From Grief to Resilience: Raising A Child with Complex Developmental Needs

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Objectives

- Learn concepts of complex grief; resilience; and positive psychology;
- Learn to recognize potential events that may trigger complex stress and support a caregiver’s ability to manage triggers;
- Understand medical vs. social models of disability
- Learn evidenced-based means to support caregivers’ resiliency during times of stress
Disclosures

• No business disclosures
• I am not the parent of a child with a complex developmental need
Parenting
Parenting a child with complex developmental needs
Grief...

DEFINITIONS OF GRIEF (HTTP://WWW.MERRIAM-WEBSTER.COM/DICTIONARY/GRIEF)

- deep and poignant distress caused by or as if by bereavement
- a cause of such suffering
- an unfortunate outcome : disaster —used chiefly in the phrase “come to grief”
- mishap, misadventure
- trouble, annoyance “enough grief for one day”
- annoying or playful criticism “getting grief from his friends”
...It’s complicated

• Complex Grief – When the process of managing loss (or unexpected change in expectations) is extended or delayed.

• Kurtzer-White and Luterman, 2003 Multi-step cycle of grief following diagnosis (of hearing loss)

“Shock, Recognition, Denial, Acknowledgement, and Constructive Action”
Triggers

Events and reminders (of a change in expectation or experience) that can hit at any time and often during times of transition, causing a re-experience of grief;

May be different for each caregiver, sibling, family member.
Anticipating Triggers: Ages and Stages

0-2  3-5  Elem  MS  HS
Receiving a diagnosis...
Not as simple as it seems

• Ex: Universal Newborn Hearing Screening
  • “Institution-led” vs. “Parent-led” diagnosis
  • Yoshinaga-Itano & DeUzcategui (2001). (Hearing parents) Receiving a newborn hearing screening produced 3% anxiety; Receiving a “refer” following a failed screen increased anxiety to 40%.
Audience Observations

• What events have you observed that have “triggered” a caregiver/family member’s feelings of regret/grief about their child’s disability or to bring that aspect of the child (back) into focus? Were the trigger related to an experience, transition, or other?
Moving to Resilience

Excellence at Work
Managing Loss and Resilience

Resilience (Bonanno; 2004)

“The ability of adults in otherwise normal circumstances who are exposed to an isolated and potentially highly disruptive event, such as the death of a close relation or a violent or life-threatening situation, to maintain relatively stable, healthy levels of psychological and physical functioning;” and “The capacity for generative experiences and positive emotions.”
Fostering Resilience

Hardiness

Self-Enhancement, Empowerment, and Strong Social Networks;

Positive Emotions (gratitude, interest, love)

LAUGHTER

Excellence at Work
Resilience and families with deaf and hard of hearing children


• Factors associated with family resilience included: “family time and routines, social support, affirming communication, family “hardiness,” problem solving skills, religion, a search for meaning, and acceptance of a child’s hearing loss.”
“Life well lived, in spite of challenges in life, not at the exclusion of them.”
"Raising children, I realized, is vastly more than fixing what is wrong with them. It is about identifying and nurturing their strongest qualities, what they own and are best at, and helping them find niches in which they can best live out these strengths." (Seligman, 2000)
Positive Psychology

Values

- Well-being, Contentment, Satisfaction (in the past);
- Hope and Optimism (for the future);
- Flow and Happiness (in the present).
Transforming How Disabilities are Perceived

Medical Model
- Disability is a deficiency
  - Located within the person
  - Disability is negative and should be ameliorated
- Remedy is the individual’s problem
- Agent of Remedy: Health care professional

Social Model
- Disability is a difference
  - Located between the person and society
  - Disability is neutral in life’s context
- Remedy is negotiated interaction with society
- Agent of Remedy: Person and people with whom the person interacts
“Deaf people can do anything Hearing people can do, except hear.”
Frederick Shriebert
Love...No Matter What

https://www.ted.com/talks/andrew_solomon_love_no_matter_what

• “Far From the Tree” Andrew Solomon
  — Vertical vs. Horizontal Identities
  — Medical vs. Social models of “disability”
Positive Psychology and Parenting a Deaf and Hard of Hearing Child
Szarkowski and Brice (2016)

• Empowerment. You are (becoming) the expert - "Parent Power" you’re the expert about your child, hearing loss, their education/therapy, etc.

• Finding the positives in the "small stuff" (running the dishwasher during naptime)

• More effort = more time with my child

• When it's good, it's REALLY Good
Positive Psychology and Parenting a Deaf and Hard of Hearing Child

Szarkowski and Brice (2016)

• I'm a better parent, because I don't take things for granted

• Learning...to "let go" - while REALLY HARD- can really help you understand what an amazing kid your child is

• Learning...about how my child learns..."can't get that from a book“
Positive Psychology and Parenting a Deaf and Hard of Hearing Child
Szarkowski and Brice (2016)

• Learning...about myself (as a parent, as a person)...and personal growth
• Learning... to be an advocate/ expert
Social Support

- Henderson, Johnson, & Moodie (2014) Proposed a conceptual, interactive framework of parent-to-parent support to include:
  - Well-being: parent, family and child;
  - Knowledge: advocacy, system navigation & education;
  - Empowerment: confidence and competence.
Social Support

Learning Parents (child recently diagnosed) and Supporting Parents (lived experience) are described related to mutuality and connectedness.
Fostering Resilience: What can we do?

➢ **Hardiness** — Be aware, label experiences/emotions if helpful, and support families riding through the “triggers”

➢ **Self-Enhancement, Empowerment, and Strong Social Networks** — Empowering families to learn; making connections to other families/parent/sibling organizations

➢ **Positive Emotions** - Promote social models of health and wellness vs. disability; Reinforce positive affirmations;

➢ **Laughter** — Provide families a safe place to laugh
Balance

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