



Highlighting Support Offerings from Parent to Parent USA

Natasha Bonhomme
Program Director
National Genetics Education
and Family Support Center

Marsha Quinn
Co-Executive Director
Parent to Parent USA

Lily Brown
Co-Executive Director
Parent to Parent USA

Carmina Cirioli
Co-Executive Director
PATH Parent to Parent
Family Voices of CT

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National Genetics Education and Family Support Center

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Housekeeping

- This webinar is scheduled to last 1 hour, including Q&A.
- All dial-in participants will be muted to enable the speakers to present without interruption.
- The webinar is being recorded and will be sent via email with the slides, regional family-led organization reference guide and a brief evaluation survey after the live presentation.
- Questions can be submitted via the chat function at any time during this presentation. We will have a dedicated time to answer questions at the end of the presentation.

Agenda

- Introduction to the Family Center
- Parent to Parent USA Presentation
- Question & Answer

National Genetics Education and Family Support Center (Family Center)

Made up of:



Funded by HRSA to:

- Help families develop skills to partner with professionals and improve systems of care
- Assist RGNs in partnering with families & family-led orgs
- Assist with outreach to diverse & medically underserved families
- Provide Education & Support



Family Center Regional Guides: Referral to Support and Partnering with Family-Led Organizations

REFERRAL TO SUPPORT AND PARTNERING WITH FAMILY-LED ORGANIZATIONS: A REFERENCE GUIDE

The National Genetics Education and Family Support Center (Genetics Education & Family Support Center) is a companion project to the Regional Genetics Networks (RGNs). RGNs link medically underserved populations to quality genetic services and provide resources to genetic service providers, Primary Care Physicians, public health officials, and families. In many cases though, linking isn't enough. Individuals and families need direct support and assistance.

The Genetics Education & Family Support Center works to:

1. Assist the RGNs in their efforts to develop meaningful partnerships with families and family-led organizations and reach medically underserved and diverse families.
2. Provide emotional, informational, and navigational support for individuals and families who have, or are at-risk of having a genetic condition;
3. Provide education and resources on genetic conditions;
4. Link individuals and families to services and supports, especially those families in underserved areas
5. Help families develop skills to partner with professionals and improve systems of care

The following family-led organizations can help families navigate the system of care system and connect families to the information, resource, and support services they may need. In addition, family-led organizations can partner with RGNs and other families to help build capacity for family leadership and engagement to improve genetic educational materials, services, and programs.

FAMILY-LED ORGANIZATIONS: MOUNTAIN STATES REGIONAL GENETICS NETWORK (MSRGN)

Texas	Texas Parent-to-Parent 512-458-8600 or 866-896-6001 https://www.txp2p.org/services/family-to-family-health-info	Texas Parent-to-Parent 512-458-8600 or 866-896-6001 https://www.txp2p.org/services/talk-to-another-parent/peer-parent-mentor-program	Texas FFCMH 512-944-9972 E-mail ffcmhtexas@gmail.com	There are 3 PTIs in Texas. Identify the PTI for your region TX at http://prntexas.org/about-prn/find-your-pti/ PATH Project 409-898-4684 or 800-866-4726 http://prntexas.org/texas-ptis/path-project/ PEN Project 915-259-8717 833-847-2686 http://prntexas.org/texas-ptis/pen-project/ TEAM Project 281-969-5944 877-832-8945 http://prntexas.org/texas-ptis/team-project-2/
Utah	Utah Parent Center 801.272.1051 or 800.468.1160 http://www.utahparentcenter.org/projects/ufv/	Contact a neighboring state	Allies with Families 801-433-2595 or 877-477-0764 www.allieswithfamilies.org	Utah Parent Center 801.272.1051 or 800.468.1160 http://www.utahparentcenter.org/projects/pti/info@utahparentcenter.org
Wyoming	SAO: UPLIFT 800-492-3199 www.upliftwy.org F2F: Wyoming Institute for Disabilities (WIND) 307-766-2761 or 888-989-9463 http://www.uwyo.edu/wind/f2f/	Contact a neighboring state	UPLIFT 800-492-3199 www.upliftwy.org	Parent Information Center 800-660-9742 307-684-2277 www.wpic.org





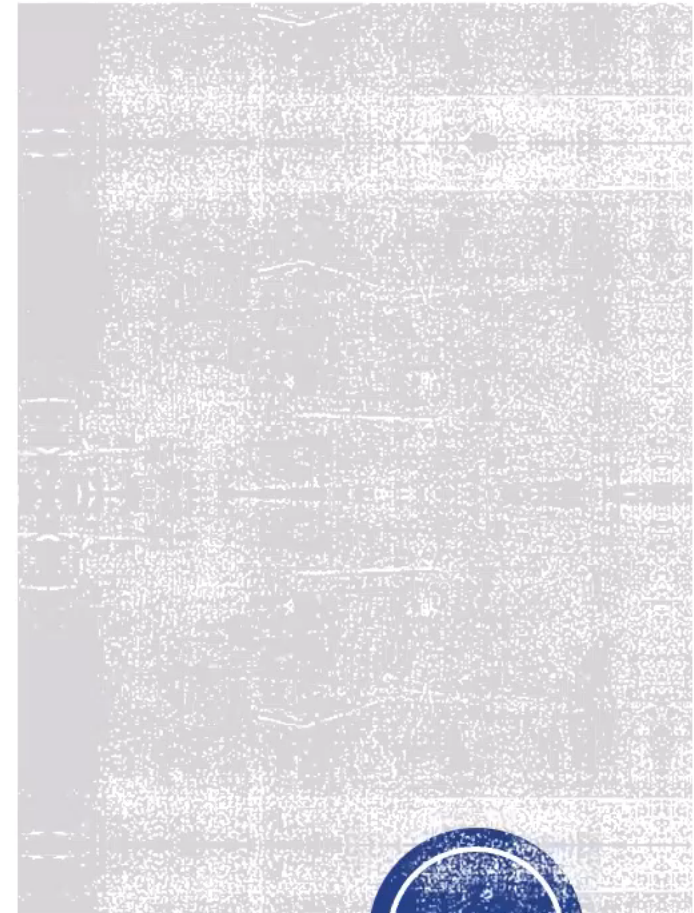
Parent to Parent USA

Presenters:

Lily Brown, Co-Executive Director, P2P USA

Marsha Quinn, Co-Executive Director, P2P USA

**Carmina Cirioli, Co-Executive Director, PATH
Parent to Parent/Family Voices of CT & Parent to
Parent USA Board President**



The Four Stages of Adaptation

by Dr. Nancy Miller

Surviving

- What you do to keep going when you are feeling completely overwhelmed
- Coping and reacting

Searching

- A time of acting, of moving forward from your reactive stage of Surviving
- The awakening of a sense of control

Settling In

- Gaining a greater sense of control over your daily life
- A shift in balance, your definition of "normal" changes

Separating

- A necessary process in development
- Small steps to independence throughout childhood

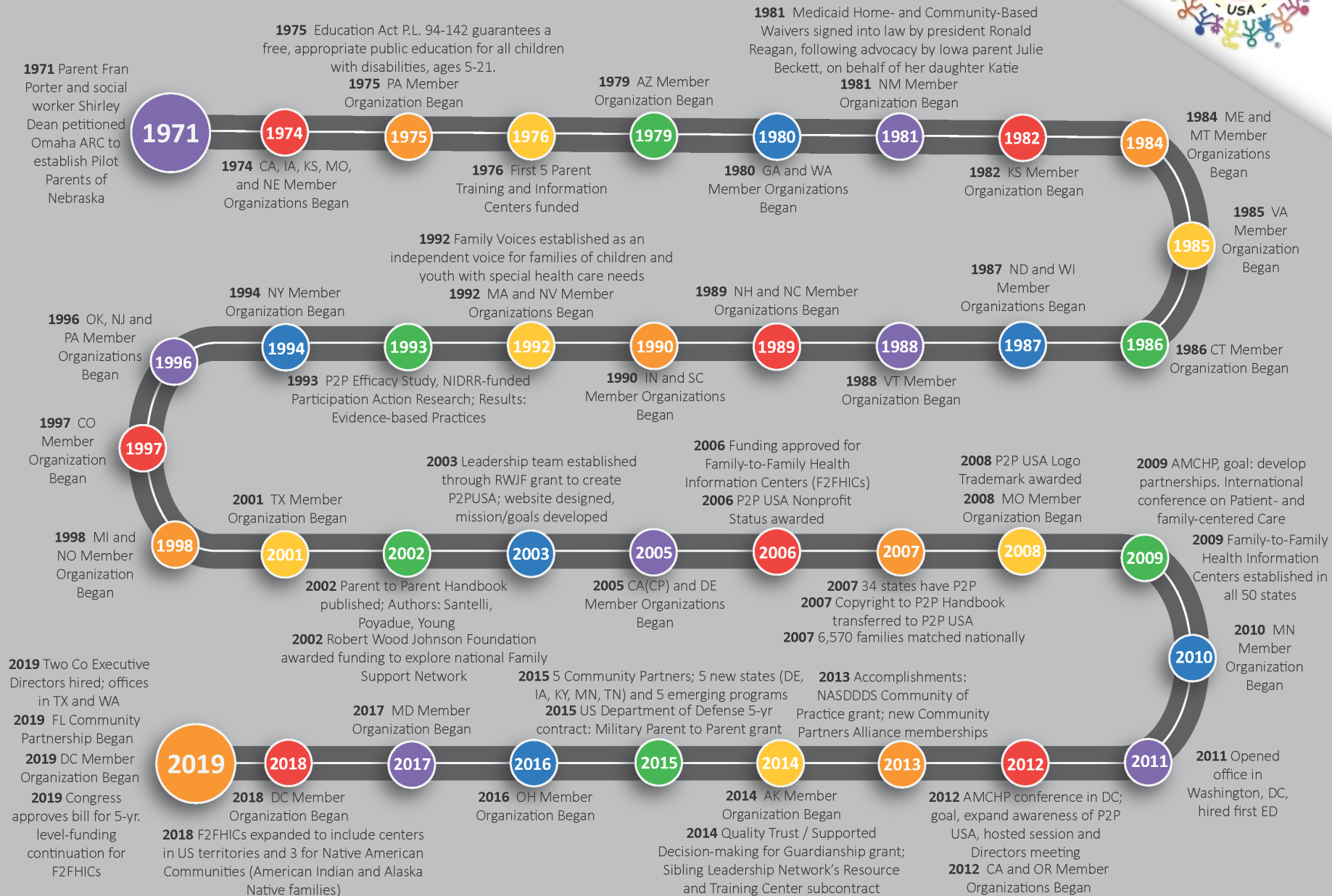


Where did we come from?

- ▶ 1971- Greater Omaha Arc in Omaha, Nebraska to establish Pilot Parents of Nebraska, a program in which parents of children with disabilities could share information and emotional support with other parents through a one-to-one match.
- ▶ **1974- Four more** Parent to Parent programs launched in Nebraska, Iowa, Kansas, and Missouri
- ▶ 2003- Parent to Parent of the United States (Parent to Parent USA) was created with funding from the Robert Wood Johnson Foundation to ensure that families nationwide whose children have special needs have access to Parent to Parent support.
- ▶ 2006 Parent to Parent USA was incorporated as a 501(c)(3).



Parent to Parent *Movement*



Our mission and vision

- ▶ **Mission:** Our mission is to support a national network of Parent to Parent programs to ensure access to quality emotional support for families of individuals with disabilities and/or special health care needs.
- ▶ **Vision:** Parent to Parent USA will support a network of viable, sustainable, fully-functioning and effective Parent to Parent programs in all 50 states through hands-on support, training and technical assistance, and high quality tools and resources. Our network's parent leadership and engaged membership will serve as strong advocates, provide robust mentoring opportunities, and develop the working partnerships with funders, service providers, and others needed to sustain and grow the program nationwide.



Our Values

- ▶ Each family's journey has value and can offer hope and inspiration to others.
- ▶ Peer support fosters mutual growth and resilience in families and among programs.
- ▶ Evidence-based practices ensure consistency and quality throughout the network.
- ▶ Leadership, integrity, and partnership build capacity and sustainability.



Support Parent Training Modules

**Part One : About
Parent to Parent**

**Part Two :
LEARNING**

- Increasing Knowledge to Support Others

**Part Three :
FEELING**

- Understanding and Coping with Emotions

**Part Four :
LISTENING**

- Communicating in a Support Role

Part Five : CARING

- Encouraging Parents to Care for Themselves

Support Parent Training



Formally Trained
Volunteers



In person/online



5 hour typically



10-12 people

Making the Match

Seeing the Support Parent as a reliable supporter depends on three components:

- ▶ Similarities, or a sense of sameness, between the parents and their children with special needs and their situations
- ▶ Flexible availability of support.
- ▶ Support that flows both ways.

Matches can be made based on many different factors:

- ▶ **Diagnosis, age of child, geography, cultural/ethnicity, language, etc.**

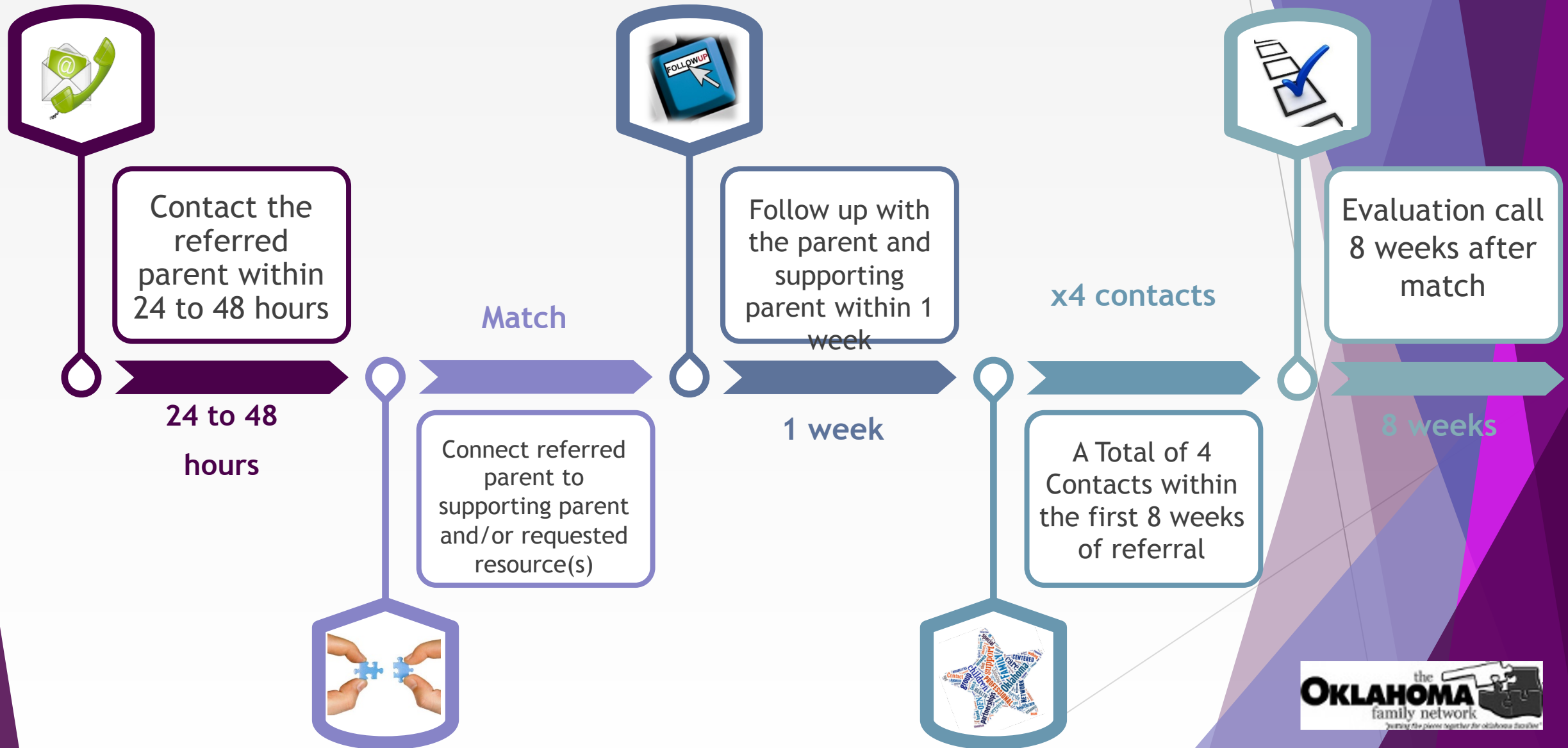


Network for Matching

- ▶ **Each organization** maintains a roster and/or database of volunteer support parents that are available for one-to-one matches with referred parents.
- ▶ **All alliance members have access to national listserv platform:**
 - ▶ **Matching Group:** allows our organization's Coordinators access to a national network of Support Parents where rare genetic and diagnosis matches can be made.



P2P Best Practice Timeline for Parent Support Match



What is our impact?



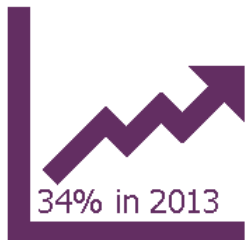
**Support
Parents**
trained in 2018



Support Parent training
lasts on average

5H20M

using a combination of
in-person and online
sessions



50%
of matches
initiated
within 48
hours of
request

8,850



1:1

Matches²

An average of



3.4 Contacts

between matches
in the first 8 weeks



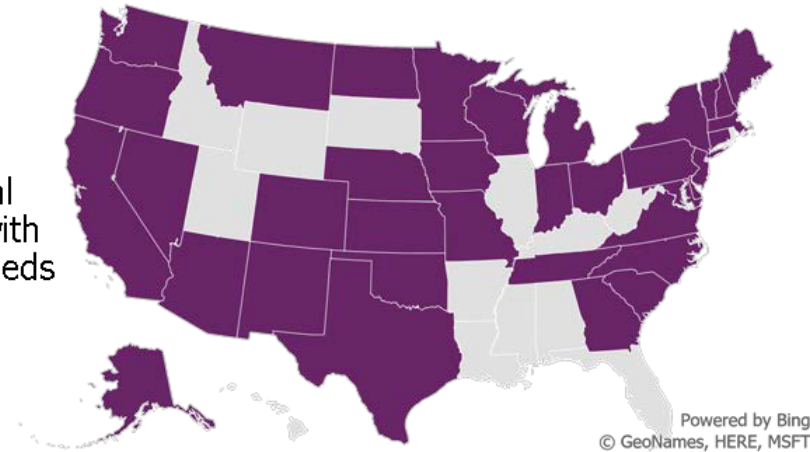
**“Mentors make a huge
difference in giving me the
confidence to care for my
child.”**

How do we execute?

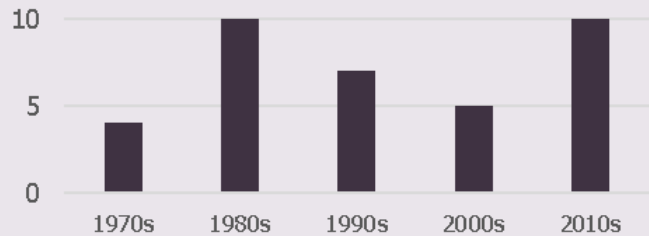
36 Alliance Members

ensuring access to quality emotional support for families of individuals with disabilities or special health care needs

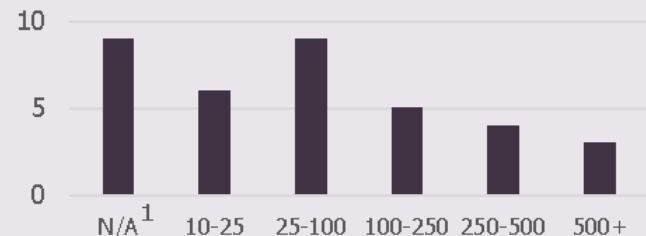
2 Community Members



Parent to Parent Program Inception



Program Budget in k\$



96% of P2P staff are parents of children or youth with disabilities or special healthcare needs



19 Languages spoken by P2P staff



Camaraderie- noun

mutual trust and friendship among people who spend a lot of time together.

synonyms:

- ▶ friendship · comradeship · fellowship · good fellowship · companionship · brotherliness · brotherhood · sisterhood · closeness · affinity · togetherness · solidarity · mutual support · sociability · team spirit · comradery · esprit de corps





► “Tennessee Parent to Parent has given me the opportunity to take my NICU experience with 25 week twins and use it to pour support and encouragement into other parents walking through the same journey”.

► The Scott Family



- ▶ “P2P connected me with a valuable resource who provided relatable advice and uplifting support while my baby was in the NICU”.
- ▶ Olivia Ganeselli parent of Stuart Anne Ganeselli- Tennessee



- ▶ “Parent to Parent introduced my husband and I to our first “Down syndrome family” while I was pregnant with our baby who had a prenatal diagnosis of Ds. Meeting the [McMahan](#) Family showed us that even though life was going to look a little different than we planned, everything was going to be OK. Spending hours playing and talking with the family was just what we needed!”

▶ Melanie Harrington, WA



- ▶ ‘Parent to Parent was the first time I said “my daughter has Down syndrome” to a stranger. It was where I could be a first time mom, and not feel like an outsider. It has been the connection to amazing and cherished friends. It means everything.’

▶ Sheila McMahan, WA

Takeaways/Collaboration Opportunities

- ▶ Disseminate materials on genetic support and family engagement to our Members and families
 - ▶ Connect with parents who receive genetic services for input
 - ▶ Share P2P resource to families who receive genetic services for ongoing support
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- ▶ To connect with Parent to Parent USA, please contact us at:
memberinfo@p2pusa.org





Thank you!

Natasha Bonhomme
nbonhomme@geneticalliance.org
www.expectinghealth.org

Marsha Quinn
mquinn@p2pusa.org
www.p2pusa.org

Lily Brown
abrown@p2pusa.org
www.p2pusa.org

Carmina Cirioli
ccirioli@pathct.org
www.pathct.org

