ASD Workgroup- Early Identification and Referral
Notes 9/1/15 in RED

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Facilitator: Sharon Flanagan-Hyde
Note-taker: Theresa Gonzales

Early Identification & Referral Work Group Key Questions

1. What are the areas of focus of this work group?

- Screening and assessment
- Referrals to providers who can diagnose ASD
- Secondary screening prior to formal diagnosis
- Communication and coordination between PCPs and intervention providers

Notes: Group confirms the areas in this section are correct.

2. What do we collectively know about each area of focus?

- **Screening and assessment**
  - We need to define more clearly what we mean by screening and assessment.
  - Difficult to determine what is and is not an appropriate referral. An assessment is needed once a referral is made. There may be a need for a secondary screening. The diagnosis process gets bottlenecked because of lack of providers able to officially/legally diagnose for ASD.

Notes: Clarify the 2nd bullet:

- One person said, once a diagnosis is made, there shouldn't be a need for another screening. The screening is to investigate a concern; it is not a diagnosis.
- Hopefully pediatricians are doing M-CHAT (most don't do the follow up interview), so the secondary screening would screen out the kids who do not have autism. The child who is at risk for autism at the second screening would go to the top of the list for a full diagnosis.
    - U of A has a program to improve accurate screening. Several of the clinics are doing well. Went from 0 to 98% and getting good referrals from Yuma. So could do things to help practices do the screening and use the follow-up interview to make it more accurate vs. checking a box.
        - Could we develop this over time? Concern that doing too much at one time creates additional bottlenecks. And there needs to be an adequate network to support that.
- The 2nd screening is a way to prioritize. It doesn't diagnose.
- The screening indicates that a child may or may not have this or that. Then they go on to an assessment by a qualified person

- There are not enough providers to conduct the 2nd screening.
- Initially, we should focus on removing barriers for families getting care. When PCP has child and there's a strong change the child has autism, should be able to make direct referral to diagnosis so treatment can begin.

➢ **Referrals to providers who can diagnose ASD**

- A key issue is how quickly a child can get an appointment with a provider who is able to diagnose.
- Because the provider network is limited and a barrier to diagnosis, need to consider other provider types who, with specialized training, could diagnose and have diagnosis accepted by DDD. (Network Capacity Work Group also is addressing this.)
- DDD requires that a psychologist or psychiatrist make an ADS diagnosis. (Exceptions have been made to allow diagnoses made by developmental pediatricians.) AHCCCS acute care does not have this psychiatrist/psychologist limitation for diagnosis; instead, AHCCCS makes services available if they are deemed "medically necessary."

  Notes: DDD statutes indicate that only a psychologist or psychiatrist can make a diagnosis. But there are unofficial exemptions allowed by DDD currently in place.
  - If diagnosis is from psychologist/psychiatrist wouldn't need to go to medical review by DDD.
  - If diagnosis is from a developmental pediatrician, needs medical review. See "Intro to DDD" publication.

  Recommendation: Statute needs to be broadened to allow developmental pediatricians to diagnose.
- Assessment that includes preliminary diagnosis. Need to determine if intermediate steps could be started before a formal diagnosis.
- STAT-MD is one tool; should consider others. [See UpToDate *Screening tools for autism spectrum disorder* in Dropbox]

Notes:
- "Intermediate steps": other non-ASD-specific protocols can be done regardless of whether there is an ASD diagnosis. For example, PT, OT, ST, etc. is an identified need. Should be occurring in the system already.
- Some kids are getting PT, OT, ST, etc. and don't get ASD diagnosis. Should improve the way info gets back to PCP (see next section re communication/coordination below)

➢ **Communication and coordination between PCPs and intervention providers**

- Communication and coordination with PCPs is critical, especially when referral comes through AzEIP.

Notes: Ideas on way to improve:

- Become more familiar with BH system and process.
- Each family has a team lead paid to coordinate services with doctor.
- Need feedback and put processes in place to help close the loop.
- For Medicaid, could be another supplemental document re services.
- Currently have good process w/ AHCCCS and has ISP services and process to communicate. Over 53% of kids in AZIPs are on AHCCCS.
- Quarterly progress reports should be sent to doctors. As long as there is permission from family info can be shared.
- BH and acute systems are segregated. HIE will help but in the meantime, one-pagers are very helpful w/ info on: who it is, diagnosis, and things that are being worked on to cover essential items doctors should be aware of. Needs to be simple to read through really fast.

Screening and Assessment: STAT-MD, M-CHAT to separate kids with ASD and not.

Referrals to providers who can diagnose

3. What data do we have?

AHCCCS Data

Revised one-page handout from August 12 ASD Advisory Committee meeting on *AHCCCS ASD Prevalence* and *Developmental Screenings*.

- Question re code used. Clarified that data pull focused on 96110.
- Explained that for individuals covered by private insurance, their claims data would not be captured here.
- Explained this only captures Medicaid members.
- Explained Performance Improvement Project (PIP) around this to increase the number of screenings occurring at pediatrician's office. For the PIP, baseline numbers have been run and plans will be doing interventions to increase these numbers.

- Point made by Committee member that pediatricians should be paid for their time for conducting the screenings.

Eligibility of Individuals with Autism

- Early Periodic Screening Diagnosis Treatment (EPSDT) – Children qualified for Medicaid and eligible for EPSDT coverage to age 21.
- 9,160 Individuals with Autism Served by DDD (27% 0f Total DDD population)

- **DDD state funded** (DD only) – Meets the eligibility requirements for enrollment in the Division per R6-6-302[1] The person does not qualify for any Medicaid services – neither acute nor long term care.
- **Targeted Support Coordination** (TSC) – Meets the eligibility requirements for enrollment in the Division per R6-6-302. The person qualifies for Medicaid acute services - not long term care. AHCCCS reviews functional needs and financial eligibility.
- **Arizona Long Term Care System** (ALTCS) – Meets the eligibility requirements for enrollment in the Division per R6-6-302. The person is considered at risk for institutionalization and eligible for HCBS.

ALTCS members by Autism diagnosis and Age as of 6/30/15

Age Range	Autism Diagnosis Count (ALTCS)
00 - 02.9	32
03 - 05.9	581
06 - 17.9	5,536
18 - 21.9	872
22 - 44.9	1,153
45+	129
Total	**8,303**

Non-ALTCS members by Autism diagnosis as of 6/30/15

(Total Autism N= 857)

Primary Diagnosis	Targeted Case Management	DDD State-only
Autism	403	454
DDD Non ALTCS Totals	**4,281**	**3,220**

[1] A person must have a developmental disability before the age of 18, attributable to a cognitive/intellectual disability, cerebral palsy, epilepsy or autism with substantial functional limitations in three or more of the following:

- Self-care: needing help with eating, hygiene, etc.;
- Receptive and expressive language: needing help with communicating with others;
- Learning: needing help with acquiring and processing new information;
- Mobility: needing help with moving from place to place;
- Self-direction: needing help with managing personal finances or making decisions;
- Capacity for independent living: needing supervision or assistance on a daily basis; and/or
- Economic self-sufficiency: not being financially independent.

Non-ALTCS by Autism and Age

Age Range	Autism Diagnosis Count (Non-ALTCS)
00 - 02.9	40
03 - 05.9	169
06 - 17.9	520
18 - 21.9	132
22 - 44.9	122
45+	13
Total	**996**

4. What data do we need to obtain?

- Can we determine how quickly screening, referral, and assessment take place?
- Can we determine frequency with which children get PT, OT, and ST referrals?

  Notes: Want to know kids who are NOT getting screened for 96110, and are receiving BH, PT, OT and ST.
- What is the percentage of PCPs engaging in ASD screening? (Concerns about very low utilization of 96110 code)

  Notes: AHCCCS is pulling this data plus 12 months of data to see if referred for BH, PT, OT and ST.
- What services are covered by AHCCCS acute care?

  Notes: All medically necessary services. Look at TriCare list of services and how the process is organized. Depends on where you are located. Contact Dr. Tramsky for info. Works for providers.
  http://www.tricare.mil/Plans/SpecialPrograms/ACD.aspx
- Obtain best practices from other best states and national best practices to educate providers and improve the assessment process, thereby impacting the system more broadly.
- Need to ensure that providers are screening, identifying and referring appropriately—providing alternatives between referring and identification—providing intermediate paths between identification and official diagnosis.
    - Consider secondary screenings that are more in-depth to help rule out one diagnosis over another. Utilize STAT-MD (see information below) out of Vanderbilt and Australia – general PCPs can be certified to use, which gives more information.

  Second Stage/Level 2/Intermediate ASD Screens
    - STAT-MD: http://vkc.mc.vanderbilt.edu/vkc/triad/training/stat/physicians/

- Stone, Wendy L., Elaine E. Coonrod, and Opal Y. Ousley. "Brief report: screening tool for autism in two-year-olds (STAT): development and preliminary data." *Journal of autism and develop ental disorders* 30.6 (2000): 607-612.
- Stone, Wendy L., et al. "Psychometric properties of the STAT for early autism screening." *Journal of autism and developmental disorders* 34.6 (2004): 691-701.
- ADEC (Autism Detection in Early Childhood): https://shop.acer.edu.au/acer-shop/group/ADE Dix, Leigh, Rachael Fallows, and Glynis Murphy. "Effectiveness of the ADEC as a Level 2 screening test for young children with suspected autism spectrum disorders in a clinical setting." Journal of Intellectual and Developmental Disability 40.2 (2015): 179-188.

- Look at Ohio's Interagency Work Group on Autism: http://www.iwg-autism.org/

  Notes: MMIC to look at what info MMIC might have.

5. What insights do we have that flow our collective knowledge and the data?

- There needs to be coordination between PCPs and early intervention providers. We don't have an easy way to access medical records and determine the tools used by providers. There is a concern that providers may not be using the most current version of M-CHAT and other tools.
- PCP may be deterred from screening due to cumbersome billing requirements.
- When screening by pediatrician indicates a child is at risk, it is not clear to the pediatrician's office staff where they should send the AHCCCS member. This slows down the diagnosis.

Notes: This is difficult to address because of staff turnover. Need to find a way that takes turnover into account.

- When referrals come through AzEIP, pediatricians often discontinue involvement, in varying degrees, in the follow-up process. The PCP and other provider types need to communicate to ensure collaboration and appropriate treatment.
- One Committee member (Dr. Robin Blitz) discussed a grant project for STAT-MD training. This is a small pilot. It is not the full 5-month training but Dr. Blitz said it does offer reliable training for pediatricians. Arizona law limits the provider types that can diagnose autism. Project will offer more training to those provider types and expand the number of providers competent and confident to make an ASD diagnosis. Goal is to expand diagnosis and allow those providers to offer a medical home. A medical home specialist will go to these pediatric practices to help the pediatrician establish medical homes. In the past, developmental pediatricians could offer diagnosis but only because of a DDD rule change. She said that this can be expanded to include these specially trained providers.
- Communication, training, and education are needed to ensure timely care.

- Assess and intervene early—autism comes in multiple variations across a spectrum—may be difficult to identify and treat beginning at an early age.
- "Watch and wait" is a reoccurring problem.
- Parents may be confused; may not understand tht an assessment is not the same as an official diagnosis. Need to clarify the next steps following an evaluation, assessment, and diagnosis, and who is responsible for providing each.

- Need to redefine and clarify "evaluation" and AzEIP's role in the AMPM (AHCCCS Medical Policy Manual). Problems may be fixed by clarifying the policy at the front end.

  Notes: Current AMPM doesn't specifically speak to this. There is confusion about "screening, assessment, diagnosis, evaluation, etc." There should be clear and consistent terminology to reduce confusion.

  Action: Create a crosswalk of terms to assist families. Would also help understand who does what.

6. **What draft recommendations related to our areas of focus do we want to bring to the full Committees that would strengthen the health care system's ability to respond to the needs of AHCCCS members with or at risk for ASD, including those with comorbid diagnoses?**

[Insert]

7. **How is each recommendation consistent with our Guiding Principles?**

[Insert]

8. **What outcomes measures do we suggest for each recommendation?**

[Insert]

OTHER ITEMS THIS GROUP SHOULD WORK ON?

Notes:

Q: Can diagnoses through DDD only be done by psychologist and psychiatrists?

A: Yes. But DDD has exceptions to allow for some diagnoses by developmental pediatricians. Rural areas have had success using pediatric specialists (neurologist) in addition to psychologists and psychiatrists. Especially since network capacity is an issue. In Nogales, telemedicine is used due to the lack of psychologists and psychiatrists. The idea of using neurologists is good, but they usually refer out because they don't feel comfortable diagnosing when it's not a clear case. Would not want to force neurologists to make diagnoses they are not comfortable making, but they should be given them the ability to make the recommendation when they are comfortable doing so.

THOUGHTS ON HOW THIS ALL TRANSLATES INTO RECOMMENDATIONS:

- Diagnosis limitations are on the DDD side and not a barrier on the rest of the Medicaid side. In Medicaid, primary care physicians can refer to make the diagnosis. AHCCCS doesn't have such restrictions.
- For DDD, expand categories of providers to include developmental pediatricians and consider expanding to child neurologists. Other providers for consideration? General pediatricians do not have the time.
- Align language and policies re screening, assessment, and evaluation across organizations to align how the terms are used.
- Look at TriWest process to improve communication and place on organizations' websites to walk families through how to get services.
    - Create a comprehensive process (roadmap) that outlines all of the doors they can come through for services.
    - Also include a path for providers.
    - Dr. Rice working at County level (Santa Cruz, Safford, etc.) on navigation maps and will share what they have so far. Will send to Sharon.
- Create an easy checklist/form so that all providers on a care team can have the same info until HIE is fully implemented.
- Improve the role of RBHAs- Referring to RBHA for diagnosis. Need to ensure that RBHAs understand the process. Education and communication.
- Keep everything simple and have a streamlined process. Then evolve from there for ALL workgroups including the larger one.

Next workgroup meeting 9/29 (801 building), same call-in #

Next full committee is 9/9 (701 building)

ACTIONS

- Don will see about MMIC data and will obtain info about local TriCare experiences
- Sydney will also ask about local TriCare experiences