ASD Advisory Committee Meeting Agenda
Wednesday, July 8, 2015
3:00-5:00 PM
AHCCCS Offices, 701 E. Jefferson St., Phoenix, 3rd Floor, Gold Room
Facilitator: Sharon Flanagan-Hyde

3:00 PM	Overview of Agenda Review of Charge to the Committee, Timeline, Intentions, Guiding Principles and Group Norms
3:15 PM	Work groups meet at separate tables: (*If you volunteered for more than one group, either choose one group for today or divide your time between groups*.) Introductions – Name, affiliation, interest in this area. Discuss Questions 1-4 — One person in each group serves as a scribe and takes notes. (Please give notes to the facilitator at the conclusion of the meeting.) Facilitator will rotate among groups and discuss meeting/communication logistics and work steps for each group.
4:10	Report-out from each group on Questions 1-4 (10 minutes per group) — Note any overlaps among groups and opportunities for cross-group collaboration.
4:55	Next steps before August 12 Committee meeting
5:00 PM	Adjourn

The agendas, meeting materials, meeting notes, and updates will be posted to http://www.azahcccs.gov/shared/ASD.aspx

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Early ID Referral

Early Identification & Referral Work Group

July 8, 2015 Work Group Discussion

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

- Clearly define assessment, intervention, and screening for best practices when identification occurs. Children get missed in identification because of the already narrow view of referral once autism is identified
- Difficult to determine what is and is not an appropriate referral. Second stage needed once a referral is made, including the need for a secondary screening. The result is that the diagnosis process gets bottlenecked because of lack of providers able to officially/legally diagnose for ASD
- M-CHAT needs to be most current version when follow-up is conducted
- Screening, identifying and referring appropriately – providing alternatives between referring and identification – providing intermediate paths between identification and official diagnosis
    - 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.
- Coordination between PCPs and early intervention crucial
- PCP may be deterred from screening due to cumbersome billing requirements
- Communication, training, and education to ensure timely care
    - Assessment and intervene early – autism comes in all variations or spectrums that may be difficult to identify and treat beginning at an early age

- Diagnosis is the most challenging piece of effectively treating ASD because once child is referred, the system slows down
- When referrals come through AzEIP, pediatricians discontinue involvement, in varying degrees, in the follow-up process – PCP needs to be included further, including other provider types to encourage collaboration and treatment
- "Watch and wait" a reoccurring problem
- Redefine and clarify "evaluation" and AzEIP's role in AMPM – may be fixed by clarifying front end of the policy
- Education - Parents may be confused in that an assessment is not the same as an official diagnosis. What are next steps following an evaluation, assessment, and diagnosis, and who is responsible for providing each
- AzEIP should not be looked at as the only resource as a guide to obtaining services
- Pediatricians only involved in surveillance
- Lack of identification, inappropriate referral, or appropriate referral that results in long waits and bottle necking
- Communication strategy between provider and families
- Network identification and adequacy
- Clearly defining the assessment
- The interagency workgroup: No ICASS http://www.iwg-autism.org/

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

[Insert]

3. What data do we have/need?

1. What percentage of PCPs are engaging in screening with the hopes of increasing (rural, urban, Pediatrician, family practice, etc.)– 96110 code (very low utilization)
2. physical health v. behavioral health utilization – PT, OT, ST up to age 6

4. What data do we need to obtain?

a. **Sources?**
   i. Screening percentages.
   ii. What other states have done to identify best practices

b. **Who will obtain the data?**

Reducing System Complexity

Notes for ASD Advisory Committee

Wednesday, July 8, 2015

Reducing System Complexity

Q: Re where to get References to health plan policy manuals. Can be accessed online.

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

As someone who uses the system, we need to know who is eligible for these services and where are they accessing the services and where the services are provided. As a parent, I balance 7 distinct provider networks, 3 due to private insurance. Different things are available in each different system. It's very difficult for parents. A lot of people who are not DD but are AHCCCS – e.g., Asperger or PDD-NOS - don't know that there are services available.

Looking at all the payors…how to people get to them all? Then eligibility; how are you eligible for services. It's very confusing about what is available, what should be available. Going back to the beginning is helpful to all of us.

Once a need is identified, the timing when a family requests a service to actually getting the service needs to be expedited.

One parent's problem with her son is the one professional charged under Medicaid law that should know where the resources should be didn't have a clue. In this case, the pediatrician.

Not just understanding how to navigate the system, figure out how to simplify so there aren't so many steps and agencies involved…that would be amazing.

That would help us make recommendations.

In order to fix system, have to understand what is going on and then we can figure how to fix it.

Do we include the adults in our discussion of focus for this workgroup?

Someone who has the diagnosis, how do they access the services? There needs to be a way to know, this is the path – and that is across the lifespan.

And even stepping back, how do you get there…how to you get there into the public system. Getting into the diagnosis, it is multiple people…pediatrician, school, etc. How about a no wrong door so if pediatrician misses it, someone else picks it (screening, assessment) up. As adults, we also have PCPs who need to know the system.

Focus is not services for this group, but it's about the system and navigating it. Maybe connecting more with community based partners.

Providers need to have codes and rates established so there isn't confusion.

An age old argument re splitting head from body from DD…etc. It doesn't work. Discussion about need for an integrated model.

Makes sense to map out how complex the system is. What are the variables of a system, fiscal, referral patterns, organization missions, mandates, laws, policies…what adds to the complexities of the system

Starting fresh…

One way to immediately simplify it, have one entry point re eligibility to a system.

Eligibility is different 0-3, 3-5… What do people mean by "eligibility." The group means eligibility for medically necessary services…I raised the issue re payor that dictates this as well. Because private payor dictates where you go for services – networks.

You would want to have whichever door the kid appears at to be able to serve that person and that there is a person trained to connect the kid to services. People are skilled at assessment, diagnosis, so wherever the kid appears, that step should happen. Then it's about simplifying … is there a team that coordinates the care.

Eligibility is for: Medicaid, ALTCS DDD, AzEIP -- your payor – and then medically necessary services, … first you have to be eligible for the program and then you have to be medically eligible for the right services that are medically necessary for you.

Train stakeholders: who can do appropriate assessment, figure out best treatment plan based on medical necessity, then having a network of providers that can provide the services

Understanding what does a service package look like and who are the players that offer those services.

Where does the care coordination piece fit into this? Why are we burdening the families? People need to be trained, there needs to be a care team and a team lead for that care team.

When we are talking about payors, make clear to families, private insurance pays first, Medicaid second, AzEIPs last. Many families, because private insurance … more people getting bunch of services from all systems and none are maximized. Becomes frantic. Especially because you can't find everything you need in one system. Some research shows private insurance reduces need for Medicaid but not in AZ.

If one agency provides x service and another agency provides x but the coding is different and the two agencies can't communicate with each other.

Capacity and capability of system…if you're not getting what you need, then there is more shopping in the system.

Sharon: what do you want to do between now and next meeting on august 12…e-mail, phone conference, face meeting, Sharon will facilitate. She wants us to make sure we get through all the questions.

2. *Data: what data do we have?*

Would help to know what data we have re diagnosis, where members with ASD access services, what services do they get.

Magellan RBHA had that data – the number of people with ASD and services they were getting.

DSM V .. explained that DSM V cannot be used for billing so it won't be captured in AHCCCS data since we have claim and encounter data.

Can we get data re age, when application for ALTCS was made, when they got services…AHCCCS reply that some of that is complex data pull, but there is data we can get and Dr. Salek has started that process. So AHCCCS will regroup and take a look at what data is available.

Process map…once I apply, how long to services…

Sharon: what would we do with that data…how to develop that into a recommendation. Group needs to focus on shaping recommendations

Key for this group: Getting in, getting what you need, getting through different parts of the system

1. *Back to 1, who is eligible, what the services are, who are all the payors, who are their providers*

Not just how you get into the system, but what happens when you get in…does it mean you've had a diagnosis, had a screening?? Lots of issues from screening to diagnosis to treatment especially if there is no assessment.

Perhaps we need to look at models – maybe we need a distinct model for the ASD population and are there some existing models we can draw from.

CRS is an interesting case study…how do kids get diagnosed…access services…and what do you give up going into a CRS type concept. Give up: choice…of provider, health plan.

Create an array within one specialty plan.

CRS in Tucson has all the specialists so it might work, what would that look like…would it be helpful. In different parts of the state, it is different.

Integrated RBHA for SMI is another model.

AzEIP? Many parents say it is a big shiny star you take home and then the glitter falls off when you take it home.

DDD is another system. They do that for a small subset. They have the care coordination. That is a model of care coordination.

Integrated systems…models.

Education. Community needs to know who should be paying the bills. Providers and parents are confused. Tie in Medicaid in the schools: School based claiming. Monica explained that may not be the best model but there is certainly need to bring in the schools

Group Wrap-up:

- Need to Look at different integrated models where there is strong care coordination component to reduce burden on families and facilitate navigation of the system to improve access to services.
- Need to look at some data – numbers of members with ASD, utilization patterns

Evidence-Based Treatment

ASD Advisory Committee Meeting 7-8-15

Evidence-Based Treatment

What are the areas of focus of this group?

Evidence-based practice is a dynamic process of the integration between professional expertise, the individual characteristics of the child and family, and the best available research.

This work group will focus on four areas:

1. Evidence-Based Practice and emerging science
2. Family and member centered care
3. Integrated physical and behavioral healthcare models
4. Establishing a committee that reviews annually evidence based treatment

What do we collectively know about each area of focus?

We have to make sure that our children are screened for comorbidity, I believe in this state we're doing a poor job in doing that…that's not reflective of AHCCCS but, it's our medical system isn't engaged. I think we need to address that as well.

Shouldn't there be genetic or mitochondrial myopathies associated with things like that…

So based on your [remark] saying not say anything bad about AHCCCS or DDD…I want to tell you guys that we don't have a big ego. If you think DDD is doing a bad job about something say so b/c I'm here to make things better…

I have private health insurance too…and I think things are more difficult in this state compared to other states..

I sat on the board of Phoenix Children's Hospital as a family council…and I know that other places such as Boston do a far better job of screening for all the comorbid conditions on a yearly basis…our children should be seen by geneticist on a yearly basis…I don't want us to focus only on the behavioral and forget about the other medical needs

Actually since CRS took over the behavioral health for 95% of its members I can tell you what happens is that the medical piece of it gets ignored and the behavioral health part takes more of a focus…and we were finding that all these kids in behavioral system have been lost…and did not get a follow up…so I totally agree with you.

Also from autism point of view, we don't want a behavior first approach…unless we've ruled out medical cause for that behavior first.

We want an integrated approach to care with both physical and behavioral health

We are here to identify what evidence-based treatment we're going to agree that AHCCCS and its subcontractors are going to fund…we need to add to it who they're going to fund do it…i.e. the qualifications of the people

We need to be careful what we consider as evidence-based because what is considered evidence-based changes rapidly with emerging treatment/ research…also each child is going to be different...so I hope that we don't take a cookie cutter approach

Well let's say evidence based and member and family centered approaches

I think what we need to remember is that evidence-based criteria can change…there are numerous research/ new evidence-based treatments studies conducted every year.. so we need to look at the CDC websites and others to see what's out there.. if I have a child with autism, I would really want to know the up to date information…the cutting edge stuff

We need to decide at what point in time and what criteria these new emerging treatments need to meet…you could find all sort of articles about [emerging treatment] that they did with 2 or 3 people...but it wasn't scientifically formulated or right process were not followed

We need to help families identify what is good emerging treatment…

What I like about EPSDT is that they look at what is working for the child and since autism is based on a behavioral diagnosis it is probably many different autism caused by many different things…so unlike leukemia [that is clear cut] autism is more messy…so we need a little bit more flexible system

re the emerging issue… other therapies have the infrastructure designed around certification/licensing rules…it's important that patient and family members have protections…having been on both sides of that...it's our responsibility to tell people that here is the things that we are very concrete on and there is infrastructure around that…and here may be some things that are up and coming and maybe there is not that infrastructure…but at some point we have to draw the line on what is considered upcoming…what is snake oil…the spirited debate that we're having back and forth is meant to be around that line…I think we all want the best things…but I do get concerned a little bit that if we open the flood gates…what that means for consumers.

We determine the levels of emerging treatment…we need to determine which ones we're going with.

Any research published is going to be 2-3 years old…you're always going to have a lag

The whole point of EPSDT for Medicaid children is that they don't have to wait for 20 years for the new therapy to be approved…so that we don't miss a couple of generations of kids

…I read it and I was disappointed with some of things that were put as emerging…

But you can disagree with it personally, but it's hard to disagree with the science that goes behind this…there is criteria behind this…just like the impact study...there is criteria

I think the difference is that you are reading now that there is a lag…and she is reading emerging as concrete as other people would be reading it

It's important that we don't wait 20 years for this…

I agree with that whole heartedly…you know it doesn't have to be a huge study replicated by 2 different universities…different from the original one…but we need to have some criteria

We don't have a good medical home for our children that is why so many things get missed…

We need to make sure that we have annual reviews

The NSP study has certain guidelines for what is higher quality research...it's got five levels….provides us with a guideline to help families and our system determine what is appropriate

My professional association the ABA has a statement about evidence-based practices, it stresses...it's fairly consistent one across the board that we need to be science-based when we make decisions, but we also have to be family-based…those decisions have to be made with family and the individual child about what they value as an appropriate treatment…not snake oil…but with support of family

Not every child is going to fit in one standard of care so families need to have some choices of what those standards are going to look like

I just want us to be cognizant that we don't lump it all together…I think I'm fine with the emerging research idea but it has to come with the caveat that they are— emerging— for whatever reason…whether they're new, just not enough research….

So what are the key elements that we want to focus on?…we want to use where there is evidence-based guidelines already and we want to include that there are emerging concepts and annual updates to guidelines to keep it current, and to make family-based and person-based, integrated (behavioral and acute)

We are looking for stakeholder input to approve additional evidence-based practices/emerging treatment.

We need people in the specific field of the emerging research to evaluate the research presented to review committee…we to have a multitude of professionals reviewing the research.

Our national committee that does policy for United Healthcare, they have a variety of specialists, developmental specialists, pediatricians, behavioral health, orthopedic surgeons…because you have some of the expertise there…the people that are not experts listen to the input of the people that have more information than them…so I'm assuming the committee of annual reviews has to have some expertise on it

How does the committee get input from stakeholders?

There is literature review and they also get consensus statements from national organizations that are impacted by it…so if it's an EMT type of policy that we are developing than we send it off to the national EMT association and get input

What data do we have?

- Arizona Academy of Pediatrics statement on ASD treatment
- The American Academy of Psychiatry best practice guidelines
- Independent groups that review best practice guidelines:
    - HASE
    - Milliman Care Guidelines
- Commercial healthcare guidelines
- State statutes
- Conduct research on sub-types of Autism—whether there is a differential responses to different treatments
- CMS guidelines
- EPSDT guidelines

What data do we need to obtain?

- Create a shared file (e.g. SharePoint, Google Drive, etc.) for the members of the work group to share documents

Who will obtain the data? Who will do what between now and Aug 12. ?

- All work group members will contribute research to the shared file.

Building Network Capacity

ASD Workgroup- Building Network Capacity

July 8, 2015

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

-The group should identify best practices for ASD.

-We need to look at the system and determine what services are covered, who can provide those services and where those services are available.

-We should look at emerging practices to help fill out the network and help develop services in a more innovative way. For example, we could identify someone other than a PhD or BCBA to do patient evaluations.

- We need to develop a tier system that correlates levels of service delivery and corresponding provider types.

- We need to address inconsistencies in billing systems between payors to avoid an unintended burden on providers and families. Right now, different payors are using different billing codes for the same services, which is burdensome on providers.

-The State should fund copays to reduce the burden on providers who must write off unpaid copays.

-There are urban and rural network capacity areas. We need to look at creative ideas to train, retain and recruit providers. For example, the State used to fund a loan repayment program to address urban and rural provider shortage issues.

-We need to start recruiting providers at the high school level, instead of waiting until college when many students have already selected a career path.

- The group needs to identify all the providers that are needed to develop network capacities including speech therapy, occupational therapy, physical therapy, private duty nursing, DME, home health, vision, hearing and dental providers.

- The group should also consider the role proposed policy changes may have on the system. For example, the KidsCare program may be reinstated and the Legislature may enact a dental benefit for adults. What impact will these changes have on the system?

-What programs do you need to be effective with ASD? How do we make sure the network can include those programs?

- What role do schools play? What do they have to pay for? What role does DDD play? What role does the RBHA play?

- What regulatory barriers exist that curtail the delivery of services and place additional burdens on providers?

-What billing standards are we going to adopt as a state and what role does the DSM-V play, especially with the adoption of ICD-10? There is disagreement about the efficacy of the DSM-V.

-Should we use the diagnosis to develop a treatment plan? There are many providers that still do and this is not the best way to develop a treatment plan for individuals with ASD.

-Should there be standardized training for providers? Who would do this training and could you develop a training curriculum everyone would agree upon? There should also be training for families who are navigating services. Who would provide this training?

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

- Supervision is not being paid for separately. Reimbursement should account for all costs incurred to care for the member.
- There are not enough providers graduating with the degrees that are needed to treat individuals with ASD. There are also not enough providers staying in practice.
- There are too few developmental pediatricians and not enough diagnosing providers to meet the need. This is creating a backlog of patients waiting for services. A number of providers are scheduling a year and a half out.
    - Idea: Stat-MD is a company that does telemedicine and could help fill the gaps in conducting initial assessments.
    - Idea: Local pediatricians could be trained to do a provisional ASD diagnosis to identify and triage at-risk kids. Children receiving these provisional screenings that are initially diagnosed with ASD could continue to receive services while awaiting the formal diagnosis.
- Some services cannot be paid for, but that does not mean they are not needed.

-It is important to prioritize quality over quantity, which is not recognized by all payors. This also speaks to the inconsistencies between payors in treatment and reimbursement for individuals with ASD.

-There needs to be some way for families to know about the quality of the services they are receiving.

-There is a lack of service supports for adult behavioral health programs.

3. What data do we have?

-Do we know how many people have autism, where they are, and what services they need? This information is available through DDD.**-**

4. August 12th Meeting Needs

-Obtain email feedback on questions from those who are not in attendance.

- Identify when/how to hold future meetings.

Report Outs

Notes for ASD Advisory Committee

Wednesday, July 8, 2015

Report Outs from Work Groups

Early Identification & Referrals

3-4 principle areas of focus

1. Screening and assessment. Define more clearly what we mean by screening and assessment
2. Second is referral sources, and there is a potential for ASD, how can we quickly get them to someone who is able to diagnose. Since that provider network is limited, also look at who is able to diagnose…do we have too many limitations or barriers as to who can diagnose?
3. Third is secondary screening. Are there intermediary steps that we can begin, even if it's not a formal diagnosis yet.

UA – saying there are other tools re defining whether an individual should really be referred STAT-MD or other tools to use as to who should be referred.

Data – 96110, 96111…let's see what is happening. Screened, referred, assessment codes…how quickly did that occur? On physical health side, did that child get PT, OT, ST referrals.

Coordination between PCPs and early intervention and use of M-CHAT. Making sure providers are using most current tools. We don't have easy way to see medical records to see what tools providers are using.

Best practices from other states and national best practices re screening to educate. Once we get it, how do we impact those identified in the assessment, thereby impacting the system more broadly. Some of these processes already exist…e.g., direct referral from a pediatrician…but it's not well known. Education!

Reducing System Complexity

Training stakeholders on what services are available.

Streamlining the process…becoming eligible in AHCCCS and then re what services are you eligible to get (are available to you) based on medical necessity

Network of providers…system

Data – we don't know what data is out there under different systems

Look at different models within the AHCCCS system or other states or private commercial insurance

Evidence-Based Treatment

Spirited discussion re evidence based treatment and practices

Was clear people care deeply re treatment that is safe and effective and getting that info to families.

Clarify process for identifying evidence based practice and keep that re emerging practices…incorporating new information

This is a dynamic process in integration of professional expertise, individual characteristics of child and family and then the best research available

Discussed current situation, using current studies and allowing for emerging evidence on annual basis, to update what is available.

Ensuring it's family/person centered and includes co-morbities, behavioral health.

Including family input is critical

Request: What we have and what we need…shared file process so workgroups can put information into these files. Want to put documents into this file. Sharon says yes, we will get a shared file for people, specifics TBD.

Building Network Capacity

Hearing a lot of consistent themes, so shared file is good.

STAT-MD brought up at their table too to get services to people prior to diagnosis.

Bringing in more providers – state used to have loan repayment program; can also outreach to high schools and colleges.

Tiered levels of providers and services. Mobilize providers to train individuals.

Inconsistencies in billing, coding, systems – whether BH, DDD, private pay – they're all different.

Data – specific number of members with ASD. One person said they thought there were 22,000 at DDD with ASD.

Lack of network support for adults because of lack of providers.

KidsCare – if we reopen, how does that affect network

Adults with ASD

Wish list data collection on adults and adolescents in AHCCCS with ASD. Medical care available. Innovating and experimental approaches to build more supportive communities

Training others re ASD – courts, schools, etc.

Job/skills development and training critical

Lack of direct support services and training.

Outcomes measures and impact studies done with identification of best practices.

There is a lot of data but little focused on adults with ASD.

Need more comprehensive picture of adults/adolescents with ASD – demographic picture including, income, race, age, etc. – and what services they receive and what is available. Request of AHCCCS to provide this data.

NEXT STEPS

Sharon: I can assist your workgroup through in person meeting, teleconferences, e-mail. I will get the shared file going. I will send e-mail with everyone listed in your workgroups. We have from now until December to complete recommendations.

The questions in the template are a starting point to help work groups develop these recommendations.

Any questions:

- One workgroup said they are worried about our focus – easier to get data on Medicaid than those on private but privately insured is an important component. Sharon said that the task is to make recommendations for the Medicaid system, so that is #1. AHCCCS clarification confirmed that as the focus but to not let things go unspoken. If there are other issues outside of Medicaid that are critical for making the Medicaid system better, please bring them into the discussion, document them for the record. Groups will probably find that as we discuss, there will be isses that are short term, middle and long term. So if there are issues, let's document them. There can come a time where we coordinate a broader dialogue with commercial payors and other systems around services for treatment of ASD.
- Understand parameters: Medicaid is the main issue; but include private payor and other issues if it is important and document it.
- One work group was not clear on next steps. Their work group topic is challenging. And the discussion was good but all over the place. What do we do? How do we get clarity for our workgroup? Sharon says not to worry; she can facilitate a meeting and next steps. Sharon is here to help all of the work groups so please don't hesitate to reach out to her. The goal is to form recommendations to advice the main ASD Advisory Committee and then they will finalize recommendations for the State.