Dear Friends,

As the National Resource Center for Participant-Directed Services (NRCPDS) begins its third year, I am delighted to share with you our 2011 annual report. Our Center was established in April 2009 with funding from the Atlantic Philanthropies, the Robert Wood Johnson Foundation, the Administration on Aging and the Office of the Assistant Secretary for Planning and Evaluation/Department of Health and Human Services. In this short time, our Center has worked hard to advance participant direction across the country, and we’ve made great strides.

Health care reform has been a driving force. The Patient Protection and Affordable Care Act (ACA) included a number of provisions expanding Medicaid authorities for developing participant-directed home and community supports and services for people with disabilities. This year, the NRCPDS has been involved in the ACA by providing comments on draft regulations, providing guidance to federal agencies on critical components of participant direction infrastructure and writing five white papers commissioned by The SCAN Foundation pertaining to the implications of Cash & Counseling in the design of the CLASS program. When the future of CLASS was recently threatened, our center drafted a letter highlighting the continued importance of long-term care financing reform given the predicted needs of a growing and more complex population of individuals requiring community-based long term services and supports.

The highlight of our extensive research this year was our National Survey of State Participant-Directed Programs, which collected important information on the growth of participant-directed programs across the nation. The survey shows that there are over 290 participant-directed programs operating today. Ongoing data collection related to existing programs and their important design elements will be critical as we advance our mission of expanding and improving participant direction opportunities.

The Veteran-Directed Home and Community-Based Services (VD-HCBS) Program is an initiative of great import. Patterned after Cash & Counseling, VD-HCBS was created to help wounded warriors returning from current conflicts in Iraq and Afghanistan, as well as aging veterans. As of this writing, VD-HCBS is active in 17 states, with plans to be nationwide by the end of 2014. VD-HCBS is not only important in its own right, but it affords the opportunity to develop the infrastructure of counseling and financial management services necessary for participants to direct their supports and services across the country.

Our core competencies work with the Administration on Aging details the competencies and training approach needed to help care managers, options counselors, outreach workers, and their supervisors embrace the paradigm shift from a “professional” or “medical” to an “empowerment” model. Without this change, participant direction will never become the norm. We hope in the year ahead to launch our e-learning platform and we envision training the current aging network as well as the professionals of tomorrow utilizing this exciting new technology.
This year, the National Participant Network (NPN) took major steps to become a powerful voice for participant direction. The group of individuals directing their own services and supports grew from fewer than 50 to over 200 members in 30 states. The NPN is just now, with the help of the Boston College Graduate School of Social Work’s Innovations Lab, beginning a business planning process to become an independent entity closely aligned with the mission of the NRCPDS.

Our NRCPDS internal organizational structure has shifted in the last year to meet the growing demand for our work. We were pleased to add several new positions, including Financial and Administration Specialist, Financial Management Services (FMS) Analyst, Research Analyst for Veterans Affairs and Staff Assistant. We are also delighted to announce the appointment of 12 members to our National Advisory Committee (NAC). The NAC held its first in-person meeting in August of this year. We are happy to have so many dedicated members of the participant direction community as part of our NAC, helping to guide the development of the center and our work.

In this report, you’ll find information about several areas of our work arranged according the key focus areas and accomplishments. I encourage you to visit our newly redesigned website, participantdirection.org, for additional information. Thank you to all of our friends and partners who have joined us in working to achieve the vision of a world where people of all ages and disabilities can seek and easily access participant-directed services and support options, with access to individual budgets to directly hire workers and purchase innovative goods and services the norm, and traditional agency-managed approaches as an option. Although we are closer to our goal, more work needs to be done. We are confident that, with your support, we will continue to make great progress in the year ahead.

Sincerely,

Kevin J. Mahoney, Ph.D.

NRCPDS Director
INFLUENCING PUBLIC POLICY

Our public policy efforts are intended to allow the NRCPDS and our key partners to identify, understand and promote participant direction opportunities and an environment that fosters its growth. With these objectives in mind, a sample of our most recent public policy activities is provided below.

THE PATIENT PROTECTION AND AFFORDABLE CARE ACT

The Patient Protection and Affordable Care Act (Affordable Care Act) is a wide-reaching reform package for both acute and long-term care services and supports. Signed into law on March 23, 2010, the Affordable Care Act includes a number of participant direction provisions, such as:

- Section 2401, which creates a new Medicaid Community First Choice Option for State Plan participant direction;
- Section 2402(a), which calls for the strengthening and streamlining of participant direction practices and infrastructure across health and human services;
- Section 2402(b), which modifies an existing Medicaid participant direction opportunity originally created as a result of the 2005 Deficit Reduction Act; and
- Title VIII, which establishes a national, voluntary financing plan for the purchasing of Community Living Assistance Services and Supports (the CLASS program).

Given that the Affordable Care Act has direct implications for participant direction, the NRCPDS has played an important role in summarizing its key components and facilitating increased understanding of the law for successful implementation. For instance, the NRCPDS presented on participant direction implications resulting from the Affordable Care Act at the Home and Community-Based Services Conference in September of 2010. The NRCPDS assisted the Administration on Aging (AoA) and the Office of the Assistant Secretary for Planning and Evaluation (ASPE) to develop guiding principles and concepts for incorporation into a concept paper that ultimately will inform the federal government’s response to the 2402(a) component of health reform. Working with our state members, the National Participant Network and financial management services providers, we also dedicated considerable time and effort commenting on the draft regulations for Community First Choice, 1915 (k), which, when implemented in the fall of 2011, will give states a 6% enhancement in their federal match if they commit to a participant-centered mode of delivery.

The most elaborate and far-reaching of the long-term care provisions of health reform is the proposed CLASS program, a voluntary social insurance providing a cash allowance patterned after Cash & Counseling. The SCAN Foundation, recognizing the value of our research, commissioned the NRCPDS to write five white papers (see below) on how the Cash & Counseling experience can inform the implementation of CLASS. In October, Secretary Sebelius of the Department of Health and Human Services announced that she did not see a method in which to allow the CLASS Act to succeed given the financial solvency requirement set forth by the law. In a letter to Senate Majority Leader Harry Reid (D-NV), Sebelius wrote: “Recognizing the enormous need in this country for better long-term care insurance options, we cast as wide a net as possible in searching for a model that could succeed. But as a report our department is releasing today shows, we have not identified a way to make CLASS work at this time.” Regardless of the current uncertainty for CLASS, what is clear is that the need for long-term care financing...
reform will not go away. Instead, it will become increasingly more urgent in years to come given the predicted increase in the population of individuals who will require community-based long term services and supports. Our response to the issues regarding CLASS is available on our website.

**Issue Briefs: How Did Cash & Counseling Participants Spend Their Budgets, and Why Does That Matter for the CLASS Act?**

*How Did Cash & Counseling Participants Spend Their Budgets, and Why Does That Matter for CLASS* by Lori Simon-Rusinowitz, Dawn Loughlin, Kevin Mahoney

*Options for Getting Purchasing Power into the Hands of Participants: Lessons from Participant Direction Programs* by Mollie G. Murphy, Lori Simon-Rusinowitz, Dawn Loughlin, Kevin J. Mahoney, and Isaac Selkow

*Financial Management Services in Participant Direction Programs* by Mollie G. Murphy, Isaac Selkow, and Kevin J. Mahoney

*Debit Card Fundamentals and Their Use in Government Programs* by Cathy Corby Parker, James Wironen, Mollie G. Murphy, and Kevin J. Mahoney

*Considerations for Debit Card and Cash Purchasing Mechanisms in the CLASS Plan* by Mollie G. Murphy, Cathy Corby Parker, Isaac Selkow, and Kevin J. Mahoney

**ADDRESSING WORKER-RELATED ISSUES AND BENEFITS**

Over the past two years, the NRCPDS and its members have been working closely with disability advocates and representatives from the Service Employees International Union (SEIU) to develop “Guiding Principles for Partnerships with Unions and Emerging Worker Organizations When Individuals Direct Their Own Services and Supports.” Without taking a position on unionization, the NRCPDS’ involvement in this project is intended to ensure that the basic tenets of participant direction philosophy are upheld, regardless of whether workers are unionized.

On November 16, 2011, the National Resource Center for Participant-Directed Services (NRCPDS) joined with members of the disability and worker communities to sign this remarkable set of guiding principles intended to ensure participant choice and control over long-term services and supports when workers organize to improve their own lives. This event marked the public release of the “Guiding Principles.” The principles and our cover letter are currently available on our website. We look forward to hearing reactions from the community as the principles are reviewed, disseminated and put into action.

*November 16, 2011 Signing of the Guiding Principles*
In February 2011, Kevin J. Mahoney, the Director of the NRCPDS and Professor at the Boston College Graduate School of Social Work, testified before a congressional committee on the implications of health care reform for the social work profession. In his testimony found here, Dr. Mahoney discussed the nation’s positive response to the Cash & Counseling demonstration, the opportunities presented within health reform and the role of the social work profession in fueling the paradigm shift required for participant direction expansion. The previous year, Dr. Mahoney testified during an Older Americans Act (OAA) Reauthorization Listening Forum. Originally signed into law in 1965, the OAA outlines objectives designed to enhance the dignity and welfare of older individuals. In 2006, the OAA was reauthorized and included many participant direction elements. With reauthorization of the OAA expected to occur in 2011, Dr. Mahoney’s testimony (found here) focused on the diversity of the aging population, existing unmet needs, and the opportunity for participant direction to provide high quality support to elders in the community.

The NRCPDS Program Membership launched in July 2011 for state agencies administering or seeking to administer participant-directed programs. We are happy to be able to offer an extensive list of benefits to program members, including webinars, newsletters, events and an enhanced member area of the website. We have also worked this year to develop a membership track for financial management services (FMS) providers. We have developed a package of benefits for the FMS audience with the support of a steering committee comprised of six FMS providers. FMS membership benefits will include access to issue briefs, webinars, and the opportunity to contribute to a FMS industry code of standards and provide feedback to key federal stakeholders including the IRS. The steering committee launched in July 2011 and the launch of FMS membership is expected in January 2012.

The Veteran-Directed Home and Community-Based Services (VD-HCBS) program continues to be one of the primary ways in which we are helping to spread participant direction. In the Veteran-directed program, the VA Medical Centers enter into provider agreements with local Aging Network agencies, which provide the supports for the Veteran to manage his/her services. The VD-HCBS experience is assisting us streamline ways to assist sites with program start-up.

In December 2010, an event was held at the New Jersey Veterans Health System Lyons Campus to highlight the VD-HCBS program. Speaking were the Director of the VA New Jersey Health Care System, Medical Director of the Lyons Campus, the Director of Purchased Care for the Veterans Health Administration Office of Geriatrics and Extended Care, the Director of the Administration on Aging Office of Program Innovation and Demonstration, the Commissioner of the New Jersey Department of Health and Senior Services, the Director of the NRCPDS and three Veterans/Caregivers who had used the VD-HCBS program (one Veteran had recently passed away and was represented by his wife). Present in the audience were approximately 60 guests, including press representatives. The event was a great success and resulted in coverage of the program by several local news outlets.
DEVELOPING CORE COMPETENCIES FOR THE AGING NETWORK

With the growth of participant-directed long-term services and supports, there is a corresponding need to transform the culture of the aging network, re-train the existing aging network workforce and train the workforce of tomorrow to develop the competencies needed for a participant-directed service delivery model. A number of NRCPDS activities in 2010-11 advanced our work in this area, including:

- As a part of our work with the AoA on culture change and workforce competencies, we conducted an environmental scan of 48 websites of national professional organizations, federal and state agencies and academic institutions focused on aging and/or disability services to determine the extent to which these organizations have developed workforce competencies in participant direction and/or curriculum that could be used for training.

- The NRCPDS also conducted a survey of 208 social work school deans and program directors to better understand coverage of participant direction in existing social work curricula.

- With the encouragement of AoA, the NRCPDS has approached both the John H. Hartford and SCAN foundations to jointly discuss three related activities that will promote culture change within the aging network and develop the workforce competencies needed for participant-directed programs serving elders.

- In 2011, we submitted an application to AoA for a grant to continue our culture change work with the aging network (Accelerating Adoption of Participant Direction Philosophy and Models in the Aging Network). Our goal is to develop participant direction and promote culture change across the aging network by defining workforce competencies, providing associated training programs and carrying out an engagement strategy for ongoing technical assistance.
AWARDING INNOVATION GRANTS

Through funding from the Robert Wood Johnson Foundation, our Center issued a Request for Information to elicit suggestions for ideas that could contribute to substantial growth in participant direction, or to test innovations. After a thorough internal review, four awards were made as summarized below:

- The Vermont Center for Independent Living (VCIL) will lead development of a peer-directed cooperative that will provide 24 hour-a-day access to care for people who use personal attendant services and live in the Burlington, Vermont, area. Members who join the Cooperative will live in close proximity to one another and pool their Choices for Care or other funding to achieve personal care services that help them live more independently as active family and community members and as valued employees. VCIL and its partners have joined together to identify and create a model that leads to full peer participation in the delivery of quality services. Cooperative members will hire and train personal care attendants. The PCAs will be paid a livable wage and provided benefits to help professionalize PCA work. It is expected that some of the people recruited as PCAs may also be people with disabilities. VCIL believes that the Cooperative model increases the ability of people with disabilities to have more control over their own lives.

- Commonwealth Care Alliance, a managed care organization in Massachusetts, has established self-directed personal care attendants (PCAs) as its preferred approach to meeting members’ personal care needs. CCA does not limit self direction to personal care and services; it applies the concept of self direction to the entire individualized plan of care and to the relationship between members and the interdisciplinary care team. In this conception, personal care is no longer isolated from the provision of other health care; it is fully integrated and extends the principle of self direction to other domains. Thus, there is no longer a distinction between the PCA and other members of the care team; they all serve the goals and preferences of the participant. In bringing the PCA into the fold of the Senior Care Option interdisciplinary team, CCA seeks not only to enhance the capacity of the PCA to meet the needs of the participant but, equally important, to strengthen the core value of self direction with respect to the entire care team. The project will use results from a participant survey to develop training to be made available to PCAs as members of the treatment team, and will also institute a program to recruit and train representatives for the members who want to have self-directed services, but can’t direct all their services themselves and who don’t already have a representative identified.

- The Michigan Department of Community Health, Mental Health and Substance Abuse will train and support self-directed peers (both individuals with developmental disabilities and individuals with serious mental illness) to provide peer support to individuals with arrangements that support self-determination. Specific supports will include developing and implementing an individual plan of service and individual budget (through the person-centered planning process), selecting and managing providers and ongoing problem-solving.

  Self-directed peers will be individuals who have a unique background and skill level from their experience in utilizing services and supports to achieve their personal goals of community membership, independence and productivity. Project activities will be held in both local areas (Kalamazoo, Oakland, Alpena, Genesee and Kent counties) and at the state level.

- The disAbility Link (an Independent Living Center in northwest Georgia) will expand its peer support network to mentor individuals who express hesitation to take on the challenges of participant-directed services. Applicants who express these concerns will be referred to disAbility Link NW by the Area Agency
on Aging for an initial consultation. If the applicant’s fears are ameliorated and the applicant chooses to enroll in participant-directed services, the applicant will be provided up to 40 additional hours of peer support to help acclimate him/her to participant-directed services. The additional peer support and mentoring is expected to expand the number of individuals enrolling in the program and increase the retention rate of individuals already enrolled in the program.

The NRCPDS innovation projects were funded in February 2011, and are all in development with a completion date of August 31, 2012. At the end of the grant period, a report, including a summary of project activities, lessons learned and the developed materials, will be distributed via social media and the NRCPDS website. You can stay up to date on the progress of our innovation grantees via our website.

LAUNCHING A NEW WEBSITE

We were happy to launch our redesigned website, participantdirection.org, in July, featuring a new library of resources, a revamped section for members including a member blog, and a map of participant-directed programs across the country. This map, based on the data collected from our national survey, is the only up-to-date resource widely available to help people with disabilities and their families find participant direction resources across the country. Viewership of our website and the program map has been overwhelming. We are continuously working to ensure all of the resources are easy to access and to provide the latest information available.

DEVELOPING OUR eLEARNING EXCHANGE

Over the past year, we have developed our first participant direction tutorials that will be offered on the NRCPDS Participant Direction eLearning Exchange. These tutorials, built on over a decade of research, technical assistance, and training experience, currently include three focus areas: 1) Introduction to Participant Direction; 2) Developing
HOLDING OUR 2011 FMS CONFERENCE

The 4th biennial Financial Management Services (FMS) Conference was held November 14 and 15, 2011 in Baltimore, MD. We took a collaborative approach to creating content for this conference by heavily surveying past and prospective conference attendees about their FMS information needs. After collecting a variety of training topics of interest from our target audience, we sought expertise in those topic areas from the FMS provider industry, federal and state program administrators and other experts, including consultants. Sessions were tailored to include not only cutting edge information, but also promising practices. Our goal with this conference was to inspire both FMS providers and program administrators around the implementation of participant direction, and to provide information that is immediately useful and actionable for conference attendees.

CONDUCTING RESEARCH

The NRCPDS conducts research to promote the improvement and expansion of quality participant-directed programs. A summary of key research projects from the year follows.

NATIONAL INVENTORY OF PARTICIPANT-DIRECTED PROGRAMS

This project cataloguing the growth of participant-directed programs and their supporting infrastructure is the highest priority for the Center’s research activities. The team involved in this major activity includes a survey research group based at Pennsylvania State University (PSU), a team of researchers within the NRCPDS and a national inventory advisory group with representatives from diverse consumer groups (elders, adults with physical disabilities and consumers with developmental disabilities and intellectual disabilities) that provided guidance in developing data collection instruments and assisted in obtaining access to key informants and distributing project findings.

Data collected has indicated that every state has at least one participant-directed program with employer authority and 43 states (including VD-HCBS) have at least one program with budget authority. So far, the project has identified 298 Medicaid or state-funded participant-directed programs operating in the United States, with approximately 810,000 individuals enrolled across those programs. The approximate participant-directed programs costs for 2010-2011 are $8.0 billion. Findings from this national survey have been used to construct the “Consumer Direction” section of the “State Long-term Care” Report Card that AARP’s Public Policy Center is constructing with funding from the SCAN Foundation and the Commonwealth Fund.

In the year ahead, we will release new papers detailing the findings of the national survey and the implications for the field.
MENTAL HEALTH AND PARTICIPANT DIRECTION PROPOSAL TO CONDUCT AN ENVIRONMENTAL SCAN

Behavioral health efforts have focused mainly on peer-provided services and shared decision-making, but not on a participant-directed budget authority model. Heavy reliance on costly inpatient and emergency services, institutional treatment, pharmacology, disparities in quality and access to care and high rates of untreated behavioral health needs is all too common in the behavioral health and substance abuse arenas, leaving participants with an understandable desire for more options. By providing budget authority to individuals who wish to self-direct their recovery from mental health or substance use disorders, we can address these issues.

This year, we developed a proposal that, with funding from the Robert Wood Johnson Foundation and consultation with experts in the mental health and substance abuse fields, will conduct a multi-part environmental scan to assess interest in and attitudes toward a budget authority model for this population, including: 1) a review of existing literature, policies and priorities relevant to implementation of the model; 2) analysis of information from interviews, surveys and focus groups with key stakeholders (e.g. state mental health program directors, service providers, participants, others; and 3) a comprehensive report describing these findings and recommendations for a budget authority demonstration and evaluation.

These efforts will provide information (including cost data) that policymakers need to know should they foster the budget authority model for a population with mental health diagnoses. The project recommendations will outline a plan for a possible large-scale demonstration and evaluation. This proposal builds on previous NRCPDS research demonstrating that participants with mental health diagnoses fared well in the original three-state demonstration and evaluation. An ultimate project goal is to create more “mental health friendly” cash option programs.

ADDITIONAL RESEARCH INCLUDED:

- Research-Based Training for Representatives in Participant-Directed Services: Creating More Dementia Friendly PD Programs
- Multi-state Survey of Support Broker/Planners in Participant-Directed Services Programs
- Understanding Purchasing Decisions of Self-Directed Participants: Analysis within a Statewide Cash & Counseling Program
- Analysis of Cost Data from the Arkansas IndependentChoices Program
- Membership Information Partnership

GROWING OUR NATIONAL PARTICIPANT NETWORK

The NPN has grown to more than 200 members representing 30 states—an increase of 17 states. As a result, the NPN has moved beyond the building of infrastructure to expand its influence. This movement has included establishing a liaison relationship with leaders at CMS for the purpose of ready exchange of information and developing several new projects, including work on a “report card” assessing state effectiveness in participant direction from the perspective of the participant.

The NPN has gone through an intensive six month process to prepare the group to become an independent nonprofit organization. The NPN anticipates reaching this independence in late 2012.
The NRCPDS’ active role in engaging key constituents and informing local, state and national public policy efforts has been a critical component of advancing our mission. As we move forward, there are a few topics on the public policy horizon that require our attention. States continue to face tremendous budget shortfalls. Because of this, they require continued support to find innovative ways for implementing the participant direction philosophy. As a leader on participant direction, it is important that the NRCPDS provide guidance on newer models of implementation to ensure that they sit soundly on participant direction principles. Similarly, the NRCPDS will continue to support the completion and dissemination of guiding principles for collective bargaining within a participant direction model. This includes informing policy decisions to ensure that program participants are at the center of decision-making, not only with regard to purchasing, but also to screening, hiring, training and supervision and termination of workers. Finally, tremendous attention needs to be devoted to ensuring that the participant direction elements of the Affordable Care Act are informed by best practices and lessons learned. This includes providing formal comments to proposed rules for new and revised programs, continuing to develop pertinent white papers and issue briefs and providing assistance with demonstrating new design models. The NRCPDS and its partners are excited by the opportunities that face our nation as more and more people with functional limitations are provided the option to direct their own lives.