Variation in Educational Services Receipt Among US Children With Developmental Conditions

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ABSTRACT

OBJECTIVE: To examine the relationship between ease of access to needed community-based services (ease of access) and educational services receipt, and variation in educational services receipt by sociodemographic and need factors among a nationally representative sample of children with autism spectrum disorder (ASD), developmental delay (DD), and/or intellectual disability (ID).

METHODS: Data from the 2009–2010 National Survey of Children with Special Health Care Needs were linked to the 2011 Survey of Pathways to Diagnosis and Services on a sample of 3502 US children aged 6 to 17 years with ASD, DD, and/or ID. Descriptive statistics, chi-square tests, and multivariable logistic regression models were used to determine associations of educational services receipt with ease of access and sociodemographic and need factors.

RESULTS: Among children with developmental conditions, nearly half (49.7%) lacked easy access to services, and 16.9% did not have an individualized education program (IEP). Among children with an IEP, those with ease of access were more likely to have an IEP that addressed parent concerns about the child's development and education than those unable to easily access services (adjusted odds ratio 2.77; 95% confidence interval 1.71–4.49). Need factors, including functional limitations status, care coordination need, developmental condition type, and early intervention receipt, were significantly associated with educational services receipt.

CONCLUSIONS: Cross-systems initiatives facilitating service access remain important to ensuring the developmental needs of children with ASD, DD, and/or ID are met. Increased interprofessional collaboration promoting quality educational services receipt for children diagnosed with developmental conditions may further reduce disparities.

KEYWORDS: autism spectrum disorder; children with special health care needs; developmental conditions; developmental delay; ease of access; individualized education program; intellectual disability; school-based therapy

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WHAT'S NEW

Among US school-age children with developmental conditions who had an individualized education program (IEP), those whose parents easily accessed services were more likely to have an IEP addressing parent concerns about the child's development and education than those whose parents did not easily access services.

THE PREVALENCE OF developmental conditions,[1] including autism spectrum disorder (ASD),[2,3] developmental delay (DD),[1] and intellectual disability (ID),[1] among US children has risen markedly. Children with developmental conditions more commonly experience functional impairment,[4] poor academic achievement,[5,6] and greater health care needs than other children.[7] They are also prone to experience unmet health care needs,[8] poor quality of care,[9] and family financial and employment impacts,[10] even compared to other children with special health care needs (CSHCN).[11–14]

Children are often diagnosed with developmental conditions in early childhood.[3,15] Under the Individuals With Disabilities Education Act (IDEA), US children with qualifying disabilities (eg, ASD, DD, ID) whose educational performance is negatively affected by their disability are eligible to receive an individualized education program (IEP).[16] An IEP can help children with disabilities receive specialized services, instruction, and/or accommodations at school to meet their needs thereby promoting functioning, academic achievement, and health.[17]

Although most children with ASD, DD, and/or ID[18] meet IEP eligibility criteria, disparities in IEP receipt[7,19,20] and quality[21]—particularly among children with ASD—persist. Recent research suggests certain sociodemographic and need factors (eg, race/ethnicity, maternal education level, care coordination need) may contribute to disparities in IEP receipt among children with ASD[19] and other disabilities.[17] Yet little is known about factors contributing to disparities in IEP receipt among children with developmental conditions more broadly, or if additional factors such as parent experiences accessing needed community-based services for children influence educational services receipt.

Overarching frameworks to promote health among CSHCN,[22,23] including those with developmental conditions, and policy statements from the pediatric medical community[24,25] recommend all needed services—delivered in health care or school-based settings—should be easily accessed and received via interconnected, community-based systems of care. However, little evidence documents linkages between ease of access to needed community-based services (ease of access) and educational services receipt among children with ASD, DD, and/or ID (children with developmental conditions).[26] Rather, research to date on children with developmental conditions has focused either on health services[27,28] or educational services access.[17,19]

It is important to elucidate this relationship given developmental conditions in early childhood are common and access to community-based health services generally—from basic medical and dental care to more specialized medical and early intervention (EI) services—may predict how likely children are to subsequently receive health promoting services in school settings. Increased evidence in this area may help policy makers and practitioners improve service access and receipt across historically separated community-based health and educational systems for children with developmental conditions. This study therefore examined the relationship between ease of access and educational services receipt and variation in educational services receipt by sociodemographic and need factors among a nationally representative sample of school-age children with developmental conditions.

METHODS

STUDY DESIGN AND DATA SOURCES

This was a secondary analysis of publicly available data linked from the 2009–2010 National Survey of Children with Special Health Care Needs (NS-CSHCN)[29] to the 2011 Survey of Pathways to Diagnosis and Services (Pathways).[30] Pathways was a follow-up survey of CSHCN aged 6 to 17 years ever diagnosed with ASD, DD, or ID by a doctor or other health care provider in the 2009–2010 NS-CSHCN according to a parent or other caregiver (parent). The same parent reported all data on the child for each survey after informed consent was obtained. The 2009–2010 NS-CSHCN had a 25.5% response rate,[29] and Pathways had a weighted completion rate of 62%.[30] Pathways was only administered in English. Detailed survey methodology has been previously documented.[29,30]

SAMPLE

The study sample included 3502 US children aged 6 to 17 years currently with ASD, DD, and/or ID and enrolled in school. Given the study's focus, 530 children were excluded because the parent indicated the child did not currently have ASD, DD, or ID and/or was not enrolled in school when Pathways was administered. Mutually exclusive developmental condition subgroups were defined as 1) DD only (DD), 2) ASD with or without ID and/or DD (ASD), and 3) ID with or without DD (ID). Because children with ASD or ID commonly experience comorbid conditions, including DD,[8,9] we were unable to stratify children with ASD or ID alone due to sample size constraints.

MEASURES

Three binary educational services receipt indicators from Pathways were used as dependent variables: 1) if the child had an IEP ("does [your child] have a written intervention plan called an Individualized Education Program or IEP?"); 2) if the child's IEP addressed parent concerns ("does [your child's] IEP address all of your concerns about [his/her] development and education?"); and 3) if the child currently used on a regular basis 1 or more of 4 school-based therapies (occupational therapy, physical therapy, social skills training, speech or language therapy) to meet his/her developmental needs. The central tendency of the number of school-based therapies children in the study sample received (mean 1.40 ± 1.31) was used to define the 1 or more cutoff in addition to wanting to determine factors associated with the receipt of any school-based therapies versus none. The second educational services receipt measure was only assessed among children with an IEP because of the survey's item skip pattern, and the third educational receipt measure was only assessed among children with an IEP to reduce selection bias given most (95.2%) of children who received 1 or more school-based therapies had an IEP.

The main independent variable was an ease of access composite measure from the 2009–2010 NS-CSHCN. It is 1 of 6 age-relevant core outcomes in the Federal Maternal and Child Health Bureau's System of Care for CSHCN framework.[22] The measure includes 1 ordinal item about how often the parent was frustrated accessing "all the types of services children may need or use" in home, school, and health care settings. Examples of services included medical care, specialized therapies, counseling, medical equipment, special education, and EI. This item was selected because we felt it best represented families' overall ability to access services in their community. The item was assessed for the past 12-months, as were 6 binary items about the following difficulties accessing needed services: child ineligible for services, services unavailable in the family's area, child put on a waiting list or parent experienced other problems getting appointments, issues related to costs, trouble getting needed information, and any other difficulties. If the parent never or sometimes (vs usually or always) was frustrated getting services for the child and did not experience any of the 6