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Findings from Rhode Island's Service Assessment and Referral Process for Birth Defects, 2020–2024

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INTRODUCTION

Birth defects, which are structural changes that develop in a baby before birth, affect about 3% of births in the United States[1] and about 4% of newborns (about 445) in Rhode Island (RI) each year.[2] While birth defects vary in how they affect a child, some are more severe and can have long-term effects on the health of the child.[1] Early identification of birth defects is important in providing needed care and support services that may improve the child's outcomes.[1]

The RI Birth Defects Program (RIBDP) at the RI Department of Health (RIDOH) is tasked with conducting birth defects surveillance and assuring children with birth defects receive timely and appropriate services up to age five (216-RICR-10-10-3). Birthing hospitals and physicians report children with any birth defect to the RIBDP. All reported birth defects are confirmed or ruled out through review of medical records prior to inclusion in the birth defects registry. To assure children receive timely and appropriate services, the RIBDP has implemented a process where its Certified Community Health Worker (CCHW) conducts service assessments with families of children up to age five. The RI birth defects registry consists of children under the age of five with any reported birth defect; however, only families of children with specific conditions are referred for a service assessment. About 15% of all birth defects cases reported in RI each year are eligible for a service assessment. The conditions were determined by the RIBDP and its Birth Defects Advisory Council and were based on the severity and long-term impacts of conditions. Recommended services were based on condition-specific national guidelines for conditions, but overall, assessments ask families about medical, educational, developmental, and family support service referral, receipt, and helpfulness. Families can also request additional resources and service referrals from the CCHW.

Previous service assessment analyses conducted by the RIBDP examined service referral and receipt for specific conditions. This analysis describes the characteristics of families completing a service assessment for any eligible condition from 2020 to 2024 and examines educational, developmental, and family support service referral, receipt, and helpfulness.

METHODS

Although the registry includes children with any identified birth defect, only children with the following conditions were identified by the RIBDP's epidemiologist from the birth defects registry (which contains only confirmed birth defects cases) and provided to the CCHW to attempt to reach the family for a service assessment: abdominal wall conditions (gastroschisis and omphalocele), congenital hearing loss, craniofacial conditions (craniosynostosis, cleft lip with or without cleft palate, cleft palate), critical congenital heart defects (CCHD), Down syndrome, microcephaly or other central nervous system conditions (CNS), and spina bifida. The RIBDP's CCHW then attempts to reach the family via mail or at a future appointment at a specialty clinic (if it is a clinic where the CCHW can conduct assessments). This analysis included assessments from 2020 to 2024 conducted in-person at specialty clinics, via mail, or via a secure online form (starting in 2021). Mail and online assessments were available in English and Spanish. Assessment information was self-reported by families and entered in Microsoft Access. Since assessments can be conducted annually until the age of five, initial assessments conducted during this timeframe were used for demographic information.

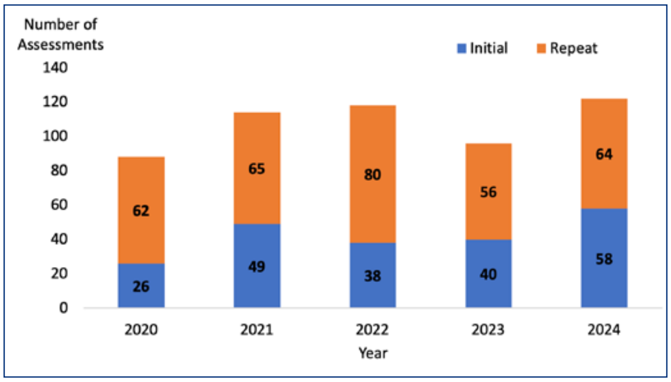
In addition to assessment type (initial or repeat) and location, demographic information collected included gender, primary parental language, and race/ethnicity (as defined in KIDSNET). Average time to first assessment (using birth and initial assessment dates) was calculated for all children except those with craniosynostosis, as it is not commonly identified at birth.[3]

Developmental and educational services examined were Early Intervention (birth to age three) and Special Education (children aged three and older at time of latest assessment). Family support services examined included: Medicaid/Katie Beckett (a Medicaid eligibility category allowing individuals under the age of 19 who have medical needs and long-term disabilities to live at home); Visiting Nurses Association (VNA)/Home visiting (First Connections family visiting program which connects parents of children up to the age of three with support services and resources); RIPIN programs (agency which connects families to other families and provides resource information), and parent support groups (non-RIPIN support groups; includes condition-specific support groups). Information on service referrals made by the CCHW at the time of the assessment was also collected. Service referral, receipt, and helpfulness was reported by families. Helpfulness was subjective as it was left to the interpretation of the families, who noted if they found the service helpful. Percents for service receipt and helpfulness were calculated for those who were referred to and received the service. Although also collected in the assessment, medical services were not examined in this analysis. Analyses were conducted in SAS Version 9.4.

RESULTS

From 2020 to 2024, there were 538 total assessments completed by families (211 initial and 327 repeat assessments). There has been an increase in both total and new assessments since 2020 and the fewest assessments were conducted in 2020 (**Figure 1**).

Figure 1. Number of Initial and Repeat Service Assessments for Service Assessment Conditions, Rhode Island, 2020–2024



Most initial and repeat assessments were conducted at a clinic (63.5% and 69.4% respectively; **Table 1**). Initial assessments were most frequently completed for craniofacial conditions (61.1%) and least frequently for abdominal wall conditions (2.4%). Children were most often male (64.0%), non-Hispanic White (49.3%), and English was their parent's primary language (83.4%). The average time from birth to initial assessment completion was most frequently more than one year from birth (39.4%), followed by less than six months (37.3%).

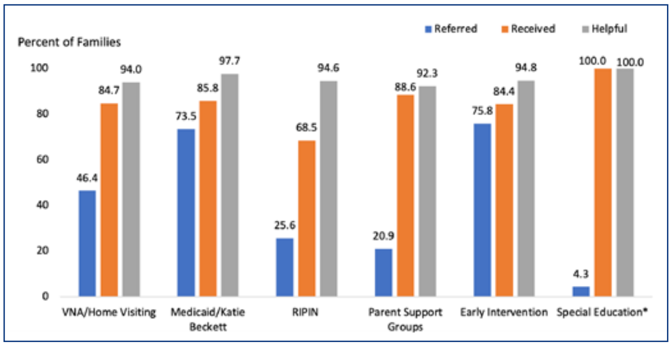
When examining educational, developmental, and parent support services, families were most likely to be referred to Early Intervention (75.8%) and Medicaid/Katie Beckett (73.5%) (**Figure 2**). Apart from RIPIN services (68.5%), of those who received a service referral, more than 80% reported receiving the service. All families who received these services found them helpful, ranging from 92.3% of families receiving parent support group services to 100% of families receiving Special Education. Of the 148 additional services families were referred to by the CCHW, Early Intervention services (46.6%) were the most frequent referral, followed by RIPIN (31.8%) and Medicaid/Katie Beckett (11.5%) (data not shown).

Table 1. Demographic and Assessment Information for Service Assessment Conditions, Rhode Island, 2020–2024.

	Count (%)
Total Initial Assessments	**211**
Initial Assessment Location	
Clinic	134 (63.5%)
Mail	59 (28.0%)
Online	18 (8.5%)
Assessment Conditions	
Abdominal wall conditions	5 (2.4%)
Congenital hearing loss	10 (4.7%)
Craniofacial conditions	129 (61.1%)
Critical congenital heart defects	13 (6.2%)
Down syndrome	33 (15.6%)
Microcephaly/Other central nervous system conditions	14 (6.6%)
Spina bifida	7 (3.3%)
Child's Gender	
Male	135 (64.0%)
Female	76 (36.0%)
Child's Race/Ethnicity	
Hispanic	66 (31.3%)
Non-Hispanic Black	15 (7.1%)
Non-Hispanic White	104 (49.3%)
Non-Hispanic Other	17 (8.1%)
Unknown	9 (4.3%)
Average time from birth to initial assessment*	
Less than 6 months	53 (37.3%)
6 months to 1 year	33 (23.2%)
More than 1 year	56 (39.4%)
Parent's Primary Language	
English	176 (83.4%)
Spanish	30 (14.2%)
Other	5 (2.4%)
Total Repeat Assessments	**327**
Repeat Assessment Location	
Clinic	227 (69.4%)
Mail	72 (22.0%)
Online	28 (8.6%)

*Includes all conditions except for craniosynostosis, which is most often diagnosed after birth.

Figure 2. Educational, Developmental, and Family Support Service Referral and Receipt by Families of Children with Service Assessment Conditions, Rhode Island, 2020–2024.



*Includes only children age three or older at time of most recent service assessment (n=23).

DISCUSSION

From 2020 to 2024, there was a 38.6% increase in total and a 123.1% increase in new service assessments. This was expected due to clinic COVID-19 restrictions and shifts to telehealth in 2020 which impacted the RIBDP's CCHW ability to interview families in clinics. Mail was the only assessment option and families may have not been likely to complete one due to other priorities. Also, the RIBDP implemented a secure online system to complete assessments in 2021 and started sharing aggregate data on completed assessments with families via an infographic provided in the mail. In addition to returning to clinics in 2021, both the online option and infographic may have increased assessment completion by providing a more convenient option and providing awareness of how results are used. Given many families prefer to conduct assessments in clinic, the RIBDP is exploring additional clinics for assessments to reach more families.

The RIBDP began collecting child's race/ethnicity and family's primary language to identify areas for improvement on referrals and assessments. Since RI's birth defects registry is the source for the assessment population, the RIBDP will link the assessment data to the registry to compare assessment completion by child and parental demographics. This will allow the RIDBP to examine any differences between those completing or not completing an assessment. Birth defects rates from 2018–2022 were highest in those children who were non-Hispanic Black and Hispanic, lived in a core city (Central Falls, Providence, Pawtucket, or Woonsocket), had a birth parent aged 40 and older, and had a birth parent with less than a high school education.[2] A more detailed comparison of assessment completion rates by some of these demographics, such as race/ethnicity, may help identify if there are additional ways to reach these families for assessments or if service referral and receipt gaps exist that should be addressed. Families not completing assessments may have different referral experiences and needs, so it is important for the RIBDP to continue to try to reach all families eligible for an assessment.

Referral gaps (lack of referrals to a service) were more common than those in service receipt or helpfulness. Parent support groups and RIPIN had low referral rates. Family members of a child with a birth defect, including siblings, may require psychological support.[4,5,6] Healthcare professionals should share support group information upon the initial diagnosis.[4] Parent support groups are a resource to connect with other families who have a similar experience,[4,6,7] and can be valuable in reiterating information received from healthcare professionals.[4] When needed during assessments, the RIBDP's CCHW provides information on RIPIN and condition-specific parent support groups to families. In addition to providing referrals, the RIBDP will continue to raise awareness of the value of parent support services with families and healthcare professionals to ensure families receive needed support.

Initial assessments were most often completed more than one year from birth. Families may not have initially required resources[7] or were initially overwhelmed with the child's diagnosis[4] but were willing to share their experiences when the CCHW reached out again.

All assessment conditions impact children and their families; however, every family may not need every service. It is important for healthcare professionals, who are the primary access point to service referrals, to recognize when a child could benefit from certain services and to refer families as needs are identified. It is also important to offer services to families often over the course of a child's care as needs may change over time.[6,7] Families may be overwhelmed with their child's diagnosis and not always recall information shared with them previously.[4] The RIBDP's service assessments also play a role in service referral, as seen with referrals made by the CCHW, including Early Intervention, RIPIN, and Medicaid/Katie Beckett. As each family completes an assessment, the CCHW identifies any new referrals needed and follows families with transitions to Special Education services if needed.

Once a family receives a referral, there may be barriers to overcome to receive the service, including language, income, education, and culture.[4] Financial barriers facing families may include taking time off or losing a job for visits, costs associated with traveling for care, medical costs not covered by health insurance, and finding and paying for home care and/or childcare.[4,6,8] During assessments, the CCHW raises awareness of and refers families to financial resources, such as Medicaid/Katie Beckett and Supplemental Security Income (SSI), and other programs for help with housing and food insecurity.

Connecting families with needed services early in the child's life can help improve outcomes for both the child and family. As part of a family-centered approach, the RIBDP's service assessment process connects families with a CCHW who can identify concerns and link them to resources. In addition to conducting more detailed analyses of assessment data, the RIBDP will continue to identify improvements to its assessment process and raise awareness of identified service referral gaps with healthcare professionals.

Limitations

Data were self-reported by families and subject to recall bias. There may also be response bias from collecting surveys via three different methods. Families who didn't complete an initial or follow-up assessment may have different referral and receipt patterns. There may also be differences in referral, receipt, and helpfulness of services between types of assessment conditions. Lastly, referral data captured the results of the most recent assessment. If a family completed follow-up assessments, service referral and receipt may have changed over time.

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