

AHCCCS ASD Advisory Committee
April 19, 2018 Meeting Notes

Notes compiled by Sharon Flanagan-Hyde, Facilitator—sharon@flanagan-hyde.com

Participants

1. Aaron Blocher-Rubin, PhD, BCBA/LBA, Chief Executive Officer, Arizona Autism United
2. Brian Kociszewski, Behavioral Health Program Manager, Arizona Health Care Cost Containment System (AHCCCS)
3. Brian van Meerten, MEd, BCBA, LBA, Director of Behavioral Health Services, Behavioral Consultation Services of Northern, Arizona, LLC (BCSNA)
4. Carey Burgess, BCBA, Clinical Director, Arizona Autism United
5. Cynthia Macluskie, Vice President, Board of Directors, Autism Society of Greater Phoenix
6. Dana Hearn, Assistant Director, Division of Health Care Advocacy and Advancement, Arizona Health Care Cost Containment System (AHCCCS)
7. Dennis Friedman, DO, Psychiatrist, Banner University Medical Center - Phoenix, University of Arizona
8. Diana Davis-Wilson, DBH, BCBA, LBA, Arizona Association for Behavior Analysis (AZABA)
9. Dominic Miller, Southwest Autism Center of Excellence (SACE), Southwest Behavioral & Health Services
10. Eric Tack, Arizona Health Care Cost Containment System (AHCCCS)
11. Jay Johnson, Education Program Specialist – PSO Initiatives, Exceptional Student Services, Arizona Department of Education
12. Jared Perkins, MPA, Director of Operations, Children’s Clinics; Vice President, Autism Society of Southern Arizona
13. Jennifer Drown, Insurance Billing and Coding Supervisor, HOPE Group
14. Joanna Kowalik, MD, Chief Medical Officer, Arizona Department of Economic Security/Division of Developmental Disabilities (DES/DDD)
15. Jon Meyers, Executive Director, The Arc of Arizona
16. Jonathan Mueller, Managing Director, Ascend Behavior Partners
17. Joyce Millard Hoie, MPA, Retired (Formerly Executive Director, Raising Special Kids)
18. Judy Walker, Arizona Health Care Cost Containment System (AHCCCS)
19. Karla Birkholz, MD, Arizona Academy of Family Physicians
20. Lauren Prole, Clinical Project Manager, Arizona Health Care Cost Containment System (AHCCCS)
21. Lindsey Zieder, Interim DDD Liaison & Special Projects Lead, Mercy Maricopa Integrated Care (MMIC), RBHA
22. Lisa Kunz, Autism and Low Incidence Specialist, Professional Learning and Sustainability, Arizona Department of Education
23. Matt Hoie, Self-Advocate

24. Paige Raetz, PhD, BCBA-D, Transition Academy Director, Southwest Autism Research & Resource Center (SARRC)
25. Ron Copeland, Senior Director of Program Development, Cenpatico Integrated Care (CIC), RBHA
26. Sara Salek, MD, Chief Medical Officer, Arizona Health Care Cost Containment System (AHCCCS)
27. Shannon Quinn, Intern, Arizona Autism United
28. Steven Sheets, MC, LPC, Senior Vice President, Southwest Behavioral & Health Services
29. Sydney Rice, MD, MSd, Board-certified Developmental Pediatrician; Associate Professor, Pediatrics, The University of Arizona College of Medicine in Tucson
30. Tatyana Farietta-Murray, MD, Children's Medical Director, Medical Management, Cenpatico Integrated Care (C-IC), RBHA
31. Terry Matteo, PhD, Clinical Child Psychologist

AHCCCS Complete Care Update

Dana Hearn, Assistant Director, AHCCCS Division of Healthcare Advocacy and Advancement (DHCAA) and Judie Walker (AHCCCS) presented an update on procurement and implementation of AHCCCS Complete Care, which will integrate physical and behavioral health care services starting on October 1, 2018.

PowerPoint slides are attached to the e-mail distribution of these notes.

Adults with ASD

Since its inception, the AHCCCS ASD Advisory Committee has recognized the importance on including the perspectives of adults with ASD when developing recommendations for system-level changes to better meet the needs of AHCCCS members with ASD. To that end, Sharon Flanagan-Hyde, the Committee's facilitator, is serving as the point person for gathering input through a range of methods.

Matt Hoie, a self-advocate, sent this information via e-mail. Matt also participated in the April 19 Committee meeting.

Most important issues:

- Friendship, social interaction
- Anxiety, depression (staying mentally healthy)
- Financial management
- Employment services
- Independent living

What changes would you like to see:

- "Health care - being smarter about managing care and help making healthy decisions"
- "Support for Independent living"
- "Coaching, tips, and planned social activities"
- "It would be nice to see offers of help from Support Coordinators" (Note: Matt is DDD TSC and not ALTCS)

What helped you in the transition to adulthood:

- “Working with family to set up personal care issues, meals, health care, set up schedules for school or job goals”
- “Job coaching”
- “Constructive feedback - compliments on strong performance as well as room for improvement”

Sharon met with 18 people in an Asperger’s Support Group in Tempe on March 10, 2018. She explained that the ASD Advisory Committee would like input on issues of importance to them. She did not use a discussion guide, bring up specific topics, or ask questions. The following is a summary of their comments:

- Recognize that autism is always present from childhood; it never arises in adulthood. Therefore, the requirement that it must be diagnosed before age 18 to receive services doesn’t make sense. Many people ages 40 and older were either misdiagnosed or not diagnosed before age 18, but they definitely have autism.
- PCPs’ lack of knowledge about autism is a major problem. Many reported being “insulted” by comments from PCPs.
- Doctors lack awareness that many people with autism are hypersensitive to medications and to sensory stimulation. For example, compression stockings that could be tolerated by a neurotypical person are intolerable for someone with autism.
- The DSM V does not include sensory disorder as a diagnostic indication of autism, yet everyone they know with autism has a sensory disorder.
- Diagnostic criteria as written are offensive. They are observations by neurotypical professionals written in terms of how people with autism affect neurotypical people. There is no input on how we experience the world.
- Autism should not be a psychiatric diagnosis. It is a neurological disorder.
- Most OTs are trained only in fine motor skills. They also need training in how to help clients improve sensory processing skills.
- Providers should talk with people about how to achieve the goals they choose. Many have experienced threats that they will be kicked out of care if they are not compliant, whether or not they agree with the goals or treatment approach.
- Sedation and antipsychotic drugs are used to achieve control and compliant behavior. This risks serious side effects and increased risk of dementia.
- It is very hard to pay for dental and vision care.
- There is confusion about getting insurance through the healthcare marketplace.
- Everyone in the meeting said they don’t like ABA. They said ABA is designed to encourage robotic behaviors and comply with neurotypical norms. “ABA sets us up to be victims of society.” “ABA tries to make us into good little robots.”
- By their 30s, most people are stressed and exhausted from trying to appear neurotypical. This increases the risk of health problems.
- It is very important to identify and treat underlying GI conditions and metabolic disorders. Insurers won’t pay for supplements that are sometimes an essential part of treatment.

- Their preference is that people not use “person first” language. “I don’t like being called a ‘person with autism’ – I am autistic.” “We are not like a ‘person with asthma’ where the asthma can be treated and eliminated and the person remains the same person.” “Autistic is who I am.” “Autism cannot be treated and taken away, no matter what some people claim. The person is always autistic, but removing stressors from the environment and improving help can impact the expressions of autism.”
- They want self-representation in all forums.

Sharon also talked with seven members of a Parents Group that meets at the same time as the Asperger’s Support Group. Again, she asked what issues are of importance:

- DDD should accept that autism was present at an early age, even if diagnosis was not made then, and make medically necessary services available.
- There is a need for more services for higher-functioning people. People may have some employment and income, but employment is not meaningful, and low income makes health insurance unaffordable, yet they are not eligible for AHCCCS.
- Vocational rehab and independent living are big concerns.
- Out-of-pocket expenses for vision, dental, OT, PT, and speech therapy mean that necessary services are prohibitively expensive.
- They are very frustrated trying to deal with DES. Calls are not returned and information confusing.
- Interactions with law enforcement is a concern.
- Medical professionals and therapists are not adequately trained on dealing with people with autism.
- Need grant money for support groups.

Sharon shared information about services and support available through various advocacy groups. Members of the parents group are unaware of many things they could access. Sharon sent links after the session.

AZ Dept. of Education Post-School Outcomes (PSO) Data on Individuals with Autism

Jay Johnson, Education Program Specialist – PSO Initiatives, Exceptional Student Services, Arizona Department of Education (ADE) gave a presentation on ADE’s data. PowerPoint slides are attached to the e-mail distribution of these notes. One of Jay’s key points is that greater use of assistive technology in schools correlates with more positive post-school outcomes.

Update: COB/TPL Work Group

The Coordination of Benefits/Third Party Liability Work Group has been working through scenarios and identifying topics to be covered in a Frequently Asked Questions document. The group has included consumer advocates, providers, health plans, DDD, RBHAs, and AHCCCS. The focus has been on operationalizing policies and/or changing rules/policies to make the experience easier for families; having private insurance is voluntary for ALTCS parents.

The areas being addressed include “pay and chase,” defining EPSDT services, and standardizing the code set used by DDD.

A key issue that requires additional discussion is the challenge of COB/TPL given that private insurers use a two-tiered model for ABA providers and DDD uses a three-tiered model. When a claim is submitted to private plans for EIBI services provided by a bachelor's or master's level provider being supervised by a BCBA, plans reject the claim; it never progresses to an issuance of a denial. As secondary, DDD needs a denial to cover the service.

The Work Group will meet on Tuesday, April 24 from 1:00-2:00 pm at AHCCCS for a targeted conversation on this issue.

Update: Crisis Response Work Group

The Crisis Response Work Group plans to develop and reach consensus on recommendations at a meeting on Thursday, April 26 from 2:00-3:00 pm at AHCCCS. The group has been discussing crisis services, avoiding crises through identifying caregiver stress, providing support to families, the transition from inpatient to outpatient care, law enforcement issues, and other topics. The group has included consumer advocates, providers (including Aurora representatives), law enforcement representatives, health plans, DDD, RBHAs, and AHCCCS.

BE SAFE Program

Cynthia Macluskie announced that providers are invited to observe a BE SAFE program on June 21 from 9:00 am through noon at Ability 360. For more information, please contact Cynthia at cynthia.marksmom@cox.net.

Future Meeting Dates

All ASD Advisory Committee meetings are from 3:00-5:00 pm at AHCCCS.

- Wednesday, July 11, 2018
- Wednesday, October 10, 2018
- Wednesday, January 9, 2019
- Wednesday, April 10, 2019