

Assessing Educational, Developmental, and Parent Support Services Received by Families of Children with Craniofacial Birth Defects

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In the United States, one in 33 babies is born with a birth defect every year.¹ Birth defects are structural abnormalities present at birth that affect the development of organs and tissues of an infant or child. They may be identified during pregnancy, at birth, or following birth.

Each year in Rhode Island, approximately 375 babies are born with a birth defect.² Rhode Island's birth defects surveillance system is important in tracking birth defects, identifying children who may require additional support services, and developing policies to reduce birth defects and infant mortality. In addition to developing and implementing a birth defects reporting, surveillance, and information system, the Rhode Island Birth Defects Program (RIBDP) is mandated by state law to assure children with birth defects receive appropriate and timely preventative, specialty, and other healthcare services up to the age of five. To accomplish this, the RIBDP conducts service assessments with families of children with specific birth defects. Children with selected birth defects are identified through surveillance and are referred for a service assessment to determine if they received the necessary medical, educational, and developmental services and parent supports based on national guidelines for the condition of interest. Ensuring children have access to necessary and appropriate services is important because early recognition and response to birth defects often prevents more serious outcomes.^{1,2}

The purpose of this evaluation was to describe selected parent support and educational/developmental service referrals and receipt of these services by families of children with craniofacial birth defects. In addition, the evaluation assessed the helpfulness of these services to families.

METHODS

The analysis examined service assessment findings for children born from 2006 to 2017 with craniofacial birth defects (cleft lip with or without cleft palate, cleft palate, and craniosynostosis) who were under the age of 5 at the time of the assessment. Children eligible for assessments were Rhode Island residents identified from birth defects surveillance data. A Parent Consultant employed by the Rhode Island Parent Information Network (RIPIN) conducted assessments from January 2009 through August 31, 2018 via mailings and interviews with families of children at physician offices and

specialty clinics. The RIBDP works in collaboration with the Parent Consultant to assure that children have received appropriate referrals and services on a timely basis. Assessment forms were available in English and Spanish. All data were self-reported by families of children with selected birth defects and entered into a Microsoft Access database.

Assessments were completed by 213 families of children with craniofacial birth defects. Some families completed multiple assessments (up to one per year) over the time frame. The most recent assessment result for each child was used for this analysis, as it contained the most complete information available at the time of analysis. The assessments gathered information on referral to selected parent support, educational, and developmental services. Families were also asked about whether the support or educational/developmental service was received once a referral was made and if they found it helpful.

Support services of interest for this evaluation included: the Visiting Nurses Association (VNA); Medicaid support (Medicaid and the Katie Beckett Program, which is an eligibility category in Medicaid allowing some children under the age of 19 with long-term disabilities and medical needs to live at home³); Home Visiting (First Connections, which is a family visiting program that meet with parents of children up to the age of three in a convenient location to connect them to family support services and resources⁴); RIPIN services (parent support programs, including Family to Family and Family Voices, which allow families to connect with other families and provide information on appropriate resources); and parent support groups (other than RIPIN support groups). Referrals to developmental and educational services analyzed included speech therapy, occupational therapy, early intervention (birth through age 3), and special education (age 3 and older). Information on medical services received was also collected in the assessment, but not examined in this evaluation.

RESULTS

Of the 213 children with completed service assessments for craniofacial birth defects, 137 (64%) had an orofacial defect (cleft lip, cleft palate, or both) and 76 (36%) had craniosynostosis. The average age at the latest assessment was 2.5 years old. The primary language spoken by families was English (n=200).

There were differences observed in family referrals to support services and receipt of these services once referred (**Figure 1**). Although a referral to a support or service can be made by anyone, including pediatric providers or hospital staff, parental consent is required for the referral and to release information to the service provider. Parents can self-refer to supports and services, but many don't because they are not aware of available services. Most families reported being referred to the VNA, which had the highest percentage of referrals (58%). Parent support groups had the lowest reported referral rates (13%). Of families who were referred to support services, parent support groups (82%) and the VNA (81%) had the largest percentage of families who received those services. Families were least likely to report receiving RIPIN services (30%). Overall, sixty-six percent of families reported receiving at least one of these family support services and 31% of families received more than one. Of the families who were referred to and received support services, the majority found them helpful, with home visiting having the highest satisfaction rate (100%).

Families deemed eligible for developmental and educational services were referred to early intervention, special education, speech therapy, and occupational therapy (**Figure 2**). Approximately 71% of all children were referred to Early Intervention, with 83% of those referred reporting receiving services. Eighty-three children were over the age of 3 at their last assessment and, therefore, eligible to receive special education services. Special education referral and receipt, along with helpfulness, were assessed in this subset of the analysis group. Fifty-one percent of children aged three or older were referred to special education, with 83% of those referred receiving this service. Most families who received early intervention and special education services were highly satisfied.

Similar percentages of families reported receiving referrals to speech therapy (44%) and occupational therapy (43%). Eighty-one percent of families who were referred to speech therapy and 88% of those referred to occupational therapy reported receiving these services. Eighty percent of families referred to occupational therapy and 73% of families referred to speech therapy found the service helpful.

Figure 1. Parent Support Service Referral, Receipt, and Helpfulness for Craniofacial Birth Defects, Rhode Island, 2006–2017

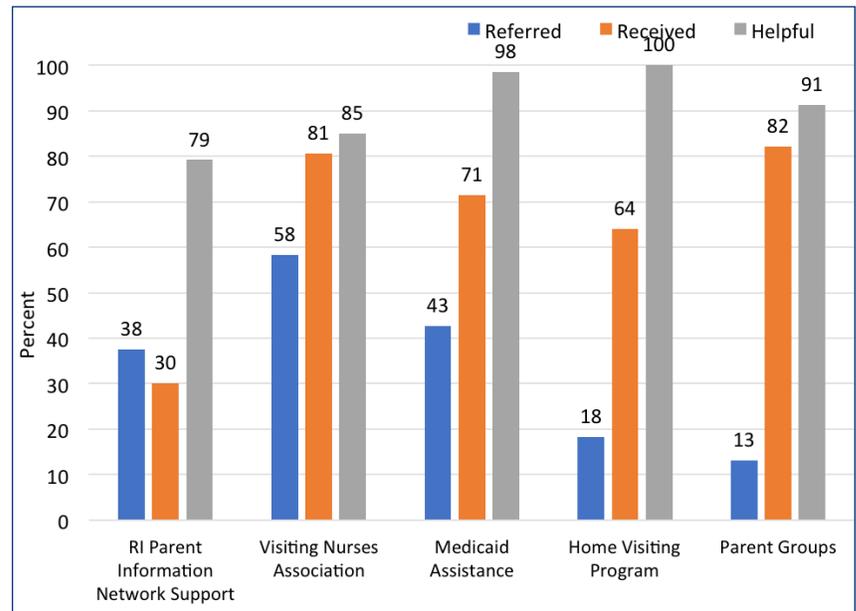
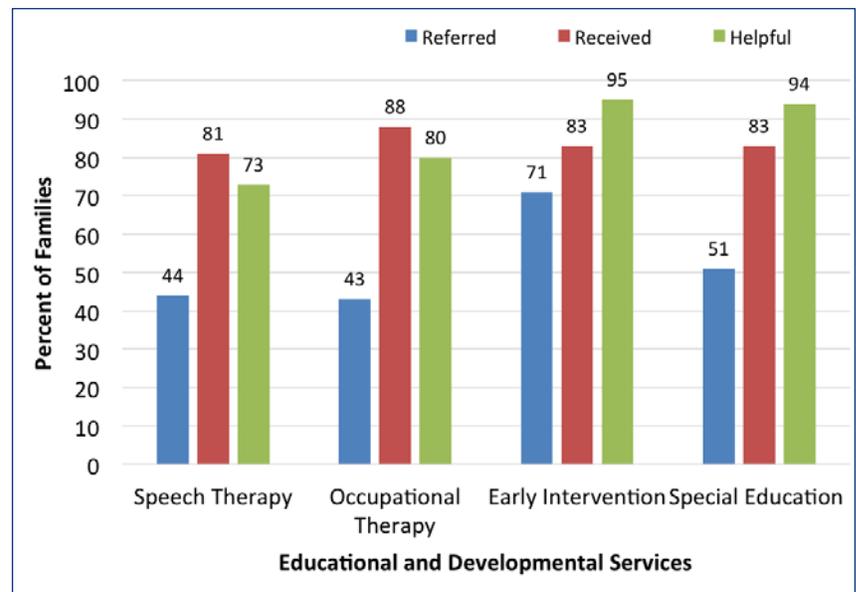


Figure 2. Educational/Developmental Service Referral, Receipt, and Helpfulness for Craniofacial Birth Defects, Rhode Island, 2006–2017



Also of note, the Parent Consultant referred 37% of families interviewed at physician offices and specialty clinics to a service during the assessment, with 69% of these referrals to Early Intervention services. Although not a primary access point to these services, the Parent Consultant is able to refer families when needed.

LIMITATIONS

All data from service assessments were self-reported by families of children with craniofacial birth defects and may be subject to recall bias, despite parent consent being required to make a referral to these services. Some response bias also may have been introduced from collecting service assessments via two different methods. There may have been differences in the referral patterns and receipt of services between families who did not return a completed mail survey and those who responded. The sample size was not large enough to stratify by type of craniofacial defect to determine if there were differences in the referral, receipt, and helpfulness of services by type of birth defect. There also may have been underreporting of speech and occupational therapy service referral and receipt since these services are often received as a part of early intervention.

DISCUSSION

Although less than three quarters of families were referred to selected parent support, developmental, and educational services, those who did receive these services found them helpful, suggesting there is value in offering these services for families of children with craniofacial birth defects. Parent support services, particularly peer support, have been shown to have positive outcomes on quality of life for families.⁵ Families of children with birth defects have also emphasized that receiving information on access to care and resources is important.⁵ In Rhode Island, RIPIN's Family to Family and Family Voices Programs, along with craniofacial-specific parent support groups, can connect parents with other families and provide resources for navigating the health system and understanding their child's condition. First Connections is also another resource to assist families with connecting to resources and services, in addition to providing general parenting support and answering child development questions. Family to Family, Family Voices, parent support groups, and First Connections are all available at no cost to families. To address the gap in referring families to these free resources, the RIBDP will increase its outreach to providers to ensure referrals are made when appropriate.

Gaps were also identified in the referral process for developmental and educational services. When compared to other developmental and educational services, fewer families reported being referred to or receiving speech and occupational therapy. Families also reported these services as less helpful than Early Intervention or special education. Developmental issues, including developmental delay, learning problems, and speech issues, are common with orofacial defects⁶, highlighting the importance of referral to educational and developmental services from an early age. When considering future outreach to families and physicians regarding educational and developmental services available to children

with craniofacial birth defects, the RIBDP will consider highlighting the value of speech and occupational therapy.

Although the child's providers are the primary access point for most service referrals, the Parent Consultant can refer families to some services if the families were not referred to, aware of, or interested in receiving a service prior to the assessment. The RIBDP will further investigate reasons why families are not being referred to certain services by providers and why they are not receiving these services (e.g., barriers to receiving service, parental belief the child does not need a service, difficulty navigating the system, lack of awareness of the benefits of certain services). Additional education for both providers and families is needed to emphasize the importance of early receipt of certain services for children with birth defects. The RIBDP will continue to educate families on available supports and services when conducting service assessments and will work to educate providers about these services and the importance of referring families to them.

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