ASD Advisory Committee Meeting Agenda
Friday, June 19, 2015
1:00-3:00 PM
AHCCCS Offices, 701 E. Jefferson St., Phoenix, 3rd Floor, Gold Room
Facilitator: Sharon Flanagan-Hyde

1:00 PM	"Flash" Introductions: Name, Affiliation
1:15 PM	Agreement on Group Norms
1:20 PM	Committee's Charge and Objectives
1:30 PM	Discussion and Agreement: Observation by or participation of non-committee members
1:45 PM	Discussion and Agreement: Principles to guide the work
2:00 PM	Discussion and Agreement: Key issues and questions to be addressed
2:30 PM	Workgroups: Topics, Charges & Composition
3:00 PM	Adjourn

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

Discussion Slides

ASD Advisory Committee Meeting

Revised through Committee Discussion

June 19, 2015

Agenda

- “Flash” Introductions: Name, Affiliation
- Agreement on Group Norms
- Committee’s Charge and Objectives
- Discussion and Agreement: Observation by or participation of non-committee members
- Discussion and Agreement: Principles to guide the work
- Discussion and Agreement: Key issues and questions to be addressed
- Workgroups: Topics, Charges & Composition

Acronyms

AHCCCS: Arizona Health Care Cost Containment System
ALTCS: Arizona Long Term Care System (part of AHCCCS)
ASD: Autism Spectrum Disorder
AzEIP: Arizona Early Intervention program (part of DES)
CRS: Children's Rehabilitative Services (part of AHCCCS)
DBHS: Division of Behavioral Health Services, Arizona Dept. of Health Services
DDD: Dept. of Developmental Disabilities (Part of DES)
DES: Dept. of Economic Security
DIR®: Developmental, Individual, Relationship-based Model (Floortime®)
DSM-5: Diagnostic and Statistical Manual of Mental Health Disorders, 5th edition
EPSDT: Early and Periodic Screening, Diagnostic and Treatment
HAB-M: Habilitation Masters
IDEA: Individuals with Disabilities Education Act
IFSP: Individual Family Service Plan
M-CHAT R/F: Modified Checklist for Autism in Toddlers, Revised and Follow-up Interview
OT: Occupational Therapy
PCP: Primary Care Provider
RBHA: Regional Behavioral Health Authority (part of AHDS DBHS)

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.

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.

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.

Objectives

- Develop recommendations through facilitated monthly Committee meetings and Work Group activities from June through December 2015.
- Keep process transparent: Post all meeting agendas, materials, notes, and updates on web site—http://www.azahcccs.gov/shared/ASD.aspx
- Present recommendations to Christina Corieri, Policy Advisor for Health and Human Services, Office of the Governor, in January 2016.

ASD Committee Members

Providers

- Karla Birkholz, MD, Arizona Academy of Physicians, Honor Health
- Robin K. Blitz, MD, FAAP, Barrow Neurological Institute at Phoenix Children's Hospital
- Bryan Davey, PhD, BCBA-D, Highland Behavioral – HOPE Group
- Danny Kessler, MD, FAAP, Southwest Human Development
- Jared Perkins, MPA, Children's Clinics and Autism Society of Southern Arizona
- Terrence Matteo, PhD, Clinical Child Psychologist
- Daniel Openden, PhD, BCBA-D, Southwest Autism Research & Resource Center (SAARC)
- Sandra Price, JD, PhD, Arizona Chapter American Academy of Pediatrics
- Sydney Rice, MD, MS, University of Arizona
- Brian van Meerten, MEd, BCBA, LBA, Behavioral Consultation Services of Northern Arizona, LLC (BCSNA)
- Ginger Ward, MAEd, Southwest Human Development

Family Member Advocates

Albert Acuña, Autism Society of Southern Arizona – Santa Cruz

Diedra Freedman, JD, Arizona Autism Coalition

Erika Johnson, Autism Society of Southern Arizona

Cynthia Macluskie, Autism Society of Greater Phoenix

Jon Meyers, The Arc of Arizona

Joyce Millard Hoie, MPA, Raising Special Kids

Ann Monahan, Arizona Autism Coalition

ASD Committee Members

Health Plans/RBHAs

- Renee Bartos, MD, MPH, FAAP, Mercy Care Plan
- Don Fowls, MD, Mercy Maricopa Integrated Care (RBHA)
- Mary Jo Gregory, FACHE, RN, Health Choice Integrated Care (RBHA)
- Leslie Paulus, MD, UnitedHealthcare
- Terry Stevens, MA, LPC, Cenpatico Integrated Care (RBHA)

State Agencies

- Paul Gladys, MBA, ADHS/DBHS Representative
- Sara Salek, MD, AHCCCS Representative
- Theresa Courtney, MD, DES/ALTCS DDD Representative
- Karie Taylor, MA, DES/AzEIP Representative

Non-Committee Members

Committee members reached the following consensus:

- Colleagues within the organizations represented on the Committee may observe in full Committee meetings and participate in discussions.
- Committee members may designate others in their organization to serve as alternates if the Committee member is unable to attend a full Committee meeting.
- Work Groups may invite others to participate, keeping in mind the goal of balanced representation by providers, family member advocates, health plans/RBHAs, and state agencies.
- Attorneys who are not members of the Committee may be called upon for expertise for specific issues, but, in the interest of supporting open conversations, will not be allowed to observe meetings.

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.
- 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.

Let’s Not Start at Square One

Key Questions and Issues

1. Early Identification & Referrals for Diagnosis

- How can delays be reduced in obtaining initial referrals for quality evaluations?
- How can we move toward the goal of diagnosis and intervention before 2 years of age?
  - Average in AZ is 4 years, 10 months

Key Questions and Issues

2. Reducing System Complexity

- In order to recommend changes, what details do we need to know about the complexity of the current systems that provide ASD evaluations and services?
- What systems-level changes are needed to simplify the multiple entities with conflicting and overlapping responsibilities?
- How can problems with age-related transitions (e.g., age 3, pre-school to school, age 18, age 21) be eliminated?
- How can EPSDT, behavioral health, physical health, and psychosocial issues be addressed in a coordinated way?
- How can treatment planning and benefits be coordinated?

Key Questions and Issues

3. Evidence-Based Treatment

- What are the evidence-based treatment modalities for ASD?
  - Age range
  - Individual needs of the child, keeping in mind that ASD is a continuum
- What innovative approaches (within CMS guidelines) can we recommend?
- How can we ensure that performance is measured?

Key Questions and Issues

4. Building Network Capacity

- How can the shortage of well-trained, qualified professionals who can diagnose autism be addressed?
- How can the categories of qualified professionals whose diagnoses are accepted (for DDD eligibility and reimbursement by all payors) be increased?
- How can the network of treatment providers be increased throughout the state?
- How can the administrative burden on providers be reduced?
- What roles can technology play?
- What assets currently exist?

Key Questions and Issues

5. Adults with ASD

- Address the needs of adults with ASD ages 18-21 and over 21.
- Address social and quality of life issues, including collaboration with other agencies and providers regarding housing and employment.

Dates & Times

Full Committee will meet Wednesday afternoons, 3:00-5:00 p.m.

- July 8 (2nd Wednesday)
- August 12 (2nd Wednesday)
- September 9 (2nd Wednesday)
- October 28 (4th Wednesday)
- November 18 (3rd Wednesday)
- December 16 (3rd Wednesday)

Work Groups

- Work Group Topics:
  1. Early Identification & Referrals for Diagnosis
  2. Reducing System Complexity
  3. Evidence-Based Treatment
  4. Building Network Capacity
  5. Adults with ASD
- Work Group composition to be determined.
- Sharon Flanagan-Hyde will facilitate each Work Group.
- Each group will develop a statement of its charge and goals.
- Meeting times to be determined by each group – some work will be done via teleconference, e-mails, etc.

Ongoing Communication

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

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

Committee Principles

ASD Advisory Committee Principles to Guide the Work

Developed by participants in the first Committee meeting on June 19, 2015, the following principles will guide the work of the full Committee and Work Groups:

- Work toward action items in a 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.
- Ensure compliance with the Medicaid Early and Periodic Screening, Diagnostic and Treatment (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.

Meeting Notes

ASD Advisory Committee Notes
June 19, 2015
AHCCCS — Gold Room

Facilitator: Sharon Flanagan-Hyde

Meeting began at 1:00 p.m.

Introductions

Review of slides

- No questions or changes on initial slides

Discussion of Observers

- Clarify if decisions apply to Advisory Committee and/or Work Groups.
- Clarify regarding including attorneys specifically.
- One person said attorneys are a valuable resource and has no problem.
- Another said it makes sense for the Work Groups, especially where we need their expertise. Her group had a call about that.
- Another said attorneys originally were facilitators and it was helpful. Saw no problem.
- Sharon clarified she is the facilitator, including for the Work Groups.
- One person said all for participation but concerned about attorneys using information for their own purposes. Part of agreement to have open discussion is information cannot be used for anything outside of the work of the Committee.
- One said that in order for us to feel comfortable, attorneys need to agree to not use the information against Committee members in litigation.
- Sharon pointed out that information will be posted on the Internet and we won't associate the names of Committee members with comments.
- One said that information from group should not be taken and used for a lawsuit.
- Another said if we are putting information on the website we can't prevent it from being used in a lawsuit.
- One said there may be times where we use organization's name to mention facts on the ground.
- One said we use attorneys all the time. I'm speaking to the spirit of the group.
- One person brought an observer because she was not included and wants her to have the information.
- Another brought an observer because of expertise and schedules; person can be backup.
- Sharon observed that there are three issues on the table: 1) bringing someone from the same organization as the Committee member for reasons of sharing information more easily and scheduling issues; 2) concerns that attorneys may hear things that could later be used against individuals and/or organizations in litigation; 3) attorneys are able to provide expertise that could be useful.
- Issue 1. No objection to people attending from same organizations as observers and backups and to contribute.
- Issues 2 and 3. Attorneys. Thumbs up/down. Some up, some down, some sideways. Not full comfort level so will continue the discussion. Reluctant to go ahead without full comfort.
- One person asked people to explain what objection is.

- One person explained that some attorneys use this information to sue the state. OK with using attorneys for technical expertise, especially in the Work Groups.
- Another said that representatives of state agencies are very uncomfortable with the presence of attorneys who might litigate.
- One person said the goal is to build consensus.
- One person said that the first meeting of this group, which included attorneys, was tight in terms of communication. Thinks the presences of attorneys inhibited the flow.
- Sharon: Seeing consensus building. Perhaps use attorneys for technical expertise for Work Groups?
- One asked, What if my substitute from my same organization is an attorney?
- What if the attorney is also a parent and advocate?
- One noted that several Committee members have JD degrees, but are not litigators.
- Sharon: Notice we didn't put titles on name tents. Want people to be on a level playing field during discussions, first name basis, feeling free to express their thoughts. Are we getting too granular in discussing issue of attorneys?
- One person said it makes sense to involve attorneys as needed for technical assistance for Work Groups.
- Sharon summarized: Substituting a person Committee member's organization who happens to be an attorney is acceptable. We won't invite attorneys who play a role as litigators as observers.
- What about adding others that didn't make the list of Committee members: Hispanic community, Native Americans, some other organizations or provider types?
- Sharon: Main issue is size of the Committee and balance among four areas (providers, family member advocates, health plans/RBHAs, state agencies). Others can be invited to join Work Groups, although it is important that the Work Groups are balanced, too.

Principles to Guide Work

- Cultural competency
- Member and family focused
- Evidence based
- Informed by best practice guidelines
- EPSDT rules
- Flexibility
- Innovation
- Optimism
- Waiver – what will it allow, what is possible, what flexibilities do we have?
- Doable. If we adopt a practice, make sure providers can achieve it.
- Network sufficiency
- Make this as uncomplicated as possible.
- How to address barriers? Instead of saying that can't be done, how do we address? But recommendation would be let's make a change to address this barrier.
- Many misunderstandings about current rules/regulations.

- Collaborative
- Guided by member outcomes – measurable. Optimizing outcomes.
- Capacity building
- Adding to collaboration. To include other networks (e.g., for people commercially insured as well as AHCCCS insured). It's 360 degrees.
- Not just those with ASD…but include those at risk. Screening element to capture all kids because we're missing some.
- Data-driven

Not starting at square one – acknowledge work that's been done by group

- Sharon: This committee is action focused. Not going to take time to redo work already done. We want to get to recommendations that can be acted upon.
- Captured group's work at summary level on five slides. Recognize there is a lot of detail under each area that will be further discussed in Work Groups. Want to capture today whether anything needs to be added at high level to these summary slides.
- <u>Early Identification & Referrals for Diagnosis</u>
    - Can we get raw numbers of children in that age group that are enrolled in AHCCCS, by age groups? By county?
    - Someone said ADHS has information about enrolled and eligible but not enrolled.
    - AzEIP potential source of data.
    - Evaluations. Clarify what that means. Some people think children are getting referred but not getting good evaluation. It's not just timeliness but quality of the evaluation.
- <u>Roadmap to a Complex System</u>
    - There is an immediate short-term need for more guidance to navigate the system as it is. Then presumably the tool would change as we change the system.
    - There are multiple systems. We have to be clear – there is DDD, BH, acute, etc.
    - We need a roadmap to a better system. Sharon said that is on the next slide.
    - You have to learn what currently exists to make it better. I see this as a system of care and she sees that as same thing as multiple systems.
    - Another agreed that we must understand what exists. May not be a tool, but a tool kit with a bunch of tools.
    - Coordinate benefits between Medicaid and commercial insurance. Sharon noted this gets to Work Group level of detail.
    - Parents must do this work of creating a tool. Raising Special Kids is the most knowledgeable organization to put a tool together.
    - Tool kits can be things that sit on shelves. Lots exist. One person said that she hears that PCPs are done navigating the system.
- <u>Reducing System Complexity</u>
    - Evaluations
    - Tool to disseminate what services are available – Sharon said gets back to navigating the system.
    - Transition from child to adult issues, but also transition at age 3, then to school age, etc.

    - Collaboration
    - Coordination
- Evidence-Based Treatment
    - New Yorker article re Beautitudes for elders with dementia. She saw it as applicable to adults with ASD. Can we be innovative?
    - Keep in mind that recommendations must stay within CMS guidelines – what they will cover – as well as EPSDT guidelines.
    - How do we measure?
- Building Network Capacity
    - Is there a role technology can play – telemedicine, applications, extension into rural areas?
    - Add the word "qualified" professionals for treatment providers.
    - "Diagnosis" accepted by whom? To be eligible for DDD? If not eligible for DDD, then what.
    - As a consumer, DDD is not the only concern. Diagnosis has to be accepted by multiple standards for different payors. "Qualified" means considered qualified by anyone who is going to pay for the service…to make sure they will pay the bill.
    - Consensus of what those qualifications are – that will be a Work Group issue.
    - Lowering administrative hassle for providers.
    - Diagnosis leads to a specific treatment. But what about kids with multiple diagnoses?
    - Care coordination. How to ensure connection to each provider.
- Sharon: There are a lot of things that, once discussed by Work Groups, will overlap and will blend together into cohesive recommendations. At this point not overly concerned about where things fall. Her role, working with each Work Group and the full Committee, will allow her to make sure the Work Groups are not working in silos.
- Sharon: Review the five slides again.
    - Recommendation to merge "Roadmap to a Complex System" and "Reducing System Complexity" because no one is really interested in building tool kit. Group agreed.
    - Merging physical and behavioral health. Seconded by another group member. Added to include psychosocial – housing, etc. Whole person, person centered.

Skipped proposed dates & times for now

Work Groups - Topics

- Acknowledging 2 & 3 combined, what else is missing?
- Cultural – e.g., native American, etc. Agreement that it's not a separate Work Group; every Work Group has to include principle of cultural sensitivity and cultural competence.
- Assets inventory, e.g., telemedicine already exists. Can we look at what assets are out there that can be included? Current inventory to be added to Building Network Capacity Work Group.
- What about a group that is specific to writing outcomes/evaluations since it is a specialized skill? All of the Work Groups needs outcomes measures. Have each group design their own measures and then have an expert review to ensure they're measurable.
- Adding back in a 5th Work Group. What about adults – need a new Work Group? Yes.

    - We know this was sparked by EPSDT…but yes, this is critical.
    - Employment – even though that's not part of AHCCCS, it has to be part of the collaboration.
    - Group homes. Identify needs – e.g., once person doesn't need HAB. Higher rates of depression. They're still AHCCCS eligible, especially if unemployed.
    - Keeping people out of the hospital – most significant needs are often social, food, housing, etc.
- Outcome measures need to include quality of life measures.
- One persona said HAB has to be provided in 2016 as a result of HCBS rule changes; need to verify.
- Review:
    - Combining 2 & 3 and adding back in a 5th Work Group on Adults with ASD.
    - Each group does its own measures.

Workgroups – Composition

- Sharon asked everyone to come up to write which Work Group you want to be in.
- It is important that there be balance in each Work Group – at least one provider, plan representative, parent/advocate, state agency representative.
- Sharon: This is a start. Let's get a sense of things today and have everyone pick and then review for balance.
- Question: Are these in-person meetings or can we do phone/teleconference. Sharon said we did make decision not to call in for the full Committee meeting because too large a group, but Work Group work may be accomplished by phone and e-mail.
- Question: Time commitment for Work Group? Once per month as well? Sharon said it's the recommendation but some of this could be e-mail or phone, but the work needs to happen.
- Question: Is there a board or chair of each Work Group? Sharon said she will be responsible for that, organizing, facilitating, notes, etc.

Proposed Dates & Times

- Sharon. Difficult with group this size. Thought about Doodle but again hard with group this size. Heard from physicians that Wednesday afternoon is good. Does this look like a doable schedule? Group consensus was yes. Danny Kessler and Robin Blitz want to be involved and Wednesday is good for them.
- Question: Will you send meeting invitations via Outlook to block times? Yes. AHCCCS will send the invitations.

Other

- Sharon: Would it be helpful to edit the slides based on today's discussion and then post those slides? Group consensus, yes. Sharon will make edits and we will post slides to web.
- Share web link with anyone interested in the Committee's work.
- Sharon: Send me information about others who want to participate in Work Groups.
- Public comment? Monica on behalf of AHCCCS said yes, we can create special e-mail address to receive public comments.

Meeting adjourned at 2:48 p.m.