Policy and Its Implementation: Where the Rubber Hits the Road

John de Miranda

RRTC on Drugs and Disability.

Wright State University. Dayton, OH

2000

Summary

After providing a brief historical context for the substance abuse and disability policy implementation issue, this essay will discuss examples of three regional efforts to implement systemic accessibility strategies to comply with federal civil rights policy for people with disabilities.

1. Early Efforts

National policy and its implementation concerning the accessibility of substance abuse treatment services for people with disabilities have evolved dramatically during the past 20-25 years. It is important to note that the gap between official policy and its implementation in practice has also been narrowing during this period. For example, during the 1970s and 1980s state substance abuse agencies charged with implementing federal policy were usually content to let contracted providers self-certify that their programs were in compliance. Today it is more likely that a state agency will conduct on-site visits to assure program access.

Prior to 1980 the issue of services for people with disabilities as a special population was not on the substance abuse "radar screen." The few programs that existed, notably at Kent State University (Addiction Intervention with the Disabled), and Falmouth, Massachusetts (Cape Cod Alcoholism Intervention and Rehabilitation Unit) were small, specialized, and isolated from the larger field. In the professional literature there were vague references to addiction as a disability and a few articles that discussed the disabilities that could arise from alcoholism and drug addiction. This "dark age" was characterized by widespread ignorance about the very existence of people with disabilities as a special population, and their accommodation needs to receive treatment and prevention services. While federal policy existed to mandate accessible services, few efforts at real, systematic policy implementation occurred.

By the end of the 80s pockets of enlightened innovation had begun to appear in California, Ohio and Massachusetts. Significantly, these efforts took a broader perspective than simply creating specialized, segregated services for addicts with co-occurring disabilities. Several factors combined to give these initiatives considerable momentum and increasing visibility.

Disability Rights Movement—Within the disability community during this period, the movement to achieve full civil rights and social justice for people with disabilities was gaining momentum. This effort would achieve a major advance in 1990 with the passage of the Americans with Disabilities Act. Activists joined with substance abuse professionals and added a "justice" aspect to what might have been viewed exclusively as a service delivery issue.

Systems Perspective—Initiatives increasingly focused on accessibility of whole service systems or regional treatment and prevention networks. Independent living philosophy and the increasing sophistication of the substance abuse treatment field required that efforts to improve access target the continuum of care, as well as individual programs receiving public funding.

Self Advocacy/Empowerment—Efforts to reform substance abuse practice were assisted by people with disabilities who had achieved recovery, often in spite of service system accessibility. Some were now ready to act as spokespersons for the needs of the disabled community, and serve as access consultants, and personal examples of recovery for peers.

Until the passage of the Americans with Disabilities Act of 1990 (ADA), the controlling legal authority for requiring disability access to alcohol and drug programs was Section 504 of the Rehabilitation Act of 1973. The law was limited to programs and services that received federal funds, and prohibited discrimination on the basis of physical or mental disability. Programs and services covered by the law were required to have equitable standards of eligibility

and provide services to people with disabilities equal to those provided to non-disabled clients. The ADA considerably broadened accessibility requirements and created more compelling incentives for comprehensive policy implementation. It was thought at the time that this important piece of federal legislation might usher in a golden age of accessible substance abuse treatment. We are still far from this goal.

2. Two Statewide Needs Assessments in California

The earliest and perhaps most ambitious effort to develop a large scale response to the requirements of Section 504 of the Rehabilitation Act of 1973 occurred in California in 1989-90. The CALADDS Project (California Alcohol, Drugs and Disability Study) was a statewide needs assessment conducted by the California Department of Alcohol and Drug Programs in partnership with experts in the fields of disability, substance abuse, service delivery, and research methodology to measure the nature and extent of modifications required to create a statewide system of services accessible to people with disabilities. In addition the study also focused on accurately documenting architectural, attitudinal, and institutional barriers to recovery for people with disabilities.

The study included involvement of a major disability advocacy organization (the Berkeley-based World Institute on Disability), and was staffed by people with disabilities in recovery.

CALADDS was part of a larger institutional change process, chronicled in the journal Alcohol, Health and Research World, that began with a few individuals...

...who perceived inequity in access to recovery services. Organizing and collaborating to increase awareness and to educate professionals in alcohol and other drug abuse treatment resulted in a network of advocates within the service delivery system. To justify institutional

change, however, policy makers needed concrete documentation of the scope of the problem and the potential need for services. Initially, advocates and philanthropies volunteered to provide resources for documentation. These resources generated the data that were used extensively in the findings of... (a state) ... oversight commission. In response to these findings, the State Department of Alcohol and Drug Programs commissioned CALADDS, a study whose resources come from the public sector.

Key recommendations from CALADDS included:

- The California Department of Alcohol and Drug Programs should declare persons with disabilities a special population at risk for alcohol and other drug related problems requiring a variety of remedial measures to assure access to treatment, recovery and prevention services.
- The California Department of Alcohol and Drug Programs should train all alcohol and drug service providers in disability issues and provide technical assistance in removing barriers to service.

While the CALADDS study focused largely on service needs as perceived by disability agencies and people with disabilities, another California research effort surveyed alcohol and drug treatment programs to determine the deficits in training and practice. This effort was prompted by the passage of the ADA and occurred in 1993-94.

The Alcohol, Drug and Disability Training Project set out to assess the program accessibility needs of persons with visual, mobility, and developmental limitations throughout the State of California. Utilizing a survey research methodology that targeted substance abuse treatment professionals, a research base was established for the construction of educational interventions to

assist substance abuse professionals to improve their skills. Key findings of this study, funded by the National Institute on Alcoholism and Alcohol Abuse, included the following:

- Nearly forty-eight percent (48%) of respondent treatment professionals indicated that their ability to serve clients with disabilities needed improvement or was seriously inadequate.
- Sixty-nine percent (69%) of respondent treatment professionals indicated that their agencies could use sensitivity training about treatment recovery issues faced by people with disabilities.
- Fifty-four percent (54%) of respondent treatment professionals stated that they felt awkward or embarrassed in their feelings towards people with disabilities.

3. Regional Responses

Three geographic regions are notable for their progress developing remedial strategies to implement federal accessibility policy for people with disabilities. Each initiative evolved its own distinctive approach. The following section summarizes selected implementation elements for each region. In California and Massachusetts change was spurred by regulatory complaints aimed at funding sources. In Pima County, Arizona, however, change resulted through voluntary community-based efforts at remediation.

State of California

In 1994, in response to a complaint filed by a disability rights activist in Los Angeles, the Region IX Office for Civil Rights of the United States Department of Health and Human Services determined that the California Department of Alcohol and Drug Programs (CDADP) had failed to enforce Section 504 of the Rehabilitation Act of 1973 and Title II of the Americans with Disabilities Act of 1990 (ADA). The investigation resulted in the following conclusions:

- CDADP permits counties to enter into new contracts and renew contracts with residential treatment programs that restrict services to ambulatory clients or that are located in inaccessible facilities.
- CDADP's practice of permitting counties to self-monitor their compliance with regulatory requirements does not effectively ensure access to services for non-ambulatory clients.
- Approximately 97% of all residential treatment programs licensed by the state agency and under contract with counties have restrictive admissions policies that result in the denial of services to non-ambulatory clients.

The negotiated consent decree to remediate the compliance deficits required CDADP to:

- notify counties of their obligation to create services that are accessible in their entirety by within 18 months.
- develop appropriate referral mechanisms for people with disabilities.
- require counties to develop assessment methodologies to measure the need for alcohol and other drug services within the county.
- develop an implementation plan that provides for services to non-ambulatory clients that are substantially equivalent to services provided to ambulatory clients, including equivalency of travel time and distances.

Failure to comply with terms of this Voluntary Compliance Agreement could have resulted in penalties including non-payment of federal funds to the state agency or individual providers.

Reporting on this event Alcoholism and Drug Abuse Weekly commented,

An agreement calling for all residential addiction treatment facilities in California to be accessible to disabled persons by the end of 1995 should have officials and providers in other

states scrambling to study their obligations under the Americans with Disabilities Act (ADA)...600 treatment sites in California will need some level of remodeling to achieve ADA compliance...

The issue of physical access is an important one in the addiction field—estimates indicate that the percentage of physically disabled individuals in the addicted population is twice the corresponding share in the public at large.

In investigating the complaint against California, the federal Office for Civil Rights found that the state addiction agency's practice of relying on counties to monitor provider compliance with access requirements offered insufficient protection to persons with disabilities.

Meeting federal ADA requirements in this case involved a wide ranging process that included:

- involving the disability community in program design and implementation.
- training treatment providers in disability issues and disability culture.
- establishing a nondiscrimination regulation and complaint resolution procedure.
- raising awareness of the disability community about the availability of accessible alcohol and drug services.
- requiring providers to develop self-evaluations and effective transition plans with realistic timelines, employment practices plans that preclude disability discrimination, and effective communications programs.
- establishment of monitoring and evaluation mechanisms.

At the termination of the compliance term (December 31, 1995) CDADP could point to a significant array of accomplishments which included more than 300 residential programs achieving access for persons with mobility limitations. The cost of modifications for these

programs ranged from very little to hundreds of thousands of dollars. In addition, at the state and local level the compliance process resulted in significantly improved linkages between alcohol and drug services and disability/rehabilitation agencies. Finally, although the original complaint focused only on residential services for persons with mobility impairments, the years following the termination of the compliance agreement have seen an ongoing, vigorous monitoring and compliance effort extending to other types of treatment services and disability categories.

Commonwealth of Massachusetts

Independent living centers are community-based organizations established by the federal government to teach independent living skills to people with disabilities, and advocate for their inclusion in compliance with federal and state law. In 1991 the affiliated independent living centers in the Bay State filed a Section 504 complaint against the Massachusetts Department of Public Health Bureau of Substance Abuse Services (BSAS). Although the centers and the state substance abuse agency had been collaborating to achieve improved access, the pace was too slow for the centers.

In response to the complaint BSAS provided a one-time allocation of $300,000 to 29 substance abuse programs to improve access. In addition, for five years the Boston Center for Independent Living provided training and technical assistance services to help treatment programs achieve compliance with the law. Each substance abuse treatment program was required to create a self-evaluation plan that would demonstrate a good-faith effort to achieve full compliance in one to three years.

Linda Mazie directed this project and wrote on its accomplishments in a 1995 issue of The Report on Alcohol, Drugs and Disability,

Programs that made an effort to complete the plans…began to understand the need for disability access. Through the Statewide Substance Abuse Disability Task Force, programs shared their access accomplishments and the requests for services that they were receiving. As people with disabilities graduated from substance abuse programs and felt ready, they came to Task Force meetings and shared their experiences with the substance abuse community.

The backbone of the initiative was BSAS's Access Policy. Key elements of the policy were:

- A mandatory clause requiring providers to stipulate non-discrimination towards people with disabilities for participation in, receiving benefits from, or being employed by BSAS licensed programs.
- Each provider is required to designate an Access Coordinator (senior management position) to develop the program's ADA/504 Self-evaluation Plan. This person is also responsible for ongoing submission of accessibility improvements, responds to complaints of unequal access, and participates in the Statewide Task Force
- All providers are required to submit a complete ADA/504 Self-evaluation Plan and an annual update form each fiscal year as a prequalification requirement for continued funding.
- Programs that relocate must find space that is accessible. Programs that renovate their existing space must meet accessibility standards in order to maintain funding.
- Agencies that have not previously contracted with BSAS must have completed an ADA/504 Self-evaluation plan and occupy accessible facilities as prequalification requirements.
- Individuals with disabilities have priority status in program admissions.

- BSAS maintains a Directory of Accessible Substance Abuse Services in which no program can be included without a site survey by project staff.
- All licensed programs are required to purchase telecommunications devices for the deaf (TDDs), amplified phones, install visual fire alarms and purchase, or know how to borrow, assistive listening devices, TV decoders, bedshakers, etc. BSAS maintains a free statewide equipment loan program, and funds interpreter services.

As a result of this initiative more than 70% of the state licensed alcohol and drug treatment service programs in Massachusetts are fully accessible, including thirty residential programs, fifteen detoxification facilities, twelve methadone dosing facilities, nine prevention shelters, and fifty-eight outpatient programs.

Pima County, Arizona

Unlike the policy implementation initiatives in California and Massachusetts that arose out of regulatory complaints, the Pima Prevention Coalition (Tucson, AZ) is involved in a groundbreaking effort to improve access to services for people with disabilities through the development of a broad, voluntary community coalition.

The geographical target area for the Pima Prevention Coalition is Tucson and Pima County, Arizona. Pima County (9,188 sq. mi.) shares a common border of 120 miles with Mexico, and has an overall population density of only 72.58 persons per square mile. The 1990 County population was 666,880, the majority of whom (68%) live in Tucson. The rural area has a density of 28 persons per square mile, while the density for the 157 square miles of incorporated Tucson is 2,665 persons per square mile. Anglos now comprise 68 percent of the population, a decrease of four percent since 1980 even though they have numerically increased

by 69,987 during that time. Minorities comprise over 32 percent of Pima County's population, and 37 percent of the city of Tucson.

A 1989 survey revealed that about 1% of E. Pima County residents 14 or younger have a physical or mental condition which limits their ability to perform certain tasks. 2.5% of area residents between the ages of 15 and 64 have a disability. The survey also found that 10.1% of those 65 or older are unable to perform certain tasks because of a disability. About 8% of all E. Pima County households have a household member with a disability. In other words, 1 out every 12 homes or apartments include 1 or more disabled persons.

The Pima Prevention Coalition consists of the Pima Prevention Partnership (PPP), and seven other organizations who have combined in a special Center for Substance Abuse Prevention (CSAP) partnership project for persons with disabilities. The Partnership for People with Disabilities consists of the following organizations: Visible Invisible People Student Association (a Pima Community College student group), 3rd Street Kids, Community Outreach Program for the Deaf, Technology Access Center of Tucson, DIRECT (an independent living center), Indoor Sports Club, Division of Developmental Disabilities. Major assistance in implementing this project comes from the Community Partnership of Southern Arizona, which is the Regional Behavioral Health Authority that administers federal substance abuse block grant funds.

The Pima Prevention Coalition is guided by a combined board of directors, consisting of 24 PPP members and includes seven board members representing each of the organizations participating in the disabilities partnership project. The present board of the PPP is multi-disciplinary and multi-ethnic, with grass-roots as well as professional representation. The board members representing each of the partner agencies bring substance abuse issues related to

disabilities to the combined board. This governance plan combines a community-wide volunteer board that is representative of key government, law enforcement and public school decision makers with advocates from the disability volunteer boards. The strong presence of disabled board members helps to sensitize non-disabled board members who are community decision makers to issues of the disabled. The 24 coalition members represent 22 public institutions and agencies in Tucson and Pima County. This configuration of systems representatives, grass-roots interests and ethic diversity promises to change local, county and state substance abuse policy regarding people with disabilities.

Overall goals of the project include

1. individuals, institutions and organizations will be motivated to include and involve more children and adults with disabilities in community, educational and social affairs.
2. individuals, institutions and organizations will be skilled, and trained in including and involving more children and adults with disabilities in their planning and evaluation processes.
3. human service institutions and organizations will work cooperatively to address substance abuse issues of children and adults with disabilities.
4. an increase in local policies to include and involve children and adults with disabilities in all aspects of substance abuse prevention will have occurred.

In addition to increasing involvement of people with disabilities in “mainstream” political, social and cultural affairs, people with disabilities will have: 1) strengthened their political base as a constituency; 2) accessed prevention, intervention and treatment opportunities formerly inaccessible; and 3) unified various groups with disabilities to address and pursue ongoing prevention, intervention and treatment needs specific to people with disabilities.

This effort involves a component to survey alcohol and drug providers to assess numbers of clients served with disabilities, program access needs, psychoactive medications policies, numbers of people with disabilities on staff and boards of directors. A similar survey for disability service agencies seeks information on clients' drug use, referral to treatment practices, obstacles to identification and treatment, and substance abuse training needs.

Larry Lattomus was the original Project Manager. A wheelchair user himself, he believes that the Pima Prevention Coalition can provide other communities a wealth of information about integrating people with disabilities and substance abuse services. "We are a kind of alcohol, drug and disability laboratory, here in the desert. To the best of our knowledge there is no other project of this scale in the United States. We hope to serve as a pilot that will guide other communities as they take on this issue."

More recently the Pima Prevention Partnership has benefited from a state technical assistance initiative supported by the Center for Substance Abuse Treatment. This project seeks to enlist managed care providers into the substance abuse/disability coalition, and has developed training curricula targeted at substance abuse treatment professionals.

4. Conclusion

The federal policy tools of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 have helped treatment programs to move in the direction of improved access to services for people with disabilities. The Golden Age of a fully accessible national treatment system, however, still eludes us. As other regions follow the examples from California, Massachusetts, and Pima County, Arizona, opportunities for equal access to treatment for people with disabilities will no doubt significantly expand.