

Capturing Unmet Therapy Need Among Young Children With Developmental Delay Using National Survey Data

Dawn Magnusson, MPT, PhD; Mari Palta, PhD; Beth McManus, PT, MPH, ScD; Ruth E. Benedict, DrPH, OTR; Maureen S. Durkin, PhD, DrPH

From the Departments of Population Health Sciences (Dr Magnusson, Dr Palta, Dr Benedict, and Dr Durkin), Biostatistics and Medical Informatics (Dr Palta), Pediatrics (Dr Durkin), School of Medicine and Public Health, Waisman Center (Dr Durkin), Department of Kinesiology, Occupational Therapy Program, School of Education (Dr Benedict), University of Wisconsin–Madison, Madison, Wis; and Department of Health Systems, Management and Policy, Colorado School of Public Health, Aurora, Colo (Dr McManus)

The authors declare that they have no conflict of interest.

Address correspondence to Dawn Magnusson, MPT, PhD, Rubenstein Child Health Building Room 2085, 200 North Wolfe Street, Baltimore, MD 21287 (e-mail: dmagnus1@jhmi.edu).

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ABSTRACT

OBJECTIVE: Estimates of unmet therapy need based on parent report overlook the unmet needs of children with developmental delay (DD) whose parents do not first recognize a need for therapy. Using national survey, data we: 1) identified children with DD who likely need physical, occupational, or speech therapy services; 2) estimated the prevalence of overall unmet therapy need; and 3) examined factors associated with unrecognized therapy need and parent-reported unmet therapy need.

METHODS: Criteria for DD were applied to children aged 0 to 4 years using the 2009–2010 National Survey of Children With Special Health Care Needs (NS-CSHCN). Multivariate logistic regression was used to identify factors associated with unrecognized or parent-reported unmet therapy need.

RESULTS: Among 5349 children with special health care needs aged 0 to 4 years, 50.2% met our inclusion criteria for DD, 21.6% had overall unmet therapy need, 15.4% had unrecognized therapy needs, and 6.2% had parent-reported unmet therapy need. The adjusted odds of unrecognized therapy

need were higher among black and Hispanic children, and children from other racial or ethnic groups than among white children (adjusted odds ratio 1.78 [95% confidence interval 1.23–2.57]). The odds of parent-reported unmet therapy need were higher for children lacking special education services.

CONCLUSIONS: Relying on parent-reported unmet therapy need, without considering children with DD whose therapy needs go unrecognized, likely underestimates overall unmet therapy need among children with DD. Exploring the mechanisms underlying racial, ethnic, and socioeconomic disparities in overall unmet therapy need should facilitate the development of effective interventions aimed at improving therapy access for children with DD.

KEYWORDS: developmental delay; occupational therapy; physical therapy; speech therapy; unmet need

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WHAT'S NEW

Unmet need for physical, occupational, or speech therapy services among young children with special health care needs is likely higher nationally than previously reported due to parents underrecognizing service needs. Moreover, important disparities in unrecognized therapy need exist.

DEVELOPMENTAL DELAY (DD) and disability are a group of chronic conditions that appear early in life, and are associated with challenges in motor, language, cognitive, or behavioral development that affect a child's ability to carry out age-appropriate activities. Early intervention and special education services, including physical, occupational, and speech therapy for children with DD have been shown to enhance development, minimize further delay, and reduce the economic pressure

subsequently placed on the special education system as children get older.^{1,2} Furthermore, increasing the proportion of young children with DD who are screened, evaluated, and enrolled in early intervention services is a top priority of Healthy People 2020.³ Thus, understanding the unmet therapy need of young children with DD is critically important for health care professionals, families, and policy makers.

Various methods for measuring unmet health care need exist, yet their application in a national sample of children with DD is limited.⁴ One alternative involves comparing service utilization to existing professional standards. While this approach may be feasible for preventive, routine, or acute care, its application among children with varying levels of DD and service need is not appropriate, given the lack of precise therapeutic standards across disciplines and diagnoses. Another alternative involves the judgment of health care professionals via direct clinical examination

or record review. The cost of conducting either an examination or record review for such a heterogeneous population makes this alternative prohibitive on the national scale. Thus, most studies examining unmet health care need among children rely on parent report.⁴

Parent-reported unmet health care needs reflect a complex web of factors⁵ encompassing 4 key elements⁴: 1) perceiving a problem; 2) recognizing and reporting a need for services; 3) recalling a situation in which services were needed but not received; and 4) reporting the unmet need. According to the National Surveys of Children with Special Health Care Needs (NS-CSHCN),⁶ between 2.4% and 3.4% of noninstitutionalized children ages 0 to 5 years living in the United States have a parent-reported need for therapy services. However, Rosenberg and colleagues,⁷ using standardized developmental assessment scores obtained from the Early Childhood Longitudinal Survey–Birth Cohort (ECLS-B), found that 13% of children at 24 months of age likely need therapy services: they had DDs that would confer eligibility for federally mandated early intervention services. Thus, it would appear that parents are underreporting therapy need among young children.

Factors related to health care access and quality, and the receipt of routine developmental screenings are believed to influence perceptions of DD and service need.^{5,8} Mayer argues that parents of children with limited access to quality health care are less likely to perceive a need for health-related services.⁵ Additional evidence suggests that social and economic factors such as race and ethnicity, parental education, and family income influence parents' ability to access health-related information and navigate the health care system.^{9–11}

The current study seeks to expand our understanding of overall unmet need for therapy services among children by: 1) identifying a subgroup of children aged 0 to 4 years old with DD who likely need physical, occupational, or speech therapy services; 2) estimating the prevalence of overall unmet therapy need, unrecognized therapy need, and parent-reported unmet therapy need; 3) examining the role of race, ethnicity, and socioeconomic status in unrecognized therapy need and parent-reported unmet need; and 4) documenting the reasons for parent-reported unmet therapy need.

METHODS

DATA SOURCE, POPULATION, AND STUDY SAMPLE

Children with DD are considered to have special health care needs given the chronic nature of their conditions and their need for therapy services.¹² We therefore used parent-reported data from the 2009–2010 NS-CSHCN, a cross-sectional random-digit-dial telephone survey conducted by the National Center for Health Statistics and the Centers for Disease Control and Prevention.¹³ The survey utilizes the State and Local Area Integrated Telephone Survey mechanism to produce a representative sample of noninstitutionalized US children with special health care needs (CSHCN) younger than 18 years. Major sponsors of the survey include the US Department of Health and Human Services, the

Health Resources and Services Administration, and the Maternal and Child Health Bureau. Of the 372,698 children from 196,195 households screened between 2009 and 2010, 40,242 were categorized as having a special health care need using the validated CSHCN screener¹⁴ and completed the full interview. Additional information regarding survey methodology has been previously described.¹⁵

One objective of this paper was to identify children with DD who likely need physical, occupational, or speech therapy services. While each state provides broad definitions of DD, there exists no standard definition for use in population-based surveys. We therefore created a set of DD inclusion criteria, informed by state definitions of DD¹⁶ and related work in this area,¹⁷ to identify CSHCN likely experiencing DD and needing physical, occupational, or speech therapy services. This subsample included 2547 children aged 0 to 4 years meeting one of the following inclusion criteria (obtained via parent report): 1) diagnosed with a condition associated with a high probability of DD (Fig. 1); or 2) difficulty in the areas of gross or fine motor development, communication, cognition, or self-help. Figure 1 illustrates the distribution of parent-reported medical diagnoses among CSHCN aged 0 to 4 years meeting the first eligibility criterion. Some children had more than one parent-reported diagnosis. Sensitivity analyses suggest this is a relatively conservative definition of DD, and that the selected diagnoses demonstrate good agreement with parent-reported functional difficulties and/or therapy need. We assume that children meeting our definition of DD need therapy services.

Analyses were limited to children under the age of 5 given the importance of early identification and intervention for children with DD, and to minimize the influence of teachers and other school staff in identifying therapy needs. A formal review and exemption for the current analyses were obtained from the University of Wisconsin—Madison's Institutional Review Board.

VARIABLES

The outcome of interest was overall unmet need for physical, occupational, or speech therapy services, and its 2 component parts: unrecognized therapy need (ie, needs that likely exist but are not reported by parents), and parent-reported unmet therapy need (among children with recognized therapy needs). Overall unmet therapy need was defined as the proportion of children meeting

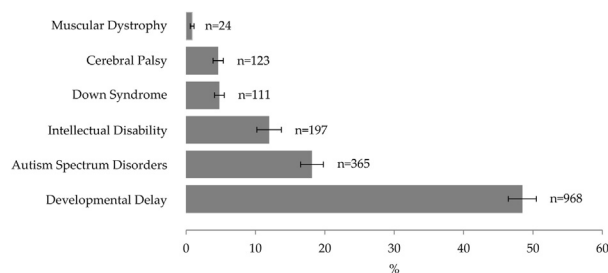


Figure 1. Weighted distribution of diagnoses among CSHCN aged 0 to 4 years meeting diagnostic inclusion criterion for DD ($n = 1147$), United States, 2009–2010.

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