



Annotated Review of Selected Consumer Directed Support Studies

INTERIM AUTHORITY FOR COMMUNITY LIVING BRITISH COLUMBIA

SEPTEMBER 7, 2003

Management of respite and personal assistance services in a consumer-directed family support programme - J. Caldwell & T. Heller, *Journal of Intellectual Disability Research*, Volume 47, Issue 4, May, 2003.

US [Illinois] study identifies benefits for both caregivers and individuals with a developmental disability with increased control of respite and personal assistance services, including the ability to hire relatives.

Key Findings

"More control in activities of hiring, training, scheduling, directing and negotiating the wages of staff seems to be associated with the increased community involvement of individuals with DD and . . . suggests that policies should allow flexibility and consumer direction when desired . . . when families are given more control in this process, becoming 'true consumers' of services, they are more satisfied . . . supports benefits associated with hiring relatives and recommends additional research in this area to guide policies".

Consumer-Directed Home and Community Services Programs in Five Countries: Policy Issues for Older People and Government - October 2000, Jane Tilly, Joshua M. Wiener, and Alison Evans Cuellar

Analysis of consumer directed programs in the USA, Germany, Austral, the Netherlands and France indicate users have more control over services [including hiring relatives] and better quality of care, with no evidence of uncontrolled program costs.

Key Findings

"Programs should be flexible enough to allow beneficiaries to manage their own services when they want to, while providing agency services for those who do not want to or are incapable of management . . . every study country allows cognitively impaired persons to participate in these programs . . . A major worker-related issue is that a high portion of independent workers are family members . . . management, training, quality assurance, and payment levels take on a very different cast if the independent provider is a family member or friend rather than a stranger. The adage that "blood is thicker than water" may account for some of the countries, and states' relatively "laissez-faire" approach to program management and for some of the positive results on consumer satisfaction."

In-Home Supportive Services for the Elderly and Disabled: A Comparison of Client-Directed and Professional Management Models of Service Delivery - Pamela Doty, U.S Dept. of Health and Human Services, A.E. Benjamin, Ruth E. Matthias and Todd M. Franke UCLA, April 1999 [Non-Technical Summary Report]

US [California] study indicates significant differences on various quality of life outcome indicators when a consumer-directed model of service financing and delivery, which includes the option of hiring family members, is compared with a professional management or agency based model.

Key Findings

"The purpose of the study was to determine whether there are significant differences, on a wide range of outcome indicators, when publicly-funded supportive services for the elderly and disabled are provided through a consumer-directed (CD) as compared to a professional management (PM) model of service financing and delivery . . . the study's principal finding is that clients in the CDM had more desirable outcomes than clients in the PMM within . . . satisfaction with services, empowerment, and quality of life . . . Altogether, the CDM had significantly better outcomes on six of fourteen specific outcome measures . . . This study's findings support the option of hiring family members as providers because . . . family providers are more likely to provide a higher quality of service than unrelated workers."

Financial Compensation versus Community Supports: An Analysis of the Effects on Caregivers and Care Receivers - Janice Keefe & Pamela Fancey, 1999.

Comprehensive synthesis of Canadian research and evidence on the effects of financial compensation on caregivers and care receivers, when compared to other community supports, indicates need to better understand the potential of this policy option for supporting informal caregivers' ongoing involvement in the care giving relationship.

Key Findings

“The challenge then is to target the compensation . . . and use the funding to sustain the care giving relationship. Direct payment to caregivers . . . reinforce social values of helping and caring, values which have become increasing more difficult to realize as a result of changing family demographics . . . we propose the following recommendations:

- *Financial compensation in the form of a direct payment should be seriously considered as a way to recognize and support family caregivers.*
- *Financial compensation and community services should be recognized as complementary.”*

Lessons from the Implementation of Cash and Counseling in Arkansas, Florida, and New Jersey: Final Report, June 2003 - Barbara Phillips, Kevin Mahoney, Lori Simon-Rusinowitz, Jennifer Schore, Sandra Barrett, William Ditto, Tom Reimers and Pamela Doty

US study [Arkansas, Florida and New Jersey] demonstrates experimental programs which provide a flexible monthly allowance that consumers can use to hire their choice of workers, including family members, to purchase needed goods and services is an adaptable approach for consumers of all ages and with all types of impairments.

Key Findings

“Nearly all consumers use the allowance to hire workers, usually relatives or acquaintances. A Cash and Counseling program can improve access to care by tapping this labor supply. The flexibility of the Cash and Counseling allowance permits consumers to meet their needs better through the purchase of goods and services not available in the traditional system . . . If fiscal services are provided at little direct expense to consumers, nearly all will rely on the fiscal agent for check writing and payroll functions (such as preparing and submitting tax returns) . . . Consumer exploitation was very rare in Cash and Counseling.”

Family Caregivers and Consumer Choice: Options for In-Home Respite, Final Report, December 1996 - Lynn Friss Feinberg, MSW and Carol J. Whitlatch, PhD.

US study [California] examining comparisons between direct pay and agency-based respite care services on various factors including preferences, consumer characteristics, costs, service satisfaction, caregiver distress and depression, and respite use shows a clear preference and cost benefit for consumer-directed respite over agency-based in-home respite.

Key Findings

“One of the most striking findings was that caregivers preferred the consumer-directed mode [i.e. direct pay] to agency-based respite by more than two to one. Compared to caregivers using agency-based respite, caregivers using the direct pay option were found to have significantly more choice and control in decisions related to the day-to-day management of their respite aides. Additionally, not only was the use of the direct pay mode associated with more hours of respite per caregiver, but it was also shown to be significantly less costly per hour of service than the use of agency-based respite . . . Both groups of caregivers had generally positive levels of consumer satisfaction, though the direct pay users were more highly satisfied overall. In particular, greater client direction [i.e., the amount of choice and control a caregiver exercised in managing in-home respite] was significantly related to higher satisfaction with the aide for those direct pay caregivers who hired relatives or friends to provide respite care.”