Disability and Health Journal 9 (2016) 464–471

Disability and Health Journal

www.disabilityandhealthjnl.com

Research Paper

Consumers' and workers' perspectives about consumer-directed services in the United States

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Abstract

Background: Consumer direction is a service delivery model that shifts decision-making from agencies to the individuals they serve. Using government funding, consumers hire, supervise, and schedule their own staff and maintain control over the delivery of their services.

Objective: This study sought to understand the process of consumer direction as well as the experiences and perspectives of both the consumers and employees. The study also sought to better understand if and how consumer direction allows the consumer to direct his or her life, the impact consumer direction may have on the individual's health and health care, and how employment in consumer directed programs impacts the workers providing direct care services.

Method: This qualitative study included interviews with consumers ($N = 20$) and workers ($N = 15$) in Virginia, a southern state in the US. Semi-structured phone interviews were conducted by one member of the research team and transcribed and coded for themes by the research team using grounded theory methodology.

Results: Consumers reported greater control over their services and increased access to health care, compared to what they previously received with traditional services. Conversely, consumers reported challenges in managing their staff and fulfilling the role of an employer. Employees reported a lack of training prior to starting their jobs, as well as an inability to live off on low hourly wages. Still, the majority of employees reported job satisfaction and fulfillment.

Conclusion: Policymakers should expand and strengthen the consumer directed program.

Keywords: Consumer directed services; Long-term care; Disability; Independent living; Health

Historically, long-term care services for people with disabilities were based on an agency-centered model, with agency staff retaining most of the decision-making power. Consumer direction is a counterpoint to this traditional model, and a rapidly growing platform for the delivery of long-term care services to people with disabilities who receive Medicaid or other publicly-funded benefits.[1,2] Consumer direction shifts control of services from agencies to consumers and their families by enabling consumers to hire, schedule, and pay care workers directly.[3] Consumer direction builds on ideas of independent living, self-determination, and person-centered supports[4] and was developed in the 1960s by disability activists who wanted more control over their services and lives.[5] According to Kosciulek (1999), the consumer directed model is based on three critical assumptions: (1) people with disabilities are experts on their service needs; (2) choice and control can be introduced into all service delivery environments; and (3) consumer direction should be available to anyone with a disability, regardless of who is paying for their services.[6] The first assumption, in particular, drives consumer direction today. Rather than an agency *telling* a person with a disability the services that might benefit him or her, the dynamic switches to the agency *listening* to what the person with a disability wants and needs for services. Table 1 further delineates the key differences and similarities between the consumer directed and agency-centered models.

In the past two decades, consumer direction has become an increasingly popular alternative to traditional agency-directed services. In the US, Medicaid waiver consumer direction programs have developed for people with physical, intellectual, and psychiatric disabilities as well as the elderly[7]; thus, the trend toward consumer direction continues to grow in state Medicaid programs.[3] In 2001, there were 139 consumer direction programs in 49 states; by 2011, there were more than 240 publicly-funded consumer direction programs in all 50 states and the District of Columbia.[8] Likewise, consumer directed based models have

Support for this research was provided by Public Partnerships, LLC and the Lurie Institute for Disability Policy, The Heller School for Social Policy and Management, Brandeis University.

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1936-6574/$ - see front matter
http://dx.doi.org/10.1016/j.dhjo.2016.01.002

Table 1
Characteristics of consumer direction

Consumer directed model	Traditional agency-directed services
Consumers make decisions about services	Agency staff having most of the decision-making power
Consumers hire, schedule, and pay care workers directly	Consumers have little or no authority over staffing or service coordination
Consumers direct their own services with assistance and support	Agency staff direct consumer's services

been developed in a number of other countries, such as the UK, Scandinavia, Australia, and New Zealand (sometimes referred to as personalization or cash-for-care).[6]

In light of the growth of the consumer directed model, researchers have begun to examine the experiences of consumers and their families receiving services. Prior research indicates consumers report positive outcomes from program participation.[9,10] Studies have also found that consumer directed services are as safe and appropriate as traditional services.[5] One meta-analysis found that consumers have better quality of life, higher levels of satisfaction and fewer unmet needs than individuals using agency-based services.[5] Moreover, family caregivers have reported lower levels of strain, fewer worries about care and safety of their relative and better overall health than family caregivers whose relatives are served using the traditional approach.[11] However, finding qualified employees can prove challenging for consumers and their families.[12]

Much less research has studied the experiences of workers, particularly those employed by people with disabilities. One study found that employees who cared for elders reported improved relationships with consumers and increased control of their work schedules while receiving also fewer fringe benefits and providing more care than traditional services.[1] To the best of our knowledge, similar studies regarding employees of people with disabilities in consumer directed programs do not exist.

The present study is unique because it included perspectives of both consumers and providers, and investigated the experiences of people with physical and intellectual disabilities and elderly individuals at risk of nursing home admission. Specifically, our aims were to understand the impact of consumer direction on participants' ability to direct their own care as well as access to health care. Additionally, this study analyzed the impact of consumer directed services on providers. Accordingly, we addressed the following research questions: (1) What are the experiences of consumers participating in consumer direction? (2) How does participating in the program affect participants' ability to direct their own care? (3) What impact does consumer direction have on the health and health care access of participants? (4) What are the experiences of employees in the consumer direction program? (5) What impact does consumer directed care have on individuals providing services?

Method

This study was part of a larger contract between researchers and a fiscal intermediary who oversaw the consumer directed program. Researchers were contracted to conduct interviews with consumers and participants to study both groups' experiences and develop recommendations to improve the program. Supplemental Data, including enrollment dates and region, were provided by the fiscal intermediary. The Institutional Review Board at the researchers' universities approved the study protocol.

Participants

The study's sample included both consumers ($N = 20$) and workers ($N = 15$) from the consumer direction Medicaid waiver program in Virginia, a southern state in the US. Initially, the fiscal intermediary provided researchers with a list of 100 randomly selected consumers and 100 randomly selected employees. The lists were from two separate pools of individuals and were not linked. We did not ask for the names of employees nor did we ask for the name of consumers receiving care from the employees. Ultimately, 35 individuals were randomly-selected interviews to create a sufficiently large sampling pool while avoiding saturation.

Consumers with physical and intellectual disabilities were included in the study. Inclusion criteria for the consumers included: (1) 30 years of age or older, (2) enrollment in state's Medicaid program for six or more years, (3) current participation in state's consumer direction program under a Medicaid waiver for three or more years. Medicaid waiver programs included are under the 1915(c) federal guidelines, and must: (1) demonstrate that providing waiver services will not cost more than providing these services in an institution; (2) ensure the protection of people's health and wellbeing; (3) provide adequate and reasonable provider standards to meet the needs of the target population; (4) and ensure that services follow an individualized and person-centered plan of care.[8]

Employees in the study was limited to those who provided one-to-one in-home direct care services to people receiving waiver services. Inclusion criteria for employees included: (1) employment with someone receiving consumer directed services through the state's consumer direction waiver program for at least one year; and (2) provided services to someone who uses the fiscal intermediary. Employees served both adult and child consumers.

Recruitment and interview procedures

The fiscal intermediary assisted with recruitment by distributing informational letters to the random sampling