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

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

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

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

### Clinical Services

<table>
<thead>
<tr>
<th>Classification: Please check the appropriate classifications that best describe your child's condition.</th>
<th>Cleft Lip and Palate</th>
<th>Cleft Lip Only</th>
<th>Cleft Palate Only</th>
<th>Other:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has Not Received</td>
<td>0-3 mos</td>
<td>4-6 mos</td>
<td>7-12 mos</td>
<td>13-18 mos</td>
</tr>
<tr>
<td>Pediatric Visits: Please check the ages when your child visited a pediatric or family medicine doctor.</td>
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</tr>
<tr>
<td>Nutritional Information: Please check when you received information from a physician or nutritionist regarding your child’s nutritional needs.</td>
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</tr>
<tr>
<td>Specialist and Procedures: Please check the ages when your child received the following.</td>
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<td></td>
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<tr>
<td>Audiology (hearing specialist)</td>
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<tr>
<td>Dentist</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>ENT (ear, nose, throat specialist)</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Neurologist</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Ophthalmologist (eye specialist)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oral Maxillofacial Surgery</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Plastic Surgery</td>
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</table>

### Genetic Test: Has your child received a Genetic Test? | Yes | No | If yes, when? (check all that apply) |

### Genetic Counseling: Did you receive genetic counseling with your child’s diagnosis? | Yes | No | If yes, when? (check all that apply) |

### Parent Support: 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? |
| Rhode Island Parent Information Network (RIPIN) | Yes | No | Not Sure | Yes | No | Not Sure | Yes | No | Not Sure |
| Family Voices | Yes | No | Not Sure | Yes | No | Not Sure | Yes | No | Not Sure |
| Visiting Nurse Association (VNA) | Yes | No | Not Sure | Yes | No | Not Sure | Yes | No | Not Sure |
| Medicaid or SSI/SSDI | Yes | No | Not Sure | Yes | No | Not Sure | Yes | No | Not Sure |
| Katie Beckett | Yes | No | Not Sure | Yes | No | Not Sure | Yes | No | Not Sure |
| First Connections (Home Visiting) | Yes | No | Not Sure | Yes | No | Not Sure | Yes | No | Not Sure |

### Other, please specify:

### Developmental & Educational Services: Was your child referred to and/or has he or she received any of these services? | Referred? | Received? | Was it Helpful? |
| Children’s Neurodevelopment Center (CNDC) | Yes | No | Not Sure | Yes | No | Not Sure | Yes | No | Not Sure |
| Early Intervention (EI) | Yes | No | Not Sure | Yes | No | Not Sure | Yes | No | Not Sure |
| Individual Education Plan (IEP) | Yes | No | Not Sure | Yes | No | Not Sure | Yes | No | Not Sure |
| Occupational Therapy (OT) | Yes | No | Not Sure | Yes | No | Not Sure | Yes | No | Not Sure |
| Physical Therapy (PT) | Yes | No | Not Sure | Yes | No | Not Sure | Yes | No | Not Sure |
| Speech Therapy (SLP) | Yes | No | Not Sure | Yes | No | Not Sure | Yes | No | Not Sure |

### Other, please specify:

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.

<table>
<thead>
<tr>
<th>Location</th>
<th>Date</th>
<th>Please Return Form to:</th>
<th>Code#</th>
</tr>
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<tbody>
<tr>
<td>Rhode Island Department of Health Center for Health Data &amp; Analysis 3 Capitol Hill, Room 407 Providence, RI 02908</td>
<td></td>
<td>Donna Lee Houle</td>
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<tr>
<td></td>
<td></td>
<td>Phone: 401-222-7460 Fax: 401-222-1442</td>
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<td>Questions or Comments, please contact:</td>
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<td><a href="mailto:Donna.Lee.Houle@health.ri.gov">Donna.Lee.Houle@health.ri.gov</a></td>
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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 Service Referral and Receipt by Families of Children with a Service Assessment Condition, Rhode Island, 2017-2021

Percent

- **RIPIN**
  - Referral: 30%
  - Receipt: 93%
  - Helpful: 60%

- **VNA/Home Visiting**
  - Referral: 54%
  - Receipt: 80%
  - Helpful: 98%

- **Medicaid Assistance**
  - Referral: 66%
  - Receipt: 80%
  - Helpful: 100%

- **Parent Groups**
  - Referral: 28%
  - Receipt: 76%
  - Helpful: 96%
Educational and Developmental Support Service Referral and Receipt by Families of Children with a Service Assessment Condition, Rhode Island, 2017-2021

Percent

<table>
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<tr>
<th></th>
<th>Referral</th>
<th>Receipt</th>
<th>Helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>CNDC</td>
<td>42%</td>
<td>93%</td>
<td>92%</td>
</tr>
<tr>
<td>Early Intervention</td>
<td>75%</td>
<td>85%</td>
<td>90%</td>
</tr>
<tr>
<td>Special Education</td>
<td>43%</td>
<td>86%</td>
<td>91%</td>
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</tbody>
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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

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

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

Background

The Rhode Island Birth Defects Program (RIBDP) is committed to improving outcomes for children with birth defects and their families by increasing access to appropriate and timely services. Special and other healthcare services vary to some degree from state to state. In 2018, RIBDP conducted a service assessment and found 11% of children with specific birth defects (e.g., spina bifida) who did not receive any of the services listed in the service assessment program.

Study Questions

• What parent support and educational developmental services are families of children with spina bifida using?

• Do families find these services helpful?

Methods

The analysis involved a service assessment using the percentage of families receiving the developmental and educational services offered by the RIBDP. Information was gathered through an online survey and a review of children’s medical records. The data were analyzed using the Statistical Package for the Social Sciences (SPSS). A significance level of 0.05 was used.

Results

There were 16 completed service assessments for children with spina bifida. Ninety-one percent of children were enrolled in one or more service categories. The follow-up rate was 93%.

The parent support services included counseling, educational services, and support groups. The follow-up rate was 93%.

Public Health Implications

The results of this analysis will be used to educate providers about the services needed by families of children with spina bifida. The RIBDP will also continue to monitor access to service and economic welfare of families of children with birth defects.

Rhode Island Birth Defects: Let’s Lower the Risk
QUESTIONS/DISCUSSION
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