

# Rhode Island Birth Defects Program: Family Engagement



# Outline

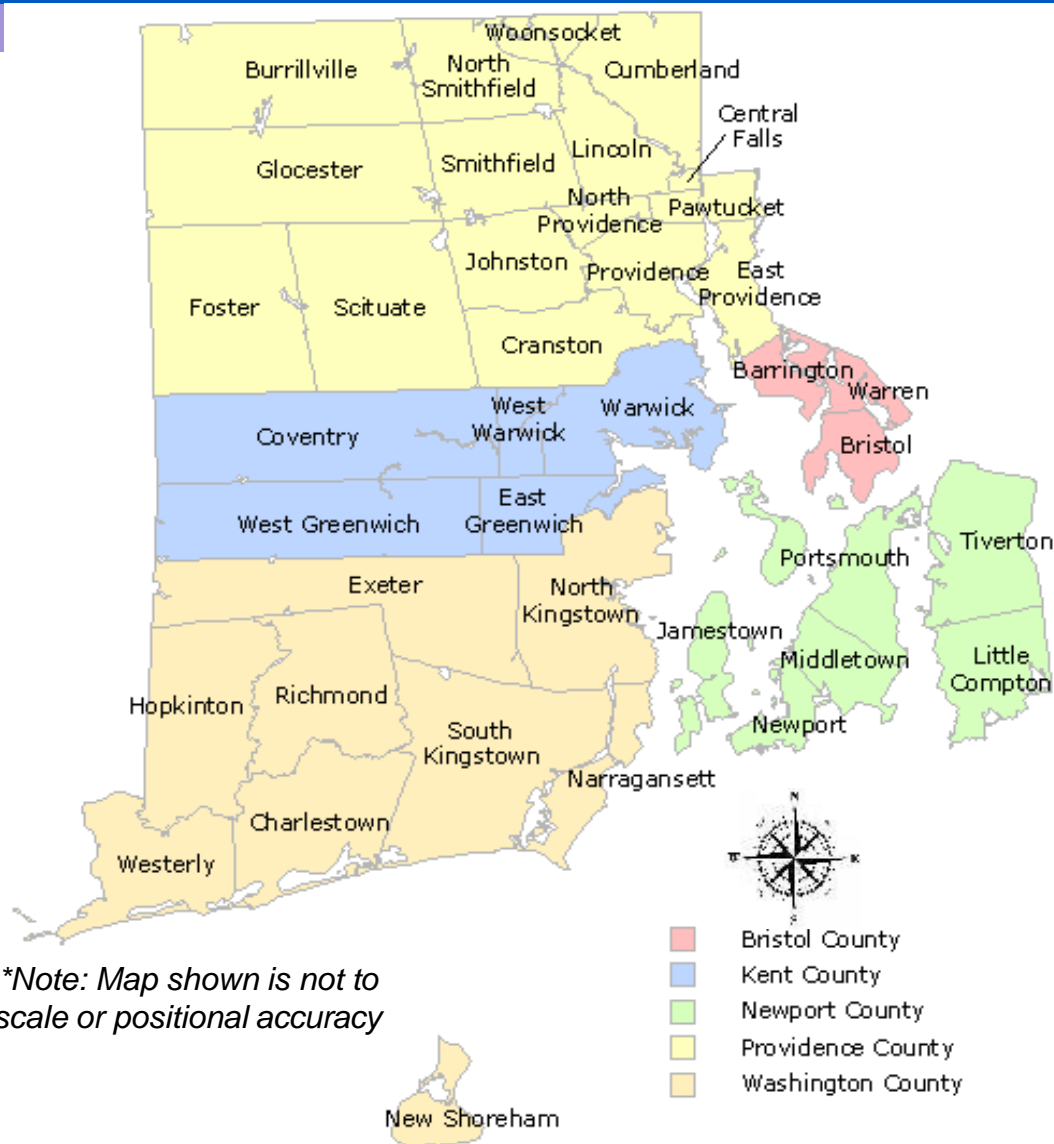


- **Overview of RI Birth Defects Program**
  - **Background**
  - **Program Description**
  - **Relation to MCH-Title V Programs**
  - **Service Referral and Assessment**
    - **Overview**
    - **Parent Consultant/Community Health Worker Role and Experiences**
  - **Data Dissemination**
- **Questions and Answers**





# Rhode Island Overview



*\*Note: Map shown is not to scale or positional accuracy*

- **Population = ~1.1m**
- **50<sup>th</sup> in size**
- **43<sup>rd</sup> in population**
- **39 cities/towns**
- **5 counties**
- **1,214 square miles**



# Rhode Island Context



- **~11,000 births among RI residents annually**
  - **~400 with birth defects**
- **Five maternity hospitals**
- **One Children's Hospital (Hasbro)**
  - **Children's Neurodevelopment Center (CNDC)**
  - **Specialty clinics and services for children and young adults with special health care needs**
- **No local health departments**

# Rhode Island Birth Defects Program



- **The Rhode Island Birth Defects Program is located at the Rhode Island Department of Health, Center for Health Data and Analysis (CHDA)**
- **Rhode Island began developing a birth defects information system in 2000 with CDC funding**
- **During 2003, the Rhode Island General Assembly enacted legislation requiring the state to develop and implement a birth defects reporting, surveillance and information system**

# Rhode Island Birth Defects Program



- The purpose of the legislated birth defects information system was to:
  - Describe the occurrence of birth defects in newborns and children up to age 5
  - Detect trends of morbidity and mortality and stimulate epidemiological research
  - Identify children with birth defects to intervene on a timely basis for treatment
- The legislation also required the establishment of reporting requirements which went into effect in November 2005; revised in 2017 and 2019

# Birth Defects Program: Goals and Objectives



- **Identify children (up to age five) with birth defects and monitor prevalence trends**
- **Develop effective strategies for primary and secondary prevention of birth defects**
- **Assure children with birth defects and their families are linked to and receive appropriate services on a timely basis**
- **Assure health care providers, professionals, families of children with birth defects and the general public have access to information re: prevalence, prevention and services**



# Rhode Island Birth Defects Program



- **Birth Defects Program Staff:**
  - Donna Houle, CCHW, Parent Consultant, RIPIN
  - Kristen St. John, MPH, Epidemiologist/Program Manager
  - Sam Viner-Brown, MS, Program Director
- **Advisory Council**
- **MCH Policy Team**

# MCH Partnership



- **MCH Policy Team – meets monthly, aligns activities and priorities as needed**
- **Title V Priority review on a quarterly basis**
- **Health Data and Analysis staff are embedded in MCH programs and especially Title V program**
- **Title V funding to support parent consultant/CHW activities**

# **SERVICE ASSURANCE: REFERRAL/ASSESSMENT**



# Service Assurance



- **One of the primary goals of the program is to assure that children with birth defects receive appropriate services on a timely basis**
- **To ensure access to services, children meeting criteria are referred for case management and follow-up**
- **Families of children with selected birth defects are asked to complete service assessment forms to determine what services and referrals they have received**

# Service Assurance



- **Determine the following:**
  - Are patients receiving optimal care?
  - Are services provided in a timely manner according to guidelines?
  - Are patients/families satisfied with care?
  - Are health care providers satisfied with system of care?
- **Conducted focus groups and surveys**
  - Families
  - Health care providers



# Service Assessment



- **Conducted with families, who have children aged less than 5 with specific (sentinel) birth defects**
- **Collect information about services and referrals received related to medical, educational, developmental, and social support services**
- **Completed by interviewing families in primary and specialty care practices and through direct mailings**
- **Follow up assessments completed annually**

# **Service Assessment: Methodology**



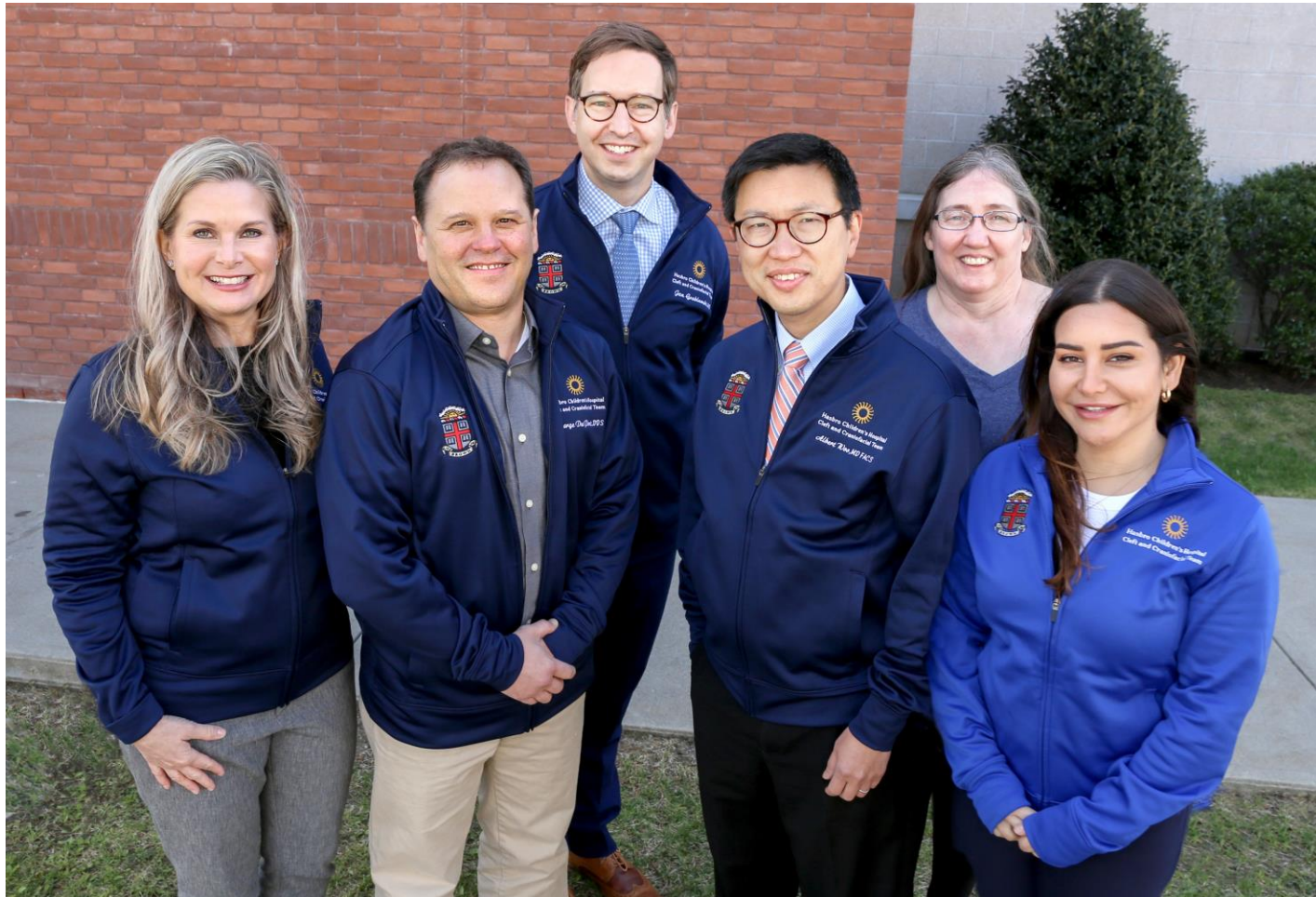
- **Implemented assessments for selected (sentinel) conditions for targeted outreach**
- **Tool: National Guidelines (recommended services by age intervals for selected conditions)**
- **Monitor service referrals and linkages via:**
  - **pediatric practices and specialty clinics that serve children with sentinel conditions**
  - **Face to face interviews with families at clinics**
  - **Mail assessment forms to families**
  - **Parent consultants at Early Intervention sites**

# Service Assessment: Parent Consultant/CHW Role and Experiences





# Cranio-Orofacial Team



# Service Assessment Conditions



- **Down Syndrome**
- **Cranial Orofacial Conditions**
- **Spina Bifida**
- **Abdominal Wall Defects**
- **Critical Congenital Heart Defects**
- **Microcephaly**
- **Hearing Loss**





## Families of Children with Craniofacial Diagnosis Survey of Healthcare Services

Child's Name: ..... Child's Date of Birth: .....  
 Parent's Name: .....  
 Child's Primary Care Physician: .....

This is to ensure families of children with a Craniofacial Diagnosis are receiving appropriate referrals and services on a timely basis.

<b>Classification:</b> Please check the appropriate classifications that best describe your child's condition.	<input type="checkbox"/> Cleft Lip and Palate <input type="checkbox"/> Cleft Lip Only <input type="checkbox"/> Cleft Palate Only <input type="checkbox"/> Other: _____									
	Has Not Received	0-3 mos	4-6 mos	7-12 mos	13-18 mos	19-24 mos	2 yrs	3 yrs	4+ yrs	Not Sure
<b>Pediatric Visits:</b> Please check the ages when your child visited a pediatrician or family medicine doctor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Nutritional Information:</b> Please check when you received information from a physician or nutritionist regarding your child's nutritional needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Specialist and Procedures:</b> Please check the ages when your child received the following.	Has Not Received	0-3 mos	4-6 mos	7-12 mos	13-18 mos	19-24 mos	2 yrs	3 yrs	4+ yrs	Not Sure
Audiologist (hearing specialist)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dentist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ENT- (ear, nose, throat specialist)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Neurologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ophthalmologist (eye specialist)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Oral Maxillofacial Surgery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Plastic Surgery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Yes	No	Before birth (prenatal)			At birth (in hospital)		After discharge from hospital		
<b>Genetic Test:</b> Has your child received a Genetic Test?	<input type="checkbox"/>	<input type="checkbox"/>	If yes, when? (check all that apply)			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
<b>Genetic Counseling:</b> Did you receive genetic counseling with your child's diagnosis?	<input type="checkbox"/>	<input type="checkbox"/>	If yes, when? (check all that apply)			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
<b>Parent Support:</b> Were you referred to and/or did you receive services (e.g. family support groups, home visits, outreach services) from any of the following?	Referred?			Received?			Was it Helpful?			
	Yes	No	Not Sure	Yes	No	Not Sure	Yes	No	Not Sure	
Rhode Island Parent Information Network (RIPIN)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Family Voices	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Visiting Nurse Association (VNA)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Medicaid, or SSI/SSDI	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Katie Beckett	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
First Connections (Home Visiting)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Any other Parent Group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Other, please specify: _____										
<b>Developmental &amp; Educational Services:</b> Was your child referred to and/or has he or she received any of these services?	Referred?			Received?			Was it Helpful?			
	Yes	No	Not Sure	Yes	No	Not Sure	Yes	No	Not Sure	
Children's Neurodevelopment Center (CNDC)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Early Intervention (EI)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Individual Education Plan (IEP)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Occupational Therapy (OT)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Physical Therapy (PT)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Speech Therapy (SLP)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Cedar	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Other, please specify: _____										
<b>Please share with us any additional information about the services provided to your child and family. Include any specialists, services or other conditions not mentioned in this survey. Your participation is greatly appreciated and will help us to address future needs for families and children in Rhode Island.</b>										

Location	Date

**Please Return Form to:** Donna Lee Houle  
 Rhode Island Department of Health  
 Center for Health Data & Analysis  
 3 Capitol Hill, Room 407  
 Providence, RI 02908

Code#

**Questions or Comments, please contact:**  
 Donna Lee Houle  
 Phone: 401-222-7460    Fax: 401-222-1442  
 DonnaLee.Houle@health.ri.gov  
 Revised March 2017

Clinical  
Services

Family Support  
Services

Developmental  
& Educational  
Services

# Resource Information Provided



- **Medical Home Portal**
- **Katie Beckett**
- **CEDAR Centers**
- **Peer Navigators (RIREACH)**
- **Early Intervention Program**
- **RIPIN (RI Parent Information Network)**

# Challenges



- **Clinic staff turnover**
- **Family no-shows**
- **Availability of interpreters**
- **Scheduling conflicts**

# **EXPERIENCES/STORIES**

# SERVICE ASSESSMENT ANALYSES

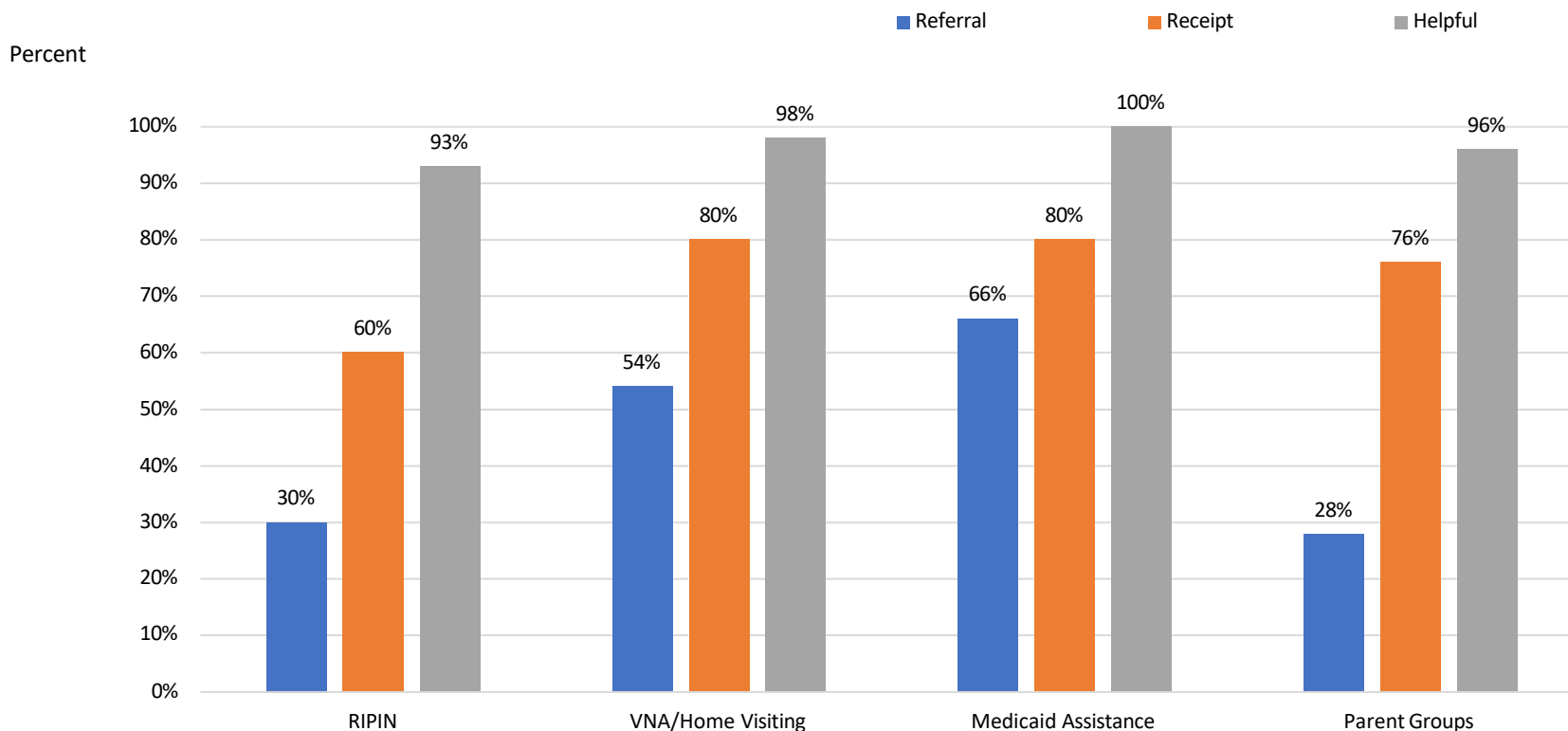




# Family Support Referrals



## Family Support Service Referral and Receipt by Families of Children with a Service Assessment Condition, Rhode Island, 2017-2021

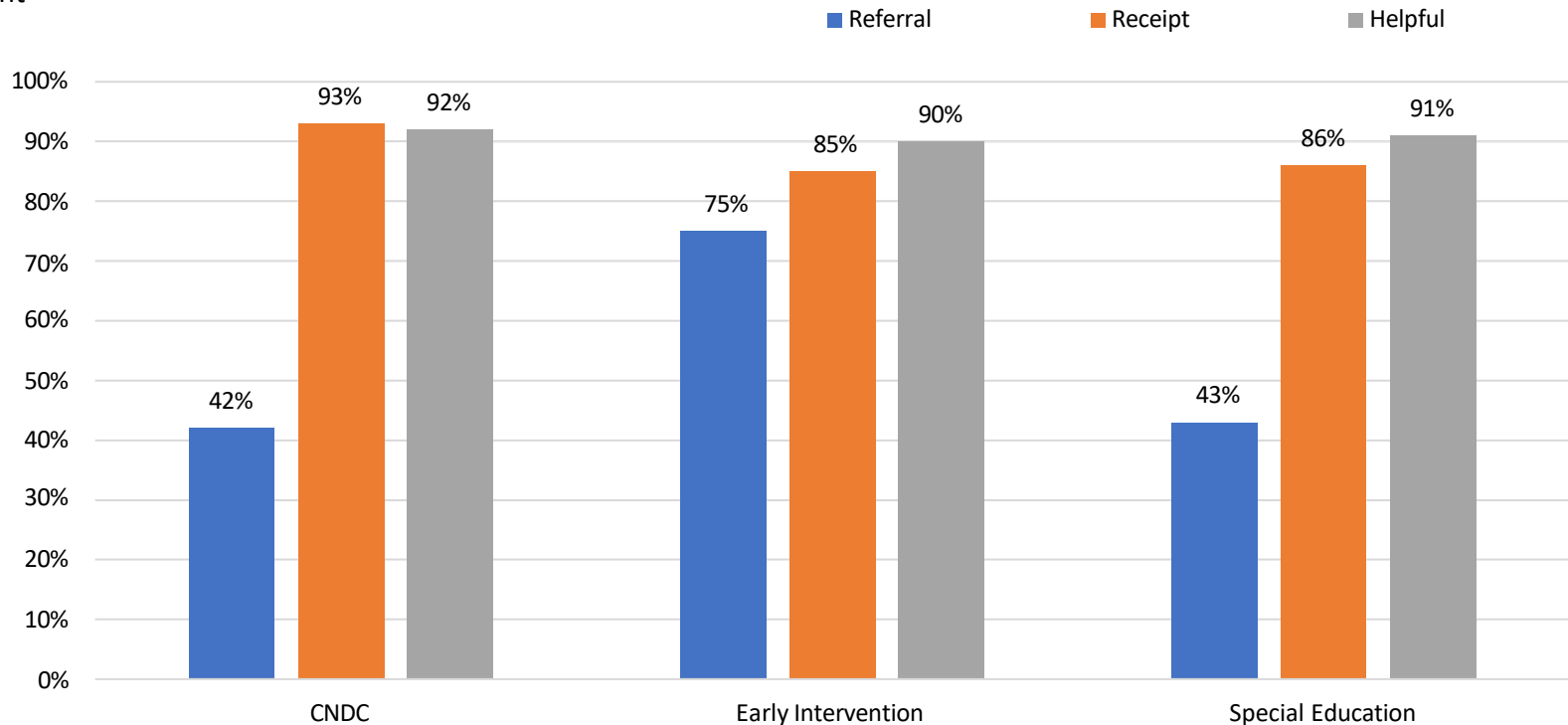


# Educational and Developmental Support Service Referrals



## Educational and Developmental Support Service Referral and Receipt by Families of Children with a Service Assessment Condition, Rhode Island, 2017-2021

Percent

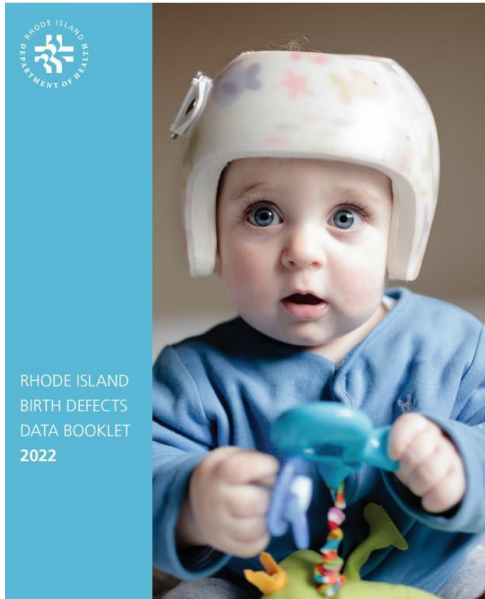


# Data Analysis and Dissemination



- **Annual Birth Defects Data Book**
- **Social Media postings**
- **Journal articles**
- **Birth Defects Story Map**
- **Infographics**
- **National Conference Posters**
- **Brown University Public Health Research Day**

# Data Analysis and Dissemination



RHODE ISLAND  
BIRTH DEFECTS  
DATA BOOKLET  
2022

## Assessing Educational/Developmental and Parent Support Services Received by Families of Children with Spina Bifida

Kristen St. John, Donna Lee Houle, and Samara Viner-Brown  
Center for Health Data and Analysis, Rhode Island Department of Health

### Background

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 up to the age of 5. Frequent analysis of service assessment data is important in determining where there are gaps in referral and receipt of services and in implementing improvements in the service assessment process.

### Study Questions

- Which parent support and educational/developmental services do families of children with spina bifida report being referred to and having received?
- Do families find these services helpful?

### Methods

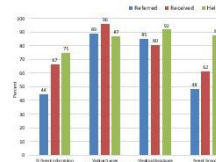
The analysis examines service assessment findings regarding parent support and educational/developmental services for children with spina bifida. Assessment were conducted from 2011 through 2018 via mailings and interviews with families of children at specialty clinics. Proportions were compared for each support service. All information was self-reported.

### Results

There were 54 completed service assessments for children with spina bifida, with 46 (84%) of them having more than one assessment completed. Forty-nine (91%) of the initial assessments were conducted at specialty clinics.

For parent support services, the Visiting Nurses Association (VNA) Home Visiting and Medicaid assistance had the highest referral rates, 87% and 85% respectively. There were fewer referrals to Rhode Island Parent Information Network (RIPIN) (44%) and parent support groups (43%).

Figure 1: Parent Support Service Referrals (n=54)



Families were most likely to receive VNA Home Visiting services (96%) and least likely to receive parent support group services (62%). Of all families who received support services, the majority found them helpful, with Medicaid assistance having the highest satisfaction rate (92%).

Families deemed eligible for developmental and educational services were referred to the Children's Neurodevelopmental Center (CNDIC) at Hasbro Children's Hospital (98%), Early Intervention (96%), and Special Education (65% of children aged 3 or older). Families who received these educational/developmental services were highly satisfied.

All service assessment data were self-reported by families of children with spina bifida and may be subject to recall bias. Some response bias may also be introduced from collecting service assessments via two different methods.

### Conclusions

Although there were high referral rates for some parental support and developmental/educational services reported by families of children with spina bifida, there were gaps identified in referrals for parent support groups, RIPIN, and Special Education services. Among those who were referred to supports and services, there was a high rate of satisfaction with the services received, which supports the need for referrals to these support services. The RIBDP will use the identified gaps to increase future family and provider outreach efforts surrounding available services for families of children with birth defects.

### Public Health Implications

The results of this analysis will be used to educate providers about services and the importance of referring families. The RIBDP will also continue to educate families on services and supports when conducting service assessments and will bolster its website to provide more information on available resources to families of children with birth defects.

## Rhode Island Birth Defects Program Service Assessment Key Findings



the Rhode Island Department of Health's Birth Defects Program (RIBDP) has been conducting service assessments with families of children with selected conditions.

The results of these service assessments provide the RIBDP with information on whether children are receiving **TIMELY**, **NECESSARY**, and **APPROPRIATE** services and referrals.

Over the last **10 YEARS**, we have increased the number of service assessment conditions from **1** to **8**

From **2016** to **2020**, we conducted **242** service assessments (in clinics and via mail) and **296** repeat assessments.

We made **57** referrals to the RI Parent Information Network (RIPIN) from 2018 through 2020.

### Other referrals frequently made were for:

- Parent support groups
- Early Intervention or Individual Education Plans (IEP)
- Social Security benefits
- Health insurance
- Speech and Feeding Therapies
- Cedar Family Centers
- Section 8 housing
- Childcare for children with special health-care needs

### Gaps identified in the process include:

- The need to increase awareness of and have more parent support groups, since families found these groups to be very helpful
- Issues with obtaining timely referrals to Early Intervention services
- Better support for transitions
- Better follow up from hospitals with referrals to specialists
- Insurance companies not covering needed services

We will continue to use this data to monitor service and referral gaps, identify ways to improve access to services, and educate providers and families.

Thanks for your participation in this program!



HEALTH BY NUMBERS  
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PUBLIC HEALTH

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

KRISTEN ST. JOHN, MPH; DONNA LEE HOULE, CCHW; SAMARA VINER-BROWN, MS



Rhode Island Birth Defects: Let's Lower the Risk

CHHA & RIBDP  
August 31, 2022

# **QUESTIONS/DISCUSSION**





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