



Welcome to Peer Support Bootcamp!



Family Support &
Empowerment Program
Child Neurology Foundation

www.childneurologyfoundation.org/FSEP



Introductions & Plan for Our Day

Sandy Cushner-Weinstein

Before we start...

A big thank you to our partners at Global Genes for sharing this beautiful venue with us, allowing us to better connect with the rare disease community.



CNF remains grateful to our 2018 industry partners, whose collective support of FSEP allowed us to be here today:

Greenwich Biosciences | Horizon Pharma | Lundbeck
Mallinckrodt Pharmaceuticals | UCB

Peer Support Bootcamp funded per Patient-Centered Outcomes Research Institute (PCORI) grant

Our Time Together

- The Peer Support Bootcamp is honored to bring together this group of passionate people who are actively engaged in providing peer support to families/caregivers in the communities we serve.
- The Peer Support Bootcamp is convened by the Child Neurology Foundation (CNF) Family Support & Empowerment Program (FSEP).
- FSEP's Peer Support Specialists will facilitate the discussion and share their real-life experiences not only as leaders in the peer support space, but also, as parents of children with neurologic conditions.



Organizations Represented in the Peer Support Bootcamp



Huntington's Disease Youth Organization

Batten Disease Support and Research Association

International Fibrodysplasia Ossificans Progressiva Association

The Bohring-Opitz Syndrome Foundation

Children's Tumor Foundation

Tuberous Sclerosis Alliance

The Global Foundation for Peroxisomal Disorders

Phelan-McDermid Syndrome Foundation

Lennox-Gastaut Syndrome Foundation

HSAN1E Society

Dup15q Alliance

Hereditary Neuropathy Foundation

The Brain Recovery Project: Childhood Epilepsy Surgery Foundation

Alpha-1 Foundation

LHON Project at UMDF

Turn Center

Hope for Hypothalamic Hamartomas

Team Titin

Child Neurology Foundation

CSNK2A1 Foundation

Cystinosis Research Network

National Tay-Sachs & Allied Diseases Association

AveXis

3 Cs: Convened by the CNF Family Support & Empowerment Program (FSEP)

Convener ~ allows us to bring partners together to achieve one voice through collaborative advocacy models


Collaborator ~ we work with families, physicians, health care providers, advocacy organizations, and industry partners to *improve the lives of children with neurologic conditions & their families*

Center • provide educational resources and trusted sources of support in the child neurology community



Convened by CNF Family Support & Empowerment Program (FSEP)

CNF's Top 5 Program Priority Areas

- Operationalizing Transition of Care (eg, resources, research, education for providers & families)
 - ***Approaching Care Coordination & Caregiver Education*** 
 - Convening and Promoting Collaborative Advocacy Models (eg, Infantile Spasms Action Network)
 - Improving Family-Professional Communication (eg, pilot using technology to discuss SUDEP risk)
 - Offering Grants and Scholarships to the Community (ie, physicians, advocates, families)
- **FSEP**
 - **PCORI Grant**
 - **Online Patient Education Library (partnership with NIH-NINDS)**



Today, FSEP's Peer Support Specialists – Brad and Kathy—will facilitate the discussion and share their real-life experiences not only as leaders in the peer support space, but also as parents of children with neurologic conditions



Brad & Kathy will be joined by Stephanie and myself



We thank Sue, Amy and Allyson for their work on the Bootcamp and of course, the Global Genes staff.



Survey Results from You – Our Partners

Primary Reasons Support was Sought

- To understand a diagnosis
- To connect with families with a similar condition
- To find for services related to diagnosis
- To find service providers

Years of Providing Peer Support

- 0-4 years = 5
- 5-15 years = 8
- 15+ years = 8



Survey Results from You – Our Partners

Number of Staff Providing Peer Support

- Most have 1-3 staff; some up to 10 paid staff
- Volunteers ranging from a few to 25, 45, 120, 350

Tell Us About Training

- 29% Do not have training
- Training methods: Webinars, self trained, mentor orientation



You Expressed These Needs

- Learn how to set up program
- Develop a structure/framework to train
- Interest in collaborative training
- Seek new ideas, perspectives and support



Our Time Together – Objectives and Flow of the Day



At the end of the Bootcamp, we will have actively participated in:

Discussing research that underscores the value, impact, and health benefits of peer support to families

Learning best practices, key elements, and effective techniques to provide peer support and promote resilience

Meeting colleagues who provide peer support and sharing our experiences

Exploring a common vision and commitment to work together, as providers of peer support, to ensure access for families and caregivers to someone who will listen and help them through their journey

Building a network with the goal of enriching and diversifying assistance opportunities for the families we serve



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Creating a Community of Support



Family Support & Empowerment Program (FSEP)

Stephanie Mucha

- Offering support to parents with children with special needs is not a new concept
- What was going to work for the community CNF served – which included a broad spectrum of neurologic conditions?
- Let's provide 1:1 support – but virtually and free





**We are here to listen and help.
We have been there.
We are parents, like you.**

***FSEP was founded
on these concepts***

KNOWLEDGE

that families seek and need the company of others who have walked similar paths with their children – quelling isolation many feel and sharing experiences

RECOGNITION

that compassionate support for families facing rare and challenging diagnoses extends beyond traditional health care services

SPIRIT

of support programs that have come before it, but with a unique focus on *relational support*—from an experienced peer—with the added goal of *renewed empowerment* through access to sound resources and linkages to advocacy partners



Getting FSEP Started



- At the heart of FSEP are the **Peer Support Specialists**
 - As you've learned, Brad and Kathy are both parents of children, now adults with special needs. They communicate directly with all who reach out to them.
 - FSEP Team includes: Sandy, Sue Yudovin (second BOD member), CNF Staff
- Inquiries come in through our FSEP website or via social media, we ask simple demographic questions, inquiries are tracked via shared document, responses are also captured there, analysis of findings.
- ***Peer Support Specialists*** will not provide medical advice. They will not critique medical advice previously provided. They will not review medical tests/records. They encourage communication and partnership with medical professionals.



Since February 2017 = Nearly 450 inquiries; 45 US States; 53 Countries



Offering FSEP Services: Families & Providers

HOW DOES FSEP HELP FAMILIES?

If you're a **Parent**, receiving a diagnosis for your child that is life-changing will shake you to your core. But you are not alone!

Having a safe place to explore feelings of "this is not the way it's supposed to be" is what FSEP is all about.

Sharing the emotional process that often comes with a new diagnosis or living with a neurologic condition, with someone who has also experienced these feelings, can be helpful to many families.

FSEP's Peer Support Specialists are trained to listen to you during along this emotional journey without judgment.

In addition, you will be provided with accessible resources and information from CNF or our trusted partners.



HOW DOES FSEP HELP HEALTH CARE PROVIDERS?

If you're a **Health Care Provider**, you aim to provide truly comprehensive, family-centered care for your patients and families.

Think of FSEP as a partner in achieving family-centered care and as a trusted resource to share with your families.

Peer Support Specialists have personally experienced the amount of time trusted providers take to answer questions and concerns from families.

FSEP's Peer Support Specialists are willing to help answer some of the more emotional or lifestyle questions families may have as it relates to their child's neurologic diagnosis.

Free notecards available for offices.

PCORI Grant

2017: CNF was awarded a Patient Centered Outcomes Research Institute (PCORI) grant to support CNF's efforts in understanding peer support models within the child neurology community, identifying gaps, and outlining opportunities for collaboration

2018: Collaborative Peer Support Workgroup joined together to lend their insights and identify solutions for the entire community





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Creating a Community of Support



A Strategy For the Journey: Peer Support and the Research Behind It

Brad Thompson

This Is Really Why I'm Here

Meet Hali Thompson



Strategy for the Journey

"Too often we underestimate
the power of a touch,
a smile, a kind word,
a listening ear,
an honest compliment,
or the smallest act of caring,
all of which have the potential
to turn a life around."

- Leo Buscaglia



There's Nothing New About Parent Support

- Since the beginning of time, parents have wondered if they were “doing it right” when it comes to raising children.
- They’ve been looking for people who’ve done it before to point them in the right direction.
- For parents of children with special needs, finding people to ask who have similar experience is more difficult.



Conversation

If you're with us today, you have felt called or led to try to help other families as they go through challenging circumstances.



- *With someone at your table:*
 - *What led you to want to help families in this way?*

PCORI Grant

CNF convened a multi-stakeholder Workgroup to assess strengths and gaps of peer support in the larger child neurology community.

- Comprehensive current literature review on peer support
- Work Group was briefed on key literature review findings and participated in a qualitative needs assessment (phone interviews with 16 representatives from 11 organizations)
- Needs Assessment report was generated from interviews
- Workgroup webinar held in July 2018 where priorities were further refined



The Case for Caregiver Support

Val Schilling and her team found:

- “There is ample evidence that parents of children with special needs are at risk of physical and psychological health problems, which are both pervasive and likely to worsen over time.”
- “Recognizing the expertise of parents is a fundamental concept in family-centered services.”

Shilling, V. et al. (2015). Peer Support for parents of disabled children part 1: perceived outcomes of a one-to-one service, a qualitative study. *Child: Care, Health & Development*, 41 (4), 524-536. doi:10.1111/cch.12223

Shilling, V. et al. (2015). Peer support for parents of disabled children part 2: how organizational and process factors influenced shared experience in a one-to-one service, a qualitative study. *Child: Care, Health & Development*, 41(4), 537-546. doi:10.1111/cch.12222



Peer Support Studies in General

- There has been a great amount of research done on peer/caregiver support in the adult world of chronic illness.
 - Peers for Progress among other groups.
- While we believe many findings from those studies can inform pediatric peer support, we also believe there are some issues unique to pediatrics that those studies don't address.
 - Ex. the grief we experience for our child
- *Are there other areas where you think there could be significant differences?*



Peer Support in General

Peer Support was found to be especially beneficial for three “hardly reached groups”. (Sokol & Fisher, 2016)

1. Individuals with low health literacy, self-efficacy skills, and education levels.
2. Individuals of lower socio-economic status.
3. Individuals who have little social support or are isolated geographically.

Fisher, EB, Ballesteros, J, Bhushan, N, Coufal, MM, Kowitt, SD, McDonough, AM (2015). Key features of peer support in chronic disease prevention and management. *Health Affairs*, 34(9), 1523-1530. doi:10.1377/hlthaff.2015.0365

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Key Elements of Effective Peer Support from the Literature

- 4 Key Functions of Peer Support
 - Assistance in daily life management
 - Social and emotional support
 - Linkage to clinical care and community resources
 - Ongoing support that reflects the lifelong nature of chronic disease
- When these 4 functions were present, **94%** of participants reported significant change favoring peer support.

Sokol, R, Fisher E. (2016). Peer support for the hardly reached: A systematic review. *American Journal of Public Health*, 106(7), e1-e8. doi:10.2105/AJPH.2016.303180.



Key Elements in Family Caregiver Support



SCHILLING FOUND THESE ELEMENTS IN SUCCESSFUL CAREGIVER SUPPORT EFFORTS

Shared Experience	Necessary component of peer support by all participating groups
Safe, Supportive Environment	Allowed parents to speak freely without fear of judgement
Continuity	Speaking with the same person over time – allowed trust to be built. <i>We get frustrated when we have to tell our story over and over to providers. Do we keep that in mind while providing support?</i>
Reduced Isolation	Having access to a parent who shares a similar life experience reduces the feeling of being alone. <i>Isolation is commonly associated with anxiety and depression.</i>
Emotional Stability	Opportunity to “offload” some of the emotional burden in a judgement-free zone was valuable in managing the ups and downs that come with CYSHCN

Shilling, V. et al. (2015). Peer Support for parents of disabled children part 1: perceived outcomes of a one-to-one service, a qualitative study. *Child: Care, Health & Development*, 41 (4), 524-536. doi:10.1111/cch.12223

Peer Support Interventions for Parents and Caregivers of Children with Complex Needs

- Additional benefits of peer support:
 - Emotional support and hope
 - Improved advocacy and self-efficacy
 - Information about specific disabilities
 - Practical ways to find and gain access to resources
 - Did not address the strategies for how to create these benefits in families.
- Supports the need for further study to determine effectiveness of various structures and strategies.

Schippke J, Provvidenza C, Kingsnorth S. (2017). Peer support for families of children with complex needs: Development and dissemination of a best practice toolkit. Child Care Health Development 43(6):823-830. doi: 10.1111/cch.12494. Epub 2017 Jul 18.



Infrastructure for Effective Caregiver Support Programs

- **Training** – equipped workers with fundamental skills and taught how to set appropriate boundaries.
- **Mutual Support of Support Givers** – having opportunity to share experiences was not only beneficial to parents, but also for those offering support to families.
- **Ongoing Supervision** – to help offset the emotional burden of providing peer support, regular supervision to process experiences and their impact on the provider was seen as valuable in maintaining emotional well-being and preventing burnout.



Shilling, V. et al. (2015). Peer Support for parents of disabled children part 1: perceived outcomes of a one-to-one service, a qualitative study. *Child: Care, Health & Development*, 41 (4), 524-536. doi:10.1111/cch.12223

Gaps: Legitimacy of peer support as a caregiver support intervention – from PCORI interviews

- 100% consensus on the need to increase child neurology community's awareness on peer support.
- Barriers to awareness: lack of technical assistance in peer support provision; lack of portal to share lessons/needs; lack of training and ongoing mentorship; physician engagement



IMPLICATIONS

- Lack of awareness may perpetuate sense of "one friend talking to another"
- Lack of awareness may inhibit more families being served
- Lack of awareness may perpetuate our own false narratives

Maybe the Most Important Gap: Physician Engagement

Quotes taken from interviews:

- "This would be a 'game changer'"
- "It would shorten the time families feel isolated"
- "It would assist families in not feeling like they're the only ones."
- "It would make it ok (legitimize) the need for support"



How many of your groups are connected with the medical community?

How did it happen?

Gaps: Need for Technical Assistance (Program Development & Training)



- Screening for those who provide peer support
- Identify program outcomes; measuring outcomes
- Consistent training for peer support "specialists"
- Provision of ongoing mentorship of peer support "specialists"

IMPLICATIONS

With reality of small staff/resources vs. great need and content...

Is a collaborative strategy to reframe peer support from organization based to community based possible?

Conclusions to Consider

- Peer support appears to be a way of improving health outcomes among groups that are hard to reach through conventional approaches (Fisher, 2015).
- In terms of reducing disparities and broadening the reach of health care, not only does peer support appear to be effective among those hardly reached, but evidence also indicates that it may be more effective among these groups (Sokol, 2016).



Fisher, EB, Ballesteros, J, Bhusahn, N Coufal, MM, Kowitt, SD, McDonough, Am (2015). Key features of peer support in chronic disease prevention and management. *Health Affairs*, 34(9), 1523-1530. Doi:10.1377/hlthaff.2015.0365

Sokol, R, Fisher E. (2016). Peer support for the hardly reached: A systematic review. *American Journal of Public Health*, 106 (7), e1-e8. doi:10.2105/AJPH.2016.303180

Need Assessment Findings and Ongoing Priorities

- Spoke of the power of in-person gatherings, when possible (*here we are!*)
- Greater awareness of the literature, evidence-based practice, and legitimacy of peer support
- Need supports specific to moments or challenges on the journey
- Need to establish a clear, shared definition of peer support; and training with models that can be shared across the child neurology community
- Coordinate resources and expertise to augment organization-focus peer support to community-based peer support services
- Provide TA in peer support program design/management and on-going mentorship

CNF will continue to facilitate Work Group and watch for subsequent Work Group outputs on CNF website.



Combining Your Thoughts with Literature Findings

- Relationships are important – how do we create spaces for them to happen – with the families we are trying to serve and each other as we try to improve on what we do?
- Training is valued – what are the "essential elements" that need to be a part of a training program?
- Assessment must happen if we are going to legitimize the role of peer support in improving health outcomes.
- The value of a network of like-minded groups to insure that families get connected to the best possible place to receive support.



Self Evaluation

- *On a scale of 1-5, how would you rate your program in these areas?*

How are you doing in serving families in these areas?

- Assistance in daily life management
- Social/emotional support
- Linkage to resources
- Ongoing support



Self-Evaluation

- *If you're scoring 1-5, how well would you say you're doing in these areas?*
 - Providing a “shared experience”
 - Creating a safe, supportive environment
 - Providing “continuity of care”
 - Training
 - Mutual Support for Support Givers
 - Ongoing Supervision
- *What do these things look like to you?*





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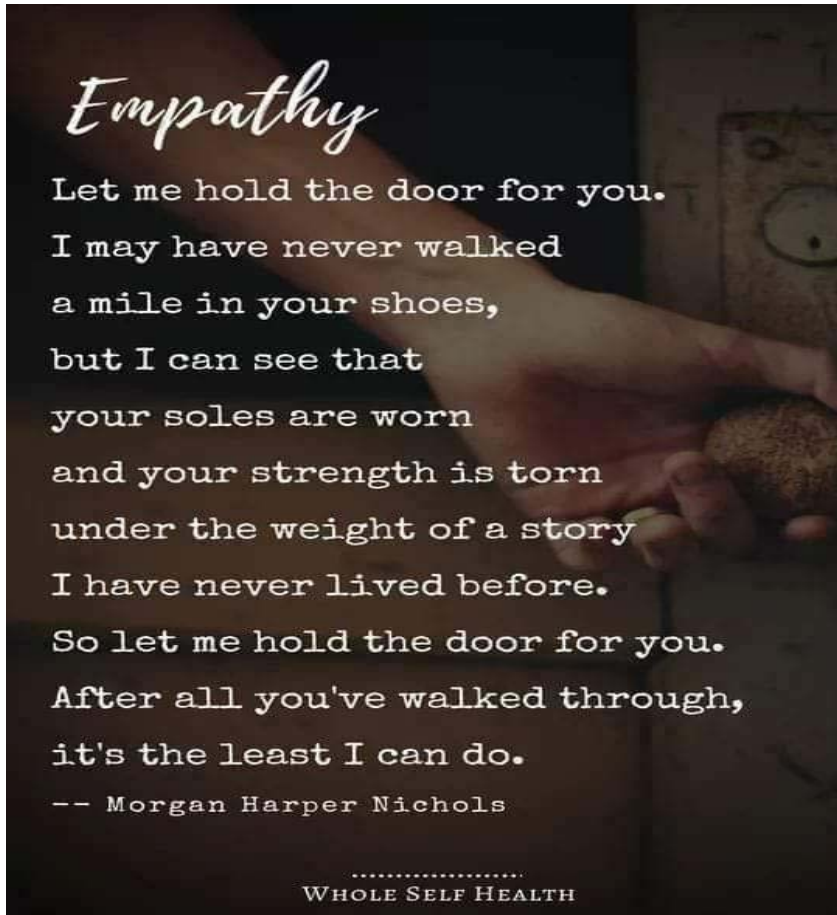
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Connecting Through Our Journey

Kathy Leavens

Creating Connections



Empathy:

The Ability to Share someone else's feelings or experiences by imagining what it would be like to be in that person's situation

Creating Connections

- Empathy – “Holding the Door” for another
 - *What does Empathy mean to you?*
 - *Let's talk about what Empathy can look like when we interact with those who we support.*
 - *Does Empathy have boundaries?*
 - *What do those boundaries look like*



Creating Connections

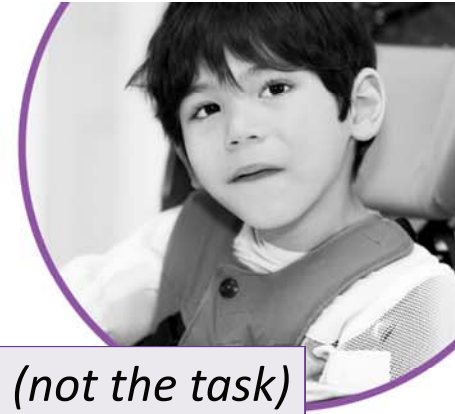
Empathy allows us to relate to the person reaching out because of some similar experience.

Empathy understands the strain of the known or unknown situations that are being faced.



Creating Connections

Think about SHOES



S tressed	➡	S top	<i>...and make the person (not the task) your priority</i>
H esitant	➡	H ear	<i>...what are they saying? Actively listen</i>
O verwhelmed	➡	O pen	<i>...your heart and try to imagine being in that person's position</i>
E ager	➡	E xpress	<i>...your understanding of their concerns, fears, and hopes</i>
S cared	➡	S upport	<i>...offer encouragement and specific assistance (when possible)</i>

Telling My Story to Create connections

- **Key elements of my story**

- Mom of multiple children with special needs
- Single mom
 - Pressure of being sole provider and meeting my own personal needs
- Experienced grief of losing children
- Looking for answers with no roadmap
- Resilience / Steadfastness
 - Steps take us where we are meant to go
 - When we do nothing, we will not get closer to a solution



Telling Your Story to Create a Connection



- If you provide direct peer support, what are the key elements of your own story that creates a connection? *or*
- If you oversee peer supporters, think of one person. What makes her/him effective because of their story?



Telling your story to create connection

- Sharing experience - Let's connect!
 - *Pick a partner at your table.*
 - *Think about an opportunity when you have used your story to serve someone.*
 - *What elements of your story helped create a connection?*
 - *Share how you “listen” virtually.*
 - *What techniques have you used that have been successful?*



Telling your story to create connection

- “My daughter is treated by Child Neurology in Louisville, Kentucky. She is 5 years old. She has failed several medications in the last 3 years and have recently become a candidate for a focal resection. We are starting the inpatient evaluation on July 9. Her diagnosis is refractory epilepsy, intractable. She has lost some cognitive abilities in the last 3 months and is also listed as having cognitive disorder at this point. It is a lonely place to be.”
- “My 15 month old son was diagnosed with Infantile Spasms at age 9 months. We as parents are still adjusting to the diagnosis, what we need to do to help him, and our new "normal".”





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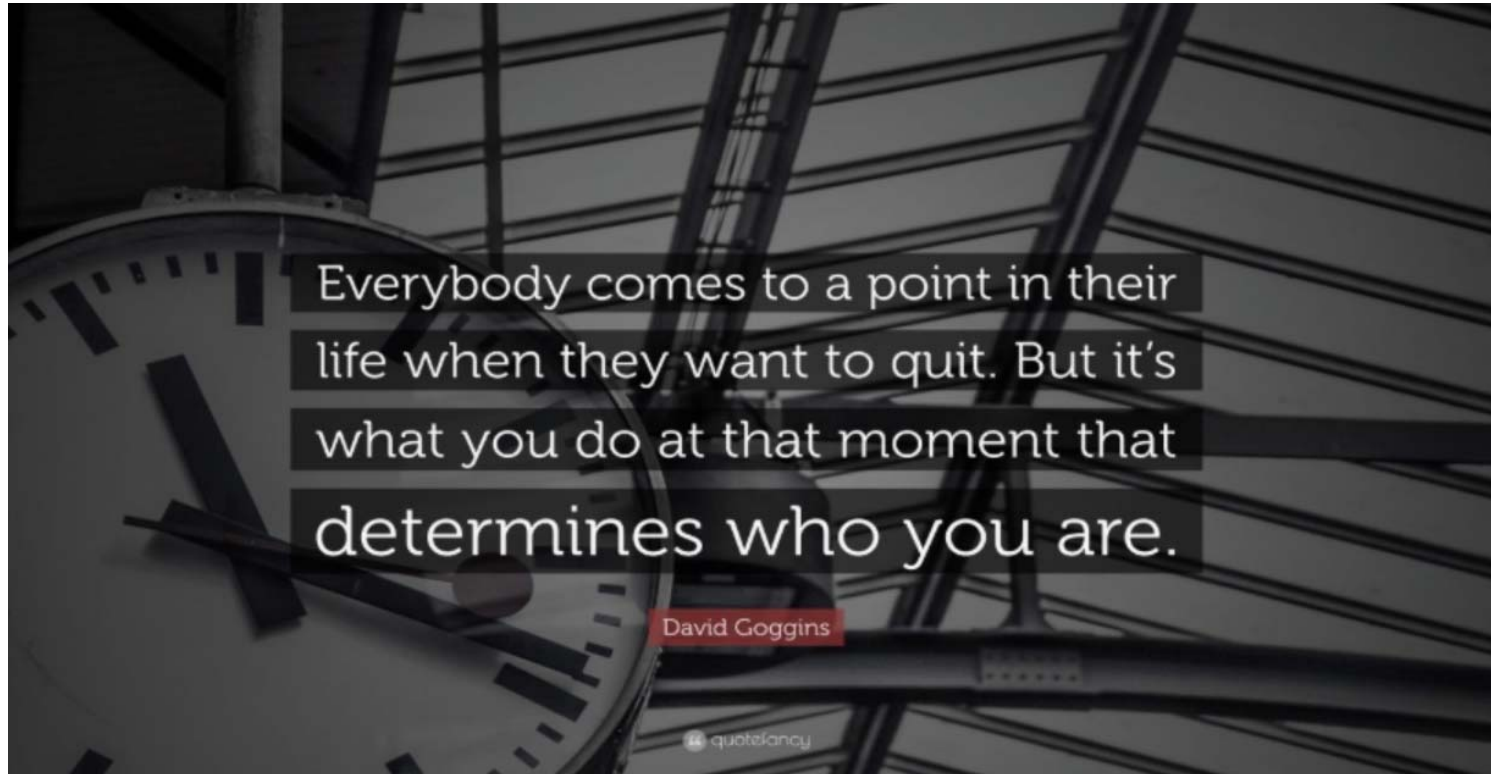
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The Emotional Process: Connecting to People Where They Are

Brad Thompson

Acceptance



The Emotional Journey

The emotional journey with a child with special needs has been described as one of chronic grief.

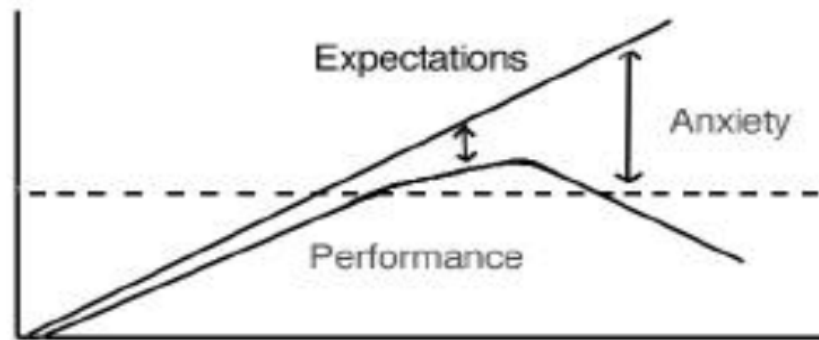
- What does that mean to you?
- What do you do with it?
- What are the things that might create new grief cycles?



First, we need to understand it...

Stages of Adapting

- 1st Stage – Survival
 - Emotions:
 - Denial
 - Anxiety
 - Fear
- 2nd Stage - Searching
 - Emotions: Guilt, Shame, Depression, Anger
 - **Guilt** – is there anything good about guilt?
 - If you see some form of self-loathing, that's **shame**
 - What else might it look like?
- Parenting is a **shame and judgment** minefield. - Brene' Brown



Stages of Adapting

3rd Stage – Settled In

- Emotions: Hope, Acceptance
- If we're working with caregivers, this is what we want to point them to.
- If we're looking for someone to work with families, we want them to have experienced this.
- What are the greatest threats to hope and acceptance?



Caveat

- We know this can be a greater challenge when connecting by phone or email. But what if we could...
- How do you try to connect emotionally with caregivers?
- As you look at these situations, consider these things -
 - Where might this person be in the emotional process?
 - Given that, how might you support them?
 - What else would you like to know?



Email Request (as received)

- *"I have an autistic kid he is 16 years old and is having a crisis at the moment . I tried several neurologist from my insurance network but they have not clue how help my kid . do you know anyone that spent most of their professional career to help people with the sindrome if you know anyone please let know i appreciate all your help"*



Email Request (as received)

"My daughter was perfectly normal and had a flu shot on 11/10/17 and around the 15th started having symptoms. Left side facial droop and started dragging left leg. We took her to the ER on Thanksgiving and at 1st thought she had bell palsy but was told her walking like that didn't match bell palsy. We went to a children's hospital in our area and was told she had a brain tumor and 15mins into 1st biopsy was told it was just a lesion. She came home but was slowly getting worst. She has had and extensive work up and a second biopsy.

in January went to another very famous hospital in our area and within 3 days there she stop walking, talking, and not able to eat. She had an extensive work there and a 3rd biopsy and muscle biopsy. They didn't find nothing wrong so she went back to the children's hospital. After all the testing and 3 brain biopsy still can't find a diagnosis. No childhood sickness but a couple of strep throat.

This is very devastating and here in 2018 I can't believe that no test warrant any diagnosis, she still understands a lot but it's like she's trapped in her body."



Worst Cases

- How do you support a parent when the outlook is dire?
 - Silence isn't a bad thing, and better than many things I've heard people say.
- When the time is right, what if we could talk about the “best life possible”?
- What if the destination is “no regret” parenting?



Email Request (as received)

"My niece was expired last Thursday. She doesn't wake up anymore."

- What would you do for this family?
- What would you do for your staff providing peer support in this situation?



Sometimes you have to
let go of the picture of what you
thought it would be like and learn
to find joy in the story you
are actually living.

tinybuddha.com





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Mentoring, Shared Experience, and Action

Brad Thompson

Encouraging Possibilities

- Motivating, Creating and Sustaining Change
 - “Switch”
- Have you ever seen a guy riding an elephant?



Encouraging Possibilities and Action

- We must balance the tension between the emotional – the Elephant ; and the rational – the Rider.
- The Rider provides education & direction.
- The Elephant provides energy.
- We all have a Rider & Elephant inside of us.
 - Knowing which role to play requires courage and humility.



Encouraging Possibilities and Action

- Encourage a clear sense of purpose.
 - Many times what looks like resistance is actually a **lack of clarity**.
 - When we aren't sure what to do, it often leads to doing nothing.
- *What's your purpose for being here?*
- *What's your purpose for the families you serve?*



Encouraging Possibilities and Action

- Things we need to move toward purpose:
 - Direct the Caregiver to become the Rider
 - No one knows your child better than you do.
 - There are others that know things about your child that you don't.
 - How do we do that?
 - Find the bright spots
 - Focus on strengths
 - What's working now?
 - Make sure the bright spot is about them
 - Encourage provider-family partnership



Encouraging Possibilities and Action

- Point them to the destination.
 - What might the best possible life look like for them?
 - When talking about this, are we being family centered or patient centered?
 - Make sure the destination is inspirational.
 - What happens if the family has a setback?



Encouraging Possibilities and Action

- “Motivate the Elephant”
 - How do you encourage other caregivers to move toward the "best life possible?"



Encouraging Possibilities and Action

“It is important to master four ways of looking at things:

- 1) as they were
- 2) as they are
- 3) as they might become, and
- 4) as they ought to be.”

-Dee Hock

“I’ll see it when I believe it.”

-Hali Thompson



Something to Ponder



If there were no services, what would you do?
What would a peer supporter do?

Encouraging Possibilities and Action

- Who are the members on your team?
 - As a caregiver?
 - As a caregiver supporter?
 - Do you have positions to fill?



The Right Kind of Action



“Things that are fought for and won are often fought for again and taken back.
Things that are mutually agreed upon last.”

- Rev. Martin Luther King, Jr



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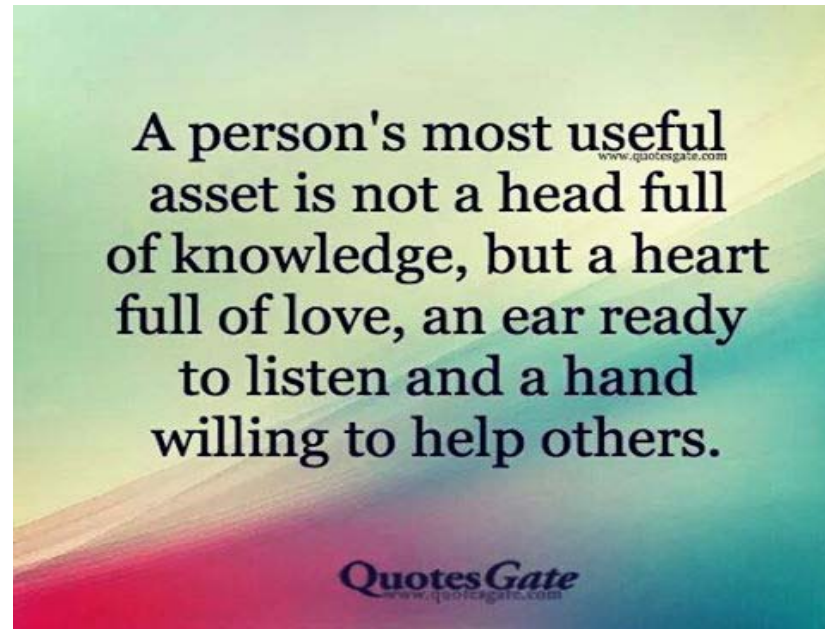
Healthy Advocacy: Putting the Pieces Together

Kathy Leavens

Putting the Pieces Together

The BIG Question:

Where is the person who walked this road before me?



- As I share my personal story, take notice for yourself:
 - How would you make a connection with me if I had come to you?
 - What approach would you use?
 - What was I really asking for when I was searching for answers?



Putting the Pieces Together

Matthew William (9/16/95 - 9/13/13)

- The Experience of Life is a Great Teacher
 - The Gift of Time
 - Resourcefulness
 - Heart
 - I not only hear but I FEEL
 - Witness to SUDEP
- My hope is for each parent to leave with knowing they have a VOICE, their VOICE matters, they are the best ADVOCATE



Putting the Pieces Together

- 2013: Available to parents through Social Media
- 2013: Became an LGS Family Mentor today known as the LGS Ambassador Program
- 2016: Joined CNF and the Family Support and Empowerment Program was born
- 2017: Officially became LGSF Program Support Specialist



Putting the Pieces Together

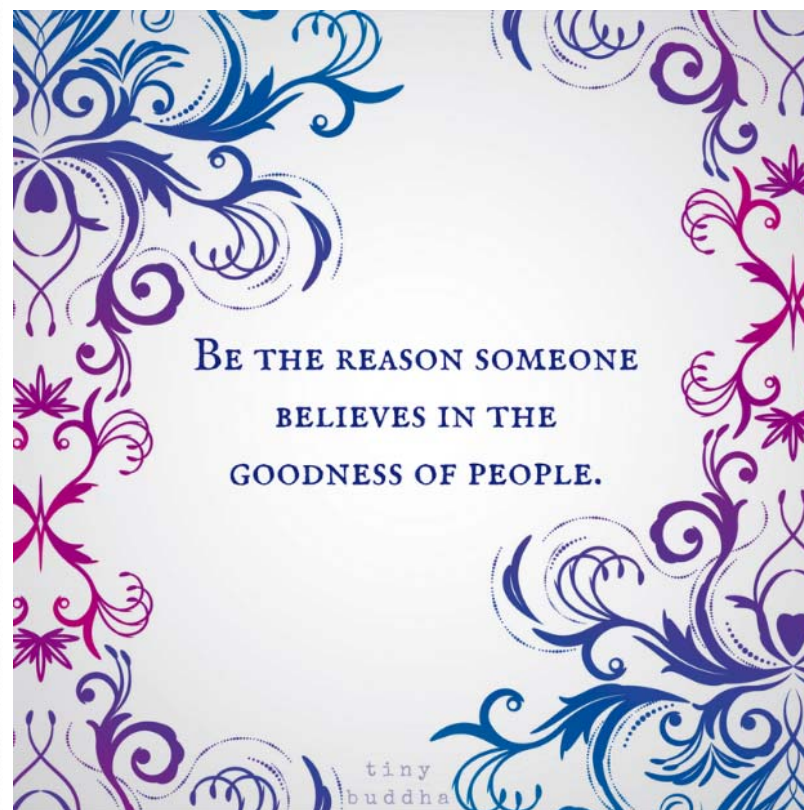
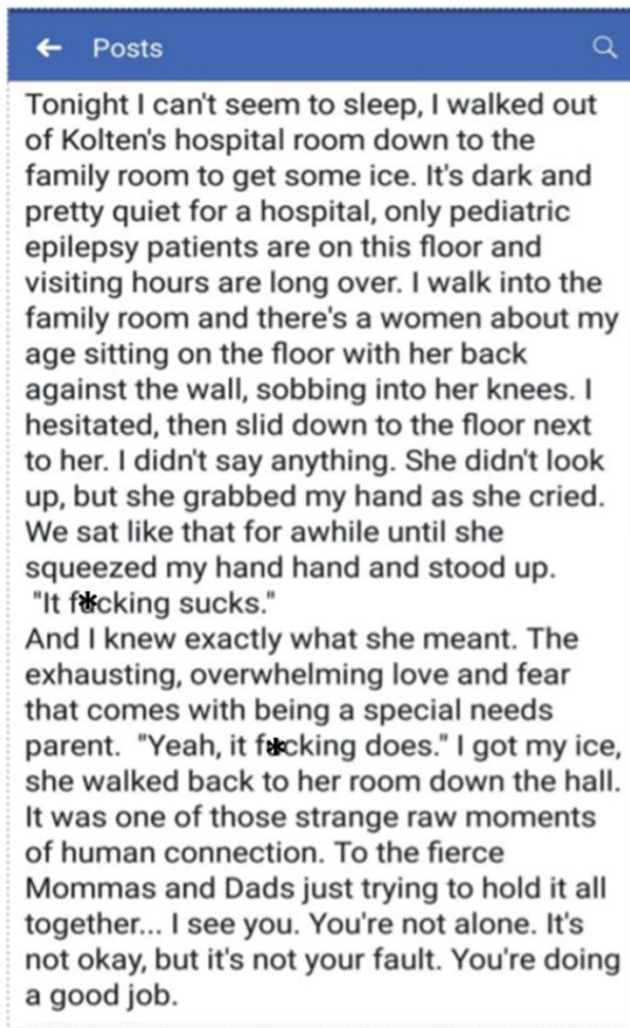


Encouraging Possibilities and Action



- My personal definition of peer support is LOVE
- It began with a love for my children. Now, that love has grown to include the families I support.
- Love is the reason I continue.







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Promoting Resilience Through Peer Support

Sandy Cushner-Weinstein

Objectives

- Challenges with chronic health
- Resilience theory
- Protective agents and factors
- Impact and benefit of peer support
- Interventions that help



Our Children Face Challenges

- Cognitive: learning and educational
- Social
- Behavioral
- Depression
- Anxiety
- Physical
- Social stigma
- Life Expectancy



Parenting stress increases with learning difficulties, depression and seizure related factors including polytherapy.

Epilepsy and Behavior, IOM
Cushner Weinstein et al

What allows some people to thrive in spite of pain, hardships, limitations and trauma?



Resilience Can Impact Quality of Life



- Resilience serves as a moderator of QOL
 - Two groups children: Symptom Severity Scale
 - Groups: Mild and Moderate/Severe
 - In general, moderate-severe group scored lower ($p < .05$) in QOL
 - Domains: Cognition ($p < .05$), Emotional Functioning ($p < .01$)
- More resilient better the overall QOL score regardless of severity of symptoms

CTF Cushner-Weinstein, 2012

Resilience

- **In health:** move from symptoms and deficits to strengths and resilience
- **Positive psychology:** focus on self awareness and positive engagement
- **Resilience Theory:** recognition of a person's capacity to withstand or rebound from adversity
 - Identifies responses, characteristics and resources that promote well being and optimal health for a good life



Resilient Individuals

- Learn to manage stress
- Become effective self managers
- **How resilient are you?**



Resilient Individuals

- Have the capacity and skills to adapt and overcome obstacles
- Peer support can promote resilience



What We Know and Observe About Resilience

- Resilient individuals:
 - Develop coping strategies
 - Connect socially with family and friends
 - Find positive meaning in challenging solutions
- Research findings resilient individuals have in common
 - Behaviors and Beliefs:
 - Contributed to the well being of others
 - Sense of hope
 - Create meaning for struggle
 - Receive: consistent source of support



Resilience is Protective

- **Protective Agents:** Individuals, groups, organizations or systems that contribute and promote psychosocial well-being
- **Protective Resources:** Family and community capacities to protect and promote psychosocial well-being
- **Protective Mechanisms:** Process of promoting competencies and capacities. Utilize mechanisms – create meaning, hope – tomorrow will be different



Peer Support Can Promote and Integrate Protective Factors

- **Agents:** Peers – community of support
- **Resources:** Education and knowledge
- **Mechanisms:**
 - Normalize the experience
 - Increase sense of belonging
 - Promote interpersonal learning
 - Build self-efficacy and peer support
 - Learn about emotional triggers
 - Develop skills to adapt



Groups Promote Resilience by Utilizing Therapeutic Factors

Factor

- Universality
- Sense of hope
- Altruism
- Cohesion
- Interpersonal learning
- Catharsis
- Identification

What is it that helps

- Similar issues, not alone
- See others doing well
- Help peers
- Acceptance and Belonging
- Relating to others
- Expression of feeling
- With mentors



Peer Support Utilizes Similar Therapeutic Factors to Promote Social Connections and Build Resilience

- **Universality:** Issues are similar – not alone
- **Sense of Hope:** See others doing well
- **Altruism:** Helping others builds strength to help self
- **Cohesion:** Acceptance and sense of belonging
- **Interpersonal learning:** Can relate with each other
- **Catharsis:** Express feelings
- **Identification:** With peers and mentors



Relationship between Beliefs, Emotions & Behaviors

Beliefs impact thoughts and thoughts impact our emotions & behavior

- What is the situation and cause?
- What are our values or beliefs?
- How do we make sense of this experience?
- How do we mobilize ourselves and others ... to take action?

For many, when something happens to their children or family member, their values are challenged. This can lead to emotional distress.

While behaviors (emotions & actions) are often the target to bring about change, we need to understand one's beliefs and listen to hear the meaning behind thoughts & emotions.



When We Provide Peer Support

- We listen – to understand
- We reflect feeling – to increase awareness
- We help caregivers separate thoughts, feelings, behavior
 - **Thoughts:** I am not a good enough parent
 - **Feelings:** Guilty, overwhelmed, worry
 - **Behavior:** Don't take time for self or focus on needs
- We help people understand their values
- Share and hear their own stories



Peer Support Helps Parents Break Through Barriers

- Peer support helps parents break through barriers
- Help shift perspectives
- We encourage acceptance and self-efficacy to promote hope
 - **Acceptance** (will pass)
 - **Self-efficacy** (I can handle it)
- We help promote tolerance and coping strategies by sharing the experience with others
- We listen and help people find their voice and strength



Peer Support Can Promote Resilience

- Peer support provides opportunities to connect with people who understand and share similar concerns
- We offer a helping hand...without judgment
 - *“We spoke for hours and laughed at ourselves and our struggles and....it felt so good just to laugh with someone who gets it.”*
 - *“We don’t need to explain since they get it!”*
 - *“My son knows he is not the only one.”*
 - *“Everyone knows my name and the issues are the same.”*
 - *“I don’t feel so alone.”*



To Listen...

When I ask you to listen to me and you give me advice
You have not done what I asked

When I ask you to listen and you tell me why I shouldn't feel
You are trampling on my feelings

When I ask you to do something to solve my problems
You have failed me, strange as that may seem

All I asked was for you to listen, not talk or do
Advice is cheap

I can do for myself. I may seem it but I'm not helpless.

When you do something for me that I can and need to do myself
You contribute to my fear and feelings of inadequacy

So please listen and just hear me. And... if you want to talk
Wait a minute for your turn and I'll listen to you

-Ralph Roughton



Life is Filled with Challenges – Each Challenge Offers an Opportunity to Learn, Connect and Build Resilience





It takes brains, work and practice to
“Live Well” with a chronic health condition

BC Mantra: Have Fun, Be Wise & Live Well





Reflection & What's Next



Thank You



Family Support &
Empowerment Program
Child Neurology Foundation

www.childneurologyfoundation.org/FSEP