

Creating or Improving a Parent Support Group or Organization for Fragile X

Some suggestions and recommendations from Robert M. Miller of

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What is “parent support?”

To answer this question we must ask the parents!

We cannot trust our assumptions.

- Sometimes a parent’s needs are much more simple than we think.
 - Examples: transportation to the doctor; respite; reassurance that no one is at fault.
- Sometimes a parent’s needs are much more complicated than we could ever imagine.
 - Example: helping restore extended family relationships that have been shattered by the diagnosis.

Why parent support is important

Providing a way for parents of children with special needs to reach other parents whose children have similar needs is one of the most important activities that professionals undertake.

Parents are often desperate to talk to other parents who are on a similar “journey.” Doing so often helps decrease the sense of aloneness or isolation that parents report feeling.

Different models of parent support

There are a number of models for setting up a parent support group or network.

A national organization can play a key role in creating and maintaining a parent support system.

However it is done, it is crucial that the needs of families not get lost in the day-to-day work of the organization.

Different models of parent support (1)

- **1 to 1 (parent to parent)**

Face-to-face, telephone or online (chat rooms, bulletin boards, social media, websites, etc.)

Parent-To-Parent

- While professionals can be very helpful to families, many parents wish they could talk to other parents who have had similar experiences! When asked who is best able to support them - emotionally, families often say their first choice is other parents who can share their experiences

FROM: National Dissemination Center for Children with Disabilities (NICHCY)

Different models of parent support (2)

- **Group: parent-led**
(Also called “Self-Help” groups)

Some parents believe that only parents can help parents.

Different models of parent support (3)

- **Group: professional-led**
(psychologists, counselors and others)

Different models of parent support (review)

- ✓ 1 to 1 (parent to parent)
- ✓ Group: parent-led
- ✓ Group: professional-led

Building a national parent support organization (1)

- **What already exists?**

Are there already existing general disability parent support groups?

If so, could parents of children with fragile X syndrome or another disability join up and become a sub-group within the existing group?

Building a national parent support organization (2)

- **How can the government help?**

Is there a government* office or program in place that could help launch, support and/or publicize the group?

For example:

- public health institutions
- medical training institutions
- research institutions
- educational institutions

* *or similar private institutions if that is more the norm in your country*

Building a national parent support organization (3)

- **How can medical and educational institutions help?**
 - Does a local hospital have a staff member with experience in counseling?
 - Will a local hospital or clinic provide meeting space, copying, mailing, etc?
 - Does a local university have a training program for counseling or mental health professionals who could get involved?

Building a national parent support organization (4)

- How can the private/corporate sector help?

- Cash or grant support (Some *for-profit* companies have non-profit foundations.)

- “In-kind” services:

- (Mailing, copying, publicity, etc.)

Building a national parent support organization (5)

- Summary:

- ✓ What already exists?

- ✓ How can the government help?

- ✓ How can medical and educational institutions help?

- ✓ How can the private/corporate sector help?

Getting from “here” to “there”

Ok, your group has formed. You’ve had some meetings, built a website, created a Facebook page, shared some information. What now?

Each country, each culture, each group and each parent may answer this question differently. But here are some questions to ask yourselves:

- What is the most consistent challenge that the majority of parents seem to face?
- Are any of these challenges similar to those of other disability groups?
- What might your existing resources (human, financial, time) allow you to address, with a high degree of confidence?

What can go wrong (1)

- **Some parents are afraid to participate. *They may:***
 - be afraid of the depth and intensity of their own feelings
 - be uncertain about what might be expected of them at a group meeting
 - feel that ones' own family should take responsibility for the family's problems
 - be overwhelmed with feelings of shame

What can go wrong (2)

- **Parent support groups have a natural evolution.**

It is common for parents of recently diagnosed children to be highly enthusiastic and willing to take on many responsibilities. The child, and his or her disability, are the focus of the family's life. This focus and enthusiasm can lead to a very active and successful group.

What can go wrong (3)

- **Over time, parents' focus may change**

The addition of non-disabled children to the family, the demands of careers, improvement in the child's day-to-day functioning and a change in the parent's interests and/or beliefs may cause their enthusiasm to lessen. This is normal and natural. *However*, it can be destructive to a group's ability to function and to meet the needs of newly diagnosed families.

What will go right!

One child, one parent, one couple, one family at a time – you will make a difference. For each person you help, you increase the likelihood that they will, in turn, help another. (The ripple effect!)

“I slept and dreamt that life was joy.
I awoke and saw that life was service.
I acted and behold, service was joy.”

- Indian author and poet Rabindranath Tagore