Mission, Association Goal, Guiding Principles, and Strategic Plan

Mission Statement
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 services and supports for people with intellectual and developmental disabilities and their families.

Association Goal
The association's goal is to promote and assist state agencies in developing effective, efficient service delivery systems that furnish high-quality supports to people with intellectual and developmental disabilities.

Guiding Principles
State service systems should be based on the following principles that people with developmental disabilities have a right to:

- be treated with respect and dignity;
- be independent and make individual choices;
- participate in family, community, and work 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.

In pursuit of this goal, NASDDDS strives to provide member state agencies with timely analyses of federal statutory and regulatory policies that affect people with disabilities; disseminate cutting edge information on state-of-the-art programs and service delivery practices; provide technical assistance and support to member states; and offer a forum for the development of state and national policy initiatives.
Reflections from the Board President

As I come to the end of my term as board president in November 2018, I thought it is a good time to reflect on how committed NASDDDS is to its members. Each year board members place calls to state directors to talk with them about the association's services, the needs of their states, and whether there are areas the association might address that it is not currently focused on. Some of the most challenging themes that came out of these calls are budgetary concerns, home and community-based services rule implementation, conflict of Interest provisions, shifting from legacy models, and building provider capacity.

The association's goal is to promote and assist state agencies in developing effective, efficient service delivery systems that furnish high-quality supports to people with intellectual and developmental disabilities. In pursuit of this goal, NASDDDS strives to provide member state agencies with timely analyses of federal statutory and regulatory policies that affect people with disabilities; disseminate cutting edge information on state-of-the-art programs and service delivery practices; and provide technical assistance and support to member states.

Because we also learned through these calls that our members find webinars and the List Serve very helpful, the board and organization’s staff will focus efforts to offer more webinar opportunities based on content related to the identified themes above, as well as, discuss the best way to share information and findings through the ListServ.

NASDDDS has also completed upgrades to the website with the sole purpose of improving the look and feel of our member’s first impressions and the ease of use when entering the site. The website now features important topics, as well as, state and federal news on the front page to ensure that the site is up-to-date and relevant.

We also know that you value our conferences. This past June the conference focused on building capacity at all levels of the system. A major theme from the presentations was the importance of using technology to build capacity and we heard from Ohio as the first state in the country to become a "Technology First State." Technology is important in everyone's lives and there are so many new and emerging technologies that may also be used to promote independence to foster opportunities for more inclusive and independent lives for people with intellectual and developmental disabilities.

I thank the NASDDDS staff for the monitoring of federal legislation and providing ongoing technical assistance to member states.

Board Changes in 2017-2018

We said goodbye to the following board members during the past fiscal year…

Beverly Buscemi – Director, South Carolina DDSN
Board member from 2013 -2017
Courtney Tarver – Associate Commissioner, Alabama DDD  
Board member from 2013 -2018

Barbara Ramsey – Deputy Director, Colorado Office of Community Living  
Board member from 2016 -2017.

I would also like to welcome our new members…

Mark Thomas – Deputy Secretary, Louisiana Department of Health  
Elected to the board in June 2017.

Mary Brogan – Chief, Hawaii DDD  
Elected to the member-at-large position in November 2017.

Lee Grossman – Administrator, Wyoming DDS  
Elected to the board in June 2018.

Jordan Scheff – Commissioner, Connecticut DDS  
Elected to the board in June 2018.

Lastly, the board of directors is pleased to provide you with this annual report of our accomplishments and continued fiscal soundness.
NASDDDS Staff

Mary Lee Fay  
Executive Director

Robin E. Cooper  
Director of Technical Assistance

katherine karol snyder  
Director of Administrative Services

Dan Berland  
Director of Federal Policy

Rie Kennedy-Lizotte  
Director of Employment Policy and Practice

Barbara Brent  
Director of State Policy

NASDDDS Board of Directors

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<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Term</th>
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<tr>
<td>Bernard Simons</td>
<td>President</td>
<td>April 2016 – November 2018</td>
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<tr>
<td>John Martin</td>
<td>Vice President/President Elect</td>
<td>June 2016 – November 2018</td>
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<td>Alex Bartolic</td>
<td>Secretary/Treasurer</td>
<td>June 2016 – November 2018</td>
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<td>Mark Thomas</td>
<td>Member-at-Large</td>
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<td>Lee Grossman</td>
<td>Member-at-Large</td>
<td>June 2018 – November 2018</td>
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Alumni Association
Contact information and links to the current alumni association members are available on the NASDDDS website (www.nasddds.org/alumni/)

Cathy Anderson  Peter Bisbecos  Laura Brackin  Stan Butkus
Max Chmura  Jim DeBeauprime  Roger Deshaies  Kathryn Du Pree
Steven Eidelman  David Evans  Jodi Fenner  Roy Gerstenberger
Jane Coorough Gruner  Sharon Jacksi  Julia Kenny  Frank Kirkland
Dan Lusk  Gerry Morrissey  James Nicholson  Laura Nuss
Peter O'Meara  Kenneth Ritchey  Wanda Seiler  Ric Zaharia
Influencing National Policy

NASDDDS is the states' voice in the nation's capital, ensuring that the perspective and collective knowledge of the members informs national policy. NASDDDS works closely with executive branch agencies; educates federal lawmakers; and provides member states with timely analysis of federal statutory and regulatory policies.

Congressional Action on the Affordable Care Act and Medicaid

The spring of 2017 marked a time of great Congressional debate related to the basic tenets of healthcare in this country. The House of Representatives passed the American Health Care Act (AHCA) on May 4, 2017. This legislation contained far-reaching provisions impacting not only the Affordable Care Act, but also the basic financing structure of Medicaid. This legislation was estimated to cut Medicaid by approximately $880 billion. Given that most I/DD systems are built upon a Medicaid service system, NASDDDS was actively engaged on the Hill to educate lawmakers about potential impacts on states and individuals with disabilities.

After passage in the House, the Senate took up its own legislation, which contained similar Medicaid provisions. This action failed to pass the Senate in the summer of 2017.

NASDDDS, representing all 50 states and the District of Columbia, does not typically take positions on legislation, and instead, aims to provide factual information to inform deliberations on issues affecting individuals with disabilities.

In the days before the Senate voted down the Healthcare Freedom Act, seemingly ending the process of attempting to pass an Affordable Care Act (ACA) repeal and restructure Medicaid through the budget reconciliation process, NASDDDS issued the following statement, opposing steep cuts to Medicaid as envisioned in several of the bills that were under consideration:

NASDDDS Statement Opposing Proposed Medicaid Cuts

"Medicaid is our nation's largest payer of long-term services and supports (LTSS), which includes home and community-based services (HCBS) and institutional services such as nursing facilities and institutions for individuals with intellectual disabilities (ICF/IID). These services maintain the health, function, independence, and well-being of millions of people with intellectual and developmental disabilities, elderly people, and individuals with physical disabilities, behavioral health diagnoses, spinal cord or traumatic brain injuries, and/or disabling chronic conditions. Total Medicaid LTSS expenditures were $158 billion in FY 2015 — nearly a third of all Medicaid spending for the year."
NASDDDS strongly believes that as a nation we must have a clear and honest conversation about how best to address and fund the LTSS needs of the people we support. This conversation must be thoughtful and deliberate, bipartisan, and informed by accurate data. The process Congress has engaged in this year to develop health care reform to meet reconciliation instructions in the 2017 congressional budget resolution has included significant alterations to Medicaid without meeting any of these criteria. Of greatest concern to state I/DD agency directors are provisions included in the House-passed American Health Care Act (AHCA) and in the main Senate bill, the Better Care Reconciliation Act (BCRA), which would dramatically reduce funding for Medicaid and for our nation’s LTSS system.

The provisions in those bills cut approximately $800 billion from Medicaid over the next 10 years, followed by even deeper cuts after 2027. These cuts would undermine the ability of states to meet the LTSS needs of individuals with developmental disabilities. While it is unclear exactly what legislation the Senate may finally vote on this week, NASDDDS firmly opposes any legislative package that includes Medicaid cuts similar to those in the AHCA and BCRA. Should the Senate pass a bill this week that leads to a conference committee, we strongly oppose the inclusion of similar Medicaid provisions in legislation coming out of that committee.

NASDDDS and its members are prepared and willing to participate in thoughtful and deliberate discussions that would consider sustainable funding of LTSS. We urge Congress to halt the rush to massive cuts in LTSS funding and engage in a process that takes a broad and inclusive look at LTSS in the United States, acknowledges Medicaid's current role as the de facto LTSS system in our nation, and seeks real bipartisan solutions to meeting the support needs of our elderly and individuals with disabilities across the nation.”

The statement was approved by the association's National Policy Work Group and members of the Board of Directors.

**NASDDDS Partnered with Other Associations to Oppose Graham-Cassidy**

NASDDDS released a statement opposing the Graham-Cassidy-Heller-Johnson legislation that would have made significant changes to Affordable Care Act (ACA) programs and also sought to restructure Medicaid financing.

**NASDDDS Statement Opposing Proposed Graham-Cassidy-Heller-Johnson Legislation**

The National Association of State Directors of Developmental Disabilities Services (NASDDDS) is a nonprofit membership organization of state developmental disabilities agency directors. Our members are the 51 state agencies that oversee long-term supports and services (LTSS) systems for individuals with intellectual and developmental disabilities, which are predominantly funded by Medicaid. The principal mission of NASDDDS is to assist state agencies in building person-centered systems of services and supports for people with developmental disabilities and their families. Medicaid is our nation's largest payer of long-term services and supports (LTSS), which includes home and community-based services (HCBS) and institutional services such as nursing facilities and institutions for individuals with intellectual disabilities (ICF/IID).
These services maintain the health, function, independence, and well-being of millions of people with intellectual and developmental disabilities, elderly people, and individuals with physical disabilities, behavioral health diagnoses, spinal cord or traumatic brain injuries, and/or disabling chronic conditions. Total Medicaid LTSS expenditures were $158 billion in FY 2015—nearly a third of all Medicaid spending for the year.

NASDDDS strongly believes that as a nation we must have a clear and honest conversation about how best to address and fund the LTSS needs of the people we support. This conversation must be thoughtful and deliberate, bipartisan, and informed by accurate data. The process Congress has engaged in this year to develop health care reform to meet reconciliation instructions in the 2017 congressional budget resolution has included significant alterations to Medicaid without meeting any of these criteria. State I/DD agency directors are particularly concerned with provisions in the Graham-Cassidy-Heller-Johnson legislation, similar to those in the House-passed American Health Care Act (AHCA) and in the Senate's previous bill, the Better Care Reconciliation Act (BCRA), which would dramatically reduce funding for Medicaid and for our nation's LTSS system. While the Congressional Budget Office (CBO) has not yet had a chance to weigh in on the impact of Graham-Cassidy, reputable analysts estimate that the per capita cap provisions in the bill will cut approximately $1 trillion from Medicaid over the next twenty years. These cuts would undermine the ability of states to meet the LTSS needs of 2 individuals with developmental disabilities.

NASDDDS firmly opposes this or any legislative package that includes Medicaid cuts of this magnitude. NASDDDS and its members are prepared and willing to participate in thoughtful and deliberate discussions that would consider sustainable funding of LTSS. We urge Congress to halt the rush to massive cuts in LTSS funding and engage in a process that takes a broad and inclusive look at LTSS in the United States, acknowledges Medicaid's current role as the de facto LTSS system in our nation, and seeks real bipartisan solutions to meeting the support needs of our elderly and individuals with disabilities across the nation.

**NASDDDS Partnered with Other Associations to Call on Congress to Reauthorize Money Follows the Person**

NASDDDS partnered with the National Association of Medicaid Directors (NAMD) and the National Association of States United for Aging and Disabilities (NASUAD) to issue a letter to the House Energy and Commerce Committee and the Senate Finance Committee in support of efforts to reauthorize and extend the Money Follows the Person Demonstration Program (MFP).

The organizations express their strong support of the reauthorization and extension of MFP for several key reasons:

- MFP has enabled categorically high need, high cost older adults and people with disabilities to transition from costly institutional settings to the community, which enables choice, self-direction, and integration in civic life;
- MFP has been a leading means of shifting the proportion of Medicaid long-term services and supports (LTSS) spending from expensive nursing homes and chronic disease hospitals to less costly home and community-based waivers, resulting in billions of dollars of savings;
- MFP has represented the leading edge of Medicaid's efforts to address social determinants of health, including housing access and stability;
• MFP’s success in systems transformation has been documented longitudinally through years of rigorous data collection and analysis through third-party evaluators; and
• States that are participating in MFP are currently exhausting their allotted funding, and will not have the means of ensuring that all those who seek transition will be served.

The letter called on Congress to "reauthorize and extend this program as soon as possible so that no individuals who could be helped by MFP are instead forced to remain in an institution."

**NASDDDS Requested EVV Guidance from CMS**

NASDDDS sent a letter to the Centers for Medicare & Medicaid Services (CMS) requesting clarity regarding the technical expectations necessary for successful compliance with the Electronic Visit Verification (EVV) requirements codified in Section 12006 of the 21st Century CURES Act. The letter offered state I/DD agencies' perspectives on most pressing issues to assist CMS efforts:

Dear Administrator Verma,

On behalf of the National Association of State Directors of Developmental Disabilities (NASDDDS) we are writing to respectfully request expedient clarity on the technical expectations necessary for successful compliance with the Electronic Visit Verification (EVV) requirements codified in Section 12006 of the 21st Century CURES Act. We are strongly supportive of the goal to reduce fraud, waste and abuse in the provision of personal care and home health services, and committed to complying with the requirements laid out in the legislation. We know that staff at CMS have been working diligently on these policies, and we thought sharing our members' perspectives on most pressing issues may be of assistance in these efforts.

We are a membership organization representing the state agencies overseeing services to individuals with intellectual and developmental disabilities (I/DD) in the 50 states and the District of Columbia. An estimated 655,000 individuals are receiving Medicaid home and community based services (HCBS) annually through the state I/DD agencies who work in partnership with State Medicaid Agencies in the operation of Medicaid HCBS.

Our members face significant implementation challenges and a short timeline for coming into compliance with the EVV requirements before facing sizable reductions to federal funding for Medicaid personal care services beginning in January 2019. These challenges are compounded by continuing uncertainty regarding the scope of the requirements. While we appreciate the guidance CMS has provided through webinars, verbal communications and sender-specific responses to questions posed through a dedicated email box, there remain sizeable questions for states with a mere eight (8) months remaining before potential penalties ensue.

The EVV requirements originated from concerns, raised by the Office of the Inspector General of the US Department of Health and Human Services (OIG/HHS) in a series of reports that personal care services delivered in consumers' own homes could be fraudulently billed due to the lack of onsite supervision. Section 12006(a) of the 21st Century CURES Act, accordingly, indicates that the new EVV requirements apply to "personal care services or home health care services requiring an in-home visit by a provider" that are provided under a Medicaid State plan or under a waiver of the plan. In home and community based
services authorities, personal care consisting of assistance with activities of daily living (ADL) or instrumental activities of daily living (IADL), may occur as a component of or incidental to another service offered by the state, such as habilitation. The specific service threshold for inclusion in EVV remains unclear, leading states to draw conclusions regarding included services that may or may not comport with Federal expectations.

In addition, the settings in which the EVV requirements apply remain uncertain. During EVV related question and answer (Q &A) sessions, CMS has left open the prospect that the requirements may apply to settings other than in-home settings, and may include settings operated by agencies on a 24-hour basis such as group homes and assisted living. These settings have shift care staff, typically support multiple clients, often are reimbursed to the provider on a per diem basis, and are licensed and regulated by the state. Including this type of setting in the EVV requirement is likely to be burdensome to both the provider implementing EVV and the state collecting the data, and may not yield data of value in the quest to stem fraud, waste and abuse.

This uncertainty regarding both services and settings is a serious impediment for states seeking to develop and deploy EVV strategies that comport with the law. Implementing the EVV requirements is a costly and time-consuming process, involving many questions of system design. Several states who have begun the process are concerned about the expense of undoing their progress and starting over if they have not correctly anticipated CMS’ interpretation of the requirements. Compounding this problem is the challenge of state legislative calendars; many state legislatures are wrapping up their legislative activity for 2018, or have already ended their sessions. These states have effectively missed the window for requesting funds and authority (where necessary) to develop an EVV system.

As we approach the implementation date of January 1st, 2019, it is crucial that states receive clarity regarding what services will be covered by the EVV requirements in the 21st Century Cures Act, and in what settings. CMS has indicated that guidance will be forthcoming in the form of a State Medicaid Director Letter (SMDL) and a compendium of Frequently Asked Questions. These resources will be essential to states as they develop and deploy their approach to EVV. However, it is also important to note that many states are ending legislative sessions without such clarity and therefore states may be lacking the needed resources to implement.

We recommend that consideration of this status be used when determining fiscal impacts to states who will take longer than the January 1, 2019 to secure an implementation strategy. Our association stands ready to assist CMS in any way in the development and dissemination of guidance necessary to ensure full compliance with the personal care provisions of the Act by January 2019.

CMS then issued Frequently Asked Questions (FAQs) and an Informational Bulletin to assist states in meeting Electronic Visit Verification (EVV) requirements specified in the 21st Century Cures Act (Cures Act) and delayed the implementation date for EVV for personal care services to January 1, 2020.

**NASDDDS Participated in the NADD Public Policy Summit**

NASDDDS participated in a public policy summit hosted by NADD (An association for persons with developmental disabilities and mental health needs), on "Ensuring Full Community Engagement for Individuals with Intellectual/Developmental Disabilities and Co-Occurring Mental Illnesses." This summit was a follow-up to NADD's 2014 summit, which focused on the topic of inclusion in health care reform.
"The Summit provided an expanded opportunity, with a more comprehensive representation of stakeholders, to address the national challenges facing individuals with intellectual/developmental disabilities and co-occurring mental illness (IDD/MI), and their families. Participants collaborated and identified recommendations and perspectives in meeting the Summit’s objective to advance the comprehensive health care and other community engagement needs of individuals with IDD-MI."

**NASDDDS Filed "Friend of the Court" Brief on Shared Living**

NASDDDS partnered with the American Network for Community Options and Resources (ANCOR), the National Association of States United for Aging Disabilities (NASUAD), and Pennsylvania Advocacy and Resources for Autism and Intellectual Disabilities (PAR), and filed an amicus curiae ("friend of the court") brief in support of a provider of shared living services in *Pendleton v. JEVS*, a case currently pending in the United States District Court for the Eastern District of Pennsylvania.

**Federal Regulations: HCBS Rule**

NASDDDS continues to provide leadership on the implementation of the HCBS rule, representing state DD agencies' perspectives on implementation opportunities and challenges. The association meets on a bi-weekly basis with the Centers for Medicare & Medicaid Services (CMS) officials and has recently begun to meet in a dedicated workgroup to assist CMS to identify areas requiring additional guidance, providing input and advice on the content and approach. NASDDDS is fortunate to have a number of member states participate in this group (Michigan, Maryland, Wisconsin, Pennsylvania, and South Carolina). The state representatives provide invaluable perspective on policy and operational feasibility of proposed courses of action. Specifically, this workgroup is tackling issues related to settings presumed institutional and the heightened scrutiny process. CMS projects the issuance of guidance in 2018.

**Federal Regulations: ABLE Act**

NASDDDS has joined the Consortium for Citizens with Disabilities Financial Security Task Force, which is where the bulk of policy work occurs for Achieving a Better Life Experience Act (ABLE). In September 2017, CMS issued some eligibility-based guidance to the ABLE act regarding the treatment of funds, contributions, distributions and post-eligibility treatment of income. Most states have active ABLE programs up and running.

**Federal Legislation: Transition to Independence Act**

NASDDDS continues to actively support this legislation, which seeks to give 10 Medicaid buy-in states an opportunity to receive bonus payments for meeting benchmarks tied to expanding individual integrated employment and reducing
subminimum wage work, congregate work settings, or facility-based day habilitation placement for people with disabilities who receive Medicaid-funded HCBS.

**Federal Legislation: Workforce Innovation and Opportunity Act**

NASDDDS staff participated in framing testimony presented to the Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities, on behalf of the Partnerships in Employment Grantee States, from their system change work to improve employment and higher education outcomes for youth and young adults. The Advisory Committee is a key component of the Workforce Innovation and Opportunity Act. NASDDDS staff in collaboration with APSE (a national organization with an exclusive focus on integrated employment and career advancement opportunities for individuals with disabilities) provided comment and recommendations for regulations in the implementation of the Workforce Act and the potential impact on people with intellectual and developmental disabilities.

**Coalition Leadership**

Dan Berland serves as the Co-Chair of the Long-Term Supports and Services Task Force of the Coalition of Citizens with Disabilities, the nation's largest coalition advocating for the rights and services for people with all disabilities.

**Supporting State Members**

The association's primary role and mission is to assist member state agencies in building person-centered systems of support for people with intellectual/developmental disabilities (I/DD) and their families.

**Technical Assistance**

One of the association's primary functions is to provide technical assistance to state agencies. Technical assistance (TA), as a standard membership service, includes responding to telephone and email inquiries, reviewing and commenting on draft proposals or plans upon request, support on approaches to serve people with significant support needs, financing strategies, providing resources, and linking members to other states and organizations that can be of assistance. NASDDDS staff respond to state agency representatives daily to offer specialized technical assistance.

**NASDDDS STAFF PROVIDED 4,693 HOURS OF MEMBER SERVICES AND TECHNICAL ASSISTANCE TO STATES IN FY 2017-2018.**

NASDDDS 2017-2018 Annual Report
www.nasddds.org
Major Technical Assistance Projects for FY 2017-2018

DELAWARE

NASDDDS worked with Delaware to develop a health home state plan amendment for the state’s Assertive Community Integration Support Team (called ACIST – pronounced “assist”). This is an innovative support structure to support individuals with co-occurring I/DD and mental health support needs. Delaware is submitting the amendment for CMS consideration. The health home benefit brings an enhanced match of 90 percent for the first eight quarters of implementation.

ILLINOIS

NASDDDS continued its partnership with the Illinois Council on Developmental Disabilities (ICDD) and the state Division of Developmental Disabilities, by providing technical assistance on many facets of the systemic redesign underway, including Medicaid options and opportunities, alignment and integration of service coordination authority, person-centered planning strategies, infrastructure considerations, and other issues related to a robust HCBS service system.

MARYLAND

NASDDDS has continued to provide support to Maryland as they embark on a significant system transformation, including the implementation of two new waivers to expand capacity within the state to serve individuals and support families. In addition, Maryland assists the state with facilitation of two key workgroups aimed at monitoring transformation efforts and establishing tiered standards to ensure the growth of modern, person-centered services within the state.

DISTRICT OF COLUMBIA

The District of Columbia has engaged NASDDDS on efforts related to the District’s Partnerships in Employment Project, known as DC Earners and Learners. This work includes meeting with the D.C. state agency in multi-stakeholder engagement to develop a plan to increase employment outcomes for youth and young adults with disabilities. NASDDDS continued its efforts to support D.C. the No Wrong Door Initiative, with a focus on integrated community supports.

In addition, NASDDDS provided technical support on the development of both a support waiver and self-directed service options.
Federal Technical Assistance Projects

NASDDDS had entered into contracts with several federal agencies directly or as subcontractors to provide technical assistance to states on the behalf of federal agencies.

**GEORGETOWN UNIVERSITY DIVERSITY COMMUNITY OF PRACTICE**

NASDDDS is pleased to partner with Georgetown University on their efforts related to a Diversity Community of Practice (CoP), furthering system capacity to support people in a culturally competent fashion. This CoP brings together state teams, including NASDDDS members, to identify strengths and opportunities within their own systems of supports.

**CMS TECHNICAL ASSISTANCE PROJECT FOR HCBS (NEW EDITIONS)**

Robin E. Cooper, Barbara Brent, Adam H. Sass, Mary Lou Bourne, Laura Vegas, Jeanine Zlockie, Mary Lee Fay, and Mary P. Sowers are now contributing to this effort. Assistance to more than 36 states has been provided on topics ranging from developing applications for new Medicaid HCBS authorities such as 1915(i) and (k), conflict of interest in case management, person-centered plan regulations, state plan behavioral health services, quality management, waiver analysis, and managed care. The contract for 2017-2018 began in October 2017, and NASDDDS has entered into a new contract for 2017-2018 starting October 2018. NASDDDS provided more than 700 hours of technical assistance to New Hampshire, Washington, Oklahoma, Missouri, Colorado, Mississippi, Alabama, Florida, and the District of Columbia under this contract.

NASDDDS staff prepared and presented three national CMS webinars:

- Conflict of Interest in Medicaid Authorities — Robin E. Cooper
- Steps to Creating a Statewide Person-Centered Service Planning System — Mary Lou Bourne
- Combining & Targeting Populations Under 1915(c) — Mary P. Sowers

**CMS INNOVATION ACCELERATOR PROGRAM IN PARTNERSHIP WITH IBM WATSON**

NASDDDS partnered with IBM Watson to provide training on I/DD systems to the state coaches assisting states with HCBS Innovation Accelerator Program (IAP) work. This effort entailed a comprehensive webinar series and ongoing consultation on I/DD-focused IAP efforts aimed at structuring outcome-based payment efforts. This engagement followed a comprehensive research effort to provide an environmental landscape of day services in HCBS nationally. For this effort, NASDDDS partnered with the Institute for Community Inclusion at the University of Massachusetts Boston.
Publications / Papers

NASDDDS Published

✧ Federal News Briefs on a weekly basis
  Writer/Editor
  Dan Berland

✧ State News Briefs on a biweekly basis
  Writer/Editor
  Jeanine Zlockie

✧ Federal Perspectives on a monthly basis
  Writer/Editor
  Dan Berland
  Layout, Design, and Distribution
  katherine karol snyder

✧ Community Services Reporter (news about states’ developments) on a monthly basis
  Writer/Editor
  Jeanine Zlockie
  Layout, Design, and Distribution
  katherine karol snyder


✧ NASDDDS and the National Association of States United for Aging and Disabilities (NASUAD) co-authored a report titled "MLTSS for People for Intellectual and Developmental Disabilities: Strategies for Success"

✧ NASDDDS authored a report "Waiting Lists and Medicaid Home and Community-Based Services"

Teleconferences / Webinars

NASDDDS holds teleconferences and webinars for member state agencies on topic areas of interest. Recordings and materials are made available on the website for state agency state unable to participate the day of the event.

- A NASDDDS webinar was held on July 18, 2017, "What Does NCI Data Tell Us About Adults Who Need Support for Self-Injurious Behavior"
• A NASDDDS webinar was held on October 5, 2017, "Quality in Home and Community-Based Waiver Services" A NASDDDS webinar was held on November, 30, 2017, "Managed Care and the Core Components of Other Medicaid Authorities"
• A NASDDDS webinar was held on January 11, 2018, "Using National Data"
• A NASDDDS webinar was held on February 27, 2018, "FY 2015 and 2016 RISP Updates and FY 2017 Data Collection Review 2017/2018"
• A NASDDDS webinar was held on May 22, 2018, "What Does NCI Data Tell Us about the Characteristics of Youth and Young Adults Receiving Services"

Membership Services, Meetings, and Conferences

NASDDDS Hosts a ListServ for state intellectual/ developmental disabilities (I/DD) services directors and their staff. There were 52 inquiries sent through the ListServ during this annual report time period for which states were able to interact and discuss among their peers.

Meetings and Conferences

2017 National Core Indicators Annual Meeting
"Celebrating 20 Years of NCI"
August 1-2, 2017
Phoenix, Arizona

2017 SELN Annual Meeting
"Sustainability and Growth through Partnerships?"
October 18-20, 2017
Alexandria, Virginia

2017 Directors Forum & Annual Conference
"Cementing the Foundation for Long-Term Services and Supports"
November 8-10, 2017
Alexandria, Virginia

2018 Supporting Families Community of Practice Annual Meeting
April 18, 2018
Kansas City, Missouri

The Charting the LifeCourse Showcase
April 19-20, 2018
Kansas City, Missouri

2018 Directors Forum & Mid-Year Conference
"Building Capacity: Setting a Strategic Direction for Systems Change"
June 6-8, 2018
Columbus, Ohio
Projects

National Core Indicators

_Data-Based Decision Making:_

_NASDDDS promotes the use of data in policy-making and program performance measurement._

For the past 21 years, **National Core Indicators** (NCI) has documented the outcomes of state developmental disabilities agencies' systems. The NASDDDS-HSRI partnership collaborates with participating state agencies to gather in-depth information on key system performance indicators and outcomes essential for effective policy planning, program operations, and system development. NCI data allows states to monitor the impact of initiatives and policy changes, benchmark key results, and compare outcomes with those of other states. NCI continues to provide member states with annual comparative reports inclusive of the results from all states participating in data collection through in-person surveys, family surveys and the newest instrument for collecting workforce and staff stability data. "At-A-Glance" report templates are now available for each member state to create their own state version of this easy to read, user friendly report. All reports are available for download from the NCI website.

**By the Numbers** — Forty-six states plus the District of Columbia participated in NCI membership between July 1, 2017, and June 30, 2018. Thirty-six states completed the In-person Survey (formerly called the Adult Consumer Survey), 11 states collected Family Guardian Survey information, 13 states collected adult-family surveys and 9 states collected the child-family surveys. Twenty states also participated in the 2016 staff stability survey, engaging more than 4,770 provider agencies, and entering 3,334 valid surveys. The staff stability survey results were published in a final report in early January 2018, and has been used by many states in public and legislative information sessions.

2017-2018 was the second year of the Administration on Community Living's support for NCI to carry out "…the work necessary to ensure that the results of the instrument are regularly and appropriately used by state and federal programs in both quality monitoring and in developing evidence based quality improvement approaches in home and community-based services." Three states piloted the expansion of indicators of person-centered planning, and analysis and testing of specific measures for future submission to the National Quality forum as person reported outcome measures continued.
2017-2018 NCI Data Briefs and Data Highlights

- What Do NCI Data Show About Respondents Who Need Support for Self-Injurious Behavior?
- What Do NCI Data Tell Us About the Characteristics and Outcomes of Young Adults Receiving Services?

New in 2017-2018 is the use of Data Highlights, a one-page exploration of a specific data element found in NCI.
- Health and Safety
- Guardianship

Article Published in the Journal of Intellectual Disability Research titled "Personal characteristics and outcomes of individuals with developmental disabilities who need support for self-injurious behavior" Written by Bradley, V., Hiersteiner, D., Rotholz, D., Maloney, J., Li, H., Bonardi, A., Bershadsky, J. (2018). The article can be found at doi.org/10.1111/jir.12518.

2017-2018 NCI Webinars (NASDDDS/HSRI)

The Sarah Taub / NCI Webinar Series offered participants a chance to learn about "Characteristics and Outcomes of Young Adults with ID/DD Receiving Services" on May 22, 2018. A recorded copy is available through the NCI website. Members of the NCI national team presented to five national audiences at the annual conferences held by AAIDD, AUCD, NADSP, APHA (American Public Health Association) and the HCBS conference. NCI continued its international presence through an invitation to present at the National Disability Authority Annual Conference, Dublin Ireland, on "Indicators of a Person-Centered Life: Experience of Developmental Disability Systems in the U.S." in October 2017.

The National Quality Forum released recommendations that included NCI in a report titled "Quality Measurement in the Medicaid Innovations Accelerator Project." NCI is included as a measure concept in recommendations for use by states participating in the Innovation Accelerator Program, within Community Based Long Term services and Supports. According to the report, "The Coordinating Committee (CC) …agreed that the survey focuses on elements related to quality of life, which is critically important to the disability and aging populations… The CC recommended this measure concept for inclusion in the Medicaid IAP CI-LTSS program."

The NCI Annual Meeting was held in Scottsdale Arizona on August 1-2, 2017. Twenty-three states and the District of Columbia participated in the meeting. NCI celebrated its 20th year by holding the annual meeting in Arizona, one of the original project states.
States shared promising practices regarding supporting self-advocates to be NCI interviewers and examples of using NCI data as part of quality assurance systems.

**National Residential Information Systems Project (RISP)**

NASDDDS staff continued close collaboration with the University of Minnesota Research and Training Center on Community Living, Institute on Community Integration on the National Residential Information Systems Project (RISP), funded under a grant from the Administration on Intellectual and Developmental Disabilities. NASDDDS' Research Committee provides ongoing recommendations to ensure the report meets the needs of state DD directors and their staff, developmental disabilities councils, state protection and advocacy agencies and University Centers on Developmental Disabilities. NASDDDS continues to serve as a liaison between the university and states to inform the survey and related process and to provide technical assistance in completion of state data submissions.

risp.umn.edu / fisp.umn.edu

**Business Acumen**

In the late summer of 2016, the Administration on Community Living (ACL) awarded a grant to the National Association of States United for Aging and Disability (NASUAD) for the purposes of supporting disability community-based organizations (CBOs) in developing the business acumen needed to carve out a new role for themselves in a managed long-term services and supports (MLTSS) environment. Because this work is so important to state DD agencies and their staff, developmental disabilities councils, state protection and advocacy agencies and University Centers on Developmental Disabilities, NASDDDS is a partner in this work along with ANCOR, NCIL, and other national organizations. This three-year grant that began October 1, 2016, will support training, technical assistance, development of a virtual resource center, and a learning collaborative for disability organizations that want to cement their role in a changing long-term services and supports delivery system.

This project will:

- Develop baseline knowledge about current disability community-based organizations involvement and ongoing needs to engage in development and implementation of integrated care systems;
- Provide training and technical assistance for the disability networks to build their capacity for operating effectively in integrated care systems;
- Convene and provide targeted technical assistance to 10-15 state teams using a learning collaborative model; and
- Engage with integrated care organizations, managed care plans, and other health care entities about the needs of consumers and the role of community-based organizations.
NASDDDS has been instrumental in the initiation and completion of many of the first year grant activities including:

- Conducted an environmental scan and needs assessment survey to determine the business acumen needs of disability community-based organizations across the country.
- Established a monthly webinar series (five webinars archived).
- Designed a toolkit to guide community-based organizations to increase their business acumen to be published in the fall of 2017 (version 1.0).
- Commenced the 2017 Learning Collaborative with five states.

As the grant moved into the second year of implementation, NASDDDS has continued to be instrumental in the initiation and completion of many grant activities including:

- Continued monthly webinar series. Webinars archived on resource center site.
- Released Step One of DISABILITY NETWORK BUSINESS STRATEGIES: A Roadmap to Financial and Programmatic Sustainability for Community-Based Organizations, Prepare: Understand the Business Environment and Your Place Within It.
- Continued the 2017 Learning Collaborative with five states, known as Business Acumen Learning Collaborative (BALC).
- Commenced and additional Learning Collaborative of three states in 2018, known as the Business Development Learning Collaborative (BDLC).

- **The Business Acumen Learning Collaborative BALC** — Texas, New Hampshire, Missouri, New York, and Maryland are the five states participating in the first Business Acumen Learning Collaborative. The shared aim of the BALC is: Develop Resources to Support CBOs to Identify, Manage, and Mitigate Risks Related to Integrated Care. The specific outcomes each state hopes to accomplish by participating in the Learning Collaborative vary in nature. However, the overarching key themes for all states are to develop systems to support:
  - Increasing CBO Capacity to Develop and Implement Sustainable Business Practices, and;
  - Promoting Disability Provider Organizations to be Successful in Building and Implementing Integrated Care Approaches.

- **The Business Development Learning Collaborative BDLC** — Illinois, Minnesota, and Virginia are the three states participating in this collaborative. The shared aim of the BDLC is: Prepare CBOs to pivot and pro-actively respond to a changing environment to ensure quality services.

The overarching key theme for all states is to evaluate the CBO business environment and develop business strategies to strengthen and sustain community-based organizations that serve people with disabilities.
Community of Practice for Supporting Families across the LifeSpan

Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities

The Goal of Supporting Families

"The overall goal of supporting families, with all of their complexity, strengths and unique abilities is so they can best support, nurture, love and facilitate opportunities for the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life for their family members." (AIDD National Agenda on Family Support Conference, 2011).

The National Community of Practice

The National Community of Practice (CoP) for Supporting Families across the LifeSpan originally began in October 2012 as a five-year grant awarded to NASDDDS by the Administration on Intellectual and Developmental Disabilities (AIDD). Grant partners included the University of Missouri, Kansas City Institute on Human Development (UMKC IHD) and Human Services Research Institute (HSRI). This partnership, working in concert with the CoP states, has and continues to serves to support states, work to impact national policies, develop products and tools, and provide technical assistance to the states.

Six states participated in the original grant, completed on September 30, 2017, with the final AIDD report submitted in October 2017. The original states were composed of Connecticut, District of Columbia, Oklahoma, Tennessee, Washington, and Missouri, as the mentor state. Key state collaborators included the state I/DD agencies and developmental disabilities councils, reaching out to other diverse stakeholders to join the CoP.

Through the lens of the Charting the LifeCourse Framework, the CoPs accomplishments have led to a common language and platform for systems change, the development of innovative policies and practices in areas of outreach, increasing family networks, support planning, cross-agency engagement and informing new waiver development and amendments. Information dissemination, peer exchange and national sharing have been and remain key components of the CoP.
Community of Practice New State Expansion and Continuation of Original States

Through an optional NASDDDS membership benefit, 10 new states joined the CoP and 4 of the original AIDD-funded states continued with the CoP beyond the federal grant period. NASDDDS and UMKC partner to support states, facilitate state-to-state learning, develop products and tools, facilitate innovation workgroups prioritized by the states, and provide technical assistance.

The new states include:

- Alabama
- Maryland
- Delaware
- Ohio
- Hawaii
- Oregon
- Indiana
- Pennsylvania
- Kansas
- South Dakota

Continuation states are Connecticut, D.C., Oklahoma, and Washington.

Using the Charting the LifeCourse Framework, the new states and continuing original states focus their planning efforts on state systems change innovations to support individuals with intellectual and developmental disabilities in the context of their families to live good lives in the communities. These targeted innovations, supported through onsite technical assistance, monthly technical assistance calls, publications, and virtual workgroups fall into general themes in supporting individuals with I/DD in the context of their families:

- Family engagement, growing family networks and having a meaningful seat at the policy table
- Policy development and implementation, cross systems influences across the lifespan, waivers and other Medicaid authorities
- Support coordination and individual support planning process
- Employment and building early expectations
- Cultural considerations in supporting families

CoP states are embedding LifeCourse into their support planning processes, developing waivers and amendments influenced by the CoP, expanding family and self-advocacy involvement in systems change initiatives, and learning new ways to incorporate LifeCourse into the front door, employment, day-to-day technology, school services and transition to adulthood. An annual CoP meeting is held for all participating states for information exchange and providing new strategies for national and state systems change implementation.

The CoP has a members-only website for state branded materials, presentations and publications. There are also webinars, products, presentations, materials and videos widely available through the project’s public websites ([supportstofamilies.org](http://supportstofamilies.org)) and [lifecoursetools.com](http://lifecoursetools.com), national presentations, workshops, and state websites.
State Employment Leadership Network

Prioritizing Employment and Community Life Engagement

The State Employment Leadership Network (SELN) is a membership-based network of state intellectual and developmental disabilities (I/DD) agencies committed to improving opportunities for competitive integrated employment for individuals receiving services from state systems.

NASDDDS and The Institute for Community Inclusion UMass Boston (ICI UMass Boston) in partnership jointly support this learning community.

The SELN provides a forum for states to:

- Discuss common questions and challenges,
- Use data to guide daily system management and improvements,
- Share effective strategies taking into account the culture and economic uniqueness of each state, and
- Inform federal policy and develop strategies for implementing policy and knowledge in practice.

This past year, a few poignant topics rose to the surface as systems refine what is a successful employment outcome:

- The need to define the role of true informed choice.
- Wrestling with the dignity of risk is essential.
- Expectations and presuming everyone is capable to participate in the general workforce.
- Recognition that everyone’s path is different, and our role is to help people figure their own path.
- Language is revealing and powerful. Language, like actions, must presume competence and set high expectations for everyone.

Read the SELN accomplishments reports: [www.selnhub.org/accomplishments](http://www.selnhub.org/accomplishments).
Community Life Engagement (Integrated Day)

Community Life Engagement (CLE) activities are meaningful, nonpaid community activities, accomplished during normal periods of activity, including day, evening, and weekends when a person is not working. This past year NASDDDS continued looking into emerging practices on how best to support and integrate services that promote Community Life Engagement into a person's meaningful day.

Previous work completed by NASDDDS in partnership with the Institute for Community Inclusion at UMASS- Boston focused primarily on the components (guideposts) of the service delivery of CLE:

- Individualize supports for each person
- Promote community membership and contribution
- Use human and social capital to decrease dependence on paid supports
- Ensure that supports are outcome-oriented and regularly monitored

A key finding from the work done through the SELN Workgroup on CLE was realizing that integrated day and employment were not two separate competing service choices, but rather two components of a meaningful day. Community Engagement was most successful when three factors were recognized.

1. CLE can focus on Leading to employment through career exploration and networking
2. CLE services are most effective when Wrapping around employment to fill gaps in time, experience, social connection
3. CLE is a key part of Supporting people in retirement in integrated ways

NASDDDS focused on two main themes (1) how providers were delivering CLE services to comply with current state structures and (2) how some leading states changed their service structures to promote community engagement.

Community Engagement Pilot Survey

NASDDDS is in the process of conducting a survey to a limited number of providers of integrated day services as a way to ascertain why providers began delivering CLE services and how they structure those services. The survey asks:

- Describe how Community Engagement services work in your organization.
- What was the primary reason that led you to develop and deliver Community Engagement services?
• Do you (or other areas of your agency) provide other services such as day habilitation, onsite employment, or community-based employment for individuals with I/DD?

• How have your state agencies done (policies, procedures, billing structures, etc.) assisted you in developing your community engagement services? Conversely, please list what (if any) state policies or procedures that currently exist hinder your efforts to deliver Community Engagement services.

By asking these questions NASDDDS staff are trying to ascertain what type of providers are delivering CLE services (day, employment, residential). Do the providers begin delivering CLE services because of a perceived need, state direction, incentivizing?

Is there a great variety of structures developed to deliver CLE? Lastly, NASDDDS wants to know how influential state’s structures were in the development of CLE services. Findings will be shared with members in spring 2019.

Environmental Scan of Emerging State Policies and Procedures for Community Engagement

NASDDDS staff conducted a content analysis of policy and procedure documents from states who have recently made changes to their structure to support Community Life Engagement. This analysis identified some key factors that were similar across states:

• Develop various distinct service definitions with associated payment rates for each.

• Have clearly defined, measurable outcomes for each service.

• Use an acuity based tiered system for determining staff ratios and rates.

• Have clear policy statements on the importance of employment and community engagement.

• Implement limits on use of facility based services.

• Allow flexibility in multiple services being delivered during the day.

• Allow services to be delivered on behalf of an individual.

• Assure a "transition period" for providers to modify their service delivery.

• Provide training to direct support professionals.

In the coming year NASDDDS staff will dive deeper into each of these factors in order to determine best practices for states wishing to meet the HCBS rules around providing people with the opportunity to a meaningful day.
Employment Special Projects

FLORIDA
NASDDDS staff participate as a subcontractor with ICI UMass Boston in a contact with Florida DD Council. In its sixth year the Florida EmployMe 1st project team continues to provide technical assistance in the implementation of Florida's Interagency Agreement. The project team provides technical assistance by disseminating information to grassroots groups; maintain Employment First Florida website, and expanding the local level interagency collaborative teams to bring to scale strategies for the integration of local issues and successes into state, local and organizational operations.

NASDDDS staff also participated as a subcontractor with ICI UMass Boston in a secondary contract with Florida Developmental Disabilities Council on a project to identify and analyze funding policies and rate models to incentivize employment and community participation as outcomes of adult long-term service systems. A final report was provided to Florida's Employment First Consortium on the study and findings.

REHABILITATION RESEARCH AND TRAINING CENTER ON EMPLOYMENT
NASDDDS is a partner with ICI UMass Boston's Rehabilitation Research and Training Center on Advancing Employment for Individuals with Intellectual and Developmental Disabilities, serving as both in advisory capacity and developing policy papers.

NASDDDS, through a subcontract with ICI, is writing one policy white paper each year on employment topics. The topic of this year's policy white paper was "System Collaboration" to support employment outcomes.

Collaborating to Achieve Our Missions

National Leadership Consortium on Developmental Disabilities

The National Leadership Consortium on Developmental Disabilities (NLCDD) convenes weeklong Leadership Institutes twice a year. Jeanine Zlockie holds a session on Demographics and Trends Impacting State I/DD Systems. The NASDDDS board of director's awards two scholarships annually to employees of member state agencies (www.nlcd.org).

Collaboration to Promote Self-Determination

This effort is a network of approximately 12 national organizations that have come together to promote employment opportunities and self-direction for those with I/DD (thecpsd.org).
The Consortium for Citizens with Disabilities (CCD)

The consortium is the nation's largest disability stakeholder's coalition and informs and advocates for people with disabilities at the state and federal level. Dan Berland serves as co-chair of CCD's Long-Term Supports and Services Task Force (c-c-d.org).

National Association for the Dually Diagnosed (NADD)

NADD works on public policies on supporting people with co-occurring developmental disabilities and mental illness, works on public policies for individuals with a dual diagnosis and provides educational webinars and publications. NADD develops standards for quality services programs to provide accreditation of services and the certification of staff involved in the delivery of supports to adults with co-occurring developmental disabilities and mental illness. (thenadd.org).

Quality Mall

The 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 (www.qualitymall.org)

Reinventing Quality Conference

The Reinventing Quality Conference is planned in collaboration with the Human Services Research Institute, the American Association on Intellectual and Developmental Disabilities, the University of Minnesota, ANCOR, and the University of Delaware (www.reinventingquality.org).

Recognizing Outstanding Achievement

Gary Smith Scholarship to the National Leadership Consortium on Developmental Disabilities

The Gary Smith Scholarship Fund was established to support the participation of one participant from state government at the University of Delaware National Leadership Consortium on Developmental Disabilities, held twice yearly. The scholarship fund in Gary Smith's name is a legacy to support others who work for state, local, or the federal government in their pursuit to improve the lives of people with disabilities and their families.
July 2017 Scholarship Recipient:

**JENNIFER RODRIGUEZ**  
Chief, Community Programs Bureau  
Mexico Department of Health  
Developmental Disabilities Supports Division

Ms. Rodriguez has over 20 years of experience in the field of intellectual and developmental disabilities. She graduated from West Chester University of Pennsylvania with a bachelor’s degree in communicative disorders. Jennifer began her career as a direct support professional and upon moving to New Mexico, worked as a Developmental Disabilities (DD) Waiver Case Manager for more than 13 years before entering state government. Jennifer first held the role of the DDSD Statewide Case Management Coordinator, then the DD Waiver Program Manager and currently the Community Programs Bureau Chief, where she oversees the New Mexico DD waiver, the Mi Via Self-Directed Waiver, the New Mexico case management system, Provider Enrollment and the clinical Outside Review process. She has been with DDSD for four years.

January 2018 Scholarship Recipient:

**LISA OTT**  
Regional Director  
Maryland Developmental Disabilities Administration

Lisa joined the Maryland Developmental Disabilities Administration in March of 2017 to lead one of Maryland’s four regional offices, supporting individuals, families and providers through the central swath of the state. The central Maryland region includes Baltimore City, Baltimore County, Howard, Ann Arundel and Harford counties. Lisa comes to DDA by way of the private sector, where she spent thirty years building and managing children's programs in the areas of child welfare, mental health and special education. At Pressley Ridge, Lisa developed therapeutic foster care and in-home service programs in Maryland, Washington D.C., Delaware, and Ohio. At PHILLIPS Programs for Children and Families, Lisa oversaw nonpublic, special education schools in Maryland and Virginia. Most recently, she led a special education association in Washington, D.C., advocating for a robust continuum of educational services for DC students with special needs. Her emphasis on building collaborative relationships with community stakeholders has led to many fruitful partnerships with families, government and community stakeholders.
Ben Censoni Award for Excellence in Public Service

The Censoni Award is the only award that recognizes public officials who strive to improve the lives of people with developmental disabilities and 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."

2017 Award Winners

ELIN HOWE

Elin M. Howe has worked in the field of intellectual and developmental disabilities for 44 years. She began her career with the New York State Department of Mental Hygiene in 1972 and was employed by the Office of Mental Retardation and Developmental Disabilities (now the Office of People with Developmental Disabilities) from 1978 to 1993. Among her positions in New York, Ms. Howe served as Deputy Director and Director at the Willowbrook Developmental Center and held positions as Associate Commissioner for the Southeast Region, Associate Commissioner for the New York City Region and Executive Deputy Commissioner. From 1989 to 1993, she served as the agency’s commissioner. Working as an independent consultant and for 10 years as a consultant and Director of Consulting Services for The Columbus Organization, Ms. Howe provided consultation to 12 states and served as the Independent Monitor on two Settlement Agreements between the U.S. Department of Justice and the state of New Jersey and as the Internal Compliance Monitor in the Jackson vs. Fort Stanton class action lawsuit in New Mexico. Ms. Howe served as Commissioner of the Massachusetts Department of Developmental Services from 2007 to 2017. During her tenure, Massachusetts was disengaged from a federal lawsuit on nursing facilities and four state institutions were closed. Ms. Howe currently works as a consultant for The Columbus Organization.

HELENE DESANTO

Helene DeSanto started working with persons with disabilities in Pennsylvania as a direct care staff working in an integrated recreation program for children with developmental disabilities. After receiving a master’s degree in special education from Syracuse University, Helene began her career in New York State in 1978 joining the newly formed Office of Mental Retardation and Developmental Disabilities, now the Office for People with Developmental Disabilities. Over the past 39 years, she has worked in various Leadership positions both in the field and central office and has been directly involved in all
of the major events in the evolution of I/DD services in New York, including the closure of over 20 institutions; the development of an extensive system of home and community based waiver supports, and most recently, planning the transformation to a care coordination in preparation for the future move to managed care. The strong involvement of stakeholders has been the foundation of this change; working in partnership with self-advocates, families, providers and government officials has been a hallmark of Helene’s work and New York’s success in building a system of high-quality, person-centered supports.

Members Who Serve…

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Kerri Zanchi  Rhode Island  Jim Copeland  New Mexico
**NASDDDS Members** *(October 16, 2018)*

Contact information and links to the state agencies are available on the NASDDDS website ([www.nasddds.org/state-agencies/](http://www.nasddds.org/state-agencies/))

<table>
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<th>Name</th>
<th>Position</th>
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<td>ALABAMA</td>
<td>Terry Pezent</td>
<td>Associate Commissioner</td>
<td>Division of Developmental Disabilities</td>
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<td>Duane Mayes</td>
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<td>Charlie Green</td>
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<td>Mary Brogan</td>
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<td>Cameron Gilliland</td>
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<td>Melissa Wright</td>
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LOUISIANA
Mark Thomas
Deputy Secretary
Louisiana Department of Health

LOUISIANA
Julie Foster Hagan
Assistant Secretary
Office for Citizens with Developmental Disabilities

MAINE
Amy MacMillan
Acting Director
Office of Aging & Disability Services

MARYLAND
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MASSACHUSETTS
Jane Ryder
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NEW MEXICO
Jim Copeland
Director
Developmental Disabilities Supports Division

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Office for People with Developmental Disabilities

NORTH CAROLINA
Kody Kinsley
Acting Director
Mental Health, DD, and Substance Abuse Services

NORTH DAKOTA
Tina Bay
Director
Developmental Disabilities Division

OHIO
John Martin
Director
Department of Developmental Disabilities

OKLAHOMA
Beth Scrutchins
Director
Developmental Disabilities Services
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<td>Evelyn Perez</td>
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<td>Developmental Disabilities Administration</td>
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<td>Beth J. Morrison</td>
<td>Acting Director</td>
<td>Intellectual and Developmental Disabilities</td>
</tr>
<tr>
<td>WISCONSIN</td>
<td>Curtis Cunningham</td>
<td>Deputy Administrator</td>
<td>Developmental Disabilities Services</td>
</tr>
<tr>
<td>WYOMING</td>
<td>Lee Grossman</td>
<td>Administrator</td>
<td>Developmental Disabilities Section</td>
</tr>
</tbody>
</table>
## NASDDDS Financials

**Balance Sheet June 30, 2018**

### ASSETS

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Current Assets</strong></td>
<td></td>
</tr>
<tr>
<td>Cash</td>
<td>$1,059,608</td>
</tr>
<tr>
<td>Investments</td>
<td>1,717,457</td>
</tr>
<tr>
<td>Accounts Receivable</td>
<td>475,457</td>
</tr>
<tr>
<td>Prepaid Expenses</td>
<td>29,023</td>
</tr>
<tr>
<td><strong>Total Current Assets</strong></td>
<td>3,281,545</td>
</tr>
<tr>
<td><strong>Fixed Assets</strong></td>
<td></td>
</tr>
<tr>
<td>Furniture &amp; Equipment - Net</td>
<td>45,194</td>
</tr>
<tr>
<td>Building - Net</td>
<td>199,063</td>
</tr>
<tr>
<td><strong>Total Net Fixed Assets</strong></td>
<td>244,256</td>
</tr>
<tr>
<td>Security Deposit</td>
<td>10,000</td>
</tr>
<tr>
<td><strong>TOTAL ASSETS</strong></td>
<td>$3,535,802</td>
</tr>
</tbody>
</table>

### LIABILITIES & NET ASSETS

### LIABILITIES

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Current Liabilities</strong></td>
<td></td>
</tr>
<tr>
<td>Accounts Payable</td>
<td>$447,001</td>
</tr>
<tr>
<td>Accrued Expenses</td>
<td>36,226</td>
</tr>
<tr>
<td>Accrued Vacation</td>
<td>149,549</td>
</tr>
<tr>
<td>Other Employee Payable</td>
<td>7,223</td>
</tr>
<tr>
<td>Deferred Dues</td>
<td>1,026,414</td>
</tr>
<tr>
<td>Deferred Grant</td>
<td>128,937</td>
</tr>
<tr>
<td><strong>TOTAL LIABILITIES</strong></td>
<td>1,795,350</td>
</tr>
</tbody>
</table>

### NET ASSETS

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unrestricted</td>
<td>1,687,388</td>
</tr>
<tr>
<td>YTD Income</td>
<td>53,064</td>
</tr>
<tr>
<td><strong>TOTAL NET ASSETS</strong></td>
<td>1,740,452</td>
</tr>
<tr>
<td><strong>TOTAL LIABILITIES &amp; NET ASSETS</strong></td>
<td>$3,535,802</td>
</tr>
</tbody>
</table>
Sources of Revenue

FY 17-18: Sources of Revenue
Total $4,505,027

<table>
<thead>
<tr>
<th>Program</th>
<th>Revenue</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administration</td>
<td>$76,161</td>
<td>2%</td>
</tr>
<tr>
<td>Publication</td>
<td>$34,774</td>
<td>1%</td>
</tr>
<tr>
<td>Membership</td>
<td>$1,270,523</td>
<td>28%</td>
</tr>
<tr>
<td>Technical Assistance</td>
<td>$741,909</td>
<td>17%</td>
</tr>
<tr>
<td>NCI</td>
<td>$965,640</td>
<td>21%</td>
</tr>
<tr>
<td>SELN &amp; Employment</td>
<td>$1,048,580</td>
<td>23%</td>
</tr>
<tr>
<td>CoP Expansion</td>
<td>$286,850</td>
<td>6%</td>
</tr>
<tr>
<td>Family Support</td>
<td>$80,590</td>
<td>2%</td>
</tr>
</tbody>
</table>

4,505,027 100%