

### Introduction

State developmental disabilities (DD) directors manage in a dynamic environment. Each state agency's mission statement, values and strategic goals set the overall direction of the state's service system. But services are affected by the larger environment. Current events, the economy, social and political trends, research findings economy, and federal policy have an impact on state service systems. These factors may influence the availability of resources; service design; program management; and the ability of states to meet the needs of growing numbers of individuals and families.

The association's primary purpose is to assist state agencies in developing effective, efficient service delivery systems that furnish high-quality supports to people with developmental disabilities. To assist states, the association disseminates cutting edge information on state-of-the-art programs and service delivery practices; provides technical assistance and support to member states; and offers a forum for the development of state and national policy initiatives as well as timely analyses of federal statutory and regulatory policies that affect people with disabilities.

The board of directors and staff of the association have identified a set of strategic activities that are responsive to identified environment factors and that will guide the association's efforts to support state DD agencies. The association's strategic activities will continue to be dynamic and responsive to the needs of member states.

Environmental factors have an impact on the capacity of states to achieve their mission. These factors may influence the availability of resources; service design; program management; and the ability of states to meet the needs of growing numbers of individuals and families. NASDDDS' efforts to support states must take into consideration the following environmental factors:

#### MISSION

The mission of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) is to assist member state agencies in building person-centered systems of support for people with developmental disabilities and their families.

#### GUIDING PRINCIPLES

The association's work is guided by a set of principles: Individuals with developmental disabilities have the right to: (a) be treated with respect and dignity, (b) be independent and make individual choices, (c) participate in family and community life, (d) have opportunities to maximize their full potential, and (e) receive outcome-based services and supports.

## 1. Economic Challenges

Uncertainty in the economy from rising energy and food prices, coupled with housing foreclosures has been eclipsed by a world-wide financial crisis that threatens the financial foundations of our society, including our social service systems. While the country's economy will no doubt improve over time, the size of the national debt; structural liabilities for Social Security; Medicare; Medicaid; and state obligations to retirees will continue to challenge federal and state budgets for the next decade. Most state developmental disability service agencies (DD agencies) can expect increased pressure to restrain the rate of growth in Medicaid and state-funded programs. In many states, DD agencies are being asked to absorb budget cuts. As states face funding restrictions and budget shortfalls, they need assistance in developing cost-effective service models that are consistent with program goals and desired outcomes for people.

## 2. Provision of In-Home Services Surpasses Residential Services

Faced with continued growing demand for services, increasingly limited resources, and a shortage of working-age adults able to staff facility-based programs, state DD agencies are placing greater reliance on in-home support services for people living with their families. During the period between 2000 and 2006, the number of individuals who resided in the family home and received publicly financed supports increased by 34 percent. The most recent edition of the University of Minnesota's *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2008* reports that over 57.4 percent of people receiving services in 2007 lived with their families. In six states, the figure was as high as over 70 percent.

Many states operating comprehensive waiver programs have expanded their scope to include people living with their families. A growing number of states are developing home and community-based services (HCBS) waiver programs that are designed to provide supports to people living with their families exclusively. States are also expanding their service alternatives with a variety of shared living options for people who can no longer reside with family members

National Core Indicators (NCI) data on adults with intellectual or developmental disabilities (I/DD) living with their families suggests that they are less likely than individuals living in provider-supported settings to have had a yearly physical or gynecological examination, or to have seen a dentist in the past six months. However, they were more likely to report that they like where they live; that they feel happy; and that they are more secure and less lonely. But at the same, families supporting people at home are more apt to feel isolated and cut off from their communities. Also, favorable employment outcomes for adults living in the family home are low, with only about 22 percent of people employed in competitive settings.

With more and more services now being provided to people living with their families and with the expansion of shared living options, we are experiencing a paradigm shift in our service systems. Such a significant shift requires a clear vision for individual and family

well-being. Services must focus on helping the person with a disability achieve personal outcomes and also on addressing the needs of family members and others who support the person.

This new service paradigm, then, requires thoughtful attention. If we are to assure that individuals can participate in community life and that they are empowered to achieve their fullest degree of self-determination, then all aspects of the service system must be considered carefully. The types of services offered, provider qualifications, and the design of reimbursement models must enable the system to be responsive to the uniqueness of each person. The role of family members, both as paid and non-paid support, will require caregiver training, as well as appropriate health and safety protections. Competitive employment, for both economic security and social connections, as well as the opportunity to join a self-advocacy organization, must become core features of service systems. In this new paradigm, the role of the case manager will be critical, and so the training and support case managers receive will require considerable attention. We must be certain that system performance measurement will focus on the quality of people's lives.

### **3. Interest in Self-Direction Continues to Grow**

As the scope of services available to people living with their families grows, interest in self-directed services continues to grow. Self-direction can play an important role in lowering service costs and creating more flexible and responsive supports. Self-directed options may involve a wide-range of support choices, including friends and family members serving as paid caregivers. As states create mechanisms to sustain self-directed supports, there will be a need for assistance in the areas of individualized resource allocation; standards development; quality assurance; rate-setting methods; and budgeting practices.

### **4. Self-Advocacy Needs On-Going Support**

As people with developmental disabilities reach adulthood, enter the workforce and continue to live with their families, it is critical that they are able to meet others with disabilities in order to share experiences and to learn to speak for themselves.

Self-advocacy organizations based on an empowerment model can provide important opportunities for peer support that enable individuals with disabilities to grow, learn, and develop self-advocacy skills.

Self-advocacy organizations, however, need on-going support to stay viable.

## **5. Emphasis on Performance Measurement and Quality Improvement**

Performance measurement is rapidly becoming a standard component of managing public services. From transportation to corrections, state governments are using data-driven processes to measure the success of programs, to hold managers accountable, to inform legislatures, and to report to the public. NASDDDS was among the first of the national associations to develop national performance measurements through the creation of National Core Indicators in 1997.

Federal expectations for performance measurement continue to intensify, as seen in the recent rollout of the Centers for Medicare and Medicaid Services' (CMS) Version 3.5 of the 1915(c) Medicaid waiver application. States now face increased requirements in developing valid and reliable methods to assure health and safety; to monitor services; and to improve service quality. States must build the capacity to collect and analyze data that is both meaningful and reliable. This will require the training and development of state personnel to conduct quality management activities; to measure performance; and to oversee contractors. The need for states to strengthen quality management through data is underscored by provisions in the Deficit Reduction Act of 2005 (DRA; P.L. 109-171). The DRA requires the federal Agency for Healthcare Research and Quality (AHRQ) to identify outcome indicators which will apply across all home and community-based (HCBS) services. The use of managed care entities to administer services requires the development of quality management programs. State agencies need information, guidance, and technical assistance on key issues related to quality assurance and improvement methods.

## **6. Increased Reliance on Information Technology**

Growing expectations for program accountability as well as for performance measurement and quality improvement, increase the need for effective and accessible information technology (IT). Increasingly, IT will be necessary to manage state service delivery systems; to support program operations; and to track expenditures. State agencies must assess their IT needs and then develop sound, business-based justifications for IT budget requests. In addition, states must prepare advanced planning documents to demonstrate the need and rationale for securing enhanced Federal Financial Participation (FFP) from CMS. This enhanced FFP will be increasingly essential to build the information technology infrastructure necessary to effectively manage Medicaid-funded services and supports system-wide.

## **7. Advances in Health Care and Technology**

State DD service systems continue to be challenged by the complex conditions and intensive needs of persons they serve. (e.g., co-existing conditions, pervasive developmental disorders, autism spectrum disorders, Prader Willi Syndrome, etc.). Current approaches may be costly; may involve varying degrees of risk; and may not

produce the positive personal outcomes and consumer satisfaction that are expected. However, advances in many areas could substantially improve the quality of people's lives, their personal satisfaction, and opportunities available to them for community involvement. These advances include discoveries in medications for mental illness; identification and treatment of post-traumatic stress disorder; bio-medical interventions; teaching strategies for people with specific disorders; and technology such as smart houses and communication devices. Information on new developments that would significantly improve the quality of peoples' lives is available, but state DD service systems are limited in their capacity to discover such information and translate it into practice at the service level.

## **8. State and Federal Initiatives to Restructure Long-Term Care Systems**

States have used a variety of approaches to manage long-term care services more efficiently. Most states continue to use a single designated state agency to manage services furnished to individuals with developmental disabilities. Some states, however, have combined all long-term care services into a single administrative structure. Others manage services through systems utilizing "single points of entry" or "no wrong door" approaches that channel referrals to specific program entities. A few states have implemented managed care approaches to managing long-term services. Several states have created designated administrative units to support individuals with specific conditions, such as autism or traumatic brain injury, or they have included additional disability groups into the DD agency. Sometimes state DD systems are incorporated into other state agencies or conversely, the DD system may be required to incorporate into their structures services for people with disabilities other than DD.

Financial limitations, combined with a growing demand for long-term care services, will continue to stress state budgets, and so too increase state interest in streamlining systems to gain efficiencies. In addition, when the new administration is sworn in January 2009, there will likely be proposals to reform health care, which will involve both Medicaid and long-term care services. It will be important to track federal Medicaid "reform" efforts at both state and federal levels. In particular, each state will want to assess the impact of any proposed changes in health care and long-term service financing on its publicly supported developmental disabilities services. State leaders will need information about the various alternative structures that have been implemented across states.

## **9. Leadership Turnover**

State directors are typically appointed by the governor and as such, often change with a new administration. Fifteen to twenty state directors are replaced each year. New directors are often new to the public sector and are sometimes new to the field of developmental disabilities.

## Strategic Activities

The complexity of state DD service systems, funding streams, and federal requirements make it necessary for newly appointed directors to "learn fast." There is a need for an organized program to support new state directors with information, guidance, technical assistance, and peer support.

The NASDDDS Strategic Activities document identifies, within the context of emerging environmental factors, seven goals designed to assist member state agencies in furnishing services and supports to people with developmental disabilities. Each goal statement below is followed by a list of strategies specific to the goal.

### Goal 1

**Assist states in developing systems of services that effectively support people living with their families or in alternative family/community options.**

#### Strategies:

- Assist states in the responsible application of the best available evidence in the improvement of state policy and the design, implementation and management of developmental disabilities services through the preparation of Evidence-Based Policy Briefs. Prepared in collaboration with the Association of University Centers of Excellence in Developmental Disabilities (AUCD), the groundbreaking series will summarize the evidence on key policy and practice issues of importance to state DD services.
- Develop and disseminate products and information detailing the core elements of effective service delivery systems: (a) models of in-home supports and shared living services, (b) case manager roles and responsibilities, (c) effective approaches for training and supervision, (d) person-centered planning processes, (e) risk management and quality assurance strategies, and (f) other core infrastructure requirements.
- Continue the support and management of the State Employment Leadership Network (SELN), which provides a framework for building a system of employment services. Share and disseminate knowledge to all state agencies.
- Continue the support and management of the CMS-funded Person-Centered Organization Project, that provides a framework for building person-centered practices into services systems. Share and disseminate knowledge to all member state agencies.
- Provide guidance and technical assistance to states in developing mechanisms to support consumer direction. This includes furnishing information and support on

individual resource allocation methods; on supervision of direct care; on mechanisms to manage conflict of interest between the individual, family, guardian, or surrogates; and on a range of other issues.

- Provide states with information and technical assistance on ways to support the growth and maintenance of self-advocacy organizations as an element critical to supporting people in the community.

## Goal 2

### **Assist states in developing the capacity to monitor and improve quality.**

#### **Strategies:**

- Continue to develop and enhance the National Core Indicators (NCI) to make it more useful to states; secure additional funding to expand the current set of key performance measures; improve administration procedures; and produce more publications.
- Increase the focus on improving and expanding employment data gathered by states participating in the SELN project.
- Work with National Association of State Mental Health Program Directors (NASMHPD) and National Association for the Dually Diagnosed (NADD) on the development of standards for services for people with co-occurring developmental disabilities and mental illness.
- Disseminate resources to assist states in meeting CMS requirements for the quality management strategies included in the newly released Version 3.5 of the Medicaid waiver application. Facilitate the sharing of state strategies.
- Provide guidance to states as they develop and monitor contracts with third party Quality Improvement Organizations to perform identified quality assurance activities.
- Develop guidance for states in managing essential functions such as emergency response planning, preparing for pandemic influenza outbreaks, and similar activities.

**Goal 3****Assist states in learning about and applying advances in health care and technology.****Strategies:**

- Conduct and disseminate to the membership research on promising and evidence-based practices in providing supports to special populations.
- Research the utilization of restraints in DD systems and the development of systemic strategies to reduce the use of restraints in service systems and disseminate the findings.
- Include information about advances in health care and new technologies in association publications, association conferences, and teleconferences.
- Explore the development of practice groups composed of key state agency staff to address critical treatment and support issues, such as the need to reduce the use of restraints; develop services for people with post-traumatic stress disorder; establish wellness and dental programs, etc.

**Goal 4****Assist states in responding to initiatives to restructure long-term care service systems.****Strategies:**

- Track developments in long-term care reform at the federal level and provide information and guidance to states.
- Participate in activities that influence the development and implementation of federal policy related to long-term care reform.
- Disseminate information on changes in state administrative structures, policies, and practices.
- Provide technical assistance to states undergoing system redesign or restructuring.
- Assure that all state personnel with responsibilities for people with developmental disabilities have access to NASDDDS resources.

**Goal 5****Assist states in developing responsive financial management strategies.****Strategies:**

- Provide information and technical assistance on resource allocation strategies.
- Provide technical assistance on the design of Medicaid waivers, on State Plan services and on other Medicaid options for managing services.
- Assist states in reviewing and improving their capacity to earn Federal Financial Participation in the delivery of Medicaid services.
- Provide technical assistance and support to states to strengthen their capacity to effectively respond to budget reductions. Collect and disseminate information on state strategies for absorbing and managing budget cuts.

**Goal 6****Assist states in the development and use of information technology.****Strategies:**

- Identify resources and develop guidance for determining Information Technology needs and for evaluating options.
- Facilitate the sharing of information on technology solutions across member state agencies.

**Goal 7****Conduct state leadership development programs.****Strategies:**

- Develop an orientation program for newly appointed state directors.
- Design and develop a mentoring program to provide ongoing support and assistance to members.

## **Emerging Environmental Factors**

Economic Challenges

Provision of In-Home Support Services Surpasses Residential Services

Continuing Interest in Self-Direction

Self-Advocacy Needs for Ongoing Support

Emphasis on Performance Measurement and Measuring Quality

Increased Reliance on Information Technology

Advances in Health Care and Technology

State and Federal Initiatives to Restructure Long-Term Care Systems

Leadership Turnover

## **Strategic Goals**

1. Assist states in developing systems of services that effectively support people living with their families or in alternative family/community options.
2. Assist states in developing the capacity to monitor and improve quality.
3. Assist states in learning about and applying advances in health care and technology.
4. Assist states in responding to initiatives to restructure long-term care service systems.
5. Assist states in developing responsive financial management strategies.
6. Assist states in the development and use of information technology.
7. Conduct state leadership development programs.

## Association Activities

The work of the association is carried out through a series of projects and activities, some of which are conducted on a routine basis and others which are episodic. Several of the activities, such as the communities of practice, are major ongoing projects that involve groups of states. These actions are the vehicles through which the goals of the Strategic Activities document will be achieved.

### ~ Association Activities ~

- ◆ **Research and Dissemination of Information**
- ◆ **Member Services**
  - National Core Indicators*
  - Emergency Preparedness Self-Assessment*
  - Technical Assistance by Phone, Email, and On-Site*
- ◆ **State and National Policy Analysis**
- ◆ **Bulletins and Newsletters**
  - Federal News Briefs and Federal Perspectives*
  - State News Briefs and Community Services Reporter*
- ◆ **Conferences and Meetings**
- ◆ **Special Studies and Reports**
- ◆ **Teleconferences**
- ◆ **Communities of Practice**
  - Building Person-Centered Organizations*
  - Supported Employment Leadership Network*
- ◆ **Collaboration with other National Associations**
- ◆ **Representation to Federal Agencies**