



## **Exploring transportation needs and obstacles to community inclusion for families of individuals with disabilities in the Northwest Suburbs of Chicago**

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## ABSTRACT

Empirical research has demonstrated that individuals with disabilities face a variety of challenges to full inclusion in their communities (Bascom & Christensen, 2014; Delbosc & Currie, 2011). While the Americans with Disabilities Act (ADA), the Individuals with Disabilities Education Act (IDEA), and Section 504 of the Rehabilitation Act protect the rights of individuals with disabilities in regard to federally funded education and school-related activities, much less is known about the experiences of individuals with disabilities as they ‘age-out’ and transition away from educational institutions. Through a partnership between the Northwest Special Recreation Association and Connect to Community, an online survey was distributed to explore the transportation needs and obstacles to community inclusion negotiated by families and care providers of individuals with disabilities in the northwest suburbs of Chicago. Following the survey, four focus groups were completed to delve more deeply into the transportation-related issues identified by participants.

Survey results indicated that the top five primary transportation needs were to and from family activities, day services, recreation activities with others, errands, and employment. Parents and care providers were overwhelmingly the ones providing transportation due to safety concerns, service boundary issues, unreliability of service providers, and lack of access to affordable, accessible public transportation. The consequences of these challenges included an increased dependence of individuals with disabilities on their families and care providers, employment limitations for both the individuals with disabilities and their families, and feelings of isolation, frustration, anxiety, and stress among the families, care providers and individuals with disabilities.

Three key themes emerged from the focus groups: Families are unique, but challenges are similar; Inconsistencies have consequences; and, Personal Development depends on community inclusion. First, while each family’s situation was unique, transportation challenges were, or will be, similar in terms of how they impact their child and family. Second, while public transportation inconsistencies, like detours, delays, and unruly riders, might be easily negotiated by individuals who can ask questions and process more complex information, they can have very dangerous repercussions for individuals with disabilities who are unable to do so. Participants did suggest that added services such as bus aides and real-time technologies could enhance the abilities of families to help individuals with disabilities navigate the inconsistencies of public transportation. The final theme that emerged from the focus groups was the high value that families and care providers place on providing individuals with disabilities opportunities for community inclusion. Families choose to prioritize opportunities for their children to participate in community activities in order for them to form strong social relationships, maintain their health and fitness, increase their financial status through employment, and develop skills for independent living which will be necessary now and as caregivers age and pass away.

## INTRODUCTION

Research has shown that community inclusion is important for individuals, be they disabled or not. It has also been demonstrated that the severity of an individual’s disability greatly impacts opportunities for inclusion. The more severe an individual’s disability the less likely they are to find opportunities for inclusion (McConkey, Abbott, Walsh, Linehan, & Emerson, 2007). Lippold and Burns (2009) found that the social networks of individuals with

intellectual disabilities consisted mainly of family members and professionals, such as doctors and recreation providers. The promotion of inclusion for individuals with disabilities can help combat poverty and unemployment (Power, Lord, & Defranco, 2013), enhance safety and protect against abuse (Quinn & Doyle, 2012), and lower negative attitudes, stereotypes, and discrimination (Mahar, Cobigo, & Stuart, 2013). Community inclusion is important for the health of all individuals, but the reality for many individuals with disabilities is that once they age out of education settings their primary social interactions may be with family members and service providers with limited opportunity to build other meaningful relationships in the community due to a lack of transportation.

In the State of Illinois, individuals with disabilities are entitled to educational and related transportation services until they reach the age of 22. At that point, families and care providers must assume the primary responsibilities for planning and providing for their transportation. While some individuals with disabilities are high functioning and able to plan their own travel and/or drive themselves, most are not. Driving to an appointment, or catching a bus to and from work may seem simple for those who are not disabled, but can require hours of planning and coordination for the caregivers of those with disabilities. Oftentimes, it is the family and caregivers who sacrifice their time in order to meet the needs of planning and providing transportation for individuals with disabilities due to a lack of safe, cost-effective, accessible options. Families and care providers are often the only option available to individuals with disabilities when the community does not provide adequate accessible transportation, or when service boundaries and safety concerns limit use. Parents may have to work different shifts, seek alternative employment, or leave employment altogether when their children's transportation needs are not met by service providers.

Based on their examination of peer-reviewed studies exploring the effect of the environment on community participation of individuals (5-21 years old) with disabilities, Anaby, Hand, Bradley, DiRezze, Forhan, DiGiacomo, and Law (2013) determined, "The most common facilitators involved social support of the family and friends and geographic location. The most common barriers included attitudes, physical environment, transportation, policies and the lack of support from staff and service providers" (p. 1589). Studies have found that significant barriers exist related to excessive hold times when calling to arrange trips, lack of door-to-door service, denials of requests and attitudinal barriers among drivers (National Council on Disability, 2015). And while there is anecdotal evidence to suggest that some individuals with disabilities are utilizing ride sharing providers (i.e., Lyft, Uber), there is a lack of empirical literature regarding these opportunities.

## **SERVICE AGENCIES**

### **Northwest Special Recreation Association**

NWSRA has enriched the lives of children and adults with disabilities as a partnership of 17 Park Districts located within the northwest suburbs of Chicago by providing outstanding recreational opportunities for over 40 years. Certified staff lead and oversee thousands of innovative recreational programs and services each year. In the heart of the community, individuals with disabilities have the opportunity to make friends, have fun, go new places, learn new things, be included and celebrate their lives at NWSRA.

## **Connect to Community**

Founded in 2013, Connect to Community (CTC) is a parent-led nonprofit serving young adults with developmental disabilities and their families in the northwest suburbs of Chicago. With a focus on preparing for and navigating the transition out of Educational Entitlements and into a full and meaningful life in the community, CTC provides Customized Employment services, hosts educational seminars and tours, and provides social and volunteer opportunities for their young adult clients. CTC is a fierce advocate for people with disabilities including their right to live, work and recreate in their own communities.

## **Public Transportation Services**

There are public transportation services dedicated to supporting the needs of individuals with disabilities in the northwest suburbs of Chicago. The most common include bus services offered through Pace Suburban Bus and Township Buses. Information provided below came directly from provider websites.

Pace's family of public transportation service offers affordable and environmentally responsible transit options for the residents of 284 municipalities in Cook, Will, DuPage, Kane, Lake and McHenry counties. The backbone of Chicago's suburbs, Pace serves more than a hundred thousand daily riders. Services provided include fixed route bus service, RideShare Matching Service, Vanpool, and ADA Paratransit Service. Paratransit service is the general term for a "demand-response" service in which a passenger must reserve a ride in advance. Unlike fixed-route service, in which buses travel the same route in a regular pattern and pick up any waiting passengers, paratransit vehicles make only pre-arranged trips for riders who are eligible for the particular service. Pace also operates a fixed route system, which is entirely accessible to people with disabilities. For senior citizens and people with disabilities, fixed route is a less expensive way to get around the community and gives people the freedom to travel without arranging a ride in advance.

Some townships in the northwest suburbs of Chicago provide transportation services for seniors (age 60 and over) and permanently disabled residents. Wheeling Township, for example, provides one round trip per day service on weekdays between 9:00 – 3:00 pm. Riders must have advance reservations and should be ready 15 minutes before the scheduled pick-up and return times. Payment must be made to the driver with exact change and passengers are limited to bringing two grocery sized bags. Buses operate within Wheeling Township only. (Wheeling Township Transportation, 2019).

## **Private Transportation Services**

While not currently available in the northwest suburbs of Chicago, Uber also offers uberWAV (wheelchair accessible vehicle). Chicago is among the cities where pilot testing is now occurring. According to their website, riders who use folding wheelchairs can request accommodations in any of its ride options and all drivers are expected to accommodate individuals using "... walkers, canes, folding wheelchairs, or other assistive devices". According to Uber, uberWAV drivers, using specialized minivans, "are certified by a third party in safely driving and assisting people with disabilities". (Uber, 2019). Uber states that the price of a uberWAV ride is similar in price to an UberX price. Malcom Glenn, Uber's head of global policy, accessibility and underserved communities, stated that while uberWAV services are subsidized and will operate at a loss, "it is very costly, but we recognize this is a thing where we

can demonstrably transform the way that people have historically thought about transportation, a population of people whom there have been huge barriers.” (Siddiqui, 2018)

## METHODS

The goal of the study was to provide transportation providers, policy-makers, practitioners, and families with better understandings of the lived experiences of individuals with disabilities for the purpose of facilitating community inclusion. The study design, purpose, and goal were consistent with previous research used to inform policy development and efficient service delivery (Bascom & Christensen, 2017; Henning-Smith, Evenson, Kozhimannil, Moscovice, 2018; Jansuwan, Christensen, & Chen, 2013).

An online survey was designed to collect demographic information, to quantify how frequently various forms of transportation were used to reach common destinations, to determine specific transportation-related constraints and barriers negotiated by families and care providers, and to develop a catalog of services and strategies used to negotiate transportation needs. The surveys were completed by parents/guardians of individuals with disabilities. Open-ended questions were used to allow respondents opportunities to describe the nuances of specific experiences. The survey asked 38 questions; 11 were open-ended to provide more information.

Broadly, the questions explored what services children/clients with disabilities were using, what types of transportation were being used to get the child/client to those services, what barriers were negotiated in regard to providing transportation, and what ideal transportation for children/clients would look like. The survey was distributed on October 29, 2018, and data was collected through November 19, 2018. The survey was emailed to roughly 5,800 individuals who participate in programs coordinated by NWSRA and/or Connect to Community. A link to participate in the survey was also posted on the agencies’ Facebook pages which have roughly 7,300 followers. Reminders were posted weekly during the collection period. In total, 341 participants began the survey from the emailed link, and 34 responded to the posted links on Facebook. Seventy-nine individuals who completed the survey volunteered to be in follow-up focus groups.

Invitations to participate in focus groups were distributed in April 2019. Four focus groups were scheduled for the summer at public locations within the NWSRA service community. Given that late spring and early summer are busy times for families, focus groups were scheduled far in advance; participants were advised that the focus group would likely take between sixty and ninety minutes. A question protocol guided the focus groups; an informal, conversational style was used by the researcher to facilitate rapport and encourage interactions between the participants (Krueger & Casey, 2015). The shortest focus group lasted just under an hour; the others finished between an hour and ninety-nine minutes. All focus groups were audio-recorded and transcribed.

Focus groups began with an overview of the research process delivered by a representative of Campfire Concepts and/or the lead researcher. The following were all explained: representatives from the sponsoring agencies were present, but would not be allowed to engage until the end of the focus group; anonymity could not be guaranteed for participants, but confidentiality would be in all subsequent publications and presentations; and, that participants would be invited to a presentation following the focus groups to verify that their experiences were being accurately reflected. During the focus groups, agency representatives took field notes regarding the emotional state of participants during the focus groups. They noted topics that they

felt seemed especially important to participants so that the researcher could focus on what was being said. At the conclusion of the focus groups, agency representatives were given the opportunity to address any questions or misinformation shared during the focus group discussions. A follow up thank you to the participants was sent at the conclusion of the focus groups.

Focus group data (transcripts and field notes) were analyzed using Nvivo 12 Mac (QSR International, 2019). Charmaz (2014) was used for procedural guidance throughout the analysis procedures. The analysis began with the researcher reading the transcript and identifying initial codes that outlined the experiences. Common codes included boundary challenges, inclusion challenges, aging issues, family effects, fostering inclusion. Focused coding was used to identify contexts, qualities, and conditions affecting participants' experiences. In this section of coding, common codes included parental responsibility, siblings, work and leisure, functional abilities. Thematic coding was used to integrate the experiences into themes.

## **KEY SURVEY FINDINGS**

### **Demographics**

Overall, the most common respondents were:

- White 88%
- Parent/guardian 93%
- With a college or advanced degree 79%
- Between the ages of 46-65 79%
- Living in a two parent/guardian home 69%
- Household of between three to five individuals 78%
- Resided in Cook or Lake County 91%

Overall, the most common characteristics of the child/client with disabilities were:

- White 78% and Hispanic, Latino, or Spanish 10%
- Had been disabled since birth 79%
- Were male 67%
- Between the ages of 19-25 45% and 26-35 27%
- With a high school education 70%

To help determine if respondents' answers were consistent across the survey questions, respondents were asked to rank how significantly their child's/client's experiences are affected by a lack of accessibility to transportation. Responses indicated that transportation issues most affected community engagement, recreation, social life and employment opportunities. Responses suggested that parents/guardians prioritized the coordination and provision of transportation to activities based on how much they felt the lack of participation in those activities-would affect their child/client's experiences.

*Please share to what degree you feel your child's/client's experiences are affected by a lack of accessibility to transportation. Responses reported in percentages.*

Aspect	Not at all	Minimally	Somewhat	Moderate	Very
Community Engagement N=124	7	9	21	27	36
Education N=110	32	22	8	15	24
Employment N=106	19	5	16	23	38
Health N=109	26	27	24	10	14
Recreation N=123	7	15	22	20	36
Social Life N=132	8	10	19	24	39

### **Transportation Needs**

Respondents were asked how much time they spent planning and providing transportation for their child/client to the selected activities during a typical week. There were many variables that affected transportation needs. Respondents with children/clients who were still in school spent little time planning or providing transportation; those with older children/clients spent more time planning and providing transportation. One parent noted, "He is still in school, but boundaries will have a significant affect when he ages out." This is consistent with the survey responses. For example, while only four percent of respondents (N=152) reported spending more than an hour per week providing transportation to day services for individuals under the age of 18, 24% of the respondents reported spending more than an hour per week providing transportation to day services for individuals between the ages of 19 and 35.

Respondents with children living in group homes reported spending little time planning or providing transportation, though it was noted that they had to step in when the staff was unable to provide rides. The functional level of the child also affected transportation needs; respondents with children who were non-verbal, had behavioral issues, and/or required accommodations not provided by public transportation spent more time planning and providing transportation. One mother noted,

I spend almost two hours each day, driving back and forth, with about four and a half hours in between. It's hard, but my son deserves a life of his own and this is the only way to achieve that.

Another parent noted,

Since there is no transportation on Sundays, I spend a total of 160 minutes driving a total of 60+ miles to get our son to work. I spend 80 minutes driving 30 miles in the morning

and 80 minutes driving the same distance to pick him up from a 5-hour shift in the afternoon.

Some respondents reported that they were unable to make up the gap in public transportation options, so their child/client was unable to participate in activities. One parent said, “We have worked hard to create a full active life away from home. For every successful activity, there becomes a new transportation need.” They were not spending time planning or providing transportation because their jobs and other commitments made it impossible for them to meet the needs.

The uniqueness of each situation should be considered in assessing the range of time families and care providers spent planning for and providing transportation. Most respondents indicated spending less than 15 minutes a week planning transportation for their child/client to activities; this could be attributed to 62% of the respondents having children/clients under the age of 25. As mentioned previously, in the State of Illinois, individuals with disabilities are entitled to educational and related transportation services until they reach the age of 22. As the chart below demonstrates, many respondents were providing more than an hour’s worth of transportation to specific activities each week; some reported spending as much as 10 hours a week providing transportation to/from activities.

*Percentage of respondents who indicated spending more than an hour a week providing transportation to activities:*

Activity	Percentage
Family Activities	44
Day Services	42
Recreation Activities with Others	41
Errands	40
Employment	32
Medical Appointments	30
Leisure Activities with Others	28
Leisure Activities by Themselves	23
Religious Opportunities	16
Other	13

A few of the open-ended responses more richly explained how providing transportation impacts the respondents’ lives:

- Transporting my children with special needs is a full-time job. No matter how independent they become at home, I have to transport them EVERYWHERE due to the nature of their disability.
- My life as a single working mom of two revolves around caring for my disabled son. I had to leave a successful career for a stay-at-home job and part-time job for the flexibility to care for my son and drive him to school, medical appointments, recreation, etc. My income is 1/3 of what it was and he's now on Federal free lunch. We are struggling financially. It is a strain on the quality of life of all three of us. Transportation is partly a cause.



- If I wanted him to be out of the house and engaged in the community, it was up to me to get him there.
- It's been THE most nerve-racking experience. I never know when the bus is going to arrive even after receiving the 15-minute warning call. I never know how long my daughter will be on the bus - how many other stops she has before she reaches her destination. My daughter has had to wait up to 2 hours past reservation time for her bus to arrive and has spent upward of 2 hours on some trips. I go crazy not knowing what is going on. In addition, I spend 15-30 minutes each morning on hold with Pace to make a reservation - I have to get to work in the morning and this is unacceptable. I don't know why at this time in history that this is not computerized. Why can't we make on-line reservations and see real time routes of the buses that our kids are riding? The system is outdated.
- I feel if she could join in recreational activities, she would have more to contribute in family talks. Right now all she talks about is work and cleaning her room. I would like to be able to have an actual conversation.
- I've sacrificed my career to be available just to transport my daughter - she's able and capable but can't access community unless I get her there. Paratransit only medical stinks. My husband and I can't go away for weekend as she's stuck home alone

### **Transportation Obstacles**

Data demonstrated that parents/guardians are providing the bulk of transportation for children/clients. Other forms of transportation that were often used included riding with siblings, riding with care provider/respite worker, riding with parent's/guardian's friends, and walking to destinations. What this data suggests is that parents/guardians are using their familial and social networks to try to meet transportation needs rather than public and/or paid options due to safety concerns, lack of affordable door-to-door options, the unreliability of paratransit, and the support needs of their child/client. Further, data demonstrated that service boundaries greatly impact the transportation options for families in the northwest suburbs of Chicago.

The study participants responded to open-ended questions asking why they did not use services that were available to them. The quotes below are indicative of the themes that emerged among the responses.

- Public transportation (Paratransit Bus for adults with disabilities, not very reliable on times- give us 1-hour window); Biking and walking not safe (have to cross too many busy streets); Taxi/Uber has not been reliable (taxi ordered & didn't show up at all or show up late)
- Pace is unreliable and they really need to have an aide or another set of eyes and ears on their buses because the riders all have special needs. Pace seems to forget this or they just don't care
- Concerns for safety. Child is unable to communicate effectively with others, especially in stressful situations. Would not be able to give directions if necessary (in Uber or Taxi).
- Don't qualify for PACE door-to-door para-transit because we don't live close enough to an existing route. Son isn't independent enough to ride traditional PACE routes. For Lyft and Uber, concerned about the qualifications of the driver (safety) and the cost. Don't often want to impose on friends. Availability and cost of using a care provider can also be challenging.

- Yes. Being 2 blocks from Lake County, it [boundary issues] has caused a lot of issues. Some of his doctors are only 5 to 15 minutes away in Lake County from our house. If he would take a bus, he would have to go to transfer point and the total ride could take up to 2 to 3 hours. Therefore, we take him to appointments and then, may have to drive him to his program. It would be easier if they would cross counties especially when you border on counties.
- Our township limits paratransit to medical only which is ridiculous since cognitive impaired daughter needs me at appointment so I'd drive her.
- It [boundary issues] will when my son turns 18 and should be able to rely on cross-township accessible travel for his job, medical appointments, and day program.

## **SUMMARY OF SURVEY FINDINGS**

The data obtained from this survey was consistent with findings from previous empirical investigations exploring ways that a lack of safe, cost-effective, accessible, public transportation negatively impacts individuals with disabilities. While the findings of this study are not generalizable beyond the respondents, the preponderance of findings suggests there are significant transportation needs and obstacles to community inclusion for individuals with disabilities and their families in the northwest suburbs of Chicago.

Results indicated that the top five transportation needs were: to and from family activities, day services, recreation activities with others, errands, and employment. Based on the perceived severity of transportation obstacles, parents and care providers were overwhelmingly providing transportation due to:

- Safety concerns
- Lack of affordable door-to-door service
- Unreliability of paratransit services
- Township and other service boundaries

The consequences of these obstacles included:

- an increased dependence of individuals with disabilities on their families and care providers
- employment limitations for individuals with disabilities
- an impact on parents'/guardians' employment due to child's/client's transportation needs
- feelings of isolation, frustration, anxiety, and stress among the families, care providers and individuals with disabilities.

## **KEY FOCUS GROUP FINDINGS**

In total, twenty individuals participated in four focus groups. The focus groups participants all answered the same questions, but were allowed the freedom to engage conversationally with one another as they responded. The researchers, and agency representatives, were struck by how meaningful the engagement with others in similar situations was for participants. Many parents spoke about the lack of resources available to them once their children aged out of public education. They spoke of the importance of engaging with day

service providers and other parents. Several parents indicated that a primary reason they participated in the focus groups was that they wanted to learn more about services that are, or would be available, to their children. While this is not addressed as a theme, it is important for policy makers, legislators, and service providers to appreciate the lack of accessible information available to parents and service providers regarding specific service provider boundaries and policies.

Three primary themes emerged from the focus groups: Families are unique, but challenges are similar; Inconsistencies have consequences; and Development depends on community inclusion. The themes identified should not be seen as encapsulating the entirety of concerns and challenges being negotiated by the focus group participants, but rather as those that were most frequently discussed and/or had the most impact on the daily lives of the participants. First, while each family's situation was unique, transportation challenges were, and likely will be similar in terms of how they impact their child and family. Second, while public transportation inconsistencies, like detours, delays, and unruly riders, might be easily negotiated by individuals who can ask questions and process more complex information, they can have very dangerous repercussions for individuals with disabilities who are unable to do so. Participants did suggest that improved services such as bus aides, technology, and reliability could enhance the families' abilities to help individuals with disabilities navigate the inconsistencies of public transportation. The final theme that emerged from the focus groups was the high value that families and care providers place on providing individuals with disabilities opportunities for community inclusion.

## **Demographics**

The majority of focus groups participants were White parents, with children ranging in age from elementary school to early 40s. While most of the participants were in two parent households, there were several single mothers who shared their unique experiences. Most of the children lived at home and family members were providing the majority, if not all, of the transportation for their children with disabilities. Parents commonly described their children in terms of sex, age, and impairments. Impairments and age, rather than sex, seemed to most affect family decisions and transportation options. Participants' children ranged from having only one impairment (e.g. special senses and speech, hematological disorders, musculoskeletal system, neurological disorders, muscular disorders, etc.) to having several (Social Security Administration, 2019). Participants were not asked to specifically identify all of their children's impairments. Similarly, participants were not asked to specifically identify their level of education or level of income. No one spoke of their education as a limitation, but across all focus groups, financial resources were identified as a constraint to providing transportation.

In addition to NWSRA's services, some participants shared that due to moving and/or other reasons, they were using other service providers such as Clearbrook or accessing available resources through their schools. In every focus group, participants shared information regarding service providers with one another. Participants' comments were commensurate with the survey data in regard to public transportation options. There were few complaints about service on township buses, but participants found their boundaries and service hours too restrictive. They were not pleased with Pace Bus services and found Uber's services to be financially prohibitive coupled with fears of drivers who were not trained on how to respond to the needs of individuals with disabilities. Comments often centered around the friendliness of the staff, scheduling procedures, reliability of pick up and drop off times, and the ability of their children to navigate the service without assistance.

## **Focus Groups Overview**

Focus Group One had eight participants; one father and seven mothers. Two primary topics emerged within this focus group: safety and services. The parents in this group were very concerned with how their child's needs could be met not only now, but also when they were no longer around to provide services. The functional abilities of their children ranged from a daughter who required full-time care to a son who was active in the community. While most of the parents did not use public bus service, those who did expressed frustration with the processes for reserving door-to-door service and the lack of aides on the buses. Those who were using Uber appreciated its safety features and dependability, but found paying for it challenging given the financial resources available to their child.

Focus Group Two had five participants; four mothers and one father. This focus group was unique in that a couple attended and shared why they had made the decision to have their child live in a community integrated living arrangement (CILA). Through the discussion it became apparent that while their son was in a CILA, he was still having to negotiate many transportation-related issues. This group also shared that there were "dead-zones" where no public transportation for individuals with disabilities was available and how this was forcing them to consider relocating. The group also discussed financial considerations in regard to what level of financial contribution the State should be making. While they recognized the financial realities of the State of Illinois, they were also aware that other Midwest states are providing more services for individuals with disabilities.

Focus Group Three had five participants; four mothers and one father. This group was unique in that it contained participants who were members of organizations that were actively advocating for individuals with disabilities. One parent in this group consistently emailed the researchers with ideas and shared information about the study with a state-wide organization focused on disability advocacy. Much like Focus Group Two, these participants acknowledged the enormity of making transportation more inclusive. In a follow-up email a parent expressed, "My ultimate concern is that the enormity of the task will result in no changes." This group discussed ways that technology (cameras, global positioning systems (GPS), streaming route updates) could be used to ease safety concerns on public transportation.

Focus Group Four was the smallest focus group. Two individuals; one mother and one father attended. While this was the smallest focus group it allowed for the most in-depth discussion of how transportation limitations affected families across individual's life spans. One family had a son in his forties while the other's child was still being provided transportation through his school. This focus group helped contextualize how institutional policies and procedures related to Medicaid and insurance can have significant impacts on families of individuals with disabilities. Another consideration that emerged during this focus group was the strength of informal networks for finding employment for individuals with disabilities.

## **FOCUS GROUP THEMES**

### **Families are unique, but challenges are similar**

While the impairments of their children, availability of support, income, job security, and benefits being utilized differed among families, participants shared that they faced challenges related to bureaucratic institutional practices, concerns about their child's safety on public transportation, and worries about what will happen to their children when they pass. One father

succinctly stated, “I think travel, the lack of accessible, cost efficient travel, impairs a lot of things.”

Parents shared that using public transportation and receiving benefits requires mastering the rules and regulations of each agency, and that it is incredibly time-consuming waiting on the phone and going to appointments to meet with service providers. For those parents whose jobs did not provide flexibility, these challenges were exacerbated.

One participant explained that she had to cut her hours using the provisions of the Family Medical Leave Act (FMLA) when her son aged out of school,

I went on FMLA so I didn't lose my mind, but I have to say that the past two years when he's been out of school have been the hardest. When he was in school, I didn't have to worry about anything. They had a bus driver and everything. But when they age out – it's been rough, rougher than his whole – it was scarier than bringing him home from the hospital when he was born.

Participants shared that they spent hours on the internet and phone seeking explanations on how to fill out forms. They described processes for obtaining letters from doctors and care providers required to document the need for benefits for their children. They described meetings with Pace Bus, and other service providers, to determine the eligibility of their children and then having to call and reserve services if their child was eligible. While some participants had positive experience arranging services, most participants described them as tedious or even negative experiences. One participant summed up these experiences as she described a recent conversation that she had with a Pace Bus scheduler. The participant stated,

They hate their job. They're tired of the phone calls. They're tired of you yelling at them. Why are you late? Why are you late? You said you'd be here now.

In addition, participants whose children's impairments did not prohibit them from using Pace still highlighted the challenges associated with using their services. First, the child had to be assessed, then actually scheduling became a challenge. In order to reserve the service, an individual must call between 6 a.m. and 6 p.m. one day before the trip to provide their paratransit ID number and travel details. Pace encourages riders to remember “If your requested pick-up time is unavailable, Pace will offer a time within one hour of your request” and to “Tell the call taker if you have a particular time you need to be at your destination” (Pace, 2019). What this effectively means is that parents had to spend time every day on the phone arranging services for their child's transportation services. Only then would they know when their child would likely be picked up the next day and a rough idea of when their child might reach their destination. Not having a reliable public transportation option meant that many of the individuals with disabilities were unable to have jobs, unless the participants or someone else provided the transportation. The unreliability of the service also intersected with parents' fears for their children's safety. Not knowing how long their child would be on the bus, who would be on the bus with them, and bus stop waiting times often led parents to decide to provide transportation on their own. Participants were all in unique situations, but every focus group identified negotiating policies as a constant challenge.

For those families with higher functioning children, Uber was an option, though an expensive one. One mother, when speaking of her twenty-three-year-old son, explained how

while he receives benefits from Social Security, they do not allow him to live independently. She shared that that maximum amount her son can receive is \$771 and due to rules, she has to charge him rent. She explained that after paying the agency-recommended \$300 in rent, her son has roughly \$440 to live on a month. Transportation costs consume the majority of his remaining money given that he takes Uber because of the unreliability of other transportation options and his work schedule. She said “Now, he’s lucky because he lives with parents who can somewhat afford stuff, right? But there’s other people out there who don’t have that luxury, you know? So how are these other people supposed to pay for food, doctor bills, and you know, other things that are real necessities?” Another parent shared that while her son works part-time three nights a week, half of his paycheck is spent just on getting to and from work using Uber.

Some individuals with disabilities received transportation from extended family members. They described themselves as lucky to have siblings and grandparents helping to provide transportation, but also explained tensions related to asking their children and extended family to take on additional duties. There were also concerns about what would happen once their typical children went away to college or started families of their own or if grandparents died. One parent summarized the reality of having her mother provide transportation for her son. She said,

I work full time. Obviously, I would love to be able to drive him to work every day, but that’s not feasible. My mom lives in Des Plaines. I live in Arlington Heights. She drives all the way from Des Plaines to Arlington Heights, gets my son, and brings him to work in Arlington Heights; and then drives home. I get it, but I’m paying her for gas money.

Lastly, each of the focus groups shared how the lack of accessible public transportation heightened the challenges of life transitions. Three life transitions were talked about frequently: their child getting a job; their child aging out of school; and the death of parents/guardians. Participants’ responses suggested that the link between transportation and social inclusion had the potential to increase the negative impacts of each of these situations for their children. They attributed the lack of transportation to limiting their children’s employment opportunities, ability to be included in community activities, and questioned how their child will be able to live independently without reliable, safe, accessible transportation when they are gone.

Participants shared that a lack of information from providers heightened their concerns and that they often found support from other families negotiating situations similar to their own. While some schools offered transition training that participants felt adequately prepared them, few participants indicated they felt supported as they negotiated the actual process. They appreciated school programs that helped their children gain employment, but expressed concern about how the lack of transportation outside of school negatively impacted their children’s abilities to keep jobs. One parent shared her story,

My daughter was working through school at a job. It’s in Gurnee, but if you don’t know the area, probably 45 minutes from this area; and the school was transporting her. When the school position, the job through school, was ending; there was the choice of maybe having her stay there; and I wasn’t going to drive 45 minutes each way twice a day. So, we checked into the Pace to qualify. We got the card, but somebody from the company came out to do mapping and a sample route and all that. And she would have had to transfer three buses because of where we live, and she would have had to get off at Hawthorne, which is

a shopping mall; get off the one bus and wait, supposedly by herself, for another bus to be picking her up; and they said they would hope that the transfer would not take too long; and it would take her so far, and then she waited for one more to take her. It had to do with, I guess – it was all the same county, but – I don't know, with the towns and the limits or whatever it was. It was the Pace boundaries. So, we said, okay, forget it.

Another parent said,

Your child needs to almost work nearby. My son only works two miles from our house, and I can't even get a bus to get him there; so it's like – God forbid if they're going to work more than a few miles from your house, because it's not going to work.

A father shared that even though his son cannot use public transportation, they prioritize schedules so that he can work because it facilitates community inclusion and will prepare him for a time when they are no longer around. He said,

We want him out, meeting people, talking to people, being in the workplace, because that's good for his development, which will go on forever, until the end of time – until whenever. But – so we chose. Look, you're going to do this job. He meets different – they know him. He's worked for the park district for 15 years, so when he's out at wherever he's working, the people there know him. So, he talks to people. So that's a good thing. That's good for his development.

Families who had made the choice to have their child in a CILA also faced transportation challenges related to their children's transportation needs and employment. A parent shared that even in group home settings, one caregiver may be unable to meet all clients' needs simultaneously. He said,

You need to talk to people that have children in CILAs and providers because there you have multiple people living in a house, likely. There is usually one car, one van, whatever it might be. There are different challenges that need to be looked at from that standpoint, because that's where the real crunch is.”

While some families and CILAs were able to provide transportation to and from employment, the lack of public transportation required them to prioritize and make choices related to time and money. In some situations, the transportation costs were simply too high compared to the financial and social benefits they perceived the child/client received from working. No participant argued that employment wasn't important; some were just unable to meet the transportation needs required to facilitate their children's social inclusion via employment.

Participants also expressed concerns related to their children's social inclusion once they aged out of school; they explained that they felt underprepared for arranging transportation to and from services.

It was a shock to us, because with all the information in the transition period that they did at school, nothing has prepared us for that. After that, you know, once you're out, you're out. There's nothing else.

A father expressed concerns saying,

I've tried to prepare for eight or nine years for the day the buses don't come. It's scaring the hell out of me, knowing that next May is going to be it. Nine years went like that. So, I'm scared to death about after May, how I'm going to feel mentally being around my child if I can't find a program – being together all the time. I'd go out of my mind. I love my son and everything, but 24 hours a day, seven days a week with nothing for him to go to would just drive both of us crazy. I'm worried about my personal health.

Another parent shared her fears saying,

I'm thinking ahead to after he's 18. He'll start the vocational training, and a lot of the things I hear is – and this is all hearsay; I've never seen it firsthand but – once they age out of school at age 22, they're kind of floundering unless you really – I don't get the sense that the schools have really figured it out in terms of working with area agencies like a Clearbrook or Little City or whoever to ease them in in a transition to some sort of program that would be enriching for that person; whether it's vocational work, whether it's a day program, whatever. It doesn't seem like there's a smooth transition out there. I feel like there's a lot of families are still kind of lost.

Participants feared that they would not know how to arrange transportation once their children aged out of school and shared concerns regarding how the lack of public transportation would create additional challenges.

End of life planning was also identified as a challenge that was heightened by the lack of public transportation. Without them to provide transportation, participants feared their children would be left without employment, medical care, and social inclusion. This concern was prevalent regardless of the family size or child's impairments. One of the primary reasons participants were so encouraging of their children working was so they could gain life skills that would better prepare them to live independently. One parent shared that the reason they decided to put their child in a CILA was they felt when they passed it would be easier on him. However, being in a CILA did not alleviate all transportation challenges as was described above. Other parents shared concerns about having siblings being responsible for their disabled sibling when they passed. She said of siblings and parents passing,

I think a lot of us go above and beyond trying to make them not be responsible so much because the reality is one day we're all going to be dead, and our kids are going to be in charge of our kids.

Participants expressed a desire for more information and services related to their passing and ways to care for their children with disabilities after they were gone. Many feared that without access to reliable transportation, their children would be left without opportunities for employment and inclusion.

### **Inconsistencies have consequences**

The second theme that emerged from the focus groups was that inconsistencies related to transportation provision had consequences at individual and collective levels. Many things



contributed to inconsistent transportation. Routes, rules, equipment, work schedules, programmatic offerings, traffic, and service costs all intersected to affect to what level an individual family could rely on public transportation. At the individual level, participants shared that individuals with disabilities' independence and development were affected negatively by transportation challenges. The lack of reliable public transportation affected not only individuals' schedules but also what their families were able to do. At the community level, inconsistencies in service provision seemed to be caused by rules that participants saw as arbitrary or unnecessary, and routes that provided greater access to some areas and no access to others. And, lastly, at the state level, the inconsistency of service provision is seen as a failure of the State of Illinois, and a reason to consider relocation. This is all important to consider given that research has shown that the promotion of inclusion for individuals with disabilities can help combat poverty and unemployment (Power, Lord, & Defranco, 2013), enhance safety and protect against abuse (Quinn & Doyle, 2012), and lower negative attitudes, stereotypes, and discrimination (Mahar, Cobigo, & Stuart, 2013). Community inclusion is important for the health of all individuals, but the reality for many individuals with disabilities is that once they age out of education settings their primary social interactions may be with family members and service providers with limited opportunity to engage in community activities, recreation, and employment.

During the focus groups, participants shared stories about how inconsistencies in transportation affected their children. In addition to negatively affecting their perceptions of their children's safety, the turnover in drivers and lack of standardized trainings created negative consequences in regard to service enrollment and employment. Quite simply, a lack of affordable, reliable transportation meant that their family had fewer opportunities for employment, activities with friends, and community inclusion. As one parent noted,

When school ends, or even if it's after school, or it's summer, it's always a puzzle. You're always fitting those puzzle pieces. Okay, where are the gaps and how do I fill those gaps? You try to get creative. We're lucky enough that financially we could pay a sitter to do that. I think about other families who can't do that. What do they do?

Participants shared that the most common activity their children engaged in were day services. Day services allowed their children to not only engage with others, but also to learn skills. Participants noted that some day service providers offered financial and vocational workshops that made their children more able to live independently. Participants noted that free transportation provided by the day service agencies has declined in recent years, and that the low-cost option still eats away significantly at a family's income. Participants were appreciative of day service providers attempting to provide centralized hubs where parents could pick up and drop off their kids if door-to-door service was too costly or unavailable.

Township and NWSRA buses, and other disability-focused agencies' transportation providers, were identified as the most reliable and best trained. Participants explained they were the most comfortable having their children in transportation where they knew the driver, had knowledge of the drivers' training in working with individuals with disabilities, and/or could monitor the driver (Uber). They shared stories about Pace drivers they witnessed being alone on buses trying to deal with lifts that often require two people. They also questioned how bus drivers keep all riders safe if a passenger has a seizure or medical complication while traveling. One parent shared a story about a time her child was supposed to be transported to a location, but

was taken to another service site. She was unaware of where her son was until the day services reported he had not arrived. She then had to call Pace to figure out where her son was and to get him to the correct site. While her son remained calm and enjoyed the bus rides, it greatly shook her confidence in them. She now provides more of the transportation for her child even though she had to adjust her work schedule. Many participants reported that they had to either change their work schedule, family members' activities, and/or quit working in order to be able to meet their child's transportation needs.

For some participants, changing work schedules or quitting work was not an option. Participants reported that both their typical and disabled children were unable to participate in some activities because of the lack of transportation. Parents shared that it is not only the time it takes to get to and from an activity, but also the wait time while the individual with disabilities completes the activities that can prohibit their involvement. One father explained that he wanted his son to participate in activities so he drove him there and then would wait during the activity. The public transportation was not an option because his son would have spent hours on the bus to participate in an hour-long activity. Furthermore, he explained there was no point in him just dropping his son off and picking him up, because with traffic it would have taken him as long to drive home and return as it took his son to participate. The consequences of the bus being inconsistent was he had to drive, and his other children were not always able to participate in their chosen activities. There simply was not enough time to get everyone where they needed to be. The father explained that the other sons had more opportunities for inclusion than the son with disabilities so his needs were prioritized.

A participant shared that while she loves the security features of Uber, it's not affordable on a regular basis for her son. She said, "Just so you know, Uber for a wheelchair is \$69 each way." Parents advocated for cameras on public transportation so that they could feel more confident about putting their children on public transportation. Participants appreciated that Uber provided them with a photo of the driver and had security features built into the experience. They felt more confident in being able to schedule with particular drivers, too. Many identified costs as a reason Uber is not a consistent transportation option for their child.

Access to public transportation is not consistent throughout the NWSRA service area. Some townships provide buses and overlapping service areas among agencies provide some neighborhoods with more services than others. Some areas have no public transportation being provided. Participants expressed dismay at what one mother termed a "dead-zone". Dead-zones were areas where no public transportation options existed for individuals with disabilities. While uberWAV is being pilot tested in Chicago, suburban township boundaries and Pace Bus route restrictions mean that transportation in the area serviced by Northwest Special Recreation Association is not fully available. A participant shared that she talked with Pace to verify that her child was not eligible for service. She said, "He pulled out a map and goes, oh yeah, like literally a dead zone." She went on to explain that she will likely move to a new neighborhood when her child ages out of school.

Participants expressed annoyance at boundary-based restrictions. A parent explained that when her child changed programs, he could no longer ride the township bus on which she felt her child was very safe. She said,

And I have to say, I didn't worry, because it was just a few drivers – maybe three different drivers. I felt very safe. He went back and forth without incidents, and it was

great. It was a buck a ride. Then he switched to Pursuit, which is in Hanover Park – which is out of our township by like a quarter of a mile. They will not go out of that.

It should be noted that after the parent voiced this concern, another parent shared that she had been given different information regarding the boundaries.

Another parent noted that relocating a short distance allowed her child to access more services. By simply moving a few miles her child was able to not only ride a township bus, but was also within the acceptable distance for Pace Paratransit. Other parents expressed their frustration with being unable to use paratransit door to door because they do not have a fixed bus stop within  $\frac{3}{4}$ -mile of their home. A mother summed up much of sentiments shared when she said, “That’s something that could be changed so easy. That stupid three-quarters of a mile from an existing route is a stupid rule that should not exist.”

Last, but not least, participants shared their perceptions on the impact the lack of accessible public transportation is having on the State of Illinois. Several participants shared their belief that certain areas of Chicago or other states had better transportation options for individuals with disabilities. One parent asked, “Do you know how many people go over the border to Wisconsin because Wisconsin has way better services for people with disabilities? Way better. Illinois is, like, right above Mississippi almost. That’s how bad it is. It’s bad.” There was widespread agreement in a focus group when a participant stated, “The State of Illinois should have these services, no matter if you live in Springfield, Macomb or Saint Charles, or whatever. You could expect these services.”

When they were asked to explain why they felt services were not being provided, responses like the following were common: “I don’t think they [individuals without disabilities] understand any of this. I just don’t.”; “They [politicians] don’t think it matters. Maybe we’re just not loud enough”; and, “They’re [service providers] not seeing the cracks in the system”. Several participants expressed concern that because, “...everybody’s needs are so individual that I think part of the problem is not having a system right now because it’s too hard.” One participant suggested that having policy makers and legislators arrange their own transportation using the options available to individuals with disabilities might help draw attention to the difficulties they face in making sure their children are provided opportunities for community inclusion.

### **Personal Development depends on Community Inclusion**

A question that emerged after the survey data was analyzed was why were families willing to spend so much time and money to facilitate work opportunities given that transportation costs used up such a significant percentage of the earnings from employment. Another question was how were siblings and family relationships being affected by transportation challenges.

While many participants expressed sentiments similar to “We all want them to have a meaningful day. Whether it’s in a good day program or whether it’s working, you just want them to have a meaningful day”, others honed in on the need for their children to be integrated in the community with a need for normalcy. One mother said, “You want them to do normal stuff, be part of a normal community. And that’s really important”. A parent said that providing individuals with disabilities opportunities for involvement lets them, “...grow up as people versus sitting at home watching TV or looking at the iPads.”

Participants reported organizing family activities and priorities around the needs of their children with disabilities. One father bluntly stated that all family activities were dependent upon

the needs of his son; he described happily sacrificing theater events and other opportunities so that his son could work and be social. Some participants did express that the lack of accessible transportation negatively impacted their other children. They discussed how often siblings helped provide transportation and several suggested that the sibling would take over as primary caregivers when they died. One mother expressed that she actively tried to discourage her child from being as involved in the day-to-day care because she felt it was not the sibling's responsibility. One parent expressed concern about how her other children were affected by growing up as a sibling to an individual with disabilities given their primary role in linking the disabled child to others. She said,

So the siblings have given up so much to begin with. You know, because I'm not a sibling of a special needs child, I can't even imagine what some of these kids have given up. Both do help in more ways than just driving. They're like their link.

Parents also shared that their family activities were affected when their children with disabilities had medical incidents, emotional or behavioral outbursts that required family activities to come to an end. A mother shared that her family has had to leave restaurants due to her autistic son's occasional outburst. Work schedules were also affected. One participant noted that facilitating transportation for her son was a duty divided among members of the family. She indicated that between her husband and the siblings, "One of us is going to have to leave work early to pick him up or arrange for somebody to do that." Participants indicated that there were also benefits for the rest of the family when their children with disabilities were engaged in meaningful activities. They indicated that such times provided opportunities for them to engage with the partner and other children.

## **SUMMARY OF FOCUS GROUP FINDINGS**

Participants shared that they faced challenges related to bureaucratic institutional practices, concerns about their child's safety on public transportation, and worries about what will happen to their children when they pass. Not knowing how long their child would be in public transportation, who would be with them, and waiting times often led parents to decide to provide transportation on their own. In addition to limiting opportunities for individuals with disabilities, the lack of affordable, reliable transportation also affected parent/guardian work schedules and sometimes necessitated involving siblings, extended family and friends to meet transportation needs. Participants were all in unique situations, but every focus group identified negotiating policies as a constant challenge. During the focus groups, participants shared stories about how inconsistencies in transportation affected their children. In addition to negatively affecting their perceptions of their children's safety, the turnover in drivers and lack of standardized trainings created negative consequences in regard to service enrollment and employment. Quite simply, a lack of affordable, reliable transportation meant that their children and family had fewer opportunities for employment, activities with friends, and community inclusion.

## **CONCLUSION**

Survey results indicated that the top transportation needs were: to and from family activities, day services, recreation activities with others, errands, and employment. Parents and

care providers were overwhelming providing transportation due to safety concerns, service boundary issues, unreliability of service providers, and lack of access to accessible public transportation. The consequences of these challenges included an increased dependence of individuals with disabilities on their families and care providers, employment limitations for both the individuals with disabilities and their families, and feelings of isolation, frustration, anxiety, and stress among the families, care providers and individuals with disabilities.

Focus group results suggested that while each family's situation was unique, transportation challenges were, or will, similarly impact their child and family. Public transportation inconsistencies, like detours, delays, and unruly riders, that might be negotiated by individuals who can ask questions or process more complex information can have very dangerous repercussions for individuals with disabilities. Having aides on buses and/or enhancing the opportunities for parents to monitor their children's transportation could allow families to better navigate the inconsistencies of public transportation. Families place a great importance on providing individuals with disabilities opportunities for community inclusion. Families prioritize opportunities for their children to participate in community activities in order for them to form strong social relationships, maintain their health and fitness, increase their financial status through employment, and develop skills for independent living which will be necessary now and as caregivers age and pass away.

Participants in this study were eager to contribute ideas for how to address their concerns. Some fixes that were suggested included real-time cameras on door-to-door buses and apps that would allow families to track where different buses were in real-time. Required trainings in best practices for transporting and working with individuals with disabilities were discussed. Participants also strongly encouraged interagency cooperation and a reduction in boundary limits on service provision.

## **RECOMMENDATIONS**

It is recommended that the results of this study be shared with families, educational institutions, disability service providers, local and state policy makers, legislators, and transportation providers. NWSRA and its partners should work to create a list of stakeholders who can help them develop a realistic timeline of incremental actions that could be undertaken to improve the safety and reliability of public transportation for the purpose of improving community inclusion opportunities for individuals with disabilities.

Based on data gathered from participants, NWSRA, CTC, Campfire Concepts, and Western Illinois University suggests the following:

1. Work with interested partners, other key stakeholders, consultants and transportation providers to create a Geographic Information System (GIS) map outlining where transportation options are and are not currently available. Pace bus maps are already available in formats compatible with GIS programs as are township boundaries. Creating an interactive GIS map would help to:
  - a. Identify common transportation areas where the need is high
  - b. Create routes to provide more predictable, timely and consistent public transportation.

- c. Enable families and service providers to better understand and coordinate transportation being provided within and across boundaries.
2. Begin conversations with interested partners, legislators, local leaders, other key stakeholders, Uber and other transportation providers to explore costs and possibilities for alternative door-to-door service. Given that Chicago is a pilot test city for UberWav, providing partners and stakeholders with data could enhance the services being offered.
3. Begin discussions with interested partners, other key stakeholders, and transportation providers to explore technological enhancements and driver trainings that could be used to enhance the safety, security and ease of use of public transportation for individuals with disabilities.
  - a. Create an app-based system that would enhance available information and tools for families who utilize public transportation.
  - b. Develop a comprehensive training for drivers working with individuals with disabilities.
4. Begin discussions with interested partners, other key stakeholders and transportation providers to discuss crossing existing transportation boundaries and analysis of service hours in order to provide more seamless transportation options for individuals with disabilities living within the northwest suburbs of Chicago.

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