Call Me Anything, Just Don't Call Me Late For Dinner!

The evolution of Family Navigation in Rhode Island

How the Department of Health and Community Organizations Built a Unique and Successful System of Support for Families with Children with Special Needs

Presented by:

Making the Connection
The Autism Project

Today's Goals

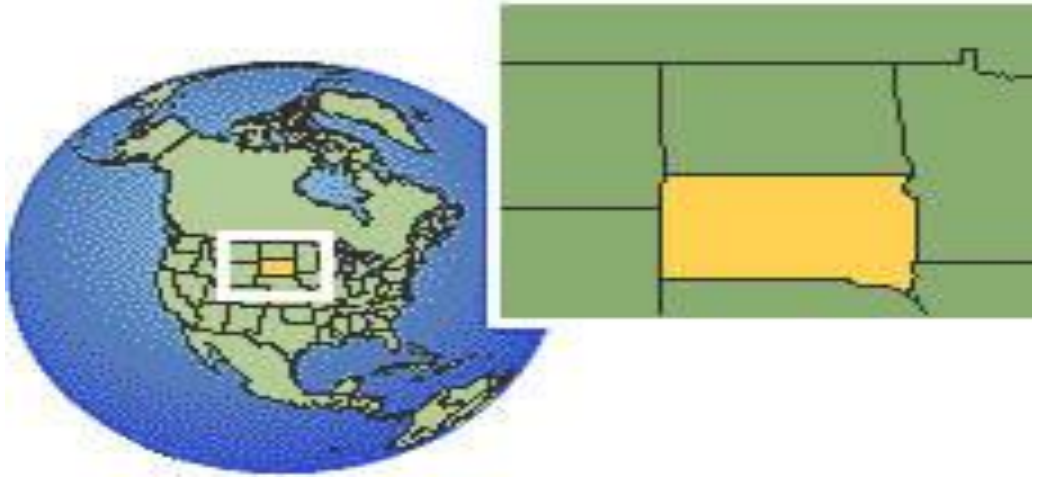
- Learn the evolution of Family Navigation in Rhode Island
  - The Autism Project's Family Support Program
  - Department of Health's PPEP Program
  - RIPIN's Collaboration with Both

Different Approaches, Similar Goals and Results

Making the Connection
The Autism Project

You're From *Where?*

Sometimes being the smallest state in the union is an advantage!



South Dakota	
Population	833,354
Land Area	75,811 Sq. Miles
Persons per Square Mile	10.7

Rhode Island	
Population	1,050,292
Land Area	1,034 Sq. Miles
Persons per Square Mile	1,018

Parents Meet Professionals

- Hired a Parent Support/Voice for new Parent Training Series: *A Starting Point*
  - Parent voice is important and needs to be a part of everything we do.
  - The commitment to Parent-Professional Collaboration
  - 99% Success Rate to Date!
- Wrote a grant/Hired as Executive Director January 2002
- Cheryl Cotter takes on the role as Parent Support for *A Starting Point*
- Products
  - ASP
  - Demo Classroom
  - Summer Institute

the Autism Project of rhode island

The Original Advisory Board

Core Values Continue to Guide Every Move

The Autism Project is a unique collaboration of **parents, professionals and community members** who provide quality support, training, and programming that is accessible to all for children and adults with an Autism Spectrum Disorder, their families and those who work with them.

Sue Baylis Hired as Parent Consultant

Call me anything, just don't call me late for supper!

- Parent Consultant
- Parent Resource Specialist
- RIPIN Parent Consultant
- Parent Navigator
- Family Support Specialist
- Manager of Family Support

Evolution of the Role of Parent Consultant

- Limited Hours
- Limited Funding
  - DOH and RIPIN Support (Moved to RIPIN payroll!)
  - RIPIN Bi-lingual Parent Consultant
- TAP Employee Again!
- RI-CART Support
- East Bay Support
- HRSA!

Taking One for the Team☺

- It's important to embed parent voices to support government on local, regional and national levels.
- Parents should be involved in any committees that are open meeting relating to people with disabilities.
- Ongoing Advocacy
  - RI Autism Coalition
  - DOH/DOE/DHS
  - First Commercial Insurance Bill in RI Legislature
- It's about the relationships.

The Autism Project
Making the Connection

Supporting Families in Consultations

- The role of a Parent Consultants in The Autism Project's work in schools.
- Early Childhood Settings with a cluster of parents
- Supporting a school in educating families on best practices
- IEP meetings to help with adversity
- What happens after the IEP? How to connect with the community?
- Refer parents to Sue for additional support after consult
- Training for families on programs we're doing in school
- Explain recommendations and how to carry-over at home

Sustainability: Cup Cakes and Grant Support

- **Work with RICART (RI Consortium of Autism Research and Treatment)**
  - Added another regular part-time in 2015 for family calls
  - Bi-lingual and culturally diverse parents worked on Per Diem
- **Bristol Rotary Foundation Support**
  - Expand hours in the East Bay through their support and RICART's increased Support

HRSA Grant!

- Allowed for huge expansion
- Proactive vs. Reactive
- Engagement with new and diverse communities
- Reaching more communities in native language
- “Cultural Brokerage” Model
  - CSEA collaboration Pilot

Sustainability

- DOH Community Worker Program
  - Getting a Code! Hopeful to gain sustainability with the certification
  - How to maintain Parent Navigator role vs. Care Manager

TAP's Annual Number of Phone calls, appts., outreach, etc.

1:1 Contact (In-person, phone and email)	Resource Recommendations	Support Groups
1,012	1,032	47

Outreach Impact	Grant Specific Professionals Trained	Grant Specific Family Members Trained
21 Resource Fairs Range of 75 to 750 people	128	140

The Autism Project
Making the Connection

RIDOH and RIPIN PPEP Program

A Collaboration to Support RI Families and CYSHCN

Presented by:

The Autism Project

Program to Bridge the Gap

- Development of a model to bridge the physician practices & community programs & resources
- Provides parent consultant services to primary and specialty care physicians dedicated to serving CYSHCNs and their families
- Pediatric Practice Enhancement Project
- Medical Home project that provides enhancement services in a high quality and cost effective manner
- Family / Client centered approach to health care
- Collaborative care that depends on all partners for success

Project

The Rhode Island Partners

- Department of Health- Health Disparities, Chronic Disease
- Executive Office of Health & Human Services – Medicaid, EI
- Rhode Island Parent Information Network
- Neighborhood Health Plan of RI
- United Healthcare & Optum Behavioral Health
- Family Voices of RI
- Governor’s Commission on Disabilities
- Rhode Island Hospital
- Chronic Care Collaborative, Care Transformation Collaborative
- American Academy of Pediatrics
- All Participating Sites

Participating Practices

- Hospital Based Primary & Specialty Care Clinics
- Federally Qualified Health Centers
- Private Physician Office
- Private Physician Group Practices
- Hospital Based Multi-Disciplinary Evaluation Sites (2)
- Intensive Clinical Services
- Disability Specific Programs: Autism, Asthma, SPMI
- Special Needs Dental Provider
- Special Intervention Teams: Housing, Behavioral Health, Women's Prison, Prevent Child Abuse, Young Parents, High Hospital Emergency Department Users

Making the Connection
The Autism Project

Making the Connection
The Autism Project

Program Evaluation

In 6 years:

- Served 6,500 people with disabilities and/or chronic health condition
- Had 28,094 contacts with participants
- Addressed 12,020 presenting concerns
- Assisted participants in achieving 89% of concerns
- 48 Family / Peer Resource Specialists statewide

Practice Level Evaluation

- Identification of people with disabilities & chronic conditions within practice
- Track and monitor people with disabilities & chronic conditions
- Practitioner productivity
- Comprehensive service delivery / provision

Practice Level Results:

↑ Physician Productivity
↑ Patient Satisfaction
↑ Physician Satisfaction
↑ Comprehensive Care
↑ Knowledge of System
↓ Patient Wait Time
↑ FAMILY / PERSON CENTERED CARE

System Level Evaluation

- Systems Barriers identified and addressed
- Integrated Service Delivery System for people with disabilities & chronic conditions
- Practices Buying-In
- Recognition as a Reimbursable Service!

System Level Results

Improved Care Coordination

Reduce Wait Lists

Increase in Patient / Family Education

Reduce Systems Barriers

INTEGRATED SYSTEM OF SERVICES

Individual Level Evaluation

Individual & Families Outcomes:

↑ Understanding of service system
↑ Satisfaction with care
↑ Feel empowered & supported
↔Change in utilization of health care

What we know when people receive care in a Medical Home:

- Patient & family-centered care is increased
- Patient & caregiver worry & burden are reduced

Care coordination & chronic condition management lead to:

- Reduced emergency room and hospital use
- Reduced redundancy in testing, referral and procedures
- Increased efficiency and effectiveness

Utilization Analysis

Conducted by Alvaro Tinajero, MD, MPH, ScM
Senior Epidemiologist at the RI Department of Health

A comparative analysis of claims and costs between PPEP and other model that do not employ a peer to peer system navigation approach.

Sample Selection:

- 20 participating sites and 1,800 families enrolled
- 1-1-04 to 12-31-07 insured by NHPRI
- 1 month to 18 years of age
- Outpatient, emergency and impatient claims/payments
- SSI/Related insurance used as proxy for identifying CSHCNs in NHPRI claims databases

Utilization Analysis

All Services Summary: 2004 – 2007

- The average number of inpatient, emergency and outpatient encounters per CSHCSs was 14% higher among PPEP participants
- The average number of claims per encounter was 3% lower in the PPEP model
- The average annual payment for all claim types was 15% lower in the PPEP model
- Period and annual claim payments were lower for the PPEP
- Paid claims for resource intensive services were lower for PPEP
- Payments for primary care/preventative claims were higher for PPEP
- Overall, costs per paid claim were $440 lower in the PPEP model
    - 98% of the savings in the PPEP model were through lower inpatient encounters and volume/type of service

Cost Savings Projection

16,173 claims for inpatient stays (non PPEP) X $449.90 = $7,276,232.70

18,565 claims for emergency visit (non PPEP) X $112.20 = $207,928.00

Total - $7,484,160.70

98, 290 claim for outpatient visits (PPEP) X $21.60 = $2,123,064

Total Cost Savings Projection: $5,361,096.70

Embedding Family Support in System

- Parent Consultants have become Certified Community Health Workers
- Cedar Standards revised to include CYSHCN Shared Plan of Care standards
- RIPIN is a Cedar Provider – providing peer led care coordination
- Community Health Teams include CHW / Peer Resource Specialists
- Care Transformation Collaborative include CHWs
- Patient Centered Medical Home Project – Kids (multi-payer medical home investment recognizes parent / peer care coordinators)

Many Programs Filling a Huge Need in Our Community!

Making the Connection
The Autism Project

"Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has." ***Margaret Meade***

Making the Connection
The Autism Project

For more information on Family Support Programming

Susan Baylis, Manager of Family Supports

sbaylis@lifespan.org

www.theautismproject.org/creating-the-connections

1516 Atwood Avenue

Johnston, RI 02919

401.785.2666 ext. 76796

Presented by:

Making the Connection
The Autism Project