ISSUE BRIEF

DO PARTICIPANT-DIRECTED WORKERS REQUIRE THE SAME TRAINING AS AGENCY WORKERS? USING RESEARCH TO INFORM POLICY

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BACKGROUND

When given an option, many individuals are choosing to recruit, hire, and supervise their workers in lieu of agency-provided personal assistance. Worker shortages and agencies' restrictions on workers' activities are typically cited as factors in this decision (Foster, Phillips, & Schore, 2005 and Benjamin, Matthias, Franke, & Doty, 1999). Often called participant direction, consumer direction, or self direction, options that allow individuals to hire workers (referred to as directly-hired workers for the remainder of this issue brief) are being administered through various funding sources and federal and state partnerships. For example, participant-directed services (including access to an individual budget to purchase goods and services) may be implemented through Medicaid Home and Community-Based Waivers as well as through the Deficit Reduction State Plan Option. Also, Older Americans Act funding provides new opportunities for elders to self-direct. Most recently, a partnership between the Administration on Aging and the Department of Veterans Affairs has led to the implementation of Veterans-Directed Home and Community-Based Services (VD-HCBS). VD-HCBS provide veterans the option to manage an individual budget for long-term supports, which includes the ability to directly hire workers. Given these opportunities, more people diverse in age and type of disability are choosing to hire workers. Some states are considering mandating uniform training for directly-hired workers. The following issue brief draws upon research from two large scale participant-directed options for people with diverse disabilities: the Cash & Counseling Demonstration and Evaluation (CCDE) and the California In-Home Supportive Services (IHSS) program. Research suggests that directly-hired workers typically have different characteristics, experiences, and training needs than agency-hired workers (Dale, Brown, Phillips, & Carlson, 2005; Simon-Rusinowitz, Mahoney, Loughlin, & Sadler, 2005; and Benjamin & Matthias, 2004). This issue brief will explore these differences and provide recommendations based on research findings.

UNDERSTANDING DIRECTLY-HIRED WORKERS AND THEIR EXPERIENCES

CCDE and IHSS research results indicate that workers directly-hired by participants have different training needs than their agency counterparts. Many assume that directly-hired workers resemble agency-hired workers. Research paints a different picture. A few of the key differences are described below.

Directly-hired workers are often family members or friends.
More often than not, the directly-hired worker is a family member who is female and married and lives with (or geographically close to) the participant (Simon-Rusinowitz, et al., 2005). Within the CCDE, almost 70 percent of the directly-hired workers knew the individual prior to being paid (Dale, et al., 2005). While the agency worker tends to have more paid personal care experience, the directly-hired worker tends to have more experience with the individual being supported (Zacharias, 2003 and Simon-Rusinowitz, et al., 2005).

Directly-hired workers perform a wide variety of tasks based on the needs of the individual.
The support provided by a directly-hired worker tends to vary significantly from one worker to the next. Some directly-hired workers provide assistance with tasks typically not conducted by agency workers due to agency restrictions (e.g., routine health care, administering medications, pressure sore care, ventilator care, and feeding tube care) (Dale, et al., 2005 and Simon-Rusinowitz, et al., 2005). Others may provide various forms of personal assistance support and household assistance (Dale, et al., 2005 and Simon-Rusinowitz, et al., 2005).

BASIS FOR WORKER TRAINING POLICY DECISIONS: MYTHS OR FACTS

Prior to making policy decisions pertaining to worker training within a participant-directed environment, typical assumptions need to be examined.

Myth #1: Agency and directly-hired workers are comparable and require the same training.
Fact: Directly-hired workers are likely to have far more experience with the participant than agency workers. Whether or not they are family, directly-hired workers tend to have experience providing support to the participant prior to their role as a paid worker. In addition, they provide an average of 26 hours of unpaid care per week (Dale, et al., 2005 and Simon-Rusinowitz, et al., 2005). Agency workers tend to serve more than one individual and, therefore, spend less time with each compared to directly-hired workers (Benjamin & Matthias, 2004).

Myth #2: If no standardized training exists, directly-hired workers are not being trained.
Fact: Participation in the individuals' healthcare (e.g., communication and visits with medical doctors as well as shadowing home health providers) and training provided by participants and/or representatives create both formal and informal training opportunities (Simon-Rusinowitz, et al., 2005 and Hershey, 2006). Given these opportunities for learning, directly-hired workers more often feel "fully prepared to meet expectations in helping the consumer" (Dale, et al., 2005). Participants agree; 97 percent of those receiving support from directly-hired workers (family and non-family) reported workers to be knowledgeable (Simon-Rusinowitz, et al., 2005). Research indicates that directly-hired workers tend to feel as informed as their agency counterparts; directly-hired workers in Arkansas and Florida felt significantly more informed than agency workers (Dale, et al., 2005).

Myth #3: Participant direction is risky and requires standardized training to minimize risk.
Fact: People who receive significant support live with their disability daily and have a vested interest in making sure their attendants are well trained to meet their needs (Hershey, 2006). Policymakers, fueled by concerns that participant direction means less monitoring and therefore more risk, often identify mandatory standardized worker training as a strategy to address these concerns. In reality, directly-hired workers often provide more complex care than agency workers, yet research has found health outcomes and quality of life outcomes do not suffer (and in some circumstances improve) (Dale, et al., 2005).

Myth #4: Directly-hired workers lack supervision.
Fact: Directly-hired workers are not intended to go without supervision. Instead, the role of the supervisor shifts from the agency to the participant (or their representative), a person who consistently observes the worker and has the power to hire and/or fire him or her. Within the CCDE, directly-hired workers and agency workers reported a similar satisfaction rate (87 percent) with supervision (Dale et al., 2005). Directly-hired workers reported stronger supervisor communication compared to agency counterparts (Dale, et al, 2005). This may be due to the quality management system required within any strong participant-directed option, including emergency back-up plans, consultant monitoring, and a representative option (Applebaum, Schneider, Kunkel, & Davis, 2004 and Doty, 2004).

RECOMMENDATIONS FOR POLICYMAKERS

Research provides insight into why mandatory and standardized training do not necessarily fit neatly into a participant-directed paradigm. Recommendations on how to address training needs within a participant-directed environment are provided below.

Tap into the existing knowledge and experiences of family members and friends.
Family members already play a significant role in providing assistance to loved ones with support needs. Allowing individuals to tap existing networks can not only minimize the effects of a worker shortage, but also minimize the need for standardized training techniques (Foster, Phillips, & Schore, 2005; Simon-Rusinowitz, et al., 2005; and Hershey, 2006). Individuals who self-direct report feeling safer when workers are friends or family (Benjamin, et al., 1999). Also, those who hire family tend to be more satisfied and less likely to report an unmet need (Doty, 2004 and Simon-Rusinowitz, et al., 2005).

Ensure that individualized, participant-driven training and supervision opportunities exist.
Despite the fact that many participant-directed options do not require standardized training, CCDE findings indicate that workers feel as informed, if not more, than their agency counterparts (Dale, et al., 2005). Through skills training and support provided by consultants, policymakers should ensure participants and/or their representatives understand their role and responsibilities in the areas of worker training and supervision (Applebaum, et al., 2004 and Sabatino & Hughes, 2004).

Adopt individualized, person-driven training in lieu of mandated or standardized training.
Research to date clearly documents the benefits of individualized and person-driven training and support on participant and worker outcomes (Benjamin & Matthias, 2004; Dale, et al., 2005; and Simon-Rusinowitz, et al., 2005). However, traditional training restrictions on how to provide support may stand in the way of workers' ability to best meet individuals' needs (Benjamin & Matthias, 2004). Participants should have the option to purchase worker training (if an individual budget exists) or seek free training within their community. If mandated and/or standardized worker training exists, such training should emphasize the participant direction philosophy and include participants in its design and implementation. Given the busy lives of workers, training opportunities should be flexible, accessible (e.g., online training and brochures), and affordable.

Address the potential for worker burnout and isolation by offering resources.
Caregiving is stressful work. While allowing individuals to directly hire workers minimizes informal caregivers' emotional strain, workers who are friends or family tend to have more emotional strain compared to agency workers (Dale, et al., 2005). Training of participants and their representatives should include the availability of resources that may be beneficial to the participant and the worker (e.g., brochures, peer support, on-line resources, etc.) to minimize stress and burnout (Zacharias, 2003; Benjamin & Matthias, 2004; and Applebaum, et al., 2004).

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The National Resource Center for Participant-Directed Services provides research-based technical assistance on all aspects of designing, implementing, managing and evaluating participant-directed programs.

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