CHILDREN AND MEDICAID PERSONAL CARE SERVICES (PCS) IN TEXAS, 2009

EXECUTIVE SUMMARY
OF A 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
PUBLIC POLICY RESEARCH INSTITUTE

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MEDICAID PERSONAL CARE SERVICES
(PCS) IN TEXAS, 2009

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PREPARED FOR:
THE TEXAS HEALTH AND HUMAN SERVICES COMMISSION

PROJECT OFFICER: MARIANNA ZOLONDEK

PREPARED BY:
Charles D. Phillips, PhD, MPHΩ
Ashweeta Patnaik, MPHª
James Dyer, PhDª
Catherine Hawes PhD
Constance Fournier, PhDΦ
Timothy Elliott, PhDΦ
Joshua Johnson, MSΩ
Emily Naiser, MPHª

Texas A&M Health Science Center
School of Rural Public HealthΩ

Texas A&M University
College of Education and Human DevelopmentΦ

Texas A&M University
Public Policy Research Instituteª

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THE EXECUTIVE SUMMARY

The Executive Summary provides only the most general information on the children receiving Medicaid Personal Care Services (PCS) in Texas. Detailed information on the characteristics and needs of children in the PCS program can be found in the full report. After the brief general information on the report data and the PCS program, demographic data are presented on all children who received PCS. Then, information is provided on those children who received PCS and were 4 to 20 years old. Finally, summary information is provided on children under four years old who received PCS.

THE DATA FOR THE REPORT

The Medicaid Fee-For-Service (FFS) program and Primary Care Case Management (PCCM) in Texas provided Personal Care Services (PCS) to over 5,400 children under the age of 21 during the spring of 2009. The strengths and needs of these children and their families were assessed using the Personal Care Assessment Form (PCAF). From September 2008 to April 2009, PCAF data from assessments completed by Department of State Health Services (DSHS) case managers were provided to the Texas A&M Health Science Center PCAF project team. These data were then weighted so that they might better reflect the characteristics of the entire population of over 5,400 children receiving PCS through these two programs in 2009. This report uses these weighted data to describe the children in Texas receiving PCS, the services they requested, and the services they received.

ASSESSMENTS AND THE PCS PROGRAM

The assessment process for PCS emphasizes three issues related to a child’s functional performance and living environment.

- First, how much assistance does the child need to perform a functional task (e.g., bathing, dressing, meal preparation)?
• Second, is the child’s ability to perform, or assist with performance of, a functional task affected by the child’s medical, developmental, or behavioral health condition(s)?

• Third, is there some barrier that reduces the responsible adults’ ability to provide the assistance needed to perform the functional task?

All three issues are crucial to the PCS program. Medicaid PCS can only be approved if all three of these requirements are met.

Children under four years old were assessed using the PCAF 0-3, while children from four to 20 years old were assessed using the PCAF 4-20. The two PCAF instruments share a common approach to assessment and many assessment items, but the two differ enough that they are appropriate for use with these divergent age groups.

ALL CHILDREN RECEIVING MEDICAID PCS

**GEOGRAPHY:** Young PCS recipients were not evenly distributed across the state. Three DSHS Regional Offices (San Antonio, Houston, and Harlingen) provided case management and administered PCS for almost 75 percent of the children in the PCS program. Region 11 (Harlingen) alone was responsible for assessing and managing the care for almost 2,600 members (47 percent) of this vulnerable population.

**GENDER:** A majority of the children receiving PCS (57%) were male.

**AGE:** Three-quarters of the overall population were between the ages of 4 years and 17 years of age. Fewer than 400 children receiving PCS (approximately 7%) were less than 4 years of age; almost 1,000 (18 %) were 18 to 20 years of age.
CHILDREN FOUR TO 20 YEARS OLD RECEIVING PCS

1. **TYPES OF PROBLEMS/CONDITIONS**: Among those over the age of 3, 51.4 percent had a combination of both medical and psychiatric/behavioral/developmental problems; 23.2 percent had only medical problems that caused them to seek PCS; just over 25 percent of these children faced psychiatric/behavioral/developmental problems without complicating medical diagnoses.

2. **INTELLECTUAL DISABILITY**: Almost one-half (46.6%) of PCS recipients between the ages of 4 and 20 years of age had a diagnosis of some type of intellectual disability.

3. **COGNITIVE SKILLS**: Either because of their age or because of their condition, over 70 percent of those 4 to 20 years of age required continual or close stand-by assistance to assure they made safe and reasonable decisions.

4. **URINARY AND BOWEL CONTINENCE**: Over one-third of the 4 to 20 year olds who were receiving PCS had little or no control of their bowel or bladder function.

5. **NEEDS IN ACTIVITIES OF DAILY LIVING**: The activities of daily living (ADLs) in which these children exhibited the most dependence were more complex, multi-step activities -- dressing, personal hygiene, toileting, and bathing. Among these ADLs, the rate of total dependence averaged 47 percent. For less complex ADLs that may have been indicative of higher levels of impairment (e.g., locomotion, positioning, and bed mobility), the distributions tended to be bimodal. Children were either completely independent or totally dependent in these specific ADLs. Over one-half of these children required hands-on assistance with five or more ADLs. Over one-third of the children receiving PCS (34.8%) often resisted when someone tried to assist them with ADLs.

6. **NEEDS IN INSTRUMENTAL ACTIVITIES OF DAILY LIVING**: All seven instrumental activities of daily living (IADLs) displayed bimodal distributions for these children; performance of these activities was either unaffected by a child’s condition(s) or it was affected, and the child was completely dependent. For example, in medication
administration, one-half (49.9 percent) of the children were independent or their condition had no effect on this task; for 38.2 percent of the children, their condition affected the performance of the task, and they were completely dependent. The highest level of total dependency was observed in doing laundry. A child’s condition affected the task, and the child was totally dependent, in 54.3 percent of the cases.

7. **CARE RESOURCES IN THE HOUSEHOLD**: Over one-third of responsible adults caring for children aged 4 to 20 and receiving PCS worked full-time; 75 percent were also caring for other children; over half were caring for other children with some type of impairment. Almost one-half of responsible adults indicated that problems with strength or stamina made them unable to assist their children with some ADL or IADL tasks.

8. **ALLOCATION OF PCS HOURS**: The average number of hours of PCS allocated to children during this time period was 25.2 hours per week. Ten percent received more than 44.3 hours of PCS per week and 10 percent received fewer than 10 hours per week. Most responsible adults or clients did not make a request for a specific number of PCS hours. Thirty-two percent made such a request and they received PCS hours equal to or greater than the number of hours requested. In only four percent of cases did case managers report that they authorized fewer hours than were requested. Only 3 percent of those requesting PCS for a child aged 4 to 20 years of age were denied PCS assistance.
CHILDREN UNDER FOUR YEARS OLD RECEIVING PCS

1. **TYPES OF PROBLEMS/CONDITIONS**: Just over one-half of those under the age of four sought PCS because of some medical conditions alone; 37.5 percent had medical and behavioral or developmental problems. The most common medical conditions faced by these children and their households included respiratory problems (33.8%), epilepsy or other chronic seizure disorder (29%), micro/hydrocephaly (22%), cerebral palsy (15.2%), failure to thrive (14.7%) or a congenital heart disorder (14%).

2. **INTELLECTUAL DISABILITY**: Almost one-third (32.6%) of children less than four years of age showed signs of an intellectual disability; almost 12 percent of the children had a pervasive developmental problem such as autism.

3. **MEDICAL OR NURSING NEEDS AND HEALTH CARE USE**: A relatively high proportion of these children had special care needs. One in five had a feeding tube; almost 13 percent had an unstable medical condition; almost 12 percent received oxygen. These infants also often needed treatment for emergent conditions or exacerbations of their chronic problems. In the 30 days prior to their PCAF assessment, almost one in five had an unplanned or urgent visit to a physician; just over 10 percent had an emergency room visit; 14 percent were admitted to a hospital.

4. **NEEDS IN ADLs**: Responsible adults reported that the child’s conditions or problems often affected their ability to perform various ADLs. The ADLs most commonly affected by their conditions were transfers (48%), using the toilet (65%), personal hygiene (68%), dressing (76%), and bathing (82%). For more than half of these young children five or more of the ten ADLs were affected by their condition(s). This means that these ADL activities took longer to perform or required the help of more than one person.

5. **NEEDS IN INSTRUMENTAL ACTIVITIES OF DAILY LIVING**: No one expects children under the age of four to perform IADL tasks. However, the problems faced by a child under four might affect how a responsible adult performed these tasks. The child’s condition(s) might have made the task take longer or required two-person assistance. For
the six IADLs on which information was recorded for children less than four years of age, the percent of children whose condition affected an IADL task ranged from fewer than one-quarter (22.9%) in grocery shopping to 44.6 percent in doing laundry. Across all six IADLs, roughly one-third of the children, on average, had problems that affected the performance of an IADL task.

6. **ALLOCATION OF PCS HOURS:** For children less than four years of age, the average number of hours of PCS allocated during this time period was 23.8 hours per week. Ten percent of these children received more than 42 hours of PCS per week and 10 percent received fewer than 8 hours per week. Most responsible adults or clients did not make a request for a specific number of PCS hours. One quarter of responsible adults made such a request, and received PCS hours equal to or greater than the number of hours requested. In 8.5 percent of the cases, case managers report that they authorized fewer hours than were requested. Slightly fewer than eight percent (7.8%) of those requesting PCS for children aged under the age of four were denied Medicaid PCS.
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AUTHORS OF THE REPORT

James Dyer, Ph.D., (Co-Investigator) is an Associate Professor of Political Science and the Associate Director of Texas A&M University’s Public Policy Research Institute.

Timothy Elliott, Ph.D., (Co-Investigator) is a Professor in the Department of Educational Psychology at Texas A&M University (TAMU). He heads that department’s clinical training program in counseling psychology, and he is a Senior Researcher at TAMU’s Children and Adolescent Health Research Laboratory and at the Center for Community Health Development in the School of Rural Public Health (SRPH).

Constance Fournier, Ph.D., (Co-Investigator) is a Clinical Professor in the Department of Educational Psychology at Texas A&M University.

Catherine Hawes Ph.D., (Co-Investigator) is a Regents Professor in the Texas A&M Health Science Center’s School of Rural Public Health (SRPH). She directs SRPH’s Program on Aging and Long-Term Care and is currently a Senior Researcher and was the founding director at SRPH’s Southwest Rural Health Research Center.

Joshua Johnson, M.S. (Research Analyst) is a doctoral student in health services research at Texas A&M Health Science Center’s School of Rural Public Health and a graduate research assistant.

Emily Naiser, M.P.H. (Research Analyst) is a researcher at Texas A&M University’s Public Policy Research Institute.

Ashweeta Patnaik, M.P.H. (Research Analyst) is a researcher at Texas A&M University’s Public Policy Research Institute.

Charles D. Phillips, Ph.D., M.P.H. (Project Director and Principal Investigator) is a Regents Professor in the Texas A&M Health Science Center’s School of Rural Public Health. He is also a Senior Researcher at Texas A&M University’s Children and Adolescent Health Research Laboratory, School of Rural Public Health’s (SRPH’s) Program on Aging, Disability, and Long-Term Care, and SRPH’s Southwest Rural Health Research Center.