AHCCCS ASD Advisory Committee January 8, 2020 Meeting Notes

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

Participants

Please let Sharon know if you participated and your name was omitted, if corrections are needed, or if your title/affiliation have changed.

- 1. Aaron Blocher-Rubin, PhD, BCBA/LBA, Chief Executive Officer, Arizona Autism United
- 2. Alicia Amundson, Quality Improvement Manager, Arizona Early Intervention Program (AzEIP), Arizona Department of Economic Security
- 3. Amy Kenzer, Director of Clinical Services, Southwest Autism Research and Resource Center (SARRC)
- 4. Amy Pawlowski, Executive Director, UnitedHealthcare
- 5. Breanna Reeser, Manager, Integrated Behavioral Health, Care1st
- 6. Cameron Cobb, MSW, Senior Manager, Children's System of Care, Banner University Health Plans
- 7. Christopher Smith, PhD, Vice President and Research Director, Southwest Autism Research & Resource Center (SARRC)
- 8. Cynthia Macluskie, Vice President, Board of Directors, Autism Society of Greater Phoenix, Parent
- 9. Daniel Kessler, MD, FAAP, Consultant
- 10. David Harvey, Principal Consultant, Vantage Point Behavioral Resources, PLLC
- 11. Debbie Hillman, Chief Administrative Officer, Mercy Care
- 12. Diana Davis-Wilson, DBH, BCBA, LBA, Consultant, Aspen Behavioral Consulting
- 13. Diedra Freedman, JD, Board Secretary/Treasurer, Arizona Autism Coalition, Parent
- 14. Heidi Eccleston, Healthcare Administrator, Magellan Complete Care of Arizona
- 15. Janna Murrell, Assistant Executive Director, Raising Special Kids
- 16. Jared Perkins, MPA, CEO, Children's Clinics; President, Autism Society of Southern Arizona
- 17. Jill Rowland, M.ED, LPC, Chief Clinical Officer, Arizona Health Care Cost Containment System (AHCCCS)
- 18. Jon Meyers, Executive Director, The Arc of Arizona
- 19. Jonathan Mueller, Ascend Behavior Partners
- 20. Judith (Judie) Walker, Program Support Administrator, Office of Grants & Project Management, Division of Health Care Management, Arizona Health Care Cost Containment System (AHCCCS)
- 21. Karrie Steving, Children's System of Care Administrator, Mercy Care
- 22. Kellie Bynum, Program Director, Southwest Autism Center of Excellence (SACE), Southwest Behavioral & Health Services
- 23. Kelly Donohue, PhD, Behavioral Health Administrator/Psychologist, Arizona Department of Economic Security/Division of Developmental Disabilities (DES/DDD)
- 24. Kelly Lalan, MSW, ASD Care Coordinator, Health Choice Integrated Care, Steward Health Care Network
- 25. Kim Dionne, Project Manager, Child and Family Support Services
- 26. Lauren Prole, Clinical Project Manager, Office of the Director, Arizona Health Care Cost Containment System (AHCCCS)

- 27. Laurie Ganzermiller, Director of Special Programs, CRS/DD, UnitedHealthcare
- 28. Leslie Paulus, MD, PhD, FACP, Medical Director, UnitedHealthcare Community Plan
- 29. Lindsey Zieder, Children's Special Projects Lead, Mercy Care
- 30. Mary DeCarlo, BCBA, Arizona Department of Economic Security/Division of Developmental Disabilities (DES/DDD)
- 31. Megan Woods, MEd, BCBA, LBA, Integrated Care Administrator, Arizona Health Care Cost Containment System (AHCCCS)
- 32. Melissa Chevalier, BCBA, Director of ABA, Hopebridge
- 33. Paul Carollo, MC, NCC, LPC, BHP, Program Manager, Child & Family Support Services
- 34. Raakel Elzy, MA, BCBA, LBA, Associate Director of Clinical Services, Hope Group
- 35. Sarah Duarte, MEd, BCBA, LBA, Executive Clinical Director, Intensive Behavioral Treatment Dept., Arian Care Solutions, LLC
- 36. Scott Van Valkenburg, MD, Arizona Complete Health
- 37. Steven Sheets, MA, LPC, President & CEO, Southwest Behavioral & Health Services
- 38. Suzanne Perry, Director /619 Coordinator, Early Childhood Special Education, Early Childhood Unit, Arizona Department of Education
- 39. Terry Matteo, PhD, Clinical Child Psychologist
- 40. Terry Nunnally, Trans. Coord., Arizona Department of Economic Security/Division of Developmental Disabilities (DES/DDD)
- 41. Terry Randolph, Children's Healthcare Administrator, Arizona Complete Health
- 42. Tina Martin, Assistant Director, Services for Children with Disabilities, Southwest Human Development
- 43. Tisha Denton, MEd, BCBA, LBA, Associate Director of Staff Development, HOPE Group
- 44. Torie Hackett, Program Manager, Children's Developmental Center, Southwest Human Development
- 45. Travis Bell, MS, Med, Behavior Analyst, Aurora Behavioral Health System
- 46. Tresure Phillips, Children's Behavioral Health Care Manager, Banner University Family Care
- 47. Victoria Tewa MS, LPC, Director of Children's Services, Health Choice Integrated Care (HCIC), RBHA
- 48. Virginia Cons, LCSW, Care1st Health Plan Arizona
- 49. Virginia Rountree, Interim Deputy Director, Arizona Department of Economic Security/Division of Developmental Disabilities (DES/DDD)

Defining ASD Centers of Excellence

Vicki Cons, LCSW, Care1st Health Plan Arizona & Children's System of Care Administrators

Each AHCCCS Complete Care (ACC) health plan has been tasked to develop centers of excellence (COEs), including a COE for ASD. Representatives of the seven ACC plans have been working to development standardized criteria for ASD COEs. They started by looking at existing criteria and information collected by the RBHAs. They then solicited input from a wide range of stakeholders, including the Arizona Council of Human Service Providers. Using focus groups, online surveys, and forums, they asked stakeholders to specify what services a COE should provide and how they would define success. The group is in the process of finalizing the development of standardized criteria. At this point, six bucket areas have been identified:

- 1. Staffing model composition of the team within the COE
- 2. Critical outcomes each plan gathers data

- 3. Key performance indicators
- 4. Continuously seeking and receiving feedback from individuals who receive services and providers who make referrals annual customer satisfaction survey
- 5. Care coordination and collaboration between entities
- 6. Leadership within the community

It was noted by an Advisory Committee participant that since autism has a lot in common with other neurodevelopmental disorders, it might be better to call the COE a Neurodevelopmental COE instead of limiting services to ASD. Another participant explained that the label ASD COE is based on what's in the contract; services could develop beyond ASD in the future.

Other comments included the importance of addressing the needs of transition age youth and adults on the spectrum; ensuring that care coordination includes addressing comorbid medical conditions; and ensuring that specialists have an understanding of ASD.

Professional Development in Autism

Suzanne Perry, Director /619 Coordinator, Early Childhood Special Education, Early Childhood Unit, Arizona Department of Education

Slides and handouts are included with the distribution of these notes

The recommendations submitted to the governor by the AHCCCS ASD Advisory Committee in February 2016 included "Special educator training/scholarships (e.g., special educators of all levels, including preschool through college)." Suzanne's presentation included relevant statistics and ASD professional development activities through the Star Program. Star is an evidence-based, ABA-based program. The Arizona Statewide Autism Plan 2019-2020 includes:

- 1. Training in Evidence Based Practices (EBPs): Assessment, Discrete Trial Training, Pivotal Response Training, Functional Routines, Reinforcement (ABA).
- 2. Coaching: Each participating district receives five coaching visits per year. The following year, repeat participants become coaches through additional training.
- 3. Leadership: Director/Principal included in all trainings and supported on implementation; ADE Autism Specialist supports outside projects (e.g., Early Access to Care).
- 4. Multi-Disciplinary: Key members of team are included in training; includes instructional resources, coaching, and modeling and hands-on support.

In response to questions:

- Statistics on slide 3, the 14,119 children with autism eligibility include children ages 5 through 21.
- Teachers in private schools that include public school children can attend a training, but may be placed on a wait list.
- Current professional development for teachers does not include helping families access services in the state; Raising Special Kids provides this support to families.
- School districts self-select participation through an application process. Districts throughout the state have participated.
- Some of the model classrooms referenced on slide 9 are self-contained, and others are regular classrooms.
- Star offers parent training, but providing training is pending funding.

• If parent training is deemed necessary for a child to progress, the IEP team can include such training in the child's IEP, with payment by the school district.

American Academy of Pediatrics Clinical Report: Identification, Evaluation, and Management of Children with Autism Spectrum Disorder

Terry Matteo, PhD, Clinical Child Psychologist

Terry provided a summary of the clinical report (distributed with these notes) published in the January 2020 issue of *Pediatrics*. Abstract:

Autism spectrum disorder (ASD) is a common neurodevelopmental disorder with reported prevalence in the United States of 1 in 59 children (approximately 1.7%). Core deficits are identified in 2 domains: social communication/interaction and restrictive, repetitive patterns of behavior. Children and youth with ASD have service needs in behavioral, educational, health, leisure, family support, and other areas. Standardized screening for ASD at 18 and 24 months of age with ongoing developmental surveillance continues to be recommended in primary care (although it may be performed in other settings), because ASD is common, can be diagnosed as young as 18 months of age, and has evidenced-based interventions that may improve function. More accurate and culturally sensitive screening approaches are needed. Primary care providers should be familiar with the diagnostic criteria for ASD, appropriate etiologic evaluation, and cooccurring medical and behavioral conditions (such as disorders of sleep and feeding, gastrointestinal tract symptoms, obesity, seizures, attention-deficit/hyperactivity disorder, anxiety, and wandering) that affect the child's function and quality of life. There is an increasing evidence base to support behavioral and other interventions to address specific skills and symptoms. Shared decision making calls for collaboration with families in evaluation and choice of interventions. This single clinical report updates the 2007 American Academy of Pediatrics clinical reports on the evaluation and treatment of ASD in one publication with an online table of contents and section view available through the American Academy of Pediatrics Gateway to help the reader identify topic areas within the report.

Terry summarized these key points:

- Completed in 2019; first update in 12 years.
- Comprehensive, reflects changes since 2007 including increased prevalence rates, increasing knowledge of risk factors, increase in awareness of co-occurring medical conditions and genetic contributions, increases in the body of evidence for interventions, and changes to diagnostic criteria.
- Focus on importance of early intervention if there are risk factors, even before diagnosis.
- Highlights disparities in early identification and intervention among people of color, and increasing awareness of potential gender biases in symptom recognition (for example, high-functioning girls on the autism spectrum).
- Examines in detail co-occurring medical and behavioral health conditions and disorders, including sleep disorders, seizures, ADHD, anxiety, mood disorders, food refusal, selfinjury, aggression, and wandering.
- Notes that diagnoses are stable at early ages; diagnoses between 18 and 36 months are highly reliable; over 80% of diagnoses under age 3 are retained to adulthood.

- Recommends ongoing developmental surveillance at all visits; general developmental screening at 9, 18, and 30 months, and autism screening at 18 and 24 months.
- Includes details about screening tools; those with higher cognitive and language skills, especially girls, may be missed in early screenings.
- Goes into details about diagnoses and the tools that can be used.
- Talks about research on potential environmental factors that may have an association with autism.
- Describes evidence-based interventions in detail and the need to expand the types of interventions available to families, such as relationship-based models (for example, DIRFloortime) and naturalistic developmental behavioral intervention.
- Discusses management of co-morbid disorders, including mental health and behavioral health.

Comments:

- AHCCCS ASD Website has links to the health plans' lists of providers who diagnose ASD and ASD-specific services. The website is: https://www.azahcccs.gov/shared/asd.html
- The report talked about introducing augmentative and alternative communication (AAC) when children do not spontaneously speak. "Examples of AAC strategies include sign language, the Picture Exchange Communication System, and speech-generating devices. The use of AAC may help promote social interaction and understanding of the purpose of communication and does not delay onset of speech. Indeed, it may enhance emergence of spoken words by pairing nonverbal and verbal communication."

Positive Outcomes: Studies and Examples in Arizona

Cynthia Macluskie, Vice President, Board of Directors, Autism Society of Greater Phoenix; Parent

Cynthia's slides and additional information are included with the distribution of these notes:

- Optimal Outcome in Individuals with a History of Autism, published in the Journal of Child Psychology and Psychiatry in 2013
- PowerPoint presentation, Autism Into Adulthood: Striving for Success, Gary Stobbe, MD Clinical Associate Professor, University of Washington, Depts. Of Neurology & Psychiatry

Cynthia described her son Mark's early history, diagnosis of moderate to severe autism, and interventions. He participated in Dr. Deborah Fein's study on individuals who lose an autism diagnosis. Cynthia talked about the high level of multiple types of interventions Mark received at an early age, and noted that her family was in a privileged position (good employer-based health plan, educated parents who could navigate the system, the financial resources for one parent to be at home), and many families lack such resources. Other factors that contributed to a positive outcome were an excellent Support Coordinator who stayed connected to family long term, intensive early intervention, early entry into systems of care, success in obtaining all requested services, the flexibility to use therapies and modalities that were best for her son and family, and educational choice. Mark left DDD and ALTCS at age 8. When he participated in Dr. Fein's study at age 11, he was diagnosed with ADHD, dyslexia, and anxiety. He is now in college with a prestigious scholarship, and college is the biggest challenge he has faced. Cynthia said that it's very hard for someone with his background to decide who he is – there is a tendency to say

become a "yes person" instead of discovering what he really wants. Cynthia can be reached at cynthia.marksmom@cox.net.

Vision for this Committee: 2020 and Beyond

Jill Rowland, M.ED, LPC, Chief Clinical Officer, AHCCCS & Sharon Flanagan-Hyde, Facilitator

The AHCCCS ASD Advisory Committee began its work in 2015. As we start a new year, it seemed appropriate to take time for reflection on what this group has accomplished, how it has benefited the people served, and the vision of AHCCCS and Committee members for the future.

Jill Rowland is the AHCCCS Chief Clinical Officer, a newly created position. She will be playing a key role with the ASD Advisory Committee moving forward.

Jill noted that participation in the Committee has grown steadily during the past five years. The Committee's accomplishments since 2015 include the creation of the AHCCCS ASD website (https://www.azahcccs.gov/shared/asd.html) and ongoing updates; assistance in developing and implementing the AMPM 320 Behavioral Intervention Policy; registration of BCBAs; availability of ABA services for early intervention, acute care, and long-term care; and the contributions of the subgroup that worked through the challenges of third-party liability/coordination of benefits. AHCCCS is committed to continuing the Committee and interested in hearing the group's vision and ongoing recommendations.

Group discussion:

What has this group accomplished? How has it benefited the people you serve and supported your work?

- Developing relationships, access to people to problem solve, opportunity to have conversations outside of meetings to learn more about issues and programs mentioned during meetings.
- Accomplishing systems change over the last few years.
- From health plan perspective, Committee has been instrumental in educating us about what's happening in the community, opportunity for experts to present literature and research, helping us navigate what ABA can and should look like in our system.
- Helped families; providers feel increased confidence in talking with families about the system who to contact, at what agency. Building relationships within the network of providers has helped families; they trust a person that they go to, and because we have relationships with other agencies, they begin to trust those people; win-win situation.
- The model created for this group was replicated for the 2019 Abuse & Neglect Prevention Task Force. A key component of the model's success was opening up workgroup participation to anyone interested, in addition to the appointed members of the group. Inclusiveness led to more robust recommendations. Another key element was the relationships that developed among the group and the development of trust, which broke down barriers that had existed.

What comes to mind when you think about a vision for this group in the coming year and beyond?

Address:

• The needs of individuals with neurological-based conditions, in addition to the needs of individuals with ASD; opportunity to learn together and ensure that all AHCCCS members get the services they need. This group can be the leader to achieve this.

- Co-morbid conditions and specialty care.
- Access to full range of treatment modalities.
- Needs in rural areas, including how to enroll in AHCCCS.
- Transition to adulthood and care for adults; coordination of care and systems; counseling and services for adults and older teens; employment and vocational rehabilitation services.
- Educate families about to navigate the system, given the changes that occurred with integration of physical and behavioral health services.
- Early intervention. There is a need to analyze the system and make sure all children 0 to 5, especially 0-3, get the supports and services they need, either through AHCCCS plans or commercial insurance plans. Need to assess timeliness, whether families aren't able to access needed services because they are locked into one provider network. There is a team at First Things First working on mapping the system in order to help families navigate diagnosis, treatment, and referrals.
- Preventing/dealing with children who are wandering, lost, or abducted. Efforts underway with first responders. Cynthia offered to do presentation about the Be Safe program at a future meeting. Interest in presentation on autism-friendly environments. The City of Mesa recently received an autism certification.
- Transgender issues for people with ASD. Some research that shows a higher incidence of transgender in the autism population. Complicated issues and factors: increased violence against transgender individuals with ASD; suicidality; within autism community, confusion or questions about how do providers support do they encourage, do they question, do they limit people's questioning and ability to identify who they are? Comes up with teens and young adults. Raising Special Kids has seen an increase in the last few years in people seeking resources on transgender issues. Interest in asking Dr. Chulani from Phoenix Children's Hospital to present to the group. Contact Terry Matteo at terrymatteophd@gmail.com if you'd like to be part of a small group talking about transgender issues.
- Education on healthy sexual relationships and preventing sexual abuse.
- Brief update at every ASD Advisory Committee meeting on the status of the recommendations of the Abuse & Neglect Prevention Task Force.
- Needs of individuals with ASD in the prison population.

Announcements

- Sharon Flanagan-Hyde will be retiring this spring; April 1 will be her last meeting. Barb Brent will be taking over as facilitator. Barb is Director of State Policy for the National Association of State Directors of Developmental Disabilities Services (NASDDDS). She has extensive experience in publicly funded systems for children and adults with intellectual and developmental disabilities. She has worked in state and county government, as well as in the private sector. From 2006 to 2012 she served as the director of DDD, and as the deputy director for six years before that. Barb plans to attend the April 1 meeting.
- On January 6, KJZZ aired two pieces on the recommendations developed by the Abuse & Neglect Prevention Task Force appointed by Governor Ducey in response to the failure to maintain appropriate standards of care at Hacienda HealthCare. Reporter Kathie Ritchie

included comments from Ann Monahan and Jon Meyers in the first piece during the *Here and Now* program, and the website transcript includes photos of De Freidman, her son Andy, and her husband Frank. *The Show* program then included an interview with Christopher Tiffany, Executive Director of Raising Special Kids, and Lindsay Ashworth, Sexual Violence Response Manager at the Arizona Coalition to End Sexual and Domestic Violence. You can listen to both pieces on the KJZZ website: kjzz.org.

• Sharon talked about the memoir she recently published about her sister Mary Jean, who has severe developmental disabilities and autism. Mary Jean was in a horrific institution in the 1960s and '70s, and then suffered abuse in group homes during the '80s and '90s. Sharon wrote *Forget They Were Ever Born* to educate people about where we've come from, and why it's so important to continue to make public policy changes to ensure safety and supportive services for individuals with I/DD and their families. She thanked the Arizona Autism Coalition and The Arc of Arizona, who co-hosted the book launch in October. She will be doing a reading and audience discussion at Changing Hands Bookstore in Phoenix on February 11 at 7 pm.

2020 Meeting Schedule

All meetings are in the Arizona Room, AHCCCS, 801 E. Jefferson, Phoenix from 3:00-5:00 pm:

- April 1
- July 8
- October 7



ASD ADVISORY COMMITTEE MEETING

Wednesday, January 8, 2019 3:00 - 5:00 pm AHCCCS - 801 E. Jefferson St., Phoenix, 4th Floor-Arizona Room

Join Zoom Meeting

ahcccs.zoom.us/j/563710267?pwd=b... (ID: 563710267)

Join by phone

(US) +1 888-475-4499

Joining instructions

Joining notes Password: 565185

Time	Topic	Presenter
3:00 pm	Welcome and Introductions	Sharon Flanagan-Hyde, Facilitator
3:15 pm	Defining ASD Centers of Excellence	Vicki Cons, LCSW, Care1st Health Plan Arizona & Children's System of Care Administrators
3:35 pm	Professional Development in Autism	Suzanne Perry, Director /619 Coordinator, Early Childhood Special Education, Early Childhood Unit, Arizona Department of Education
3:55 pm	American Academy of Pediatrics Clinical Report: Identification, Evaluation, and Management of Children with Autism Spectrum Disorder	Sharon Flanagan-Hyde
4:05 pm	Positive Outcomes: Studies and Examples in Arizona	Cynthia Macluskie, Vice President, Board of Directors, Autism Society of Greater Phoenix; Parent
4:15 pm	Vision for this Committee: 2020 and Beyond	Jill Rowland, M.ED, LPC, Chief Clinical Officer, AHCCCS Sharon Flanagan-Hyde
4:45 pm	Additional Issues, Announcements, and Future Agenda Topics	Sharon Flanagan-Hyde
5:00 pm	Meeting Adjourned	

2020 Meeting Schedule

All meetings are in the Arizona Room, AHCCCS, 801 E. Jefferson, Phoenix from 3:00-5:00 pm: April 1

July 8

October 7





Arizona Department of Education Professional Development: Autism

SUZANNE PERRY

DIRECTOR EARLY CHILDHOOD SPECIAL EDUCATION

FORMER AUTISM AND LOW INCIDENCE DISABILITIES SPECIALIST

SUZANNE.PERRY@AZED.GOV

2016 ASD Advisory Workforce Development Report Recommendations

- o Recruitment of underrepresented medical sub-specialists who care for children and adults with ASD (e.g., rural specialists, developmental pediatricians, child psychiatrists).
- o Therapist training/scholarships (e.g., speech, occupational, physical therapists).
- o ABA/BCBA training/scholarships for specialists in treatment expertise (e.g., BCBA-B, BCBA-M, BCBA-D).
- o Special educator training/scholarships (e.g., special educators of all levels, including preschool through college).
- o Internships with provider agencies that specialize in working with individuals with ASD.

Setting the Stage: School Enrollment Statistics 2018-19



of children enrolled in public schools 1,125,599

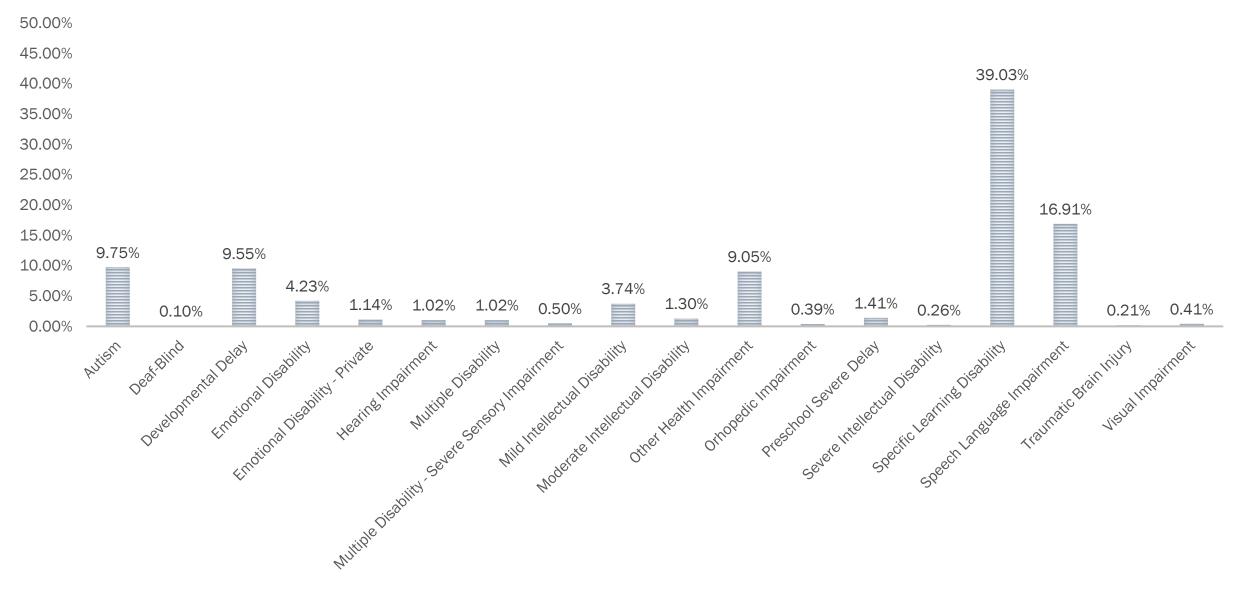


of children with disabilities PK-12 144,812 (12.8%)



of children with autism eligibility 14,119 (9.75%)

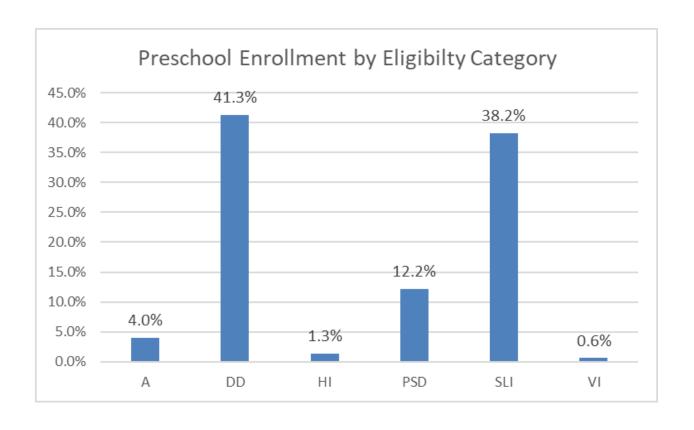
ELIGIBILITY CATEGORIES 2018-19



Preschool 2018-19

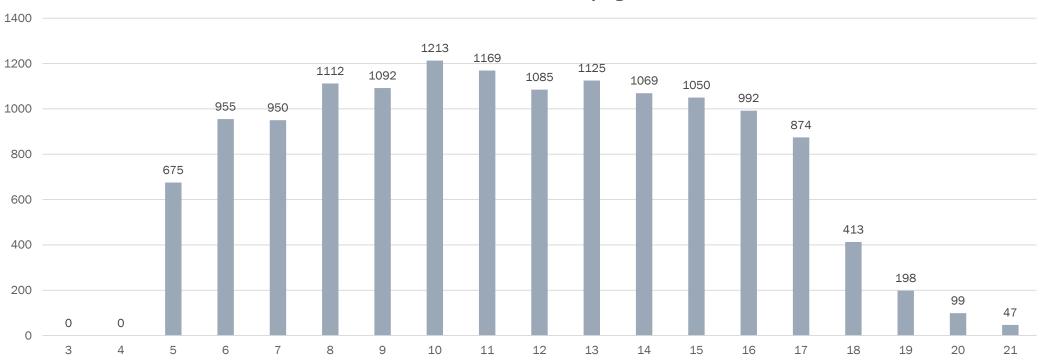
3-5 year old children with disabilities n=16,714

3-5 year old children in pre-k only n=10,240



of Children w/Autism Eligibility, by Age SY 2018-19







Professional Development

- >>> Recognize the NPDC on ASD for EBPs https://autismpdc.fpg.unc.edu/evidence-based-practices
- State required to follow procurement process to obtain outside professional development services
- Current contract with STAR Autism Support
- * Started in 2012 in Early Childhood only
- 2014 expanded to elementary, middle and high school teams
- Goal to establish district training sites to become self-sustaining in using EBP's

Arizona Statewide Autism Plan 2019-20



Training in EBP's:

Assessment, Discrete Trial Training, Pivotal Response Training, Functional Routines, Reinforcement (ABA) all included



Coaching:

Each participating district receives 5 coaching visits per year.

Following year, repeat participants become coaches through add'l training



Leadership:

Director/Principal included in all trainings, supported to look for implementation

ADE Autism Specialist supports outside projects (e.g., Early Access to Care)



Multi-Disciplinary:

Key members of team are included in training, includes instructional resources, coaching and modeling and hands on support

Key Outputs as of 2018-19

	2013-14	2014-15	2015-16	2016-17	2017-18	2018-19
# districts participating (teams of 5-10)	25	20	10 elem. 7 high sch.	12 elem. 14 high sch.	15 elem. 10 high sch.	7 elem. ~7 High sch.
# participants	250	200	250	250	250	250
# trained to be coaches					17	15
# model classroom sites					19	22

Results:

Student in districts implementing STAR with fidelity-students making progress in all areas of development—see report.

Goal: Quality Sustained Systems

Our goals is that Public Education Agencies have the capacity to serve children with developmental delays such as autism. The following are important components:

- PEA's Offer PD and require the use of EBP's
- PEA's utilize a system of quality evaluation procedures that result in educational programs that benefit the child
- PEA's offer ongoing coaching to support implementation of practices
- ADE continues to offer PD for ASD

How to Help

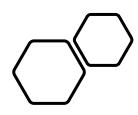
Parent Training

Autism and Low Incidence Disability Specialist position open

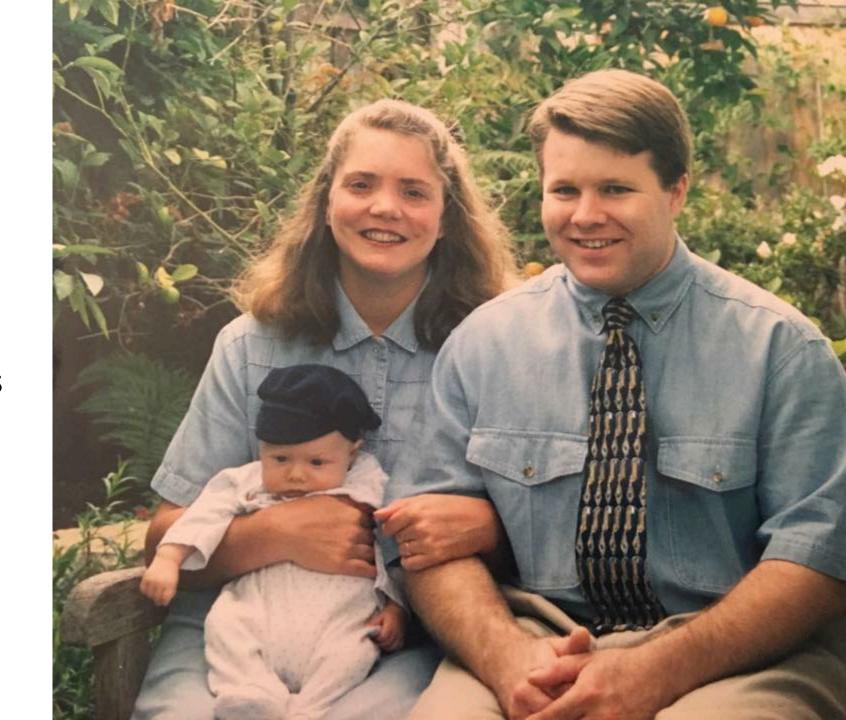
Optimal Outcome in Individuals with a History of Autism

Deborah Fein, Marianne Barton, Inge-Marie Eigsti, Elizabeth Kelley, Letitia Naigles, Robert T. Schultz, Michael Stevens, Molly Helt, Alyssa Orinstein, Michael Rosenthal, Eva Troyb, and Katherine Tyson

"The purpose of the current study was primarily to demonstrate the existence of a cohort who had clear autism at a young age and no longer demonstrated any significant autistic impairments. The data clearly support the existence of this group. The possible presence of subtle limitations or differences in social behavior, social cognition, communication, or executive functions remain to be elucidated in further analyses, as do many other crucial questions, such as the biology of remediable autism, the course of improvement, and the necessary and sufficient conditions, including treatment, for such improvement."



- Walks at 8 months
- Never crawls
- Talking at 10 months
- Two word combinations at 12 months
- Loses all language at 15 months
- Head banging at 2





Autism Diagnosis

"You should consider institutionalizing him and try to have another baby" UC Irvine Neurologist

"Mark will never be in a mainstream classroom and will never go to college. You need to have realistic goals for him" Cave Creek School District Psychologist



Therapy

- 2 hours of speech
- 2 hours of OT
- 20 hours of hab when in school
- 40 of hab when not in school
- Total of 45 hours a week of therapy
- Floortime, Relationship Development Intervention, Social Thinking, music therapy
- Homeschooled

Losing His Diagnosis

- Left DDD and ALTCS at age 8
- Participated in Good Outcome Study by Dr.
 Fein at age 11.
- Officially lost diagnosis of autism
- Diagnosed with ADHD, dyslexia, and anxiety.
- Only 1 or 2 willing to be interviewed



Off To College

 Every new social and emotional stage required additional support.

• Challenges in creating an identity



Feedback From Families

System Success

- Excellent Support Coordinator who stayed connected to family long term.
- Got every service requested
- Allowed the flexibility to use therapies and modalities that were best for child and family
- Allowed educational choice
- Intensive early intervention
- Early entry into systems of care

Individual Success

- Active parent involvement
- High IQ of child
- Highly educated parents who were experts at advocating and navigating systems
- Ability for one parent to work part time or stay home
- Had employer health plans that were robust, and families were higher income



Every Child Can Improve



Supporting Children with Autism and Other Developmental Delays in Childcare and Preschool Settings

Presented by Arizona Statewide Autism Project (AzSAP)

A cooperative project between Arizona Department of Education Early Childhood Education Unit and STAR Autism Support

This training opportunity will provide preschool staff, childcare staff and quality first coaches with a greater understanding of working with children with autism spectrum disorders. Topics discussed will include learning characteristics, behavioral strategies and simple activities to encourage social and language skill development. This workshop will provide specific examples of evidence-based practices that can be implemented immediately in the childcare setting.

Learn:

- · The characteristics of children with autism
- Evidence-based strategies for working with children with autism and other developmental delays
- · Practical instructional supports to improve social and language skill development
- Activities, behavioral supports and visual supports that can be used to immediately support children in a preschool or childcare setting

Who Should Attend:

 Preschool Development Grant participants, Quality First coaches, childcare center teachers, Head Start teachers, assistants, and other staff providing services to preschool-age children.

What You Will Receive:

- · Visual support bag, including behavior supports and social supports
- Access to additional on-line training modules
- Certificate of participation for 6 hours upon completion of the session
- Six hours of continuing education units (CEUs)



Game Rules

	Currently Scheduled Workshops	
*	*	*
October 18, 2019	October 23, 2019	October 24, 2019
Flagstaff, AZ	Phoenix, AZ	Tucson, AZ