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By: Allyson G. Hall, PhD1, **Erin D. Bouldin, MPH1**, Elena M. Andresen, PhD2,
& Ayad K. Ali, MSPharm1

Abstract

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[Allyson G. Hall](#), Ph.D., [Erin D. Bouldin](#), MPH, [Elena M. Andresen](#), Ph.D., [Ayad K. Ali](#), MSPharm

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[Allyson G. Hall](#), PhD¹, [Erin D. Bouldin](#), MPH¹, [Elena M. Andresen](#), PhD², [Ayad K. Ali](#), MSPharm¹

¹University of Florida, Gainesville, USA

Corresponding Author: Allyson G. Hall, University of Florida, P.O. Box 100195 Gainesville, FL 32610, USA

Email: hallag@phhp.ufl.edu

Abstract

Many individuals with developmental or intellectual and other disabilities are on waitlists to receive supportive services through state Medicaid waiver programs. Being waitlisted can place considerable burden on the ability of a caregiver to maintain employment outside the home. This article reports on results of a survey of 442 caregivers of individuals waitlisted for services within the Florida Medicaid program. Logistic regression was used to model characteristics of caregiver and clients that are associated with the need for additional supports in order for the caregiver to maintain employment. Male caregivers and caregivers in fair or poor health were more likely to report needing support. Caregivers of clients who had behavior problems or problems with self-care were also more likely to need support to maintain employment. Policy responses to these findings include a call for increased supports or prioritization of services for

caregivers who are in poor health or those who care for individuals with particularly problematic behaviors.

Keywords [Medicaid](#), [waitlist](#), [caregivers](#), [intellectual disability](#)

Individuals living with certain kinds of intellectual, developmental, or other disabilities may experience multiple impairments with their vision, hearing, communication, mobility, or cognition. As such, their needs are typically complex, and they require a range of medical and social support services. In the past, individuals with certain kinds of disabilities were often institutionalized. However, recent movement of care away from large state inpatient institutions to community-based settings is an important trend in care for individuals living with certain disabilities. In the United States, the average daily census of individuals living with developmental or intellectual disabilities residing in large state institutions (i.e., those with 16 or more residents and staffed by state employees) decreased by 69% from about 131,345 individuals in 1980 to 40,434 individuals in 2005 ([Coucovanis, Lakin, Prouty, & Webster, 2006](#)). In Florida, the average daily census declined from 3,750 individuals in 1980 to 1,341 in 2005 ([Coucovanis et al., 2006](#)). This trend is viewed as positive from the perspective of national public health goals for persons with disabilities, including Healthy People 2010 ([Lollar & Crews, 2003](#); [U.S. Department of Health and Human Services, 2000](#)). However, there are significant implications for family members and other persons who have responsibility for caring for people with disabilities who are living in the community.

Perhaps the biggest implication is that individuals with developmental, intellectual, or other disabilities often need assistance in managing their daily lives. Informal caregivers such as family members or friends who provide unpaid care to a person with a disability may assist with some of these needs.

State Medicaid programs provide social support or home and community-based services to individuals with developmental, intellectual, and other disabilities primarily through Home and Community Based Services (HCBS) 1915(c) waivers, home health benefit programs, and optional state plan personal care services benefits (Henry J. Kaiser Family Foundation & Kaiser Commission on Medicaid and the Uninsured, [2006](#); [Kitchener, Hernandez, Ng, & Harrington, 2006](#); [LeBlanc, Tonner, & Harrington, 2000](#)). These programs are designed to provide alternatives to institutionalization and to support families' abilities to care for their relatives at home ([Heller, Miller, & Hsieh, 1999](#)).

Medicaid social support programs have been shown to be beneficial to individuals and their families. For example, a study of one program for individuals with developmental disabilities demonstrated that program participants had fewer unmet needs and used more services such as respite care, social and recreational activities, educational/vocational training, behavior management training, and transportation assistance relative to a control group ([Heller et al., 1999](#)).

Studies and reviews of other populations with disabilities have shown that participation in a Medicaid waiver program is linked to a number of positive outcomes. For example, waiver programs have been associated with a reduction in unmet needs for physical functioning, socialization, medical care, and social support services ([Weissert, Cready, & Pawelak, 1988](#)); an increase in home health, transportation, and personal care services ([Fox & Kim, 2004](#)); a reduction in hospitalizations; a greater likelihood of remaining in the community; and a lower need for residential treatment ([Solhkhah, Passman, Lavezzi, Zoffness, & Silva, 2007](#)). Caregivers who were receiving supports from a consumer-directed program reported “fewer out-of-pocket expenses, greater access to health care, engagement in more social activities and greater leisure satisfaction” than caregivers who were on a waitlist for such services ([Caldwell, 2006](#), p. 405).

Since 1981, there has been considerable growth in the number of people who are enrolled in Medicaid HCBS waiver programs. Between 1992 and 2007, across all states the number of beneficiaries receiving HCBS services more than doubled. Nationally in 2007, state HCBS programs provided services for approximately 500,000 individuals with intellectual or developmental disabilities. As expected, expenditures increased extensively as well. Between 1992 and 2007, expenditures rose by more than 1,000% from US\$1.65 billion to US\$20.94 billion ([Lakin, Prouty, Alba, & Scott, 2008](#)). This increase in spending is of concern for states, particularly during times of fiscal downturns. The Medicaid 1915(c) waiver is required to remain budget neutral, and states have great flexibility to limit spending (Henry J. Kaiser Family Foundation & Kaiser Commission on Medicaid and the Uninsured, [2006](#)). States limit spending via a number of mechanisms including instituting restrictive financial eligibility standards, using stricter functional eligibility criteria, and using waitlists when the number of applicants exceeds the number of program slots (Henry J. Kaiser Family Foundation & Kaiser Commission on Medicaid and the Uninsured, [2006](#)).

In 2005, 30 states reported operating waitlists for a total of approximately 261,000 individuals. Waivers for individuals with developmental or intellectual disabilities had approximately 138,000 people on their waitlists, which is about a 48% increase from 2004 (Henry J. Kaiser Family Foundation & Kaiser Commission on Medicaid and the Uninsured, [2006](#)).

The implications of being on a waitlist and not receiving supportive services are significant for individuals and their informal caregivers. Being on a waitlist means that the individual is not receiving some of the social, vocational, and medical support services he or she needs ([Weissert et al., 1988](#)). Waitlisted families report higher rates of needing social/recreational services, educational and vocational/training and assistance, and dental care than families enrolled in a consumer-directed program ([Caldwell & Heller, 2007](#)). As such, caregivers in waitlisted families may be likely to forgo employment to provide support for their family member ([Parish, 2006](#)). Indeed, caregiving has been found to be associated with reductions in labor force participation and earnings, especially for women ([Wakabayashi & Donato, 2006](#)). For example, having a child with a disability (as measured by activity limitations, certain hospitalizations, or general health status) is associated with reduced parental employment and reduced family income ([Heck & Makuc, 2000](#); [Kuhlthau & Perrin, 2001](#); [U.S. Government Accountability Office \[GAO\], 1999](#)). The inadequacy of care supports outside the home is a major reason for reduced employment

among women ([Parish, 2006](#)). Not working or having to reduce work hours affects the ability of caregivers to purchase needed services ([U.S. GAO, 1999](#)).

Study Objective

Given the large number of individuals on waitlists for services and increasing budgetary constraints, states may wish to consider prioritizing certain groups for services. This prioritization can be based on the likelihood of unemployment among caregivers resulting from the individual with disabilities being on a waitlist for services. Therefore, the purpose of this study was to examine the correlates or predictors associated with caregivers reporting that in order for them to maintain their current employment, they need additional supports to care for the individual who is on the waitlist. The identification of a set of significant correlates would aid in the prioritization of services to individuals and families who are most in need. In this analysis, we considered characteristics of caregivers, characteristics of the client on the waitlist, and family characteristics as potential predictors of whether a caregiver reported needing services at home.

Method

Study Population

The Agency for Persons With Disabilities (APD) provides services to Floridians with developmental or intellectual disabilities and their families through the Medicaid Developmental Disabilities/HCBS (DD/HCBS) waiver program and Family and Supported Living waiver program (Agency for Health Care Administration, 2007; [APD, 2008a](#)). APD services include medically necessary medical and dental services, medically necessary supplies and equipment, assistance in securing a safe place to live, supported living, transportation to access necessary services, personal care services, respite care, and supervision and training in daily living skills, employment, and behavior services (Agency for Health Care Administration, 2007; [APD, 2009](#)).

In 2008, approximately 17,000 Floridians eligible to receive waiver-funded services were on the APD waitlist for these services ([APD, 2008](#)). Recognizing the damaging effects of not receiving services can have on an individual with disabilities and/or their family members, the Florida Developmental Disabilities Council commissioned a survey of clients and caregivers of clients who were on the APD waitlist to explore their immediate and long-term needs.

Survey Development

Other states have developed and used tools to assess the urgency of need for services. One such tool used in the development of the APD survey was the Prioritization of Urgency of Need for Services (PUNS) used by the Pennsylvania Department of Public Welfare. Although not previously used as a telephone survey, the team adapted a number of items covered on the PUNS for the current survey. In addition, questions used previously on the Behavioral Risk Factor Surveillance System and the U.S. Census were also included ([Andresen, Catlin, Wyrwich, & Jackson-Thompson, 2003](#); [Centers for Disease Control and Prevention, 2007, 2008](#); [Pruchno, Burant, & Peters, 1997](#)). Finally, APD staff and the authors created new questions to meet the evaluation needs of this project.

The survey asked questions about caregiver employment, whether additional supports for the client were needed in order for the caregiver to maintain employment, the kinds of support needed, the health and disability status of the caregiver, caregiver gender and age, caregiver relationship to the client, and whether a family crisis had occurred within the last 6 months. In addition, the survey collected information on the areas in which the client needed help because of his or her disability, client problem behaviors, and long-term housing and other needs of the clients. A copy of the survey is available on request from the primary author.

Before fielding the survey, APD asked several families to provide feedback on content and length. The research team pilot-tested the programming of the questions to confirm sequencing, wording, and skip patterns of the computer-assisted telephone survey. The research team's university Institutional Review Board provided human subject approval for the study.

Survey Implementation and Data Collection

The sample for this survey was drawn from the full APD waitlist as of February 1, 2008. The study population included clients of any age who resided in their own home or a family home according to APD records. Clients who lived in a group home or any other state-licensed residential setting, such as nursing home or assisted living facility, were excluded from the sample. APD's statistician selected a random sample of 3,066 clients from the study population within program-specific age strata (under 21, and 21 or above as of February 1, 2008) and provided telephone contact information to the University of Florida Survey Research Center. The Survey Research Center called the provided telephone numbers and asked to speak to the client on the waitlist. If the sampled client was physically or mentally unable to complete the survey or if the sampled client was below the age of 18, the interviewer asked to speak to someone aged 18 or above who knew the most about the individual's service needs. The proxy respondent was asked during the survey whether he or she provided care to the client. The survey was conducted from February to May 2008.

Of the 3,066 calls made by the University of Florida Survey Research Center, 1,729 had nonworking numbers, had ineligible respondents, or were fax or data lines. Of the 1,337 remaining, a total of 985 surveys were completed resulting in a cooperation rate of 73%. A total of 844 surveys were completed by a caregiver. This study reports on responses from the caregiver survey only and is limited only to those who were currently employed.

Variables

The dependent variable was whether the caregiver self-reported needing additional support to maintain current employment. Characteristics of caregivers included gender, race, and ethnicity (non-Hispanic White, non-Hispanic Black, and Other race/ethnicity); disability status (activity limitation, no activity limitation); health status (excellent/very good/good or fair/poor); age (less than 45 years, 45 years or older); and relationship to the client (parent/foster parent or other). Caregiver's disability status was defined according to the recommendation in Objective 6.1 of *Healthy People 2010* ([Armour, 2008](#); [U.S. Department of Health and Human Services, 2000](#)). Caregivers were characterized as having a disability if they answered "yes" to either of the two questions: "Are you limited in any way in any activities because of physical, mental, or

emotional problems?” or “Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone?”

Client characteristics include age (less than 21 years, 21 years or older), clinical diagnosis (mental retardation, autism, other [cerebral palsy, spina bifida, or Prader Willi syndrome]), presence of a problem behavior such as running away, damaging property, self-injury, or causing harm to others (yes, no); whether the client has a problem with learning, remembering, and confusion (yes, no); whether the client has a problem with self-care (yes, no); and whether the client has a problem communicating with others (yes, no). Family characteristics included two variables as follows: annual household income (less than US\$25,000; US\$25,000 to US\$50,000; and more than US\$50,000 or income not reported) and whether there was a family crisis such as a death or divorce within the past 6 months (yes or no). Clinical diagnosis of the client was the only variable obtained from the administrative data files maintained by APD.

Statistical Analysis

Statistical analysis was limited to caregivers who responded that they were currently employed ($n = 460$) and who did not have missing responses to all variables of interest ($n = 442$) with the exception of income. There were a large number of respondents who did not report their annual income. To prevent further reduction of the sample, we coded respondents with missing income data as “income not reported.”

We first described the data by calculating univariate descriptive statistics for the analytic sample. Then logistic regression models were used to predict the likelihood that a caregiver would report needing additional support to maintain employment. Odds ratios (ORs) and 95% confidence intervals (CIs) were calculated, and two-sided p values of $\alpha < .05$ were considered statistically significant. Finally, we calculated the predicted probability for categories of caregivers of the likelihood of reporting needing additional support and examined the frequency distributions of the kind of supports caregivers in fair or poor health reported that they needed. All statistical analyses were conducted using Stata (Version 10).

Results

[Table 1](#) describes the characteristics of the caregivers and the individuals who were on the waitlist in the analytic sample. Among the 442 employed caregivers, a little less than half (47%) reported needing additional support to maintain their employment. A majority of caregivers were female (83%), non-Hispanic White (77%), had no activity limitations (84%), and were in excellent, very good, or good health (88%). A total of 44% of employed caregivers were below 45 years and 90% were the parent or foster parent of the APD client.

Table 1. Characteristics of Caregivers and Clients

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Variable	Percentage (%)
Caregiver needs additional support to maintain employment	
Yes	47.06
No	52.94
Caregiver characteristics	
Caregiver gender	
Female	82.58
Male	17.42
Caregiver Race	
Non-Hispanic White	77.15
Non-Hispanic Black	14.71
Other race/ethnicity (including those who report Hispanic)	8.14
Caregiver disability status	
No activity limitation	84.16
Activity limitation	15.84
Caregiver health status	
Excellent/very good/good	88.24
Fair/poor	11.76
Caregiver age	
Less than 45 years	43.89
45 years and above	56.11
Caregiver relationship to client	
Parent/foster parent	90.50
Other	9.50
Waitlisted client characteristics	
Client's age	
Less than 21 years	66.29
21 years and above	33.71
Client's clinical diagnosis	
Mental retardation	61.76
Autism	24.53
Other (including cerebral palsy, spina bifida, and Prader-Willi syndrome)	13.71
Client has a problem behavior*	
Yes	63.80
No	36.20
Client has a problem learning, remembering, and confusion	
Yes	47.96
No	52.04
Client has a problem with self-care	
Yes	48.42
No	51.58
Client has a problem communicating with others	
Yes	43.44
No	56.56
Family characteristics	
Annual household income	
Less than US\$25,000	21.72
US\$25,000-US\$50,000	30.09
More than US\$50,000	39.59
Income not reported	8.60
Family crisis within past 6 months	
Yes	14.25
No	85.75

Note: Clients are on a waitlist for services from the Florida Agency for Persons With Disability (n = 442).
*Includes running away, damaging property, self-injury, and causing harm to others.

About two thirds of the individuals on the waitlist who were assisted by employed caregivers were less than 21 years old (66%). The majority of individuals who were on the waitlist live with mental retardation (62%) and exhibited some form of problem behavior (64%). A little less than half were reported to have problems with learning, remembering, and confusion (48%) and to have problems with self-care (48%). A total of 43% had problems communicating with others.

Almost half (52%) of the households of individuals with employed caregivers reported incomes of US\$50,000 a year or less, and 14% had a family crisis such as a death or divorce in the past 6 months.

[Table 2](#) presents the results of the logistic regression multivariate model that predicts caregiver need for additional client supports to maintain employment. Male caregivers (OR = 1.75; 95% CI = [1.00, 3.06]) and those in fair or poor health (OR = 3.16; 95% CI = [1.50, 6.64]) were more likely to say they needed additional supports to maintain employment. Caregivers who supported clients with problem behaviors (OR = 1.73; 95% CI = [1.09, 2.74]) or had problems with self-care (OR = 1.93; 95% CI = [1.24, 3.00]) also had higher odds relative to caregivers of clients without these attributes to need additional support to maintain employment. Neither of the

family-related characteristics (family crisis in the past 6 months or family income) were found to be statistically significant predictors of employed caregivers needing additional support to maintain employment.

Table 2. Multivariate Logistic Regression: Correlates of Caregiver Needing Additional Support to Maintain Employment

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	Beta coefficient	Odds ratio	95% confidence interval		p value
Caregiver gender					
Females					
Males	.56	1.75	1.00	3.06	.047
Caregiver race/ethnicity					
Non-Hispanic White					
Non-Hispanic Black	-.004	0.99	0.54	1.84	.990
Others including Hispanic	.51	1.67	0.79	3.55	.182
Caregiver disability status					
No activity limitation					
Has an activity limitation	.45	1.58	0.84	2.97	.152
Caregiver health status					
Excellent/very good/good					
Fair/poor	1.15	3.16	1.50	6.64	.002
Caregiver age					
Less than 45 years					
45 years and above	-.23	1.26	0.82	1.94	.287
Caregiver relationship to client					
Parent/foster parent					
Other kind of relationship	.56	1.75	0.84	3.65	.134
Client's clinical diagnosis					
Mental retardation					
Autism	-.29	.74	0.44	1.26	.276
Other (including cerebral palsy, spina bifida, and Prader-Willi syndrome)	.04	.96	.51	1.78	.90
Client has a problem behavior ^a					
No					
Yes	.54	1.73	1.09	2.74	.020
Client has a problem learning, remembering, and confusion					
No					
Yes	-.42	0.65	0.41	1.01	.060
Client has a problem with self-care					
No					
Yes	.66	1.93	1.24	3.00	.003
Client has a problem communicating with others					
No					
Yes	.10	1.10	0.70	1.75	.655
Annual household income					
Greater than US\$50,000					
US\$25,000-US\$50,000	.27	1.31	0.79	2.17	.652
Less than US\$25,000	.50	1.66	0.93	2.96	.086
Income not reported	.17	1.19	0.55	2.60	.652
Family crisis within past 6 months					
No					
Yes	.20	1.22	0.68	2.18	.502

^aIncludes running away, damaging property, self-injury, and causing harm to others.

To present our findings in a different format, we calculated separate predicted probabilities of needing additional support for those caregivers in fair/poor health, male caregivers, those caregivers who care for clients who have problem behaviors, and those caregivers of clients who have a problem with self-care, while each time holding all other variables at the mean. The predicted probabilities for caregivers in fair/poor health, male caregivers, caregivers who care for individuals with problem behaviors, and caregivers who care for individuals who cannot care for

themselves were 0.70 (95% CI = [0.56, 0.85]), 0.49 (95% CI = [0.43, 0.54]), 0.55 (95% CI = [0.46, .64]), and 0.55 (95% CI = [0.47, 0.62]), respectively. That is of these groups, caregivers who are in fair or poor health had the highest predicted probability of needing additional support.

[Table 3](#) shows the kinds of support needed among the caregivers in fair or poor health who need additional support. A sizable majority of caregivers reported needing respite care or behavioral analysis, whereas about half needed family counseling. Between 40% and 48% needed physical therapy, home health care, occupational therapy, and adult day care. Roughly one third needed speech therapy, durable medical equipment, and supported employment.

Table 3. Services Needed by Caregivers in Fair/Poor Health Who Need Additional Support to Maintain Employment (*n* = 208)

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Service	Proportion of employed caregivers in fair/poor health needing service for client
Respite care	70.11
Behavioral analysis	68.39
Family counseling	55.17
Physical therapy	47.70
Home health care	44.83
Occupational therapy	44.83
Adult day care	40.80
Speech therapy	33.33
Durable medical equipment	32.18
Supported employment	30.46
In-home supports	27.01
Environmental adaptations	15.52
Transportation	11.49
Assistive technology	9.77

Discussion

Based on our analysis, employed caregivers who reported needing additional support to maintain their employment are more likely to be male, to be in fair/poor health, to care for clients who have a problem behavior, and to care for clients who have a problem with self-care. As the loss of employment could be detrimental to the family and to the client specifically, states must figure out how to prioritize services to those individuals and families who are in the greatest need. Knowing what client and caregiver characteristics tend to be associated with greater risk of unemployment could be a factor in assigning priorities for services. In Florida's case, caregivers who are at greatest risk for losing their employment are those who are in fair or poor health and those who care for clients with behavior or self-care problems, with additional high risks for men. Calculations of predicted probabilities for these groups also show that caregivers who are in fair or poor health are most at risk.

Policy responses to our findings could likely include a call for increased supports or prioritization for services for caregivers who are in poor health or those who care for individuals with particularly problematic behaviors. Policy makers may have to consider the ethical issues of providing support specifically to families where caregiver ill health is largely due to poor health behaviors (i.e., addiction or obesity) on the part of that caregiver. Although on the surface it may appear unreasonable to “reward” caregivers whose ill health is a result of the caregivers' health behaviors, it is also important to remember that the intent of the Medicaid policy is to ensure that individuals living with disabilities receive the necessary supports to remain in the community.

It may be difficult to advocate that men should be given priority for services over women if they are the primary caregiver. Nevertheless, this finding does bring into question whether there are certain characteristics of male caregivers or their caregiving that make them more susceptible to employment instability relative to women. The literature is replete with studies of gender differences in coping, stressors, health, and social resources associated with caregiving ([Barusch & Spaid, 1989](#); [Miller & Cafasso, 1992](#); [Pinquart & Sörensen, 2006](#); [Yee & Schulz, 2000](#)). A recent meta-analysis noted that female caregivers were more likely to report more caregiver burden, higher rates of depression, and providing more care than male caregivers ([Pinquart & Sörensen, 2006](#)). Perhaps more importantly, the caregiver stressors and resulting burden are likely determined by the needs of the client rather than by gender differences in socialization or caregiving motives ([Pinquart & Sörensen, 2006](#)). It is important to note that studies reviewed in the meta-analysis are of caregivers of elderly individuals or individuals living with dementia and Alzheimer's disease. Thus, these findings may not be completely applicable to our study of caregivers of individuals on Medicaid waitlists. However, the analysis conducted by [Pinquart et al. \(2006\)](#) emphasizes the importance of understanding whether there are certain unique features of male caregiving that are worth investigating.

In conjunction with prioritizing who among waitlist recipients should receive services sooner, consideration should be given to the specific kinds of supports to be provided. Among caregivers in fair or poor health who indicated they needed support, 70% needed respite care and 68% needed behavioral analysis. Given that caregivers of clients who have problem behaviors and self-care needs also were at higher risk for losing employment, it is not surprising that a vast majority of caregivers are in need of these services. To be able to provide immediate support to

caregivers and clients who are in the most jeopardy, states could consider providing only the services that are in the greatest demand.

There are a number of limitations associated with this study. First, although the survey instrument was pilot-tested and a subset of caregivers provided feedback on content and interpretability, it is possible that there is a degree of respondent bias. For example, some respondents could have believed that by answering the survey in a specific way, their wait time for services could be reduced. Substantive checks on the reliability of survey items (e.g., on whether caregiver was in fact unemployed) were not conducted. Second, the study results are limited to the reports of caregivers. If the client was old enough and able to participate, then that client was the one interviewed. Clients who were interviewed were not asked about their caregiver's employment status. Consequently, we are unable to make inferences about these clients and their caregivers. This, however, was a small percentage of the sample. Finally, the sample size also did not permit specific examination of the experiences of Hispanic families. Florida has a significant Hispanic population, and it will be important to get a strong understanding of the experiences of these families in future evaluations.

Despite these limitations, this study provides a good example of an approach that can be used to identify clients and families who are most at risk for disruptions in life such as loss of employment. Assuring that individuals with disabilities and their families receive adequate and appropriate supports to maintain employment and satisfactory living situations is key to ensuring that individuals with disabilities live healthy and happy lives in the community. Budgetary constraints limit a state's ability to provide a comprehensive array of services to all waitlisted clients. An alternative approach could be the provision of limited services to a subset of families in most jeopardy.

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References

Agency for Health Care Administration. (2010). Developmental disabilities services coverage and limitations handbook Retrieved from

http://portal.flmmis.com/FLPublic/Provider_ProviderSupport/Provider_ProviderSupport_ProviderHandbooks/tabId/42/Default.aspx

Agency for Persons With Disabilities. (2008). Legislative Budget Request 2009-2010. Retrieved from <http://apd.myflorida.com/publications/legislative/>

Agency for Persons With Disabilities. (2009). About us. Retrieved from <http://apd.myflorida.com/about/>

Andresen, E. M., Catlin, T. K., Wyrwich, K. W., Jackson-Thompson, J. (2003). Retest reliability of surveillance questions on health related quality of life. *Journal of Epidemiology & Community Health*, 57, 339–343.

Armour, B. S., Swanson, M., Waldman, H. B., Perlman, S. P. (2008). A profile of state-level differences in the oral health of people with and without disabilities, in the U.S., in 2004. *Public Health Reports*, 123, 67-75.

Barusch, A. S., Spaid, W. M. (1989). Gender differences in caregiving: Why do wives report greater burden? *Gerontologist*, 29, 667–676.

Caldwell, J. (2006). Consumer-directed supports: Economic, health, and social outcomes for families. *Mental Retardation*, 44, 405–417.

Caldwell, J., Heller, T. (2007). Longitudinal outcomes of a consumer-directed program supporting adults with developmental disabilities and their families. *Intellectual and Developmental Disabilities*, 45, 161–173.

Centers for Disease Control and Prevention. (2007). The characteristics of caregivers and care recipients: North Carolina. *Morbidity and Mortality Weekly Report*, 56, 529–532.

Centers for Disease Control and Prevention. (2008). Behavioral Risk Factor Surveillance System Survey Questionnaires. Atlanta, GA: Author.

Coucouvannis, K., Lakin, K. C., Prouty, R., Webster, A. (2006). Reductions continue in average daily populations of large state facilities: Nearly 70% decrease between 1980 and 2005. *Mental Retardation*, 44, 235–238.

Fox, M. H., Kim, K. M. (2004). Evaluating a medicaid home and community-based physical disability waiver. *Family & Community Health*, 27, 37–51.

Heck, K. E., Makuc, D. M. (2000). Parental employment and health insurance coverage among school-aged children with special health care needs. *American Journal of Public Health*, 90, 1856–1860.

Heller, T., Miller, A. B., Hsieh, K. (1999). Impact of a consumer-directed family support program on adults with developmental disabilities and their caregivers. *Family Relations*, 48, 419–427.

The Henry J. Kaiser Family Foundation, & Kaiser Commission on Medicaid and the Uninsured. (2006). Medicaid 1915(c) Home and Community-Based Services Programs: Annual Data Update (No. 7575). Retrieved from <http://www.kff.org/medicaid/7575.cfm>

Kitchener, M., Hernandez, M., Ng, T., Harrington, C. (2006). Residential care provision in Medicaid home- and community-based waivers: A national study of program trends. *Gerontologist*, 46, 165–172.

Kuhlthau, K. A., Perrin, J. M. (2001). Child health status and parental employment. *Archives of Pediatrics & Adolescent Medicine*, 155, 1346–1350.

Lakin, K. C., Prouty, R., Alba, K., Scott, N. (2008). Twenty-five years of Medicaid Home and Community Based Services (HCBS): Significant milestones reached in 2007. *Intellectual and Developmental Disabilities*, 46, 325–328.

LeBlanc, A. J., Tonner, M. C., Harrington, C. (2000). Medicaid 1915(c) home and community-based services waivers across the states. *Health Care Financing Review*, 22, 159–174.

Lollar, D. J., Crews, J. E. (2003). Redefining the role of public health in disability. *Annual Review of Public Health*, 24, 195–208.

Miller, B., Cafasso, L. (1992). Gender differences in caregiving: Fact or artifact? *Gerontologist*, 32, 498–507.

Parish, S. L. (2006). Juggling and struggling: A preliminary work-life study of mothers with adolescents who have developmental disabilities. *Mental Retardation*, 44, 393–404.

Pinquart, M., Sörensen, S. (2006). Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. *Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 61, P33–P45.

Pruchno, R. A., Burant, C. J., Peters, N. D. (1997). Coping strategies of people living in multigenerational households: Effects on well-being. *Psychology and Aging*, 12, 115–124.

Solhkhah, R., Passman, C. L., Lavezzi, G., Zoffness, R. J., Silva, R. R. (2007). Effectiveness of a children's home and community-based services waiver program. *Psychiatric Quarterly*, 78, 211–218.

U.S. Department of Health and Human Services. (2000). *Healthy People 2010: With Understanding and Improving Health and Objectives for Improving Health*. Washington, DC: U.S. Government Printing Office. Retrieved from <http://www.healthy.gov/2010/Document/tableofcontents.htm#volume1>

U.S. Government Accountability Office. (1999). *SSI children: Multiple factors affect families' costs for disability-related services (GAO/HEHS-99-99)*. Washington, DC: Author.

Wakabayashi, C., Donato, K. M. (2006). Does caregiving increase poverty among women in later life? Evidence from the Health and Retirement survey. *Journal of Health and Social Behavior*, 47, 258–274.

Weissert, W. G., Cready, C. M., Pawelak, J. E. (1988). The past and future of home- and community-based long-term care. *Milbank Quarterly*, 66, 309–388.

Yee, J. L., Schulz, R. (2000). Gender differences in psychiatric morbidity among family caregivers: A review and analysis. *Gerontologist*, 40, 147–164.