

WEBINAR: January 11, 2012 1:00 PM EST

Choosing an Exceptional Life: Family Directed Resource Organizations

Choosing an Exceptional Life Session 1 of 3

Presenter: Ann Turnbull



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My Story



Best School Year Ever!





Sisyphus, from Greek Mythology, has to continually start over



Family Quality of Life

DoD Directive #1342.17

Statement on DoD Families

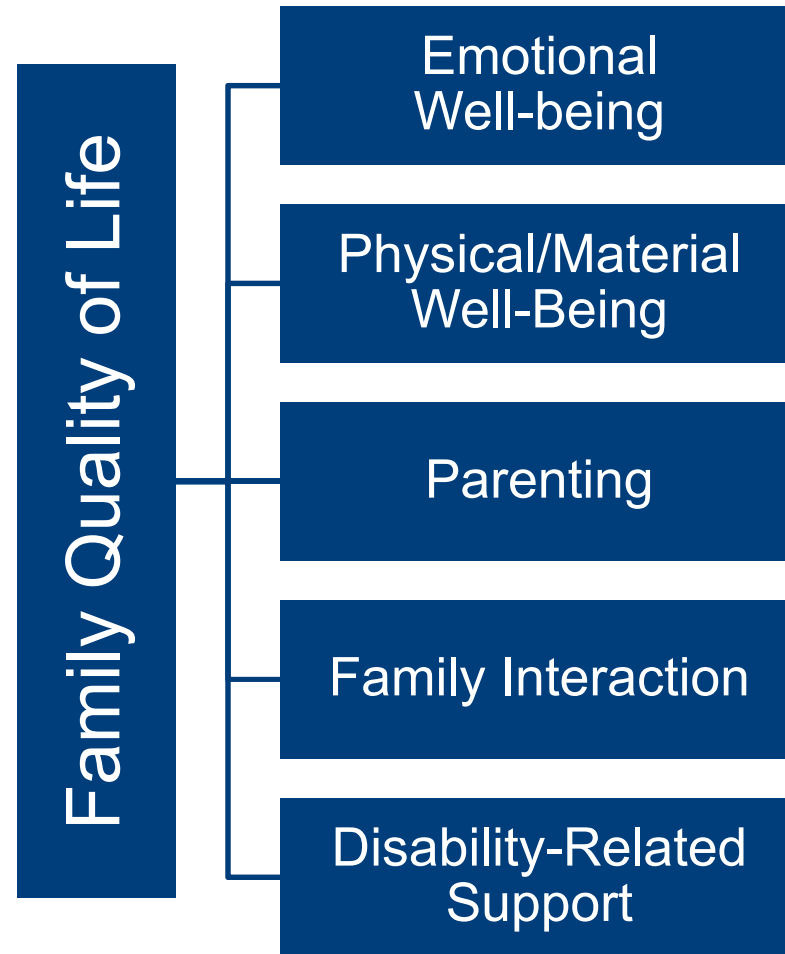
“The goal is a combat-ready force supported by families whose **quality of life** reflects the high standards and pride of the Nation they defend.”

Definition of Family Quality of Life

Families experience the highest quality of life when:

- The family's needs are met, and
- Family members enjoy their life together as a family, and
- Family members have opportunities to pursue and achieve goals that are meaningful to them

Family Quality of Life Domains



Emotional Well-Being

Definition: Refers to the feeling or affective parts of family members and family life

Sample Needs:

- My family members have friends or others who provide support
- My family members have the support we need to relieve stress

Physical/Material Well-Being

Definition: Refers to the resources available to the family to meet its members' needs

Sample Needs:

- My family members get the government benefits to which they are entitled
- My family gets medical care when needed
- My family has a way of taking care of expenses

Parenting

Definition: Refers to activities that parents do to help their sons and daughters develop.

Sample Needs:

- Parents help children learn to be independent
- Parents have time to take care of the individual needs of each of their children

Family Interaction

Definition: Focuses on the relationships among family members

Sample Needs:

- My family enjoys spending time together
- My family members support each other to accomplish goals

Disability-Related Support

Definition: Focuses on support from family professionals, friends, and provided in order to benefit the family member with a disability

Sample Needs:

- My family member with special needs has support to achieve goals at school or work place
- My family member with special needs has support to achieve goals at home
- My family has a good relationship with the people who provide services and supports to our family member with a disability

Helping to Identify Family Quality of Life Priorities

- What are the times during the week that you are experiencing the most stress?
- What is happening when things seem to be going very well?
- What services and supports would truly make a difference for your family?
- What are your hopes and dreams for your child?
- What would an ideal day be for your child and family and what would it take to make an ideal day happen?

In 1999, I moved to Any Town, New State. Even though I had been involved with the Arc of Some Town since 1969, I had no idea that there was such an incredible waiting list in New State. Before moving I had gone down to research the programs available in New State. Even then I was not made aware of the waiting list. When I moved and then two weeks later went down to get my daughter enrolled I was then made aware. When I asked how come I was not told beforehand the response was “you did not ask.”

Shirley Dove, National Arc Board member, 2007





Connecting to Allies

Progressive allies – People who have state-of-art values and who know the potential and believe in the full citizenship of individuals with disabilities.

Reliable allies – People you can trust and on whom you can rely to use sound judgment, maintain confidentiality, and act in your best interests.

Family-Directed Networks

Family Questions

The teacher keeps calling me and telling me to come pick up my daughter because she is “out of control” at school. How can I get an effective behavior plan that can be used at school and at home?

Educational rights don't mean anything if you go to a meeting and you feel outnumbered by having 10 or 12 professionals all telling you how big of a problem your child is. Is anyone available to go to the IEP conference with me and help me advocate for my child's rights?

Parent Training and Information Center (PTI)

Parent Technical Assistance Center Network

Home | National | Regions - | Region 1 | Region 2 | Region 3 | Region 4 | Region 5 | Region 6

Improving outcomes for children with disabilities and their families

National Parent Technical Assistance Center
The National Parent Technical Assistance Center provides Parent Centers with innovative technical assistance, up-to-date information, and high quality resources and materials.
[More Information >>>](#)

Regional Parent Technical Assistance Centers
The six Regional Parent Technical Assistance Centers (RPTACs) provide direct technical assistance to Parent Centers to increase their capacity to more effectively serve and support families.
[More Information >>>](#)

Parent Centers
Parent Centers provide training, information and assistance to families of children with all disabilities ages birth to 26 years and the professionals who work with them.
[More Information >>>](#)

Featured Content
Find the Parent Center in Your State
[Click Here To Get Started](#)

Search Parent Center Resources
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Featured Items:

- OSEP Spanish: Glossary of IDEA Terms
- 2011 OSEP Leadership Mega Conference Materials

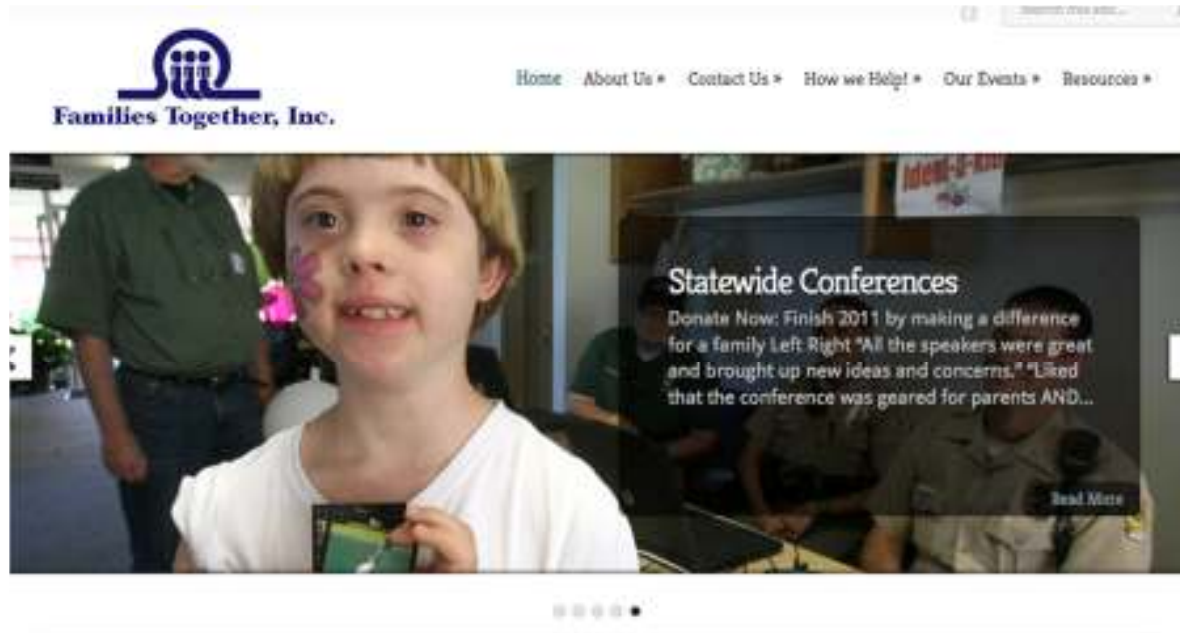
www.parentcenternetwork.org

PTI Directory



www.parentcenternetwork.org/parentcenterlisting.html

Families Together Inc.



"Encouraging, Educating & Empowering"

www.familiestogetherinc.org



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Heather Hebdon



Family Questions

I don't know anyone who has walked a mile in my shoes. Where can I meet another parent who has a child whose diagnosis and needs are similar to my child?

I need to find assistive technology so that my son can communicate, but I have no idea where to start. I wish I could talk with another parent who has had successful experiences to give me direction and hope.

Parent to Parent (P2P)

The screenshot shows the P2P USA website homepage. At the top left is the P2P USA logo, a colorful circle of people icons. To its right is the text "P2P USA Parent to Parent USA". Further right is a "Member Login" button. Below the header is a navigation menu with links: Home, How Does it Work?, Looking for Support?, Become a P2P USA Member, Program Support, and About. The main content area features a photograph of a family with a child in a wheelchair. To the right of the photo is the text: "Emotional & Informational support for families of children who have special needs. For over 38 years Parent to Parent programs across the country have been providing emotional and informational support to families of children who have special needs most notably by matching parents seeking support with an experienced, trained 'Support Parent'." Below the photo is a green banner with the text: "Promoting access, quality and leadership in parent to parent support across the country". At the bottom, there are two columns of support options. The left column is titled "Support for ORGANIZATIONS" and contains two boxes: "Become a P2P USA Member" (green) and "Program Support" (teal). The right column is titled "Support for PARENTS" and contains two boxes: "How Does it Work?" (orange) and "Looking for Support?" (purple).

P2P USA Parent to Parent USA

Member Login

Home How Does it Work? Looking for Support? Become a P2P USA Member Program Support About

Emotional & Informational support for families of children who have special needs.

For over 38 years Parent to Parent programs across the country have been providing emotional and informational support to families of children who have special needs most notably by matching parents seeking support with an experienced, trained "Support Parent".

Promoting access, quality and leadership in parent to parent support across the country

Support for ORGANIZATIONS

- Become a P2P USA Member**
Discover the benefits and privileges of membership. Read the
- Program Support**
Learn from experienced leaders how to design a successful Parent to

Support for PARENTS

- How Does it Work?**
Find answers to commonly asked questions. Your quick
- Looking for Support?**
Find a program near you. List our convenient program finder by locale

www.p2pusa.org



- How Does It Work?
- Looking for Support?
- Become a P2P USA Member
- Program Support

Looking for Support?

Click on a state to find out what's available near you.

Find P2P Programs in:



www.p2pusa.org



- How Does It Work?
- Looking for Support?
- Become a P2P USA Member
- Program Support

How Does It Work?

- What is Parent to Parent?
- What is a Parent to Parent Support?
- "How does it work?" The Learning channel (TLC)
- What are Parent to Parent USA Endorsed Practices?
- How are P2P Matches made and supported?
- What are the characteristics of Parent to Parent?
- What is the history of Parent to Parent?
- How is Parent to Parent Part of a Comprehensive System of Family Support?
- Will there be an International Parent to Parent Conference?

What is Parent to Parent?



Organizationally, Parent to Parent programs offer parent to parent support as a core resource for families with children who have a special health care need, disability, or mental health issue. Through a one to one "match" experienced support parents provide emotional support to families and assist them in finding information and resources. Parent to Parent programs are committed to listening and learning from families and developing an array of services and supports in response to family identified needs.

The Parent to Parent network is a growing national resource for families. Statewide, regional and local community-based programs continue to emerge out of grassroots efforts; new statewide Parent to Parent programs are being developed to support the efforts of local programs; national needs are being addressed as they arise; and international interest in Parent to Parent is growing every year. The strength of Parent to Parent comes directly from the parents who dedicate themselves to its continuing success.

What is Parent to Parent Support?



Parent to Parent USA defines parent to parent support as the connection between a

www.p2pusa.org

Family Questions

It feels like a full-time job to coordinate my child's health care across his pediatrician, psychiatrist, psychologist, and other specialists. We need a health care coordinator to help me keep up with it all. Does insurance cover health care coordination?

I know I need to keep good medical records, but I'm not sure where to start. Have notebooks or folders been developed that are specifically aimed at helping families of children with special needs organize health records?

I get lost in health insurance and Medicaid lingo. Where can I learn the basics in a way that doesn't confuse me?

Family to Family Health Information Centers (F2F HIC)



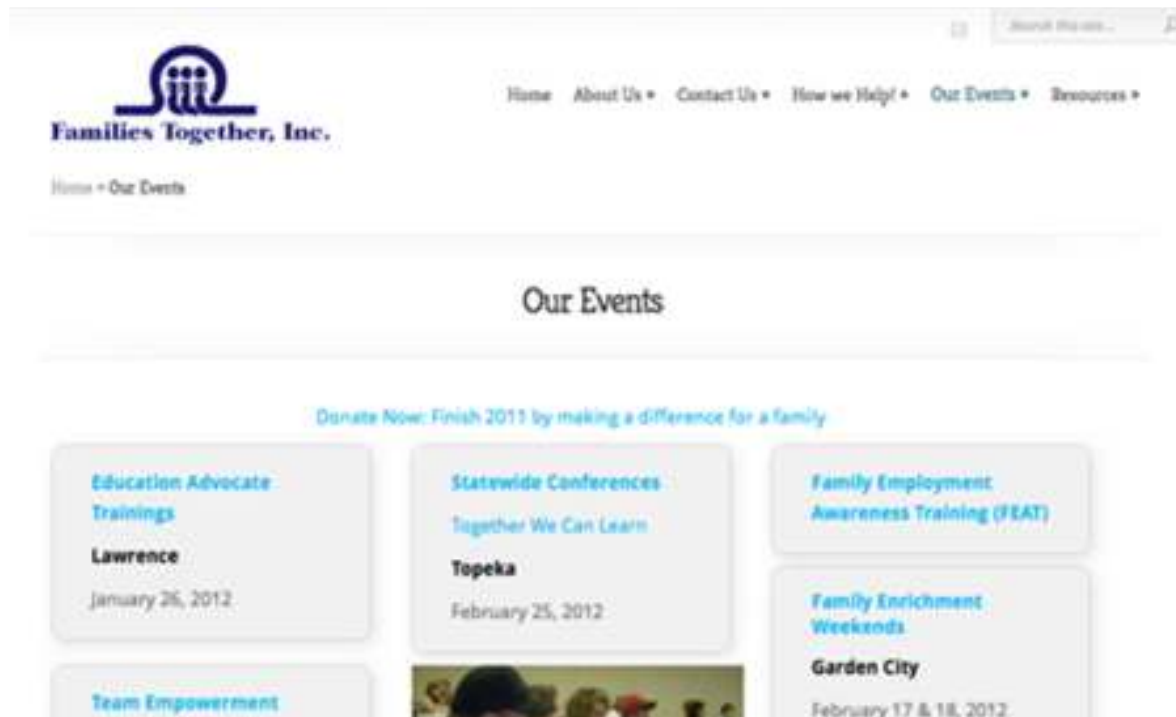
www.familyvoices.org

Family to Family Health Information Centers (F2F HIC)

The screenshot shows the Family Voices website with the following content:

- Logo:** FAMILY VOICES® ...keeping families at the center of children's health care
- Navigation:** ABOUT US | OUR WORK | RESOURCES & PUBLICATIONS | NEWS | PROJECTS | EVENTS | TAKE ACTION
- Section Header:** FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS (F2F HIC)
- AK (Alaska):** *Share Soup Group*
Address: 307 East Northern Lights Boulevard Suite 100 - Anchorage, AK 99503
Phone: (907) 561-3701 - Fax: (907) 561-3702 - Toll-Free: (877) 786-7327
Primary Contact/s: *Amy Westfall* (907) 561-3701
- AL (Alabama):** *Family Voices of Alabama*
Address: 1050 Government Street - Mobile, AL 36604
Phone: (877) 771-3862 - Fax: (877) 771-3862 - Toll-Free: (877) 771-3862
Primary Contact/s: *Patricia Switzer* (877) 771-3862 - *Susan M. Colburn* (334) 293-7041 - *Dr. Gerald G. Gwerson* (877) 771-3862
- AR (Arkansas):** *Arkansas Disability Coalition*
Address: 1501 N. University Avenue Suite 258 - Little Rock, AR 72207
Phone: (501) 614-7020 - Fax: (501) 614-9082 - Toll-Free: (800) 223-1330
Primary Contact/s: *Bryan Cozart* (501) 614-7020 - *Wanda Sovall* (501) 614-7020
- AZ (Arizona):** *Raising Special Kids*
- TAKE ACTION sidebar:** SHARE YOUR STORY, KEEP INFORMED, ADVOCATE, JOIN US, CONTACT US, DONATE NOW

www.familyvoices.org/f2f-grantees



www.familiestogetherinc.org

What priority question will you address over the next month?

Your Best Effort

“You have no conception of what your best effort is so you must continually strive to do better today than you were able to do yesterday. If you will make a concerted effort every day, your best effort will grown in ever-increasing circles.”

What if your best effort grows every day?





Thank you for joining us today.

For more information, log on to www.MilitaryOneSource.mil or call 1-800-342-9647.