



Sunday, August 4, 2019

Breakout Session F35 • 1:30-2:30 pm • Governors Lecture Hall

Sensing Connections: Peer-to-Peer Grief Support for Families

**Megan Cote, National Center on Deaf-Blindness
Jody Wolfe, CHARGE Syndrome Foundation**

Presenter Information

Megan Cote is the Initiative Lead at the National Center on Deaf-Blindness (NCDB) for Family Engagement. In her 26-year career in special education, she has been a classroom teacher, educational consultant, director of the Kansas Deaf-Blind Project, and has worked on multiple grant projects. Megan earned her Master's degree at the University of Kansas in Special Education. As a board member for the CHARGE Syndrome Foundation, she has worked to expand and shape the CHARGE State Liaison program and the outreach services they provide to families.

Jody Wolfe has a B.A. in accounting from the University of Missouri. Early in her career, she practiced as a CPA, and later worked at McDonald's Corporation and Nextel Communication in finance and human resources. She completed the Illinois Family Leadership training for families of children who are deaf-blind, served on the Illinois Advisory Board for the deaf-blind, worked with the National Center on Deaf-Blindness in the creation of online intervener modules, and was a parent mentor for the Lurie Children's Hospital ParentWISE program. Since 2009, she served as committee chair for registration and assisted with other parts of conference including volunteers, sales table, and camp program for the CHARGE Syndrome Foundation's International conferences. Jody currently serves as Director of Administration for the CHARGE Foundation. In her spare time, Jody also volunteers at John Powers Center for the deaf and hard of hearing in Vernon Hills, IL.

Presentation Abstract

Over the course of the past 8 years, an average of 91 children birth to 21 years of age have died annually on the national deaf-blind child count. Due to this, the National Center on Deaf-Blindness brought together a group of parents from across the deaf-blind network (with kids of varying age and etiology) to talk about what would have helped them in terms of support that could have been provided by the deaf-blind community when their child died. As a result, individuals were trained in grief support, a 10 week curriculum was created, and the "Sensing Connections Peer-to-Peer Grief Support " began to provide much needed connection and healing for these families.

Learning Objectives

- How Sensing Connections was created.
- The levels of support offered through Sensing Connections
- What is grief?
- How might grief be the same or different for families of children with deaf-blindness compared to families of children who aren't disabled
- Healing - what's involved and what a community of support can provide
- What can providers do to help support families?
- What can these families give back to the community?



SENSING CONNECTIONS: PEER-TO-PEER GRIEF SUPPORT FOR FAMILIES OF CHILDREN WITH DEAF-BLINDNESS

Presenters:

Megan Cote, NCDB Initiative Lead for Family Engagement

Jody Wolfe, Director of Administration for the CHARGE Syndrome Foundation

WE WOULD LIKE TO THANK THE 15 WOMEN
WHO HAVE HELPED TO BUILD THE TRAINING,
AND THE SUPPORTIVE COMMUNITY THAT
EMBODY THIS WORK.



Session Outcomes:

Participants will learn about:

- 1) How Sensing Connections came to be
- 2) The levels of support offered through Sensing Connections
- 3) What is grief?
- 4) How might grief be the same or different for families of children with deaf-blindness compared to families of children who aren't disabled
- 5) Healing - what's involved and what a community of support can provide
- 6) What can providers do to help support families?
- 7) What can these families give back to the community?

How & why was Sensing Connections created?

Over the course of the past 8 years, an average of 91 children birth to 21 years of age have died **annually** on the national deaf-blind child count.

Because of this, NCDB brought together a group of moms from across the deaf-blind network with kids of varying age and etiology to talk about what would have helped them in terms of support that could have been provided by the deaf-blind community when their child died.

3 things were identified:

- 1) A list of resources for where they could go for support
- 2) A connection to other families of children and young adults with deaf-blindness who had died
- 3) Permission to know that what they learned from raising and loving their child still mattered and could help others

We took the following steps:

- 1) Collected a list of resources that parents and providers could access of where to go for support -
<https://nationaldb.org/wiki/page/10/753>
- 2) Training in peer-to-peer grief facilitation
- 3) Created a curriculum to guide the group
- 4) Advertised the offer of support across the network
- 5) Facilitated the first ever national peer-to-peer grief support group for families of children with deaf-blindness virtually - facilitators were family members who have experienced the loss of a child

Facilitating the first group

Prior to the first meeting, every participant received a “Grief Kit” in the mail containing an introductory welcome letter, the curriculum, a handmade blanket, a battery operated candle, and journal.

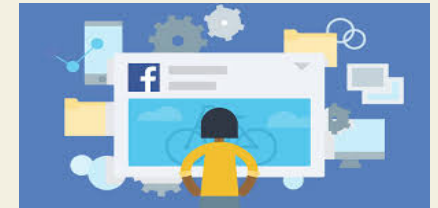
We met for a total of 10 sessions, 2 sessions per month for 90 minutes each session. 7 women participated in the group covering 3 time zones across the US. AND... not a single person dropped out of the group.

Participants were encouraged to review the curriculum prior to each meeting and come prepared to share their experiences and questions, if they felt comfortable to do so. Passing was always an option.



Phase 2 was created

Three levels of support now exist:



1. **Online Death Education Resources** available here:

<https://nationaldb.org/wiki/page/10/753>

2. **Phase 1** - Ten week - virtual Peer-to-Peer Grief Support

3. **Phase 2** – Monthly conversations on topics chosen by the group members themselves. It provides an opportunity for group members to do a “deeper dive” into topics they feel need further exploration. This happened as a result of the continued interest in participants to stay connected.

Also, we created a private Facebook page for all group members. Participation is optional.

What is grief?

Grief is the price we pay for **love. – Queen Elizabeth II**

Grief is a multifaceted response to loss, particularly to the loss of someone or something that has died, to which a bond or affection was formed. Although conventionally focused on the emotional response to loss, it also has physical, cognitive, behavioral, social, and philosophical dimensions.

Wikipedia

“It changes you, the same way that your child’s life changed you. Those changes are not in and of themselves good or bad, but you will never be the same, or look at the world/others in the same way again” (A Grief Group Participant)



5 Stages of Grief

Denial - In this stage, the world becomes meaningless and overwhelming. Life makes no sense. We are in a state of shock and denial. We wonder how we can go on, if we can go on, why we should go on. We try to find a way to simply get through each day.

Anger - The more you truly feel it, the more it will begin to dissipate and the more you will heal. Underneath anger is your pain.

Depression - When the loss fully settles in your soul, the realization that your loved one didn't get better this time and is not coming back is understandably depressing. It feels as though it will last forever.

Bargaining - We want life returned to what it was; we want our loved one restored. "What if..."

Acceptance - accepting the reality that our loved one is physically gone and recognizing that this new reality is the permanent reality. We will never like this reality or make it OK, but eventually we accept it. We learn to live with it.

Possible Manifestations of Grief

- Physical/Physiological expressions of grief often include crying and sighing, headaches, loss of appetite, difficulty sleeping, weakness, fatigue, feelings of heaviness, aches, pains, and other stress-related ailments.
- Emotional expressions of grief include feelings of sadness and yearning. But feelings of worry, anxiety, frustration, anger, or guilt are also normal.
- Social expressions of grief may include feeling detached from others, isolating yourself from social contact, and behaving in ways that are not normal for you.
- Spiritual expressions of grief may include questioning the reason for your loss, the purpose of pain and suffering, the purpose of life, and the meaning of death. After a death, your grieving process is influenced by how you view death.

How might the grief of this group be unique?

- 1) Being intimate caregivers of our children
- 2) Sense of role or identity has changed
- 3) Secondary Losses
- 4) Unexpected reaction from family/community
- 5) Unexpected shock of death, even when loss was anticipated**
- 6) Concern about supporting surviving siblings
- 7) Impact on relationships with individuals who assisted in the care of the child

"I didn't know on the day my child died that I would miss cleaning syringes, cleaning up your puke, changing diapers, going to the hundreds of appointments and seeing all those doctors and nurses at the hospital. It's like I had this family of medical people and then they all just disappeared when you were gone. Feeling emptiness." (Grief Group Participant)

What does research tell us?

In 2008 Jennifer Stepanek published her dissertation called "The Experiences and Needs of Parents Whose Children Died Due to Degenerative Disabilities: A Qualitative Analysis"

She interviewed 7 bereaved parents whose children died between the ages of 3 and 21 due to complex health care needs.



Parent Experience Themes from her research:

The themes that emerged for parent **EXPERIENCES** include:

- abundant stress from dissonance
- exhaustion
- chronic changes
- unanticipated shock
- profound grief
- ongoing struggles for validation
- the positive impact of formal and informal supports

Parent Needs Themes from her research:

The themes that emerged for parent **NEEDS** include:

- Hope
- Information
- Useful resources
- Helpful networks
- Healthy partnerships
- Choices
- Validation

Parent Preferred Support Themes from her research:

The themes that emerged for **PREFERRED SUPPORTS** during loss and bereavement include:

- professionals' awareness of and attention to parent experiences and needs throughout the child's lifespan
- Ongoing connections with providers and activities that were a part of the child's life
- Support options beyond traditional bereavement groups

Things to consider if you are Grieving:

Time - there's no time clock for when grief is "over"

Identify your self-care needs

Going **through** one's grief, not **around** it

"The best advice I received was the only way to get through grief is by grieving. I didn't know on the day my child died that joy and pain could live together so seamlessly in my remembrances of him. And that I would welcome the pain, if they were a package deal." (Grief Participant)

Expect the waves of emotions for a very long time

Surrounding yourself with support is crucial - thus group was born out of need

Strategies for Supporting Someone Who is Grieving (1 of 2)

- 1) Have an understanding and patience about the fact that things will never be the same again

"It's been years, and we have a new normal. There is a hollow place in it, sometimes. But most of the time, I feel I carry you with me throughout my day, almost like when I was pregnant with you, and you were here/not here at the same time. Except this time, instead of just in my womb, you are in my heart. " (Grief Participant)

- 2) Talk and share memories from time to time about the Child

"It has given me an opportunity to speak about my child, to people that understand." (Grief Participant)

Strategies for Supporting Someone Who is Grieving (2 of 2)

- 3) There is no timeframe for grieving - check in with them from time to time

"There is no right way or time-frame for grief-it's forever-just like my love for my son." (Grief Participant)

- 4) Invite the parents to continue to use their expertise to support other families, as time and interest permits

"Ironically, he has taught me to be both more loving and forgiving with myself, and also more assertive/vocal in advocating for myself and others."(Grief Participant)

- 5) Suggest they join the Sensing Connections Group

What surprised us as facilitators?

- 1) Immediate connection with total strangers
- 2) Because structure and content were provided, discussion happened effortlessly
- 3) Constancy in attendance despite family obligations & life
- 4) The courage that participants gained to share their need for the group with family members and loved ones

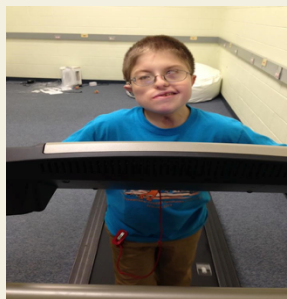
Next Steps for Sensing Connections

- 1)Continue to offer the Phase 1 Group
- 2)Provide training for additional facilitators
- 3)As a group, continue to educate providers about the importance of supporting families during their grief
- 4)Empowering families to continue to spread their knowledge and skill in the deaf-blind community

Our inspiration...



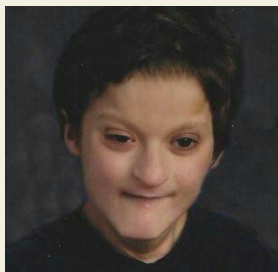
Christian,
son of Melanie
07/5/1990 - 11/3/2005



Ethan,
son of Jody
6/14/2002-10/15/2014



Jonathan, son of Kim
1/8/1991- 4/15/2016



Alden,
son of Megan
3/7/2001 - 6/30/16



Alex,
son of Molly
07/11/1991 0 07/20/2013



DEAF-BLIND NETWORK
TECHNICAL ASSISTANCE ACROSS THE NATION

Our inspiration... (cont.)



Ginny,
daughter of Melissa
08/05/2008 0 04/25/2015



Emily,
daughter of Mary
05/14/1986 - 12/18/2013



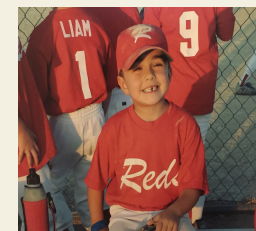
Rylan,
son of Jennifer
4/5/09-5/13/16



Martin,
son of Ana
6/20/2014- 10/20/2015



Norman,
son of Myrna
02/20/1996 - 02/15/2016



Ben,
son of Megan
01/18/1999 - 9/7/2007

Our Contact Information:

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Resources

List of Online Resource List for Grieving Families:
<https://nationaldb.org/wiki/page/10/753>

Information about the 2 levels of grief support:
<https://nationaldb.org/wiki/page/10/757>

