

Management of respite and personal assistance services in a consumer-directed family support programme

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Abstract

Background The present study explores the management of respite and personal assistance services by families with relatives with developmental disability (DD). It focuses on the control of families over recruiting, hiring, training, scheduling, directing and negotiating wages of the staff they hire to provide services.

Methods Surveys from 97 families using paid respite or personal assistance services were used to test associations between: 1) level of control of services and outcome variables; 2) hiring relatives to provide services and outcome variables.

Results More control by families in the management of their respite/personal assistance services was associated with increased service satisfaction, increased community involvement of individuals with DD and increased employment of mothers. Families tended to hire friends, neighbours, and to a great extent, other family members. Hiring of other relatives to provide services was associated with the increased community involvement of individuals with DD.

Conclusions The present study supports the idea that there are benefits for both caregivers and individuals with DD with increased control of respite and personal assistance services. The study also supports benefits associated with hiring relatives and recommends additional research in this area to guide policies.

Keywords consumer direction, direct payments, family support

Introduction

While families are the predominant providers of life-long support to individuals with developmental disability (DD), family support policies often receive little funding. Within the USA, over 60% of individuals with DD live at home with family caregivers (Fujiura 1998), but the funding allocated for family support accounts for only 2.8% of all funding within the DD service system (Braddock *et al.* 2000). Traditionally, formal family support has been agency-directed, providing discrete services such as respite, counselling and parent education. More recently, consumer-directed programmes have emerged internationally, providing control of money to design and purchase supports. The present study concerns consumer direction in one such programme, the Illinois Home Based Support Services Program (HBSSP).

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This study explores the management of respite and personal assistance services by families, and outcomes associated with having control of services.

Research on consumer direction in personal assistance services

Over the past several decades, the Independent Living Movement has guided the reconstruction of service provision. Countries have increased community-based services and implemented policies giving people with disabilities and their families more control of resources. For example, Halloran (1998) provided an overview of the development of direct payments in 10 European Union member states. Tilly *et al.* (2000) compared programmes in five countries, and reported that, while agency-directed models are predominant in the Netherlands and the USA, consumer-directed models are more prevalent in France and Germany, and are the only models utilized in Austria.

Given the predominance of agency-directed services, research on consumer direction, especially within the USA, has been limited to small-scale pilot and individual state-funded projects. Several studies have compared outcomes, primarily for individuals with physical disabilities, between agency-directed and consumer-directed personal assistance programmes (Prince *et al.* 1995; Adams & Beatty 1998; Beatty *et al.* 1998). Prince *et al.* (1995) found that individuals in a consumer-directed programme received more hours of paid assistance, experienced fewer hospitalizations, had a better perception of their health, and expressed increased satisfaction with their services. Studying a consumer-directed personal assistance programme in Virginia, Adams & Beatty (1998) reported that consumer direction resulted in greater productivity and employment, higher preventative healthcare utilization, and increased feelings of control over life. Studying the same programme, Beatty *et al.* (1998) found that individuals receiving consumer-directed personal assistance were significantly more satisfied with their personal assistance services. Satisfaction with personal assistance services is a key variable in the general life satisfaction of people with disabilities. Underscoring a social model of disability, Noseck *et al.* (1995) demonstrated a significant positive correlation between satisfaction with personal assistance and general life

satisfaction, while degree of impairment was not significantly related to life satisfaction.

Another line of research on consumer-directed personal assistance services has explored reasons for interest in such programmes. Within the USA, research from the Robert Wood Johnson 'Cash and Counseling' demonstration projects has highlighted flexibility as a desired aspect of programmes. Receiving services on days and times when needed, flexibility in hiring that includes hiring family and friends, and flexibility in using money to purchase different services or home modifications were frequently reported reasons of interest in consumer-direction (Simon-Rusinowitz *et al.* 1997, 2001; Mahoney *et al.* 2002). Surrogates, most often informal family caregivers, were also interested in flexibility in hiring and felt that participation in the consumer-directed programme would 'make things easier for them'. Similarly, individuals with disabilities receiving direct payments in the UK reported the benefits of increased flexibility in range of services, improved continuity and the development of trusting relationships with personal assistants (Glendinning *et al.* 2000).

Research on consumer direction in family support

Only a handful of studies have explored the impact of consumer-directed family support for people with DD. Evaluating a consumer-directed family support programme in Minnesota, Zimmerman (1984) found that family caregivers reported less stress and increased feelings of providing better care at home. Similarly, from studies on a Michigan consumer-directed family support programme, caregivers reported less family stress, less financial stress, enhanced life satisfaction, increased service satisfaction and decreased anticipation of needing out-of-home placement after participating in the programme (Meyers & Marcenko 1989; Herman 1991; Herman 1994).

In one of the few studies focused on a consumer-directed family support programme targeting adults with DD living at home, Heller *et al.* (1999) compared families in the Illinois HBSSP with families on the waiting list for the programme. The families in the programme used more services and had fewer unmet service needs than the individuals on the waiting list. Adults with disabilities participating

in the programme were more involved in the community and had higher monthly wages. Family caregivers were more satisfied with the services which their relative received and were less likely to desire out-of-home placement. While a measure of caregiving burden was not significantly different between groups, family caregivers participating in the programme reported higher measures of self-efficacy, indicating feelings of confidence in their caregiving abilities.

Consumer-directed family support programmes allow families to use resources to design supports to meet their unique needs. The most frequently sought supports are often personal assistance services or respite (Heller *et al.* 1999); consumer-directed programmes allow families to have increased control in hiring and managing staff. There is some evidence that families desire more control and prefer less formal and individual relationships with providers in contrast to more traditional agency-directed services. In a large-scale survey of respite services in the USA, the majority of families felt that they had little or no control over their respite services (Knoll & Bedford 1989). With regard to different respite models, families ranked in-home respite services provided by family, friends and neighbours as the most strongly preferred model. Families indicated that limited allocation of respite time, inflexibility in scheduling to meet their needs and leaving their family member with a disability with a stranger were major problems for them.

Present study

The Illinois HBSSP presents the opportunity to expand research on consumer-directed family support. Little is known about how control of respite/personal assistance services is related to different outcome variables, affecting both caregivers and individuals with DD. Previous studies have suggested that satisfaction with personal assistance, self-appraisals and community involvement of individuals with disabilities are important outcome variables related to consumer-directed services (Prince *et al.* 1995; Adams & Beatty 1998; Beatty *et al.* 1998; Heller *et al.* 1999). The employment of mothers who are primary caregivers is also an outcome variable to explore. Several other studies have reported that that lifelong caregiving can reduce workforce participation of

mothers of children with DD (Todd & Shearn 1996; Heller *et al.* 1997; Seltzer *et al.* 2001). It is hypothesized that having increased control in hiring and managing individuals providing personal assistance or respite may increase the employment of mothers.

Very little is known about who families hire to provide respite/personal assistance services when they are given control. There appears to be interest in hiring previously known individuals, i.e. friends, neighbours and other family members. However, hiring other relatives can be a controversial area as policies are developed. Some programmes like the HBSSP have allowed families to hire other relatives living outside of the immediate home. Research has not yet explored the outcomes associated with hiring relatives to provide personal assistance and respite services. In summary, there are two main areas of questioning explored in the present study:

- 1 How is the level of control in the management of respite/personal assistance services related to caregiver appraisals (caregiving burden, caregiving satisfaction and caregiving self-efficacy), service satisfaction, community involvement of individuals with DD and employment of the mothers?
- 2 Who have families in the HBSSP hired to provide respite/personal assistance, and what have been their experiences with recruitment and staff turnover? Is hiring other relatives associated with significant differences in service satisfaction, staff turnover and the community involvement of individuals with DD?

Subjects and methods

Sample

The study sample included 97 families using paid respite or personal assistance services. As part of an ongoing evaluation of the HBSSP, 520 families were surveyed (305 families participating in the HBSSP and 215 families on the waiting list for this programme). Some families ($n = 132$) were selected based on their previous participation in the evaluation. Other families were randomly selected: 189 out of the total of 1542 families participating in the HBSSP and 199 out of the total of 3242 families on the waiting list for the programme.

One hundred and forty-one families returned surveys. Fourteen of the surveys were returned to sender because of an incorrect address, 11 individuals with

disabilities had passed away and four individuals with disabilities were no longer eligible to be in the HBSSP (i.e. they had entered a residential setting). Therefore, the corrected response rate was 28.72%. Out of the 141 returned surveys, 97 families were using paid respite or personal assistance services; these families comprise the sample for the current study, except for the analyses involving employment of mothers. For the analysis involving the employment of mothers, the sample size was reduced to 91 surveys. In six households, a mother was not present (two siblings, two fathers only, one legal guardian/foster parent and one grandparent). These surveys were not used for that particular analysis since the question focused on the employment status of mothers.

Measures

Caregiving burden

The caregiving burden scale consisted of nine statements about the effects of caring for a relative with a DD on job opportunities, finances, future worry, personal time, social opportunities for leisure and the caregiver's marriage (Heller *et al.* 1994). Each statement was rated from (1) 'strongly disagree' to (4) 'strongly agree'. The alpha reliability of this scale was 0.80.

Caregiving satisfaction

The caregiving satisfaction scale consisted of five statements about satisfaction in the role of caregiver. Examples of statements include: 'My relative shows real appreciation for what I do for him/her' and 'My relative's pleasure over some little thing gives me pleasure'. Each statement was rated from (1) 'strongly disagree' to (4) 'strongly agree'. The alpha reliability of this scale was 0.90.

Caregiving self-efficacy

The caregiving self-efficacy scale was based on Bandura's (1986) concept of self-efficacy, modified by Heller *et al.* (1999) to apply to families of individuals with DD. The scale consisted of six statements; for example, 'I honestly believe I have the skills necessary to be a good caregiver to my relative' and 'If

anyone can find the answer to what is troubling my relative, I can'. Each statement was rated from (1) 'strongly disagree' to (4) 'strongly agree'. The alpha reliability of this scale was 0.64.

Service satisfaction

Service satisfaction consisted of seven items. Five of the items were from a scale previously used (Heller *et al.* 1999). Examples of these items include: 'To what degree do you get the kind of services you want?' and 'In an overall sense, how satisfied are you with the services you receive?' This scale was rated from (1) 'not at all' to (5) 'very much'. An additional two questions were added to this scale which specifically asked about satisfaction with respite/personal assistance services and the individuals providing these services. These questions were also measured on a five-point scale from (1) 'very dissatisfied' to (5) 'very satisfied'. The alpha reliability of the seven-item scale was 0.90.

Community involvement of individual with a developmental disability

This was measured through the Community Integration Scale (Heller & Factor 1991). This scale consisted of eight items which measure frequency of participation on a six-point scale from (1) 'not at all' to (6) 'daily'. Examples of items include: 'Go to restaurants or bars', 'Go to movies, concerts, sports events, etc.' and 'Visit with friends'. The alpha reliability of the scale was 0.66.

Employment of mothers

Employment of mothers was measured by the number of hours per week of employment.

Staff turnover

Staff turnover was measured by one item asking the approximate number of times that 'new staff replaced old staff' within the past year. A second question asked about reasons new staff replaced old staff and included 'fired', 'reassigned', 'quit' and 'other (specify)'. An open-ended question asked for experiences of finding individuals to provide respite/personal assistance services and experiences with staff turnover.

Control in the management of respite/personal assistance services

Based on a review of the literature, the scale for control of respite/personal assistance services included six areas of direction in the management of staff. These areas included: recruitment of individuals; hiring and firing of individuals; training of individuals; deciding what activities are performed by individuals; deciding what days/time services are provided; and determining the wages of individuals providing services. Each item was rated on the amount of control in each area from (1) 'no control' to (5) 'total control'. The alpha reliability of the scale was 0.87.

Unmet service needs

A modified version of the Family Support Index (Heller & Factor 1993; Heller *et al.* 1999) was used to measure the services used, services needed and unmet service needs. This index included a list of 28 types of services. Some examples include: in-home respite, occupational therapy, social or recreational activities, and transportation services. Services used were measured by asking families, 'Do you use this help?' Services needed were measured by asking families, 'Do you need this help?' Each service for each question received a rating of (1) 'yes' or (0) 'no'. Then, unmet service needs were calculated by scoring a rating of one for each service that families indicated that they needed but were not using. These scores were then added for a total measure of unmet service needs for the 28 types of services.

Maladaptive behavior of the individual with a developmental disability

The scale for maladaptive behavior consisted of eight items from the Inventory for Client and Agency Planning (Bruinicks *et al.* 1986). Examples of the items include: 'hurtful to self' and 'destructive to property (breaks or throws things)'. Each item was rated on a five-point frequency scale from (1) 'never/does not exhibit' to (5) 'one or more times an hour'. The alpha reliability of the scale was 0.84.

Health status of the individual with a developmental disability

Health status was measured by a one-item appraisal of health made by the caregiver: 'How would you rate

your relative's overall health at the present time?' Health was rated on a four-point scale (i.e. 'excellent', 'good', 'fair' and 'poor'). A lower score indicated 'better' health and a higher score indicated 'worse' health.

Design

The present study was a cross-sectional design. Families were surveyed at one point in time between October 2000 and May 2001. Hierarchical multiple regression was used to control for variance and test the significance of relationships. This involved entering variables into the model in three blocks based on theory to control for descriptive variables and unmet service needs.

Results

Descriptive characteristics of the sample

First, descriptive characteristics of age, ethnic minority status, and group were compared between the 141 families who returned surveys and the 379 non-respondents. Chi-square analyses indicated no significant differences between respondents and non-respondents on the gender and age of the individual with DD. Participants in the HBSSP were significantly more likely to return surveys [$\chi_{(1)}^2 = 25.91$, $P < 0.01$]. Compared with ethnic minority families, White families were significantly more likely to return surveys [$\chi_{(1)}^2 = 9.88$, $P < 0.01$]. A *t*-test indicated no significant difference in the mean age of the individual with DD between respondents and non-respondents. The results of the comparisons between respondents and non-respondents are shown in Table 1.

Out of the 141 surveys which were returned, 97 of the families were receiving paid respite or personal assistance services. These 97 surveys were used in the particular analyses of this study. Groups of families receiving paid respite/personal assistance and families not receiving these services were also compared on descriptive characteristics. Groups were compared on the age of the caregiver, and the age, maladaptive behaviour and health status of the individual with DD using *t*-tests. Chi-square analyses were used to compare caregiver relationship, marital status, annual income of the household and employment status.

Table 1 Descriptive characteristics of individuals with developmental disability (DD) by groups returning surveys: (SD) standard deviation; and (HBSSP) Home Based Support Services Program

Variable	Returned survey (n = 141)	Did not return survey (n = 379)	Total (n = 520)
Age (years) (mean ± SD)	31.63 ± 8.21	32.03 ± 10.80	31.93 ± 10.18
Gender [n (%)]:			
male	52.5 (74)	53.5 (201)	53.1 (275)
female	47.5 (67)	46.7 (176)	46.9 (243)
Ethnic minority status [n (%)]: ^{**}			
yes	26.7 (36)	42.0 (157)	37.9 (193)
no	73.3 (99)	58.0 (217)	62.1 (316)
HBSSP status [n (%)]: ^{**}			
participant	76.6 (108)	51.9 (196)	58.6 (304)
waiting list	23.4 (33)	48.1 (182)	41.4 (215)

* $P < 0.05$; ** $P < 0.01$.

Chi-square analyses also compared the HBSSP status, gender, ethnic minority status, diagnoses and day programme/employment status of the individual with DD. The only differences between groups using paid respite/personal assistance were in HBSSP status and diagnoses of the individual with DD. Participants in the HBSSP were significantly more likely to use paid respite/personal assistance services [$\chi_{(1)}^2 = 25.24$, $P < 0.01$]. Furthermore, families with individuals with a diagnosis of severe/profound intellectual disability [$\chi_{(1)}^2 = 6.90$, $P < 0.01$] and families with individuals with a diagnosis of autism [$\chi_{(1)}^2 = 5.94$, $P < 0.05$] were significantly more likely to use paid respite/personal assistance services. The results of the comparisons between groups using respite/personal assistance services are shown in Table 2.

Analyses

The present study employed a series of separate hierarchical multiple regressions. There were two main objectives to address the questions of the study. One was to test the associations between the amount of control in the management of respite/personal assistance services and five outcome variables: caregiving burden; caregiving satisfaction; caregiving self-efficacy; service satisfaction; community involvement of individual with DD; and the number of hours of weekly employment of the mother. The second objective was to compare

groups of families based on whether or not they hired other relatives to provide respite/personal assistance services on three outcome variables: service satisfaction; staff turnover; and the community involvement of the individual with DD. In all the regression models, independent variables were entered into the regression in three blocks to control for descriptive characteristics and unmet needs. The first block consisted of four descriptive variables: the age of the caregiver; ethnic minority status; maladaptive behaviour; and the health status of the individual with DD. The second block consisted of unmet service needs. Depending on the objective, the third block consisted of either level of control or the dichotomous variable of whether families had hired other relatives or not to provide respite/personal assistance services.

Zero-order correlations of all the variables used in the analyses are summarized in Table 3. Means, standard deviations and ranges of all variables are summarized in Table 4. Table 4 also shows the descriptive variables by groups of families who hired other relatives or not. The present authors used *t*-tests to compare all the variables between groups, except for ethnic minority status in which a chi-square test compared frequencies of ethnic minorities between groups. There were significant differences between groups on the amount of current control ($P < 0.01$) and the amount of community involvement of individual with a disability ($P < 0.01$). Families who hired

Table 2 Descriptive statistics by groups using respite/personal assistance: (SD) standard deviation; (DD) developmental disability; (HBSSP) Home Based Support Services Program; and (ID) intellectual disability

Variable	Using respite/personal assistance (n = 97)	Not using respite/personal assistance (n = 44)	Total (n = 141)
<i>Caregiver</i>			
Age (years) (mean ± SD)	57.52 ± 10.48	56.53 ± 13.42	57.36 ± 11.48
Relationship to relative [n (%)]:			
mother	80.4 (78)	79.1 (34)	80.0 (112)
father	15.5 (15)	7.0 (3)	12.9 (18)
other	4.1 (4)	14.0 (6)	7.1 (10)
Marital status [n (%)]:			
married	73.1 (68)	66.7 (28)	71.1 (96)
not married	26.9 (25)	33.3 (n4)	28.9 (39)
Annual income of household [n (%)]:			
<\$20 000	32.6 (28)	37.8 (14)	34.1 (42)
\$20 000–40 000	27.9 (24)	40.5 (15)	31.7 (39)
>\$40 000	39.5 (34)	21.6 (8)	34.1 (42)
Employment status [n (%)]:			
employed	52.1 (49)	33.3 (12)	46.9 (61)
not employed	47.9 (45)	66.7 (24)	53.1 (69)
<i>Individual with DD</i>			
Age (years) (mean ± SD)	31.15 ± 8.12	32.66 ± 8.24	31.62 ± 8.16
Maladaptive behavior (mean ± SD)	13.60 ± 5.99	11.70 ± 4.88	13.01 ± 5.72
Health status (mean ± SD)	2.36 ± .78	2.19 ± .86	2.31 ± .81
HBSSP status [n (%)]:**			
participant	88.7 (86)	50.0 (22)	76.6 (108)
waiting list	11.3 (11)	50.0 (22)	23.3 (33)
Gender [n (%)]:			
male	49.5 (48)	59.1 (26)	52.2 (74)
female	50.5 (49)	40.9 (18)	47.5 (67)
Ethnic minority status [n (%)]:			
yes	21.6 (21)	31.8 (14)	25.5 (36)
no	77.3 (75)	68.2 (30)	74.5 (105)
Diagnosis [n (%)]:			
severe/profound ID**	55.7 (54)	31.8 (14)	48.2 (68)
mild/moderate ID	23.7 (23)	38.6 (17)	28.4 (40)
autism*	20.6 (20)	4.5 (2)	15.6 (22)
cerebral palsy	24.7 (24)	27.3 (12)	25.5 (36)
other	21.6 (21)	9.1 (4)	17.7 (25)
Day programme or employed [n (%)]:			
yes	68.8 (66)	82.9 (34)	73.0 (100)
no	31.3 (30)	17.1 (7)	27.0 (37)

* $P < 0.05$; ** $P < 0.01$.

other relatives had more control and the individual with a disability had a higher level of community involvement.

In the regressions, the tolerance values of the independent variables did not indicate significant levels

of multicollinearity. Other assumptions for the use of multiple regression were also met. List-wise deletion of cases was used when missing data were present, except for the variable of staff turnover. Seven cases were missing data on staff turnover. After ensuring

Table 3 Zero-order correlations between variables used in analyses: (DD) developmental disability

Variable	Variable													
	1	2	3	4	5	6	7	8	9	10	11	12	13	14
(1) Caregiver age	1.00	0.10	-0.20*	0.13	-0.07	-0.02	0.06	0.13	-0.03	-0.08	0.08	-0.01	-0.40**	0.01
(2) Ethnic minority		1.00	-0.20	-0.18	0.21*	-0.10	-0.10	-0.05	0.09	0.20*	0.04	-0.04	-0.14	0.01
(3) Maladaptive behaviour			1.00	0.03	0.24*	0.05	0.02	-0.17	-0.10	0.23*	-0.23*	0.04	0.03	0.07
(4) Health status (DD)†				1.00	-0.10	-0.01	0.02	-0.19	-0.13	0.10	-0.12	-0.25*	0.05	0.17
(5) Unmet needs					1.00	-0.22*	-0.19	-0.44**	0.04	0.18	-0.10	-0.07	-0.04	0.14
(6) Current control						1.00	0.29**	0.32**	-0.03	-0.11	-0.01	0.27**	0.20	-0.22*
(7) Hired relatives							1.00	0.11	0.01	0.02	-0.12	0.26**	0.02	-0.07
(8) Service satisfaction								1.00	0.18	-0.29**	0.17	0.30**	0.00	-0.42**
(9) Caregiving satisfaction									1.00	0.08	0.48**	-0.09	0.12	-0.09
(10) Caregiving burden										1.00	0.29**	-0.18	0.10	0.20
(11) Caregiving self-efficacy											1.00	0.03	0.00	-0.07
(12) Community involvement												1.00	0.18	0.00
(13) Employment of mothers													1.00	0.10
(14) Staff turnover														1.00

* $P < 0.05$; ** $P < 0.01$.

†A lower score indicates a rating of better health.

Table 4 Descriptive statistics of variables by groups of families hiring other relatives: (SD) standard deviation; and (DD) developmental disability

Variable	Hired other relatives (n = 51)			Did not hire other relatives (n = 46)			Overall (n = 97)		
	Mean	SD	Range	Mean	SD	Range	Mean	SD	Range
Caregiver age (years)	58.06	10.06	37–77	56.91	11.01	39–79	57.52	10.48	37–79
Maladaptive behaviour	13.72	5.74	1–4	13.43	6.34	7–31	13.58	6.00	4–31
Health status (DD)	2.37	0.75	1–4	2.35	0.82	1–4	2.36	0.78	1–4
Unmet needs	3.65	4.02	0–13	5.15	4.02	0–14	4.36	4.07	0–14
Level of control **	25.78	4.48	12–30	22.33	6.94	6–30	24.14	6.01	6–30
Service satisfaction	30.12	6.86	10–40	28.52	7.56	12–39	29.36	7.20	10–40
Caregiving burden	25.63	4.57	15–34	25.43	5.61	16–36	25.54	5.07	15–36
Caregiving satisfaction	16.31	2.96	8–20	16.24	2.65	6–20	16.28	2.81	8–20
Caregiving self-efficacy	17.84	2.89	8–24	18.57	3.09	9–24	18.19	2.99	8–24
Community involvement **	21.60	6.13	8–35	18.20	6.45	8–33	19.97	6.48	8–35
Employment of mother (h week ⁻¹) [†]	15.49	19.22	0–65	14.60	19.19	0–53	15.07	19.10	0–65
Staff turnover (number year ⁻¹) [‡]	0.79	1.40	0–5	0.98	1.46	0–5	0.88	1.42	0–5
Ethnic minority status [% (n)]	17.6 (9)	–	–	26.1 (12)	–	–	21.6 (21)	–	–

** $P < 0.01$.

[†]The number of cases was lower because only surveys where mother was a caregiver were used (91 cases overall).

[‡]The number of cases was lower because seven cases were missing data on staff turnover. A mean substitution (0.88) was used to impute data in seven cases for regressions.

that the data on staff turnover were missing completely at random, mean substitution was used to impute data for the seven cases. For all regressions no more than two cases were deleted because of missing data.

Control in management of respite/personal assistance services

The results of the regressions of level of control in management of respite/personal assistance services are summarized in Table 5. With regard to caregiving appraisals (i.e. burden, satisfaction and self-efficacy), a higher level of maladaptive behavior was significantly associated with higher caregiving self-efficacy in the first block only ($P < 0.05$). Unmet needs, in the second block and final model, and level of control, in the final model, were not significantly related to any caregiving appraisals.

With regard to service satisfaction, higher rating of health status of individual with DD was significantly associated with higher service satisfaction in the first

block ($P < 0.05$), and remained significant in the second block ($P < 0.01$) and final model ($P < 0.01$). The fewer unmet needs variable was significantly associated with higher service satisfaction in the second block ($P < 0.01$) and final model ($P < 0.01$). In the final model, higher level of control was significantly associated with higher service satisfaction ($P < 0.05$). The final model was statistically significant ($P < 0.01$) and accounted for 27% of the variance in service satisfaction.

With regard to community involvement of individual with DD, a higher rating of health status of individual with DD was significantly associated with more community involvement in the first block ($P < 0.01$), and remained significant in the second block ($P < 0.01$) and final model ($P < 0.05$). The unmet needs variable was not related to community involvement in the second block or final model. In the final model, higher level of control was significantly associated with more community involvement ($P < 0.05$). The final model was statistically significant ($P < 0.05$), and accounted for 9% of the variance in community involvement.

Table 5 Summary of hierarchical regressions of current control on outcome variables: (SE) standard error; and (DD) developmental disability

Variable	Caregiving burden		Caregiving satisfaction		Caregiving self-efficacy		Service satisfaction		Community involvement		Employment of mothers	
	β	SE	β	SE	β	SE	β	SE	β	SE	β	SE
<i>Block 1: Descriptive</i>												
Caregiver age	-0.03	0.05	-0.05	0.03	0.05	0.03	0.13	0.06	0.04	0.06	-0.45**	0.17
Ethnic minority	-0.19	1.29	0.05	0.75	0.02	0.79	-0.01	1.64	-0.05	1.68	-0.10	4.67
Maladaptive behaviour	0.15	0.09	-0.11	0.05	-0.21	0.06	-0.05	0.12	0.04	0.12	-0.11	0.33
Health status (DD) [†] 1	0.09	0.66	-0.10	0.38	-0.14	0.40	-0.24*	0.84	-0.27*	0.86	0.10	2.37
<i>Block 2: Unmet needs</i>												
Unmet needs	0.18	0.13	0.05	0.08	-0.06	0.08	-0.39**	0.17	-0.05	0.17	0.03	0.47
<i>Block 3: Control</i>												
Level of control	-0.10	0.09	-0.01	0.05	0.01	0.05	0.23*	0.11	0.25*	0.11	0.22*	0.30
Adjusted R ²	0.07*	-	-0.03	-	0.01	-	0.27**	-	0.09*	-	0.20**	-
R ² change (blocks 2-3)	0.01	-	0.00	-	0.00	-	0.05*	-	0.06*	-	0.05*	-

* $P < 0.05$; ** $P < 0.01$.[†]A lower score indicates a rating of better health.

With regard to the employment of mothers, younger caregiver age was significantly associated with more hours of employment in the first block ($P < 0.01$), and remained significant in the second block ($P < 0.01$) and final model ($P < 0.01$). The unmet needs variable was not related to the employment of mothers in the second block or final model. In the final model, higher level of control was significantly associated with more employment of mothers ($P < 0.05$). The final model was statistically significant ($P < 0.01$) and accounted for 20% of the variance in employment.

Hiring of other relatives

The results of the regressions of hiring other relatives are summarized in Table 6. With regard to service satisfaction, a higher rating of health status of individual with DD was significantly associated with higher service satisfaction in the first block ($P < 0.05$), and remained significant in the second block ($P < 0.01$) and final model ($P < 0.05$). The fewer unmet needs variable was significantly associated with higher service satisfaction in the second block ($P < 0.01$) and final model ($P < 0.01$). In the final model, hiring other relatives was not significantly related to service satisfaction.

With regard to staff turnover, no variables were significantly related to staff turnover in any of the blocks. The final model was not significant. With regard to the community involvement of individual with DD, higher rating of the health status of the individual with DD was significantly associated with more community involvement in the first block ($P < 0.01$), and remained significant in the second block ($P < 0.01$) and final model ($P < 0.01$). The unmet needs variable was not related to community involvement in the second block or the final model. In the final model, hiring other relatives was significantly associated with more community involvement ($P < 0.05$). The final model was statistically significant ($P < 0.05$) and accounted for 6% of the variance in community involvement.

Descriptive data involving respite/personal assistance

Over half of the families (52.6%) hired other relatives to provide respite/personal assistance services, 36.1% had hired friends, 7.2% had hired neighbours, 35.1% had hired agency staff and 19.6% had hired other individuals. Families recruited other individuals through schools, churches, day programmes, recreational programmes, newspaper advertisements and

Table 6 Summary of hierarchical regressions of hired relatives on outcome variables: (SE) standard error; and (DD) developmental disability

Variable	Service satisfaction		Staff turnover		Community involvement	
	β	SE	β	SE	β	SE
<i>Block 1: Descriptive</i>						
Caregiver age	0.13	0.07	0.00	0.01	0.02	0.06
Ethnic minority	-0.02	1.70	0.02	0.37	-0.05	1.65
Maladaptive behaviour	-0.03	0.12	0.04	0.03	0.05	0.12
Health status (DD) [†]	-0.25*	0.87	0.18	0.19	-0.28**	0.84
<i>Block 2: Unmet needs</i>						
Unmet needs	-0.44**	0.18	0.13	0.04	-0.06	0.17
<i>Block 3: Hired relatives</i>						
Hired relatives	0.02	1.34	-0.04	0.29	0.26*	1.30
Adjusted R ²	0.22**	-	-0.02	-	0.09*	-
R ² change (blocks 2-3)	0.00	-	0.00	-	0.06*	-

* $P < 0.05$; ** $P < 0.01$.

[†]A lower score indicates a rating of better health.

'word of mouth'. Thirty-four of the 97 families had experienced staff turnover in the past year. For families who experienced staff turnover, this ranged from one to five staff in the past year. Exploring reasons for staff turnover, 52.3% of families indicated that staff quit, 14.7% said that they were re-assigned 8.8% reported that they were fired.

Answers to open-ended questions about staff turnover and staff recruitment were explored. Forty-six per cent of families indicated difficulty with staff recruitment. For example, one family member said, 'Now I have money to pay help but no one to do it!' Several said it is 'next to impossible' to find good staff. Two investigators coded responses having to do with inability to find quality staff to provide services; inter-rater reliability was 97.3%. Themes surrounding the difficulty of finding staff included: the low wages paid to the staff; the poor qualifications of staff/reliability and trust; the difficulty of finding staff to fill certain part-time hours; the difficulty of finding staff to work with individuals with severe disabilities; and the difficulty of finding staff in rural areas. The responses seemed to indicate that staff recruitment rather than staff turnover was a more pressing issue. Some families indicated that, if they did not rely on relatives or friends, they would not be able to find staff. Other families commented on long-term and close relationships which they developed with the staff they hired through the programme.

Discussion

Consumer-directed family support targets the family unit and allows families to have greater control and flexibility in designing supports to meet their needs. While each family's needs are unique, respite and personal assistance services are frequently sought services. Consumer-directed family support provides families with opportunities to hire and manage staff. The present study supports the idea that benefits exist for both caregivers and individuals with disabilities when families are given greater control in managing their respite and personal assistance services.

Like other studies of consumer-directed personal assistance programmes, primarily for individuals with physical disabilities (Prince *et al.* 1995; Adams & Beatty 1998; Beatty *et al.* 1998), families with more

control were more satisfied with services. More control was also related to increased employment of mothers. Through control of such areas as hiring and scheduling, mothers appear to tailor respite to meet specific needs, allowing increased employment. Employment may not be directly related to perceived caregiving appraisals. Consistent with previous research (Heller *et al.* 1997), the present study found no direct associations between employment and caregiving burden. However, research has supported economic impacts on families related to the decreased employment of mothers providing care and increased out-of-pocket costs incurred by families for disability-related services (Fujiura 1998).

In the present study, increased control was associated with more community involvement of individuals with DD. This might be explained by families hiring more qualified individuals or, as indicated in the present study, families hiring other relatives. It is also likely that families direct staff to provide transportation and support in community activities. The present study did not explore the community involvement of caregivers or the employment of people with DD. However, these two outcomes are recommended for exploration in future studies. In the previous study of the HBSSP (Heller *et al.* 1999), individuals with DD who participated in the programme earned slightly higher wages than individuals on the waiting list. Future research might explore satisfaction with day programme/employment or extent of community employment.

It was somewhat surprising that caregiving appraisals were not significantly related to control. Assuming more responsibility in staff management did not impact ratings of caregiver burden. In the previous study of the HBSSP (Heller *et al.* 1999), family caregivers in the programme reported higher self-efficacy than caregivers on the waiting list. Perhaps it is the combination of other services and supports, in addition to just respite/personal assistance services, that contributed to this difference.

Future research might also better explore health-related outcomes for both caregivers and individuals with DD. In previous studies on consumer-directed programmes, there were positive impacts on health of people with disabilities (Prince *et al.* 1995; Adams & Beatty 1998). Benefits might also occur for family caregivers, especially ageing caregivers who might be experiencing age-related health issues.

The majority of families surveyed (52.6%) had hired other relatives to provide respite and personal assistance services. HBSSP regulations permit families to hire other relatives living outside the immediate home. Some exceptions are made to this regulation if no other staff can be located to provide services. In addition to other relatives, over one-third of families (36.1%) hired friends and 7.2% hired neighbours. This is consistent with other studies of consumer-directed personal assistance programmes for people with physical disabilities, indicating high rates of hiring previously known individuals (Doty *et al.* 1996; Tilly *et al.* 2000). This pattern is also consistent with the study by Knoll & Bedford (1989), which indicated that family preferences were for respite provided by family, friends and neighbours. In the present study, only 35.1% of families were using respite/personal assistance services provided through agency staff. Families indicated that they recruited non-agency staff through schools, churches, day programmes, recreation programmes, placing job advertisements in newspapers and 'word of mouth'.

Little, if any, research has explored outcomes associated with hiring other family members to provide services. While hiring other relatives was not significantly related to service satisfaction or staff turnover in the present study, it was associated with more community involvement of individuals with disabilities. Perhaps other relatives are more aware of the interests, desires and needs of their family members with DD. It may also be that caregivers are more trusting of other relatives to engage in community activities.

Staff turnover was explored more closely. Only 35% of the families experienced any change in staff during the previous year. When staff turnover occurred, the most common reason was staff quitting (52.3%). Other reasons included staff being re-assigned (14.7%), primarily when using agency staff, and staff being fired (8.8%). Having increased control in management of respite and personal assistance services seemed to improve staff continuity. Increased control was significantly correlated with less staff turnover ($r = -0.22$, $P < 0.05$).

Study limitations

Since families in the HBSSP were significantly more likely to receive respite/personal assistance services

(Heller *et al.* 1999) and participants in the HBSSP were more likely to return surveys, the sample consisted of considerably more families participating in the HBSSP than on the waiting list. There were not enough families in the sample who were on the waiting list for the HBSSP but receiving respite/personal assistance to compare groups based on participation in the programme.

Another limitation to the present study involves some of the measures used. Caution should be given to the low alpha reliabilities of two measures: caregiving self-efficacy and the community involvement of the individual with a disability. In a previous study (Heller & Factor 1991), an expanded 12-item scale of community involvement resulted in a higher alpha reliability and could be used in future research. The variable of unmet needs measured whether or not families had unmet needs for a particular service, but not the extent of unmet needs. In the previous study of the HBSSP (Heller *et al.* 1999), unmet needs proved to be a better measure than total services used and theoretically is more sensitive to diversity among families. However, both studies did not account for families receiving some respite/personal assistance, but still having unmet needs for more. Future research should incorporate a measure of additional needs for respite and personal assistance services. Future research might also consider a measure of satisfaction more specific to the delivery of respite and personal assistance services similar to those used in previous studies (Nosek *et al.* 1995; Beatty *et al.* 1998).

Finally, future research should include the perspectives of individuals with DD. Given the level of impairment required for eligibility in the HBSSP, this was difficult to directly explore with the methods of the present study. However, important questions remain for future research: How much control do individuals with DD have in hiring and directing staff? How do individuals with disabilities feel about hiring other relatives?

Policy implications

Consumer-directed family support is not a new concept. The first consumer-directed family support programme in the USA existed over 200 years ago. In 1793, prior to opening their first institution, the state of Kentucky 'granted an allowance of \$50 per annum

to each needy family afflicted with the burden of a feeble-minded child' (Fernald 1917). With the rise of institutional models, superintendents of institutions adamantly opposed the cash subsidy programme. (Wolfensberger 1975). Superintendent Stewart compared the law to a scalp law for foxes where every fox scalp was rewarded with a \$2.50 bounty until people took to raising foxes. He expressed his bias, 'Now there is premium offered for idiots . . . The system is heinous' (Wolfensberger 1975). The law was subsequently repealed. Money was allocated to the construction of institutions while the overwhelming majority of families continued to support their relatives with DD at home and in the community.

Family support has historically not received adequate funding, and families and individuals with disabilities have received little control of existing resources. However, within the past 10 years, funding has gradually increased within the USA and approximately half the states currently offer some type of cash-subsidy family support programme (Braddock *et al.* 2000). The Illinois HBSSP recently began utilizing funding from the Medicaid Home and Community Based Services Waiver programme, which will hopefully result in expansion and waiting list reduction and serve as a model for expansion in other states.

As consumer-directed services expand internationally, research on outcomes and comparisons of programmes is needed to guide policy development. Hiring other relatives to perform services is likely to be a controversial issue. In fact, exploration of this in the present study was prompted by proposed changes to the Illinois HBSSP which would have limited flexibility in hiring relatives. Similar to the rhetoric in the Kentucky programme over 200 years ago, policy makers may view caregiving as a moral duty of the family, precluding the hiring of other family members. However, for some families and individuals with disabilities, this may be preferred and necessary in circumstances where staff recruitment is difficult. The present study supports an association between hiring other relatives and increased community inclusion of people with disabilities. Furthermore, it highlights the needs for additional research on preferences and outcomes surrounding this issue.

The present study supports the idea that there are benefits for both family caregivers and individuals with DD with increased control in managing per-

sonal assistance and respite services. 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 the increased employment of mothers. While there are individual considerations in the amount of control desired by people with disabilities and families, the present study suggests that policies should allow flexibility and consumer direction when desired. Consumer direction is fundamentally based on control of resources and purchase of services. The present study supports that when families are given more control in this process, becoming true 'consumers' of services, they are more satisfied.

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