

**Rhode Island Department of  
Health Birth Defects Program**



**Background:**



## Rhode Island Birth Defects Program:

- Identify
- Track and monitor
- Quality Assurance

## Rhode Islands Solution:

**A Two pronged  
Approach**

## Our Solution:

Case Ascertainment

Quality Assurance

## Case Ascertainment:

- **Hospital Discharge Data**
- **Kidsnet:**
  - Birth Records
  - Pediatric Providers
  - Family/Primary Care Doctors
  - Health Clinics
  - Laboratory Reports from Newborn Blood Spots
  - WIC Program
  - Childhood Lead Poisoning Prevention Program
  - Early Intervention Programs
  - Newborn Developmental Risk Assessment
  - Family Outreach Program
  - Hearing Assessment Program
  - Birth Defects Program

## The Million Dollar Question.....

### What is the Rhode Island Parent Information Network

- Founded in 1991, the Rhode Island Parent Information Network (RIPIN) is a statewide, 501(c)(3), charitable, nonprofit organization with a collective programmatic reach that extends to every Rhode Island community, the state's major family-serving systems, schools, associations, and agencies
- Currently employs over 75 individuals
- Last year served over 65,000 families

## RIPIN'S Parent Consultant Program-

**Eligibility:** A Rhode Island parent of a child who is currently or has been, within the last three years, enrolled in a DFH program who is available to work up to 20 hours/week, depending on the availability of funds, and who carries with them a vast knowledge of the system of care within the State of Rhode Island for Children with Special Needs.

## Parent Consultant Objectives:

**Objectives:**

- To strengthen partnerships between families and direct care providers, and between families and their own communities across Rhode Island
- To identify and build opportunities for families of consumers to participate in the design, and implementation of new programs
- To identify the benefits to families participating in DFH programs, as well as barriers to service delivery
- To train parents and family members to be informed spokespersons and effective advocates for themselves and others as it pertains to issues like healthcare, and education.

## Where Are Our Parent Consultants?:

- Children's Neuro-Developmental Center @ Hasbro Children's Hospital
- Memorial Hospitals Children's Neuro-Development Center
- Specialty Care Clinics
- Primary Care Offices
- Local Health Centers

## Quality Assurance:

Birth Defect Parent Consultant at the Department of Health

Manage the Collection of the Incoming Data

Rhode Island Parent Information Network Parent Consultant Program (RIPIN)

Acquire Data



Providers



Families

