage is $8.98 per hour.[5] For DSPs who provide daily and complex supports to people with disabilities, low wages force skilled workers out of their jobs and increase financial hardships on the ones who stay. DSPs may have to take multiple jobs

outside of the direct support field or work with multiple people with disabilities to make ends meet. However, as a result of legislation passed in 2010, Minnesota's DSPs cannot work more than 275 hours per month regardless of how many people with disabilities they work with, which effectively limits their earning capacity. This limitation on hours has been particularly burdensome for family members who work as DSPs; often, they forgo other full-time employment to provide round-the-clock support for their disabled parents, adult children, or siblings, and only earn wages for roughly nine hours per day.

One of the effects of low earnings is a high turnover rate: nationally, the turnover rate for DSPs ranges from 15 percent to 39 percent.[6] High turnover rates result in higher administrative costs for provider agencies and also put people with disabilities at risk when they have to replace DSPs. In Minnesota, legislation that increased administrative procedures for hiring new DSPs in 2009 increased the time it takes to start working to a month or more. This long wait discourages potential DSPs from entering the profession and also puts people with disabilities in a precarious position of losing their daily, necessary supports as they wait for a new DSP to begin work. The demand for DSPs remains the same and is projected to increase in the near future while demand in other sectors of employment has decreased due to the present economic crisis.[7] However, lower wages, limited hours, and outright red tape is nonetheless creating a shortage of direct care professionals in Minnesota.

These barriers also reinforce broader, nationwide inequalities. Many direct support professionals are women, people of color, and people from diverse ethnic backgrounds, including immigrants, refugees, and naturalized citizens. Many are also the female head of single-parent households. Of the nearly two million direct support professionals in the United States, approximately 40 percent of them receive public assistance because their wages fall below poverty levels, even when they work full-time.[8] Nationally, fewer than half of DSPs have access to employer-provided health insurance.[9] Moreover, federal law has labeled these workers in an ambiguous category of "companion caregivers" for over thirty years, which prevented them from receiving overtime pay and minimum wage protections.[10] While some states, including Minnesota, have laws that extend overtime coverage and minimum wage protection to DSPs, limited reimbursement rates and restrictions on the amount of hours a DSP can work per month effectively prevent them from earning an adequate income. The combination of poor wages and lack of employment-related protections exacerbate longstanding inequalities for women, people of color, and ethnic minorities in the workforce. In spite of the fact that DSPs provide crucial support for people with disabilities, work long hours, and often perform difficult and complex tasks, they are among the most marginalized workers in America.

Minnesota's cuts to the personal assistance program also reveal another trend in the inequalities of caregiving: the increasing burden placed on families who already subsidize the state with unpaid labor caring for their disabled members. Family caregivers keep people with disabilities out of group and nursing homes, thereby absorbing costs that would otherwise go into their care. A growing body of literature on caregiving shows that families, and most often women, forgo other economic opportunities to stay home and care for disabled or aging family members. These caregivers often give up paid employment working outside the home—or limit their employment prospects—by providing full-time care for their disabled family members. In many cases, family caregivers have little choice when they make this decision. People with disabilities who lose the direct support of their families may be forced to live in nursing homes, group homes, or lose their care altogether. The fact that the personal assistance program allows family members to be employed as direct support professionals essentially reimburses them for the labor subsidies that they already provide to the state, though their wages rarely account for all of the hours actually spent providing care.

Effects on People with Disabilities

Cuts to the personal assistance program have left some disabled Minnesotans without adequate care. Recent eligibility restrictions for personal assistance services affected Minnesotans with severe mental illnesses, developmental disabilities, and chronic medical conditions. These Minnesotans are experiencing cuts in the amount of care they receive from DSPs and some are losing that care entirely. Legislation passed in 2009 and implemented July 2011 caused over 3,000 children and adults with chronic health and behavioral needs to lose almost all of their personal assistance.11 Now, these individuals can only receive a maximum of 30 minutes of direct support per day, regardless of the amount of support they received before the changes took effect. What this restriction means is that people with health and behavioral needs are now more vulnerable to worsening of their conditions, diminishing quality of life, and at greater risk for emergency interventions such as hospitalization. It will also become more difficult for these individuals to find DSPs, who may not consider it economically feasible to spend time and money traveling to a worksite where they are paid minimum wage for only 30 minutes of labor.

In spite of these eligibility cuts for the personal assistance program, it is unlikely that Minnesotans who had their support reduced will be able find care in other settings to account for their loss. Rather, these individuals are simply disappearing from the public's awareness. For many Minnesotans who lost direct support, their DSPs were their primary link to the health system and public participation. Without this link, provider agencies and state officials have virtually no connection to these disabled Minnesotans. Some may return to the homes of family members, placing an unexpected burden of care on them, while others who lack family connections may find themselves alone, uncared for, and even facing homelessness. While a multitude of factors went into Minnesota policymakers' decision to cut direct support services for people with mental illnesses, developmental disabilities, and chronic health conditions, stigmatization of these groups undoubtedly played a role. The public's opinion of people with less visible disabilities, especially mental illnesses, remains skeptical and policymakers have shown little sympathy for disabled individuals who appear "normal." Yet, invisible disabilities such as mental illnesses, traumatic brain injury, autism spectrum disorders, intellectual impairments, and learning disabilities account for the largest (and growing) disability category in Minnesota and nationally.[12]

Moreover, 50 percent of Minnesotans who experienced severe cuts to their direct support eligibility are people of color.[13] People of color who are disabled experience "double jeopardy"—discrimination based on both race and disability—and have higher poverty levels among Americans with disabilities. The issues of race, disability, and discrimination came to a head in the lawsuit against Minnesota's proposed 20 percent wage cut for family caregivers. A group of direct support professionals, provider agencies, and people with disabilities, the majority of whom were people of color, brought this lawsuit against Minnesota's governor and the director of the Department of Human Services. These groups, which are already highly marginalized, faced even greater hardship from the 20 percent wage cut. For some of the claimants, the link between family caregiving and racial identity was particularly strong: a high level of cultural competency, including fluency in a language other than English, was necessary for the care of disabled Minnesotans who were Native American, Hmong, and other ethnicities, which family members were well-equipped to provide. The loss of income for these family direct support providers meant deepening financial hardship for themselves, but also the loss of quality care for their disabled family members.

Conclusion

At worst, cuts and restrictions to the personal assistance program directly endanger the lives of people with disabilities. As some Minnesotans with complex physical and mental health needs are "cut off," the risks to their personal safety and well-being will increase. These changes also exacerbate inequalities for direct support professionals, and place undue burden on families of people with disabilities who already experience economic and personal hardship. Since Minnesota's

personal assistance program is financed at both state and federal levels, these cuts are expected to result in the loss of $46 million in federal funding in order to save roughly $24 million in state funding.[14]

Historically, Minnesota's policies for people with disabilities have received broad bi-partisan support and been among the most progressive in the U.S. Yet, legislative changes and cuts over the past three years have reversed important victories and crippled effective programs. Minnesotans with disabilities are finding themselves increasingly in crisis, with little to fall back on when they lose essential services.

Footnotes

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4. Danny Hakim, "At State-Run Homes, Abuse and Impunity, *New York Times*, Mar. 13, 2011.
5. National Clearinghouse on the Direct Care Workforce, *State Chart on Wages for Personal Care Aides, 2000-2010*.
6. American Network of Community Options and Resources, *Direct Support Professionals Wage Study*.
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9. National Clearinghouse on the Direct Care Workforce, *Who are direct-care workers?*
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12. Minnesota State Rehabilitation Council, *2010 Annual Report*.
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