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## **Standing in the Cold: Mobility and the Mentally Challenged**

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Public policy in a democracy does not begin with the rights of the empowered, but rather with the rights of all citizens. Transportation policy formation should similarly begin with mobility accessible to all. Assessment of access to mobility begins with and is accountable to individuals.

Among our valued citizens are individuals who are mentally challenged. There is a need for systemic change to help ensure their access to mobility. Change is recommended in mobility need analysis, public participation, and technology deployment. These recommendations begin with an individual.

Jeannie Patrick lives in a residential community with other mentally challenged adults. She graduated from Good Will Industries, and sells newspapers at a grocery store. The grocery store is less than a ten minute automobile drive from her apartment. Jeannie cannot drive, so she uses nearby public transportation.

Jeannie leaves her apartment a little after 6:00 am, and arrives at the bus stop at 6:10 or 6:15 am. The bus is not scheduled to depart until 6:30 am.

Most days Jeannie arrives before the bus. There once was a bench for waiting passengers, but it was removed after being damaged by vandals. So she stands and waits.

Some days the bus also arrives early, and the driver takes a break while parked at Jeannie's bus stop. Not to be disturbed, the driver keeps the door closed and Jeannie waiting outside until the break has ended. Sometimes it is cold, and sometimes it is raining or snowing while the door remains closed.

Asked why Jeannie is left standing in the cold, the bus driver responds, "Look, I want some quiet. I've told these people time and again not to come so early to the bus stop, just come when I'm supposed to leave...but they don't listen." The bus driver turns to face Jeannie and three other mentally challenged persons who take the same bus. "You don't listen, do you?"

The driver doesn't understand the consequence of Jeannie missing the bus. She cannot be late to work. It is a competitive economy, and Jeannie is afraid of appearing

irresponsible if late. It is a justifiable fear, because she knows friends who have been fired for just this reason. Work is vital. If taking the bus to work means standing for fifteen minutes in the cold, Jeannie stands in the cold.

At 6:30 am the bus door opens and Jeannie enters. The bus departs, traveling in the opposite direction from Jeannie's work place. She will need to make two bus transfers. If all is well, Jeannie is dropped at her work place at 7:55 am. She has five minutes to get to work.

In the almost two hours of travel from her apartment to work, Jeannie has worried about making connections and being late. Relieved at arriving on time, she is proud to work. At the end of the work day, Jeannie reverses the bus routes and returns home having completed a fourhour commute.

Jeannie is fortunate. She lives near a bus stop, and some combination of routes will take her to work. Jeannie is also willing and able to speak to secure her right to get to work. As a result of her effort, and the good will of an urban transit administrator, a bench was installed at the bus stop. Discussions were also initiated with the labor union so that when the weather is poor, customers may be allowed to enter the bus during driver breaks.

Jeannie attended a conference on transportation planning. She spoke about her and her friends' need for improved transportation. During the conference, she had lunch with a group which included Michael Huerta, Director of the Office of Intermodalism, U.S. Department of Transportation. Jeannie is good, if not necessarily polite, company: "I want a better way for me and people like me to get to work." A mentally challenged person speaking for their right to mobility had an impact. Over the course of the day, Jeannie took part in large and small groups, and was interviewed several times.

As the conference came to a close, Jeannie was exhausted, and asked to be driven home. I told her I was concerned how tired she had become. She responded, "I know. I'm tired. Rut, I am speaking for thousands."

The need for systemic change begins with strong individuals such as Jeannie. It then must move to assessment of the larger community, the thousands, on whose behalf she spoke. One of the deficiencies in transportation is the absence of data on mobility needs of the mentally challenged.

### **Mobility Need Analysis**

Mobility needs must be analyzed if our nation is to ensure mobility of the mentally challenged. An important resource in understanding mobility is the Nationwide Personal Transportation Survey (NPTS). Demographic reports of NPTS include neither the mentally nor physically challenged. 1/ The NPTS questions would need to be modified to include, for example, whether or not the person surveyed were mentally challenged. Mobility needs of the mentally challenged are not addressed by NPTS in part because

of the economics of sample size and number of clarifying questions which would need to be asked.

The absence of information on mobility and the mentally challenged is not limited to the recent NPTS. It is a longstanding need. A synthesis of transportation practice for the handicapped, elderly and economically disadvantaged was sponsored by the National Cooperative Highway Research Program and published in the mid 1970's. The mobility disadvantaged were defined as including both the mentally and physically handicapped. However, only aggregate statistics were presented concerning the "handicapped," and "chronic conditions". At the time of the synthesis, there were some 13 million handicapped persons, of whom a little more than half were elderly. No estimates were provided concerning the mentally challenged, and no information concerning their mobility needs.

There is some information which the transportation community may find useful as it considers new policies toward mobility of the mentally challenged. General mental health information provides a framework for understanding the significance of this segment of our population.

Mental health treatment in the United States is represented as an annual rate per 100,000 population. In 1988, inpatient and residential treatment in the United States was 819.1 per 100,000 population. The outpatient treatment rate was 1,223.8, and partial care treatment was 113.1. Combined, approximately 2% of the population received mental health treatment in the reporting year.<sup>3/</sup>

This annual estimate does not reflect the proportion of the population experiencing mental illness during their lifetime. Persons who have experienced a mental disorder is estimated at 32.2% of the non-institutionalized population over the age of eighteen. The number of persons who are mentally challenged now, and who will be for the rest of their life, is much smaller.

At any given point in time, approximately one percent of the population is mentally retarded, with or without related developmental disabilities; of these 15 percent are in institutions and the remaining 85 percent live with their families or otherwise independently. <sup>4/</sup>

A relatively small proportion of our population is mentally challenged throughout their life. They are valued citizens of the United States, and on their own merit deserve mobility needs analysis by the transportation community. It is noteworthy that a much larger proportion of our population experiences some form of mental illness at some point in their life. This may influence the way in which the transportation community understands and responds to the economics of mobility needs of the mentally challenged.

## Public Participation

To understand and improve transportation service there must be rigorous analysis of the mobility needs of all persons, including the mentally challenged. Understanding does not end with quantitative studies.

A second policy recommendation is the mentally challenged should be enabled to participate in transportation public process. From their participation, personal stories such as that of Jeannie Patrick will change how they are valued, and how transportation is evaluated.

In communities, many intellectually disabled people are part of innovative learning, occupational, and living arrangements. Public schools, which had only two decades ago regularly excluded retarded children, no longer do so. Since 1975, "individualized educational plans" mandated by federal legislation (principally Public Law 94142) have insured that these children are more likely than before to get an education geared to their specific needs. Even severely and profoundly retarded children and adults, who only little more than a decade ago were treated as hopeless "vegetables," are proving that they can develop, learn, and work. More capable retarded citizens hold fulltime jobs, have families, and pay taxes and wreck cars, have extramarital affairs, and get audited by the IRS. 5/

Our nation has been changing how we perceive and respond to these individuals. The difference between describing someone or a group as mentally retarded may lead to quite different attitudes and initiatives than describing them as mentally or intellectually challenged. It is an important difference if the transportation community is to actively seek and enable the mentally challenged to participate in public meetings.

Among the insights which would be gained by the transportation sector by enabling the mentally challenged to share, none is perhaps more important than how closely transportation is related to employment. Employment of the mentally challenged can be described in terms of Intelligence Quotient, residential status, and transportation. James W. Trent, Jr., described the economic vulnerability of the mentally challenged.

Yet, most needs of people labeled mentally retarded are the same as those of people not labeled mentally retarded: meaningful work and economic security, fulfilling personal and community relations, dignity and a measure of control over one's own life. 6/

Trent suggests that we need to look at "mental acceleration," which in transportation would be the ability to positively challenge persons by making work, and recreation, accessible.

...I hold that the tendency of elites to shape the meaning of mental retardation around technical, particularistic, and usually psychomedical themes led to a general ignoring of the maldistribution of resources, status, and power so prominent in the lives of intellectually disabled people. Finally, I find that the economic vulnerability of these

people and their families, more than the claims made for their intellectual or social limitations, has shaped the kinds of treatment offered them. 7/

The mentally challenged should be involved in the public process because they have mobility needs, and their needs may be directly related to the workrelated experiences of others.

The mentally challenged should also be involved in the public process because the transportation sector is an employer. Transportation is a recurring theme in literature related to employment for the challenged. For all sized employers, proportionately more transportation, public administration and service industries hire persons who are mentally challenged. 8/

The mentally challenged have mobility needs and represent a portion of the transportation work force. They should also be intentionally involved in public meetings because there is legislative direction to do so. The Americans with Disabilities Act, combined with the stakeholder language of the Intermodal Surface Transportation Efficiency Act (ISTEA), provide the mandate for transportation to be thoughtfully inclusive and make the economic commitment to understand and serve these customers.

Involving the mentally challenged in the public process is timely. There is a growing awareness that the transportation system is not a collection of modes, but a system in which all modes function as a system. This creates an opportunity to define system performance measures that include access to mobility. The importance of innovative performance measures is found at all levels of government and public participation. Not all persons today have access to the transportation system, and in part lack of access is disability related. 9/

Public participation is also timely because of innovations in transportation. This is an important period in transportation system design. A system architecture is being developed for the Intelligent Transportation System (ITS) America. The architecture will integrate advanced technologies to improve the safe, efficient and environmentally responsible movement of people, goods and information. As the architecture is being crafted, the needs of all citizens should be included. The intentional enabling of the mentally challenged to directly participate in the public process has the potential to enhance the architecture and the understanding of the architects.

## **Technology Deployment**

Improvements in transportation procedures were described in the first two policy recommendations. Improved procedures need to be matched with improved technologies.

The third transportation policy recommendation is that technologies should be developed and deployed which benefit the broadest possible percentile of the population. This should intentionally include the mentally challenged.

Transportation research and development has been stimulated in the last part of this century. The stimulation has been through landmark legislation such as ISTEA, and through historic change in national and international politics.

Transportation research, development and deployment should be need based. A specific transportation need should be identified. The nation's technology base would then be utilized by scientists and engineers to identify technologies which are appropriate in responding to the need. Integration with the private sector is important to ensure that the technology can be fielded and maintained.

During review of transportation needs, concerns of the mentally challenged should be heard. To response to the needs, there will be a assessment of alternative, appropriate technologies. Technology assessment should include the potential access for all persons. When the resulting technology is deployed, it should be deployed so its benefits accrue to as many as possible.

This is a policy issue, requiring a change in research, development and deployment. The principle underlying the policy is if public funds are used to deploy advanced transportation technology, the results should benefit as many as possible. Intentional review of the impact on challenged citizens, including the mentally challenged, can enhance the process and help realize the principle.

The policy issue is not restricted to traditional transportation agencies and organizations. National and federal laboratories, supported by public funds, have a unique technology base and exceptional personnel. There are efforts underway to transfer this investment to fields such as transportation.

The defense mission of the national and federal laboratories has changed. Defense requirements remain stringent, and are perhaps more complex following the demise of the Soviet Union. However, the role of these laboratories is being broadened to respond not only to the defense mission, but also economic competitiveness and public well being.

Resources of the U.S. Department of Transportation can and need to be leveraged with resources of the U.S. Department of Energy and the U.S. Department of Defense.

Improving the performance of the transportation system can enhance economic competitiveness, public well being, and national defense.

Enhancing the mobility of the mentally challenged not only serves the public well being, their employment adds to the economic strength of the nation. Transportation technology deployment should be led by transportation, in cooperation with other vitally interested public and private organizations.

## **Summary**

Our nation is rich in its diversity. The diversity includes Jeannie Patrick, you and me. The individual can be respected by investing to understand the mobility needs of all, including the mentally challenged. We can also better understand mobility needs by acting to ensure an inclusive public participation. Both needs assessment and public participation will require enduring commitment. The commitment must then be matched with innovative technologies designed to make the ideal real. It can be accomplished.

There is a cost of understanding needs and then responding. There is also a cost of maintaining ignorance and being unresponsive. The attempt to define access to mobility on the basis of power and privilege has a cost that may well be more severe than enabling the powerless. There is a cost of actions which leave some standing in the cold, actions which engender anger and cynicism. There is, I believe, a great benefit from actions which affirm the Republic is true to its history, true to its word that pursuit of happiness is a right accorded each person.

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