

An Evaluation of Transportation Best Practices for People with DD

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Report prepared by:

Caitlin Crabb, PhD, MPH
Institute on Disability and Human Development

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Executive Summary

Background: Transportation is a significant barrier to independent living for people with disabilities, including people with intellectual and developmental disabilities.

Transportation barriers are prevalent across the United States and are not specific to Illinois.

Recommendations:

Travel Training and Planning:

Key Takeaway: Training and planning is very helpful in facilitating transportation independence and use of transportation by people with IDD. Many curricula exist and the delivery of training takes several forms.

Recommendation 1: Explore existing travel training and planning curricula.

Recommendation 2: Disseminate information to providers through an Information Bulletin or webinar.

Recommendation 3: Prioritize peer-to-peer travel training and planning methods.

Technology Solutions:

Key Takeaway: The use of smartphone apps that provide detailed instructions on using public transportation show promise in increasing travel independence of people with IDD. This could work in cities across the state with public transit, not just in Chicago. However, this generally requires the use of an app/smartphone which would need to be purchased and available for individuals to use to ride transit.

Recommendation 1: Connect with AbleLink and provide a training to providers on the use of WayFinder for individuals with IDD.

Ridesharing:

Key Takeaway: Ridesharing may be a good option for people with IDD who have higher levels of independence, fewer support needs, and do not use wheelchairs. The training/screening of drivers and the physical accessibility of vehicles are areas of concern. Additionally, ridesharing typically requires a smartphone, so users would need to own or have access to a smartphone.

Recommendation 1: Explore additional options to fund ridesharing (outside of paratransit) for people with IDD.

Recommendation 2: Partner with Pace and self-advocates to deliver IDD-specific training to rideshare providers and drivers.

Enhanced Mobility of Seniors & Individuals with Disabilities - Section 5310:

Key Takeaway: Section 5310 funding could be an excellent resource for provider agencies, especially larger agencies, to obtain a Mobility Manager to facilitate transportation for individuals with disabilities. Additionally, it could be used to test novel approaches to transportation, such as using volunteer drivers.

Recommendation 1: Provide a webinar to providers about Section 5310 Funding opportunities, potentially with providers that are already using Section 5310 funding.

Background

Transportation Barriers

Transportation is a significant barrier to independent living for older adults and people with disabilities. Adults with disabilities are less likely to own or access vehicles than adults without disabilities (Brumbaugh, 2018). A survey of organizations across the United States that provide transportation for older adults and people with disabilities found that for people who do not drive, finding alternative modes of transportation was difficult (NADTC & KRC Research, 2020). Therefore, adults with disabilities are more dependent on other forms of transportation outside of personal vehicles.

Issues related to transportation for people with intellectual and developmental disabilities (IDD) contributes to limitations in employment and independence (Price et al., 2018), religious participation (Vogel et al., 2006), physical activity (Bodde & Seo, 2009), and leisure participation (Buttimer & Tierney, 2005). A study of 12 adults with IDD in Philadelphia identified physical barriers, wait time, planning, lack of control/anxiety, navigation, and limited availability as barriers to transportation (Pfeiffer et al., 2021). Meanwhile, facilitators included technology, travel time, training, convenience, personnel support, and safety.

The purpose of this report is to 1) describe the landscape of public transportation and paratransit in Illinois; 2) identify promising and best practices in the provision of transportation for people with IDD; 3) describe approaches to providing transportation to people with IDD across the United States; and 4) provide recommendations to improve transportation for people with IDD in Illinois.

Illinois Landscape

Living in an area with a large population (and likely a more established public transportation infrastructure) was one of the most powerful predictors of sustained employment for people with autism and intellectual disability in a study of factors associated with sustained community employment (Chan et al., 2018). Illinois is home to Chicago, the third-largest city in the United States. The Chicagoland area includes public transportation systems like the Chicago Transit Authority (CTA), the METRA, and Pace. The CTA represents the second largest transit agency in the United States

(following the MTA in New York) (American Public Transportation Association, 2021). Additionally, Pace Suburban Bus is within the top 50 largest bus agencies in the United States, and the CTA is the second. Pace paratransit is the second largest demand response agency in the United States.

As for the rest of Illinois, as of March 2021, 58 transit systems were operating in 96 of Illinois' 102 counties; 452 million transit passenger trips were taken over the past year (Illinois Department of Transportation, 2021). The following Illinois cities, Chicago not included, have larger transit agencies (defined as more than two million boardings per year): Bloomington (Connect Transit), Champaign (Champaign-Urbana MTD), Peoria (CityLink), Rock Island (MetroLink), and St. Louis (Madison County Transit, St. Louis Metro).

Challenges to transportation for people with IDD are not unique to Illinois. For example, the 2017-2018 National Core Indicators In-Person Survey indicated that there was not a significant difference between Illinois and the rest of the NCI-participating states regarding the number of people who could not see their friends because of lack of transportation (Human Services Research Institute, n.d.). Additionally, there was not a significant difference in the percentage of people who had transportation to go places that they need to go or want to go. The percent of people who had additional transportation service needs was lower in Illinois (3%) than the rest of the participating NCI states (10%), though this difference was not statistically significant.

Staff turnover and the inability of organizations to hire and retain staff contributes to transportation challenges: reduced staffing often means that if one person needs to go somewhere, everyone else in the house has to go, too. Or, that everyone has to stay home. In the 2020 Staff Stability Survey, part of the National Core Indicators, Illinois indicated 44% turnover, which falls about in the middle of the participating states (National Core Indicators, 2022).

Transportation Best and Promising Practices

The Arc of the United States Transportation Position Statement

In 2019, the Arc of the United States released a position statement related to transportation of people with IDD (The Arc of the United States, 2020). Some

components include the following (see the link in the references for the entire statement):

- Transportation is available to everyone at comparable cost and modes
- Individuals with IDD are involved in transportation planning and decision-making
- Existing transportation is enhanced through better coordination
- Public transportation is appropriately funded, accessible, reliable, and meets everyone's needs
- Transportation technological innovations consider accessibility, usability, and reliability
- Travel training is available for all modes of transportation, preferably using peer-to-peer training
- Disability awareness training is available to transportation providers
- Transportation barriers within suburban and rural areas are addressed
- User privacy is protected and data sharing is transparent
- Riders may share information with a third party in order to address safety and efficiency issues
- People with IDD may choose to own vehicles or use other types of transportation modes at affordable costs
- All vehicles meet safety requirements

The National Aging and Disability Transportation Center 2021 Trends Report

The National Aging and Disability Transportation Center (NADTC) 2021 Trends Report lays out suggestions to support people with autism when riding transportation, both for the person with autism/caregiver and for drivers (NADTC, 2022). Suggestions for people with autism and/or their caregiver include:

- Using headphones to block out noise
- Travel at less busy times if possible
- Sit in an empty row and by the window if possible
- Carry a familiar item with you

Some suggestions for drivers that are supporting someone with autism in a difficult situation include:

- Understand communication needs of regular riders
- Share/review rules with riders
- Describe the steps of the trip to the rider
- Let riders know in advance of any changes to routine
- Have sensory items available in the vehicle

The Council on Quality and Leadership

The Council on Quality and Leadership provides the following advice to organizations and DSPs to strengthen transportation skills of people with IDD (Friedman et al., 2022):

- Accompany individuals on their routes (walking and riding)
- Practice potentially challenging situations
- Work with individuals to problem solve on their own when issues arise
- Reduce supports gradually as an individual becomes more confident in navigating transportation
- Develop relationships with drivers and others using transportation
- Ensure that individuals have an emergency contact when an issue arises

Transportation Approaches for People with IDD in the US

Travel Training and Planning

A study of the impact of a comprehensive travel training program on individuals with IDD found that the skills needed to use public transportation improved after the training, especially for those with intellectual disability compared to those with ASD and/or no intellectual disability (Pfeiffer, Sell, et al., 2020). While a number of travel training curricula have been developed and used, none have been tested for their efficacy with the exception of the study just mentioned. The following paragraphs describe approaches to providing travel training for people with IDD, but they have not been empirically tested.

In Michigan, a program called Community Active Transportation Program provides travel training for individuals with IDD 18 years or older (PEAC, n.d.). The program takes a novel approach in that students of the program volunteer at different

places, like community gardens and festivals and to get to the volunteering location, they learn skills to use three different modes of transportation: fixed route buses, biking, and walking. A similar program, School Active Transportation Program, targets students in special education programs.

The Transportation Advocacy Mentoring Initiative, while not specific to people with IDD, pairs youth with disabilities from Massachusetts with youth with disabilities from Michigan who already had experience in transportation advocacy (Easterseals et al., 2018). The pilot found that participants were better able to describe transportation options in Massachusetts, better able to identify transportation solutions, and more experienced in transportation advocacy. A guide is available to help organizations implement a peer mentoring program aimed at transportation advocacy (see references).

Community mobility plans (CMPS) support all modes of transportation while recognizing and addressing person- and environment-level barriers to community mobility (Classen & Pfeiffer, 2020). CMPS includes “goal-development, assessment, targeted instruction on specific travel skills, and attainment of resources to reduce environmental barriers” (Pfeiffer, Falo, et al., 2020). Results of a study on the feasibility of CMPS for people with DD found that participants had significant improvements in pre- and post-test scores for travel skills and goal attainment (Pfeiffer, Falo, et al., 2020).

Key Takeaway: Training and planning is very helpful in facilitating transportation independence and use of transportation by people with IDD. Many curricula exist and the delivery of training takes several forms.

Technology Solutions

Technology has the potential to address transportation barriers: currently, smartphones with GPS are the most “readily available” technology transportation solutions (Stock et al., 2019). Several studies have evaluated the impact of technology solutions on transportation for people with IDD, particularly focused on AbleLink technologies like WayFinder.

AbleLink WayFinder is an app that is designed for people with intellectual disabilities to get around, either using transit or walking (AbleLink, n.d.). WayFinder allows individualized travel routes to be created by staff, a caregiver, or a family

member in which content can be personalized to fit the needs of the individual. Once an individual has begun a route, the staff, family member, or caregiver can view location updates. The WayFinder app provides the user with visual and audio instructions and is available for both iPhones and Android phones. A study of an early prototype of WayFinder found that people with IDD who use WayFinder to navigate fixed-route bus systems had fewer supports needed and were able to use transportation successfully (Davies et al., 2010). Another study found that the use of WayFinder resulted in fewer training sessions needed and the successful completion of a route by 92% of participants, while also showing the potential for cost savings to agencies (Stock et al., 2013).

The Smart Travel Concierge System (STCS) is a collection of technology tools that include pre-trip assessment, training, and planning activities to support greater independence of people with IDD in navigating public transportation (Stock et al., 2019). Stock et al. (2019) conducted a study on two pilot programs that used the training and planning components of the STCS and found significant improvements from pre- to post-test after the implementation of the STCS components, supporting the potential for technology to better equip individuals with IDD in using fixed route public transportation.

New Star is a service provider supporting individuals in the Chicagoland and Northwest Indiana areas. New Star received funding from the Illinois Council on Developmental Disabilities (ICDD) to develop an app so that its consumers could receive on-demand rides from volunteer drivers familiar to the organization. However, due to the pandemic, the app has not yet launched.

Key Takeaway: The use of smartphone apps that provide detailed instructions on using public transportation shows promise in increasing travel independence of people with IDD. This could work in cities across the state with public transit, not just in Chicago. However, this generally requires the use of an app/smartphone which would need to be purchased and available for individuals to use to ride transit.

Ridesharing

Ridesharing is on-demand travel in which a rider requests a ride from driver's private vehicle, typically through a smartphone app. To the author's knowledge, no studies have been conducted to date on the impact and/or usage of ridesharing by

people with intellectual/developmental disabilities. Two programs that facilitate ridesharing for people with intellectual and developmental disabilities are described in the proceeding paragraphs, though again, they have not been empirically evaluated.

In January 2022, Pace launched a pilot project with Uber in DuPage County, Illinois (Pace, 2022). For Pace ADA Paratransit passengers, they may opt to use Uber (up to a \$30 ride) as an alternative to traditional Pace paratransit services. Eligible passengers who have a smartphone can use the Uber app to book on-demand trips or to schedule upcoming trips. Eligible passengers who do not have a smartphone can make reservations by telephone. This program was modeled on Pace's Taxi Access Program (TAP) in Chicago. The TAP program allows for Pace ADA Paratransit riders to use taxis on-demand instead of the traditional Pace paratransit services (Pace, n.d.). Riders pay \$3 for rides up to \$30 (the \$3 fee has been waived since the onset of the COVID-19 pandemic). Riders are responsible for the any costs over \$30.

Rise is a non-profit organization that serves individuals in Minnesota and Wisconsin. Rise works to support access to employment, housing, and other "life-enrichment" services. Rise partnered with Lyft to provide rides to people with intellectual disabilities to get to and from competitive, integrated employment. Around 40 individuals are participating in this program. Rise helps individuals schedule their rides and uses a credit card to pay for them, which is then reimbursed by the state Medicaid waiver program.

Some have suggested that ridesharing may not always be a good option for people with IDD. For instance, a report on ridesharing within non-emergency medical transportation (NEMT) indicated that people who required hand-to-hand assistance may not be ideal riders for ridesharing, though some may be more able to use ridesharing NEMT if they had a companion with them (Fraade-Blanar et al., 2021). Those requiring hand-to-hand assistance would not be ideal riders for ridesharing NEMT because they may require more support than a driver would or could provide. Challenges associated with ridesharing within NEMT include low pay for drivers, incomplete driver screening, and safety issues for both drivers and passengers (Chaudhry et al., 2018; Ganuza & Davis, 2017). Another criticism of ridesharing more broadly is a lack of accessibility for

people with disabilities, and in some cases, this has led to lawsuits against Uber and Lyft (Lien, 2018; Said, 2018).

Key Takeaway: Ridesharing may be a good option for people with IDD who have higher levels of independence, fewer support needs, and do not use wheelchairs. The training/screening of drivers and the physical accessibility of vehicles are areas of concern. Additionally, ridesharing typically requires a smartphone, so users would need to own or have access to a smartphone.

Enhanced Mobility of Seniors & Individuals with Disabilities - Section 5310

Section 5310 provides formula funding to states to support private non-profit organizations to address transportation needs of older adults and people with disabilities when transportation is insufficient (Federal Transit Administration, n.d.). Each state is apportioned funds based on their share of the population for older adults and people with disabilities. Funds are apportioned to either the state's Department of Transportation (in rural and small urban areas) or at the discretion of the governor (in large urban areas) – these are the “direct recipients”. The recipients of the funds from direct recipients may be states/local government authorities, private non-profit organizations, and/or public transportation operators. Traditional project examples include vehicles and mobility management programs while nontraditional project examples include volunteer driver programs and travel training. A survey of organizations that provide transportation for older adults and people with disabilities in the United States found many positive attributes associated with receipt of Section 5310 funding including: a higher likelihood of having a Mobility Manager position, greater coordination with other providers, a greater likelihood of providing rider assistance, and more flexible weekend scheduling (NADTC & KRC Research, 2020).

Bayside Community Network, Inc. is a service provider located in Cecil County, Maryland. Bayside provides at-door transportation services for individuals enrolled in their various programs. Bayside, in partnership with Cecil County Transit (Cecil County's public transportation), applied for, and received, a Section 5310 formula grant (authorized through 49 U.S.C. Section 5310 / Fixing America's Surface Transportation Act 3006 (FAST)) and hired a Mobility Manager. The project is called “Mobility 4 All”. The project's purpose was twofold: 1) to provide gap-filling NEMT rides to Cecil Transit

Customers through direct referral and 2) to identify Bayside consumers to participate in Cecil Transit's Travel Training program to increase their independence. At Bayside, the Mobility Manager is responsible for organizing routes, managing drivers' schedules, and maintaining the efficiency of the vehicle fleet. Additionally, the Mobility Manager identifies individuals who may be able to utilize other modes of transportation outside of Bayside's fleet/drivers, including Cecil Transit and Uber. However, due to the pandemic, individuals who were identified as being able to use other modes of transportation have not been able to do so, yet.

Key Takeaway: Section 5310 funding could be an excellent resource for provider agencies, especially larger agencies, to obtain a Mobility Manager to facilitate transportation for individuals with disabilities. Additionally, it could be used to test novel approaches to transportation, such as using volunteer drivers.

Recommendations

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