



PARTICIPANT-DIRECTION:
A THEME IN HEALTH CARE REFORM
WITH MAJOR IMPORT FOR THE SOCIAL WORK PROFESSION

Kevin J. Mahoney, Ph.D.

Professor, Boston College Graduate School of Social Work, and
Director, National Resource Center for Participant-Directed Services

Presented at a Congressional Briefing on
The Implications of Health Care Reform for the Social Work Profession
Washington, DC
February 16, 2011

Representative Towns, Dean Zabora, Members of the Congressional Social
Work Caucus and Honored Guests:

It is an honor to speak with you today, but it is also a humbling experience to try to capture, in my few moments with you, those critical elements in the Affordable Care Act (ACA) that have the most import for our profession of social work. As the final speaker on today's panel, I will focus my remarks on one theme that is woven throughout Health Care Reform: person-centered planning and participant direction. Whereas that theme appears in both the acute and long-term care portions of the legislation, I will zero in on the provisions dealing with long-term supports and services in the community.

Participant-directed services are long-term care services that help people of all ages, across all types of disabilities, maintain their independence and determine for themselves what mix of personal care services and supports works best for them. Sometimes they are also referred to as consumer-directed or self-directed services. Under the participant-directed model, individuals have control over who helps them with the basic, personal activities of daily living such as bathing, dressing and getting out of bed

(employer authority) and how their funds are used (budget authority). Within the constraints of their budget, they can purchase any combination of goods, services and human assistance that meets their personal assistance needs and helps them stay independent in the community. If they need help in managing, they can appoint an unpaid family member or friend to be their representative; and they have readily available support services to help them handle the book keeping, taxpaying, and check writing responsibilities (financial management services) and develop person-centered plans, find resources, develop back-up plans, meet training needs, etc. (support broker or counseling services). This approach not only meets present and future needs for flexibility and choice, but also (under the Cash & Counseling demonstration) has proven itself under rigorous comparative effectiveness (CER) testing. Here is a summary of what research, conducted by Mathematica Policy Research, teaches us.

Research Results from the Cash & Counseling Randomized Controlled Experiment

- Improves Access
- Improves Quality of Care
 - Increased Satisfaction
 - Reduced Unmet Needs
 - Same or Better Health Outcomes
- Caregivers Benefit
- Costs Controllable
- Can Reduce Nursing Facility Usage



Clearly, interest in participant-direction is increasing. The National Survey of Participant Direction Programs, which our National Resource Center for Participant-Directed Services (NRCPS) is completing, shows that all states

have at least one program offering employer authority, and 41 states have at least one program with the budget authority option.

But this movement, even before Health Care Reform, will only increase. In 2006, AARP released a survey (AARP Public Policy Institute, 2006) where they asked a representative group of members over the age of 50 how they would like to receive services if in the future they needed help in basic daily activities of living like bathing, dressing or getting out of bed. 75% preferred managing for themselves over receiving care from agencies. Furthermore, no one needs to remind us of the increasing diversity of our nation's older population. Between 1990 and 2030 elders in four ethnic groups are expected to grow from 14% to 25% of the over 65 population. Our nation is diverse in terms of race, gender, ethnicity, sexual orientation, functional and cognitive ability, to name but a few dimensions. So, we need a system that is flexible. Let me repeat, it is clear that one size does not fit all. Participant direction allows individuals and families to tailor supports to their unique needs and preferences. No wonder the 2008 Commonwealth Fund Opinion Leader's Survey (Miller, Mor, & Clark, 2009) found that 61% of the 1,147 leaders responding favored expansion of consumer direction efforts like Cash & Counseling as a potential strategy for reform of publically funded services (and we all know how hard it is to get 60% of any group to agree!)

Health Care Reform fueled this paradigm shift. Three provisions in the ACA are especially important to note:

- Section 2402(a) calls on the Secretary of the Department of Health and Human Services (DHHS) to develop a common framework establishing principles and process elements supporting participant direction across the whole department and all of its programs.
- The Community Living Assistance Services and Supports (CLASS) Program establishes a federally-administered, voluntary long-term care financing plan to help individuals with functional limitations maintain their independence and live in the community. The very essence of CLASS is a participant-directed cash allowance.
- The ACA also includes a number of reforms expanding Medicaid funding authorities encouraging participant direction including

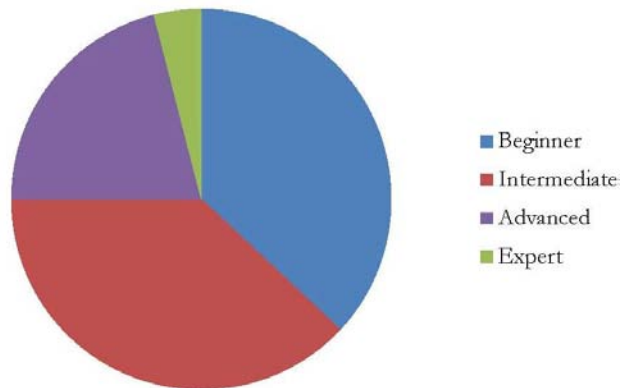
Community First Choice (Section 1915(k)), and revisions in the 1915(i) authority, as well as Money Follows the Person and a major funding increase for Aging and Disability Resource Centers (ADRCs) providing options counseling in a person-centered manner.

A more complete discussion of provisions in the new law can be found by accessing the power point presentation on “Opportunities for Participant Direction: A Closer Look at the Affordable Care Act” from the National Association of States United for Aging and Disabilities’ 2010 HCBS Conference (see www.hcbs.org).

So, what does all this mean for the Social Work Profession? First, I think we should take a bit of credit. Social Work is built on a tradition of EMPOWERMENT. The current emphasis on participant direction clearly builds from the very set of ideas and principles Jane Addams pioneered at Hull House. Furthermore, much of the research that laid the foundation for this paradigm shift was led and implemented by social workers. We, at the Boston College Graduate School of Social Work, are very proud of the role we have played over the last ten years in implementing, evaluating and refining the participant direction approach. Many of the state project directors, and a substantial percentage of the support brokers, who implemented Cash & Counseling were and are social workers.

But, the paradigm shift from a “professional/medical model” to an “empowerment/person-centered approach” doesn’t just happen. It requires training for support brokers, care managers and their supervisors to develop the knowledge and skills needed to support this approach; without this, participant direction will never become the norm. The necessity of such training becomes obvious when you look at the following chart.

How would you rate your knowledge of consumer direction BEFORE the webinar?



Nearly 75% of the care managers who attended a recent nationwide webinar we ran for the AoA rated themselves as beginners or intermediate when it comes to knowledge about the ins and outs of participant direction. There are many care managers in the Aging Network who are doing participant direction, as evidenced by the successful collaboration with the Veterans Administration in implementing Veterans-Directed Home and Community-Based Services (VD-HCBS) programs that provide self direction for Veterans. But the AoA recognizes that, to make participant direction the norm, a major training program is needed; such training has been initiated. It is a collaborative, consensus-based process that includes all stakeholders which will take time and require commitment and resources.

The AoA is committed to making participant direction the norm; and to that end has embarked on a major enterprise to develop and implement training for all levels of aging network staff.

But, in the end, the reason for doing this can be found in the profound affect being more in control of one's life and being able to fit supports to the rhythm of individual needs has on people's lives. Let me conclude with words from Frank Zampella, a current participant in the new VD-HCBS

Boston College Graduate School of Social Work
314 Hammond Street
Chestnut Hill, MA 02467
Phone: (617) 552-6727
Fax: (617)552-1975
www.ParticipantDirection.org

program (a fine example of this participant-directed approach). Mr. Zampella, speaking at a conference at the Veterans Medical Center in Lyons, New Jersey in December, told how he used his budget to move out of a nursing facility and back into his own home. Referring to the new program he concluded by saying, "It's a godsend. Believe me when I tell you."

Contact Information:

Kevin J. Mahoney, Ph.D.
Professor, Boston College Graduate School of Social Work
Director, National Resource Center for Participant-Directed Services
Boston College
314 Hammond Street
Chestnut Hill, MA 02467
kevin.mahoney@bc.edu
www.participantdirection.org