

National Association of State  
Directors of Developmental  
Disabilities Services

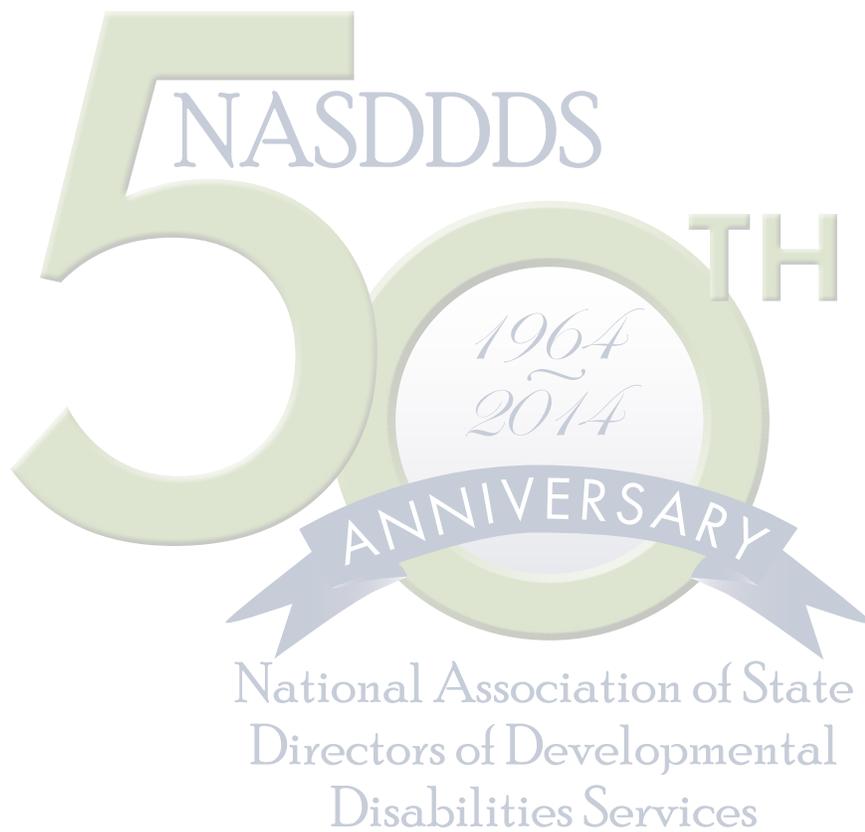
## **NASDDDS: 50 YEARS OF HISTORY**

**By Robert M. Gettings**

and Nancy Thaler

*Future Directions in State Policy: The Path Ahead*





## **NASDDDS: 50 YEARS OF HISTORY**



Robert M. Gettings

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Over a period spanning four decades, Mr. Gettings participated in the development and passage of numerous pieces of landmark federal legislation. Collectively, these statutes revolutionized national disability policy. He also has helped many states to solve a variety of financing and service delivery problems over the years and has written and lectured extensively on the impact of federal legislative and administrative policies on services to persons with intellectual and other developmental disabilities.

A Life Member of the American Association on Intellectual and Developmental Disabilities, Mr. Gettings was recognized in 2000 by the National Historic Trust on Mental Retardation as one of 36 major contributors to the field during the 20th Century.

# PREFACE

*The winds and the waves are always on the side of the ablest navigators.*

Edward Gibbon

## **Decline and Fall of the Roman Empire**

On February 28, 1963 eight men gathered in Columbus, Ohio to discuss state government's role in improving public services for individuals with intellectual and other developmental disabilities. By the end of the meeting the participants had decided to establish an organization to represent chief state mental retardation officials. Officials from other states were invited to participate in an organizational meeting held on May 23, 1963 in Portland, Oregon, and by the following January the National Association of Coordinators of State Programs for the Mentally Retarded was incorporated as a non-profit, charitable organization in the State of Washington.

The purpose of this book is to trace the history of the Association as part of a year-long celebration of the organization's fifty years of service to the disabilities field. What factors contributed to the establishment of the Association? How did early leaders of the organization envision the Association's primary goals and determine the related services to be furnished to member state agencies? How have Association activities evolved over the past five decades and what were the major turning points in the evolution of membership services? How have Association operations been financed over the years? What lessons can be learned from the organization's experiences and how can these lessons be applied as Association leaders prepare to face the challenges and opportunities that lie ahead? These and other questions are addressed in this volume.

NASDDDS was founded during a period when people with intellectual and developmental disabilities began to emerge from the shadows of

American society. The opening chapter explains why "combating mental retardation" emerged as a national priority during the early 1960s and the relationship of this development to the creation of the Association. Chapter I briefly reviews the origins of the Kennedy Administration's legislative initiatives to expand the federal government's role in mental retardation research, training, and services and how the Association emerged in response to these developments. Chapter II discusses early efforts by Association leaders to keep member state agencies informed about relevant national developments and ensure that state governments gained a voice in the formulation of national mental retardation policy. These efforts eventually led to opening a headquarters office in the Washington, D.C. area in October 1970 and hiring qualified personnel to staff the office.

The next four chapters of the report examine major functions of the Association and how they have evolved over the years. Chapter III examines the organization's role in representing the interests of member state agencies in the formulation of federal legislative and administrative policy. The Association's involvement in promoting the enactment of major disability laws and regulations – especially laws and rules expanding funding for specialized services to persons with intellectual disabilities under the federal-state Medicaid program – is briefly summarized in this chapter. Chapter III also describes the way in which the internal management of the Association's activities in the national legislative and administrative arena evolved over the years.

Chapter IV summarizes the Association's involvement in gathering and disseminating

nationwide information on new and emerging developments in services to people with intellectual and developmental disabilities. In addition to describing the evolution of Association newsletters, news bulletins and special reports over the past five decades, this chapter also reviews the impact continuing improvements in information technology have had on the organization's information dissemination activities.

The origins and evolution of the Association's technical assistance activities are discussed in Chapter V. This chapter traces the history of on-site and off-site technical assistance to member state agencies from the late 1970s to the present. Chapter VI describes the various interstate and inter-organizational alliances the Association has forged over the years in the pursuit of broad system change initiatives such as the development of system-wide performance measures and the expansion of employment opportunities for adolescents and adults with developmental disabilities. The chapter illustrates the advantages of forging strategic partnership with other organizations with similar values and capabilities that complement those of the Association.

Chapter VII examines the methods Association leaders have used over the years to finance organizational activities. In addition to tracing the history of state membership dues, this chapter examines the changing mix of other funding streams NASDDDS has relied on to meet operating costs during various periods over the past five decades.

The concluding chapter highlights the social, demographic, and political forces confronting state developmental disabilities agencies today and sketches out a radically new approach to serving individuals with developmental disabilities that is responsive to these trends. The emphasis of this chapter is on the new capabilities the Association will need to develop in order to help member state agencies navigate the difficult transition to a service system that enhances individual and family choices and builds secure, inclusive, valued lives for individuals with lifelong disabilities in communities across the nation.



“Lodestar” is a term derived from celestial navigation – i.e., a star that leads or guides a seaman to his intended destination. In current usage, however, lodestar means “one who serves as an inspiration, model or guide.”<sup>1</sup> It is a word that accurately characterizes the role the National Association of State Directors of Developmental Disabilities Services (NASDDDS) performs on behalf of state agencies serving people with intellectual and developmental disabilities.

For decades, member state agencies have looked to NASDDDS for guidance in navigating the constantly shifting shoals of public policy and program practices. The Association's fiftieth anniversary is an appropriate time to examine why the organization was formed and how its activities have evolved over the past five decades. A review of the Association's history, however, should be more than just a nostalgic stroll down memory lane. This volume, therefore, attempts not only to examine the historical events that helped shape the organization we know today but also to distill key lessons from the Association's experiences and ask how these lessons should be applied to illuminate the path forward for member state agencies.

<sup>1</sup> Merriam-Webster Dictionary at: [www.merriam-webster.com/dictionary](http://www.merriam-webster.com/dictionary)

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# I CHAPTER

*Americans of all ages, all stations of life, all types of disposition are forever forming associations...*

Alexis de Tocqueville,  
Democracy in America, 1835

## THE FOUNDING OF THE ASSOCIATION: *Catching a Wave*

The idea of forming a national organization to represent state mental retardation agencies emerged in the early 1960s as a by-product of efforts by President John F. Kennedy and his administration to lay the foundation for a nationwide campaign to “combat mental retardation.” The early 60s was a period of transformational change in public attitudes and policies toward people with intellectual disabilities. Suddenly the needs of persons with lifelong disabilities were removed from the shadowy recesses of individual family struggles and thrust into the spotlight of national attention. Longstanding assumptions concerning the federal government’s role were being challenged; and the states, in turn, were beginning to question their “out of sight, out of mind” approach to serving children and adults with intellectual disabilities in segregated classrooms and huge, overcrowded institutions, far removed from the mainstream of American society.

Prior to the Kennedy era, the states received virtually no financial aid from the federal government to assist in furnishing public services to persons with intellectual disabilities. Modest amounts of federal dollars were available to support basic and applied research, train professionals (primarily special educators and vocational counselors), and for the construction of specialized facilities. Individuals meeting the eligibility criteria were entitled to receive Disabled Adult Children’s benefits under the Social Security program; but, with the exception of a small amount of funds expended through the

federal-state vocational rehabilitation program, the federal government played no role in financing direct services to persons with intellectual and related developmental disabilities. A May 1962 report published by the U.S. Department of Health, Education and Welfare concluded that collectively the various units of the agency expended a total of \$48 million on mental retardation-related activities in FY 1960, about two-thirds of which represented Social Security payments to DAC beneficiaries.<sup>1</sup>

The long-term services provided by the states were confined largely to large, multi-purpose institutions, which typically were overcrowded, grossly underfunded, and poorly staffed. In 1960, public mental retardation institutions in the United States employed on average 31.3 full-time staff members for every 100 facility residents. The average cost per person of operating these state facilities in 1960 was \$4.20 a day!<sup>2</sup> Some (but certainly not all) states subsidized day activity centers for children and adults with intellectual disabilities (or “mental retardation” as such disabilities were referred to at the time). Typically these facilities were operated by local chapters of the Association for Retarded Children or other non-profit community organizations. The subsidy levels, where they existed at all, were extremely modest in most states, making up only a small portion of the state’s mental retardation budget.

With the election of John F. Kennedy in 1960, this grim picture began to change. Shortly after assuming

office, Kennedy appointed a prestigious panel of experts and assigned the group the task of preparing a comprehensive national plan to “combat mental retardation.” Within a year, the President’s Panel on Mental Retardation had filed a report summarizing its findings and offering 97 recommendations for improving mental retardation-related research,

training, income maintenance, and service programs. And, before his assassination in November 1963, President Kennedy signed into law legislation aimed at building a federal-state partnership in improving services to children and adults with mental retardation and related disabilities.\*

## A THE FORMATION OF AN ASSOCIATION

Primarily in response to the excitement generated by the report of the President’s Panel and the legislation it spawned, a group of state officials with “major responsibility” for mental retardation services within their respective states met in Columbus, Ohio on February 28, 1963 to discuss state mental retardation planning. The following eight individuals attended the meeting:\*

<u>NAME</u>	<u>STATE</u>	<u>POSITION</u>
Charles E. Acuff	Kentucky	Director, Division of Mental Retardation
Louis Belinson	Missouri	Deputy Director, Division of Mental Diseases
Van R. Hinkle	Washington	Supervisor, Division of Children and Youth Services
Maurice G. Kott	New Jersey	Director, Division of Mental Retardation
J. Wylie McGough	Ohio	Acting Chief, Bureau of Mental Retardation
Bert W. Schmickel	Connecticut	Deputy Commissioner, Department of Health
Vernon Stehman	Michigan	Deputy Director, Department of Mental Health
Wesley D. White	Colorado	Director, Division of Mental Retardation

The group considered a proposal advanced by Dr. Louis Belinson of Missouri that called for the formation of an organization representing state officials “having administrative responsibility for the complex problems of mental retardation.”<sup>3</sup> In a paper distributed to the participants, Belinson called attention to “the rapid developments taking place ... in the field of mental retardation” and suggested that an organization be formed “... to take advantage of the tremendous national interest presently developing as a result of the support of the President of the United States and the work of his Panel on Mental Retardation.” Pointing out that such an organization might be modeled after the

Directors of Mental Health Programs, which had been created a few years earlier, Belinson suggested the group be called the “Coordinators of State Programs in Mental Retardation.” He also stressed the importance of structuring the organization in a manner that would take into account “... the significant differences from State to State relating to the attitude and sophistication of the general public, general revenue situation, resources, as well as geography and climate.”<sup>4</sup> Finally, in an attempt to avoid an inconclusive outcome to the Columbus meeting, Belinson proposed that the group appoint a set of temporary officers and plan to hold an open, organizational meeting in conjunction with the May

\*Readers interested in learning more about Kennedy-era legislation are encouraged to read Chapter II of a companion volume, entitled *Forging a Federal-State Partnership: A History of National Developmental Disabilities Policies over the Past Five Decades*, available from the American Association on Intellectual and Developmental Disabilities, 501 3rd St., NW, Suite 200, Washington, D.C. (Price: \$49.95).

\* Five of the eight participants in the Columbus meeting later served as President of the Association: Louis Belinson (1963-65); Wesley D. White (1965-67); Bert W. Schmickel (1967-69); Charles E. Acuff (1971-73); and Maurice G. Kott (1974-76).

1963 Annual Meeting of the American Association on Mental Deficiency, which was scheduled to be held in Portland, Oregon.

The Columbus discussions proved to be “so fruitful and stimulating” that the participants agreed to name temporary officers and invite their colleagues in other states to attend an organizational meeting in Portland. Dr. Belinson was named temporary chairman of the as yet un-named organization; Van Hinkle was appointed vice-chairman and Bert Schmickel was appointed secretary-treasurer.

In the weeks following the Columbus meeting, Dr. Belinson sent a letter to the director of the state agency in each state and the District of Columbia responsible for overseeing mental retardation services, extending an invitation to attend the May meeting in Portland. He asked recipients of the letter to designate “... the person in your organization responsible for the direction and coordination of programs in mental retardation.”<sup>5</sup> In the letter, he also noted that the proposed association would serve as “... a medium for the exchange of information on projects, programs, and experiences and achieve the maximum effectiveness of the budget dollars appropriated for mental retardation services.”<sup>6</sup>

The initial organizational meeting of the “Coordinators of State Programs in Mental Retardation” was held in Portland, Oregon on May 23, 1963. Seventy-five individuals from 38 states attended the meeting, with 24 of the participants self-identifying themselves as their state’s coordinator of mental retardation programs.<sup>7</sup>

The minutes of this organizational meeting offer important clues regarding the motivating factors that led to the formation of the group. “Since mental retardation is a multidisciplinary problem,” the minutes point out,

there may likely develop an interagency commission in each state, the chairman of which ... may well serve as [the state’s] coordinator [of mental retardation services]. The available resources within the borders of any state could be explored and made known to all cooperating agencies. Through the office of the coordinator there would be a fruitful exchange of plans and experiences between the states.

The minutes go on to say that,

“... the new organization would provide a vehicle for effective communication between the Federal agencies and the various states concerned with research, training, programs and finance.”<sup>8</sup>

During the May meeting in Portland, the participants agreed to appoint a committee to prepare the articles of incorporations and by-laws of the new association. The group also agreed to hold the next meeting in October in Washington, D.C. The following officers were elected to guide the development of the organization:

<b>PRESIDENT</b>	Louis Belinson, M.D. <i>Deputy Director</i> Division of Mental Diseases Jefferson City, Missouri
<b>VICE-PRESIDENT</b>	Van R. Hinkle <i>Supervisor</i> Division of Children and Youth Services Olympia, Washington
<b>SECRETARY</b>	Vernon Stehman, M.D. <i>Deputy Director</i> Department of Mental Health Lansing, Michigan
<b>TREASURER</b>	Bert W. Schmickel <i>Deputy Commissioner</i> Department of Health Hartford, Connecticut





The October meeting was held in conjunction with the Annual Meeting of the National Association of Retarded Children, where President Kennedy addressed the opening luncheon shortly after signing into law a bill authorizing the mental retardation planning amendments. At an October 23rd meeting, Van Hinkle, who, in addition to his leadership role in state government, was an attorney with extensive experience in non-profit law, presented for the group's consideration draft articles of incorporation and by-laws for the "National Association of Coordinators of Public Programs for the Mentally Retarded." Recognizing the need to create a single conduit for information and action within each state, the participants agreed to limit membership in the new organization to "coordinators or their delegates." Action on a motion to approve the draft articles of incorporation and by-laws, however, was deferred until a follow-up meeting scheduled for the afternoon of October 25. During the intervening period, Hinkle was granted authority to amend the draft articles.<sup>9</sup>

The mission of the new organization, as delineated in the Articles of Incorporation, was (and still is) to conduct:

... educational, benevolent, and scientific activities pertinent to the field of mental retardation. To this end, the corporation shall promote mutual assistance, cooperation and research in the administration of programs in mental retardation,

- 1 – through development of data, studies, and trends in mental retardation, and
- 2 – through encouragement of the exchange of information, experience, and ideas relating to care, treatment, training, research, institutional facilities, financial factors and other relevant data in the administration of public mental retardation programs in the various states.<sup>10</sup>

Membership in the Association would be limited to the "duly constituted state officials in charge of public mental retardation programs of the various states."<sup>11</sup> Recognizing that the designation of a state's representative might be a matter of dispute in some states due to the "... lack of uniformity in administrative structures," the Articles empowered

the Association's Board of Directors to reconcile such disputes "... after consultation with and receiving the recommendation of the Governor of such State."<sup>12</sup>

Under the proposed Articles of Incorporation and By-Laws, leadership of the Association was to be vested in a seven-member Board of Directors, composed of four officers (a President, a Vice-President, a Secretary-Treasurer, and an Immediate Past-President), each serving a two-year term, and three Board Members-at-Large, who would serve staggered three-year terms.<sup>13</sup>

During the October 25th meeting, the participants agreed to substitute the word "State" for "Public" in the title of the organization.\* Following this action, Wesley White of Colorado moved that the articles of incorporation and by-laws of the National Association of Coordinators of State Programs for the Mentally Retarded (NACSPMR) be approved and Van Hinkle be authorized to refine the language and seek to have the association incorporated as a non-profit, charitable organization under the laws of the State of Washington. The motion was seconded by Charles Acuff of Kentucky and approved by the participants.<sup>14</sup>

Charles Acuff also moved that the temporary officers of the Association be authorized to act on behalf of the organization until the Association's next meeting, scheduled for May 1964, again in conjunction with the Annual Meeting of the American Association on Mental Deficiency. This motion was seconded by Mr. Schmickel and approved by the participants.<sup>15</sup>

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\* Although the minutes of the meeting are not clear, apparently the name originally proposed was the National Association of Public Programs for the Mentally Retarded. The objection to the use of the word "public" apparently grew out of a concern that the purview of the organization's activities might be misinterpreted as extending to the activities of municipal, county and federal, as well as state, governments.

The mechanics involved in creating a new, non-profit organization are rather simple and straight-forward. The founders of the organization are required to file an application with the state agency responsible for granting non-profit status and demonstrate that its proposed mission comports with applicable provisions of state laws governing non-profit organizations. Typically, proposed articles of incorporation and by-laws must accompany the organization's application.

By January 1964, Hinkle had filed NACSPMR's incorporation papers with the Office of the Secretary of State and received confirmation of the Association's status as a registered non-profit, tax-exempt corporation in the State of Washington. The Association was officially in business. But it would be years before the vision of the founders was fully realized. Some of the early attempts by NACSPMR leaders to breathe life into the nascent organization will be described in the next chapter.

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END NOTES

- <sup>1</sup> U.S. Department of Health, Education and Welfare, *Mental Retardation Activities of the U.S. Department of Health, Education, and Welfare*. U.S. Government Printing Office: Washington, D.C., May 1962.
- <sup>2</sup> Department of Health, Education, and Welfare, Division of Mental Retardation, *Public Institutions for the Mentally Retarded: Trends in Caseload, Manpower and Expenditures*. Washington, D.C., July 1968.
- <sup>3</sup> "A Proposition," prepared by Louis Belinson, M.D. and dated February 28, 1963.
- <sup>4</sup> Ibid.
- <sup>5</sup> Sample of letter from Louis Bellinson, M.D., as temporary chairman, to various state health, mental health, welfare and social services officials, dated April 11, 1963.
- <sup>6</sup> Ibid.
- <sup>7</sup> Minutes, *Organizational Meeting: Coordinators of State Programs in Mental Retardation*, Portland Hilton Hotel, Portland, Oregon, May 23, 1963.
- <sup>8</sup> Ibid.
- <sup>9</sup> Minutes of a meeting of the National Association of Coordinators of State Programs for the Mentally Retarded, Washington, D.C., October 23, 1963.
- <sup>10</sup> Article III, *Articles of Incorporation, National Association of Coordinators of State Programs for the Mentally Retarded*, as approved January 24, 1964.
- <sup>11</sup> Ibid, Article VII(a).
- <sup>12</sup> Ibid.
- <sup>13</sup> Article IV, *By-Laws of the National Association of Coordinators of State Programs for the Mentally Retarded*, as approved January 24, 1964.
- <sup>14</sup> Minutes of a meeting of the National Association of Coordinators of State Programs for the Mentally Retarded, Washington, D.C., October 25, 1963.
- <sup>15</sup> Ibid.

# III CHAPTER

*If you're doing something new you've got to have a vision. You've got to have some north star you're aiming for, and you just believe somehow you'll get there.*

Steve Case,  
former CEO of America Online

## THE EARLY YEARS: *The Search for a Defining Purpose*

Existing as a legal entity is not the same as having a clearly defined operational mission that is well understood by the organization's membership – as well as by external parties with which the organization must interact. During the years immediately following the formation of the Association, leaders of the National Association of Coordinators of State Programs for the Mentally Retarded (NACSPMR) struggled to develop such an operational mission and secure the resources necessary to implement it.

Between 1964 and 1970, the activities of the Association consisted almost entirely of an annual membership meeting, interspersed with correspondence and occasional meetings of the organization's executive committee. The minutes from these meetings reflect an uncertainty about the organization's goals and only sporadic attempts

to initiate activities that would be of benefit to member state agencies. Among the recurring topics of discussion during these years were: (a) the mission of the Association; (b) the designation of the appropriate official in each state to serve as the state's official representative to NACSPMR; (c) the initiation of a periodic Association newsletter to keep the membership informed of program and policy developments across the nation; (d) representation of the views of state mental retardation officials on pending federal legislative and administrative issues; (e) financing Association activities; and (f) the opening of a national program office and obtaining the funds necessary to support its operations. The resolution of these issues would have a profound impact on the basic character of the organization and, in important ways, would continue to influence decision-making within the Association for decades to come.

### A THE BASIC PURPOSE OF THE ASSOCIATION

The fact that a group is able to band together to form a new organization does not necessarily mean that a firm consensus has been reached regarding the organization's principal functions and the services it will provide to the membership. NACSPMR leaders struggled during the organization's early years to translate the global aims of the Association's Articles of Incorporation into a set of services valued by the membership.

During NACSPMR's June, 1965 meeting in Miami Beach, one member raised the central question when he asked: "Does this organization have a unique contribution to make?" The minutes of the meeting provide few details regarding the discussion which ensued, except that it was lengthy and ended with an agreement to "... mark time for two or three years until a definite pattern emerge[s]." By then, it was suggested, the group should be in a better position

to evaluate "... the appropriate role of the organization."

Two factors contributed to the early uncertainty about the value of maintaining a separate organization of state mental retardation program officials. First, the Association lacked the resources necessary to hire staff to organize and carry out activities of benefit to the membership. All organizational activities, including routine administrative and clerical duties, had to be performed by volunteers. And, considering the fact that the membership consisted entirely of state officials with high level job responsibilities, not surprisingly the Association provided few tangible membership services during the early years. NACSPMR leaders were acutely aware that the retention of staff was a key to creating a viable organization; consequently, possible strategies for generating the revenue necessary to open a headquarters office was a recurring topic of conversation during these years (see additional discussion under Section F).

The second source of doubt regarding the long term viability of the organization was the resistance from existing associations to creating a new organization to represent state executive branch officials. At the time, in the vast majority of states, responsibility for administering institutional and community services for persons with intellectual disabilities was lodged with the state mental health agency. And state mental health officials had formed their own national association a few years earlier. Some members of this organization felt that the creation of a splinter group of mental retardation officials would dissipate the power of their newly formed association and, therefore, pressed for the creation of associate membership status for state MR officials within the state mental health directors' association.

This issue surfaced even before NACSPMR was officially incorporated. At an October 1963 meeting held in conjunction with the Annual conference of the National Association of Retarded Children, Dr. Wesley White of Colorado mentioned the "hostility" toward the formation of the Association voiced during recent meetings of the Association of State and Territorial Health Officers and the

National Association of State Mental Health Program Directors (NASMHPD). Dr. Louis Belinson attributed this "sudden interest" in mental retardation among state health and mental health officials to the likelihood that new federal funding soon would be available and the resulting "...rush to control these monies." He recommended that the membership stay the course in the face of this opposition. The group proceeded to discuss the merits of separately administering mental health and mental retardation programs at the state level.<sup>1</sup>

During the Association's 1968 Annual Meeting in Boston, NACSPMR President Bert Schmickel mentioned that a few state mental retardation coordinators had been invited to join NASMHPD as associate members. He added, however, that there was no evidence that NASMHPD was systematically recruiting state MR officials to become members of the association.<sup>2</sup> But later that same year the situation apparently had changed. During a late October meeting of the NACSPMR executive committee, the minutes indicate that "many" state MR coordinators had received invitations to join NASMHPD as associate members with the right to participate in the group's discussions but not to vote on issues brought before the membership.<sup>3</sup>

The competition between NACSPMR and NASMHPD to be recognized as the preeminent national spokesperson for state mental retardation officials continued for a number of years. NASMHPD maintained an active Division of Mental Retardation that took positions on national policy issues, especially issues related to pending federal legislation and appropriation levels for existing programs. Overlapping memberships between the two organizations was fairly common, at least in those states where mental health and mental retardation programs were co-administered by the same state agency.

By the late 1970s, however, responsibility for administering services to persons with intellectual disabilities had been transferred out of the state mental health agency in a number of states (typically with strong backing from the state Association for Retarded Citizens and other MR advocates, who

generally felt that mental retardation programs would continue to play “second fiddle” as long as they were part of a mental health agency). Even in states where mental retardation programs remained part of the mental health agency, often the MR program unit had gained greater organizational visibility and clout by the late 70s. Generally this increased visibility took the form of a distinct, high level administrative office within the agency and the appointment of a top-tier official (deputy commissioner, etc.) to spearhead the development of services to persons with lifelong disabilities.

NASMHPD eventually disbanded its Mental Retardation Division and the two organizations (i.e., NACSPMR and NASMHPD) began to collaborate on issues of mutual interest. Initially, this collaboration was limited to pending federal legislative and administrative issues of shared concern to both organizations. Over time, however, the two associations began to work together on a broader range of issues, including the promotion of improved services at the state and local level to individuals with co-occurring developmental and behavioral disabilities.

## **B STATE REPRESENTATION IN ASSOCIATION AFFAIRS**

As pointed out in Chapter I, the aim of the founders of NACSPMR was to have one official in each state serve as the state’s voting representative to the Association. In other words, NACSPMR membership was to be limited to a single official from each of the 50 states and US territories, with the designated official responsible for representing the interests of that state in all organizational deliberations.

NACSPMR leaders were keenly aware of the recommendations of the influential President’s Panel on Mental Retardation and the growing support for an interagency coordination model within the states. Dr. Wesley White, the second President of NACSPMR, reflected this point of view in an April 1966 memo updating the membership on the activities and plans of the Association. He pointed out that:

The concept of a single state representative was based on the widespread belief that: (a) multiple departments of state government would have to be involved in developing their own, unique programs and strategies if the public sector was to forge a comprehensive response to the needs of individuals with intellectual disabilities; and (b) state governments would need to create a mechanism to coordinate the plans and activities of the separate state agencies involved in formulating and executing the state’s comprehensive strategy to “combat mental retardation.”

Although the various directors of mental retardation programs come from different professional backgrounds and are attached to different agencies [of state government], it might be helpful if we could agree that mental retardation is the responsibility of many and that overall supervision cannot be given to a single state agency. Each state department should provide the services to the retarded that they normally provide to other citizens of the state. For example, Health – health services; Education – educational services; Institutions – residential care; Welfare – foster home services; etc. ... Several states [as part of their comprehensive mental retardation planning documents] plan to recommend [that] an overall commission or commissioner, responsible to the Governor, be appointed with power to coordinate the activities of the different state agencies in the field of mental retardation. As an organization of state program directors, we cannot ignore the planning recommendation [emerging from the states P.L. 88-156 planning efforts].<sup>4</sup>



Dr. White went on to recommend that the membership discuss the implications of statewide mental retardation planning during the Association's upcoming annual meeting in Kansas City and come up with recommendations on how the results of such state plans might be advanced through the work of NACSPMR.

It soon became evident, however, that the concept of a coordinated, multi-agency approach to organizing state services clashed with the realities of Association membership policies. In theory, states would select as their Association representative the official responsible for orchestrating the activities of various state agencies with MR-related research, training and service delivery responsibilities (e.g., the staff director or chairman of the state's interagency coordination body). In practice, however, most early NACSPMR leaders were responsible for administering specific service programs in their respective states – typically overseeing the operation of state-run residential centers and, in some instances, state assisted community-based services, such as sheltered workshops and day activity centers. In defining the term “public mental retardation programs,” NACSPMR's Articles of Incorporation appeared to embrace this concept of Association membership. Article III stated that: “The term “public mental retardation programs” is meant to encompass the total institutional and community programs serving the mentally retarded...”<sup>5</sup>

The potential problem that might be encountered in identifying the appropriate state delegate to the Association was raised by a federal official during the Association's 1964 Annual Meeting in Kansas City, Missouri. Wallace K. Babington, the Executive Vice-Chairman of the Secretary's Committee on Mental Retardation within the U.S. Department of Health, Education and Welfare (HEW),\* advised NACSPMR leaders to define the term “coordinator of state programs” clearly – since the same term was to be used in departmental specifications governing the receipt of federal comprehensive statewide planning grants under P.L. 88-156. He also suggested that Association leaders cooperate with HEW in identifying the proper locus of mental retardation services in each state – since the department needed

to gather such information in any event in order to administer the P.L. 88-156 grant program.<sup>6</sup>

The question of the designation of the proper official to serve as the state's representative to NACSPMR arose on several occasions during subsequent Association meetings. It was suggested at the Association's 1965 Annual Meeting in Miami Beach that the term “Administrator” or “Chief Administrator” be substituted for “Coordinator” in NACSPMR's title.<sup>7</sup> During the 1967 Annual Meeting in Denver, the term “Director” or, possibly, “Authority” was proposed as a replacement for the word “Coordinator.”<sup>8</sup> During this same meeting, a question arose concerning the designation of the appropriate state official to represent California – the recently appointed Coordinator of Mental Retardation Programs within the umbrella Health and Welfare Agency or the official responsible for overseeing residential and community MR programs within the California Department of Mental Hygiene.<sup>9</sup> The membership decided to contact the Governor of California and abide by his recommendation.

These seemingly semantic discussions masked a more fundamental question concerning the composition of the organization's membership and ultimately how the organization might best serve the collective interests of state governments. Would the membership of the organization be comprised of officials responsible for statewide planning and coordination of services; or would the Association be an organization composed of state officials with primary responsibilities for administering specific long-term service programs for children and adults with mental retardation?

The question ultimately was resolved by the passage of the Developmental Disabilities Services and Facilities Construction Amendments of 1970 (P.L. 91-517), which authorized a federal formula grant program to support the establishment and operation of a Developmental Disabilities Council in each state and territory. Among the primary responsibilities of these councils were to develop and maintain comprehensive statewide plans, coordinate the activities of relevant state and local service agencies, and stimulate the development of cutting

edge service, training, and evaluative programs. Under the provisions of the P.L. 91-517, a majority of the members of state DD councils had to be consumers of services or members of their families, with the balance of the membership consisting of representatives of concerned state agencies, provider organizations, university affiliated centers, and other interested parties. One key aim of the legislation was to insulate the state DD council from the dominance of any single state executive branch agency so that it could successfully carry out its system-wide planning and coordination functions.\*\*

Within two years following the enactment of P.L. 91-517, an organization was formed to represent state DD council chairs and staff directors\* and, as the years passed, NACSPMR increasingly became an organization representing the chief state officials in charge of long-term services and supports for, at first, persons with mental retardation and, later, individuals with a broader range of intellectual and developmental disabilities. The change in the composition of the Association's membership, however, occurred gradually. During the early 1970s, there was a considerable degree of overlap between the membership of NACSPMR and the Association of state DD councils. But, by the late 1970s, the extent of cross-organizational membership had dwindled, as symbolized by the 1977 decision to change the name of the Association to the National Association of State Mental Retardation Program Directors.†

The shift in the Association's membership, however, also reflected wide-spread disenchantment with a coordinated, interagency model of managing

the delivery of mental retardation services. In its 1963 report, the Kennedy Panel's Task Force on Coordination identified three essential elements of effective interagency coordination: communication, cooperation, and use of authority, stressing that "... authority is probably the most over-valued condition of coordination."<sup>10</sup> But states that experimented with this model over the next decade discovered that, while interagency coordinating bodies can be a useful device to promote the exchange of information, they rarely serve as a sound foundation for ongoing, cross-agency planning and resource sharing in large bureaucratic organizations. Differences in statutory missions, external constituencies, and operating cultures, plus the tendency to protect one's organizational turf, often thwart even the best laid attempts at cross-agency planning and collaboration. As a result, the organizational model proposed by the President's Panel gradually fell out of favor.

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\* When Congress enacted legislation establishing a separate Department of Education in 1979 (P.L. 96-88), DHEW was renamed the Department of Health and Human Services.

\*\* Readers interested in learning more about the relationship between state DD councils and state administering agencies during this period are referred to Chapter II of *Forging a Federal-State Partnership: A History of National Developmental Disabilities Policies over the Past Five Decades*, available from the American Association on Intellectual and Developmental Disabilities, 501 3rd St., NW, Suite 200, Washington, D.C. (Price: \$49.95).

† Today, this organization is known as the National Association of Developmental Disabilities Councils.

‡ In 1993, the name of the Association was changed to the National Association of State Directors of Developmental Disabilities Services, this time to reflect the growing number of members state agencies whose statutory mission had been expanded to encompass services to persons with developmental disabilities other than mental retardation (see the Minutes of a Special Membership Business Meeting held in San Diego, California on April 22, 1993).

## C

## BUILDING AN INFORMED CONSTITUENCY

The possibility of issuing a membership newsletter was first broached shortly after the formation of the Association. The initiation of a quarterly newsletter was proposed during the Association's 1964 Annual Meeting in Kansas City. One participant stressed the importance of reporting on topics of particular interest to state MR officials, rather than repeating information available through other, existing sources. Another participant suggested the establishment of a

network of regional reporters to feed information to the editor of the newsletter, thereby creating a steady flow of relevant information from across the nation. The discussion ended with the adoption of a motion directing the President of NACSPMR to "... develop a medium of communication."<sup>11</sup>

Apparently, efforts to establish a newsletter were derailed, since there are no back issues or other

documentary evidence in the Association's archives of a newsletter from this period. But the idea did not die. It came up again during a 1967 meeting of the NACSPMR executive committee. While the participants viewed the initiation of a newsletter as an "extremely important" step, they also recognized that it would be difficult to sustain such a publication in the absence of a headquarters staff. So the discussion turned to the actions necessary to establish a Washington office (see further discussion under Section F).<sup>12</sup>

Another attempt to launch an Association newsletter occurred in 1969. The minutes from NACSPMR's annual meeting that year noted that Don Sellin had agreed to edit a newsletter, but he had encountered problems due to a recent change in job assignment within the state agency and the fact that his fellow state coordinators were not forwarding him information that could form the basis for newsworthy articles.<sup>13</sup>

Finally, in 1969 an Association newsletter, entitled "NACSPMR News and Views" was initiated, with George Thomas of Nebraska serving as editor. But, again, problems were encountered in obtaining information from member state agencies. A discussion during the 1969 Annual Membership Meeting generated a number of ideas concerning the contents and format of the Association's newsletter as well as potential sources of information on newsworthy developments. Several participants

emphasized the importance of describing newsworthy events in a concise, easy-to-read format. Avoiding reports on developments covered in other publications, including in news bulletins issued by NASMHPD, also was stressed. In response to Mr. Thomas' request for guidance on obtaining feedback on relevant developments from member state agencies, the group agreed that: (a) each state with an intra-state newsletter or news bulletin should forward a copy of each issue to Mr. Thomas; (b) members also should forward to Mr. Thomas any additional ideas they had regarding the contents and format of the Association's newsletter; and (c) the preparation and distribution of a periodic newsletter should be one of the key functions of the NACSPMR headquarters office should grant funds be secured to hire staff and open such an office (see additional discussion under Section F).<sup>14</sup>

Despite this well-meaning advice and the obvious interest in issuing a regularly scheduled newsletter, "NACSPMR News and Notes" ceased publication following the distribution of one or two issues. The absence of paid staff proved to be too formidable a barrier to completing all of the necessary functions involved in preparing and distributing a periodic newsletter. The initiation of such a newsletter had to await the receipt of grant funds that made it possible for the Association to hire staff and open a headquarters office (see Chapter IV for a description of the Association's information dissemination activities in the 1970s and beyond).

## D

## GAINING A VOICE IN THE FORMULATION OF NATIONAL POLICY

The early records of the Association make it clear that the desire to have a national spokesperson for the interests of state governments was one of the most compelling arguments for creating and maintaining an Association (see discussion in Chapter 1). The potential impact of new and pending federal legislation, moreover, was a recurring theme during virtually every NACSPMR membership and executive committee meeting held between 1964 and 1970.

It should come as no surprise, therefore, that influencing national policy – and especially the emerging policies of the federal government – would become a driving force in Association affairs given the events of the mid-to-late 1960s. The new mental retardation programs authorized under legislation sponsored by the Kennedy Administration were coming online and, as pointed out in Chapter I, the states were assigned a central role in implementing

several of these new grant programs – particularly the comprehensive mental retardation planning grants and the community facilities construction program. In addition, by mid-decade it became clear that some of the “Great Society” programs of the Johnson Administration would have direct and indirect impacts on the capacity of state governments to furnish services to children and adults with intellectual disabilities. Understandably, state disability officials wanted to have representatives at the table as decisions regarding the formulation and execution of these new federal programs were being made.

The minutes from most of the NACSPMR meetings held between 1964 and 1970 contain references to the desire of organizational leaders to take an active role in shaping national disability policy. President Wesley White, for example, at the group’s 1966 Annual Membership Meeting referenced NARC’s (the National Association of Retarded Children) efforts to convince Congress of the need for federal assistance to hire staff for the new community mental retardation facilities that were being constructed with funds authorized under P.L. 88-164 – and recommended that NACSPMR express its support for such staffing aid.<sup>15</sup> In a letter to his fellow state directors earlier that same year, Dr. White pointed out that Congress had included language in the new Elementary and Secondary Education Act of 1965 authorizing states to seek federal reimbursement for the cost of educating children with disabilities enrolled in state-financed school programs.\* He noted that his home state of Colorado expected to receive \$500,000 in federal aid on behalf of children residing in the state’s two MR residential facilities, which would permit his division to add 36 additional instructional staff at the Wheat Ridge facility and 24 new staff members at the Grand Junction facility.

Key federal officials participated in many of the Association’s early meetings and encouraged

NACSPMR leaders to play a pro-active role in the formulation of policies governing the operation of federal programs affecting persons with mental retardation. Dr. Stafford Warren, Special Assistant on Mental Retardation to the President of the United States, addressed the participants during a May 23, 1963 organizational meeting of the as yet unnamed association. He told the group that the new association was a potentially powerful force in formulating federal program policies and invited association leaders to forward suggestions and questions to his office. He also mentioned that plans were underway to convene a national meeting of state leaders to discuss implementation of the recommendations of President Kennedy’s Panel on Mental Retardation, including pending legislation to implement a number of the Panel’s key recommendation.<sup>16</sup>

Federal officials were frequent presenters at NACSPMR meetings between 1965 and 1970. They described efforts that were underway to expand the federal government’s role in mental retardation-related research, training, and direct services. Top leaders of other national organizations interested in the welfare of people with mental retardation also met with NACSPMR members during this period, including representatives of the National Association of Retarded Children and the American Association on Mental Deficiency.\*\* Generally, these discussions focused on ways in which NACSPMR might more closely coordinate its activities with these other, better-established groups.

In 1966, the possibility was raised of creating an Association Legislative Committee and coming up with consensus statements articulating NACSPMR opinions on pending issues before Congress and the Executive Branch of the federal government.<sup>17</sup> There is no direct evidence in the Association archives to indicate that these steps were taken. However,

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\*This provision was added as a rider to a disaster relief measure (P.L. 89-313) in the fall of 1965 at the instigation of Sen. Robert Kennedy (D-NY), after Congress had enacted the landmark Elementary and Education Act in the spring without including any provisions for state aid to children with disabilities who were not receiving their education through local school districts. It is important to keep in mind that the enactment of Education for All Handicapped Children was still a decade away and local school districts in many parts of the country refused to serve children deemed not to be “educable” or “trainable.” Such children – if they received any education at all – obtained it through state-run residential facilities or day service facilities that in some states were the recipients of state aid.

\*\* Now known as the American Association on Intellectual and Developmental Disabilities (AAIDD).

in 1967 Dr. Charles Barnett of South Carolina did appear before a U.S. Senate committee as an Association representative to offer testimony on amendments to the Community Mental Retardation Facilities Construction act (P.L. 88-164).<sup>18</sup>

In summary, from the founding of the organization, Association leaders recognized the importance of gaining a voice in the formulation of national

policy. Even though the Association's involvement in national policy debates was limited and sporadic during its formative years – due to the lack of an ongoing presence in Washington and staff to follow through on leadership directives – there is no question that helping to shape national policy was the most clearly defined and widely accepted Association role to emerge during the organization's first six years.

## E FINANCING ASSOCIATION ACTIVITIES

The financial resources of NACSPMR were meager, to say the least, during the early years. A motion was adopted at the Association's 1964 Annual Meeting establishing yearly membership dues of \$10 per state. Assuming that all fifty states and the District of Columbia paid their Association dues, the Secretary-Treasurer pointed out that total operating revenue for the year would be \$510. That amount, he concluded, should be enough to cover the organization's modest operating expenses, which – with allowances for supplies, printing, and secretarial services – he estimated would total \$320.

The financing of Association activities is a serious topic that deserves sober reflection – but the May 1964 discussion of this subject was not without its light moments. One unnamed member proposed that a state be permitted to contribute \$10 in postage stamps in lieu of a monetary contribution. The meeting minutes indicate that the motion died for lack of a second.<sup>19</sup>

Thirty-six (36) states paid their membership dues in FY 1964-65, which yielded \$360 in total revenue, but the only expenses incurred during the fiscal year were a few dollars in bank charges. As a result, the Association ended the year with a \$358.55 balance in its checking account.<sup>20</sup>

Annual membership dues were raised to \$20 per state in 1967. The minutes of the meeting noted that over



the past year the President of the Association (Wesley White of Colorado) had absorbed most of the organization's costs out of his own pocket or through in-kind goods and services supplied by the state Division of Mental Retardation. As a wry aside, the meeting minutes expressed the Association's appreciation for "the generous State offices who did not question our expenses."<sup>21</sup>

State membership dues were increased once more in 1968 – this time to \$200 per state, per annum – but the number of states remitting dues payments to the Association declined to 18 in FY 1968-69 and 21 in FY 1969-70.<sup>22,23</sup> Clearly the leadership of the Association faced a classic "chicken and egg" proposition when it came to financing organizational operations. Unless NACSPMR leaders were able to demonstrate to member state agencies the practical, day-to-day benefits of being part of the Association, additional increases in membership dues could not be justified. And yet, without increased revenues, it would be impossible for the Association to retain the staff necessary to initiate activities beneficial to the membership.

The solution to this dilemma, NACSPMR leaders agreed, was to obtain the grant funds necessary to hire staff and launch a series of activities that would prove to the membership the value of being part of the Association. The actions that eventually led to the receipt of such grant support are discussed in the next section of this chapter.

## F ESTABLISHING A NATIONAL HEADQUARTERS

The vision of opening a national program office existed even before the Association was officially formed. In his February 1963 paper proposing the establishment of the organization, Dr. Louis Belinson mentioned the possibility of obtaining funds from the National Institute of Mental Health (NIMH) to open a “small [association] office” to collect, compile and analyze service data.<sup>24</sup> [N.B., At the time, the Biometrics Branch of NIMH was responsible for gathering statistical information on “patient movement” in public institutions for persons with mental retardation as part of its series of statistical reports on mental health facilities nationwide.\*] Dr. Belinson also mentioned that Wythe Laboratories, a major pharmaceutical firm, might be willing to provide grant funds to underwrite the costs of Association operations.<sup>25</sup>

Efforts to secure the funds necessary to open an Association headquarters office, however, did not begin in earnest until early 1967, when the federal Division of Mental Retardation, under the leadership of Dr. Robert Jaslow, arranged a series of meetings with members of the NACSPMR executive committee to pinpoint areas of possible collaboration between NACSPMR and DMR. These meetings were held on January 30th, March 10th and November 19th, 1967.

Originally established in December 1963 as a branch within the U.S. Public Health Service’s Division of Chronic Diseases, Bureau of State Health Services, DMR was responsible for administering a small pool of project grant funds intended to demonstrate new service delivery techniques and train professional workers in the field. Following the enactment of the Kennedy legislation, DMR was upgraded to division status and assigned responsibility for administering the new state mental retardation planning grants,

authorized under P.L. 88-156, and later community MR facilities construction grants, authorized under Part C, Title I of P.L. 88-164. Shortly thereafter, as a result of a Congressional earmark, the Division’s demonstration grant funds were nearly tripled to \$4.5 million.<sup>26</sup>

The initial two meetings between DMR and NACSPMR representatives proved to be inconclusive, with the group focusing mainly on DMR’s need for additional information on state policies and practices in the areas of service definitions and data utilization as well as operating standards and terminology. Before the third meeting of the group could be held, the Division was transferred to the newly created Social and Rehabilitation Services, where it became a unit of the Rehabilitation Services Administration.\*\* Part of the motivation for this transfer was to place the division within an HEW organizational context where it would be better positioned to pursue the interdisciplinary, cross-agency aims of the Kennedy legislation. Program advocates, both within and outside government, concluded that those objectives were unlikely to flourish in an organizational setting where the focus was limited to health services.

During its third and final meeting in November 1967, the joint DMR/NACSPMR committee came up with a list of areas of mutual interest. This list included:<sup>27</sup>

- Collecting comparative service data from all states;
- Developing joint training sessions on data collection and usage;
- Initiating a study of inter-state movement within the service population;
- Gathering data on state utilization of computer-assisted data systems;

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\* Dr. Wesley White also referenced the role of NIMH in the founding of the Association during a December 1965 meeting of NACSPMR members, noting that the “... leadership of NIMH felt the need for a point of communication to the people in the states having basis administrative responsibility for programs in Mental Retardation.” (Minutes of NACSPMR meeting, held in Chicago, Illinois, December 2, 1965).

\*\* The transfer took effect on January 1, 1967. (see remarks by Robert I. Jaslow during the 1967 Annual Membership Meeting of NACSPMR, *Ibid*, May 18, 19, 1967)

- Sponsoring workshops on record keeping and uniform accounting;
- Contacting members of Congress to rally support for DMR programs;
- Gathering complaints regarding the operation of federal programs;
- Developing a personnel registry to address national manpower needs; and
- Issuing a periodic newsletter to facilitate the dissemination of information.

During the group’s discussions, DMR officials indicated that they would entertain a grant application from the Association aimed at accomplishing some of the above objectives. Work on this grant application began in 1968, with Dr. Charles Barnett of South Carolina taking the lead in preparing the application. The Association submitted its grant application to the Division of Mental Retardation in late 1968.<sup>28</sup>

Entitled “A Coordinated Inter-State and Inter-Agency Approach to Mental Retardation Service Development, Implementation and Assessment,” the central aim of the project was to improve and expand services to persons with mental retardation.<sup>29</sup>

While the Association’s grant application was under development, NACSPMR President Bert Schmickel met with E. B. Whitten, the executive director of the National Rehabilitation Association, to explore the feasibility of opening a D.C. headquarters office

in space to be shared with NRA. There also were preliminary discussions of sharing office space, and possibly staff, with AAMD during this period. However, for undocumented reasons, neither arrangement reached fruition.

NACSPMR’s grant application was passed over during the FY 1969 round of awards under the Division’s demonstration grants program. But the application eventually was funded during the FY 1970 round of awards. NACSPMR leaders received the official grant notice in the spring of 1970 and launched a nationwide search for a project staff director.

Bob Gettings was selected to head up the grant project in September 1970. At the time of his selection, Mr. Gettings was serving as the Management Officer for the President’s Committee on Mental Retardation, where he was responsible for tracking federal legislation, providing staff support to several PCMR task forces, managing the Committee’s budget, and overseeing the agency’s administrative support functions.

Efforts to locate office space and hire additional staff began shortly after Mr. Gettings joined the Association’s staff in early October. Within the next month, office space was secured in the Crystal City area of Arlington, Virginia and Mr. Gettings hired an Administrative Assistant/Office Manager, Ms. Jane Hawks, a former employee of the Arkansas Children’s Colony and that state’s Division of Mental Retardation. A new era in the Association’s history was underway.

## G

## CONCLUSION

Like many newly minted organizations, NACSPMR struggled during its early years to identify a compelling organizational mission and translate that mission into specific services beneficial to the membership. Organizational building activities of this sort were impeded by the lack of funds and the very limited time busy state executives were able to devote to the Association. These three factors – lack of financial resources, ill-defined organizational purposes, and very limited membership services –

tended to feed off one another. Organization leaders were unable to initiate the types of sustained services required to engender membership loyalty and, in turn, found it difficult to justify to the states the importance of providing financial and in-kind support to the Association.

Gradually, however, the Association began to establish a distinctive organizational identity, mainly due to the hard work and persistence of a small



cadre of NACSPMR leaders who believed deeply in the organization's potential. This identity initially manifested itself in the public policy arena, where the leadership of the Association was able to demonstrate to the membership that state mental retardation officials had valuable information to contribute to the formulation and administration of national laws affecting services to individuals with intellectual disabilities.

The fact that the mid-to-late 1960s was a dynamic period of growth in federal financing of mental retardation services contributed significantly to the Association's efforts to gain an organizational foothold. Beginning with legislation sponsored by the Kennedy Administration and continuing into the Johnson Administration's "Great Society" initiatives, a variety of new federal programs came on line during this period that were targeted, directly or indirectly, to improving services to children and adults with lifelong disabilities. Recognizing that the capacity and commitment of state governments were indispensable ingredients to the success of these programs, federal officials were eager to have a strong state executive branch association that could serve as an intermediary between federal and state program administrators. This convergence of interests eventually made it possible for the Association to qualify for federal grant support that would allow the organization to hire staff and open a headquarters office in the nation's capital.

By late 1970, a core staff had been hired, executive offices had been opened and the Association was in a

position to begin initiating a greatly enhanced range of services to member state agencies. The provisions of the DMR grant application laid out the general parameters of the services to be furnished to the membership. But the way in which these services were designed and implemented – and how they have evolved over the past four decades – provides the true picture of the Association as it exists today.

With this thought in mind, the spotlight will shift at this point to the development of Association activities in discrete functional areas, such as the disseminating of information, influencing public policy, providing technical assistance, conducting special studies, and launching ground-breaking special initiatives. In other words, rather than continuing to tell the story in chronological order, we intend now to examine, in-depth, broad areas of activity that have come to define the Association's membership services and ask the following questions:

- What were the factors that influenced the basis design of services within the particular area?
- How and why have the Association's services in this area evolved over the years? and
- What are the challenges Association leaders are likely to face in the years ahead as they attempt to sustain the relevance of the organization's activities within the particular service area?

In Chapter III, we will begin by discussing the organization and management of the Association's efforts to influence national policy over the years.

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END NOTES

- <sup>1</sup> Minutes of a Meeting of the National Association of Coordinators of State Programs for the Mentally Retarded, held in Washington, D.C., October 23, 1963.
- <sup>2</sup> Minutes of NACSPMR Annual Meeting, held in Boston, Massachusetts, May 2, 1968.
- <sup>3</sup> Minutes of NACSPMR Executive Committee Meeting, held in Detroit, Michigan, October 24, 1968.
- <sup>4</sup> Memorandum from Wesley D. White, Ed.D, President of the National Association of Coordinators of State Program for the Mentally Retarded, to All Officers and Members of NACSPMR, dated April 14, 1966.
- <sup>5</sup> Article III, NACSPMR Articles of Incorporation, as approved January 24, 1964.
- <sup>6</sup> Minutes of the Annual NACSPMR Meeting in Kansas City, Missouri, May 7, 1964.
- <sup>7</sup> Minutes of the Annual NACSPMR Meeting in Miami Beach, Florida, June 10, 1965.
- <sup>8</sup> Minutes of the Annual NACSPMR Meeting in Denver, Colorado, May 18, 1967.
- <sup>9</sup> Ibid.
- <sup>10</sup> *Report of the Task Force on Coordination*, Ibid, page 13.
- <sup>11</sup> Minutes of NACSPMR's 1964 Annual Membership Meeting, held in Kansas City, Missouri, May 7, 1964.
- <sup>12</sup> Minutes of a NACSPMR Executive Committee meeting, held in Chicago, Illinois, November 19-20, 1967.
- <sup>13</sup> Minutes of NACSPMR's 1969 Annual Membership Meeting, held in San Francisco, California, May 15, 1969.
- <sup>14</sup> Minutes of NACSPMR's 1970 Annual Membership Meeting, held in Washington, D.C., May 26, 1970.
- <sup>15</sup> Minutes of NACSPMR Membership Meeting, held in Chicago, Illinois, December 2, 1966.
- <sup>16</sup> Minutes of an organizational meeting of "Coordinators of State Programs in Mental Retardation, held in Portland, Oregon, May 23, 1963.
- <sup>17</sup> Minutes of NACSPMR's 1966 Annual Meeting.
- <sup>18</sup> Minutes of NACSPMR Executive Committee, November 19-20, 1967. Dr. Barnett's testimony marked the first time that a representative of the Association appeared before a Congressional committee to present testimony.
- <sup>19</sup> Ibid, Minutes of NACSPMR's 1964 Annual Meeting.
- <sup>20</sup> Ibid, Minutes of NACSPMR's 1965 Annual Meeting.
- <sup>21</sup> Ibid, Minutes of NACSPMR's 1967 Annual Meeting.
- <sup>22</sup> Ibid, Minutes of NACSPMR's 1969 Annual Meeting.
- <sup>23</sup> Ibid, Minutes of NACSPMR's 1970 Annual Meeting.
- <sup>24</sup> "A Proposition," a paper prepared and circulated by Dr. Louis Belinson, dated February 28, 1963.
- <sup>25</sup> Minutes of an NACSPMR membership meeting held in Washington, D.C., October 23, 1963.
- <sup>26</sup> Elizabeth M. Boggs, "Federal Legislation," in *Mental Retardation*, Vol. III (Joseph Wortis, M.D., Editor), New York: Grune & Stratton, 1971.
- <sup>27</sup> Minutes of a meeting of the NACSPMR Executive Committee, November 19, 1967.
- <sup>28</sup> Ibid, Minutes of NACSPMR's 1969 Annual Meeting.
- <sup>29</sup> Ibid, Minutes of NACSPMR's 1970 Annual Meeting.

# III CHAPTER

*When I consider the great events which are passed, and the greater which are rapidly advancing, and that I may have been instrumental in touching some springs and turning some small wheels, which have had and will have such effects, I feel an awe upon my mind which is not easily described.<sup>1</sup>*

John Adams,  
2nd President of the United States

## THE FORMULATION OF NATIONAL POLICY: *Influencing Legislative and Administrative Outcomes*

**A**s emphasized throughout this monograph, the National Association of State Directors of Developmental Disabilities Services (NASDDDS) assists member state agencies in a variety of ways. But, of all the major services offered by the Association, none is better understood and appreciated by the membership and the public at large than NASDDDS' role in influencing national policies that impact the delivery of state and local services to persons with developmental disabilities.

This chapter traces the evolution of the Association's efforts to become an effective representative of

the interests of member state agencies within the national policymaking arena. More specifically, in this chapter we: (a) examine the methods used over the years to establish and pursue the Association's national legislative and administrative goals; and (b) highlight important lessons that can be gleaned from the Association's experiences. The chapter also underscores some of the Association's key accomplishments in the federal policy arena over the past forty years.

### **A** MANAGING THE ASSOCIATION'S LEGISLATIVE AND ADMINISTRATIVE ACTIVITIES

At the time the National Association of Coordinators of State Programs for the Mentally Retarded (NACSPMR)<sup>▼</sup> opened its first headquarters office, there already were a number of Washington-based organizations advocating on behalf of people with disabilities, including the National Association for Retarded Children (NARC),<sup>◆</sup> the Council for Exceptional Children (CEC), the National Rehabilitation Association (NRA), and the National Association of State Mental Health Program Directors (NASMHPD), to name just a few. One

of the major challenges facing the leadership of NACSPMR was to carve out a unique role for the Association in shaping federal policies within the context of a larger disability policy agenda. With the limited resources available, the Association's advocacy efforts had to be focused on policy issues of primary concern to member state agencies. At the

<sup>▼</sup> The name under which the National Association of State Directors of Developmental Disabilities Services was originally incorporated in 1964.

<sup>◆</sup> Currently known as The Arc of the United States.

same time, these objectives had to be pursued in a collaborative manner with other national disability groups which, while sharing the same general goals, often had different priorities shaped by the distinctive constituencies they represented.

As pointed out in Chapter II, there was strong membership interest from the onset in having the Association act as a forthright voice for the national policy interests of state mental retardation agencies. But, in the absence of a national program office, NACSPMR leaders found it difficult to formulate common positions on pending legislative and administrative issues and to develop and execute effective strategies for informing key legislators and executive branch officials of the Association's views.

## 1. Getting Started

The establishment of a national headquarters and the hiring of a full-time executive director created a platform for collaborative action by state mental retardation officials across the United States. But, because virtually all of the Association's operating funds – including the salaries of the Executive Director and other staff members – were subsidized through a grant from the federal Division of Mental Retardation, the Association had to proceed with care.

At a January 1971 meeting of the NACSPMR Board of Directors, Association President Charles Barnett, the moving force behind obtaining the federal grant, alluded to the perilous course the organization faced in pursuing its national policy goals. He said Mr. Gettings would be unable to “play a leading role in advocating [for] new Congressional legislation on behalf of the Association since his salary is paid through a federal grant.” He attributed the lengthy delay in approval of the Association's grant application to fears among top HEW officials that “grant funds would be used as a ‘back door’ means of financing a lobbying group.”<sup>2</sup> Using federal funds for lobbying purposes was (and still is) a violation of federal law. Furthermore, as a Section 501(c)(3) charitable organization, NACSPMR could devote no more than an “insubstantial” portion of its overall budget to influencing legislation.

Since one of the primary objectives of the grant project was to improve the quantity and quality of information disseminated to state mental retardation agencies, the Board concluded that it was permissible for Mr. Gettings and other members of the NACSPMR staff to distribute factual information to members state agencies about pending and proposed federal legislation, as well as about regulations and administrative policies issued by relevant federal executive branch agencies. For the first three or four years of operation, therefore, the focus of the headquarters' staff was on information dissemination. Of course, there were occasions on which the staff played a behind-the-scenes role in rallying membership support for actions on bills pending before Congress, as well as on regulatory initiatives by the U.S. Department of Health, Education, and Welfare and other federal agencies. Some of the results of this work are alluded to below.

Once NACSPMR adopted a new membership dues structure in the mid-1970s, a portion of the Executive Director's salary was assigned to non-federal funds. And, as a result, Mr. Gettings and eventually other members of the staff were able to play a more proactive role in representing the shared national policy interests of member state agencies. Still, keeping member agencies informed of pending federal legislative, administrative and judicial developments has remained the backbone of the Association's work in this arena. The unwritten rule, established in the early 1970s, that member state directors testify before Congressional committees and represent the Association at meetings with top level executive branch officials continues to be observed; however, it is not adhered to as rigidly as it was in the early days when the organization was heavily reliant on federal funds to sustain its operations.

## 2. Formulating a Policy Agenda

During its April 1971 meeting, the NACSPMR Board of Directors approved the Association's first legislative and administrative (L&A) program.<sup>3</sup> The purpose of this document, as explained at the meeting, was to “articulate specific legislative goals for the Association during the 1st Session of the 92nd Congress.”<sup>4</sup>

The preparation of an annual legislative and administrative program afforded Association leaders an opportunity to discuss and reach consensus on modifications in federal laws, regulations, and administrative policies that would be of particular assistance to member state agencies. The practice of preparing and issuing this annual compendium of policy goals was to continue through 1995. At this point, the Board and staff concluded that the time and energy required to put together an annual L&A program could be used more effectively in preparing commentaries and testimony on policy issues of most critical interest to member state agencies.

In the Association's initial legislative and administrative program, launched in the early 1970s, the emphasis was on obtaining adequate formula grant funding for the newly enacted Developmental Disabilities Act. Support also was expressed for other programs administered by HEW's Division of Developmental Disabilities. In addition, the L&A program voiced the Association's strong support for legislation to create a separate Medicaid coverage option for residents of state-operated institutions serving persons with mental retardation. Other legislative issues addressed in the programs include: (a) education aid to state-operated and state-supported schools under P.L. 89-313; and (b) opposition to capping social services payments to the states under the public assistance titles of the Social Security Act.

Support for adequate funding of DD Act programs remained a high priority objective of NACSPMR through the mid-to-late 1970, as did efforts to amend various provisions of the original legislation (e.g., revising the statutory definition of a "developmental disability" and clarifying the relationship between state DD councils and state administering agencies). But, by the late 1970s, the Association's attention had shifted primarily to: (a) ensuring the effective implementation of the ICF/MR coverage option; (b) clarifying the components of daytime community services for persons with intellectual and developmental disabilities which could be covered under various Medicaid state plan options; and (c) ensuring that selected segments of the

I/DD population were not denied benefits under the Supplemental Security Income (SSI) program.

### 3. Volunteer Leadership

In early 1972, the NACSPMR Board of Directors established a Legislative Committee to oversee the formulation of the organization's statutory and administrative goals and to map out strategies for pursuing these goals.<sup>5</sup> The appointment of the committee was an outgrowth of a recommendation by the Ad Hoc Committee on Organizational Goals and Objectives, chaired by Otto P. Estes, Commissioner of Mental Retardation Services in the State of Louisiana. The Ad Hoc Committee's assignment, in part, was to identify ways of involving member state agency directors in the activities of the Association. One approach recommended by the committee was to create several NACSPMR standing committees, including a legislative committee, and to appoint state directors to serve on these advisory panels.<sup>6</sup>

David Ray, Jr., the director of the Tennessee Division of Mental Retardation, agreed to chair the new Legislative Committee.<sup>7</sup> Because he had previously served as Executive Director of the President's Committee on Mental Retardation (and worked as a key advisor to the Joseph P. Kennedy Foundation), the Board felt that Ray would be an ideal legislative strategist and spokesperson for the Association. Having a standing committee to speak on the Association's behalf by presenting testimony before Congress and representing NACSPMR at meetings with high-level federal officials was a way of keeping the staff in the background and, thus, avoiding allegations that the organization was using federal grant funds to further its legislative and administrative goals.

One of the early activities of the Legislative Committee was to develop an operating protocol. This protocol required preparing an annual legislative and administrative program. The annual L&A program was to be assembled by the Legislative Committee for review and approval by the NACSPMR Board of Directors. Recognizing that in many circumstances it would be unwieldy to involve all members of the committee in day-to-day

strategy decisions, the Board, upon the Committee's recommendation, delegated responsibility to the Committee chair to make such strategic decisions in close consultation with the Association's Executive Director.

The Legislative Committee was disbanded in 1975 following Ray's resignation as director of the Tennessee Division of Mental Retardation. It was replaced by a series of time-limited, ad hoc task forces which were asked to provide input to the Board on particular legislative and administrative topics.

After operating for approximately four and a half years without a legislative committee, the Association's Board agreed in early 1980 "to consolidate the activities of three ad hoc task forces on specific federal program issues into a single, standing Committee on Legislative and Administrative Policy."<sup>8</sup> Shortly thereafter, Jennifer Howse, Pennsylvania's Deputy Secretary for Mental Retardation, was named chair of the committee (which later that year was renamed the Governmental Affairs Committee).

Meetings of the Association's Governmental Affairs Committee (GAC) became a major forum for the discussion of contemporary federal policy issues facing state MR/DD agencies. The Committee met separately, usually in conjunction with meetings of the Association's Board of Directors. Two of the GAC and Board meetings were held prior to (or following) the mid-year and annual membership meeting, respectively. The remaining two GAC meetings each year were held the day before the Board's separate quarterly meetings. Officials from all member state agencies (both state directors and other key staff members) were invited to sit in on GAC meetings and it wasn't long before the number of states represented at these meeting – especially at meetings held in conjunction with membership meetings – rivaled the number of states represented at membership meetings.

The inclusion of representatives from a majority of member states promoted awareness of the Association's activities in the federal policy arena and also gave officials from many states an opportunity

to: (a) learn about the ways in which other states were deploying federal dollars to accomplish their program goals; and (b) obtain advice and guidance from their counterparts in other states. But, as a result, the character of GAC meetings changed. Rather than being a forum in which the particulars of the Association's legislative and administrative priorities were hammered out, these meetings became primarily seminars on the effective utilization of federal resources to advance the goals of member state agencies. Often key federal policymakers and Congressional staffers were invited to address participants and respond to questions. In addition, officials from member state agencies engaged in innovative approaches to deploying federal resources were frequently asked to describe their initiatives and answer questions.

Because GAC meetings no longer functioned as a forum for determining the Association's legislative and administrative goals and how they should be pursued, responsibility for carrying out these tasks shifted to the staff in consultation with the Chair of the Governmental Affairs Committee. Consequently, in the 1980s and 1990s, the GAC Chair was a key leadership post within the Association. After Jennifer Howse left her position as Pennsylvania's Deputy Secretary for Mental Retardation in 1985, she was succeeded by Ben Censoni, Deputy Director of the Michigan Department of Mental Health. Censoni served as Chair of the Committee until his untimely death from lung cancer in 1988. He was replaced by James Toews, the Administrator of Developmental Disabilities Services in the State of Oregon. Toews served as Chair of the Committee from 1989 to 1993 when he was elected Association President. He was replaced by Ric Zaharia of Utah (1993-95) and later by Jaylon Fincannon of Texas (1995-96). Charlie Allison, Director of the Colorado Division of Developmental Disabilities, was appointed Chair of the Governmental Affairs Committee in 1996 and served in this capacity until his death in 2001.

Following Allison's death, the Association's Board of Directors disbanded the Governmental Affairs Committee and reformatted GAC meetings as a biannual Directors' Forum. The Directors' Forum was billed as a chance for state directors to gather twice a

year to discuss in closed session critical issues facing state developmental disabilities agencies. Attendance was (and still is) limited to state directors and other state agency staff members.

Discussions of current federal policy issues and interactions with key federal policymakers remain prominent features on Directors' Forum agendas. But other topics also are discussed, including the status of other Association initiatives, such as the National Core Indicators (NCI) program and the State Employment Leadership Network (SELN) (see Chapter VII for an extended discussion of the history of these and other Association-sponsored interstate collaborations).

When the Governmental Affairs Committee was disbanded, day-to-day management of the Association's legislative and administrative activities was shifted to the Executive Director, with the Board responsible for overseeing these as well as other organizational activities. The effects of this shift in responsibility were largely invisible to outsiders because of the interlocking memberships of the GAC and the Board for many years prior to the change.

#### **4. Staff Responsibilities**

For most of the 1970s, Mr. Gettings had sole staff responsibility for pursuing the Association's legislative and administrative goals, including supporting the work of the Legislative Committee as well as the ad hoc groups on policy issues which subsequently were established. In 1978, however, a professional staff member was hired to assist Mr. Gettings in tracking and reporting on federal legislative and administrative developments. Initially, the incumbent in this position, Stephanie Mensh, worked half-time on a federal grant project and half-time on L&A activities. But, within a year, she was working full-time on L&A activities.

From 1979 to the present day, the Association has employed a full-time staff member responsible for tracking and reporting on federal legislative and administrative policies. While the duties and title of the position have varied to some degree over the years, the incumbent has always been primarily responsible for monitoring and reporting on federal

legislation and assisting the Executive Director in planning and carrying out the Association's legislative and administrative activities. As will be discussed in greater detail in Chapter IV, the vehicles used to disseminate information about national legislative, administrative, and judicial developments have evolved over the years. Beginning in the mid-1970s, the Association issued a series of frequent, single-subject bulletins, called *Intelligence Report* bulletins, plus a monthly newsletter, called *Capitol Capsule*. At present, the Association issues a monthly electronic newsletter, called *Federal Perspectives*, and a weekly bulletin, called *Federal News Briefs*, summarizing policy developments that impact on services and benefits to persons with intellectual and developmental disabilities. Throughout the organization's history, the Association's commitment to having a fully informed constituency has been unwavering.

Although for more than three decades tracking and reporting on relevant developments has been primarily the responsibility of the Federal Policy Analyst,\* the Association's Executive Director has continued to play an active role in formulating and promoting the adoption of the organization's positions on pending legislative and administrative issues. Federal policy is so central to the interests of member state agencies that the Executive Director must play an active role in advocating on the organization's behalf. Moreover, the Association's budget is too small to support a semi-autonomous, generously staffed public policy department similar to those which exist in larger, better-financed advocacy organizations.

#### **5. Inter-organizational Collaboration**

In 1970, NACSPMR was part of a loosely-knit coalition of organizations committed to advancing the federal policy interests of persons with intellectual and developmental disabilities. Called the Ad Hoc Liaison Committee on Mental Retardation/Developmental Disabilities, this group initially was brought together by NARC in an effort to rally support for passage of the Developmental Disabilities

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\* Again, the title of the position has varied over time, but the principle duties have been similar.

Act. One of the weaknesses of the group was the absence of an effective mechanism for following through on agreements, since at the time only two of the participating organizations had a staffed office in the Washington, D.C. area.

During the lead-up to (and immediately following) the enactment of the Developmental Disabilities Act in October 1970, however, the situation changed as, in rapid succession, NACSPMR, United Cerebral Palsy, and the Epilepsy Foundation established Washington area offices. Soon thereafter, the staff from these offices, along with representatives from other Washington-based organizations, began to meet regularly to discuss federal policy issues of mutual concern. The initial focus of the group's discussions was on obtaining adequate appropriations for programs authorized under the Developmental Disabilities Act. But it wasn't long before the committee began to collaborate on other contemporary disability policy issues: the passage of legislation authorizing a Medicaid coverage option for ICF/MR services; the federalization of income assistance payments for low-income elders and individuals with disabilities (the Supplemental Security Income (SSI) program); the recognition of statutory rights of all persons with disabilities under Title V of the Rehabilitation Act; and the right under federal law to a free, appropriate public education for all children with disabilities.

In 1973, the participating organizations decided to formalize the arrangement by establishing the Consortium for Citizens with Developmental Disabilities (CCDD). The charter members of this non-incorporated coalition included the National Association for Retarded Citizens,\* the United Cerebral Palsy Associations,\* the National Association of Coordinators of State Programs for the Mentally Retarded,♥ and the National Association of State Mental Health Program Directors. Shortly thereafter they were joined by a representative of the Epilepsy Foundation of America. As the policy agenda of CCDD expanded through the remainder of the 1970s and the 1980s, many other organizations with an interest in disability policy joined the Consortium.

The member organizations of the Consortium decided, early on, to adopt a streamlined structure where all of the substantive work of the group would be carried out by a series of largely autonomous task forces. Meetings involving all Consortium members were held once a year in order to elect officers and determine the task forces which would be in operation during the upcoming year. Task forces were formed on appropriations, health services, education, Social Security and SSI, long-term services, rights, housing, developmental disabilities, vocational rehabilitation and employment, transportation, etc. Affiliated organizations were free to participate in any task force they wished to join and to associate themselves (or not) with positions taken by a given task force. The role of the CCDD chairperson (with the help of other elected officers) was mainly to organize the annual membership meeting, act as a central contact point, and sort out jurisdictional disputes among the various task forces – in essence functioning as traffic cops for the Consortium.

As a general rule, organizations with a strong interest in disability policy joined the Coalition because they saw it as a way of: (a) broadening the base of support for their highest federal policy priorities; and (b) helping to influence the direction of federal policy in areas where they, as organizations, otherwise would be unable to participate actively. Thus, for example, CCDD task forces routinely would divide up responsibility for covering Congressional hearings, preparing testimony and comments on regulatory and administrative proposals, and attending agency briefings. All organizations gained by their participation. Staff from an organization with especially strong interests in a particular policy area might perform a disproportionate share of the task force's work, but they did so knowing that, in all probability, they would be able to line up broad organizational support for positions central to the interests of their own constituency, thereby projecting an image of unity within the disability community. On the other hand, staff from organizations that played a marginal role in task force activities nonetheless could report to their respective memberships that they had participated in legislative and administrative advocacy efforts which

otherwise would have been beyond the organization's capabilities.

During the 1970s and 1980s, NACSPMR (NASMRPD) staff played an active role in several CCDD task forces, including the task forces on appropriations, developmental disabilities, education, Social Security and SSI and, especially, long-term services. Mr. Gettings chaired the CCDD Task Force on Long-Term Services for most of this twenty-year period. Representatives of the participating organizations in this as well as other CCDD task forces arrived at the table with differing perspectives and priorities, reflecting the distinctive constituencies they served. But they shared a commitment to improving and expanding services to individuals with disabilities through federal policy enhancements; and, as a result, in most instances were able to hammer out a consensus position on issues before Congress and executive branch agencies of the federal government.

In 1992, following the enactment of the Americans with Disabilities Act (in 1990), the mission of Consortium was expanded to encompass federal policies affecting all persons with disabilities, regardless of the nature, origin or onset of the disability, and the coalition's name was shortened to the Consortium Concerned with Disabilities (CCD). This change formalized a trend which had been

underway for a number of years and resulted in a further expansion in the Consortium's policy agenda as well as in the number of affiliated organizations. By the mid-1990s, over one hundred organizations had signed on as CCD members.

NASDDDS remains an affiliated member of CCD, but the level of the staff's involvement in the activities of the Consortium has become less intense over the past 15-20 years. In part, this reduced involvement reflects a shift in the Association's national policy priorities toward administrative, rather than legislative, issues – especially issues related to Medicaid-funded home and community-based services (an area in which the Consortium's Task Force on Long-Term Services and Supports has devoted comparatively little time in recent years). It also reflects the importance Association leaders assign to representing the unique policy interests of individuals with intellectual and developmental disabilities at a time when CCD's primary objective is to promote a cross-disability federal policy agenda.

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\* Formerly known as the National Association for Retarded Children and later renamed The Arc of the United States.

\* Later shortened to United Cerebral Palsy.

♥ Subsequently (in 1977) renamed the National Association of State Mental Retardation Program Directors (NASMRPD) and later (in 1993) the National Association of State Directors of Developmental Disabilities Services (NASDDDS)

# B

## LEGISLATIVE AND ADMINISTRATIVE ACCOMPLISHMENTS

Individuals with intellectual and developmental disabilities typically require supports and services that are comprehensive, needs-based, and life-long in duration. Public I/DD systems must be designed to offer direct assistance in meeting personal care needs and in helping individuals and families gain access to the supports they need to function successfully. The scope of services and supports required by children and adults with developmental disabilities is extremely broad, including: training to provide individuals with the skills necessary to become employed and to engage in community

life; treatment to address co-occurring medical and health-related conditions; and ancillary assistance in carving out a meaningful life in the community, such as transportation, support coordination, income maintenance, and housing assistance.

Due to the breath of this population's needs, NASDDDS has worked on behalf of member state agencies to help shape a wide range of federal domestic assistance programs. A detailed summary of the Association's work in the federal policy arena is beyond the purpose and scope of the present

volume. But we will attempt to highlight some of the organization's more prominent accomplishments. Readers are encouraged to review this chapter in conjunction with a companion volume which traces the history of national developmental disabilities policies over the past fifty years and the Association's role in helping to shape these policies.\*

## THE 1970s

As pointed out in Chapter II, during the 1960s the Association lacked the necessary resources to become actively involved in influencing federal policy on a sustained basis. The situation changed, however, in October 1970 when an executive director was hired and the Association opened a headquarters office in the Washington, D.C. area.

During the decade of the 1970s, the Association was instrumental in:

- Supporting the passage of legislation adding an optional coverage of intermediate care facility services for persons with mental retardation and related conditions (ICF/MR) under state Medicaid plans;
- Shaping the initial regulatory standards governing ICF/MR services, which were promulgated in final form by the U.S. Department of Health, Education, and Welfare (HEW) in January 1974;<sup>9</sup>
- Helping to convince HEW officials of the need to extend the original regulatory deadlines for complying with federal ICF/MR standards;
- Creating regulatory exceptions to federal ICF/MR standards for small (15 beds or less), community-based ICFs/MR;
- Adopting a functional definition of the term "developmental disability" as part of the federal Developmental Disabilities Act;
- Clarifying the relationship between the responsibilities of state developmental

disabilities councils and the state agencies responsibility for administering federal funds under the DD Act;

- Protecting social services benefits to persons with intellectual and developmental disabilities under Section IV-A, XIV and XVI (and later Title XX) of the Social Security Act; and
- Ensuring that the income maintenance (SSI; OASDI) and medical assistance (Medicaid; Medicare) benefits of persons with lifelong disabilities are appropriately synchronized (e.g., qualifying institutionalized persons for pre-placement SSI benefits; and allowing residents of publicly operated group homes to qualify for full SSI benefits).

## THE 1980s

During the decade of the 1980s, the focus of the Association's legislative and administrative advocacy shifted almost entirely to financing home and community-based services through the federal-state Medicaid program, as deinstitutionalization initiatives gained momentum in many member states. One important victory during the early part of the decade (1981) was the enactment of the Medicaid home and community-based (HCB) waiver authority. The Association played a key role, first in ensuring that persons with developmental disabilities qualified for HCB waiver services and, second, in furnishing member state agencies with timely, accurate information on the process of applying for the required Secretarial waivers. As a result of



these efforts an increasing numbers of states took advantage of this new waiver option and, by the end of the decade, three out of every four dollars expended on HCB waiver services were being used to support persons with intellectual and developmental disabilities.

NASDDDS\* also was instrumental in achieving a number of changes in Medicaid law aimed at preserving and expanding access to home and community-based services, including:

- Reversing administrative attempts on the part of the Health Care Financing Administration (HCFA) and the Office of Management and Budget to restrict access to HCB waiver services;
- Adding targeted case management services as a free-standing coverage option under Medicaid law and, subsequently, removing statutory and administrative obstacles to covering such services for persons with intellectual and developmental disabilities;
- Mandating pre-admission screening and resident reviews for all nursing facility residents with mental illnesses, intellectual disabilities and related conditions; and
- Permitting states to use average annual ICF/MR expenditure data in calculating the cost-effectiveness of HCB waiver services for nursing facility residents with developmental disabilities when they were being transitioned to community services.

In addition, the Association spent a considerable amount of time during the mid-to-late 80s weighing the merits of legislation aimed at encouraging states to close large, multi-purpose institutions in favor of developing home and community-based alternatives for individuals with intellectual and developmental disabilities. The debate centered around a series of bills introduced by Sen. John Chafee (R-RI), although alternative measures also were introduced during this period by Sen. Lowell Weicker, Jr. (R-CT) and Rep. Henry Waxman (D-CA). Congress failed to enact these bills; but in 1990, language sponsored by Sen. Chafee was added to a budget reconciliation bill

authorizing the coverage of Community Supported Living Arrangements (CSLA) services for Medicaid-eligible individuals with developmental disabilities.

## THE 1990s

NASDDDS was not only a key participant in the development of the CSLA coverage option but also worked closely with HCFA officials in formulating rules and administrative policies governing this new program authority. While, by law, only eight (8) states were allowed to provide CSLA services and the legislative authority expired in 2006, the CSLA coverage option had a far-reaching impact on the organization and financing of community I/DD services across the nation. It demonstrated for the first time in federal long-term services policy the feasibility of delivering individually tailored, self-directed community supports.

During the 1990s, NASDDDS\*\* also convinced Congress to revise the statutory definition of “habilitation services” to encompass day habilitation and supported employment services for all adult HCB waiver participants. Under this amendment, states were permitted to claim federal payments for day habilitation and supported employment services on behalf of waiver participants whether or not they had previously resided in a Medicaid-certified institution. In addition, during the mid-1990s, the Association joined with many other advocacy and state executive branch organizations in opposing the imposition of a global cap on federal financial participation in the cost of Medicaid services (i.e., the so-called MediGrant program).

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\* For more extended explanations of the Association’s involvement in these and other I/DD-related federal legislative and administrative policies during the 1970s and beyond, see *Forging a Federal-State Partnership: A History of National Developmental Disabilities Policies over the Past Five Decades*, available from the American Association on Intellectual and Developmental Disabilities, 501 3rd St., NW, Suite 200, Washington, D.C. (Price: \$49.95).

\*\* The association’s name was changed in 1993 from the National Association of State Directors of Mental Retardation Programs (NASMRPD) to the National Association of State Directors of Developmental Disabilities Services (NASDDDS) to reflect the broader target population served by member state agencies.

# IV THE 2000s

Following the U.S. Supreme Court’s 1999 ruling in *L.C. v. Olmstead*, NASDDDS worked closely with officials of the Health Care Financing Administration (later renamed the Centers for Medicare and Medicaid Services (CMS)) and other federal executive branch agencies to clarify actions states could take to help persons with disabilities access services in the most integrated setting consistent with their needs and aspirations. Launched during the Clinton Administration and continued in the Bush and Obama administrations (as the “New Freedom” and “Community Living” initiatives, respectively), these efforts led to useful clarifications in many existing federal policies and the implementation of new programs, such as:

- Real Choice System Change Grants;
- Money-Follows-the-Person Demonstration Grants; and
- Grants to establish Aging and Disability Resource Centers.

During the past decade, NASDDDS also was part of a unique collaboration between CMS and state executive branch organizations which led to: (a) the adoption of a new approach to monitoring and improving the quality of Medicaid-funded home and community-based services; (b) the development of a completely revised home and community waiver application process; and (c) the establishment of clear and appropriate guidelines on the definitions of employment services furnished under the Medicaid waiver program. As a result of this work, CMS in recent years has forged more effective working relations with states in formulating and carrying out Medicaid long-term services policies. Among the early products of improved intergovernmental collaboration are: (a) the elimination of a requirement that states provide detailed, case-by-case reports to CMS on all alleged irregularities in the delivery of HCB waiver services; and (b) greater attention to the role of families in recent CMS guidelines on applying managed care principles to the delivery of Medicaid-funded long-term services and supports.

## C

## LESSONS LEARNED

Looking back over the history of the Association’s efforts to influence federal disability policy, a number of guiding principles emerge. These principles can be summarized as follows:

### 1. The Interactive Nature of Association Activities

The pursuit of the organization’s federal legislative and administrative goals should not be viewed as a unitary endeavor. Rather it should be seen as part of a coordinated set of undertakings geared toward helping member state agencies accomplish their goals and improve the services and supports furnished to people with I/DD and the families who support them. NASDDDS’ continuing efforts to track and report on relevant federal, legislative, administrative and judicial developments is directly linked to

the organization’s capacity to influence public policy. Timing and a nuanced understanding of the issues and personalities involved are critical to the achievement of policy goals; and you can’t acquire such knowledge without continuously monitoring the ever-changing policy scene.

The dissemination of timely, accurate, complete information enables member state agencies to bring critical federal policy issues to the attention of top-level elected and appointed officials in their respective states and to take advantage of new and emerging funding opportunities. A well-informed constituency, in other words, is the foundation of any successful legislative and administrative advocacy program.

Similarly, the Association’s technical assistance activities are both informed by and benefit from

the organization's work in the federal policy arena. From the onset, NASDDDS' technical assistance services have been built upon two basic pillars: (a) an intimate familiarity with the federal laws, regulations and administrative interpretations governing the program or programs under consideration; and (b) an encyclopedic knowledge of how states have utilized federal programs and policies to organize, finance and deliver long-term services and supports to persons with intellectual and developmental disabilities. Through its efforts to influence federal policy, the Association gains valuable insights into policies governing federal programs and the ways in which they intersect with the interests of persons with disabilities and their families. These insights are used to advise states on the most effective approaches to employing federal programs to serve individuals with lifelong disabilities. The information gleaned from helping states design and implement federal programs in turn often reveal gaps and discontinuities that need to be addressed as part of the Association's efforts to influence federal policies.

In essence, the Association must engage in a variety of activities in order to help member state agencies take advantage of federal assistance programs. The best example of this interactive approach is the Association's effort to shape the Medicaid home and community-based waiver program over the years. As noted earlier, the Association worked behind-the-scenes to ensure that persons with developmental disabilities could benefit from the waiver authority when it was initially authorized in 1981; and, on several subsequent occasions during the 1980s and 1990s, NASDDDS successfully sought statutory amendments to the waiver authority in order to eliminate administrative obstacles imposed by HCFA (CMS); and, more recently, during the development of the Affordable Care Act of 2010 the Association played an instrumental role in promoting conflict-free case management services; the use of standardized, population-specific assessment instruments, and the removal of barriers to state utilization of the HCBS state plan coverage option.

The Association's efforts, however, were not limited to the legislative arena. Immediately following the passage of legislation authorizing Medicaid home and

community-based waivers, the staff of NASMRPD prepared and distributed a paper (after consulting with responsible HCFA officials) containing several scenarios that sketched out alternative ways in which state MR/DD agencies might employ the waiver authority to advance their program goals.\* The aim of this paper was to help member state agencies grasp the far-reaching implications of this new statutory authority. Unquestionably, it helps to explain why many of the early waiver requests approved by HCFA were targeted, in whole or in part, to persons with intellectual and developmental disabilities.

During 1982-83, the Association also issued a detailed summary of each MR/DD home and community-based waiver program as it was approved by HCFA – with the aim, again, of assisting members state agencies to understand how the waiver authority could be – and, indeed, was being – used to help persons with developmental disabilities gain access to community-based services.

Between 1982 and 2000, NASDDDS published ten more reports detailing the evolution of Medicaid home and community-based waiver policy and how the waiver authority was being used to expand and improve I/DD services nationwide.<sup>10</sup> In addition, the Association's technical assistance staff provided advice and support to virtually every state in the nation as they designed and implemented their I/DD waiver programs. With respect to utilization of the HCB waiver authority, there is no question that NASDDDS member state agencies were the best supported constituency among the affected state executive branch agencies; the proof lies in the number and scope of I/DD waiver programs mounted by states during this 20-year period. The larger point to keep in mind, however, is that NASDDDS leaders recognized the enormous potential of the HCB waiver authority and decided to mount a broad-scale effort to influence not only related federal policies but also state-level utilization of the program.

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\* This paper was subsequently included in an Association publication entitled, *The Medicaid Home and Community-Based Care Waiver Authority*, National Association of State Mental Retardation Program Directors, December 1981.

## 2. Focusing on Priority Issues

To be effective in the federal legislative and administrative arena, an organization must zero in on the issues of greatest relevance to its membership, which, in the case of NASDDDS, consists of the 51 member agencies (the 50 states and the District of Columbus). As pointed out earlier in this chapter, the policy interests of individuals with lifelong disabilities are extremely broad, spanning virtually the entire spectrum of human services. But state I/DD agencies are charged specifically with the provision of long-term services and supports to individuals with developmental disabilities. Individuals so classified often require access to services not provided by or through state DD agencies, including primary, secondary and higher education, vocational rehabilitation, income assistance, primary and acute health services, housing, public transportation, food and nutrition services (including Food Stamps), and mental health services (plus early intervention services in some states). Certainly, state DD agencies have a strong interest in ensuring that qualified individuals receive the “generic” public services they require. Indeed, furnishing assistance in accessing such generic services, directly or indirectly, is a core function of state DD agencies.

Yet, in setting national legislative and administrative goals, there are two primary reasons why Association leaders have focused first and foremost on federal policies which directly impact the capacity of member state agencies to carry out their assigned mission. First, the resources which the Association is able to devote to activities aimed at influencing federal policy are extremely limited. Therefore, for very practical reasons, it is critical that staff members and volunteers concentrate on issues with the greatest potential payoff for member state agencies.

Second, and of at least equal importance, the Association’s ability to influence federal policy is far greater in areas where member state agencies have a direct role in organizing, financing and overseeing the delivery of the affected services, compared to areas in which another federal, state or local agency has primary responsibility. On many, many occasions over the years, the Association has joined with other

national disability organizations in endorsing pending measures aimed at advancing the general or specific interests of children and adults with disabilities. And there is no doubt that this work has resulted in improvements in services as well as in societal treatment of people with developmental disabilities. But a “me too” approach to advocating for public policy changes does little or nothing to address deficits in services to people with lifelong disabilities.

NASDDDS’ work in the public policy arena is best conceptualized as a series of concentric circles, where the outer circle represents proposed legislative and administrative reforms which the Association supports without devoting a lot of organizational time and energy to the cause; whereas, the inner-most circle represents issues where NASDDDS leaders are willing to commit considerable time and resources to seek outcomes especially favorable to the I/DD population. Issues within this conceptual framework can change over time. So, for example, during the 1960s and 1970s, children with severe intellectual disabilities often were denied educational services in the local public schools and their parents had to rely on day training centers funded through state mental retardation agencies. At that time, establishing and sustaining federal aid to state-operated and supported schools through the Elementary and Secondary Education Act was a core interest of the Association; whereas, today, with members state agencies no longer involved (except in rare circumstances) in providing educational services, this area of policy is no longer defined as a core Association policy interest.

For many years now, the Association’s primary policy interests have revolved around the Medicaid home and community-based waiver program. But that situation could change in the coming years. As part of the “Patient Protection and Affordable Care Act of 2010,”<sup>11</sup> Congress removed a number of obstacles to covering home and community-based services under state Medicaid plans.<sup>12</sup> It will be years before we can fully assess the impact of these and other new statutory provisions on future developmental disabilities services. But it is quite possible we will see a shift in the primary sources of federal financial support for state/local developmental disabilities

services in the future. If so, the Association will have to modify its core legislative and administrative activities accordingly.

### **3. Balancing the Individual and Collective Interests of Member State Agencies**

Each member state agency has its own federal legislative and administrative priorities as well as channels through which it can make its views known to state and national policymakers. At any given point in time, a member state agency's priorities may mesh neatly with, or diverge from, the priorities of other member state agencies. Association leaders, therefore, need to be able to distinguish between the individual and collective interests of member state agencies. The Association's legislative and administrative goals should focus on issues where a significant majority of member state agencies stands to benefit from the adoption, rejection or modification in a particular federal policy or policies.

At the same time, the organization cannot afford to ignore the policy priorities of individual member state agencies. Here the Association's obligation should be limited to offering member state officials guidance and assistance – but not necessarily direct support – in pursuing their unique policy objectives.

In most instances, the primary national policy goals of member state agencies are quite similar and there is little difficulty in formulating a shared set of policy goals. But, on a few occasions over the years, situations have arisen where one member state agency has pursued national policy goals which were out of synch with the goals of the majority of state agencies. This situation arose in the mid-1980s, for example, when officials of the New York Office of Mental Retardation and Developmental Disabilities (OMRDD) concluded, based on an internal analysis, that the state would be better able to achieve its long-range goals if it were relieved of the constraints imposed by federal Medicaid statutory and regulatory policies. Furthermore, in order to achieve such managerial flexibility the state was willing to operate its service programs for people with I/DD under a global federal Medicaid spending cap, indexed to an inflationary growth factor.

OMRDD officials lobbied their counterparts in other states to support the New York State proposal, which in 1985 was submitted to the federal Health Care Financing Administration (HCFA) as a Section 1115 demonstration waiver request. Recognizing the enormous pent-up demand for I/DD services and the states' growing reliance on federal Medicaid funding, officials from other member states concluded that a cap on federal Medicaid funding would hinder the growth in I/DD services within their respective states and, consequently, they were unwilling to lend their support to New York's 1115 waiver request. NASMRPD staff and volunteer leaders were trapped in the middle of the dispute, recognizing that a Medicaid spending cap would have a detrimental impact on the expansion of I/DD services in most states – but also wanting to be of assistance to a member state agency which paid disproportionately higher Association dues.

Eventually, HCFA refused to approve New York's Section 1115 waiver request and the concept of a self-imposed Medicaid spending cap (in exchange for enhanced operating flexibility) faded away. It took considerably longer, however, to restore a sense of camaraderie and trust among member state agencies.

### **4. Working Collaboratively with Other National Organizations**

Advocates for federal policy changes often feel like Sisyphus, the mythic Greek king who was repeatedly forced to push a huge boulder up a steep hill throughout eternity. With scores – sometimes hundreds – of disparate interest groups vying for attention, it is difficult to make your voice heard, much less have your views reflected in government policy. The task becomes even more challenging if your position on a pending policy issue is at odds with prevailing opinions among your natural allies. Inter-organizational dissonance breeds inaction in the policymaking arena. For this reason, the prospects of legislative and administrative success are almost always enhanced if one is able to resolve in advance any differences that may exist between directly affected parties and to speak with a single voice in communications with key legislators, legislative aides, and/or executive branch officials.

Since the founding of the Association, NASDDDS leaders have partnered with other disability organizations in efforts to achieve shared legislative and administrative goals. The fact that the disability movement has been able to reconcile internal differences on most major policy issues and speak with one voice to Congress and succeeding administrations has, unquestionably, contributed in a significant way to the renaissance in national disability policy that we've witnessed over the past forty years.

Successful coalition building is based on four basic attributes: (a) an atmosphere of trust among the participating organizations; (b) a willingness to seek middle ground when it is not possible to achieve all of the goals of every participating organization; (c) a willingness, in the interest of group cohesion, to support both policy changes central to the aims of your organization as well as policy changes deemed critical by other partner organizations; and (d) a willingness as a coalition to share credit for victories as well as criticism for defeats.

Participation in a coalition, however, does not mean an organization has to sacrifice its autonomy in "the interests of the greater good." In coalition work, representatives of an organization need to be able to distinguish between proposals of direct interest and those which are not. Sometimes it is difficult to ascertain the difference and one's inclination may be to "go along to get along." However, as suggested earlier, an organization like NASDDDS, with limited resources to invest in influencing federal policies, must maintain a laser-like focus on issues of greatest potential benefit to member state agencies. To do so, the Association must have a thorough understanding of member agency needs, the capability to translate those needs into specific policy proposals, and the tenacity to pursue desired ends in its interactions with other organizations seeking compatible outcomes.

NASDDDS' most noteworthy legislative and administrative achievements usually have occurred in clearly delineated policy areas where the Association was able to use information and data derived from the experiences of member state agencies to build a convincing case for revisions in statutory, regulatory, or administrative policies. Examples of such

circumstances can be found in the series of statutory amendments to the Medicaid home and community-based waiver authority which the Association helped to shepherd through Congress during the mid-to-late 1980s. Another, more contemporary, example is the adoption by CMS in 2005 of a completely revamped HCB waiver application process which incorporated many policy interpretations that NASDDDS had been championing for years.

Conversely, the Association has been far less successful in promoting broad-scaled reforms in federal laws governing the financing and delivery of long-term services and supports to persons with disabilities. The attempts that were made during the mid-to-late 1980s to legislate through Medicaid law the elimination of large, multi-purpose I/DD institutions and the development of alternative community-based services such attempts illustrate the enormous difficulty of reaching consensus when opinions within the wider advocacy community are deeply polarized. In this case, as mentioned earlier, the Association eventually played a central role in negotiating a constructive alternative (i.e., the Community Supported Living Arrangements program), but the resulting policy changes were not nearly as transformative as advocates of the original Chafee bill had hoped.

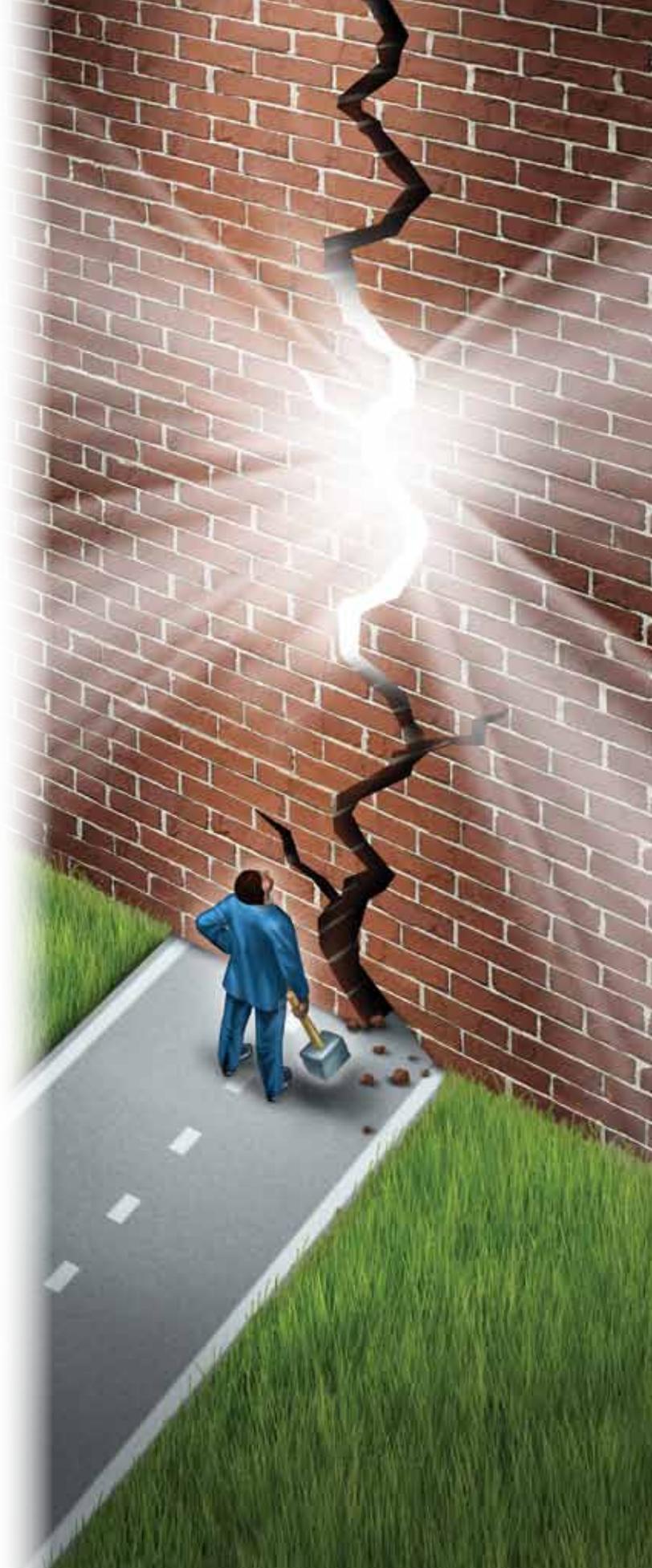
Efforts to shift the financing of home and community-based waiver services to a Medicaid state plan coverage represents another case study in frustration. NASDDDS, along with many other national organizations, has supported legislation to accomplish this objective since the 1980s. But, despite repeated attempts, federal lawmakers have been unable to formulate a workable set of state plan requirements which balance the entitlement (universal access) goals of disability advocates with the fiscal realities facing state governments. As this situation illustrates, NASDDDS' ability to influence federal policy outcomes is limited when: (a) the fiscal interests of the states clash with the understandable desire of citizen advocates to use federal law (or administrative policy) to leverage rapid, costly policy changes in service entitlements at the state and local level; and (b) the interested constituencies reach far beyond the developmental disabilities field.

## 5. The Importance of Perseverance

As the saying goes, “Rome was not conquered in a day.” And, similarly, legislative and administrative goals often take years – sometimes decades – to accomplish. NASDDDS began advocating for the coverage of day habilitation and supported employment services under the Medicaid HCB waiver authority in the early 1980s, and managed to convince Congress to add this coverage option for previously institutionalized individuals with developmental disabilities as part of the Consolidated Omnibus Budget Reconciliation Act of 1985.<sup>13</sup> Later, as part of the Omnibus Budget Reconciliation Act of 1987, the Association sought and obtained amended language clarifying that all previously institutionalized waiver participants – not just those residing in an institution immediately prior to enrollment in the waiver program – were eligible to receive such extended habilitation services under a HCB waiver program.<sup>14</sup> Due to the uncertain fiscal consequences, however, lawmakers refused to permit federal financial participation in the cost of such extended habilitation service for waiver participants who had never resided in a Medicaid-certified institution – a group representing the vast majority of MR/DD waiver participants.

The Association, however, continued to press for the expansion of day habilitation and supported employment coverage to all I/DD waiver participants. Finally, Congress agreed to add this coverage in 1997, as part of that year’s Balanced Budget Act.<sup>15</sup> It took eleven years to enact this fine-tuned statutory change. And, during the intervening years, the required statutory language had been included in House-passed bills on two separate occasions – only to be dropped from the final conference committee version of the measure due to a political deadlock over unrelated policy issues.

Small but important statutory revisions often are at the mercy of much broader political forces – forces which lie outside your control. In these circumstances, success often depends on a willingness to persevere.



## 6. Maintaining a Forward-Leaning Legislative and Administrative Agenda

The responsibilities of the Association reach beyond assisting member state agencies to achieve current goals within the federal policy arena. NASDDDS also has an obligation to help member state officials understand emerging trends in federal-state policy and the ways in which these developments are likely to impact the future delivery of services to the I/DD population.

During the early-to-mid 1970s, the Association advocated for the certification of community group homes as providers of ICF/MR services. At the time, the vast majority of public funding was directed to large, state-operated residential facilities serving individuals with intellectual disabilities. But a few states were striving to create a network of state-funded community residences and looking for ways of qualifying such residences for federal financial assistance. The leadership of the Association realized the importance of establishing community-based residences as viable alternatives to institutional care and knew that if this goal was to become a reality a reliable stream of federal funding would be essential. Consequently, NASDDDS elected to highlight, through its publications, the work underway in these states and successfully promoted, through its work in the public policy arena, special accommodations for small, community-based residences in final federal ICF/MR standards. A rapid growth in community-based ICFs/MR ensued during the latter half of the 1970s and through most of the 1980s.

During the late 1980s, Association leaders sensed the emerging shift away from congregate living settings toward more personalized living arrangement. In 1990, the Association showcased the ways in which several states were attempting to organize and finance such supported living settings in a special report, entitled *Supported Living: New Directions in Services to People with Developmental Disabilities*. Later that same year, as noted earlier, NASMRPD spearheaded the enactment of legislation establishing the Community Supportive Living Arrangements (CSLA) program. While the CLSA authority was limited in scope (eight state were selected to offer this

coverage) and duration (it sunset after 4 ½ years), it demonstrated how concepts such as self-determination and individual programming could be employed in designing and financing person-centered residential supports. The rapid growth of supported living settings throughout the 1990s and 2000s was, in part, an outgrowth of these initiatives by the Association.

In the mid-1990s, concern about the use of managed health care as a cost-containment tool lapped over into the developmental disabilities sector. In 1995, the Association partnered with the Human Services Research Institute (HSRI) in preparing a definitive guide to potential applications of managed care technologies within the DD sector. This guidebook pointed out both the potential risks and rewards of employing a managed care framework to organize, finance, and deliver long-term supports to persons with intellectual and developmental disabilities. It also contained several case studies of attempts to apply managed care principles to I/DD services. Over the next decade several states used the Association's guidebook as a reference point in launching major long-term services reform plans based on a managed care model. Indeed, the guidance the Association offered nearly twenty years ago still remains relevant today.

Finally, more recently, the Association's work during the debate leading to the enactment and eventual implementation of national health reform legislation, again, demonstrates the way in which NASDDDS can assist member state agencies to find their niche within a much larger set of policy reforms. Throughout Congress' consideration and eventual passage of President Obama's signature legislative initiative, the Association sought to ensure that the interests of people with developmental disabilities and the agencies which serve them were not overlooked. Several years will have to pass before it will be possible to complete an accurate assessment of the impact of the Affordable Care Act of 2010 on individuals with developmental disabilities. But it is clear already that NASDDDS, working in close collaboration with other organizations, managed to position the assemblage of I/DD forces as a player in this unfolding drama.

Many of the guiding principles enunciated above apply to any organization attempting to influence public policy. Regardless of its objectives, an organization must avoid high profile distractions in order to concentrate on achieving its own priority goals; synthesize other activities with its public policy goals; and be prepared to persevere when the occasion arises. NASDDDS, however, has unique strengths and weaknesses which need to be taken into account in pursuing its national legislative and administrative goals.

One of the Association's key strengths is that its member state agencies are responsible for implementing federal policies within the program areas they oversee. The membership, therefore, is keenly aware of the effectiveness (or lack thereof) of specific federal policies; and, as a result, the Association has access to information "from the frontlines" to support its positions on pending policy issues. Furthermore, Medicaid, the primary source of funding for developmental disabilities services, is a federal-state program in which state governments have a considerable degree of latitude in determining how and to whom services are provided, within the parameters of federal law. Federal policymakers, consequently, are highly reliant on the states to accomplish their policy objectives. If a federal program is poorly designed or includes unacceptable conditions of participation, states are likely to opt out.

The optional Medicaid state plan coverage of home and community-based services illustrates how federal legislative goals can be thwarted when state policymakers elect not to take advantage of a new funding vehicle. The original statutory requirements governing the HCBS state plan coverage under Section 1915(i) of the Social Security Act contained several problematic provisions. As a result, few states elected to add this coverage to their state Medicaid plans – and those which did narrowly defined the eligible target population, mainly focusing on individuals and services which otherwise would not qualify for federal financial participation.

Many of the defects in the original statutory language of Section 1915(i) were corrected via amendments included in the 2010 health reform legislation.<sup>19</sup> Congress, however, also amended the language of Section 1915(i) to require states to furnish services to all qualified recipients on an open-ended, entitlement basis. While it is too early to assess the states' response to these statutory revisions, it seems unlikely that states will choose to roll their existing I/DD waiver programs into a state plan coverage in the foreseeable future, given the huge backlog in unmet needs for community I/DD services and the precarious fiscal situation facing many states.

Among the weaknesses of NASDDDS in the federal policy arena are: (a) the scant resources which the Association has available to support its L&A activities; and (b) the barriers member state agency officials face in becoming actively involved in promoting federal policy changes. In an era in which money has become an increasingly important prerequisite to gaining access to political decision-makers (especially legislators), NASDDDS does not operate a Political Advocacy Committee nor, indeed, does it make any contributions to political campaigns, directly or indirectly. "Money," as the old saw goes, is the "mother's milk of politics." It may not directly influence votes but it buys access to lawmakers and key legislative aides, which often is critical to ensuring that one's views are seriously considered. With each passing year, the corridors of Capitol Hill become more and more crowded with lobbyists for every conceivable interest group – and convincing lawmakers of the merits, based solely humanitarian appeals, becomes more and more challenging. Perhaps that explains why NASDDDS' successes in recent years have been achieved primarily in the arena of administrative, rather than legislative, policy.

Grassroots support is another frequently cited yardstick of success in influencing federal policy. Elected officials are always looking for assurances that "the folks back home" strongly support positions taken by their national organization. In this area,

again, NASDDDS is at a disadvantage because member agency officials are rarely in a position to speak independently on pending national policy issues. In every state government there are policy clearance channels, since, understandably, the governor, as the state's chief executive, wants to be sure that the executive branch speaks with one voice on critical national policy questions.

Typically, a chief state DD administrator has to go through three, four, or even more levels of clearance in order to obtain the state's official endorsement of the agency's position on a measure pending before Congress. And, usually at each succeeding stage of the process, the key decision-makers are less knowledgeable about the state's DD service system and its needs. This attenuated process also poses problems for the Association, particularly when an immediate response is necessary. As a result, in order to buttress its case on pending policy issues (especially pending legislation), NASDDDS frequently has to rely on summary information it

collects from member state agencies, rather than on direct communications from member state officials to their elected representatives in Washington.

State DD agencies typically have somewhat greater latitude in commenting on regulatory or administrative policies, particularly if they focus directly on programs administered by the agency. However, even in this arena, there is an understandable tendency for member state agencies to concentrate on issues of immediate concern to the state's own DD services, rather than addressing the broader, cross-cutting implications for all member state agencies. Comments on the latter issues tend to be left to the Association.

Of course, in the final analysis, the Association has to "play with the cards it has been dealt." In federal legislative and administrative arena, this means striving to accentuate NASDDDS' strengths and minimize its weaknesses.

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#### END NOTES

- <sup>1</sup> Taylor, Robert J., et. al. (eds.), *The Papers of John Adams*. Cambridge, MA, Vol IV, page 93, letter from John Adams to Abigail Adams, May 17, 1776.
- <sup>2</sup> Meeting Minutes, NACSPMR Board of Directors, Arlington, Virginia, January 23, 1971, p. 7-8.
- <sup>3</sup> Meeting Minutes, NACSPMR Board of Directors, Arlington, Virginia, April 17, 1971, pp. 1-5.
- <sup>4</sup> *Ibid*, p. 1.
- <sup>5</sup> Meeting Minutes, NACSPMR Board of Directors, March 18, 1972.
- <sup>6</sup> Meeting Minutes, NACSPMR Board of Directors, December 11, 1971.
- <sup>7</sup> Meeting Minutes, NACSPMR Board of Directors, March 18, 1972.
- <sup>8</sup> Meeting Minutes, NASMRPD Board of Directors, January 31-February 1, 1980, page 6.
- <sup>9</sup> *Federal Register*, Vol.39, No.12, dated January 17, 1974, pp. 2223-2235.
- <sup>10</sup> *An Update on the Medicaid Home and Community Care Waiver Authority*, NASMRPD, July 1982; *Federal Administrative Constraints on State Medicaid Outlays for MR/DD Recipients*, NASMRPD, April 1985; *Medicaid Home and Community-Based Services for Persons with Developmental Disabilities: The Home and Community-Based Waiver Experience*, NASDDDS, September 1989; *The HCB Waiver Program and Services for People with Developmental Disabilities: An Update*, NASMRPD, 1991; *Medicaid in the Community: The HCB Waiver and CSLA Programs*, NASMRPD, 1992; *Medicaid-Funded Home and Community-Based Services for People with Developmental Disabilities*, NASMRPD, March 1993; *The HCB Waiver and CSLA Programs: An*

- Update on Medicaid's Role in Supporting People with Developmental Disabilities in the Community*, NASDDDS, October 1994; *The Medicaid Home and Community-Based Waiver Program: Recent and Emerging Trends in Serving People with Developmental Disabilities Through 1997*, NASDDDS, 1997; *Managing Medicaid Home and Community-Based Waiver Programs: An Analysis of State Policymaking and Operational Responsibilities for Waiver Program Serving People with Developmental Disabilities*, NASDDDS, 2000.
- <sup>11</sup> Public Law 111-148, as signed into law by President Barack Obama on Federal 23, 2010.
- <sup>12</sup> The Community Living Assistance and Services and Supports (CLASS) Act, as authorized under the "Patient Protection and Affordable Care Act" (P.L. 111-148).
- <sup>13</sup> P.L. 99-272.
- <sup>14</sup> P.L. 100-103.
- <sup>15</sup> Section 4743, Public Law 105-33.
- <sup>16</sup> Smith, Gary A., *Supported Living: New Directions in Services to People with Developmental Disabilities*, National Association of State Mental Retardation Program Directors, Inc., 1990.
- <sup>17</sup> Ashbaugh, John and Gary Smith, *Managed Care and People with Developmental Disabilities: A Guidebook*, National Association of State Directors of Developmental Disabilities Services, 1995.
- <sup>18</sup> Gettings, Robert M., *Reassessing the Impact of Managed Care in the Developmental Disabilities Sector*, National Leadership Consortium on Developmental Disabilities, Bulletin No. 1, March 2009.
- <sup>19</sup> "Patient Protection and Affordable Care Act (P.L. 111-148).

# IV CHAPTER

*Point thy tongue on the anvil of truth.*

Pindar, ancient Greek lyric poet  
(522 BC – 443 BC)

## INFORMATION DISSEMINATION: *Maintaining an Informed Constituency*

From the organization's earliest days, leaders of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) have assigned high priority to keeping member agencies informed about relevant developments in federal and state policy and programmatic practices. As pointed out in Chapter II, developing and maintaining an association newsletter was a recurring topic of discussion at early meetings of the membership and of the organization's Board of Directors. Association leaders also were aware of the potential advantages of collecting and synthesizing information from state mental retardation program offices and discussed alternative approaches to accomplishing this goal on multiple occasions.

The purpose of this chapter is to review the history of NASDDDS' involvement in collecting and disseminating information concerning new and emerging developments in public services to persons with intellectual and developmental disabilities. Among the topics to be covered are the origins and evolution of Association newsletters and news bulletins as well as special studies and reports. In addition, we will examine the ways in which advances in information technology have influenced the Association's information dissemination activities. The chapter will conclude with a series of observations regarding key lessons that can be gleaned from the organization's activities in this arena over the years.

### A

## NEWSLETTERS AND NEWS BULLETINS

### Newsletter Origins

Early efforts to initiate an Association newsletter failed due to the lack of feedback from member state agencies. During the October 24, 1968 meeting of the NACSPMR Board of Directors, Don Sellin, the newsletter editor, told the Board he had been unable to prepare a newsletter because member state agencies had failed to send him reports on newsworthy developments. State coordinators, he said, had been asked to bring newsworthy developments to his attention but he had received no news items.<sup>1</sup>

Even before Sellin's statement, Association leaders had concluded that staff assistance would be an essential ingredient in producing a high quality organizational newsletter. They recognized that member agency officials had demanding, full-time positions and could not devote the hours necessary to gather and report on relevant developments.

At the invitation of Dr. Robert Jaslow, the director of the federal Division of Mental Retardation (DMR), NACSPMR executive officers met with Division staff

members on two occasions during 1967 to discuss steps that might be taken to forge a closer working relationship between DMR and state mental retardation program offices. These meetings were arranged because Jaslow realized that the Division would be unable to administer several new federal grant assistance programs effectively without cooperation from the states.

During the second 1967 meeting with DMR officials, NACSPMR Executive Committee members identified 12 areas of mutual interest that could form the basis for an ongoing relationship between the DMR and the Association. NACSPMR representatives, led by President Bert W. Schmickel, presented Dr. Jaslow with a rough draft of a grant proposal, entitled “Proposed Division of Mental Retardation Data Collection Program.”<sup>2</sup> This document, which included as Point #12 the publication of an Association newsletter, later formed the basis of a grant proposal which was initially submitted to DMR in 1968 and eventually approved and funded in May 1970. The minutes of the Executive Committee’s November 19-20, 1967 meeting referred to the newsletter as “an extremely important responsibility for this organization” and linked the production and distribution of an Association newsletter to hiring staff to carry out these and other organizational functions, noting that “if NACSPMR is to be effective we must consider the appointment of an Executive Director in a Washington office...”<sup>3</sup> The DMR/SRS grant application acknowledged the need for “increased communication flow between states relative to mutual concerns and interests, successful modes of attack on service delivery matters, patterns of funding and effective manpower utilization.”

## Launching a Newsletter

The federal DMR grant allowed NACSPMR to hire an executive director in the fall of 1970. Bob Gettings was selected to fill this position and shortly thereafter the Association opened a headquarters office in Arlington, Virginia. One priority of the NACSPMR Board was to establish a newsletter in order to demonstrate to member state agencies the benefits of belonging to the Association. During a January

1971 meeting of the NACSPMR Board, Mr. Gettings reported on the status of plans to issue a newsletter. According to the meeting minutes, he told the Board:

... there exists a real need for timely information in two broad areas: (1) national level program developments (Congressional legislation, federal administrative actions, developments among relevant national organizations, etc.) and (2) new and innovative developments in state and local mental retardation programs.<sup>4</sup>

Mr. Gettings recommended that consideration be given to issuing two separate newsletters – one focused on national policy developments and the other on state and local developments.<sup>5</sup>

At the next meeting of the Board, Gettings passed out advanced copies of the first issue of the Association’s monthly newsletter, called *New Directions*. He said work was proceeding on two additional newsletters – one, titled *Capitol Capsule*, focusing on policy developments in Washington, D.C., and the other, titled *State Capitol Capsule*, reporting on significant legislative happenings in the fifty states and territories.<sup>6</sup>

Each monthly issue of *News Directions* included a series of articles about noteworthy policy developments and program innovations within state and local mental retardation programs across the nation. The Association’s staff obtained information through a network of contacts within state MR agencies, supplemented by information gleaned from scores of newsletters and other publications issued by state and local agencies and organizations serving persons with lifelong disabilities. Each article concluded with the name, address and phone number (when available) of a contact person willing to furnish additional information and answer questions. *Capitol Capsule* and *State Capitol Capsule*, in contrast, were issued periodically and featured information on pending and enacted national legislation and administrative actions (*Capitol Capsule*) and disability-related laws enacted by the 50 states and the District of Columbia (*State Capitol Capsule*).

Since the federal DMR grant underwrote a major portion of staff salaries, complimentary copies of *New Directions*, *Capitol Capsule*, and *State Capitol Capsule* were distributed to the executive directors of state DD councils, university affiliated centers, and state Arc chapters. However, because demand to be placed on the newsletter mailing list exceeded the grant funds available to support this activity, in August 1971 the NACSPMR Board of Directors established an annual subscription rate of \$15 for other parties interested in receiving monthly issues of *New Directions*. The vast majority of paid newsletter subscribers were local and statewide provider organizations. By the end of the federal grant period, the number of paid subscribers was large enough to offset most of the direct costs involved in preparing and distributing *New Directions* and *Capitol Capsule*. Subsequent federal grants and contracts (see Chapter VIII) underwrote the cost of distributing the newsletters to the executive offices of state DD councils, university centers of excellence (formally known as university affiliated facilities), state protection and advocacy agencies, and state Arc chapters.

## Expanded National Coverage

NACSPMR launched a new, single-subject bulletin series in March 1973 to expand its coverage of national policy developments. Titled *Intelligence Report* (IR), the aim of this bulletin series was to get information into the hands of member state agency officials as rapidly as possible. By restricting distribution to directors of member state agencies and limiting the focus of each bulletin to a single, noteworthy development, the staff was able to transmit information to member state agencies much more rapidly. Thus, for example, if a federal agency issued a grant solicitation or a proposed regulation, NACSPMR member agencies would receive information about this development in sufficient time to submit an application or file comments on the proposed rule. Similarly, when a House or Senate committee was in the process of considering legislation with potential implications for state/local DD service systems, member state agencies would have details in sufficient time to share their views with member of their respective Congressional delegations.

IR bulletins summarized the most salient features of the subject bill, public law, regulation, administrative policy, or court ruling and indicated where additional information could be obtained (e.g., bill numbers and order instructions; *Federal Register* volume, issue and page numbers; etc.). In those instances where a document was of particular interest to member state agencies, the NACSPMR staff would attach to the bulletin a photocopy of the entire document or selected portions thereof.

For member state agencies, *Intelligence Report* bulletins rapidly became one of the most valued forms of communication in the Association's arsenal. The mailing list was limited to member state agencies (one copy per state) and, as a result, the staff was able to handle the photocopying and mailing of these bulletins in-house, thus expediting the distribution process. But many member state agencies reproduced copies and shared them with their district, regional and county offices plus interested provider and advocacy agencies across the state. The frequency of the bulletins increased from 48 in 1973, to 81 in 1975, 95 in 1977, 93 in 1981, 100 in 1985 and 115 in 1988. Throughout the 1980s and into the 1990s, the Association was mailing between two to three IR bulletins a week – and there were weeks when as many as six or seven bulletins were mailed to member state agencies.

After the *Intelligence Report* bulletin series was launched, it soon became evident that NACSPMR lacked the staff capabilities to issue four newsletters on a regularly scheduled basis. So in 1974 the staff discontinued *State Capitol Capsule* and instead began issuing an annual summary of state legislation as a supplement to the January or February issue of *New Directions*. The Association continued to publish *Capitol Capsule* – but on a regular monthly basis, rather than episodically. Most of the articles in *Capitol Capsule* after this date were digested from previous *Intelligence Report* bulletins, thus significantly reducing the amount of staff time involved in its production. Printing and distribution of both monthly newsletters was outsourced to a local sheltered occupational center.

## Changing the Focus

In the late 1980s, it became clear that the Association would have to modify its news bulletins to take into account the states' growing reliance on federal-state Medicaid dollars to finance services to individuals with intellectual and developmental disabilities. With this reality in mind, the Association launched a bi-weekly news bulletin series called *Medicaid Developments* (MD) in the fall of 1988. Unlike the *Intelligence Report* series, MD bulletins were issued on a regularly scheduled basis, dealt exclusively with Medicaid-related topics (rather than the entire spectrum of federal programs), and encompassed noteworthy developments at both the federal and state policy level. Each MD bulletin began with brief updates on Medicaid-related legislative developments in Washington and then summarized new developments in federal administrative policy as well as critical federal and state court rulings. But readers of *Medicaid Developments* also were kept abreast of the latest Medicaid-related developments within particular state I/DD programs – which states had submitted, or received approval of new or amended home and community-based waiver programs, instituted revised nursing home admission screening programs, established new ICF/MR rate setting policies, etc. MD bulletins, like *Intelligence Report* bulletins, were distributed exclusively to state I/DD agency directors and soon gained recognition as a definitive source of accurate, up-to-date information on the latest developments within Congress, the Health Care Financing Administration and individual state I/DD agencies.

But the workload associated with issuing two monthly newsletters, bi-weekly *Medicaid Developments* bulletins, and frequent *Intelligence Report* bulletins gradually began to restrict the amount the staff time available to pursue other, high priority activities, such as the provision of technical assistance to member state agencies (see discussion in Chapter V) and the preparation of in-depth analyses and reports on topical program and policy developments (see discussion under “Special Publications”). Moreover, there was a significant degree of overlap in the information being conveyed in Association newsletters and news

bulletins. *Capitol Capsule* had become primarily a digest of news previously reported in *Intelligence Report* bulletins, and on occasion the same federal policy developments were covered in *Medicaid Developments* bulletins as well. So, in late 1995, the NASDDDS Board and staff decided to realign the Association's periodicals, primarily to eliminate duplication and deploy staff resources more effectively. The following year, *New Directions* was replaced by *Community Services Reporter* (CSR). In addition, later that same year, the *Medicaid Developments* and *Intelligence Report* bulletin series were discontinued and replaced by a new monthly newsletter summarizing critical national policy developments, titled *Perspectives*.<sup>7</sup>

Like *New Directions*, the aim of *CSR* was to summarize recent innovations in state and local programs and policies affecting persons with intellectual and developmental disabilities, with the predominant emphasis on home and community-based services. The new title was intended to better reflect the focus of the newsletter. Reporting on national policy developments, previously covered in *New Directions*, *Medicaid Developments* and *Intelligence Report* bulletins, was shifted to *Perspectives* (which in June 2009 was renamed *Federal Perspectives*).

In addition, the summer of 1996, NASDDDS launched a new episodic bulletin series, titled *Directors' Alert* bulletins. These bulletins were similar to *Intelligence Report* bulletins in purpose and format – i.e., the aim of both bulletin series was to analyze, in-depth, a particular development in national legislative, administrative, or judicial policy. But *Directors Alert* bulletins were reserved for policy developments with potentially significant impacts on the activities and plans of state developmental disabilities agencies. Consequently, the intent was to issue fewer bulletins, with each bulletin containing a concluding section pointing out likely implications for NASDDDS member agencies.

Beginning in 2001, newsletter recipients were given the choice of receiving issues electronically or via regular mail.<sup>8</sup> The distribution of printed copies of

the newsletters was discontinued in 2002 in an effort to reduce operating expenses (printing, handling, and mailing). For the same reason, the NASDDDS Board of Directors agreed to discontinue the distribution of printed copies of special publications, relying instead on the electronic transmission of such documents.<sup>9</sup> Since that time, all Association newsletters, new bulletins and special publications have been exclusively transmitted electronically. The transition saved the association almost \$50,000 annually in printing and distribution costs for newsletters and news bulletins alone, while at the same time providing recipients instant access to information distributed by NASDDDS.

While the dissemination vehicles used by the association have evolved over the years to meet the changing needs of the membership, the purpose

of NASDDDS periodicals has remained constant over the past five decades – i.e., to ensure that members state officials are fully informed about significant developments in service delivery policies and practices, both nationally and within other states. Today, NASDDDS publishes two monthly newsletters, *Community Services Reporter* and *Federal Perspectives*, and two regularly scheduled e-bulletins, *State News Briefs* (issued bi-weekly) and *Federal News Briefs* (issued weekly). The contents of *Community Services Reporter* are digested primarily from earlier *State News Briefs* articles, while the contents of *Federal Perspectives* are derived largely from articles which appeared in earlier *Federal News Briefs*. All four publications are transmitted electronically. Printed copies are no longer mailed to member state agencies or individual subscribers.

## B

## OTHER PUBLICATIONS

The founders of NACSPMR recognized that the organization was uniquely positioned to gather and disseminate information and data concerning public I/DD services and service delivery trends. The potential to serve as a hub of information about state disability services and programs soon became the principal *raison d'être* for a federal grant project that allowed the Association to hire staff and open a headquarters office in the national capital area (see discussion above). Association leaders saw the collection and sharing of information as a critical ingredient in binding state disability leaders together as a cohesive force, while officials of HEW's Division of Mental Retardation needed better, more timely information on state/local services and service trends to effectively manage the Kennedy-era assistance programs they were responsible for administering.



In 1973, the Association published a report analyzing the organizational structure of mental retardation services within the 50 states and the District of Columbia. Titled *Organization of State Services for the Mentally Retarded*, the aim of this publication was to document the wide variations in organizational arrangements among the states.

During this same general period (the early-to-mid 1970's), the Association's staff prepared several summaries of federal legislative developments affecting individuals with intellectual disabilities under a series of small contracts with the U.S. Department of Health, Education, and Welfare.<sup>10</sup> The Association also prepared a report on trends in state disability services for the President's Committee on Mental Retardation.<sup>11,12</sup> These latter publications enhanced the Association's reputation as a preeminent source of information on federal-state programs and also supplemented organizational revenues at a time the Association received limited funding from member states.

In late 1976, HEW's Office of Human Development Services awarded a two-year, \$349,000 grant to

NACSPMR to provide technical assistance on the utilization of generic federal assistance programs to help children and adults with developmental disabilities (see additional discussion of grant related in activities in Chapter V (Technical Assistance) and Chapter VII (Association Finances)). During the grant period, the Association issued several reports exploring the opportunities and impediments

to employing major health, housing and income maintenance programs to assist persons with developmental disabilities.<sup>13</sup> The project also afforded the Association the opportunity to design and pilot test an approach to providing targeted technical assistance services to member state agencies, an activity that later was to become a core membership service (see additional discussion in Chapter V).

## C EMPLOYING COMMUNICATIONS TECHNOLOGY

The advances in communication technology that have occurred over the past fifty years have had – and undoubtedly will continue to have – a profound impact on the Association’s information dissemination activities. Indeed, the modes of communications used during the 1970s and 1980s seem downright primitive when viewed from the perspective of 2014.

### Life Before the Internet

In the late 1960s and through the 70s, Association correspondence and other documents were prepared on electronic typewriters. A plain paper copier was used when multiple copies of a document, such as meeting minutes and membership reports, had to be reproduced and disseminated. The U.S. Postal Service was virtually the only means of transmitting Association correspondence, reports, newsletters and other documents, except for those rare occasions when it became necessary to hand-carry documents to Capitol Hill or a nearby federal office.

The preparation of newsletters was a tedious, time-consuming undertaking. Initial drafts of all articles were hand-written and then typed in rough manuscript form by the clerical staff. The draft copy was edited and prepared in final form using an IBM Selectric typewriter, with interchangeable type balls each of which had a distinctive font style and size. A typical issue of a newsletter involved the use of at least three type balls, which meant the typist had to switch type balls on multiple occasions during the preparation of final newsletter copy. In addition, the lines of newsletter copy were justified, left and right, which involved counting the number of key strokes in each line and then typing the line so it was

properly spaced on the page. This part of the process alone would take a skilled typist the better part of a working day to complete a two-page newsletter.

Next, the copy of each finished article was cut out, pasted on a sheet of cardboard and instructions to the printer were added using a special blue pencil. This so-called “blue line” copy was hand carried to the printer where it was photographed and the image was converted to a photographic plate for printing. The Association contracted with a nearby sheltered workshop<sup>14</sup> to print and distribute copies of the newsletter. The workshop maintained a current list of paid and unpaid newsletter subscribers in cooperation with the Association’s staff. Responsibility for folding, addressing and sorting newsletters for bulk mailing by zip code was the responsibility of the workshop staff. The Association minimized mailing costs by using a non-profit bulk mailing permit. But the receipt of newsletters often was delayed because of the low priority the Postal Service assigned to bulk mailings. As a result, the time lag between the initial preparation of the newsletter and its arrival in a recipient’s mail box could be three weeks or, in some cases, even longer.

### Harnessing Modern Communication Technology

The Association purchased its first office word processor in 1983.<sup>15</sup> Although the capabilities of this machine were primitive by current standards, the word processor allowed the Association for the first time to edit and store documents electronically and, eventually, to access the Internet.



Shortly thereafter, Association leaders began discussing possible ways of harnessing the capabilities of Internet technology to create a communication network linking member state agencies together. Effective March 1, 1984, the Association entered into a contract with GTE Communication Network to operate an online electronic mail system for participating member state agencies.<sup>16</sup> Despite repeated efforts to promote network participation over the next two years, the number of state subscribers remained too low to maintain a vibrant network and therefore the service was discontinued.

By the mid-1980s, new, lower-cost methods of creating Internet networks were emerging. Shortly after dropping the GTECN service, NASDDDS established two online listservs – one for state directors and the other for state I/DD waiver program managers – with the objective of facilitating an ongoing interstate dialogue around contemporary policy and service delivery issues. The Association paid a flat, \$600 subscription fee for each listserv. Participation was limited to member state agency officials and available at no charge to participating member state agencies.

The introduction of office computers in state government offices occurred more slowly than it did in the private sector. As a result, the number of state officials participating in the two Association listservs was limited during the early years. But as the use of computers in state offices increased during the late 1980s, the number of listserv participants also grew. By the early 1990s most states had multiple state participants and the listservs became an increasingly valuable communication tool for state I/DD officials. State officials could query their counterparts in other states concerning current practices and policies and receive rapid feedback. Response strands were archived and could be retrieved online. Eventually, the NASDDDS staff began analyzing and distributing summaries of responses to inquiries – generating widespread interest. The listservs over time built a sense of community among state I/DD officials that had been difficult to maintain through infrequent, Association-sponsored meetings.

Taking advantage of improvements in teleconferencing, the Association began to conduct topical conference calls for member state agency officials in February 2003.<sup>17</sup> The topics covered during these calls ranged from recent and impending developments in federal policy to promising practices in serving individuals with intellectual and developmental disabilities.<sup>18</sup> Participation was limited to officials of member state agencies. One major advantage of these teleconferences was that they allowed state officials who were unable to attend Association-sponsored meetings to interact around contemporary policy and practice issues across state boundaries.

Officials from states involved in cutting edge initiatives frequently were recruited as presenters when the call topic focused on service delivery and financing practices. NASDDDS staff members usually facilitated calls dealing with new developments in federal policy, often inviting responsible federal officials to act as presenters. In response to the popularity of the topical call series, the Association's staff began to make audio recording of calls available to member state agencies – so officials who were unable to participate could gain access to the information.

Beginning in the late 2000s, the topical membership conference calls morphed into Association-sponsored webinars. Webinars offer several advantages compared to traditional conference calls. First, presenters can (and usually do) post PowerPoint presentations so participants can track online the main threads of the presenter's oral remarks. Second, since webinars are transmitted via the Internet, the number of participants is not limited by the number of phone lines the sponsoring organization obtains through a conferencing support vendor. And finally,

participants can post questions on line so the webinar moderator is in a position to ensure that the full range of participant inquiries is covered during the discussion period.

The Association continues to sponsor membership conference calls and webinars on a variety of timely topics. In addition, the Association often co-sponsors webinars with other national organizations that are open to member state agency officials.

## Establishing an Association Website

While the listservs proved to be a vital tool for connecting member state agency officials, the Association still needed a way to reach out to the broader community of interests online and to archive documents so they were accessible to member state agency officials with a few mouse clicks. The first step in this direction was taken in the mid-1990s when NASDDDS purchased a registered web address. An Association website was activated in March 1997,<sup>19</sup> but, in the absence of qualified staff to maintain it, the website languished for several years. The contents were largely static and, as a result, the

site drew little traffic. After several false starts, a redesigned Association website was activated in the spring of 2001<sup>20</sup> and Karol Snyder, the Manager of Membership Services, was assigned responsibility for serving as webmaster. In the ensuing years, Karol has been instrumental in transforming the Association's website into a vital communication tool.

Rapid developments in web-based technology along with the growing expectations of members and the general public, led to replacing the Association's website with a new platform in 2013. With the introduction of a content-management system that enabled any and all staff to post information with ease, the website now included more complete information about the association, now contained more complete information about the Association, including postings of the annual audit and IRS 990 reports; information about major projects such as National Core Indicators, the State Employment Leadership Network, and the Supporting Families project – with links to their own robust websites; a resource library organized to address the most pressing issues of state agency members; and the capacity for ordering or purchasing publications.

# D

## LESSONS LEARNED

The many changes that occurred in the Association's information dissemination activities over the past five decades have not altered the central precepts underlying the organization's activities in this area. These precepts include:

### 1. Serving the Information Needs of Member State Agencies

Over the years the success of NASDDDS' efforts in the information dissemination arena has been rooted in a persistent, laser-like focus on the information needs of member state agencies. Through all of the changes in programming techniques, funding methods and service delivery strategies that have occurred, the basic needs of the membership have remained constant over the past fifty years: (a) information concerning the emerging policies of the federal government as they impact people with

disabilities; and (b) information about promising new service delivery and funding practices within state and local I/DD programs.

Other state executive branch organizations have made the mistake of limiting their information dissemination activities largely to news concerning recent and emerging developments in federal legislative and administrative policy. This "inside-the-beltway" approach, however, ignores the interactive nature of policymaking at the federal and state level. Federal policies almost always have a major bearing on state/local service delivery strategies. States, therefore, need to be aware of, and learn from, the efforts of other states to promote positive changes within their respective I/DD service delivery systems.

States have often been referred to as "the laboratories of democracy." As states forge new strategies for



servicing individuals with developmental disabilities, one of the Association's primary roles is to facilitate the interstate transfer of information concerning such innovations. Failure to perform this often overlooked but vital role shortchanges member state agency officials.

## 2. Capitalizing on the Association's Activities in the Public Policy and Technical Assistance Arenas

The Association's information dissemination activities can and should be informed by its efforts both to influence federal policy and to assist states in mapping out new, more effective strategies for financing and delivering I/DD services. The lessons learned in assisting individual states to solve service delivery and funding issues enhance the Association's efforts to keep all member state agencies informed about new innovations and emerging practices. It also is a useful way of identifying impediments in federal policy that need to be addressed through the Association's activities in the public policy arena.

During the late 1970s and early 1980s, the Association assisted dozens of member state agencies in their efforts to certify community residences as providers of ICF/MR services, thus substantially expanding federal financial participation in the cost of furnishing community I/DD services. Reports growing out of these technical assistance projects were shared with other member state agencies, many of which used the information to convert their own community residences to ICF/MR providers (see discussion of this topic in Chapter V). In addition, the Association's staff gained a deeper understanding of the barriers to certifying community residences – which in several instances was used successfully in efforts to leverage changes in federal legislative and administrative policy.

Similarly, the assistance the Association has provided to member state agencies over the years in expanding access to Medicaid-funded home and community-based services illustrates the interactive nature of the organization's work in the technical assistance, public policy and information dissemination arenas. Involvement in problem-solving exercises in a given state increases the organization's capacity to help

other member state agencies to manage their HCBS waiver programs more effectively. In addition, it has allowed the Association to better represent the states' interests in its ongoing dialogue with CMS officials and members of Congress, including their key staff members.

## 3. Harnessing Technological Improvements

As pointed out earlier in this chapter, rapid advances in technology over the past three decades have greatly simplified the preparation and transmission of information, thus reducing the workload of the Association's staff. Even faster and more convenient modes of transmission lie over the horizon.

Association leaders must adapt to future changes in technology. At the same time, it is important to be selective about the types and volume of information transmitted to member state agencies. In an age of information overload, the Association must help state officials to sort through the deluge by focusing attention on items of maximum relevance to the key planning and operation decisions state I/DD agencies face today.

## 4. Using Various Modes of Communication

In organizing its communication program, the Association must take into account the different learning styles of member state agency officials. Physical meetings and online webinars meet the needs of oral learners, while newsletters, news bulletins, policy briefs and longer reports meet the needs of those who prefer written material. Clarity and brevity are critical in conveying information to busy state executives regardless of the mode of communication used. But it is also important to include links to more in-depth information for those who choose to delve more deeply into the topic under discussion.

Rapid advances in information technology over the past fifty years have greatly simplified the process of collecting and disseminating information to member state agencies. Yet, despite all the changes that have occurred, NASDDDS' role remains fundamentally unchanged – to keep member agencies informed about new and emerging developments in federal policy and about innovative policies and practices in

delivering and financing I/DD services at the state and local level, nationwide. Now that all member state agencies have virtually instantaneous access to information through the Internet, synthesizing and helping member state agencies to evaluate the relevance of information – rather than simply generating new information – has become an expanded part of the Association's role.

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 END NOTES

<sup>1</sup> Meeting Minutes, NACSPMR Executive Committee, November 19-20, 1967, pp. 1-2.

<sup>2</sup> National Association of Coordinators of State Program for the Mentally Retarded, "A Coordinated Interstate and Interagency Approach to Mental Retardation Services Development, Implementation and Assessment," a project grant application submitted to the Social and Rehabilitation Service, U.S. Department of Health, Education and Welfare, April 4, 1970.

<sup>3</sup> Minutes of the November 19-20, 1967 meeting of the NACSPMR Board of Directors, *Ibid*.

<sup>4</sup> Meeting Minutes, NACSPMR Board of Directors, January 23, 1971, p. 1.

<sup>5</sup> *Ibid*.

<sup>6</sup> Meeting Minutes, NACSPMR Board of Directors, April 17, 1971, p. 8.

<sup>7</sup> The title of the newsletter was changed to *Federal Perspectives* in 2008.

<sup>8</sup> Meeting Minutes, NASDDDS Board of Directors, October 1, 2001.

<sup>9</sup> Meeting Minutes, NASDDDS Board of Directors, January 25, 2002.

<sup>10</sup> Department of Health, Education, and Welfare, "A Summary of Selected Legislation Relating to the Handicapped, 1971", U.S. Government Printing Office, 1971; Department of Health, Education and Welfare, Office of Handicapped Individuals, Programs for the Handicapped, "A Summary of Selected Legislation Relating to the Handicapped: 1974", April 20, 1974; Department of Health, Education, and Welfare, "A Summary of Selected Legislation Relating to the Handicapped, 1974", U.S. Government Printing Office, 1975; Department of Health, Education and Welfare,

Office of Handicapped Individuals, Programs for the Handicapped, "A Summary of Selected Legislation Relating to the Handicapped: 1975", April 20, 1975.

<sup>11</sup> President's Committee on Mental Retardation, *Mental Retardation: Trends in State Services*, U.S. Government Printing Office, 1976.

<sup>12</sup> The President's Committee on Mental Retardation was renamed the President's Committee for People with Intellectual Disabilities by executive order of President George W. Bush on July 25, 2003.

<sup>13</sup> Gettings, Robert M., Harold Tapper and Myrl Weinberg, *Income Maintenance and the Developmentally Disabled: An Analysis of Policy Issues*, National Association of State Mental Retardation Program Directors, Inc. December 1977. Gettings, Robert M., "Generic vs. Specialized Services: The Ying and Yang of Programming for Developmentally Disabled Clients" in *State of the Art Report on Serving Developmentally Disabled Clients*, Urban Institute, 1979.

<sup>14</sup> For over twenty years, all Association newsletters and special publications were printed by the Sheltered Occupational Center of Northern Virginia.

<sup>15</sup> Meeting Minutes, NASMRPD Board of Directors, May 30, 1983.

<sup>16</sup> Meeting Minutes, NASMRPD Board of Directors, January 26-27, 1984.

<sup>17</sup> Meeting Minutes, NASDDDS Board of Directors, January 6, 2003.

<sup>18</sup> Meeting Minutes, NASDDDS Board of Directors, October 1, 2004.

<sup>19</sup> Meeting Minutes, NASDDDS Board of Directors, September 27, 1996.

<sup>20</sup> Meeting Minutes, NASDDDS Board of Directors, January 25, 2002.

# CHAPTER

*The true meaning of life is to plant trees, under whose shade you do not expect to sit.*

Nelson Henderson, Irish rugby star in Scotland in the late 19th Century

## TECHNICAL ASSISTANCE: *Leveraging Knowledge to Promote Change – One State at a Time*

States learn from one another because there is no other reliable source of practical, hands-on knowledge about state-of-the-art public policies and management practices. Often, however, reading about or observing innovative practices in another state is not enough. State officials frequently need help in tailoring innovations pioneered in other states to the unique political, social, and geographic contours of their own jurisdiction. This chapter traces the origins and evolution of NASDDDS' work in the technical assistance arena.

The foundations of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) are embedded in the concept of mutual support and joint learning. But it took several years before Association leaders were able to identify an effective way of facilitating the interstate transfer of knowledge.

### A

### ROOTS OF THE TECHNICAL ASSISTANCE PROGRAM

In late 1976, the Association\* was awarded a two-year, technical assistance grant by the Office of Human Development Services, a unit of the U.S. Department of Health, Education and Welfare.\* Entitled "Policy Issues in the Utilization of Generic Federal Assistance Programs for Developmentally Disabled Persons," the main purpose of the project was to explore the ramifications of federal social welfare programs and policies for individuals with intellectual and developmental disabilities (I/DD). At the time the project was conceptualized, most state I/DD agencies relied largely on state general revenues to finance the community services they offered.

Medicaid claims for specialized services for persons with intellectual and developmental disabilities were limited almost exclusively to residents of large, state-operated residential centers. The Supplement Security Income (SSI) program had been initiated a couple of years earlier (in January 1974), but very few states had figured out how to integrate these benefits into a broader plan to expand access

\* At the time, the Association was known as the National Association of Coordinators of State Programs for the Mentally Retarded (NACSPMR).

\* Renamed the U.S. Department of Health and Human Services in 1980 when Congress elevated the HEW Office of Education to cabinet-level status.



to community-based living opportunities. The limited use of generic federal assistance programs to support I/DD services is evident in the FY 1977 expenditure figures reported by the Coleman Institute on Cognitive Disabilities. Of the estimated \$3.5 billion expended on I/DD services that year about one-quarter (\$869 million) was derived from federal sources – primarily in the form of ICF/MR payments on behalf of Medicaid-eligible residents of large, state-run I/DD institutions. Most of the balance (\$2.5 billion) came from state general revenues and, to a much lesser extent, local governments (counties, cities, etc.). [N.B., In sharp contrast, again according to the statistics gathered by the Coleman Institute, the federal government was the source of over 60 percent of the \$56.7 billion expended on specialized I/DD services in FY 2011, with the balance derived from state (36%) and local (3%) governments.]<sup>1</sup>

The main premise underlying the OHDS grant project was that federal generic assistance programs, such as Medicaid, Social Security, SSI and various housing subsidy and food assistance programs, held enormous, untapped potential as funding sources for public I/DD services. Moreover, the key to unlocking this potential was to promote a better understanding of program eligibility requirements and benefits and how they might be linked to the programmatic objectives of state and local I/DD agencies. Consequently, the main aim of the project was to conduct an in-depth assessment of selected federal generic assistance programs to determine: (a) the steps necessary to employ such programs to expand access to and improve the quality of I/DD community services; and (b) identify existing impediments to the use of such programs on behalf of persons with intellectual and developmental disabilities.

By early 1977, the Association had hired a project director, Harold Tapper, and an assistant project director, Myrl Weinberg.<sup>2</sup> In addition, a project advisory – a sounding – board was formed to aid in implementing the project. Board members included disability advocates, providers, and professionals. The project advisory board, in concert with the Association’s board, helped the staff to select three study areas: income maintenance; housing; and long-term services.

Over the course of the next two years, reports were prepared and disseminated on each of the three targeted topics. These reports summarized pertinent provisions of federal laws and regulations and analyzed the potential impact on selected benefits and programs for persons with developmental disabilities.<sup>3</sup> The Association also contracted with the Human Services Research Institute to complete a ground level assessment of the barriers to accessing income maintenance and housing assistance benefits on behalf of individuals with developmental disabilities in three selected states. The results of these assessments were summarized in a series of project reports and used in the preparation of the summary reports on the selected topic areas.

The association’s 1977-78 study of generic federal assistance programs was not the first attempt to point out the advantages of qualifying persons with intellectual disabilities for benefits under Medicaid, Social Security, SSI and other social entitlement programs. Elizabeth Boggs, an iconic figure in the disability advocacy movement, had been calling attention to the untapped potential of these programs for nearly two decades. But the study did take the public policy efforts of the Association in an important new direction. Instead of concentrating on expanding funding opportunities under categorical assistance programs such as the Developmental Disabilities Act, the Rehabilitation Act and the Education of the Handicapped Act, by the early 1980s Association leaders were spending the bulk of their time assisting member state agencies to qualify for reimbursement under the federal-state Medicaid program and other major social entitlement authorities.

# B

## LAUNCHING AN ASSOCIATION TECHNICAL ASSISTANCE PROGRAM

As the OHDS project period was drawing to a close in 1978, the Association applied for and received a one year supplement to the grant project. The purpose of the supplemental grant was to design and field test an approach to providing on-site technical assistance services to state I/DD agencies on the use of federal generic assistance programs. The project staff, Suzanne Turner and Karen Percy,<sup>4</sup> solicited requests for assistance from member state agencies. Responses were received from 21 states; and, using selection criteria approved by the Project Advisory Panel, four states were chosen as technical assistance test sites (CT, IL, SD and TN).<sup>5</sup> The focus of the technical assistance varied from state to state:

- Tennessee – accessing medical assistance funding;
- Connecticut – using housing assistance programs;
- Illinois – accessing medical assistance funding and housing subsidies; and
- South Dakota – using housing assistance programs.

The approach used to organize and deliver technical assistance was grounded in the belief that the best way of helping states to make better use of federal assistance programs was to draw on the experiences of states that already were using such programs effectively to finance I/DD services. If for example a state requested assistance in certifying small community residences as ICF/MR providers, the project staff would identify officials in two or three other states who had surmounted the barriers to claiming Medicaid payments on behalf of residents of such facilities within their own respective jurisdictions. These individuals then were asked to serve as consultants to the requesting states. The project staff assumed responsibility for: (a) assembling the TA team; (b) gathering and sharing with team members detailed information about I/DD

services and existing Medicaid and non-Medicaid funding arrangements in the requesting state; (c) completing all of the logistical arrangements for an on-site visit (arranging travel, coordinating housing and local meeting logistics, etc.); (d) assuring that TA team members were compensated for their time and travel expenses; and (e) preparing, with the assistance of the TA consultants, a follow-up report summarizing the consultants' findings, conclusions, and recommendations.

Officials in the four participating states were appreciative of the help they received, and soon other states were asking the Association for similar assistance. Based on the response, the Board decided to continue to offer technical assistance on a self-financing basis following the termination of grant funding. Bob Gettings summarized the advantages of providing technical assistance to member state agencies in his 1979 Executive Director's Report to the membership. He pointed out that:

1. It constitutes a direct, tangible benefit which the Association can offer member state agencies...
2. Through the provision of TA services the staff is able to keep apprised of the problems state MR/DD agencies are encountering in attempting to use various federal assistance programs on behalf of developmentally disabled clients and adjust its legislative/administrative activities in Washington to address these problems...
3. The NASMRPD staff and selected consultants, through ... site visits and TA sessions in the target states, can learn a great deal about the general systemic, fiscal and programmatic issues facing MR/DD agencies across the country...
4. The TA-related visits foster an exchange of information between and among states in an area where there is a great deal of commonality of interest...<sup>6</sup>

Initially, the volume of technical assistance work was sufficient to cover the direct costs of paying consultant fees and travel expenses, but not to offset the full cost of staff salaries and benefits. After Ms. Turner resigned to take a new position in Kentucky, Ms. Percy became the coordinator of technical assistance services. But her former position of assistant coordinator was not filled in order to reduce the cost of administering the program.

Demand for technical assistance remained high but frequently member state agencies lacked the \$10,000 to \$30,000 in discretionary funds required to contract with the Association for desired consultative services. As a result, at least half of technical assistance requests the Association received failed to reach fruition. Mr. Gettings reported to the Board in May 1981 that the Association expected a \$39,000, two-year shortfall in technical assistance revenue.<sup>7</sup> Finally, after several unsuccessful attempts to bring TA revenues into line with expenditures, the Board decided to phase out the position of technical

assistance coordinator by the fall of 1982. Ms. Percy resigned from her position with the Association in August of that year and the Board agreed to continue technical assistance activities on a time-available basis.

For the next five years, the Association's technical assistance program limped along, with most of the work performed by the Executive Director, Bob Gettings, and Ruth Katz, who was initially hired as a part-time newsletter editor but later promoted to the newly created position of Assistant Executive Director. During the period of 1982-87, the Association's staff successfully completed TA projects in 17 states (AK, AL, CO, DE, HI, IL, IN, LA, MA, ME, MD, NH, NM, NY, ND, TN and VA). Most of these projects focused on actions the state could take to expand Medicaid funding for community I/DD services. Several projects during this period also addressed how the state could qualify people with lifelong disabilities for federal housing subsidies.

## C

## MATURATION OF THE PROGRAM

Nineteen eighty-seven marked an important turning point in the Association's technical assistance services. In the fall of that year, the Board agreed to hire a full-time director of special projects, with responsibility for conducting special studies and spearheading the organization's technical assistance services. Gary Smith, formerly the assistant director of the Colorado Division of Developmental Disabilities, was recruited to fill this position. Prior to his five-year tenure with CO/DDD, Smith had worked for the state Medicaid agency and the governor's budget bureau in Colorado as well as the budget agency in Illinois. As a result, in addition to his knowledge of contemporary I/DD policy issues, Smith had a well-rounded understanding of federal-state Medicaid policy as well as state budgeting procedures.

During his years with CO/DDD, Smith regularly attended meetings of the NASMPD Governmental Affairs Committee and became an active participant in the Committee's deliberations. He also authored

a groundbreaking study of state rate-setting policies and practices which the Association published in the fall of 1987.<sup>8</sup>

Smith was hired based on the assumption that the additional contract revenue generated by a full-time director of special projects would more than offset the salary and benefits associated with the position. And, indeed, that's exactly what happened. Total revenue from technical assistance project grew from \$43,039 in fiscal year 1987-88 to \$69,893 by FY 1992-93.<sup>9</sup> More importantly, the Association no longer had to restrict the number of TA projects it undertook to a time-available basis. Consequently, the number of on-site and off-site technical assistance engagements grew substantially after 1987. Technical assistance services were furnished to 15 states in FY 1992-93, up from five in FY 1986-87.<sup>10</sup>

The nature of the technical assistance provided by the Association also changed during this period. Rather than relying on outside consultants, Mr. Smith

completed most of the work on his own or, later, with the assistance of Robin Cooper (see discussion below). As a result, the average costs incurred by participating states declined considerably. TA contracts were priced according to Mr. Smith's estimate of the time he would spend on the particular project, plus actual travel expenses if on-site consultation with state officials was requested (as it often was). [N.B., Telephonic consultations and staff comments on draft documents were considered membership services for which dues-paying member state agencies were not required to compensate the Association separately.] In many instances for a total cost of \$5,000-\$10,000, a member state agency was able to acquire expert advice on complex financing and service delivery issues – that would have cost the state three or more times that amount had it retained a private consulting firm.

Given his wide-ranging experiences in state government, Mr. Smith did more than explain the actions necessary to qualify for additional federal assistance. He also analyzed the strengths and weaknesses of a state's service delivery infrastructure and offered advice on the changes necessary to support targeted expansions and improvements in community I/DD services. In addition, states were able to draw upon his encyclopedic knowledge of state I/DD services and service systems to forge solutions that fit their own unique circumstances.

It soon became clear that the Association was in a position to chronicle the changes occurring in the delivery of I/DD services as a result of ground level information gained through numerous technical assistance projects. The result was the issuance of

a number of special reports summarizing recent developments and trends in I/DD services (see discussion in Chapter IV). In addition, subject to the prior approval of officials in the states receiving technical assistance, the NASDDDS Board decided to make copies of TA reports available to any member state agency upon request. The requesting state was asked to cover the cost of reproducing and mailing the requested documents.

The increasing volume of technical assistance requests, however, eroded the time Mr. Smith was able to devote to special studies and projects, such as the National Core Indicators program launched in 1996 and a study of the implications of managed care for people with developmental disabilities begun in late 1994 (see Chapter VI for an extended discussion of the origins and evolution of these two initiatives). In order to allow Mr. Smith to devote more time to these and other cross-cutting activities, in May, 1994 the Association retained Robin Cooper to assist Mr. Smith in providing on-site and off-site technical assistance to member state agencies. Ms. Cooper had recently resigned from her position with the Wisconsin Bureau of Developmental Disabilities and, as a result of her experience in designing and coordinating that state's home and community-based waiver program for people with developmental disabilities, was eminently qualified to assist member state agencies. The technical assistance workload was gradually shifted to Ms. Cooper, thus allowing Mr. Smith to complete a landmark study of managed care arrangements for people with developmentally disabilities, map out plans for expanding the NCI program, and undertake other special studies.

## D

## THE CONTINUING EVOLUTION OF TECHNICAL ASSISTANCE SERVICES

Mr. Smith resigned from his position with the Association in 2001 to join the staff of the Human Services Research Institute. He was replaced as Director of Special Projects by Chas Moseley, former director of the Vermont Division of Developmental Disabilities and later co-director of the Robert Wood

Johnson Foundation's Self-Determination Project. Dr. Moseley's responsibilities focused primarily on coordinating the NCI program and several other projects that were initiated subsequent to his arrival (see discussion of these projects in Chapter VI). However, he also supplemented Ms. Cooper's work

in the technical assistance arena by performing occasional on-site projects, plus preparing resource guides on contemporary topics of interest to member state agencies.

Ms. Cooper initially functioned as an independent contractor, working half-time on Association activities. In July 1996, however, she transitioned to a three-quarter time Association employee, working out of her home in Madison, Wisconsin. Initially, states called on her mainly for assistance in designing and implementing their Medicaid home and community-based waiver programs and qualifying case management services for federal Medicaid funding under Section 1915(g) of the Social Security Act. During the mid-1990s, CMS began to relax its policies governing Medicaid funding of community-based I/DD services, and Ms. Cooper helped many states to take advantage of the new funding opportunities resulting from these more flexible federal funding policies.

As time passed, states began to call on Ms. Cooper for assistance in dealing with a broader range of service planning and implementation initiatives, including consultation on: designing self-directed services; instituting individual budgeting; improving access to health care services; revenue maximization; support coordination; and quality management of HCB services. The Association's staff also joined forces with other organizations in undertaking broader technical assistance projects. For example, in 2001-2002, NASDDDS partnered with PNP Associates in completing a year-long study of DD-related revenue-enhancement opportunities in the State of Illinois. As federal agencies (e.g., CMS, the Department of Labor's Office of Disability Employment Program (ODEP), the Administration on Intellectual and Developmental Disabilities (AIDD)) began to outsource technical assistance through a network of "task order" contractors and technical assistance grants, the Association frequently was called upon to serve as sub-contractor. Sub-contracts with Acumen, EconSys, and the University of MASS, Boston have enabled NASDDDS to provide technical assistance to state agencies, including mental health authorities and Medicaid agencies, on a wide range

of topics from the design of 1915 (c) waivers, to 1916 (i) state plan services, and employment services.

In addition to technical assistance, the National Council on Disabilities has contracted with NASDDDS to develop white papers to guide policy and practice in the field. These include Medicaid Managed Care for People with Disabilities Policy and Implementation Considerations for State and Federal Policy Makers; A Medicaid Block Grant Program – Implications for People with Disabilities; and – still in development – a piece on the definition of Home and Community Based Services.

By 2010, technical assistance had grown to be a significant part of the Association's activity leading to the recruitment of staff with considerable background in state operations. Rie Kennedy Lizotte, with experience in the Georgia Department of Developmental Disabilities, added expertise in employment services; Barbara Brent, the former director of Arizona's Division of Developmental Disabilities, added knowledge in managed care operations and positive behavioral supports; Mary Lee Fay, the former director of Oregon's Developmental Disability Services, broadened the Association's capacity to assist states in the development of family supports and the design of support brokerage services; and Jeanine Zlockie, Policy Specialist in the Pennsylvania Office of Developmental Programs, added expertise in support coordination. Mary Sowers, former Senior Policy Advisor, DEHPG (Disabled and Elderly Health Programs Group); and former Director, Division of Community and Institutional Services (CMS); and former waiver coordinator in the state of Maryland, expanded the Association's capacity to provide technical assistance on a wide range of federal programs.

Through contracts directly with states, state Developmental Disabilities Councils, and as a subcontractor to other firms such as the Human Services Research Institute (HSRI) and Health Management Associates (HMA), NASDDDS approaches its 50th anniversary providing direct technical assistance to more the half of all state DD agencies.

## Technical Assistance

Technical assistance services have been provided to member state agencies under a set of operating policies that have been largely unchanged over the years. Billing rates have been adjusted from time to time to reflect changes in staff compensation and related operating costs. The NASDDDS Board of Directors approved the most recent revision to the organization's TA operating policies in November 2006. These policies are grounded in the following principles:

- **Guiding Principle #1:**  
The Association responds to all mail, e-mail and telephonic requests for information and advice regardless of the source of the inquiry as long as the requested information can be easily assembled and quickly dispatched. But priority is given to informational requests emanating from member state agencies.
- **Guiding Principle #2:**  
The Association's staff will agree to undertake technical assistance assignments only when the nature of the tasks to be performed comport with the mission and strategic goals of the Association.
- **Guiding Principle #3:**  
The Association will agree to furnish technical assistance services only when the staff either possesses the requisite skills and knowledge base to complete the necessary tasks or can supplement

staff resources by securing the services of other qualified individuals through sub-contractual arrangements.

- **Guiding Principle #4:**  
The Association's staff will avoid performing, as part of a technical assistance contract, design and implementation tasks that are rightfully the province of a state agency.
- **Guiding Principle #5:**  
When a particular technical assistance project or activity will require a significant commitment of staff time over an extended period, there must be evidence that the work to be performed is likely to yield not only benefits to the requesting state agency but significant indirect benefits to other member state agencies as well.
- **Guiding Principle #6:**  
Before the staff agrees to undertake a technical assistance project on behalf of another state agency or organization (e.g., a state developmental disabilities council, a state Medicaid agency, or a statewide provider coalition), it will consult with the member state agency. The staff's agreement to undertake or participate in such a project will be contingent on an affirmative indication of support from the member state agency.

These policies include specific decision-making guidelines to assist the staff in applying the above principles.<sup>11</sup>

## E

## LESSONS LEARNED

The history of the Association's technical assistance services has taught us the following lessons:

### 1. Capitalizing on Technical Assistance Experiences

By helping member state agencies to solve service delivery problems, the Association's staff gains deeper insights into contemporary policy issues and practices in the I/DD field. This knowledge in turn assists the Association in: (a) organizing membership

meetings focused on issues of priority concern to member agency officials; (b) pinpointing topics for special reports analyzing issues facing the field and delineating current best and promising practice across the United States; and (c) identifying federal legislative and administrative policies that limit the provision of appropriate, person-centered services to individuals with intellectual and developmental disabilities – and advocating for the removal of such barriers.



Over the years numerous federal policy impediments have been uncovered during Association-sponsored technical assistance activities. For example, during the 1970s, the Association discovered numerous barriers to certifying small, community residence as ICF/MR provider agencies. Working with Congress and the officials of the Department of Health, Education and Welfare,\* the Association eventually was able to get these impediments removed. From 1981 through the present, the Association has assisted virtually every state to design and expand HCBS waiver services for Medicaid-eligible individuals with intellectual and developmental disabilities and the lessons learned in doing so has allowed NASDDDS to play a leading role in the transformation which has occurred in national long-term services policy.<sup>12</sup>

With in-depth knowledge of the on-the-ground implications of federal statutory and administrative policies, the Association's TA staff has played an instrumental role over the years in shaping NASDDDS' federal policy agenda. The Association's legislative proposals and comments on CMS

regulations and other administrative policies frequently have been (and continue to be) heavily influenced by input from the TA staff. The TA staff also participates extensively in topic selection and the preparation of NASDDDS' special publications and in organizing membership meetings, conference calls, and webinars.

## **2. Recruiting and Retaining Qualified Staff**

The success of the Association's technical assistance program lies to a significant extent in hiring and retaining staff with extensive experience in managing state I/DD services. A though familiarity with the internal operations of state disability agencies is a distinct asset in providing technical assistance because, while organizational

structures and operational nomenclature vary from state to state, the presenting issues and the general framework in which they must be addressed are similar across the nation. Previous management level experience within a state I/DD agency, therefore, is a distinct advantage. Leadership continuity is also important because the staff is able to forge close working relations with program managers in many member state agencies. NASDDDS has been fortunate in this respect to have had only two TA directors over the past quarter century.

## **3. Effectively Utilizing Staff Resources**

The operational policies governing the provision of technical assistance to member state agencies allow the Association to maximize the benefits of staff expertise. The staff is able to provide assistance to a larger number of member state agencies by limiting the scope and circumstances under which TA services are furnished. These policies are the product of years of experience in furnishing technical assistance. They

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\* Renamed the Department of Health and Human Services in 1980.

take into account the realities of the limited resources that can be devoted to the Association’s technical assistance activities as well as the benefits of drawing upon the TA staff’s experiences in shaping the Association’s public policy advocacy efforts.

## 4. Developing Strategic Alliances

Initially, the Association’s technical assistance activities were limited in scope, typically involving short-term, narrowly targeted consultative agreements

between the Association and member state agencies. But, as time passed, the Association began to forge partnership with other disability organizations that had complimentary goals. Increasingly these alliances have offered member state agencies a wider range of assistance. In addition, these alliances have allowed NASDDDS to capitalize on the growing availability of federal grants and contracts, thus reducing the proportion of TA expenses financed through membership dues and other revenue sources.

# F

## CONCLUSION

NASDDDS has provided technical assistance to member state agencies for over thirty-five years. Initiated in 1978 as part of a federal grant project, technical assistance soon became a mainstream membership service. During the ensuing years, the methods used to deliver assistance, as well as the focus of TA requests, have changed, but the fundamentals of the Association’s technical assistance program have remained the same. The aim is to help a requesting state to address perceived barriers to financing and delivering state-of-the-art home and community-based supports to individuals with developmental disabilities. In providing such assistance, the Association’s staff strives to take into

account relevant local social, political, and historical realities and to draw upon the experiences of other states, as well as the staff’s wide-ranging knowledge of applicable federal policies.

Rather than a stand-alone service, technical assistance has evolved into an integral component of the Association’s activities, with linkages to policy advocacy, meeting planning and communications, including newsletters, special publications, membership teleconferences and webinars. These linkages contribute to the continuity of Association services and assure maximum use of staff expertise.

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### END NOTES

<sup>1</sup> Personal communication between Robert Gettings and David Braddock, Director of the Coleman Institute on Cognitive Disabilities at the University of Colorado/Boulder, March 27, 2013.

<sup>2</sup> Mr. Tapper and Ms. Weinberg were selected due their prior experience in serving individuals with developmental disabilities at the state and local level – Mr. Tapper in Minnesota and Ms. Weinberg in Arkansas.

<sup>3</sup> Only one of these reports was issued in print form due to budgetary limitations (see *Income Maintenance and the Developmentally Disabled: An Analysis of Policy Issues* (Robert Gettings, Harold Tapper and Myrl Weinberg), National Association of State Mental Retardation Program Directors, Inc. 1977).

<sup>4</sup> Turner replaced Harold Tapper as Project Coordinator in the fall of 1977 and Percy replaced Myrl Weinberg as Assistant Project Director the following year.

<sup>5</sup> Executive Director’s Report: 1979, presented NASMPD’s Annual Meeting, December 3-4, 1979.

<sup>6</sup> Executive Director’s Report, National Association of State Mental

Retardation Program Directors, Inc., delivered at the Association’s Annual Meeting, December 3-4, 1979.

<sup>7</sup> Minutes, NASMRPD Board of Directors meeting, May 27, 1981.

<sup>8</sup> Smith, Gary, *Paying for Services*, Alexandria, VA: National Association of State Directors of Developmental Disabilities Services, 1987.

<sup>9</sup> White and Associates, NASMRPD Audit Report for the fiscal year ending June 30, 1988 and the NASDDDS Audit Report for the fiscal year ending June 30, 1993.

<sup>10</sup> Ibid, June 30, 1987 and June 30, 1993 audit reports.

<sup>11</sup> Memorandum from Nancy Thaler, NASDDDS Executive Director, to All State Directors, dated March 28, 2007, subject: “Technical Assistance Policies, Fees and Capability Statement.”

<sup>12</sup> See Chapter III for additional discussion of the Association’s role in modifying federal Medicaid policies affecting the I/DD population over the years.

# VI CHAPTER

*Small opportunities are often the beginning of great enterprises.*

Demosthenes  
Greek orator and statesman

## INTER-ORGANIZATIONAL COLLABORATION: *Creating and Sustaining System-wide Reforms*

Prior to the 1960s, negative stereotypes of persons with intellectual and developmental disabilities permeated American society. The lingering effects of the eugenics movement of the early 20th Century still prevailed in the minds of many Americans. Individuals with lifelong disabilities were viewed as human castoffs, often denied access to a public education and relegated to large, rural institutions where they lived in sub-human conditions isolated from the mainstream of community life.

The Association was formed in 1964, a time of renewed hope for persons with lifelong disabilities and their families. As discussed in greater detail in Chapter I, the election of John F. Kennedy led to the development of a broad, national strategy for addressing the needs of children and adults with intellectual disabilities (referred to as mental retardation at the time). This strategy was set forth in the 1962 report of the President's Panel on Mental Retardation. Congress, in keeping with the panel's recommendations, enacted laws to improve access to education and maternal and child health services, underwrite the cost of constructing a network of research, training and community service centers, and provide grant assistance to help states develop their own plans for expanding and improving services to people with intellectual disabilities. The formation of

the Association was a direct by-product of this surge in national legislation. State officials responsible for implementing the new federal laws were seeking to ensure that the views of state government were represented in the formulation of related federal laws, regulations and administrative policies.

From the start, Association leaders assigned priority to forming alliances with other disability and state executive branch organizations. As a small, fledgling organization with extremely limited resources but broad aspirations, the Association had little choice but to partner with other, more seasoned organizations such as the National Association for Retarded Children\* and the American Association on Mental Deficiency.\* For the first two decades of its existence, the Association collaborated with other national organizations in seeking changes in federal legislative and administrative policies (see Chapter III). Beginning in the mid-1990s, however, the nature and scope of NASDDDS' collaborations began to broaden. This chapter describes the origins, aims and operational underpinnings of various inter-organizational alliances the Association has forged over the past two decades and briefly summarizes the results of these ventures. In addition, the principal lessons derived from the Association's collaborations with other organizations are summarized at the end of the chapter.

# Past and Present Inter-Organizational Collaborations

## A MANAGED CARE COLLABORATIVE

By 1990 many commercial health plans had converted to a managed care format and the concept of prepaid health care delivery systems had spilled over to the Medicare and Medicaid programs. Initially the emphasis in most states was on enrolling low-income children and adults without disabilities in commercial managed care plans funded through Medicaid and, later, the Children's Health Insurance Program (CHIP). By the mid-1990s, however, individuals with physical and especially behavioral disabilities were being enrolled in Medicaid managed care programs and officials in scores of states were exploring the feasibility of expanding managed care to long-term services and supports programs for low-income elders and other adults with severe chronic disabilities, including persons with intellectual and developmental disabilities.

Recognizing this emerging trend, the NASDDDS Board of Directors in May 1995 decided to enter into a collaborative agreement with the Human Services Research Institute (HSRI), a non-profit policy research center specializing in mental health and developmental disabilities issues, to gather and disseminate information on the implications of managed care for the I/DD population.<sup>1</sup> This alliance, Association leaders agreed, made sense given NASDDDS' strong ties to its member state agencies and HSRI's extensive analytical capabilities and knowledge of both mental health and developmental disabilities policy issues. The first product of the so-called Center for Managed Long-Term Supports for People with Developmental Disabilities was a guidebook to assist state I/DD officials and other disability stakeholders in gaining an understanding of the principal components of managed health care systems and the special challenges and opportunities associated with delivering I/DD services and supports within a managed care framework. The guidebook, entitled *Managed Care and People*

*with Developmental Disabilities*, was released in December 1995<sup>2</sup> and soon became a "must read" for state policymakers, practitioners and consumer advocates across the nation.

The following year, the Association and HSRI co-sponsored a series of well-attended workshops on the ramifications of managed care for the I/DD population in Chicago, Baltimore and Los Angeles. In addition, the Association issued a policy statement, entitled, "Keeping Faith: System Change, Managed Care, and Long-Term Supports for People with Developmental Disabilities." This policy statement identified the fundamental elements of a managed long-term services system responsive to the needs of individuals with disabilities and their families.<sup>3</sup> The NASDDDS staff also provided on-site technical assistance to a number of states interested in designing managed care delivery systems for persons with developmental disabilities, including Arkansas, Missouri, New Hampshire, New Jersey, Pennsylvania, Texas, Vermont, Virginia and Wisconsin.<sup>4</sup>

Over the next five years, a few states converted long-term supports for Medicaid-eligible individuals with developmental disabilities to a managed care format, most notably Michigan and Wisconsin. But, most states continued to administer I/DD long-term services on a fee-for-service basis. Interest in enrolling people with developmental disabilities in Medicaid managed care plans receded during the following decade (only to be revived in recent years). Association leaders, however, took away from the managed care collaboration of the mid-to-late 90s a better understanding of the benefits of forging inter-organizational alliances. This knowledge would pay dividends over the following two decades.

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\* Subsequently renamed the Arc of the United States.

♣ Later renamed the American Association for Intellectual and Developmental Disabilities.

As work on the managed care initiative was winding down, the possibility of a new collaboration between NASDDDS and HSRI emerged. Building upon the growing interest in outcome measurement in health and human service programs, the staff of HSRI and NASDDDS decided to explore the possibility of developing a set of indicators to assess the performance of state I/DD service systems. Discussions regarding such an initiative began at the Association's 1996 Mid-Year Meeting and continued through the summer and fall of that year. Finally, the Board of Directors, at its December 4, 1996 meeting, authorized the Executive Director to enter into a cooperative agreement with HSRI to develop a valid and statistically reliable set of measures to assess the performance of state I/DD service systems.<sup>5</sup>

A project steering committee was formed in early 1997, comprised of representatives from seven states that agreed to serve as test sites and eight other states with a strong interest in developing I/DD system indicators. Using performance indicators employed by various states as a base, the steering committee reached consensus over the following year on the major performance domains and sub-domains of such a system and selected a set of indicators to be tested, plus the measures and data sources to be used in benchmarking performance against each indicator. The criteria used in selecting indicators took into account whether results were: (a) measurable; (b) capable of being influenced by state-level actions; and (c) outcomes important to individuals with disabilities and their families.<sup>6</sup>

The resulting 61 indicators were piloted in seven states: Arizona; Connecticut; Missouri; Nebraska; Pennsylvania; Vermont and Virginia. During this initial phase, data collection protocols were prepared and field tested, including a face-to-face Adult Consumer Survey, dealing with services to recipients 18 years of age and older, and a mail-out Adult Family Survey, targeted to families supporting an individual with disabilities in their homes. Much of this work was performed by the HSRI staff under a contract with NASDDDS. Representatives of the pilot

states served on the project steering committee, along with representatives of the following states: Alabama; Colorado; Florida; Michigan; New York; Oklahoma; Rhode Island and South Carolina.

The results of the initial phase of the project proved to be highly promising and NASDDDS and HSRI decided to continue and gradually extend the collaboration, with the bulk of the financing coming from annual assessments paid by the participating states. During subsequent years, the indicators and data collection protocols were refined and expanded. Two additional survey instruments were added – a Family Guardian Survey to assess the perceptions of family members with an adult receiving residential services outside the family home and a Children Family Survey to examine the experiences of and outcomes for family with children and young adults (under age 22) living in the family home. In addition, states began submitting aggregated incident and mortality data and some states started to use a Staff Stability Survey to gather data on staff turnover and vacancy rates among provider agencies.<sup>7</sup>

The number of participating states gradually increased and the “project” was converted to an ongoing enterprise. Furthermore, as accountability demands from federal and state policymakers increased, NCI became a critical component of state quality management systems.

From the start NCI has been a state-driven initiative. Participating states are responsible for making their own arrangements for gathering and reporting NCI data, including conducting face-to-face interviews and collecting survey and system performance data. The shared costs of analyzing and warehousing NCI data, preparing summary reports and convening steering committee and other meetings has been covered through special assessments paid by participating I/DD agencies. HSRI in turn has received contractual payments from NASDDDS for the NCI-related functions it performs.

Among the early decisions of the NCI Steering



Committee was to: (a) make publicly available all NCI instrumentation, including the indicator set and related measures and data collection protocols; (b) publish the results of NCI surveys, including performance comparisons among the participating states; and (c) afford qualified researchers access to NCI data to conduct special studies and analyses. Today NCI data offers researchers a rich source of longitudinal information with which to seek answers to important policy questions. Requests to access the data have grown over the years and have led in recent years to the publication of a number of articles in peer-reviewed journals.

The Research and Training on Center on Community Integration at the University of Minnesota (RTCCL/UMN) was the first university-based center to partner with the NCI staff in conducting analytical studies. This partnership was a spinoff from earlier collaborations between NASDDDS, HSRI and RTCCL/UMN (see discussion of Reinventing Quality below). The studies conducted as part of this collaboration have resulted in articles published in peer-reviewed journals on topics such as social relationships and community participation among adults with intellectual disabilities and the relationship between place of residence and access to preventive health care.

In 2009, NASDDDS expanded the scope of NCI-related research by entering into an agreement with the Association of University Centers on Disabilities (AUCD) aimed at fostering research on key topical areas to generate evidence to support public policy decisions. By establishing an active working relationship with AUCD and its network of university-based researchers and scholars, NASDDDS aims to build a solid knowledge base to inform policymaking in such critical areas as:

- Increasing opportunities for self-determination and personal control for persons with lifelong

disabilities and their families;

- Providing opportunities for people with disabilities to live and participate in their own communities;
- Improving the quality of life, as they define it, of individuals and families;
- Supporting families in their efforts to protect and provide lifelong assistance to persons with intellectual and developmental disabilities;
- Investing in each individual's developmental potential and capacity to contribute in age-related roles as productive, respected community members; and
- Assuring access to sufficient, high quality health and social supports to protect each person's health, safety, rights and well being.

A website has been established to facilitate access to information about the NASDDDS-AUCD "Evidence Based Policy Initiative" (<http://www.evidence-basedpolicy.org/main/>). This website includes background information on the aims of the initiative, author guidelines, and an example of a policy brief. Joint NASDDDS-AUCD webinars and conference presentations also have been arranged to explain the utility of NCI data in policymaking and program development.

In addition to issuing an annual summary report, the NCI staff has coordinated the preparation of a series of data briefs on a variety of critical policy issues such as the use of psychotropic medications, employment outcomes, services to older I/DD adults, self-directed supports, services to persons with co-occurring mental illnesses and developmental disabilities and supporting individuals living with family members. These briefs and a wide range of other materials are posted on the NCI website (<http://www.nationalcoreindicators.org/>).

In 2011, NASDDDS received a five-year, \$1.5 million grant from the federal Administration on Intellectual and Developmental Disabilities to improve and expand NCI. One primary goal of the grant project is to enroll all fifty states and the District of Columbia as program participants.<sup>8</sup> Eleven additional states had joined NCI (CT, DC, IN, MD, MI, MS, OR, SC, UT, WI, VA) by the summer of 2013. With the addition of several state and state sub-entities, the number of participating states is 43 for the 2014-2015 membership year. Recently, NASDDDS and HSRI have launched a new website for the National Quality Data Management Project that showcases the activities of states that have recently joined to NCI program ([www.nationalcoreindicators.org/aidd](http://www.nationalcoreindicators.org/aidd)).<sup>9</sup>

In 2014, all of the surveys associated with National Core Indicators were formally copyrighted and are jointly owned by NASDDDS and HSRI.

Concerned about the limited information currently available to help states assess the quality of long term services and supports (LTSS) for seniors, adults with physical disabilities, and caregivers, the National Association of States United on Aging and Disabilities (NASUAD), with support from

their steering committee, began working with HSRI and NASDDDS to expand NCI to include a focus on services for seniors and adults with physical disabilities. The expanded scope of NCI is called the National Core Indicators-Aging and Disabilities (NCI-AD) Project.

NASUAD, NASDDDS, HSRI and a steering committee of state directors of aging and disabilities services reviewed and revised the NCI Adult Consumer Survey to reflect the needs of the aging and disabilities long term services population. This includes a background survey, which gathers data about the consumer that is found in agency records, and an in-person survey, which includes subjective satisfaction-related questions that can only be answered by the consumer. The survey also include objective questions that can be answered by the consumer or, if needed, their proxy.

Three states, Georgia, Minnesota, and Ohio, piloted the tool between February and August 2014. The survey is being modified to reflect the learning from the pilot. NASUAD and HSRI will make the revised survey available for state participation by June 2015. As of October 2014, thirteen states have committed to participate in the NCI-AD survey.

## C

## REINVENTING QUALITY

In the fall of 1999, NASDDDS was awarded a three-year grant by the federal Administration on Developmental Disabilities to improve nationwide access to best practice information regarding the provision of individually tailored supports to children and adults with developmental disabilities.<sup>10</sup> The main aim of the grant project, a collaborative undertaking involving the Association, HSRI and the University of Minnesota's Institute on Community Integration (UM/ICI), was to disseminate state-of-the-art information about person-centered practices by leveraging the existing capabilities of the three partner organizations, while also taking advantage of recent advances in information technology. A project advisory committee, composed primarily of self-advocates and family members, provided guidance

in organizing project activities throughout the entire grant period.

The Reinventing Quality project included four major activities:

### **Consensus Statement**

The preparation of a statement spelling out the essential principles, elements and features of a person-centered system of publicly-funded, consumer- and outcome-oriented community supports, including related quality assurance and improvement methods. This statement was the product of an invitational conference held in Baltimore on April 14-15, 2000 and was subsequently summarized in a concise project report entitled "Person-Centered Support – They're for Everyone."<sup>11</sup> For the first

time, this document pulled together the strands of a groundbreaking new approach to supporting individuals with intellectual and developmental disabilities. It became the lode star of subsequent project activities, but more importantly, the rallying cry for proponents of broad system change initiatives across the United States.

## Quality Mall

One of the primary objectives of the RQ project was to put information about person-centered practices at the finger tips of everyone, regardless of where they lived. To accomplish this objective, the staff of UMN/ICI launched a website in the fall of 2000 which was designed to serve as a repository of written and audio-visual materials on supporting persons with intellectual and developmental disabilities. Called the “Quality Mall,” the website was organized around the theme of a shopping mall, with a variety of stores and specialty departments in each store. The initial inventory of “merchandise” was assembled by systematically collecting items from the three partner agencies as well as other disability organizations. Knowledgeable individuals were selected from within and outside the partner organizations to manage the various stores and departments – i.e., to ferret out interesting new materials and post them on the website. The number of visitors to the site grew steadily over the grant period and, consequently, when grant funding expired, the project partners decided to continue operating the website. Indeed, over a decade later the Quality Mall (<http://www.qualitymall.org/main/>) is still operating, with 3,313 products posted on the site when last checked.

## State Case Studies

In 2000, the project staff visited four states that had made noteworthy strides toward building individualized, person-centered community service delivery systems and summarized their findings and conclusions. The purpose of these case study reports was to identify the critical factors contributing to the success of each state in instituting person-centered policies and practices. The general lessons gathered during the series of on-site visits then were synthesized in a final project report

## Reinventing Quality Conference

In an effort to showcase cutting edge approaches to supporting individuals with disabilities and their families and expand awareness of the theory and practice of person-centered supports, the project team held a national Reinventing Quality Conference in August 2001. Modeled after a 1992 meeting co-sponsored by NASDDDS and UMN/ICI, this conference was held in Chicago. It was so successful that the project team decided to make the conference an annual event. For the first six years, the conference was organized by NASDDDS, with the assistance of HSRI and UMN/ICI. Responsibility for organizing the conference shifted to UMN/ICI in 2008, but the Association and HRSI continued to provide program planning and logistical support. In more recent years, biennial, rather than annual, conferences have been held. The 10th Reinventing Quality Conference was held in Baltimore in August 2014.



## D STATE EMPLOYMENT LEADERSHIP NETWORK

In the spring of 2005 Dr. William Kiernan, Director of the Institute on Community Inclusion (ICI) at the University of Massachusetts/Boston, approached the NASDDDS staff about launching a State Employment Leadership Network (SELN). The proposed network, he said, would function as an interstate cooperative, designed to assist participating state developmental disabilities agencies to expand and improve employment opportunities for individuals with intellectual and developmental disabilities.

With funding from the federal Administration on Developmental Disabilities, the National Institute on Disability and Rehabilitation Research and the U.S. Department of Labor, ICI had been conducting research and providing technical assistance on employment services for persons with intellectual and developmental disabilities for more than a decade. One component of the Institute's activities involved a biennial survey of state developmental disabilities and vocational rehabilitation agencies to determine the number of individuals with I/DD enrolled in competitive and supported employment, versus segregated employment, settings (i.e., sheltered workshops, work adjustment centers, etc.). Despite two decades of efforts at the national level to promote competitive and supported employment opportunities,

the ICI survey data revealed that a persistently low percentage of individuals with intellectual and developmental disabilities were employed in integrated work settings and being paid at or above the minimum wage level. The SELN initiative was aimed at spearheading a renewed, state-level emphasis on helping adolescents and adults with I/DD find a sustainable pathway toward becoming productive, properly compensated workers.

Dr. Kiernan discussed the goals and operational components of the SELN initiative with members of the NASDDDS Board of Directors at the group's September 21, 2005 meeting. He said the main purpose of the network would be to assist member states to improve the capacity of local community provider agencies to help adults with developmental disabilities acquire and retain jobs in integrated work settings.<sup>12</sup> Over the next few months, ICI and NASDDDS staff hammered out the terms of a draft cooperative agreement between the two organizations. The NASDDDS Board of Directors approved the Association's participation in the SELN initiative during its February 12, 2006 meeting, contingent on recruiting enough state I/DD agencies to participate.<sup>13</sup>

The State Employment Leadership Network was officially launched on July 1, 2006 with 13 participating states (AZ, CT, DE, FL, HI, MA, NM, OR, SC, TX, WA, WV and WI).<sup>14</sup> After ICI and NASDDDS each hired a project coordinator, the project team completed a site visit to each of the 13 participating states. The results of this site visit were summarized and shared with key state officials. During the succeeding months, an individually tailored work plan was negotiated with each participating state. These work plans identified a series of activities designed to strengthen the particular state's capacity to improve employment outcomes for adolescents and adults with I/DD. The plan, with subsequent updates and revisions, formed the roadmap for subsequent in-state activities to be supported through the network.



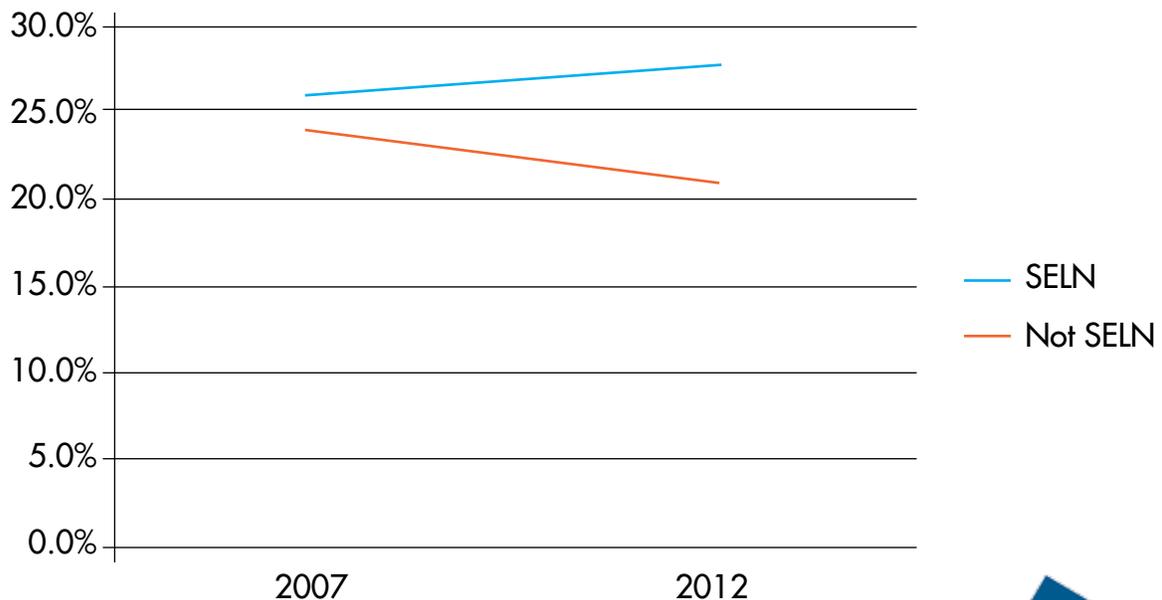
Participation in the network has grown steadily over the years, from 15 states in FY 2007-08 to 29 in FY 2012-13.<sup>15</sup> Representatives of SELN member states meet regularly to connect, collaborate and share information and lessons learned across state boundaries. Participating state agency staff members seek common solutions to pressing employment-related issues at the state and federal level. Each participating state focuses on a customized work plan that addresses the state’s unique needs and circumstances. The network offers participating states a forum to:

- Dialogue about issues and barriers of common concern;
- Use data to guide decision-making and daily system management;

- Share employment strategies of proven effectiveness; and
- Gain information concerning current and impending federal policy initiatives.

An analysis of data from the ICI National Survey of Day and Employment Services finds that states participating in the SELN had better outcomes than non-participating states. Between 2007 and 2012, the percentage of individuals receiving integrated employment services increased in SELN member states while the percentage of people in integrated employment services in nonparticipating states decreased.

## Percent in Integrated Employment Services Mean of States 2007 to 2012



### IDD Agency Survey

Complete data for 2007, 2012  
 SELN=14 (Member in at least 2011 and 2012) Not SELN=22



# E

## SELF-ADVOCACY INITIATIVES

At a Directors' Forum held in conjunction with the Association's 2005 Mid-Year Meeting, the NASDDDS Board agreed to undertake three initiatives designed to strengthen the capacity of member state agencies to address the collective interests of persons receiving publicly-funded services and supports: (a) developing guidelines for involving self-advocates in Association-sponsored activities; (b) creating a self-advocacy assessment instrument that member state agencies could use to evaluate their own activities in support of self-advocacy; and (c) reporting on new and innovative approaches to supporting self-advocacy in *Beyond the Beltway*, the Association's bi-weekly electronic bulletin, and in *Community Services Reporter*, an NASDDDS monthly newsletter.<sup>16</sup> These activities were to be carried out in conjunction with the leadership of Self-Advocates Becoming Empowered, a national group of self-advocates.

A new feature, entitled "Self-Advocates on the Move," was added to *Beyond the Beltway* and *Community Services Reporter* in the fall of 2005. A handbook on organizing and conducting meetings that include self-advocates was issued by the Association in March 2006<sup>17</sup> and the instrument to assess a state agency's activities in support of self-advocacy was released the following year after an earlier draft was field tested in several states.<sup>18</sup> As a result of the field test, the final assessment instrument was revised so that it could be used by multiple parties, including: (a) state I/DD agency staff; (b) groups or committees representing provider organizations/agencies; (c) groups or committees representing a state's self-advocacy association(s); (d) citizen advocacy groups or coalitions, representing the state Arc chapter or other family advocacy groups; and (e) a committee or task force of the state developmental disabilities council.<sup>19</sup>

# F

## EMERGENCY PREPAREDNESS

Following the Gulf Coast hurricane disaster of 2005, NASDDDS leaders decided to develop a set of best practice guidelines for responding to disasters of all kinds that threaten the well-being of persons with developmental disabilities.<sup>20</sup> The purpose of the proposed guidelines was to help member state agencies as they reviewed the adequacy of their own, intra-state disaster response plans and capabilities.

The Association subsequently contracted with the Research and Training Center on Community Living at the University of Minnesota for assistance in developing these guidelines. Following an extensive review of state and federal emergency preparedness planning documents, the end-product of the project was re-defined as a flexible self-assessment instrument that state officials could use to determine the extent to which their respective agencies' emergency preparedness plans adequately addressed key issues critical to protecting and supporting individuals with developmental and other severe disabilities during a natural or man-made disaster or crisis.<sup>21</sup>

The instrument was developed over a two-year period with significant input from the NASDDDS Ad-Hoc Emergency Preparedness Advisory Committee, a group of state I/DD officials from seven states, as well as content experts from the University of Minnesota and state developmental disabilities agencies. The instrument was subject to extensive usability testing and was field-tested in six states (LA, CT, MA, UT, TX and OH) prior to release. It can be accessed through the Quality Mall website (<http://rtc.umn.edu/erp/main/using.asp>).

While the self-assessment instrument is not used widely (probably due to the plethora of broader, cross-cutting state and local preparedness guidelines adopted in the wake of the Gulf Coast storm), it remains an excellent tool for assessing a state's or a locality's readiness to protect persons with severe disabilities in the event of a disaster.

The chief executive officers of the principal national organizations advocating on behalf of individuals with intellectual and developmental disabilities began meeting on a regularly scheduled basis in the early 2000s. The initial purpose of these informal, brown bag luncheon meetings was to exchange information about current organizational activities and plans, with the general aim of fostering closer working relations on issues of common concern. Among the organizations regularly represented at these meetings were: the Arc of the United States, the American Association on Intellectual and Developmental Disabilities, the American Network of Community Options and Resources, the American Association of University Centers on Disabilities, the Council on Quality and Leadership, the Kennedy Foundation, the National Association of Councils on Developmental Disabilities, NASDDDS, and United Cerebral Palsy.<sup>22</sup> For many years, these organizations had collaborated on federal policy issues, but inter-organization collaboration rarely extended beyond the legislative and administrative policy arena.

In late 2003, the chief executives' group began to discuss the possibility of co-sponsoring a major national meeting that would showcase the sweeping changes underway within I/DD service systems nationwide. Agreement eventually was reached on co-sponsoring a "disability summit" and a limited liability corporation, called the Alliance for Full Participation, was formed to solicit and disburse meeting funds. Several other organizations subsequently agreed to join in sponsoring the summit.<sup>23</sup> The first disability summit was held in Washington, D.C. in September 2005. Built around the theme of "Many Voices, One Vision," the meeting brought together over 2,400 self-advocates, public officials, provider agency staff, academicians, researchers, family members and others to hammer out a common agenda to achieve full societal participation for individuals with developmental disabilities. Recognizing that an enormous amount of grass roots work would be required to fulfill the summit agenda, the AFP founding organizations formed a cross-organizational team in every state and the District of Columbia

to oversee the work. Following the 2005 summit, the founding organizations continued to monitor the activities of the state teams and report on their progress through the AFP website (<http://www.allianceforfullparticipation.org/>).

Based on the overwhelmingly favorable response to the 2005 summit, the AFP founding organizations decided to organize a follow-up summit once every five years to take stock of the progress achieved and modify the national action agenda accordingly. The timing of the second summit was pushed back by a year due to the effects of a severe, nationwide economic recession in 2008-10, but eventually it was held in Oxen Hill Maryland (just outside of Washington, D.C.) in November 2011. The theme of the second summit was "Real Jobs – It's Everybody's Business." The summit participants set a goal of doubling the employment rate among working age adults with developmental disabilities by 2015. Work toward achieving this goal continues, spearheaded by the AFP state teams.<sup>24</sup>



# H CREATING PERSON-CENTERED ORGANIZATIONS

The emphasis on person-centered planning within the developmental disabilities sector began during the 1980s. NASDDDS was an early and consistent proponent of person-centered planning (see discussion under “Reinventing Quality”). But, as the years passed, it became increasingly clear that planning on a person-centered basis does not necessarily result in the individualized delivery of services. For this to happen, the commitment to person-centeredness has to permeate all levels of the service delivery system.



In 2007 the Association joined with Virginia Commonwealth University (VCU), Support Development Associates and six state developmental disabilities agencies to seek funds for a three-year project aimed at building person-centered capacity at all levels of the service delivery system – from individuals, to service agencies to system-wide management. The applicants were awarded a \$2.1 million “Real Choice Systems Change” grant by the Centers for Medicare and Medicaid Services in September 2007. The six demonstration states (GA, OR, NC, SD, TN and VA) agreed to adhere to the tenets of Essential Lifestyle Planning – i.e., all people want to lead their own lives as they define them, where a continuous balance is struck between the presence of what is important to them (preferences) and what is

important for them (health, safety and access to valued social roles).<sup>25</sup>

The overarching purpose of the project was to assist individuals with long-term disabilities and severe, chronic illnesses to reside in their own homes and participate fully in their communities. The specific project aims included: (a) changing the basic model of planning services and supports from one directed by the needs of provider agencies to one responsive to the needs of the individual; and (b) assisting states and territories to develop ways of identifying the strengths, capacities, preferences, needs and desired health and quality of life outcomes for persons in need of assistance. The project focused primarily the following four, core elements:

- Strengthening and expanding the use of person-centered planning (PCP) models in the participating states;
- Assuring that the state’s PCP process systematically incorporates informal support and community network assessment tools;
- Training professionals working in key long-term services and supports roles in the use of community networking and assessment tools; and
- Developing new interventions to support caregivers and build ongoing ties for the individual to his or her community network of organizations and friendships.

Targeted changes were sought at the following levels: (a) day-to-day practices that impact the lives of individuals receiving supports and their relationships with formal and informal sources of support (Level 1); (b) organizational policies, practices and program outcomes at the provider agency management and leadership level (Level 2); and (c) modifications in the service delivery infrastructure that result in revised regulations, state policies and system design that supports person-centeredness (Level 3).<sup>26</sup>

According to a follow-up evaluation of the project, among the primary factors influencing the spread, scale and sustainability of person-centered behaviors at the local level in the six participating states were:

***Training in “person-centered thinking” –***

This training, provided initially by consultants affiliated with Support Development Associates, helped local site participants to acquire practical, concrete techniques for learning more about people with disabilities and for instituting person-centered practices.

***Strong Organizational leadership –***

Greater strides were achieved in building person-centered organizations in locales where the initiative received strong support from provider agency leaders.

***Staff buy-in –***

At local sites where staff members were drawn into the planning and implementation process, person-centered behaviors developed stronger roots and spread to other agencies faster.

***Availability of resources –***

A significant commitment of staff time was required to institute the model because of the release time required to train staff and the frequent leadership meetings. This factor proved to be a major challenge at many of the local sites since the project was being carried out during a period of recession-induced budget reductions.

***Building the internal capacity –***

Training and mentoring staff in the new person-centered techniques proved to be a key to building person-centered organizations at the local level.<sup>27</sup>

At the statewide level the keys to building person-centered delivery systems included:

***Strong state agency leadership –***

Similar to the local level, committed leadership at the top of the agency emerged as an important predictor of success in promoting the acceptance of person-centered, system-wide practices.

***Inter-organizational collaboration –***

State I/DD agencies that forged partnerships with other organizations and agencies, such as a state university centers of excellence, the state DD council, and providers of training and technical assistance, tended to be more successful in fostering the spread of person-centered practices.

***Training capacity –***

The ability to create training capacity at the state level also positively influenced the scope, scale and spread of person-centered activities.

***Partnerships with other, related entities –***

State agencies that developed working relationships with local school systems, public employee unions, independent case management agencies, employment providers, and employee unions, generally were more successful in expanding the reach of person-center practices within local I/DD service delivery systems.

***Availability of resources –***

Access to trained personnel – especially trainers qualified to teach “person-centered thinking” – and the resources necessary to deploy such trainers throughout the service system, were a key factor in the acceptance and use of person-centered behaviors.<sup>28</sup>

While acknowledging the resource-intensive nature of accomplishing broad, system-wide changes, all of the participating state and local agencies expressed overwhelming support for the system change approach adopted by the project. Furthermore, by the end of the project, each state had in place a plan to sustain and expand its person-centered change process.<sup>29</sup>

On May 6-8, 2011 a diverse group of national and state family support leaders met at the Wingspread Conference Center in Racine, Wisconsin to forge a national support agenda for families of individuals with intellectual and developmental disabilities. A conference summary was later disseminated by the Johnson Foundation, which operates the center. The conference participants recommended that:

- The structure and functions of state service systems be designed to include a focus on supporting families, recognizing that most people with I/DD are living with their families in the community.
- National family support initiatives be developed and funded that explore principles, practices and data indicators that will inform practice and policy related to supporting families across the lifespan.
- A national data collection initiative be developed to gather consistent and uniform data to identify the impact of supports on families and people with I/DD and the cost-effectiveness of supporting families across local, state and federal systems.
- Recognition of the role of families and the need to support families should be elevated within key federal policies and national programs.<sup>30</sup>

As a follow-up to the Wingspread Conference, the Administration on Intellectual and Developmental Disabilities awarded a five-year, \$1.2 million grant to NASDDDS in September 2012 to develop systems of support for families of persons with I/DD throughout the lifespan of the affected family member. The grant project is being carried out in conjunction with the Institute for Human Development at the University of Missouri/Kansas City (IHD/UMKC), the Human Services Research Institute (HSRI), and the National Association of Councils on Developmental Disabilities (NACDD).

The Lifespan Family Support project is structured around a multi-level Community of Practice (CoP) that brings together individuals with intellectual

and developmental disabilities, family members, policy makers and others to think, learn and act collaboratively in the pursuit of more effective family-centered services and service policies. Faced with a continually growing demand for services, resource constraints and a shortage of working-age adults to staff facility-based programs, state I/DD agencies are placing increased emphasis on the provision of non-shift-based support models and the development of policies and programs that emphasize family involvement, including the provision of in-home supports for individuals residing in the homes of family members. Between 1999 and 2009, the number of individuals living in a home owned, leased or rented by a family member increased by 40.7 percent, while the percentage of persons residing in such settings grew as a proportion of all recipients of public I/DD services from 51 percent to 57.5 percent.<sup>31</sup> When the approximately 3.5 million persons with I/DD not presently enrolled in services are taken into account, an estimated 88 percent of all individuals with I/DD are living in homes with their families.<sup>32</sup>

Five states (CT, DC, OK, TN, and WA) have been selected to participate in NASDDDS' Lifespan Family Support project. Each state will create a multi-tiered "community of practice" to develop a model framework for supporting families. As an early adopter, Missouri is serving as the mentor state for the development of CoPs. The primary assignment of these "Communities of Practice" will be to:

- Facilitate a comprehensive assessment of policies and practices capable of informing the development of a state-level work plan;
- Identify existing expertise and common needs across states to promote mutual learning and collaboration; and
- Help each state to develop a sustainability plan for continuing the communities of practice both across and within states. A community of practice at the national level also will be established to allow interested stakeholders to participate in ongoing project dialogues.<sup>33</sup>

In each state a CoP team, consisting of representatives of the state I/DD agency, the state DD council, self-advocates, family members and other stakeholders, will be formed to oversee project activities. Among the primary responsibilities of

the state team will be to conduct a self-assessment and prepare an action plan with the assistance of the project staff. This action plan will form the basis of future policymaking and implementation activities in the state.

## J

## LESSONS LEARNED

There are a number of key lessons to be gleaned from NASDDDS' experiences in collaborating with other organizations to achieve shared programmatic goals, including:

### 1. Synergistic Impacts

By selecting partners with capabilities the Association lacks, NASDDDS is able to undertake broad system change initiatives that otherwise would be beyond its reach. The National Core Indicators program offers a good example of how NASDDDS has been able to create dynamic partnerships that support the interests of member state agencies. In this case the Association capitalized on the growing interest among member state agencies in measuring system-wide performance objectively by enlisting a partner – HSRI – with experience in building standardized performance measurement systems and the technical capability to collect, analyze, store and retrieve systemic performance data.

When responsibility is shared with a partner organization(s), tasks can be distributed among the partners based on prior experiences and expertise. In organizing the NCI initiative, NASDDDS, due to its ongoing interactions with key state I/DD officials, assumed responsibility for enlisting and enrolling new member states, coordinating Steering Committee meetings and managing program finances. HSRI, in contrast, was tasked with spearheading the collection and analysis of NCI data as well as the preparation of reports and presentations highlighting survey results and data trends. Overall responsibility for establishing program directions was assigned to a steering committee composed of representatives from each of the participating states. The project team, made up of key NASDDDS and HSRI staff members, was charged with overseeing the day-to-day activities

of the collaboration and providing staff support to the steering committee.

These arrangements have proven to be successful not only because they draw upon the mutual strengths of the participating organizations but also due to the long history of collaboration between HSRI and NASDDDS. The numerous joint activities undertaken by the two organizations over the past three decades have fostered a sense of shared values and trust which facilitates planning and implementation activities.

Additional collaborators also can be enlisted as an initiative matures. As NCI's longitudinal data base expanded, the program team recognized the potential opportunities it presented for examining important questions involving the organization, financing and delivery of I/DD services. Researchers at the University of Minnesota's Institute on Community Integration – another long-time NASDDDS collaborator – began to conduct studies using NCI data and summarizing the results, both in its own publications as well as in peer-reviewed journal articles. The message soon spread to researchers affiliated with other university centers and, in recent years, the number and diversity of NCI-based studies has expanded. These studies have not only showcased the value of the NCI program but also have offered important insights into the relationship between planned service interventions, environmental factors and favorable person-centered outcomes.

### 2. A Sense of State Ownership

The shared goals of member state agencies have served as the genesis of some of NASDDDS' most important collaborative ventures. The State Employment Leadership Network illustrates how the

Association has been able to launch ground breaking system change initiatives by harnessing the energy and commitment of member state agencies.

By the mid-2000s it had become abundantly clear that attempts to expand integrated employment opportunities for adolescents and adults with developmental disabilities had stagnated in many states.<sup>34</sup> After increasing steadily between the late 80s and the late 90s, participation in integrated employment programs plateaued nationally, while enrollment in non-work-related day activities continued to grow. Concern about the lack of progress in this area surfaced during a 2002 membership survey conducted by NASDDDS as part of a strategic planning process. So, when ICI Director Bill Kiernan approached Association leaders about intensifying the focus on employment, he found a sympathetic audience.

Thirteen states agreed to pool their resources to establish a multi-state initiative aimed at improving access to integrated employment supports. From the start, the product of this initiative, the State Employment Leadership Network, has been directed and controlled by the participating states. Because the sponsoring organizations – NASDDDS and UMass/ICI – had to demonstrate to the participating states the value of being part of the collaborative, a strong emphasis was placed on identifying best practices and providing hands-on assistance to state officials in adapting these practices within their own, unique policy environments.

This mutual assistance model, where state officials learn from one another with the help and guidance of the project staff, has proven to be highly effective. Between 2004 and 2009, the number of individuals participating in integrated employment services in SELN states increased by 34 percent, while service enrollment in non-SELN states grew by only one percent during the same period.<sup>35</sup> The fact that the total number of states participating in the SELN program has increased from 13 in 2006-07 to 29 in 2012-13 is another measure of the success of the program.

A sense of state ownership is particularly important

when undertaking broad-scaled system change initiatives that are likely to take years, if not decades, to complete. The Association has demonstrated through the NCI and SELN programs the feasibility of a shared financing model where interested states pool their resources to initiate and sustain a collective systems change initiative that provides access to the best technical expertise available nationwide. The result is a financial base for continued operations that is difficult to replicate through time-limited government and foundation grants. Moreover, when control is vested solely in the participating states, the need to satisfy multiple interests – the participating state agencies and the grant agency – can be avoided.

### **3. Shared Values and Continuity of Relationships**

Inter-organizational partnerships work best when the participating parties share a common set of values. As a result, the choice of partners is a critical factor in initiating and sustaining a successful inter-organizational collaboration. By partnering with organizations that are committed to affording individuals with lifelong disabilities and their families opportunities to live productive, inclusive lives in communities of their choice, NASDDDS has been able to contribute to major advances in the delivery of I/DD services over the years.

The longitudinal relationships the Association has maintained with HSRI, UMN/RTTCCL, and ICI/UMass over the past few decades have spanned numerous collaborations, including some of the organization's most important contributions to the I/DD field (e.g., the NCI and SELN programs). The sense of trust that has been fostered among the leaders of these organizations has allowed the Association to serve member state agencies in ways that otherwise would not have been possible. Importantly, all parties derive benefits from participating because each organization contributes its own, unique expertise to the joint venture and gains from the contributions of its partners.

The Association, however, also has successfully partnered with organizations that shared the same general organizational goals but, due to the nature

of their constituencies, pursued different priorities from NASDDDS. The best example of such cross-organizational collaborations is the two disability summits which NASDDDS has helped to plan and carry out in conjunction with a variety of professional, provider, research and training and self- and family-advocacy organizations. These summits have underscored the commonality of interests among the sponsoring organizations, provided a forum for establishing shared national goals, and created mechanisms to support ongoing collaboration among the groups at the national, state and local level. Similar outcomes have been achieved through the working relationships NASDDDS has forged with Self-Advocates Becoming Empowered and other self-advocacy organizations as well as with the National Leadership Consortium on Developmental Disabilities, based at the University of Delaware.

#### **4. Focusing on Emerging Systemic Challenges and Opportunities**

NASDDDS' collaborative ventures have focused largely on cutting edge examinations of the contours of next generation challenges facing public disability support systems. The Association explored the intricacies of managed care during the mid-to-late 1990s because of the uncertain impacts proposed reforms might have on the financing and delivery of Medicaid services to people with developmental disabilities. More recently, the Association has assumed the lead in nationwide efforts to map out a new, family-centered service paradigm that is responsive to the social, demographic and political forces that are reshaping American society. These and other examples of past and current Association initiatives underscore the importance of targeting the Association's collaborations to issues with the potential to fundamentally reshape the delivery of I/DD services and supports.

In the early 2000s, Association leaders adopted a more formal approach to identifying organizational goals and objectives by formulating a multi-year strategic plan. Based on a membership survey conducted during the winter of 2001-02, the Board of Directors, with the assistance of the staff, prepared the Association's first strategic plan. This plan,

which was presented to the membership during the Association's 2002 Annual Meeting, was built around five primary goal areas and included a series of objectives and implementation strategies associated with each goal area.<sup>36</sup>

NASDDDS' strategic plan has been updated on several occasions during the intervening years. The current version of the plan establishes seven goals and related implementation strategies. Goal 1, for example, reads as follow: "Assist states in developing systems of services that effectively support people living with their families or in alternative family/ community options."<sup>37</sup> The current lifespan family supports project, being carried out in collaboration with IHD/UMKC, HSRI and NADDC, is a direct response to this goal area, as is the State Employment Leadership program. To cite another example, the National Core Indicators program is being conducted in pursuit of Goal 2 of the plan, which reads: "Assist states in developing the capacity to monitor and improve quality."<sup>38</sup>

The resources available to the Association are finite. As noted earlier, NASDDDS has been able to undertake broader system change initiatives by partnering with other organizations that have complementary capabilities and intersecting interests. It is important, nonetheless, for the Association to choose its areas of concentration strategically so they reflect the needs of the membership and the broader DD field.

#### **5. Seizing Opportunities.**

Agility in responding to opportunities as they arise is another hallmark of building effective partnerships. Association leaders had no specific plans to launch a broad, new initiative in the area of quality monitoring and improvement during the summer of 1999. But, when the Administration on Developmental Disabilities\* chose quality improvement as one of the priority areas for that year's DD Projects of National Significance Grant awards, the NASDDDS staff, with the cooperation and support of RTCCL/UMN and HSRI staff, was able in the course of three or

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\* Later renamed the Administration on Intellectual and Developmental Disabilities.

four weeks to prepare a successful grant application that allowed the partner organizations to launch the Reinventing Quality project, an initiative that fifteen years later continues to pay dividends.

The trajectory of the lifespan family support project was more gradual. For a couple of years, the NASDDDS staff discussed the challenges facing state/local I/DD service systems with AAIDD Commissioner Sharon Lewis. Eventually these discussions led to a decision to approach the Robert Wood Johnson about sponsoring an invitational workshop at the Wingspread Conference Center on strengthening family supports. “*Building a National Agenda for Supporting Families with a Member with Intellectual and Developmental Disabilities*,” the report from this event, had as one of its four recommendations to develop and fund National Supporting the Family Initiatives that explore principles, practices, and data indicators that will inform practice and policy related to supporting families across the lifespan.

When AAIDD announced following the conference that it planned to support a project aimed at pinpointing improved methods of providing age-appropriate lifespan supports to families, the Association was able to quickly pull together a top-tier team to successfully compete for the grant

project. A proposal was submitted by NASDDDS with the University of Missouri/Kansas City and the Human Services Research Institute as collaborators. The project invited states to make application to participate in a five state community of practice.

Five states were approved to join the community of practice— Tennessee, Washington, Oklahoma, the District of Columbia, and Connecticut; and Missouri participates as a mentor state. By sharing information and experiences the members states learn from each other and have the opportunity to apply what they learn. Members meet virtually and in person to share, create, and disseminate knowledge related to their shared concern.

Based on the five-year plan, states will develop policies that support family networks, provide family-centered support coordination, expand services available in the home and strengthen the role of families in all models of services.

The choice of partners and the choice of targeted activities, as emphasized above, are important. Often, however, it comes down to taking advantage of serendipitous opportunities. This is especially true when it comes to obtaining the third party funding necessary to get a far-reaching activity off the ground.

## G

## CONCLUSION

Through carefully selected partnerships with other disability organizations, NASDDDS over the past two decades has engaged (and continues to engage) in a variety of groundbreaking system change activities. The keys to the success of these ventures include: (a) choosing partner organizations with capabilities that complement those of NASDDDS; (b) allowing participating states to exercise control over the basic directions of the initiative; (c) building intentional communities of practice both within and across participating states in order to facilitate information dissemination and problem solving; (d) selecting

organizational partners and management team members who share a common values base consistent with the aims of the initiative; (e) selecting initiatives that are positioned at the cutting edge of policy and practice within the I/DD service sector; (f) ensuring that the results of the initiative will benefit all member state agencies, not just states that elect to actively participate and, in some cases, provide direct financial support to the particular activity; and (g) maintaining the agility to respond creatively to opportunities to forge dynamic new ventures that promise to advance the Association’s mission.

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END NOTES

- <sup>1</sup> Minutes, NASDDDS Board of Directors, May 26, 1995.
- <sup>2</sup> Center for Managed Long-Term Supports for People with Developmental Disabilities, *Managed Care and People with Developmental Disabilities: A Guidebook*, Alexandria, VA: National Association of State Directors of Developmental Disabilities Services and the Human Services Research Institute, 1995.
- <sup>3</sup> National Association of State Directors of Developmental Disabilities Services, "Keeping Faith: System Change, Managed Care, and Long-Term Supports for People with Developmental Disabilities: A Working Document," Alexandria, VA: NASDDDS, 1996.
- <sup>4</sup> Minutes, NASDDDS Board of Directors Meeting, September 29, 1995.
- <sup>5</sup> Minutes, NASDDDS Board of Directors Meeting, December 4, 1995.
- <sup>6</sup> Information obtained from the National Core Indicators website at: <http://www.nationalcoreindicators.org/>.
- <sup>7</sup> Ibid.
- <sup>8</sup> Ibid.
- <sup>9</sup> Ibid.
- <sup>10</sup> Minutes, NASDDDS Board of Directors' meeting, February 11, 2000.
- <sup>11</sup> Reinventing Quality Project, "Person-Centered Supports – They're for Everyone!," Alexandria, VA: National Association of State Directors of Developmental Disabilities Services, December 2000.
- <sup>12</sup> Minutes, NASDDDS Board of Directors' Meeting, September 21, 2005.
- <sup>13</sup> Minutes, NASDDDS Board of Directors' Meeting, February 12, 2006.
- <sup>14</sup> Minutes, NASDDDS Board of Directors' Meeting, September 14-15, 2006.
- <sup>15</sup> Information obtained from the NASDDDS website (<http://www.selnmembers.org/about>).
- <sup>16</sup> Minutes, NASDDDS Board of Directors' Meeting, September 21, 2005.
- <sup>17</sup> "The Guide: The NASDDDS Handbook on Inclusive Meetings and Presentations," Alexandria, VA: NASDDDS, March 2006.
- <sup>18</sup> Minutes, NASDDDS Board of Directors' Meeting, September 14-15, 2006.
- <sup>19</sup> Moseley, Charles, "Instrument for Assessing State Developmental Disabilities Agency Support for Self-Advocacy Activities," Version 3.5, Alexandria VA: National Association of State Directors of Developmental Disabilities Services, January 2011.
- <sup>20</sup> Minutes, NASDDDS Board of Directors meeting, September 21, 2005.
- <sup>21</sup> Minutes, NASDDDS Board of Directors meeting, September 14-15, 2006.
- <sup>22</sup> Information obtained from the AFP website (<http://www.allianceforfullparticipation.org/>).
- <sup>23</sup> These groups included: ASPE, the Autism Society of America, the Human Services Research Institute, the National Alliance for Direct Support Professionals, NISH, and TASH.
- <sup>24</sup> Ibid, AFP website (<http://www.allianceforfullparticipation.org/>).
- <sup>25</sup> Real Choice System Change Person-Centered Planning Implementation Grant FY 2007, "Building Person-Centered Organizations: Fulfilling the Promise of Person-Centered Planning," a grant application submitted to the Centers for Medicare and Medicaid Services by the Partnership for People with Disabilities, Virginia Commonwealth University, July 25, 2007.
- <sup>26</sup> Ibid.
- <sup>27</sup> Dinora, Pathenia, "Becoming a Person-Centered Organization: Evaluation Results, 2009-10," Richmond, VA: Partnership for People with Disabilities, Virginia Commonwealth University, 2011, pp.12-13.
- <sup>28</sup> Ibid, pp. 13-14.
- <sup>29</sup> Ibid, p. 14
- <sup>30</sup> Hecht, Elizabeth and Michele Reynolds, *Building a National Agenda for Supporting Families with a Member with Intellectual or Developmental Disabilities*, Racine, WI: Wingspread Conference Center, March 6-8, 2011 (<http://familysupportagenda.org/FSNA/>).
- <sup>31</sup> Larson, S., P. Salmi and A. Webster, *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2010*, Minneapolis: Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota, 2011.
- <sup>32</sup> Ibid.
- <sup>33</sup> Project abstract, "Community of Practice: Focusing on Life Span Supports for Self-Advocates and Their Families," from the website of the Administration on Intellectual and Developmental Disabilities, Administration on Community Living, U.S. Department of Health and Human Services (<http://www.acf.hhs.gov/programs/aidd/resource/community-of-practice-focusing-on-life-span-supports-for-self-advocates-and>).
- <sup>34</sup> "Accomplishments Report: State Employment Leadership Network, Membership Year 2010-11," Alexandria, VA: National Association of State Directors of Developmental Disabilities Services, 2012, p. 5.
- <sup>35</sup> Ibid, p. 7.
- <sup>36</sup> Minutes, NASDDDS Board of Directors meeting, September 20, 2002.
- <sup>37</sup> "NASDDDS Strategic Activities," undated, p.6 (downloaded from the NASDDDS website at: (<http://www.nasddds.org/pdf/NASDDDS%20Strategic%20Activities.pdf>).
- <sup>38</sup> Ibid, p. 7.

# VIII CHAPTER

*If you know how to spend less than you get,  
you have the philosopher's stone.*

Benjamin Franklin  
U.S. author, diplomat,  
inventor, politician and printer

## ASSOCIATION FINANCES: *Balancing the Books*

All organizations, regardless of their mission and size, have to identify and cultivate sustaining sources of financial support if they are to survive. Non-profit organizations are especially vulnerable to financial instability because, by definition, they cannot depend on profits from the sale of goods and products to cover their operating costs.

NASDDDS, like tens of thousands of other non-profit organizations established before and since,

began life with a compelling mission – to improve public services for individuals with intellectual and developmental disabilities and their families – but uncertain financial prospects. This chapter traces the financing of Association operations from the organization's early years to the present day. It's a tale of steady growth and adaptation as NASDDDS leaders discovered new ways to support the mission-oriented activities of the organization.

# A

### THE EARLY YEARS: 1964 – 1974

Prior to 1970, Association meetings were either held in conjunction with the meetings of other, related professional organizations, such as the American Association on Mental Deficiency,♦ or underwritten by the federal Division of Mental Retardation.♥ The Association had very limited resources of its own and, therefore, had to schedule Board and membership meetings during the meetings of other organizations so member travel expenses could be reimbursed through their home state agencies.

Membership dues were initially set at \$10 a year in 1964.<sup>1</sup> Often state directors paid the dues out of their own pockets. At the November 19-20, 1967 meeting of the NACSPMR Executive Officers, Treasurer Dr. Charles Barnett reported that the Association had \$358.55 in its checking account, with one unpaid bill

of \$60 outstanding.<sup>2</sup> The following year membership dues were increased to \$200 per annum, per state and the Executive Committee of the Association made a concerted effort to have each governor designate a lead official to represent the state in NACSPMR's deliberations. But, progress in lining up state financial support was slow. At the October 24, 1968 meeting of the Association's Executive Committee, Secretary-Treasurer Charles Acuff reported that 12 states had paid their Association dues and six others had informed him that, for one reason or another, they were unable to pay dues to the organization. The balance of funds available in the Association's account, he said, totaled \$2,481.68.<sup>3</sup>

After several years of negotiations, in 1970 Association leaders were able to obtain a grant

from the Division of Mental Retardation,<sup>\*</sup> a unit of the U.S. Department of Health, Education, and Welfare.\* The grant allowed them to open offices in the Washington, D.C. area and hire staff to administer the grant project. As discussed in greater detail in Chapter 2, the DMR/HEW grant provided the Association with the resources necessary to initiate a variety of services to member state agencies.

Because virtually all of the Association's operating expenses were to be paid for with grant funds, NACSPMR leaders had to navigate around statutory prohibitions against using federal funds for lobbying purposes. At its initial meeting with NACSPMR's new Executive Director, Bob Gettings, the Association Board instructed Mr. Gettings "to avoid expending any grant monies on activities that might be interpreted as influencing federal legislation." At the same time, the Board agreed that "the distribution of factual information about federal legislation" impacting on the provision of public services to individuals with intellectual disabilities fell within the stated objectives of the grant project.<sup>4</sup>

During the first, partial year of grant operations, the Association expended a total of \$44,995, of which \$43,703 was derived from grant payments. NACSPMR collected a total of \$5,600 in membership dues during the fiscal year ending June 30, 1971. Because membership expenditures during the year were small (totaling \$1,292), the fund balance in the membership account grew from \$6,638 on July 1, 1970 to \$10,946 as of June 30, 1971.<sup>5</sup>

Initially Association leaders focused on providing services of value to the states in order to solidify membership support for the organization. Dues levels remained unchanged, with the emphasis placed on bringing as many member states "into the fold" as possible. In the summer of 1971 an Ad Hoc Committee on Organizational Goals and Objectives was appointed by the Board to: (a) review the current activities of NASPMR and recommend a comprehensive set of organizational goals for the immediate future; and (b) suggest ways of achieving greater membership involvement in the Association's affairs. The committee filed its final report on December 10, 1971. Among its recommendations

were that: (a) a standing Committee on Legislative and Administrative Developments be established to advise and assist the Board in formulating and carrying out a national legislative and administrative agenda; and (b) the Association hold its Annual Membership meeting in the Washington, D.C. area in order to enhance the visibility of the organization and its efforts to shape national disability policy.<sup>7</sup>

The number of dues paying states increased steadily following the opening of the Association's headquarters offices. In fiscal year 1971-72, forty-three states paid their dues, yielding total income of \$8,600.<sup>8</sup> Forty-seven states paid membership dues the following fiscal year, resulting in \$9,400 in total dues receipts.<sup>9</sup>

During its May 16, 1972 meeting the NACSPMR Board of Directors authorized the creation of an ad hoc study group to review the Association's future financial needs and recommend a membership dues formula that would yield sufficient funds to cover core operating expenses once funding from the DMR/HHS grant ended.<sup>10</sup> According to calculations performed by the Association's staff, membership dues receipts would have to increase to \$90,000 a year by the end of the grant period for the organization to become self-sustaining.

The Ad Hoc Committee on Dues and Assessments recommended the adoption of a dues structure linked to the annual amount of federal aid each state received under the Developmental Disabilities Assistance Act. By basing dues on the federal allocation formula, Association leaders sought to take into account differences among the states in population, per capita income and service needs. Maximum and minimum dues payment were set at \$5,000 and \$500 respectively and, to simplify

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◆ Later renamed the American Association on Mental Retardation and, still later, the American Association on Intellectual and Developmental Disabilities.

♥ Currently known as the Administration on Intellectual and Developmental Disabilities.

♣ Ibid.

\* Later redesignated the Department of Health and Human Services when the Department of Education was established in 1980.

administration, payments were grouped into 11 payment levels, with no state required to pay 15 percent more or 15 percent less than the median for a particular level.\* The Board considered and approved the recommendations of the Ad Hoc Committee on Dues and Assessments at its March 9, 1973 meeting<sup>11</sup> and membership adopted the Board's recommendation during the 1973 Annual Business Meeting.<sup>12</sup> The new dues structure became effective in FY 1973-74.<sup>5</sup>

In view of the resulting steep increase in membership dues, the ad hoc committee recommended and the Board agreed to grant waivers to states that were committed to paying their dues but had insufficient lead time to build dues into their agency budgets. At its August 21, 1973 meeting, the Board approved waiver requests that had been received from eight states and delegated to the Executive Director and the President of the Board authority to approve additional waiver requests that might be received.<sup>13</sup>

## **B** MOVING TOWARD FINANCIAL SELF-RELIANCE: 1975 – 1985

Despite the generally successful transition from grant funding, membership dues receipts failed to keep pace with the growing cost of Association operations, resulting in a widening gap between operating costs and the amount of revenue collected during the latter half of the 1970s. Two main factors contributed to the shortfall. First, NACSPMR leaders were reluctant to raise dues rates following the initial adoption of the new dues structure because of a decline in the number of dues-paying states. And, second, Association leaders were wary of over-reliance on government and foundation grants to finance core services.

While the number of dues-paying states declined, total dues revenue increased to \$50,885 in FY 1973-74 and \$70,885 in FY 1974-75, or by more than sevenfold compared to collections during FY 1972-73.<sup>14</sup> The organization was on the path toward self-sufficiency but a significant gap remained to be filled. The membership approved a dues increase at its May 31, 1976 meeting (+25%) and, again, at its May 30, 1977 meeting (+10%).<sup>15</sup> By the time grant funding began to taper off in FY 1976-77, membership dues receipts had increased to \$88,703<sup>16</sup> and the Association was able to transition relatively smoothly to alternative funding sources.

At its 1978 meeting the membership also adopted a by-law change authorizing the Board of Directors to approve inflation-related, across-the-board dues increases of up to 5 percent.<sup>17</sup> This authority

permitted the Board to approve small, annual cost-of-living increases in dues rates as part of the budget development process, thus avoiding the need to gain membership approval of larger increases once every three or four years.

The 1979 energy crisis forced inflation to double-digit levels, averaging 11.3 percent in 1979 and 13.5 percent in 1980.<sup>18</sup> Crude oil prices doubled in the course of few months, interest rates rose to unprecedented levels, unemployment increased and economic growth and consumer confidence declined. In the face of hyper inflation and sagging revenues, dues receipts again trailed behind core operating expenses. The need for another dues increase, however, was temporarily averted when NACSPMR received a two-year, \$349,000 grant from the HEW Office of Human Development in the fall of 1976 to identify new approaches to using low-income federal assistance programs, such as Medicaid, Social Security and SSI benefits and housing subsidies, to enhance services and supports for individuals with intellectual and developmental disabilities (see discussion in Chapter V).<sup>19</sup>

As the HEW/OHD grant project wound down in 1979, the challenges of identifying alternative funding sources re-emerged. A four-year projection of future revenue needs, completed for the Association's Ways and Means Committee in January 1980, revealed that membership revenue

would have to increase by at least 65 percent over the four-year period to stabilize the organization's finances over the long term.

Two options for raising the necessary funds were proposed by the committee: (a) increase FY 1980-81 dues by 41 percent, followed by an additional 8 percent increase in each of the next three fiscal years; or (b) increase membership dues by 17.5 percent in each fiscal year between

FY 1980-81 and FY 1983-84. Later, the Board lowered the projected FY 1981-82, across-the-board dues increase to 12.5 percent, with similar increases projected for FY 1982-83 and FY 1983-84,<sup>20</sup> subject to subsequent reviews of the Association's finances.<sup>21</sup> The membership approved a 12.5 percent, across-the-board dues increase during its 1980 annual meeting, plus an additional increase during its 1981 annual meeting designed to bring revenue from this source closer to core operating expenses.\*<sup>22</sup>

In order to minimize reliance on membership dues, Association leaders attempted to generate revenue from other, non-grant sources throughout the 70s and 80s. These sources included newsletter subscriptions, publication sales and contractual studies and analyses performed for government agencies such as the President's Committee on Mental Retardation and the HHS Office of Handicapped Individuals. The contract work involved summarizing federal legislation and completing special studies on disability-related topics. Total revenue from non-grant sources increased from around \$17,000 in FY 1973-74 to over \$40,000 a year between FY 1977-78 and FY 1979-80.<sup>23</sup> The Association's core staff performed all of the work required to generate this non-grant revenue and consequently the income received directly offset the need for steeper dues increases.



When HHS/OHD grant funding ended in FY 1979-80, the NASMRPD Board decided to continue to offer technical assistance services to member state agencies on a pay-as-you-go basis. Between FY 1979-80 and FY 1982-83, the Association provided technical assistance services to 20 states and received payments totaling \$184,818. But, the revenue generated from technical assistance contracts failed to cover the full costs incurred by the Association. As a result, in 1982 the Association's Board decided to eliminate the position of technical assistance coordinator and restrict the scope of future TA activities to projects the core staff could undertake and complete.<sup>24</sup> It would be another five years before the Association would hire a full-time Director of Special Projects and expand its technical assistance services to member states (see Chapter V for an extended discussion of the history of NASDDDS' technical assistance services).

\* During its September, 1985 meeting, the NASMRPD Board of Directors trimmed the number of dues levels from eleven to eight.

\* At its 1981 Annual Meeting, the membership also approved a by-law amendment allowing the Board to increase membership dues by an amount equal to the inflation rate, as measured by the Consumer Price Index. This provision replaced the Board's previous authority to increase dues by no more than 5 percent. The latter authority had never been used because inflation exceeded 5 percent in every year after the authority was authorized (1978).

## C

EXPANDING MEMBERSHIP SERVICES:  
1986 – 1999

After four years in which the Association experienced budget surpluses ranging from \$20,000 to \$56,000 per annum and added some \$65,000 to the fiduciary reserve account, the Board of Directors in July 1987 authorized the Executive Director to hire an additional professional staff member to spearhead special projects, including the provision of technical assistance to member state agencies, the conduct of special studies and the preparation of topical reports. As detailed in Chapter V, Gary Smith was hired in October 1987 to fill this new position.

The total number of states receiving technical assistance services grew from five in FY 1984-85 to 22 in FY 1995-96. Meanwhile the total revenue from technical assistance contracts increased from \$49,352 in FY 1984-85 to \$82,103 in FY 1995-96.<sup>25</sup> By 1994, the volume of technical assistance requests had reached the point where an additional staff position was required. The Association retained the services of Robin Cooper, former coordinator of I/DD waiver programs and case management services for the Wisconsin Bureau of Developmental Disabilities.<sup>26</sup> Ms. Cooper initially served as an independent contractor, with a half-time workload. Later her work schedule was expanded and she became a part-time employee of the Association.

The retention of Ms. Cooper allowed Mr. Smith to spend more time on special projects, which led to

the release of a series of Association publications between 1990 and 1995.<sup>27</sup> Revenue from the sale of these publications also helped to offset Association operating costs. Publication sales grew from \$7,181 in FY 1986-87 to \$61,930 in FY 1992-93<sup>28</sup> and peaked in FY 1995-96 after the Association published a groundbreaking guide book on *Managed Care and People with Developmental Disabilities* (see discussion of the guidebook and related activities in Chapter VI). Publication sales income reached \$141,649 that year, mostly due to sales of the managed care guidebook. This revenue was partially offset by printing costs and NASDDDS' revenue sharing agreement with HSRI, its partner in preparing the guidebook.<sup>29</sup> The remaining funds were used to cover the Association's personnel and other operating expenses.

During a December 1998 meeting, the membership approved a 17 percent, across-the-board increase in Association dues, effective July 1, 1999. The membership's action marked the first above-inflation dues increase in nine years. During the intervening years, the proportion of total operating expenses obtained from membership dues had declined from 67 percent to 54 percent. As a result of the increase, membership dues were restored to approximately 62 percent of operating revenues.<sup>30</sup>

As a result of the staff's expanded activities, the Association's operating revenues increased from \$252,141 in FY 1979-80 to \$824,550 in FY 1998-99. Eighty-five percent of this revenue was derived from core membership services (including membership dues and technical assistance payments).<sup>31</sup> The remaining income came from payments by states participating in the National Core Indicators program, which was launched in 1997 (see discussion of the origins, aims and evolution of the NCI program in Chapter VI). In other words, as the 90s drew to a close, the Association derived virtually none of its operating revenues from time-limited grants and contracts with federal agencies or foundations.



# D

## THE FRUITS OF COLLABORATION: 2000 TO PRESENT

The National Core Indicators program marked an important turning point in Association activities because, as noted in Chapter VI, it was the first time the Association partnered with another organization with common goals and complementary capabilities to undertake a major, longitudinal system change initiative. The theme of inter-organizational collaborative was reinforced in 1999 when NASDDDS received a three-year grant from the federal Administration on Developmental Disabilities (ADD) to improve nationwide access to best practice information. The Association's co-collaborators on this Reinventing Quality project were, again, HSRI and the University of Minnesota Research and Training Center on Community Living, a partnership that has pursued many other joint ventures over the past 15 years.

The award of the Reinventing Quality grant also marked a turning point of sorts for ADD which heretofore had limited its discretionary Projects of National Significance grants to projects aimed solely at strengthening the organizational entities established under the DD Act – i.e., state DD councils, state protection and advocacy systems and university centers of excellence. Because NASDDDS and its member agencies were interested in broader system change initiatives, the Association usually did not qualify for ADD grants. Furthermore, few other viable federal funding options were open to the Association prior to 2000. While the Centers for Medicare and Medicaid Services was (and is) virtually the exclusive source of federal funding for direct, long-term services and supports to individuals with intellectual and developmental disabilities, the preponderance of the agency's discretionary grant projects were focused on acute health services during the 70s, 80s and 90s.

The Supreme Court's 1999 ruling in *Olmstead v. L. C.*, in which the high court found that individuals with disabilities have a constitutional right to live in integrated community settings,<sup>32</sup> triggered significant

changes in federal funding patterns. President Clinton and his successors in office developed government-wide initiatives to promote expanded community living opportunities for people with disabilities. Federal agencies began devoting a larger share of their discretionary grant funds to fostering community living opportunities for children and adults with disabilities. CMS, for example, began funding "Real Choice System Change Grants" in 2001 to help states build the infrastructure necessary to support an expanded community service delivery system.<sup>33</sup> The main focus of these grant projects fell squarely within the wheelhouse of NASDDDS, which had assisted states for decades in institutional downsizing and community expansion initiatives.

Due to this and other factors, the Association has been more successful in competing for federal grants and contracts in recent years, mainly as part of collaborative teams. In 2007, the Association was part of a team that successfully competed for a three-year, \$2.1 million Real Choice System Change grant to demonstrate new approaches to creating person-centered organizations. In 2011 NASDDDS received a five-year, \$1.5 million grant to expanded participation in the National Core Indicators program to all states. And in 2012, the Association received a \$1.2 million, five-year grant from AIDD to demonstrate new approaches to building lifespan support systems for families caring for sons and daughters with disabilities in their homes. The latter project is being carried out in conjunction with the Institute for Human Development at the University of Missouri/Kansas City, the National Association of Developmental Disabilities Councils and HSRI. (see Chapter VI for summaries of these recent grant projects).

In 2006 NASDDDS launched a second state collaboration, to promote expanded employment opportunities for individuals with developmental disabilities, in partnership with the Institute on Community Inclusion at the University of

Massachusetts/Boston (see discussion in Chapter VI). By the end of FY 2013-14, 39 states and 22 sub-state jurisdictions are expected to be participating in the State Employment Leadership Network. Network revenues totaled \$752,500 in FY 2011-12.

A growing portion of Association revenues have been derived from NCI and SELN activities in recent years. Revenues from these two programs have grown from 36 percent of total NASDDDS revenues in FY 2006-07 to 47 percent of total revenues in FY 2011-12. Payment to NCI and SELN contractors (HSRI and ICI/UMass), however, also have increased over the five year period.

As noted above, over the past eight years the Association has derived more of its revenue from government grants and special state-funded initiatives than in preceding years. During FY 2002-03, 65 percent of organizational revenue was derived from membership sources, 23.6 percent from government grants and 12 percent from payments

by NCI participating states. By contrast, in FY 2011-12, 28 percent of Association revenue came from membership dues, 44 percent from payments from states participating in the SELN program and/or the NCI program, 21 percent from government grants and contracts and the remainder (7%) from miscellaneous membership sources.<sup>34</sup>

Revenue from government grants and contracts grew from \$158,407 in FY 2005-06 to \$496,549 in FY 2011-12, although, as might be expected, there have been year-to-year fluctuations in revenue from this source. Membership dues payments, in contrast, have fluctuated within a rather narrow range over the past five years, dropping to \$576,349 in FY 2007-08, when the Great Recession struck, and recovering to \$696,908 in FY 2011-12. Overall, membership dues receipts have declined as a share of all Association revenues from 35 percent of total revenue in FY 2006-07 to 28 percent of total revenue in FY 2011-12.<sup>35</sup>

# E

## ACCUMULATING AND MANAGING FINANCIAL RESERVES

Because the vast majority of operating expenses were paid for through a government grant during the early years, the Association was able to accumulate significant financial reserves. By June 30, 1980 the dollar value of the Association's reserve accounts had reached \$184,058.<sup>36</sup> Having these reserve funds helped to stabilize the Association's finances in three ways. First, the Association was able to avoid wrenching changes in staff operations during years when total expenditures exceeded total revenues. For example, in FY 1980-81, the Association ran a cash deficit of \$55,170 and was able to draw upon reserve funds to continue staff operations.<sup>37</sup> Second, beginning in FY 1979-80, the Association began treating earnings on invested reserve funds as current operating revenue, thus reducing the amount of income that needed to be raised from other membership and grant sources. And, third, despite the elevated mortgage rates in the early 80s, the

Association was able to make a down payment on a headquarters office building in 1982.

By financing the building purchase through the Alexandria redevelopment bonding authority, the Association was able to qualify for a below-prime mortgage interest rate (i.e., 75% of the prime rate --11.67% at the time). The annual cost of financing the mortgage, utilities, property taxes, cleaning fees and relocation expenses (amortized over a 5-year period) was about \$4,800 less than the renewal lease costs on the Association's existing quarters or comparable office rental properties in the area.<sup>38</sup>

Initially, reserve funds were held in a savings account and certificates of deposits with varying maturity dates. In January, 1976, however, the NACSPMR Board of Directors decided to open a fiduciary trust account with the Arlington Trust Company in

order to ensure that the reserve funds were held in a professionally managed, diversified investment portfolio.♥ From this point on NASDDDS reserve funds have been managed in accordance with an investment strategy approved by the Board. Over the

years, the Board has met annually with investment advisors from the bank to review the performance of the Association's investments and determine whether any modifications should be made in the organization's investment strategy.

## F KEEPING TRACK OF ASSOCIATION FINANCES

From 1971 to 2005, the Association's financial accounts were maintained by an in-house bookkeeper, with the advice and assistance of a local Certified Public Accountant (CPA). A general ledger of receipts and disbursements was maintained by the staff Assistant for Financial Affairs and reconciled monthly with the assistance of the CPA. The CPA also completed an annual audit of the Association's accounts and his report was shared with, and discussed and accepted by, the Board.

Initially, the organization's accounts were maintained manually, but by the early 1980s they were being stored in computer files, using increasingly sophisticated accounting software. Financial statements were shared with Board members and regularly discussed at quarterly Board meetings, along with status reports on membership dues receipts and fiduciary trust performance reports.

Since maintaining the financial accounts was a part-time activity, the Assistant for Financial Affairs was able to carry out a number of other, essential administrative duties, such as maintaining newsletter mailing lists, arranging to have newsletters and special publications printed and distributed, fulfilling publication orders, and coordinating frequent mailings to member state agencies. These additional duties were scaled back or eliminated, however, as the Association began to take full advantage of rapid advances in information technology during the 1990s and early 2000s. The Association launched several electronic news bulletins in 1996 to replace other long-running bulletin series, thus eliminating most mailings to member state agencies. And, in 2002, NASDDDS's two monthly newsletters were transitioned to electronic distribution only (see Chapter IV for details).

Meanwhile, due to more rigorous accounting requirements and the added complexities of the Association's finances, the frequency of reporting delays and erroneous and incomplete entries increased during the 1990s and early 2000s. When Mae Davis, long-time incumbent in the bookkeeper position, announced plans to retire in early 2005, Executive Director Bob Gettings recommended to the Board that an outside accounting firm be retained to maintain the Association's financial accounts and the position of Assistant for Financial Affairs (AFA) be eliminated. He pointed out that due to new national accounting standards mandated under the Sarbanes-Oxley law■ it would be necessary to retain a firm to keep track of the Association's accounts and a separate firm to complete an independent annual audit. The cost of the accounting and auditing contracts, Mr. Gettings noted, should be largely, if not entirely, offset by the salary and benefit reductions associated with the elimination of the AFA position.

A request for proposals (RFP) was prepared by the staff and distributed to local accounting firms in February 2005. At its April 27, 2005 meeting, the Board selected from among five bidders Johnson, Lambert and Company to serve as the Association's accounting support firm.<sup>39</sup> Using a similar process,

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♥ Over the years, through a series of mergers and acquisitions, the Association's reserve funds have been managed by the Arlington Trust Company, the 1st American Bank and Trust of Virginia, the Riggs National Bank and Trust, and beginning in 2005, PNC Financial Services.

■ The Public Company Accounting Reform and Investor Protection Act (P.L. 107-204), better known as the Sarbanes-Oxley Act, was approved by Congress in 2002 in the wake of a series of accounting scandals at Enron, Tyco, Adelphia and a number of smaller firms. While the main rationale for the act was the misappropriation of shareholder assets at large commercial firms, the accounting reform provisions of the legislation also apply to non-profit corporations.

the Board selected Rogers and Company to serve as NASDDDS' auditor during a June 13, 2005 conference call.<sup>40</sup> In 2010, Gelman, Rosenberg and Freedman replaced Rogers and Company as the Association's audit firm.

The accuracy and timeliness of Association financial reports improved dramatically following the retention of Johnson, Lambert and Company, as did the

professional quality of the annual audit reports and income tax filings once a dedicated audit firm came on board. Over the years the association has adopted the practice of bidding audit functions in five year intervals. The combination of professional accounting services and audit services enables the association, despite having a small administrative staff, to adhere to the highest standards of financial accountability.

## G

## RE-BASING MEMBERSHIP DUES

In 2011 the NASDDDS Board of Directors approved a revised membership dues structure that links dues assessments to comparative state I/DD Medicaid receipts, rather than to the level of federal assistance under the Developmental Disabilities Act. By adopting this revised methodology for determining state dues rates, the aim of the Board was to gradually increase the share of operating revenues derived from membership dues and distribute the burden of supporting the Association more equitably.

At the time of the Board's action, the old methodology for determining dues had been in place for more than 35 years. All dues increases during the intervening years were applied on a flat, across-the-board basis. The underlying distribution formula remained unchanged and, consequently, the dues ranges were unaltered. Meanwhile, the relative population, need and per capita income data on which the original DD Act grant allocation formula was based had changed dramatically. As a result, some states were paying much higher dues, while other states paid considerably lower dues, than equity would have demanded.

In its 2010-11 audit report, the Association's auditor, Gelman, Rosenberg and Freedman, pointed out this flaw and recommended that "... NASDDDS re-evaluate its membership rates and fully document dues calculations."<sup>41</sup> The Board also discovered that membership dues had slipped as a proportion of overall Association revenue from 67 percent of the total in FY 1998-99 to 50 percent of the total in FY 2010-11.<sup>42</sup>

To eliminate distortions associated with an antiquated dues formula and create a more logical foundation for setting membership dues, the Board, after consulting with members state agency officials, decided to base future dues assessments on relative state Medicaid receipts. Since Medicaid payments were the predominant source of federal aid to state I/DD agencies and since advocacy for positive changes in federal Medicaid policy was a principal benefit of Association membership, the Board concluded that it would make sense to tie dues assessments to the relative amount of federal Medicaid payments each state received for specialized I/DD services. Data on state Medicaid receipts was taken from the most recent edition of the *State of the State in Developmental Disabilities Services*, as published by the University of Colorado's Coleman Institute on Cognitive Disabilities.<sup>43</sup> To cushion the effects of shifting to a new dues formula, the Board decided to phase the new dues rates in over a three-year period beginning on FY 2011-12 and culminating in FY 2014-15. Aggregate dues payments were projected to increase from \$706,939 in FY 2011-12 to \$911,550 by FY 2015-16 as a result of the new dues formula. States with the largest three-year increases in dues are given four years to phase in their new dues rate, while states currently paying dues exceeding the FY 2014-15 rates will have their dues reduced beginning in that year.<sup>44</sup>

Implementation of the new dues formula has helped to stabilize the organization's finances and promises to promote the reduction of the Association's

reliance on time-limited grants and contracts to sustain core operations in the years ahead.

Changing the dues structure also established an equitable formula for determining dues that is based on each state's overall budget, allowing growth over time commensurate with budget growth. The dues formula stabilizes the organization's finances in order to sustain core operations in the years ahead.



# H

## LESSONS LEARNED

The main take away lessons from the Association's experiences in managing its finances over the years include:

### 1. Maintaining Diversified Funding Streams

It makes sense to develop multiple revenue sources so the organization does not become overly reliant on one or two funding streams. There were periods in NASDDDS' history when revenue from several relatively smaller funding sources helped the Association avoid sizeable deficits that otherwise would have occurred due to a steep decline in revenue from a major funding stream. For example, when the Association's initial federal grant project ended in the mid-1970s, the organization was able to make a reasonably smooth financial transition because the staff had cultivated alternative ways of securing funds (e.g., small, time-limited government contracts; newsletter subscriptions; and meeting registration fees). Considered singularly, none of these activities yielded a sizeable percentage of the Association's revenues; but collectively they helped create a financial bridge as membership dues were phased in to replace grant funding.

During the 1990s, the Association was able to expand its operations without sizeable increases in membership dues or sustaining support through government grants or contracts by entering into technical assistance contracts with a large number of member state agencies, increasing paid newsletter

subscriptions and elevating publication sales. As information technology improved the Association had to adjust by phasing out printed newsletters and special publications and moving to online publications. Meanwhile, over the past decade the Association has been able to increase the scope of organizational activities substantially by undertaking large system change initiatives in collaboration with other organizations and launching two major interstate collaboratives (NCI and SELN).

All of these financial adjustments offer us one familiar lesson: "don't put all of your eggs in one basket." As is the case with financial investments, diversification and agility are the keys to building a stable, sustainable funding platform.

### 2. Building a Solid Foundation of Membership Support.

Over the years NASDDDS has managed to maintain a reasonably balanced portfolio of membership and external, third party support. Striking this balance has not always been easy. As illustrated above, federal grants and contracts can allow a small organization like NASDDDS to undertake large scale system change initiatives that otherwise would be beyond its reach, both financially and logistically. To be a tenacious advocate for the interests of member state agencies, however, the Association must be able to chart its own course and not rely on third party grants and contracts to finance its core operations. Acting independently includes, when the occasion arises,

“biting the hand that feeds” in the organization’s relationship with federal agencies with which it has grants and contracts.

Some executive branch organizations have allowed themselves to become little more than auxiliaries of the federal agency they depend on for financial support. Government grants and contracts can be a siren song, luring an organization away from its stated mission. A symbiotic relationship based on the pursuit of mutual interests can end with the association serving as a thinly disguised federal task order contractor, carrying out governmental functions the funding agency lacks the qualified personnel and expertise to perform.

To avoid such an outcome, current and future NASDDDS leaders must ensure, as their predecessors have, that:

- Association participation in third party grants and contracts is limited to projects that promise to advance NASDDDS’ mission and are consistent with the organization’s current strategic goals and objectives. The operative question in evaluating the Association’s involvement in any grant or contract-funded activity should be: will the Association’s involvement result in improvements in the accessibility and quality of publicly-funded services and supports for people with intellectual and developmental disabilities;
- Membership revenues, obtained through state dues and other non-grant/contract sources, are sufficient to cover the cost of core activities undertaken on behalf of member state agencies, including advocating on the membership’s behalf for changes in federal laws, regulations and administrative policies designed to advance the interests of the I/DD population; and
- The Association’s strategic goals and objectives are established in consultation with member state agency officials, rather than being influenced by the availability of federal and foundation funding opportunities.

### 3. Maintaining Adequate Financial Reserves

As noted earlier, the availability of financial reserves has helped to stabilize the Association’s finances over the years. Since the mid-1970s NASDDDS’ liquid reserves have been invested in a fiduciary trust account, an instrumentality that provides Association leaders with expert investment advice while allowing them to retain control over the organization’s global investment strategy. The value of the account fluctuates with market conditions, but has never dipped below \$225,000 since 1990 and has ranged between \$750,000 and \$1.1 million over the past four years.

Having a financial reserve has added an important layer of security to Association operations over the years. First, the NASDDDS staff is able to manage cash flow fluctuations without relying on short-term loans or other extraordinary steps to pay outstanding bills. During years in which the organization has run cash deficits, the Association has been able to continue operations without a hitch, knowing that funds are available to cover the temporary shortfall. Second, earnings on the fiduciary trust account generate operating revenues that are used to modulate demands on other revenue sources. Investment income has never represented a major source of operating revenue for the Association. For example, over the past four fiscal years investment income has ranged between \$23,500 and \$43,775, or about one and two percent of total revenues. Still, that’s \$23,000 to \$44,000 that does not have to be raised through increased membership dues or from other sources. And, finally, financial reserves provide a security blanket that allows Association leaders to make important investments in the future that otherwise they might not have the latitude to pursue. For example, the Association was able to purchase a headquarters building in the early 1980s, despite historically high mortgage interest rates, because accumulated reserves were available to cover the upfront costs (e.g., a down payment on the mortgage and the substantial legal costs involved in qualifying for a lower redevelopment loan rate). More recently, when Association revenues declined in the face of the 2007-11 recession, NASDDDS leaders could devise

a plan for weathering the shortfall knowing that they had the option of drawing on reserves if the situation demanded such action.

The primary take away lesson is that broader choices will be available to current and future organizational leaders if the Association continues to maintain adequate, effectively managed financial reserves.

## 4. Retaining Professional Accounting Support

National accounting standards have been tightened in recent years in response to major scandals such as the misappropriation of funds that occurred during the downfall of Enron and other major corporations, as well as the fallout from the financial collapse of 2008. During this same period, the non-profit sector has experienced its own, less widely publicized scandals.

Generally Accepted Accounting Principles (GAAP) was developed by the American Institute of Certified

Public Accountants (AICPA). Since 1999, the Federal Accounting Standards Advisory Board (FASAB) has been designated by AICPA as the sole body responsible for applying GAAP standards to federal government programs. NASDDDS and other non-profit organizations are required to adhere to GAAP standards in maintaining their financial accounts. The recent increase in grant funding has pushed NASDDDS over the \$500,000 threshold that triggers more rigorous reporting requirements on federal grants and contracts. This elevates the importance of having a sophisticated accounting system.

After years of relying on an in-house bookkeeper to maintain the Association's accounts, NASDDDS leaders decided in 2005 to outsource the accounting and auditing functions. As a result of this decision, today the Association's financial reports are more timely, accurate and professional than in the past. Furthermore, Association leaders now have access to expert advice on managing the Association's finances, and at the same or lower cost than had accounting been retained as an in-house function.

# I CONCLUSION

Organizations succeed or fail based on the effectiveness with which they perform their assigned functions and achieve their stated missions. But, inevitably, the most effective organizations are those that prudently manage their financial resources. As this chapter demonstrates, NASDDDS' long

track record of success is tied to a resolute focus on accomplishing its assigned mission, obtaining financial support from multiple sources, prudently managing the resources at its disposal, and maintaining liquid reserves to tide the organization over when shortfalls occur.

## END NOTES

<sup>1</sup> Meeting Minutes, Annual Meeting of the National Association of Coordinators of State Programs for the Mentally Retarded, May 7, 1964.

<sup>2</sup> Meeting Minutes, Executive Officers of the National Association of Coordinators of State Programs for the Mentally Retarded, Chicago, IL, November 19-20, 1967.

<sup>3</sup> Meeting Minutes, NACSPMR Executive Committee, Detroit, MI, October 24, 1968.

<sup>4</sup> Meeting Minutes, NACSPMR Board of Directors, Arlington, VA, October 4-5, 1970, p. 6.

<sup>5</sup> NACSPMR Audit Report: FY 1970-71, Alven M. Gaskins, C.P.A., Arlington, VA, September 20, 1974.

<sup>6</sup> Meeting Minutes, NACSPMR Board of Directors, Arlington, VA, August 14, 1971, pp. 1-2.

<sup>7</sup> Memorandum from Otto P. Estes, Chairman of the Ad Hoc Committee on Organizational Goals and Objectives, to NACSPMR Officers and Board Members, December 10, 1971.

<sup>8</sup> NACSPMR Audit Report: FY 1971-72, Alven M. Gaskins, C.P.A., Arlington, VA, September 20, 1974.

<sup>9</sup> NACSPMR Audit Report: FY 1972-73, Alven M. Gaskins, C.P.A., Arlington, VA, September 20, 1974.

<sup>10</sup> Meeting Minutes, NACSPMR Board of Directors, Minneapolis, MN, May 16, 1972, p. 5.

<sup>11</sup> Meeting Minutes, NACSPMR Board of Directors, Arlington, VA, March 9, 1973, p. 1-2.

<sup>12</sup> NACSPMR Annual Business Meeting Minutes, May 28, 1973, Atlanta, Georgia.

- <sup>13</sup> Meeting Minutes, NACSPMR Board of Directors, Seattle, WA, August 21, 1973, p. 1-2.
- <sup>14</sup> NACSPMR Audit Reports: FY 1973-74 and FY 1974-75, Alven M. Gaskins, C.P.A., Arlington, VA, September 20, 1974 and August 6, 1975.
- <sup>15</sup> Annual Membership Meeting Minutes, May 31, 1976, Chicago IL and May 30, 1977, New Orleans, LA.
- <sup>16</sup> NACSPMR Audit Report: FY 1976-77, James C. White, C.P.A., Springfield, VA., September 2, 1977.
- <sup>17</sup> Annual Meeting Minutes, December 4, 1978, Arlington, VA.
- <sup>18</sup> *Statistical Abstracts of the United States*, Washington D.C.: U.S. Department of Commerce, 1988.
- <sup>19</sup> Meeting Minutes, NACSPMR Board of Directors, Arlington, VA, December 5, 1976, p. 2.
- <sup>20</sup> Meeting Minutes, NASMRPD Board of Directors, Rosslyn, VA, January 31-February 1, 1980, p.3.
- <sup>21</sup> Meeting Minutes, NASMRPD Board of Directors, Alexandria, VA, September 11-12, 1980, p.6.
- <sup>22</sup> Annual Membership Meeting Minutes, December 1, 1980, Alexandria VA, and December 7, 1981, Washington DC.
- <sup>23</sup> Ibid, Association Audit Reports: FY 1973-74 through FY 1983-84.
- <sup>24</sup> Meeting Minutes, NASMRPD Board of Directors, Arlington, VA, January 28-29, 1982 and Alexandria VA, September 23, 1982.
- <sup>25</sup> Ibid, Association Audit Reports: FY 1984-85 and FY 1995-96.
- <sup>26</sup> Meeting Minutes, NASDDDS Board of Directors, Alexandria VA, September 16, 1994.
- <sup>27</sup> Gettings, Robert M., *Eliminating Inappropriate Nursing Home Placements: An Analysis of Federal-State Implementation of OBRA-87's PASARR Requirements* (1990); Smith, Gary A., et. al., *Supported Living: New Directions in Services to People with Developmental Disabilities*; Smith, Gary A., *Community Supported Living Arrangements: A Guide to Section 1930 of the Social Security Act* (1991); Gettings, R.M. and Gary A. Smith, *The HCB Waiver Program and Services to People with Developmental Disabilities: An Update* (1991); Gettings, R.M. and G.A. Smith, *Supported Employment and Medicaid Financing* (1991); Gettings, R.M., *1991 State Legislation Affecting People with Developmental Disabilities* (1992); Gettings, R.M. and G.A. Smith, *Medicaid in the Community: The HCB Waiver and CSLA Programs; Summary of Existing Legislation Affecting People with Disabilities* (1992); Smull, Michael and Susan Burke Harrison, *Supporting People with Severe Reputations in the Community* (1992); *1991 and 1992 State Legislation Affecting People with Developmental Disabilities* (1993); Smith, G.A. and R.M. Gettings, *Medicaid-Funded Home and Community-Based Waiver Services for People with Developmental Disabilities* (1993); Gettings, R.M. and G.A. Smith, *Medicaid's ICF/MR Program: Present Status and Recent Trends* (1993); Gettings, R.M. and G.A. Smith, *The HCB Waiver and CSLA Programs: An Update on Medicaid's Role in Supporting People with Developmental Disabilities in the Community* (1994); Ashbaugh, J. and G.A. Smith, *Managed Care and People with Developmental Disabilities: A Guidebook* (1995).
- <sup>28</sup> Ibid, NASDDDS Audit Report for FY 1986-87 and FY 1992-93.
- <sup>29</sup> Meeting Minutes, NASDDDS Board of Directors, Alexandria VA, September 20, 1996.
- <sup>30</sup> Annual Business Meeting Minute, NASDDDS, Alexandria VA, November 19, 1998.
- <sup>31</sup> Ibid, NASDDDS Audit Reports, FY 1979-80 and FY 1998-99.
- <sup>32</sup> Olmstead, 138 F.3d, affirmed in part, vacated in part, and remanded, June 22, 1999.
- <sup>33</sup> Gettings, Robert M., *Forging a Federal-State Partnership: A History of Federal Developmental Disabilities Policy*, Washington D.C.: American Association on Intellectual and Developmental Disabilities and Alexandria VA: National Association of State Directors of Developmental Disabilities Services, 2011, pp. 110-111.
- <sup>34</sup> Based on NASDDDS accounting records from FY 2001-02 through FY 2011-12.
- <sup>35</sup> Ibid.
- <sup>36</sup> Audit Report, FY 1979-80, White and Associates, C.P.A., Arlington, VA, November 3, 1980.
- <sup>37</sup> NASMRPD Audit Report: FY 1980-81, James C. White, C.P.A., Springfield, VA., September 1981.
- <sup>38</sup> Meeting Minutes, NASMRPD Board of Directors, Arlington VA, January 28-29, 1982, pp. 7-8.
- <sup>39</sup> Meeting Minutes, NASDDDS Board of Directors, Portland, Oregon, April 27, 2005.
- <sup>40</sup> Conference Call Minutes, NASDDDS Board of Directors, June 13, 2005.
- <sup>41</sup> Add citation for Gelman, Rosenberg and Freedman's 2010-11 audit report.
- <sup>42</sup> Memorandum to NASDDDS members from NASDDDS Board President Mary Lee Fay, April 13, 2012.
- <sup>43</sup> Braddock, David, Richard Hemp and Mary C. Rizzolo, *The State of the States in Developmental Disabilities: 2011*, Department of Psychiatry and the Coleman Institute for Cognitive Disabilities, The University of Colorado, distributed in collaboration with the American Association on Intellectual and Developmental Disabilities, Washington, D.C., 2012.
- <sup>44</sup> Ibid, April 30, 2012 memorandum from Mary Lee Fay to member states.

# VIII CHAPTER

By Nancy Thaler,  
NASDDDS Executive Director

*Progress, far from consisting in change, depends on retentiveness. When change is absolute there remains no being to improve and no direction is set for possible improvement. ... When experience is not retained....infancy is perpetual.*

George Santayana

## FUTURE DIRECTIONS IN STATE POLICY: *The Path Ahead*

**D**uring the June 1965 meeting of NACSPMR one member asked: “Does this organization have a unique contribution to make?” The answer, after these 50 years, is surely still, “Yes – of course.”

The chapters in this book, so carefully crafted by Bob Gettings, provide not only a description of how NASDDDS began and what it has accomplished, they also provide a summary of lessons learned that explain what lies behind the effectiveness of NASDDDS as an organization. Those lessons learned will be valuable to the future leadership of NASDDDS - and could serve any organization working to advance a social purpose.

**So – What’s next?  
How should NASDDDS be  
thinking about the future?  
How should it help states  
prepare for that future?**

The next-generation challenges facing public disability support systems cannot be examined apart from the challenges facing our society as a whole.

Our state service systems operate in a real world environment – and are affected, as is the society as a whole, by the national and world economy, by the political sphere, by scientific advancements, by social change and movements, and by national demographics. Some things are constant; some things change gradually; and occasionally there are what seem to be tectonic shifts.

### THE CONSTANTS

*One constant is that both state and federal governments will continue to support people with developmental disabilities.*

In the future we can be confident that the federal government will still be funding services and establishing requirements for those services. States will still be funding and administering programs. Changes are likely to occur from state to state, as they have for the past 50 years, as to which state agency is given the responsibility to operate programs - but we can be reasonably sure that state governments will keep on exercising these responsibilities through some state agency.

And what has been clear over the past 50 years will continue to be true in the future: that states will

benefit from having a national association to inform them, support them, and advocate for good policy at the federal level.

*Another constant is the right of people with disabilities to fully participate in the life of their communities.*

Building on the gains made through federal legislation and the courts, federal and state policies continue to advance the full inclusion of people in the community. This growing full inclusion will stimulate the development of new service models that empower individuals and their families, giving them more control over their lives and services.

*Finally, the focus on quality will remain constant, and the use of data will become the basis for determining quality.*

Information from real time interactions, along with direct consumer reporting and the use of data analytics, will become the foundation for improving quality.

The Association's ability to provide information, training, and technical assistance will continue to be instrumental in increasing the capacity of states to build quality into their programs and to measure performance.

## THE GRADUAL (and Predictable)

*The gradual – and predictable – change we can see is demographic.*

The aging of the baby boom generation (born between 1946 and 1964) will significantly shape the future for at least the next 25 years. As this generation ages, service products will be developed to meet their needs – and these new service products will also benefit people with disabilities. But meeting the needs of this generation as it ages will require resources both financial and human. As the demand for long-term care services grows, so too will the

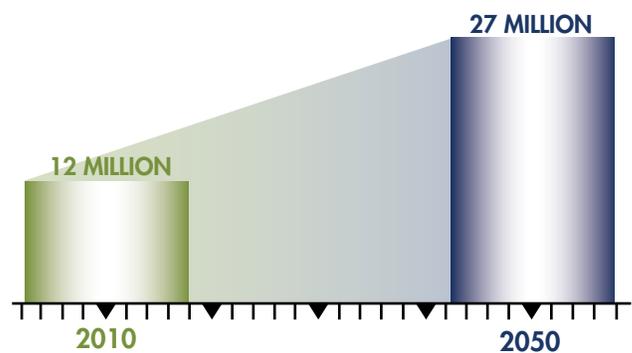
## The Number of Americans Aged 65 Years and Older is Growing Dramatically



Baby boomers (those between 1946 and 1964) will turn 65 between 2011 and 2019.

During this time, 10,000 Americans will turn 65 everyday.

## The Number of Americans Needing Long-Term Care Will More Than Double by 2050



## 48% of Americans 40 Years or Older Say That Almost Everyone Will Need Long-Term Care as They Age



35% SAY THEY HAVE SET ASIDE MONEY TO PAY FOR THEIR LONG-TERM CARE NEEDS

### 2012

Nursing home care = \$82,000/year

Home health care (at 20 hours/week) = \$22,000/year

Source: Kaiser Family Foundation ([www.kff.org](http://www.kff.org)) analysis. Original data and detailed source information are available at [http://facts.kff.org/jama\\_082813](http://facts.kff.org/jama_082813)

costs to Medicaid and Medicare. At the same time the need for care-givers will grow at a rate that will outstrip the pool of working-age adults available to provide care. And so competition for resources will become a larger factor than it has been in the past.

The Association's responsibility in response to these changing demographics will be to help states understand and plan to meet these challenges. Cost-effective services and supports for people with I/DD and for family care-givers have been important in our systems in the past - but in the future they will need to become a primary focus. The Association's role will be to research and disseminate information about service and support models for people with I/DD and for family care-givers: services and models that lead to good outcomes while using the minimum resources necessary to achieve those outcomes.

The Association must also maintain its assertive relationship with federal agencies responsible for national long-term care policy - including service design and payment policies that support family care-givers.

***The demographics of the United States are changing in other ways that are predictable.***

Today, one in four newborns is Hispanic; of children under age 5 more than 50% are non-white; 48% of births are to unmarried women – most in their twenties; and poverty rates are growing for people with disabilities and their families across all races and cultures.

These trends will compel changes: in how we conduct outreach to families; in the kind of supports we provide to families; and in the cultural sensitivity of our programs.

And poverty, both a cause of and a consequence of disability, will require collaboration among social support systems.

The Association must be prepared to assist states, first, in understanding the implications of serving

individuals with IDD and families from diverse cultures and, second, in developing the cultural competency necessary to provide services that are meaningful and helpful.

The Association must be alert to - and involved in - national policy developments affecting people living in poverty - including in the areas of housing, family services, and income supports.

## Facts

- One in four newborns are Hispanic
- Of children under age 5, more than 50% are non-white
- Poverty rates of toddlers
  - 41% Black
  - 32% Hispanic
  - 13% White
  - 11% Asian



- 48% of births are to unmarried women – most in their twenties
- The *Great Cross Over* – the median age at birth (25.7) now fall before the median age at first marriage (26.5)

Pew Research NY Times 6.8.13

## THE TECTONIC

*Climate change is one of these seemingly abrupt developments.*

Tectonic shifts are often experienced as abrupt and sometimes violent events. But in truth, while they often manifest as crises, they can also be seen as opportunities, since the pressures that prompt such events are, more often than not, well known.

Hurricanes and floods have become more frequent and more damaging in recent years. Hurricane Sandy in 2013, with its impact on New York, New Jersey and Connecticut, demonstrated that people with disabilities are subject to the same general threats as all citizens, but meeting their needs during such upheavals requires more preparation and a more organized response. And so, in areas that can now anticipate that nature may very well disturb the status quo, emergency planning with families and with community agencies must become a more compelling function of state agencies.



*Developments in the fields of science and technology are just beginning to be revealed.*

In the same way that the Internet was under development for decades before it became available to the general public - and changed our society quickly and profoundly – in science and technology today, products and services are now being researched and developed that will have impact equally as profound. Smart cars, smart glasses and smart homes; wearable electronics; brain-computer interfaces; and robotics may well become part of our lives in the not-too-distant future.

These technological developments have the potential to make the world far more accessible to people with I/DD, to increase independence, and to expand opportunities. Every dimension of a person's life may soon be positively transformed: from



simple communication with others, to traveling, to controlling one's home, to contributing in the work place and participating in sports and recreation.

The ability of people with I/DD to access technological advances will depend on state and federal funding policies and on structures that make the new technology available. NASDDDS can assist states by developing model policies for supporting the use of technology and by designing strategies to build the necessary understanding and capacity in state service systems.

*Advancements in the neurosciences  
are rapidly expanding our  
knowledge of the brain.*

The BRAIN Initiative (Brain Research through Advancing Innovative Neurotechnologies, also referred to as the Brain Activity Map Project) is a proposed collaborative research initiative, announced by the Obama administration in 2013, with the goal

of mapping the activity of every neuron in the human brain. But the study of the neural mechanisms involved in mental processes, emotion, and behavior are already leading to an understanding of how the brain is always changing - and of our capacity to learn throughout life.

Understanding the impact of early life experiences on brain development is transforming early intervention and education strategies as well as family training. Also new are programs to enhance learning capacity and brain function, and devices implanted to treat neurological disorders.

The Association must disseminate information about these advances in neuroscience - with an emphasis on how such advances can be applied to the services and supports provided to people with I/DD and their families. In addition, the application of advances in neuroscience will require guidance on policies and ethical issues that will undoubtedly arise.



# THE ROLE OF NASDDDS

We may think that the world of 2014 is very different from that of Bert Schmickel and Dr. Louis Belinson in 1964 when they and their fellow state directors met to create a national association. But a paper distributed to the early potential members referred to the same realities we face in 2014: “...the significant differences from State to State relating to the attitude and sophistication of the general public, general revenue situation, resources, as well as geography and climate.”

The lessons learned catalogued in this publication, along with the principles for supporting the States and the guidelines for affectively managing the organization, are the foundation of NASDDDS. Social, environmental, economic, and political contexts will change over the decades - but not the basic functions and responsibilities of NASDDDS, as Bob Gettings has so thoroughly spelled out in this book:

- Influencing Legislative and Administrative Policy
- Maintaining an Informed Constituency Through the Dissemination of Information
- Providing Technical Assistance: Leveraging Knowledge to Promote Change – One State at a Time
- Creating and Sustaining System-wide Reforms Through Inter-Organizational Collaboration
- Managing the Association’s Finances Effectively

# APPENDIX

## LESSONS LEARNED

### *Influencing Legislative and Administrative Outcomes*

#### **The Interactive Nature of Association Activities**

The pursuit of the organization's federal legislative and administrative goals should not be viewed as a unitary endeavor. Rather, it should be seen as part of a coordinated set of services geared toward helping member state agencies accomplish their goals and improve the services and supports furnished to people with I/DD and the families who support them.

#### **Focusing on Priority Issues**

To be effective in the federal legislative and administrative arena, an organization must zero in on the issues of greatest relevance to its membership, which, in the case of NASDDDS, consists of the 51 member state agencies.

Yet, in setting national legislative and administrative goals, there are two primary reasons why Association leaders have focused first and foremost on federal policies which directly impact the capacity of member state agencies to carry out their assigned mission. First, the resources which the Association is able to devote to activities aimed at influencing federal policy are extremely limited. Second, the Association's ability to influence federal policy is far greater in areas where member state agencies have a direct role in organizing, financing and overseeing the delivery of the affected services, compared to areas in which another federal, state or local agency has primary responsibility.

#### **Balancing the Individual and Collective Interests of Member State Agencies**

Each member state agency has its own federal legislative and administrative priorities as well as channels through which it can make its views known to state and national policymakers. At any given point in time, a member state agency's priorities may mesh neatly with, or divert from, the priorities of other member state agencies. Association leaders, therefore, need to be able to distinguish between the individual and collective interests of member state agencies

#### **Working Collaboratively with Other National Organizations**

Advocates for federal policy changes often feel like Sisyphus, the mythic Greek king who was repeatedly forced to push a huge boulder up a steep hill throughout eternity. With scores – sometimes hundreds -- of disparate interest groups vying for attention, it is difficult to make your voice heard, much less have your views reflected in government policy.

#### **Maintaining a Forward-Leaning Legislative and Administrative Agenda**

The responsibilities of the Association reach beyond assisting member state agencies to achieve current goals within the federal policy arena. NASDDDS also has an obligation to help member state officials understand emerging trends in federal-state policy and the ways in which these developments are likely to impact on the future delivery of services to the I/DD population.

## *Information Dissemination*

### **Serving the Information Needs of Member State Agencies**

Over the years the success of NASDDDS's efforts in the information dissemination arena has been rooted in a persistent, laser-like focus on the information needs of member state agencies.

### **Capitalizing on the Association's Activities in the Public Policy and Technical Assistance Arenas**

The Association's information dissemination activities can and should be informed by its efforts to influence federal policy and assist states in mapping out new, more effective strategies for financing and delivering I/DD services.

### **Harnessing Technological Improvements**

It is important to be selective about the types and volume of information transmitted to member state agencies. In an age of information overload, the Association must help state officials to sort through the deluge by focusing attention on items of maximum relevance to the key planning and operation decisions state I/DD agencies face today.

### **Using Various Modes of Communication**

In organizing its communication program, the Association must take into account the different learning styles of member state agency officials. Physical meetings and online webinars meet the needs of oral learners, while newsletters, news bulletins, policy briefs and longer reports meet the needs of those who prefer written material. Clarity and brevity are critical in conveying information to busy state executives regardless of the mode of communication used. But, it is also important to include links to more in-depth information for those who choose to delve more deeply into the topic under discussion.

## *Technical Assistance*

### **Capitalizing on Technical Assistance Experiences**

By helping member state agencies to solve service delivery problems, the Association's staff gains deeper insights into contemporary policy issues and practices in the I/DD field. This knowledge in turn assists the Association in: (a) organizing membership meetings focused on issues of priority concern to member agency officials; (b) pinpointing topics for special reports analyzing issues facing the field and delineating current best and promising practice across the United States; and (c) identifying federal legislative and administrative policies that limit the provision of appropriate, person-centered services to individuals with intellectual and developmental disabilities and advocating for the removal of such barriers.

### **Recruiting and Retaining Qualified Staff**

The success of the Association's technical assistance program lies to a significant extent in hiring and retaining staff with extensive experience in managing state I/DD services

### **Effectively Utilizing Staff Resources**

The operational policies governing the provision of technical assistance to member state agencies allows the Association to maximize the benefits of staff expertise. The staff is able to provide assistance to a larger number of member state agencies by limiting the scope and circumstances under which TA services are furnished.

### **Developing Strategic Alliances**

Forging partnerships with other disability organizations that have complimentary goals offers member state agencies a wider range of assistance. In addition, these alliances have allowed NASDDDS to capitalize on the growing availability of federal

grants and contracts, thus reducing the proportion of TA expenses financed through membership dues and other revenue sources.

## Principles for Providing Technical Assistance Services

### GUIDING PRINCIPLE I

The Association responds to all mail, e-mail and telephonic requests for information and advice regardless of the source of the inquiry as long as the requested information can be easily assembled and quickly dispatched. But, priority is assigned to informational requests emanating from member state agencies.

### GUIDING PRINCIPLE II

The Association's staff will agree to undertake technical assistance assignments only when the nature of the tasks to be performed comport with the mission and strategic goals of the Association.

### GUIDING PRINCIPLE III

The Association will agree to furnish technical assistance services only when the staff either possesses the requisite skills and knowledge base to complete the necessary tasks or can supplement staff resources by securing the services of other qualified individuals through sub-contractual arrangements.

### GUIDING PRINCIPLE IV

The Association's staff will avoid performing as part of a technical assistance contract design and implementation tasks that are rightfully the province of a state agency.

### GUIDING PRINCIPLE V

When a particular technical assistance project or activity will require a significant commitment of staff time over an extended period, there must be evidence that the work to be performed is likely to yield not only benefits to the requesting state agency but significant indirect benefits to other member state agencies as well.

## GUIDING PRINCIPLE VI

Before the staff agrees to undertake a technical assistance project on behalf of another state agency or organization (e.g., a state developmental disabilities council, a state Medicaid agency, or a statewide provider coalition), it will consult with the member state agency. The staff's agreement to undertake or participate in such a project will be contingent on an affirmative indication of support from the member state agency.

### *Inter-Organizational Collaboration*

#### Synergistic Impacts

By selecting partners with capabilities the Association lacks, NASDDDS is able to undertake broad, system change initiatives that otherwise would be beyond its reach. The National Core Indicators program developed and managed in conjunction with HSRI, and the SELN project developed and managed in conjunction with ICI University of Mass. offer good examples of how NASDDDS has been able to create dynamic partnerships that support the interests of member state agencies.

#### A Sense of State Ownership

The shared goals of member state agencies have served as the genesis of some of NASDDDS' most important collaborative ventures. The State Employment Leadership Network illustrates how the Association has been able to launch groundbreaking system change initiatives by harnessing the energy and commitment of member state agencies.

#### Shared Values and Continuity of Relationships

Inter-organizational partnerships work best when the participating parties share a common set of values. As a result, the choice of partners is a critical factor in initiating and sustaining a successful inter-organizational collaboration. By partnering

with organizations that are committed to affording individuals with lifelong disabilities and their families opportunities to live productive, inclusive lives in communities of their choice, NASDDDS has been able to contribute to major advances in the delivery of I/DD services over the years.

## Focusing on Emerging Systemic Challenges and Opportunities

NASDDDS' collaborative ventures have focused largely on cutting edge examinations of the contours of next generation challenges facing public disability support systems.

## Seizing Opportunities

Agility in responding to opportunities as they arise is another hallmark of building effective partnerships.

## *Balancing the Books*

### Maintaining Diversified Funding Streams

It makes sense to develop multiple revenue sources so the organization does not become overly reliant on one or two funding streams.

### Building a Solid Foundation of Membership Support

NASDDDS has benefited from maintaining a reasonably balanced portfolio of membership and external, third party support.

NASDDDS has successfully operated according to a set of financial principles that ensure that:

- Association participation in third party grants and contracts is limited to projects that promise to advance NASDDDS' mission and are consistent with the organization's current strategic goals and objectives. The operative question in evaluating the Association's involvement in any grant or contract-funded activity is: will the Association's involvement result in improvements in the accessibility and quality of publicly-funded

services and supports for people with intellectual and developmental disabilities;

- Membership revenues, obtained through state dues and other non-grant/contract sources, are sufficient to cover the cost of core activities undertaken on behalf of member state agencies, including advocating on the membership's behalf for changes in federal laws, regulations and administrative policies designed to advance the interests of the I/DD population; and
- The Association's strategic goals and objectives are established in consultation with member state agency officials, rather than being influenced by the availability of federal and foundation funding opportunities

### Maintaining Adequate Financial Reserves

The availability of financial reserves has helped to stabilize the Association finances over the years.

### Retaining Professional Accounting Support

NASDDDS and other non-profit organizations are required to adhere to GAAP standards in maintaining their financial accounts. Grant funding over the \$500,000 threshold triggers more rigorous reporting requirements on federal grants and contracts under Circular A-133, which can best be provided by professional accounting support.





# NASDDDS

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