Increasing Access to ASD/DD Diagnosis and Intervention Among Medically Underserved Children: Streamlining Evidence, Strengthening Families, and Empowering Self-Advocates

Moderator: Paige Bussanich

— Brittany Powers
— Bridget Landry
— Joanne Quinn

— Jean-Marie Dymond
— Michelle Hoffman
— Lynn Hrabik
Integrating care across systems through the implementation of innovative, evidence-informed models of 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
Building Bridges

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*. 
Building Bridges

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!
Building Bridges

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
Building Bridges

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
Building Bridges

Key Activities & Progress:

• Increased access to autism evaluations
  – Nemours, DPH, CDW, DOE
  – Ongoing conversations re sustainability planning

• Families connecting with care coordination services at time of diagnosis
  – Autism Delaware, Nemours, CDW, Beebe Healthcare
  – Reimbursable service model, QI: Family interviews
Meaningful Family Engagement

Meaningful Family Engagement

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
Meaningful Family Engagement

The What… What Do We Do?

– Build a community of support
  • Family Navigators
    – Support
      » In person support
      » 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
      » FB Live
    – Resources
      » In depth knowledge on navigating RI Systems of Care
      » RI Medical Portal
  • Engagements Activities
    – Santa Photos
    – Create and Connect
    – ASD Adult Activities
    – 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
Meaningful Family Engagement

The When... Determining the point of their journey.

• Point in Journey
  – Newly diagnosed (under 36 months, school age, adult, parent of a child in our programming)
  – Referred to us from community or medical community
  – Looking for programming
  – 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

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!

• Roadmap Tool
  – How they can receive information
  – How much information
  – Do they want information

• 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

The Why… it’s all about trust.

- Family Navigator vs. Care Coordinator or Professional
  - Different 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 the same 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

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

• Lessons learned
  – Work with Community Champions and Advocates
  – Multiple Languages
  – Bring it to the community
  – Cultural training and expectations are ongoing!
Meaningful Family Engagement

*What Does SUCCESS Look Like?*

• Different for each family and family member
  – Better Understanding of Child’s Challenges
    • More Information of “Why he does that!”
    • Knowledge of the disability’s impact on their functioning across the day
      – For 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
  – Decrease Feeling of Isolation
“If you ask for something, they would... pull something out of their Mary Poppins’ bag... and handed it to you.”
Bridget Landry, MA  
TAP HRSA Manager  
blandry@lifespan.org

Joanne G. Quinn, BA  
Executive Director  
jquinn5@lifespan.org

www.theautismproject.org  
1516 Atwood Avenue * Johnston, Rhode Island  02919
Inclusion of Autistic Adult Perspectives

Moving towards meaningful partnership
Grant Activities

- Intergroup Dialogues
- Peer-to-Peer 2018
- WAAC 2018
- Policy ad hoc committees
- CARES 2018 - Ableism presentation
Wisconsin Care Integration Initiative
Lynn Hrabik, MPH, RDN

- QI vs traditional evaluation
- Why QI?
- Levels of QI implemented
- How we made it happen
- What worked?
- What didn’t work as well?
Design parent education curriculum

Provide 6 interactive training sessions with handouts

Targeted parents attend

Parents increase knowledge of child development

Parents use improved parenting skills

Parents learn new ways to discipline

Reduced rates of child abuse and neglect among participants

KEY EVALUATION QUESTIONS

Were the inputs sufficient, timely?

Was the curriculum produced? Were all 6 sessions delivered? How effectively?

Did all parents attend that we intended? Who did/did not attend? Did they attend all 6 sessions? Why/why not?

Did knowledge increase? Did they learn new approaches? What happened?

Are parents actually using improved skills? So what? What difference do these skills make?

Has there been a decrease in rates among participants? Were goals met?

Are assumptions correct?

- Do parents attend as anticipated?
- Does knowledge change lead to behavior change?

Were there any local events that kept parents from attending?
**Accelerate Learning & Improvement**

**AIM:** What are we trying to accomplish?

**CHANGES:** What changes can we make?

**MEASURES:** How will we know if it is an improvement?

**CYCLES:** How can we test if we are on the right track before moving full speed ahead?

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Implement a part of a process and test

Modify the process and test

Include additional parts of the process and test

Source: Model for Improvement from The Improvement Guide, API
Engaged Community Quality Improvement (ECQuIP) Sites

Northwoods ECQuIP (rural)
Southwest ECQuIP (rural)
Milwaukee ECQuIP (urban)

Wisconsin Care Integration Initiative (WiCII) Leadership and Implementation Staff

WI Act Early State Team
What’s the smallest thing we could try that would have the biggest impact?
TRAINING

PRACTICE

APPLY

REVIEW
# ECQuIP Debrief

<table>
<thead>
<tr>
<th>Record ID</th>
<th>Act Early State Team meeting 11-7-18</th>
</tr>
</thead>
<tbody>
<tr>
<td>NOTE: This form is meant to be used when an external meeting or event is hosted, or when a presentation/training is conducted.</td>
<td></td>
</tr>
<tr>
<td>Brief description of event/activity:</td>
<td>November Act Early State Team Meeting</td>
</tr>
<tr>
<td>Date of event/activity: Enter as month-day-year.</td>
<td>11-07-2018</td>
</tr>
<tr>
<td>Audience of event/activity:</td>
<td>Act Early State Team meetings</td>
</tr>
</tbody>
</table>

### What new information did we learn during the event/activity?
- others learned new information
- Adults from other grant that we could connect to our groups (Molly Cooney’s presentation)
- More happening at Well Badger than we knew about
- great responses to their survey

### What worked well? (i.e. If we did this again, what would we do the same?)
- The range of people who shared information was good
- Space worked well
- Successfully adjusted the schedule
- Worked to have lunch embedded in the activity
- Getting presenter slides well in advance of the preso so that we can redirect if need be
- Gail did a nice job of making the connections between all the speaker’s presentations and the work of this group

### What didn’t work well? (i.e. If we did this again, what would we do differently?)
- A couple of the groups were initially confused about where to start/what to do when they started the group work
- Bringing new people up to speed was a little difficult
- Only one other person brought resources for the table
- People were talked at until 11:20a - but did they mind?
- Hard when starting with new group each meeting; 80 minutes to agree upon an action with little scope was difficult - maybe pre-assign roles

### What will we do differently before/when we complete a similar event/activity?
- Better task clarification at the start of group work (add a question or prompt to help frame it - what’s the smallest thing we could do to make the biggest change); continual reiteration of how can we go smaller?
- Remind them of the QI process
- Should we make work groups even smaller next time?
- How do we work in more group time? (Always end up talking at the group a little too long)
- add a host role at each small group (someone outside of our team) - make sure everyone talks
Northwoods ECQuIP | BAR-AAR | DATE 1/3/19

Brief description of event/action: Feb 1, 2019 Community Conversation
Framing question(s): How do we create community awareness of what families experience when trying to obtain a diagnosis and/or services for autism in the Northwoods? How do we garner commitment to action on improving the system?

<table>
<thead>
<tr>
<th>BEFORE ACTION REVIEW</th>
<th>AFTER ACTION REVIEW</th>
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</thead>
<tbody>
<tr>
<td>Date of BAR: 1/3/19</td>
<td>Date of AAR: 2/?/19</td>
</tr>
<tr>
<td>Participants: Jenny Felty, Cory Dart, Kari Mueller, Lynn Hrabik</td>
<td>Participants:</td>
</tr>
<tr>
<td><strong>What are our intended results?</strong></td>
<td><strong>What were our actual results?</strong></td>
</tr>
<tr>
<td>• Engage families from Parent Café into planning/hosting event</td>
<td>•</td>
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<tr>
<td>• Garner participant commitment (advocacy, funds, time) to do one small thing to improve the system</td>
<td>•</td>
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<tr>
<td>• Increased community awareness of what families experience (i.e. their struggles navigating the system)</td>
<td>•</td>
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<tr>
<td>• Get connected to families that don’t know about ECQuIP but need the support</td>
<td></td>
</tr>
<tr>
<td><strong>What will that look like?</strong></td>
<td><strong>What caused/contributed to these results?</strong></td>
</tr>
<tr>
<td>• Families in leadership roles (planning event, making personal invitations, table hosts, etc.)</td>
<td>•</td>
</tr>
<tr>
<td>• Diverse participant attendee list (families impacted by autism, healthcare providers and/or clinic managers, public health, Birth to 3 Program Supervisor and/or line staff, school district Early Childhood Special Ed programs, childcare directors, CYSHCN regional center staff, Autism Society staff, United Way, large industry/business, faith-based leaders, family support providers, civic orgs such as Lions/Kiwanis/Rotary, elected officials and media)</td>
<td>•</td>
</tr>
<tr>
<td>• A list of participants identified in each county/community (including partners that haven’t been engaged before) with stated commitment to putting time and energy towards this effort; advocacy, funds and/or time</td>
<td>•</td>
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<tr>
<td>• # of new family navigation referrals</td>
<td>•</td>
</tr>
<tr>
<td><strong>What challenges might we encounter?</strong></td>
<td><strong>What will we sustain or improve? (If we could turn back the clock, what would we do differently?)</strong></td>
</tr>
<tr>
<td>• Low attendance</td>
<td>•</td>
</tr>
<tr>
<td><strong>When is our next opportunity to test what we have learned?</strong></td>
<td>•</td>
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</tbody>
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Family Navigation Services Protocol Flowchart v3.0

for families consenting for enrollment in FN services following concerning ASD screen result

1. Conduct Enrollment Home Visit(s)
2. Complete Enrollment Documents
3. Complete Family Needs Assessment
4. Enter data into REDCap
   - Do family needs require additional community supports?
5. Complete Family-Centered Care Plan
6. Does child have a developmental assessment completed?
   - Yes
     - Has child had a medical assessment completed for ASD diagnosis?
       - Yes
         - Facilitate scheduling of diagnostic assessment with medical provider
       - No
         - Provide additional resources and supports until appointment(s) completed
   - No
     - Facilitate referral to Birth to 3 or Child Find based upon age of child
     - No
       - Refer to appropriate Community Partner based on need
   - Yes
     - Reassess family needs regularly and again prior to closure

7. Connect family to needed services and supports
Reflection
what worked
Thank you!
Please take a moment to fill out the session evaluation. We greatly value your input!

Paige Bussanich
pbussanich@amchp.org

Brittany Powers
bblument@udel.edu

Bridget Landry
Blandry@Lifespan.org

Joanne Quinn
Jquinn5@Lifespan.org

Jean-Marie Dymond
jean-marie.Dymond@doh.wa.gov

Michelle Hoffman
Michelle.Hoffman@doh.wa.gov

Lynn Hrabik
hrabik@wisc.edu