



# 2011 ANNUAL REPORT

NASDDDS

NASDDDS ANNUAL REPORT  
For Fiscal Year 2010-2011

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## Mission and Guiding Principles

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 intellectual/developmental disabilities (I/DD) and their families.

The guiding principles for the association's activities reflect the position of the membership that individuals with developmental disabilities have the right to:

- Be treated with respect and dignity;
- Be independent and make individual choices;
- Participate in family and community life;
- Have opportunities to maximize their full potential; and
- Receive outcome-based services and supports.

### Strategic Plan

The association's Strategic Plan connects our mission and guiding principles to priorities for action, research, and policy development. The Strategic Plan is a dynamic document that adapts to changing expectations and new challenges.

### 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 developing and using information technology; and
7. Conduct state leadership development programs.



### Message from Mary Lee Fay

President, NASDDDS Board of Directors  
and Administrator, Office of Developmental Disability Services  
Oregon Department of Human Services

State budgets across the country were still heavily impacted by the economic downturn in Fiscal Year (FY) 2010-2011. Budget cuts in states, as well as concern in Washington, D.C. over deep federal deficits, have left state systems in the mode of defending programs and finding ways to maintain quality services for people with developmental disabilities with fewer resources.

NASDDDS has taken a leading role in pushing state systems forward despite the difficulty of the times. Recognizing the new reality that more than half of all the individuals we serve are living at home with their families, the association held a successful mid-year conference addressing the opportunities and challenges for our systems in adapting to serving individuals and the families that they live with.

NASDDDS has also kept a strong focus on employment for people with developmental disabilities — through technical assistance to states as part of projects like the State Employment Leadership Network (SELN), collaboration with federal policymakers at CMS and elsewhere, and carrying the message about the importance of employment to Capitol Hill.

NASDDDS staff have shown amazing strength and leadership this year, but they also experienced a great loss in the passing of Kara LeBeau. Kara was the NASDDDS Director of State Policy. State members saw much of her work in the monthly *Community Services Reporter* and her work on the NASDDDS annual and mid-year conferences. Kara was known for her passionate and thoughtful approach to work and is deeply missed by all who knew and worked with her.

### Message from Nancy Thaler

Executive Director  
NASDDDS



The 2010 mid-term election brought significant turnover among the nation's governors, which led to what may be unprecedented turnover among state directors, with 20 agencies changing leaders this past year. Despite leadership transitions and a continuing fiscal crisis, state agencies and federal policymakers continue to work toward improving services and outcomes for people with developmental disabilities.

Health care reform is providing both challenges and opportunities. New options for providing Medicaid home and community-based services have led CMS to focus on defining community-based settings. An emphasis on dual eligibles in the Affordable Care Act has led to increased attention to managed care as a means of improving care coordination while streamlining costs. Advocates have continued to emphasize employment outcomes, pushing for legislation focused on jobs for people with disabilities.

The association was especially active at the federal level in FY 2010-2011 tracking developments, collaborating with policymakers, and educating legislators.

## I. Supporting Member States

### PROJECTS

#### National Core Indicators

The National Core Indicators (NCI) performance measurement system has been an integral component of state developmental disabilities agency quality management systems for the past 14 years. Operated as a collaborative effort between NASDDDS, the Human Services Research Institute (HSRI), and participating state developmental disabilities agencies, the NCI program gathers in-depth information on key system performance indicators and individual outcomes that are essential to effective policy planning and program development. The NCI data set comprises one of the most comprehensive sources of information on intellectual and developmental disabilities service system performance in existence today. The NCI framework is made up of over 100 key outcome indicators that are designed to gather valid and reliable data across five broad domains: individual outcomes; family outcomes; health, welfare, and rights; and system performance. NCI is in alignment with the basic quality assurance requirements of the Medicaid waiver program and can be used to set performance benchmarks and make cross-state comparisons and has become an integral component of over half of all states' quality management systems.

Currently, 25 states and 24 regions or counties use the data on individual and service outcomes to assess individual satisfaction and experience with services, benchmark system performance and track key outcomes across multiple years, services, and states. Participating states include: Alabama, Arizona, Arkansas, California, District of Columbia, Florida, Georgia, Hawaii, Illinois, Kentucky, Louisiana, Maine, Massachusetts, Missouri, New Hampshire, New Jersey, New Mexico, New York, North Carolina, Ohio, Oklahoma, Pennsylvania, South Dakota, Texas, and Washington state. Sub-state entities include 21 regions in California and 3 counties in Ohio.



The final survey reports for the 2009-2010 data cycle have been completed and reports are available from the project website, [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org), including:

- The NCI Annual Survey Report
- The Consumer Outcomes Report
- The Adult Family Survey Report
- The Family Guardian Survey Report
- The Child Family Survey Report

In addition, state-specific reports are available on the website summarizing data on each of the participating state developmental disabilities agencies. During 2010-2011, three topical 'Data Briefs' were written, published, and distributed to NASDDDS member state agencies, members of the developmental disabilities network, and other state and federal agencies. These technical

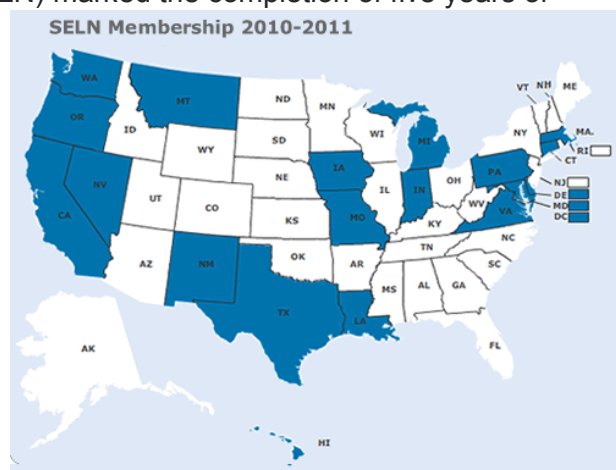
documents analyzed NCI findings with respect to: (a) choice and self-direction, (b) dual diagnosis, and (c) autism. The NCI Project Team launched a series of quarterly webinar presentations on a variety of related topics of interest to participating states agency staff. The NCI project team continues to work with states to improve the survey tools and administration procedures, and streamline the ODESSA web-based data interface.


NCI received national attention from federal agencies as they intensified their focus on measuring service quality and the experiences of individuals receiving support. Information on the NCI program and the use of NCI data was presented to CMS and a large group of data contractors during a national "Long-Term Support System Research and Data Summit" held by CMS in October. Go to [nationalbalancingindicators.com](http://nationalbalancingindicators.com) and click on "National Conference" to obtain electronic copies of the presentation on NCI and others shared during the summit. It is important to note that the NCI is the only instrument that actually measures the perceptions of individuals with I/DD regarding the services they receive, the places that they live and the staff who provides them with supports.

During 2010-2011, NASDDDS staff worked closely with Sharon Lewis, Commissioner of the Administration on Developmental Disabilities and others to place NCI data within the context of the three other national data bases on developmental disabilities services including *Residential Services and Trends for People with Developmental Disabilities* produced annually by the University of Minnesota Research and Training Center on Community Living, Center for Community Integration, the *State of the States in Developmental Disabilities Services* prepared by the University of Colorado and *State Data: the national Report on Employment Services and Outcomes* written by the University of Massachusetts/Boston Institute on Community Inclusion. Taken together these data sets provide valuable information on the experiences of people with DD receiving support (NCI), the numbers of individuals receiving services and the types of supports received (UMN), the costs of DD services nation-wide (UC), and access to employment and day supports (UM/Boston). NASDDDS staff laid the groundwork for expanding the NCI program to additional states

## State Employment Leadership Network

The State Employment Leadership Network (SELN) marked the completion of five years of operation, June 30, 2011. The SELN is a joint initiative of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Institute for Community Inclusion (ICI) at the University of Massachusetts Boston, the SELN supports states to improve employment outcomes. The SELN is a membership-based network of state developmental disability agencies committed to making changes in their service systems to improve employment outcomes among individuals receiving support. The SELN utilizes a framework for employment based on the 'High Performing States' model which





guides technical assistance and system change for members of the SELN. Trends in the ICI national day and employment survey of state DD agencies is showing that SELN member states have a higher growth rate in integrated employment services over two time periods (2004 to 2009 and 2007 to 2009). Different states are included in the two calculations as not all states were able to report in all three years. For the period 2004-2009, SELN member states show a 23.6 percent increase in integrated employment services while non SELN states show a 7.2 percent increase and for the period 2007-2009, the percentage change for SELN members is 13.6 and 0.6 percent for nonmember states.

The SELN is an active community of practice where members meet to connect, collaborate, and share information and lessons learned across state lines and system boundaries. Participating state agency officials build cross-community support for pressing employment-related issues and policies at state and federal levels. States commit to working together and engage in a series of activities to analyze key elements in their systems to improve the integrated employment outcomes for their citizens with developmental disabilities. With the membership year running July 1 – June 30, states focus the work over 12 months based on a tailored work plan unique to each state's circumstances. The SELN assists states in developing, implementing, and supporting integrated employment initiatives that are designed to improve employment outcomes for people with developmental disabilities. The 2010-2011 year concluded with 20 member states.

Top Discussion Topics of 2010-2011:

- Waiver service definitions
- Employment first policies and strategies
- Funding and rate methodology changes
- Sharing data across state agencies
- Role of case management in career planning

A special webinar series on the topic of "Embedding Employment in the Individual Planning Process" held on February 9 and March 8 had the largest participation of any topical webinar held with participating SELN members to date creating demand for the SELN to expand our participant capacity.

The second highest participation in the SELN special webinar services was for the topic "Business Ownership: Em and Jerry's Coffee Shop; what it took from the whole team."

## **Evidence-Based Policy**

In 2010 NASDDDS and the Association of University Centers on Disability (AUCD) entered into a partnership to develop products and activities that would promote evidence-based policymaking. NASDDDS defines evidence-based policy as "the responsible application of the best available evidence in the design, administration, and reform of programs, services, and supports in a manner consistent with achieving independence, productivity, inclusion, and self-determination for individuals with developmental disabilities."

NASDDDS is seeking to establish a stronger foundation of knowledge to achieve national goals for people with intellectual and developmental disabilities, including:

- Increasing self-determination and personal control in decisions affecting people with disabilities and their families;
- Providing opportunities to people with disabilities to live and participate in their own communities;
- Improving quality of life for individuals and families as they define it for themselves;
- Supporting families as the most important and permanent unit of development, protection, and lifelong assistance to persons with disabilities;
- Investing in each individual's developmental potential and capacity to contribute in age-related roles as productive, respected community members;
- Assuring access to sufficient, high-quality health and social supports to protect each person's health, safety, rights, and well-being.

The concept of "evidence-based policy" as conceived by NASDDDS derives from the widely endorsed focus on "evidence-based practice" in clinical health services. Evidence-based policy recognizes that just as clinical practitioners, policymakers also share professional responsibility for the acquisition and application of the best available knowledge in their professional roles. Specifically, it acknowledges the responsibility of policymakers for the conscientious and efficacious use of evidence to design, manage, and reform systems of support for persons with intellectual and developmental disabilities in a manner that predictably yield outcomes of benefit.

In addition to promoting the development of comprehensive objective reviews of literature on key policy topics in developmental disabilities, this initiative is also focused on substantially expanding access and use of outcome based research and evaluation within the states and nation. As part of this effort, states and universities will be supported to work together in the development and analysis of outcome-based assessments of program, service, and policy options.

In pursuing the best available research and evaluation as the foundation for evidence-based policy there is recognition that while one might always wish for studies of the highest clinical rigor, the absence of the ability to random assign people "treatment/ non-treatment" has not impeded some of the most important policy decisions in the United States (e.g., seat belt laws, protection from secondhand smoke) which have depended on a preponderance of research in which random assignment was not possible (or ethical).

### **Activities of the NASDDDS and AUCD Partnership in Evidenced-Based Policy**

Among the activities being jointly pursued by the NASDDDS and AUCD networks are:

- Identifying the topics of highest importance and/or recurring attention in policy discussions within the states or nation on which a comprehensive and objective review of high quality research and evaluation is needed;

- Developing policy relevant summaries of research and evaluation findings related to topics of highest importance and/or recurring attention to policies affecting persons with developmental disabilities;
- Creating a jointly supported website for the posting of research/evaluation summaries, related research documents and other publications and presentations to serve the purpose of educating public officials, advocates and others with key roles in the policy process;
- Maximizing the use and benefits of National Core Indicators or other outcomes assessment data sets within the states with a specific goal of promoting policy relevant research questions, analyses and products;
- Developing capacities through cross-UCEDD technical assistance in states with National Core Indicators or other outcome-related data sets in personnel of the state UCEDD is relatively inexperienced and unfamiliar with policy research and outcome evaluation;
- Serving as a training opportunity to increase the expertise of graduate students and state staff in policy research and evaluation, and in the development of policy relevant research questions and analyses;
- Undertaking other activities with promise of increasing the effective gathering and use of the best available information in designing, evaluating and improving policies, programs and services for individuals with developmental disabilities and their families.

## **Person-Centered Systems Change**

Participating States:

Georgia, North Carolina, Oregon, South Dakota, Tennessee, and Virginia

### **Becoming a Person-Centered System – Six State Initiative**

The Real Choices Change Grant continued to advance knowledge and understanding in the implementation of person-centered thinking. Approval was obtained to continue beyond the three year grant period for a no cost extension fourth year for implementation of planned activities. The states of Georgia, North Carolina, Oregon, South Dakota, Tennessee, and Virginia participated in the six-state collaborative to incorporate person centered planning tools and practices as integral components within the infrastructure of each state's service delivery system.

The association continued its partnership with Support Development Associates (Michael Smull, Mary Lou Bourne, and their staff) and Virginia Commonwealth University (VCU) to implement and support this six-state initiative. Each entity in the partnership engages in the collaborative management of the grant, held by VCU. Project activities are based on the central tenets of Essential Lifestyle Planning (ELP): that all people want to lead their 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 values and social roles).

NASDDDS hosted monthly community of practice forums bringing integral players from each of the six states together to share lessons learned to become a person centered system. The central concern of the community of practice is how learning from site-based, person-centered practice implementation has been spread throughout provider communities within states; how the practices have been "scaled-up" to promote individual choice and control in state policies and practices; and how person-centered systems changes will be sustained in the future.

Capacity and sustainability are addressed using a model that engages in three levels of change.

Training is furnished simultaneously to all levels of system personnel from state agencies, county and regional program entities, provider organizations, and others. Leadership, middle management, and direct support staff are included, as well as ancillary personnel from organizations providing additional supports or services to the individual. Training and development takes place in an open environment where people learn from each other through candid communication and honest discussions of change that are anchored by a commitment to the development of systems that reflect person-centered practices.

The grant activities ended on September 30, 2011, however there is interest among the six states in continuing the monthly community of practice meetings as one means to sustain the work.

## Technical Assistance

One of the association's primary functions is to provide technical assistance to state agencies. Technical assistance, as a standard membership service, includes responding to telephone and email inquiries, reviewing and commenting on draft proposals or plans upon request, providing resources, and linking members to other states and organizations that can be of assistance. NASDDDS staff respond to state agency representatives almost every day to provide this type of technical assistance.


The association provides more intensive technical assistance services through specific contracts with members or with other organizations in support of member agencies (such as developmental disability councils, and/or University Centers for Excellence in Developmental Disabilities [UCEDDs]). This technical assistance either is provided on site or requires extensive activity off site as part of the contract (research, preparing reports). NASDDDS provided contracted technical assistance to 29 states in FY 2010-2011.

### Levels of Change

**Level One** change occurs in the day-to-day practice that impacts persons' lives and their relationships with paid direct support professionals. Changes are facilitated through instruction and support provided by trained coaches.

**Level Two** changes occur in provider management and leadership affecting organizational policy, practice, and program outcomes implemented as organizational leadership adapts their organizations business practice to support person-centered service delivery.

**Level Three** changes in service delivery system infrastructure statewide brought about through changes in regulations, state policy, and system design to assure application of person-centered practices through the state I/DD system.



**Mission Analytics (formerly Acumen, LLC)** under a contract with CMS to provide technical assistance, sub-contracted with NASDDDS' Robin Cooper to provide technical assistance to states on the 1915(i) state plan HCBS option and participant-directed services. During FY 2011, NASDDDS provided assistance to the following states:

- Arkansas
- California
- Connecticut
- Florida
- Indiana
- Kentucky
- Michigan
- North Carolina
- Pennsylvania
- Oregon

Four of these projects involved development of community services for individuals with mental health needs along with other populations including individuals with I/DD and those with co-occurring disabilities.

NASDDDS has finished the project with the **Illinois Developmental Disability Planning Council**. This was a collaboration with HSRI and Burns and Associates, looking at service payment rates. The project was completed in September 2010.

The **Arizona Division of Developmental Disabilities** contracted with association staff to facilitate a Sustainability and Innovation Work Group to review Arizona's systems of services and supports for people with developmental disabilities and their families, in order to develop and propose systems change recommendations for sustainable, consumer-driven, quality, and cost-effective developmental disabilities services.

Ms. Cooper was engaged by the **Missouri Division of Developmental Disabilities** to assist in the renewal of their waivers. She was involved in gathering public input through facilitating stakeholder groups and reviewing drafts of waiver documents.

Facing consecutive budget shortfalls and with interest in rethinking the array of services provided in the state, the **Virginia Office of Developmental Services** contracted with the association to assist in the development of a Strategic Plan with state agency staff and stakeholders.

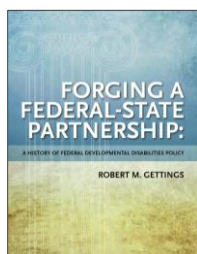
## MEMBERSHIP SERVICES

### Information Dissemination

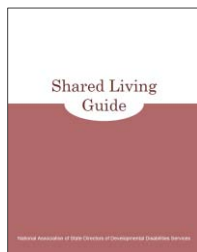
#### NASDDDS published:

- *Federal News Briefs* on a weekly basis
- *State News Briefs* on a biweekly basis
- *Federal Perspectives* on a monthly basis
- *Community Services Reporter* (news about states' developments) on a monthly basis
- *Litigation Updates* (bi-annually)
- *NASDDDS Annual Report*
- *SELN Annual Report*
- *NCI Annual Report*

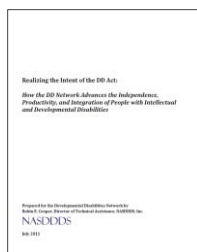
#### Special Publications:



*Forging a Federal State Partnership: A History of Federal Developmental Disabilities Policy.* This groundbreaking study of the revolutionary changes in public policy toward persons with intellectual and developmental disabilities over the past fifty years is written by Bob Gettings, former Executive Director of NASDDDS, an active participant in the events.



*Shared Living Guide.* This guide, prepared by Robin Cooper, Kara LeBeau, and Nancy Thaler, is about creating the opportunity for people with developmental disabilities to have a home and people to share everyday life with. Building on the experiences of states, the guide explains the service system components necessary to develop and sustain shared living.



*Realizing the Intent of the DD Act: How the DD Network Advances the Independence, Productivity, and Integration of People with Intellectual and Developmental Disabilities.* This report, prepared by Robin Cooper, used six states as examples to illustrate how the DD Network partners, working with each other and in collaboration with state developmental disability agencies and others, have positively affected the lives of individuals with intellectual and developmental disabilities.

## Association ListSers

NASDDDS hosts two ListSers: one for state intellectual/developmental disabilities (I/DD) services directors and their staff, and the other for state I/DD attorneys.

## Teleconferences/Webinars

The association held 12 teleconferences/webinars during the fiscal year:

Complex and Challenging Conditions (series of three)	July-August, 2010
Federal Quality Assurance Principles	September 23, 2010
Equal Access to Health Care	October 7, 2010
Georgia Lawsuit Settlement	December 9, 2010
Rethinking the Role of Government	January 20, 2011
Waiver 101	January 26, 2011
APDDA	February 22, 2011
EMDR Treatment for PTSD	February 24, 2011
Dialectical Behavior Therapy	March 17, 2011
Trauma-Informed Care	April 14, 2011

## Special Projects and Studies

The **DD Network** (which includes the Councils on Developmental Disabilities, Protection and Advocacy agencies, and the University Centers for Excellence in Developmental Disabilities) contracted with NASDDDS to prepare a white paper on the impact of the DD Network activities on the lives of individuals with I/DD. The paper, titled, "Realizing the Intent of the DD Act: How the DD Network Advances the Independence, Productivity and Integration of People with Intellectual and Developmental Disabilities" was published in July 2011.

**RTI International.** CMS Medicaid primer update (*Understanding Medicaid Home and Community Services: A Primer*). Robin Cooper and Chas Moseley authored and/or edited sections of selected chapters of the Medicaid primer originally authored by Gary Smith (and others). The 2010 edition of the primer was released in spring 2011.

**State of the States in Autism Services.** Association staff have been working with Thompson-Reuters on a contract with L&M Policy Research on the development and implementation of a national survey documenting the services and supports furnished to children and adults with autism spectrum disorders across the U.S. Data detailing the nature of the supports available in each state will be published in a comprehensive "state of the states" in autism services report to be published at the conclusion of the three-year project. After a lull of several months, the project received Office of Management and Budget (OMB) approval and will be implemented during the winter of 2012.

**Boston University Center/Psychiatric Rehabilitation Knowledge Dissemination and Utilization Contract.** NASDDDS worked on a contract with Boston University to assist in the identification and dissemination of research findings on employment for adults with DD to state DD directors and key policymakers. Specific activities include:

- Assisting in the systematic review conducted by research staff at the center on employment outcomes for individuals with developmental disabilities.
- Assisting center staff in using the results of the systematic review to develop consensus statements, evidence-based policy information, and targeted messages that are appropriate for NASDDDS policymakers.
- Assisting center staff in developing appropriate strategies for the dissemination of findings from the systematic review of employment outcomes.
- Facilitating dissemination activities.
- Assisting center research staff in conducting an evaluation of the effectiveness of the dissemination methods and materials, including facilitating key informant interviews, focus groups, and online surveys mounted by NASDDDS.

A comprehensive review of the literature revealed that very few research studies documented the effectiveness of the various strategies and interventions that are typically used to help people with I/DD become employed in integrated community jobs. In the absence of outcome data the project is performing a review of the research on employment to identify the breadth and scope of the existing evidence base.

**NIDRR Grant Assessing DD System Performance.** NASDDDS continued to participate with the University of Minnesota Research and Training Center on Community Living, Institute on

Community Integration on a four-year grant from the [National Institute on Disability and Rehabilitation Research](#) (NIDRR) to perform a comprehensive study on community service outcomes-based on NCI data on more than 10,000 individuals from 23 participating states. NASDDDS staff provide ongoing technical assistance, review, and editorial input. The association's Research Committee forms the Project Advisory Committee and met to review and provide feedback on the project's interim findings. Chas Moseley assisted in the reviewing the validity of the NCI interview and data gathering process in Washington state in January. The final report and research studies that were generated by this project will be presented to the NASDDDS membership in 2012.

**National Residential Information Systems Project (RISP).** NASDDDS staff worked on an ongoing basis with the University of Minnesota Research and Training Center on Community Living, Institute on Community Integration in the National Residential Information Systems Project (RISP), funded under a grant from the Administration on Developmental Disabilities. Two activities are associated with this project. The first involves the publishing select findings from the annual RISP report, *Residential Services for Persons with Developmental Disabilities: Status and Trends* in the *Community Services Reporter*, NASDDDS' monthly newsletter detailing activities, emerging trends and policy developments in association member state agencies across the country.

In the second project NASDDDS staff is conducting an evaluation of the extent to which the information and data provided in the annual *Residential Services for Persons with Developmental Disabilities: Status and Trends* meets the needs of state DD directors and their staff, Developmental Disabilities Councils, and directors of University Centers on Developmental Disabilities for information and data on developmental disabilities services, costs, and outcomes.

## Meetings and Conferences

Annual Conference  
"The Future"  
November 18-19, 2010  
Alexandria, Virginia

Mid-Year Conference  
"Building a Sustainable Service System"  
May 25-26, 2011  
Philadelphia, Pennsylvania

## Research Committee

The NASDDDS Research Committee met several times during 2010-2011. The committee addressed multiple key issues over the course of the year including: (a) the review and implementation of the association's policy on research and the release of data, (b) continuing efforts to collaborate with the *State of the States* data project in the development of a streamlined format for gathering data on the services and supports provided to adults and children with DD who live in the family home, and the launch of the association's Evidence-Based Policy Initiative. A listing of Research Committee members is found on page 21.

**Research.** The most extensive use of the NCI data in research is taking place in the assessment of developmental disabilities system performance being undertaken by researchers

at the University of Minnesota Research and Training Center on Community Living funded through NIDRR (see NIDRR information on previous page). Three additional data requests were received by researchers in North Carolina, Kentucky, and Ohio.

**Improving Data on Supports to Families and Individuals Living in the Family Home.** A subgroup of the Research Committee was formed to assist researchers at the University of Colorado Coleman Institute in gathering specific data on the nature and extent of services furnished to adults with I/DD living in the family home and to the families who support them. This project has been ongoing for the past several years.

**Evidence-Based Policy (EBP).** The launching of the NASDDDS-AUCD Evidence-Based Policy Initiative represents a significant action on the part of the association to assist state DD agency directors in developing and adopting policies and practices that are consistent with the latest research and evidence of best practice in the field. Implemented in collaboration with the Committee on Research and Evaluation (CORE) of the Association of University Centers on Disabilities (AUCD). The Evidence-Based Policy initiative will establish a repository of evidence in support of best and promising practices in the field of developmental disabilities. The project is designed to 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 that will be posted on the association's website. A website was established, to provide an overview of the initiative, a copy of a policy brief on the benefits of community living, resources, author guidelines and other information see [www.evidence-basedpolicy.org](http://www.evidence-basedpolicy.org) for more information.

The "Policy Brief" series will be authored by national leaders in developmental disabilities research, in collaboration where possible with NASDDDS directors, and will summarize the evidence on key policy and practice issues of importance to state DD services. This first of its kind research-to-practice initiative will document the research data in support of key state policy goals and practice decisions. Sample research briefs topics include:

Deinstitutionalization:

- The financial implications of facility closure and community transition
- State policies, program models, support strategies, and system infrastructure components that are associated with successful reductions in states' reliance on large residential facilities.
- The comparative benefits and developmental outcomes associated with moving to community settings from large facilities and institutions.
- The benefits (personal, programmatic, financial) of integrated employment for people with I/DD and/or autism spectrum disorders (ASD).

An introductory webinar attended by approximately 150 participants was held on March 15, 2011. Charlie Lakin and Chas Moseley described the goals, purpose, and planned activities of the new initiative; the topics to be considered; and the development of a new website. Their presentation was followed by a discussion on the use of NCI data in state policy by Steve Hall, Commissioner, Department for Behavioral Health, Developmental and Intellectual Disabilities and Harold Kleinert, director of the UCEDD in Kentucky. A follow-up webinar was held again featuring the use of NCI data for policy development and strategic planning that included

presentations from John Martin, state DD director in Ohio and Mark Tasse, the director of the UCEDD in Ohio. The first EBP report was completed providing an analysis and review of the research data in support of institutional closure and community living. Additional documents covering the various topics will be prepared in the months ahead.

## COLLABORATIONS

**Alliance for Full Participation.** NASDDDS is a member of the [Alliance for Full Participation](#) (AFP), a formal partnership of leading organizations serving the developmental disabilities field that share a common vision to help create a better and more fulfilling quality of life for people with developmental disabilities

Other partners in AFP include the American Association on Intellectual and Developmental Disabilities (AAIDD), American Network of Community Options and Resources (ANCOR); Association for Persons in Supported Employment (APSE); Employment Network Association of University Centers on Disabilities (AUCD); Autism Society of America (ASA); Best Buddies International; National Association of Councils on Developmental Disabilities (NACDD); National Alliance for Direct Support Professionals (NADSP); The Arc of the United States; NISH; United Cerebral Palsy (UCP); The Council on Quality and Leadership (CQL); and Self-Advocates Becoming Empowered (SABE).

The AFP mission is: To dream, plan, work, mobilize, and organize with people with developmental disabilities, their families, and supporting communities and organizations to make the promise of inclusion, integration, productivity, independence, and quality of life a reality in policy and practice. In FY 2011, NASDDDS actively participated in planning for the 2011 AFP Summit 2.0: Real Jobs--It's Everyone's Business, to be held in Washington, D.C. in November.

**National Leadership Consortium on Developmental Disabilities (NLCDD).** As part of the association's commitment to helping states cultivate and train its workforce leaders of today and tomorrow, NASDDDS came together with other national s to create the [National Leadership Consortium on Developmental Disabilities](#) at the University of Delaware. The consortium convenes week-long Leadership Institutes twice a year. NASDDDS Executive Director Nancy Thaler has served as Leadership Institute faculty.

**Association of University Centers on Disabilities (AUCD).** Members of the NASDDDS Research Committee and association staff participated in a meeting and related activities sponsored by the [Association of University Centers on Disabilities](#) (AUCD). Funded by the Administration on Developmental Disabilities, the two-day symposium brought state directors together with their counterparts from the University Centers of Excellence and Developmental Disabilities Education, Research, and Service (UCEDDs) programs from five states in an effort to identify areas and issues for productive dialogue and collaboration. Association staff are additionally participating in the NASDDDS-AUCD collaborative project on the evidence-based policy initiative (see previous page).

**Collaboration to Promote Self-Determination.** The association continued to participate as a member of the Collaboration to Promote Self-Determination (CPSD). CPSD is a network of approximately 12 national organizations, including the National Fragile X Foundation, National



Down Syndrome Society, and the Autism Society of America, that have come together to promote employment opportunities and self-direction for those with I/DD.

**The Consortium for Citizens with Disabilities (CCD).** The association once again participated as a member of the [Consortium for Citizens with Disabilities](#), ensuring that state I/DD directors had a voice in the largest disability advocacy group. CCD played a key role in the effort to include long-term supports and services reform in the health care reform bill. NASDDDS represented the perspective of state I/DD agencies to the CCD during these efforts.

**National Association for the Dually Diagnosed (NADD).** NASDDDS continues to work NADD to provide review and input on the development of a Standards for Quality Services Program that will provide for the accreditation of services and the certification of staff involved in the delivery of supports to adults with co-occurring developmental disabilities and mental illness. The proposed program will accredit:

**Organizations**, ensuring that participating organizations or programs meet the clinical, program, and agency standards established by NADD in the area of mental health care for people with intellectual disabilities. The accreditation process will include (1) face-to-face interviews, (2) records review on specific cases to ensure clear documentation that reflects appropriate biopsychosocial services, and (3) a review of policies and procedures to insure that they reflect best practices as established by the NADD accreditation standards.

**Clinicians and Professionals**, establishing a competency-based certification program process to certify the competency of professionals who work with persons who have MI/ID with the overall goal of improving the clinical skill and ability of professionals who work with this population and to create an awareness of best practices. Individuals seeking the certification will need some form of licensing or governing body recognition as well as an MA/MSW, Ph.D., M.D., Psy.D., Ed.D., N.P., or other terminal degree. Applicants will need to meet experience and licensing requirements and provide a work sample demonstrating their competency in services for persons with mental illness and intellectual disability (MI/ID).

**Direct Support Professionals**, implementing a competence based certification process for DSPs working with individuals who have MI/ID. The process will address five competency categories: (1) behavior supports, (2) community collaboration and teamwork, (3) assessment and observation, (4) crisis prevention and intervention, and (5) promoting health and wellness. Candidates for the DSP certification must have completed 1,000 hours of direct support work in the MH or DD field.

The final draft program is being distributed to NASDDDS, NASMHPD and other groups for review and ratification.

**Quality Mall.** NASDDDS staff provided information, support, and assistance to the [Quality Mall](#), operated by the Research and Training Center on Community Living, Institute on Community Integration at the University of Minnesota. The Quality Mall is an online information clearinghouse providing resources and materials showcasing promising practices and innovations that promote quality of life for persons with developmental disabilities. To help maintain the site, three NASDDDS staff members serve as managers to review and approve products to be listed at the Quality Mall.

## II. Influencing National Policy

**Team Act - the Role of DD Agencies in Employment.** NASDDDS was active on Capitol Hill educating staff in the House and the Senate about the Transitioning towards Excellence & Achievement in Mobility Act (TEAM Act), a series of three bills that share the TEAM name with one designated as "Education," one as "Empowerment," and one as "Employment." The legislation seeks to align existing federal programs providing publicly funded systems and supports to focus on ensuring that every youth with a significant disability has the opportunity, encouragement, and support to become gainfully employed in an integrated setting, pursue a post-secondary education, and contribute to and meaningfully engage in typical community settings upon leaving high school. During the visits association staff stressed the importance of employment services for individuals with DD and the importance of the TEAM Act's grants to states to aid with transition. In addition, NASDDDS Board President Mary Lee Fay participated in a Congressional Briefing on the TEAM Acts.

**Addressing Quality Oversight Requirement Issues.** Responding to growing member concerns about developments in CMS quality oversight for the 1915(c) home and community-based services waiver program, NASDDDS took a lead role in working with CMS to identify short- and long-range solutions to challenges for states such as the number of performance measures states must report on, the requirement for 100 percent compliance with assurances, the push for remediation at the individual level, and data collection requirements that are growing beyond the states' capacity to collect data. In response to NASDDDS concerns, CMS established a work group made up of state representatives, staff of the state associations, and CMS officials, to collaborate on changes and improvements to CMS's quality oversight methodology.

**Responding to CMS Regulations.** NASDDDS submitted comments on multiple CMS regulations during FY 2010-2011. Among the most significant were: a Notice of Proposed Rulemaking (NPRM) implementing the Community First Choice Option (CFCO) as authorized by the Affordable Care Act (ACA) and an NPRM attempting to define home and community-based settings and to allow states to combine target populations into one waiver. NASDDDS responded to the CFCO regulations with a set of comments and clarifying questions. Prior to the publication of the NPRM defining community, the association engaged CMS staff in a series of teleconferences to discuss the issue. In response to the NPRM, NASDDDS submitted extensive comments representing the experience of state DD agencies in building and maintaining community service systems, worked with partner associations to identify joint concerns and areas of support, and worked with the advocacy community to build an understanding of the impact of this regulation.

**Involvement in Administration on Developmental Disabilities Self-Advocacy Summits**  
To strengthen and enhance self-advocacy efforts in the states and nationally, the Commissioner of the Administration on Developmental Disabilities (ADD) asked the DD Network to work with Self Advocates Becoming Empowered (SABE) and State Developmental Disabilities Services Agencies to plan and hold a series of regional self-advocacy summits. Member state directors and NASDDDS staff played key roles in several of the summits at the invitation of Administrator Lewis. The purpose of the summits was four-fold:

1. to assess what is currently happening in the states in self-advocacy – the support structures, activities, accomplishments and challenges;
2. to plan steps we can take to strengthen and enhance current efforts at the state level;
3. to develop recommendations for actions that we can take at the national level; and
4. to develop policy recommendations that can lead to a stronger, more effective, and long lasting self-advocacy movement across the country.

**NASDDDS Testimony at ADD ENVISION 2010.** NASDDDS was involved in ADD's process to solicit input from stakeholders on the administration's five-year plan and reauthorization of the DD Act including a series of hearings around the country, facilitating one session, and participating in several others. NASDDDS also submitted testimony to ADD through this process, recommending that a formal relationship between ADD and State DD Agencies be included in future reauthorizations of the DD Act. Executive Director Nancy Thaler also participated in the final two-day session with national leaders to review the testimony from the envision listening sessions and determine trends and themes relevant to the administration's strategic plan and the DD Act.

**National Family Support Policy.** NASDDDS staff are participating with a small group of policymakers, researchers, advocates and others from the Developmental Disabilities Network (DD Councils, UCEDDs, and P&A Organizations) on a committee established by the Commissioner of ADD to consider and propose recommendations to ADD on possible changes to the DD Act to better address the needs of families of children and adults with developmental disabilities. Association staff participated in a summit at the invitation of the commissioner of ADD to consider and propose recommendations to ADD on possible changes to the DD Act to better address the needs of families of children and adults with developmental disabilities.

**Dual Eligibles.** Thanks in large part to the ACA, approaching the challenges posed by dual eligibles has become a key focus of the Obama administration. At the request of the HHS Office on Disability, NASDDDS has become engaged in the issue. Through several meetings with HHS staff and other coalition partners, the association has worked to frame the challenge of ensuring that the specific needs of duals with DD are met by new federal initiatives, most of which center around managed care.

**NASDDDS Influences Medicaid Employment Policy.** NASDDDS instigated a process of examining core service definitions related to employment, culminating in recommendations to CMS for changes to definitions in the "Medicaid Application for a 1915(c) Home and Community-Based Services Waiver Program [Version 3.5] Instructions, Technical Guide, and Review Criteria." The recommendations clarify employment outcomes in the delivery of services and supports under the Medicaid waiver programs. [N.B., Early in FY 2012, CMS published an informational bulletin encapsulating many of the changes that grew out of NASDDDS conversations with CMS, as well as the association's formally delivered recommendations.] Additionally, NASDDDS staff served on the CMS Associations Employment Subcommittee, which is tasked to identify ways to improve CMS' policies and technical support to increase states' ability to use HCBS waivers to train more individuals and help them find meaningful jobs in the community.

### III. Addendum

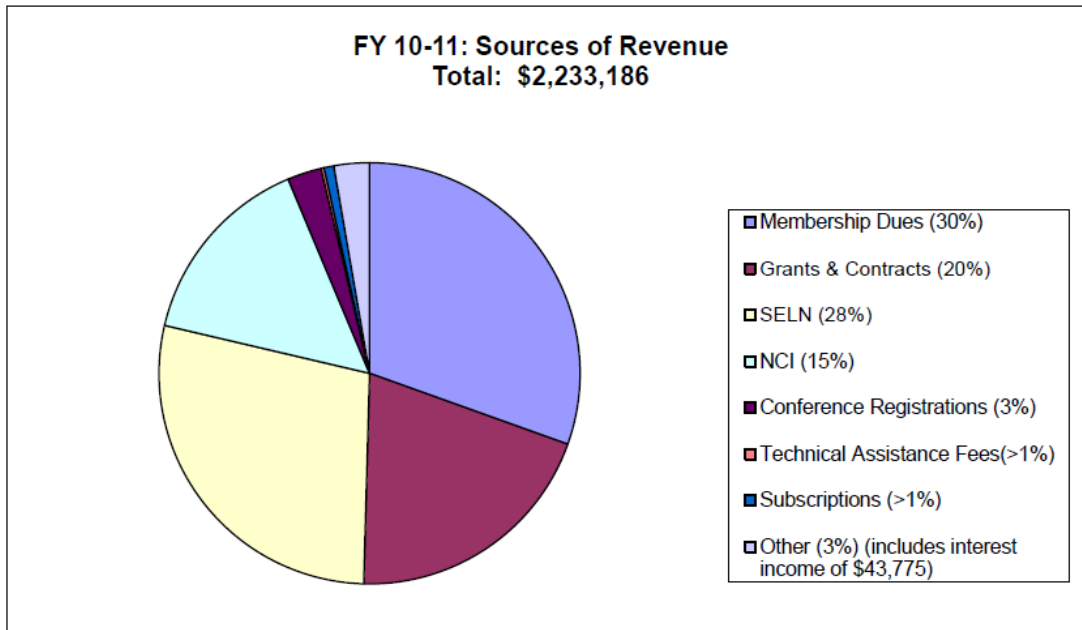
#### STATEMENTS OF FINANCIAL POSITION

#### STATEMENTS OF ACTIVITIES AND CHANGES IN NET ASSETS FOR THE YEARS ENDED JUNE 30, 2011 AND 2010

	<u>2011</u>	<u>2010</u>
<b>REVENUE</b>		
Contracts	\$ 1,063,170	\$ 947,525
Government contracts	355,827	608,990
Investment income (Note 2)	190,665	98,255
Membership	738,875	678,858
Professional development classes	5,231	16,171
Sales	3,138	496
Publications	16,824	16,207
Other revenue	<u>17,740</u>	<u>8,040</u>
Total revenue	<u>2,391,470</u>	<u>2,374,542</u>
<b>EXPENSES</b>		
Program Services:		
Membership	368,539	272,867
Virginia Commonwealth University Project	153,335	160,677
UMN/ NIDRR	31,011	858
Technical Assistance	93,046	201,376
Other Program	<u>1,190,882</u>	<u>1,098,437</u>
Total program services	<u>1,836,813</u>	<u>1,734,215</u>
Supporting Services:		
Management and General	<u>350,710</u>	<u>402,875</u>
Total expenses	<u>2,187,523</u>	<u>2,137,090</u>
Changes in net assets	203,947	237,452
Net assets at beginning of year	<u>884,016</u>	<u>646,564</u>
<b>NET ASSETS AT END OF YEAR</b>	<b><u>\$ 1,087,963</u></b>	<b><u>\$ 884,016</u></b>

DRAFT AUDIT REPORT

## SOURCES OF REVENUE



Membership Dues (30%)	680,433
Grants & Contracts (20%)	446,086
SELN (28%)	630,013
NCI (15%)	335,505
Conference Registrations (3%)	58,442
Technical Assistance Fees(>1%)	5,231
Subscriptions (>1%)	16,824
Other (3%) (includes interest income	60,652

2,233,186

Note: Chart does not include Unrealized Gains on Investments of \$146,891

## NASDDDS BOARD OF DIRECTORS, NATIONAL POLICY WORK GROUP, RESEARCH COMMITTEE, STAFF, AND ALUMNI ASSOCIATION

### Board of Directors

Kenneth Ritchey	(NJ)	President	(ended January 2011)
Mary Lee Fay	(OR)	President	(beginning January 2011)
		Vice President/President Elect	(ended January 2011)
James Nicholson	(OK)	Vice President/President Elect	(beginning January 2011)
		Secretary/Treasurer	(ended January 2011)
Jane Gallivan	(ME)	Secretary/Treasurer	(beginning January 2011)
		Member-at-Large	(ended January 2011)
Stephen R. Hall	(KY)	Member-at-Large	
Laura Nuss	(DC)	Member-at-Large	
Bernard Simons	(MO)	Member-at-Large	(beginning May 2011)

### Research Committee

#### Association Members

Stephen Hall	Kentucky (Chair)
Linda Rolfe	Washington
Kathryn duPree	Connecticut
John Martin	Ohio
Bernie Simons	Missouri
Lee Price	Virginia
Mike Head	Michigan

#### Non-Association Members

Rick Hemp	University of Colorado
Charlie Lakin	University of Minnesota Research and Training Center on Community Living, Institute on Community Integration
Bill Kiernan	University of Massachusetts Boston Institute for Community Inclusion
Val Bradley	Human Services Research Institute

### National Policy Work Group

Jane Gallivan	Maine (Chair)
Alex Bartolic	Minnesota
Julia Holloway	Indiana
Julia Kenney	Louisiana
Jim Nicholson	Oklahoma
Laura Nuss	Washington, DC
Linda Rolfe	Washington

## NASDDDS Staff

Nancy Thaler	Executive Director
Charles R. Moseley, Ed.D.	Associate Executive Director
Robin Cooper	Director of Technical Assistance
katherine karol snyder	Director of Member Services
Dan Berland	Director of Federal Policy
Kara LeBeau, M.A.	Director of State Policy
Rie Kennedy-Lizotte	Director of Communities of Practice
Megan Rose	Office Manager

## Alumni Association

Cathy R. Anderson  
Steven Cook  
Catherine Crabtree  
Norm Davis  
Gary Lind  
Gerry Morrissey  
Kingsley Ross  
Wanda Seiler  
Shirley York  
Deborah Wehrlen  
Theresa A.M. Wood  
Ric Zaharia

## NASDDDS MEMBERS (as of October 2011)

ALABAMA	Ann White-Spunner, Interim Associate Commissioner Division of Intellectual Disability Services
ALASKA	Duane Mayes, Director Senior and Disabilities Services
ARIZONA	Barbara Brent, Assistant Director Division of Developmental Disabilities
ARKANSAS	Dr. James "Charlie" Green, Director Division of Developmental Disabilities Services
CALIFORNIA	Terri Delgadillo, Director California Department of Developmental Services
COLORADO	Barbara Ramsey, Interim Director Division for Developmental Disabilities
CONNECTICUT	Terrence W. Macy, Ph.D., Commissioner Department of Developmental Services

DELAWARE	Jane Gallivan, Director Division of Developmental Disabilities Services
D.C.	Laura Nuss, Director Department on Disability Services
D.C.	Cathy Anderson, Deputy Director Department on Disability Services, DD Administration
FLORIDA	Michael Hansen, Director Agency for Persons with Disabilities
GEORGIA	Beverly D. Rollins, MPA, Executive Director Division of Developmental Disabilities
HAWAII	Dr. Jeffrey Okamoto, Acting Chief Developmental Disabilities Division
IDAHO	Chad Cardwell, Program Manager Developmental Disabilities Program
ILLINOIS	Kevin T. Casey, Director Division of Developmental Disabilities
INDIANA	Julia Holloway, Director Disability and Rehabilitative Services
IOWA	Rick Shults, Division Administrator Division of Mental Health & Disability Services
KANSAS	Steve Leary, Director Department of Community Supports and Services
KENTUCKY	Stephen R. Hall, Ph.D., Commissioner Department for Behavioral Health, Developmental & Intellectual Disabilities
LOUISIANA	Julia Kenny, Assistant Secretary Office for Citizens with Developmental Disabilities
MAINE	Ricker Hamilton, Acting Director Office of Adults with Cognitive and Physical Disability Services
MARYLAND	Frank Kirkland, Director Developmental Disabilities Administration
MASSACHUSETTS	Elin Howe, Commissioner Department of Developmental Services
MICHIGAN	Judy Webb, Director Division of Quality Management & Planning
MINNESOTA	Alex Bartolic, Director Disability Services Division
MISSISSIPPI	Kris Jones, LMSW, CMHT, LCMRT, Interim Director Bureau of Intellectual & Developmental Disabilities

MISSOURI	Bernard Simons, Director Division of Developmental Disabilities
MONTANA	Jeff Sturm, DD Program Director Disabilities Services Division
NEBRASKA	Jodi Fenner, Director Division of Developmental Disabilities
NEVADA	Jane Gruner, Statewide Coordinator for Developmental Services Division of Mental Health & Developmental Services
NEW HAMPSHIRE	Matthew Ertas, Bureau Chief Bureau of Developmental Services
NEW JERSEY	Dawn Apgar, Ph.D., Deputy Commissioner Division of Developmental Disabilities
NEW MEXICO	Cathy Stevenson, Acting Director Developmental Disabilities Supports Division
NEW YORK	Courtney Burke, Acting Commissioner Office for People with Developmental Disabilities
NORTH CAROLINA	Steve Jordan, Director Division of Mental Health, DD & Substance Abuse Services
NORTH DAKOTA	Tina Bay, Director Disability Services Division
OHIO	John Martin, Director Department of Developmental Disabilities
OKLAHOMA	James Nicholson, Division Administrator Developmental Disabilities Services Division
OREGON	Mary Lee Fay, Administrator Office of Developmental Disability Services
PENNSYLVANIA	Kevin M. Friel, Deputy Secretary Office of Developmental Programs
RHODE ISLAND	Craig Stenning, Director Department of Behavioral Healthcare, DD & Hospitals
SOUTH CAROLINA	Dr. Beverly A. H. Buscemi, Director Department of Disabilities and Special Needs
SOUTH DAKOTA	Dan Lusk, Director Division of Developmental Disabilities
TENNESSEE	James M. Henry, Commissioner Department of Intellectual & Developmental Disabilities
TEXAS	Jon Weizenbaum, Deputy Commissioner Department of Aging and Disability Services

UTAH	Paul Smith, Acting Director Division of Services for People with Disabilities
VERMONT	Marybeth McCaffrey, Esq., Director Division of Disability and Aging Services
VIRGINIA	C. Lee Price, Director Office of Developmental Services
WASHINGTON	Linda Rolfe, Director Division of Developmental Disabilities
WEST VIRGINIA	Beth Morrison, Commissioner Division of Intellectual and Developmental Disabilities
WISCONSIN	Beth Wroblewski, Director Bureau of Long Term Support
WYOMING	Chris Newman, Administrator Behavioral Health Division

## ASSOCIATION AWARDS

### Robert M. Gettings Compass Award



**John O'Brien** was awarded the Robert M. Gettings Compass Award by the NASDDDS Board of Directors in 2011 in recognition of his lifelong advocacy of person-centered planning, through which he has changed how people are supported across the states. The Compass Award recognizes the achievements of individuals who, while working in the private sector, have made significant contributions to the development of publicly funded state service systems for people with developmental disabilities through research, the design of new service models, training, technical assistance, and consultation.

### Ben Censoni Award For Excellence In Public Services

The NASDDDS Board of Directors in 2011 honored **James Toews**, Oregon Department of Human Services Assistant Director for the Seniors and People with Disabilities Division, with the Ben Censoni Award for Excellence in Public Services. Toews became Oregon's state DD director more than 25 years ago and has not only served as a leader in changing the field but also as a mentor to a number of DD professionals who have gone on to leadership positions around the country. The Censoni Award is the only award that recognizes public officials who strive to improve the lives of people with developmental disabilities. The award is named after the late Ben Censoni, former developmental disabilities director for Michigan and Chair of the association's Governmental Affairs Committee. Ben's motto was "People are what really matter."



## IN MEMORIAM

**KARA LEBEAU**  
**MARCH 7, 1956 – MAY 30, 2011**



Kara LeBeau served as the association's State Policy Analyst/Director of State Policy beginning in May 2004. As editor of *State News Briefs* and *Community Services Reporter*, Kara brought an understanding of the important work of states in meeting the needs of individuals with developmental and intellectual disabilities and the need for states to learn from each other's experiences. Kara conducted research and edited special publications including the recently released *Shared Living Guide*. In addition to her research and publishing responsibilities, Kara provided support to the NASDDDS Attorneys Group which included maintaining and publishing a summary of litigation cases of interest to states and managing the association's conferences.

Kara's interest in writing and publishing was preceded by an interest in Asian studies. She received a B.A. in Chinese from the University of Minnesota, lived in Taiwan for a year and worked for the Southeast Asian Refugees Studies Project for the University of Minnesota from 1990-1995 during which time she earned an M.A. in religious studies at the same university. Her interest in the east and eastern religions was a constant in her life. Kara's turn to journalism began by earning an M.A. in print journalism at the Annenberg School of Communication, University of Southern California and then an M.A. in science writing from Johns Hopkins University. In 1997, Kara began her career as a writer and editor at Summit University Press in Montana then later with the Geological Society of America in Boulder, Colorado and the American Geophysical Union in Washington, D.C.