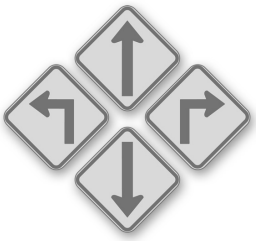
The 5 A's: Current Barriers Facing Mental Health Consumers

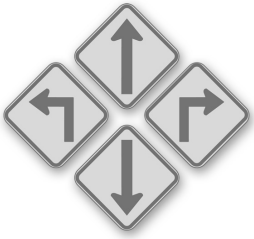


The Federal, local, and State governments and transit authorities have attempted to address the transportation needs of people with disabilities by supporting public transit infrastructure and by developing specialized transportation. Dozens of Federal programs support transportation for people with disabilities; key examples are paratransit, Medicaid transportation, and the half-fare program.

Paratransit is a curb-to-curb service offered by public transportation to people whose disabilities make taking public transportation difficult. The Americans with Disabilities Act (ADA) mandates that transit authorities provide this alternative service. In addition, Federal Medicaid regulations require that States ensure that recipients have transportation to covered medical services, and States typically provide curb-to-curb service to Medicaid recipients for visits to the doctor and other medical services. Under the Transportation Equity Act, States that receive transportation block grant funding must offer half-fare prices on non-rush hour transit to eligible individuals. These individuals are older adults, Medicare recipients, and people whose disability interferes with their capacity to use public transportation.

Despite these programs, difficulties in meeting the transportation needs of people with disabilities remain. The President noted in his February 2004 Executive Order (No. 13330):

> Transportation plays a critical role in providing access to employment, health care, education, and other community services and amenities. The importance of this role is underscored by the variety of transportation programs that have been created in conjunction with health and human services programs, and by the significant



Federal investment in accessible public transportation systems throughout the Nation. These transportation resources, however, often may be difficult for citizens to understand and access.

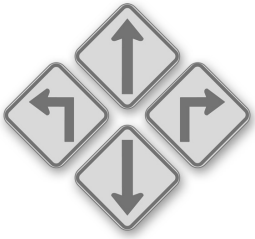
For mental health services consumers, the difficulties frequently are compounded because they often are ineligible for programs serving people with other types of disabilities. The transportation barriers that face mental health consumers fall into five categories that can be called the five A's: Affordability, Accessibility, Applicability, Availability, and Awareness (Adapted from the Beverly Foundation, 2004).

Barrier One: Affordability

For many people, cost is the primary barrier to getting from place to place. The cost of owning and operating an automobile, or even the cost of using public transit, can be prohibitive to people living in poverty. Without affordable transportation, the opportunity for full community integration may elude many mental health consumers.

People with disabilities, particularly mental health services consumers, are found in disproportionate numbers in the Nation's lowest-income groups, especially in the group relying on Supplemental Security Income (SSI) payments as their primary source of income. SSI is a need-based cash assistance program administered by the Federal Social Security Administration (SSA). For many mental health consumers, SSI provides a safety net, but recipients still live in poverty. In 2004, the monthly SSI benefit paid to individuals by SSA was $564; the annual total of $6,768 is well below the Federal poverty guideline of $9,310. As disability advocacy groups have reported, "As a national average, SSI benefits in 2002 [$6,540] were equal to only 18.8 percent of the one-person median household income" (O'Hara and Cooper, 2003). Although some States provide monthly cash supplements

to people receiving SSI, individuals receiving these supplements still live in poverty.

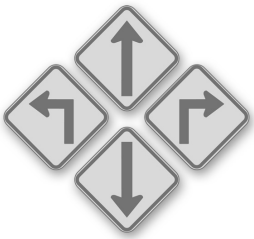


The staggering number of mental health consumers relying on SSI payments reveals the magnitude of the transportation affordability problem. According to 2002 SSA data, over 1.6 million people with mental disorders other than mental retardation received SSI payments. This figure is 34 percent of the nearly 4.8 million people under age 65 receiving SSI. No other category of disability constitutes as large a percentage.

Owning an automobile usually is not within the means of a person relying on SSI for income. According to the Bureau of Transportation Statistics, the average cost of owning and operating a car was over $7,500 annually in 2002, the latest year for which statistics are available. This amount is more than the annual Federal SSI benefit. It is little wonder that fewer than 20 percent of SSI recipients with disabilities owned a vehicle in 1999.

Public transit and paratransit, although more affordable than owning an automobile, are not necessarily within the financial means of people with disabilities who have very low incomes or who rely on SSI. Even in major urban areas where transit costs tend to be lowest, the cost of monthly transit passes can represent a significant portion of monthly SSI benefits. Here are some examples of monthly transit pass costs: Chicago, $75; Philadelphia, $70; Milwaukee, $56, based on weekly cost; Atlanta, $53; and Dallas, $40. In these cities, the cost of transit passes is equal to 7 to 13 percent of the Federal SSI benefit.

In rural areas, transit providers often charge higher fares to cover their costs, making it even more difficult for some to afford. Furthermore, paratransit providers are permitted to charge up to twice the cost of public transit. When they met with focus groups of people with disabilities in rural communities, representatives of the Association of Programs for Rural Independent Living (APRIL) found that “many consumers . . . were



forced to walk, bike, or miss work during extremely difficult travel conditions due to affordability issues" (APRIL, 2003).

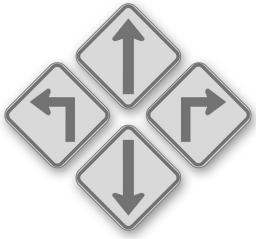
Clearly, mental health services consumers need access to affordable transportation. A large proportion have limited incomes, so they are unable to pay for reliable transportation. These circumstances can have a direct impact on their participation in the work force and on their full integration into the community.

Barrier Two: Accessibility

The Americans with Disabilities Act (ADA) mandates accessibility to public transit. Public transit agencies have responded to ADA requirements by making buses and trains accessible to people who are blind, or who use wheelchairs or other mobility aids. However, "[t]he system is less responsive to hidden disabilities," says consumer advocate Cliff Hymowitz, who lives in Suffolk County, New York. He hopes to make transit systems aware of some of the difficulties encountered by people with cognitive and mental disabilities. As an example, he cites the new transit ticket machines in the New York metropolitan area. Although the machines were designed to be accessible to people using wheelchairs, their operation confused too many people with hidden disabilities, including those with mental disorders,

"Other aspects of the public transit system can pose problems for people with cognitive or mental disabilities," says Mr. Hymowitz. For example, the signs at bus stops providing route information might be difficult to interpret; all bus stops might not be marked with the same types of signs, making them difficult to recognize. "Most people don't realize that a person with a hidden disability (might not be able) to venture out and find a bus stop," he says. Other aspects of fixed-route transit, such as route maps that are difficult to understand, can further hinder people's ability to navigate the transit system without assistance. Because the accessibility needs of mental health consumers have

not been documented in studies, transit agencies do not have the information they need to respond to these needs in a systematic way.

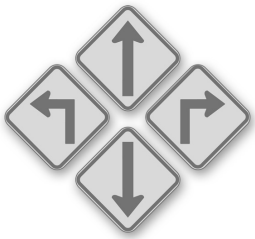


Federally mandated programs that provide curb-to-curb transportation for people with disabilities often are unreliable and inconvenient. Most curb-to-curb programs require 24-hour to 1-week advance scheduling and generally ask for a 30-minute window during which the rider is expected to be ready to travel. These requirements often limit the flexibility of the rider's lifestyle. In the words of one State transit planner, "I don't (always) know what I am doing a day from now, and to subject another segment of the population to this requirement is a little paternalistic." He and other transit planners, as well as disability advocates, think that if mainstream transit were more affordable, accessible, and widely available, much of this inconvenience could be eliminated.

The transit system has provided accommodations that may address the needs of people with disabilities, but not the needs of mental health consumers. Transit agencies have not documented the accessibility needs of these consumers, whose limitations are hidden and are not so well defined. Further, Federal programs are not always responsive to the needs of people with disabilities. Transit planners and disability advocates believe that making transit more affordable, accessible, and available could meet many of those needs.

Barrier Three: Applicability

Federal, State, and local governments have created many programs to address transportation affordability and accessibility for people with disabilities. Unfortunately, as one advocate observed, although the Federal Transit Administration (FTA) provides funding for older adults and people with disabilities, many communities offer varied transportation options for older adults but very limited options for younger people with disabilities. If transportation options for people with disabilities do



"Mental illness is the least likely reason for people to apply for paratransit. Most often, people (who have mental illnesses) are not eligible."
—Metropolitan area transit authority official

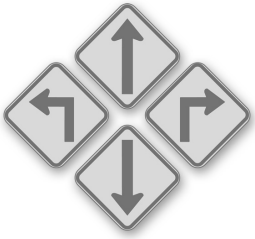
exist, mental health consumers often cannot demonstrate that they meet eligibility requirements. These requirements, rather than being based on financial need, may be based on whether consumers can use public transit without assistance. Even some programs serving mental health consumers are not always available to help them for shopping, education, employment, social visits, and other activities central to integration into the fabric of the community. For example, people participating in vocational rehabilitation programs might have access to transportation for employment-related purposes, but not for social events, advocacy groups, or peer support.

Three major federally established programs implemented by local and regional transit authorities, in particular, present applicability barriers for mental health consumers. These are paratransit, the half-fare program, and Medicaid transportation.

Paratransit. Many mental health consumers considered disabled under the ADA or Social Security guidelines nonetheless are not considered eligible for paratransit programs. Under Federal law, a person with a disability qualifies for paratransit service if he or she "is unable, as the result of a physical or mental impairment (including a vision impairment), and without the assistance of another individual (except the operator of a wheelchair lift or other boarding assistance device), to board, ride, or disembark from [a] vehicle" such as a bus or train (49 C.F.R. §37.123).

Unfortunately, making eligibility determinations is complicated by a lack of clear standards to determine the ability of mental health consumers to ride transit without assistance. According to one transit official, no real assessment tool exists to determine whether someone is unable to use public transit as the result of a mental disability. Although many mental health consumers can ride transit unassisted and, therefore, do not meet the Federal standards for paratransit eligibility, the lack of clear standards increases the likelihood that some people fall through the cracks. People applying for paratransit often are given a "functional assessment" that measures

their ability to ride transit. Frequently, the Functional Assessment of Cognitive Transit Skills (FACTS), a test developed and validated for people with mental retardation, is used to measure the transportation abilities of mental health consumers. While FACTS might identify obstacles such as disorientation, confusion, or inability to navigate the system, it is less likely to identify problems associated with agoraphobia, anxiety, or panic attacks, which can impair a person's ability to use public transit.

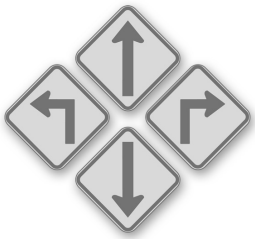


The Half-Fare Program. Eligibility for the half-fare program is subject to difficulties similar to those found in the paratransit program. Many people considered "disabled" for other purposes, including many of those whose disability qualifies them for SSI payments, nevertheless are ineligible for half-fare on public transit. According to Federal law, half-fare is mandated for: individuals 65 and older, Medicare recipients, and "individuals who, by reason of illness, injury, age, congenital malfunction, or other permanent or temporary incapacity or disability, including those who are nonambulatory wheelchair-bound and those with semi-ambulatory capabilities, are unable without special facilities or special planning or design to utilize mass transportation facilities and services as effectively as persons who are not so affected" (49 C.F.R. § 609.23). This is a much narrower definition than the eligibility criteria for Medicaid and SSI.

"I don't see the reason why only 'transportationally disabled' people qualify for a Federal program. Every other definition of 'person with a disability' is inclusive, and we don't tolerate discrimination among disabilities (in the services we provide)."
—Service provider

Under Federal regulations, a person with a disability who receives Medicaid and SSI might not be eligible for the half-fare program, while a person with an identical disability who receives Medicare automatically qualifies. Further, a person who uses a wheelchair automatically qualifies regardless of his or her income, while a mental health consumer who struggles to subsist on SSI payments might not qualify. Some people have criticized what they perceive to be discrimination against people with certain disabilities, particularly mental disabilities.

Federal regulations do allow transit authorities to use a broader definition of disability, but many continue to



"Transportation providers in a lot of places go right by the house of someone who needs a ride, and (then) Medicaid sends a taxi 20 miles (to pick up that same person)."
—Advocate

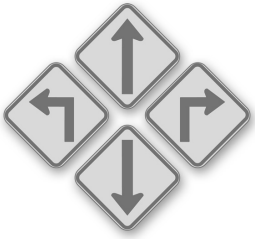
use the narrow Federal definition. In these jurisdictions, many mental health consumers remain ineligible for half-fare discounts because they cannot demonstrate that their disability impairs their ability to use transit.

Medicaid Transportation. Many mental health consumers do qualify for at least one transportation program mandated by Federal regulations: Medicaid transportation. However, this program presents a different type of applicability limitation—the transportation is available only for limited purposes. To ensure that Medicaid recipients can access the medical services covered by the program, States provide transportation to and from services covered by Medicaid. Unlike paratransit and half-fare programs that are available for any and all purposes, the scope of Medicaid transportation is very limited. Advocates are quick to point out that Medicaid transportation is not available for many services critical to a person's recovery, such as consumer-run drop-in centers and mental health services not covered by Medicaid. Similarly, Medicaid transportation is unavailable for many purposes necessary for community integration, such as getting to and from home, shopping, and social events.

The result of this patchwork of transportation programs is the inefficient use of existing limited resources available for transportation. One advocate blames conflicting funding rules: Transportation providers funded by a State department of transportation must charge Medicaid the actual cost of service, often higher than the discounted rates the provider normally charges. However, Medicaid rules prohibit charging more for Medicaid transportation than for other forms of transportation. The result, she says, is that State-funded transportation providers that offer discounted fares would have to charge everyone a higher rate to accept Medicaid clients, which they choose not to do. This leaves Medicaid clients no choice but to use providers that charge the higher rates reimbursed by Medicaid.

Difficulties such as these are common. A study conducted by the U.S. General Accounting Office

(GAO) in 2003 concluded that in many areas, Federally funded transportation services were "overlapping, fragmented, or confusing" (GAO, 2003).



Barrier Four: Availability

In many areas, public transit is not available at all; therefore, people who cannot afford their own vehicles have extremely limited transportation options. Mental health consumers, especially those relying on SSI or with limited income, are disproportionately unable to afford their own vehicles. According to the Association of Programs for Rural Independent Living (APRIL), the problem is especially severe in rural areas:

> For 41 percent of rural residents, there's NO public transportation available at all. Another 25 percent live in areas where public transportation is extremely inadequate, providing fewer than 25 trips per year for each household without a personal vehicle. Lack of transportation is one of the most frequently cited problems facing people with disabilities living in rural areas (APRIL, 1998).

"If a person wants to attend a social event at night, he or she is probably out of luck. Even when advocacy groups meet at night, (many) people can't get there."
—Service provider in a rural area

Even in places served by public transit, transportation might not be available at the times needed, or to and from needed destinations. Betty Newell, board president of Community Association for Rural Transportation (CART) in Rockingham County, Virginia, notes, "People's lives don't stop and start at the county line and don't start at 8:00 a.m." In her semi-rural county, CART provides rides when and where people need them, but in most rural communities, transportation options are severely limited by both time and place.

Because of insufficient public transportation, many mental health consumers are unable to access needed services. This inability can have dire consequences, according to the National Association for Rural Mental Health (NARMH). An article in the group's newsletter relates the story of one Vermont woman: "[B]ecause of her remote residence, she was too far for the day service

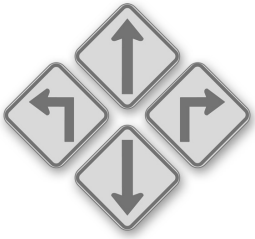
program or for more than limited visits from a case worker. She returned again and again to the hospital and to community care homes, unable to become independent" (Donahue, 2000).

Barrier Five: Awareness

Even in communities with transportation options, many people miss out on the limited opportunities available to them because they don't know the options or the fact that they are eligible for the services. Part of the problem is a lack of outreach to mental health consumers. An advocate for people with disabilities noted, "People with mental illnesses are the most underserved because they're invisible (to many transportation providers)." Several providers of flexible transportation for people with disabilities noted that they received calls requesting rides that were readily available from other sources. For example, some people requested rides for dialysis, even though the rides could have been paid for by Medicaid. Others requested rides, despite being eligible for transportation for older adults.

People who train mental health consumers to use transit independently note that efforts to increase consumer awareness of transportation options are sometimes complicated by competing interests. For example, a treatment program that provides billable services can maintain attendance levels by transporting people using the program's vans, instead of by encouraging consumers to learn to use transit independently. In other cases, consumers' family members have expressed safety concerns about consumers' use of public transit, fearing that they might get lost or become the victim of a crime. Travel trainers note that sometimes these concerns motivate people to steer consumers away from available travel training programs, so trainers often must be persistent in their efforts to recruit participants.

Even the best-run, most easily accessible transportation options available cannot help the mental health consumer who is unaware of them.



In short, these barriers to transportation are barriers to independence and community involvement for many, and they need to be addressed:

- **Affordability**. Keeping the cost of transportation within the means of consumers, even those who are living in poverty.
- **Accessibility**. Creating accommodations to be appropriate for mental health consumers.
- **Applicability**. Ensuring that hidden disabilities are recognized and addressed within both eligibility requirements and actual transportation services.
- **Availability**. Creating transportation options where none currently exist.
- **Awareness**. Ensuring that the information is in the hands of the people who most need it.

Although existing programs have a good start at providing greater freedom of movement and access to transportation for people with disabilities, the issues that specifically affect many mental health consumers remain. Identifying these issues is the first step to addressing them.