

# Special Needs Agency Meeting

Wednesday, May 17<sup>th</sup>, 2017



# 2014 Mohave County CYSHCN Survey

# Children and Youth with Special Health Care Needs (CYSHCN)

- ▶ Defined as *“children up to age 21, who have or are at risk for a chronic physical, developmental, behavioral, emotional or potentially disabling condition and who also require health and related services of a type or amount beyond that required by children generally”*

~Maternal and Child Health Bureau~

# 2014 Mohave County CYSHCN Survey

- ▶ **383** surveys collected: **49** youth, **116** parents/caregivers, **71** providers, & **147** school staff
- ▶ **66%** of parents/caregivers said their child had public insurance; **39%** had private insurance
- ▶ **84%** of parents/caregivers reported being somewhat to very satisfied with health care services
- ▶ **51%** of parents/caregivers reported being somewhat to very satisfied with educational services; **56%** reported the IEP process could be improved
- ▶ **50%** of *youth* said their disabilities do not inhibit them from participating in activities; **80%** said their disabilities did not prevent them from going places
- ▶ **62%** of parents/caregivers said their child was limited or prevented in some way in his/her ability to do the things most children of the same age can do

# 2014 Mohave County CYSHCN Survey:

- ▶ According to parents/caregivers, when asked about their child:
  - ▶ **22%** had mental/emotional conditions
  - ▶ **24%** had medical/physical challenges
  - ▶ **35%** had behavioral issues
  - ▶ **70%** had developmental or genetic diagnosis


# 2014 Mohave County CYSHCN Survey: The Wheelchair Playground Success Story

- ▶ **103 out of 116** parents/caregivers (87%) reported they did not have a playground in the area with accommodations for CYSHCN
- ▶ **Six out of ten** school staff members said their school did not have a wheelchair-accessible playground
- ▶ **One out of four** youth said they were not able to use the playground where they live
- ▶ Parents and volunteers from Kingman SNAC Parent Support group came together to raise the funds needed (\$4,500) for a wheelchair swing
  - ▶ Various events were held throughout the community: 50/50 raffles, auctions, a rummage sale, frozen yogurt deals, large private donations

# 2014 Mohave County CYSHCN Survey: The Wheelchair Playground Success Story cont.

- ▶ Over **\$14,000** was raised, far exceeding original \$4,500 goal
- ▶ Donations were sent to La Senita Elementary School
- ▶ Wheelchair accessible playground was dedicated to Kaylee Shuffler, who passed away earlier that year and loved to swing in her wheelchair
- ▶ Playground is called “Kaylee’s Playground”
- ▶ **Outcome** of 2014 CYSHCN Survey: Special Needs Agency group and Special Needs School group formed

# Arizona Children's Health Survey Report 2016





# AZ Children's Health Survey

- ▶ **768** surveys collected in Mohave County; **3,680** total collected in Arizona
- ▶ Mohave County had highest percentage of surveys completed: **17.90%**
  - ▶ Mohave County used Kindles and tablets to get community to complete survey
  - ▶ Used existing groups and resources to recruit
  - ▶ Also hired additional people to recruit for survey
  - ▶ Went to parks, libraries, after school events, etc.
- ▶ **68.23%** of Mohave County respondents *did not* have a CYSHCN compared to **68.04%** in Arizona
- ▶ **31.77%** of Mohave County *did* have a CYSHCN; **31.96%** in Arizona

# AZ Children's Health Survey:

## Basic statistics

Question/Topic from Survey	State of Arizona	Mohave County
# that completed survey	<b>3,680</b>	<b>768 (17.90%)</b>
Primary Language: English	89.06%	95.18%
Primary Language: Spanish	9.65%	4.30%
% of families with annual income less than \$50,000	<b>45.61%</b>	<b>56.76%</b>
White	66.67%	85.42%
Hispanic, Latino, or Spanish origin	34.94%	21.88%
Black or African American	3.64%	2.99%
American Indian, Alaska Native	8.62%	2.47%
Asian, Native Hawaiian, or other Pacific Islander	2.59%	2.21%
CYSHCN: No	<b>68.04%</b>	<b>68.23%</b>
CYSHCN: Yes	<b>31.96%</b>	<b>31.77%</b>

# AZ Children's Health Survey: Insurance

Question/Topic from Survey	State of Arizona	Mohave County
Public insurance	32.28%	36.72%
Private insurance	54.08%	43.10%
Public and Private insurance	8.15%	8.85%
None	<b>5.49%</b>	<b>11.33%</b>
Does your child's insurance coverage and benefits meet his/her needs?: <b>Yes</b>	91.30%	86.78%
Does your child's insurance coverage and benefits meet his/her needs?: <b>No</b>	<b>8.7%</b>	<b>13.22%</b>

## Highlights:

- Twice as many children have no insurance in Mohave compared to state.
- And 50% more children in Mohave have insurance that ***does not meet their needs.***

# AZ Children's Health Survey: Prescription Medication

**Question 1:** Does your child currently need or use medicine, prescribed by a doctor or other healthcare provider, other than vitamins?

**Question 2:** Is the prescription medicine because of any medical, behavioral, or other health condition?

Question/Topic from Survey	State of Arizona	Mohave County
Medication for child: YES	28.02%	27.47%
Medication for child: NO	71.86%	72.53%
Medication because of condition? YES	22.40%	20.96%
Medication because of condition? NO	5.59%	7.03%

# AZ Children's Health Survey: Services

**Question:** Does your child need or use more medical care, mental health, or educational services because of ANY medical, behavioral, or other health condition?

Examples: diabetes, autism, hearing loss, asthma, etc.

Question/Topic from Survey	State of Arizona	Mohave County
YES	26.15%	26.17%
NO	73.73%	73.83%

# AZ Children's Health Survey: Limitations

**Question:** Is your child limited or prevented in any way in the ability to do the things most children of the same age can do?  
Examples: diabetes, autism, hearing loss, asthma, etc.

Question/Topic from Survey	State of Arizona	Mohave County
YES	15.90%	17.84%
NO	83.87%	82.16%

# AZ Children's Health Survey: Therapy

Question: Does your child NEED or GET special therapy such as physical, occupational, or speech therapy?

Question/Topic from Survey	State of Arizona	Mohave County
YES	15.13%	14.45%
NO	84.17%	85.55%

# AZ Children's Health Survey: Counseling Services

**Question:** Does your child have any kind of emotional, developmental, or behavioral condition for which he/she needs or receives treatment or counseling?

Question/Topic from Survey	State of Arizona	Mohave County
YES	17.79%	18.23%
NO	82.10%	81.77%
Expected to last for 12 months or longer? YES	16.39%	17.06%
Expected to last for 12 months or longer? NO	1.61%	1.56%



# AZ Children's Health Survey: Child's Conditions

Question/Topic from Survey	State of Arizona	Mohave County
Allergies	24.29%	18.62%
Asthma	11.52%	10.29%
Anxiety problems	7.97%	7.94%
Attention Deficit Disorder (ADD) or Attention Deficit Hyperactive Disorder (ADHD)	8.95%	9.77%
Autism, Autism Spectrum Disorder, Asperger's Disorder, Pervasive Development Disorder, PDD	5.22%	5.60%

# AZ Children's Health Survey: Child's Conditions cont.

Question/Topic from Survey	State of Arizona	Mohave County
Behavioral or conduct problems	5.55%	6.38%
Developmental delay	5.92%	5.47%
None	52.59%	55.47%
% without Multiple Conditions	77.86%	81.90%
% with Multiple Conditions	22.14%	18.10%

# AZ Children's Health Survey:

## Reported limitations

Does your child's condition interfere with doing any of the following? Please indicate all the options that apply.

- ▶ Daily activities ~ 7.6%
- ▶ Sports, clubs, other organized activities ~12%
- ▶ Play with others ~ 10.5%
- ▶ Outings, parks, library, or zoo ~ 9%
- ▶ None ~ 80%

# AZ Children's Health Survey:

## Use of services

Question/Topic from Survey	State of Arizona	Mohave County
Behavioral or Mental health care or counseling	13.45%	15.63%
Hearing care	4.62%	5.34%
Physical, Occupational, or Speech Therapy	12.91%	13.28%
Preventive dental care	40.63%	32.68%
Specialty care	10.0%	10.81%
Substance Abuse Treatment or counseling	0.82%	1.04%
Vision Care	24.43%	23.57%
None	13.57%	15.63%
Other	1.91%	0.91%

# AZ Children's Health Survey:

## Use of services – Unmet Needs

Question/Topic from Survey	State of Arizona	Mohave County
Behavioral or Mental health care or counseling	42.81%	45.00%
Hearing care	28.79%	48.78%
Physical, Occupational, or Speech Therapy	32.67%	35.29%
Preventive dental care	11.76%	21.91%
Specialty care	27.51%	37.35%
Substance Abuse Treatment or counseling	20.00%	25.00%
Vision Care	16.51%	27.62%

# AZ Children's Health Survey:

## Topics for other Unmet Needs

- ▶ Lack of specialty services or providers
  - ▶ Includes PT, OT, doctors, special needs services at schools, etc.
- ▶ Traveling out of town to appointments
- ▶ Access to insurance
- ▶ Lack of recreation and events
- ▶ Transportation (public)

# AZ Children's Health Survey: Handout #1

## Highest % of conditions for Mohave:

- 55.47% No conditions
- 18.62% Allergies
- 10.26% Asthma
- 9.77% ADD or ADHD
- 7.94% Anxiety problems
- 6.38% Behavioral/conduct problems
- 5.60% Autism Spectrum/PDD
- 5.47% Developmental Delay
- 2.99% Intellectual/Cognitive Disability

Others conditions(less than 3%): a heart problem or congenital heart disease, arthritis, blood diseases, Cerebral Palsy, Cystic Fibrosis, Diabetes, Genetic Metabolic or Endocrine disorders, Head Injury or Traumatic Brain Injury, Migraines, Neuromuscular conditions, Other



## Arizona Children's Health Survey Report 2016: Comparisons between Mohave County and the State of Arizona

<u>Topic</u>	<u>State of Arizona</u>	<u>Mohave County</u>
# that completed survey	3,680	768
Primary language: English	89.06%	95.18%
Primary language: Spanish	9.65%	4.30%
Yes: Has child with special health care needs	31.96%	31.77%
No: Does not have child with special health care needs	68.04%	68.23%
Child's Insurance: Private	32.28%	36.72%
Child's Insurance: Public	54.08%	43.10%
Child's Insurance: Private & Public	8.15%	8.85%
Child's Insurance: None	5.49%	11.33%
YES: insurance covers child's needs	91.30%	86.78%
NO: insurance doesn't cover child's needs	8.7%	13.22%
% of children that need or use Medication	28.02%	27.47%
% of children with Allergies	24.29%	18.62%
% of children with Asthma	11.52%	10.29%
% of children with Anxiety problems	7.97%	7.94%
% of children with ADD or ADHD	8.95%	9.77%
% of children with Autism Spectrum	5.22%	5.60%
% of children with Behavioral problems	5.55%	6.38%
% of children with Developmental delay	5.92%	5.47%
% of children with no conditions	52.59%	55.47%
% of children with multiple conditions	22.14%	18.10%
% of children with only one condition	77.86%	81.90%
% of children with limitations such as sports, clubs, outings, or daily activities	20.21%	18.62%
% of children without limitations	79.79%	81.38%



**Reported unmet needs for children in both the state of Arizona and Mohave County include:** behavioral or mental health counseling, physical, occupational, or speech therapy, specialty care or providers, vision care, preventive dental care, substance abuse treatment or counseling, transportation, access to insurance, schools and services, and traveling out of town for appointments



# AZ Children's Health Survey: Handout #2 for CYSHCN

Mohave CYSHCN reported **higher**

- % of having public insurance (43% vs. 34%) and no insurance (10% vs. 4%).

**Both** Mohave CYSHCN and non-CYSHCN reported **higher**

- % of unmet needs for insurance coverage—10% vs. 5% (CYSHCN) and 21% vs. 16% (non-CYSHCN)

Mohave CYSHCN reported **less**

- % of having multiple conditions (48% vs. 59%).

**Both** AZ and Mohave CYSHCN report **less** adequacy of insurance than their non-CYSHCN peers

# Arizona Children's Health Survey Report 2016:

## Comparisons between Mohave County and the State of Arizona



	<u>Arizona</u>	<u>Mohave</u>
# that completed survey	3,680	768
Yes: has child with special health care needs (CYSHCN)	31.96%	31.77%
No: Does not have CYSHCN	68.04%	68.23%
% that need or use medication	28.02%	27.47%



<u>Child's Insurance</u>	<u>Arizona</u>	<u>Mohave</u>
<b>All Children</b>		
Has Public insurance	32.28%	36.72%
Has Private insurance	54.08%	43.0%
Both private and public	8.15%	8.85%
No insurance	5.49%	11.33%
<b>Non-CYSHCN</b>		
Has Public insurance	31.41%	33.59%
Has Private insurance	57.12%	47.90%
Both private and public	5.36%	6.68%
No insurance	6.11%	11.83%
<b>CYSHCN</b>		
Has Public insurance	34.14%	43.44%
Has Private insurance	47.63%	32.79%
Both private and public	14.08%	13.52%
No insurance	4.16%	10.25%



<u>Adequacy of Insurance:</u> Does your child's insurance coverage and benefits meet his/her needs?		
	<u>Arizona</u>	<u>Mohave</u>
<b>All Children</b>		
Yes	91.30%	86.78%
No	8.70%	13.22%
<b>Non-CYSHCN</b>		
Yes	94.88%	90.26%
No	5.12%	9.74%
<b>CYSHCN</b>		
Yes	83.85%	79.45%
No	16.15%	20.55%



<u>Child's Condition</u>	<u>Arizona</u>	<u>Mohave</u>
<b>All Children</b>		
A heart problem or congenital heart disease	1.96%	1.17%
Allergies	24.29%	18.62%
Anxiety problems	7.97%	7.94%
Arthritis or Joint problems	0.72%	0.39%
Asthma	11.52%	10.29%
ADD or ADHD	8.95%	9.77%
Autism Spectrum, Asperger's, PDD	5.22%	5.60%
Behavioral or Conduct problems	5.55%	6.38%
Blood problems— <i>anemia, sickle cell disease, hemophilia</i>	0.61%	0.65%
Cerebral Palsy (CP)	1.05%	1.04%
Cystic Fibrosis	0.02%	0.00%
Developmental Delay	5.92%	5.47%
Diabetes—Type I or II	0.86%	1.69%
Epilepsy or Seizure disorder	1.82%	1.56%
Genetic metabolic or endocrine disorders	1.86%	0.91%
Head injury or Traumatic Brain Injury	1.00%	0.39
Intellectual disability, cognitive disability, or mental retardation	2.91%	2.99%
Migraine or frequent headaches	2.77%	2.21%
Neuromuscular condition, such as muscular dystrophy	0.42%	0.91%
Other	9.07%	5.73%
None	52.59%	55.47%

<u>Has Multiple Conditions</u>	<u>Arizona</u>	<u>Mohave</u>
<b>All Children</b>		
Yes	22.14%	18.10%
No	77.86%	81.90%
<b>Non-CYSHCN</b>		
Yes	4.76%	4.20%
No	95.24%	95.80%
<b>CYSHCN</b>		
Yes	59.15%	47.95%
No	40.85%	52.05%

# 2016 AZ Children's Health Survey: Next Steps

- ▶ Inform the public:
  - ▶ Press release to newspaper
  - ▶ Updates to SNAC Facebook page and [snacmc.org](http://snacmc.org) website
- ▶ Work within community to continue to connect parents with resources in Mohave County & use all available resources
- ▶ Continue/begin to have more parent support meetings
- ▶ Resource Fair in the fall for all ages of special needs
  - ▶ Ensure as many special needs agencies are represented so community can see all available resources

## Activity: Challenges

What are the biggest **challenges** you see facing the special needs population in Mohave County?

## Activity: Solutions

What are some **solutions** for these challenges?

# Activity: Challenges

## Group Responses

### Specialized Health Care & Insurance

- Local health care specialist providers/limited providers to meet demands
- Limited services for specialty services
- Services: PT, OT, speech
- Speech therapy services outside of school settings
- Medical specialist
- Lack of providers
- Lack of knowledge on providing medical care in a hospital/doctor's office setting. Example: a person in a wheelchair & they don't know how to transfer. Almost like they are afraid to break them
- Specialists (doctors)
- Access to quality health services in rural areas
- Access to providers (therapy specialists)
- Benefit loss – changes in public health insurance/coming down
- Therapy providers
- Lack of counseling services covered by insurance for those with mental health needs
- Specialists (therapists, neuro-specialist)

### Recreation/Events

- Activities where families with children with special health care needs are included with children with no special health care needs
- No money for outings for members to do things
- Dances
- Lack of handicap accessible activities
- Not enough resources for the individuals to go and do fun things
- Adults recreation or field trips

# Activity: Challenges

## Group Responses

### Special Education

- Special education
- Care and support that follows a special needs student after graduation. Once they graduate and don't have their IEP to support them they are left with no help/support. (also in **Employment**)
- Behavior support in homes and schools (also in **Parent Support or Training**)

### The Individual with Special Health Care Needs

- Children or adults with DD being heard
- Recognized as individuals
- Recognized as a person

### Employment

- Job training
- Care and support that follows a special needs student after graduation. Once they graduate and don't have their IEP to support them they are left with no help/support. (also in **Special Education**)

### Parent Support or Training

- Parent support
- Jobs for adults with disabilities
- Guardians who don't full support their loved one "just in it for their money"
- Behavior support in homes and schools (also in **Special Education**)

### Miscellaneous

- Resources
- Find children with special needs
- Housing
- Caregivers who are in it for the individuals, not just the paycheck
- Lack of transportation

# Activity: Solutions

## Group Responses

### **Training**

- Parent and professional training for positive behavior support and special education process (also under **Parent Support & Training**)
- Additional support and training for school nurses/health aides
- Additional support and training for SPED staff at schools (SPED= Special Education)
- More training for providers

### **Community & Public Awareness**

- Public awareness
- Educate the community on why our individuals deserve the same support
- Educate the community on reporting if they know someone being abusing someone's funds

### **Funding**

- Raise more money for special needs park
- Obtain funding for more services and/or providers (also in **Specialized Health Care & Insurance**)

### **Specialized Health Care & Insurance**

- Medical groups recruiting traveling doctors
- Obtain funding for more services and/or providers (also in **Funding**)
- More training for providers (also under **Training**)
- Consider consortiums or other structures for service delivery to get services in remote areas
- Network of services for support and referrals that is consistent



# Activity: Solutions

## Group Responses

### **Recreation/Events**

- More community activities/sports to accommodate special needs
- Recreation department having special rec activities

### **Policies/Government**

- Involving parents in the solutions to challenges to create either policies or communities of inclusion (also under **Parent Support or Training**)
- Get involved and communicate need for health services and programs with our representatives

### **Webinars**

- Webinars to help reduce travel

### **Parent Support or Training**

- More parent and community involvement
- More consistent parent support groups and better advertising for groups
- Involving parents in the solutions to challenges to create either policies or communities of inclusion (also under **Policies/Government**)
- Parent and professional training for positive behavior support and special education process (also under **Training**)

### **Miscellaneous**

- Better public transportation

THANK YOU!

ANY QUESTIONS?