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SAYING GOOD BYE TO COUNCIL
CHILDREN WITH SPECIAL HEALTH CARE NEEDS LIVING IN THE COMMUNITY:

Personal Care Services and Psychological Issues
Children requiring early and periodic screening, diagnostic, and treatment services (EPSDT) number about 31 million in the U.S. In 2009, the almost three million children in Texas eligible for EPSDT benefits resulted in Medicaid expenditures of approximately $1.8 billion for health care. There is a subset of these children who also require personal care service (PCS) provided by personal care assistants to compensate for impairments in activities of daily living (ADL) and instrumental activities of daily living (IADL) due to illness or chronic conditions.

Psychologists are often unaware of the needs of families who have children with special health-care needs (SHCN), as these individuals are disproportionately represented in public assistance programs. Traditional forms of psychological services are often inaccessible to these individuals: Indeed, parents of children with special health care needs experience the same adverse financial and medical effects of caregiving as seen in other scenarios across the lifespan, yet they are less likely than other caregivers to seek health care services. In a collaborative project with the Texas Health and Human Services Commission, our interdisciplinary team has studied over 5,000 children under the age of 21 and their families, assessed (from September 2008 to April 2009) by Department of State Health Services (DSHS) case managers with instruments we developed to help them determine a child's need for PCS. We included ADL items to assess bed mobility, positioning when upright, eating, locomotion inside, locomotion outside, transfer, using toilet, dressing, personal hygiene, and bathing. These are rated on a 6 point scale: independent, needs set up only, needs supervision, needs limited assistance, needs extensive assistance, or total dependence.

In this project, we learned much about these children that merit the attention of professional psychology and others invested in the behavioral, social, health and educational issues facing these children and their families:

In this project, we learned much about these children that merit the attention of professional psychology and others invested in the behavioral, social, health and educational issues facing these children and their families:

1. 51.4% 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. Almost one-half (46.6%) of these children had a diagnosis of some type of intellectual disability

3. Either because of their age or because of their condition, over 70% required continual or close stand-by assistance to assure they made safe and reasonable decisions.

4. Over one-third had little or no control of their bowel or bladder function.

5. 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%. 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.

6. 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%) of the children were independent or their condition had no effect on this task; for 38.2% 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% of the cases.

7. 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. The vast majority of these children were attending school. Forty-one percent were in elementary school; 19% were attending middle school; just over one-quarter of the...
children were in high school (25.3%). Less than one percent attended college, and less than one percent attended kindergarten.

The medical conditions with more than 5% prevalence rate included asthma (29%), some seizure disorder (29%), Attention Deficit Hyperactivity Disorder (26%), cerebral palsy (24%), Autistic Spectrum Disorder (24%), bed-bound (16%), and paralysis (11%). About 5% prevalence rates were seen in hydro/microcephaly, apnea, congenital heart disorder, spina bifida or some other spinal cord injury, and traumatic brain injury. Almost 17% of the children had problems with chronic pain, and almost 13% had a problem with falling.

Behavioral problems reported with more than 5% prevalence rate included socially inappropriate behavior (31%), repetitive behavior (30%), physically abusive (29%), wandering (26%), verbally abusive (23%), injury to self (18%), elopement (15%), bullying/menacing behavior (14%), and deliberate damage to property (13%). Autism, anxiety, depression, and disruptive behavior had prevalence rates ranging between 10 and 17%.

Where is personal care assistance needed? Complex tasks typically associated with the bathroom required the most hands-on assistance. These include bathing (83%); dressing (80%); personal hygiene (79%), and toileting (72%). The next level of complexity includes mobility and eating tasks: locomotion outside (42%); locomotion inside (41%); transfer (38%), eating (34%); upright positioning (30%); and bed mobility (28%).

The Need for Psychological Services and Expertise

Of note for psychologists is the degree and variety of behavioral issues that compromise the well-being of these children and their families. These data clearly indicate that behavioral interventions may be helpful, yet only 17% of the sample are reported receiving some form of mental or behavioral health treatment, and 4% reported as needing but not receiving this treatment. In terms of urgent need, about 7% reported as needing referral to mental or behavioral health specialists.

Psychologists are urged to consider ways to assist these children and their families in community, home, and school-based programs.
school-based programs. This may require strategic and innovative uses of non-doctoral level providers to meet the various behavioral and health concerns of these individuals. Psychological expertise is needed to inform meaningful policies and implement creative programs to improve the quality of life of these children.

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Information about the project described in this article may be found at the project website: http://pcaf.tamu.edu/

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