

New Jersey Alcohol and Drug
Abuse Program for the Deaf,
Hard of Hearing and Disabled:

*From Advocacy to
Implementation*

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I. Introduction



On January 5, 1996, Governor Christine Whitman signed Public Law 1995, Chapter 318, establishing the “Alcohol and Drug Abuse Program for the Deaf, Hard of Hearing and Disabled.” P.L. 1995, Chapter 318 is the first set-aside in the nation to provide funding for substance abuse services for people with disabilities—\$350,000 annually. This groundbreaking legislation is the result of a grassroots advocacy effort of nearly fifteen years.

National Significance

Although P.L. 1995, Chapter 318 is a state law in New Jersey, it is a victory for advocates across the nation, who have been working to open alcohol and drug prevention and treatment doors to persons with disabilities for over two decades. On a national scale and within local communities, groups of advocates, service providers, and persons with disabilities in recovery as well as their families have been strategizing on how to make substance abuse services accessible to persons with disabilities for over two decades.

Local tasks forces and workgroups such as the ones described in this case study, have been toiling for several years in communities across the country to make substance abuse services accessible to persons with disabilities. The voices in this case study represent individuals all over the nation who experiences the calamity of having a client, friend or family member who is in need of substance abuse treatment and cannot get it because they have a disability.

This issue has turned many individuals into advocates, from service providers to average 12 steppers. An employment coach may have a client with mental retardation who is continually fired from her job because of alcoholism. Although the client is eligible for treatment services because of an undeniable addiction, the job coach cannot find a program that will accept her. An alcoholic attending his home AA meeting is finally fed up seeing a fellow alcoholic who is deaf attend meeting after meeting, unable to understand what is being said, clearly unable to receive “the message.”

Individuals are spurred to action. Advocates have not been silent. Around the country, individuals have written letters, testified before state legislatures, met with government representatives, urging policy makers and administrators to take action. Such actions have had an impact on both state and national levels.

Several states have taken steps to open treatment doors to people with disabilities. As early as 1991, states such as Massachusetts and California developed partnerships between the state substance abuse agency and advisory bodies of disability experts. These state agencies have contracted with community-based agencies to advise their publicly funded substance abuse programs about modifying services.

On a national scale, advocacy groups are addressing the issue in various ways. The National Association on Alcohol, Drugs and Disability (NAADD) is currently the only national group addressing the issue. NAADD is a collection of individuals who, having worked tirelessly on this issue for decades, joined together in 1996 to strengthen their cause. NAADD is forming a broad-based coalition of various groups to educate

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Historically, most disability advocacy associations have not actively focused on the lack of access to substance abuse prevention and treatment services. Usually, when brought to their attention, they recognize the problem as a civil rights issue. However, it does not rank as high on the priority list as employment rights, housing or education. Unless, of course, the problem personally affects one of their members. Recently, one national disability rights organization has identified a man with a physical disability who was denied treatment in (the entire state of) Maryland. As a result, a

group of activists have now turned their scrutiny to the entire alcohol and drug field, and are considering legal action.

Beginning in the early 1990's, the federal government has taken steps to investigate and address the problem. Substance Abuse Mental Health Services Administration (SAMHSA)'s Center for Substance Abuse Prevention had a fairly active Disability Workgroup in the early 1990's. Over the years, the Center on Substance Abuse Treatment funded a handful of projects, convened disability forums and is currently assembling a Disability Workgroup. Since 1992, the Department of Education's National Institute on Disability Rehabilitation and Research (NIDRR) has funded a Research and Training Center on Drug Abuse and Disability, housed at Wright State University.

But some argue that the set aside of funds for discrete programming is the most—if not only—effective method to ensure the provision of services to the disability population. Likened to the "twenty acres and a mule" philosophy, rights and access can be legislatively mandated, but there is never a guarantee of enforcement. And, as the Americans with Disabilities Act has demonstrated, compliance and enforcement are extremely slow processes.

Disabled substance abusers need services now and the only guaranteed strategy is funding discrete services as well as activities that promote systemic change. New Jersey's P.L. 1995, Chapter 318 is an outcome and unique example of this way of thinking. Assistant Commissioner of the New Jersey Department of Health and Senior Services, Division of Addiction Services, Terrence O'Connor states, "History indicates that unless you get a set-aside, there is a constant challenge to ensure that discrete populations get the services they need. It would be an extraordinary challenge to modify existing services for many reasons, mainly that there are numerous competing priorities in the service community."

This case study will describe the history of the legislation: the period of time when advocates came together to discuss the problem among themselves, the various methods they employed to solve the problem—including other forms of legislation, how the current legislation was drafted and passed, how it was implemented and the impact to date.

Replication

This account serves as an instructional piece for groups and individuals working in the substance abuse, disability and other related fields that wish to replicate all or part of this process in their communities and states. Set-asides can be utilized to guarantee a variety of essential services (e.g., domestic violence, homeless shelters, reproductive health) for various populations (e.g., women, youth, ethnic/cultural populations, gay/lesbian/bisexual/transgender communities). Disability coalitions can learn from the model used by the New Jersey advocates who joined together. The New Jersey group included advocates who were deaf, hard of hearing and those with other disabilities. This group first educated one another on each other's issues, then went throughout the state to make cross-disability presentations to rally support for the legislation.

Administrators and policy makers as well can learn from the story which documents avenues followed, barriers encountered and outcomes. For administrators, the story illustrates the problems people with disabilities face in trying to access services and how to overcome obstacles. By understanding the story, all can see the huge difference one piece of legislation can make to a statewide constituency.

II. A Scattering of Seeds:

Description of the landscape before the legislation was passed

Advocates Recognizing the Problem

New Jersey Task Force on Alcoholism and the Hearing Impaired

In the 1980's there was a large number of deaf persons dying from alcoholism and drug addiction in New Jersey. They were unable to access treatment because there were no services available to them. A handful of strong advocates from diverse backgrounds within the deaf community, including Anna Terrazzino, who runs the Phone TTY in Whippany and Eileen Forestal who is an ASL/Interpreting teacher at Union County College, joined together to strategize about possible solutions. At that time, there were two separate divisions in the Department of Health—the Division of Alcoholism (DOA) and the Division of Narcotics and Drug Abuse Control. This advocacy group convinced Regan Riley, Director of Division of Alcoholism, that measures should be taken to serve this population. Riley granted \$10,000 to the Union County Council on Alcoholism to form a task force charged with compiling recommendations to DOA on how to address this problem. Union County Council Director Gladys Kearns staffed the Task Force.

Recommendations developed by the Task Force included the following:

- ◆ Creation of position within DOA, Project Specialist on Deafness and Disabilities, to ensure recommendations were implemented
- ◆ Funding for inpatient and outpatient programs
- ◆ Funding for prevention programs
- ◆ Provision of interpreters for 12-step meetings

All the recommendations were, in fact, implemented. Janet Dickinson, who had served on the Task Force on Alcoholism and the Hearing Impaired as the DOA representative, was hired as the first Project Specialist on Deafness and Disabilities. She remained in that position after the divisions merged into the Division of Addiction Services (DAS).

Dickinson's first job was to implement the three remaining recommendations. Initial funding was granted to the following agencies to provide outpatient services: 1) Center for Family Services (CFS), then known as Reality House, and 2) the University of Medicine and Dentistry of NJ-University Behavioral HealthCare. In subsequent years, Marie Katzenbach School for the Deaf (MKSD)'s Halfway Home Project was funded. The Division on Deaf and Hard of Hearing was granted funds to oversee the provision of interpreters for 12-step meetings. In terms of pre-

vention programming, Dickinson worked with Drug Free Schools Program staff at the Department of Education to ensure that those funds were used for deaf students.

As DOA undertook more initiatives to serve the disability population, Dickinson's responsibilities subsequently increased. She was grants manager for the first disability-related projects, Signs of Sobriety and the New Jersey Coalition on Disabilities, Alcoholism and Drug Abuse, as well as serving as the DAS agency representative to the Coalition and other disability statewide committees and agencies. After the Americans with Disabilities Act (ADA) was passed in 1990, Dickinson became a certified Barrier Free Advocate and conducted training for addictions prevention and treatment providers, including how to work with individuals who are deaf and hard of hearing. Dickinson also wrote the initial ADA Compliance Plan for the Division of Addiction Services.

New Jersey Coalition on Disabilities, Alcoholism and Drug Abuse

Susan Turner, a woman with a physical disability, was working in New Jersey as a social worker in a mental health agency in the early eighties. She had moved to New Jersey from New York, having worked in a variety of disability service agencies including the Independent Living Center in Yonkers and United Cerebral Palsy, assisting persons with mental retardation to transition into the community, through group homes, sheltered employment, etc. Since the beginning of her career as a social worker, Turner had recognized the problem of substance abuse among her clients with disabilities, from persons who had acquired their spinal cord injuries while using, to persons with dual diagnosis issues and persons with mental retardation who socialized in bars in an attempt to integrate into their communities. "Drinking is a common way to transition into the community. When one is uncomfortable in a social setting, going to a bar is easy. When you're drunk, everyone acts the same." In New York, when Turner had outreached to local substance abuse agencies to identify services for her clients, she found that although none were equipped to serve persons with disabilities, most were interested in learning how.

In New Jersey, Turner started a support group for persons with post polio. Her co-facilitator was Ray Jayco, a businessman in recovery. Turner was interested in replicating her efforts in New York to improve substance abuse services for persons with disabilities in the Garden State. She asked Jayco if he would join with her in this venture. She reasoned that having a person in recovery by her side would add credibility and additional expertise as she approached substance abuse agencies. Together, Turner and Jayco formed the New Jersey Coalition on Disabilities, Alcoholism and Drug Abuse. The Coalition was initially formed as an ad hoc group of service providers in the disability and alcohol and drug fields.

The Coalition was cross-disability from its inception, addressing issues pertaining to all disability groups—physical, deaf/hard of hearing, developmental, cognitive disabilities, blind and chronic illnesses.

Turner states the Coalition's long-range goals were twofold:

- 1) To make sure that all treatment services in New Jersey were accessible and
- 2) To make sure that those working in the disability community had tools to properly identify and refer deaf and disabled alcoholics and addicts to services.

The Coalition met its goals through education and training in various venues, including

- ◆ Individual agency trainings
- ◆ Cross trainings among diverse disability and addictions provider agencies
- ◆ Workshops at conferences, including Rutgers Summer Institute
- ◆ Hosting statewide conferences on substance abuse and disability

In the early 1980's Debra Maslansky moved to New Jersey from New York where she had worked as a special educator and rehabilitation counselor. In New Jersey she was employed at the ARC (previously the Association of Retarded Citizens) as the Director of Advocacy Services. In this capacity, she conducted trainings on numerous issues, including fetal alcohol syndrome. This topic sparked her interest in the connection between disability and substance abuse. In the late 1980's she began attending the Coalition's monthly meetings. She was impressed with the group and found it to be very organized with a strong committee structure. She quickly joined the Board of Directors and headed up the Education Committee as Chair. Maslansky began conducting trainings and speaking at statewide conferences on the issue of substance abuse and disability. Maslansky's supervisor, the Executive Director of the ARC, recognized the relevance and allowed her to participate fully in the Coalition.

In addition to community networking and training, the Coalition also took steps to raise awareness of the issue among high-level administrators. In 1989, their efforts paid off and Riley Regan, the Director of the Division on Alcoholism granted the Coalition \$30,000 to provide information and referral services. By that time, the Coalition had incorporated as a non-profit and received the money directly.

In 1993, the group changed its name from the New Jersey Coalition on Disabilities, Alcoholism and Drug Abuse to the New Jersey Coalition on Disabilities and Addictions. The change was made to match the state agency's new identity. The Department of Alcoholism and Drug Abuse had changed its name to the Division of Addiction Services (DAS) to expand its focus and include issues like gambling, nicotine, etc.

In 1998, the Coalition was able to provide each of the 18 NCADD county affiliates a \$3500 mini-grant to work on a local substance abuse project related to a disability issue.

In 1993, the Division of Addiction Services funded the Coalition to create a statewide coordinator position and Debra Maslansky assumed that role for the next seven years. The organization was housed in a local chapter of the NCADD National Council on Alcohol and Drug Dependency (NCADD) in Monmouth County. For the first grant year in 1989, the Coalition kept its identity as an autonomous organization. But maintaining status as an independent agency proved to be too costly and complex, requiring a yearly audit, book-keeping system, personnel policies, etc. Subsequently,

it gave up its non-profit status and became a project of the NCADD of Monmouth County. Later, NCADD of Monmouth County changed its name to Substance Abuse Resources, then Prevention First.

The Coalition continued its work, creating and supporting regional task forces, providing information and referral and conducting statewide conferences and presentations. In 1995, the Coalition conducted a survey of alcohol and drug treatment providers to gauge their level of accessibility. Based on these results, the Coalition was able to convince the DAS Assistant Commissioner, Terrence O'Connor to incorporate accessibility information in the state directory of treatment programs. In 1998, the Coalition was able to provide each of the 18 NCADD county affiliates a \$3500 mini-grant to work on a local substance abuse project related to a disability issue. Projects ranged from raising awareness about general disability issues to providing educational seminars on issues linking learning disabilities and risk factors for substance abuse to educating pregnant women about preventing developmental disabilities and fetal alcohol syndrome.

John Hulick Working the Legislative Angle



John Hulick

Around the same time the New Jersey Coalition on Disabilities, Alcoholism and Drug Abuse Coalition was established, another advocacy effort was beginning.

John Hulick approached this problem as a self-proclaimed advocate. After attending for six weeks, he left law school and was sitting in a 12-step meeting. It was 1987 and he was in New Jersey. A deaf man was there as well, his mother trying to interpret what was going on with her limited knowledge of sign language. Hulick decided to help the man. First, he became his sponsor, then he placed upwards of sixty calls around the state trying to find services for deaf persons. Each time, he was told, "we know this is a problem, but we have nothing for you." The counties told him it was the state's responsibility and the state claimed it was the counties' problem.

News spread quickly in the deaf community that someone was trying to help deaf alcoholics. Soon, three other deaf men began attending the meetings, one of them became Hulick's sign language teacher. Hulick began with the alphabet, then learned sign language, becoming known as "sign language John," and interpreting, ad hoc at meetings.

With his background in public policy, Hulick's immediate inclination was to solve the access problem legislatively. These were publicly funded services and there needed to be some accountability somewhere. He identified Senator John Ewing (R-Somerset) as someone sympathetic because of his interest in deaf education as well as his track record of sponsoring progressive substance abuse legislation. Senator Ewing viewed substance abuse as a disease that can destroy families and ruin lives. He had seen firsthand the impact substance abuse had on an aide's family years before. It didn't take much explanation for him to understand that substance abuse is "a disease that affects all humans, disabled or not."

Hulick met with Ewing and explained the problem. Ewing recalls that Hulick "brought to his attention that disabled addicts and alcoholics are not treated the same as [non-disabled] substance abusers, yet many people with disabilities have substance abuse problems" and "John really pushed me to do something about it." Ewing called Riley Regan, Director of the Division of Alcoholism, with whom he had a close personal friendship based on his respect for the obstacles Regan had overcome in relation to his own alcoholism. Ewing told Regan, "you've got to do something for this guy." And Regan did.

In 1988, Hulick founded Signs of Sobriety and DOA granted the agency \$30,000 start-up funding in September 1989. Initially, Signs of Sobriety filled the role that Hulick identified as the most crucial—an information and referral source for deaf and hard of hearing persons seeking substance abuse services. Hulick wanted to fill the gap that he had encountered and wanted to save others from the daunting experience of making scores of phone calls that led nowhere.

Legislation That Failed to do the Job

In the late 1980s and early 1990's, two pieces of legislation mandated the inclusion of accessible substance abuse programming for people with disabilities. One was spearheaded by Senator Ewing and John Hulick in New Jersey, the other was national in scope. Neither proved effective in addressing the need.

New Jersey Senate Bill 1891

In 1989, Senator Ewing sponsored legislation that would establish the New Jersey's Governor's Council on Alcoholism and Drug Abuse, a Division on Drug Abuse, and an Alliance to Prevent Alcoholism and Drug Abuse. Among other objectives, this legislation amended an existing county-based planning process. Hulick worked with Ewing to ensure that "the disabled" was identified as a population needing special attention in county-based alcohol and drug abuse plans that were to be submitted to the state. Hulick had found that counties claimed they would serve the population if only they were able to plan and allocate funding appropriately. Therefore, the legislation sought to give counties an opportunity to plan for disability specific substance abuse services—to conduct needs assessments on the potential need and develop county-based strategies to meet those needs. Unfortunately, very few of the county plans reflected these changes, and no changes in services were implemented that benefited people with disabilities.

The Americans with Disabilities Act

The most comprehensive disability civil rights legislation to date is the Americans with Disabilities Act of 1990. Under Title II of the ADA, each government entity is obligated to conduct a self-evaluation of all publicly funded programs and services, including those related to substance abuse, and develop a transition plan for the removal of architectural barriers. In New Jersey this meant that the state, counties and cities should have been working toward full compliance throughout the 1990's. Advocates believed the ADA was having only limited impact on services. Statewide compliance was slow and there were still great, unmet needs. Terrence O'Connor, DAS Assistant Commissioner summarized the dilemma: "With all of the substance abuse treatment field's competing needs and priorities, it is a monumental challenge to modify existing services. And, even then, there will always be a need for discrete services for certain sub-populations, such as the deaf."

Why a Set Aside was the Solution

Opinions about set asides differ. Legislators can use them to ensure that public monies are meeting constituents' needs. Administrators find them a problem because they constrain their flexibility in operating programs.

Advocates are split on the issue. Some feel that, as was demonstrated by special education policy, providing separate services is a way to segregate people with disabilities and deny them access to services with more substantial funding. On the other hand, some advocates feel that "ear-marked" funding is the only way to guarantee access.

III. Setting the Stage: Advocacy Effort

Prior to legislative attempts for a set-aside, John Hulick and Senator Ewing made one attempt to include disability into another piece of legislation. In February 1989, Senator Ewing introduced S2786 of 1988-1989, a bill that would increase wholesale tax on alcoholic beverages. A percentage of the tax would be set aside for alcohol education and treatment. Hulick made sure that a percentage of the revenue would be used to establish such programming for persons with disabilities. The legislation passed through the Senate, but died in the Assembly. At the time, the Speaker of the Assembly was running for Governor and didn't want to support a tax increase.

About a year later, Hulick became aware of legislation that established a substance abuse program for senior citizens. He thought if a program could be proposed for seniors, why not the disability population? Hulick approached Senator Ewing with the idea.

Hulick worked with Senator Ewing for the next four years, trying to get a set-aside of funding for disability specific substance abuse programming. Ewing introduced several iterations of the legislation before the final one was signed into law in 1996. The initial versions are listed below. All previous versions of the legislation died in committee.

<i>Date</i>	<i>Legislation</i>	<i>Funding Source</i>
Feb. 4, 1991	S3284 of 1990-1991 is introduced which establishes an "Alcohol and Drug Abuse Program for Deaf and Disabled," appropriates \$200,000.	Casino revenue fund
March 16, 1992	S570 of 1992-1993 is introduced which establishes an "Alcohol and Drug Abuse Program for the Deaf and Disabled," appropriates \$200,000.	General Fund
April 2, 1992	An amendment changes the source of funding for S-570 to Drug Enforcement Demand Reduction (DEDR) fund.	DEDR fund

Although funding sources and amounts changed, the essential legislation was the same. It is unclear how the \$200,000 figure was derived.

Nothing further happened with the bill until 1994. At that time, Hulick resigned as Director of Signs of Sobriety. Although he found the direct service work gratifying, the crisis management aspect was draining and he craved more advocacy-related work. When he applied for the position of Director of Public Policy at the statewide NCADD, he thought he had "died and gone to heaven." It was exactly the type of job he wanted.

He got the position and getting a set aside for disability-specific substance abuse programming was at the top of his list of priorities. Hulick was the pivotal force behind the legislation's enactment. His legislative and public policy acumen were essential in the ultimate success of the legislation. Hulick credits the passage of the bill largely to the fact that someone could devote full-time attention to it.

Although having a full-time advocate was crucial to the bill's passage, there were a few other hurdles to jump.

Hurdle One: *Lack of Coordination Between the Deaf and Disability Communities*

When he stepped down, Hulick hired Steve Shevlin to replace him as Director of Signs of Sobriety. Shevlin moved from New York to accept the position. Shevlin recalls Hulick telling him that one of his duties would be to form an advisory committee that would generate interest in, and garner support for, the bill. Shevlin was skeptical about forming alliances with other disability groups because, in his experience, "the deaf community and the disability community don't always get along so well." He describes the complex relationship as multi-layered. First, most deaf people do not identify themselves as having a disability. They experience a "communication barrier"—if the general population knows sign language, deaf people are not hindered in society. Second, some deaf people want to avoid the stigma of having the label of disability, and in doing so, offend persons with other disabilities who do not view their own disabilities as negative. In working together, deaf people often find that although someone may be blind or have a physical disability, they are still hearing, and don't necessarily understand the experiences and frustrations of a deaf person. For instance, it is commonly believed that providing an interpreter is creating equal access for a deaf person, when in fact an interpreted conversation is not the same as direct communication, where both people are speaking the same language. In an interpreted conversation, nuances and subtleties that are crucial to communication are lost.

Despite his misgivings, Shevlin assembled an effective cadre of representatives from the deaf, hard of hearing and other disability groups to work on the legislation. He believes the group was effective and worked well together because they openly discussed their fears of working together, what might go wrong, and how the alliance could hurt the individual groups they represented. This open communication led to educating one another and made it possible for people to put their differences aside and work collaboratively. Ultimately, everyone realized that there was enough common ground on this issue for cohesion.

This group made presentations and conducted all day workshops all over the state for various agencies in the substance abuse and disability fields. Most importantly, they met with key local stakeholders to describe the needs of the population and demonstrated how the individual counties were not meeting them.

Hurdle Two: *The Governor's Council on Alcoholism and Drug Abuse (GCADA) Opposed the Legislation, Calling it "Flawed Policy."*

Changing the source of funding to the Drug Enforcement Demand Reduction (DEDR) Fund should have been a non-controversial move. The DEDR Fund is the pot of money collected from drug fines. The Fund collected more revenue than was obligated, so the appropriation was essentially an unspent balance that would have to be returned to the state's General Fund anyway.

However, the Governor's Council on Alcohol and Drug Abuse (GCADA) had a different view. The GCADA receives its appropriation from the DEDR Fund, dispensing its share to local municipalities to fund prevention, treatment and aftercare programs. The GCADA was very protective of the DEDR Fund. In 1994, the legislative session when the bill gained ground, the GCADA began to pay attention. First, the Council was concerned that if legislation appropriated a portion of the fund for one purpose/group, it would set precedent for others, potentially draining the fund. Second, the GCADA asserted that the provision of services to persons with disabilities should be planned and implemented on a local level—addressing the needs of persons with disabilities was in their legislative mandate. According to the GCADA, local communities knew best what the needs of their constituents were. The GCADA also asserted that large amounts of the DEDR Fund had been diverted to the Department of Health and Senior Services for the past five years, over which programs for special populations could have been established.

For these reasons, the Council went on record opposing the legislation. While the GCADA was supportive of providing services to the disability population, it thought that using DEDR funds was the wrong way to go.

In order to collect information about the need and thereby propose an alternate way to serve the population, the GCADA held a series of public hearings to get input from deaf, hard of hearing and disabled persons of how best to meet their substance abuse needs. Several individuals working within the disability community, such as Hulick and Maslansky, advised the GCADA that the forum of public hearings was not an effective way to get input from persons with disabilities, particularly from the deaf community, whose members tend not to air their business publicly. Nonetheless, the GCADA went ahead, spending a great deal of effort publicizing the hearings. But, as anticipated, the turnout was quite low, yielding little information. GCADA staff also conducted telephone and individual interviews with various professionals regarding the substance abuse needs of persons who are deaf, hard of hearing or with other disabilities.

They compiled the results and published a report with recommendations pertaining to the pending legislation, including the following: specifying where the money would go, how it would be allocated and spent, funding projects that have clear goals and objectives, supporting mainstream programs as opposed to specialized ones, collecting reliable statistics on alcohol and drug problems among the specified population, and calling for qualitative assurance procedures conducted several times a year. Some of these recommendations had an impact on the legislation and the program, such as the requirement for projects to have clear goals, objectives and measurable outcomes and the conducting of a needs assessment.

Additionally, the GCADA wrote letters to the legislature and testified at the senate and assembly committee hearings, opposing the legislation. The deaf and disability advocates made presentations to the GCADA and its local affiliates explaining the need for the legislation. As it became apparent that the bill had unanimous public support and was going to pass, the GCADA changed its stance to support the bill with the stipulation that the recommendations outlined previously were included.

At the bill's final hearing in the New Jersey Assembly on November 20, 1995, several people testified, weighing in to support the bill, including representatives from Signs of Sobriety, the New Jersey Coalition on Disabilities and Addictions, the GCADA, and DAS.

Key Dates Relating to Passage of Public Law 1995, Chapter 318

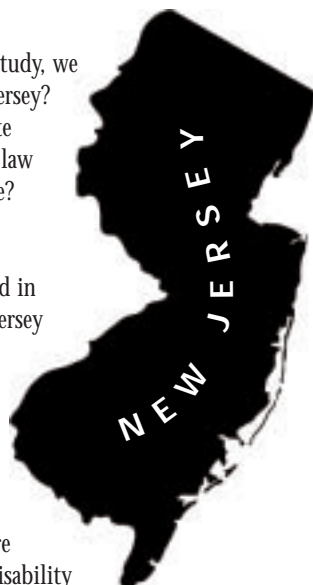
<i>Date</i>	<i>Legislation</i>
May 5, 1994	S-946 of 1994-1995 was introduced (mistakenly omitting "Hard of Hearing") that establishes an "Alcohol and Drug Abuse Program for the Deaf and Disabled," appropriates \$200,000 from Drug Enforcement Demand Reduction (DEDR) fund (only difference was title and \$ amount)
May 12, 1994	S-1054 of 1994-1995 introduced by Senator Ewing to establish an "Alcohol and Drug Abuse Program for the Deaf, Hard of Hearing and Disabled," appropriates \$350,000 from the DEDR fund
June 27, 1994	A-1975 of 1994-1995 introduced by Assemblymen Cotrell and Malone to establish an "Alcohol and Drug Abuse Program for the Deaf, Hard of Hearing and Disabled," appropriates \$350,000
May/June 1995	GCADA holds public hearings regarding the treatment needs of Deaf, Hard of Hearing and other disabled persons
October 19, 1995	S1054 passed in the Senate
Nov. 20, 1995	Public testimony on S-1054 before the Assembly Senior Citizens and Social Services Committee
Dec. 21, 1995	S1054 passed in the Assembly
January 5, 1996	Public Law 1995, Chapter 318 signed by New Jersey Governor Christine Whitman

Why New Jersey?

In conducting field work for this case study, we asked several interviewees Why New Jersey? What elements were present in the state that created an environment for such a law to be developed and pass the legislature?

A Small State

Several advocates had previously worked in New York and commented that New Jersey had a smaller, more organized service system. Because of its size, networking was easier. There was a stronger connection between local services and the state agency. There were more opportunities for networking in local communities. There was a smaller, more organized service system. In terms of disability services, there were more independent living centers and strong disability leadership.



Strong, Cohesive Addictions Field

Many remarked that the addictions field in New Jersey was very organized, and worked together effectively as a collaborative network. The GCADA structure made representatives of the field accessible to the advocacy groups as they tried to promote the legislation.

State Agency's Commitment to Continuum of Care

DAS focused on maintaining a continuum of care and resourcing it to meet the needs of persons with disabilities. As the Division on Alcoholism, then the Division on Addiction Services, New Jersey state government developed a continuum of care in the area of deaf (and other disabilities), and also grew a core of professionals to work in these new programs. These individuals, many of who were members of the groups they represented, then collaborated, to ensure that quality services were being delivered throughout the state.

IV. The Legislation and its Implications

Title: **Public Law 1995, Chapter 318**
Alcohol and Drug Abuse Program for the Deaf, Hard of Hearing and Disabled

Funding: *\$350,000 annually*

The law is groundbreaking for a number of reasons, but mainly because it is the first set-aside in the country for substance abuse services for persons with disabilities. Several states have had strong advocacy movements on the issue, but none to date have secured a set aside. As noted previously, a set aside is a significant step in assuring that the substance abuse needs of persons with disabilities are met.

Civil Rights Language

The document itself is important because it publicly asserts the substance abuse needs of the population and acknowledges the lack of access. In doing so, the document is unique in that it frames the problem in a sociopolitical context. Some key passages are excerpted below.

“The Legislature finds and declares that:

- ◆ There is growing evidence that people with deafness, hearing loss or other disabilities are at greater risk of being involved with alcohol or other drugs or abuse than the general population;
- ◆ The deaf and hard of hearing have a communication disability which prevents them from receiving and communicating information that would enable them to make more informed decisions about their own use, abuse or addiction to alcohol and other drugs; and
- ◆ The combined impact of physical impairment, attitudinal and architectural barriers, societal discrimination and the psychological stresses that accompany disability may create a special vulnerability for substance abuse in people with disabilities.”

“The Legislature further finds and declares that:

- ◆ Few rehabilitation centers and professionals working with the deaf, hard of hearing and other disabled persons are adequately prepared or trained to identify, recognize, or deal with signs of substance abuse; and
- ◆ New Jersey needs the development of specialized services for people with disabilities who abuse, misuse and are addicted to alcohol and other drugs.”

Key Program Elements

The legislation calls for the following:

Establishment of a Program Advisory Committee to advise the Commissioner of the Department of Health and Senior Services

The provision of an Advisory Committee gives advocates a direct link to the state agency, the Division of Addiction Services, ensuring that the legislation is implemented with integrity. The Advisory Committee guides the program, assuring that it continually meets the needs of the community and that the funds are utilized to the maximum potential.

Provision of public awareness of, and development of advocacy efforts for, the deaf and hard of hearing and other disabled persons who are in need of treatment services for alcoholism and drug abuse, and development of treatment modalities and specialized training programs for this population

The program does not fund services. A component of the program is focused on system change while direct services grantees are required to coordinate their efforts and seek to develop models that can be replicated.

Funding under the legislation cannot be used to supplant monies that would otherwise have been made available to provide alcoholism and drug abuse services for the population, nor shall the moneys be used for the administrative costs of the program

Again, the funds are not to be used to operate services or make existing services accessible by making architectural modifications, etc., unless these adaptations are made while designing a specific model program. Due to the limited appropriation, the emphasis of the legislation is on expanding and building upon the already established foundation of accessible substance abuse services, whether in an integrated setting, or provided discretely.

V. Implementing the Legislation

Convening the Advisory Committee

It took over a year before there were any noticeable moves to implement the legislation. The first step was to assemble the Advisory Committee. Names were forwarded to Commissioner of Health and Senior Services, then members were appointed. The initial Advisory Committee was comprised of several long time activists such as Debra Maslansky. John Hulick, the one who initiated the process, served as the Advisory Committee's first Chair.

The legislation was passed in **January 1996** and the first Advisory Committee meeting was convened in **March of 1997**.

Now that the Advisory Committee has been assembled, additional members and replacements are appointed in the following steps:

Process for Appointment

1. Potential candidates are referred to the Advisory Committee for consideration.
2. The Advisory Committee approves candidacy and recommends appointment to the Commissioner of Health and Senior Services.
3. Commissioner ultimately appoints all members.

Advisory Committee Composition

The legislation mandated that the Advisory Committee include the following members:

- ◆ Five members who are either deaf, hard of hearing, or disabled,
- ◆ Two members of the public with an interest in issues relating to alcohol and drug abuse, and
- ◆ One representative from the following entities:
 - Governor's Council on Alcoholism and Drug Abuse,
 - Developmental Disabilities Council,
 - Division of Vocational Rehabilitation Services in the Department of Labor, and
 - Division of the Deaf and Hard of Hearing in the Department of Human Services

The legislation also mandated that the Commissioner serve as an ex officio member of the Advisory Committee. The DAS Disability Specialist attends each meeting as a representative of the Assistant Commissioner.

The Assistant Commissioner has appointed an additional representative from the Division of the Disabled, Department of Human Services.

The Advisory Committee developed governing by-laws and uses Robert's Rules of Order to conduct its business. They build consensus to make all decisions.

Barriers to accomplishments have mainly been:

1. **Developing a model program with no pre-existing prototype.** One of the downsides of being a part of a groundbreaking model is that you are developing something from scratch. Steve Shevlin notes that, "we're setting a precedent and everyone wants to be careful not to make any mistakes." Every member is passionate about the issue and wants to be sure they "get it right."
2. **Taking steps to ensure that all disability groups are represented.** The lack of involvement of specific disability groups has been an ongoing issue for the advocacy movement and is mirrored in the make up of the Advisory Committee. Even among the groups represented, educating one another about each other's issues is a continuing process. Though time-consuming, disability cross-training is a critical piece to coalition building and is one of the elements that makes the Advisory Committee a national model.
3. **Working within a complex bureaucratic system.** It took over two years after the passage of the legislation for any funds to be disbursed to programs. First, the Advisory Committee needed to create and follow their process. Second, DAS, being a government entity had to work to fit the Request for Applications the Advisory Committee created into their RFA prototype without losing its intent and integrity. The RFA went from various DAS departments, back to the Advisory Committee several times before being approved and released. Debra Maslansky comments that the "bureaucracy has crawled at a snail's pace."

Needs Assessment

After P.L. 1995, Chapter 318 was passed, the provision of a (current) Needs Assessment was one of the first orders of business. A needs assessment was in the GCADA's recommendations and the Advisory Committee also advocated for it as a means to tailor the funding application to what was needed in the field. In addition, the Commissioner of the Department of Health and Senior Services was reticent to release funding until the needs assessment was complete.

Dr. Clark had twenty years' experience working with persons who were deaf, hard of hearing, and had other disabilities as a licensed social worker and mental health worker in New York, giving her direct knowledge of the subject matter.

In December 1997, a year after the Advisory Committee had been formed and two years after the law had been passed, an independent (non Advisory Committee member, non-DAS staff) evaluator was hired, Dr. Rebecca Clark. By this time, over one million dollars had accumulated (\$350,000 annually), creating considerable pressure to complete the needs assessment quickly, so funds could be released.

Advisory Committee member, Steve Shevlin identified Dr. Rebecca Clark as a qualified candidate to conduct the needs assessment. When hired, Dr. Clark was working as an independent researcher, but had twenty years' experience working with persons who were deaf, hard of hearing, and had other disabilities as a licensed social worker and mental health worker in

New York, giving her direct knowledge of the subject matter. In her clinical capacity, she was highly involved in addressing substance abuse issues. As she explained, "Because of the lack of access to services, (as social workers) we are the be-all and end-all (to our clients) by default." The Advisory Council interviewed Dr. Clark, her references were checked and she was hired. The contract for the needs assessment was \$25,000.

A Sub-Committee made up of Advisory Committee members and DAS staff oversaw the Needs Assessment. The following information is culled from the final document, New Jersey Alcohol, Tobacco, and Other Drugs Services For People with Disabilities: Needs Assessment, by Dr. Rebecca Clark, completed May 1999.

◆ **Needs Assessment's Purposes**

The Sub-Committee, in collaboration with the full Advisory Committee, defined the goals of the Needs Assessment.

1. Identify knowledge levels and attitudes of alcohol and other drug service providers and prevention, education and treatment options available to the disabled in New Jersey.
2. Identify knowledge levels and attitudes regarding alcohol and other drug problems of disability service agencies and prevention, education and treatment options available through these agencies in New Jersey.
3. Assess the extent and geographical distribution of alcohol and other drug problems in the disabled population by specific disability i.e., physically challenged (sic), blind/visually impaired, deaf/hard of hearing, and developmentally disabled.
4. Create a final report containing findings and recommendations for a three to five year plan to implement prevention, education and treatment options.

- ◆ **Methodology**

Dr. Clark designed the study's methodology—The gathering of information from diverse sources, about both the general topic of substance abuse and disability and the specific program needs of the New Jersey system. The approach borrowed heavily from needs assessments conducted in California by John de Miranda. The New Jersey Needs Assessment consisted of the following:
- ◆ *Literature Review covering the following topics*
 - Disability and Substance Abuse
 - Deaf and Hard of Hearing and Substance Abuse
 - Blind and Visual Impairments and Substance Abuse
 - Mobility Impairments and Substance Abuse
 - Developmental Disabilities and Substance Abuse
- ◆ *Public Hearings*
 - 3 public hearings
 - Bergen County College
 - Camden County College
 - Marie Katzenbach School for the Deaf (MKSD)
 - Limited response: a total of 5 persons testified
- ◆ *Survey of Disability Service Providers*
 - Instrument developed by John de Miranda
 - Mailed to 198 agencies
 - 40 respondents
 - 20.2 % response rate
- ◆ *Survey of Alcohol and other Drug Service Providers*
 - Instrument developed by John de Miranda
 - Mailed to 109 Prevention agencies
 - Mailed to 303 Treatment agencies
 - 139 respondents
 - 33.7 % response rate
- ◆ *Focus Groups*
 - 5 Focus Groups
 - A 12 step meeting for people who are deaf and hard of hearing
 - Marie Katzenbach School for the Deaf (MKSD) Students
 - Middlesex County Monday Morning Advocacy Network
 - New Jersey Commission for Blind/Visually Impaired
 - State Independent Living Council (SILC) and independent living centers (various disabilities)
 - Approximately 100 participants
 - An almost equal number of men and women
 - Mostly White and African American
 - Majority of disability groups represented were deaf, mobility impaired and blind
 - Half were aged 30-50
 - Half were unemployed

Major Findings

The major findings of the New Jersey Needs Assessment are similar to results from several other regional and national studies conducted over the past decade. The results are outlined below.

- ◆ There may be 200,000 persons with various disabilities in New Jersey in need of alcohol and drug treatment services.
- ◆ Persons with disabilities are not utilizing the alcohol and drug service system in numbers commensurate with their representation in the general population.
- ◆ Although ATOD agencies believe they are moderately accessible to people with disabilities, they in fact, are not accessible.
- ◆ ATOD service agencies reported a great interest in becoming accessible, but identified lack of funding as a major barrier.
- ◆ Persons working in ATOD service agencies are not adequately trained about the needs of people with disabilities.
- ◆ Persons working in disability service agencies are neither adequately trained nor knowledgeable about alcohol and drug problems among people with disabilities.
- ◆ A majority of responding ATOD agencies are available to cross-train those in the disability field. In contrast, the majority of (responding) disability service agencies are not willing to serve on local task forces to improve ATOD services for people with disabilities.

The recommendations that came out of the Needs Assessment had significant impact. They drove the RFA that was developed after its completion and therefore, what programs were funded. The list of recommendations is summarized below.

- ◆ **Accessibility to Prevention, Treatment and Aftercare Services**
All programs should examine their programs and policies (including medication policies), take steps to comply with accessibility standards and if found out of compliance, DAS should make sanctions against them. County plans should address the needs of persons with disabilities. Strategies for providing accommodations for 12-step meeting participation should be explored. Informational materials should be developed in accessible formats. Accessible programs should target youth.
- ◆ **Education and Training**
Cross-trainings for substance abuse service providers and disability service providers should be facilitated. Disability service providers should be trained to discuss substance abuse issues with their clients, provide them information and make appropriate referrals to appropriate services. Substance abuse certification programs should include training on disability issues. Substance abuse agencies on all levels should include disability in their data collection procedures.

- ◆ **Agency Coordination**

County administrators should designate a staff person to coordinate services and to serve as chief liaison between substance abuse services, disability services, DAS and persons with disabilities. Local task forces should be developed to improve the coordination of substance abuse and disability services. People with disabilities should be integrated into substance abuse services by working as staff and serving on boards of directors.

- ◆ **Funding**

Mechanisms should be explored to create a fund for 1) sign language interpreters, 2) captioned videotapes, 3) real time captioning, and 4) the development of materials for persons with limited English comprehension skills. The feasibility of a regional or central location should be explored to develop multi-county funding for treatment and aftercare services for low



incident disabilities. Substance abuse agencies at all levels should develop monitoring and enforcement mechanisms to ensure compliance with accessibility standards. Funding resulting from the cancellation of contracts of non-compliant programs should be earmarked for and given to programs that are in compliance.

Barriers to the Needs Assessment

Although the Division of Addiction Services, the Advisory Committee and Dr. Clark were all satisfied with the Needs Assessment, everyone acknowledges that there were snags in the process.

- ◆ **Low participation in public hearings and focus groups by consumers in general and specific disability groups.** There is a general feeling among those involved in the Needs Assessment (the Advisory Committee and the evaluator) that the methods used to solicit input were not adequate, the consensus being that there needed to be more creative ways to engage consumers. Another possible barrier identified by the evaluator was that perhaps there was a perception that the legislation was specifically aimed at persons who were deaf and hard of hearing, which may have contributed to the lack of feedback given by other disability groups. Other factors she believed may have contributed to that perception were the make up of the Advisory Committee and the fact that evaluator is deaf. Because of the lack of input from various groups, the data should be considered inconclusive.

- ◆ **Low participation in public hearings, focus groups. Timeline was tight.** Everyone (the Advisory Committee, the Commissioner, the Assistant Commissioner, and the GCADA) was eager for the Needs Assessment to be completed so that funds could be disbursed to the field. The time pressure did not allow for the development of instruments specific to New Jersey. The evaluator adapted a survey prototype that was developed for providers in California.
- ◆ **Resources were inadequate.** The contract did not allow enough resources for the evaluator to perform some tasks that may have ensured a better response rate such as follow up calls to agencies, etc.

Funding of Programs

Three years after the legislation had been enacted, an RFA process was still not in place. The Advisory Committee was waiting for the Needs Assessment to be completed because they wanted to base program funding on the study results. But three years of unspent revenue had accumulated—over one million dollars—raising a red flag to the New Jersey Treasury. The Advisory Committee was in a bind. They were afraid of losing the money, but not quite ready to solicit applications for extensive program funding. They didn't feel they had enough needs-based data to identify projects and commit multiple-year funding.

An Interim Solution

◆ **Concept Papers**

The Advisory Committee decided to fund “seed” programs. The Commissioner and the GCADA allowed the Advisory Committee to release half of the funding that had accumulated. A request for “concept papers” was issued on **June 22, 1998**. The maximum grant amount was \$75,000 and the grant period was twelve months. Several of the grantees would be refunded for a second year.

The funding eligibility criteria were simple, making it possible for a broad range of agencies to apply: “public non-profit agencies who had a demonstrated history of quality service to the target populations.”

Applicants needed to submit a four page concept paper that included: 1) a brief agency description, 2) project description including needs, goals, objectives, implementation plan, target population and number of persons to be served, and 3) budget. Unlike the subsequent RFA, this application did not split the funding between programs for deaf and hard of hearing and those for other disability groups. Nor did this application require agencies to have a strong background in providing substance abuse services to the disability community. The Concept Paper initiative encouraged qualified and committed agencies to take a chance and broaden their current scope of services.

Besides meeting the immediate goal of disbursing the money, the Concept Papers also served as an awareness-raising tool. For some working in either the substance abuse or the disability fields, the issue of substance abuse among people with disabilities had not crossed their radar screen until the Request for Applications for Concept Papers.

The Advisory Committee received thirty-six applications which were reviewed by a subcommittee consisting of a select number of Advisory Committee members (in particular, those who were not themselves bidding for funding) as well as members of DAS staff. Applying agencies made a presentation before the subcommittee. Thirteen projects were awarded funding for total of \$643,279. Grants ranged from \$25,000 to \$75,000. The range of projects and types of disabilities addressed were diverse—the development of a videotape describing the problem of substance abuse and disability, the provision of training interpreters on addiction issues and language, training of medical rehabilitation professionals on addictions and physical disabilities. All but two projects were awarded further funding in subsequent cycles. After projects had been funded, there was some additional money with which DAS provided interpreters for Certified Alcohol and Drug Counselors (CADC) course, so deaf persons could become certified counselors.

◆ **Major Funding for Programs**

Following completion of the Needs Assessment, the Advisory Committee drafted criteria for the Request for Applications. The Advisory Committee and DAS collaborated extensively on criteria development. As Wanda Cintron, Chief of Special Populations, DAS notes, “It took a village to write that RFA.” All Advisory Committee members were strongly committed to ensuring the program be as comprehensive as possible to meet the needs of the constituents they were representing. DAS was committed to utilizing the wisdom and expertise of the Advisory Committee. Everyone’s dedication to create a valuable process, coupled with the bureaucracy of the funding cycle led to an arduous process, and somewhat confusing proposal.

The RFA was broken up into the following six sections

1. **Establishment of Regionally-Based Task Forces(\$200,000/yr for 3 years). The grantee would be responsible for:**
 - Improving local and regional coordination between alcohol/drug abuse and disability service providers
 - Improving the county-based alcohol and drug abuse planning process as it relates to treatment and prevention service needs of persons with disabilities

- Developing a three-year county-based action plan for meeting the alcoholism and drug dependence prevention and treatment needs of persons with disabilities
 - Improving training opportunities for alcohol/drug abuse and disability service providers
 - Hosting regionally based forums and/or statewide forum to discuss county-based action plans and develop a statewide action plan to determine the feasibility of developing services and funding for low incidence disabilities
 - Ensuring that appropriate educational materials are disseminated in each county
 - Ensuring that the task force membership includes people with disabilities
2. **Request for Support of Interpreter Services (\$25,000/yr for 3 years). The grantee would be responsible for:**
- Ensuring communication accessibility to alcoholism and drug dependence services for persons who are deaf/hard of hearing via American Sign Language, or computer assist real time (CART) services
 - Developing a sliding scale rate schedule for for-profit and non-profit agencies requesting services
3. **Establishment of a Scholarship Fund (\$10,000/yr for 3 years). The grantee would be responsible for:**
- Making scholarships available to alcohol and drug abuse service professionals to pursue a proposed disability specialty within the current addiction certification process
 - Making scholarships available to disability service professions to pursue training as Certified Alcohol and Drug Counselors
4. **Enhancement of Statewide Libraries (\$29,163 one time only). The grantee would be responsible for:**
- Developing and maintaining a resource library on substance abuse issues for persons who are deaf/hard of hearing and for persons with other disabilities
 - Disseminating resources for free or on loan to requesting parties
 - Making available information on statewide events for alcohol and drug awareness, as well as events sponsored by disability agencies statewide

5. **Establishment of a Model Program for Treatment of Addictions/Disabilities (\$230,000/yr for 3 years – \$115,000 for a program for persons who are deaf/hard of hearing, \$115,000 for a program for persons with other disabilities). The grantee would be responsible for:**
 - Identifying the specific disability populations to be served and developing appropriate treatment modalities to address the programmatic, attitudinal, communications and architectural barriers that often exist and limit the accessibility to treatment by persons with disabilities and by persons who are deaf/hard of hearing
 - Assisting other treatment programs identified through the county-based planning process in establishing accessible treatment services
6. **Establishment of Statewide Community-Based Prevention Programs (\$120,000/ yr for 3 years—\$60,000 to establish and implement a statewide community-based prevention program for persons who are deaf/hard of hearing, \$60,000 to establish and implement a statewide community-based prevention program for persons with other disabilities). The grantee would be responsible for:**
 - Organizing disabled, deaf/hard of hearing community members to develop a plan and activities to prevent alcoholism and drug dependence
 - Implementing the community developed statewide plan and statewide activities to prevent alcoholism and drug dependence among persons who are deaf/hard of hearing and with other disabilities

The first four parts equaled the balance of accumulated funds (\$734,163) and parts 5 and 6 were the initial \$350,000 set aside by the legislation.

On **August 21, 2000**, the Request for Applications for “Provision of Services for Deaf/Hard of Hearing and Disabled Persons” was released. DAS held a Bidder’s Conference on **September 22, 2000**. Proposals were due **October 13, 2000**.

Although notification that funding was available was sent to 500 agencies and full application packages were sent to 185, there were far less applicants than anticipated. Reasons for the limited number of proposals submitted included the following:

- ◆ Not enough time to write proposals
- ◆ Not enough expertise in the field
- ◆ RFA cumbersome and confusing

The grantees are listed below.

<i>Part</i>	<i>Program Priority</i>	<i>Funding Amount</i>	<i>Grantee Agency</i>
1	Establishment of Regionally-Based Task Forces	\$200,000/yr for 3 years	New Jersey Prevention Network
2	Request for Support of Interpreter Services	\$25,000/yr for 3 years	Signs of Sobriety
3	Establishment of a Scholarship Fund	\$10,000/yr for 3 years	No applicant— DAS will hold and release funding as requested by agencies
4	Enhancement of Statewide Libraries for the Blind and Handicapped	\$29,163 one time only	New Jersey Library
5	Establishment of a Model Program for Treatment of Addictions/Disabilities—program for persons who are Deaf/Hard of hearing	\$115,000/yr for 3 years	Signs of Sobriety
5	Establishment of a Model Program for Treatment of Addictions/Disabilities—program for persons with other disabilities*	\$115,000/yr for 3 years	Raritan Bay Medical Center
6	Establishment of Statewide Community-Based Prevention Programs—program for persons who are Deaf/Hard of hearing	\$60,000/yr for 3 years	Signs of Sobriety
6	Establishment of Statewide Community-Based Prevention Programs—program for persons with other disabilities	\$40,000/yr for 3 years	United Cerebral Palsy Assoc. of New Jersey
6	Establishment of Statewide Community-Based Prevention Programs—program for persons with other disabilities	\$20,000/yr for 3 years	New Jersey Prevention Network

**Program serves only persons with spinal cord injuries*

Funding began on **June 1, 2001.**



VI. Impact of the Legislation

How it has Altered the System

The impact of the legislation can be measured far beyond the actual programming it has established. The effects have been far reaching, raising awareness of the issue within the disability and substance abuse services community and within the New Jersey Division of Addiction Services.

Funding of Disability-Specific Programming for Three Years

The most obvious benefit of the law is the funding of new projects. To date, the Program has had two funding cycles, granting \$1,727,442 to support 21 projects and programs. The broad range of projects include a three-year effort to establish and support regionally-based task forces, a one-year prevention program for disabled teens, and the development of a videotape documenting the issue of substance abuse among persons with disabilities. The first funding cycle under the Concept Paper initiative created an opportunity for agencies that had expertise in either the substance abuse or the disability field to take a risk and expand their scope of services. Therefore, the Program was able to provide seed money to those agencies that demonstrated their desire and ability to expand services, as well as continue to support agencies with a well-established history of services to the population.

All projects have measurable, quantitative goals that are monitored by the DAS. To ensure compliance with program agreements, the projects submit quarterly written progress reports and are visited by this DAS staff person periodically.

Advocacy/Systems Change

The legislation is innovative in that its goal is not to fund services per se, but instead to make systemic changes in the state's substance abuse service infrastructure. The strategy includes multiple interventions such as instituting an advocacy network to create and implement a statewide needs-based strategic action plan and design effective treatment modalities for replication as opposed to creating treatment beds. The legislation specifically states that funds are not to be used to operate services or make existing services accessible by making architectural modifications, etc.

With the limited appropriation, the emphasis of the legislation is on building a foundation of accessible substance abuse services, whether in an integrated setting, or provided discretely. The New Jersey Prevention Network, a statewide agency, was awarded the three-year grant to facilitate and support regionally based local task forces.

With three years of funding, Hulick is hopeful, stating that, “This group has the capacity to reach out to their county-based alcoholism and drug abuse authorities and plan for disability in their county plans.”

Advisory Committee’s Role and Accomplishments

The Advisory Committee plays a pivotal role in not only implementing the legislation, but in ensuring that the needs of persons who are deaf, hard of hearing and with other disabilities continue to be addressed within DAS.

Lily Kaufmann, current DAS Deafness/Disability Specialist sees the Advisory Committee’s role as not only advising the Commissioner on how to spend the \$350,000, but also making suggestions that will improve the overall quality and availability of services to persons with disabilities in New Jersey. Kaufmann reports that the Assistant Commissioner considers all suggestions made by the Advisory Committee. For instance, based on a recommendation by the Advisory Committee, leftover funding from the Concept Paper initiative was used to provide sign language interpreters for CADC classes, so deaf persons could become certified addictions counselors. Similarly, due to a proposal by the Advisory Committee, a disability segment in CADC credentialing was added. Because of their expertise and experience in the field, the Advisory Committee is invaluable in their role as a referral source for recommending qualified staff for disability programs.



Lily Kaufmann

The partnership between the Advisory Committee and the Division of Addiction Services is one of mutual respect. Tim Cronin, representing the Division of Vocational Rehabilitation on the Advisory Committee, compliments DAS as “top notch” and “knowing what needs to be done.” Likewise, DAS holds the Advisory Committee in high regard, Kaufmann observing the group to be “bright, committed professionals.”

Raised Awareness of the Issue among Substance Abuse Community on all Levels

Almost all persons interviewed cited the increase in awareness of disability on all levels—from the Division of Addiction Services to the Governor’s Council on Alcoholism and Drug Abuse to local alcoholism and drug abuse prevention and treatment programs—as the biggest impact of the legislation.

The Division of Addiction Services has gained greater awareness about disability access issues through the hands-on experience of setting up the Advisory Committee meetings. Ensuring that the meetings sites are wheelchair accessible, hiring sign language interpreters, translating written materials into alternative format—all of these tasks have been instructional for DAS staff.

Steve Shevlin asserts that the Advisory Committee is successful because they are working to integrate disability into county plans, not add on something separate and different. Where the GCADA once opposed the legislation, they now work with the Advisory Committee and the disability constituency across the state. He believes this change of heart is because, even before the legislation was passed, the (informal) coalition had stated their intent to integrate disability needs into services and, over eight years later, are still working toward that goal.

In this spirit, the Governor’s Council on Alcoholism and Drug Abuse passed a Resolution for Alliance events to be held in Architecturally Barrier Free Locations, following testimony given by Maslansky in 1997.

Additionally, by appointing an Advisory Committee that meets with the Assistant Commissioner and by funding an advocacy network, DAS demonstrates their commitment to the disability issue. “Providers now know that we’re serious about providing services to the disability population,” states Wanda Cintron, Chief of Special Populations.

Legislation Gives the DAS Deafness/Disability Specialist a Stronger Defined Role

Since created in 1989, the position of Deafness/Disability Specialist has been a strong force within DAS to establish and monitor disability specific services. However, the role is strengthened even further by the legislation in that this DAS staff person has a legislatively mandated program to oversee and a direct link to the Assistant Commissioner.

VII. Identified Gaps & Recommendations

During each interview, we asked, “What else is needed to make substance abuse services accessible to persons with disabilities?” While respondents agreed they were satisfied with the legislation and the results had exceeded expectations, they all viewed the Program as a jumping off place for a larger effort. Advisory Committee member Tim Cronin states, that he’s “very satisfied. We’re finally to the point where the money can be realized; we’re at the end of the tunnel.” But he also acknowledges, “Do we need to do a lot more? Yes, a lot more.” Several recommendations reflect the Needs Assessment findings. They are listed below.

1. More Money for Disability-Related Programs

All respondents stated that although it was an excellent start, the amount of funding in the current legislation is inadequate. In relation to the breadth of the problem, considering the number of people with disabilities in the state that have a need for services, Shevlin characterized the appropriation as “ridiculously small.” Terrence O’Connor agreed, stressing that “even with a conservative estimate of the affected numbers in the population, \$350,000 isn’t very much money.” Whether for disability-specific services, the development of model programs, or activities that facilitate systemic change, substantially more funding is needed.

2. Inclusion and Discrete Services

In addition to more funding, several respondents cited the ongoing need for discrete services for certain populations. For instance, persons with communication differences such as deaf persons or significant cognitive impairments such as persons with traumatic brain injuries may not benefit from mainstream programs. Hence, it is critical to collect reliable data on the need of substance abuse services by low incidence disabilities of all types.

3. Disabled People in Counselor Roles, Opportunities for People with Disabilities to Become Trained as Counselors

Steve Shevlin reported that another critical gap is the lack of deaf/hard of hearing persons and persons with other disabilities in direct service roles. He pointed out that, when talking about inclusion in the substance abuse service field, all aspects should be considered, including service provider positions. He and other Advisory Committee members continue to press DAS to create opportunities for people with disabilities to become trained as counselors by providing scholarships and ensuring that accommodations are available in certification classes.

4. Conclusive Data Collected on a Consistent Basis

O'Connor noted that, "We'll always be faced with the challenge of how to spend the limited appropriation and reliable data is critical to guide that process." The Needs Assessment was not conducted to establish a general need for substance abuse services, but to gather information on the specific needs of various disability groups, types of providers and geographic communities. But due to the problems noted previously, the data were generally inconclusive. Each county needs to institute a method of collecting data on their citizens with disabilities and uniformly report that information to the state. With solid data, counties will be able to allocate resources and plan services appropriately for persons with disabilities.

5. Disability Included in County Plans

Hulick identified the New Jersey Prevention Network as the key player to ensure that appropriate data is collected over the next three years. Among the NJPN's objectives is the development of a comprehensive, statewide needs-based plan. "At a minimum, that plan should inform local entities how to address low-incidence disabilities on a regional and/or county-wide basis."

Possible Next Steps

Because the legislation is new and programs are just finishing their first year, everyone acknowledged that its impact cannot be adequately measured at this point in time. There are many expectations for outcomes of P.L. 1995, Chapter 318's programs that are, as grantee Dr. Roberta Schaffer states, "just in their infancy."

John Hulick, the prime mover of the legislation, sees this first round of three-year projects providing a foundation for improved substance abuse prevention and treatment services. The outcomes of the various projects—the model program designs for deaf people and people with other disabilities, the support for persons with disabilities to become certified counselors, the regional task forces and the statewide needs-based plan—should form a base from which to build a strong, comprehensive service infrastructure.

Hulick and the other advocates who toiled to put the legislation and its projects in place are committed to seeing the process through. As Hulick says, "It's just getting good."

VIII. Conclusion: A Replicable Model

In the mid 1980s, social workers, vocational rehabilitation counselors, special educators and others began meeting over lunch to brainstorm solutions to the lack of substance abuse services for their clients, friends and family members. These discussions were taking place all over the country, in all types of communities, not just in New Jersey. Passionate activists around the country have spent countless hours and considerable energy into opening treatment doors for people with disabilities, by employing a multitude of strategies—facilitating cross trainings, surveying programs for accessibility, etc. But New Jersey is the first state to create legislation that earmarks funding to create accessible substance abuse prevention and treatment programming.

Replication Aspects—How to do this at Home

There are several elements that were in place that were crucial to New Jersey's success.

- ◆ Form a broad, representative coalition. Working with diverse groups is not easy. It takes patience and dedication. Advocates in New Jersey were successful because they found common ground and kept the ultimate goal in sight. They realized that open communication and discussing misgivings about working together, whether perceived or real, is critical.
- ◆ Educate all parties on the importance of the issue to garner support. Once formed, the coalition found that the more supporters they could cultivate, the stronger their movement. And they were persistent—making presentations before the GCADA even though they were not always warmly received.
- ◆ Find a local legislator who is sympathetic to your cause. Senator Ewing's involvement was key to the legislation's passage. He was knowledgeable about addiction issues and committed to seeing that services were delivered to all who needed them.
- ◆ Identify someone in your movement who is acquainted with the legislative process. John Hulick was a pivotal player in the advocacy movement for a number of reasons, one being his skill and experience working with the legislature. He credits the final version passing because "someone was able to make it their full-time job."

Senator Ewing offered this last piece of advice. He said, "If you believe in something, you can't get discouraged. You have to keep pushing."

Appendix A: Program Timeline

Timeline for the New Jersey's Alcohol and Drug Abuse Program for the Deaf, Hard of Hearing and Disabled

Date	Event
(mid 1980's)	NJ Task Force on Alcoholism and the Hearing Impaired funded by Department of Alcoholism, housed in Union County Council on Alcoholism (pre-NCADD)
1985*	New Jersey Coalition on Disabilities, Alcoholism and Drug Abuse founded October 1986 NJ Coalition on Disabilities and Addictions convenes first statewide conference
1988	Signs of Sobriety founded
August 4, 1988	Legislation introduced to increase wholesale tax on alcoholic beverages. A percentage of the tax would be set aside for alcohol education and treatment, a percentage of which would establish such programming for persons with disabilities. Legislation died in the assembly.
March 27, 1989	Legislation that established the Governor's Council on Alcoholism and Drug Abuse signed into law. This legislation required county-based planning; disability was included as a population that counties were required to address.
1989*	Project Specialist—Deafness and Disability position in DAS created. Janet Dickinson hired.
Sept. 1989	Division of Alcoholism funds Signs of Sobriety and NJ Coalition on Disabilities, Alcoholism and Drug Abuse for \$30,000 each
Late 1980's	Per recommendations from the NJ Task Force on Alcoholism and the Hearing Impaired, DOA funded a handful of prevention, inpatient and out patient programs for the Deaf as well as interpreters for 12-step meetings
Early 1990's	
Feb. 4, 1991	S3284 of 1990-1991 is introduced which establishes an "Alcohol and Drug Abuse Program for Deaf and Disabled," appropriates \$200,000 from Casino Revenue fund
March 16, 1992	S570 of 1992-1993 is introduced which establishes an "Alcohol and Drug Abuse Program for the Deaf and Disabled," appropriates \$200,000 from General Fund
April 2, 1992	An amendment changes the source of funding for S-570 to Drug Enforcement Demand Reduction (DEDR) fund
May 1993	New Jersey Coalition on Disabilities, Alcoholism and Drug Abuse changes its name to match the state agency's (Division of Addiction Services) to the New Jersey Coalition on Disabilities and Addiction. Debra Maslansky hired as Statewide Coordinator with DAS funding.
May 5, 1994	S946 of 1994-1995 was mistakenly (without Hard of Hearing) introduced that establishes an "Alcohol and Drug Abuse Program for the Deaf and Disabled," appropriates \$200,000 from DEDR
May 12, 1994	S1054 of 1994-1995 was introduced in the state senate that establishes an "Alcohol and Drug Abuse Program for the Deaf, Hard of Hearing and Disabled," appropriates \$350,000 from DEDR

1994*	Steve Shevlin hired as ED of Signs of Sobriety
1994*	John Hulick left Signs of Sobriety to take advocacy/legislative position at NJ NCADD
June 27, 1994	A-1975 of 1994-1995 introduced in the state assembly that establishes an "Alcohol and Drug Abuse Program for the Deaf, Hard of Hearing and Disabled," appropriates \$350,000 from DEDR
1995*	NJ Coalition on Disabilities and Addiction conducts accessibility survey of ATOD service programs
May/June 1995	GCADA holds public hearings regarding the treatment needs of Deaf, Hard of Hearing and other disabled persons
Oct. 19, 1995	S-1054 passed in the Senate
Nov. 20, 1995	Public testimony on S-1054 before the Assembly Senior Citizens and Social Services Committee
Dec. 21, 1995	A-1975 (identical to S-1054) passed in the Assembly
Jan. 5, 1996	Public Law 1995, Chapter 318 signed by New Jersey Governor Christine Whitman
March 1997	First Meeting of the Advisory Committee for the Alcohol and Drug Abuse Program for Deaf, Hard of Hearing and Disabled.
Dec. 1997	Rebecca Clark hired to conduct the Needs Assessment
Dec. 9, 1997	GCADA to passes a "Resolution Regarding Alliance Events in Architecturally Barrier Free Locations" as a result of testimony by Debra Maslansky.
June 22, 1998	Concept paper RFP released
May 1999	The Needs Assessment was completed
Sept. 1999	Concept Paper funding commences
August 21, 2000	Request for applications for Provision of Services for Deaf/Hard of Hearing and Disabled Persons is released
Sept. 22, 2000.	DAS holds Bidder's Conference for potential applicants
Oct. 13, 2000	Proposals due
April 2, 2001	Grants awarded
June 1, 2001	Program funding commences

**month unknown*

Appendix B: Methodology

Information for this case study was gathered by two methods: 1) interviews with key informants and 2) a review of written documents.

The following people were interviewed:

Wanda Cintron	Chief of Special Populations Division of Addiction Services NJ Department of Health and Senior Services
Dr. Rebecca Clark	Needs Assessment Consultant
Tim Cronin	Program Planning Development Specialist* Division of Vocational Rehabilitation Services New Jersey Department of Labor
Senator Ewing (R-Somerset)	New Jersey State Senator, 1978-1998
John Hulick*	Director of Public Policy, NCADD
Lily Kaufmann	Deafness/Disability Specialist Division of Addiction Services New Jersey Dept. of Health & Senior Services
Debra Maslansky	Director of Substance Abuse Prevention* Cerebral Palsy of New Jersey
Terrence O'Connor	Assistant Commissioner Division of Addiction Services New Jersey Dept. of Health & Senior Service
Javier Robles*	Deputy Director Division of Disability Services New Jersey Department of Health Services
Dr. Robert Schaffer**	Raritan Bay Medical Center
Steve Shevlin*	Executive Director, Signs of Sobriety
Susan Turner	Licensed Clinical Social Worker



Debra Maslansky



Steve Shevlin

*denotes Advisory Committee members

**grantee of legislated funding

All interviews were conducted by Harilyn Rousso, except for the John Hulick and Terrence O'Connor interviews, were conducted by John de Miranda. All interviews were recorded on audiotape. Janet Dickinson contributed greatly to the early history portion via e-mail. No one from the Governor's Council on Alcoholism and Drug Abuse was available to be interviewed. Tapes and gathered documents were sent to the primary author, who gleaned relevant facts, verified them and composed a draft.

The draft was sent out for review by individuals who were quoted extensively.

The primary document utilized was *New Jersey Alcohol, Tobacco, and Other Drugs Services For People with Disabilities: Needs Assessment*, by Dr. Rebecca Clark. In addition to the needs assessment protocols and findings, the document includes a concise history of legislative process and its appendices included the legislation, the letter requesting proposals for Concept Papers, and the list of Concept Paper Grantees.

Other documents used were: *A Report to the Governor's Council on Alcoholism and Drug Abuse Regarding A-1975/S-1054* by Matthew T. Sherman and the *Request for Applications for "Provision of Services for Deaf/Hard of Hearing and Disabled Persons,"* released by DAS.

Lily Kaufmann provided numerous materials on DAS funded programs. John Hulick and Debra Maslansky provided valuable historical pieces—copies of correspondence, articles and brochures from meetings and conferences.

Appendix C: Further Reading

Further Reading on Alcohol, Drug and Disability Policy

de Miranda, John and Linda Cherry, (1989) California responds: changing treatment systems through advocacy for the disabled, *Alcohol, Health and Research World*, (13)2, pp. 154-157.

de Miranda, John (1999) Policy and its implementation: Where the rubber hits the road, *Substance Abuse Resources and Disability Issues Online*, (9)1, pp. 1-7.

de Miranda, John (1999) Policy, accessibility, and disability: barriers to substance abuse services, *Impact*, (12)3, p. 4.

de Miranda, John (1999) Treatment services offer limited access for people with disabilities, *The Counselor*, May/June. pp. 24-25.

National Association on Alcohol, Drugs and Disability, (1999) Access Limited, *Substance Abuse Services for People with Disabilities: A National Perspective*.