



# Division of Developmental Disabilities Statewide Member and Family Forums 2019

## Project Summary

### *About Families and for Families*

Prepared by: Raising Special Kids

On Behalf of: The Division of Developmental Disabilities



## General Purpose:

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.

## Primary Purpose:

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'.

# Facilitated conversation with members & families to elicit broad feedback on:

What is going well with DDD LTSS?

What needs to be improved?

What are the solutions for improvement?

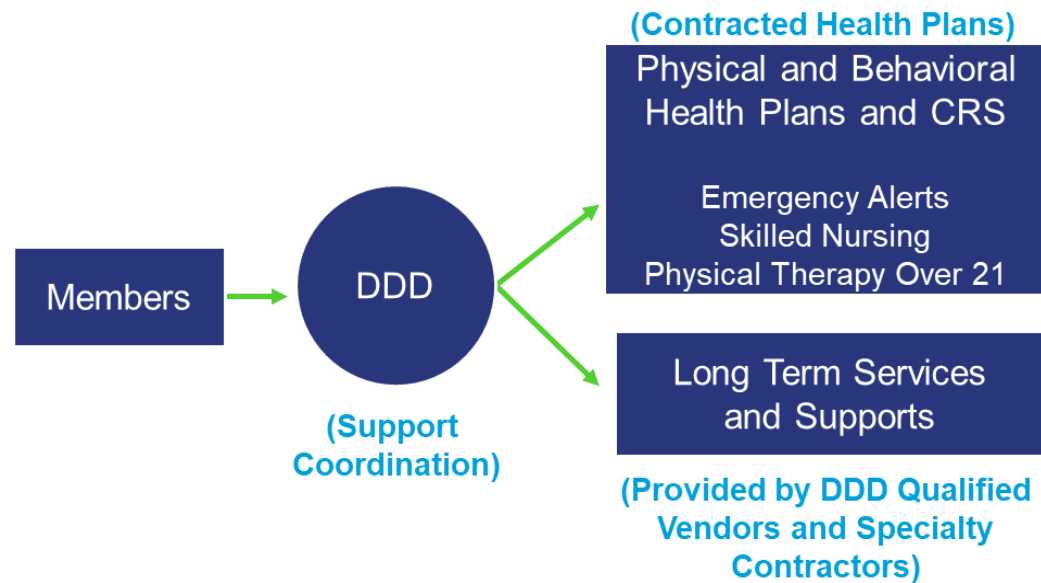
Thoughts on alternate service delivery model

Thoughts on the Governor's Executive Order

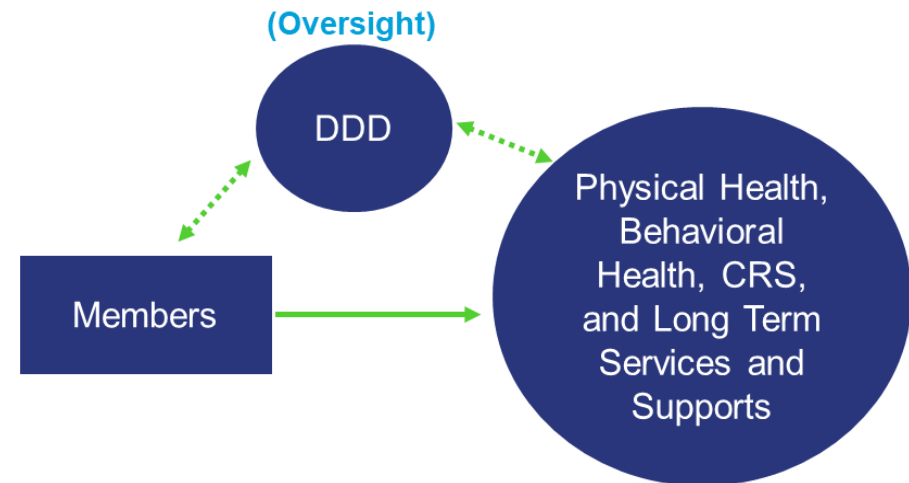
What does your blue sky look like?

# Alternate Service Delivery Model as presented

October 1, 2019 Service Delivery Model



Alternate Service Delivery Model





Raising Special Kids  
Families Helping Families

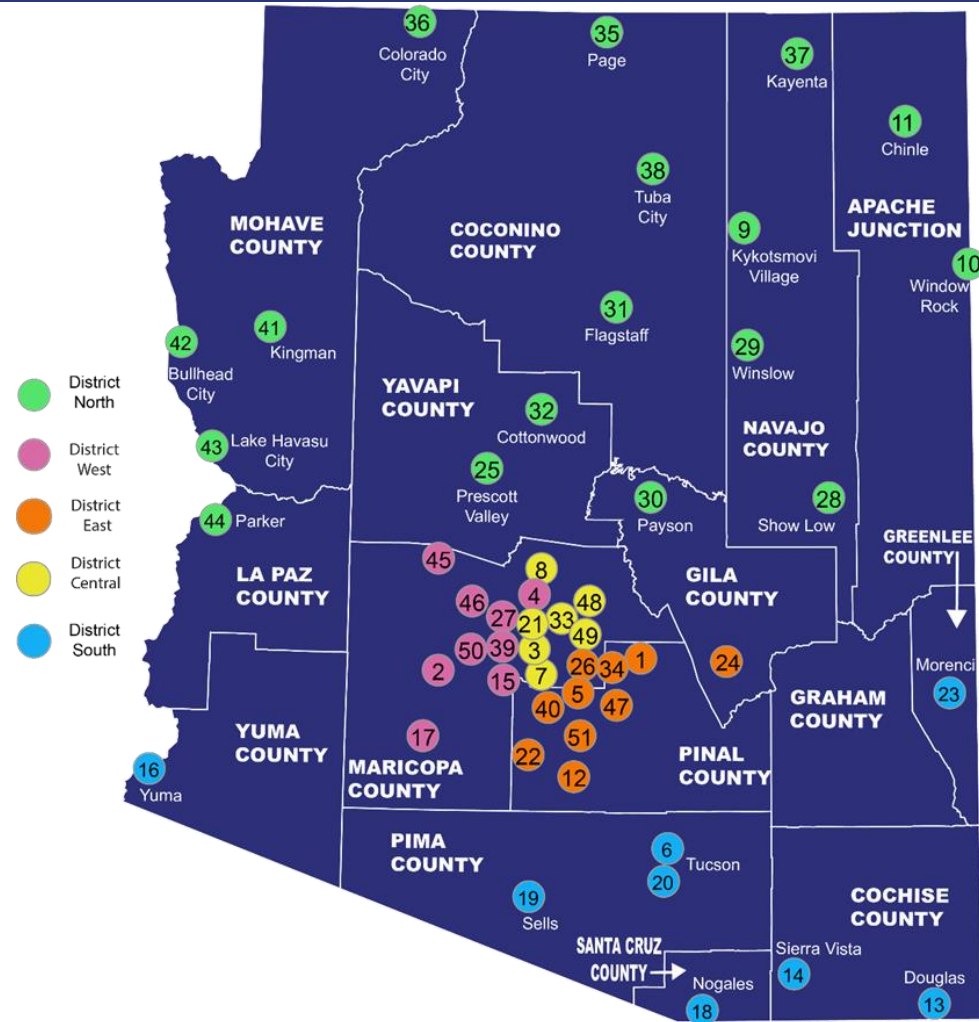


DEPARTMENT OF  
ECONOMIC SECURITY

Division of Developmental Disabilities

# Forum Locations

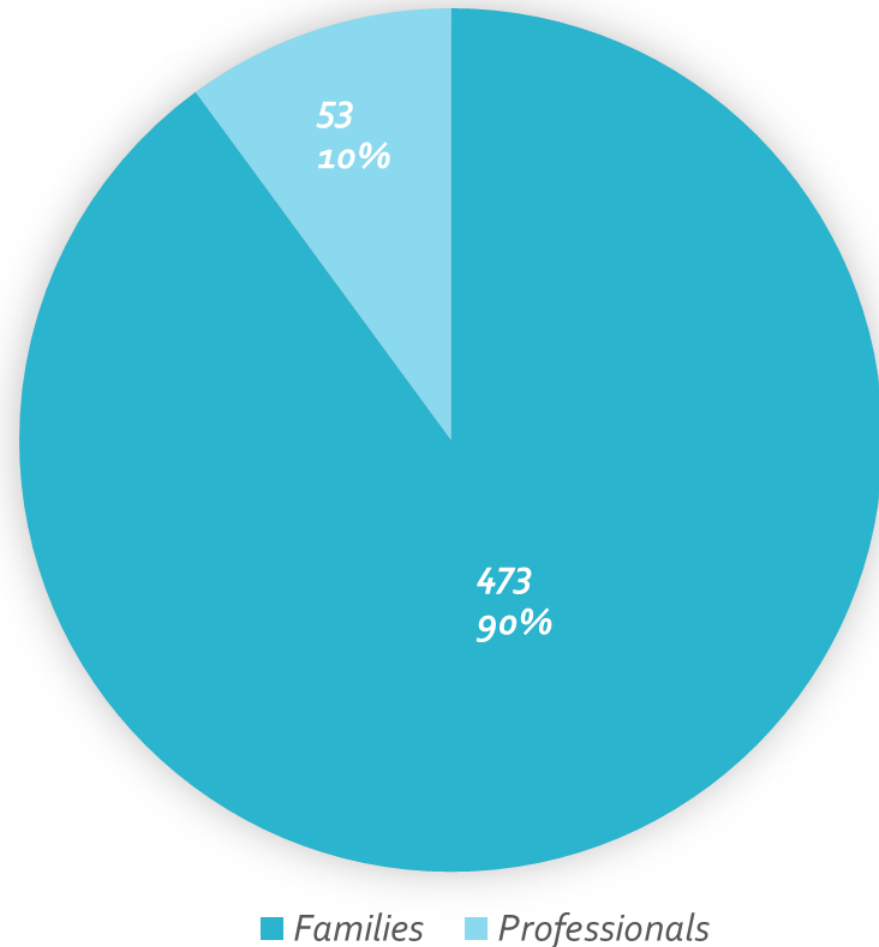
- 51 Forum Sites
- 2 Statewide via WebEx



# Statewide Participation

- Total attendance: 526
  - Members and Families participation: 473 (90%)
  - Professionals attendance: 53 (10%)

*Families and Professionals*



# What is going well with DDD LTSS?

352 comments recorded

115 Comments – 33%

Support Coordination/Support Coordinator:

- Care for the member and supportive
- Invested in the well being and progress of the member

101 Comments – 29%

Home and Community Based Services:

- Respite care
- Habilitation
- Attendant care
- Therapies

72 Comments – 20%

Service Provider Personnel:

- Day programs
- Jobs
- Group homes
- Summer programs

# What needs to be improved?

517 comments recorded

149 Comments – 29%

Support Coordination:

- High turnover
- Insufficient training and knowledge of information and resources for families
- Communication (timely response)

138 Comments – 27%

Service Providers:

- General lack of service providers (provider shortage)
- Over half of these comments (78) related specifically to therapy

44 Comments – 9%

DDD Processes and Procedures:

- Vendor calls
- Communication device
- Releasing assigned hours



# What are the solutions for improvement?

429 comments recorded

87 Comments – 20%

Increase training for Support Coordinators

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

84 Comments – 20%

Increase in salary (49 comments) for Support Coordinators was suggested, and members and families also expressed a need for more service providers for the DDD network (35 comments)

35 Comments – 8%

Members and Families reported a desire for more information and a higher level of transparency from DDD

# Thoughts on an alternate service delivery model

593 comments recorded

280 Comments – 47%

Members and families expressed various concerns:

- General Doubts
- Loss of Support Coordinator and/or services,
- Conflict of Interest

136 Comments – 23%

Members and Families had many questions about the model presented:

- “How will it affect my family?”
- “What will happen to our Support Coordinator?”
- “What if my providers are not contracted with the health plan?”

# Thoughts on an alternate service delivery model

Continued

88 Comments – 15%

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

34 Comments – 6%

Though presented as an information item members and families had positive comments about, the Oct 2019, partially integrated model

# Thoughts on an alternate service delivery model

## Continued

### 30 Comments - 5%

Members and Families reported that they did not want the alternative model for their family

### 25 Comments - 4%

Members and Families reported conditional support for the alternate service delivery model:

- “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”



# Thoughts and suggestions on The Governor's Executive Order.

308 comments recorded

Overwhelming support for the Governor's Executive Order. Additional recommendations:

- Increase funding, monitoring and oversight
- Training and education for staff and families
- Strengthen background checks
- Increase advocacy training and reporting requirements
- Review hiring practices for people that work with individuals with disabilities.

## Blue sky

*The ideal vision of the world the members and families live in*

317 comments recorded

Participants responded with a wide range of unique comments having a general theme of:

- community inclusion
- employment
- independent living
- and communities working together to support all people.



# Conclusion

Members and families reported concern (398 comments) about the alternate service delivery model presented and the need for more information (136 questions) to make an informed opinion.

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 at each of the forums, and expressed a desire to stay engaged in the conversation started with the Statewide Member and Family Forums 2019.



# Thank You

Raising Special Kids would like to thank:

- The Division of Developmental Disabilities
- The Arizona Health Care Cost Containment System
- Providers and Professionals that work in the field of disability

# Special Thank You

Raising Special Kids sincerely thanks the Members and Families who participated in the Statewide Member and Family Forums by providing their honest input and sharing their lived experience.