Modeling caregivers’ perceptions of children’s need for formal care: Physical function, intellectual disability, and behavior


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Abstract

Background: Like most caregivers, informal caregivers for children (typically parents) with special needs supply the majority of the care provided. Formal care is sometimes needed to supplement informal caregivers’ efforts. For those interested in children with special needs, there is a paucity of research on those factors affecting the amount of formal care that caregivers’ request.

Objectives/Hypotheses: This research investigates factors affecting the amount of Medicaid personal care services (PCS) requested by primary caregivers for children with special needs. The research focuses especially on the roles played by the child’s functional status, intellectual abilities, and behaviors in determining the level of assistance requested by caregivers.

Methods: The data used in this research are cross-sectional information on 262 children with special needs who were Medicaid recipients in a single southwestern state. These data were collected in 2007 by master’s trained social workers or registered nurses using a standardized assessment instrument.

Results: The results indicate that a child’s ability to independently perform activities of daily living (ADLs) tasks plays the major role in determining caregivers’ perceptions of the need for PCS. The severity of a child’s intellectual disability, like some other factors investigated, has an effect on caregivers’ perceptions, but it is an indirect effect that operates through the level of the child’s ADL impairment. A child’s age and behaviors have direct effects on caregivers’ perceptions of need, as does the presence of barriers to the caregiver providing care.

Discussion: Much of the research on children with special needs has emphasized the importance of the child’s medical or behavioral diagnoses. Little attention has been given to modeling caregivers’ perceptions of children’s needs. This analysis of caregivers’ requests for formal PCS brings to the forefront the role of ADL or functional status in this process. Many factors that one would expect to directly affect caregivers’ perceptions of need, instead, have indirect effects filtered through their impact on the child’s functional status.

Keywords: Caregivers; Children with special needs; Intellectual disabilities; Behavioral problems; ADL; Medicaid

As health care costs and utilization rise, individuals facing physical or behavioral challenges are increasingly dependent on the ability of family or other informal caregivers to operate competently as de facto health care providers [1,2]. In families with a child who has a chronic, disabling condition, the health and well-being both of caregivers and care recipients are issues of increasing importance. Among all caregiver scenarios, families including children with special needs typically experience the most adverse financial and medical effects of caregiving, and they are at the same time less likely than other caregiving families to seek medical services [3]. Families with caregiving responsibilities who have lower income levels or lower levels of education are less likely than other families to request special needs and services, in part because they are unaware of special services or do not recognize the need1 [4].

These issues are part of the assessment process for programs that endeavor to establish partnerships with

1 Throughout this article, the term “caregiver” will be used, rather than parent. This is the common term used in the research literature, and it is the most general term in that it encompasses care provided by any family member and all other informal caregivers. However, for these children, primary caregivers are largely parents.
family caregivers to provide services that address the “realities of their daily lives” [5, p. 284] Ideally, supportive services for family caregivers work best when caregivers’ perspectives concerning the problems they face and possible solutions are valued and actively solicited [6,7]. Caregiver information can then be used to provide services tailored to the specific care recipient’s needs [8]. A collaborative partnership with family caregivers should be responsive to caregiver opinions about needs and solutions regarding their desire for community and home-based services [9].

This consideration of caregiver perceptions and preferences has clear precedent in the field of education, particularly in the Individuals with Disabilities Education Improvement Act 2004. Parent (caregiver) input into a child’s Individualized Educational Program (IEP) is considered essential. Parents have, in fact, legal protections to ensure this occurs (see www.ed.gov and www.nichcy.org for specific information).

Integrating caregiver preferences into the calculus of service programs or providers’ thinking as they consider how to distribute resources constitutes an important stride forward in health service delivery to populations with special needs. We attempt to contribute to the knowledge base surrounding this issue by developing multivariate models indicating what factors affect caregivers’ perceptions of how much assistance a child with special needs requires from the personal care services (PCS) program funded by Medicaid. In doing so, we pay special attention to the roles of the level of functional disability, the level of intellectual disability, and the degree to which the child manifests behavior problems associated with mental or behavioral health issues.

Understanding caregivers’ and care recipients’ strengths and needs is critical in decision-making related to service distribution. Unfortunately, for caregivers in the community one finds few measures of caregiver needs or limitations. In addition, the available measures of children’s functional needs and functional abilities are usually medically focused and typically insensitive to environmental contexts [10-12]. Greater attention to limitations and restrictions that vary dramatically from home to home is essential for understanding disability in community-based programs [13]. This is particularly true for “evaluating needs and planning services” for children with disabilities and their families [10, p. S51]. Despite the value placed on functional assessment and consumer input in most areas of service delivery in the health community (e.g., [14]), many Medicaid programs rely heavily on medical diagnoses and give little weight to caregivers’ perceptions of care recipients’ level of disability when allocating care resources.

Children with more profound special needs who have some level of intellectual disability (ID) and demonstrate some problematic behavior patterns may create more stress for families (e.g., [15]). However, researchers, service providers, and policy-makers face a paucity of studies when looking at mental health needs in populations with intellectual disabilities, particularly in children who have low levels of ability [16-18]. Similarly, no extant research is available that evaluates the impact of problem behaviors on caregiver perceptions of the care needs of children with or without some level of intellectual disability.

 Estimates of the prevalence rates of specific mental health disorders in persons with ID vary widely. Kerker et al. [18] found 22% of the children with ID in their sample had anxiety disorders. In administrative reports, conduct disorders are estimated to affect 45% of children with ID [18]. Other work indicates that children with ID almost uniformly exhibit a higher prevalence of emotional disorders than children without ID [19,20].

Problem behaviors associated with these conditions may affect caregivers’ perceptions of children’s needs. Externalized behaviors derived from these mental health problems, such as verbal or physical aggression, bullying, menacing, or resisting care may make children with special needs more difficult care recipients. In the same sense, internalized behaviors driven by mental health issues, such as withdrawal, fatigue, inactivity, or passive resistance may also contribute to these children being troublesome care recipients.

In this study, we used data drawn from a sample of children with special needs, who face disabilities that require not only the help of their informal caregivers, but also the assistance available in a public program for low-income families (Medicaid). We examined structural equation models predicting personal care hours these informal caregivers believed their children needed. We paid special attention to the role of intellectual disability, functional status, and behavior problems in shaping the caregivers’ judgments.

**Methods**

**Data collection**

Data collection using the personal care assessment form (PCAF) (available on the Disability and Health Journal’s website) was done as a part of regularly scheduled evaluations of the long-term care needs of children receiving or seeking Medicaid PCS. The assessors were full-time case managers employed by the Texas Department of State Health Services. All of these case managers regularly evaluated clients, and they were among the most experienced working in their regions. A total of 39 case managers from the state’s eleven health service regions were trained to use the PCAF instruments. The training was 16 hours long and was spread over 2 days. It included a detailed consideration of the instrument and use of the instrument to evaluate an analog client followed by a group debriefing. During the course of the data collection, research staff monitored the assessments and provided feedback to the evaluators when coding errors or other problems were discovered.
The target population for the study was children between the ages of 4 and 20 who were seeking or receiving PCS under the Medicaid PCS program throughout the 11 health regions of the state. All clients being assessed by a case manager were invited to participate in the PCAF assessment until the target number of evaluations from the region had been obtained. A $30 incentive in the form of a VISA gift card was paid for participation. Of the 287 contacts, only 22 declined to participate, giving the study a cooperation rate of 92%. The assessment of the child, including both the routine state assessment and the PCAF, took an average of 160 minutes to complete. The case managers evaluated those clients they would normally have evaluated in the course of their work. Data were collected over a 3-month period between November 2007 and January 2008. A total of 265 evaluations were obtained; however, three were deleted from the analysis because too much data were missing. These 262 cases constituted roughly a 5% sample of all children aged 4 to 20 who received or sought PCS services at this time. Analyses indicate that 48% of the study households included only one parent; two parents resided in 36% of the study households; and 16% of households had no parent in residence. Following an assessment’s completion, the PCAF was sent from the regional offices to the Public Policy Research Institute (PPRI) at Texas A&M University. There the forms were reviewed, and data were coded, entered, and verified.

Measures

The PCAF for children 4 to 20 years of age (PCAF 4-20) was used in this effort. This assessment was purpose-built by the authors for the Texas Health and Human Services Commission, but it was also based in large measure on items, or variants of items, included in the Minimum Data Set for Nursing Home Resident Assessment (MDS [21]) and the Minimum Data Set for Home Care (MDS-HC© [22]). Both the MDS and the MDS-HC© were developed for use with frail elderly and have proven reliability and validity when used with older populations [23-25]. Considerable evidence suggests that the MDS, when implemented nationally, improved the quality of nursing home care [26-30].

The dependent variable in our analyses was the amount of weekly Medicaid personal care time requested by the child’s primary caregiver, or by the child if they were between 18 and 20 years of age. This information was gathered by the case managers who completed a 7-day 24-hour flow sheet that identified the personal care time needed by the child, based on information provided by the caregiver or child.

A major independent variable in our analyses was a scale reflecting the intensity of the child’s needs for assistance with activities of daily living (ADLs). The PCAF used those MDS items related to activities of daily living. The PCAF included ten ADL items that focused on the assistance usually provided to participants in bed mobility, positioning while upright, eating, transfer from one surface to another, mobility inside the dwelling, mobility outside the dwelling, toilet use, dressing, personal hygiene, and bathing. All ADL items but bathing used the same response set. The response set ranged from total independence (0) to total dependence (5). The additional codes included set-up help only (1); supervision, cueing, and redirection (2); limited assistance (3); hands-on assistance but only rare weight-bearing assistance; and extensive assistance (4), which denotes some involvement by the participant but regular weight-bearing help from a caregiver. The codes for bathing also ranged from total independence (0) to total dependence (5), but they differed slightly from the codes for the other ADLs. All items referenced ADL performance over a 7-day period. The additive scale based on a child’s ratings on these ten ADL items had excellent internal consistency (α = .94).

The terms intellectual disability and mental retardation are considered synonyms by the research team. The term intellectual disability (ID) is the preferred term; however, the education law (IDEIA 2004), which is used to provide children with education services, uses the term mental retardation. Two dichotomous measures of ID were used: ID diagnosis (0 = no diagnosis; 1 = yes, condition diagnosed) and ID level (0 = mild, moderate, unknown; 1 = severe, profound). A medical problems or diagnoses measure was constructed (0 = none of these conditions diagnosed; 1 = one of the condition diagnosed, 2 = two or more of the conditions diagnosed) using 10 medical diagnoses items identified as likely to affect a child’s need for PCS—cerebral palsy, congenital heart disorder, cystic fibrosis, epilepsy/chronic seizure disorder, fetal alcohol syndrome, hydro/microcephaly, muscular dystrophy, paraplegia/tetraplegia/quadruplegia, spina bifida/other spinal cord dysfunction, and traumatic brain injury. Similarly, a dichotomous measure of health conditions was constructed (0 = none of these conditions diagnosed; 1 = one or more conditions diagnosed) using four health conditions—recurrent aspiration, bed-bound/chair-fast, contractures, and limitations in range of motion. Age was calculated in years using the assessment date and client date of birth.

Cognitive function was measured by adding together four items in the section dealing with cognitive function—short-term memory, long-term memory, procedural memory, and daily decision-making. Communication was similarly

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2 The initial sampling plan used quotas so that the clients would be selected approximately proportionally to the Medicaid population size of the region in which they were located. The planned sample size was 264 clients aged 4 to 20. The planned sample size was reached, but assessments reflected current patterns of application for PCS services rather than the size of the overall Medicaid population in the region.

3 Children for whom the level of ID was recorded as unknown closely resembled those children classified as mild or moderate ID in terms of their levels of cognitive function and ADL function and were, therefore, grouped with those children for the analyses.
measured by adding together the two items in the section dealing with communication; making oneself understood and the ability to understand others. A dichotomous measure of two-person assistance with any ADL task was constructed (0 = no assistance two-person assistance received; 1 = any two-person assistance received). A dichotomous measure of continence was constructed (0 = continent; 1 = incontinent of bowel or bladder) using the two items in the section of the assessment dealing with continence.

In addition, the analyses included two measures created from items in the section of the assessment dealing with mood and behavior. An “externalizing” scale was created by taking the average of items identified as externalizing behaviors (e.g., persistent anger/irritability, compulsive behavior, verbally abusive etc); these eleven items also exhibited good internal consistency (α = .83). An “internalizing” scale was created by taking the average of items identified as internalizing behaviors (e.g., change in sleeping patterns, diminished concentration, etc.); these eleven items also exhibited good internal consistency (α = .87). An “internalizing” scale was created by taking the average of items identified as internalizing behaviors (e.g., change in sleeping patterns, diminished concentration, etc.). These six items had adequate internal consistency (α = .68).

**Analysis strategy**

To examine relationships among a child’s ID, a child’s needs for assistance with ADLs, a child’s problem behaviors, and the hours of PCS requested by their primary caregiver, analyses were done using Structural Equation Modeling (SEM). SEM models were developed in Mplus V. 5.2 using maximum likelihood (ML) estimation. To test the model fit of our a priori model, five fit indices were used: (a) chi-squared test of model fit (χ²), (b) comparative fit index (CFI), (c) Tucker-Lewis Index (TLI), (d) root mean squared error of approximation (RMSEA), and (e) standardized root means squared residual (SRMR). The RMSEA and SRMR were used as measures of absolute fit, and the CFI and TLI were used to measure incremental fit [31]. The CFI and TLI of above .90 are usually considered an indication of adequate fit between the model and the data, and good fit is indicated if these indicators are above .95 [32]. For the RMSEA and SRMR, scores below .08 typically indicate adequate fit, and scores below .05 indicate good fit [32].

The a priori model for the total sample is presented in Figure 1. In the a priori model, it is hypothesized that a serious medical diagnosis, the number of health conditions or problems, the presence of communication deficits, the necessity of two-person assistance with some ADLs, urinary or bowel incontinence and the presence of an ID have a direct effect on an individual’s reported ADL status. It was also believed that ADL status or assistance needs would have both a direct effect on number of requested hours and a mediated effect through symptoms indicative of a behavioral health problem. These symptoms were categorized as external (e.g., aggressiveness) or internal (e.g., withdrawal) manifestations of the underlying behavioral health problems. Finally, it was believed that age and caregiver barriers to care (e.g., physical challenges) would also affect the number of hours of personal care requested by primary caregivers.

As post-hoc analyses, a series of additional SEM models were tested. For the total sample, a second model was examined that included dummy variables representing the severity of the child’s ID. The presence of mild or moderate ID was set as the reference category. Two dummy variables representing those with no ID problem or those children severe or profound ID were then included in the model. Using only individuals who were diagnosed with an ID problem, a third model was tested using a dummy variable with severe/profound ID coded as 1 and mild/moderate ID coded as 0. Finally, using only individuals with no indication of ID were included in a fourth model. This model examined the a priori model without any ID variables.

**Results**

**ADLs and requested hours**

Table 1 presents descriptive data on our sample of 262 children seeking PCS. As the table indicates, roughly 60% of the children were male. In terms of race or ethnicity, children of Hispanic origin were most numerous (42%), while African American and white non-Hispanic children each make up about a quarter of the population. Over half of these children had an ID, and a majority had one or more medical diagnoses. Almost 60% had incontinence of bladder or bowel. Roughly a quarter of the children exhibited some type of behavior problem. Twenty percent of the caregivers reported a personal limitation that restricted the amount of care they could provide the child. In regard to ADL needs, the mean level of ADL impairment was 27.4 on a scale ranging from zero to 50 (SD = 18.3).

On average, caregivers requested 25.3 (SD = 18.3) hours of formal PCS care for their child-in-need. Of those requesting care, only 14% failed to receive PCS assistance from the Medicaid program.

**Model evaluation**

The a priori model (see Figure 1) was found to have poor model fit across the various fit indices (χ² [51,
Modification indices were examined and suggested a number of relationships required in order to fit the model to the data. These changes were determined to be theoretically justifiable and included in the corrected, best fit model in Figure 2. A Chi-squared test of model fit for this corrected model was found to be statistically significant, which suggested that the model did not fit the data perfectly, $\chi^2 (36, n = 262) = 61.11, p < .001$. However, this test is especially sensitive to sample sizes, and this rejection of model fit was expected [32]. The CFI, TLI, RMSEA and SRMR (.947, .944, .052, and .043, respectively) were indicated adequate or good fit. Based on these results it was determined that the model had adequate fit, which allowed for appropriate interpretation of the path coefficients.

**Prediction of ADLs and requested hours**

Findings from the model lend support for the research hypothesis that an individual’s level of ADL impairment is affected by medical diagnoses, but no effect was found for the presence of ID ($\beta = -0.042, p > .05$). These relationships suggested that higher levels of ADL impairment were derived in part from more serious medical diagnoses ($\beta = 0.272$), a greater number of health conditions ($\beta = 0.231$), greater difficulty communicating ($\beta = 0.195$), the need for two-person ADL assistance ($\beta = 0.145$), and incontinence ($\beta = -0.269$). These variables in total accounted for 55% of the variance in the level of ADL impairment ($R^2 = 0.547$).

Results also lend support to the hypothesis that number of requested hours is affected by the level of ADL impairment, symptoms indicating internalizing behavioral health problems, age and the primary caregivers’ barriers to providing care. However, the model indicated that symptoms of externalizing behavioral health problems were not directly linked to number of requested hours ($\beta = -0.007, p > .05$). These relationships suggested by the model imply that individuals for whom a greater number of hours were requested were those children with more severe ADL impairment ($\beta = 0.453$), those exhibiting more symptoms of internalizing behaviors ($\beta = 0.235$), those who were older ($\beta = 0.232$), and those whose primary caregiver reported more barriers to informal care provisions ($\beta = 0.184$). These significant relationships accounted for 30% of the variance in the number of hours of PCS requested by primary caregivers ($R^2 = 0.302$).

**Post-hoc model testing**

Findings from the corrected, best fit model did not lend support for the hypothesis that ID levels affected an individual’s reported ADL limitations or the number of requested hours of service. To further examine this relationship, it was hypothesized that ID severity might be confounding this relationship. Thus, a second model was examined, which included dummy variables to account for ID severity (Fig. 3). Like the previous model, this model was found to adequately fit the data ($\chi^2 [42, n = 262] = 69.38, p = .005$; CFI = .943; TLI = .943; RMSEA = .050; SRMR = .044). This model supported the hypothesis that severity of ID diagnosis was important in determining ADL limitations and, through its effects on ADL limitations, affected the number of requested hours. In the model results presented in Figure 2, when no ID problems was compared to the presence of an ID problem there was not a statistically significant path ($\beta = 0.084, p < .05$). However, when those with a severe

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6 Figure 2 does not include the covariance relationships in order to provide a simpler, more readable model presentation. However, full path and covariance statistics can be viewed on the *Disability and Health Journal*’s website.
or profound ID problem diagnosis were compared to all other individuals, a significant path was found ($\beta = .109, p = .038$). Individuals with a severe or profound ID problem were more likely to have higher levels of ADL limitations than other children.

To further examine this finding, a third model (Fig. 4) was estimated using only individuals with an identified ID problem. This model was able to specifically examine whether severity of diagnosis impacted reported ADL limitations and to determine if different relationships existed in the data that were exclusive to the ID sample. The resulting model had adequate fit ($\chi^2 [35, n = 124] = 54.18, p = .020$; CFI = .924; TLI = .918; RMSEA = .066; SRMR = .071). The model results further suggested that ID severity was important in determining the severity of reported ADL limitations, while simply the presence of an ID was not. This suggested that individuals with severe or profound ID diagnoses were more likely have higher levels of ADL impairment than those with less severe ID diagnoses ($\beta = .184$).

Finally, a fourth model was examined that included only those individuals who had no ID problem. This was estimated to determine if the relationships between variables in the ID sample were unique to those individuals. This model also had adequate fit ($\chi^2 [29, n = 137] = 47.34, p = .02; CFI = .927; TLI = .914; RMSEA = .068; SRMR = .064$). The results of this model supported the hypothesis that a few of the relationships between variables in the ID sample were unique to that sample. While number of health conditions, and communication problems were not related to reported ADL limitations for the ID sample, they were related ADL limitation in the non-ID sample ($\beta = .330, p < .001; \beta = .292, p < .001$, respectively). Further, in the non-ID sample, age was no longer a statistically significant predictor of number of requested hours ($\beta = .151, p > .05$). However, with these few exceptions, relationships observed in the model estimated for the ID sample were also observed in the model for children with no ID problem.

### Discussion

As noted earlier, caregivers of children with special needs face some of the most difficult challenges of any caregivers. This research focused on what characteristics of the child-in-need affected caregivers’ judgments concerning how many hours of Medicaid PCS were needed to provide the best care for the child. Our analyses, though considerably broader in execution, focused on the impact of

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Table 1: Descriptive Data on the Sample of 262 Children Seeking Personal Care Services

<table>
<thead>
<tr>
<th>Client Characteristics</th>
<th>Response</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client gender</td>
<td>Male</td>
<td>157</td>
<td>59.9%</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>105</td>
<td>40.1%</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td>White non-Hispanic</td>
<td>74</td>
<td>28.5%</td>
</tr>
<tr>
<td></td>
<td>Hispanic</td>
<td>110</td>
<td>42.3%</td>
</tr>
<tr>
<td></td>
<td>African American</td>
<td>63</td>
<td>24.2%</td>
</tr>
<tr>
<td></td>
<td>Asian</td>
<td>2</td>
<td>0.8%</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>11</td>
<td>4.2%</td>
</tr>
<tr>
<td>Diagnosis—intellectual disability</td>
<td>ID diagnosed</td>
<td>124</td>
<td>47.5%</td>
</tr>
<tr>
<td>Diagnosed ID level (among those diagnosed)</td>
<td>Mild</td>
<td>24</td>
<td>19.4%</td>
</tr>
<tr>
<td></td>
<td>Moderate</td>
<td>28</td>
<td>22.6%</td>
</tr>
<tr>
<td></td>
<td>Severe</td>
<td>25</td>
<td>20.2%</td>
</tr>
<tr>
<td></td>
<td>Profound</td>
<td>26</td>
<td>20.9%</td>
</tr>
<tr>
<td></td>
<td>Unknown</td>
<td>21</td>
<td>16.9%</td>
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<tr>
<td>Special medical diagnoses</td>
<td>No special medical diagnoses</td>
<td>102</td>
<td>38.9%</td>
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<td></td>
<td>One special medical diagnosis</td>
<td>71</td>
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<td>Two or more special medical diagnoses</td>
<td>89</td>
<td>33.9%</td>
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<td>Special health conditions</td>
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<td>119</td>
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<td>One or more special health condition</td>
<td>143</td>
<td>54.6%</td>
</tr>
<tr>
<td>Two-person assistance with ADLs</td>
<td>No two-person assistance received</td>
<td>201</td>
<td>76.7%</td>
</tr>
<tr>
<td></td>
<td>Two-person assistance received</td>
<td>61</td>
<td>23.3%</td>
</tr>
<tr>
<td>Continence</td>
<td>Continent</td>
<td>112</td>
<td>42.9%</td>
</tr>
<tr>
<td></td>
<td>Urinary or bowel incontinence</td>
<td>149</td>
<td>57.1%</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Continuous Variables</th>
<th>Mean</th>
<th>Standard deviation</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hours requested</td>
<td>25.3</td>
<td>18.30</td>
<td>0.0</td>
<td>93.5</td>
</tr>
<tr>
<td>ADL score</td>
<td>27.4</td>
<td>16.87</td>
<td>0.0</td>
<td>50.0</td>
</tr>
<tr>
<td>Age</td>
<td>11.9</td>
<td>5.02</td>
<td>4.0</td>
<td>20.0</td>
</tr>
<tr>
<td>Cognitive skills</td>
<td>4.3</td>
<td>2.13</td>
<td>0.0</td>
<td>7.0</td>
</tr>
<tr>
<td>Communication</td>
<td>3.0</td>
<td>2.03</td>
<td>0.0</td>
<td>6.0</td>
</tr>
<tr>
<td>Externalizing</td>
<td>0.2</td>
<td>0.23</td>
<td>0.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Internalizing</td>
<td>0.3</td>
<td>0.27</td>
<td>0.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Parent limitations</td>
<td>0.2</td>
<td>0.22</td>
<td>0.0</td>
<td>1.0</td>
</tr>
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</table>
ADL function, ID levels, and the child’s behavior problems on caregivers’ perceptions of need. The type of care under investigation was the number of PCS hours requested by caregivers to provide children and their caregivers’ assistance with a range of functional problems. As might be expected, the level of ADL impairment was of overwhelming importance in determining caregivers’ perceptions.

For populations with chronic health problems or with multiple health conditions, ADL impairment constitutes the best measure available for summarizing the total functional challenge of these problems. Medical diagnoses, health conditions, communication problems, and incontinence have no direct effect on the number of hours caregivers believe they need. Instead, all these factors affect

Figure 2. Corrected, best fit structural equation model of health diagnosis, ID diagnosis, assistance needs, ADLs, and requested hours. Note. N = 262. Standardized coefficients are presented. E’s are associated errors. # Commun = # communication problems *p < 0.05.

Figure 3. Post-hoc structural equation model of health diagnosis, ID severity, assistance needs, ADLs, and requested hours. Note. N = 262. Standardized coefficients are presented. E’s are associated errors. # Commun = # communication problems *p < 0.05.
a child’s functional status, which in turn translates those effects into the perceived hours needed for PCS. These results imply that a child’s overall level of ADL impairment may serve as an important conduit through which messages are transmitted from a variety of sources (e.g., medical conditions or problems with continence) and translated by the caregiver into the need for formal care time.

In our models, behavior problems constitute intervening variables resting between ADL impairment and hours requested. For both externalizing and internalizing behaviors, heightened ADL impairment makes these behaviors less likely to occur. But, when they occur, it is not the externalizing behaviors (e.g., physical or verbal aggression) that affect the amount of help caregivers want. Instead, internalized behaviors (e.g., withdrawal or anxiety) have a significant positive relationship to hours requested.

These behaviors seem to trouble or frustrate caregivers to the degree that they feel the need for more help. This might at first seem incongruent, as externalizing or acting out behaviors would appear on the surface to require more need for assistance. However, it may be the case that those who externalize disorders may also be more able to communicate their needs to caregivers, either through overt behavior or vocalization. In contrast, it may be the case that those who engage in internalizing behaviors may make a caregiver feel that they require more care, as the caregiver is forced to guess at needs and try predict behaviors through subtle, nonverbal behaviors.

The most complex relationship that we see in our data is that between ADL impairment and intellectual disability. Simply including an indicator of the presence of ID in our model had no significant effect on ADL function. Only when the level of ID was entered into the model did a significant relationship appear. Estimated models for the entire sample, however, show that the models for those with ID and those without ID were quite similar. In both of these models, ADL function was the transmitter of needs from a variety of disparate problems; behavior problems were intervening variables; and internalized behaviors significantly affected perceived care needs. In all these models, caregiver limitations worked independently to increase the caregiver’s sense of need.

Limitations to this study may raise questions about external validity of our findings. Our sample is one of children with special needs in low income families, two-thirds of whom are Hispanic or African American. Estimating our models with different populations may result in different findings. The authors hypothesize that the dynamics of how caregivers construct their perceptions of need are not likely to differ significantly across populations; however, more research with differing populations is required to support or disprove that hypothesis.

The results of this research provide guidance to researchers concerning three issues important to the study of the needs of children with special challenges. First, valid and reliable measurement of functional impairments may be the most important part of any model attempting to estimate these children’s needs. Second, behavior problems, not necessarily mental health diagnoses, affect the amount of help a caregiver believes is needed to assist the child. Third, knowledge about the severity of a child’s ID, not just its presence, may be required to understand caregivers’ develop their perceptions of the need for assistance.

The next logical steps in this line of research would involve testing both the assessment tool and the models in different geographical settings and with different populations of children with special needs. A few other aspects of this research also seem to deserve further exploration. First,
the role played in this research by problem behaviors could be investigated. The findings in this study concerning problem behaviors were somewhat counter-intuitive. This may mean that the results are idiosyncratic or that we require more finely-grained qualitative studies to help us understand how a child’s problem behaviors translate into a caregiver’s desire for more assistance. Such research would certainly be a welcome addition to the literature. Second, the ADL summary scale, of such importance in determining caregivers’ perceptions, was a simple additive scale with no real clinical content. A score of 27 out of 50 was simply five points higher than a score of 22. But, underlying these individual scores, were there groups of children with relatively similar patterns of ADL needs? If so, then might these groups serve as clinically meaningful clusters that could be used for treatment planning by case managers or more consistent resource allocation by social program administrators? Only further research will answer these questions.

Finally, our models explained over one-half the variance in our ADL scale and just under one-third of the variance in perceived need. Obviously, some element of that unexplained variance is simply random error. But if added to our models, what major unmeasured constructs might result in much higher levels of explanation? In this instance, we suspect that a larger element of information concerning the caregivers themselves might be one of those elements. Additional research will support that suspicion or possibly lead us in some other fruitful direction.

**Supplementary data**

Supplementary data associated with this article can be found, in the online version, at doi: 10.1016/j.dhjo.2009.10.005.

**References**


