



PARENT<sub>TO</sub>PARENT  
USA

**Connecting caregivers to never feel alone.**



# Leveraging Parent to Parent in State Needs Assessments and Services for CYSHCN

- **Introductions & Overview of Parent to Parent**
- **Colorado Partnership Examples**
- **South Carolina Partnership Examples**
- **Q&A**
- **Next Steps**





# Introductions



**Nichole Arp**

Program Manager, Parent to Parent of Colorado  
Colorado Title V Family Leader



**Lily Brown**

Co-ED, Parent to Parent USA



**Amy Holbert**

CEO, Family Connection of South Carolina  
Board President, Parent to Parent USA  
South Carolina Title V Family Delegate

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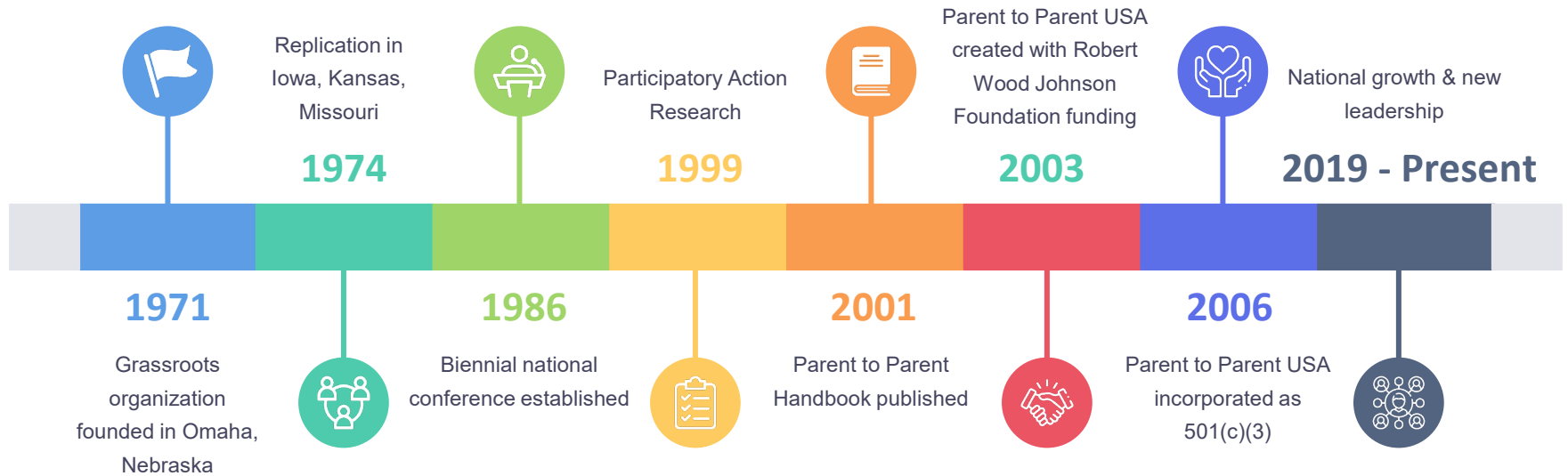
# Our Purpose.

No parent should feel alone. Ever.



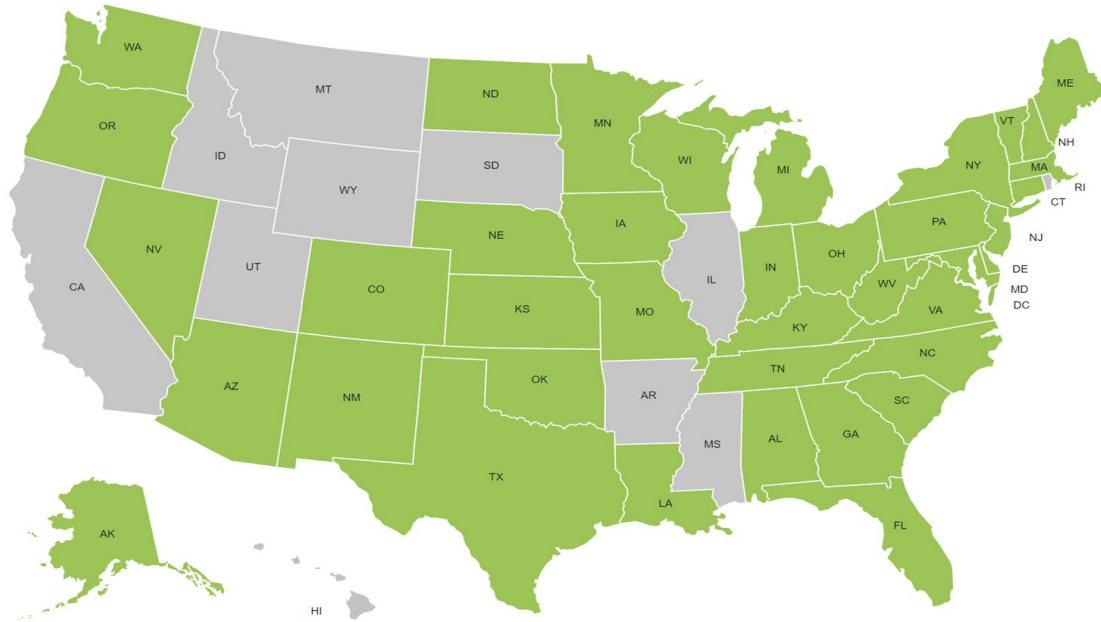


# Our Journey.





# Our National Community.



- 40** Alliance Members
- 7k** Trained Support Parents
- 9M** Families Reached
- 17** Partnered Organizations



# Who are we?



## Community

Statewide Organizations  
Support Parents



## Tools

Personalized Training  
Online Platform



## Resources

Webinars  
D.E.I. Support Teams



# How it works.



## **Contact local Alliance Member**

Interactive map



## **Coordinator selects Support Parent**

Personalized match



## **Support Parent reaches out**

Match made, no cost







# We serve all families.



## Medical to Mental

Autism Spectrum  
Intellectual & Developmental  
Emotional & Mental  
Down Syndrome  
Other Conditions



## All Ages

Newborn  
Toddler  
Child  
Teen  
Adult



## Social to Cultural

Social  
Cultural  
Racial  
Religious  
Geographic



# Authentic care, research backed.

- We build resilient, stronger families.
- We improve quality of life.
- We reduce stress. Helping families thrive.

**15 k+**

**1:1 matches  
annually**

“

One conversation with my Support Parent  
**CHANGED** the trajectory of  
**MY DAUGHTER'S LIFE, FOR THE BETTER.**

”

- Tennessee Parent

“

Thank you for your incredible **INSIGHTS & PERCEPTIONS**. We can't thank you enough for sharing your experiences.

”

- Partner Organization

**Colorado**

Parent to Parent of Colorado  
&  
Colorado's MCH Program

*Collaborating to amplify family voice*

# Serving as the Title V Family Leader for CO

## Ongoing projects:

CoPPCAP



Family Coalition



Community Advisory Board (CAB)

Regular meetings with targeted local public health departments to recommend family engagement strategies

# Serving as the Title V Family Leader for CO

## Ongoing Projects Cont.

### Children's Hospital CO Special Care Clinic Family Affinity Group





# Serving as the Title V Family Leader for CO

## One-time projects:

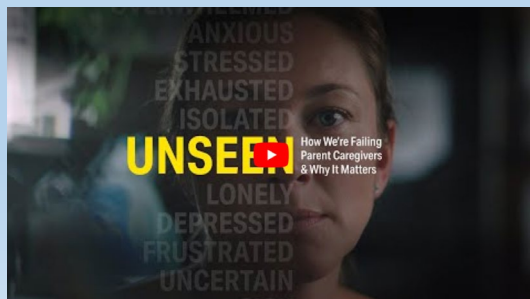
Surveys/Feedback



**Maternal and Child Health  
Listening Tour**

Course content for [CO's BHA Own Path Learning Hub](#)

Unseen parent panel



## My contact info:

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**South Carolina**



## Who is Family Connection of South Carolina?



service options. Our healthcare team answers questions regarding Medicaid, TEFRA, appeals, and managed care information.

# Alignment of Parent Services with SC MCH's Action Plan

Domain	NPM	Strategies/Deliverables
<p><b>CYSHCN</b>  <b>Priority Need:</b> Improve care coordination for children and youth with special health care needs.</p>	<p><b>NPM 11-</b> Percent of children with and without special needs, ages 0 through 17, who have a medical home.</p>	<ol style="list-style-type: none"> <li>1) 1:1 assistance to families/professionals that need information or assistance in understanding or applying for public/private insurance, understanding SC's Medicaid waiver programs, understanding TEFRA, HIPPA, and SSI.</li> <li>2) 1:1 assistance in obtaining, accessing and establishing a medical home.</li> <li>3) FCSC will host a Parent Advisory Council (PAC) with trained, volunteer, parent leaders who provide feedback, consultation, and recommendations to help inform CYSHCN programs and policies.</li> </ol>
<p><b>CYSHCN</b>  <b>Priority Need:</b> Enhance and expand transition in care/services for CYSHCN from pediatric/adolescent to adulthood.</p>	<p><b>NPM 12-</b> Percent of adolescents with special health care needs, ages 12 through 17, who received services to prepare for the transition to adult health care.</p>	<ol style="list-style-type: none"> <li>1) 1:1 support for families who have a child 12 or older-for support and anticipatory guidance in preparation for transition services (medical &amp; school).</li> <li>2) Hire a Youth Transition Specialist</li> <li>3) Offer parent/youth trainings on topics related to transition.</li> </ol>

# Alignment of Parent Services with SC MCH's Action Plan

Domain	NPM	Strategies (Deliverables)
<p><b>Perinatal/Infant Health</b>  <b>Priority Need:</b> Strengthen implementation of evidence-based practices that keep infants safe, healthy and prevent mortality.</p>	<p><b>NPM 5-</b> A) Percent of infants placed to sleep on their backs, B) Percent of infants placed to sleep on a separate approved sleep surface, C) Percent of infants placed to sleep without soft objects or loose bedding.</p>	<p>Disseminate accurate, up-to-date, culturally and linguistically appropriate safe sleep messaging via FCSC's digital platforms.</p> <p><b>**To make this work, you have to TRUST your parents/parent center to create the messaging, Or approve your messaging.</b></p>
<p><b>Child Health</b>  <b>Priority Need:</b> Increase developmental screenings and referral to early intervention services for children.</p>	<p><b>NPM 6-</b> Percent of children, ages 9 through 35 months, who received a developmental screening using a parent completed screening tool in the past year.</p>	<ol style="list-style-type: none"> <li>1) 1:1 referrals to early intervention services for children who are screened w a developmental delay using FCSC's ASQ-3/SE link in English and Spanish.</li> <li>2) FCSC will provide a Parent Leader to participate on the Child Well Being Coalition.</li> <li>3) Disseminate accurate, up-to-date, culturally and linguistically appropriate messaging on importance of developmental screenings via FCSC's digital platforms.</li> </ol>

# Results from 2024

6,950



Families Referred

5,756

Families received  
1:1 peer support

15,133



Services provided

1,163



Assistance with  
Healthcare navigation

"Answering the Call of SC Families!"						
Year	2020	2021	2022	2023	2024	% of Increase
Number Referrals Across All Programs	3,406	4,052	5,346	6,562	6,950	104%
Year	2020	2021	2022	2023	2024	% of Increase
Number of Referrals for Education	2,110	2,724	3,722	4,935	5,221	147%
Year	2020	2021	2022	2023	2024	% of Increase
Number of Referrals TEFRA/Medic aid/Waiver Information	585	617	681	899	1,163	99%

**2,745 funded by  
SCMCH-B partnership**



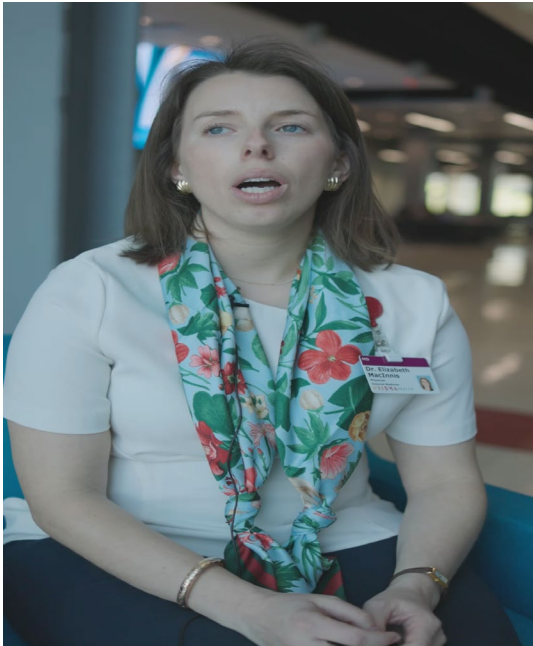
# Targeted Outreach Campaigns to Educate and Engage Families

**38** prevention messages were disseminated across FCSC's digital platforms 'engaging' over **30,000** families.

Topics included:

- Safe Sleep
- Developmental Milestones
- Early Intervention
- Transition





Video Dr. MacInnis did for families for social media

## Big Win!

Established a partnership with Teaching Hospital, Prisma Health and University of South Carolina's, School of Medicine, Internal Medicine Clinic:

**“Prisma Health Center for Young Adults with Developmental Disabilities.”**

Split Funding with MCH-B:

- FCSC's **Transition-Youth Specialist** staffs the Clinic,
- In-person providing families/caregivers/young adults with information/resources/tools to help in navigating their future needs.



Thank you for attending

# HOPES & DREAMS



**FCSC total trainings**  
**700 people trained**  
**49% Parents**  
**51% Professionals**

**4 Transition Workshops**  
**128 attendees**

**Youth Learning Track**

**38 Additional Transition Trainings**  
**Offered**

# Connect with Us!



Family Connection was the first organization that made us feel like it was okay that we didn't grieve Ayers' diagnosis. Everyone else expected us to feel sad or be overwhelmed, and FC was the first to communicate Ayers' inherent worth and the joy that his life could bring to us. They were the first to provide us with community and that was priceless.

**Brandynne Herrington**

Mother of Ayers





# Our Alliance Members.





# Thank You

Lily Brown

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