Medicaid Personal Care Services for Children With Intellectual Disabilities: What Assistance Is Provided? When Is Assistance Provided?


Abstract
We report on the nature and timing of services provided to children with an intellectual disability (ID) identified by a new comprehensive assessment and care planning tool used to evaluate children’s needs for Medicaid Personal Care Services (PCS) in Texas. The new assessment procedure resulted from a legal settlement with the advocacy community. Participants in the study were 1,109 children ages 4–20 with an intellectual disability diagnosis who were assessed between January and April of 2010. The need for assistance is higher on Saturday and Sunday, when school services are not available. We report differences in service patterns for children who vary in ID severity. Finally, we consider the implications of our results for policies and programs that serve families with children with an ID.

Key Words: Medicaid Personal Care Services; intellectual disabilities; caregivers; home-based care; community-based services and supports

Family members usually provide the majority of care, assistance, and coordination of services for children with an intellectual disability (ID) (Heller & Schindler, 2009). For those who qualify, Medicaid home care services can play a critical role in helping families of children with an intellectual disability (ID). Home-based support services for all vulnerable populations have grown considerably over recent years (Rizzolo, Hemp, Braddock, & Schindler, 2009) and are likely to continue to expand as the provisions in the Affordable Care Act that increase the availability of home- and community-based services for Medicaid recipients are implemented (Caldwell, 2010; Reinhard, Kassner, & Houser, 2011). State policies concerning home- and community-based services (HCBS) vary tremendously, and research that informs these policies is needed (Rizzolo, Friedman, Lulinski-Norris, & Braddock, 2013).

Several issues complicate and potentially compromise the effective allocation and provision of Medicaid home-based services to families of children with an ID. Some of these barriers derive from the social and organizational context in which Medicaid services are delivered. Family members often have difficulty understanding the array of program services available or how to access the services (Resch et al., 2010). They also experience difficulty determining if they are receiving all appropriate services available for their child (Pollack, 2011). These barriers to proper care are especially serious for families in which the caregivers have lower levels of education (Porterfield & McBride, 2007).

More importantly, families often encounter confusing and inconsistent eligibility requirements for home-based services because many policy makers traditionally view home care for children with disabilities as a family responsibility (Buhler-Wilkerson, 2007). This perspective among policy makers and program administrators leaves officials greatly concerned that the PCS provided to a child will be requested or used for “babysitting” rather than to compensate for or overcome impairments in functionality.

Legal and other problems can ensue when states, as they too often do, fail to conduct appropriate assessments and, based on those assessments, develop
treatment plans that provide needed services (Musumeci, 2011; Peters, 2006). However, states continue to vary widely in the strategies used to determine a child or youth’s need for personal care services. Some assessment processes are elaborate, while others are strikingly informal. These assessments range from an “eyeball” impression of a child’s apparent disability (in South Carolina) to determining if a child has one of 100 medical conditions that can qualify the child for services (in North Dakota; Musumeci, 2011).

Until 2005, the assessment system used for children in Texas was far from ideal. State staff members, whose main responsibility was assessing frail older persons, also assessed children with special health care needs. The assessment tool used to understand a child’s functional needs and strengths was the same instrument used to evaluate frail older adults. In addition, rules were interpreted in such a way that many children with psychosocial or developmental challenges were denied services. Also, the families of infants (less than four years old), no matter what the child’s challenges, were routinely denied service because infant care was considered a “family responsibility.”

In Texas, many children in the Medicaid program receive PCS through the EPSDT-Comprehensive Care Program when they require assistance with activities of daily living (ADLs); instrumental activities of daily living (IADLs); or health related functions because of a physical, cognitive, or behavioral limitation related to their impairment or chronic health condition. According to citizen advocates, the Texas EPSDT program did not provide services for all physical and mental conditions found during screenings. This dissatisfaction resulted in legal action.

As part of the 2005 partial settlement agreement of Alberto N. et al. v. Suehs, the Texas Health and Human Services Commission was required to implement a new comprehensive assessment of the personal care needs of Medicaid-eligible children with special needs. The case was originally presented in the Alberto N. et al. v. Don A. Gilbert lawsuit filed in 1999 in the U.S. District Court for the Eastern District of Texas. Alberto N. et al. v. Don A. Gilbert (2002) was part of a series of Olmstead cases brought against the state of Texas and was the initiating case in a group of partial settlement agreements known collectively as “the Alberto N. Agreement.”

Using the Personal Care Assessment Form 4–20 (for individuals 4 to 20 years of age), one of the comprehensive assessments mandated in the 2005 settlement agreement, state staff began assessing individuals seeking or currently receiving PCS. Following this evaluation, assessors authorized a specific number of hours of PCS to support the primary caregiver in providing ADL/IADL assistance to the youth. Assessors based their recommended authorization of hours on a discussion between the assessor and the household concerning the need for assistance with each activity of daily living and instrumental activity of daily living for each day of the week. Part of this discussion was devoted to what caregiver challenges (e.g., work, school, disability) affected the need for Medicaid attendant care.

The implementation of these new assessment tools helped standardize the assessment process. In addition, the data collected during these assessments provided a truly fine-grained picture of the assistance required to meet the day-to-day functional needs of children with an ID, taking into consideration their needs during the week (when these children spend much of the day at school) and on the weekend (when they are home with family). In this research, we use these detailed data to address three issues that should help us understand how best to evaluate the attendant service needs of children with an ID:

- What types of attendant services were provided?
- When were these services provided?
- Did the severity of a child’s ID affect these services?

Addressing these three questions requires relatively simple descriptive analyses. However, data such as these have not heretofore been available to the research and advocacy communities. The results of this study should offer policy makers and others some of the in-depth information needed to assist them to clearly understand how best to determine the needs of children with an ID. The responses to these three questions should be of assistance to policy makers, advocates, and researchers who hope to revise or refine the procedures in their states for authorizing attendant care to children with special health care needs, particularly children with an ID.

**Methods**

**Data**

The Personal Care Assessment Form (PCAF; Phillips et al., 2011; available at http://pcaf.tamu.edu/) for children ages 4 through 20 was used in this study. The PCAF was partially based on variants of
items included in the Minimum Data Set (MDS) for Nursing Home Resident Assessment (Hawes, Phillips, Morris, Mor, & Fries, 1997). The MDS was developed for the Centers for Medicare and Medicaid Services (CMS). CMS has also mandated its use in skilled nursing facilities for reimbursement under its postacute care prospective payment systems (Heinemann & Mallinson, 2010).

Some PCAF items were also based on variants from the Minimum Data Set for Home Care (MDS-HC©) developed by interRAI (Morris et al., 1997), now labeled the interRAI HC, as well as the interRAI assessment for adults 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 an ID provide strong evidence of their reliability and validity in the adult ID population (Martin et al., 2007). The selection, tailoring, and reworking of items to make them applicable to children with special health care needs, as well as the development of additional items, 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 and the advocacy community. Previous research using the PCAF has shown high internal consistency for a variety of PCAF scales representing functional status (α's range of .89 to .94, Fournier et al., 2010; Phillips et al., 2012). It also provides evidence of acceptable to excellent interrater reliability for almost all PCAF items (Phillips et al., 2011). The study and its associated protocols were reviewed by the Institutional Review Board at Texas A&M University.

Texas Department of State Health Services case managers completed the PCAF assessments in a home visit in which the primary caregiver and the child were present. A few case managers trained as nurses, but licensed social workers with a master's degree in social work (MSW) comprised the vast majority. The process of completing the assessment involved a review of records prior to the home visit. The activities in the home visit involved querying the caregiver, observing the child, and questioning the child (if the child was capable of responding).

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 appeared.

This study used data collected from January to April of 2010 for 2,642 children ages 4 through 20 years. The study sample included all children assessed for PCS during those four months, but this study focused on the 1,109 children in the sample with a diagnosis of intellectual or developmental disability and a classification of the severity of that disability. Case managers coded ID on a PCAF item that identifies children with an intellectual disability (ID, the current terminology), mental retardation (the term used prior to ID in Federal Special Education law), or developmental disability (the term used in Federal Special Education law for children before age 7; this term changes to ID by age 7). This excluded children separately coded for autism, Down syndrome, attention deficit disorder, or some other pervasive developmental disorder (e.g., Rett syndrome, Asperger syndrome) who did not have an indication of the severity of their disability.

Analyses
The determination of hours of Medicaid PCS support authorized is a dynamic process involving both the case manager and the primary caregiver or child (Patnaik et al., 2011). Based on information obtained during the assessment, case managers completed a seven-day record on the PCAF that identified the PCS hours authorized for the child. This detailed worksheet required case managers to record the time of the day that PCS was needed, the ADL/IADL task for which PCS was needed, and the amount of PCS minutes that were needed for each task. Twenty-four rows were available for each day of the week, enabling case managers to record details of the PCS authorized at every hour of the day for every day of the week.

The rich PCS authorization data allowed us to examine the amount of PCS authorized for each day of the week, broken down by the ADL or IADL for which PCS were provided. This effort examined nine activities of daily living (ADLs): bed mobility, eating, transfers, locomotion inside the dwelling, locomotion outside the dwelling, toilet use, dressing, personal hygiene, and bathing. We also examined assistance with seven instrumental activities of daily limitations (IADLs): meal
preparation, medication assistance, telephone use, escort to medical appointments, laundry, light housework, and grocery shopping.

We do not offer or evaluate hypotheses about the nature and timing of services. Instead, our analyses answer basic questions about the personal care services provided to these children. These analyses examine trends in PCS authorizations over the week and compare children with a mild or moderate ID (n = 612) to children with a severe ID (n = 351) or a profound ID (n = 144). Previous research using discriminant function analysis supported combining children coded as mild or moderate into a single category (Patnaik et al., 2011).

**Results**

**Characteristics of Sample Members**

Table 1 presents descriptive data on our sample and compares the children with an ID included in our sample to other members of the sample. As these data indicate, in each ADL and IADL, a higher percentage of children with an ID receive attendant care than do other sample members. The average absolute difference between these groups, across all ten ADLs, is 6.6%. One observes the greatest differences in assistance with eating, toilet use, and locomotion. Only the differences in assistance in bathing, transfer, and positioning are not statistically significant (p < .003).

The average absolute difference in IADLs is somewhat larger (9.6%). The IADLs in which the difference is greatest were telephone use and escort to medical appointments (13%), followed by meal preparation (11%). These children, generally, did not prepare their own meals. Like assistance in all IADLs, this was assistance to the caregiver because their child’s condition affected the performance of this task, making it more time consuming or requiring more than one person to perform. All

<table>
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<tr>
<th>Table 1</th>
<th>Descriptive Data for Children Receiving PCS With an ID (n = 1109) and Without an ID (n = 1533)</th>
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<tbody>
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<td>Child Characteristics</td>
<td>Response</td>
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<tr>
<td>Child gender</td>
<td>Male</td>
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<tr>
<td>Need assistance with completing ADL</td>
<td>Bed mobility</td>
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<tr>
<td></td>
<td>Positioning</td>
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<td></td>
<td>Eating</td>
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<td>Transfers</td>
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<td>Toilet use</td>
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<td>Personal hygiene</td>
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<td>Bathing</td>
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<td>Need assistance with completing IADL</td>
<td>Meal preparation</td>
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<td>Medication assistance</td>
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<td>Telephone use</td>
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<td>Escort to medical appointments</td>
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<td>Laundry</td>
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<td>Ordinary/light housework</td>
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<td>Grocery shopping</td>
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<td>Continuous variables</td>
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<td>Age</td>
<td>Children with an ID</td>
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<td>PCS hours authorized</td>
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differences among our two groups were statistically significant.

Children with an ID also received a few more hours of PCS (2.69) on a weekly basis, on average, than did other children receiving attendant services. However, this difference was not statistically significant.

When one focuses on only those children with information on ID severity, one also sees differences. Those with a mild/moderate ID received an average of 21.2 hours of PCS, those classified as severe received an average of 27.6 hours, and those children placed in the profound ID category received an average of 31.0 hours of attendant care each week. In a simple analysis of variance, ID level explained over 8% of the variance in PCS hours.

When one delves deeper into the characteristics of these groups, one sees that level of ID severity affects a number of important determinants of PCS authorizations: the number of medical diagnoses, the number of health problems, the likelihood of incontinence, the need for two-person assistance, cognitive and communication skills, and ADL impairment. Structural equation modeling with this sample in an earlier study indicated that ID severity affects PCS hours indirectly through these differences in health status and functionality (Patnaik et al., 2011).

Patterns in PCS Provided for ADLs
When we look only at the average number of hours of attendant care, we assume that PCS is something like a water faucet emitting a steady flow of services across the week. As Figure 1 demonstrates, that is not the case. This figure clearly shows that children with different levels of ID severity receive significantly different levels of attendant care service on every day of the week. While PCS flows into a home relatively steadily during the weekdays, the flow increases during the days of the weekend. This change is most notable for those children with a profound ID.

Patterns in PCS Provided for IADLs
Figure 2 shows that assistance with IADLs is almost an entirely different type of endeavor than ADL assistance. With IADLs, one sees no consistent pattern related to ID severity or across the days of the week.
Discussion

These findings illustrate the kind of information required for informed Medicaid policies that serve families of children with an ID. Prior to the Alberto N. agreement, these children would have experienced unmet needs because the state tied PCS awards to a woefully inadequate assessment instrument and process. In addition, under the previous policies, the EPSDT program did not consistently consider the caregiver's inability (physical or otherwise) to provide for the functional needs of eligible children. This, too, left many children with an ID without necessary services. The restructuring of the EPSDT program in Texas in the wake of the Alberto N. agreement provided a much-needed benefit to children with disabilities and their families.

One of the important policy lessons that emerged from this research is that information about the level of ID severity, not just the presence of an ID, must be included in assessment tools used to ascertain the need for attendant services among children with an ID. While the need for such information seems obvious, it is not universally acknowledged. The initial PCAF reliability tested by the research team included ID severity level. However, state staff members requested that the research team remove ID severity level from the instrument; they claimed they did not need that information to assess for PCS needs. Therefore, the state dropped the item from the initial PCAF implemented across the state.

After additional investigation by the research team using the reliability test data (Fournier et al., 2010) and showing that the level of severity was a significant factor in PCS decision making, the state returned the item to the assessment the next year in its first round of revisions. Policy makers with very different goals and perspectives who are interested in implementing assessment systems for children may have little knowledge of the nature and needs of children with an ID. The availability of information from earlier implementations of such instruments, like that in Texas, can provide valuable information for both officials and advocates.

We found that both groups of children with an ID require, and are provided, more PCS hours overall on weekends compared to weekdays. Unlike residents of nursing homes who are in the same setting seven days a week, most children with an ID
are in school during the week. Many ADLs that require adult monitoring or application are done in the school setting as part of the child's Individual Education Plan (IEP). This results in a pattern of significantly more PCS provided on weekends than weekdays for ADLS such as locomotion outside, toilet use, and eating. In contrast, other functional tasks are performed regularly through the week by the caregivers in the home and hence the amount of PCS provided for these tasks remains steady through the week (e.g., bed mobility, locomotion inside, bathing, and dressing). The changes in a child’s environment over a 7-day period are important to understanding the child’s overall needs. The changes from weekday to weekend vary by ID severity. Many adult home care instruments assess needs over the 3 days prior to assessment. Our findings clearly support the use of a 7-day time period for assessing child home care assistance and needs. At the very least, every effort should be made to assess both weekend assistance needs and weekday needs.

These findings also support the necessity of sensitivity to the vagaries of school attendance and to school calendars in assessment and service systems for children. Schools are an important source of functional assistance to children with an ID or other special health care need. Attendant service in the Medicaid program authorized for a child of school age should vary with the amount of time a child is in school. At a minimum, that seems to call for separate care plans for the school year, school holidays, and school vacations.

The lack of observed differences in the pattern of IADL needs indicates that a child's ADL needs and ID severity provide no guidance about his or her IADL assistance needs. In order to provide all medically necessary assistance, service programs must evaluate ADL and IADL assistance separately.

The present study reports information that resulted from a sensitive, comprehensive assessment of child and family needs as perceived and reported by the family caregiver and recorded by a trained caseworker who conducted the assessment. This collaboration is consonant with informed disability policy that promotes personal capacity development, empowerment, and involvement in decision making (Shogren & Turnbull, 2010). In our view, policies that promote a collaborative partnership between service providers and family caregivers are more likely to result in the delivery of appropriate services that serve the best interests of the child and the family.

Finally, our research demonstrates the positive role that advocacy and litigation can play in assuring proper service allocation to vulnerable populations. Often, children with an ID in our sample received between 20 and 30 hours of PCS each week. For many of these children, those services would not have been available prior to legal action, pre-trial settlement, and the resultant reforms. Many states will make needed reforms without legal action brought by a cadre of tenacious and dedicated advocates like those in Texas. Others will follow Texas down the trail to court and into a transparent, court-monitored trek to reform. The experience in Texas implies that meaningful reform can occur, even following long and arduous legal conflict.

References
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Authors:
Timothy R. Elliott (telliott@tamu.edu), Texas A&M University, Educational Psychology, 4225 Harrington, College Station, TX 77845-4225, USA; Ashweeta Patnaik, Emily Naiser, Constance J. Fournier, and James A. Dyer, Texas A&M University; Darcy K. McMaughan and Charles D. Phillips, Texas A&M Health Center.