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Practice Summary & Implementation Guidance

Connecting Families to Supports through Service Assessments

The Rhode Island Birth Defects Program connects families of children with certain conditions to medical, educational, developmental, and family support services by conducting service assessments to assure children and their families are receiving appropriate services in a timely manner.

Location	Topic Area	Setting
Rhode Island	Birth Outcomes, Care Coordination, Family and Youth Engagement, Primary and Preventative Care	Clinical, Community

Population Focus	NPM	Date Added
CYSHCN, Infant	NPM 6: Developmental Screening, NPM 11: Medical Home, NPM 15: Adequate Insurance	October 2023

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Section 1: Practice Summary

PRACTICE DESCRIPTION

Per legislation enacted in 2003, the Rhode Island Birth Defects Program (RIBDP), located in the Rhode Island Department of Health (RIDOH), is required to assure children with birth defects up to the age of 5 are receiving appropriate services and referrals in a timely basis. In 2005, the RIBDP, along with its Birth Defects Advisory Council (BDAC), determined the best way to accomplish this would be to conduct an assessment with families of children with birth defects to identify the services and referrals they received. Initially, the RIBDP met with the RI chapter of the American Academy of Pediatrics and other physicians to determine the feasibility of them to provide this information. Although we received positive feedback on our one-page form, the consensus was it was not practical from a time and effort standpoint for practices to provide service and referral information. The RIBDP also considered implementing another approach, which was subsequently eliminated.

This approach would involve the Parent Consultants who were embedded in major pediatric practices, seeing the population of interest, to review medical records to determine service referral/receipt. However, the parent consultants did not feel comfortable reviewing the medical records. Due to limited resources and staff capacity, a list of selected birth defects was created to focus the assessments. These “sentinel conditions” were identified using criteria established by the BDAC and included the prevalence of the condition, available treatments, etc. Initially, we started with 3 conditions and have expanded and refined our condition list over the years based on identified need for service assurance.

Service assessments are currently conducted with families of children who have Down syndrome, spina bifida, craniofacial defects, critical congenital heart defects, abdominal wall defects, hearing loss, and microcephaly or other central nervous system conditions (added when Zika became an emerging concern). Condition-specific forms were developed to ensure children’s different medical, educational, developmental, and support service needs were being met. The assessment forms were also translated into Spanish, based on language spoken among the affected children and their families. The key population our practice impacts is children with selected birth defects and their families. The RIBDP, in collaboration with RIPIN, employs a Community Health Worker (CHW) who conducts service assessments with families who have children up to age five with specific birth defects to determine whether these children have received appropriate referrals and services on a timely basis.

The CHW meets with families at pediatric and specialty care practices that serve children with birth defects or mails forms to those families who cannot be interviewed in a practice. Starting in 2021, the RIBDP added the option to complete an assessment via a secure online form. Follow-up service assessments are conducted to ensure continuity of referrals and services until the child is five years old. Service assessments help the RIBDP determine what services and referrals were provided to children based on the national guidelines for specific conditions. The CHW can also refer or recommend services to families when there is a gap.

CORE COMPONENTS & PRACTICE ACTIVITES

The core components of our program include: (1) an assessment form for each condition which can be used for in-person, mail, or provides a QR code to conduct online, based on the family preference; (2) CHW referrals to

services; (3) an educational/data dissemination component including infographics summarizing outcomes/observations from assessments over the previous year and an infographic of family resources; (4) our service assessment database, and (5) conducting analyses of data to track outcomes over time/identify areas for improvement.

Core Components & Practice Activities		
Core Component	**Activities**	**Operational Details**
Service Assessment	Assessment Form	Complete service assessments on children from birth to age 5 with specific birth defects (7 conditions) to ensure that they receive appropriate and timely service and supports
Services and Linkages	Connect Families with Services	Identify children with birth defects and provide appropriate referrals, supports and resources to families. Work with other programs/service providers to determine if children have been referred
Data Dissemination	Educational infographics, data dissemination, and social media messaging	Disseminate information to families through infographics and other data products. Develop a Birth Defect Data book, story map, posters for national conferences, articles, webpages, and social media prevention
Service Assessment Database	Access Database	Enter information from completed assessment forms into Access Database
Data Analyses	Track Outcomes	Analyze data and track outcomes over time to identify gaps in service and develop improvements to process

HEALTH EQUITY

The RIBDP provides families with connections to community resources and supports that help with food insecurities, financial supports, immigration concerns, healthcare coverage, and housing issues. We also work with other programs within the Rhode Island Department of Health (RIDOH), including WIC, First Connections/Home Visiting, Early Hearing Detection and Intervention, and Immunization. We have translated our assessment form and infographics into Spanish and are working to determine if there is a need for any other languages by collecting information on the primary language spoken by each family. In recent years, we have

started collecting race/ethnicity information that can be used to look at disparities in service referral/receipt by race/ethnicity. We also provide referrals to address social determinants of health and health equity such as housing resources, health insurance, pro bono services provided by dentists and other healthcare providers, etc.

EVIDENCE OF EFFECTIVENESS

In 2003, the state of RI enacted legislation that required the Rhode Island Birth Defects Program (RIBDP) to assure children with birth defects up to the age of 5 are receiving appropriate services and referrals in a timely basis. After discussing other potential options to gather service referral/receipt info, which included having physicians report this information and using the Parent Consultants embedded in each practice, the RIBDP, along with its Birth Defects Advisory Council (BDAC) determined the best way to do so would be to have a RIDBP Certified Community Health Worker (CCHW) conduct interviews with families of children with birth defects. We developed a one-page service assessment form based on recommendations from national guidelines for specific birth defect conditions. These assessment forms could then be used to determine if the children were being referred to medical services, family supports, and developmental and educational services. We could also determine if they received these supports and they found helpful.

We have several approaches to gathering evidence of effectiveness of our program. First, we can evaluate overall if families completing assessments for the first time have received referrals to services and where the gaps lie. We can track these trends over time for all conditions and for each assessment condition. We also try to reach families as quickly as possible after birth so they can access services if they were not already referred by a provider. We use our service assessment database, where the CCHW has entered all assessment results, to look at the services frequently referred to/gaps. Second, we have testimonials from families and providers that share how they benefit from the assessment process and how the CCHW has connected them to services beyond the initial scope of our assessment process (i.e., dental assistance, connections with an agency assisting with immigration/resettlement).

Using our evaluation data, over the last 10 years (2013-2022), we have increased the percent of families who were referred to and received services who received the service for home visiting (57% to 90%), Medicaid/Katie Beckett (57% to 87%), and RIPIN family support groups (24% to 78%). Our evaluation of service referral and receipt patterns pre- and post-COVID-19 show that we have increased the following reported referrals that had seen a decrease in 2020: Children's Neurodevelopmental Center (36% to 41%) and Medicaid/Katie Beckett (48% to 59%). We have also seen an increase in families who reported receiving the following services from 2020-2022: RIPIN family support services (40% to 78%) and parent support groups (78% to 86%).

In general, most of the families we serve experience health inequities. Many of the impacts of our program are with individual families who meet one on one with our CCHW. The CCHW helps families with social determinants of health by assisting with housing, health insurance coverage, obtaining other medical care, etc. Looking more at the individual impact of the process on families, two of the many examples of the impact are shared below:

- The CCHW was in contact with a Physician Assistant (PA), who works in the craniofacial clinic. The PA was struggling with finding a pediatric Periodontist who could help an immigrant family that had a child with cleft lip and palate. This child needed extensive dental work, but the family didn't have any insurance. The CHW contacted a dentist in the Oral Health program at RIDOH to see if he knew a periodontist who could provide the services pro-bono. The CHW providing the coordination between the RIDOH dentist, the PA, and the periodontist helped the child receive the needed services at no cost to the family.

- The CCHW received a completed assessment from a family looking for help with housing. She referred the family to the RIPIN Family Voices program who provided the family with community agencies and information that could help with housing and other basic needs.

Since we conduct surveys with families, there may be recall bias affecting our results. Families may not accurately recall service referrals or their receipt, especially if they refer to a program by a different name. Since the surveys are conducted annually, parents may not recall all services referred to/received in a previous year. There may also be selection bias present. Those who choose to complete the survey may be different from those families who do not respond. They may have been less likely to have received referrals or services and require the CCHW to refer to services.

An unexpected outcome of our service assessment activities was how families and providers reach out to the CCHW for assistance with other services not covered in the assessment. The CCHW has built a relationship with each family and the providers at clinics where she conducts in-person assessments. The families and providers will reach out to her with questions about where to obtain additional assistance for needs, such as dental care or resettlement assistance, and she will connect them with the appropriate resource. This sometimes requires reaching out to other RIDOH programs, such as Oral Health, where staff members have connections to other providers or community agencies who can assist families.

Section 2: Implementation Guidance

COLLABORATORS AND PARTNERS

To implement our service assessment process, the RIBDP, which consists of a CCHW, epidemiologist, and Project Director, works with families, physicians/providers, and community partners to conduct assessments and evaluate our process.

Practice Collaborators and Partners			
Partner/ Collaborator	**How are they involved in decision-making throughout practice processes?**	**How are you partnering with this group?**	**Does this stakeholder have lived experience/come from a community impacted by the practice?**
Families of children with selected birth defects	Parents are interviewed during the service assessment process to understand what services and supports are needed. Supports have been made based on parents' information	Completed service assessment interviews allow us to have conversations about needs of families and services available to them	Yes, parents are the primary contact for what services the children were referred to, received from providers and if the services were helpful
Physicians/Providers & Community Partners	Physicians/providers and community partners were involved with the design and development of the service assessment process. They are also involved in quality improvement (where we identify gaps in the referral process or service system)	The physicians/providers and community partners were part of an advisory council that met quarterly to decide how to implement the service assessment process. We also connect with providers to conduct in-person interviews and when we identify gaps in referrals	Many of the physicians/providers and community partners serve the population
Families of children with selected birth defects	Parents are interviewed during the service assessment process to	Completed service assessment interviews allow us to have	Yes, parents are the primary contact for what services the children were

	understand what services and supports are needed. Supports have been made based on parents' information	conversations about needs of families and services available to them	referred to, received from providers and if the services were helpful

REPLICATION

To our knowledge, this process has not been Implemented in other jurisdictions. In RI, we've added and removed conditions and specific questions over the years to ensure we are targeting families who may require assistance and referrals. The RIBDP tailored Its form for each of the assessment conditions, since each condition varies with recommendations for medical, educational, developmental, and support services. We were able to adapt our forms over time as we Identified areas for improving data collection. Additionally, we have been able to adapt our process for additional conditions that we have added over time, as all follow a similar process using the form and finding clinics who serve the population of Interest to conduct In-person assessments. Having a basic process in place allows for additional conditions or questions to be added rather quickly, without having to re-Invent the process.

Making a connection with physicians/providers serving the population of interest is a critical part of conducting in-person assessments. When the physicians/providers understand the importance of the process and how it tries to improve outcomes of children, it is easier for the CCHW to work with clinic staff to obtain appointment information and to be integrated into the clinic to interview families.

Being tied into the local community of physicians/providers and community agencies serving the population is also important to the process. Frequent communication with partners is valuable for the quality improvement process and when service referral gaps are identified. The relationship already exists with providers and community partners, which facilitates any needed communication about areas for improvement in service referral. This can also provide valuable context to certain trends we are observing in our data.

The implementation of Redcap or another secure online survey platform allows families to complete assessment forms via a QR code and can be applied to any program that is looking to expand their reach to provide services and resources to families. When the assessment is completed on-line, the families have an option to request more information regarding supports and follow up can be conducted.

INTERNAL CAPACITY

RIDOH's RIBDP is responsible for assuring children with birth defects are receiving timely and appropriate services. Prior to starting the service assessment process, the RIBDP had existing relationships with community partners and physicians/providers through Its Birth Defects Advisory Council. We developed our process and decided upon the conditions selected after many discussions with our Advisory Council. This close relationship also helps facilitate closing any gaps Identified from our assessments, as we can work with our Advisory Council to understand how to best Implement Improvements.

The RIBDP key program staff Include: 1) CCHW who conducts the assessments and all associated data entry; 2) epidemiologist who provides Information on children with assessment-eligible conditions that were recently reported to the RIDBP through surveillance; and 3) Program Director who provides oversight on the process and helps facility the Advisory Council. The most Important staff member for this process is the CCHW, who makes connections with the physician/providers which is critical for CCHW's interaction with families at clinics. Once the connections are made, the CCHW will attend clinics and interact with families to complete the forms and identify any gaps in services and supports. The CCHW can then make referrals and offer resources to community partners who can provide the services needed.

The project can be implemented on a smaller or larger scale, depending on the needs of each program. Rhode Island is a small state, so it was not difficult to Implement statewide, but we also limited the conditions for which we conduct assessments to ensure we could handle the workload and still reach families. Larger states or jurisdictions could begin by implementing on a municipality or county level. Once the process is established, they could expand to more areas or additional conditions if they have adequate resources, as the RIBDP has done by adding additional conditions in recent years. Because the basic process is in place and is similar for all conditions, changes can be easily implemented. If we obtain additional funding in the future, we could also add more CCHW to conduct assessments using the same process.

PRACTICE TIMELINE

The following activities are recommended for developing and maintaining a service assessment process.

Phase: Planning/Pre-Implementation		
Activity Description	**Time Needed**	**Responsible Party**
Decide on criteria for conditions to include, identify and finalize list of conditions for assessments	6 months	RIBDP, Birth Defects Advisory Council, Providers/Physicians, Community Agencies
Outline process for conducting assessments, including how to determine families eligible for assessments, frequency of outreach, clinics to see families, etc	6 months- 1 year; ongoing	RIBDP, Birth Defects Advisory Council, Providers/Physicians, Community Agencies
Identify any clinics/provider offices to conduct in-person assessments	Varies, based on relationship with providers/physicians	RIBDP, Birth Defects Advisory Council, Providers/Physicians, Community Agencies

Develop any educational materials and letters to be provided with assessments	2 months	RIBDP, with input from Birth Defects Advisory Council and final language/format approved by RIDOH communications staff
Develop assessment form (using national guidelines/recommendations for conditions) and any online platforms (if offering online response option)	3-4 months (for initial assessment form); Additional forms can be easily modified and require less time once have basic form	RIBDP, with input from Birth Defects Advisory Council and final language/format approved by RIDOH communications staff

Phase: Implementation

Activity Description	Time Needed	Responsible Party
Launch assessment form (mail, in-clinic, online if using)	1 day	RIBDP
Provide list of eligible families to CCHW from surveillance	1 hour	RIBDP epidemiologist
Coordinate with clinics to find appointment times for in-person assessments	1 week to receive list of appointments after outreach to clinic	RIBDP
Conduct mailings for families not seen in clinic	Monthly (or more frequently, depending on program size); ongoing	RIBDP
Data entry for assessment results	1 day	RIBDP

Phase: Sustainability		
Activity Description	**Time Needed**	**Responsible Party**
Conduct quality improvement activities and implement changes identified	Ongoing	RIDBP
Collaborate with providers/physicians to resolve referral gaps identified from assessment process	Ongoing	RIBDP
Ongoing outreach to families to conduct assessments	Ongoing	RIBDP
Identify additional clinics to conduct in-person assessments	Ongoing	RIBDP, Birth Defects Advisory Council

PRACTICE COST

Cost to Implement this practice will vary based on the program and mainly consistent of staff costs for a CCHW.

Budget			
Activity/Item	**Brief Description**	**Quantity**	**Total**
Printing/Mailing of Assessment Forms	Printing paper forms and address labels, cost for mailing assessments	Varies	Dependent on number of mailings and the cost of postage, paper, and labels at that time
CCHW (or other staff to conduct assessments and data entry for	Staff time to: conduct outreach to clinics to determine if families will be seen, conduct in-	Varies	Varies

completed assessments)	person assessments, put together monthly mailings, and conduct data entry for completed assessments.		
Data analysis	Staff time for epidemiologist to provide list to CCHW for possible assessments and to conduct analyses/evaluations using service assessment data	Varies	Varies
		Total Amount:	**Varies**

For more information on this practice startup costs and budgets, please contact Samara Viner-Brown directly at samara.vinerbrown@health.ri.gov.

LESSONS LEARNED

One example of continuous quality improvement for this process is updating our service assessment form. When completing service assessments, families often report needing extra help with specific supports and services. The CCHW noticed a need for families who requested connections to these services when completing the forms via mail, online or in person. The CCHW makes note of the assistance the family requests for her records when completing in-person assessments. The CCHW, along with the RIBDP epidemiologist and director, discussed how to capture this information and decided on a redesign of the assessment form. The RIBDP redesigned the service assessment forms to include a section where families can request extra supports with healthcare coverage, special education, support groups, community resources (food/housing), early intervention or other programs. The RIBDP's Parent Consultant can then connect families with these services, even when an in-person assessment is not conducted. This change has resulted in providing extra needed supports to families.

We have learned that although the process was meant to assure families are receiving needed medical/educational/developmental/support services, the scope of the referrals the CCHW makes is well beyond what was initially intended. She connects with families and providers, so they reach out to her with questions about other services they need to help identify/make referrals outside of the annual assessments. One additional lesson learned has been how staff turnover at clinics for in-person assessments impacts the ability to conduct those assessments. It is often difficult to receive notice of clinic appointments when the staff contact leaves their position. There have also been delays in holding clinics when clinic coordinators leave the practice and there is a gap in hiring someone to fill the role. These turnovers delay in-person assessments, which is the most popular method for completing assessments for some conditions.

One recent problem we had was declining use of mail to complete assessments. We noticed declining response rates and decided to look at how families could complete assessments online. The solution was to create our assessment forms in REDCap. We added a QR code to the letter that accompanies our paper assessment form explaining the additional option available to families.

We would have implemented our online assessment option earlier than we did, especially with COVID-19 affecting assessment response rates and the impact it had on the CCHW's ability to conduct in-person assessments at clinics. Also, given clinic staff turnover in recent years, we would have identified a back-up contact so staff turnover did not impact the CCHW's ability to conduct in-person assessments.

NEXT STEPS

We will continue this practice indefinitely. We are also always looking to expand our list of Birth Defect service assessments when we identify additional conditions of concern where families could use extra support services.

We will add new conditions of concern, particularly emerging threats like Zika, when the need arises. We also continuously evaluate if we need to modify our assessment form, if there are new clinics that we can connect with to conduct in-person assessments, or if there are new services that could be of value to the families we serve.

RESOURCES PROVIDED

- RI Birth Defects Program Service Assessment Forms

APPENDIX

- RI Birth Defects Program, Service Assessment Infographic (RI Birth Defects Program- Service Assessment Key Findings)
- RI Birth Defects Program, Family Resources (HelpForFamiliesOfChildrenWithBirthDefects2020 (ri.gov))