

# **Early Access to Care – AZ**

## **Early Diagnosis, Intervention, and Medical Home Care for Children with ASD**

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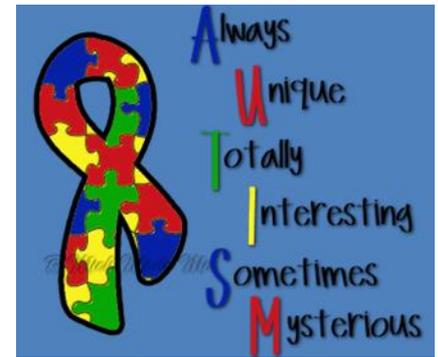
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**First Things First**  
**August 23, 2016**



# WHAT IS AUTISM?

# What is Autism?



- Impaired communication
- Difficulties with social interactions
- Repetitive or ritualistic behaviors, activities and interests
- Sensory processing hypersensitivities – light, noise, chaos, new places, people, things

# Symptoms of Autism

TYPE	SYMPTOMS
BEHAVIORAL	<ul style="list-style-type: none"><li>Repetitive movements</li><li>Routines or rituals</li><li>Constant movement</li><li>Uncontrollable tantrums</li><li>Obsessed with specific object</li><li>Self-injurious behaviors</li><li>Pica</li><li>Heightened sensation</li><li>Challenging behaviors</li></ul>
COMMUNICATIVE	<ul style="list-style-type: none"><li>Delayed speech, unable to speak</li><li>Loss of language or words</li><li>Abnormal tone of voice</li><li>Avoid eye contact</li><li>Diff. initiating / sustaining conversation</li><li>Echolalia</li><li>Diff. understanding question / direction</li></ul>
SOCIAL	<ul style="list-style-type: none"><li>Failure to respond to name</li><li>Poor eye contact</li><li>Resistance to holding and touch</li><li>Preference to playing alone</li><li>Failure to develop peer relationships</li><li>Lack of empathy</li></ul>

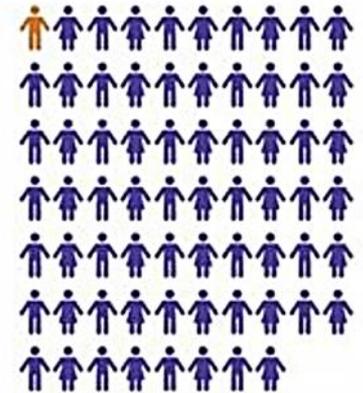
# **WHAT DO WE KNOW ABOUT AUTISM and ARIZONA?**

**And why do pediatricians  
in Arizona need training?**

# ASD – Why Identify Early?

- Autism causes severe disruptions for children and their families
- Autism spectrum disorders are common
  - 1 per 68 (1/42 boys, 1/189 girls)
    - 1/66 in Arizona
  - Recurrence risk in siblings: 18.7%
  - Lifetime per capita societal cost of autism: \$3.2 million (2007)
- Age of diagnosis in Arizona – 4 yrs, 7 mos

NUMBER OF CHILDREN IDENTIFIED WITH ASD



1 in 68

# Access for children with Special Needs, including Autism

Clinic Visits - January 1, 2015 to August 20, 2015		
Diagnosis	Maricopa County	Other Counties
Autism Diagnosis	728	182
ADHD	492	123
Down Syndrome	350	87
Fragile X Clinic	66	16
Ccrib	20	5
Developmental Delay	286	72

- **01.2015-08.2015 - 2,069**
- **Access to Diagnosis and to Care**
- **Children with ASD need:**
  - **multiple subspecialities**
  - **stay in the hospital longer**
  - **Need coordinated care**



# Medical Conditions

## Care of a child with ASD is

### 24 / 7 / 52

- **GI: 9-70%** - chronic constipation / diarrhea, recurrent abdominal pain, celiac, GER
- **Seizures: 11-39%**
- **Sleep problems: up to 80%**
- **Common childhood illnesses**
  - Ear infections, headaches, allergies, asthma, dental
- **Not so common**
  - Diabetes, JRA, leukemia

# Healthcare / hospitalization of Children with ASD

- Higher healthcare utilization and medical expenditures
- 2007 HealthCare Utilization Project Nationwide Inpatient Sample database:
  - Significantly longer length of stay, higher hospitalization charges, and more diagnoses at discharge
- Respite care decreases need for hospitalization:
  - Each \$1000 spent for respite associated with 8% decrease in odds of hospitalization

# PCP's and Autism Screening

- **Current detection rates of developmental disorders are lower than their actual prevalence, which suggests that the challenges to early identification of children with developmental disorders have not been overcome.**

Sand, Silverstein, Glascoe, Gupta, Tonniges & O'Connor. (2005)

# Autism In Arizona

**Early intervention works, but is not accessible to all**





# WHAT IS A MEDICAL HOME?



# Medical home for the child with Autism

- Family-centered care in a medical home
  - 2005-2006 National Survey of CYSHCN prevalence of 13.9%; only 47.1% had access to a medical home
  - Children with ASD have the least access to a medical home

# Medical Home

- A medical home is not a place-it is the way care is provided to children, youth, and their families.
- It is an approach to providing health care services in a high-quality and cost-effective manner.
- Is as much an attitude as it is a way of delivering care.

# Why Medical Home Care?

- Other benefits of Medical Home Care include but are not limited to:
  - Improved safety
  - Decreased cost of care
  - More satisfactory experience for the parents, child, and pediatrician

# PCP's Need Help!

- PCP's report:
  - Overall lower competency, less confident and less comfortable
  - Greater need for primary care improvement
  - Greater desire for education for children with autism



**What are other  
states doing?**

# Other States' Programs

- Arkansas – CoBALT Program
  - <http://www.arpediatrics.org/specialties/developmental-pediatrics/cobalt-program>
- Missouri – Echo Autism
  - <https://thompsoncenter.missouri.edu/training/echo-autism/>
- Indiana – Early Evaluation Hubs
  - <http://pediatrics.iu.edu/chsr/research/chipin/current-projects/>

# Other States' Programs

- Ohio – ADEPT / OCALI
  - <http://www.ocali.org/project/adept>
- Utah – Autism Learning Collaborative
  - <http://pediatrics.aappublications.org/content/early/2016/05/02/peds.2015-1850>
  - <https://projects.upiq.org/upiq-public-content/previous-projects-content/upiq-autism-collaborative/upiq-autism-binder>



# HOW DO WE FIX THIS in Arizona?

# Board of Visitors Grant Funding



**Care Card – Unrestricted Grant to Developmental/ Behavioral Pediatrics Clinic at Phoenix Children’s Hospital**

- \$261,000 (2015)
- \$200,000 (2016)
- + Additional funding 2017

**BoV**  
THE BOARD OF VISITORS

# Early Access to Care – AZ

## Goals



- Implement and evaluate a **model program** in community settings
- Decrease the **age of diagnosis** of ASD in Arizona (and time from parent concern to dx)
- Increase **access** to early intervention
- Target communities that are **underserved**
- Increase access to **medical homes**
  - Increase accessibility of subspecialty support in rural/remote areas via **telemedicine**

# Early Access to Care – AZ

## Program Methods



- Develop a training program for **PCP's**
- Implement trainings for **AzEIP and School** personnel to provide supportive data to PCP's
- Develop **telemedicine** subspecialty support network for PCP's
- **Assess:**
  - PCP's **competence and confidence** in diagnosing ASD
  - PCP's **medical home provision**

# Early Access to Care – AZ

## Expected Results



- Improve **quality of life** through earlier dx and access to interventions
- Enhance dx and tx of **underserved populations**
- Address **medical comorbidities** through provision of medical homes
- Improve PCP's **competence and confidence** in caring for children with ASD
- Provide **telemedicine** support
- Increase **evidence-based practice** in Arizona

# EAC-AZ Mini-Fellowship / Learning Collaborative

- **Conferences**
  - #1 - STAT and ADOS training, Regional Team meetings
  - #2 – Medical Comorbidities
- **Twice monthly webinars**
- **Learning Modules**
  - CDC ACT Early
  - OCALI Strategies
- **Monthly reading materials**
- **QI Projects:**
  - M-CHAT-R
  - Sleep

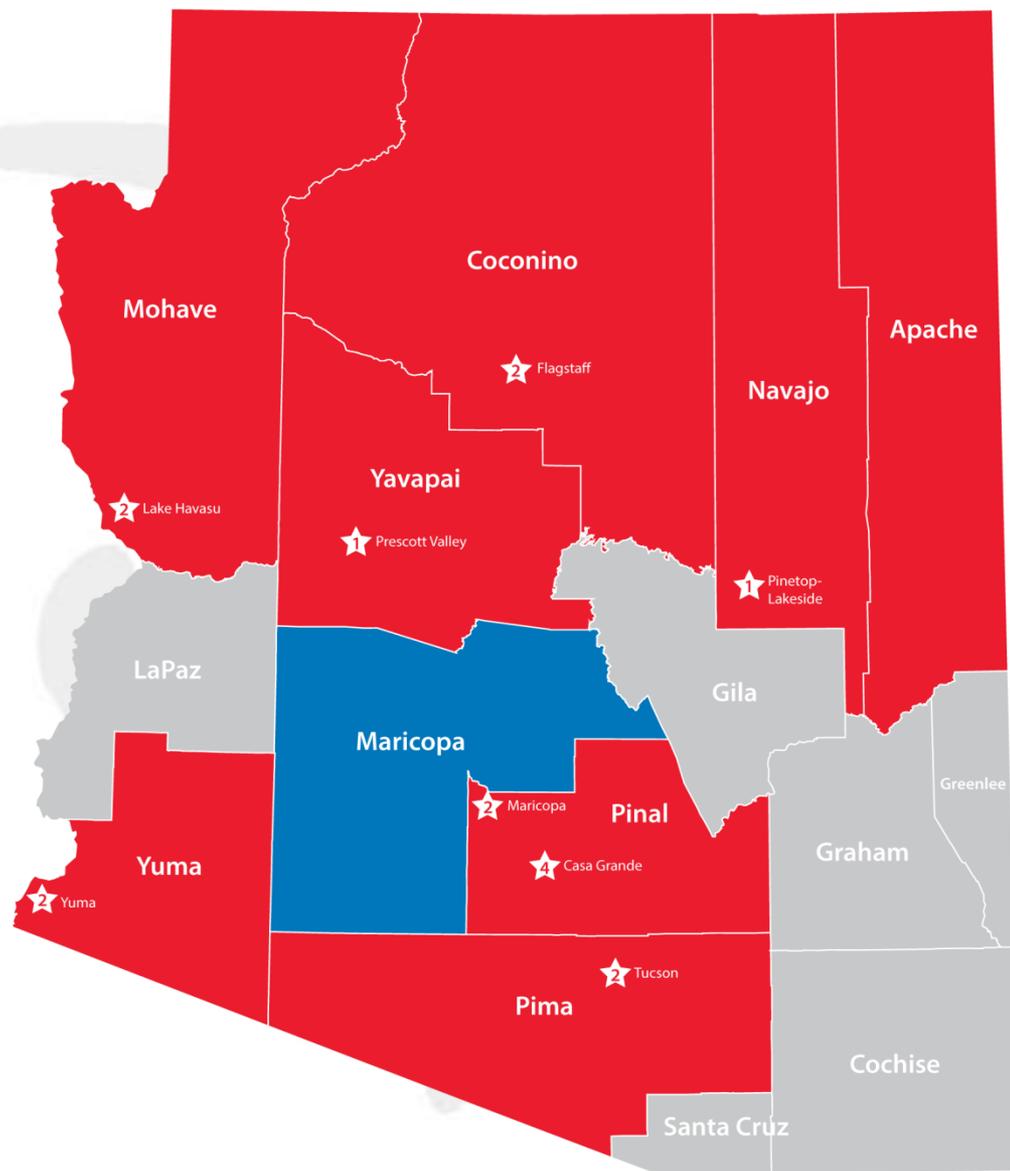
# Early Access to Care – AZ Telemedicine Support Network A Work in Progress



- **Subspecialists from PCH**
  - GI, Neurology, Psychiatry, Psychology, DBPeds, Genetics, Special Education
- **Zoom software**
  - HIPPA compliant
  - Easy to use

# Early Access to Care – AZ Project Update

Region	# of practices	# of children with ASD - County
Casa Grande	3	1769- Pinal
Flagstaff	2	609 - Coconino
Lake Havasu	1	698 – Mohave
Maricopa	13	17,707 - Maricopa
Pinetop-Lakeside	1	543 – Navajo
Prescott /Cottonwood	2	690 – Yavapai
Tucson	3	4008 - Pima
Yuma	1	1001 – Yuma



# Local People, Local Solutions

- **Build Community Networks**

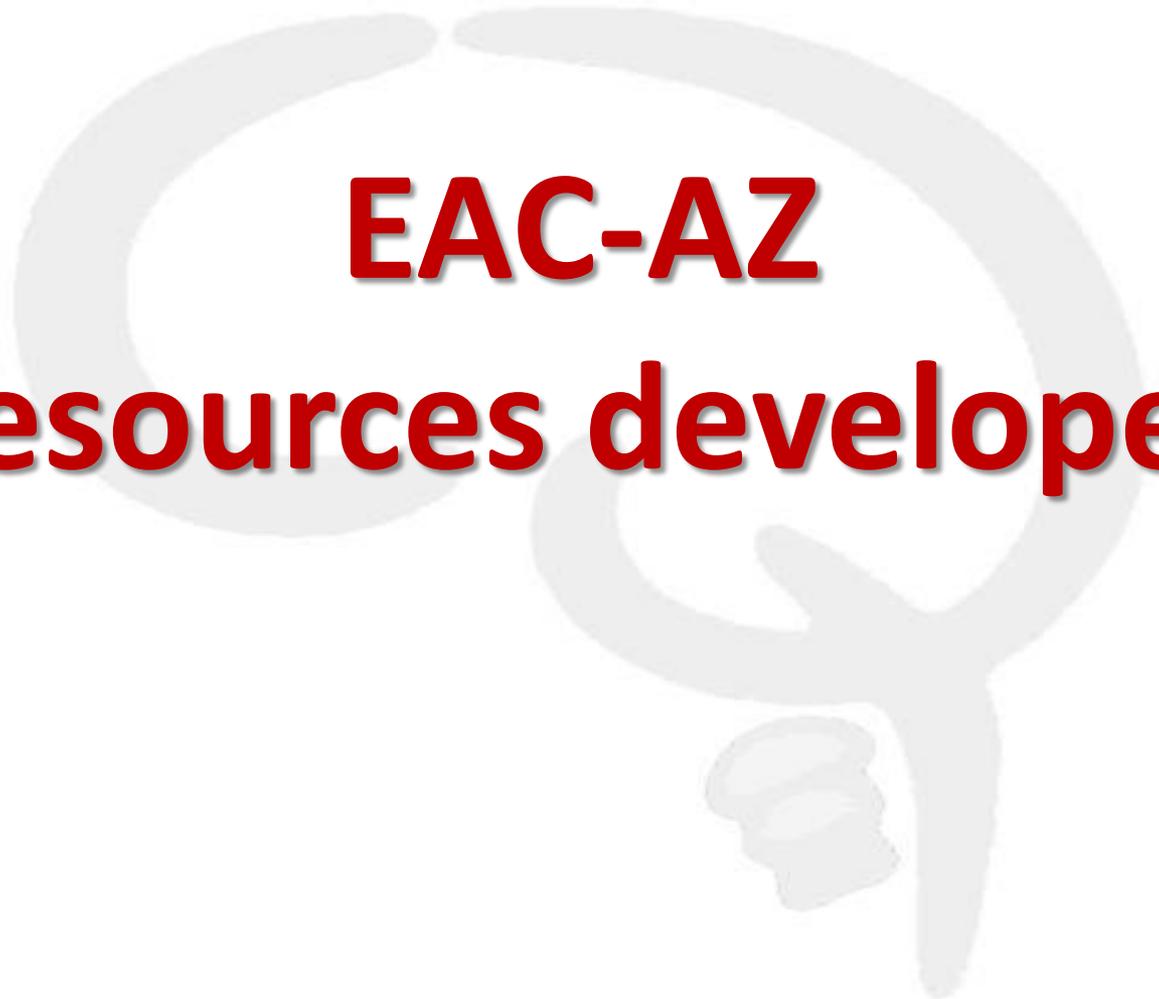
- Host networking events to bring together stakeholders and partners
- Expand “treatment teams” by adding consultants, agency providers, etc.
- Ask questions

- **Build Partnerships**

- Work with providers on improving referrals specific to the provider-physician relationship
- Work with providers on improving provider-physician informal care coordination

# Autism Patient Navigator

- **Beth Mishkind Roth, et al, Rainbow Autism Diagnostic (RAD) Clinic, Case Western Reserve**
  - [www.jdbp.org](http://www.jdbp.org), April 2016
  - **More success in scheduling or completing appts recommended for:**
    - Medical
    - Educational
    - Therapies
    - Parent resources

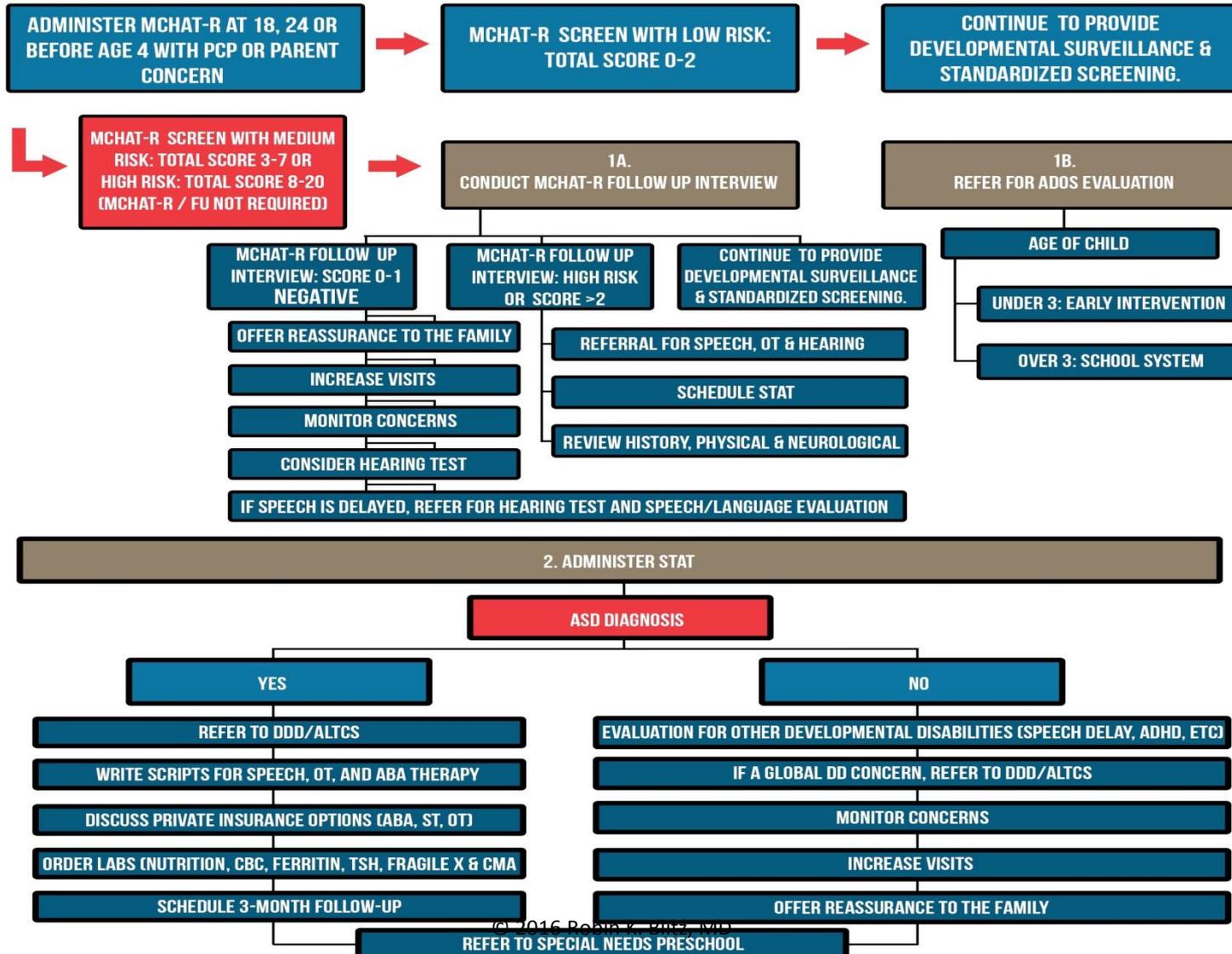


# **EAC-AZ**

# **Resources developed**



# EARLY ACCESS TO CARE - ARIZONA PEDIATRIC PRACTICE ROAD MAP



# Resource Directory

## PINAL COUNTY - AUTISM RESOURCES

### ABA Service Providers

Company	Address	City	Phone/Fax	Contact	Email	Website
ACCENT on Family Care Services, LLC	19322 E. Calle De Flores Queen Creek, AZ 85142	Queen Creek	480-518-2285 480-677-3477	Debbie Belnap	debbie@accentonfamily.com	www.accentonfamily.com
All Aboard Services, LLC	1892 S. Arroyo Lane Gilbert, AZ 85295	Gilbert	480-233-9967	Katie Krietemeyer	allaboardhab@gmail.com	www.facebook.com
Alexander's Abilities	1116 W. Palo Verde Dr Chandler, AZ 85224	Chandler	480-964-7676 480-668-4977	Kristin Younger	kyounger@alexandersabilities.com	www.alexandersabilities.com
All In The Family LLC	4365 E Pecos Rd. #121 Gilbert, AZ 85296	Pecos	480-968-2912 480-968-6278	Chris Chandler	chris@allinthefamilyllc.com	www.allinthefamilyllc.com
Arion Care Solutions	540 N Saguaro St. Chandler, AZ 85224	Chandler	480-722-1300 480-422-3824	Sonia Dykhuizen	wreed@arioncaresolutions.com; mmulligan@arioncaresolutions.com; skykhuizen@arioncaresolutions.com	arioncaresolutions.com
Autism Spectrum Therapies	5960 South Cooper Rd, Suite 100 Chandler, AZ 85249	Chandler	480-339-2884			www.autismtherapies.com
Edward O'Neill MA, MEd	1629. E Cardinal Drive Casa Grande, AZ	Casa Grande	520-971-3161	Edward O'Neill		

### After School Programs

Company	Address	City	Phone/Fax	Contact	Email	Website
Exceptional Expectations, LLC	505 W. Warner Rd. Chandler, AZ 85225	Chandler	480-809-5552 480-323-2285	Vanessa Ramirez		www.autismspeaks.org
Gutherie Mainstream Services LLC	3200 N. Dobson Rd. Bldg. E Chandler, AZ 85224	Chandler	480-633-8881 480-633-7095	Mathew Gutherie		guthriemainstream.org
Legacy Traditional School	1274 E O'Neil Drive, Casa Grande, AZ 85122	Casa Grande	520-421-2323 520-421-4443		CasaGrande-Info@LegacyTraditional.org	casagrande.legacytraditional.org
City of Casa Grande - Evergreen After School	1000 N. Amarillo St., Casa Grande AZ 85122	Casa Grande	480-836-6694			childcarecenter.us/provider_detail/city_of_casa_grande_evergreen_after_school_casa_grande_az
Boys & Girls Club - Ironwood Elementary School	1500 N. Colorado St., Casa Grande	Casa Grande	520-483-3061 520-876-5454			www.cgkids.org
Lauren's Institute for Education/L.I.F.E.	3341 E. Queen Creek Rd. Ste. 109 Gilbert, AZ 85297	Gilbert	480-621-8361 480-621-8513	Margaret Travillion		laurensinstitute.org
Sunrise Preschool	1114 W. Elliot Rd. Chandler, AZ 85221	Chandler	480-214-2461 480-214-0920	Jo Davis		www.sunrisepreschools.com
Sunrise Preschool	3270 E. Ray Rd. Gilbert, AZ 85296	Gilbert	480-214-2461 480-214-0920	Jo Davis		www.sunrisepreschools.com

I can tell you what bothers me or worries me most about my child's condition.

I can tell you what medical tests my child is getting, and what they are for.

I can tell you how to comfort my child.

I can tell you about my child's treatments.

I can tell you how what my child eats affects this condition.

I can tell you why we are here today.



PHOENIX  
CHILDREN'S  
Hospital



I can tell you about my child's medicines.

↑ Start

Home

# My Journey

I can show you how I use my child's home medical equipment and supplies.

I can tell you about my child's follow-up appointments.

I can tell you who I can call if I have a concern.

I can tell you signs my child is getting worse, and how I will respond.

I can tell you when my child can return to school.

I can tell you what my child is able to do.

# Autism Journey Board

## Patient Education Components

- I can tell you about my child's diagnosis
- I can tell you what bothers or worries me about my child's condition
- I can tell you about my child's medical tests
  - What medical tests
  - Why they are done
- I can tell you about my child's education
  - Assessments
  - Interventions
- I can tell you about my child's treatments
  - Intensive behavior intervention – what and why
  - Therapy – what and why
  - Treatments – what and why
  - Interventions – what and why
  - I can tell you about my child's schedule and sleep
- I can tell you about my child's behavior
  - What the behavior means
  - How to respond
- I can tell you what my child is able to do
- I can tell you about my child's medications, nutrition needs and sleep habits.
- I can tell you signs my child is getting worse, and how I will respond
- I can tell you who provides my child services and how to contact them
- I can tell you who I can call for information and support
- I can tell you about my child's follow-up appointments

Back

I can tell you about my child's education



Teach Back

Resources

My Notes

- I can tell you about my child's education evaluation.
- I can tell you about my child's educational intervention.
- I can tell you the name of the organization providing my child's education (school, early intervention, other).

Back

I can tell you about my child's education



Teach Back

Resources

My Notes



AZEIP 0-3



Child Find



Department of Education Autism Resources



Empowerment Scholarship



Family Modules



How to Get the Best Education for Your Child With Special



IDEA Part C Modules



Navigating the Special Education System



Preparing for College

Back

Clear Note

I can tell you about my child's education



Teach Back

Resources

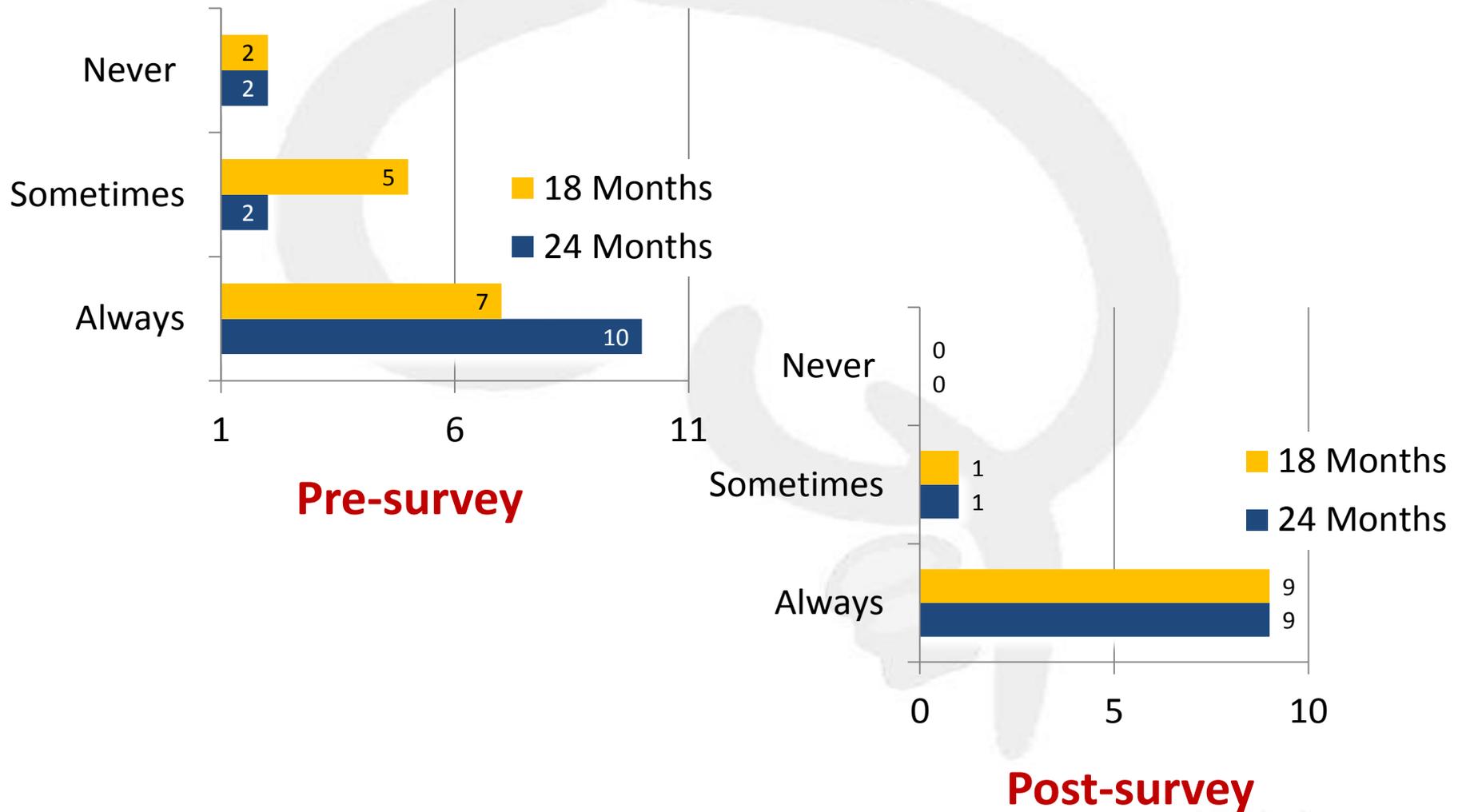
My Notes





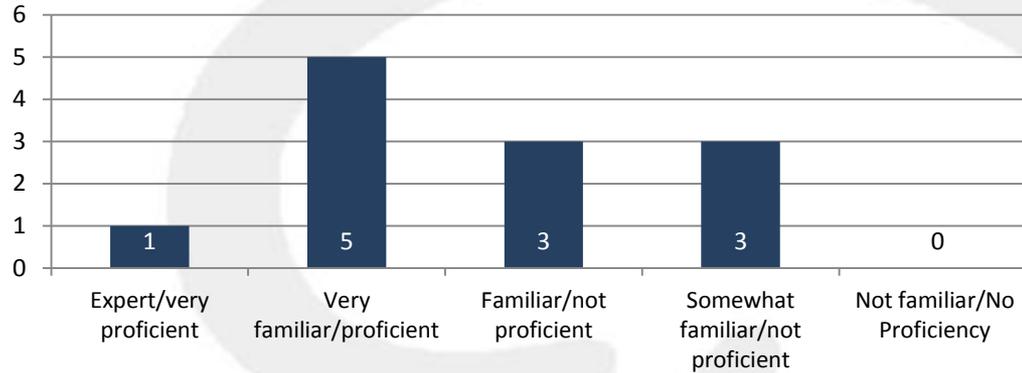
# Preliminary Data

# DO YOU USE THE MODIFIED CHECKLIST FOR AUTISM IN TODDLERS (M-CHAT) AT THE WELL CHILD VISITS?

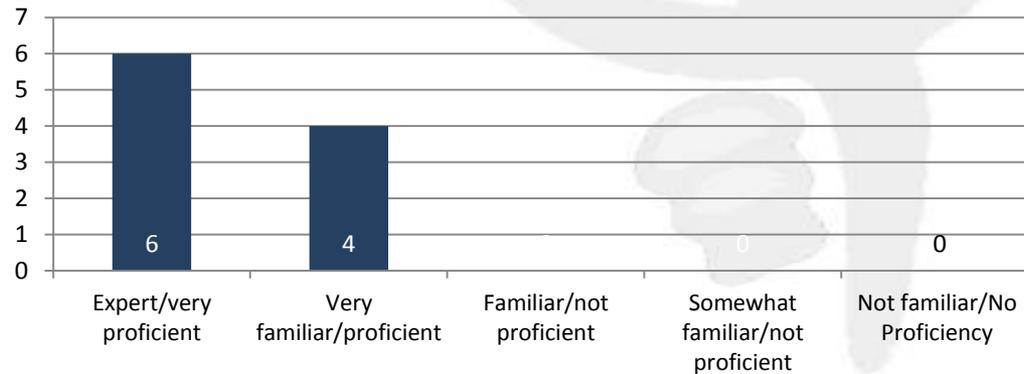


# HOW WOULD YOU RATE YOUR PROFICIENCY TO SCREEN CHILDREN FOR AUTISM?

## Pre-survey

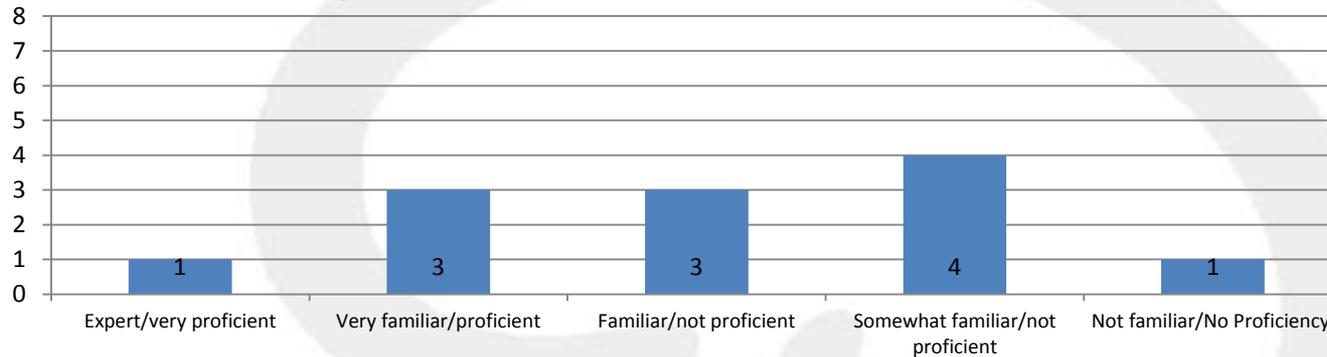


## Post-survey

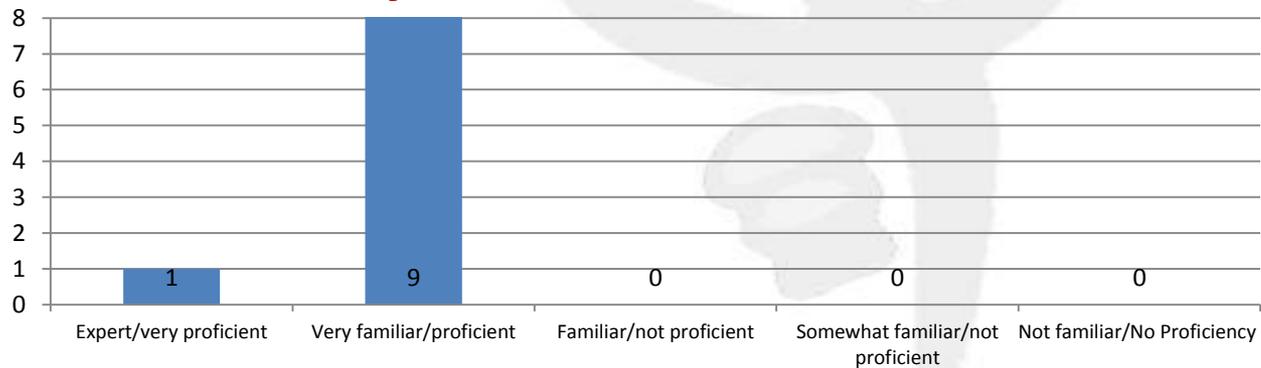


# HOW WOULD YOU RATE YOUR PROFICIENCY TO DIAGNOSE CHILDREN WITH AUTISM?

## Pre-survey



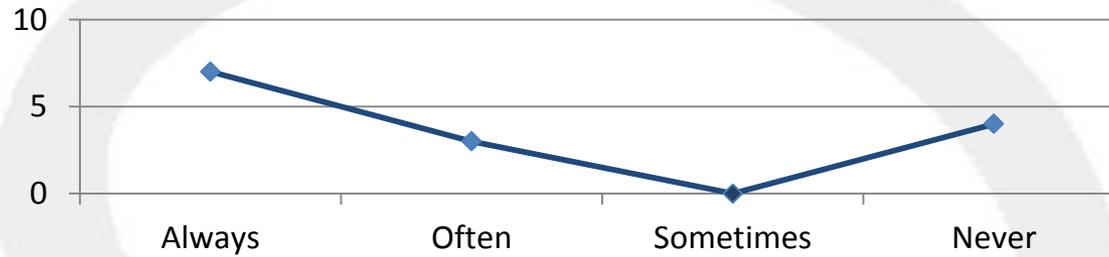
## Post-survey



# DO YOU USE M-CHAT FOLLOW-UP INTERVIEW WHEN A PATIENT “FAILS” THE M-CHAT SCREENING?

## Barriers

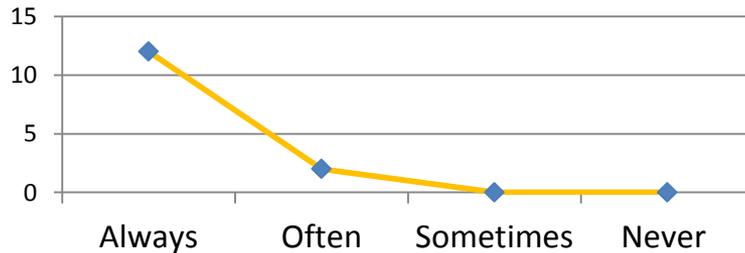
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DO YOU REFER TO THE ARIZONA EARLY INTERVENTION PROGRAM WHEN YOU SUSPECT DEVELOPMENTAL DELAYS FOR CHILDREN UNDER THE AGE OF 3 YEARS.?

## Barriers

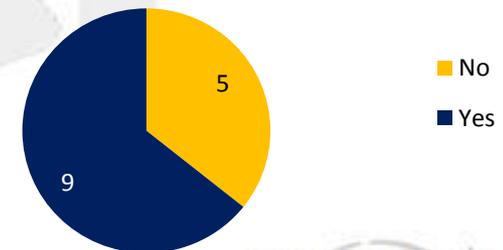
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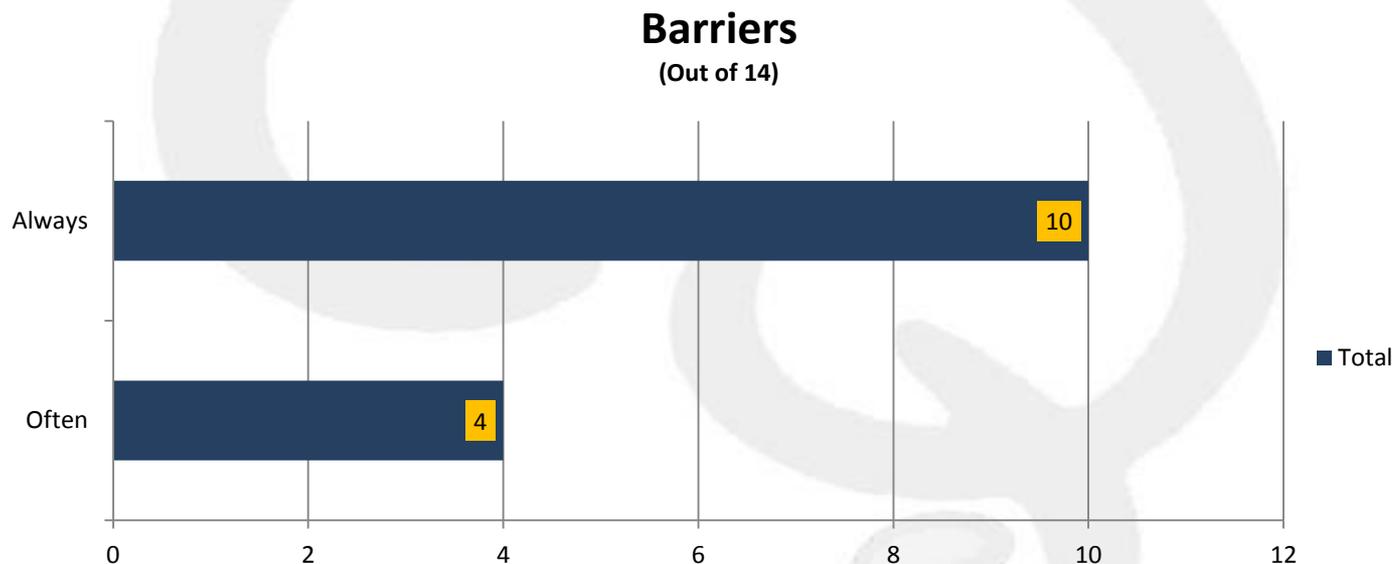
DO YOU RECEIVED REPORTS FROM AZEIP AFTER YOU MAKE A REFERRAL?

## Barriers

(Out of 14)

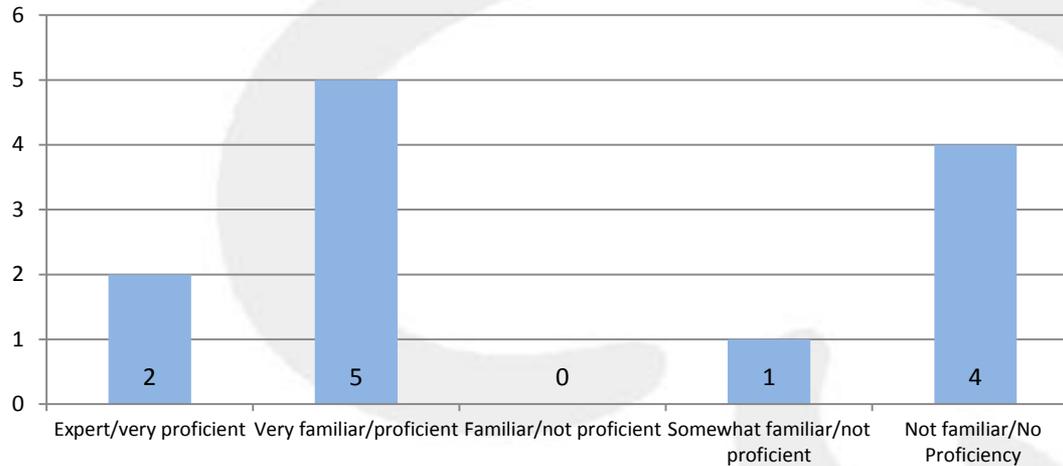


# DO YOU REFER TO THE SCHOOL DISTRICT FOR SPECIAL EDUCATION SERVICES WHEN YOU HAVE CONCERNS REGARDING DEVELOPMENTAL/BEHAVIORAL PROBLEMS FOR CHILDREN AGES 3 YEARS AND OLDER?

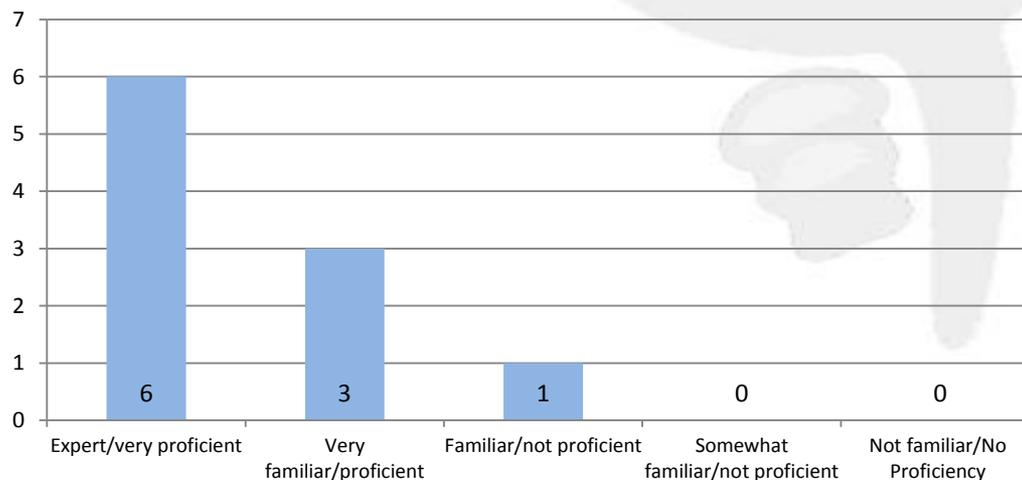


# HOW WOULD YOU RATE YOUR PROFICIENCY TO PROVIDE A MEDICAL HOME FOR CHILDREN WITH AUTISM?

## Pre-survey



## Post-survey



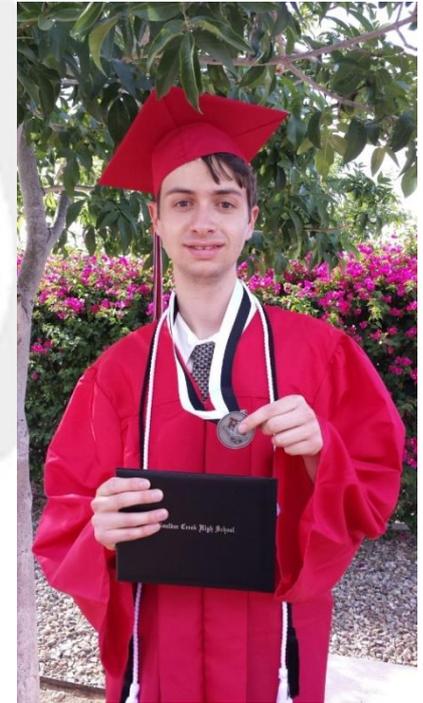
Patient ID Number	Age of Concern	Age of M-CHAT	Age of STAT	STAT Positive or Negative	Age of Diagnosis	Age of ADOS-2	Age of EI	Hearing Test?/When?	Genetic Test?/When?	Comments	Next Appt	Payment tracking
	18m--speech delay	18m-nl, but abnl at AZEIP eval	27m (12/4/15)	Pos--Score 3.5	27m	Not needed	18m	Pending--needs sedated testing	Chromosome microarray neg, Fragile X neg	Teleconf with Dr. Blitz confirmed dx.	18-Apr	96111--pd \$55, 99354--pd \$134
	N/A	18m-normal	29m (12/15/15)	Neg--this was a practice STAT	Normal child	N/A	N/A	N/A	N/A		N/A	
	15m--speech delay	15m--failed 8 items	18m (1/14/16)	Neg--Score 1.5	Unlikely Autism, speech delay	N/A	15m--mom declined EI	15m--mom declined audiology eval	N/A		N/A	Not paid
	24m--behavioral problems	24m--failed 4 items	31m (1/26/16)	Pos--Score 2.75	31m	Normal ????	24m	Normal hearing for speech but possible mild loss, unable to determine for sure d/t uncooperative.	Chromosome microarray neg, Fragile X neg		5-Jul	96111 paid 111
	24m--speech delay	18m--normal, 24m--failed 10 items	27m (2/19/16)	Pos--Score 3.75	27m	Pending--scheduled 5/16	24m	Normal hearing for speech but possible mild loss, unable to determine for sure d/t uncooperative.	Chromosome microarray neg, Fragile X neg		None scheduled	96111 paid 111
	13m--global delay parents concered about CP vs autism	14m--failed 9 items	15m (2/18/16)	Neg--Score 1.5	Unlikely Autism	N/A	12m	Pending	Chromosome microarray neg, Fragile X neg, Rhett's neg	RE-eval when older	13-May	billed as 96110-{:
	3yr	36m--failed 4 items	38m	Neg--Score 1.5	Unlikely Autism, likey issues d/t neglect. Now in foster care and thriving. + Global DD, at risk for intellectual disability	Pending	3yr	Pending	Pending		19-May	
	2yr	26m--failed 10 items, 36m failed 15 items	37m	Uncooperative x 2 attemps	36m	Pending--scheduled 8/5	3y	Pending	Chromosome microarray neg, Fragile X Neg			not paid yet
	47m	not done	not done	N/A	59m	Pending	4y	Passed--Banner BAER	Chromosome microarray--Chromosome 22q11 microduplication, Fragile X neg			
	2yr	not done	pending--parent unwilling to schedule		Pending	Pending	3y--parent did follow through, re-referred at April 2016	Pending	Pending		3-May	
	2yr	not done	not done	N/A	Unlikely Autism, Global DD, intellectual disability	4y	2y	Passed	Chromosome microarray--Chromosome 8 anomaly, Fragile X neg	Prior dx of GDD, Chromosome anomaly. Seen by PCH Dev. Not likely autism. DX by Carrejo--see notes.		
	4y	not done	not done	N/A	Unlikely Autism	not done		passed	Not done	Behavioral problems not consistent with ASD. Psych eval pending		
	1y	22m--Failed 4 items	23m (5/5/16)	Pos--Score 3.25	23m	Pending	18m	Pending	Pending			

# What else are 'graduates' saying?

- “I feel that I now have the tools to organize the evaluation of children with developmental delays and shorten the time it takes them to receive a diagnosis and/or meaningful intervention.”
- “Familiarity with the M-CHAT-R and STAT have really helped me understand what autism ‘looks like’.”
- “I feel more confident in identifying at risk behaviors even when parents don’t report them.”
- “To be able to provide this service in our community, will set a precedent for the future development of an organized developmental program for all children.”

# Early Access to Care – AZ is:

- Innovative
- Community-based
- Supported by multiple stake-holders in the state
- Will exponentially increase the numbers of children in Az who will get early diagnosis and early intervention for ASD
- Become a model program for other states in the USA





# Arizona moving forward

# TRICARE

## Comprehensive Autism Care

- **Covers medical and behavior modification services:**
  - OT, PT, Speech
  - Physician services, prescription drugs
  - Psychological services, psychological testing, ABA
- **Approved ASD-Diagnosing Providers:**
  - PCP's with ADOS or specialized ASD-dx provider
- **Specialized ASD-Dx providers:**
  - Dev Peds, child neurology, adult or child psychiatry, licensed clinical psychology

# Future Possibilities for Az Telemedicine / Telehealth and Parent-mediated Treatments

- Functional Communication Training, Dr. Scott Lindgren's study
  - <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2846575/>
  - <http://www.ncbi.nlm.nih.gov/pubmed/26908472>
- Project ImPACT, Dr. Brooke Ingersoll
  - <http://psychology.msu.edu/autismlab/projectimpact.html>

# Future Possibilities for Az Telemedicine / Telehealth and Parent-mediated Treatments

- The Play Project, Dr. Rick Solomon
  - <http://www.playproject.org/>
- Early Start Denver Model
  - <http://nationalautismnetwork.com/about-autism/autism-treatments/early-start-denver-model.html>
  - <https://www.autismspeaks.org/what-autism/treatment/early-start-denver-model-esdm>



# Questions?

# Complete the Breakout Session Evaluation on the Mobile App

