

## Consumer-Directed Supports: Economic, Health, and Social Outcomes for Families

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### Abstract

The impact of a consumer-directed support program on family caregivers of adults with developmental disabilities was explored. Economic, health, and social outcomes were compared between families in the program and families on the waiting list for the program. Caregivers of adults in the program reported fewer out-of-pocket disability expenses, greater access to health care, engagement in more social activities, and greater leisure satisfaction. There also appeared to be greater impacts on lower income families; these caregivers reported better mental health and access to health care than did similar caregivers on the waiting list.

Consumer-directed supports have grown rapidly within the United States and many other industrialized countries over the last decade (Lundsgaard, 2005; Tilly, Wiener, & Cuellar, 2000; Tritz, 2005). Although a continuum of models exists, a common goal of consumer direction is to shift more authority in the design and direction of services to recipients. In its purest and most empowering form, consumer direction provides control of financial resources through cash allowances or individualized budgets. Although there are deep historical roots of consumer direction in the United States, recent initiatives, such as the Robert Wood Johnson Cash and Counseling Demonstrations and the New Freedom Initiative System Change Grants, have catalyzed the growth of many new programs.

Consumer direction is most often discussed within a disability rights framework (DeJong, Batavia, & McKnew, 1992), yet there are also important connections with supporting families (Simon-Rusinowitz, Mahoney, Loughlin, & Sadler, 2005). Over 80% of long-term care services are provided informally, predominately through female family members (Doty, Stone, Jackson, & Drabek, 2001). Furthermore, over 75% of adults with developmental disabilities live at home with family (Fujiura, 1998). The predominance of informal family supports and the limited amount of financial resources provided through most consumer-directed programs seem to drive connections.

First, some consumer-directed programs have specifically targeted families. This has been most common within the developmental disabilities and aging service systems. Within the developmental disabilities system, programs exist in 22 states that provide cash allowances or individualized budgets to families with relatives living at home (Rizzolo, Hemp, & Braddock, 2006). Within the aging system, the National Family Caregiver Support Program, authorized under the Older Americans Act, has been instrumental in developing consumer-directed supports that specifically target the needs of family caregivers (Feinberg & Newman, 2005).

A second way consumer direction is connected with family support concerns the practice of hiring family members to provide paid services. In a survey of consumer-directed programs in the United States, Doty and Flanagan (2001) identified 139 programs and reported that 80% permitted hiring family members to provide services. In perhaps the largest and most established program in the country, California's In Home Supportive Services program, nearly half of all paid employees are family members (Benjamin, Franke, Matthias, & Park, 1999). Furthermore, in the Cash and Counseling Demonstrations, 40.7% of paid assistants in Florida, 50.3% in New Jersey, and 66.8% in Arkansas were family members (Cash & Counseling Interactive Data Tool, 2006). However, there has been little research

on potential impacts of these programs on family caregivers (National Council on Disability, 2004).

Relatively few researchers have empirically evaluated outcomes of consumer-directed supports. Most studies have been focused on personal assistance services for individuals with physical disabilities, and investigators have compared consumer-directed and agency-directed models. Many researchers have identified greater service satisfaction with consumer direction (Beatty, Richmond, Tepper, & DeJong, 1998; Benjamin & Matthias, 2001; Benjamin, Matthias, & Franke, 2000; Benjamin et al., 1999; Doty, Kasper, & Litvak, 1996). Several authors have also found that individuals in consumer-directed programs have fewer unmet service needs (Benjamin & Matthias, 2001; Benjamin et al., 2000; Foster, Brown, Phillips, Schore, & Carlson, 2003). In general, researchers have reported no significant outcomes concerning health status (Foster et al., 2003) or safety (Beatty et al., 1998; Foster et al., 2003). However, some have reported greater feelings of empowerment (Beatty et al., 1998) and greater perceived quality of life for individuals with disabilities in consumer-directed programs (Foster et al., 2003).

Very little research has been conducted to explore consumer direction and individuals with developmental disabilities. Some investigators have found potential quality of life outcomes (Bradley et al., 2001; Conroy, Fullerton, Brown, & Garrow, 2002; Conroy & Yuskas, 1997). Results of studies of consumer-directed programs for families with minor children with developmental disabilities have supported outcomes of decreased caregiver stress, decreased financial stress, enhanced caregiver life satisfaction, increased service satisfaction, and decreased anticipation of needing out-of-home placement (Herman, 1991, 1994; Meyers & Marcenko, 1989; Zimmerman, 1984).

One of the few lines of research focused on consumer-direction of adults with developmental disabilities and their families has been generated from the study of the Illinois Home Based Support Services Program (Caldwell & Heller, 2003; Heller & Caldwell, 2005; Heller, Miller, & Hsieh, 1999). Research results have supported many positive outcomes of this program, including greater service satisfaction and fewer unmet service needs for families as well as greater employment, greater community participation, and fewer placements of adults with developmental disabilities in nursing homes and

other institutions (Caldwell & Heller, 2003; Heller & Caldwell, 2005; Heller et al., 1999).

Previous researchers, however, have not fully explored potential economic, health, and social impacts of consumer-directed supports on family caregivers. Furthermore, investigators have not examined the extent to which there may be specific benefits for lower income families. Families with relatives who have developmental disabilities are more likely than other families to live in poverty (Fujiura, 1998). Study findings have indicated that mothers of individuals with developmental disabilities have lower rates of employment (Parish, Seltzer, Greenberg, & Floyd, 2004; Seltzer, Greenberg, Floyd, Petee, & Hong, 2001; Shearn & Todd, 2000). In addition, families with relatives who have developmental disabilities incur many out-of-pocket disability-related expenses (Fujiura, Roccoforte, & Braddock, 1994). Participation in a consumer-directed family support program might increase employment and reduce out-of-pocket expenses.

In general, the health of caregivers of adults with developmental disabilities has been found to be similar to that of the general population (Chen, Ryan-Henry, Heller, & Chen, 2001; Seltzer et al., 2001). However, a number of contextual factors have been associated with psychological well-being, such as the extent of social support networks, presence of maladaptive behaviors, socioeconomic status, and minority cultural context (Greenberg, Seltzer, Krauss, & Kim, 1997; Heller, Hsieh, & Rowitz, 2000; Hong, Seltzer, & Krauss, 2001; Magaña, Seltzer, & Krauss, 2004; Orsmond, Seltzer, Krauss, & Hong, 2003). The impact of services, particularly consumer-directed supports, on the health status of caregivers has not been fully explored. Furthermore, few, if any, researchers have investigated access to health care for this population. Finally, although previous research has demonstrated increased community participation of individuals with developmental disabilities through consumer-directed supports, little attention has been paid to social participation and leisure of caregivers. In their longitudinal study, Seltzer and colleagues (2001) reported lower rates of social participation of mothers over the lifespan. Control over services, particularly respite, could benefit social and leisure outcomes for caregivers.

Therefore, the following research questions were addressed in the current study: (a) Does participation in a consumer-directed support program improve economic outcomes (greater employment

and fewer out-of-pocket disability expenses), health outcomes (better physical health, mental health, and access to health care), and social outcomes (greater social participation and leisure satisfaction) for family caregivers? and (b) Are there greater benefits for lower income families on these outcomes?

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## Method

### *Illinois Home Based Support Services Program*

The Illinois Home Based Support Services Program (HBSSP) originated in the late 1980s as a small, state-funded demonstration project. Initially, the program targeted families with adult relatives (ages 18 and older) living at home who had severe developmental disabilities. In 2002, the program was converted to obtain federal funding through a Medicaid Home and Community-Based Services Waiver. Eligibility restrictions concerning severity of developmental disability were removed, opening the program up to the broader population of adults qualifying for the Waiver.

Adults with developmental disabilities and their families in the program are provided with a monthly budget, set at a rate of three times Supplemental Security Income (SSI). During the current study period, the budget amount was approximately \$1,656 a month. A plan is developed with the assistance of a service facilitator. Decisions about what services are purchased are made jointly by individuals with disabilities and their families. Given the severity of disability of many individuals in the program, the majority of families seem to make decisions based on their familiarity with preferences and desires of their relative. In other situations, individuals with disabilities are more actively involved in communicating their decisions during planning meetings. The state serves as the fiscal agent and makes payments to providers. Frequently purchased services typically include respite, personal assistance services, home modifications, assistive technology, employment services, therapies, and transportation.

However, since the conversion of the program to Medicaid, more restrictions have been placed on spending. For example, families have lost the flexibility to use money for most recreational services and additional therapies, medical expenses, and adaptive equipment outside of traditional Medicaid coverage. The state also decided to require families

to pay for sheltered workshop services from the budget. Originally, primary family caregivers were discouraged from becoming paid caregivers through the program. However, since the Medicaid conversion, primary family caregivers have been permitted to be hired. Approximately half of families have billed for some hours of services provided by family caregivers. It appears that some families may have done this to bypass restrictions on spending and retain the original flexibility (Caldwell, 2005). However, this payment is taxable income for caregivers and is at their disposal to use for their own and broader family needs.

An extensive waiting list for the program exists. Selection is based on a random lottery from the applicant pool as additional money is allocated by the state. In other words, families who have been waiting 10 years have the same chance as families who recently applied. This randomization has made the program ideal for research. However, there are a few caveats to the random selection. First, during the original pilot phase of the program, families were randomly selected by region of the state to ensure state-wideness. This negatively impacted minority families concentrated in populated urban areas. Selection by region no longer occurs. However, there remains an overrepresentation of minority families on the waiting list. Second, due to tight state budgets, there has been no significant expansion of the program since 2002. Therefore, there are many younger families in search of services who have joined the waiting list. Also, changes in program eligibility have contributed to more individuals with higher functional abilities on the waiting list.

### *Sample*

The Illinois Department of Human Services, Division of Developmental Disabilities, randomly selected 700 families from the total of 1,436 families in the HBSSP and 700 families from the total of 1,632 families on the waiting list for the program. Surveys were mailed to families with postage-paid return envelopes in December 2004. Primary family caregivers of adults with developmental disabilities were asked to complete and return the surveys. All measures were completed by family caregivers. A reminder post card was mailed to families who had not responded within 2 months.

A total of 294 surveys were returned (209 families in the HBSSP and 85 families on the waiting list); 117 surveys were returned to sender due to incorrect addresses, 34 individuals with disabilities

had moved into a residential setting or were no longer eligible for the program, and 3 individuals with disabilities had passed away. This reduced the recruitment sample to 692 families in the HBSSP and 554 families on the waiting list. The corrected overall response rate was 23.6%. The response rate for families in the HBSSP was 30.2% and the response rate for families on the waiting list was 15.3%. Chi-square and independent sample *t* tests were used to compare respondents with nonrespondents on available demographic variables (see Table I). Families with younger relatives with developmental disabilities,  $t(1244) = -6.23, p < .05$ , families with male relatives with disabilities,  $\chi^2(1, N = 1241) = 4.62, p < .05$ , and families in the HBSSP,  $t(1244) = 2.40, p < .01$ , were significantly more likely to respond.

**Measures**

*Demographic measures: Household income.* Household income was measured with eight categories: under \$10,000, \$10,000-\$19,999, \$20,000-\$29,999, \$30,000-\$39,999, \$40,000-\$49,999, \$50,000-\$59,999, \$60,000-\$69,999, and \$70,000+.

*Level of functioning of individuals with developmental disabilities.* Level of functioning was measured with seven Activities of Daily Living (ADLs) and 8 Instrumental Activities of Daily Living (IADLs). This scale was completed by caregivers. Each activity

was rated on needs for assistance: 1 (*total assistance*), 2 (*some assistance*), and 3 (*no assistance*). Activity scores were totaled for a functional measure of disability, with higher scores indicating less functional needs. The alpha reliability of the scale was .93.

*Economic outcomes: Out-of-pocket disability expenses.* A modified version of a survey by Fujiura, Roccoforte, and Braddock (1994) was used to measure out-of-pocket disability-related expenses in eight categories: Transportation, Respite and Personal Assistance Services, Recreation/Leisure Services, Medical and Dental Services, Medication or Other Related Expenses, Therapies, Adaptive Devices or Home Modifications, and Miscellaneous.

*Employment.* Caregiver employment was measured by number of hours of employment per week.

*Health outcomes: Physical and mental health.* The SF-36, Version 1, was used to measure physical and mental health (Ware & Kosinski, 2001; Ware, Kosinski, & Gandek, 2000). This scale is a self-report measure of health that was completed by caregivers. Norm-based scoring with 1998 population data, was employed, which aids with the interpretation and comparability of scores. Higher scores indicate better health. A score of 50 represents the general population norm, with standard deviations (SDs) of 10. The alpha reliability of the physical health scale was .93 and the alpha reliability of the mental health scale was .88.

**Table 1** Demographics of Adults With Developmental Disabilities by Family Response

Variable	Responded ( <i>n</i> = 294)		Did not respond ( <i>n</i> = 952)		Total ( <i>N</i> = 1246)	
	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>
Age, mean ( <i>SD</i> )	31.13 (10.21)		32.99 (12.01)		32.55 (11.64)	
Gender*(%)						
Female	39.1	115	46.3	438	44.6	553
Male	60.9	179	53.7	509	55.4	688
Ethnicity (%)						
African American	21.6	63	26.1	247	25.0	310
Hispanic/Latino	11.0	32	9.5	90	9.9	122
White/Caucasian	63.6	185	59.5	563	60.4	748
Other	3.8	11	5.0	47	4.7	58
Group**						
HBSSP <sup>a</sup>	71.7	209	50.7	483	55.5	692
Waiting list	28.9	85	49.3	469	44.5	554

<sup>a</sup>Home Based Support Services Program.

\**p* < .05. \*\**p* < .01.

*Health care access.* A six-item scale was developed to measure health care access. The scale was modeled on items used by Hanson, Neuman, Dumin, and Kasper (2003) in a study of cost-related barriers to health care access. The first item covered whether individuals had health insurance. For Items 2 through 6, caregivers were asked whether costs had prevented them from seeing a doctor and obtaining vision care, dental care, prescription drugs, and mental health care during the past year. Each item was answered yes or no. Items were totaled so that a higher score indicates better access to health care. The alpha reliability of the scale was .81.

*Social outcomes: Social activities.* Social activities were measured by the number of social/leisure organizations caregivers were active within (such as social and athletic clubs, unions, advocacy groups, and churches). Caregivers could list up to five organizations (Heller, Rowitz, & Farber, 1992).

*Leisure satisfaction.* This scale consisted of 12 items from the Psychological, Social, and Relaxation domains of the Leisure Satisfaction Scale (Beard & Ragheb, 1980). Examples of items included: "My leisure activities help me to relax" and "I have social interaction with others through leisure activities." Items were rated on a 5-point scale from *almost never true* to *almost always true*, with a higher score indicating higher leisure satisfaction. The alpha reliability of the scale was .88.

### Analyses

First, families in the program and families on the waiting list were compared on demographic measures to explore differences between groups. Hierarchical multiple regression analyses were then performed to compare groups (HBSSP and waiting list) and group by household income interactions after controlling for demographic variables.

## Results

Demographic variables for the sample are presented in Table 2. Chi-square and independent *t* tests were performed in order to compare the families in the program with families on the waiting list. There were several significant differences between groups. First, caregivers in the program were significantly older than those on the waiting list,  $t(266) = -4.12, p < .01$ . Second, there were significantly more African American caregivers on the waiting list than in the program,  $\chi^2(1, N = 294) = 5.97, p < .05$ . Third, there were differences con-

cerning level of functioning and diagnoses. Adults with disabilities in the program had significantly lower levels of functioning than did individuals on the waiting list,  $t(289) = 2.57, p < .05$ . Similarly, there were more individuals with diagnoses of severe/profound intellectual disabilities in the program,  $\chi^2(1, N = 291) = 14.51, p < .01$ .

Hierarchical multiple regression analyses were performed in order to control for the following demographic variables: caregiver age, ethnic minority status (which was dichotomized as 1 = minority and 0 = White/Caucasian), level of functioning of individual with developmental disabilities, and household income. In all regression analyses, the first block consisted of these demographic variables; the second block, group (1 = HBSSP and 0 = waiting list), and the third block consisted of the Group  $\times$  Household Income interaction. Missing data existed, primarily on household income (20 cases) and caregiver age (26 cases). However, testing indicated that data were not missing completely at random. Therefore, rather than imputing data, I performed list-wise removal of cases with missing data. Assumptions for the use of multiple regression analyses were tested. All tolerance values were less than .1. This indicates no significant difficulties with multicollinearity, which refers to the linear intercorrelation or distinctness of variables in the equation.

Table 3 contains a summary of the hierarchical regressions on economic outcomes: out-of-pocket disability-related expenses and caregiver employment. After controlling for demographic variables, I found that families in the program had significantly fewer out-of-pocket expenses than did families on the waiting list. The Group  $\times$  Income interaction was not significant. The final model was statistically significant and accounted for approximately 10% of the variance, with about 2% attributed to being in the program. Older caregiver age was significantly associated with lower employment, and higher household income was significantly associated with higher employment. However, there was no significant difference between groups on caregiver employment. Furthermore, the Group  $\times$  Income interaction was not significant.

Table 4 contains a summary of the hierarchical regressions on caregiver health outcomes: physical health, mental health, and health care access. Higher caregiver age was significantly associated with poorer physical health. However, there was no significant difference between groups on caregiver physical health nor was the Group  $\times$  Income in-

**Table 2** Demographics of Home Based Support Services Program (HBSSP) and Waiting List Groups

Variable	HBSSP (n = 209)		Waiting list (n = 85)		Total (N = 294)	
	% or Mean (SD)	n	% or Mean (SD)	n	% or Mean (SD)	n
<b>Caregiver</b>						
Age, **Mean (SD)	58.31 (9.93)		52.67 (10.10)		56.77 (10.27)	
Gender (%)						
Female	85.6	179	91.8	78	87.4	257
Male	14.4	30	8.2	7	12.6	37
Relationship to relative (%)						
Mother	79.9	167	81.2	69	80.3	236
Father	14.4	30	8.2	7	12.6	37
Sibling	2.4	5	5.9	5	3.4	10
Other	3.3	7	4.7	4	3.7	11
<b>Race/Ethnicity</b>						
African American**	16.7	35	29.4	25	20.4	60
Asian	2.4	5	3.5	3	2.7	8
Hispanic/Latino	11.0	23	7.1	6	9.9	29
White/Caucasian	69.9	146	60.0	51	67.0	197
<b>Household annual income (%)</b>						
Under \$20,000	23.6	46	22.8	18	23.4	64
\$20,000-\$39,999	37.9	74	39.2	31	38.3	105
\$40,000-\$59,999	24.6	48	21.5	17	23.7	65
\$60,000 and over	13.8	27	16.5	13	14.6	40
Individual with DD <sup>a</sup>						
Age, Mean (SD)	30.94 (9.29)		28.63 (12.33)		30.27 (10.30)	
Gender (%)						
Female	37.3	78	43.5	37	39.1	115
Male	62.7	131	56.5	48	60.9	179
ADL/IADL <sup>b</sup> functioning, * Mean (SD)	23.01 (7.18)		25.34 (8.43)		23.69 (7.63)	
<b>Diagnosis (%)</b>						
Mild/moderate ID <sup>c</sup>	30.1	62	42.4	36	33.7	98
Severe/profound ID**	51.5	106	27.1	23	44.3	129
Autism	13.6	28	12.9	11	13.4	39
Cerebral palsy	32.0	66	21.2	18	28.9	84
Other	33.0	68	43.5	37	36.1	105

<sup>a</sup>Developmental disability. <sup>b</sup>Activities of daily living/instrumental activities of daily living. <sup>c</sup>Intellectual disability.  
\*p < .05. \*\*p < .01.

**Table 3** Summary of Regressions on Economic Outcomes

Variable	Out-of-pocket		Employment	
	Beta	SE	Beta	SE
Block 1: Demographics				
Caregiver age	-.04	2.80	-.34**	0.12
Minority status	-.04	61.61	.07	2.67
DD <sup>a</sup> functioning	-.10	55.44	.09	2.40
Income	.20**	14.18	.26**	0.64
Block 2: Group				
Group	-.15*	60.10	.02	2.69
Block 3: Interaction				
Group × Income	-.06	27.84	.04	1.26
Adjusted R <sup>2</sup>	.10**	—	.21**	—
R <sup>2</sup> change (1 to 2)	.02	—	-.00	—
R <sup>2</sup> change (2 to 3)	.00	—	-.00	—

<sup>a</sup>Developmental disability.

\**p* < .05. \*\**p* < .01.

teraction significant. There was also no significant difference between groups on caregiver mental health. However, there was a significant Group × Income interaction on mental health. Tests of simple effects indicated that lower income families in the program had significantly better mental health than did lower income families on the waiting list, although there were no significant differences for higher income families. The final model was statis-

tically significant and accounted for approximately 4% of the variance, with about 2% attributed to the Group × Income interaction.

Older caregiver age and higher household income were significantly associated with better caregiver health care access, whereas ethnic minority status was significantly associated with worse health care access. Controlling for demographic variables resulted in the finding that caregivers in the pro-

**Table 4** Summary of Regressions on Health Outcomes

Variable	Physical health		Mental health		Health care access	
	Beta	SE	Beta	SE	Beta	SE
Block 1: Demographics						
Caregiver age	-.29**	0.07	.13	0.08	.29**	0.00
Minority status	-.06	1.63	-.06	1.71	-.09	0.03
DD <sup>a</sup> functioning	.09	1.46	.06	1.54	.01	0.03
Income	.13	0.39	.06	0.41	.49**	0.01
Block 2: Group						
Group	.10	1.61	.11	1.70	.15**	0.03
Block 3: Interaction						
Group × Income	.01	0.77	-.16*	0.81	-.13*	0.02
Adjusted R <sup>2</sup>	.10**	—	.04*	—	.34**	—
R <sup>2</sup> change (1 to 2)	.01	—	.00	—	.01	—
R <sup>2</sup> change (2 to 3)	-.00	—	.02	—	.01	—

<sup>a</sup>Developmental disability.

\**p* < .05. \*\**p* < .01.

gram had significantly better health care access than did those on the waiting list. Furthermore, there was a significant Group × Income interaction on health care access. Tests of simple effects indicated that lower income families in the program had significantly better health care access than did lower income families on the waiting list, whereas there were no significant differences for higher income families. The final model was statistically significant and accounted for approximately 34% of the variance, with about 1% attributed to being in the program and about 1% attributed to the Group × Income interaction.

Table 5 contains a summary of the hierarchical regressions on caregiver social outcomes: social activities and leisure satisfaction. Higher level of functioning of relatives with developmental disabilities was associated with more caregiver social activities. After demographic variables were controlled, caregivers in the program had significantly more social activities than did caregivers on the waiting list. The Group × Income interaction was not significant. The final model was statistically significant and accounted for approximately 5% of the variance in social activities, with about 2% attributed to being in the program. Similarly, after demographic variables were controlled, caregivers in the program had significantly higher leisure satisfaction,  $p < .05$ ; the Group × Income interaction was not significant. The final model was not statistically sig-

nificant, and only about 2% of the variance was accounted for by being in the program.

### Discussion

The current study expands knowledge about the impact of consumer-directed supports on family caregivers. Specifically, caregivers in a consumer-directed program reported fewer out-of-pocket disability expenses, greater access to health care, engagement in more social activities, and greater leisure satisfaction than did caregivers on the waiting list. The program also appeared to contribute to greater benefits for lower income families. Caregivers from lower income families in the program reported better mental health and access to health care than did similar caregivers on the waiting list.

Consistent with previous research, families in the current study had considerable out-of-pocket expenses for disability-related services (Table 6). Overall, the average amount of annual out-of-pocket expenses was \$4,032.60 for the entire sample (\$3,462.12 for families in the program and \$5,358.60 for families on the waiting list). These figures are similar to those previously reported by Fujiura and colleagues (1994) after adjusting for inflation. The greatest impact seemed to be associated with respite and personal assistance services. Families in the program were not only using more of

**Table 5** Summary of Regressions on Social Outcomes

Variable	Social activities		Leisure satisfaction	
	Beta	SE	Beta	SE
<b>Block 1: Demographics</b>				
Caregiver age	.06	.01	.01	.01
Minority status	-.13	.20	-.04	.17
DD <sup>a</sup> functioning	.17*	.18	.07	.15
Income	.05	.05	.05	.04
<b>Block 2: Group</b>				
Group	.15*	.21	.17*	.16
<b>Block 3: Interaction</b>				
Group × Income	.12	.10	-.09	.08
Adjusted $R^2$	.05*		.02	
$R^2$ change (1 to 2)	.02		.02	
$R^2$ change (2 to 3)	.01		.00	

<sup>a</sup>Developmental disability.

\* $p < .05$ .



**Table 6** Out-of-Pocket Expenses of Home Based Support Services Program (HBSSP) and Waiting List Groups

Expense	HBSSP ( <i>n</i> = 209)		Waiting list ( <i>n</i> = 85)		Total ( <i>N</i> = 294)	
	Mean	<i>SD</i>	Mean	<i>SD</i>	Mean	<i>SD</i>
Transportation	55.90	88.71	71.97	117.17	60.75	98.22
Respite/personal assistance*	36.53	93.17	111.55	289.28	59.18	179.66
Recreational services	42.36	51.28	46.55	72.52	43.62	58.39
Medical and dental	35.16	72.84	33.49	53.13	34.66	67.47
Medications/related supplies	49.95	80.21	60.68	80.53	53.18	80.30
Therapies	13.98	95.45	33.88	130.84	20.02	107.54
Adaptive devices/home modifications	16.20	43.79	26.93	100.12	19.44	66.03
Miscellaneous	39.65	153.38	61.92	160.82	46.38	155.68
Total*	288.51	327.96	446.55	639.01	336.05	449.50

\**p* < .05.

these services but were spending less out-of-pocket than were families on the waiting list.

One hypothesis was that the program might contribute to more employment to caregivers, based on previous research (Parish et al., 2004; Seltzer et al., 2001; Shearn & Todd, 2000). However, this did not appear to be the case. Labor force participation of women in the current sample was only slightly lower than national averages for women (U.S. Department of Labor, 2005). Approximately 67.9% of women in the current sample between 25 and 54 years of age were employed versus 71.4% nationally. Similarly, 52.4% of women in the current sample between 55 and 64 years of age were employed versus 54.3% nationally. One factor that may have clouded results is whether caregivers receiving payment from the program reported this as employment. In the current study, 65.6% of families in the program had hired relatives, and in 41.6% of families, the primary caregiver was paid through the program. Billing the program for hours of care is taxable income for caregivers. However, qualitative interviews with families in the program suggested that some may view this as a way to enhance flexibility rather than employment (Caldwell, 2005). Future researchers should make better efforts to clarify this issue when asking about employment. Also, rather than focusing on hours of weekly employment, future researchers could explore the impact of supports on meeting personal desires and satisfaction with employment.

The health and well-being of family caregivers is important to maintaining existing supports for many adults with developmental disabilities. Al-

though the program did not seem to impact the health of caregivers in general, there did appear to be benefits in the mental health of lower income caregivers. Future researchers should explore these interconnections between the stresses of poverty and the demands of caregiving in more detail, perhaps incorporating the health of lower income caregivers within larger health promotion efforts. Although no differences in physical health were observed, other measures of health, such as the presence of chronic conditions, might also be important for future investigators to explore.

The program appeared to have significant impacts on access to health care. Lower income caregivers, in particular, seemed to benefit (Table 7). One hypothesis was that this might be connected with barriers to health care coverage for women providing care. However, the rate of being uninsured for working-age female caregivers in the current sample was similar to national averages (Salganicoff, Ranji, & Wyn, 2005). Instead, the program seemed to assist mostly with the ability to afford additional health care costs, such as co-pays, premiums, and other uncovered expenses. Access to health care was severely limited for caregivers on the waiting list and appears to be much worse than the national averages for working-age women (Salganicoff et al., 2005).

Future researchers should explore the access to health care of caregivers in greater detail. Only financial access barriers were considered in this study. Other access barriers, such as cultural/ethnic disparities and barriers imposed by caregiving time demands, could be explored. Furthermore, there is

**Table 7** Health Care Access of Home Based Support Services Program (HBSSP) and Waiting List Groups

Access	HBSSP (n = 209)		Waiting List (n = 85)		Total (N = 294)	
	%	n	%	n	%	n
Have health insurance	88.8	183	82.1	69	86.9	252
Able to afford						
Doctor visit**	83.7	169	61.7	50	77.4	219
Vision care*	78.8	160	66.7	54	75.4	214
Dental care**	73.2	145	56.8	46	68.5	191
Prescription drugs**	87.6	177	66.7	54	81.6	231
Mental health care**	97.0	195	88.8	71	94.7	266

\*p < .05. \*\*p < .01.

some evidence of rationing of care within families with a relative who has disabilities (Altman, Cooper, & Cunningham, 1999). In other words, caregivers may be more likely to forego their own health care to provide for other family members. Very little research has been conducted to explore the extent to which this occurs in families with relatives who have developmental disabilities. Researchers should also focus on access of caregivers to preventative health care, such as screenings for breast and cervical cancer, high blood pressure and cholesterol, and osteoporosis.

Finally, results of the current study appear to support social and leisure benefits for family caregivers in the program. Their frequently listed activities included involvement in church, advocacy groups, fitness, and exercise. Caregivers in the program were also more satisfied with their leisure activities than were those on the waiting list. Leisure satisfaction was significantly associated with engaging in more social activities, so this likely contributed to the difference. The Leisure Satisfaction Scale consisted of three domains: Social, Psychological, and Relaxation. Further exploration indicated that caregivers in the program had more positive ratings on the Psychological and Relaxation domains, whereas there were no differences between groups on the Social domain, which focused on social relationships developed through leisure.

*Study Limitations*

There are several limitations of the current study. First, there was a low response rate, particularly by families on the waiting list. There were also response biases, where younger caregivers, families with a male relative who had disabilities, and families in the program were more likely to respond.

Second, the study was cross-sectional, which raises internal validity issues concerning possible selection-interaction threats. Although families were randomly selected for the program from the waiting list, there were a number of existing differences between groups. Due to the initial construction of the waiting list, changes in eligibility for the program, and little expansion of the program for several years, the waiting list consisted of more minority and younger families, as well as individuals with less functional ADL/IADL needs. Although these variables were controlled for in the analyses, there may be other unknown differences between groups that could influence the findings.

Third, the present study is limited in its generalizability. Consumer-directed programs vary considerably from state to state and internationally (e.g., differ in focus, eligibility, benefits, and regulations on how benefits are used). Also, comparisons were made between families in the program and those on the waiting list for the program. Results primarily concern the impact of a particular consumer-directed support program rather than influences of consumer-directed versus agency-directed supports. These limitations suggest the need for additional research across various consumer-directed programs and additional opportunities for rigorous research through pilot and demonstration projects. Finally, the current study was focused solely on outcomes for family caregivers. Previously, research conducted on the program has identified positive outcomes for adults with disabilities, including greater employment, greater community participation, and fewer placements in institutional settings (Heller et al., 1999; Heller & Caldwell, 2005). However, additional research is specifically needed to gain the perspectives of adults with developmen-

tal disabilities in consumer-directed programs and the extent to which they are involved in decisions about services and hiring family members.

### Policy Implications

The developmental disabilities services system provides residential services to only approximately 11% of individuals with developmental disabilities (Braddock et al., 2005). The majority of adults rely on informal supports, predominately provided by family caregivers. Although some states have significantly increased their efforts over the past decade, less than 5% of funding within the developmental disabilities system is allocated towards family support (Rizzolo et al., 2006). As consumer-directed programs have grown, there appear to be connections with supporting families and informal supports. However, complex ideological and economic issues remain that are similar to those which have impeded the development of family support policy.

There appear to be ideological barriers within Medicaid to providing flexible supports that target the family. The Illinois HBSSP emerged as an early family support program. It targeted a limited amount of financial resources towards families with adult relatives living at home. With the conversion of the program to Medicaid, the focus has shifted more towards the individual with disabilities. However, similar to many other consumer-directed programs funded through Medicaid, payment of family caregivers has become common. This may raise tensions between responsibilities of the state and the family in providing long-term services (Simon-Rusinowitz, Mahoney, & Benjamin, 1998), yet it also acknowledges the economic value of informal caregiving and economic impacts of disability on the family (Arno, Levine, & Memmott, 1999; Fujiura, 1998).

Perhaps the larger issue still remains the overall lack of public commitment to disability services. Extensive waiting lists for residential services underscore the oppressive lack of financial resources in the current system (Prouty, Smith, & Lakin, 2005). Distributing a limited amount of resources to more individuals and their families may be more equitable. It may also be more effective in achieving particular outcomes, such as strengthening informal networks of support and decreasing placements in more costly institutional settings. However, inadequate amounts of resources with which to control will continue to undermine the rights and opportunities for individuals with disabilities and their families.

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