MEDICAID PERSONAL CARE SERVICES FOR TEXAS CHILDREN, 2010 & 2009

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REPORT TO

THE TEXAS HEALTH AND HUMAN SERVICES COMMISSION

PREPARED BY

TEXAS A&M HEALTH SCIENCE CENTER
SCHOOL OF RURAL PUBLIC HEALTH

TEXAS A&M UNIVERSITY
COLLEGE OF EDUCATION AND HUMAN DEVELOPMENT

TEXAS A&M UNIVERSITY
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MEDICAID PERSONAL CARE SERVICES FOR TEXAS CHILDREN, 2010 & 2009

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EXECUTIVE SUMMARY

Since September of 2008, children for whom responsible adults have sought Medicaid Personal Care Services (PCS) have been assessed using a Personal Care Assessment Form (PCAF). Data from all PCAF assessments during the first six months of its use were analyzed by the research team with members from various components of the Texas A&M University System. Some revisions were made to the instrument in the fall of 2009 (n = 3,068), and data from all PCAF assessments during the first four months of 2010 (n = 2,966) were provided to the research team.

This report provides a comparison of the data from these first and second waves of PCAF assessments. One set of analyses compares all those assessed in the first wave with those children entering the program in 2010. These analyses allow one to address the issue of how much or little program entrants in 2010 differ from children in or entering the program in 2008 and 2009. These analyses involved data on children from 4 to 20 years of age who were assessed using the PCAF 4-20 and children fewer than 4 years of age assessed with the PCAF 0-3. Other analyses focused on those children assessed in both samples with the PCAF 4-20 (n = 836). Too few children under four years of age were assessed in both samples to allow reasonable comparisons.

The Executive Summary presents the major finding of these analyses, so that they may be easily accessible, in the form of a series of bullet-points organized by report chapter.

CHAPTER 1: THE STUDY AND REPORT

- Our data indicate that the number of children in the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) program receiving PCS increased significantly from 2009 to 2010. In 2009, case managers completed an average of 511 assessments per month; in 2010, they completed and average of 661 assessments per month. That difference constitutes an increase of 29 percent on a monthly basis in the number of children being assessed and for whom services are authorized.

CHAPTER 2: A COMPARISON OF CHILDREN AGES FOUR TO TWENTY FIRST ASSESSED IN 2010 VS. 2009

- Children entering the program in 2010 differed from the population served in 2008 and 2009 in their primary need for care. A significantly lower proportion of those entering the program in 2010 had a strictly medical condition, while a significantly larger proportion (66% vs. 52%) has both medical and behavioral/developmental health issues.
- Children entering the program in 2010 exhibited significantly higher rates of anxiety, autistic spectrum, mood, and attention deficit disorder. They were also much more likely to have an intellectual disability (59% vs. 48%).
- 2010 entrants were significantly likely to be moderately or completely dependent in decision-making (79% vs. 72%); to need cueing, redirection, or monitoring (90% vs. 83%); and to engage in a range of problem behaviors.
- In terms of receiving services, new program entrants were less likely to receive physical or occupational therapy but were more likely to receive mental health services (24% vs. 20%).
- Children coming into the program were significantly less likely to be totally dependent in any of the ten activities of daily living (e.g., transfers (29% vs. 23%)).
- The differences noted above provide the basis for significant differences in the percent of clients/responsible adults requesting assistance with activities of daily living or instrumental activities of daily living. New entrants requested less assistance.
- At the same time, the percent of individuals denied requested services uniformly dropped from 2009 to 2010. The differences were small but consistent.
- The need for new or different assistive devices (DME) changed as well. In 2009, 16 percent of clients expressed a need for DME, while in 2010, only 13 percent did so.
- Consistent with these reductions in requests for services, the average number of hours of PCS authorized went down from 26 hours in the earlier sample to 21 hours in the 2010 sample.

CHAPTER 3: A COMPARISON OF CHILDREN UNDER FOUR YEARS OF AGE ASSESSED IN 2010 VS. 2009

- The infants and younger children entering the program in 2010 differ from the population served in 2008 and 2009 in their primary need for care. A significantly lower proportion of those entering the program in 2010 had a strictly medical condition (31% vs. 46%); while a significantly larger proportion (59% vs. 41%) had both medical and behavioral or developmental health issues.
- The younger children entering the program in 2010 resisted Activities of Daily Living (ADL) care (53% vs. 37%), engaged in disruptive behavior and exhibited self-injurious acts (42% vs. 30%) at significantly higher rates than those in the program during the first wave of data collection.
- New program entrants (0-3) in 2010 were not significantly different from other program participants in their needs for assistance in ADLs) or Instrumental Activities of Daily Living (IADLs) due to their conditions or problems.
- New entrants also requested significantly less assistance with activities of daily living or instrumental activities of daily living.
- The denial rate for requested assistance was lower in 2010 for 13 of 14 types of assistance.
- The average number of hours of PCS authorized went down from 24 hours in the earlier sample to 20 hours in the 2010 sample.

CHAPTER 4: COHORT COMPARISON FOR CHILDREN AGES FOUR TO TWENTY

- Over 800 clients were assessed using the PCAF 4-20 during both waves of data collection. This chapter will highlight the differences in the two waves of data collection for those clients.
- A significantly higher percentage (62%) of children re-assessed in 2010 had received a new diagnosis of intellectual disability/MR/DD in the interim. This change is most likely a result of those younger children, earlier characterized with developmental delay resulting from an intellectual impairment, receiving an official diagnosis of intellectual disability.
- The proportion of children reported to have contractures and limitations in range of motion increased significantly from 15 percent and 35 percent in 2009 to 22 percent and 41 percent, respectively, in 2010.
- The proportion of children moderately or completely dependent on others for safe, reasonable decisions also increased significantly from 73 percent in 2009 to 80 percent in 2010.
- The only statistically significant changes in total dependence in ADLs were apparent in the more complex ADLs, such as toilet use, dressing and personal hygiene. The rates of total dependence increased for all of these activities.
- The approved requests for assistance for the cohort members increased significantly for transfers, locomotion, and bathing.
- Denial of requests for individual services did not change significantly for these children between 2009 and 2010. However, in 12 of the 14 potential areas of assistance, the percent of requests for assistance went down. This is true for all requests for ADL assistance.
- The average PCS hours authorized per week for these children increased significantly from 24 hours in 2009 to 26 hours in 2010.

LIST OF EXHIBITS

CHAPTER 1: THE STUDY AND THE REPORT

September 2007, under the leadership of the Texas Health and Human Services Commission (HHSC), case managers in the Department of State Health Services (DSHS) have been assessing children with special needs, newborns to those 20 years of age, to determine their level of need for Medicaid Personal Care Services (PCS). For the first year of this new arrangement, assessments were performed using an interim assessment instrument.

In September 2008, case managers began using assessment forms developed through a contract issued by the HHSC. This contract called for the development of assessment instruments specially designed for use in determining the PCS needs of children enrolled in the Fee For Service (FFS) system. Two multi-dimensional assessment instruments were developed and tested as part of this contract. The first instrument was the Personal Care Assessment Form 0-3 (PCAF 0-3) that is used to assess the PCS needs of all children seeking or receiving assistance who are under four years of age and enrolled in the FFS system. The second instrument was the Personal Care Assessment Form 4-20 (PCAF 4-20) that case managers use to assess all children who are from 4 years to 20 years old in the FFS system and seeking or receiving PCS services.

Many of the items on the PCAF instruments were initially developed as part of the Minimum Data Set for Nursing Home Resident Assessment and Care Screening (MDS) or the Minimum Data Set for Home Care (MDS-HC)©. These instruments and items were chosen after a review of the assessment tools used by other states to assess children receiving home care services. One of the reasons MDS-based instruments were chosen was their explicit focus on functional status, which is a key issue in determining the need for personal care. In addition, these assessment tools are used in other sectors of the health care arena in Texas (e.g., nursing homes, managed care, and home health), so the possibility for continuity of information across care settings was enhanced. Where necessary, the items and the training material were modified to assure their relevance to children with chronic conditions or impairments. In addition, a variety of items were purpose-built by the research team for the assessment.[1]

For the first six months of operations using the PCAFs, DSHS case managers submitted all completed PCAFs to Texas A&M University.[2] These paper forms were reviewed and entered into an electronic database. Texas A&M University's Public Policy Research Institute (PPRI) received a total of 3,068 assessments. One hundred and seven of these assessments were not included in our analyses. Eight of the assessments could not be used due to high levels of missing data, and 99 assessments involved no allocation of PCS hours. The analyses presented here are restricted to data on 2,961 children. The PCAF 0-3 data include 201 children. The PCAF 4-20 data include 2,760 children.

In the second year of the use of the PCAF assessments, DSHS case managers submitted all PCAF assessments completed between January 1, 2010 and April 30, 2010 to PPRI at Texas A&M University. The research team received 2,694 completed assessments during that time period. Fifty-two were not used because of high levels of missing data or no allocation of PCS hours. These figures indicate a significant increase in the number of children in the Early And Periodic Screening, Diagnostic and Treatment (EPSDT) program receiving PCS. In 2009, the case managers completed 511 assessments per month; in 2010, they completed 661 assessments per month. That difference constitutes an increase of 29 percent in the number of children being assessed on a monthly basis.

This report is devoted to presenting data on any differences that appear between the assessments done in 2010 and those done in 2009. Chapter 2 presents comparison of those children 4-20 years of age who were assessed in 2009 and those children assessed for the first time in 2010. Chapter 3 presents similar data for those children who were assessed and were

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[1] The MDS-HC© was developed by inter*RAI*, which is an international organization of health professionals in more than 30 countries. inter*RAI* is dedicated to the development of assessment instruments for vulnerable populations around the world. More information on inter*RAI* can be obtained www.interrai.org.

[2] Nine of the eleven state health regions provided PCAF data from September 2008 through February 2009. Implementation was delayed in two regions because of the demands placed on DSHS staff by hurricane damage. These regions supplied data from December 2008 through March 2009.

under four years of age. These chapters represent “snapshots” of who is in the PCS program at two different time points. These two chapters allow readers to see in what ways the PCS population is changing.

Chapter 4 provides information on those children ages 4-20 who were assessed both in 2009 and 2010. Chapter Five consists of a short note indicating why such comparisons were not possible for those children under four years of age.

Information on items other than those provided in the text or on items not discussed in the text can be found in the appropriate appendix to this summary report. In addition, the exhibits presented in the text do not present standard errors of the estimates. Such items introduce a great deal of “clutter” into a presentation largely aimed at stakeholders rather than behavioral scientists. Standard errors, however, are presented in Appendices B and C along with the frequency distributions. Asterisks are used to identify those characteristics on which the two samples differ significantly. The different number of asterisks indicate the degree (* = $p < .05$; ** = $p < .01$; *** = $p < .001$) to which the observed difference is likely to be due to sampling or processing error. Given the larger number of comparisons, which increases the likelihood of significant findings, it is best to give serious consideration to those differences marked with two or three asterisks.

CHAPTER 2: A COMPARISON OF CHILDREN AGES FOUR TO TWENTY FIRST ASSESSED IN 2010 VS. 2009

This chapter presents frequency distributions for some of the assessment items for children ages four to twenty who were assessed for the first time in 2010, and compares them to children assessed in 2009. Information on those items not highlighted in this chapter can be found in Appendix B.

In 2010, PCAF assessments were completed for 2,694 children ages four to twenty. Fifty two assessments were not used because of high levels of missing data or PCS hours not allocated. Of the remaining, 1765 children (67%) had not been assessed during the previous round of data collection in 2009. In this section, we compare these 1765 children to the 2,760 children ages four to twenty who were assessed in the previous round of data collection in 2009. These comparisons make evident any differences in those children in the program in 2009 and those children entering the program in 2010.

Case managers identified whether the child was facing only medical challenges, only psychiatric, behavioral, or developmental challenges, or both types of challenges. In the second round of data collection in 2010, case managers indicated 13 percent of the children ages 4 to 20 had a medical condition alone that qualified them for services, 66 percent had both a medical and a behavioral or developmental problem to be addressed by the Medicaid PCS program, and the remaining 21 percent were classified as having only a behavioral or developmental problem with no accompanying medical conditions.

This distribution is significantly different from the previous round of data collection in 2009 where nearly a quarter of the children ages four to twenty (24%) had a medical condition only, 52 percent had both a medical and a behavioral or developmental problem and 24 percent had only a behavioral or developmental problem. This higher proportion of children with behavioral or developmental problems coming into the program in 2010 compared to those first assessed in 2009 results in some of the significant differences discussed in the sections below.

SPECIFIC DIAGNOSES, PROBLEMS, AND CONDITIONS

Exhibit 2.1 provides prevalence rates for the most common disorders and conditions reported for children ages four to twenty. Asthma or other respiratory disorders, cerebral palsy and epilepsy or other seizure disorders were the most common medical problems faced by both groups of children. The prevalence rates for medical diagnoses were very similar for the two groups, with a few exceptions: a significantly smaller proportion of children first assessed in 2010 were diagnosed with asthma or other respiratory disorders, cerebral palsy, epilepsy or other seizure disorders and paraplegia/tetraplegia/quadriplegia compared to children first assessed in 2009.

The prevalence rates for psychiatric/developmental/behavioral diagnoses were significantly higher for the children entering the program in 2010 compared to children assessed in 2009. About 60 percent of children assessed in 2010 displayed intellectual disability/MR/DD, while more than a third displayed attention deficit disorder (35%) and about one-fifth displayed autistic disorders (22%) or mood disorders (19%).

The medical, behavioral, and developmental problems with which these children and households were dealing resulted in a variety of conditions that profoundly affected their personal care. Prevalence rates for these health conditions were very similar in both groups of children with one exception: a significantly smaller proportion of children assessed in 2010 were bed bound or chair-fast (11%) compared to children assessed in 2009 (16%). In both rounds of data collection about one-third of the children had limitations in range of motion. About 15 percent had contractures or falls related to their condition. Approximately one-fifth had problems with chronic pain. In terms of sensory deficits, both groups of children were similar, with about 13 percent having impaired hearing and a little over a third having impaired vision.

Exhibit 2.1: Prevalence of Medical, Behavioral, or Developmental Problems in

Children Ages Four to Twenty

DISORDER OR PROBLEM	PERCENT	
	2009 (n = 2760)	**2010 (n = 1765)**
MEDICAL DIAGNOSES		
Asthma/respiratory disorder**	24.8%	28.9%
Cerebral palsy***	24.4%	19.8%
Epilepsy or other seizure disorders*	28.8%	26.0%
Paraplegia/tetraplegia/quadriplegia**	11.2%	8.4%
PSYCHIATRIC/DEVELOPMENTAL/BEHAVIORAL DIAGNOSES		
Anxiety disorders***	13.6%	17.7%
Autistic disorders***	16.7%	21.8%
Attention deficit disorder***	25.7%	35.1%
Disruptive disorders***	10.7%	14.1%
Intellectual disability/MR/DD***	48.4%	59.3%
Mood disorders***	14.1%	19.2%
HEALTH CONDITIONS		
Bed bound or chair fast***	16.1%	10.9%
Contractures	14.9%	16.2%
Fall related to condition	13.5%	15.5%
Limitation in range of motion	35.3%	33.3%
Pain interferes with normal activities	17.1%	19.0%
SENSORY PROBLEMS		
Impaired hearing	13.6%	13.6%
Impaired vision	33.9%	34.2%

COGNITIVE FUNCTION

A child's ability to independently perform the activities considered under the PCS benefit is not simply a function of their physical conditions (e.g., chair-fast) or medical diagnoses (e.g., arthritis). It is also a function of the child's cognitive function. A child of four and a young person of twenty are unlikely to be at the same developmental stage cognitively. Nonetheless, a problem with cognition in either individual may significantly affect their ability to care for themselves or to help others care for them.

A significantly higher proportion of children assessed in 2010 faced cognitive challenges compared to children assessed in 2009 (see Exhibit 2.2). Approximately 60 percent of the children assessed in 2010 had problems with short-term memory or long-term memory, while approximately 90 percent needed cueing or monitoring to complete most or almost all multiple-step tasks (e.g., go to your room, get your shoes, and bring them back to me in this room).

Their abilities to make safe or reasonable decisions in their everyday lives were also compromised - about 46 percent were completely dependent on others for safe, reasonable decisions. The change in decision-making came in the much higher prevalence of those who were moderately dependent and the lower prevalence in 2010 of children who were independent or only mildly impaired.

Exhibit 2.2: Cognitive Challenges in Children Ages Four to Twenty

COGNITIVE CHALLENGES	**PERCENT**	
	2009 (n = 2760)	**2010 (n = 1765)**
Short-term memory/recall problem*	58.7%	62.2%
Long-term memory/recall problem***	54.6%	60.2%
Needs cueing, redirection or monitoring***	82.7%	89.5%
COGNITIVE SKILLS FOR DAILY DECISION-MAKING* **		
Independent	11.5%	6.3%
Modified independence	16.2%	14.3%
Moderately dependent	25.5%	32.9%
Completely dependent	46.8%	46.5%

BEHAVIOR PATTERNS

The assistance someone needs with their personal care depends in part on the level of cooperation between the responsible adult and the care recipient. Within this population, barriers to smooth cooperation existed frequently and these barriers often manifested themselves in behaviors that made caregiving more difficult (see Exhibit 2.3). Children assessed in 2010 exhibited problematic behaviors in significantly greater percentages than children in 2009. This may be attributed to the greater proportion of children with behavioral or developmental problems in 2010 compared to 2009. In 2010, about 40 percent of these children exhibited physically abusive behavior, socially inappropriate or disruptive behavior, repetitive behavior, or resisted assistance with ADL help. About a third of children exhibited wandering or verbally abusive behavior. About a fifth of these children exhibited bullying/menacing behavior, self-injurious behavior, or deliberate damage to property.

Exhibit 2.3: Behavior Patterns for Children Ages Four to Twenty

BEHAVIOR	**PERCENT**	
	2009 (n = 2760)	**2010 (n = 1765)**
Wandering**	25.1%	29.4%
Verbally abusive***	24.6%	33.0%
Physically abusive***	28.6%	37.9%
Bullying/menacing behavior***	15.1%	19.5%
Socially Inappropriate or disruptive behavior***	30.2%	40.5%
Repetitive behavior***	30.2%	39.1%
Resists ADL care***	34.3%	42.3%
Injury to self***	17.6%	23.1%
Deliberate damage to property***	14.0%	21.1%

NURSING NEEDS, URGENT CARE USE, AND THERAPY NEEDS

Exhibit 2.4 presents information on nursing needs, urgent care use and therapy needs for the two groups of children ages four to twenty. Nursing needs were similar for both groups with a few exceptions: a significantly lower proportion of children assessed in 2010 had nursing needs for medication management (10%) and uncontrollable seizure disorder (7%) compared to children assessed in 2009 (12% and 10% respectively).

Urgent care use was very similar for the two groups of children. About 10 percent of these children had an unplanned visit to a physician in the last 30 days, while about 5 percent visited the emergency room or were admitted to a hospital.

Therapy needs in children ages four to twenty were also similar in 2009 and 2010 with a few exceptions: a significantly lower proportion of children assessed in 2010 received physical therapy and occupational therapy compared to children assessed in 2009.

As noted earlier, a higher proportion of children with behavioral health needs entered the program in 2010. As one would expect, the proportion of children receiving mental health services also increased from 2009 to 2010. The change from 19.7 to 21.4 percent constitutes a 20 percent increase in the proportion of children who received PCS and mental health services.

Exhibit 2.4: Nursing Needs, Urgent Care Use, and Therapy Needs in Children Ages Four to Twenty

TYPE OF NEED OR SERVICE	PERCENT	
	2009 (n = 2760)	2010 (n = 1765)
MEDICAL/NURSING NEEDS		
Medication management*	12.0%	10.0%
Feeding tube	11.6%	12.6%
Nasopharyngeal suctioning	6.3%	6.3%
Oxygen	5.6%	5.7%
Uncontrollable seizure disorder***	9.6%	6.6%
Unstable medical condition	7.3%	6.4%
Other periodic assessment	7.3%	6.5%
USE OF EMERGENCY MEDICAL SERVICES IN LAST 30 DAYS		
Emergency room visit	8.0%	6.4%
Hospital admission	5.3%	4.4%
Urgent (unplanned) visit to physician	11.1%	10.2%
THERAPY NEEDS		
Physical therapy**	40.0%	35.3%
Occupational therapy*	43.6%	40.2%
Speech therapy	43.0%	45.1%
Mental health services***	19.7%	24.1%

BLADDER AND BOWEL CONTINENCE

Another important aspect of personal care revolves around the client's ability to control his or her bladder and bowel function. An inability to control these functions constitutes an additional burden on responsible adults. Reported continence was very similar in 2010 and 2009 (see Exhibit 2.5). In both years, only about one-third of children had complete control over their bladder function, while almost two in five children had full control over their bowels. A significantly higher proportion (64%) of children assessed in 2010 had nighttime incontinence compared to children assessed in 2009 (61%).

Exhibit 2.5: Continence in Children Ages Four to Twenty

CONTINENCE	**PERCENT**	
	2009 (n = 2760)	**2010 (n = 1765)**
Urinary continence	31.5%	34.2%
Bowel continence	39.2%	42.4%
Nighttime incontinence*	61.0%	64.1%

PHYSICAL FUNCTION

A child or a responsible adult's ability to perform IADLs such as meal preparation, medication assistance, and laundry constitutes one type of assistance that can be provided as part of Medicaid PCS. The performance of ADLs such as positioning, transferring, mobility, dressing, and bathing comprise the other crucial dimensions of that assistance.

However, in assessing children's needs in these two arenas, one must be cognizant that children ages four to twenty represent a wide range of developmental stages. For example, one might expect a twenty year-old to be able to prepare a meal, but one would certainly not expect a five year-old to be independent in meal preparation. For that reason, the PCAF instrument asks two questions about each IADL and ADL. The first of these is how independent the client is in performance of each activity. The second question is whether the child's condition affects the performance of the task (i.e., makes it more difficult or causes it to take longer to complete). For example, a six year-old child may be totally dependent in meal preparation, but the child's condition doesn't make meal preparation more difficult or more time-consuming. In such an instance, no PCS is needed. However, if the child's condition demands a special diet that requires extra time or the child's behavior problems interfere with meal preparation, then PCS may be needed. The information presented in Exhibit 2.6 reflects this reality.

Significantly lower proportions of children assessed in 2010 were totally dependent for IADLs and ADLS, compared to children assessed in 2009. Despite these changes, approximately half of children ages four to twenty were totally dependent in bathing, while about 40 percent of children were totally dependent in toilet use, dressing and personal hygiene.

Exhibit 2.6: Total Dependence for ADL/IADL Assistance in Children Ages Four to Twenty

TYPE OF ACTIVITY	**PERCENT**	
	2009 (n = 2760)	**2010 (n = 1765)**
IADLS		
Meal preparation***	48.7%	43.6%
Medication assistance	39.9%	38.5%
Telephone use	24.4%	22.4%
Escort***	46.3%	42.5%
Laundry*	55.9%	52.9%
Ordinary/light housework***	50.9%	44.3%
Grocery shopping***	40.8%	34.3%
ADLS		
Bed mobility***	19.4%	13.9%
Positioning***	22.3%	17.0%
Eating***	24.4%	19.9%
Transfers***	28.6%	22.7%
Locomotion inside***	23.2%	18.7%
Locomotion outside**	27.6%	23.3%
Toilet use**	45.1%	40.5%
Dressing***	44.7%	38.2%
Personal hygiene***	47.5%	39.9%
Bathing***	54.3%	48.8%

The information on individual ADLs is important, but the total amount of care needed by children is related to the number of ADLs in which assistance is needed, especially hands-on assistance. Exhibit 2.7 presents information on the total number of ADLs in which these children needed/received hands-on assistance in the week prior to their assessment. Roughly, 90 percent needed/received hands-on assistance with at least one ADL. On average, children assessed in 2010 needed/received hands-on assistance with slightly fewer ADLs than children assessed in 2009. While 40 percent of the children assessed in 2009 needed hands-on assistance with six or more ADLS, only 34 percent of those entering the program in 2010 needed that same level of assistance.

The information on ADLs and IADLs provides only a partial portrait of a child's needs for assistance. About 17 percent of these children needed two-person assistance for a transfer, while about 12 percent needed two-person assistance with some other ADL. A significantly lower proportion (26%) of children assessed in 2010 used a wheelchair as their main mode of locomotion compared to children assessed in 2009 (32%). A significantly lower proportion of children assessed in 2010 believed that they needed new or additional DME or assistive devices (13%) compared to children assessed in 2009 (16%).

Exhibit 2.7: Number of ADLs in Which Children Ages Four to Twenty Received Hands-On Care

NUMBER OF ADLs	PERCENT	
	2009 (n = 2760)	2010 (n = 1765)
0	9.2%	10.1%
1	6.1%	5.5%
2	5.5%	6.2%
3	9.5%	9.2%
4	17.1%	19.5%
5	12.2%	15.1%
6	4.9%	5.2%
7	5.3%	4.2%
8	4.9%	5.3%
9	7.2%	6.2%
10	18.1%	13.5%

HOUSEHOLD RESOURCES

Primary responsible adults or responsible adults faced a number of situations that affected their ability to provide care to their child with special health care needs. The challenges or barriers to caregiving reported by responsible adults were very similar for both groups of children (see Exhibit 2.8). A little over a third of responsible adults worked full-time while approximately a quarter had part-time or some other type of working arrangement. Around half of responsible adults experienced interrupted sleep because of the child's needs for assistance or had a physical limitation that made it impossible for them to assist the child with at least some ADLs or IADLs.

It is interesting to note that one sees significant differences in the types of children in the program in 2009 and those entering the program in 2010. At the same time, however, the household resources available to these two groups of children were very similar.

Exhibit 2.8: Household Resources for Children Ages Four to Twenty

HOUSEHOLD RESOURCE	**PERCENT**	
	2009 (n = 2760)	**2010 (n = 1765)**
Responsible adult works full-time	37.8%	36.1%
Responsible adult's sleep interrupted	53.4%	54.6%
Responsible adult physical limitations	49.0%	48.3%

STRENGTHS, NEEDS, AND CARE

Exhibit 2.9 displays the results of the analyses of the types of tasks for which responsible adults were most, or least, likely to request PCS assistance. A significantly lower proportion of children assessed in 2010 reported a need for PCS assistance with IADLs compared to children assessed in 2009. The denial rates for IADL assistance in these two samples were quite similar. The highest denial rate was for requests for medication assistance.

For ADLs, a significantly lower proportion of children assessed in 2010 had reported assistance needs for those ADLs indicating a higher level of ADL impairment. These ADLs include bed mobility/positioning, transfers and/or locomotion/mobility. Denial rates for requested assistance for ADLs remained quite low. Across all the ADLs, the average denial rate was less than two percent. That rate went down in 10 of the 14 potential areas of assistance.

Exhibit 2.9: PCS Assistance Requested and Approved for Children Ages Four to Twenty[¥]

ASSISTANCE WAS REQUESTED FOR A SPECIFIC ACTIVITY	PERCENT REQUESTING & RECEIVING ASSISTANCE[€]		PERCENT REQUESTING & DENIED ASSISTANCE[Λ]	
	2009 (n = 2760)	2010 (n = 1765)	2009 (n = 2760)	2010 (n = 1765)
IADLS				
Meal preparation***	50.3%	39.6%	7.9%	7.9%
Medication assistance***	17.2%	12.0%	10.8%	10.5%
Escort***	21.4%	14.5%	6.0%	8.7%
Laundry***	55.4%	45.2%	6.8%	6.9%
Ordinary/light housework***	51.4%	38.5%	7.4%	7.1%

Grocery shopping***	21.4%	13.8%	8.3%	6.5%
ADLS				
Bed mobility ***	24.8%	19.7%	2.9%	2.1%
Eating	50.6%	50.1%	3.9%	4.8%
Transfers***	36.5%	29.8%	2.3%	1.5%
Locomotion/mobility*	32.8%	31.0%	2.5%	1.5%
Toilet use*	80.2%	77.9%	1.5%	1.0%
Dressing	90.9%	91.8%	1.7%	1.0%
Personal hygiene	88.5%	90.3%	2.3%	1.7%
Bathing	91.6%	93.2%	1.9%	1.4%

[¥] This table includes only those individuals requesting PCS assistance with an IADL or ADL task.
[€] This is the proportion of the total population who requested and received assistance for the task.
[Λ] This is the proportion of the total population who requested task assistance and it was denied.

Exhibit 2.10 presents the distribution of PCS hours authorized for this cohort of children. The average PCS hours authorized per week were significantly lower for children assessed in 2010 (average of 21 hours) compared to an average of nearly 26 hours for children assessed in 2009. However, the hours authorized were lower than the number of hours requested by the client or responsible adult for only about 3 percent of the 2010 population. These results are consistent with those presented in the previous table (2.9), which indicated that less assistance was requested for those children entering the program in 2010.

Exhibit 2.10: Distribution of PCS Hours Allocated for

Children Ages Four to Twenty

POPULATION PERCENTILE	NUMBER OF HOURS	
	2009 (n = 2760)	**2010 (n = 1765)**
90th	44.3	37.6

75th	32.5	27.6
50th	22.1	18.2
25th	15.0	12.3
10th	10.0	8.2

CHAPTER 3: A COMPARISON OF CHILDREN UNDER FOUR YEARS OF AGE ASSESSED IN 2010 VS. 2009

This chapter presents frequency distributions for some of the assessment items for children under four years of age who were assessed in 2010, and compares them to similarly aged children assessed in 2009. Information on those items not highlighted in this chapter can be found in Appendix C.

In 2010, PCAF assessments were completed for 250 children under four years of age. Of these, 42 were renewal assessments and 208 children (83%) had not been assessed during the previous round of data collection. In this section, we compare these 208 children to the 201 children under four years of age who were assessed in the previous round of data collection in 2009. These comparisons make evident any differences between those children in the program in 2009 and those children entering the program in 2010.

Case managers identified whether the child was facing only medical challenges, only psychiatric, behavioral, or developmental challenges, or both types of challenges. In the second round of data collection in 2010, case managers indicated that 31 percent of children under four years old had a medical condition alone that qualified them for services, 59 percent had both a medical and a behavioral or developmental problem to be addressed by the Medicaid PCS program, and the remaining 10 percent were classified as having only a behavioral or developmental problem with no accompanying medical conditions.

This distribution is significantly different from the previous round of data collection in 2009 where nearly half (46%) of the children under age 4 had a medical condition only, 41 percent had both a medical and a behavioral or developmental problem and 14 percent had only a behavioral or developmental problem. This higher proportion of children with both medical and behavioral or developmental problems in 2010 compared to 2009 is the basis for some of the significant differences discussed in the sections below.

SPECIFIC DIAGNOSES, PROBLEMS, AND CONDITIONS

Exhibit 3.1 provides prevalence rates for the most common disorders and conditions reported for this group. The prevalence rates for medical diagnoses were very similar across both waves of data collection. Asthma and respiratory disorders, epilepsy or other seizure disorders, cerebral palsy and failure to thrive were the most common medical problems faced by both groups of children. The prevalence rates for psychiatric/developmental/behavioral diagnoses were also very similar for the two groups, with attention deficit disorder, autistic disorder and intellectual disability/MR/DD as the most common problems faced by these children. The medical, behavioral, and developmental problems these children were dealing with resulted in a variety of conditions that profoundly affected their personal care. Prevalence rates for these health conditions were similar in both groups of children with a few exceptions. A significantly higher proportion of children assessed in 2010 had shortness of breath (21%) compared to children assessed in 2009 (11%).

A significantly higher proportion of children assessed in 2010 had difficulty making themselves understood (90%) compared to children assessed in 2009 (81%). In terms of sensory deficits, both groups of children were similar, with about 15 percent having impaired hearing and a little under one-third having impaired vision.

These results do not contradict those discussed above. The largest change in the population came among those with both a medical and behavioral problem. This means that the children entering the program in 2010 had roughly the same types of medical or behavioral problems as those in the program in 2009. The difference is that more of the children entering the program in 2010 had some combination of medical and behavioral problems.

Exhibit 3.1: Prevalence of Medical, Behavioral, or Developmental Problems in Children Under Four Years of Age

DISORDER OR PROBLEM	**PERCENT**	
	2009 (n = 201)	**2010 (n = 208)**
MEDICAL DIAGNOSES		
Asthma/respiratory disorder	34.3%	29.0%
Cerebral palsy	15.9%	17.4%
Congenital heart disorders	13.9%	10.2%
Epilepsy or other seizure disorders	26.9%	26.0%
Failure to thrive	16.4%	17.3%
Micro/Hydrocephaly	15.9%	12.0%
PSYCHIATRIC/DEVELOPMENTAL/BEHAVIORAL DIAGNOSES		
Attention deficit disorder	10.0%	8.7%
Autistic disorders	11.9%	16.4%
Intellectual disability/MR/DD	30.5%	36.5%
HEALTH CONDITIONS		
Recurrent aspirations	11.9%	18.8%
Bed bound or chair fast	19.0%	12.5%
Shortness of breath*	11.4%	20.7%
Contractures	10.9%	11.1%
COGNITIVE PROBLEMS		
Difficulty making self understood*	81.0%	90.1%
Difficulty understanding others	75.9%	81.2%
SENSORY PROBLEMS		
Impaired hearing	15.4%	14.9%
Impaired vision	30.4%	31.7%

BEHAVIOR PATTERNS

Although young, these children exhibited behaviors that may have been problematic for both their formal and informal responsible adults. Children assessed in 2010 were reported to exhibit problematic behaviors in significantly greater percentages than children in 2009 (see Exhibit 3.2). This may be attributed to the greater proportion of children with behavioral or developmental problems in 2010 compared to 2009. In 2010, approximately half (53%) of these children resisted ADL care, two in five children exhibited sleep disturbances (42%) and disruptive behavior (42%), while approximately one-third engaged in repetitive behavior (34%) and self-injurious behavior (31%).

Exhibit 3.2: Behavior Patterns for Children Under Four Years of Age

BEHAVIOR	**PERCENT**	
	2009 (n = 201)	**2010 (n = 208)**
Repetitive behavior	25.4%	34.3%
Resists ADL care**	36.8%	52.5%
Injury to self**	19.4%	30.9%
Sleep disturbances	33.7%	41.9%
Disruptive behavior**	29.9%	42.4%

NURSING NEEDS, URGENT CARE USE, AND THERAPY NEEDS

Exhibit 3.3 presents information on nursing needs, urgent care use and therapy needs for the two groups of children under four years of age. Nursing needs and urgent care use were very similar for both groups with one exception: children assessed in 2010 reported a significantly higher use of feeding tubes (28%) compared to children assessed in 2009 (22%). Though relatively small in absolute numbers, these children made considerable use of acute care and of emergency medical services; one in five children had an unplanned visit to a physician in the last 30 days, while about one-tenth of children visited the emergency room or were admitted to a hospital.

Therapy needs in children under four years of age were also similar in 2009 and 2010 with one exception: a significantly lower proportion of children assessed in 2010 needed occupational therapy (57%) compared to children assessed in 2009 (67%). Approximately two-thirds of children under four were receiving physical therapy, occupational therapy and/or speech therapy.

Exhibit 3.3: Nursing Needs, Urgent Care Use, and Therapy Needs for Children Under Four Years of Age

TYPE OF NEED OR SERVICE	PERCENT	
	2009 (n = 201)	2010 (n = 208)
MEDICAL/NURSING NEEDS		
Medication management	15.0%	19.2%
Feeding tube	21.9%	27.9%
Nasopharyngeal suctioning	12.9%	14.9%
Oxygen	14.4%	13.5%
Unstable medical condition	13.4%	12.0%
Other periodic assessment	12.4%	12.5%
USE OF EMERGENCY MEDICAL SERVICES IN LAST 30 DAYS		
Emergency room visit	12.9%	19.2%
Hospital admission	11.0%	12.5%
Urgent (unplanned) visit to physician	20.4%	17.8%
THERAPY NEEDS		
Physical therapy	66.7%	57.7%
Occupational therapy*	67.2%	57.2%
Speech therapy	68.2%	64.9%
Home health aide	20.9%	16.4%

PHYSICAL FUNCTION

Like their older counterparts, these children's needs for PCS were highly dependent on their functional status. Unlike their older counterparts, who were four to twenty years of age, these children would not be expected to perform any IADLs and very few ADL tasks independently. In fact, bed mobility, positioning in a chair, transfer, and locomotion would be among the few ADLs one might expect them to do without assistance. So, the basic question for the PCS program became "whether the child's condition or special circumstances" affected the amount of assistance required of responsible adults as they provided ADL care and carried out an IADL task? Did the child's condition(s) make the task take longer or did it require two-person assistance? This information on whether a child's condition affected the performance or completion of each IADL and ADL appears in Exhibit 3.4. Physical function patterns were very similar in 2009 and 2010 with one exception: the percentage of children with conditions that affected the responsible adult's ability to do ordinary/light housework was significantly lower in 2010 (32%) compared to 2009 (43%).

About half of the children under four had conditions that affected the responsible adult's ability to prepare meals and do laundry. About a third of these children had conditions that affected the responsible adult's ability to do ordinary/light housework and escort. About a quarter of these children had conditions that affected the responsible adult's ability to grocery shop or provide medication assistance. Approximately three-quarters of these children needed assistance for eating, in using the toilet, for dressing, for personal hygiene, and for bathing. For all ADLs, an indication of assistance being needed meant that the child's ability to perform the task, or assist with the task, was compromised by her or his condition. Either more time was required, or two persons were needed to accomplish the task.

The information on ADLs and IADLs provides only a partial portrait of a child's needs for assistance. About 12 percent of these children needed two-person assistance for a transfer or two-person assistance with some other ADL. Approximately a quarter of these children used a wheelchair as their main mode of locomotion. About 14 percent of responsible adults believed that the children needed new or additional DME or assistive devices.

Exhibit 3.4: Prevalence of Instances in Which Condition Affected ADL/IADL Assistance in Children Under Four Years of Age

TYPE OF ACTIVITY	PERCENT	
	2009 (n = 201)	2010 (n = 208)
IADLS		
Meal preparation	39.8%	48.3%
Medication assistance	23.9%	27.5%
Laundry	46.5%	40.6%
Ordinary/light housework*	43.3%	31.9%
Grocery shopping	22.9%	22.4%
Escort	31.8%	30.4%
ADLS		
Bed mobility	25.9%	26.0%
Positioning	39.3%	36.1%
Eating	71.6%	75.9%
Transfer	46.3%	46.6%
Locomotion inside	41.8%	43.3%
Toilet use	68.2%	70.7%
Dressing	76.1%	77.8%
Personal hygiene	68.2%	70.5%
Bathing	80.6%	78.7%

HOUSEHOLD RESOURCES

Primary caregivers or responsible adults faced a number of situations that affected their ability to provide care to their child with special health care needs. The challenges or barriers to caregiving reported by responsible adults were very similar in 2010 and 2009 (see Exhibit 3.5). Over a third of responsible adults worked full-time while about a quarter had part-time or some other type of working arrangement. About two-thirds of responsible adults experienced interrupted sleep because of the child's needs for assistance, and more than one-third had a physical limitation that made it impossible for them to assist the child with at least some ADLs or IADLs.

Exhibit 3.5: Household Resources for Children Under Four Years of Age

HOUSEHOLD RESOURCE	**PERCENT**	
	2009 (n = 201)	**2010 (n = 208)**
Responsible adult works full-time	37.8%	38.0%
Responsible adult's sleep interrupted	62.5%	69.7%
Responsible adult physical limitations	36.3%	42.3%

STRENGTHS, NEEDS, AND CARE

Exhibit 3.6 displays the results of the analyses of the types of tasks for which responsible adults were most, or least, likely to request PCS assistance. Patterns of requests for assistance with IADLs were very similar in 2010 and 2009, with a few exceptions: a significantly greater proportion of responsible adults did not request PCS assistance with laundry and ordinary/light housework in 2010 compared to 2009. Patterns of requests for assistance with ADLs were similar in 2010 and 2009, with several exceptions: a significantly greater proportion of responsible adults did not request PCS assistance with bed mobility/positioning, dressing, personal hygiene and bathing in 2010 compared to 2009. Responsible adults or primary responsible adults usually requested assistance with more complex ADLs like eating, using the toilet, dressing, personal hygiene, and bathing.

Exhibit 3.6: PCS Assistance Requested and Approved For

Children Under Four Years of Age[¥]

ASSISTANCE WAS REQUESTED FOR A SPECIFIC ACTIVITY	PERCENT REQUESTING & RECEIVING ASSISTANCE[€]		PERCENT REQUESTING & DENIED ASSISTANCE[Λ]	
	2009 (n=201)	2010 (n = 208)	2009 (n=201)	2010 (n = 208)
IADLS				
Meal preparation	31.8%	36.7%	12.4%	7.7%
Medication assistance	7.5%	3.9%	15.9%	12.1%
Laundry**	41.8%	27.6%	7.5%	6.7%
Ordinary/light housework**	18.0%	14.6%	9.0%	6.8%
Grocery shopping	36.5%	23.8%	10.5%	6.8%

Escort	13.4%	10.1%	8.5%	4.3%
ADLS				
Bed mobility *	26.4%	26.0%	7.0%	1.9%
Eating	56.5%	60.6%	12.0%	12.5%
Transfer	35.8%	35.8%	7.0%	3.4%
Locomotion/mobility	29.4%	26.6%	8.5%	4.4%
Toilet use	65.5%	63.3%	9.5%	6.8%
Dressing*	72.6%	71.5%	9.5%	3.4%
Personal hygiene*	65.7%	62.8%	9.5%	3.9%
Bathing***	79.6%	69.6%	9.0%	4.4%

[¥] This table includes only those individuals requesting PCS assistance with an IADL or ADL task.
[€] This is the proportion of the total population who requested and received assistance for the task.
[Λ] This is the proportion of the total population who requested task assistance and it was denied.

The percentage of denials for only two IADLs and one ADL were large enough to be ($p < .01$) significant with this relatively small sample. However, the pattern of change is quite clear. Among the eight ADLs and six IADLs, only one exhibited a slight increase in denials. In all other 13 areas of potential need, denials of requests for services decreased.

Exhibit 3.7 presents the distribution of PCS hours authorized for this cohort of children. The average PCS hours authorized per week was significantly lower for children assessed in 2010 (average of 20 hours) compared to an average of nearly 24 hours for children assessed in 2009. Approximately three-quarters of responsible adults made no request for a specific number of PCS hours of assistance. Hours authorized was less than the number of hours requested for only about five percent of this population.

Exhibit 3.7: Distribution of PCS Hours for Children Under Four Years of Age

POPULATION PERCENTILE	**NUMBER OF HOURS**	
	2009 (n = 201)	**2010 (n = 208)**
90th	39.3	36.5
75th	28.8	26.1
50th	21.7	17.5
25th	15.0	11.0
10th	9.2	7.0

CHAPTER 4: COHORT COMPARISON FOR CHILDREN AGES FOUR TO TWENTY

This chapter presents frequency distributions for some of the assessment items for children who were assessed in both 2009 and 2010. Information on those items not highlighted in this chapter can be found in Appendix D.

In 2010, 2642 children ages four to twenty were assessed using the PCAF. Of these, 1765 children were being assessed for the first time while 836 children (32%) had been assessed earlier in 2009. The sections below focus on these 836 children in both databases and compare their assessment data from 2009 to information gathered in 2010.

The discussion will focus on those factors or characteristics that seemed to have changed for this population of children over the course of the year between assessments.

SPECIFIC DIAGNOSES, PROBLEMS, AND CONDITIONS

Exhibit 4.1 provides prevalence rates for the most common disorders and conditions diagnosed in this cohort of children ages four to twenty. The prevalence rates for medical diagnoses in these children remained more or less unchanged from 2009 to 2010, with no significant differences. Asthma or other respiratory disorders, cerebral palsy and epilepsy or other seizure disorders remained the most common medical problems faced by these children.

The prevalence rates for psychiatric/developmental/behavioral diagnoses in these children also remained more or less unchanged from 2009 to 2010. Anxiety disorders, autistic disorders, attention deficit disorder and mood disorders remained the other most common psychiatric/developmental/behavioral problems faced by these children. One major change did occur. A significantly higher percentage (62%) of children assessed in 2010 had received a new diagnosis of intellectual disability/MR/DD in the interim. This change is most likely a result of those younger children, earlier characterized with developmental delay resulting from an intellectual impairment, receiving an official diagnosis of intellectual disability.

The medical, behavioral, and developmental problems with which these children were dealing resulted in a variety of conditions that profoundly affected their personal care. Prevalence rates for these health conditions also remained more or less unchanged from 2009 to 2010. However, two somewhat troubling exceptions appear in the data. The proportion of children reported to have contractures and limitations in range of motion increased significantly from 15 percent and 35 percent in 2009 to 22 percent and 41 percent, respectively, in 2010.

Exhibit 4.1: Prevalence of Medical, Behavioral, or Developmental Problems in Children Ages Four to Twenty

DISORDER OR PROBLEM	**PERCENT**	
	2009 (n=836)	**2010 (n = 836)**
PSYCHIATRIC/DEVELOPMENTAL/BEHAVIORAL DIAGNOSES		
Anxiety disorders	13.9%	15.5%
Autistic disorders	17.8%	18.7%
Attention deficit disorder	25.1%	28.3%
Disruptive disorders	10.7%	10.1%
Intellectual disability/MR/DD***	49.3%	62.0%
Mood disorders	12.4%	14.9%
HEALTH CONDITIONS		
Bed bound or chair fast	15.8%	15.5%
Contractures***	15.6%	22.1%
Fall related to condition	13.4%	14.9%
Limitation in range of motion*	35.1%	40.6%
Pain interferes with normal activities	17.7%	19.3%

COGNITIVE FUNCTION

Exhibit 4.2 reports the cognitive challenges faced by this cohort of children ages four to twenty. The data provide some evidence of cognitive decline during the year. The proportion of children reported to need cueing or monitoring to complete most or almost all multiple-step tasks increased significantly from 84 percent in 2009 to 89 percent in 2010. The proportion of children reported to be moderately or completely dependent on others for safe, reasonable decisions also increased significantly from 73 percent in 2009 to 80 percent in 2010.

Exhibit 4.2: Cognitive Challenges in Children Ages Four to Twenty

COGNITIVE CHALLENGES	**PERCENT**	
	2009 (n=836)	**2010 (n = 836)**
Short-term memory/recall problem	58.1%	63.0%
Long-term memory/recall problem	54.5%	59.3%
Needs cueing, redirection or monitoring***	83.8%	89.4%
COGNITIVE SKILLS FOR DAILY DECISION-MAKING**		
Independent	10.0%	8.0%
Modified independence	15.7%	12.5%
Moderately dependent	25.6%	33.5%
Completely dependent	48.8%	46.1%

BEHAVIOR PATTERNS

Exhibit 4.3 presents behaviors exhibited by this cohort of children ages four to twenty that make care giving difficult. Behavior patterns in these children remained more or less unchanged from 2009 to 2010 with one exception: the proportion of children reported to be verbally abusive in the last month increased significantly from 25 percent in 2009 to 30 percent in 2010. Wandering, being physically abusive, socially inappropriate or disruptive behavior, repetitive behavior and resisting ADL care were the other most common problematic behaviors exhibited by these children.

Exhibit 4.3: Behavior Patterns for Children Ages Four to Twenty

BEHAVIOR	**PERCENT**	
	2009 (n=836)	**2010 (n = 836)**
Wandering	25.5%	23.4%
Elopement	15.3%	15.7%
Verbally abusive*	24.9%	30.4%
Physically abusive	31.1%	31.1%
Bullying/menacing behavior	16.3%	16.3%
Socially inappropriate or disruptive behavior	31.1%	34.4%
Repetitive behavior	31.8%	34.5%
Resists ADL care	35.9%	38.6%
Physically resists treatments	16.3%	13.1%
Injury to self	20.0%	20.0%
Deliberate damage to property	14.3%	15.4%

NURSING NEEDS, URGENT CARE USE, AND THERAPY NEEDS

Exhibit 4.4 presents nursing needs, urgent care use and therapy needs for this cohort of children ages four to twenty. Nursing needs and urgent care use in these children remained more or less unchanged from 2009 to 2010 with two exceptions: the proportion of children reported as needing medication management and other periodic assessment decreased significantly from 13 percent and 8 percent respectively in 2009 to 10 percent and 6 percent respectively in 2010. From 2009 to 2010, hospital admissions and urgent (unplanned) visits to a physician in the last month remained unchanged at about 4 percent and 12 percent respectively. However, the proportion of children using the emergency room in the last month decreased significantly from 9 percent in 2009 to 6 percent in 2010.

Therapy needs in these children remained more or less unchanged from 2009 to 2010 with several exceptions: the proportion of children needing physical therapy, occupational therapy and speech therapy monthly decreased significantly from 2009 to 2010. This result may reflect the entry of a number of children into school programs that provide these services.

Exhibit 4.4: Nursing Needs, Urgent Care Use, and Therapy Needs in Children Ages Four to Twenty

TYPE OF NEED OR SERVICE	PERCENT	
	2009 (n = 836)	2010 (n = 836)
MEDICAL/NURSING NEEDS		
Medication management*	13.2%	9.8%
Feeding tube	12.3%	12.7%
Nasopharyngeal suctioning	7.2%	7.8%
Oxygen	6.5%	6.9%
Uncontrollable seizure disorder	9.5%	7.3%
Unstable medical condition	8.7%	6.7%
Other periodic assessment*	8.4%	5.8%
USE OF EMERGENCY MEDICAL SERVICES IN LAST 30 DAYS		
Emergency room visit*	8.6%	6.2%
Hospital admission	4.4%	3.8%
Urgent (unplanned) visit to physician	12.0%	12.6%
THERAPY NEEDS		
Physical therapy*	42.0%	36.4%
Occupational therapy*	47.4%	41.8%
Speech therapy*	45.8%	40.3%
Mental health services	20.4%	18.5%
Home health aide	22.5%	23.4%

BLADDER AND BOWEL CONTINENCE

Exhibit 4.5 presents information on continence for this cohort of children ages four to twenty. Continence in these children remained more or less unchanged from 2009 to 2010 with about one-third of children reported to be urinary continent, about 40 percent reported to be bowel continent and about two-thirds reported to be nighttime incontinent.

Exhibit 4.5: Continence in Children Ages Four to Twenty

CONTINENCE	PERCENT	
	2009 (n = 836)	2010 (n = 836)
Urinary continence	31.0%	29.0%
Bowel continence	38.4%	38.3%
Nighttime incontinence	64.1%	67.1%

PHYSICAL FUNCTION

Exhibit 4.6 presents information on the need for assistance with ADLs and IADLs for this cohort of children ages four to twenty. IADL needs in these children remained more or less unchanged from 2009 to 2010 with responsible adults needing most assistance with meal preparation, escort to appointments, laundry and ordinary/light housework. ADL needs in these children also remained more or less unchanged from 2009 to 2010 with a few exceptions.

One result displayed in

Exhibit 4.6 is that the only statistically significant changes in ADL status came in the more complex ADLs, such as toilet use, dressing and personal hygiene. This result implies that some proportion of the children assessed in 2009 learned to master these more difficult tasks by the time they were re-assessed in 2010.

Exhibit 4.6: Total Dependence for ADL/IADL Assistance in Children Ages Four to Twenty

TYPE OF ACTIVITY	**PERCENT**	
	2009 (n = 836)	**2010 (n = 836)**
IADLS		
Meal preparation	47.7%	49.8%
Medication assistance	40.7%	41.0%
Telephone use	27.8%	23.4%
Escort	49.0%	47.8%
Laundry	57.4%	60.4%
Ordinary/light housework	52.0%	48.8%
Grocery shopping	40.1%	38.6%
ADLS		
Bed mobility	19.5%	19.8%
Positioning	23.1%	23.4%
Eating	25.2%	23.2%
Transfers	29.6%	28.1%
Locomotion inside	24.1%	23.1%
Locomotion outside	29.0%	27.3%
Toilet use**	46.7%	43.7%
Dressing***	46.5%	42.0%

Personal hygiene***	50.2%	44.6%
Bathing	59.7%	55.1%

The information on individual ADLs is important, but the total amount of care needed by children is related to the number of ADLs in which assistance is needed, especially hands-on assistance. Exhibit 4.7 presents information on the total number of ADLs in which these children received hands-on assistance in the week prior to their assessment. Roughly, 92 percent received hands-on assistance with at least one ADL, while about 20 percent received hands-on assistance with all 10 ADLs. On average, these children received hands-on assistance with 5 ADLs.

Exhibit 4.7: Number of ADLs in Which Children Ages Four to Twenty Received Hands-On Care

NUMBER OF ADLs	Percent	
	2009 (n=836)	2010 (n = 836)
0	7.1%	7.9%
1	5.5%	6.2%
2	6.2%	4.4%
3	9.7%	7.9%
4	17.1%	17.2%
5	12.7%	13.6%
6	4.1%	4.9%
7	5.1%	5.9%
8	4.9%	5.5%
9	7.3%	6.2%
10	20.3%	20.2%

The proportion of children who needed two-person assistance with any ADL increased significantly from 13 percent in 2009 to 18 percent in 2010, although need for two-person assistance with transfers stayed steady at about 20 percent.

When considering unmet care needs for these children, an important issue is the availability of appropriate durable medical equipment. These results indicate that the proportion of responsible adults/clients who believed that the child needed new or additional DME or assistive devices decreased significantly from 16 percent in 2009 to 9 percent in 2010.

HOUSEHOLD RESOURCES

Exhibit 4.8 presents information on the challenges or barriers to caregiving reported by responsible adults, which remained more or less unchanged from 2009 to 2010. A little over a third of responsible adults worked full-time while approximately a quarter had part-time or some other type of working arrangement. Around half of responsible adults experienced interrupted sleep because of the child's needs for assistance or had a physical limitation that made it impossible for them to assist the child with at least some ADLs or IADLs.

Exhibit 4.8: Household Resources for Children Ages Four to Twenty

HOUSEHOLD RESOURCE	**PERCENT**	
	2009 (n = 836)	**2010 (n = 836)**
Responsible adult works full-time	38.2%	34.7%
Responsible adult's sleep interrupted	53.7%	51.1%
Responsible adult physical limitations	49.5%	52.3%

STRENGTHS, NEEDS, AND CARE

Exhibit 4.9 displays the results of the analyses of the types of tasks for which responsible adults were most, or least, likely to request PCS assistance. Patterns remained more or less unchanged from 2009 to 2010. Meal preparation, laundry and ordinary/light housework were the IADLs with which PCS assistance was most commonly requested. The percent of families requesting assistance with these IADL tasks did not differ significantly from 2009 to 2010.

Eating, toilet use, dressing, personal hygiene and bathing were the ADLs with which PCS assistance was most commonly requested. The proportion of children with no requests for PCS assistance with bed mobility/positioning and transfers decreased significantly from 2009 to 2010. One result displayed in

Exhibit 4.6 is that the only statistically significant changes in ADL status came in the more complex ADLs, such as toilet use, dressing and personal hygiene.

Also, the level of denial of requests for individual services did not change significantly for these children between 2009 and 2010. However, in 12 of the 14 potential areas of assistance, the percent of requests for assistance went down. This is true for all requests for ADL assistance.

Exhibit 4.9: PCS Assistance Requested and Approved For Children Ages Four to Twenty[¥]

ASSISTANCE WAS REQUESTED FOR A SPECIFIC ACTIVITY	PERCENT REQUESTING & RECEIVING ASSISTANCE[€]		PERCENT REQUESTING & DENIED ASSISTANCE[Λ]	
	2009 (n=836)	2010 (n = 836)	2009 (n=836)	2010 (n = 836)
IADLS				
Meal preparation	44.1%	46.2%	10.6%	9.7%
Medication assistance	14.4%	12.2%	12.8%	11.8%
Escort	18.8%	17.2%	7.8%	9.8%
Laundry	51.8%	53.5%	8.8%	9.6%
Ordinary/light housework	46.3%	42.8%	10.1%	9.9%
Grocery shopping	18.2%	16.0%	11.0%	8.2%
ADLS				
Bed mobility**	27.5%	26.0%	4.3%	1.8%
Eating	54.5%	54.2%	4.1%	4.0%
Transfers**	36.2%	36.9%	3.7%	1.3%
Locomotion/mobility***	33.2%	39.7%	3.9%	1.3%
Toilet use	82.2%	83.3%	1.9%	1.6%
Dressing	92.8%	95.1%	1.9%	1.4%
Personal hygiene*	89.8%	93.5%	2.6%	1.6%
Bathing**	92.6%	96.1%	2.2%	1.1%

[¥] This table includes only those individuals requesting PCS assistance with an IADL or ADL task.

[€] This is the proportion of the total population who requested and received assistance for the task.

[Λ] This is the proportion of the total population who requested task assistance and it was denied.

Exhibit 4.10 presents the distribution of PCS authorized for this cohort of children ages four to twenty. The average PCS hours authorized per week for these children increased significantly from 24 hours in 2009 to 26 hours in 2010. About 60 percent of responsible adults made no request for a specific number of PCS hours. Hours authorized were more than or equal to the number of hours requested for about one-third of this population. Hours authorized were less than the number of hours requested for only about 4 percent of this population.

Exhibit 4.10: Distribution of PCS Hours Allocated For Children Ages Four to Twenty

POPULATION PERCENTILE	**NUMBER OF HOURS**	
	2009 (n = 836)	**2010 (n = 836)**
90th	40.6	45.6
75th	30.1	34.7
50th	21.0	23.5
25th	15.0	15.8
10th	10.0	10.1

CHAPTER 5: COHORT COMPARISON FOR CHILDREN UNDER FOUR YEARS OF AGE

Of the 250 children under four years of age who were assessed in 2010, 208 children were being assessed for the first time, while only 39 of these children (16%) had been assessed earlier in 2009. Because of this small sample size, data on children under four years of age who were assessed both in 2009 and 2010 will not be presented.

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