

“Conversations that Matter” Open Space Notes

Strand: Increasing Equity

Group Interests

- Access, Privilege, Community providers, Transition, Autistic representation, Social model of disability

Meaningful Inclusion of Self-Advocates

- Community organization challenge (looking at self-advocates in a broader perspective)
- Families are the primary educators, but children also have perspective and grow into leaders
- How to build trust with families to accept services?
 - Fee for Service models; building partnership from day one – a couple of key people that families deal with for real heart-to-heart conversations (trust and transparency)

Disparities in Diagnosis/Treatment of Autism across Race

- “You met one person with autism. Congratulations, you met with one person with autism.”
- DSM criteria is based off white male child and not representative of general population
- Medical interactions matter: how can clinicians, families, pediatricians identify autistic children properly with current diagnostic criteria?
- Pediatricians and clinicians are white; this impacts interaction between pediatricians/clinicians, and families (families don’t challenge pediatricians because they are viewed as all-knowing)
 - Organizations to help families figure out what to ask PCPs/how to confront
 - Pre-work for families before appointments re: speaking up/sharing information
 - Payers (not just providers) should help develop flexible models that meet community needs

Safe Places that Welcome Self Advocates

- How to include more self-advocates/voices that are part of transition without placing all responsibility on them? Items to consider:
 - How is person is compensated (fairly) for emotional labor; building trust is key (can be a long process, i.e. 5-6 years); need a training group; safe and inviting space for diverse voice (struggle with making invitation – appropriate environment first)

Overcoming Challenge of “Not Doing Enough”

- You learn more when you don’t achieve your goal than when you do
- Appreciate steps made (when you’re in your work, it’s hard to see positives because its often small; it comes down to perspective in relation to “achieving a desired outcome” so think about the growth along the way)
- Systems work is not for you if you want instant gratification
- Always have someone as a sounding board that can add perspective to process and build in feedback (community ambassador)

Equity Measures

- Measures are insufficient and doesn’t tell us what we need to do for this work
- Needs: transition measure; change in provider culture (survey); address issues that aren’t currently being taught or advocated for; consumer friendly evaluation tools that encourage participation and trust; transparency for families re: data collection

Strand: Achieving Population-Level Outcomes

What population level outcomes are you trying to achieve?

- Increasing screening and access to treatment
- Trying to address many outcomes at the same time (next steps/improvement opportunities)
- Public Health framework (think about systems-level impact, which can be hard for clinicians)

What question would you want answered to help achieve population-level outcomes?

- Age of diagnosis – worry about outcomes for those who aren't receiving timely EI
- Features (behavioral/medical comorbidity) of kids with diagnoses to help with pre-screening
- How long is the waitlist to get a diagnosis for autism
- If parents indicated concerns vs. providers did not listen
- How often the responsibility of diagnosis is transferred to someone else who may not be trained

Changes/considerations to impact population-level outcomes

- Screening and diagnosis process
 - Culture in early intervention (improve evidence base)
 - Including girls in the diagnostic criteria
 - Tracking autism with other comorbidities (e.g. mental and behavioral health, deafness)
 - Screening matters – data shows that families mentioned no developmental concerns until day screening failed (telling us something but don't know why)
- Access (kids are on waitlist for diagnosis, then another waitlist for ABA and other services)
 - Figure out who needs to jump the line vs. “watch and wait”
 - 6-9 month wait for children <3 years (the system is overwhelmed)
 - Figure out which models of treatment work best for certain kids
- Integration
 - Medicaid/insurers will pay for ABA, but only for autism
 - PCP thinks EI should provide diagnosis, so often will refer and rely on EI, but families often don't have EI
- Provider Training
 - Pediatricians are nervous about diagnosis conversations; they feel unprepared, but don't know what to do
 - Teaching and training as a means of addressing population challenges
- Consulting and Working with Education Systems
 - Education/school team need to be part of the diagnostic process
 - Create connections – different agencies, different providers, balance of partners
 - Interested in school readiness (preschools aren't equipped to meet the needs of children with autism and other disabilities)
- Inequities
 - Access standpoint – partnerships with EI; physicians will participate in screening and EI
 - Take the physician-EI partnership model and apply to rural EI team for telehealth so kids 0-3 can get service
 - Pediatric provider relationship with Navajo population via telehealth
 - ABA services – letters is sufficient for Medicaid provider letter is sufficient but other insurers require additional documentation