The Emergence of Mental Health Self-Direction: An International Learning Exchange

Bevin Croft, M.A., M.P.P., Kaipeng Wang, M.S.W., Benjamin Cichocki, Sc.D., C.R.C., Anne Weaver, M.A., L.M.H.C., Kevin Mahoney, Ph.D.

Self-direction has emerged worldwide as a promising practice for persons with serious mental health conditions and as a means toward creating more person-centered service systems. In self-direction, service users control an individualized budget, purchasing goods or services that can help them achieve personal recovery goals. This Open Forum describes an international learning exchange meeting, held in September 2015, in which experts in self-direction and mental health from seven nations convened for sharing best practices, discussing challenges, and laying the groundwork for a learning community to support the continued development of self-direction. Meeting participants identified three themes that represent next steps toward ensuring that the promise of self-direction is realized. First, self-direction involves creating a culture shift for value-based systems change. Second, people with lived experience must be involved and supported at every level, including direct support, leadership, and oversight. Third, stakeholder communication about self-direction's impact is critical.

Psychiatric Services 2017; 68:88–91; doi: 10.1176/appi.ps.201600014

In recent years, general medical and mental health service systems have placed increasing emphasis on person-centered approaches to service delivery and organization (1,2). In this context, self-direction—also known as self-directed care, participant direction, personalization, and individualized budgeting—has emerged as a promising practice to support recovery and well-being for persons with mental health conditions. Self-direction is a model for financing services and supports in which service users control a flexible budget to work toward recovery and wellness goals. Self-directing service users control public resources typically used to reimburse traditional providers; the resources are used to purchase a range of services and goods, including transportation, gym memberships, and employment-related goods and services, as well as traditional mental health services (3).

Typically, a specially trained support broker works with the self-directing person to identify hopes and dreams through a person-centered planning process, helps the person develop a budget based on his or her person-centered plan, and supports the person in developing the skills to manage the budget and make sound financial decisions. In a mental health context, the support broker is often someone with lived experience in terms of navigating the mental health system (often referred to as a peer worker). A financial management service handles the tax and payment details, and administrators monitor expenditures and support brokerage activities to ensure quality.

Evidence suggests that self-direction can improve recovery outcomes while keeping costs at a level similar to those of traditional arrangements (4). In the Cash and Counseling Demonstration and Evaluation project—the most significant test of the self-direction model to date—6,700 Medicaid beneficiaries with needs for long-term care were randomly assigned into self-directed arrangements or services as usual. The intervention group reported significantly higher levels of satisfaction and quality of life, with health outcomes and costs similar to those of the group receiving services as usual (5,6). A subanalysis of the data indicated a comparable positive effect for individuals with psychiatric diagnoses (7,8). In a pre-post study of the Florida Self-Directed Care program, one of a small number of self-direction efforts for persons with serious mental health conditions in the United States, people who were self-directing spent fewer days in inpatient or criminal justice settings and had higher Global Assessment of Functioning scores after one year of self-direction (9).

In a randomized study of self-direction in the United Kingdom that included individuals with serious mental health and substance misuse conditions, evaluators observed significant increases in care-related quality of life and psychological well-being along with significant decreases in inpatient and primary care costs for self-directing individuals compared with a control group (10). A recent systematic review of self-direction in mental health—which included the aforementioned studies and 11 others—concluded that although outcomes were mostly positive, most studies had methodological limitations and that larger, higher-quality

experiments are needed to inform policy and practice (4). Recent environmental scans in the United States supported by the Office of the Assistant Secretary for Planning and Evaluation of the Department of Health and Human Services (11) and the Robert Wood Johnson Foundation (3) have reached similar conclusions. Results from a number of studies—including randomized trials in Pennsylvania and Texas, a quasi-experimental evaluation of processes and outcomes that involved multiple sites in the United States, and continued evaluation of self-direction efforts abroad—will add to the evidence base in coming years.

In 2009, 40 senior leaders from health and social care organizations in the United Kingdom were surveyed about their views on self-direction. These leaders reported concerns regarding cost and complexity, organizational culture as a barrier to handing over control of public dollars, and the risk of compromising safety and service quality (12). However, the respondents also expected that self-direction could lead to positive system change through opening the market to lower-skilled providers and increasing competition and could contribute to a culture that better responds to the needs of service users (12). A 2013 study found that mental health leaders in the United States saw a high degree of promise in the self-direction approach but voiced similar concerns, including concerns about competing priorities of health and behavioral health agencies, provider resistance, and administrative challenges (3).

An International Learning Exchange on Self-Direction

In September 2015, government officials, researchers, policy experts, administrators, and peers from seven countries convened at Boston College in Newton, Massachusetts, for a learning exchange prior to the plenary meetings of the International Institute for Mental Health Leadership, an international collaborative focused on sharing innovative practices to improve mental health services. [All meeting participants granted the authors permission to identify them in a list in an online supplement to this report.]

With support from the Robert Wood Johnson Foundation, the learning exchange brought together 45 people from seven nations, most of whom are either currently involved in self-direction efforts or preparing to launch such efforts. About one-fifth of the participants self-identified as having lived experience of the mental health system. The primary aim of the meeting was to gather experts in the burgeoning field of mental health self-direction in order to develop collaborative relationships, define best practices, and chart a course for the future of self-direction. The specific objectives of the learning exchange were to share developments across participating countries, to identify common challenges in implementation, to identify best practice approaches, and to develop a shared agenda to promote the adoption of self-direction among mental health leaders. We participated in the learning exchange, and we distributed drafts of this Open Forum to all other participants and incorporated their feedback into the final draft.

Current approaches to self-direction. Although most of the countries represented at the meeting were actively pursuing the implementation of self-direction, there were obvious differences in how self-direction was being operationalized. In particular, the scope of implementation, the roles of brokers and administrators, and the way in which funding sources are utilized in the respective projects offered illuminating contrasts. For example, although some U.S. states are implementing self-direction in small pilots, Australia is incorporating self-direction as part of the reorganization of its entire disability insurance system. Likewise, although most states and countries tend to offer some form of budget authority (that is, the use of a personalized budget to purchase services and supports not traditionally considered medical care), details regarding how that budget is put into operation vary widely. [A more detailed overview of the self-direction approaches of the states and countries participating in the learning exchange is provided in the online supplement.]

During the two-day learning exchange, participants discussed their self-direction efforts, highlighting their unique areas of expertise along with their challenges. The first day of the learning exchange included in-depth small-group discussions about key topics associated with self-direction, identified in advance of the learning exchange by the participants. These topics included culture change, the role of peer support, financing considerations, implementation strategies, and self-direction as a means to effect broader change within mental health systems. The small-group discussions had two goals: to allow for in-depth discussion between participants and to make note of meaningful subtexts arising out of these discussions that could inform and enrich the discussions and planning during the following day's sessions.

Identifying Key Directions for the Future of Self-Direction

On the second day, learning exchange participants defined the following three themes as being of primary importance for mental health self-direction projects and research in the coming years.

Self-direction involves creating a culture shift for value-based systems change. Self-direction is not merely a mental health program. Rather, it is an arrangement that rebalances traditional power relationships between service users and service providers. The premise of self-direction is that personal recovery outcomes can be achieved in numerous ways, not just through participation in the traditional mental health service system. As such, self-direction is driven by the needs and wishes of individuals and the resources available to them, such as Medicaid payments in the case of the United States, and not by the dictates of the brokers, providers, or administrators involved in the self-direction effort. The guiding principles that undergird self-direction should fully inform all efforts to develop and implement self-direction efforts. These principles have yet to be fully articulated in

the context of mental health; however, meeting participants agreed that self-direction represents and requires a significant culture shift away from a diagnostic, treatment-oriented model of mental health (often referred to as a "medical model" approach) and toward a more holistic understanding of wellness and recovery. One first step may be to develop a common language and reach consensus on specific values or principles. Significant training and ongoing retraining in these guiding principles will be needed for administrators, providers, and service users alike.

People with lived experience must be involved and supported at every level, including direct support, leadership, and oversight. The practice of peer support, which has been increasingly adopted in mental health systems worldwide, aims to facilitate self-managed and self-defined wellness through the development of mutual relationships focusing on shared experience, hope, and respect (13,14). In the context of self-direction, people with lived experience who have been trained in peer support are uniquely qualified to act as support brokers, providing assistance with person-centered planning and budgeting. However, the involvement of peers as direct service support brokers alone is insufficient. To truly bring about system change, employees with lived experience of the mental health system must be represented at all levels of implementation, including leadership and oversight. Achieving this goal depends on training and support to prepare and retain people in leadership roles, along with development and promotion of peer career pathways, are critical. System change can be effected only when the values of person-directed and wellness-oriented services and supports are adopted by all levels of a mental health organization and its funders, with peers leading the process as experts.

Stakeholder communication about self-direction's impact is critical. All participants agreed that research and evaluation are critical to support the adoption, implementation, and sustainability of self-direction. Communications about self-direction should be derived from a mix of quantitative and qualitative data and tailored to ensure relevance for a range of stakeholders, from service users to policy makers. Although a focus on service cost and other quantifiable outcomes is needed to demonstrate self-direction's effectiveness, personal stories are equally important and must reflect the diversity of the populations that are self-directing. Personal stories illustrate the possibility of self-direction for improving individuals' lives through creative and individualized approaches to support wellness. Taken together, the results of rigorous quantitative analysis and personal narratives will help stakeholders to understand the value of self-direction.

Establishing an Ongoing Learning Exchange

The meeting closed with a discussion of next steps for the group. Participants unanimously expressed an interest in, and a need for, continuing learning exchanges. Participants discussed plans to develop, grow, and coordinate a learning platform to improve ways in which knowledge, practice, and evidence is used by peers, individuals, families and caregivers, practitioners, managers, planners, politicians, and local and national government officials to deliver and support better personal outcomes for people and communities.

Conclusions

The learning exchange described in this Open Forum represents the largest known gathering of experts in mental health self-direction to date. Many of the participants had never met prior to the meeting. The three key themes articulated by meeting participants represent next steps for the self-direction learning community and highlight the need for continued conversations and collaborations to further develop the approach and ensure that the promise of self-direction is realized.

AUTHOR AND ARTICLE INFORMATION

Ms. Croft, Dr. Cichocki, and Ms. Weaver are with the Human Services Research Institute, Cambridge, Massachusetts (e-mail: bcroft@hsri.org). Mr. Wang and Dr. Mahoney are with the National Resource Center for Participant-Directed Services, Boston College Graduate School of Social Work, Chestnut Hill, Massachusetts.

Support for the international learning exchange meetings and for the preparation of this Open Forum was provided by grant 71920 from the Robert Wood Johnson Foundation.

The authors report no financial relationships with commercial interests.

Received January 10, 2016; revision received March 18, 2016; accepted April 25, 2016; published online August 15, 2016.

REFERENCES

1. Institute of Medicine: Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC, National Academy Press, 2001
2. Achieving the Promise: Transforming Mental Health Care in America. Pub no SMA-03-3832. Rockville, Md, Department of Health and Human Services, President's New Freedom Commission on Mental Health, 2003
3. Croft B, Simon-Rusinowitz L, Loughlin D, et al: An Environmental Scan of Self-Direction in Behavioral Health: Summary of Major Findings. Chestnut Hill, Mass, Boston College National Resource Center for Participant-Directed Services, 2013
4. Webber M, Treacy S, Carr S, et al: The effectiveness of personal budgets for people with mental health problems: a systematic review. Journal of Mental Health 23:146–155, 2014
5. Carlson BL, Foster L, Dale SB, et al: Effects of Cash and Counseling on personal care and well-being. Health Services Research 42: 467–487, 2007
6. Dale S, Brown R: The Effect of Cash and Counseling on Medicaid and Medicare costs: Findings for Adults in Three States. Princeton, NJ, Mathematica Policy Research, Inc., 2005
7. Shen C, Smyer M, Mahoney KJ, et al: Consumer-directed care for beneficiaries with mental illness: lessons from New Jersey's Cash and Counseling program. Psychiatric Services 59:1299–1306, 2008
8. Shen C, Smyer MA, Mahoney KJ, et al: Does mental illness affect consumer direction of community-based care? Lessons from the Arkansas Cash and Counseling program. Gerontologist 48:93–104, 2008
9. Cook JA, Russell C, Grey DD, et al: A self-directed care model for mental health recovery. Psychiatric Services 59:600–602, 2008

10. Forder J, Jones K, Glendinning C, et al: Evaluation of the Personal Health Budget Pilot Programme. Discussion paper 2840_2. Canterbury, United Kingdom, University of Kent, Personal Social Services Research Unit, 2012
11. Slade E: Feasibility of Expanding Self-Directed Services to People With Serious Mental Illness. Washington, DC, US Department of Health and Human Services Assistant Secretary for Planning and Evaluation Office of Disability, Aging and Long-Term Care Policy, 2012
12. Shaping Personal Health Budgets: A View From the Top. London, National Mental Health Development Unit, National Health Service Confederation, 2009
13. Davidson L, Chinman M, Sells D, et al: Peer support among adults with serious mental illness: a report from the field. Schizophrenia Bulletin 32:443–450, 2006
14. Chinman M, George P, Dougherty RH, et al: Peer support services for individuals with serious mental illnesses: assessing the evidence. Psychiatric Services 65:429–441, 2014

Submissions by Residents and Fellows Invited

TRAININGrounds is a continuing series of articles by trainees that was introduced to highlight the academic work of psychiatric residents and fellows and to encourage research by trainees in psychiatry.

Submissions should address the planning and delivery of psychiatric services in any setting, including those of special interest or concern to trainees. Submission of original research is encouraged. Literature reviews will be considered if they are mentored or coauthored by a senior scholar in the field.

Joseph M. Cerimele, M.D., is the editor of this series. Prospective authors—current residents and fellows—should contact Dr. Cerimele to discuss possible submissions. He can be reached at the University of Washington School of Medicine (e-mail: cerimele@uw.edu).

All TRAININGrounds submissions undergo the same rigorous peer review and editorial decision making as other submissions. Accepted papers will be highlighted in the issue in which they appear.