DEVELOPING A CLASSIFICATION MODEL FOR CHILDREN RECEIVING MEDICAID PERSONAL CARE SERVICES IN TEXAS

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

TEXAS A&M UNIVERSITY
PUBLIC POLICY RESEARCH INSTITUTE

June 2010

DEVELOPING A CLASSIFICATION MODEL FOR CHILDREN RECEIVING MEDICAID PERSONAL CARE SERVICES IN TEXAS

PREPARED FOR:
THE TEXAS HEALTH AND HUMAN SERVICES COMMISSION
PROJECT OFFICER: MARIANNA ZOLONDEK

PREPARED BY:
Charles D. Phillips, PhD, MPH[Ω]
Ashweeta Patnaik, MPH[€]
James Dyer, PhD[€]
Catherine Hawes PhD[Ω]
Constance Fournier, PhD[Φ]
Timothy Elliott, PhD[Φ]
Thomas Miller, PhD, MBA[Ω]
Joshua Johnson, MS[Ω]
Emily Naiser, MPH[€]

Texas A&M Health Science Center
School of Rural Public Health[Ω]
Texas A&M University
College Of Education and Human Development[Φ]
Texas A&M University
Public Policy Research Institute[€]

June 2010

TABLE OF CONTENTS

DEVELOPING A CLASSIFICATION MODEL FOR CHILDREN RECEIVING MEDICAID PERSONAL CARE SERVICES

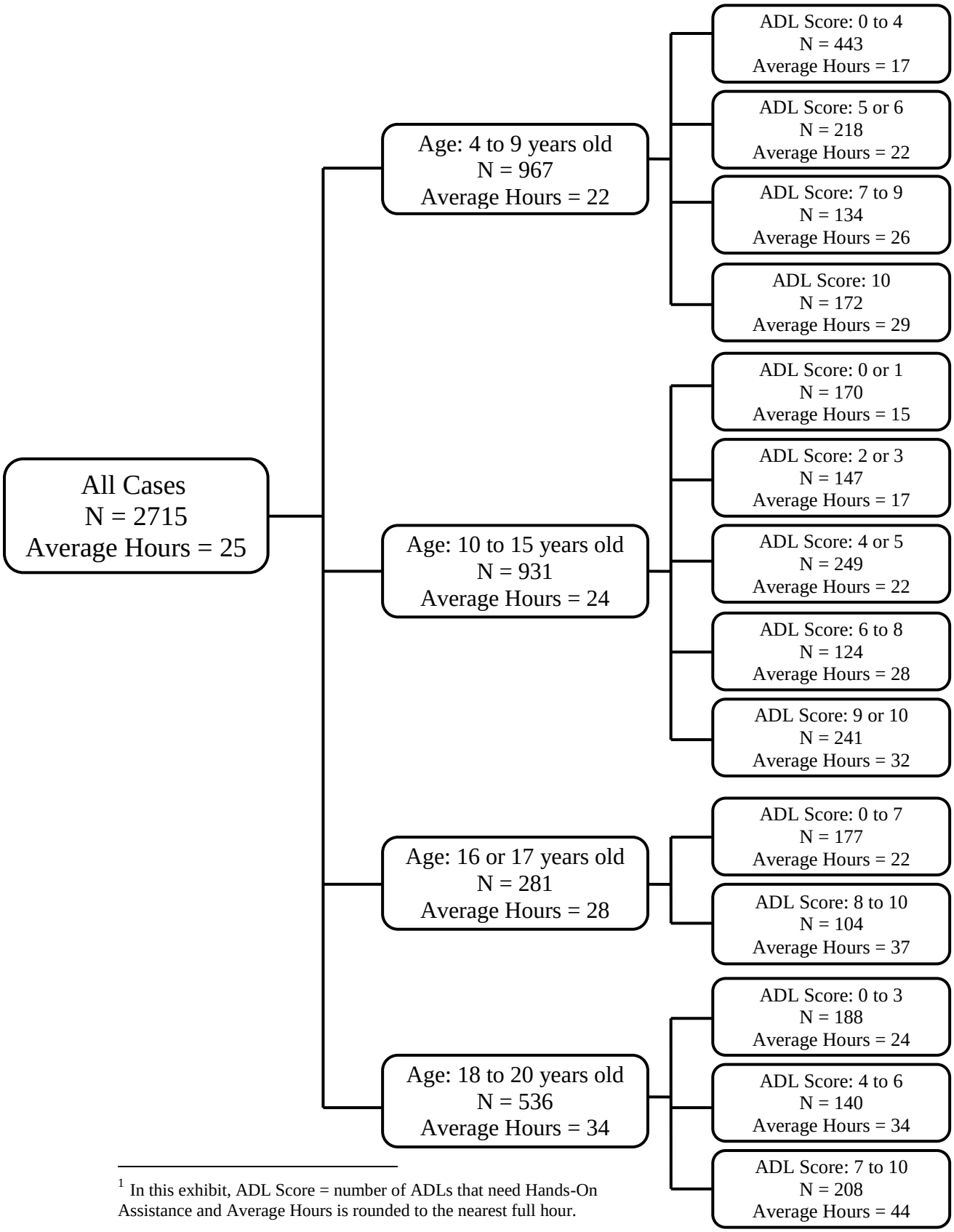
EXECUTIVE SUMMARY

The Medicaid Personal Care Services Program (PCS) provided services to over 5,800 children under the age of 21 during 2009. Since September, 2008, the needs and strengths of all children seeking PCS have been assessed using the Personal Care Assessment Forms (PCAF). This research uses PCAF data from assessments completed by Department of State Health Services case managers from September, 2008 to April, 2009.

The report presents the results of the TAMHSC research team's efforts to develop, using these data, a needs-based classification model for children receiving PCS. Our goal of this effort was to develop a classification model that mimicked, as closely as possible, the basic logic underlying the allocation of hours of PCS per week to children in the Medicaid PCS Program.

A variety of models were tested. These models included a wide range of characteristics of the children receiving PCS. Finally, a preferred model was chosen based on its ability to predict PCS hours, its applicability to all children, and its conceptual simplicity and clarity. The preferred model explained roughly 30 percent of the variation in PCS hours authorized for the almost 2,800 children in the study sample. The model has 14 categories. The average number of PCS hours in these 14 groups ranged from 15 hours per week to 44 hours per week. The model is based on the child's age when assessed and the number of activities of daily living in which the child needed assistance. A graphical presentation of the preferred model appears in Exhibit One.

EXHIBIT ONE: THE PREFERRED MODEL[1]



[1] In this exhibit, ADL Score = number of ADLs that need Hands-On Assistance and Average Hours is rounded to the nearest full hour.

LIST OF EXHIBITS

DEVELOPING A CLASSIFICATION MODEL FOR CHILDREN RECEIVING MEDICAID PERSONAL CARE SERVICES

FOCUS OF THE REPORT

This reports presents the results of the TAMHSC research team's efforts to develop a needs-based classification model for children receiving PCS. Our goal was to mimic as closely as possible the basic logic underlying how PCS hours are currently allocated in the Medicaid program. The process is the same as that undertaken when developing needs-based classification models like those used for adults receiving nursing home care or home care. The ultimate goal of this process is to produce a set of client categories (case-mix or classification groups) composed of children who receive roughly the same amounts of care and who share a variety of important characteristics (Phillips, 2009).

PROJECT BACKGROUND

Since 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 newborns to those 20 years of age to determine their level of need for PCS. For the first year of this new arrangement, assessments were performed using an interim assessment instrument.

In September 2008, DSHS case managers began using assessment forms developed by a research team from the Texas A&M Health Science Center and the main campus of Texas A&M. The project team developed assessment instruments specially designed for use in determining the PCS needs of children in the EPSDT Program. Two multi-dimensional assessment instruments were developed and tested. The first instrument was the Personal Care Assessment Form 0-3 (PCAF 0-3) used to assess the PCS needs of all children under four years of age who are seeking or receiving assistance. The second instrument was the Personal Care Assessment Form 4-20 (PCAF 4-20) used

to assess children from 4 years to 20 years old who are 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 personal care needs. 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 seeking PCS. In addition, a variety of items were purpose-built by the research team for the assessment.[2]

EVALUATING CLASSIFICATION MODELS

When considering how well different models predict the hours of PCS a child will receive, a convenient measure with which to compare models is the R-square (R^2) statistic. This statistic takes the total variation in PCS hours among all sample members and estimates what proportion of that variation is explained by a model. For example a model with an R^2 of 0.50 indicates that the model explains (the variables included in the model account for) half of the differences among the sample members in the number of hours of PCS they receive. Obviously, one prefers models with higher, rather than lower, R^2 statistics.

In addition, those assessing or providing services to program participants should recognize the importance of the indicators used in the classification model and, in essence, recognize the client groups as distinct in their needs. This type of "face validity" for the groups created in our models is an important factor in the acceptance and use of

[2] The MDS-HC© was developed by inter*RAI,* which is a not-for-profit international organization of health professionals in more than 30 countries. inter*RAI* is dedicated to the development of assessment instruments for vulnerable populations round the world. More information on inter*RAI* can be obtained www.interrai.org.

the model by administrative staff, program staff, advocates, and program participants. Finally, in order for the estimate of hours for each group to be stable, largely unaffected by any idiosyncratic characteristics of the particular individuals in the group, we required that at least 100 children comprise each classification group in the model.

The implications of this discussion are that the models presented below have been developed using a "balanced" approach to model building that requires that statistical criteria be blended with clinical and common sense notions of usefulness. This approach should result in the development of case-mix groups that are clearly recognizable to program participants and program staff at the same time that more rigorous standards of statistical accuracy are not compromised.

MODELS BASED ON CLIENT CHARACTERISTICS

If one has a uniform assessment process, then why might a classification system based only on children's needs be useful? The most telling response to this query is empirical (based on the available data). When the TAMHSC research team developed models of the allocation of PCS hours in our sample, a substantial proportion of the variation among children in the allocation of PCS hours depended solely on the identity of the case manager completing the assessment ($R^2 = 0.18$). This result implies that almost one-fifth of the variation in the allocation of PCS hours for children in Texas may depended on which DSHS case manager assessed them.[3]

Variation in resource allocation that has no basis in client characteristics can quickly lead to inefficient, inequitable, and potentially ineffective allocation of the scarce program resources available to provide care to this vulnerable population. When two children with the same basic needs receive different levels of service, this introduces inequity into the program. Also, one of those two children may have the needed number

[3] Case managers in some areas do assess children with higher impairment levels than case managers in other areas or with different panels or caseloads of children. So, one should reasonably expect the identity of the case manager to explain some of the variation in PCS hours authorized. However, the figure presented here is the change in the model's R^2 when the case managers' identity is added to a model that already included the relevant characteristics of the children. The R^2 for the model with the individual-level variables alone is 0.29; the R^2 for the model with these characteristics and the case managers' identity is 0.47 (increase of 0.18). When one estimates a model using only the case managers' identity, the R^2 equals 0.25. These results imply that there is some, but not a great deal, of acuity-based "clustering" of child across the caseloads or panels assigned to different case managers.

hours authorized. If the other child receives a higher level of services than needed, then this introduces inefficiency into the program; if the other child receives a level of services that is too low, then the child and family have unmet care needs. This reality should clarify the potential importance of the development of predictive or classification models based solely on the characteristics of individual clients.

The average number of hours allocated to children in each group, along with any "corridors" surrounding those estimates for each group of children can be seen as potential benchmarks for the administrative review of PCS allocations by the HHSC or child advocacy groups. They might also be used by DSHS case managers as rough starting points for their consideration of the services needed by specific children.

However, either of these uses must recognize that the classification model provides a structure based on those characteristics shared by children involved in the PCS program. Yet, beyond these shared characteristics, a wide array of special circumstances affect a specific child's care needs and have to be considered in the decision to authorize PCS hours.

PREDICTING THE AMOUNT OF HOME CARE

One can find other efforts to construct classification models that predict hours of home care services or the cost of home care for different populations of community-dwelling individuals with impairments. By reviewing these efforts, we get some sense of how useful such models usually are in their ability to predict hours of home care services. One such effort looked at the characteristics (ADL, IADL, cognition, continence, special problems, etc.) of elderly PCS clients in Texas. The classification model in that research explained just under 30 percent of the variation ($R^2 = 0.29$) in the number of hours allocated to each elderly client (Phillips, Dyer, Hawes, Janousek & Halperin, 2008).

The R^2 noted above is not as high a level of explanation as one finds in nursing home case-mix classification models. However, the findings in Texas are clearly in line with other published results focusing on building classification models for home care clients. For example, a RUG-III based classification model for home care that included skilled services (e.g., nursing, therapists), which should help increase the R^2, explained only 26 percent of the variance in formal home care costs using data from Michigan's

Medicaid program. When the two categories in the model that included those individuals receiving skilled services were deleted, leaving only those receiving PCS services, the R^2 dropped below 0.10 (Bjorkgren, Fries & Shugarman, 2000).

DATA USED IN THE MODELING

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

In our modeling or classification effort, we used our sample of 2,760 PCAF 4-20 assessments and the hours of PCS authorized by the case manager for each sample member. We used these data to develop relatively homogeneous groups of children, children who don't differ dramatically in their medical, behavioral, demographic, or functional characteristics. An in-depth presentation of the characteristics is available in an earlier project report (Phillips et al., 2010).

THE MODELING/CLASSIFICATION STRATEGY

The analyses for which results are presented were derived from a statistical procedure that used hours as a dependent variable and then optimized a model's R^2 by picking certain breaks on the variables included in the model or classification system (SAS, 2008). For example, if using six years of age as a cut-point generates a higher R^2 than using eight years of age, then the software indicated that the cut-point should be six years of age. One can allow this software to completely control the analysis and classification. The software, if one wishes, picks and choose variables from an entire

[4] 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.

database and select cut-points on those variables in whatever order maximizes the explained variance.

As noted earlier, this simplistic, purely statistical approach was not taken in our efforts. The research team used a "blended" approach to model-building. This approach involved specifying some aspects of the classification model (e.g., age is the first variable entered, then ADLs, and then other factors were considered), based on conceptual or clinical considerations, and letting the software determine specific cut-points on these dimensions.

VARIABLES INCLUDED IN THE ANALYSES

The criterion variables in our analyses, the variable that we attempt to predict, as accurately as possible, is the weekly level of PCS services authorized by a DSHS case manager. Specifically, our dependent variable is the number of hours of PCS per week authorized by the DSHS case manager after the PCAF assessment was completed. This figure may have been changed at some point after the assessment. This could have been done either by DSHS administration or on the basis of an appeal by the adult responsible for the child. However, the research team was most concerned with the decision made by the DSHS case manager after completing the assessment.

After a review of the literature and the database, the research team chose a relatively long list of variables to be considered in our modeling effort. After a close evaluation of the potential impact of a wide range of factors, the results indicated that the characteristics listed in Exhibit Two might have a significant impact on PCS authorizations (serve as important independent variables or predictors of PCS hours). These included the characteristics of the PCS client and their primary caregiver that appear in Exhibit Two.[5] All of these items were drawn from the PCAF 4-20. A copy of the assessment form appears in Appendix A with those items. Those PCAF 4-20 items included in our analyses are shaded so that they can be easily identified.

[5] Each of the variables on the PCAF was analyzed to determine if differences on that variable discriminated between the hours of PCS authorized for the children in the sample. The list in Exhibit Two includes the discriminating variables.

EXHIBIT TWO: EXAMPLES OF VARIABLES CONSIDERED IN BUILDING THE CLASSIFICATION MODEL
Age Gender ADL needs (a single scale summarizing ADL needs) IADL needs (a single scale summarizing IADL needs) Presence of an intellectual disability Bed-bound Medical diagnoses Health Conditions Cognitive impairment Behavioral problems Urinary or bowel incontinence Need for two-person assistance with any ADL Use of wheelchair Barriers to care by responsible adults -- Responsible adult's sleep frequently interrupted Adult responsible for care of others in household Adult is in school Adult works full-time or part-time

DEVELOPING THE CLASSIFICATION MODEL

In all case-mix classification systems that focus on personal care, the most important client characteristic is ADL function (Bjorkgren, Fries, & Shugarman, 2000; Phillips, Preece, and Hawes, 2005; Phillips, Dyer, Hawes, Janousek, & Halperin, 2008). The research team's simplest model that explained a reasonable amount of the variation in PCS hours authorized included only a summary ADL scale. This summary scale was based on the number of ADLs in which the child needed or received hands-on assistance (Hands-On ADL Scale). This scale was chosen over a variety of other potential ADL scales because it resulted in a comparable R^2, had a good measure of transparency, and each level in the scale has a clear meaning.

Alternatively, the research team could have chosen to use an ADL scale that was the sum of a child's score on each of the ten individual ADL measures. Children would have scored from zero to fifty on this scale. Were this scale used, the only two points with clear conceptual or clinical meanings would be zero and fifty. Zero would mean the child was completely independent in all ADLs, and a score of fifty would mean the child was totally dependent in all ten ADLs. The meaning of a score of 20 on such a scale bears no clear relationship with a child's level of need. It simply indicates the ADL

scores summed to more than 19 and less than 21. The use of such a scale would have resulted in a slightly higher R^2, but it would have populated the classification model with groups of children without clearly discernable clinical or functional characteristics.

However, a score of six on the Hands-On ADL Scale has clear meaning. The child needed or received hands-on assistance with six of the ten ADLs. The model using only this ADL scale resulted in an R^2 of 0.20 and resulted in six distinct groups of children. The details of the model appear in Exhibit Three. The lowest care category was the largest, and members of that category averaged 18 hours of PCS per week. The children in the highest need category received an average of 35 hours per week. The rough difference between average hours for adjacent groups within the classification model was three to four hours, roughly one-half day of care during the week.

EXHIBIT THREE: CLASSIFICATION SCHEME FOR FOUR TO TWENTY YEAR OLDS USING ONLY AN ADL SCALE (N=2,759; Mean hours=25.4) R^2=0.20

Hands-On help in	AVERAGE HOURS	NUMBER OF CLIENTS
three or fewer ADLS	18	835
four ADLS	22	473
five ADLS	24	336
six or seven ADLS	29	282
eight ADLS	33	335
nine or ten ADLS	35	498

The research team explored another classification model that first created categories of children on the basis of the child's age. It then, within each age group, used the child's score on the Hands-On ADL scale. This model generated 14 groups of children. The lowest need group received or needed an average of 17 hours, while the children in the highest need group had an average of 44 hours of PCS authorized by DSHS case managers. The initial model in Exhibit Three had only two groups of children with hours of care exceeding 30 hours and no group with average hours higher than 36 hours of care. The model in Exhibit Four has four groups where the average hours authorized exceeded thirty hours and one group where the average hours authorized exceeded forty hours. The model used for Exhibit Four also fits the data much better,

with the R^2 increasing from 0.20 to 0.30 (an increase of 50%). This model also explained 22 percent of the variation in total Medicaid payments and 27 percent of payments for all types of home care for the children in the sample.

Within each age grouping in Exhibit Four, one finds a different number of subgroups. Also, in each of these groups, the Hands-On ADL Scale makes distinctions among PCS clients at different points. This occurs because the statistical algorithm used by the grouping software chooses breaks on independent variables so that the breaks maximize the explained variation or R^2. A consistent number of subgroups in each age category and consistent breaks on the ADL Scale would be more orderly. However, that consistency would be gained at the cost of reducing the models ability to predict PCS hours in our sample.

EXHIBIT FOUR: CLASSIFICATION SCHEME FOR FOUR TO TWENTY YEAR OLDS USING AGE AND THE ADL SCALE
(N=2,715; Mean hours=25.4)
R^2=0.30

GROUP (1-14)	AVERAGE HOURS	NUMBER OF CLIENTS
4 TO 9 YEARS OF AGE		
1. Hands-On Assistance in up to 4 ADLs	**17**	443
2. Hands-On Assistance in 5 or 6 ADLs	**22**	218
3. Hands-On Assistance in 7 to 9 ADLs	**26**	134
4. Hands-On Assistance in 10 ADLs	**29**	172
10 TO 15 YEARS OF AGE		
5. Hands-On Assistance in up to 1 ADL	**15**	170
6. Hands-On Assistance in 2 or 3 ADLs	**17**	147
7. Hands-On Assistance in 4 or 5 ADLs	**22**	249
8. Hands-On Assistance in 6 to 8 ADLs	**28**	124
9. Hands-On Assistance in 9 or 10 ADLs	**32**	241
16 OR 17 YEARS OF AGE		
10. Hands-On Assistance in up to 7 ADLs	**22**	177
11. Hands-On Assistance in 8 to 10 ADLs	**37**	104
18 TO 20 YEARS OF AGE		
12. Hands-On Assistance in up to 3 ADLs	**24**	188
13. Hands-On Assistance in 4 to 6 ADLs	**34**	140
14. Hands-On Assistance in 7 to 10 ADLs	**44**	208

Other variables (see Exhibit Two for examples and see Appendix A) were considered and tested in alternative models. These variables added little explanatory power to the model, affected only a limited number of groups defined by age and ADL function, or involved so few children that a reliable estimate of the PCS needed by these children could not be developed. To maintain the model's ability to be used with all children and to make the model less bound to the specifics of the children in this sample, these indicators were not included in the model.

The client or caregiver characteristics included in the model were chosen only after an extensive review of the model results when different variables or different orderings of these variables were used. The R^2s for all these models differed little. What the research team considers the preferred model was chosen on the basis of its statistical fit, its general applicability, and its conceptual clarity. The preferred model is based on two fundamental questions asked in sequence:

- How old is the child?
- In how many ADLs does the child need hands-on assistance?

EXCLUSIONS FROM THE MODEL

A few glaring omissions come to mind when one considers the preferred model presented in Exhibit Four. For example, the model contains no information on the child's diagnoses or conditions. This is the case because the effects of diagnoses and conditions on hours of PCS operate through the child's ADL needs (Fournier et al., in press). Diagnoses affect a child's physical function, and the child's physical function in turn affects the level of need for Medicaid PCS. A very large proportion of the children in the PCS program have multiple diagnoses. Separating the needs for assistance created by one diagnosis versus another is quite difficult. But, that process is unnecessary because a child's ADL function serves as a summary measure of the child's total disease burden and functional challenges, as it relates to personal care needs.

In the same way, a child's level of cognitive function does not appear in our preferred model. But, a child's cognitive function does affect the child's need for PCS. Like diagnoses, cognitive function has what is called an "indirect" effect on the authorization of PCS. The child's cognitive function affects her or his need for assistance

with ADLs, and those ADL needs affect the level of PCS authorized (Fournier et al., in press).

In other instances, some indicators were so highly correlated with age and the ADL scale that they added no additional predictive power to the model. Two of the most notable instances of this came with IADLs and continence. Those children who required more assistance in IADLs also required more assistance in ADLs. Both measures were not needed in the model. Those children who had continence problems were children with more ADL needs. The addition of continence problems and IADL function to the model added no information about PCS authorizations over and above the information provided by a child's ADL function.

One expects that parental barriers to care would also play a prominent role in a model of PCS authorizations. However, that was not the case. Barriers had no effect for a simple reason. Those independent variables (presence of a barrier) that have no variance (everyone has a barrier) will have no effect on the variation in the criterion variable (authorized hours). In all families receiving PCS the responsible person had some barrier to providing all the ADL assistance the child needed. Our information on the nature of that barrier (e.g., school, work, or stamina) had no statistically significant effect on the number of hours of PCS authorized.

BUILDING CORRIDORS FOR EACH GROUP

The average number of hours authorized for each group is clearly important information. But, the specific hours authorized for members of group are distributed around this average. If one wishes to use the groups as guidelines for DSHS case managers or for administrative quality review, then "corridors" must be built around these averages. Exhibit Five presents an example of how these corridors might be built. In this example, we look at the cumulative distribution of hours within each of the 14 groups. The cumulative distribution allows the research team to determine what proportion of the sample is above or below any number of hours.

For this example, we included 50 percent of the population in the corridors in Exhibit 5. The mean of each group is at approximately the 55^{th} percentile of the cumulative distribution. Going up the distribution by 25 percent and going down it by 25

percent gives us corridors at the 30th percentile and the 80th percentile of the cumulative distribution. Looking at Group 1, which is composed of the 443 children 4 to 9 years of age who needed hands-on assistance with up to 4 ADLs, the average number of hours of PCS authorized for children in this group was 17 hours. The corridors (30% and 80%) indicate that 30 percent of this group had 11 or fewer hours of PCS authorized and that 20 percent (100% minus 80%) had 23 or more PCS hours authorized.

EXHIBIT FIVE: CORRIDORS AROUND GROUP MEANS (H-OA= HANDS-ON ASSISTANCE ADL SCALE)

GROUP (1-14)	Hours at 30% of Cumulative Distribution	MEAN HOURS (Percent Cumulative)	Hours at 80% of Cumulative Distribution
4 TO 9 YEARS OLD			
1. H-OA in up to 4 ADLs	11	**17** (54)	23
2. H-OA in 5 or 6 ADLs	16	**22** (56)	30
3. H-OA in 7 to 9 ADLs	20	**26** (55)	35
4. H-OA in 10 ADLs	21	**29** (57)	40
10 TO 15 YEARS OLD			
5. H-OA in up to 1 ADL	10	**15** (58)	21
6. H-OA in 2 or 3 ADLs	12	**17** (60)	22
7. H-OA in 4 or 5 ADLs	17	**22** (61)	29
8. H-OA in 6 to 8 ADLs	21	**28** (56)	38
9. H-OA in 9 or 10 ADLs	22	**32** (56)	44
16 OR 17 YEARS OLD			
10.H-OA in up to 7 ADLs	16	**22** (53)	28
11.H-OA in 8 to 10 ADLs	27	**37** (56)	43
18 TO 20 YEARS OLD			
12.H-OA in up to 3 ADLs	17	**24** (55)	32
13.H-OA in 4 to 6 ADLs	27	**34** (55)	43
14.H-OA in 7 to 10 ADLs	32	**44** (55)	58

Of course, the corridors surrounding the mean hours authorized could be of any width. They could include 75 percent of the sample, 85 percent, or any other percentile the HHSC wished to use. Appendix B contains more detailed information on the distributions for all 14 groups of children.

CLASSIFICATION MODELING FOR CHILDREN AGES 0-3

The research team used a very similar list of variables to that used in the analyses of children over the age of four in our attempts to develop a classification model for

children receiving PCS who were under four years of age. The results were disappointing. No classification model achieved an R^2 above 0.11. Such a low level of explained variance (11%) indicates that the variables in our models could not capture well those factors that determined differences in the hours of PCS care received by children less than four years of age. Because of the poor quality of the models, no classification system was developed for children under four years of age who were receiving PCS.

LIMITATIONS/STRENGTHS OF THE CLASSIFICATION MODEL

A number of important factors must be kept in mind when one reflects on classification models like those developed using the PCAF data. These models are designed to mimic as closely as possible the current patterns of care provision. Those current patterns of care provision may or may not reflect the ideal pattern of care provision. Unfortunately, identifying the ideal level of care provision for groups of children receiving PCS is a daunting, if not impossible, task.

However, one would do well to remember another characteristic of the classification models that the research team has presented. In essence, the classification models in this report represent as best we can the collective wisdom of hundreds of DSHS case managers (social workers with post-baccalaureate training or licensed nurses) as they attempt to meet the needs of thousands of children facing a wide variety of challenges in a diverse array of settings or environments. They also reflect the requests for services made by thousands of concerned adults seeking personal care for the children for whom they are responsible.

These models can provide a starting point (the average number of hours) for DSHS case managers or Medicaid officials in their thinking about how much care a child needs from the Medicaid PCS Program. The corridors around those means provide flexibility to consider a child's circumstances. And beyond those corridors lies room to consider the unique or unusual challenges faced by a child and the child's caregivers.

REFERENCES

Bjorkgren, M., Fries, B. E. & Shugarman, L. (2000). Testing a RUG III based case-mix system for home care. *Canadian Journal on Aging*, 19(S2), 106-25.

Fournier, C. J., Davis, M. J., Patnaik, A., Elliott, T. R., Dyer, J., Jasek E. E. & Phillips, C. D. (in press). Understanding caregivers' perceptions of the personal care requirements of children with special needs. *Disability and Health Journal*.

Phillips, C. D. (2009). Case-Mix Adjustment. pp. 129-132 in Mullner, R. M., Rich, R. F., & Johnson, T. J., eds. *Encyclopedia of health services research, Volume One*. Thousand Oaks, CA: Sage Publishing.

Phillips, C. D., Dyer, J., Hawes, C., Janousek, V., & Halperin, L. (2008). Providing appropriate services to individuals in the community: A preliminary case-mix model for allocating personal care services. *Journal of Health and Human Services Administration*, 30(4), 378-401.

Phillips, C. D., Patnaik, A., Dyer, J., Hawes, C., Fournier, C.J., Elliott, T. R., Johnson, J.A., & Naiser, E. (2010). *Children and Medicaid Personal Care Services in Texas, 2009.* College Station, Texas: Texas A&M Health Science Center, School of Rural Public Health.

Phillips, C. D., Preece, C., & Hawes, C. (2005). Investigating case-mix classification for elderly residents in assisted living. S*enior Housing and Care Journal*, 13(1): 21-34.

SAS. (2008). SAS data mining solutions. Retrieved September 16, 2009 from http://www.sas.com/resources/brochure/ brochure_data_text_mining.pdf

APPENDIX A

PERSONAL CARE ASSESSMENT FORM FOR CHILDREN FOUR TO TWENTY YEARS OF AGE (PCAF 4-20) WHO ARE SEEKING MEDICAID PERSONAL CARE SERVICES

PCAF 4-20 items highlighted were considered in the classification modeling effort.

PERSONAL CARE ASSESSMENT FORM (PCAF) FOR CHILDREN AGES 4-20

AA. CLIENT/CASE MANAGER INFORMATION

Client Information	
Client Name (Last, First, MI):	
Client's Gender (circle one): Female Male	Age:
Medicaid Number (PCN):	Date of Birth:
Address:	Phone Number:
Name of Client's Parent/Guardian:	
PCS Provider Information—(Providers Selected by Client/Parent/Guardian)	
Name:	Telephone Number:
Address:	Fax Number:
TPI:	NPI:
Taxonomy:	Benefit Code:
Name:	Telephone Number:
Address:	Fax Number:
TPI:	NPI:
Taxonomy:	Benefit Code:
Name:	Telephone Number:
Address:	Fax Number:
TPI:	NPI:
Taxonomy:	Benefit Code:
Name:	Telephone Number:
Address:	Fax Number:
TPI:	NPI:
Taxonomy:	Benefit Code:
Assessment Date	
Date of this Assessment:	

Client/Parent/Guardian Acknowledgment—(must be signed by the client/parent/guardian)

By signing this acknowledgment, the client/parent/guardian agrees with the following:

- I understand information from this assessment may be needed to help with obtaining PCS and other referrals. I give my consent for my case manager to share this information as needed to help with these. I understand the information will be shared only with agencies listed on this sheet, the primary practitioner, and other referrals deemed necessary by me and my case manager. The information shared will be only what is needed to complete the referral, determine eligibility, or provide services to my child or to me. I understand I may take back or cancel this consent anytime. To cancel, I must write to my case manager. I understand this consent will not affect my (or my child's) treatment, payment, enrollment, or eligibility for benefits. I understand anyone who gets information as a result of this consent may share it with others as the law allows.

- If PCS is approved, the client/parent/guardian has chosen the following PCS provider option based on a review of the roles and responsibilities of the client/parent/guardian and PCS providers in each option:

Home Health Agency or PCS-only Provider ☐ Consumer Directed Services ☐ Service Responsibility Option ☐

Signature of Client/Parent/Guardian:	
Printed Name of Client/Parent/Guardian:	
Date:	
PCS Services Determination	Dates of Service
Approved/Denied/Modified Hours:	From: / /
	To: / /
DSHS Information	
Signature of DSHS case manager:	
Printed Name of DSHS case manager:	
Date:	DSHS Health Services Region:
Regional Telephone:	Regional Fax:
Signature of Translator:	
Printed Name of Translator:	
Date:	

PERSONAL CARE ASSESSMENT FORM (PCAF) FOR CHILDREN AGES 4-20

A. OTHER PROGRAM/AGENCY INVOLVEMENT

A.1 OTHER CURRENT PROGRAM/AGENCY INVOLVEMENT WITH CLIENT/PARENT/GUARDIAN
(DARS, DADS, WIC, MRA, MHA, DFPS, IHFS, Waiver Programs, Other)

AGENCY/PROGRAM (1)	CLIENT/FAMILY MEMBER (2)	RECEIVING/REFERRED/ APPLIED/WAITING (3)	CONTACT PERSON (4)	PHONE NUMBER (5)
a.				
b.				
c.				
d.				
e.				
f.				

Code for last 7 days, unless otherwise indicated, throughout remainder of assessment

B. REASON FOR ASSESSMENT AND SCHOOL SERVICES

B.1 REASON FOR ASSESSMENT ☐

Code: 0 = Intake assessment
1 = Scheduled reassessment
2 = Change in status assessment
3 = Other (specify): _____

_____

The information in Items B.2 is CONFIDENTIAL. The parent/guardian of the client/child is NOT required to respond to these in order to qualify for services.

B.2 SERVICES PROVIDED AT SCHOOL/DAY PROGRAM

Code: 0 = Not needed at school/day program
1 = Provided at school/day program
2 = Needed but not provided at school/day program

a.	Personal care attendant	
b.	Nursing services	
c.	Durable medical equipment	
d.	Other *(specify):*	

B.3 NAME OF SCHOOL OR DAY PROGRAM

_____

C. DIAGNOSES & HEALTH CONDITIONS

*For C1, C2, C3, and C4: Code only for those active diagnoses that currently affect the client's functional, cognitive, or behavioral status or require treatment, therapy, or medication **AND** were diagnosed by a licensed or certified health care professional. For C5, code only for conditions or problems that currently affect the client's functional, cognitive, or behavioral status or require treatment, therapy, or medication.*

Code: 0 = No 1 = Yes, condition active and diagnosed

C.1	MEDICAL DIAGNOSES	
a.	Anemia	
b.	Apnea	
c.	Arthritis	
d.	Asthma/respiratory disorder	
e.	Cancer	
f.	Cerebral Palsy	
g.	Cleft Palate	
h.	Congenital heart disorder	
i.	Cystic Fibrosis	
j.	Diabetes	
k.	Epilepsy or other chronic seizure disorder	
l.	Explicit terminal prognosis	
m.	Failure to thrive	
n.	Hemophilia	
o.	Hydro/microcephaly	
p.	Metabolic disorders (e.g., PKU)	
q.	Muscular Dystrophy	
r.	Paraplegia/tetraplegia/quadriplegia	
s.	Pathological bone fracture	
t.	Renal failure	
u.	Spina Bifida or other spinal cord dysfunction	
v.	Substance abuse related problems at birth (e.g., fetal alcohol syndrome, cocaine dependency)	
w.	Traumatic brain injury	

C.2	**OTHER MEDICAL DIAGNOSES**	
a.	Specify:	
b.	Specify:	
c.	Specify:	
C.3	**INFECTIONS**	
a.	Antibiotic resistant infection (e.g., MRSA)	
b.	Other (specify):	
C.4	**PSYCHIATRIC, DEVELOPMENTAL, OR BEHAVIORAL DIAGNOSES**	
a.	Anxiety disorders (e.g., OCD, separation anxiety)	
b.	Autistic disorder or other pervasive developmental disorders (e.g., Asperger's, Rett's)	
c.	Attention Deficit Disorder or ADD	
d.	Disruptive behavior disorders (e.g., conduct disorder, oppositional defiant disorder)	
e.	Down Syndrome	
f.	Intellectual disability	
g.	Mood disorders (e.g., depression, bipolar disorder)	
h.	Schizophrenic, delusional (Paranoid), schizoaffective, and other psychotic disorders	
i.	Somatoform, eating, and tic disorders (e.g., anorexia nervosa, bulimia, pica)	
j.	Other (specify):	
k.	Other (specify):	
C.5	**HEALTH CONDITIONS/PROBLEMS** **Code: 0 = No 1 = Yes, currently active**	
a.	Bed-bound or chair-fast (because of health condition; spends at least 23 hours per day in bed or in chair – not wheelchair)	
b.	Contracture(s)	
c.	Fall(s) related to client's condition	
d.	Fracture(s)	
e.	Limitation in range of motion – limitations that interfered with daily functions or placed client at risk of injury	
f.	Pain interferes with normal activities (e.g., school, work, social activities, ADLs)	
g.	Pressure ulcers, wounds, or skin lesions	
h.	Recurrent aspiration	
i.	Shortness of breath during normal activities	
j.	Other (specify):	

C.6 CLIENT'S CURRENT CONDITION

Code: 1 = Medical
2 = Psychiatric/Developmental/Behavioral
3 = Both

⇨ ***COMPLETE ITEM O.1.a.(3) NOW***

D. COGNITIVE FUNCTION

D.1 COMATOSE OR PERSISTENT VEGETATIVE STATE

Code: 0 = No 1 = Yes

IF "YES" – SKIP TO SECTION H

D.2 SHORT-TERM MEMORY – Recalls very recent events (e.g., most recent meal, object displayed then put away for a few minutes)

Code: 0 = Memory/recall ok

1 = Memory/recall problem

D.3 LONG-TERM MEMORY – Recalls information beyond recent events (e.g., age, town, own family name, neighbors' names, pets' names)

Code: 0 = Memory/recall ok

1 = Memory/recall problem

D.4 PROCEDURAL TASK PERFORMANCE – Ability to perform steps in a multi-step sequence without cues or supervision (e.g., retrieving specific object from other room; dressing self properly; preparing snacks)

Code: 0 = Performs most or all multiple-step tasks without cueing or supervision
1 = Needs cueing or supervision for most or all multiple-step tasks

D.5 COGNITIVE SKILLS FOR DAILY DECISION-MAKING – About such issues/daily tasks as when to get up, clothing to wear, how to organize the day, activities to do, or how to remain safe

Code: 0 = Independent – Decisions consistent/reasonable
1 = Modified independent – Consistent/reasonable decisions in customary situations or environments but experienced difficulty with new/unfamiliar tasks or in specific situations (e.g., crowds)
2 = Moderately dependent – Decisions consistently poor; cues or supervision required frequently
3 = Completely dependent – Never/rarely made decisions; cues or supervision required continually

⇨ ***COMPLETE ITEM O.1.b.(3) NOW***

E. COMMUNICATION

E.1 MAKING SELF UNDERSTOOD – Expressing information content, however able (with appliance if normally used)

Code: 0 = Understood – Expressed desires/needs without difficulty
1 = Usually understood – Some difficulty finding words or finishing thoughts but usually understood
2 = Sometimes understood – Ability was limited to making concrete requests understood (e.g., hunger)
3 = Rarely/never understood – Communication limited to interpretation of highly individual, person-specific sounds, behaviors, or body language understood by a limited number of people

E.2 ABILITY TO UNDERSTAND OTHERS – Understanding verbal information content, however able (with hearing appliance, if normally used)

Code: **0 = Understands** – Clear comprehension
1 = Usually understands – Sometimes missed some part or intent of message
2 = Sometimes understands – Responded only to simple, direct messages or communication
3 = Rarely/never understands – Observer has difficulty determining whether the child comprehended messages. Or, the client/child can hear sounds but did not understand messages

⇨ ***COMPLETE ITEM O.1.c.(3) NOW***

F. HEARING AND VISION

F.1 HEARING – Ability to hear (with hearing appliance, if normally used)

Code: **0 = Hears adequately** – No difficulty in normal conversation, social interaction, TV, phone
1 = Some impairment – Problems with specific types of sounds (e.g., low register) or with specific situations (e.g., requires quiet setting to hear well)
2 = Highly impaired – Absence of useful hearing

F.2 VISION – Ability to see near or far in adequate light (with glasses or with other visual appliance, if normally used)

Code: **0 = Vision adequate** – Saw fine detail, including fine detail in pictures, regular print in books
1 = Some impairment – Limited vision; was able to see large print or numbers in books; identify large objects in pictures
2 = Highly impaired – No vision or saw only light, colors, or shapes; eyes do not appear to follow objects

⇨ ***COMPLETE ITEM O.1.d.(3) NOW***

G. BEHAVIOR PATTERNS

G.1 SIGNS AND SYMPTOMS IN LAST 30 DAYS

Code: **0 = No occurrence in last 30 days**
1 = Occurred in last month but not during last 7 days
2 = Occurred once or more in the last 7 days

a.	Wandering – moved (locomotion) with no apparent rational purpose; seemingly oblivious to needs for safety	
b.	Elopement – attempted to or exited/left home, school, etc. at inappropriate time, without notice/permission, with impaired safety awareness	
c.	Verbally abusive – threatened, screamed at, or cursed others	
d.	Physically abusive or injuries to others –shoved, scratched, pinched, bit others	
e.	Bullying/Menacing behavior – no physical contact, but others made to feel unsafe/at-risk; invaded personal space of others in a threatening manner	
f.	Socially inappropriate or disruptive behavior – disruptive acts or sounds; noisiness; screaming; smeared /threw food/feces; hoarding; rummaging through other's belongings	
g.	Repetitive behavior that interferes with normal activities – e.g., finger flicking, rocking, spinning objects	
h.	Inappropriate sexual behavior – e.g., sexually abused/attacked others; inappropriate sexual activity or disrobing; masturbating in public	
i.	Resists ADL care – resisted assistance with ADLs, such as bathing, dressing, toileting, eating	
j.	Physically resists prescribed treatments and therapies – e.g., range-of-motion exercises, chest percussion	
k.	Injury to self – self-abusive acts; non-accidental injuries (e.g., cutting arms, head banging) that are not suicide attempts	
l.	Suicide attempt – effort(s) by client to end his/her life	
m.	Suicidal ideation – recurrent thoughts of death or suicide; saying that they wished they were dead or that they are going to kill or hurt themselves	
n.	Injury to animals – deliberate physical injury to/torture of animals	
o.	Dangerous, non-violent behavior – e.g., falling asleep while smoking, leaving candle lit or range burner turned on, playing with fire	
p.	Deliberate damage to property – e.g., intentional fire-setting, smashing furniture, breaking household objects	
q.	Other (specify):	

G.2 URGENT MENTAL/BEHAVIORAL HEALTH SERVICE USE IN LAST 30 DAYS

Code: **0 = No occurrence in last 30 days**
1 = Occurred only once in last 30 days
2 = Multiple occurrences in last 30 days

a.	Admission to inpatient treatment for mental or behavioral health problem (includes hospital)	
b.	Visit to emergency room for care or treatment of a mental or behavioral health problem	
c.	Urgent visit to physician, psychiatrist, or mental or behavioral health specialist office (not a regularly scheduled visit or assessment) because of a mental or behavioral health issue	
d.	Other (specify):	

G.3 CHILD MAY REQUIRE REFERRAL TO A MENTAL OR BEHAVIORAL HEALTH SPECIALIST

Code: **0 = No** **1 = Yes**

⇨ ***COMPLETE ITEMS O.1.e.(3) AND O.7.a NOW***

H. WEIGHT & HEIGHT

H.1 WEIGHT – Base weight on most recent measure **in last 30 days**

Weight in lbs.			OR	Weight in kilos		

H.2 HEIGHT – Base height on most recent measure **in last 30 days**

Feet		inches	OR	Centimeters		

⇨ ***COMPLETE ITEM O.1.f.(3) NOW***

I. MEDICATIONS

Count all medications taken in the last 7 days, including all prescribed medications and over-the-counter (OTC) medications, as well as any medications prescribed on an "as needed" or PRN basis. Include medications by any route of administration (e.g., pills, injections, ointments, inhaler).

I.1 NUMBER OF DIFFERENT MEDICATIONS TAKEN ☐☐

⇨ ***COMPLETE ITEM O.1.g.(3) NOW***

J. LICENSED/PROFESSIONAL NURSING NEEDS

J.1 CARE ACTIVITIES NEEDED OR PROVIDED DURING LAST 7 DAYS THAT MAY REQUIRE NURSING CARE OR SUPERVISION (i.e., nursing services or nurse delegated tasks)

Code: 0 = Not needed
1 = Needed and provided
2 = Needed but not provided

a.	Medication management – includes injections and other nursing activities	
b.	Intravenous medications	
c.	Intravenous feeding (parenteral or IV)	
d.	Feeding tube	
e.	Nasopharyngeal suctioning	
f.	Tracheostomy care	
g.	Wound or skin lesion care – treatment or dressing of stasis or pressure/decubitus ulcer, surgical wound, burns, open lesions	
h.	Oxygen – administration or supervision	
i.	Urinary catheter care – insertion or maintenance (e.g., change, irrigation)	
j.	Comatose or persistent vegetative state – care to manage the condition	
k.	Ventilator or respirator – to manage equipment	
l.	Uncontrolled seizure disorder – care and supervision for safe management	
m.	Unstable medical condition – assessment, observation, and management on a daily basis	
n.	Other periodic assessment, management, supervision – once or twice a month	
o.	Other (specify)**:**	

J.2 URGENT MEDICAL CARE USE IN LAST 30 DAYS

Code: 0 = No occurrence in last 30 days
1 = Occurred only once in last 30 days
2 = Multiple occurrences in last 30 days

a.	Visit to emergency room for care or treatment of a medical problem	
b.	Admission to hospital for medical care	
c.	Urgent visit to physician's office for physical illness (not a regularly scheduled visit or checkup)	
d.	Other (specify):	

J.3 REFERRAL FOR NURSING ASSESSMENT – (e.g., unstable medical condition; significant change in health or functional status; needs more/different care, additional services, or supervision)

Code: 0 = No 1 = Yes ☐

⇨ ***COMPLETE ITEM O.7.b NOW***

K. TREATMENTS AND THERAPIES

K.1 TREATMENTS OR THERAPIES RECEIVED OR NEEDED IN LAST 30 DAYS – outside of day program/school

Code: 0 = Not needed
1 = Needed and provided
2 = Needed but not provided

a.	Chemotherapy	
b.	Radiation therapy	
c.	Hemodialysis	
d.	Peritoneal dialysis	
e.	Hospice	
f.	Physical therapy	
g.	Occupational therapy	
h.	Speech therapy	
i.	Mental health services (includes substance abuse treatment)	
j.	Home health aide	
k.	Restorative nursing care/habilitative care	
l.	Other (specify):	

K.2 REFERRAL TO CONSIDER NEED FOR NEW/DIFFERENT TREATMENT OR THERAPY

Code: 0 = No 1 = Yes ☐

⇨ ***COMPLETE ITEM O.7.c NOW***

L. CONTINENCE

L.1 BLADDER AND BOWEL PROGRAMS & APPLIANCES IN LAST 7 DAYS

Code: 0 = Not needed or available and adequate
1 = New or different program or appliance may be needed because of condition or problem

	Appliances			Programs	
a.	Indwelling catheter		**f.**	Bladder retraining	
b.	Intermittent catheter		**g.**	Bowel retraining	
c.	External catheter		**h.**	Scheduled toileting	
d.	Ostomy		**i.**	Toilet training	
e.	Pads/briefs		**j.**	Other (specify):	

L.2 URINARY CONTINENCE – Code client's performance over 24 hours a day during last 7 days (with device or continence program, if used) ☐

Code: 0 = Continent – Complete control and did not use any type of catheter, urinary collection device, or toileting program
1 = Complete control with device or program – (e.g., catheter, ostomy, scheduled toileting)
2 = Usually continent – Incontinent episodes once a week or less frequently
3 = Occasionally incontinent – Episodes 2 or more times a week but not daily
4 = Frequently incontinent – Tended to be incontinent daily but some control present (e.g., during day)
5 = Always/almost always incontinent – Had inadequate control, multiple daily episodes
8 = Did not occur – No urine output from bladder during last 7 days (e.g., dialysis)

L.3 BOWEL CONTINENCE – Code person's performance over 24 hours a day during last 7 days (with device or continence program, if used) ☐

Code: 0 = Continent – Complete control and did not use any type of ostomy
1 = Complete control with device/program/medication (e.g., ostomy)
2 = Usually continent – Incontinent episodes once a week or less
3 = Occasionally incontinent – Episodes 2 or more times a week but not daily
4 = Frequently incontinent – Tended to be incontinent daily but some control present (e.g., during day)
5 = Always/almost always incontinent – Had inadequate control, multiple daily episodes
8 = Did not occur – No bowel movement during last 7 days ☐

L.4 NIGHTTIME INCONTINENCE (BOWEL/BLADDER)
Code: 0 = No 1 = Yes

⇨ ***COMPLETE ITEM O.1.h.(3) NOW***

M. PHYSICAL FUNCTION

M.1 INSTRUMENTAL ACTIVITIES OF DAILY LIVING (IADLs) – Code for assistance provided to client in routine activities around the home or in the community during the last 7 days. Consider assistance provided over 24-hours per day

Code: 0 = No help/Independent – No set-up help, supervision/cueing, or hands-on assistance **OR** some type of help provided only 1 or 2 times
1 = Set-up help only – Set-up help provided ≥ 3 times
2 = Intervention/Cueing/Redirection – Oversight, standby assistance, encouragement, cueing, redirection provided ≥ 3 times
3 = Limited assistance – Child/client highly involved in activity; received help on some occasions (at least ≥ 3 times) but not all the time
4 = Extensive assistance – Child/client received help throughout task most of the time, or full performance by others some, but not all, of the time
5 = Total dependence – Full performance of the activity by others during entire period
8 = Activity did not occur – During 7 day period

M.2 EFFECTS OF ILLNESS OR CONDITION ON IADL NEEDS/CARE (Code M.2 as you complete M.1)

Code: 0 = Client/Child's condition did not affect the performance of the task (i.e., time it takes to do task or the number of persons needed to do task)
1 = Client/Child's condition affected the performance of the task (because of child's condition, task regularly takes longer to perform OR two-person assistance regularly provided/needed)

	IADLs	M.1 Help	M.2 Effect?
a.	Meal preparation – prepared light meals/snacks (e.g., planning, cooking, assembling ingredients, setting out food & utensils)		
b.	Medication assistance (e.g., remembering to take medicines, opening bottles)		
c.	Telephone use – made and received telephone calls (using assistive devices, such as large numbers, amplification); includes finding number, making calls		
d.	Getting to places outside the home – arranged for transportation; including knowing where to go and ability to travel alone/independently		
e.	Laundry – sorting, washing, folding, putting away personal laundry (e.g., clothing,		

	underwear), bedding, and towels		
f.	Ordinary/light housework – ordinary work around the home (e.g., doing dishes, dusting, sweeping or vacuuming, making bed, cleaning bathroom, tidying up)		
g.	Grocery shopping – shopping for food and household items (e.g., could take longer because of child's special diet or behavior)		

COMPLETE ITEMS O.2.a.(2) – O.2.h.(2) NOW

M.3 ACTIVITIES OF DAILY LIVING (ADL) – Code for assistance provided to client in last 7 days, including all 24 hours in a day

Code: 0 = No help/Independent – No set-up help, intervening/cueing, hands-on assistance **OR** some type of help provided only 1 or 2 times

1 = Set-up help only – Set-up help provided ≥ 3 times

2 = Cueing/Redirection/Monitoring – Oversight, standby assistance, encouragement, cueing, redirection provided ≥ 3 times

3 = Limited assistance – Child/client highly involved in activity; received physical/hands-on help (e.g., guided maneuvering of limbs) that is non-weight-bearing ≥ 3 times

4 = Extensive assistance – While child/client performed part of activity, over last 7-day period, help of the following type(s) provided 3 or more times:

- Weight-bearing support
- Full caregiver performance during part (not all) of last 7 days

5 = Total dependence – Full caregiver performance of activity during entire 7 days (e.g., each time activity occurred)

8 = Activity did not occur during entire 7 days

M.4 EFFECTS OF ILLNESS OR CONDITION ON ADL NEEDS/CARE IN LAST 7 DAYS
(Code M.4 as you complete M.3)

Code: 0 = Client/Child's condition did not affect the performance of the task (i.e., time it takes to do task or the number of persons needed to do task)

1 = Client/Child's condition affected the performance of the task (because of child's condition, task regularly takes longer to perform OR two-person assistance regularly provided/needed)

	ADLs	M.3 Help	M.4 Effect?
a.	Bed mobility – moved to/from lying position, turns side to side and positions in bed		
b.	Positioning – moved/positioned in chair or other piece of furniture or equipment		
c.	Eating – ate and drank (regardless of skill)		
d.	Transfers – moved between surfaces, to/from bed, chair, wheelchair, standing position (EXCLUDE bath/shower transfers)		
e.	Locomotion Inside – moved between locations in the home; if uses wheelchair/electric cart, self-sufficiency once in chair/cart		
f.	Locomotion outside – moved between home and other places outside the home (e.g., school, doctor's office)		
g.	Toilet use – used the toilet room (or commode, bedpan, urinal); transferred on and off toilet; cleansed; changed pad/incontinence supplies; adjusted clothing		
h.	Dressing – put on, fastened, and took off all items of clothing, including donning/removing shoes, prostheses		
i.	Personal hygiene – maintained personal hygiene, including combing hair, brushing teeth, shaving, applying makeup, managing feminine hygiene, washing/drying face, hands, perineum (EXCLUDE bathing)		
j.	Bathing – took full bath/shower, including transfer in and out. Code for **most dependent** performance in last 7 days – using codes below: 0. Independent 1. Set-up help only 2. Monitoring/oversight/cueing 3. Physical/hands-on help limited to transfer 4. Physical/hands-on help in part of bathing activity 5. Total dependence – full performance by other 8. Activity (full bath) did not occur during entire 7 days		

COMPLETE ITEMS O.2.i.(2) – O.2.p.(2) NOW

M.5 ANY TWO-PERSON ASSISTANCE RECEIVED

Code: 0 = No 1 = Yes

a.	With any transfer – bed/chair/standing, toilet, or bathing, during the last 7 days	
b.	With any other ADL – during the last 7 days	

M.6 CLIENT NEEDS SPECIAL ASSISTANCE (CUEING, REDIRECTION, INTERVENTION,ETC.) FOR SAFETY OF SELF OR OTHERS DURING ADLs OR IADLs

Code: 0 = No 1 = Yes

a.	Needs special assistance for safety of self or others during ADLs or IADLs while in home	
b.	Needs special assistance for safety of self or others during ADLs or IADLs when outside the home	
c.	Other (specify):	

COMPLETE ITEMS O.2.q.(2)—O.2.r.(2) NOW

M.7 MAIN MODE OF LOCOMOTION IN LAST 7 DAYS

Code: 0 = No 1 = Yes

a.	Walking was ***main*** mode of locomotion	
b.	Wheelchair/cart/scooter was ***main*** mode of locomotion during last 7 days	
c.	Walking and wheelchair/cart used about equally	

M.8 USE OF & NEED FOR ASSISTIVE DEVICES TO MAXIMIZE/SUPPORT FUNCTIONING

Code: 0 = Not needed or available and adequate
1 = Referral to assess for unmet DME needs

Durable Medical Equipment (DME)/Assistive Devices		
a.	Hospital bed	
b.	Bed mobility aids – e.g., bed rails, special mattress, postural supports like foam wedges, bed enclosure	
c.	Transfers aids – e.g., trapeze, transfer board, seat lift chair, Hoyer lift	
d.	Wheelchair, cart	
e.	Mobility aids/devices—e.g., cane, quad cane, crutches, walker	
f.	Bathing aids – e.g., shower chair, tub transfer bench	
g.	Medication management – e.g., talking clock, daily medication organizer	
h.	Meal preparation – e.g., rocker knife	
i.	Telephone use – e.g., voice activated telephone	
j.	Transportation – e.g., swivel cushion	
k.	Augmentative communication device	
l.	Gait trainer	
m.	Transcutaneous Electrical Nerve Stimulation (TENS) unit	
n.	Chest Physio Therapy (CPT) vest	
o.	Other (specify):	
p.	Other (specify):	

M.9 RESULTS OF DISCUSSION OF DME NEEDS WITH CLIENT/FAMILY

Code: 0 = No concerns expressed about current DME needs
1 = Yes, family/client believes new or additional DME needed

Specify: _____

_____

_____

_____

⇨ ***COMPLETE ITEM O.7.d NOW***

N. HOUSEHOLD RESOURCES

IF CLIENT IS 18 OR OLDER, THEN SKIP THIS SECTION AND GO DIRECTLY TO SECTION O

N.1 PARENT/GUARDIAN STATUS/CHALLENGES

Code: 0 = No 1 = Yes

a.	In school full-time			
b.	In school part-time (not full-time)			
c.	Working full-time outside home			
d.	Working part-time outside home (not full-time)			
e.	Other work situation (specify):			
f.	Responsible adult for other children			
	(1)If YES, record number of other children (use "0" to fill); if none, record "00"			
	(2) Number of dependent children in household, other than client, with special needs			
g.	Caregiving for a disabled or challenged adult family member in household (specify):			
h.	Caregiver's sleep is interrupted frequently throughout the night because of caregiving responsibilities related to child's condition			
i.	Because of physical limitations or disabilities (strength/stamina) parent/guardian is unable to assist client with some ADL or IADL tasks			
j.	Other (specify):			

N.2 NOTES ON HOW PARENT/GUARDIAN BARRIERS MAY AFFECT MEETING CLIENT'S ADL AND IADL NEEDS

(May be continued on pg. 11 if necessary)

O. STRENGTHS AND NEEDS

O.1 ADDITIONAL CONSIDERATIONS AND POTENTIAL COMPLEXITIES
Column (3): Review items noted in Column (2)
Code: 0 = No problems noted **1** = At least one problem noted

(1) ISSUES		(2) ITEMS	(3) PROBLEMS	(4) Impact on ADL/IADL needs (may be continued on p. 14)
a.	Diagnoses/Conditions	**C.1 - C.5**		
b.	Decision-making	**D.1 - D.5**		
c.	Communication	**E.1 - E.2**		
d.	Hearing/Vision	**F.1 - F.2**		
e.	Behavior	**G.1 - G.3**		
f.	Weight /Height	**H.1 - H.2**		
g.	Medications	**I.1**		
h.	Continence	**L.1 - L.4**		
i.	Other			

O.2 PERSONAL CARE ASSISTANCE IN AVERAGE OR USUAL WEEK
Column (2): Potential PCS need (based on PCAF assessment)

Code: 0 = No functional limitation
1 = Functional limitation present but the limitation is not affected by child/client's condition or problem
2 = Functional limitation is present and is affected by child/client's condition or problem

Column (3): PCS decision

Code: 0 = No PCS assistance requested
1 = PCS assistance requested and approved
2 = PCS assistance requested but denied because of no functional limitation
3 = PCS assistance requested but denied because requested assistance is not covered by PCS services
4 = PCS assistance requested but denied because functional limitation is not related to child's condition/problem
5 = PCS assistance requested but denied because functional limitation must be addressed by a skilled health professional
6 = PCS assistance requested but denied because PCS need is currently being met by another agency or program
7 = PCS assistance requested but denied because parent/guardian can meet needs (not applicable to client ≥18)
8 = PCS requested by denied for other reason; specify in Column (4)

(1) ACTIVITY		(2) NEED	(3) PCS	(4) ADDITIONAL INFORMATION
a.	Meal preparation			
b.	Medication assistance			
c.	Communication assistance			
d.	Arranging transportation			
e.	Accompaniment – Client/child needs to be accompanied when outside the home for personal care			

f.	Laundry			
g.	Light housework			
h.	Grocery shopping			
i.	Bed mobility or positioning in chair/wheelchair			
j.	Eating			
k.	Transfers			
l.	Locomotion			
m.	Toileting needs			
n.	Dressing			
o.	Personal hygiene			
p.	Bathing			
q.	Special assistance (cueing, redirection, etc) in home for safety of self or others during ADLs or IADLs			
r.	Special assistance (cueing, redirection, etc) outside home for safety of self or others during ADLs or IADLs			
s.	Escort to appointment for health services			
t.	Other (specify):			
u.	Other (specify):			

O.3 INDICATE THE NUMBER OF MINUTES OF PCS CARE FOR EACH HOUR OF EACH DAY DURING AN AVERAGE/USUAL WEEK. If two persons are needed for 20 minutes during one hour, then the total for that hour is 40 minutes.

24–Hour Flow Sheet															
	Time of Day	SUNDAY Minutes of PCS needed (1)			MONDAY Minutes of PCS needed (2)			TUESDAY Minutes of PCS needed (3)			WEDNESDAY Minutes of PCS needed (4)			THURSDAY Minutes of PCS needed (5)			FRIDAY Minutes of PCS needed (6)			SATURDAY Minutes of PCS needed (7)		
a.	12:00 AM																					
b.	1:00 AM																					
c.	2:00 AM																					
d.	3:00 AM																					
e.	4:00 AM																					
f.	5:00 AM																					
g.	6:00 AM																					
h.	7:00 AM																					
i.	8:00 AM																					
j.	9:00 AM																					
k.	10:00 AM																					
l.	11:00 AM																					
m.	12:00 PM																					
n.	1:00 PM																					
o.	2:00 PM																					
p.	3:00 PM																					
q.	4:00 PM																					
r.	5:00 PM																					
s.	6:00 PM																					
t.	7:00 PM																					
u.	8:00 PM																					
v.	9:00 PM																					
w.	10:00 PM																					
x.	11:00 PM																					
y.	Total number of minutes per day																					
z.	Total number of minutes per week. Sum daily totals in O.3.y.(1) through O.3.y.(7)																					

O.4 PCS HOURS AUTHORIZED

DIVIDE TOTAL MINUTES OF PCS CARE AUTHORIZED (O.3.z) BY THE NUMBER SIXTY (60). If the division does not result in a whole number (5.00, 9.00, etc) or a fraction representing a quarter-hour (e.g., 9.25, 9.50, 9.75), then you should round up to the next quarter-hour (e.g., .01 - .25 = .25; .26 - .50 = .50; .51 - .75 = .75; .76 - .99 = go up to next full hour).	

O.5 PCS HOURS REQUESTED AND PCS HOURS AUTHORIZED

Code: **0 =** Responsible person made no request for a specific amount of PCS assistance
1 = PCS hours authorized equal or exceed hours requested by responsible person
2 = PCS hours authorized are less than hours requested by responsible person

O.6 NATURE OF ANY DISAGREEMENT ABOUT PCS HOURS/RATIONALE FOR DIFFERENCE

O.7 REFERRALS AND SERVICES NEEDED

Code: **0 = No** **1 = Yes**

Referrals will be made for:			**Notes:**
a.	Mental or behavioral health specialist services (G.3)		
b.	Nursing services assessment (See J.3)		
c.	Therapies or Treatments (See K.2)		
d.	Durable Medical Equipment (DME) assessment (See M.8 and M.9)		
e.	Other referrals related to PCS (specify):		

O.8 TARGET DATE FOR NEXT ASSESSMENT

Date:

O.9 ADDITIONAL COMMENTS RELATED TO CLIENT'S NEEDS FOR PCS, NURSING SERVICES, OR DME

O.10 CASE MANAGER (CURRENT ASSESSMENT)

a. SIGNATURE:		**c. DATE:**
b. PRINTED NAME:		

APPENDIX B

CUMULATIVE DISTRIBUTIONS FOR THE 14 GROUPS

EXHIBIT B.1: PCS HOURS AT DIFFERENT POINTS ON THE CUMULATIVE DISTRIBUTIONS FOR THE 14 GROUPS OF CHILDREN FOUR TO TWENTY YEARS OF AGE (H-OA= HANDS-ON ASSISTANCE ADL SCALE)											
	PERCENTILE IN THE CUMULATIVE DISTRIBUTION										
GROUP (1-14)	**5**	**10**	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**95**
4 TO 9 YEARS OLD (HOURS)											
1. H-OA in up to 4 ADLs	5	7	10	11	14	16	18	20	23	28	33
2. H-OA in 5 or 6 ADLs	9	11	15	16	19	21	23	26	29	36	42
3. H-OA in 7 to 9 ADLs	10	13	17	20	22	25	27	30	35	40	43
4. H-OA in 10 ADLs	8	12	15	21	23	27	30	35	41	47	54
10 TO 15 YEARS OLD (HOURS)											
5. H-OA in 1 ADL	4	5	7	10	12	13	15	18	21	25	29
6. H-OA in 2 or 3 ADLs	8	9	11	12	14	15	17	19	22	28	33
7. H-OA in 4 or 5 ADLs	10	11	14	17	18	20	22	26	29	35	40
8. H-OA in 6 to 8 ADLs	12	15	18	21	23	26	28	32	38	45	50
9. H-OA in 9 or 10 ADLs	12	15	19	22	27	30	34	38	44	50	62
16 OR 17 YEARS OLD (HOURS)											
10.H-OA in up to 7 ADLs	7	9	12	16	19	21	24	26	29	35	41
11.H-OA in 8 to 10 ADLs	12	16	22	27	30	34	39	41	43	62	82
18 TO 20 YEARS OLD (HOURS)											
12.H-OA in up to 3 ADLs	9	12	15	17	21	22	25	28	32	38	46
13.H-OA in 4 to 6 ADLs	15	16	22	27	30	33	36	39	43	51	57
14.H-OA in 7 to 10 ADLs	18	21	27	32	37	41	47	52	58	71	78

ACKNOWLEDGEMENTS

The PCAF instruments were developed with commentary and review from a wide range of individuals involved in advocating for or providing services to children in Texas. The authors, however, would like to give special acknowledgement to Marianna Zolondek and Billy Millwee of the Texas Health and Human Services Commission for their support and leadership in this effort to assure that children in the Medicaid program receive the services they require. Margaret Bruch and her staff at the DSHS provide crucial input to assist the project team in tailoring the instruments to the special needs of the DSHS case managers so pivotal in the PCS process. They provided invaluable guidance to the project team.

COPYRIGHT INFORMATION

To protect the instruments from unwarranted changes or re-organization that might damage their reliability or validity, both PCAF 0-3 and PCAF 4-20 are copyrighted. The copyrights for Texas are held by the Texas A&M Health Science Center. In return for unrestricted use of the MDS and MDS-HC© items in the PCAFs, the copyrights for the remainder of the United States and other nations are held by inter*RAI,* the organization responsible for the development of the MDS-HC©. As noted, through arrangements with inter*RAI*, all governmental agencies, service providers, and researchers are granted licenses for free use of all inter*RAI* copyrighted assessment tools. More information can be obtained concerning inter*RAI* at www.interrai.org.

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 the Center for Community Health Development at 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 . 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. 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.

Thomas R. Miller, Ph.D., M.B.A., Co-Investigator, is an Assistant Professor in the Health Policy and Management Department at Texas A&M Health Science Center's School of Rural Public Health.

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

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

Charles D. Phillips, Ph.D., M.P.H. serves as the Project Director and Principal Investigator for the PCAF project. Dr. Phillips 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 TAMU's Children and Adolescent Health Research Laboratory, SRPH's Program on Aging, Disability, and Long-Term Care, and SRPH's Southwest Rural Health Research Center.

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