



Research Agenda

*National Association of State Directors of Developmental Disabilities Services
August 2003*

I. Introduction

Background, Purpose and Audience

In November 2002, the membership of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) ratified a new Strategic Plan to direct the Association's efforts to assist states in developing high quality, person-centered systems of support for people with developmental disabilities and their families. The Strategic Plan¹ identifies five priority policy goals that address key challenges currently confronting public developmental disabilities service systems in the areas of quality improvement, system design, workforce development, and finance.

Following the completion of the Strategic Plan, the NASDDDS Board of Directors initiated the development of an Research Agenda for the Association to guide the collection and dissemination of information related to the broad policy goals included in the plan. An Ad Hoc Advisory Committee on Research (See Appendix) was named by the Board to recommend strategies for gathering data regarding strategic plan priorities that: (a) are consistent with the Association's mission, goals and guiding principles; (b) lead toward improvements in the lives of the people receiving support, and; (c) reflect with the day to day realities of contemporary service practices. The Research Agenda places a strong emphasis on practical and useful outcomes to realize the intention of the Board that the document be designed not as a narrowly construed plan for empirical inquiry, but rather, as a guide for the collection, generation and application of new knowledge drawn from a broad array of demonstration and evaluation activities concerning services and supports for people with developmental disabilities.

The Research Agenda is written to address the needs of people directly involved in organizing, financing and delivering developmental disabilities services, as well as those individuals whose decisions regarding public policy and finance have an impact on the nature and level of support available for such services. The intended audience includes:

- *State DD Agency Officials* who are required to make day-to-day operational and policy decisions in an environment where the current state of knowledge contains major gaps and incongruities.

¹ See NASDDDS Strategic Plan, October 2002.

- *State Agency Officials* including department heads and finance and budget officers who are in a position to influence public policy decisions affecting individuals with developmental disabilities.
- *Elected and Appointed Officials*, including state legislators, members of state Congressional delegation, Congressional staff, high-level government officials and others who are in a position to influence departmental budget allocations, state agency organizational structure and functions as well as statutory and regulatory decisions.
- *Professionals* working in the developmental disabilities field and those based in universities, philanthropic organizations, and other non-governmental settings conducting research, outcome evaluation, and planning and policy analysis.
- *Federal Officials* who are responsible for funding disability research, demonstration and evaluation studies, as well as for disseminating new knowledge related to serving individuals with developmental disabilities.
- *People with Interest and Expertise* in developmental disabilities policy, including families, advocates and people with disabilities.
- *People with Disabilities, their Families and Advocates* who need information on effective and appropriate support alternatives that facilitate their involvement in community life.

Design Parameters

The NASDDDS agenda for research and demonstration incorporates several conceptual parameters to align activities with the Association's mission and guiding principles. The agenda is designed to emphasize research approaches that lead to the accomplishment of scientifically legitimate and valid outcomes that: (a) have a positive impact on the lives of people receiving support, (b) increase the capacity of people receiving support to live and work in the community, and (c) affirm each person's rights to equal treatment, equal access and quality support. The Research Agenda expresses the Association's support for research, evaluation and demonstration activities that fall within design parameters that:

Demonstrate Respect for People Receiving Support. Topics selected for investigation demonstrate respect for the privacy, individuality, and self-determination of the people receiving support.

Emphasize Relevant Activities. Research and demonstration activities are designed to provide information on topics that have meaning to the people who are the subjects of the investigation and relevant to their daily lives.

Address Issues of Affordability. Research is grounded in the day-to-day financial realities of service provision, and demonstrates an understanding of cost and expenditure data that are related to the current and future affordability of long-term systems of support.

Demonstrate Practical Use and Functionality. Research focuses on the development of practical solutions to day-to-day problems faced by state agencies, providers, consumers, and families. Emphasis is placed on developing tools state agencies can use to improve the quality and capacity of support systems, reduce costs, document change, and replicate effective models of service provision.

Provide Evidence on the Effectiveness of Support. Research and demonstration initiatives provide factual qualitative and quantitative evidence on the effectiveness of support methodologies as well as state systems of funding, quality assurance, program evaluation, and data management.

Produce Valid and Reliable Results. Research provides data that accurately describe the events being investigated, that can be replicated by other investigators to improve services and that can be relied upon to consistently produce the intended results.

Discover New Approaches. Projects identify, document and implement new service designs that demonstrate improvements in support outcomes.

II. Research Goals

The Association's Strategic Plan identifies goals that cut broadly across the range of policy and practice responsibilities typically held by state developmental disabilities agencies. The Research Agenda focuses Strategic Plan implementation on more narrowly defined practical objectives reflecting the overlap of policy and practice and the need to accommodate to unanticipated activities arising from the non-linear and sometimes chaotic decision making processes that typically characterizes state policy development. At a functional level, this means that research goals: (a) are relevant to the daily lives of people receiving support, (b) reflect attention to the process of governing and state operations, and (c) further the accomplishment of the policy objectives in the Association's Strategic Plan.

<p>Research Goal 1: Examine the relationship between self-directed services and the health and safety of the individual receiving support.</p>

Relevance. Developmental disabilities policy is evolving at both the state and federal levels toward a new emphasis on self-directed services. State agencies are restructuring their service delivery systems in answer to calls from consumers and professionals alike for more flexible, *self-determined* support and assistance alternatives. The federal Center for Medicare and Medicaid Services (CMS) has launched a number of initiatives designed to facilitate a change in Medicaid policy toward consumer control through the President's New Freedom Initiative, including awarding grants to the states to support Real Choice Systems Change and by initiating a new Independence Plus Medicaid waiver format. While acknowledging that this policy shift is long overdue, many observers express concern that state officials, as administrators of the Medicaid program, are being placed in the difficult position of having to nurture individuals' capacity to control their services and make independent decisions while simultaneously taking responsibility for guaranteeing their health and welfare. At a practical level, however, there is little data available to guide states in their efforts to design appropriate policies governing the decisions that must be made regarding risk, personal responsibility, freedom, and control. The success of state's efforts to sustain self-directed support initiatives rests to a great extent on a successful resolution of this issue.

Research Questions.

- What is the impact on individuals' health, safety, and welfare when they take charge of the services they receive?
- How does the health and safety of people who direct their own supports compare with that of people who receive support from traditional systems of care?
- What behavioral, attitudinal or personal factors are correlated with high levels of health, safety, and welfare among people who direct their own services?
- What structural components of an individual's system of support are positively correlated with high levels of health, safety, and welfare?

- How do rates of abuse, neglect, maltreatment, and injury among people who receive traditional services differ from those among individuals who direct their own supports?
- How do feelings of personal satisfaction, independence, and accomplishment among people who direct their own services differ from those individuals who receive services from traditional service providers?
- What is society’s tolerance level with respect to the “dignity of risk?”

Relationship to Strategic Plan. This research goal addresses the following Strategic Plan priorities:

- Strengthening system-wide quality assurance and improvement capabilities.
- Building the community infrastructure needed to under-gird a system of individualized supports.
- Building community capacity to support people with multiple and complex needs.
- Developing a skilled workforce.
- Developing responsive financial systems and strategies.

Research Goal 2: Assess the effectiveness of existing methods of support delivery at producing the outcomes intended.

Relevance. State developmental disabilities agencies are responsible for ensuring that increasingly scarce tax dollars are used to accomplish outcomes established by state and federal policy. As state revenues decline in the face of escalating demand for services and supports, public administrators must direct resources to program options that have the greatest likelihood of success and the highest rate of return. Decision makers need assurance that: (a) the benefits of the support methodologies used justify their costs; (b) that service options funded by the state deliver the greatest outcomes for the lowest cost, and; (c) where possible, high cost services are replaced by lower cost alternatives that produce outcomes of comparable or higher quality and effectiveness. State administrators and policy makers need to have accurate outcome data to justify the decisions they are called upon to make, and to help them make the right choices.

Data on the efficacy of standard interventions and treatment approaches, however, typically is incomplete, flawed, or unavailable. Research is needed to document the efficacy of programs, training approaches and management technologies; in addition, studies are needed to describe the impact of services on individuals, families, and communities and to compare the costs and benefits of existing support alternatives.

Research Questions.

- What is the nature of the relationship between sheltered work and integrated employment?

- How effective is the continuum approach to service delivery? Do day treatment programs lead to sheltered employment, supported employment, integrated employment?
- What are the outcomes of self-determination? Do people with disabilities who direct the services and support they receive: (a) express higher rates of satisfaction, (b) experience less staff turnover, (c) cost less to support, or (c) earn higher wages?
- Are people receiving support accomplishing the outcomes they desire?
- Does family support offer families the flexibility they need to meet their needs as they define them?
- How effective are current quality assurance systems at actually improving quality?
- To what extent do the interventions and supports that are provided actually improve a person's life, decrease his or her reliance on other services or individuals for support, and improve the capacity of the individual to live without support?

Relationship to Strategic Plan. This research goal addresses the following Strategic Plan priorities:

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- Building community capacity to support people with multiple and complex needs.
- Developing a skilled workforce.
- Developing responsive financial systems and strategies.

Research Goal 3: Assess the challenges and opportunities presented by the growing cultural diversity among people receiving support as well as those who provide it.

Relevance. Developmental disabilities service delivery systems reflect the broader cultural trends and population demographics of society at large. Increasingly, states are being called upon to support larger numbers of individuals from widely diverse ethnic and cultural backgrounds. At the same time, the composition of the direct care workforce is undergoing similar changes. It is not unusual for provider agencies to employ staff from ethnic/cultural backgrounds that are not representative of those of the individuals receiving support.

The most recent data from the U.S. Census Bureau reveals an increasingly diverse national demographical picture. These current population trends are reflected in the referrals being received by state/local developmental disabilities agencies and in the cultural make-up of the workforce. Ethnic and cultural differences in child rearing practices, the role of the family, the nature of professional services and views regarding independent living and the responsibilities of government can have a significant impact of the ability of a state agency to carry out its mission. Research in this area can address any of a number of questions regarding the differences existing between people from varying backgrounds who need services including: the nature of the supports to be offered, the treatment of the individual

vis-à-vis the family, and the meaning of self-determination. Research also should address the impact of cultural differences on staff recruitment and retention policies, supervision, and overall performance expectations.

Research Questions.

- What is the impact of cultural differences on people receiving support, their families, their staff, provider organizations, and their communities?
- What challenges does a culturally diverse workforce pose for the administrators of state/local service delivery systems?
- What is the impact of cultural differences in the nature, quality, quantity or scope of supports requested?
- What is the impact of cultural differences in the nature, quality, quantity or scope of supports provided?
- What does cultural diversity within the work force mean to the people receiving support?
- What are the challenges of supervision in a multi-culture, multi-language environment?

Relationship to Strategic Plan. This research goal addresses the following Strategic Plan priorities:

- Strengthening system-wide quality assurance and improvement capabilities.
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- Developing responsive financial systems and strategies.

Research Goal 4: Perform meta-analyses of states' experiences with deinstitutionalization and community integration to identify the components of successful change.

Relevance. Deinstitutionalization has been a primary focus in the design and implementation of state service delivery systems for the past thirty years. Although state reliance on large congregate service settings continues to decline, the relatives of some institutional residents remain vociferously opposed to community living for their own sons, daughters, sisters, and brothers. Broad-based analyses are needed that synthesize data and lessons learned from longitudinal and cross-sectional studies completed over the past several years on the impact of deinstitutionalization and community integration.

Research Questions.

- What has the field learned from the community placement process that can and should be applied to current efforts to strengthen and improve the community infrastructure?
- What are the primary conclusions of studies of the effectiveness of community service alternatives for people with “severe reputations” who were formerly supported in institutions?
- What approaches do states use to divert people in crisis from institutional admission?
- What treatment approaches most effectively divert, treat and provide long term support to individuals with multiple needs, co-occurring developmental and behavioral support or intensive medical needs?
- What are the key lessons learned by states through the process of institutional closure?
- What does deinstitutionalization mean to the people moving out of the institution? What does it mean to previously institutionalized individuals to live in the community?

Relationship to Strategic Plan. This research goal addresses the following Strategic Plan priorities:

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- Developing responsive financial systems and strategies.

Research Goal 5: Identify and analyze effective approaches for supporting people with challenging behaviors.

Relevance. In some situations, a few individuals with developmental disabilities and co-occurring conditions need a level of intervention, treatment and care that requires the community based service delivery system to develop highly specialized programs. Sometimes referred to as “special populations,” these individuals may require intensive clinical treatment offered by specialized medical, psychological, or specialized programs that involve high costs and, in some cases, limited community involvement. People with major cognitive and/or physical disabilities, challenging behavior patterns, pervasive or terminal degenerative conditions or any of a number of low incidence disorders may experience difficulty locating the support and professional involvement they need to succeed. Individuals with the most severe disabilities may be exposed to new and promising treatment approaches that do not have data supporting their effectiveness or impact on the individual. It is important to understand the efficacy of intrusive treatment alternatives and the extent to which evidence is present to document the positive changes that take place as a result of their application.

Research Questions.

- How effective are specialized treatment programs for people with developmental disabilities whose behavior constitutes a danger to themselves or others, sex offenders, arsonists, or perpetrators of other crimes? What are the key programmatic or treatment components that are related to successful treatment or intervention?
- What results have been achieved by demonstration programs testing new or innovative approaches to developing comprehensive community based services for people with low incidence, multiple, or intensive behavioral or mental health needs?
- How effectively do psychotropic or other medications manage the mental or physical conditions of people with developmental disabilities in the community?
- To what extent do specific treatment and support interventions actually improve peoples' lives, decrease their reliance on other services or individuals for support, and improve their capacities to live in the community?
- What are the long and short-term costs of providing intensive community support and supervision to people with dual diagnoses, challenging or threatening behaviors? What treatment approaches are the most cost effective?
- What emergency and crisis management strategies have been demonstrated to be successful?
- What are the characteristics of effective collaborative approaches to supporting people with co-occurring conditions of serious emotional disturbance in combination with developmental disabilities by involving state/local mental health and developmental disabilities agencies?

Relationship to Strategic Plan. This research goal addresses the following Strategic Plan priorities:

- Strengthening system-wide quality assurance and improvement capabilities.
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- Building community capacity to support people with multiple and complex needs.
- Developing a skilled workforce.
- Developing responsive financial systems and strategies.

Research Goal 6: Identify performance benchmarks related to clinical interventions and high cost treatment alternatives.

Relevance. People with developmental disabilities may require a level of intervention, treatment and care that can challenge the capacity of community based service delivery systems and individuals with diagnoses of autism, significant cognitive and/or physical disabilities, pervasive or terminal degenerative conditions or any of a number of low incidence disorders may experience difficulty locating the support and professional involvement they need to live productive lives in the community. Individuals with the most severe disabilities can require specialized treatment provided by skilled medical, dental,

psychological and other health professionals that are frequently hard to access, costly and limited. Individuals with very challenging conditions may be exposed to new and promising treatment approaches that do not have data supporting their effectiveness or nor their impact on the live of the individual. It is important to understand the efficacy of intrusive treatment alternatives and the extent to which evidence is present to document the positive outcomes that result from their application.

Research Questions.

- What are examples of innovative approaches to organizing, financing and delivering community supports for people with low incidence, multiple, or intensive physical, emotional, or health related needs?
- What methodologies do states use to determine the relationship between the Support intensity and outcome achievement?
- How effective are specific medications in ameliorating the physical or health related conditions they are designed to treat? What factors influence the effectiveness of specific medications?
- How do outcomes resulting from different clinical treatments and interventions compare in terms of increased community participation, enhanced self-care skills, increased satisfaction, etc.?
- What changes are occurring in the caseloads of states serving individuals with Autistic Spectrum Disorders? What are the factors associated with such change?
- What treatment and intervention factors are associated with effective community based supports for people with Autism Spectrum Disorders?
- What key treatment factors are associated with effective community based dental services for people with developmental disabilities?
- How do innovative community based systems of support enable people with the most intensive needs to function in non-institutional settings?

Relationship to Strategic Plan. This research goal addresses the following Strategic Plan priorities:

- Strengthening system-wide quality assurance and improvement capabilities.
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Research Goal 7: Identify and analyze the key factors related to the development and maintenance of responsive financial management systems.

Relevance.

State developmental disabilities agencies operate under constant pressure to assure that the service delivery system functions in a cost effective manner producing the greatest value possible for each public dollar spent. Working within an environment of cost containment in the best of economic times and service reduction during periods of fiscal retrenchment, state agency officials need effective systems of financial management and analysis backed by timely data linking revenue, fund disbursements and program costs with indicators of system performance and individual outcome achievement.

Research Questions.

- What financial strategies are the most effective at enabling states to achieve the systemic and programmatic goals desired?
- What financial strategies most effectively assure the fair and equitable distribution of funding and resources?
- What impact do financial decisions have on healthcare outcomes?
- How do policymakers determine the boundaries of the financial universe within which state developmental disabilities must operate?
- What assumptions and operational principles are used by state policymakers to set the criteria for determining the scope and extent of the funding required to provide appropriate services to all who are eligible to receive them?
- What information is needed by states to effectively project service need, costs, and rates of growth?
- What individual, programmatic and system outcomes are key indicators of system performance?

Relationship to Strategic Plan. This research goal addresses the following Strategic Plan priorities:

- Strengthening system-wide quality assurance and improvement capabilities.
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Overview of the Relationship of the Research Goals to the Strategic Plan

<i>Research Goals</i>	<i>Strategic Plan Goals</i>						
	1	2	3	4	5	6	7
1. QA & Self Direction							
2. Effective Support							
3. Cultural Diversity							
4. Community Integration							
5. Performance Benchmarks							
6. Challenging Behaviors							
7. Resp Financial Strategy							

Content and Context

The Research Agenda is intended to provide general guidance to state agencies in their efforts to improve the quality of support and assistance offered to people with developmental disabilities and their families. The contents of the agenda were distilled from a series of conversations involving members of the Association's Ad Hoc Committee on Research over several extended telephone conference calls completed in early 2003. One need only review the goals of NASDDDS' Strategic Plan to realize that the number of appropriate research, demonstration, and evaluation activities that could be undertaken in pursuit of the plan goals is virtually endless. Because of the breadth and scope of its charge, the Committee had to sift through many excellent ideas to pinpoint research goals that would provide direction to future investigations related to the organization, delivery and financing of publicly-funded services and supports to people with developmental disabilities. The goal statements are purposely broad and open-ended so as not to foreclose upon other relevant lines of inquiry that might be relevant to the policy aims of the Association and its member state agencies. The list is by no means all encompassing and should be seen as a departure point for further inquiry.

Several key themes ran through the Advisory Committee's discussions. These themes reflect the desire of member state agencies, as expressed in the Strategic Plan, to ensure that the recommended activities: (a) emphasize the need to develop and maintain effective collaborative relationships with other organizations and individuals, (b) identify ways to involve people with disabilities in research, demonstration and evaluation activities, and (c) produce practical, tangible results.

A significant amount of interest was expressed in the use of National Core Indicator² data as a source of information that is grounded in the needs and experiences of state developmental disabilities agencies. Committee members were additionally interested in collaborative interstate initiatives to investigate some of the specific elements of support provision related to case management, quality improvement, workforce development and new ways to facilitate community participation among the individuals receiving support. Finally, throughout the discussions committee members emphasized the need for each of the various research goals to reference, if not specifically address, financial factors that influence the topic under study.

² The National Core Indicators Project is a collaboration among participating NASDDDS member state agencies and HSRI, with the goal of developing a systematic approach to performance and outcome measurement. Through the collaboration, participating states pool their resources and knowledge to create performance monitoring systems, identify common performance indicators, work out comparable data collection strategies, and share results. The NCI Steering Committee, composed of participating state coordinators, determines the overall direction of the initiative. The project has collected data in five phases beginning in 1997.

Next Steps

The Research Agenda is a working document designed to guide activities on three levels, functioning: (a) *within states* as a conceptual base for developing state-specific strategies for research and demonstration; (b) *among states* as common ground facilitating multi-state research, demonstration and evaluation of new and innovative methods of providing support, and; (c) *beyond states* as a catalyst stimulating collaboration between NASDDDS and other organizations including the University Centers for Excellence, CMS, the Administration on Developmental Disabilities, and the National Institute on Disability and Rehabilitation Research (NIDRR), in the support of national research efforts on services for people with developmental disabilities.

The Research Agenda will be updated at regular intervals to remain consistent with the Association's strategic goals and objectives and to respond to new or emerging issues. Comments are encouraged.

Appendix A

NASDDDS Ad Hoc Research Advisory Committee

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Appendix B

Ad Hoc Advisory Committee on the Development of a Research Agenda:

MISSION AND RESPONSIBILITIES

Mission

The mission of the NASDDDS Ad-Hoc Advisory Committee on the Development of a Research Agenda is to advise the Association's Board of Directors and staff on the development of a Research Agenda for the Association. The role of the Committee is to provide advice and counsel regarding: (a) the identification of areas for empirical inquiry that are consistent with the priorities identified in the strategic plan; (b) the implications of proposed research outcomes for state systems of services, and; (c) the selection of experimental design methodologies and research parameters that are consistent with the Association's goals and guiding principles.

ACTIONS AND ACTIVITIES

To accomplish its mission the Committee will:

1. Advise the Association's Board of Directors and staff in the development of a Research Agenda that outlines areas for research and investigation that are directly related to the accomplishment of NASDDDS' Strategic Plan and are consistent with the Association's mission, goals and guiding principles.
2. Provide advice on the development of a research plan that models positive practice and steers decision-making toward areas of exploration that are relevant to the lives of people with developmental disabilities, demonstrate respect for the independence and individuality of people receiving support and provide data and knowledge that can be used to improve services and supports for all people with disabilities.
3. Provide advice on the development of an approach to the selection of topics for research and inquiry that drives decisions toward those that are directly related to one or more of the Association's five strategic priority policy goals and are consistent with the organization's missions and guiding principles.
4. Assist the Board and staff to identify possible barriers, challenges, and benefits associated with particular lines of investigation, anticipated outcomes, and implications for policy and practice.
5. Provide advice on the development of strategies to identify potential sources of external financial and logistical support for research, demonstration, evaluation, and

knowledge dissemination activities, as well as possibilities for generating revenue through the publication and distribution of work products and the provision of related technical assistance.

6. Provide advice and assistance to the Association's Board of Directors and staff in the identification of opportunities for collaboration with other individuals and groups with common research, evaluation and demonstration interests, such as Self Advocates Becoming Empowered, People First, the Arc of the United States, the National Association of State Medicaid Directors, the Centers for Medicare and Medicaid Services, and the National Association of State Mental Health Program Directors.

Composition and Work Plan

The Ad Hoc Advisory Committee will be composed of state directors and senior staff members of state DD agencies with expertise and interest in disability related research, demonstration and evaluative studies, as appointed by the President of the Association. The President will appoint one of the members of the Committee to serve as the Chairperson. The Chairperson will be responsible for facilitating Committee meetings and conference calls and working with the Association staff's to establish meeting agendas, determine work activities, and otherwise ensure that the Committee work is carried out efficiently and effectively.

The Committee has been established as an *ad-hoc advisory* group, whose activities are limited in scope and duration as described in the mission statement above. It is anticipated that the work of the Committee will be completed during the course of five telephone conference calls of approximately one hour in length over the next three-four months. The Committee Chair will report to the Board on the progress and outcomes of the group at the Association's Mid-Year Meeting in May 2003.