Severity of Children’s Intellectual Disabilities and Medicaid Personal Care Services

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Objectives: This research investigated the relationship between a child’s reported intellectual disability (ID) level and caregivers’ reports of the child’s health status to predict Medicaid Personal Care Services (PCS) hours authorized for that child. We also investigated how activity limitations in the home varied with the level of ID. Design: The sample included 1,108 community-residing children with a reported level of ID in the Texas Medicaid system and who were assessed for the PCS program. All data were collected with the Personal Care Assessment Form (PCAF), an instrument developed by the authors for evaluating children’s PCS needs. Case managers completed the PCAF in the child’s home with the child and primary caregivers present. Structural equation modeling (SEM) was used to test a model reflecting the role of ID and other characteristics of the child in determining the number of PCS hours authorized. Additional analyses revealed the degree to which variation among the case managers affected the number of hours authorized. Results: ID level and other individual characteristics had a significant effect on reports of a child’s activity limitations ($R^2 = .67$), which in turn affected the hours of PCS authorized ($R^2 = .27$). We found no significant direct relationship between ID level and PCS hours: ID level had an indirect relationship on PCS hours through activity limitations. When the variance in hours authorized was decomposed, individual characteristics accounted for 20% of the variance and case managers accounted for 14%. Conclusions: Assessments of caregiver and child strengths and limitations in the home are critical in the allocation of Medicaid home-based services, above and beyond the information conveyed by demographic and diagnostic data. Implications for home-based assessments of functional limitations and needs for family caregivers and their children with ID are discussed.

Keywords: Medicaid Personal Care Services, intellectual disabilities, developmental disabilities, caregivers, activity limitations, activities of daily living

Medicaid home care services play a critical role in helping individuals with disabilities live in communities (U.S. Department of Health & Human Services, 2000). Ideally, these programs enable individuals with disabilities to have greater choice in everyday decisions and about the services they receive that promote community residence (Heller & Schindler, 2009; Lakin, Doljanac, Byun, & Stancliff, 2008). In many ways, home care programs reflect several core concepts of informed disability policy, including person and parent capacity development, empowerment, and involvement in decision-making (Shogren & Turnbull, 2010). Home-based personal care services are also consonant with recommendations for family-centered programs that facilitate the “rituals and routines in family life” and enrich the alliance between the family, the care recipient, and formal health care service providers (Elliott et al., in press; Weih, Fisher, & Baird, 2002).

Home-based support services for persons with intellectual and developmental disabilities have grown considerably over the recent past (Rizzolo, Hemp, Braddock, & Schindler, 2009). There is evidence, for example, that the Medicaid Personal Care Services (PCS) program, crucial to assisting families with home care, may reduce long-term costs for institutional care for some populations (Kaye, LaPlante, & Harrington, 2009). PCS can include assistance in dressing, feeding, bathing, cleaning, and a variety of other tasks and supports in the home. Unfortunately, the PCS program varies in funding across the states. Families of children with intellectual disabilities (IDs) and with other special health care needs find the differences in funding and eligibility across programs fragmented and disruptive to the care and services that are ostensibly available to them in the community (Farmer, Clark, & Marien, 2003).

A number of elements of The Affordable Care Act of 2010 (ACA) imply that these services will grow in importance over the

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next few years. A number of the ACA’s provisions directly intend to increase the use and availability of home- and community-based services for Medicaid recipients. For example, the Community First Choice program offers state Medicaid programs financial incentives to provide person-focused home care to those who wish to stay in the community, despite the presence of conditions or impairments that might imply the need for residential services. The Balancing Incentives Payment Program offers higher Medicaid payments to states that implement reforms in their home care programs. These reforms include the use of a statewide standardized assessment tool to determine the types of supports and services are needed by the populations served by Medicaid (Justice, 2010; Reinhard, Kassner, & Houser, 2011).

Generally, PCS programs assist those children in the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) program with a significant disability or health condition that substantially affects the child’s ability to engage in physical and social activities. However, a quick perusal of state policies reveals considerable variation in the degree to which these determinations are made by a “doctor or medical professional” or a “comprehensive needs assessment.” From our perspective, as well as that of the Balancing Incentives Payment Program in the ACA, the authorization of PCS hours, like other Medicaid services, should be determined by an informed, omnibus assessment of a child’s functional ability and environmental factors that impede or facilitate full participation across a range of life domains (Farmer et al., 2003; Lollar, 2008; Lollar & Crews, 2003; Simeonsson et al., 2003). This kind of assessment—consonant with the International Classification of Function (ICF: World Health Organization, 2001)—requires a systematic evaluation of child functional abilities, the home environment, and family resources, including the ability of the responsible adult to provide the needed assistance to the child (LeBlanc, Tonner, & Harrington, 2001).

Although many functional status instruments are available in rehabilitation practice, most available measures “... do not capture function as a person-environment interaction” (Heinemann & Mallinson, 2010, p. 149), and most are designed to assess functioning in a fairly controlled and structured health care setting (and not for use in home and community environments; Lollar, 2008). Furthermore, fewer still are concerned with the assessment of resources, needs, and other relevant issues (e.g., child externalizing behaviors) in collaboration with family members, who are best qualified to address these issues and direct care in the home. Parents of children with disabilities experience considerable frustration when a mismatch exists between the stated needs of the family and the available services, resources, and environmental supports (Resch et al., 2010). Consequently, a thorough and accurate assessment involving family caregivers is essential to provide PCS that adequately addresses the needs of the child and the family.

In the present study, we examine the degree to which the family caregivers’ reports of the child’s ID level, activity limitations, behaviors, conditions, as well as the primary caregiver’s limitations in providing assistance drive the authorization of PCS hours for children with ID. In prior work, we found impairments in activities of daily living (ADL) accounted for a significant amount of the explained variance in the number of PCS hours requested by a family caregiver of a child with special health care needs (Fournier et al., 2010a). It is interesting to note the presence of ID was not statistically significantly in the initial model for children with all types of problem conditions.

Further investigation, however, among only those with ID demonstrated that severe and profound diagnoses were associated with greater ADL limitations, and this in turn significantly predicted requested hours (Fournier et al., 2010a). A subsequent study, relying on PCS assessments conducted throughout the state of Texas, found evidence that the presence of ID had a small but significant negative association with activity limitations, suggesting that ID was associated with less impairment and resulted in the authorization of fewer hours of PCS. Unfortunately, the level of ID was not available in these data (Elliott et al., in press).

These somewhat contradictory results provide part of the impetus for the present investigation of factors that predict the PCS hours authorized for families of a child with an ID. In addition, the future of long-term services and supports lies in the community and community-based assessment strategies, which makes the understanding of home care increasingly important. In this research, we specifically examined the degree to which a child’s reported level of ID, other health conditions, impairments, activity limitations, and problem behaviors—as experienced and reported by the family—were predictive of the amount of personal care support services authorized by Medicaid case managers. Based on our previous work, we used an a priori structural equation model that emphasized the centrality of activity limitations in the PCS allocation process. Specifically, we expected child ADLs to be significantly predictive of PCS hours authorized. However, we were less certain of the effect levels of ID would have on ADLs in the context of other limitations, impairments and coexisting health conditions. Given the importance of ADLs in support allocation decisions, we investigated differences in activity limitations among children with different levels of ID. Finally, we decomposed the variance in PCS hours authorized to determine the degree to which individual characteristics versus variation among case managers affected the authorization.

Method

Procedures

Medicaid case managers in each of Texas’ 11 Health Regions collected data over a 4-month period in early 2010. Case managers conducted assessments in a home visit in which the primary caregiver and the child were present. Case managers were employed by the Texas Department of State Health Services. All case managers participating in this project had a graduate degree in social work, unless they were nurses. The majority of case managers had previous field experience with the PCS program for children and the state’s Medicaid Women, Infants and Children program. Data were received from over 140 case managers. On average, a case manager completed 18 assessments, but there was considerable variability as some case managers completed few assessments while some case managers completed scores of assessments.

Case managers were assigned to evaluate the need for PCS support for children enrolled in the Texas Medicaid Early and Periodic Screening, Diagnostic and Treatment (EPSDT) Program. In the Texas PCS program, case managers have the authority to
determine the eligibility and number of PCS hours for a qualifying child, unless the decision is challenged by a family. All information about a child’s health status came from family caregiver responses recorded by a case manager or from a case manager’s observations of the child during the assessment process. Children who were old enough to provide information elaborated on their caregivers’ responses.

A total of 2,694 assessments were completed and transmitted to the research team; however, 52 assessments were not included in the database because of high levels of missing data or because no PCS hours were authorized for the children assessed. The final sample included 2,642 children evaluated for PCS.

**Measurement**

The Personal Care Assessment Form (PCAF) for children 4–20 years of age was used in this project. The PCAF was developed by the authors for the Texas Health and Human Services Commission (HHSC) for use in the Medicaid PCS program (available at http://pcaf.tamu.edu/AssessmentInstruments.asp). The study and its associated protocols were reviewed and approved for research ethics and compliance by the Institutional Review Board (IRB) at Texas A&M University for human subjects’ involvement. The PCAF was based largely on variants of items included in the Minimum Data Set (MDS) for Nursing Home Resident Assessment (Hawes et al., 1997). The MDS was developed for the Centers for Medicare and Medicaid Services and it is used in skilled nursing facilities and mandated by CMS for reimbursement under its postacute care prospective payment systems (Heinemann & Mallinson, 2010). PCAF items were also based on variants from the Minimum Data Set for Home Care (MDS-HC) developed by interRAI (Morris et al., 1997), and now labeled the interRAI HC, as well as the assessment for persons with an Intellectual Disability (interRAI ID) assessment instrument (Martin, Hirdes, Fries, & Smith, 2007). All of these instruments share a common core of items. Psychometric analyses of these items as they apply to individuals with ID provide strong evidence of their reliability and validity in the adult ID population (Martin et al., 2007). The selection and wording of items for the PCAF was achieved by an interdisciplinary team (including experts in health policy, public health, special education, school psychology, rehabilitation psychology, and health care management) and with input from representatives and staff in the Texas Department of State Health Services.

Case managers received 20 hours of training on the use of the PCAF. Training included a detailed consideration of items, use of the instrument in example scenarios, and a group debriefing after case managers scored these scenarios. During data collection, research staff monitored assessments and provided feedback to case managers when coding errors or other problems were discovered.

**Dependent variable.** The number of hours of Medicaid PCS support authorized for a child by a case manager was the dependent variable in our predictive model. Case managers completed a 7-day record on the PCAF that identified the PCS hours needed by a child, based on information obtained during the assessment. The determination of the hours authorized is a dynamic process involving both the case manager and the primary caregiver or child (Elliott et al., in press). That determination largely evolves during the course of the assessment. Case managers reported that over two-thirds of caregivers or children in the sample made no request for a specific number of hours of PCS assistance. In only 8% of the cases were fewer hours authorized by case managers than were requested by the family (Phillips et al., 2011).

In our examination of support provided for each activity of daily living for individuals with different levels of ID, each ADL item was a dependent variable.

**Independent variables.** We used several independent variables obtained from the PCAF in the model predicting PCS hours authorized by the case manager.

**Activity limitations.** This variable was measured by a 10-item, additive scale of support provided to a child to overcome any activity limitations (i.e., ADL assistance). The scale included supports on 10 ADLs: bed mobility, positioning, eating, transfers, locomotion inside the dwelling, locomotion outside the dwelling, toilet use, dressing, personal hygiene, and bathing. All items referenced ADL support over a 7-day period. All ADL items used a response set that ranged from total dependence (5) to total independence (0). Field trials indicate the PCAF has considerable reliability in the Texas Medicaid PCS program (Phillips et al., 2011; Phillips et al., in press). Internal consistency for the present sample was excellent (α = .93).

Caregivers were asked for each ADL if the child’s health condition or impairment affected the level of support needed. If the level of support for an ADL was not affected, then the child was considered independent for the purposes of PCS allocation for that ADL. A younger child is not expected to be independent in dressing. If the level of support provided to the child was not affected by the child’s conditions or impairments, then the child was coded as independent in dressing; the caregiver provided only the support one would expect to provide a younger child. However, dressing the child might have required more intense assistance, taken longer, or required two people because of the child’s medical conditions or impairments. If that was the case, then the child received the code for the level of support provided (e.g., limited assistance, regular hands-on help, etc.). This allowed the research team to distinguish between support needs resulting from the child’s age and support needs resulting from health conditions or impairments.

**Medical conditions.** In accordance with the World Health Organization’s (WHO) International Classification of Function, Disability, and Health (ICF) model, medical diagnoses were identified as “conditions” (e.g., cerebral palsy, epilepsy, asthma). A dichotomous measure of the presence of a condition that significantly affected the support time awarded was constructed (0 = none of these conditions diagnosed; 1 = one or more of these conditions diagnosed). This item included cerebral palsy, congenital heart disorder, cystic fibrosis, epilepsy/chronic seizure disorder, macro/microcephaly, muscular dystrophy, any paralysis, spinal cord dysfunction, substance abuse-related problems at birth, and traumatic brain injury. Because a small number of children presented with more than one of these conditions, the variable was constructed to indicate the presence or absence of any of these conditions.

**Health impairments.** Problems associated with one or more conditions (e.g., shortness of breath, paralysis, amputation) were considered “health impairments” (World Health Organization, 2001). A binary variable indicating the presence of any of four impairments was included in the model; bed-bound/chair-fast,
contractures, other limitations in range of motion, and recurrent aspirations. These impairments were combined into a single, dichotomous measure because each individual condition exhibited low prevalence.

**Cognitive problems.** Cognitive impairment was measured with a six-item, additive scale assessing short-term memory, long-term memory, procedural memory, daily decision-making, making oneself understood, and the ability to understand others. The scale displayed good internal consistency in the present sample ($\alpha = .85$).

**Two-person assistance.** Impairments with relatively high prevalence were included in the model. The need for two-person support with any ADL was derived from this single item on the PCAF ($0 =$ no two-person support; $1 =$ any two-person support).

**Incontinence.** Another impairment with relatively high prevalence was created from the items that assessed the degree to which the child controlled his or her elimination ($0 =$ always continent of bowel and bladder; $1 =$ any incontinence of bowel or bladder).

**Child age.** The assessment date and child’s date of birth were used to calculate each child’s age in years.

**Externalizing behavior.** Another variable was created from items reflecting behaviors in which children often engage to express fears, anxiety, or needs. Externalizing behaviors such as aggression or resisting care may make children with special needs more difficult care recipients (Fournier et al., 2010a) and earlier work revealed a significant minority of children evaluated for PCS exhibit externalizing behaviors (Fournier et al., 2010b). Our externalizing behavior scale was created by summing items identified as externalizing behaviors (e.g., verbally abusive, bullying/menacing behavior, injury to animals). The additive scale based on these 13 items displayed good internal consistency ($\alpha = .83$).

**Caregiver limitations.** A dichotomous measure of caregiver physical limitations was included in the model ($0 =$ No physical limitations that might affect support; $1 =$ Unable to provide support to child because of physical limitations).

**ID level.** As part of the PCAF, case managers asked the family member to report if the child had an ID diagnosis, and if so, the level of ID. Analysis of the results indicate that 1,554 (58%) of these children had a reported ID diagnosis. However, only 1,108 (71%) had a recorded ID level. To determine the effect of analyzing data on only those children with a recorded level, we ran an OLS using all 2,642 children. Along with other covariates, each level of ID, as well as ID level missing, was included in the model as a separate binary variable with no ID diagnosis serving as the reference group. Each child’s ADL scale score was the dependent variable. The indicator representing those missing on ID level was not statistically significant ($p = .54$), and the observed relationships were the same for other variables. Since the presence or absence of these children with no reported ID level did not affect the results, subsequent analyses focus only on those 1,108 children with an identified ID level.

The next step was to determine how best to enter ID level into our model. To determine if the four ID levels contained children with the same characteristics, we estimated a discriminant function model with the four levels as the dependent variable and the other variables in our model as the independent variables. These analyses indicated that the mild and moderate groups should be combined. Children whose ID level was severe or profound remained in two separate groups. Thus, we used a three level variable to represent ID level: mild/moderate, severe, profound. For our more detailed analysis of ADL support by ID level, we categorized support in each ADL as independent or monitoring, limited or extensive hands-on assistance, and total dependence.

**Analyses**

The conceptual model underlying the analyses is the WHO ICF framework, supported by previous research in this area (Elliott et al., in press; Fournier et al., 2010a; Lollar & Simeonsson, 2005; Simeonsson et al., 2003; World Health Organization, 2001). As noted earlier, conditions refer to specific disease diagnoses (e.g., asthma). Impairments (e.g., shortness of breath, incontinence) are health problems that may result from any number of conditions. We defined activity limitations as problems experienced in performing ADLs.

We used structural equation modeling (SEM) to estimate the effects of conditions, impairments, and limitations on the PCS hours authorized by Medicaid case managers for each child in our sample. SEM is a recommended procedure for testing a priori relationships between variables in the prediction of an important outcome (Weston, Gore Jr., Chan, & Catalano, 2008). SEM is also preferred in studies in which the contextual relationships that may exist between predictor variables (e.g., ID level, cognitive problems, ADL limitations) need to be statistically controlled in an attempt to understand their unique contribution in the prediction of a criterion variable. Maximum likelihood (ML) estimation in IBM SPSS Amos 18 was used. To test model fit, we evaluated four indices: (1) chi-squared test of model fit ($\chi^2$), (2) comparative fit index (CFI), (3) Tucker-Lewis Index (TLI), and (4) root mean squared error of approximation (RMSEA). The RMSEA measures the absolute fit of a model, and the CFI and TLI measure incremental fit. The model fit is considered adequate when CFI and TLI values are above .90, and good fit is indicated if these indicators are above .95; for the RMSEA, adequate fit is indicated by scores below .08; scores below .05 indicate good fit (Browne & Cudeck, 1993; Hu & Bentler, 1995).

We then estimated multilevel models (MLM) to determine the degree to which individual child characteristics and variation among case managers explained the variance in hours authorized. Such models allow one to analyze variation arising from data captured at different levels of aggregation (Kreft & de Leeuw, 1998). Level 1 in our model was composed of children’s characteristics. Level 2 was the identity of the case manager completing the assessment. The aspect of the model on which we focused was the amount of the total variance explained by each level in the analysis. The results discussed were calculated using a varying intercepts model.

Finally, we conducted more fine-grained analyses of the relationship between ID level and the type of ADL support needed. For all 10 ADLs, we investigated the degree to which types of support (total dependence, regular hands-on assistance, independence or monitoring provided) varied across reported ID levels.

**Results**

Table 1 presents descriptive data for children in this investigation. One must remember that these children have health problems that
Table 1

Descriptive Data for the Sample of Children Receiving Medicaid Personal Care Services (PCS; n = 1,108)

<table>
<thead>
<tr>
<th>Child characteristics</th>
<th>Response</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child gender</td>
<td>Male</td>
<td>667</td>
<td>60.2</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>441</td>
<td>39.8</td>
</tr>
<tr>
<td>Medical conditions</td>
<td>No special medical conditions</td>
<td>455</td>
<td>41.1</td>
</tr>
<tr>
<td></td>
<td>One or more special medical conditions</td>
<td>653</td>
<td>58.9</td>
</tr>
<tr>
<td>Health Impairments</td>
<td>No special health impairments</td>
<td>618</td>
<td>56.1</td>
</tr>
<tr>
<td></td>
<td>One or more special health impairments</td>
<td>484</td>
<td>43.9</td>
</tr>
<tr>
<td>Intellectual disability (ID) level</td>
<td>Mild/Moderate</td>
<td>614</td>
<td>55.4</td>
</tr>
<tr>
<td></td>
<td>Severe</td>
<td>351</td>
<td>31.7</td>
</tr>
<tr>
<td></td>
<td>Profound</td>
<td>143</td>
<td>12.9</td>
</tr>
<tr>
<td>Urinary or bowel incontinence</td>
<td>Continent</td>
<td>231</td>
<td>20.8</td>
</tr>
<tr>
<td></td>
<td>Any incontinence</td>
<td>877</td>
<td>79.2</td>
</tr>
<tr>
<td>Two-person assistance with activities of daily living (ADLs)</td>
<td>No two-person assistance received</td>
<td>828</td>
<td>74.8</td>
</tr>
<tr>
<td></td>
<td>Any two-person assistance received</td>
<td>279</td>
<td>25.2</td>
</tr>
<tr>
<td>Caregiver limitations</td>
<td>No physical limitations</td>
<td>456</td>
<td>48.7</td>
</tr>
<tr>
<td></td>
<td>Physical limitations</td>
<td>481</td>
<td>51.3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Continuous variables</th>
<th>Mean</th>
<th>SD</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>PCS hours authorized</td>
<td>24.5</td>
<td>13.32</td>
<td>1.3</td>
<td>119.2</td>
</tr>
<tr>
<td>Cognitive problems scale</td>
<td>8.9</td>
<td>2.78</td>
<td>0.0</td>
<td>12.0</td>
</tr>
<tr>
<td>Externalizing behaviors</td>
<td>5.1</td>
<td>5.31</td>
<td>0.0</td>
<td>24.0</td>
</tr>
<tr>
<td>ADL limitation scale</td>
<td>26.4</td>
<td>14.77</td>
<td>0.0</td>
<td>50.0</td>
</tr>
<tr>
<td>Age</td>
<td>12.0</td>
<td>4.73</td>
<td>4.0</td>
<td>20.0</td>
</tr>
</tbody>
</table>

demand PCS, and are thus more impaired than other children covered by Medicaid and living in the community. Almost 60% of the children in this sample had a special condition that required more PCS support; just over 40% had an impairment that required more PCS support. A quarter of the sample (25.2%) needed some measure of two-person assistance. The average age was 12, and study participants were authorized by case managers to receive an average of 24.5 hours of PCS support per week, which was very near the mean for all 2,642 children in our original sample (25.4 hours).

We used an a priori model in our structural equation modeling based on similar analyses of a much smaller database (Fournier et al., 2010a). The a priori model, when estimated, also proved to be the corrected best-fit model (Figure 1). The results clearly illustrate that the ADL support scale serves as a conduit through which a wide range of information about a child’s support needs pass. The following had statistically significant and independent effects on activity limitations and assistance provided: the presence of one or more special conditions, the presence of one or more impairments, ID level, the presence of cognitive difficulties, the need for two-person ADL assistance, and incontinence. These variables explained 67% of the variance in the ADL scale score. Activity limitations directly affected the number of hours authorized and had an indirect effect mediated by externalizing behaviors. Age had an independent, direct effect on PCS hours. Caregiver limita-
tions did not have a significant effect, but that may be because for a child to receive PCS, a caregiver must have some type of limitation. The variables in the model explained 26% of the variance in hours authorized.

We then conducted a MLM to determine the degree to which variation among the case managers affected the number of hours authorized. This multilevel model was used to analyze a data structure where children (level-1) were nested within case manager (level-2). This was examined to answer the question: How much of the variance in the allocation of PCS hours depends on the case manager? The MLM analysis included two models: an intercept-only (null) model with only case manager identification (level-2), and a intercepts-plus slopes (full) model with children’s characteristics and case manager identification. The analysis was performed in Stata 11 (Stata, 2009) using the default restricted maximum likelihood (REML) regression, as the sample size was large enough to diminish any difference between REML and full maximum likelihood regression (FML). The child-level characteristics were not centered around the mean for each case manager. Grand mean centering was not utilized as we were only interested in the partitioning of the variance across the two levels, not in the relationship between level characteristics and outcome. The data-set included only children’s records with complete data. Case managers who conducted only four or less assessments were grouped together as a single assessor. This resulted in a sample of 912 children’s records and 88 unique case managers.

The null model regressed case manager identification, as a random effect, on the number of PCS hours allocated. The resulting intraclass correlation coefficient can be used to partition the variance across levels. This coefficient is equal to 0.165, meaning 16.5% of the variance in the number of PCS hours allocated is attributable to case manager.

The full model regressed case manager identification as a random effect plus children’s characteristics (including all the variables from the main analysis) as fixed effects. In full model we used the level-2 (case manager) variance to calculate what proportion of the total variance is represented by the level-2 (case manager) variable. According to this calculation, 14% of the variation in the allocation of PCS hours is determined at the case manager level when child-level characteristics are included in the model. We then subtracted the level-2 (case manager) variance and the full model error variance from the total variance. We divided that sum by the total variance to get the variance explained by the level-1 (children) variables. This was determined to be 20.5%. Considering the explained variance for each level, case manager identity (level-2) explained 14% of the total variance. Children’s characteristics explained 20% of the total variance (Rabe-Hesketh & Skrondal, 2008; Snijders & Bosker, 1999).

Given the importance of support for functional limitations in determining service levels, we embarked on more finely grained analyses of the relationship between ID level and support needs in different ADLs. We analyzed data on each of the 10 ADLs. In all instances, higher ID severity resulted in more intense support. However, two basic patterns of support emerged. The first of these applied to what might be considered “less complex activities” (bed mobility, positioning, locomotion inside, locomotion outside, and transfers). These activities involve clearly delineated task sequences and depend on the most part on large muscle group strength and gross motor control. The results for these types of activities are illustrated with the example of transfers in Figure 2. As one expects, the need for total assistance increased and the level of independence decreased for more severe ID levels. However, these distributions were largely bimodal. Children needed either no hands-on assistance, or they were totally dependent. For these tasks, few children needed hands-on assistance while they actively participated in the completion of the task.

For more complex ADLs that involve sequences of activities and fine motor control the pattern of the results changed (eating, toilet use, personal hygiene, dressing, and bathing). Figure 3 displays this change using the results for toilet use. The fundamental difference in Figures 2 and 3 is the degree to which hands-on assistance becomes an important part of care. For those identified as profound, almost all were totally dependent in these more complex activities. For other children, the bimodal pattern of the less complex ADLs disappeared, and hands-on assistance became more important, especially for those reported with mild or moderate ID.

![Figure 2](image2.png)  
**Figure 2.** Levels of support provided in transfers and intellectual disability (ID) level. $\chi^2 = 278.13/df = 4; \phi = 0.50$.

![Figure 3](image3.png)  
**Figure 3.** Levels of support provided in toilet use and intellectual disability (ID) level. $\chi^2 = 257.16/df = 4; \phi = 0.48$.

Discussion

Although perceived needs of the individual are predictive of PCS and other home care services to persons with ID (Harrington & Kang, 2010; Kang & Harrington, 2008), imbalances in service allocation exist and these may be attributable, in part, to problems in program administration (Harrington, Ng, Kaye, & Newcomer,
On average, children with between 3 to 13 years of age receive less PCS than adults with ID (Harrington & Kang, 2010), so it is imperative to identify factors that influence decisions about the services these children receive. In the present study, we were chiefly concerned with the degree to which PCS hours authorized for children with ID was determined by family reports of child needs in the home.

Our model revealed that several factors affected family reports of children’s activity limitations. Presence of profound and severe ID, for example, was associated with greater impairments in ADLs, and ADL impairments were directly associated with the number of PCS hours authorized. ID severity has been associated with PCS hours in prior work (Harrington & Kang, 2010), but to our knowledge the present study is the first to indicate this effect occurs primarily as a function of reported impairments in ADLs. Moreover, the variance accounted for in ADLs (67%) and PCS hours authorized (26%) in the current model were quite similar to the variance accounted for in these variables in our previous investigation of all children assessed for PCS in Texas (58%, 29%, respectively; Elliott et al., in press).

These results indicate that older age, greater ADL impairments, and more externalizing problem behaviors are influential in determining the allocation of PCS hours. Older children may be difficult to manage for a variety of practical reasons (e.g., increased height and weight), but our findings indicate that problematic behavioral patterns—such as verbally abusive behavior, aggressive acts, menacing and bullying behavior—necessitate more care assistance in the home. To our knowledge, this study may be among the first to document the independent contribution of externalizing behaviors for increased PCS hours among children with ID.

ID level is determined by a child’s IQ score and by deficits in adaptive behavior. Various observational and psychometric measures assess adaptive behavior. The present study indicates that an assessment of a child’s ADL limitations in the home environment is vital in determining the care needed by a child, above-and-beyond any information conveyed by the ID diagnosis alone. Knowledge of a specific diagnosis or condition is insufficient for understanding the functional needs of the child in the home environment. The findings of the current study reveal that the relationship between diagnostic conditions and the hours of PCS authorized by case managers are best understood as factors affecting the presence of ADL limitations and externalizing behaviors.

The results of the MLM to determine the impact of who performed the assessment on hours authorized told the same tale. Individual characteristics dominate the explained variance. Roughly, two thirds of the explained variance derives from individual characteristics, while the remaining third is attributable to variation among assessors. However, it is clear that assessors’ personal attitudes and varying interpretations of what they hear and see in the home play a significant role in determining the amount of care they authorize for a child with ID. It is interesting to note that research on all children in the EPSDT program receiving PCS indicates that for the population as a whole, assessors are more important. Their variation accounted for almost one half of the variation in models predicting PCS hours authorized (Elliott et al., in press).

This research also identified the two basic patterns of ADL support provided by formal caregivers. For less complex activities, children either exhibit total dependence or require no regular hands-on assistance. In performing complex activities, children with less than profound ID need considerable hands-on assistance that falls short of total dependence. These results underline the necessity of assessment systems and service packages capable of differentiating among and providing widely varying levels and patterns of support, depending on a child’s level of ID.

The results of the present study take on some measure of importance, given the drive to move more long-term services and supports to the community. Our results underscore the need to scrutinize family reports of child’s needs, generally, and to develop a greater appreciation of the factors that influence the interaction between the family caregiver (an informal care provider) and the case manager (a representative of a formal care service provider). These family members usually provide the majority of care, assistance and coordination of services for children with ID, and they are sensitive to imbalances that may occur between their needs and the services available to them (Resch et al., 2010). Unmet needs are strongly associated with decreased well-being among these families (Blumberg & Carle, 2009). Coordinated and effective service that promotes optimal community integration and the optimal well-being of the family relies upon a strategic collaboration between these informal care providers and formal health services (Carter, 2008).

The authors recognize several study limitations. We do not know the amount of time each case manager spent interviewing each child and family. Data were obtained in the field under routine, clinical conditions. Therefore, we do not know the actual medical and health data other than that recorded by the case managers, nor do we know the degree to which idiosyncratic factors may have influenced the assessments. Data on the case managers administering the assessments were not collected; hence, assessor characteristics could not be examined. Children in the EPSDT program in the Texas Medicaid system constituted our sample. Therefore, we do not know the degree to which our results would generalize to other state programs.

However, we do feel that the results of the present study provide further evidence of the importance of understanding the dynamics of assessing child and family needs in the home, including the assessment of needed supports, child functional limitations and ADL assistance, externalizing behaviors and co-occurring health conditions. The development and utilization of assessment tools sensitive to person-environment interactions are necessary to inform and guide meaningful public and health policy now and in the future, a future that has the potential to involve large-scale, community-based assistance to empower families living with disability (Elliott & Rath, in press). In addition, the study reinforces the value of working collaboratively with the families in determining the supports and services most useful to family in the home and in the community.

References


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