AHCCCS ASD Advisory Committee
October 23, 2019 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.

1. Aaron Blocher-Rubin, PhD, BCBA/LBA, Chief Executive Officer, Arizona Autism United
2. Amy Kenzer, Director of Clinical Services, Southwest Autism Research and Resource Center (SARRC)
3. Ann Monahan, Board President, Arizona Autism Coalition; Vice President, State and Governmental Affairs, H.O.P.E. Group, LLC
4. Brian Kociszewski, M.Ed., BCBA, Centria Autism
5. Cameron Cobb, MSW, Senior Manager, Children's System of Care, Banner University Health Plans
6. Charlton Wilson, MD, Chief Medical Officer, Mercy Care
7. Cheryl Lovell, Assistant Director, Division of Developmental Disabilities (DDD), Arizona Department of Economic Security
8. Christopher Smith, PhD, Vice President and Research Director, Southwest Autism Research & Resource Center (SARRC)
9. Cynthia Macluskie, Vice President, Board of Directors, Autism Society of Greater Phoenix, Parent
10. Dana Flannery, Assistant Director, Arizona Health Care Cost Containment System (AHCCCS)
11. Daniel Kessler, MD, FAAP, Consultant
12. David Harvey, Principal Consultant, Vantage Point Behavioral Resources, PLLC
13. Debbie Hillman, Chief Administrative Officer, Mercy Care
14. Debra Wertzberger, Deputy Director, Programs, Division of Developmental Disabilities/Division of Aging and Adult Services (DDD/DAAS), Arizona Department of Economic Security
15. Diana Davis-Wilson, DBH, BCBA, LBA, Consultant, Aspen Behavioral Consulting
16. Diedra Freedman, JD, Board Secretary/Treasurer, Arizona Autism Coalition, Parent
17. Don Fowls, MD, Psychiatrist
18. Jared Perkins, MPA, CEO, Children's Clinics; President, Autism Society of Southern Arizona
19. Jon Meyers, Executive Director, The Arc of Arizona
20. Jonathan Mueller, Ascend Behavior Partners
21. Judith (Judie) Walker, Program Support Administrator, Office of Grants & Project Management, Division of Health Care Management, Arizona Health Care Cost Containment System (AHCCCS)
22. Kelly Lalan, MSW, Clinical Care Coordinator/DDD Liaison, Health Choice Integrated Care, Steward Health Care Network
23. Kim Dionne, Project Manager, Child and Family Support Services
24. Kyle Lininger, MPA, LBA, Divisional Director, CDC Arizona Act Early Ambassador, Intermountain Centers, Co-Chair, Arizona Association for Behavior Analysis (AzABA) Public Policy Committee
25. Leslie Paulus, MD, PhD, FACP, Medical Director, UnitedHealthcare Community Plan

26. Lindsey Zieder, Children's Special Projects Lead, Mercy Care
27. Megan Woods, MEd, BCBA, LBA, Integrated Care Administrator, Arizona Health Care Cost Containment System (AHCCCS)
28. Paul Carollo, MC, NCC, LPC, BHP, Program Manager, Child & Family Support Services
29. Paul Fawson, Senior Director of Value Based Solutions, Mercy Care
30. Raakel Elzy, MA, BCBA, LBA, Associate Director of Clinical Services, Hope Group
31. Sara Salek, MD, Chief Medical Officer, Arizona Health Care Cost Containment System (AHCCCS)
32. Sarah Duarte, MEd, BCBA, LBA, Executive Clinical Director, Intensive Behavioral Treatment Dept., Arian Care Solutions, LLC
33. Sherri Wince, ALTCS Administrator, Arizona Department of Economic Security/Division of Developmental Disabilities (DES/DDD)
34. Steven Sheets, MA, LPC, President & CEO, Southwest Behavioral & Health Services
35. Suzanne Perry, Director, Early Childhood Special Education, Arizona Department of Education
36. Terry Nunnally, Trans. Coord., Arizona Department of Economic Security/Division of Developmental Disabilities (DES/DDD)
37. Terry Randolph, Children's Healthcare Administrator, Arizona Complete Health
38. Tina Martin, Assistant Director, Services for Children with Disabilities, Southwest Human Development
39. Travis Bell, MS, Med, Behavior Analyst, Aurora Behavioral Health System

Value-Based Purchasing and Delivery of Compassionate Care

Charlton Wilson, MD, Chief Medical Officer, and Paul Fawson, Senior Director of Value Based Solutions, Mercy Care

Dr. Wilson defined compassion as kindness, caring, and a willingness to help others. He described the Health Care Payment Learning & Action Network (LAN) payment model framework. He emphasized the distinction between payment models and delivery models. Examples of delivery models that can improve coordination and efficiency of care include Centers of Excellence (COEs), Patient Centered Medical Homes (PCMHs) and Accountable Care Organizations. A given delivery model can accommodate a wide range of payment arrangements:

- Category 1: Fee-for-service, no link to quality and value
- Category 2: Fee-for-service, link to quality and value
- Category 3: APMs (Alternative Payment Model) built on fee-for-service architecture
- Category 4: Population-based payment

He shared examples from Mercy Care's experience with different delivery and payment models for services to members with ASD, and described potential areas for payment model development.

He suggested that the AHCCCS ASD Advisory Committee consider proposing measurements and identifying outcomes for ASD. He said that outcomes measures and incentives for providers caring for individuals with ASD in a value-based purchasing model should focus on standards of care (such as comprehensive evaluations, screening for comorbidities, and timely access to care), quality of life indicators, use of best practices identified by professional organizations, individual/family satisfaction, and family-centered care.

Meeting participants suggested that the agenda for the January 8, 2020 Committee meeting include an update and discussion about defining centers of excellence and performance-based measures for ASD outcomes, including outcomes for co-morbid medical conditions.

Recommended resource on payment models: Alternative Payment Model Framework — https://hcp-lan.org/workproducts/apm-refresh-whitepaper-final.pdf

The PowerPoint slides were distributed to the AHCCCS ASD Advisory Committee e-mail list.

Supported Decision-Making

Jon Meyers, Executive Director, The Arc of Arizona

Southwest Institute for Families and Children (SWI), Arizona Center for Disability Law (ACDL), and The Arc of Arizona are collaborating on a multi-year pilot project to educate the disability community and those that support them on the benefits of Supported Decision-Making (SDM). Funding for this coalition and pilot project is provided by the Arizona Developmental Disabilities Planning Council (ADDPC). The coalition's white paper, *Supported Decision Making in Arizona* (2019), is being distributed with these notes.

A person using SDM chooses a team of people to help him or her make decisions. It can be formal or informal, and can be used by anyone, including people with intellectual and/or developmental disabilities (I/DD), people with mental health issues, and seniors. Supporters agree to be available for advice and assistance, but do not make decisions for the person using SDM, except in specific circumstances.

The Arc's position statement on self-determination states that people with (I/DD) have the same right to, and responsibilities that accompany, self-determination as everyone else. They must have opportunities, respectful support, and the authority to exert control in their lives, to self-direct their services to the extent they choose, and to advocate on their own behalf. This includes the right to take risks, choose their own allies and to lead in decision-making about all aspects of their lives.

The "dignity of risk" is a concept that acknowledges risk is a natural part of life that helps all people learn and develop, and affirms the freedom to make mistakes and decisions for ourselves, even if others believe that the choices could be in error.

SDM agreements can serve as an alternative to guardianship; it does not replace guardianship as an option. Currently, nine states in the U.S. and the District of Columbia have passed a law recognizing SDM agreements, and five more are pending. SDM acts at the national level are in place in Australia, Canada, Ireland, Israel, Sweden, and the United Kingdom. Education and advocacy are needed to overcome barriers to implementing SDM.

Effective SDM laws recognize the right of person with disability to voluntarily enter into SDM agreement with supporter(s); determine scope of agreement; terminate agreement; specify protections against abuse, neglect, exploitation; provide templates of required content; and mandate reporting.

The PowerPoint slides were distributed to the AHCCCS ASD Advisory Committee e-mail list.

Introducing a Diagnostic Collaboration to Reduce the Average Age of Autism Diagnosis in Arizona

Christopher Smith, PhD, Vice President and Research Director, Southwest Autism Research & Resource Center (SARRC)

Chris summarized research by SARRC and the University of California San Diego School of Medicine on The Get SET Early Model designed to lower the age of ASD diagnosis. SET is an

acronym for Screen, Evaluate, Treat. Screening was done in the offices of a network of 109 pediatricians using the validated CSBS DP™ Infant-Toddler Checklist. This tool asks the parent/caregiver to respond to 24 queries about behavior with "Not Yet," "Sometimes," or "Often." Screening was conducted during visits at 12, 18, and 24 months. When the screen indicated the need for evaluation, psychologists were available for prompt, free, in-depth evaluation. The tool screens for all types of developmental delays, not just ASD.

Diagnosis dropped from the average of 56 months in Arizona reported by the CDC to an average of 22 months in the study. Early diagnosis enables interventions during a critical period of development.

Coordination between pediatricians and psychologists was an important component of the success of The Get SET model. The study coordinator was the link between the pediatric practices and SARRC psychologists. When pediatricians know that families don't have access to prompt evaluation, they tend to take a "wait and see" approach if developmental delays are suspected.

Putting the model into practice requires that all pediatricians conduct early screening and that professionals are readily available to conduct evaluations. SARRC is partnering with other organizations to expand the existing Arizona Autism Diagnostic Network (AADN) to increase the number of psychologists offering evaluations. In addition to expanding the diagnostic network, early diagnosis depends on securing funding for the care coordinators needed to connect families with diagnosticians and helping them navigate payment.

The PowerPoint slides were distributed to the AHCCCS ASD Advisory Committee e-mail list.

DDD Updates

Debra Wertzberger, Deputy Director Programs, DDD/DAAS and Cheryl Lovell, Assistant Director, DDD

- It was suggested that the agenda for the January 8, 2020 Committee meeting include a presentation by the DES Division of Employment & Rehabilitation (DERS) on the Phoenix Precision Project, established in collaboration with The Precisionists, Inc. (TPI), which provides employment opportunities for adults with autism. One area of focus is screening at a young age and socializing families to begin thinking about employment when a child with ASD is still young. DES is working with First Place to make the model more sustainable, and is talking with AHCCCS about the potential to bring in more federal funding.
- In response to a question about barriers to obtaining AzEIP services, Debra said to let Cheryl Lovell, Assistant Director, DES/DDD, (CLovell@azdes.gov) know about any problems. Further, contact Cheryl or Debra (dwertzberger@azdes.gov) about anything of concern regarding customer service, eligibility, or other issues.
- In response to a question about when billing mechanisms will be changed to incorporate bill codes (CPT codes, HCPCS codes), Debra explained that the Division has brought in a third party to help with systems. Because the systems are old, it will be at least 18 to 24 months before a solution is in place. Cheryl explained that the long timeframe is due both to technical challenges and the need to wait for funding in the state budget. The new system will require a new portal. They are also moving toward an Electronic Medical Record (EMR) model, which will take two to three years. Meeting participants talked about the Division utilizing Arizona's Health Information Exchange (HIE), and about the

challenges of not being able to see codes on the front end. When third-party liability (TPL) billing can't be done, it costs the state more money.

- In response to a question about billing at published rates, Debra said she would set up a meeting with interested individuals to share information and answer questions. People should send e-mails to Cheryl (CLovell@azdes.gov) with questions.
- Article 9 revisions will go out for public comment in November.
- DDD is closely monitoring the availability of providers, especially in rural areas, with the October 1 integration of physical and behavioral health services. Meeting participants talked about misunderstandings about rates on the part of providers, and the anxiety of families when they are told they will lose services.
- United Cerebral Palsy (UPC) and the American Network of Community Options and Resources (ANCOR) Foundation have released *The Case for Inclusion Report* (2019). This annual report ranks how well state Medicaid programs service people with I/DD and their families. Arizona holds the #1 ranking nationally.

  The report is being distributed with these notes.
- Dr. James Evans is the new DDD Chief Medical Officer.

AHCCCS ABA Policy Update

Sara Salek, MD, Chief Medical Officer, and Megan Woods, Integrated Care Administrator, AHCCCS

The AHCCCS ABA policy has been in development for almost two years. After substantial feedback during the first public comment period, AHCCCS asked the ASD Advisory Committee to form an ABA Policy Workgroup. The Workgroup submitted a draft policy in April 2019, which then went through internal AHCCCS review. A revised version was posted for public comment, and again, there was substantial feedback — 80 comments. Thirty dealt with appropriately identifying what is behavior analysis and making clear the acronyms for the different roles in delivering. There was agreement that there needs to be a three-tiered model that allows a licensed behavior analyst to supervise behavior analyst trainees and/or behavioral health technicians (BHTs). There were 34 comments on scope of practice, specifically communication — speech and language. Another large group dealt with definitions, including comments about the medical necessity. Behavior analyst services are covered when medically necessary; there are no age or diagnostic restrictions. AHCCCS made some revisions to address public comments. The final policy will be posted at the end of October.

Additional Issues, Announcements, and Future Agenda Topics

- Dr. Salek talked about the efforts of Phoenix Children's Hospital to provide training to primary care practitioners in order to expand early diagnosis and treatment for children with ASD.
- Cynthia Macluskie would like to offer a short presentation in January about positive outcome studies and examples of the good job providers are doing in Arizona.
- Sherri Wince will offer a presentation in January on National Core Indicators (NCI), a collaborative effort between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). NCI uses a series of surveys to measure member satisfaction and efficacy of DDD programs and services. The purpose of the program is to support NASDDDS member agencies to gather a standard set of performance and outcome

measures that can be used to track performance over time, compare results across states, and establish national benchmarks.

NCI reports are available on DDD's NCI website:
https://des.az.gov/services/disabilities/developmental-disabilities/accomplishments-and-initiatives/nci

2020 Meeting Schedule

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

- January 8
- April 1
- July 8
- October 7

AHCCCS
Arizona Health Care Cost Containment System

AGENDA

ASD ADVISORY COMMITTEE MEETING

Wednesday, October 23, 2019 3:00 - 5:00 pm
AHCCCS - 801 E. Jefferson St., Phoenix, 4th Floor-Arizona Room
Link for Google Hangouts Meet: meet.google.com/iwt-yjtp-mzr
Or dial: +1 404-947-5409 PIN: 262316#

Time	Topic	Presenter
3:00 pm	**Welcome and Introductions**	Sharon Flanagan-Hyde, Facilitator
3:15 pm	**Value-Based Purchasing and Delivery of Compassionate Care**	Charlton Wilson, MD, Chief Medical Officer, and Paul Fawson, Senior Director of Value Based Solutions, Mercy Care
3:35 pm	**Supported Decision-Making**	Jon Meyers, Executive Director, The Arc of Arizona
3:55 pm	**Introducing a Diagnostic Collaboration to Reduce the Average Age of Autism Diagnosis in Arizona.**	Christopher Smith, PhD, Vice President and Research Director, Southwest Autism Research & Resource Center (SARRC)
4:15 pm	**DDD Updates**	Debra Wertzberger, Deputy Director Programs, DDD/DAAS Cheryl Lovell, Assistant Director, DDD
4:35 pm	**AHCCCS ABA Policy Update**	Sara Salek, MD, Chief Medical Officer, AHCCCS
4:50 pm	**Additional Issues, Announcements, and Future Agenda Topics**	Sharon Flanagan-Hyde
5:00 pm	**Meeting Adjourned**	

2020 Meeting Schedule

All meetings are in the Gold Room, AHCCCS, 801 E. Jefferson, Phoenix from 3:00-5:00 pm:
January 8
April 1
July 8
October 7

Value-Based Purchasing and Delivery of Compassionate Care

AHCCCS ASD Advisory Committee October 23, 2019

Dr. Charlton Wilson, Chief Medical Officer

Paul Fawson, Sr. Director of Value Based Solutions

Compassion

…kindness, caring, and a willingness to help others.

Objectives

Identify a framework used for understanding value-based purchasing

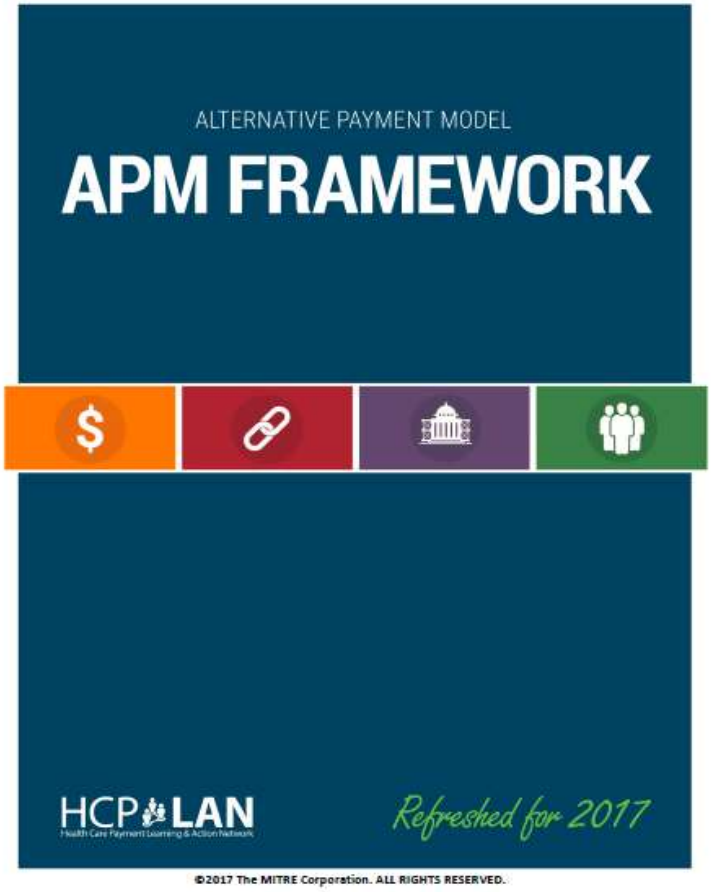
- Become familiar with the Health Care Payment Learning & Action Network (LAN) payment model framework
- Distinguish payment from delivery models
- Name some real-world examples from Mercy Care's experience
- Explore potential areas for payment model development

Identify areas where the AHCCCS ASD Advisory Committee can continue to provide valuable contributions

- List options to consider in developing next steps

Resource

https://hcp-lan.org/workproducts/apm-refresh-whitepaper-final.pdf



CATEGORY 1

FEE FOR SERVICE – NO LINK TO QUALITY & VALUE

CATEGORY 2

FEE FOR SERVICE – LINK TO QUALITY & VALUE

A

Foundational Payments for Infrastructure & Operations

(e.g., care coordination fees and payments for HIT investments)

B

Pay for Reporting

(e.g., bonuses for reporting data or penalties for not reporting data)

C

Pay-for-Performance

(e.g., bonuses for quality performance)

CATEGORY 3

APMS BUILT ON FEE-FOR-SERVICE ARCHITECTURE

A

APMs with Shared Savings

(e.g., shared savings with upside risk only)

B

APMs with Shared Savings and Downside Risk

(e.g., episode-based payments for procedures and comprehensive payments with upside and downside risk)

3N

Risk Based Payments NOT Linked to Quality

CATEGORY 4

POPULATION – BASED PAYMENT

A

Condition-Specific Population-Based Payment

(e.g., per member per month payments, payments for specialty services, such as oncology or mental health)

B

Comprehensive Population-Based Payment

(e.g., global budgets or full/percent of premium payments)

C

Integrated Finance & Delivery System

(e.g., global budgets or full/percent of premium payments in integrated systems)

4N

Capitated Payments NOT Linked to Quality

Payment Models vs Delivery Models

The APM Framework is limited to payment models, as opposed to delivery models.

Centers of Excellence (COEs), Patient Centered Medical Homes (PCMHs), and Accountable Care Organizations

- Delivery models that can improve coordination and efficiency of care
- Can accommodate a wide variety of payment arrangements

For example, a PCMH that participates in a:

- Bonus payment for achieving quality measures will be a Category 2
- Shared-savings payment will be classified in Category 3
- Population-based payments linked to value will be classified in Category 4

Mixed payment models may occur

Mercy Care Experience

Payments to providers who serve members on the spectrum:

- Timeliness of claims submission: claims submitted within 30 days of date of service (to allow timely data capture)
- Access to care: members have contact with provider within 14 days of being enrolled (timeliness)
- Multidisciplinary team visit: percent of members enrolled in the program that are seen by the team within the year (as a process for improving care coordination)

Shared Savings with ACOs (and ACO-like entities)

- Estimated total cost of care based on previous year(s)' experience
- Well child visits in the 3rd, 4th, 5th, and 6th years of life (at least one visit annually with a PCP)
- Developmental screening in the first three years of life
  - Two organizations have shown notable improvement (45%+ compared to baseline)

Potential Areas for Payment Model Development

Paying for ASD services as an episode/bundle payment

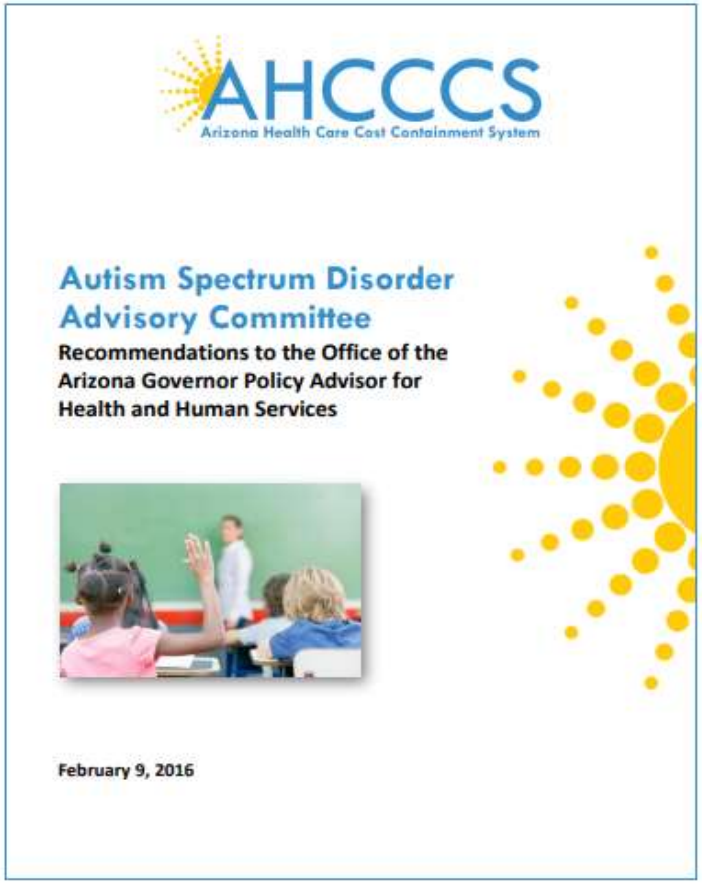
- Possibly “stratified” by the intensity of services needed
- This would require the development of quality measures and outcomes associated with the episode/bundle
- Arkansas Medicaid has used bundle payment models for Attention deficit hyperactivity disorder (ADHD) and oppositional defiant disorder (ODD)

Paying for ASD as a population-based payment

- Global payments inclusive of all services
- This would also require the development of quality measures and outcomes expected

Resource

https://www.azahcccs.gov/shared/Downloads/ASDAdvisoryCommReport.pdf



Areas the ASD Advisory Committee May Want to Consider

Proposing measurements and identifying outcomes for ASD

- Outcomes, measures and incentives for providers caring for individuals with ASD in a VBP model should focus on standards of care (such as comprehensive evaluations, screening for comorbidities, and timely access to care), quality of life indicators, use of best practices identified by professional organizations, individual/family satisfaction, and family-centered care

Exploring the opportunities and challenges of common vs unique payment models

Compassion

…kindness, caring, and a willingness to help others.

Thank You

Power to the Person

Supported Decision-Making and Self-Determination

ASD Advisory Committee

October 23, 2019

Jon Meyers

Executive Director, The Arc of Arizona

The Arc
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What are Decision-Making Supports?

Formal and informal ways people can have others help them make decisions:

- Advice and Guidance
- Representative Payee
- Powers of Attorney for Financial Matters and Health Care Matters
- Supported Decision-Making

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What is Supported Decision-Making?

- Supported Decision-Making (SDM) can be used by anyone, including people with I/DD, people with mental health issues, seniors
- SDM can be informal or formal
- Person using SDM chooses a team of people to help him/her make decisions
  - Supporters agree to be available for advice and assistance
  - Supporters do not make decisions for person using SDM, except in specific circumstances

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What is Supported Decision-Making?

- Increasingly, around the world, there is legal recognition of SDM agreements
- Texas was first US state to pass a law recognizing SDM agreements
- 9 states plus DC currently recognize, with 5 more pending

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Supported Decision-Making – We All Do It!!

Think about everyday choices you make:

- Changing jobs
- Moving
- What to have for dinner
- …and the list goes on

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Why Supported Decision-Making Matters

- Moving away from paternalistic and medical model of disability
- Empowerment vs. Substitution
- Natural way to grow a circle of support

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Self-Determination

People with intellectual and/or developmental disabilities (I/DD) have the same right to, and responsibilities that accompany, self-determination as everyone else. They must have opportunities, respectful support, and the authority to exert control in their lives, to self-direct their services to the extent they choose, and to advocate on their own behalf.

Including:

- The right to take risks
- The right to choose their own allies
- The right to lead in decision-making about all aspects of their lives

(excerpts from The Arc's Position Statement on Self-Determination)

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Conflicting Points of View

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Presuming Competence

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Consequences of NOT Presuming Competence

- Failure to focus on building skills, assuming people belong on a single "track"
- Individuals with disabilities may be left out of decisions around their services and everyday lives
- Ignorance about medical care
- Difficulties entering into contracts

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Dignity of Risk

- The concept that acknowledges risk is a natural part of life that helps all people learn and develop
- The freedom to make mistakes, to make decisions for ourselves, even if others believe that that choices could be in error.

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Right to Risk

"Security is mostly a superstition. It does not exist in nature, nor do the children of men as a whole experience it. Avoiding danger is no safer in the long run than outright exposure. Life is either a daring adventure or it is nothing."

- Helen Keller

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Differentiating SDM from PCP

Supported Decision-Making

- *Focuses on creating a process*
- *Affects interactions with the world*
- *Covers the universe of decisions*

Person-Centered Planning

- *Focuses on setting goals*
- *Affects interactions with agencies*
- *Covers activities within agencies' purview*

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Basic Components

- Gathering necessary information
- Educating individual about that information
- Identifying possibilities and alternatives
- Aiding individual in weighing choices and understanding consequences
- Helping communicate decisions to others
- Assisting in implementation of decisions

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SDM Alternatives to Guardianship

- Third-party financial management
- Specified case management/support coordination
- Advance directives
- Limited or standby guardianship – *when properly applied*

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Conflicts of Interest

- Retaining capacity provides protections from many forms of abuse or exploitation
- Power dynamic shifts
- Conflict of interest provisions should restrict who may serve as supporter:
  - Doctors
  - Those with major financial interest
  - Provider staff

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Conflicts of Interest

Others with potential conflicts:

- Parents
- Spouses
- Friends
- Personal support workers

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Where It Works

Outside U.S., notable nations with Co-Decision Making acts include:

- Australia
- Canada
- Ireland
- Israel
- Sweden
- United Kingdom

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Where It Works

Effective SDM Laws:

- Recognize right of person with disability to:
  - Voluntarily enter into SDM agreement with supporter(s)
  - Determine scope of agreement
  - Terminate agreement
- Specify protections against abuse, neglect, exploitation
- Provide templates of required content
- Mandate reporting

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Barriers to Acceptance

- Limited experience
  - Few examples from which to learn
  - Brief history of U.S. laws
- Lack of conceptual understanding
  - Policymakers
  - Support providers
  - Individuals & family members
- Concerns about coercion & abuse
- History of third-party authority

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Barriers to Acceptance

- Individual & institutional attitudes
  - Fear
  - Uncertainty of political climate
  - Equity
- Individualized approach
  - Not cookie-cutter solution
  - Investment of time, expertise, money
- Funding
- Institutional inertia: Power of the Status Quo

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Overcoming Barriers

Overcoming barriers to Supported Decision-Making requires more than simply changing Guardianship laws.

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Overcoming Barriers – Education & Advocacy

- Individuals with disabilities
- Communities
  - Grassroots – families & support networks
  - Advocacy & service organizations
- Legal professionals
- Healthcare providers
- Financial institutions
- Education entities

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Overcoming Barriers – Education & Advocacy

- Housing providers
- I/DD Service Providers
- State & Federal Governments
  - Agency leadership
  - Legislators
  - Courts

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Overcoming Barriers – Systems Change

- Focus on individual rather than preservation of system
- SDM options first consideration; full guardianship a last resort
- Safeguards built into SDM structure
- Understanding & acceptance of risk
  - Trial & error
  - Ongoing training, revision, reinforcement
- Collective action – *It Takes a Village*

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What "Systems Change" is Needed to Make Supported Decision-Making a Reality?

- Work together to gain recognition of SDM:
  - Public
  - Financial & Educational Institutions
  - Health Care System
  - Judicial System
- Build Decision-Making Skills
  - For adults
  - For children

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Change Offers Opportunities

- Put public face on ability, not disability
- Transform attitudes about competence
- Meet unique needs of each individual
- Maximize self-determination
- Increase community integration & inclusion
- Drive improvements in guardianship & conservatorship
- Increase efficiency & cost-effectiveness of support systems

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Supported Decision-Making Pilot Project

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Arizona's Developmental Disabilities Planning Council

Each state and territory of the United States has a council on developmental disabilities focused on advocacy, inclusion and improving access and services, as outlined in the Developmental Disabilities Assistance and Bill of Rights Act of 2000.

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Grant Partners

Southwest Institute for Families and Children supports people with disabilities through empowerment, advocacy, and knowledge.

ACDL is a non-profit law firm that assists Arizonans with disabilities to promote and protect their legal rights to independence, justice, and equality.

The Arc of Arizona advocates for the rights and full community participation of all people with intellectual and developmental disabilities by improving systems of supports and services, connecting families, inspiring communication, and influencing public policy.

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Project Goal

Increase the use of Supported Decision-Making among individuals with intellectual and developmental disabilities as an alternative to legal guardianship.

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White Paper

- Forums conducted in northern, central, and southern Arizona
  - Parents and caregivers
  - Young adults with IDD
- Interviews with relevant stakeholders
  - Medical providers
  - Education professionals
  - legal professionals
  - Social service providers

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Our Findings

- Widespread misunderstanding about legal guardianship – necessity, process, responsibilities, implications, limitations
- Misinformation is rampant
  - Spread by institutional as well as informal sources
  - Rural areas, in particular, have few reliable resources
- Continues to be seen as default option

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Our Findings

- Very little familiarity with concept of Supported Decision-Making
  - Families/caregivers
  - Individuals with IDD
  - Professionals
- Resistance likely from some stakeholder communities
- *But*, eagerness to learn more

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How We Will Reach Our Goal

- Teach family members and caregivers, individuals with IDD, and all relevant stakeholders about Supported Decision-Making.
- Pass legislation recognizing Supported Decision-Making as a less restrictive alternative to legal guardianship.

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Curriculum

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People with IDD, families, and caregivers

- Learn how to advocate for themselves
- Learn the history and philosophy of the self advocacy and independent living movements
- Learn the differences between Supported Decision-Making and legal guardianship
- Learn how to create a supported decision-making agreement

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Legal & Judicial Community

- Learn about intellectual and developmental disabilities
- Learn the differences between Supported Decision-Making and legal guardianship
- Learn the proper role and responsibilities of trusted advisors within a Supported Decision-Making relationship

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Social Service Providers, Medical and Education professionals

- Learn about Supported Decision-Making and its benefits
- Learn how to develop a Supported Decision-Making relationship with a client or patient
- Learn how to best work with a client or patient who uses Supported Decision-Making

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Legislation

- Collaborate with disability partners to develop legislation
- Introduce in the 2020 AZ legislative session
- Educate lawmakers and state agency leaders
- Encourage advocacy for proposed legislation among various stakeholder communities

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Resources

National Resource Center for Supported Decision-Making

http://supporteddecisionmaking.org/

Center for Public Representation

https://supporteddecisions.org/

The Arc Wisconsin – Learn about Supported Decision-Making in Wisconsin

https://arcwi.org/2018/04/13/supported-decision-making/

The Arc's Center for Future Planning

https://futureplanning.thearc.org/

The Arc
Arizona

Questions?

Jon Meyers

(602) 290-1632 / jon@arcarizona.org

The Arc.
Arizona

The Get SET Early Model

Lowering the age of ASD Diagnosis

UC San Diego
SCHOOL OF MEDICINE

SARRC

I. Model Review: The Get S.E.T. Early Model


CSBS DP Infant-Toddler Checklist

Model Refinement

Examine Get SET Metrics

- Engage all racial/ethnic communities
- Create pediatrician network
- Use validated broadband screening
- Start screening at 12 months
- Triple screen at 12, 18, & 24 months
- Screen digitally when possible
- Track referrals

+ reasons for non referral

Screen

Evaluate

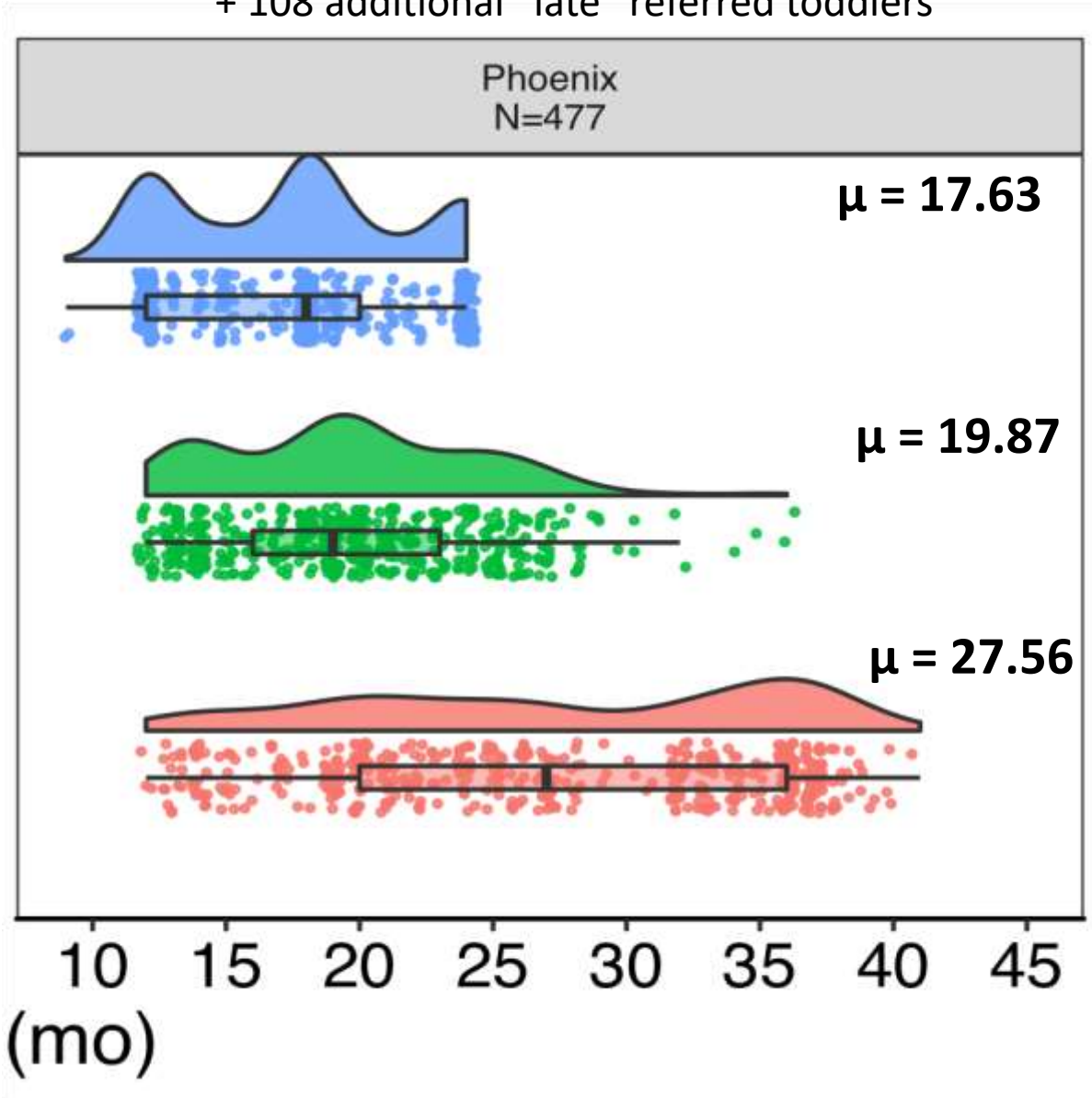
Treat

- Track treatment engagement
- Optimize Treatment
- Provide In-depth Evaluation
- Create ASD-Expert Evaluation Center

Formerly the "***1-Year Well-Baby Check-Up Approach" Pierce et al., (2011)***

Phoenix: 27,301 Screens

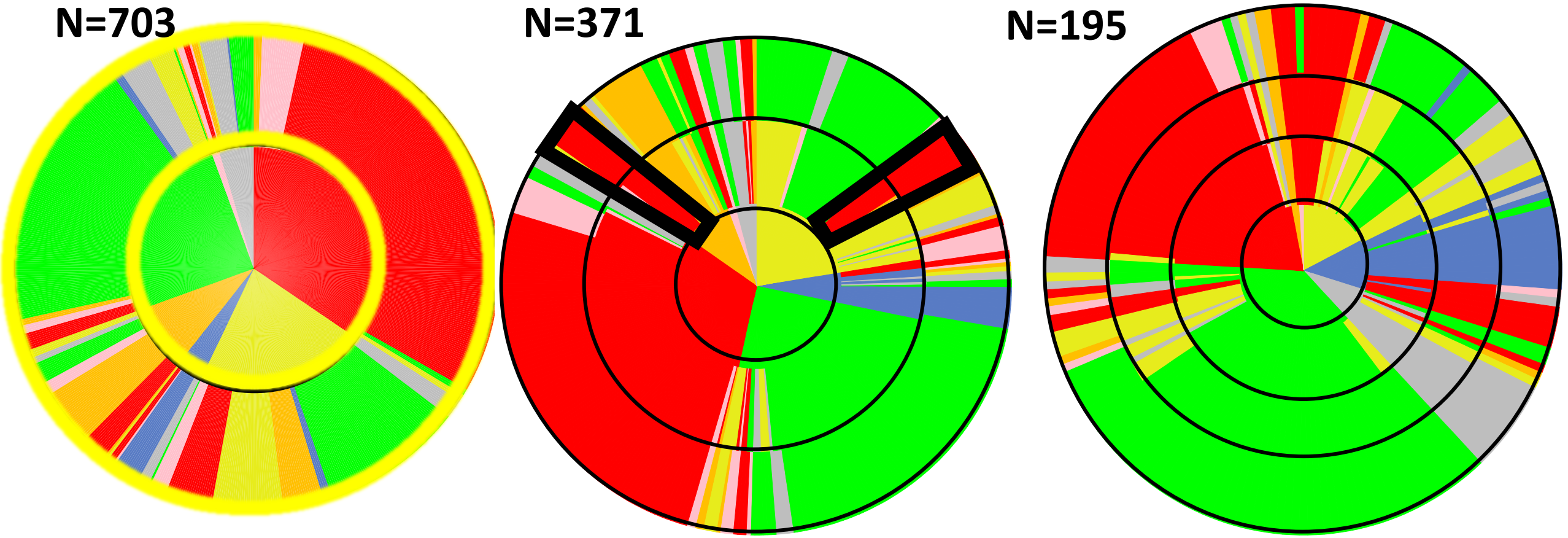
+ 108 additional “late” referred toddlers



Diagnostic Outcomes: N =477

ASD	Feat	DD	LD	TD
186	84	87	63	59
39%	**17%**	**18%**	**13%**	**13%**

"Late Onset" DIAGNOSTIC "HEAT MAPS" Total N = 1,269



24% of ASD cases missed at 1st Dx Evaluation

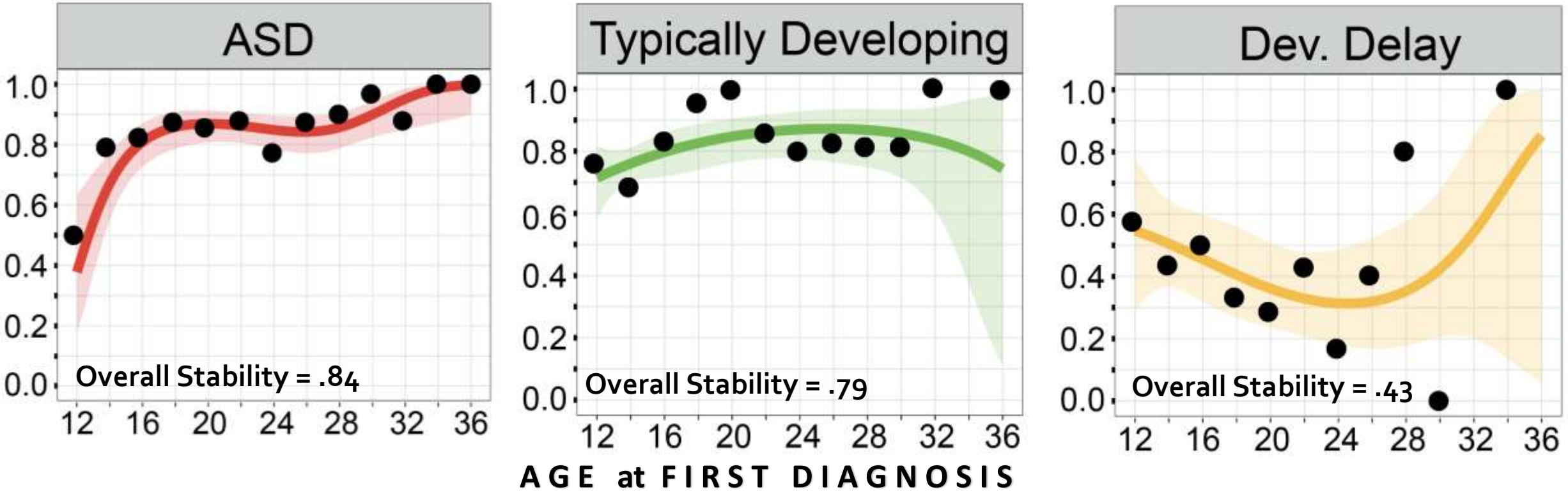
Pierce et al., 2019

JAMA Pediatrics | Original Investigation

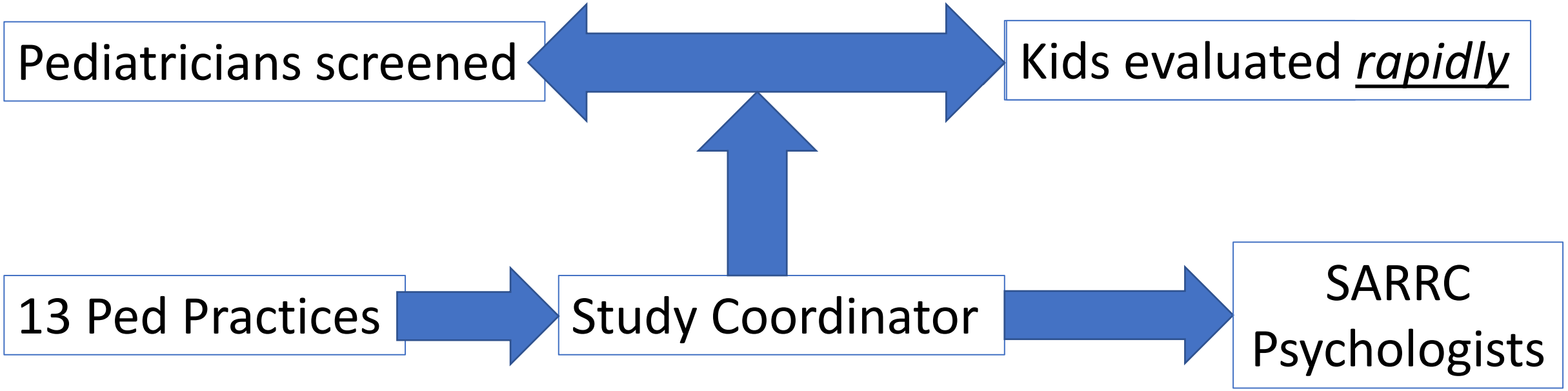
Diagnostic Stability of the Early Autism Spectrum Disorder Phenotype in the General Population Starting at 12 Months

Karen Pierce, PhD; Vahid Gazestani, PhD; Elizabeth Bacon, PhD; Cynthia Carter Barnes, PhD; Debra Cha, PhD; Srinivasa Nalabolu, PhD; Linda Lopez, BS; Adrienne Moore, PhD; Sunny Pence-Stophaeros, MA; Eric Courchesne, PhD

N =1,269



Get SET was successful because:



How do o practice?

All Arizona Pediatrician Screening an Referring

Arizona Licensed Psychologists Diagnostic Network

Arizona A etwork

Dear Healthcare Partner,

The organizations above are collaborating to lower the age of autism diagnosis in Arizona. We are reaching out to gauge your interest in being a critical component of achieving this goal.

Currently, the median age of ASD diagnosis in Arizona is 56 months (CDC, 2014). A late diagnosis can rob a child of the opportunity to receive treatment during the early developmental period when the brain has significantly more neural plasticity and treatment can have the greatest impact.

We can solve this problem by providing rapid access to diagnostic evaluations for young children. More licensed psychologists to diagnose autism is critical to our success, so we are expanding on the existing Arizona Autism Diagnostic Network (AADN). Join a community of practitioners dedicated to helping children be diagnosed early and in treatment before the age of three.

As a provider in the AADN network, you will:

- Help lower the age of autism diagnosis to less than 36 months.
- Receive a steady stream of referrals (matching your availability) for diagnostic evaluations of young children.
- Potentially have the opportunity to receive training (and CEU credits) pertaining to the diagnosis of autism.

As we grow, we may provide assistance with scheduling, insurance credentialing, and billing for services, but at this point, we are in the development phase. One of our first steps is gathering the names of professionals who are interested in solving this public health crisis. If you have an interest in staying informed of our progress, please email csmith@autismcenter.org and I will personally add your name to the interest list. Future communications will only be sent to the AADN interest list, so please let us know!

Looking forward!

Chris

Christopher J. Smith, Ph.D.
Vice President & Research Director
Southwest Autism Research & Resource Center

P.S. Learn about the evidence that shows this approach is effective for lowering the age of diagnosis by clicking here.