Increasing Access to ASD/DD Diagnosis and Intervention Among Medically Underserved Populations: Lessons Learned from Family Navigation, Telehealth/education, and Shared Resources

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Joanne Quinn  
James Mancini  
Gail Chodron

Moderator: Paige Bussanich  
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Integrates care across systems through the implementation of innovative, evidence-informed models

1. Family support and navigation,
2. Shared resources, and
3. Telehealth and/or telemedicine health information technologies.
Working Collaboratively Across Agencies to Create Positive Change for Children & Families

“Building Bridges”
Delaware

Brian Freedman
GOALS

Create a coordinated, comprehensive, family-centered and culturally competent system of care for all young children in Delaware with Autism Spectrum Disorder and other DD.

The Delaware State Plan will be implemented and sustained through coordination and collaboration of all ASD stakeholders in Delaware with emphasis on family participation.
Partners

• University of Delaware Center for Disabilities Studies
• Autism Delaware
• Nemours/Al duPont Hospital for Children
• Delaware Family Voices
• Department of Education
• Division of Public Health
• Birth to Three/Part C
...and more!
Strategies for Collaboration

Monthly stakeholder meetings
  • Project partner updates
  • Discussion of community needs
  • Identify collaborative next steps

Work groups & cross-agency meetings
  • Formation of targeted work groups
  • Small stakeholder meetings for specific goals
Family-Centered Approach

Family Council

• Parents of individuals with ASD

Family participation in program activities

• Monthly stakeholder meetings
• New program development
• Family perspective for trainings
• Focus groups
Key Initiatives

Family-centered practice

Family navigation/coordination

Cross-sector collaboration

M-CHAT-R integration in Primary Care and CDW
Difficult conversations

Autism evaluations at Child Development Watch
Systemic coordination with schools and providers

Project ImPACT across settings
Telehealth intervention
Measuring Progress:

Strong partnership with program evaluation team (UD CRESP)

- Facilitated needs assessments
- Supported partners with evaluating progress
- Tools for disseminating information and results
Nemours Shipley: Early Screening Pilot

MCHAT-R Administrations

- Month 0 (M0): 30
- Month 1 (M1): 23
- Month 3 (M3): 21
- Month 4 (M4): 20
- Month 5 (M5): 17
- Month 6 (M6): 21

Percent of Children 18-37 Months Screened with MCHAT-R

Referrals by Gender

Prepared by the University of Delaware Center for Research in Education and Social Policy (CRES) (I19-011)
Sustainability planning begins early

• Telehealth intervention
• Autism evaluations at CDW
• Third party payment for family navigation
• Continued coordination among stakeholders and leaders

HOW??
• Consideration in the original design
• Buy-in from stakeholders
• Patience!
Meaningful Family Engagement


Rhode Island

Joanne G. Quinn
The Who... there are many members in a family band!

Family Defined

• Nuclear Family
• Caretakers
• Extended Family
• Anyone else the family brings to the table

Professionals Supporting Families
The What… What Do We Do?

Build a community of support and CONNECTIONS

Family Navigators

- Support
  - Community Champions
  - In-person support at office AND in the community
  - Telephone support
  - Groups and Closed Facebook Group

- Education
  - Creating the Connections (Typical Development and LTS.AE. Milestones)
  - Parent to Parent (5-Week Coaching Model Series)
  - 1:1 Education
  - Workshops
  - Facebook Live Training
  - Family Navigators Training
    - Meet Community Health Worker Requirements
    - Extensive training on ASD and related disorders
    - Teach family and community key interventions and supports

- Resources
  - In-depth knowledge on navigating RI Systems of Care
  - RI Medical Portal (RI's Shared Resource)

• Engagements Activities
  - Santa Photos
  - Create and Connect
  - ASD Adult Gatherings
  - Social Media (Promote TAP events and Community Partners’ events)

• Community Events and Outreach

“I always take too long to take down my table and I do it purposefully. I just wait. I try to be the last one to leave because, when nobody else is there, then somebody would approach us and ask questions.” TAP, Family Support Specialist
The When… Determining the Point in Their Journey.

- Newly diagnosed at any age (under 36 months, school age, adult, parent of a child in our programming)
- Referred to us from community or medical community
- Looking for programming, support or resources
- School/Medical issues
- Transition Points (EI to preschool, Middle and High School transitions, Adult World)
- Okay, I’m ready to hear you!

Meaningful Family Engagement
Meaningful Family Engagement

The Where… Meeting the Family Where They Are At!

Assessment of the Family’s State

• Okay, get a pen and paper this is what you need to do!
• One size doesn't fit all, even within a community

Roadmap Tool

• How they can receive information?
• How much information?
• Do they even want information currently?

Listening First

• We have goals, but sometimes listening and building trust goes a long way to establishing a long-term relationship of support and resource sharing if we don’t overwhelm family members.
• “Sometimes I just need to be heard.”
• The phone and your ear are often your best tools of support.

Meaningful Family Engagement
**Caller Assessment Tool**

**NEWLY DIAGNOSED KIDDO**

**How do you feel about the diagnosis?**

<table>
<thead>
<tr>
<th>IM/WE ARE</th>
<th>STOP</th>
<th>SLOW</th>
<th>GO</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ SURPRISED</td>
<td>□ CONFUSED</td>
<td>□ BELIEVED</td>
<td>□ NOT SURPRISED</td>
</tr>
<tr>
<td>□ SHOCKED</td>
<td>□ DON'T KNOW</td>
<td>□ NOT SURPRISED</td>
<td>□ EXPECTING IT</td>
</tr>
</tbody>
</table>

**CONVERSATION STARTERS**

- [ ] RI great place for kiddos with ASD
- [ ] Still the same kiddo, but now we have more information on how he/she learns, perceives the world, & how best to support their independence & success
- [ ] “I have a child w/ ASD and I remember when my child was diagnosed; starting out was one of the most difficult times”

**SOME THINGS TO THINK ABOUT DURING CONVERSATION**

- May not be ready for resources
- Mention support group and benefits of connections
- If fitting mention you have a child with ASD and you know the beginning stage can be difficult
- Email or Mail out information about TAP w/ business card

**YOUR ROLE**

- Connecting & Supporting
- Providing Information Support

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**RESOURCE CHEAT SHEET**

**INSURANCE INFO**

- **KATE BECKETT**
  - Executive Director, Rhode Island
  - How to access Medicaid based on child's needs, not family income
  - The child must meet the medical criteria at risk of hospitalization / institutionalization
  - Acceptance of Medicaid is based on: Self-Care, Safety, & Social Skills

**SUPPORT GROUPS**

- **PARENTS/CAREGIVERS**
  - The Autism Project
  - Johnson, East Bay, North County
  - RI Chapter of ASPEER'S Association of New England Parent Support Group
  - Parents of Miracles Group for families & caregivers of children with special healthcare needs (RIPM)

- **GRANDPARENTS**
  - The Autism Project

**SPECIAL EDUCATIONAL/ INFORMATONAL SUPPORTS**

- **THE AUTISM PROJECT**
  - Parent to Parent: Starting Point, ASIF, Peer-to-Peer, Effective Advocacy & Positive Communication, and more
  - Autism Speaks, Healthy Communities RI, I Can Do It, Autism Speaks, Healthy Communities RI, I Can Do It, Autism Speaks, Healthy Communities RI, I Can Do It

**TRAININGS & WORKSHOPS**

- **THE AUTISM PROJECT**
  - Parent to Parent: Starting Point, ASIF, Peer-to-Peer, Effective Advocacy & Positive Communication, and more

**HOME-BASED SUPPORTS**

- **HIPS**
  - (must have access to Medicaid)
  - (must have access to Medicaid)

- **ABA**
  - Gateway ABA Program

**ADULT SERVICES**

- **AAAE**
  - Parent to Parent: Starting Point, ASIF, Peer-to-Peer, Effective Advocacy & Positive Communication, and more

- **RI Home Portal**
  - (must have access to Medicaid)

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**© January 2017, The Autism Project**
The Why… It’s All About Connections.

Family Navigator vs. Care Coordinator or Professional

- Different kind of relationship
- We can relate, **but don’t make it an “all about me” show!**
- Decrease the feeling of isolation, there are others out there too!
- This happened to you too!
- We’re walking in very similar shoes.
Meaningful Family Engagement

And... HOW we do it!

Personal Contact

- Phone
- 1:1 at TAP or at school (not IEP)
- Small group training
- Large group training
- Community partner sites

Updated Website, The Cloud! Webinars, Social Media, Closed-Facebook Support Group

Lessons learned

- Invest in people vs. Bus ads!
- Work with Community Champions and Advocates
- Multiple Languages
- Bring it to the community
- Cultural training and expectations are ongoing!
What Does SUCCESS Look Like?

Different For Each Family and Family Member

• Better Understanding of Person's Challenges and Strengths
  o More Information to answer, “Why he does that!”
  o Knowledge of the disability’s impact on their functioning across the day
    Example:
    ▪ More than he struggles with Theory of Mind. What??
    ▪ This is what TOM looks like at school and why he’s failing.

• Hang Up and Feel Empowered, Even if Only a Little Bit
  • "I learned something to help me support my son."
  • "I understand the IEP language now. The next meeting will be better as we build my daughter’s school team."

• Decrease Feeling of Isolation

Meaningful Family Engagement
THE FAMILY SUPPORT TEAM’S IMPACT ON THE COMMUNITY

2016-2019

OUR FAMILY SUPPORT TEAM HAS:

SUPPORTED

1,151
Parents

449
Professionals

154
Grandparents/Other

TRAINED

3,170
Parents

Professional Caregivers

CALLED

Made Over

2,000
Support Calls

THE FAMILY SUPPORT TEAM PROVIDES:

- Support for Families
- One-on-One Parent Meetings
- Navigation of Resources
- Parent to Parent Training
- Community Outreach
- Multilingual Parent Support

FAMILY SUPPORT SPECIALISTS:

- Answer the calls of family members who’ve received a new diagnosis.
- Ensure that newly diagnosed families and caregivers are aware of and trained to use the tools and resources available to them.
- Provide training for parents, professionals, and caregivers caring for children with ASD and other developmental disabilities.
“If you ask for something, they would... pull something out of their Mary Poppins’ bag...and handed it to you.”

The Autism Project Family Navigators, 2016-2019
Inclusion of Autistic Adult Perspectives

Moving towards meaningful partnership

Washington

Jim Mancini
Let’s wipe out cancer, diabetes and autism in his lifetime.
Autism 200 Series

- **Autism 211: We Have a Voice—A Panel of Individuals with ASD**, November 20, 2014; Facilitator: Charles Cowan, MD
- **Autism 211: In Our Own Words: A Panel of Adults with Autism Spectrum Disorder**, November 17, 2016; Facilitator: Gary Stobbe, MD
- **Autism 208: Hiding in Plain Sight: Girls with Autism Spectrum Disorder**, September 20, 2018; Instructors: Sara Webb, Ph.D. & Karen Barnes, Ph.D.
- **Autism 210: We are All in this Together: Finding Common Ground between Autistic and Parent Advocates – A Panel Discussion**, November 15, 2018; Facilitator: Zack Siddeek, MSW
- **Autism 206: Transition to Adulthood: “My physical body and mind started shutting down”: Autistic burnout and the costs of coping and passing**, July 18, 2019; Instructor: Dora Raymaker, PhD
- **Autism 210: A Panel Discussion: Perspectives from the Autism Community**, November 21, 2019; Facilitator: Gary Stobbe, MD
INTERGROUP DIALOGUE
LISTEN. TALK. CONNECT.
ECHO Autism Washington will mentor clinicians in the diagnosis and management of autism spectrum disorder (ASD) using case-based learning, didactics, and expert consultation. Program funded by the Washington State Legislature and UW LEND.

LEARNING OBJECTIVES
Increase your ability to use evidence-based strategies to:
- Identify patients at risk for ASD
- Diagnose patients with ASD
- Refer patients for appropriate treatment

WHO IS ELIGIBLE?
Clinicians identified by Washington Health Care Authority as an Autism Center of Excellence (COE), including primary care providers.

WHEN
Dec 11, 2019 - Dec 9, 2020
11:30AM-1PM
Every 2nd and 4th Wednesday via Zoom

* The University of Washington School of Medicine is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians.

The University of Washington School of Medicine designates this live activity for a maximum of 1.5 AMA PRA Category 1 Credits™. Physicians should claim only the credit commensurate with the extent of their participation in the activity (Each session is 1.5 credits).
Moving Forward

• Proactive vs. Reactive Approach
• Listen to and seek to understand others’ perspective
• Opportunities for inclusion
• Identify the differences and try to bridge the gaps
Leveraging Quality Improvement Methods

Wisconsin Care Integration Initiative

Gail Chodron
Leveraging Quality Improvement

Multiple Levels:

- State systems / statewide collaborations
- Community action
- Individual action
Membership has grown dramatically since 2007.
Approximately 55 members representing 38 organizations
What are we trying to accomplish?

How will we know that a change is an improvement?

What change can we make that will result in improvement?

Model for Improvement

- Time-bound, measurable AIM statement
- Theory of Change
- Testing Cycle(s)

Quality Improvement

Act

Plan

Study

Do
State systems – Act Early State Team

• Adopting a QI approach

• Action groups address 2 priorities:
  1) Support the build and promotion of Well Badger Resource Center
  2) Identify strategies for meeting families where they’re at
Well Badger Resource Center
Support is out there. We’ll help you find it.

Attention Wisconsin residents:
- Not sure how to pay for healthcare?
- Need assistance feeding your family?
- Want more resources for your special needs child?
- Would you like help buying new baby supplies?
- Worried your child has autism or delayed development?
- Wondering if you can get a free health screening?
- Looking for assistance caring for a loved one?

Then you’ve come to the right place! Well Badger Resource Center connects you with support that can make a real difference in your family’s health and well-being.

Here’s how it works
When you call the Well Badger Resource Center, you talk with trained information & referral specialists.

Top Taglines:
- Not sure where to turn? Start here.
- You have questions. We find answers.
- Connecting you to the resources you need.
- Support is out there. We’ll help you find it.
- Start Here.
What are we trying to accomplish?

How will we know that a change is an improvement?

What change can we make that will result in improvement?

Model for Improvement

Time-bound, measureable AIM statement

Theory of Change

Testing Cycle(s)
Community action – Equity Action Lab

- 100 Million Healthier Lives
  - Robert Wood Johnson Foundation & Institutes for Healthcare Improvement
- Community-based, locally led

https://www.100mlives.org/
https://changelibrary.100mlives.org/
http://www.ihi.org/resources/Pages/Tools/Quality-Improvement-Essentials-Toolkit.aspx
What is an Equity Action Lab?

**Prep**
- Data Analysis
- Leadership Team Forms

**Action Lab**
- Develop Solutions
- Set Ambitious Goals
- Develop Action Plans

**Sprint!**
- Regular Team Meetings
- 100 days

**Sustain**
- 1-day Momentum Lab
  - Celebrate success
  - Set new goals

Goal Achieved!
Individual action – ECQuIP family navigators

Drive change by mobilizing community partners to address barriers to access.

Help families navigate access to services.

Continuously collect data on service availability as well as enablers and barriers to access.

Family Navigators
Local community members (parents or professionals)
What are we trying to accomplish?

How will we know that a change is an improvement?

What change can we make that will result in improvement?

Model for Improvement

- Act
- Plan
- Study
- Do

Time-bound, measurable AIM statement

Theory of Change

Testing Cycle(s)
Thank you!
Please take a moment to fill out the session evaluation. We greatly value your input!

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