

BEYOND THE SPECIAL NEEDS DIAGNOSIS:

Understanding the Impact on Families and
how to Meet their Support Needs



Lin Perry
Project Director
Family to Family Health Information Center
Parent to Parent of NYS

A quick introduction

Parent to Parent of NYS

Our Mission Statement:

“Parent to Parent of New York State builds a supportive network of families to reduce isolation and empower those who care for people with developmental disabilities or special healthcare needs to navigate and influence service systems and make informed decisions.”

Parent to Parent to New York State

is a parent-driven non-profit organization whose mission is to connect and support families of individuals with special needs.

- Regional offices throughout the state.
- Network of over 1,200 trained volunteer Support Parents is the foundation of the parent to parent program.
- Additional networking capabilities with parent to parent programs throughout the United States.
- Well maintained website with regional announcements, news and events.
- Funded by NYS Office For People with Developmental Disabilities (OPWDD) and HRSA through MCHB.



Family to Family Health Information Center (F2FHIC)

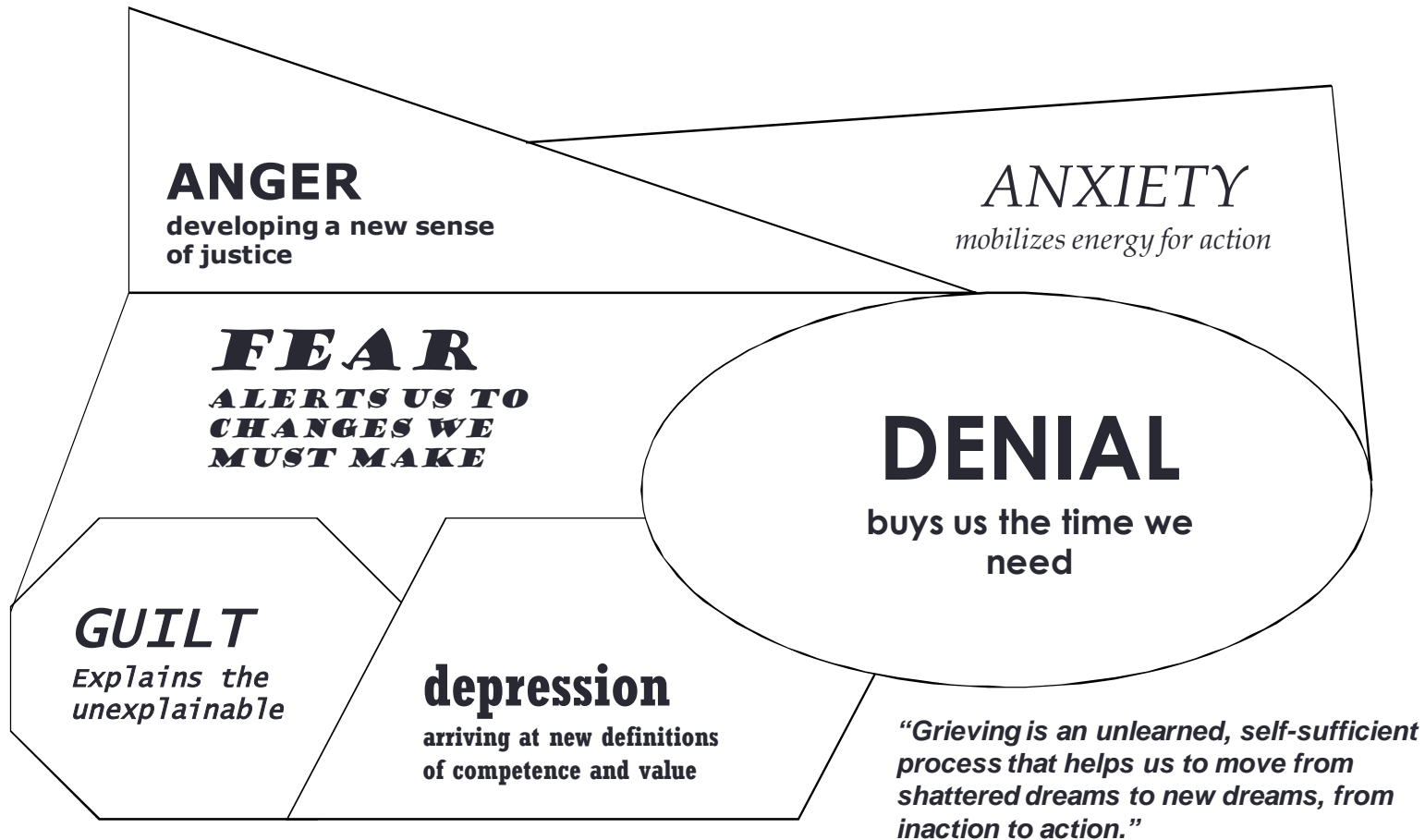
(as defined by the Maternal Child Health Bureau)

“those who have or are at risk for chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children and youth generally.”

“The Perry Fab Four”



The journey...



Based on “The Impact of Childhood Disability: The Parent’s Struggle”
by Ken Moses, Ph.D., 1987

Some challenges that families face

- Caregiver guilt
 - Do I have what it takes to take care of this child
 - How will I care for and make time for my other children?
 - How will I take care of me?
 - Is it okay to take care of me without feeling guilty?
- Family stress
 - Spousal
 - Sibling
 - Extended family
 - Employment
 - Financial

Some challenges that families face

- Navigating complex systems
 - Medical
 - Health insurance
 - Disability services
 - Education
- Permission to admit that and mourn that the their world has changed and to find hope for a “new normal”

What parents wish providers knew...

- Listen to me. Don't just hear.
- Speak to me in plain language.
- If you don't know, admit it.
- Explain the diagnostic criteria to me in more than one way.

What parents wish providers knew...

- If you are giving my child a diagnosis, understand that you are about to change my whole world.
- Provide me information about evidence-based research regarding my child's diagnosis.
- Let me know that I haven't done anything wrong.
- Find a way to get information to my child's other parent.

What parents wish providers knew...

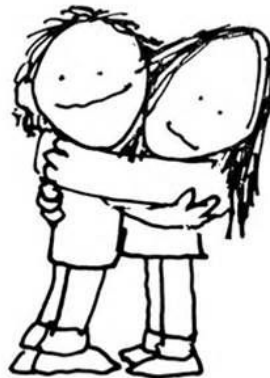
- Making decisions that impact my child is scary for me.
- Communicate with my child's other providers.
- Follow up.
- Ask me how I am doing. How is this impacting my family?

What parents wish providers knew...

- I am not a super-parent.

Last and probably most important

- Understand that the best support comes from other parents who are raising children with special needs.



Parent to Parent of NYS can help

We offer parents/caregivers the opportunity to connect one to one with a parent/caregiver of an individual with the same or similar disability, special health care need or family situation through our *parent matching program.*

Talk to someone who has “been there”.

When parents feel that no one else understands what they are facing.....



What is a support parent?

- A parent or caregiver of a person with a disability or special health care need.
- A trained volunteer
- A parent who
 - Has “been there”
 - Has “walked the walk”
 - Knows the importance of connecting with others



Parent to Parent of NYS (c)

The importance of support parents

- Most parents react in the same way
 - Shock, panic, denial, anger, fear, sadness, hope, acceptance
- Similar experiences and feelings
- Comfort of one-to-one dialogue
- A wide range of disabilities and family situations for which there may be no support group



Parent to Parent of NYS (c)

Parents who receive a support parent ...

- Feel less isolated
- Gain access to resources from another lived experience
- Are better connected with community
- Less stressed
- Find their voice
- Permission to feel
- Permission and encouraged to take care of oneself
- Reminder that they are not doing “anything wrong”
- Permission to live at their own standard
- Understanding of “there is so much you can take” at once

My support parent experience

- Genetic Hypotonia
- Connective Tissue Disorders (CTD) like Ehlers Danlos Syndrome
- Asperger's/ADHD with CTD co-morbidity

Support Parent Matching

How Does it Work?-



P2P of NYS Regional Coordinator gathers information from parent requesting to be matched with another family.

Coordinator selects appropriate match for requesting parent.

Coordinator calls SP to see if they can assist requesting parent. **If it is not a good time, SP may refuse the referral. If they accept...

Coordinator gives SP the requesting parent's information and asks them to call within 48 hours. Coordinator calls requesting parent and gives them SP name and information.

Both parents are asked to call coordinator after speaking or if they are not able to connect. Coordinator remains in contact to see how match progresses, or if a new match needs to be made.

How can a parent request a support parent or volunteer to be one?

- Contact a Parent to Parent of NYS Regional Office.
- Submit a request through our website
 - Parent Matching
<http://parenttoparentnys.org/support/parent-matching/>
 - Support Parent training
<http://parenttoparentnys.org/support/support-parents/>
- Support Parent training is available via the P2P On-line Training Center or webinar.

Thank you!



Lin Perry
Project Director
Parent to Parent of NYS
Family to Family Healthcare Information Center
607-240-4573
email: lperry@ptopnys.org

1-800-305-8817
www.parenttoparentnys.org
<https://www.facebook.com/ParentToParentNYS>