

Erken Müdahale Hizmetlerinin Önündeki Engeller: Amerika Birleşik Devletleri'nde Gelişim Geriliği olan Göçmen Çocuklar Örneği

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Özet

Erken müdahale hizmetleri, gelişimsel geriliği olan bebek ve küçük çocukların ihtiyaçlarını karşılamak üzere tasarlanmıştır. Bu makale, ABD'de göçmen aileler ile göçmen olmayan ailelerin çocukları arasındaki sağlık hizmetlerine erişim farkının erken müdahale hizmetleri için de söz konusu olup olmadığını anlamaktır. Bir göçmen ülkesi olan Amerika Birleşik Devletleri'ndeki genel tablo, göçmenlere ev sahipliği yapan ülkeler için fikir verici olabilir. İlk olarak özel sağlık gereksinimi olan göçmen ya da azınlık statüsüne sahip çocukların sağlık hizmetlerine erişimi ile ilgili literatür incelenmektedir. İkinci olarak, azınlık statüsüne sahip olmakla erken müdahale hizmetlerine erişim arasındaki ilişkiye dair literatür değerlendirilmektedir. Bu literatür taraması ABD'de azınlık statüsünün çocukların sağlık ve erken müdahale hizmetlerine erişimini engelleyebileceğini göstermektedir. Benzer şekilde Türkiye başta olmak üzere göçmen çocuklarının sayısının yüksek olduğu ülkelerde göçmen çocukların acil sağlık ihtiyaçlarına erişiminin önündeki engeller incelenmelidir.

Anahtar Kelimeler

Erken müdahale hizmetleri • ABD'deki göçmen çocuklar • Gelişim Geriliği • Engellilik

Barriers to early intervention services: The case of immigrant children with developmental delays in the United States

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Abstract

Early intervention services are designated to meet the needs of infants or toddlers with developmental delays. This article reports the results of a literature review that was conducted to determine whether the well-known discrepancy between the health care access of children in immigrant families and those in non-immigrant families was also present in early intervention services in the United States. The United States is a country of immigrants; therefore this country can set an example for others with immigrant populations. First, studies on the relationship between the immigrant/ minority status of children with special health care needs and health care access are reviewed. Second, a review is conducted to understand the relationship between minority status and access to early intervention services. This review shows that minority status may hinder children's access to health care and early intervention services in the United States. Similarly, there is a need to study minority and immigrant children's barriers to their most urgent health needs in countries with a high number of immigrant children.

Keywords

Early intervention services • Immigrant children in the United States • developmental delay • disability

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Introduction

According to the U.S. Department of Education (USDE), early intervention services are designated to meet the developmental needs of an infant or toddler with a disability in the areas of physical, cognitive, communication, social, emotional or adaptive development. The target population of early intervention services consists of “children under three years of age who are experiencing developmental delays or have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay” (USDE, 2004). The Individuals with Disabilities Education Act (IDEA) Part C ensures services to children with disabilities and governs the implementation of services.

There is a substantial body of research that demonstrates the importance of providing intervention services to children with disabilities and developmental delays at young ages and to their families (Hebbeler et. al., 2007). The overrepresentation of minority children in special education and their underrepresentation in early intervention services are well-known phenomena based on the analysis of the National Early Intervention Longitudinal Study (Hebbeler, Spiker, & Mallik, 2003). The 2020 data of U.S. Department of Education also reveal that minority children are still underrepresented in early intervention services: While minority children are approximately 53% of all children between

ages 0-4 (The Annie E. Casey Foundation, 2022), they are underrepresented in early intervention services. In 2020, 390,375 minority children received early intervention services as opposed to 395,845 White children (U.S. Department of Education, 2022). Poverty faced by the families of minority children can be one of the underlying factors behind these children’s disabilities or developmental delays. The overrepresentation of minority families in the special education leads one to think that minority children may have problems accessing early intervention services. Hence, it is vital to develop our understanding of the barriers that minority families might experience in accessing early intervention services. Constituting a subgroup within the larger group of the minority population, immigrant children might be experiencing unique barriers to utilizing early intervention services due to their immigrant status. The population trends also point to the importance of addressing immigrant children’s needs. The growth rate of immigrant children within the U.S. population is quite high. Although immigrants make up approximately 14% of the total population (Center for Immigration Studies, 2022), children of immigrants are 25% of the population of all children under 6 years old (Urban Institute, 2019). This proportion was 22% in 2005 (Capps et. al., 2005) and moderately increased from 2006 onwards. Furthermore, immigrant children are reported to be at increased risk of autism and in-

tellectual disability compared to non-immigrant children and the risks were higher if the mother originated in a developing country (Abdullahi et al., 2017).

Accordingly, the question addressed in this article is what factors hinder or facilitate access to early intervention services for immigrant families. However, this is an area that remains understudied. Because of the paucity of literature on the barriers immigrant families face in accessing early intervention services; this literature review examines two different bodies of research. First, the literature on the barriers that immigrant children with special needs experience in their access to general health care services is reviewed. Then, the literature on the barriers that minority and immigrant children encounter in accessing early intervention services will be explored.

Methods

A search was conducted to identify research on factors that might affect the use of early intervention services by minority and immigrant children. Key search words were early intervention services, early childhood intervention, children with special needs, barrier, access, utilization, immigrant, and minority. Searches were run in Social Sciences Citation Index (SSCI), ArticleFirst, JStor, PsycarticlesCSA, Psycinfo (Proquest), Social Work Abstracts, PubMed, ScienceDirect, Sociological Abstracts (CSA), Sociological

Abstracts (Proquest), and Multiple Resources Database. As a result, two studies were identified that addressed the issues of primary interest, which was minority children’s access to early intervention services. No studies were found specifically on immigrant children’s access to early intervention. Given the scarcity of research, a second search was conducted for studies of barriers to health services among children with special health care needs (CSHCN). Although this second body of literature is not an exact match, it may be informative because children in need of early intervention consist of a subgroup within the category of CSHCN. In addition, this body of literature addresses the problems of minority and immigrant children with special health care needs.

Results

Children with Special Health Care Needs (CSHCN) and Minority/Immigrant Status

The literature suggests that there is a disparity of access to health care in general between minority children and white children (Brousseau, Hoffmann, Yauck, Nattinger & Flores, 2005; Granados, Puvvula, Berman & Dowling, 2001). There is another body of literature on the barriers that CSHCN experience in health care access. CSHCN are defined as “children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions.

They also require health and related services of a type or amount beyond that required by children generally.” (Health Sources and Services Administration, 2021). The related literature is based on analysis of large-scale survey data and suggests that special needs children with minority status and/or with minority parents experience unique health care access barriers compared to nonminority children. However, minority status is apparently a marker of poverty and lack of insurance in these studies. Because CSHCN category includes children in need of and receiving early intervention services, the research on CSHCN in immigrant families may be relevant to understand the possible barriers of immigrant children accessing early intervention services.

There is a substantial body of research documenting barriers that children with special health care needs in minority and immigrant families face in accessing needed health care (Javier et. al, 2007; Huang et. al., 2005; Seid, Sobo, Gelhard & Varni, 2004; Newacheck, Hung & Wright, 2002). According to these studies, the barriers that CSHCN encounter include poverty, lack of health insurance, lack of knowledge about programs’ eligibility criteria, cultural, language and communication problems, transportation, and limited/distorted beliefs/knowledge about health issues.

Javier, Wise & Mendoza (2007) conducted a study using 2001 and 2003 data from

the California Health Interview Survey on 2,600 children ages 1 to 11 with chronic asthma. The findings suggest that children with asthma in immigrant families had decreased access to and utilization of health care compared to children in nonimmigrant families and that parents’ immigration status may pose unique barriers to health care access for children of immigrant parents with asthma. At the same time, their data also indicated that immigrant children were more likely to have parents with less education, live in poverty, and be uninsured or to have an unemployed parent. The findings also asserted that access and utilization were associated with poverty status and lack of insurance. As the authors also acknowledged, their analyses did not present results peculiar to each ethnic group, thus masking possible between-group differences. Also, because the study’s main focus was children with asthma, the findings cannot be generalized to the early intervention services.

Another study by Newacheck et. al. (2002) analyzed data on 57,553 children younger than 18 years old, who were included in the 1994–95 National Health Interview Survey on Disability. The study examined disparities in access to health services among black, white, and Hispanic children with special health care needs. The findings revealed that minority children were more likely to be without health coverage, more likely

to be without a usual source of care, and were more likely to receive health care in sites other than physicians (e.g., health centers, outpatient clinics, or emergency rooms). In addition, children from minority groups were almost twice as likely as were white children to lack a regular healthcare provider at their usual site of care. Although the effect size of minority status diminished when income and insurance coverage were taken into account, there were still significant differences between white and minority children with respect to insurance coverage, the presence of a usual source of care and of a regular clinician. The main contributors to poor access were found to be inadequate income and lack of insurance coverage with race and ethnicity as markers for these disadvantages. The study did not analyze the influence of nonfinancial barriers. However, the authors suggest that nonfinancial barriers such as cultural differences, attitudes and beliefs about health care, availability of providers, and discrimination should be explored to fully understand the racial and ethnic disparities in special needs children’s health care access. It is well-known that primary care physicians are crucial actors in detecting developmental delays and making referrals to early intervention services (Sices et. al., 2004). That is why; the reviewed study increases concerns that minority children may be deprived of this important access channel, if these

findings are also relevant for children in need of early intervention services.

Huang et. al. (2005) analyzed 2001 National Survey of Children with Special Health Care Needs data and explored joint and independent contributions of race, ethnicity, family income, parents’ education, English proficiency, health insurance coverage, and health status on delayed or foregone care. The overall prevalence of CSHCN was 12.8% nationally and among CSHCN, 9.7% had delayed or foregone care in the past 12 months. The study findings revealed that delayed care was most likely to happen to minorities and Hispanic youth rather than to non-Hispanic whites. After sociodemographic characteristics were adjusted, family poverty remained a significant factor associated with delayed or foregone care. In addition, lack of insurance was the strongest indicator for delayed care. The shortcoming of these two studies is that they do not present any findings on any ethnic groups other than Hispanic, nor did the study include any analysis regarding immigrant status.

Early Intervention Services and Minority Status

There are far fewer studies of the use of early intervention services by minority and/or immigrant families; however, a similar pattern of underutilization and decreased access has been reported (Feinberg, Silverstein, Donahue & Bliss, 2011; Sontag & Schact, 1993; Arcia

et. al., 1992). Some of the factors for the underutilization of health care by CSHCN are similar to the factors for the underutilization of early intervention in these studies. Minority status and poverty are associated with underutilization of early intervention services (Feinberg et. al, 2011; Sontag & Schact, 1993). None of these studies include immigration status in their variables. The findings of these studies are based on African American, Hispanic and American Indian populations. Among these categories, only Hispanics can include immigrants. Hence, the results can hardly be generalized to other immigrant groups. While immigrant groups may experience similar barriers with these groups due to their minority status, they may also have some unique barriers due to their immigrant status. Although the studies mention possibilities of clinician bias and cultural issues, they do not analyze these factors. Interestingly, a national longitudinal study reveals that African American children are overrepresented in early intervention services, but does not present any further data on the reasons. Therefore, early intervention service utilization by immigrant children remains as an unexplored area.

Sontag et. al. (1993) interviewed with 536 families to understand the nature of early intervention services received. They investigated differences in the type and the level of services utilized by families

across ethnicity, income, and the age of the child. The sample was representative of state population characteristics. The results showed the differences in the use of physical or occupational therapy, home visitor, and transportation services by the three ethnic groups (White, Hispanic, and American Indian). For instance, the possibility of the use of physical or occupational therapy by American Indian children was lower compared to that of Hispanics and Whites. American Indian children were also less likely to receive medically related services compared to White and Hispanic children. Hispanic families were identified to receive a home visitor much less frequently than the other ethnic groups. Ethnicity was also among the factors that affect individuals' early intervention services utilization patterns along with geographic location and disability status. The study identified the barriers for families that were already using early intervention services. The question remains of what the barriers may be for families who have not accessed service. Moreover, the study did not include any analysis on the immigration status of the families.

The study of Feinberg et. al. (2011) uses the data from the Early Child Longitudinal Study, Birth Cohort. Data were collected from a representative sample of 1000 children at 9 months and again at 24 months. Non-Hispanic black and non-Hispanic white children were

included in the sample. Their findings showed there were no racial differences in the receipt of the services in the first data collection at 9 months of age. However, at the second data collection round, a racial difference was apparent: black children were almost 5 times less likely to receive these services. The authors argue that they are the first to explore the evolution of racial disparities in EI services receipt and to detect the emergence of racial differences from month 9 to month 24. Their findings suggested that black children with cues of developmental delays were less likely to receive EI services even though they were all eligible for these services. That is why; the authors focus on differences in identification and referral to explain why black children were less likely to receive these services. They suggest that clinicians might be less likely to identify developmental delays in black children. In addition to the clinician bias, the authors discuss another possibility, which is related to families' beliefs and cultural values. They indicate that there is only one study that considered racial differences in parental concerns on developmental delays. According to this study, there are no differences between white and nonwhite subjects in the likelihood of reporting concerns. However, they point to some existing studies exploring factors affecting black mothers' willingness of talking about their health related concerns. These factors are listed as stigma, fear

of blame, and child protective services involvement. The authors suggest that similar concerns related to their children's health issues are worth studying.

Another study proposes some clues about the possible barriers for minority clients of early intervention services. The study (DeGangi et. al., 1994) elaborates the challenges to family-professional collaboration stemming from cultural diversity and socioeconomic status. The perceptions of 26 professionals from early intervention programs vis-à-vis the impact of cultural diversity and SES on family-professional collaboration are studied through interviews and case vignettes. The small sample only consists of professionals from the greater Washington DC area. Participants are voluntary and the participating professionals were already interested in working with culturally diverse families; therefore, the findings could be worse if the participant professionals were randomly selected. Although the professionals appeared sensitive to the effects of culture on the families they worked with, only half of the sample reported that they incorporated customs and values into the goals of their family plans. Based on this, professionals' perceptions may be a service barrier for immigrant families.

There is an interesting finding on the utilization of early intervention services by African American children. The

study of Feinberg et. al (2011) suggests that African American children face barriers in accessing early intervention services and argue that this can be due to under diagnosis by clinicians. Interestingly, the descriptive results of the National Early Intervention Longitudinal Study (Hebbeler et. al., 2007) showed that African American children were overrepresented in the population of children receiving early intervention services, while white children were underrepresented. While the reporters indicate that they do not know to what extent minority children are overrepresented, they argue that the overrepresentation of African American children may be due to the bias of the clinicians who diagnose developmental delays more in African American children. These arguments suggest that clinicians may have biases in diagnosing developmental delays in minority children, which may again constitute unique barriers in minority children's access to early intervention services. The study does not present any information on the immigrant status of the early intervention service recipients.

Conclusion

According to the results of this literature review, researchers seldom address immigrant status as a factor affecting access to early intervention services. There are studies on the effect of minority status on the use of early intervention services, but the results of

these studies cannot be generalized to immigrant populations, who might have their unique challenges. Immigrant status was considered in some studies on access to general health care by children with special needs. These studies point to poverty, unemployment, lack of health insurance, lack of knowledge about programs' eligibility criteria, cultural, language, communication, transportation problems and limited or distorted beliefs about health issues as possible barriers to health care services. Some studies suggest that parents' fears about their immigrant status can also prevent children from health care access. Researchers also speculate about the possible influences of clinician bias, fear of stigmatization and cultural values on access to health care. None of these findings or arguments automatically generalizes to immigrant families. However, the results of the existing research can guide the study of future researcher on the relationship between immigrant status and access to early intervention services. Future research should study children from different immigrant groups and address between-group differences. Environmental, economic, informational or attitudinal factors should be analyzed as independent variables that influence service utilization of immigrant families. Along with the influences of immigrant status on service seeking and utilization patterns, special attention should be given to the barriers that may originate

in the service providers side. Clinician bias in diagnosing developmental delays in children of immigrant families also needs to be explored. The increasing number of immigrant children and children living with immigrant parents presents an urgent need for research in this area. These experiences in the United States also highlight the importance of studying immigrant children's experiences with early intervention services in other countries with a high number of immigrants such as Turkey. Lack of timely and proper early intervention services leads to more severe and costly problems in these children.

References

Abdullahi, I. de Klerk, Glasson, E. Mutch, R. Cherian, S. Leonard, H. (2017). The risk of neurodevelopmental disabilities in children of immigrant and refugee parents: current knowledge and directions for future research. *Rev J Autism Dev Disord*, 5, 29-42 <https://doi.org/10.1007/s40489-017-0121-5>

Brousseau, D. C., Hoffmann, R. G., Yauck, J., Nattinger, A. B., & Flores, G. (2005). Disparities for Latino children in the timely receipt of medical care. *Ambulatory Pediatrics*, 5, 319-325.

Capps, R., Fix, M. E., Ost J., Reardon-Anderson J., Passel, J. S. (2005). The health and well-being of young children of immigrants. Retrieved from the Urban Institute website: <http://www.urban.org/publications/311139.html>

Center for Immigration Studies (2022). Foreign-Born Population Hit Record 47 Million in 2022. Retrieved from Center for Immigration Studies website: <https://cis.org/Report/ForeignBorn-Population-Hit-Record-47-Million-April-2022>

DeGangi, G. A., Wietlisbach, S., Poisson, S., Stein, E., & Royeen, C. (1994). The impact of culture and socioeconomic status on family-professional collaboration: Challenges and solutions. *Topics in Early Childhood Special Education*, 14(4), 503.

Feinberg, E., Silverstein, M., Donahue, S., Bliss, R. (2011). The impact of race on participation in Part C Early Intervention Services. *Journal of Developmental*

Behave Pediatrics, 32, 284-291.

Granados, G., Puvvula, J., Berman, N., Dowling, P. T. (2001). Health care for Latino children: Impact of child and parental birthplace on insurance status and access to health services. *American Journal of Public Health*, 91, 1806-1807.

Health Sources and Services Administration (2021). Children and Youth with Special Health Care Needs. Retrieved from <https://mchb.hrsa.gov/programs-impact/focus-areas/children-youth-special-health-care-needs-cyshcn#i>

Hebbeler K., Spiker D., Bailey D., Scarborough A., Mallik S., Simeonsson R., Singer M., & Nelson L. (2007). Early intervention for infants and toddlers with disabilities and their families: participants, services, and outcomes. Retrieved from The National Early Intervention Longitudinal Study website: http://www.sri.com/neils/pdfs/NEILS_Final_Report_02_07.pdf

Hebbeler, K., Spiker, D., Mallik, S. (2003). National early intervention longitudinal study: Demographic characteristics of children and families entering early intervention. Retrieved from The National Early Intervention Longitudinal Study website: <http://www.sri.com/neils/EFI1report.pdf>

Huang, Z. J., Kogan, M. D., Yu, S. M., & Strickland, B. (2005). Delayed or forgone care among children with special health care needs: An analysis of the 2001

national survey of children with special health care needs. *Ambulatory Pediatrics*, 5(1), 60-67.

Javier, J. R., Wise, P. H., & Mendoza, F. S. (2007). The relationship of immigrant status with access, utilization, and health status for children with asthma. *Ambulatory Pediatrics*, 7(6), 421-430.

Newacheck, P. W., Hung, Y. Y., & Wright, K. K. (2002). Racial and ethnic disparities in access to care for children with special health care needs. *Ambulatory Pediatrics*, 2(4), 247-254.

Seid, M., Sobo, E. J., Gelhard, L. R., & Varni, J. W. (2004). Parents' reports of barriers to care for children with special health care needs: Development and validation of the barriers to care questionnaire. *Ambulatory Pediatrics*, 4(4), 323-331.

Sices, L., Feudtner, C., McLaughlin, J., Drotar, D., & Williams, M. (2004). How do primary care physicians manage children with possible developmental delays? A national survey with an experimental design. *Pediatrics*, 113(2), 274.

Sontag, J. C., & Schacht, R. (1993). Family diversity and patterns of service utilization in early intervention. *Journal of Early Intervention*, 17(4), 431.

The Annie E. Casey Foundation (2022). Kids Count Data Center. Retrieved from the Annie E. Casey Foundation's website: <https://datacenter.kidscount.org/data/tables/8446-child-population-by-race-and-age-group#detailed/1/any/>