

STATEWIDE MEMBER & FAMILY FORUMS 2019



Raising Special Kids

*Conducted on behalf of:
Division of
Developmental
Disabilities*

*Prepared by:
Raising Special Kids*

July 2019

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PURPOSE FOR THE FORUMS

Proposal approved

February 7, 2019

- *'Raising Special Kids in collaboration with the Division of Developmental Disabilities proposes to conduct a series of 51 member and family stakeholder input forums across the state of Arizona with multiple opportunities in all five of the Division's service districts (North, South, East, West and Central Districts).'*
-

Engage Arizona's communities to provide Arizona State Agencies with authentic stakeholder feedback to understand the unique needs of Arizona's families and members who require, and use, Long Term Services and Supports (LTSS), also known as Home and Community Based Services (HCBS), through the Division of Developmental Disabilities.

The primary purpose of the project: to engage members and families in a discussion, and hear from them, about an alternate model for healthcare delivery in Arizona that has been referred to as 'fully integrated care'.

This stakeholder engagement activity also provided an opportunity to educate and inform DDD/ALTCS eligible members and families on upcoming changes to their health plan on October 1, 2019. For the purposes of this forum this was referred to as 'partially integrated care'.

MEMBER AND FAMILY FORUMS PROJECT DESIGN

Leadership and project teams from DDD and Raising Special Kids co-designed this activity over a period of six weeks with a series of planning meetings to develop:

- *Facilitation discussion items*
 - *Script for facilitation*
 - *Presentation materials*
 - *Outreach and recruitment strategy*
-

Raising Special Kids under a scope of work, and in collaboration with The Division of Developmental Disabilities (DDD), set out to develop and design a project to facilitate a discussion across the state in regard to DDD/ALTCS Long Term Services and Supports.

Member and Family Forums were designed to be about families and for families to hear their successes, challenges, questions, concerns, thoughts and ideas relating to the system that serves them and/or their family member who has a developmental disability.

Great efforts were taken in planning multiple, accessible, opportunities across the State:

- *Forums in 51 locations: urban, rural and on tribal lands*
- *Two online Forums via WebEx*
- *Forums scheduled on weekdays in the evening*
- *Forums scheduled in the late morning and early afternoon on weekends*

RAISING SPECIAL KIDS

WHO WE ARE

The mission of Raising Special Kids is: Strengthening families and systems of care to improve the lives of children who have disabilities.

A majority of the Board of Directors and staff are parents of children with disabilities. Our areas of core competence are:

- *increasing parent knowledge*
 - *parent to parent mentoring*
 - *developing parent leadership skills*
 - *systems-level advocacy in designing programs and services*
 - *achieving effective partnerships with professionals*
 - *serving families of diverse language and culture*
-

Raising Special Kids is an Arizona nonprofit organization serving families of children with the full range of disabilities, statewide. As a family-led organization for 40 years, programs are based on the peer support model of "families helping families."

Our values and beliefs are articulated in the organization's Credo of Family Support:

- *We believe that experienced families are a key source of knowledge and support to help new parents become effective advocates for their children*
- *We believe that professionals are important allies for families. The shared wisdom, counsel, respect and support creates enhanced positive outcomes for children*
- *We value diversity and celebrate our commitment to serving families in many forms*
- *We believe in supporting the role of the family in establishing public policy, and promoting public awareness related to families and disabilities*
- *We believe that parents who model effective self-advocacy encourage a child's pursuit of his or her own dreams*

RAISING SPECIAL KIDS

RELEVANT EXPERIENCE

In 2018 Raising Special Kids provided information, training and individual assistance to over 11,000 parents and family members of children who have disabilities and to the professionals that serve them.

60% of families served reported having children with DD eligible diagnoses:

- *Cerebral Palsy*
 - *Epilepsy*
 - *Autism*
 - *Intellectual Disability*
 - *Down Syndrome*
 - *Developmental Delay*
-

As a long-time partner with the Arizona's state agencies that serve families and children with disabilities, Raising Special Kids understands the value of engaging Arizona's diverse communities and collecting authentic Parent and Family input and feedback to inform systems of care that serve individuals who have disabilities.

Recent Relevant Experience includes:

- *2016 – 10 statewide Family Forums on behalf of First Things First to gain a better understanding of the family perspectives on raising a child with developmental concerns and navigating systems to get needed resources/services for their children*
- *2014 – 4 regional Family Forums to assess the information and training needs of parents and family members with children who have disabilities*
- *2012-2013 - gather stakeholder input with Arizona Department of Education to inform systems changes in response to Results Driven Accountability (RDA)*

FACILITATION METHODOLOGY

FACILITATION METHODOLOGY DEVELOPMENT OF DISCUSSION ITEMS AND QUESTIONS

Raising Special Kids and the Division of Developmental Disabilities collaboratively developed 6 discussion items. Those discussion items were designed to elicit broad input and perspective on strengths and challenges of the current delivery system, capture participant's suggestions for improvement then narrowed focus to asking for thoughts, questions and input on an alternate healthcare delivery model for Long Term Services and Supports (LTSS), known as Home and Community Based Services (HCBS) among DDD/ALTCS members and families.

An additional discussion item was added to hear from participants their thoughts, questions or suggestions specific to the Governor's Executive Order Relating to Enhanced Protections for Individuals with Disabilities.

The final discussion item, 'Blue Sky' was intended to capture the ideal vision of a future Arizona as seen through the eyes of members and families.

METHODOLOGY

FAMILY FORUM

DISCUSSION ITEMS

AND QUESTIONS

The discussion items/questions for facilitation were intentionally ordered to transition smoothly from one item to the next: what is going well?, what needs to be improved?, solutions for improvement?, here is another way to deliver healthcare services – what do you think, and what questions do you have?, have you heard of the Governor’s Executive Order – what are your thoughts?, think about your ideal/perfect world – what does it look like?



What is going well with DDD LTSS?

What needs to be improved?

What are the solutions for improvement?

Thoughts on alternate service delivery model.

Thoughts on the Governor’s Executive Order.

What does your blue sky look like?

METHODOLOGY

FAMILY FORUM

INFORMATION

AND REVIEW

Leadership at DDD reviewed the facilitation discussion items, questions, scripts, presentation materials, and overall content of the activity. Raising Special Kids and DDD staff met with staff at AHCCCS to review and discuss the activity and the content.

This stakeholder engagement activity provided an opportunity to educate and inform DDD/ALTCS members and families on upcoming changes to their health plan on October 1, 2019.

- *'We will have a model that integrates physical and behavioral health care, and some LTSS (partially integrated)'*

This information item was strategically placed in the flow of the facilitated activity to precede the discussion on an alternate service delivery model. This intentional placement of key information was meant to provide context to the following discussion item – Thoughts on an Alternate Service Delivery Model. Facilitators provided the following context:

- *'This model is similar to Elderly and Physically Disabled Long Term Care Services and Supports, also known as ALTCS E/PD, that has been in existence for 30 years in Arizona'*
- *'This would look like members, or family members, choosing a health plan responsible for all health care needs, physical and behavioral health; including home and community based services (respite, habilitation, day and work programs, nursing, attendant care, etc.) institutional services, and support coordination'*

METHODOLOGY

PROCESS

Raising Special Kids senior management selected nine (9) staff members for facilitation, including staff located in:

- *Kingman*
 - *Phoenix*
 - *Sierra Vista*
 - *Tuba City*
 - *Tucson*
 - *Yuma*
-

As outlined in the scope of work, Raising Special Kids facilitators were trained to defer to DDD staff for technical questions about systems delivery, DDD policy, or other DES/DDD related questions or comments.

Customized training for facilitators

Upon completion of the overall Forum project development Raising Special Kids senior management staff designed customized training for staff selected as facilitators.

Training consisted of two group meetings to familiarize facilitators with content and to provide direction on facilitation practices:

- *Issue neutrality*
- *Staying on script*
- *Checking for understanding*
- *Asking for clarification*
- *Use of 'parking lot' for issues not relating to topic*
- *Redirection to topic*
- *Time keeping*

One 'practice session' forum was conducted at the Raising Special Kids central office with staff, many who are parents of children who are eligible for Division of Developmental Disabilities, Long Term Services and Supports .

METHODOLOGY

RECRUITMENT

Forum information was shared widely (219 times) on social media

2959 people engaged with social media marketing

'Engagement' means:

- *Clicked registration link*
 - *Made a comment*
 - *'Liked' the post*
 - *'Shared' the post*
-

Phone calls:

- *Local DES/DDD Offices in advance of forum dates to remind DDD Supervisors and Support Coordinators*
- *Raising Special Kids Parent Leader Network (350) across the state*
- *Targeted phone calls inviting families connected to Raising Special Kids to participate.*
- *Reminder phone calls to individuals who had registered for an upcoming forum*

Social Media:

Multiple posts from 3/13/2019 through 5/15/2019:

Posts link to information and registration page

- *Social media reach: 25,517*
- *Post engagements: 2,959*
- *Number of Likes: 212*
- *Number of Comments: 13*
- *Number of Shares: 219*

METHODOLOGY

RECRUITMENT

Engagement with local parent support groups/organizations including but not limited to:

- *Arizona Autism Coalition*
- *Autism Society of Greater Phoenix and of Southern Arizona*
- *Down Syndrome Network*
- *GANE*
- *Salt River Pima Maricopa Indian Community Office of Special Needs*
- *Santa Cruz Love Connection*
- *Sharing Down Syndrome*
- *Special Needs Advocacy Coalition (SNAC) – Mohave County*
- *Special Needs Support Group – Tuba City*
- *Yuma support group for families of children with Autism*

Email communication:

Action Alert email to entire Raising Special Kids list serve that reaches over 13,000 parents, families and professionals that work in the field.

Weekly information in the Raising Special Kids Monday Memo – e-newsletter with link to Forum registration webpage.

Print Communication:

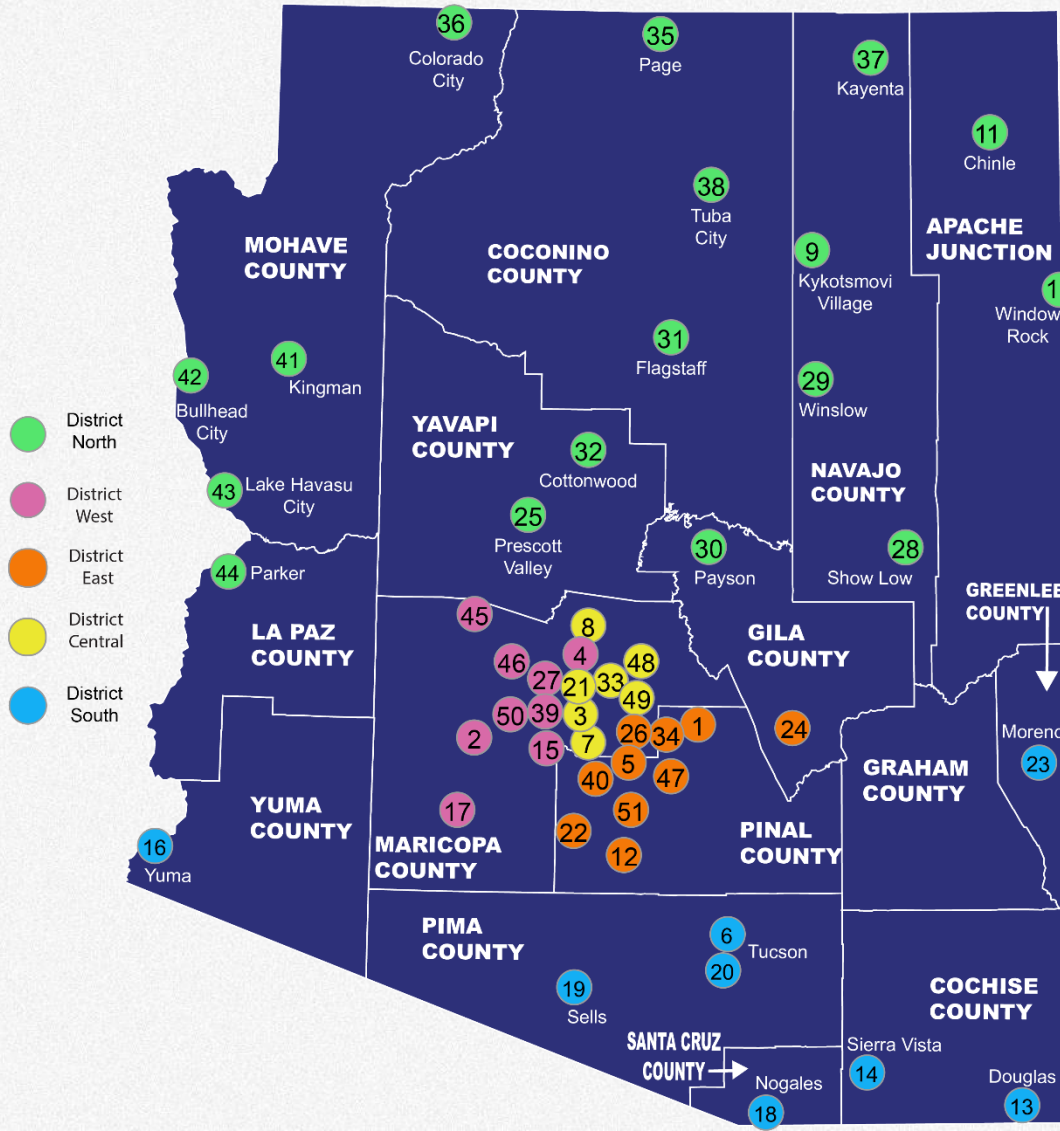
Flyers, by district, were created for distribution to parents, providers, support coordinators, and other professionals in the field.

Raising Special Kids staff of 14 Family Support Specialists, that provide individual assistance to parents and family members, provided information (primarily print and electronic flyers) daily on Forums to the people they supported. The organization takes between 20 – 30 phone calls per day from families seeking assistance.

FORUM LOCATIONS

FAMILY FORUM LOCATIONS

51 Family Forums were held throughout the entire state of Arizona; as well as 2 WebEx Forums. Traveled miles totaled 8,164.



DISTRICT NORTH

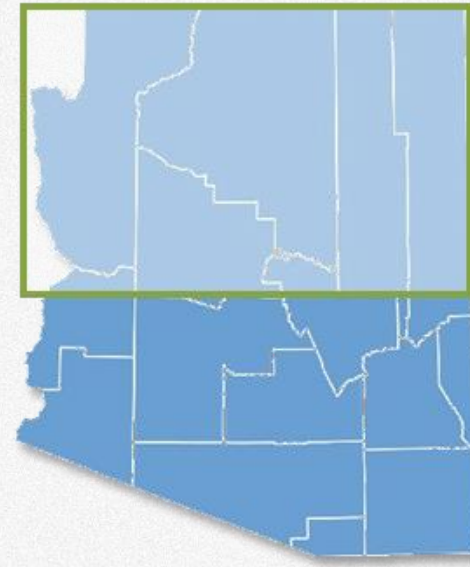


1	Kykotsmovi Village	Friday March 29	5:30PM-7:30PM
2	Chinle	Saturday March 30	1:30PM-3:30PM
3	Window Rock	Saturday March 30	9:30AM -11:30AM
4	Prescott Valley	Tuesday April 23	6:00PM-8:00PM
5	Show Low	Friday April 26	5:30PM-7:30PM
6	Payson	Saturday April 27	3:00PM-5:00PM
7	Winslow	Saturday April 27	10:00AM-12:00PM
8	Flagstaff	Tuesday April 30	6:00PM-8:00PM
9	Cottonwood	Wednesday May 1	5:30PM-7:30PM

DISTRICT NORTH

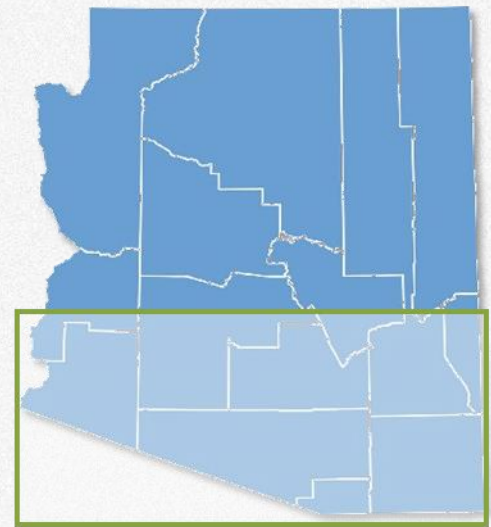
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10	Page	Thursday May 9	5:30PM-7:30PM
11	Colorado City	Friday May 10	5:30PM-7:30PM
12	Kayenta	Saturday May 11	10:00AM-12:00PM
13	Tuba City	Saturday May 11	2:30PM-4:30PM
14	Kingman	Thursday May 16	5:30PM-7:30PM
15	Bullhead City	Friday May 17	5:30PM-7:30PM
16	Lake Havasu City	Saturday May 18	9:30AM-11:30AM
17	Parker	Saturday May 18	2:30PM-4:30PM



DISTRICT SOUTH

1	Central Tucson	Tuesday March 26	6:00PM-8:00PM
2	Douglas	Tuesday April 2	6:00PM-8:00PM
3	Sierra Vista	Wednesday April 3	5:30PM-7:30PM
4	Yuma	Tuesday April 9	6:00PM-8:00PM
5	Nogales	Friday April 12	5:30PM-7:30PM
6	Sells	Saturday April 13	9:30AM -11:30AM
7	South Tucson	Saturday April 13	2:30PM-4:30PM
8	Morenci	Wednesday April 17	5:30PM-7:30PM



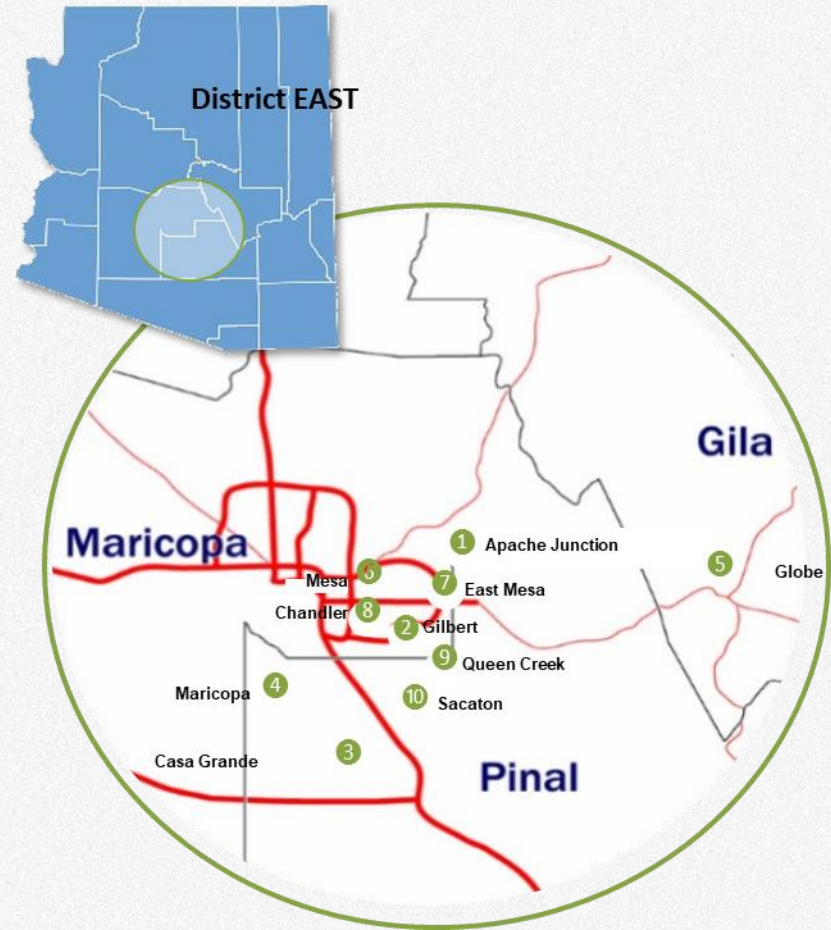
DISTRICT CENTRAL

1	Central Phoenix	Wednesday March 20	6:00PM-8:00PM
2	South Phoenix	Wednesday March 27	5:30PM-7:30PM
3	Anthem	Thursday March 28	6:00PM-8:00PM
4	Sunnyslope	Monday April 15	6:00PM-8:00PM
5	Paradise Valley	Thursday May 2	6:00PM-8:00PM
6	Fountain Hills	Thursday May 23	6:00PM-8:00PM
7	Salt River Community	Tuesday May 28	6:00PM-8:00PM



DISTRICT EAST

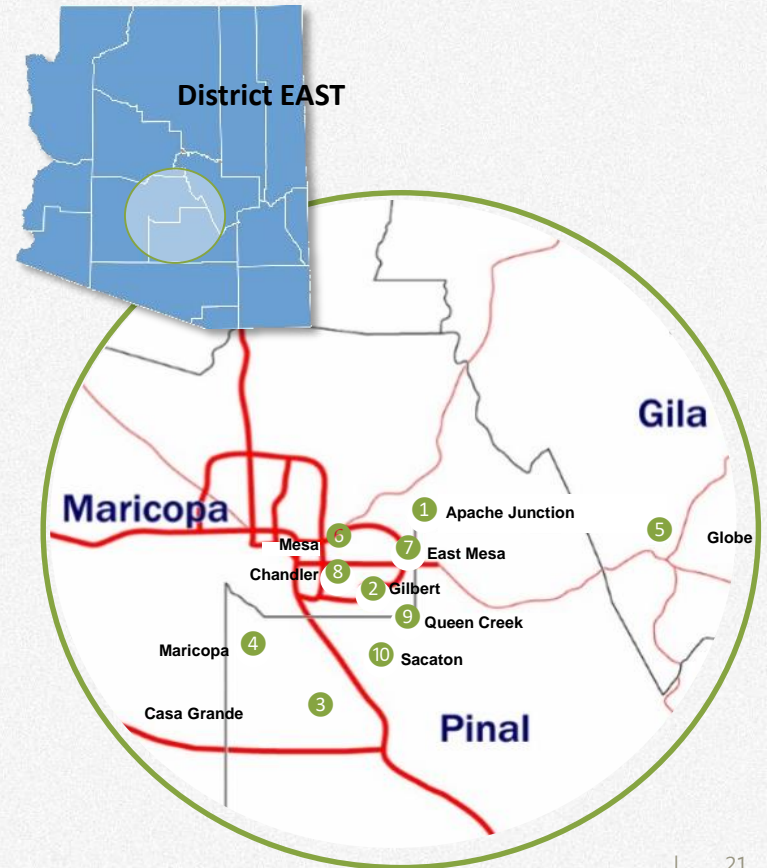
1	<i>Apache Junction</i>	<i>Monday March 18</i>	<i>6:00PM-8:00PM</i>
2	<i>Gilbert</i>	<i>Saturday March 23</i>	<i>2:30PM-4:30PM</i>
3	<i>Casa Grande</i>	<i>Monday April 1</i>	<i>6:00PM-8:00PM</i>
4	<i>Maricopa</i>	<i>Tuesday April 16</i>	<i>6:00PM-8:00PM</i>
5	<i>Globe</i>	<i>Thursday April 18</i>	<i>5:30PM-7:30PM</i>



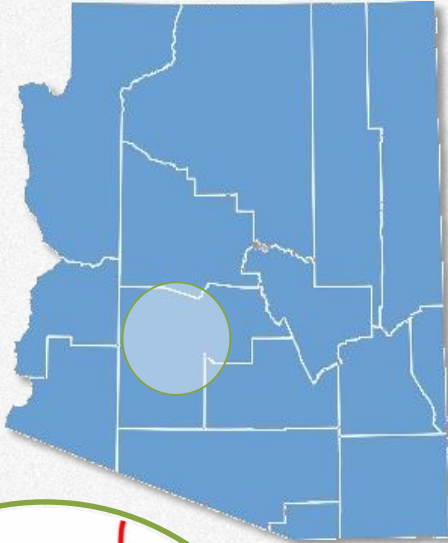
DISTRICT EAST

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6	Mesa	Wednesday April 24	6:00PM-8:00PM
7	East Mesa	Tuesday May 7	6:00PM-8:00PM
8	Chandler	Tuesday May 14	6:00PM-8:00PM
9	Queen Creek	Wednesday May 22	6:00PM-8:00PM
10	Sacaton	Thursday May 30	5:30PM-7:30PM



DISTRICT WEST



1	Buckeye	Tuesday March 19	6:00PM-8:00PM
2	Peoria	Saturday March 23	9:30AM -11:30AM
3	Laveen	Thursday April 4	6:00PM-8:00PM
4	Gila Bend	Wednesday April 10	5:30PM-7:30PM
5	Glendale	Thursday April 25	6:00PM-8:00PM
6	Maryvale	Monday May 13	5:30PM-7:30PM
7	Wickenburg	Monday May 20	5:30PM-7:30PM
8	Surprise	Tuesday May 21	6:00PM-8:00PM
9	Avondale	Wednesday May 29	6:00PM-8:00PM

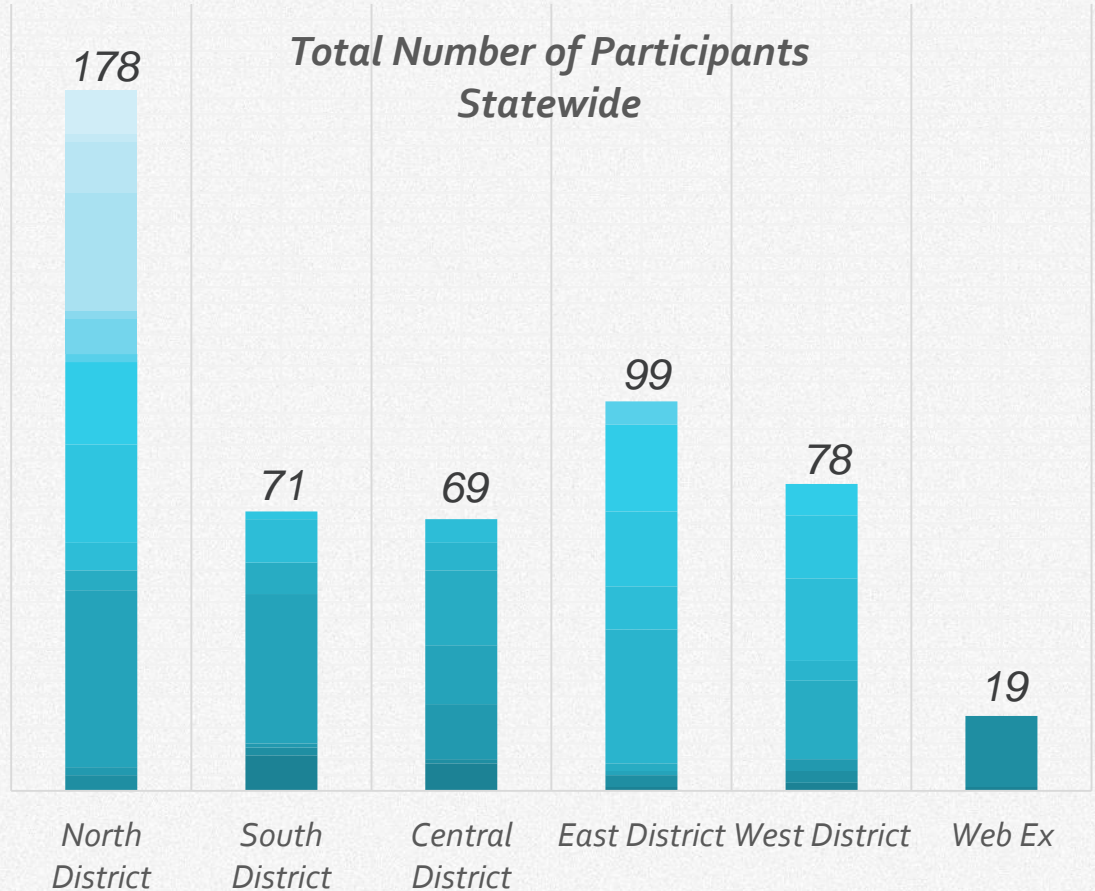
STATEWIDE PARTICIPATION

PARTICIPATION IN ALL OF ARIZONA INCLUDING WEB EX FORUMS

526

Total statewide participants

*There were a total of 19 callers
to the WebEx Forums held on
April 29th & May 24th*



PARTICIPATION FAMILIES AND PROFESSIONALS

About families and for families

From facilitator's script:

"For those of you that are here in a professional capacity, you are welcome to observe and listen, however, we ask that you please not comment. This forum is specifically to collect the input from DDD members and families."

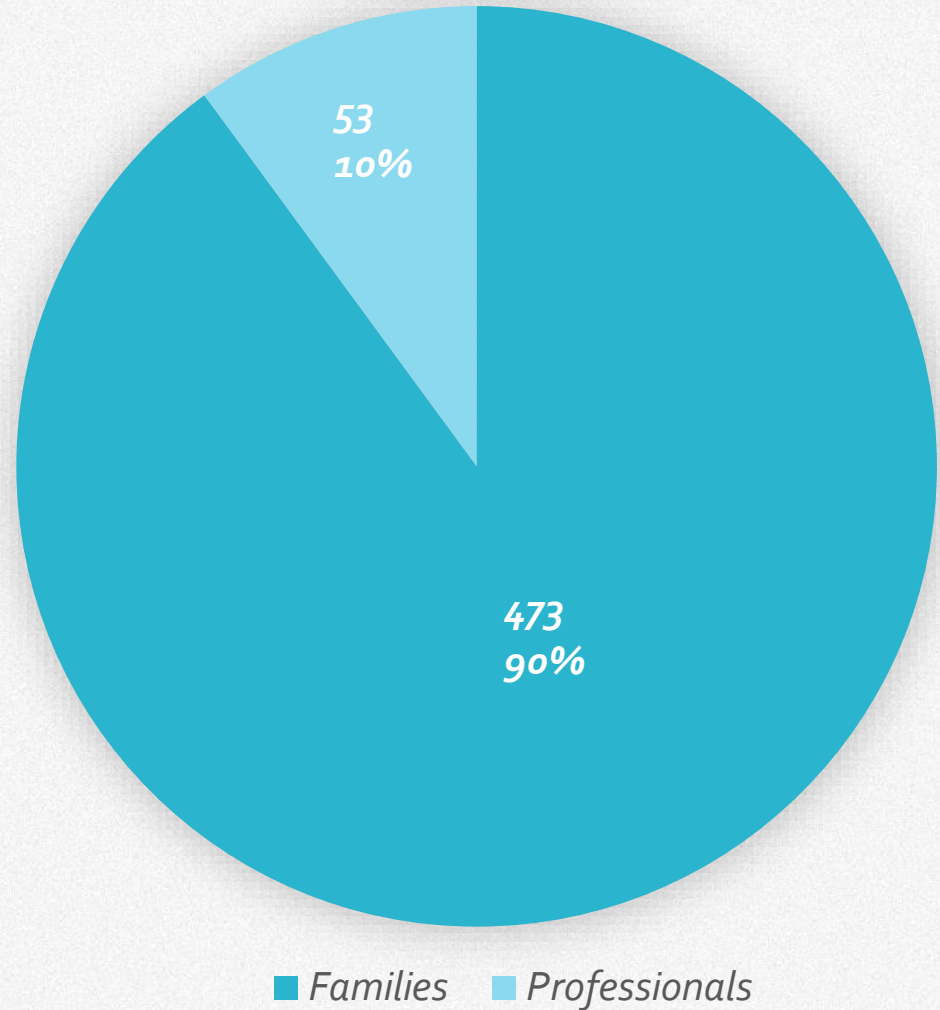
Members and Families participation:

473 (90%)

Professionals attendance:

53 (10%)

Families and Professionals

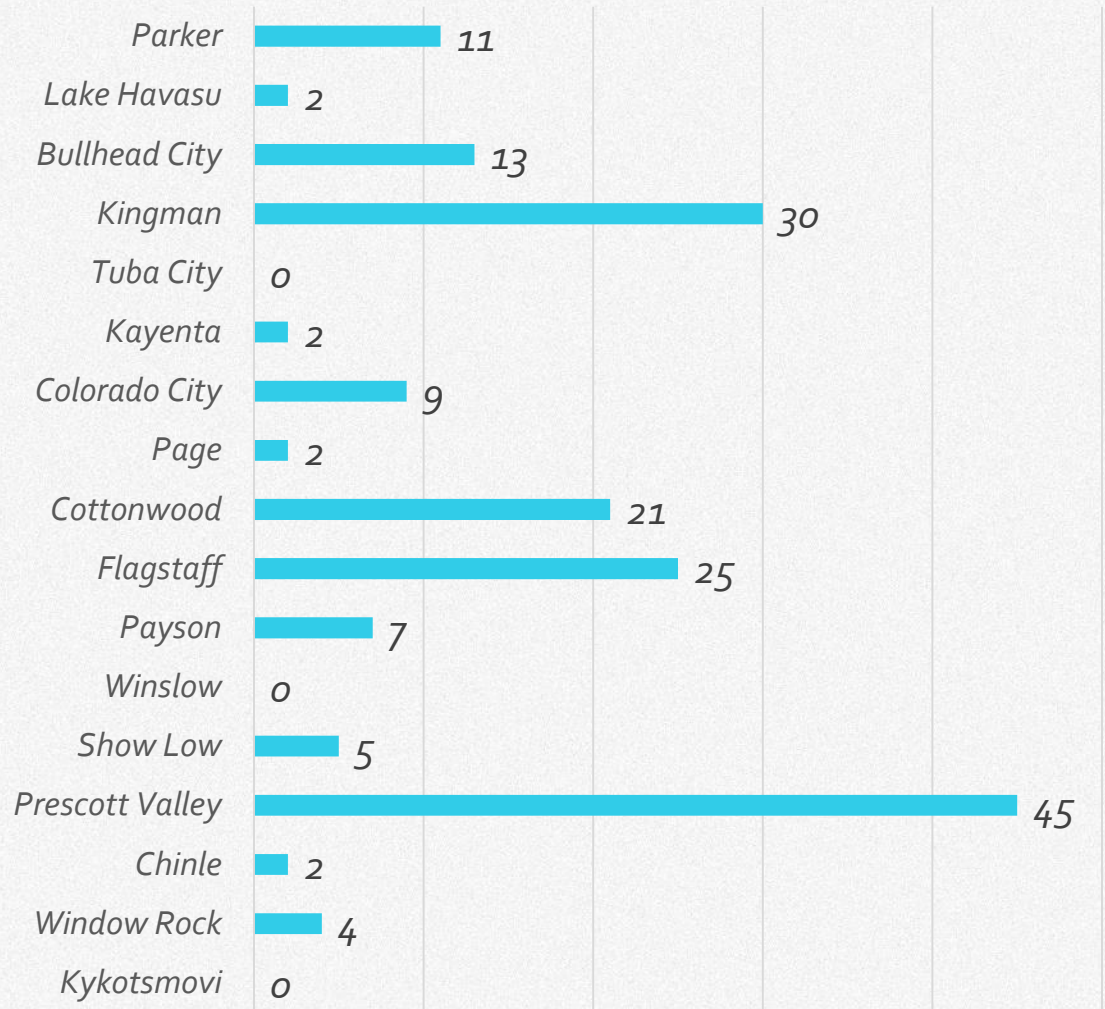


PARTICIPATION DISTRICT NORTH FORUMS

*178 total participants in
District North*

*North District forums
were well-attended in
Prescott 45, Kingman
30, and Flagstaff 25*

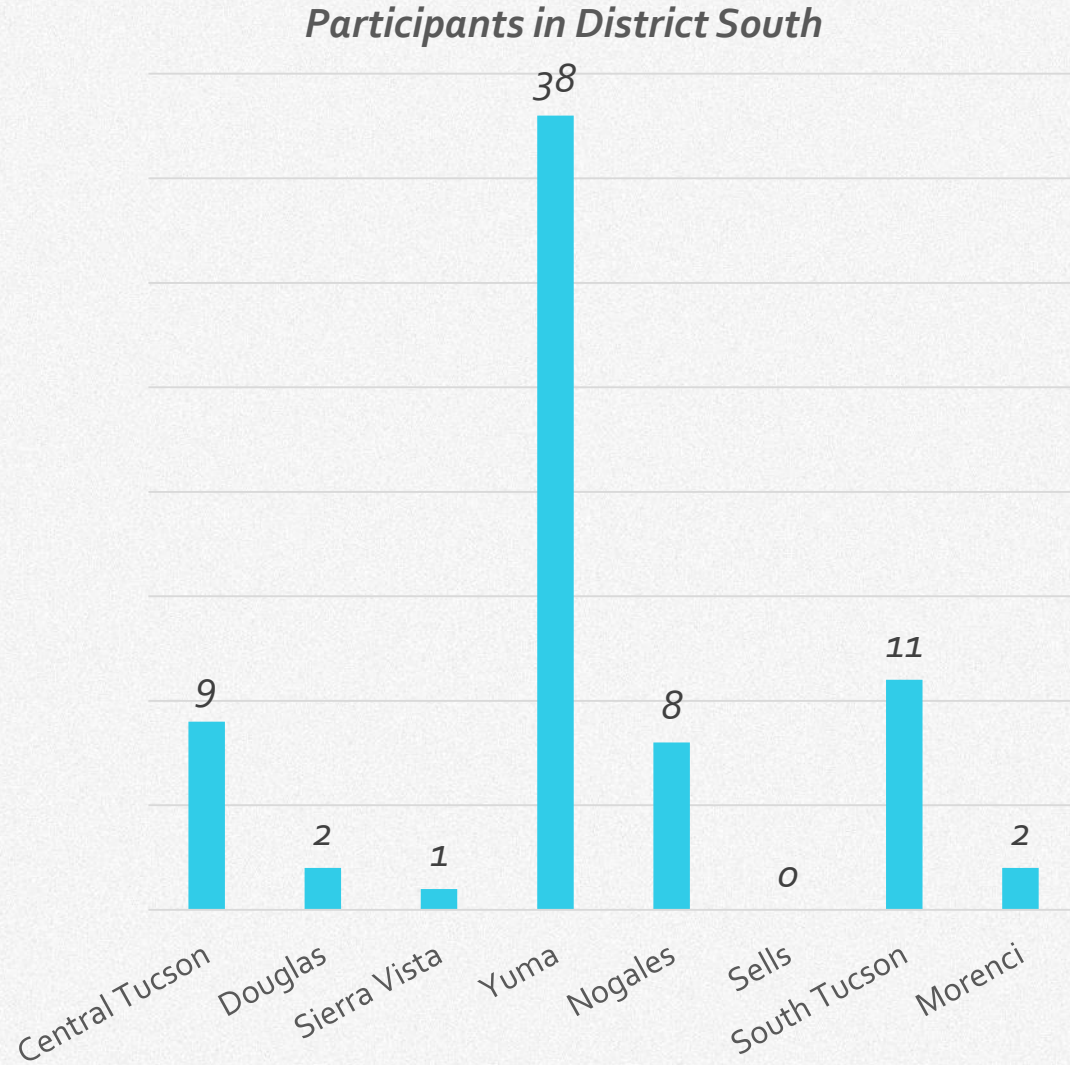
Participants in District North



PARTICIPATION DISTRICT SOUTH FORUMS

*71 total participants in
District South*

*Yuma had the largest
turnout with 38
participants*

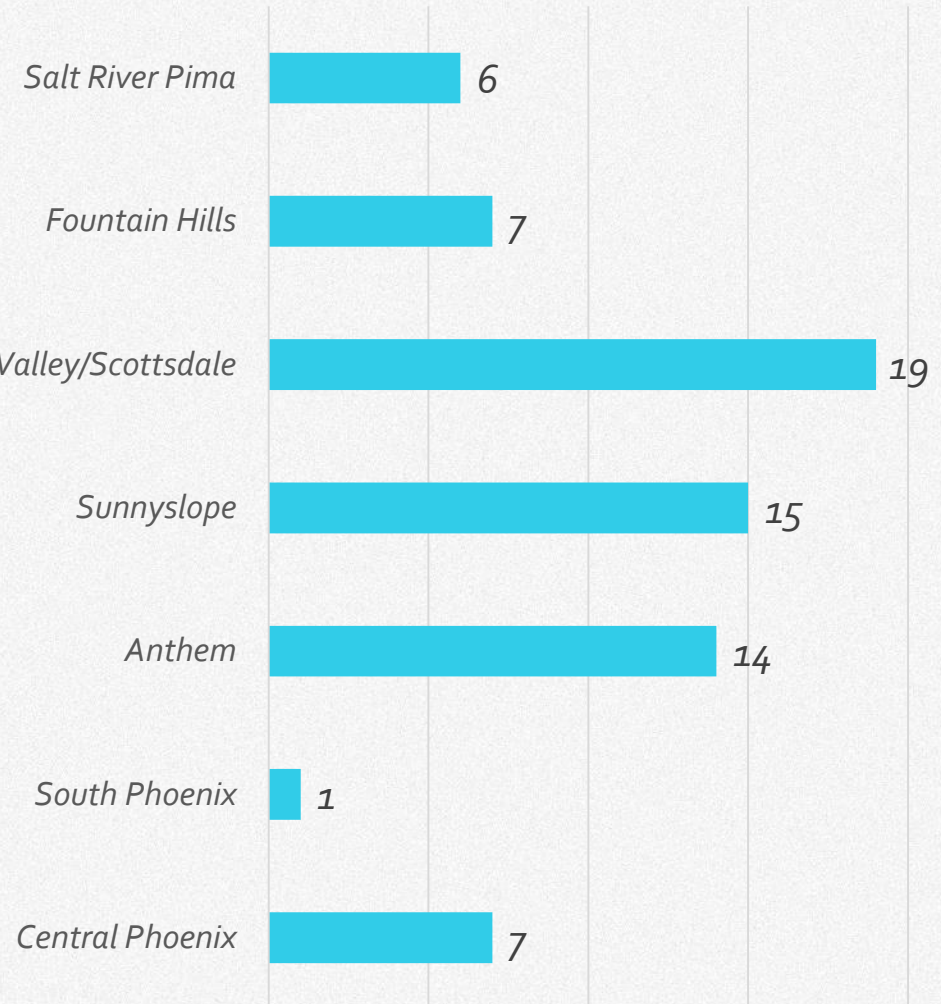


PARTICIPATION DISTRICT CENTRAL FORUMS

*69 total participants in
District Central*

*Forums were well-
attended in Paradise
Valley/Scottsdale 19,
Sunnyslope 15, and
Anthem 14*

Participants in District Central

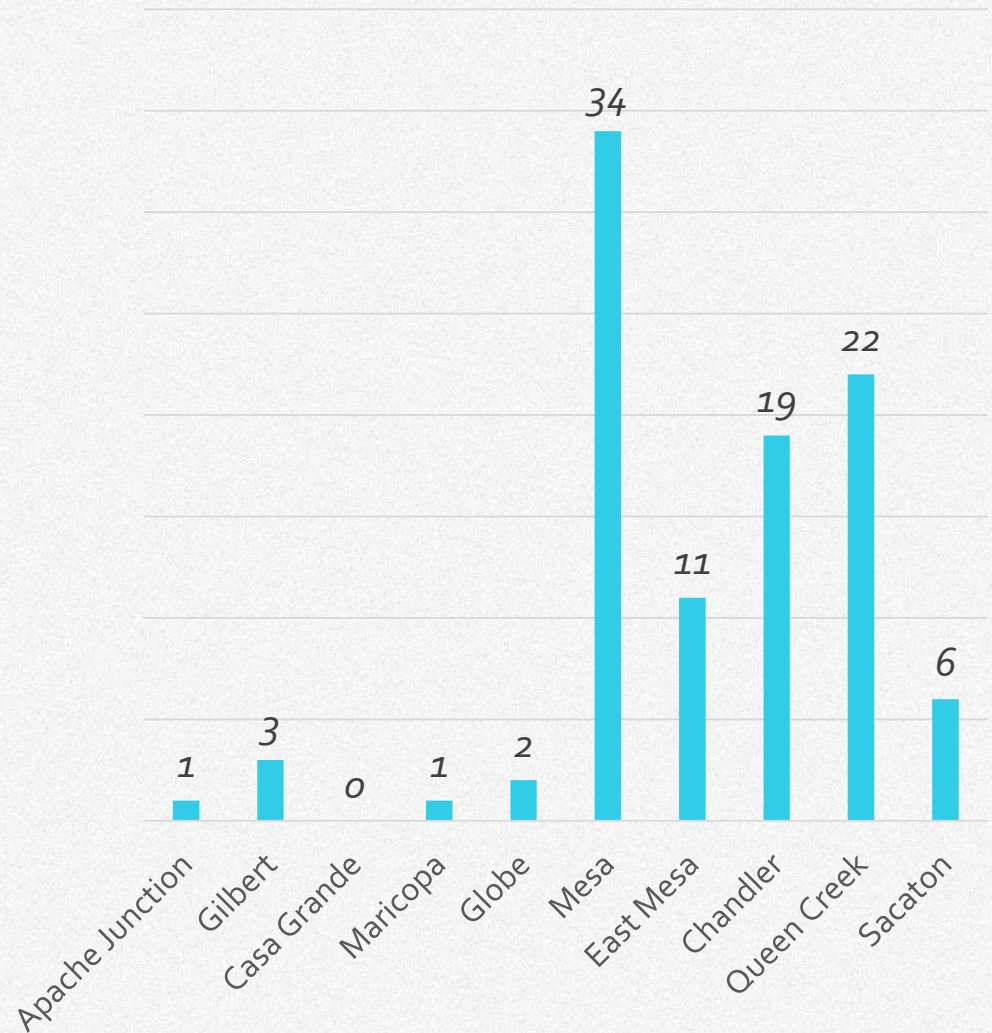


PARTICIPATION DISTRICT EAST FORUMS

*99 total participants in
District East*

*Forums were well-attended
in Mesa 34, Queen Creek
22, and Chandler 19*

Participant in District East

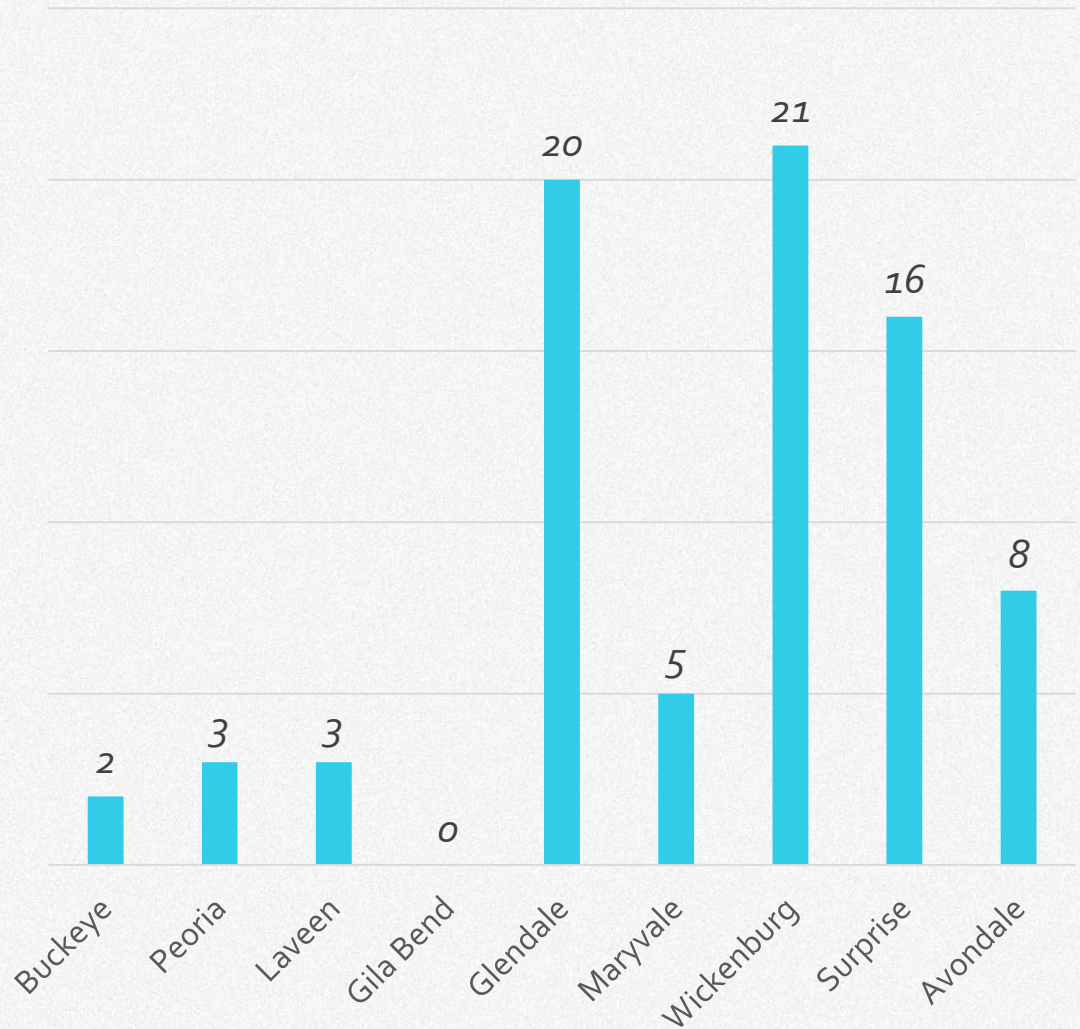


PARTICIPATION DISTRICT WEST FORUMS

*78 total participants in
District West*

*Forums were well-
attended in Wickenburg
21, Glendale 20, and
Surprise 16*

Participants in District West



THEMES & KEY FINDINGS

WHAT IS GOING WELL WITH DDD LTSS?

"My Support Coordinator involves my child in the conversation"

In Prescott there were many families happy with their day treatment program in town "I feel lucky to be part of our DTA"

"We are able to attend this forum thanks to respite"

"Not having to deal with copays thanks to the health plan was a blessing"

In all the forums we had 352 comments on what is going well with DDD LTSS.

115 comments were families sharing positive interactions with their Support Coordinator

101 of the comments were families reporting they were happy with the home and community based services their children were receiving (e.g.: Respite, Habilitation, Attendant Care, Speech, Occupational Therapy, etc.)

72 comments were made by the families that they were happy with the quality of their providers (e.g.: service providers, day programs, jobs, group homes, summer programs, etc.)

15 comments families said they were happy with their DDD health plan benefits

WHAT NEEDS TO BE IMPROVED?

"We have had 8 different Support Coordinators in the last 10 years" from a family in Yuma

"The vendor calls do not work"

"My child has Respite, Hab, OT, Speech and Music Therapy approved, but there are no providers in our area available"

"Caregiver wages may not get you the best quality person"

There were 517 comments for what needs to be improved

149 comments on support coordination in general as needing improvement:

- *Support Coordinator turnover was high*
- *Support Coordinator's lack training in getting information and offering resources to families*
- *Support Coordinator's communication with families*

138 comments parents said there was a lack of service providers:

- *78 of these were therapy-related providers*

44 families commented on DDD processes and procedures needing improvements (vendor calls, augmentative communication device, release of hours from service provider agencies).

20 comments from families reflected that pay rates to both Support Coordinators and service providers are low and contributes to the lack of quality.

WHAT ARE THE SOLUTIONS FOR IMPROVEMENT?

"Support Coordinators should have a cheat sheet so that they know the different services and resources available"

"Wage increase with experience for Support Coordinators"

"Convince vendors to open a DTA in Morenci"

"Brochures and videos should be available for all DDD services available"

There were 429 comments on solutions for improvements.

87 members and families reported support coordinators needed more training

49 suggestions were made that the State increase pay for better quality Support Coordinators

35 comments reflected the need for more providers and DDD building a larger provider network

32 participants reported wanting more information and transparency from DDD

THOUGHTS ON ALTERNATIVE SERVICE DELIVERY MODEL

"Physicians struggle with understanding the unique needs of families with kids with disabilities. I feel they understand physical needs, but do not understand the HCBS needs."

"We need a lot more information to comment on this Alternative Delivery Model"

593 total comments were collected in 'Thoughts on an Alternative Service Delivery Model' discussion item

280 comments show families reported concern about the alternative model with the following themes:

- doubts in general*
- loss of Support Coordinator*
- potential barriers to services*
- loss of advocacy rights*
- loss of services*
- lower quality of life for members*
- conflict of interest - concern that the payer of services decides to what extent the services are provided*

Though presented as an information item, 34 comments captured the families liking, or having a positive comment about, the Oct 2019 model

THOUGHTS ON ALTERNATIVE SERVICE DELIVERY MODEL CONTINUED

"Would health plan coordinators offer the full range of services and supports?"

"What will happen to our Support Coordinator?"

136 comments show families asking specific questions that needed clarification:

- "What if my providers are not contracted with the health plan?"*
- "How will it affect my family?"*
- "Would a change to a managed care system retain all the positive aspects of the current system?"*

88 Families reported that the model presented felt impersonal or that it appeared to be a for profit business model

30 comments specifically reflect that families reported not wanting the alternative model for their family

25 comments reflect conditional support for the alternate service delivery model presented, comments like:

- "If all things stay the same, no problem"*
- "Comfortable with the service delivery model change as long as my providers don't change"*
- "As long as there is good communication"*

WHAT ARE YOUR THOUGHTS AND SUGGESTIONS ON EXECUTIVE ORDER

"Public places like football games should have security with cameras and walkie-talkies to protect people"

(Comment by a Division member in Northern Arizona)

"We need to have 2 providers per member at all times to insure safety"

"Personality test should be part of hiring process for hiring people to work with this community."

Members and families supported the executive order and provided additional recommendations, and 308 comments were collected.

Increase provider monitoring and oversight was commented on 51 times

Provide training and education was commented on 23 times

Increase funding was commented on 21 times

Strict background checks was commented on 21 times

Advocacy and reporting was commented on 20 times

Hiring practices was commented on 17 times

WHAT DOES YOUR BLUE SKY LOOK LIKE?

"A community that does not look down on our child and our family"

"No Bullying"

(Comment made by a Member in South Arizona)

Blue sky is the ideal vision of the world the members and families live in. If you could have anything you want for yourself or your family, what would it be? (Comments 317)

Participants responded with a wide range of unique comments. Many comments had a general theme of inclusion, employment, independent living, and communities working together to support all people.

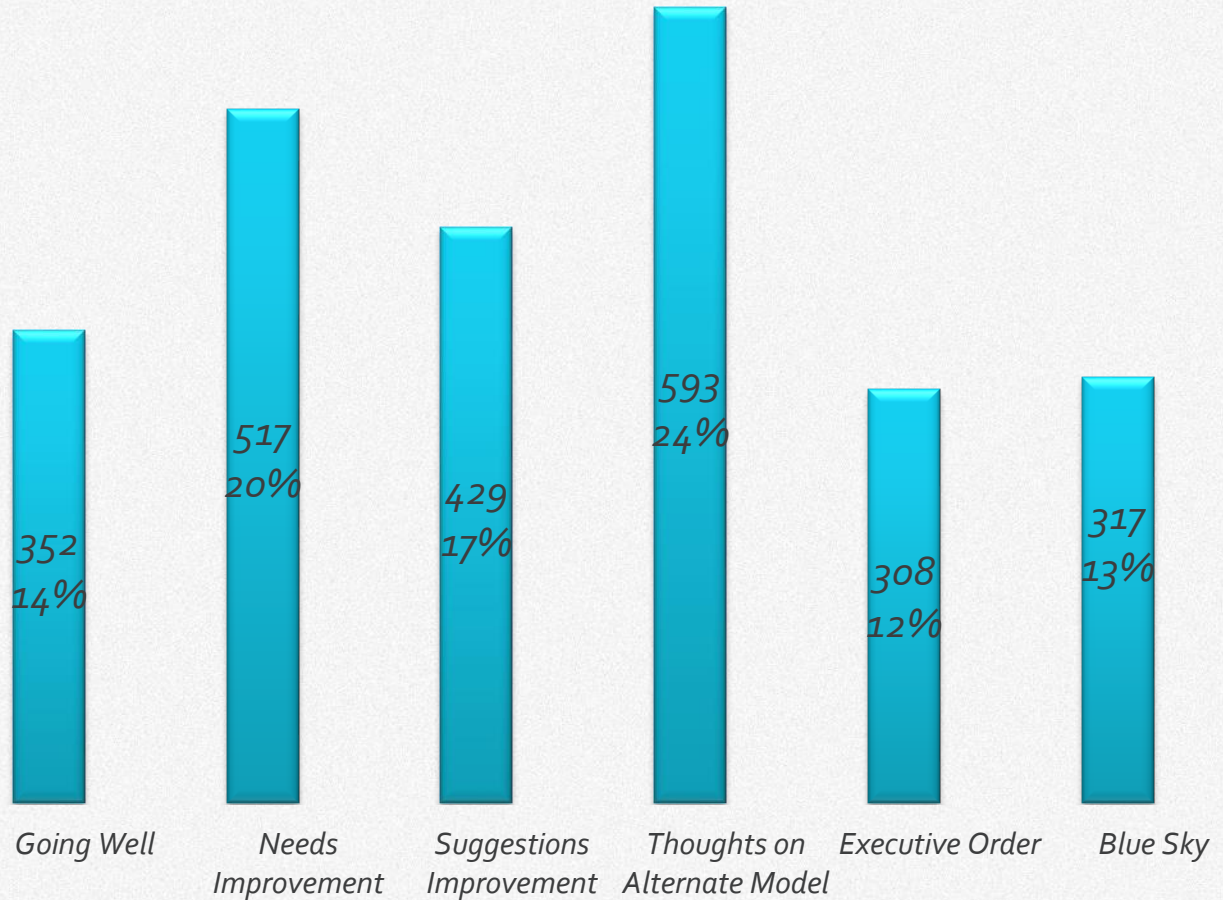
- *"For my son to be living independently and working" (Kingman)*
- *"Collaboration by all" (South Tucson)*
- *"Schools have a better understanding of children with disabilities needs" (Morenci)*
- *"I want my son to be happy" (Prescott Valley)*

TOTAL COMMENTS COLLECTED

Comments and Input

There was a total of 2516 Comments

The majority of the comments were centered around the thoughts on the Alternative Delivery Model



UNIQUE ISSUES

FAMILY FORUMS

AZ/UTAH ISSUES

Special thank you to First Things First Regional Director La Paz/Mohave Regional Partnership Council, Vijette Saari, for connection with Cherish Families organization who provided cultural competency training prior to engagement with the Colorado City community.

Colorado City has specific issues based on their location and cultural differences.

Location: Families reported that like most areas there were limited doctors, specialists, and LTSS providers. What makes their issues unique is their proximity to Utah. It is easier to go to Utah than Arizona with regards to specific needs.

- *"We have to travel long distances for specialties like neurology"*

Culture: The culture of this region also makes it a more likely underserved community. We learned that there is historical mistrust of state agencies, government agencies and public schools within the community. Mothers of children with disabilities are less likely to seek out services needed for their members.

- *"Having my kids come to a point where they can live independently"*

FAMILY FORUMS

TRIBAL COMMUNITIES

"Advocate to stop violence against Native American Women"

"Amber Alert in Navajo land"

"Data and statistics on violence against women, suicide and social issues like abuse against native American woman"

"Navajo and tribal background checks include background from all entities"

"Be transparent with sex offender registries"

"Require sex offender registration on tribal lands, no exception"

"Sentencing from crimes against vulnerable children and adults should be consistent on and off tribal land" (Window Rock)

Executive Order

Work Groups

The Page community voiced that the tribes are represented in the abuse and neglect work groups, and they recommended that the work groups respect the issues of the Native American Population.

Quotes:

Quotes were taken during the thoughts on the Governor's executive order facilitation item, at our forums on tribal lands, and express strong concern regarding differences between AZ State and Tribal law.

CONCLUSION

CONCLUSION

The primary purpose of the Member and Family Forums was to collect broad stakeholder feedback on an alternate service delivery model.

Raising Special Kids would like to thank the Division of Developmental Disabilities, The Arizona Health Care Cost Containment System, Professionals that work in the field of disability, and most of all the Members and Families who participated by sharing their lived experience and providing their honest input.

There was a high number of total comments of concern (398 recorded) toward the alternate service delivery model presented. Members and families had many questions (136 recorded) and expressed the need for more information to make an informed opinion.

It is important to note that the role of the facilitator was to seek and record member and family input and feedback, rather than to answer specific questions participants had about the alternate service delivery model, or 'fully integrated care' model, presented. Members and families reported general confidence in the current, familiar, service delivery system. That being said, there were 517 comments on 'what needs to be improved?' and 352 comments on 'what is going well?'

Members and Families were appreciative that DES/DDD staff were in attendance to discuss any specific issues they may have been having at the time, or to hear about their personal experience with services and supports through the Division of Developmental Disabilities.