ASD Advisory Committee Meeting

Session 3

August 12, 2015

Agenda

- Review of intention and logistics
- Data requests
- Work group activities: review and discussion
  - Overlaps? Opportunities for collaboration?
- Next steps before Sept. 9 Committee meeting

Charge to Committee

- Articulate a series of recommendations to the State for strengthening 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.
  - Focus on individuals with varying levels of needs across the spectrum, including those who are able to live on their own and those who may require institutional levels of care.
  - Address early identification of ASD and the development of person-centered care plans.

Line of Sight

Timeline

- Develop recommendations through facilitated monthly Committee meetings and Work Group activities from June through December 2015.
- Full Committee will meet Wednesday afternoons, 3:00-5:00 p.m.
  - September 9 (2nd Wednesday)
  - October 28 (4th Wednesday)
  - November 18 (3rd Wednesday)
  - December 16 (3rd Wednesday)
- Present recommendations to Christina Corieri, Policy Advisor for Health and Human Services, Office of the Governor, in January 2016.

State of Arizona Intentions

- Break down silos in health care.
- Drive value-based purchasing efforts that reward quality over quantity.
- Bring together behavioral health and physical health.
- Reduce burdens on families of children with special health care needs in the CRS program.
- Coordinate care for people with behavioral health needs that interface with the justice system.
- Align care for dual-eligible members.

Sharing Information

- Dropbox Issues
  - Some employers block Dropbox access
  - Dropbox will continue to be used but will be augmented with e-mail to share documents

- All meeting agendas, materials, notes, and updates for the full Committee and Work Groups will be posted at:

http://www.azahcccs.gov/shared/ASD.aspx

Principles to Guide the Work

Committee members reached consensus that the following principles will guide the work of the full Committee and Work Groups:

- Work toward action items in a strength-based, positive way.
- Keep recommendations as simple as possible.
- Include members at risk for ASD as well as those with a diagnosis.
- Keep discussions and recommendations:
  - Person- and family-focused
  - Culturally sensitive and competent
  - Evidence-based
  - Data-informed
  - Informed by best practice
  - Cognizant of network sufficiency considerations
  - Focused on building capacity
  - Cognizant of AHCCCS merging physical and behavioral health.

Principles to Guide the Work

- Ensure compliance with the Medicaid EPSDT requirements.
- Focus on optimizing outcomes (when possible, measurable outcomes).
- Seek innovative, system-level change with optimism, recognizing that Arizona's Medicaid waiver allows flexibility and that barriers and systems can be changed.
- Work toward collaboration among all entities and stakeholders, including other provider networks.
- Each Work Group is tasked with incorporating outcomes measures in their recommendations.

Group Norms

- Help create an environment that allows all to speak freely and without concern:
    - Listen with an open mind and a collaborative mindset.
    - Speak concisely and respectfully.
    - One person speaks at a time, as called upon by the facilitator.
- The full Committee focuses on the overall goals—details and tactics will be handled by Work Groups.
- Stay focused on the topic at hand and self-monitor to avoid tangents.
- When expressing agreement with other speakers, don’t use up time repeating what has been said.
- Work towards consensus on recommendations.

Data Requests

- Adults with ASD work group obtained data from DDD on ALTCS and non-ALTCS autism diagnosis counts by age range, and additional information on DDD adult residential and employment options for individuals with autism.
- Additional data requests by work groups are being consolidated for submission to AHCCCS and DDD.
- If a work group needs data that have not yet been mentioned in a meeting, send an e-mail to Sharon with the data request.

Work Group Meeting Calendars

- Intention is for all five groups to get a monthly meeting on the calendar for September through December.
- Reducing System Complexity Work Group calendar has been circulated.
- In process of creating calendars for other four groups.

Work Groups

1. Early Identification & Referrals for Diagnosis
2. Reducing System Complexity
3. Evidence-Based Treatment
4. Building Network Capacity
5. Adults with ASD

Early Identification & Referrals

- Screen, identify and refer appropriately.
  - Provide alternatives in the pathways between identification and official diagnosis.
  - STAT-MD provides more in-depth diagnostic information.
- Diagnosis is the most challenging piece of effectively treating ASD because once child is referred, the system slows down.
- Ensure that the most current version of M-CHAT is used for follow up.
- Communication and coordination with PCPs is critical, especially when referral comes through AzEIP.

Reducing System Complexity

- PCPs' lack of awareness & confusion about entry points, eligibility, and how the system operates result in delays in evaluation and treatment:
    - PCPs are confused about how to utilize RBHA services for evaluation for ASD.
    - There is a shortage of developmental pediatricians available to AHCCCS members.
    - Confusion about psychologists and psychiatrists evaluating for ASD.
- Confusion about process for AzEIP-enrolled children who are DDD-eligible to get into DDD.
- Once in DDD, confusion about process to get ALTCS and what to do if the member does not qualify for ALTCS.
- Need for greater payor and provider communication and clarity.
- Need for integrated care coordination.

Evidence-Based Treatment

- ASD is a spectrum — there is not a “one size fits all” treatment approach.
- ABA includes variations; different approaches may be more or less appropriate for different individuals.
- Behavioral manifestations (e.g., aggression) should result in further evaluation of a possible underlying medical condition — comorbidities are common.
- A “whole person” approach integrates ASD manifestations, behavioral health, and physical health.

Building Network Capacity

- Work group needs a greater understanding of:
  - What services are covered
  - Who can provide services
  - Who is providing services and where
- Need to gain great clarity about the barriers that make providers reluctant to serve this population.
- Explore telemedicine opportunities for evaluation, diagnosis, and intervention supervision.
- Explore opportunities for greater collaboration between providers and schools.

Adults with ASD

- What are the indicators of good health for adults with ASD and how do we know if we've achieved them?
- System design should focus on identifying those in the system with ASD, with an equal focus on whether or not the system is meeting the needs of each member.
- Gather data on the economic impact of ASD and focus attention on reduced costs when the needs of adults with ASD are appropriately addressed.
- Adult programs often don't focus on continued learning – Medicaid won't pay for "education" yet interventions and therapies can benefit adults with ASD.
- Members who are enrolled in DDD but not ALTCS eligible would benefit from expanded services that members in ALTCS receive.

Discussion

- What common themes are emerging?
- Thinking about "line of sight," what can the work groups accomplish in the next month to bring us closer to coming to consensus on specific recommendations by December?

Next Steps before Sept. 9

Facilitator will assist each Work Group, through in-person meetings, teleconferences, and e-mails, to move forward in answering the questions in the template and addressing other questions and/or issues identified.

Sharon Flanagan-Hyde, facilitator, can be reached at sharon@flanagan-hyde.com

Data Handout

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AHCCCS ASD Prevalence

Objective: Identify the current ASD prevalence in the AHCCCS system

- 2014 Prevalence Aged 0-20: 10,097/762,110 = 1.3%
    - ASD Aged 0-20 Distinct Member Count: 10,097
    - 2014 AHCCCS Member Enrollment 0-20 Years Old on 12/1/2014: 762,110
- Methodology
    - Timeframe: 1/1/2014 – 12/31/2014
    - Members equal or less than 20 years of age on Date of Service
    - Member had to have 2 or more paid claims or encounters with ASD in the primary diagnosis position
        - Claims are submitted with ICD-9 diagnosis code
        - ASD ICD-9 Diagnosis Codes
            - 29900/29901 – Autistic disorder
            - 29910/29911 – Childhood disintegration disorder
            - 29980/29981 – Other specified pervasive developmental disorders
            - 29990/29991 – Unspecified pervasive developmental disorder

Developmental Screenings

Objective: Understand the current utilization of developmental screening during the 9, 18 and 24 month EPSDT visits in the AHCCCS system

- Procedure Code 96110 - Developmental Screening, with interpretation and report, per standardized instrument
    - AHCCCS approved developmental screening tools are:
        - The Parent's Evaluation of Developmental Status (PEDS)
        - Ages and Stages Questionnaire (ASQ)
        - The Modified Checklist for Autism in Toddlers (MCHAT)
    - Policy updated in April 2014 allowing expanded reimbursement to incentivize providers to perform developmental screenings during an EPSDT visits for members under the age of two*
- Methodology
    - Paid Claims and Encounters
    - Timeframe: 10/1/2013 – 12/31/2014

Distinct Member Counts for Members Who Received Developmental Screening by Quarter

		CAL2013-Q4	**CAL2014-Q1**	**CAL2014-Q2***	**CAL2014-Q3**	**CAL2014-Q4**
Age	<1	1,414	1,486	1,716	2,234	2,278
	1	1,280	1,454	1,784	2,165	2,187
	2	727	794	1,084	1,650	1,756
	Total	**3,421**	**3,734**	**4,485**	**6,049**	**6,221**
	% Change		+9.1%	**+22.8%**	**+32.0%**	+2.8%

- Percentage of members who received Developmental Screening compared to the total EPSDT Visits performed for ages 0-2 years old from 10/1/2013 – 9/30/2014
    - Members aged <1: 6,850/36,486 = 18.8%
    - Members aged 1-2: 10,938/71,362 = 15.3%

Meeting Notes

ASD Advisory Committee

August 12, 2015

Gold Room, AHCCCS Offices

Sharon intro: Explained some process and housekeeping issues and that the agenda for this meeting was not distributed in advance, nor were slides. With vacation and summer, etc., we had to consolidate workgroup meetings, notes, the slides for today and agenda, etc. In the future, we will space out workgroup meetings and Committee meetings better. Sharon will also update roster and workgroup rosters. So with summer ending, we hope to settle in and update notes and web postings sooner.

Introductions:

Dr. Rice was only person attending by phone. (But we later heard another phone attendant; Sharon paused to ask, but no response.)

Review of slides (posted to web):

- No discussion on first few slides
- Data request slide. Pause for Lauren Prole to discuss data one-pager re ASD prevalence and use of developmental screenings. Lauren began with prevalence.

    Prevalence:

    - Discussion of methodology
    - Request for understanding how many of the 10,097 are ALTCS DDD.
    - Explained the 762,110 number is the entire universe of children 0-20 in the AHCCCS program.
    - Request to breakdown by age groups: 0-3, 3-6, 6-12, 12-18, ?? Sharon said she has the age buckets requested by the Adults with ASD work group.
    - Wondering about how many have not received services or were diagnosed with something else…and other kids we may be missing.
    - Interesting that the prevalence is so close to the national.
    - Dr. Salek explained this is a first step and that we will take a closer look at other issues, as recommended by the workgroups

    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 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
  - Sharon wrapped up to discuss that there is more to come on data, particularly as the workgroups come to conclusions around their data needs.
- <u>Slides on workgroups</u>. Sharon explained this is her attempt to synthesize in a few bullets the main themes in the workgroups (in italics below). These main points were highlighted by Sharon and then opened for discussion.
- *Early Identifications and Referrals*
  - What does "it slows down"…mean?
  - Explained that screening gets done but pediatrician is not clear where to send member so diagnosis is slowed down, then break down of getting them referred to DDD for ALTCS assessment.
  - One member discussed a grant project for STAT training…it is not the full 5-month training but it does offer reliable training. Arizona law limits providers that can diagnose autism. So, they want to offer more training to those provider types to expand this process and number of people competent and confident to make this diagnosis. Goal is to expand diagnosis and allow those providers to offer a medical home. This is for pediatricians. This is a small pilot but 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 rule change for DDD. So this can be expanded to include these providers.
  - What about other kids, though, who don't qualify for DDD who have to get services through the RBHA. Is AHCCCS looking at this? To clarify, AHCCCS does not have these limitations. If it is medically necessary, then the services should be made available. AHCCCS acute program does not have the psychiatrist/psychologist limitation for diagnosis.
  - So who will make the determination that medical services on the acute side should be covered? The health plans and the RBHAs will make those determinations.
  - There is confusion around what the acute plans cover.
- *Reducing System Complexity*
  - We had a section of discussing solutions: Looking at 3 different systems. Need for one system versus many systems competing with each other; two systems; keeping multiple but having a strong care coordinator with knowledge of ASD. Additional discussion of confusion that providers experience, so for instance, in DDD, many people's experience depends on a good case manager.
  - Additional discussion around confusion about how to get in and we need to get services no matter where you fit into the system so we aren't making people go through so many hoops. There is a way to streamline the system.

  - PCPs are confused about how to refer to RBHA for ASD. One Committee member says his experience is the RBHA psychiatrist is unwilling to make that diagnosis. Where are we enabling the RBHA providers to make that diagnosis?
  - Is the system better simplified by putting resources into creating one system, or one care coordinator, or… The question is how are resources best spent – reducing the numbers of systems??
  - One member said, in my experience, I had a diagnosis and my private insurance care coordinator took care of everything across all spectrums. In my mind, one system is so much easier to navigate. DDD was supposed to be that but it is fragmented.
  - Integrated care is happening. Dr. Salek said she would help us clarify CMS. Monica clarified the CMS health home concept.
  - Remember to be family centered. Families have siblings. So we don't want to force families to a pediatrician that serves persons with ASD but have to take other kids to a different provider.
  - We also have to remember the care has to be family-centered. Keep in mind the members not eligible for ALTCS. We have to expand the view beyond ALTCS. If the system is there, it shouldn't matter what your eligibility bucket is.
  - DDD serves most of the AHCCCS members with ASD. What DDD does has to be modeled after what the whole state does.
  - What is the smoothest way to transition into a simpler system? Everyone is enrolled in a RBHA, so maybe that is the right place. But not everyone knows that and many people feel that process (RBHA) does not work. So people aren't referring anymore. So do you fix that or do you do something else?
  - Sharon explained that these are just some headlines to promote discussion that will sharpen thoughts on next steps.
- *Evidence Based Treatment*
  - How do we make sure that availability and codes etc. are adaptable to change as the services and research changes?
  - Something today that is evidence based may not be next year, so we know we have to be flexible.
  - We need to include other things beyond ABA like Floortime, Social Thinking, others.
  - Screening of co-morbid conditions for kids with ASD like seizures.
  - The issue of screenings for common co-morbid conditions raises a lot of questions. There isn't sufficient evidence for some of those kinds of screenings (e.g., allergy and connection to auto-immune) we will spend a lot of money without direction.
  - Point 3 – aggression leading to co-morbid conditions. Not sure about that. This behavior could just be related to something else – dislike of a food – but brings back to whole person approach.
  - Wanted to be sure that emerging behaviors of persons with ASD were not necessarily related to ASD or DD conditions. Explained example of behaviors related to dental issue. But point that workgroup was trying to be made was to make sure to look at what is the story behind the story. This is a best practice.

  - As a parent, would like to see development of evidence-based provider cooperation treatment – e.g., a care team.
  - Agree if it's medical, the issue needs to be ruled out by someone experienced.
  - Points 3 and 4 – providers feel least confident treating persons with ASD. Resources for more education to not just screen for ASD but to understand ASD. Critical for primary care providers. But one person said we need to simplify the system first.
  - Use the list from CMS as a minimum to cover.
  - We may not want to mandate but we need awareness that the community often focuses on treating issues behaviorally when there is a medical issue underlying.
  - One person clarified there are not variations within ABA. There are 7 core principles but not variations.
- *Building Network Capacity*
  - Dr. Blitz excited to expand her pilot program. Concerned about rural areas. Hoping to contribute expanding provider network that can diagnose.
  - To be clear, we want to expand network that can also treat.
  - Want to build competency for providers to serve members with ASD. Need to discuss rates and travel.
  - Need to support the parents in interacting with their kids. And child care.
  - Not just what services are covered but what services need to be covered. Dental, feeding therapy, registered dieticians, etc.
  - Group did discuss dental, diagnostic, other. We want data re what services get authorized, by whom, where so we can see if services were delivered.
  - Education. Education. Education.
  - If you pay them, it will come. If you pay practices to increase their capacity to make the diagnosis, etc., and they get extra.
  - What are the majority of the services that we found related to the AHCCCS data pull? Top 3: Habilitation, respite and case management.
  - ABA – comprehensive 20-40 hours per week, that is usually in the DDD.
  - The other way to think of hab – OT, PT, Speech. So that wouldn't be going through the RBHA. That is in acute.
  - Clarifying the top 3 services, there will be more claims for respite, CM, and hab so it is volume that may drive these services being in the top 3.
  - Sharon wants the group to identify what do you need to know and how will that be useful in terms of the recommendations that you will be developing. Dr. Salek explained that sometimes these data runs take a while – 24 hrs+ -- but we just need to prioritize so we're not spinning our wheels.
  - Tying back to first slide, happy to see exploring telemedicine. We're talking about big system change to impact a lot of people but at the individual levels, it is difficult. Innovative approaches, technology, to streamline. We just need to think bigger. SARRC has an app to diagnosis, etc. But looking at all of the issues around building the network based on all of the services we think we need to provide. Let's ask ourselves, what makes the biggest impact? We have a major capacity issue.

  - Don't want to forget respite. Kids with ASD are hospitalized 1 ½ times longer than kids without ASD. For every $1,000 we spend on respite, we decrease hospitalization by 8%. So we don't want to forget this as a benefit.
- *Adults with ASD*
  - My understanding, unless you get into DDD before age 18 you can't get into DDD? Not correct. You just have to show that your diagnosis existed before you were age 18.
  - Question around transitions into adulthood – to housing, employment. This committee is focused on AHCCCS services.
  - Estate planning for families is a big issue.
  - Raising Special Kids has trainings for families around transition. Family resource center has a packet on transitioning. Nurses at Emily Center are a great resource. This is a huge issue.
  - It would be good to incorporate these pieces into the medical home so that it gets used.
  - One member didn't understand number 4. Can someone explain? The idea is that there is a focus on young kids and the point was made that there are things that can continue to happen throughout the life of a person with ASD but Medicaid doesn't pay for education. Bigger issue we discussed is there are programs funded for adults that are thought of as activity focused like a day treatment program. Medicaid should pay for things that build skills, etc. Monica wanted to make a point that things like living skills are covered that can help people with things like budgeting and life skills.
  - AHCCCS has a unit within AHCCCS to Jared's point that can clarify what can be owned and what cannot be owned. ABLE accounts at federal level also available.
- Sharon to Committee: What do you hear as common themes?
  - Expand capacity
  - Provide education
  - Simplify
  - Medical home
  - More holistic approach
  - Think outside the box – value based purchasing, creating flexibility that changes how we pay for things so we pay for things that are efficient and effective
  - Quality not quantity. Our current system is about quantity – how many services
  - One member said he is worried about December deadline. Maybe a tool to force us to fill out a here is what we accomplished…Sharon reminded we have a tool.
  - Do others feel like they are closer to their line of sight – have clear steps? Sharon explained that we are at the muddle in the middle. So we have lots of information out there, lots of resources, outstanding data requests, etc. So it will get clearer but Sharon will help with milestones, etc.
- Sharon will send a master calendar and then invitations for the workgroups.
- Sharon will be assisting workgroups, answer questions, etc., before next big meeting. You can email Sharon anytime.