Family Experience Network

Assuring Better Child Health & Development

Healthy Development, Thriving Families

We are a network of families with different experiences and backgrounds who walk alongside other families, offering understanding, hope, and connection.

This network brings together the voices of Colorado families raising children ages 0 to 5 to better understand their experiences, discuss their child's learning and development, participate in developmental screenings, navigate referrals, and access services when concerns arise. Their stories highlight what is working well, the challenges families face, and opportunities to make support systems more responsive and family-centered.



Colorado Voices Represented

Family Experience Network:

- 17 Family Leaders
- 2 ABCD Team Members
- Across 9 Colorado Counties
- Languages Represented:
  - English, Spanish, Arabic & Dari

Health & Early Childhood Providers, Community Partners & Additional Families:

- Statewide Family Experience Survey
  - 346 Responses, 30 counties and 8 languages
  - 61% White, 30% Latino/Hispanic/Latinx, 8% Asian, 3% Black/African Am.
- 3 Provider and Family Focus Groups
  - 25 Participants representing 13 counties

What We Learned

Families vary in their knowledge and understanding of developmental milestones, expectations, & concerns.

39% of families reported they somewhat or didn't know what to expect.

"I wasn't sure if I should be worried"

"More information about child development, so we can act in time."

"In my culture, this isn't something we talk about openly"

Where families get their information:

- 88% medical setting
- 54% online
- 15% support group

Families benefit from personalized support as they navigate the complex journey from concerns to services.

30% of families reported they didn't know or only somewhat knew what to do after a concern was identified.

"Explain things clearly, especially what supports are available and how to access them. Also be aware this may be emotionally difficult for caregivers so they need encouragement and time/space for questions."

After the screening, families were asked to:

- 68% get an evaluation
- 52% join a program or service
- 50% talk with another provider
- 27% watch and wait
- 19% get more information

Families frequently face a long, overwhelming, and isolating journey.

50% of families say getting connected to services is hard.

"It took almost 2 years to receive a diagnosis and start services. I didn't know what to do while we waited."

"It can be overwhelming and is essentially another part time job on top of full time work and parenting. I'm already exhausted and burnt out."

- 13% had support from another parent or caregiver
- 33% felt emotionally supported
- 29% had some help getting connected to services

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What Matters Most to Families

- **Family Voice**
- **Lived Experience**
- **Cultural Safety**
- **Emotional Safety & Connection**
- **Genuine Openness and Curiosity**
- **Family Pace & Readiness**
- **Empathy and Understanding**
- **Partnership**
- **Opportunities**

Family Experience Network Recommendations

1. Families and teams partner to design culturally and emotionally safe experiences

Family-designed and family-led learning opportunities that help families explore:

- Child development
- How culture and lived experiences shape perspectives and decisions
- Emotional support throughout the process

2. Create intentional opportunities for families to connect with others who share similar experiences, cultures, identities, diagnoses and concerns

Strengthen pathways for family connection and support by connecting families to:

- Peer mentors
- Family navigators
- Support groups

3. Partner with families from the beginning to create individualized resources, tools, and experiences that support them along the way

Develop family-informed navigation tools that support:

- Understanding the system and process
- Clarifying next steps
- Identifying questions to ask along the way
- Tracking progress and planning next steps

4. Offer multiple ways for families to personalize and explore their child's growth, development, strengths, and areas of need

Offer individualized resources that support:

- The child's development and emotional well-being
- Explore concerns and questions
- Connecting with other families through classes and support groups
- Accessing tools, resources, and learning opportunities while waiting for services

5. Develop a family-to-family Care Coordinator model that is grounded in peer support and shared experience

Provide peer support that reflects:

- The cultures, languages, and lived experiences of families accessing supports and services

Special Olympics Health

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Have questions or want to learn more?
Contact Nikki Fitch:
Nikki@coloradoabcd.org