Research *to* Practice

Using Self-Directed Transportation Services to Support Competitive Integrated Employment

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Issue No. 75

Year II Special Study Brief #4

Introduction

For nearly 20 years, ThinkWorkStories! has been studying and developing stories about the practices and strategies that support people with intellectual and developmental disabilities (IDD) to live and work successfully in their communities. The focus of this year's stories is on the use of self-directed services to achieve competitive integrated employment (CIE) and community life engagement (CLE).

Self-direction is a Medicaid service model that allows people with IDD to directly manage their own services and supports. Research shows that the use of self-directed services significantly enhances quality of life and offers an alternative path to achieving CIE and CLE outcomes (Kulchinsky et al., 2021; Caldwell & Heller, 2007; Bogenschutz et al., 2019). Internationally, self-direction is viewed as a valuable service model due to its person-centered nature, individualized approach, and promotion of community integration (Bradley et al., 2021). In the US, nearly one-third of Medicaid Home and Community-Based Services (HCBS) have the option for self-direction, which can include a range of employer authority (e.g., hiring and managing staff) and budget authority (e.g., managing HCBS funds; Friedman, 2024).

Although about 80% of states allow self-direction within their HCBS waivers for people with IDD, only about 13% of people with IDD nationwide self-directed their HCBS in FY 2021 (Friedman, 2024). This is despite Centers for Medicare & Medicaid Services (CMS) (2014, 2019) urging states to expand self-direction and make HCBS more person-centered in alignment with the HCBS Settings Rule (CMS, n.d.). This results in missed opportunities to promote choice, individual control, respect, and self-determination, while ensuring full access to work, community involvement, and a fulfilling life.

The integrated employment rate for people with IDD is impacted by many factors, including access to transportation. Several researchers (Wasfi et al., 2017) have identified the link between transportation and independent living , and the link between community involvement, reported quality of life, and self-directed transportation for individuals with IDD (Harry et al., 2017).

The Institute for Community Inclusion at UMass Boston conducted a qualitative study to learn about the experiences of individuals with IDD who self-direct their employment services. The study aimed to identify strategies and practices that have been effective in achieving employment outcomes. The study conducted semi-structured interviews with people with IDD, their family members, and supports brokers from different states across the country to better understand their experiences with self-directed services, resulting in seven individual ThinkWork! stories.

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This brief is #4 in a series highlighting the self-directed services strategies people with IDD and their family members use. Brief #4 highlights the ways that employment was supported by the choice to self-direct services for transportation.

Self-Directed Transportation Services

Transportation and employment are closely linked, as reliable access to transportation determines whether people can reach job opportunities consistently and on time. When transportation options are limited or inefficient, it can restrict where individuals are able to work and reduce their participation and inclusion in their community. As one participant shared:

> ***"Transportation really is a lifeline for the disability community. It's one of the biggest unmet needs that Medicaid systems struggle to meaningfully address; to get people living with disabilities where they want to go, when they want to go there."***

Access Transportation for Employment

The need to secure reliable and accessible transportation for employment is a key opportunity to incorporate self-directed services. When people have access to self-directed transportation, they are empowered to make service plans and budgets for their needs.

Several participants in the study self-directed their transportation services to and from work. For example, one person's job requires him to travel regularly to conferences and presentations. He included multiple plans and backup plans for transportation in his personalized plan for employment; he realized that having a manageable backup plan for transportation was important because his job required him to travel to various jobsites.

Several other participants who self-directed their transportation services purchased their own accessible vehicles. One participant with a personal vehicle uses self-directed services funding for his staff to drive him to work and healthcare appointments. This has improved the overall accessibility of transportation to work, which was previously complex due to the challenges of navigating public transit or needing to rely on carpooling.

Participants also reported using public transit options. One individual is a substitute teacher who uses self-directed services to purchase transit passes and shared rides. In addition to teaching, she runs her own business where she educates individuals with disabilities to become confident travelers on public transit. She self-directs payments to her job coach to pay for supports that help manage her business. The same participant also uses self-directed funds to support her costs for providing training sessions. Her example highlights the way self-directed transportation services support the individual's job, while also creating space for her to pursue both her passion and self-employment.

Manage Transportation Services for Employment

The ability to manage and organize transportation services, especially for employment, means people have the flexibility and control to purchase the transportation services they need to live their lives. Managing transportation includes hiring staff, making

budget decisions, and paying for travel training.

Some participants required customized options for transportation to work locations, and hiring support staff to provide services related to transportation was essential. One of the participants who used self-directed funds to purchase his own accessible vehicle, then used his HCBS-funded staff to drive him to work and other locations. Having his own mode of transportation through self-directed services allowed him the most flexibility and control, ultimately supporting his employment and CLE. He spoke highly of self-direction for transportation, stating: "I think being able to buy an accessible vehicle was one of the most important decisions I made for myself."

Other participants lived within walkable communities and had frequent support from family members and other trusted adults for transportation. One participant could walk to work, the grocery store, and her parents' house, and only used transportation services for specific travel needs that she could not walk to, such as travelling to and from the airport or events outside her neighborhood. This participant ultimately decided to use her self-directed funds to hire accessible transportation services as needed through an independent provider, rather than through her case management company. This decision was supported by her case manager and family as it was a more cost-effective option for her budget.

Another participant spoke about how public transportation became a barrier to employment because it "is a little tricky" to use regularly; the transit system was described as hard to use, complex, and often unreliable. The ability to self-direct transportation services enabled this participant to navigate issues accessing public transportation and explore transit alternatives that work better for this individual. Having alternative transportation options and transit training allowed her to pursue employment at a business that was a good match for her interests and skills. Having the ability to self-direct her transportation greatly improved her access and integration into her local community and her employment outcome.

Benefits of Transportation

The flexibility that self-directing transportation services provides often extends beyond employment. One participant uses his accessible vehicle and staff support so he can access community activities, visit family, and pursue advocacy work that is important to him. When asked about the benefits of using self-directed services, the person said: "I'm [one] hundred percent happy that… I have that control and that I have the support that I need because it makes it easier for people with disabilities. It's wonderful! I wouldn't trade it for anything."

The previously mentioned participant who became a small business operator providing travel training to others, reported the growing sense of independence in herself and others with disabilities:

> ***"People are coming out of their shell, they're gonna need to learn how to take the new metro system and like, because it's so new. One participant stated that having access to transportation that met her budget and her unique needs was essential for her employment. Being able to manage her own transit options gives her a sense of freedom and integration into her community; when asked about self-direction, she said that 'I love being independent and out in the community; [self-direction] is the optimal service to make it possible for me to do things I want to.'"***

Strategies & Suggestions for People with IDD and Their Families

» **Think about what kind of transportation best supports independence and meets your unique needs and budget.** For example, consider how often you need to use transportation, where and when you need to travel, if you will feel comfortable navigating routes, and what transit options will be accessible.

» **Explore the full range of transportation options available in your community.** These may include public transportation, ride-share services, taxis, specialized para-transportation, hiring a support worker to provide rides, or even purchasing an accessible personal vehicle. Comparing the reliability, flexibility, and accessibility of these options, as well as how well they meet your needs, can help you decide which option will work best for your lifestyle and budget.

» **Work closely with your case manager and other trusted individuals, such as family members or support staff, to support the planning process.** They can help you understand your options, manage funding, and plan for emergencies or backup transportation. Taking the time to plan carefully can help ensure that self-directed transportation services support greater independence, confidence, and participation in your job and your community.

Conclusion

Individuals can use self-directed services to address the barriers they face and find solutions for their unique needs. This is especially important when it comes to transportation, which has been identified as a common barrier to community inclusion.

Several participants spoke about the benefits of self-directed transportation services for their lives and employment outcomes. Having access to reliable and affordable transportation has enabled individuals to work. By addressing this barrier to both employment and community life engagement, many participants reported feeling more independent, connected to their community, and capable of pursuing more interests and advanced careers.

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The contents of this report were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90IFRE0058). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this report do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the Federal Government.

Suggested Citation

White, A., Powers, B., Bose, J., Kamau, E., & Winsor, J. (2026). Using Self-Directed Transportation Services to Support Competitive Integrated Employment Research to Practice No. 75. University of Massachusetts Boston, Institute for Community Inclusion.

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