



From Triggers to Solutions: Challenges and Treasures of Parenting a Child who is Deaf or Hard of Hearing



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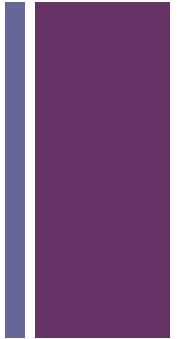
+ Acknowledgements

- Shawn Rhine Kalback, Ph.D., Edmund N. Ervin Pediatric Center, Maine General Health
- The importance of listening, learning together, understanding one another regardless of whether we share the same perspectives.
- Recognition that parents, and ultimately their children, need to be the directors of their services.



+ Objectives

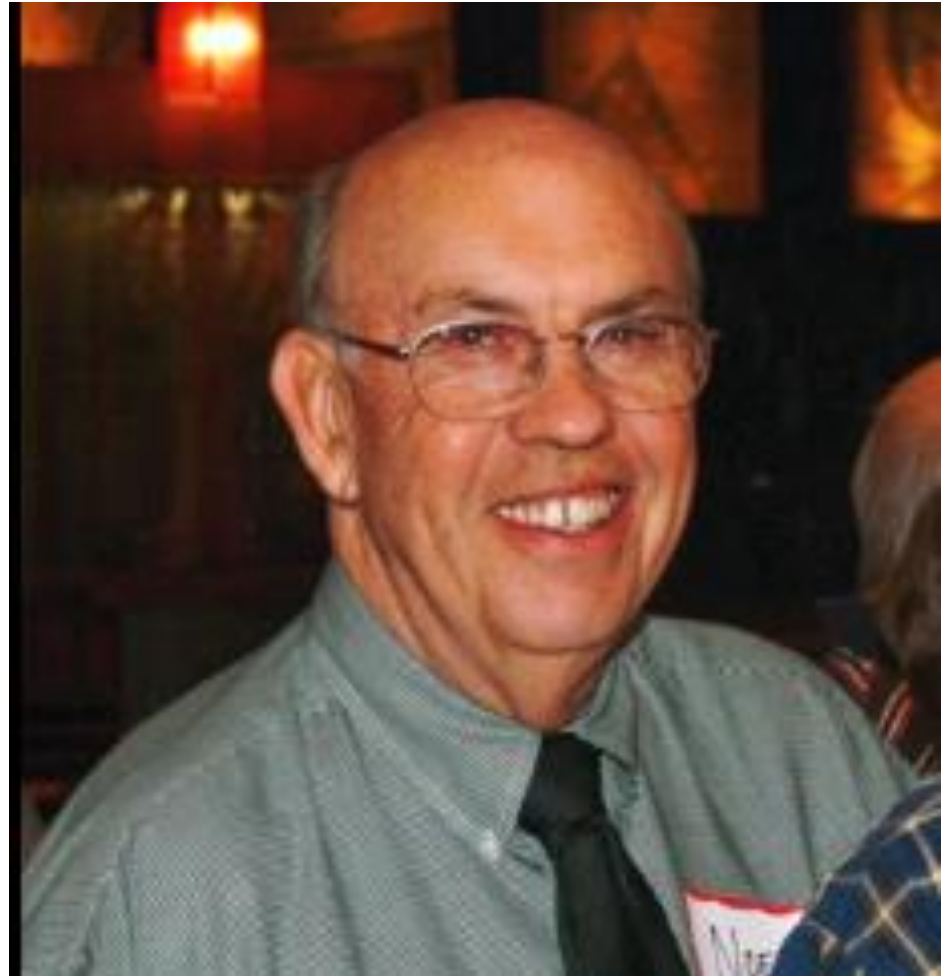
- Learn concepts of grief and positive psychology that might be useful when raising a child who is deaf or hard of hearing;
- Learn means of strengthening your own ability (as a parent) to manage "triggers" and/ or "stressors" as they come along in your child's life, including parent-to-parent support; and
- As a professional, learn and understand how the above concepts and skills might support your work with deaf and hard of hearing children and their families.



+ Remembering Noel D. Matkin

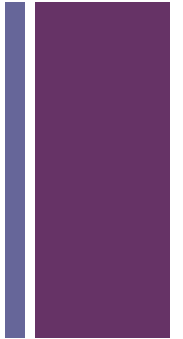
Grief is a complex and evolving emotional response that is internalized differently and triggered differently at various times throughout the time span of parenting a child with hearing loss.

Although families learn to cope with adversity over time, they still revisit old concerns and experience old feelings, but often with better developed coping skills and with greater cognitive awareness. (2008)





Receiving a diagnosis of hearing loss...Not so simple as it seems



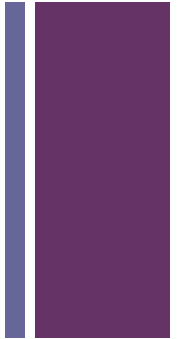
- Universal Newborn Hearing Screening and diagnosis of hearing loss...Seems simple, right?
- Parental Response to diagnosis of hearing loss...Also not so simple.
- Kurtzer- White & Luterman, 2003, “Shock, Recognition, Denial, Acknowledgement, and Constructive Action”

+ 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”

+ Grief...It's complicated

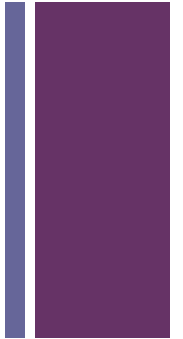


■ But what about?

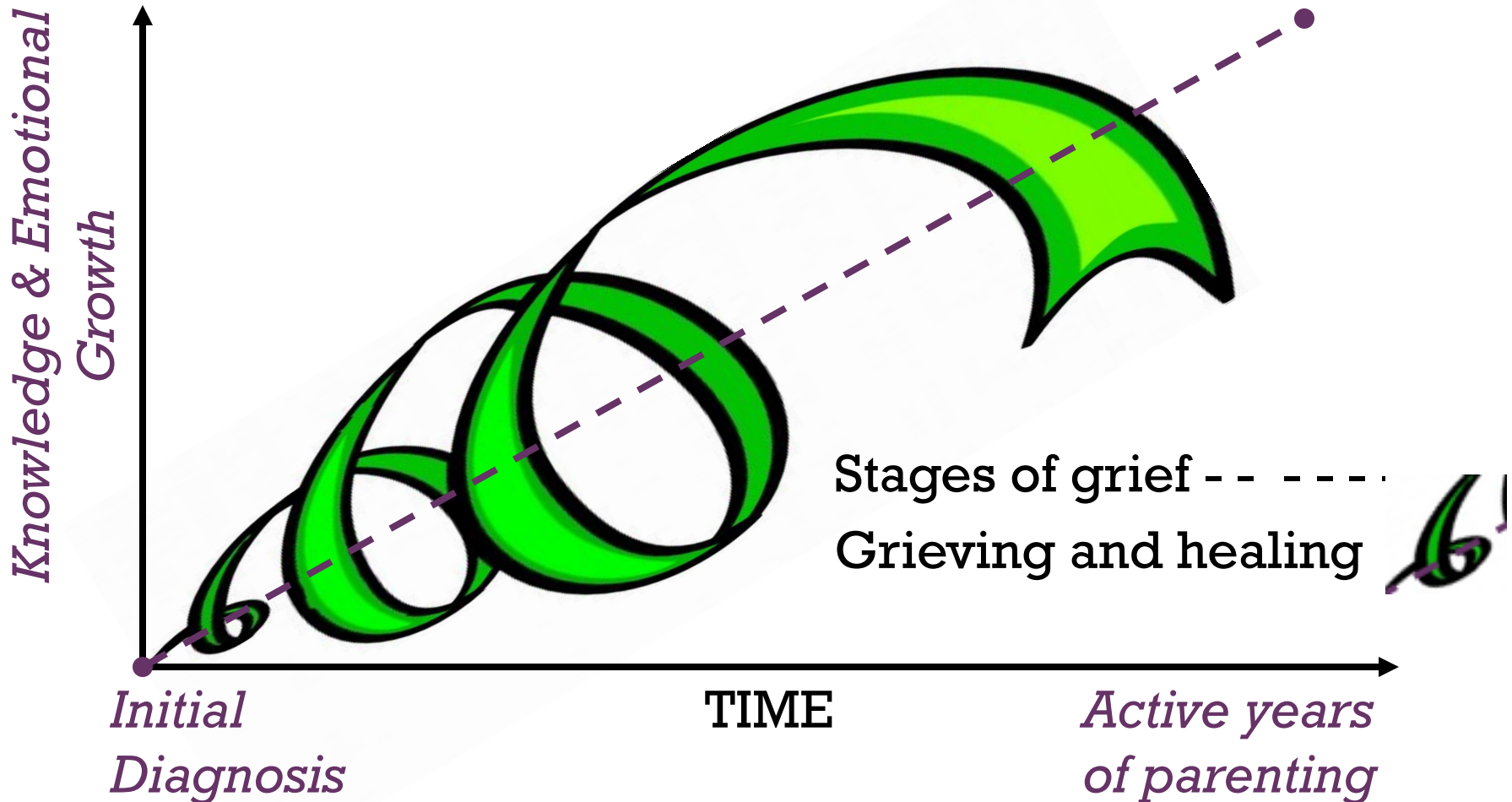
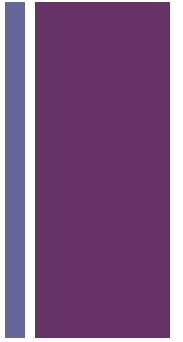
- Relief- Finally! We know what's going on!
- Overwhelmed - by what you might have to learn
- Loss - related to a shift in expectations from your own experiences
- Joy - that your child may share the same experiences as you
- ASL sign for Grief

+ Grief...It's complicated

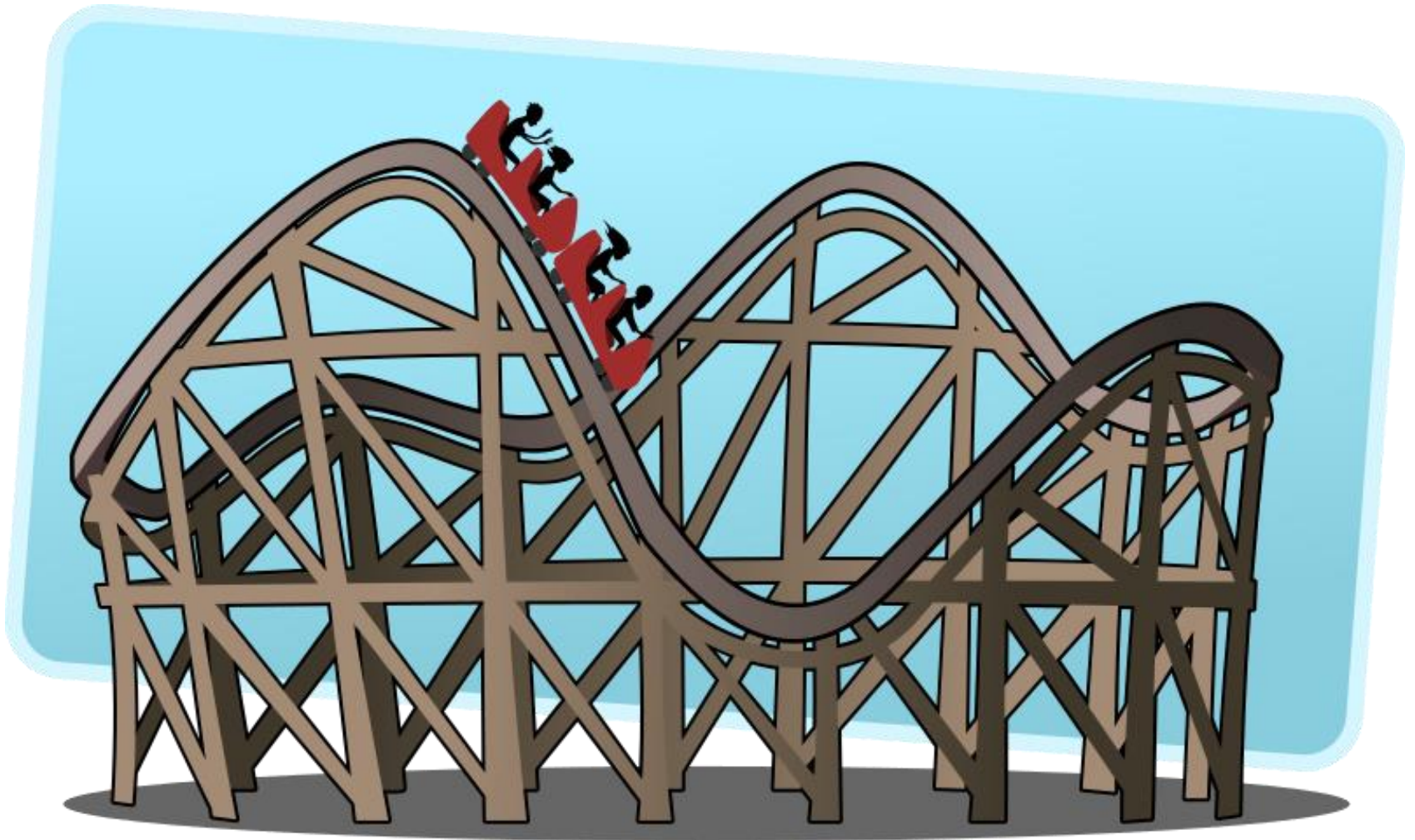
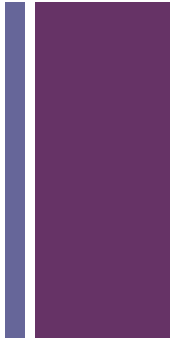
- **Complicated Grief** – When the process of managing loss (or unexpected change in expectations) is extended or delayed.
- **“Triggers”** – Reminders (of that change) that can hit at any time; May be different than what your partner/close family member, or your other children may experience.



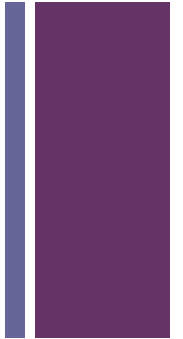
+ Various emotions reflect different “states” rather than different “stages” of grief (Matkin, 2008)



+ Roller Coaster: Raising a child who is deaf or hard of hearing



+ Audience Reflection: Parents....



- What events or incidences have “triggered” feelings that cause you to regret/grieve your child has a hearing impairment or deafness, or to bring that aspect of your child into focus?
- Think about examples from early childhood, preschool, elementary school, middle school, high school, transition to adulthood.

ROLLER COASTER OF RAISING A CHILD WHO IS DEAF OR HARD OF HEARING

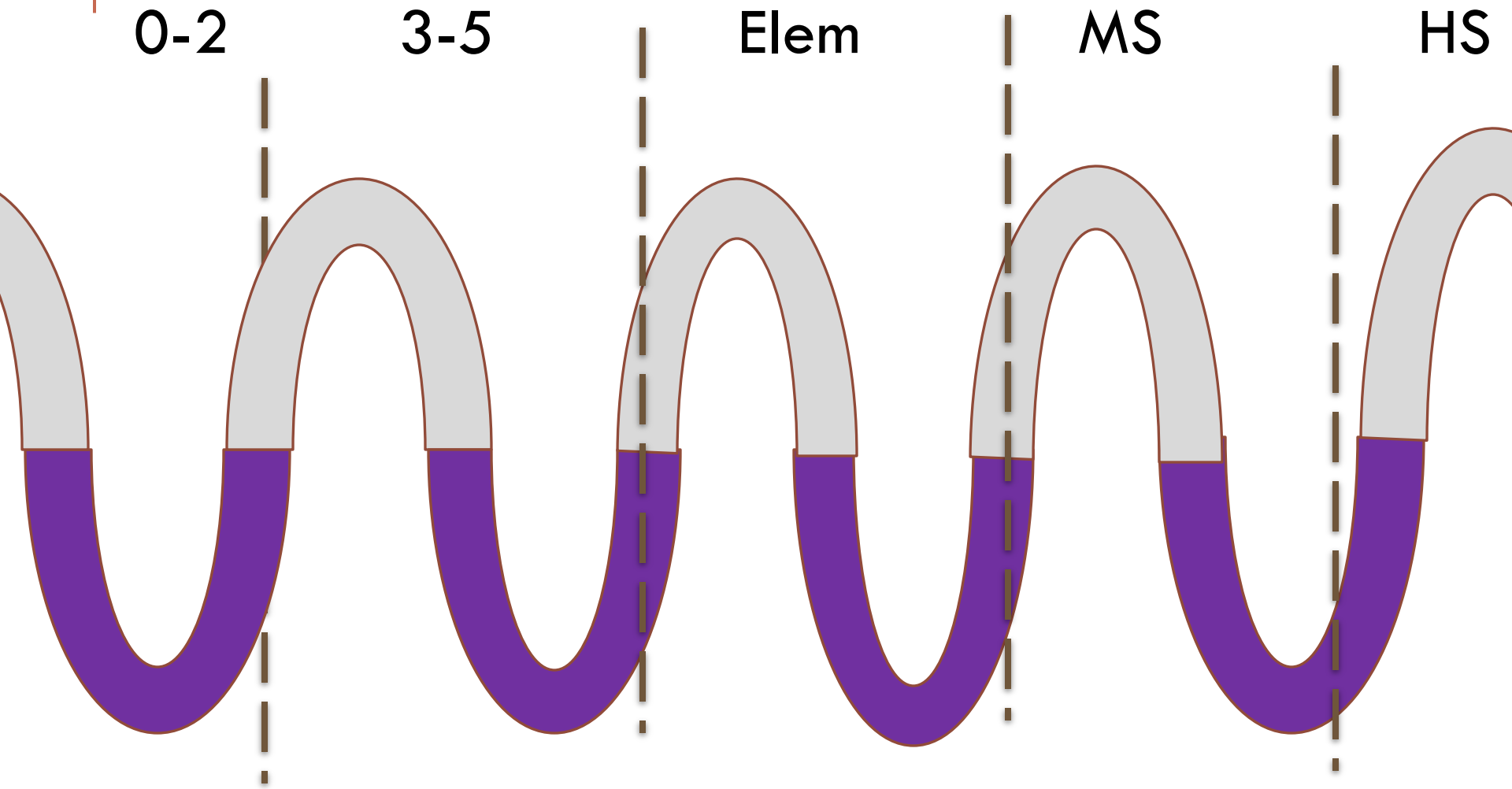
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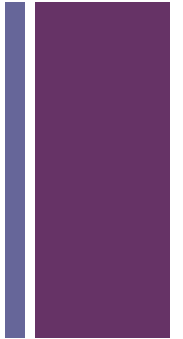
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+1. At what TIME did you find these triggers most frequent or difficult?

- A. First year of life
- B. Ages 1-3
- C. Preschool
- D. Elementary School
- E. Middle School
- F. High School
- G. Post Graduation



+2. Who was your greatest source of support at this time?

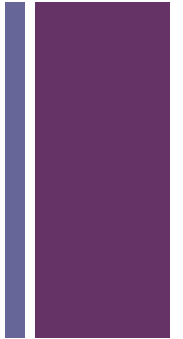
- A. Family members
- B. Your child's teacher
- C. Early intervention or school professionals in your child's life
- D. Private counselors or therapists
- E. Other parents



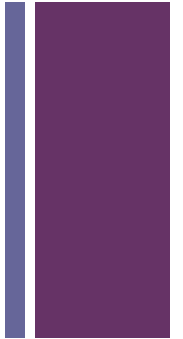
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3. How do you tend to respond?

- A. Retreat
- B. Dive in to fix/address the problem.
- C. Talk to others (parents, family members)
- D. Talk to professionals



+ Audience Reflection:



■ Parents....

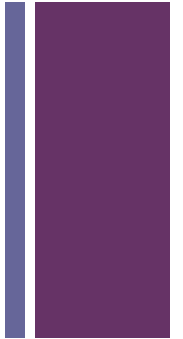
■ What would help you to address these feelings?

■ Professionals...

■ What would you do to address the feelings of parents?

+ Getting to resilience:

The treasures of raising a child who is deaf or hard of hearing.

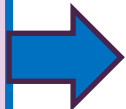
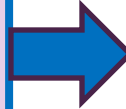


+ Transforming how disabilities are perceived

www.who.int/classifications/icf/beginnersguide.pdf

Medical Model

- Disability is a deficiency
 - located within the person
 - Disability is negative and should be ameliorated
- Remedy is 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

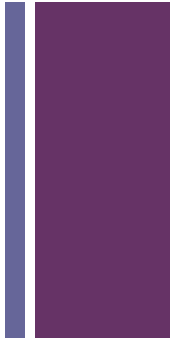
+ Positive Psychology



"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)



Managing “Loss” and Resilience



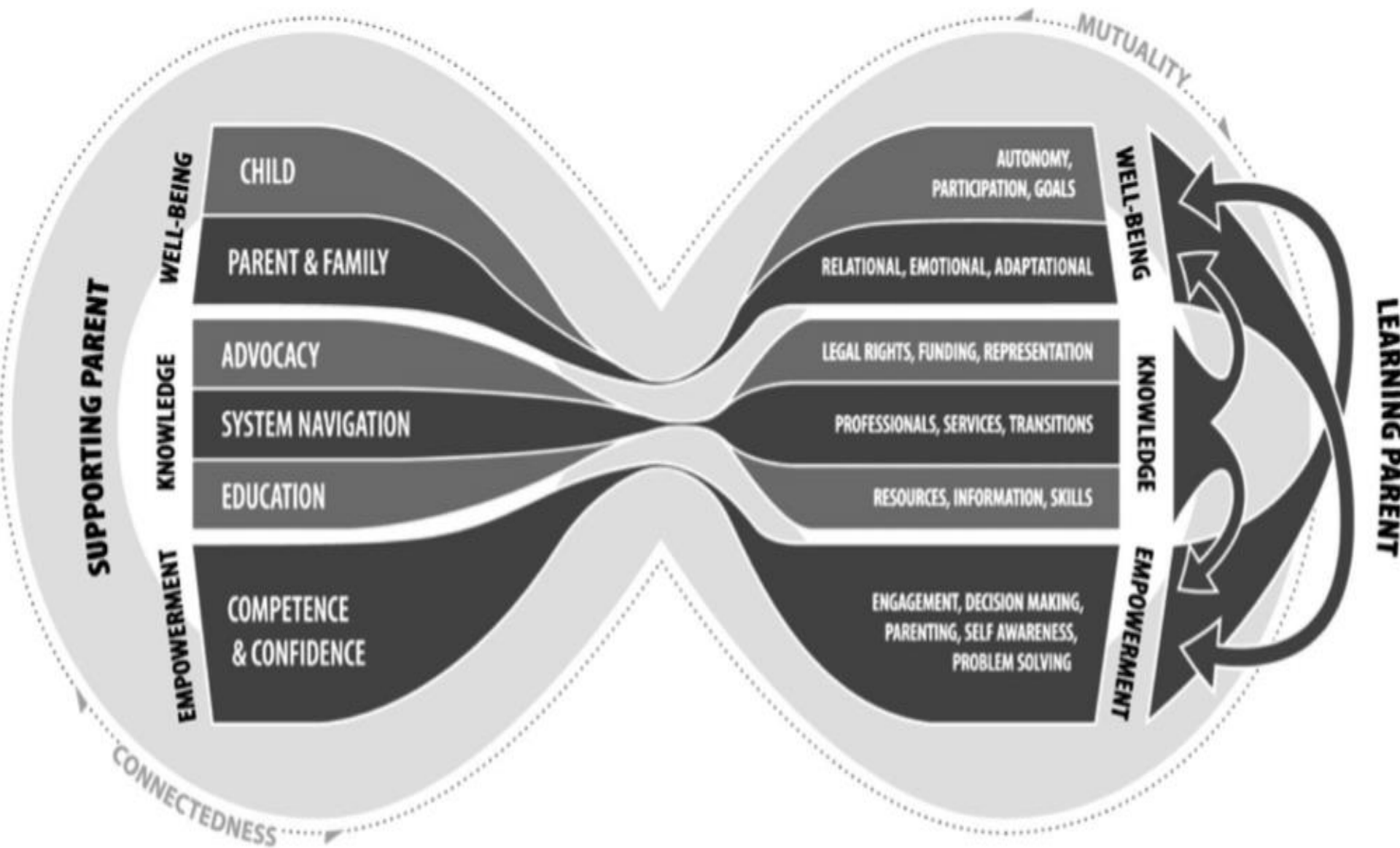
- *Resilience* (Bonanno; 2004) - “The ability of adults in otherwise normal circumstances who are exposed to an isolated and potentially highly disruptive event, such as the death of a close relation or a violent or life-threatening situation, to maintain relatively stable, healthy levels of psychological and physical functioning” as well as “the capacity for generative experiences and positive emotions.”

+ Parent to Parent Support

Parent-to-Parent Support for Parents with Children who are Deaf or Hard of Hearing: A Conceptual Framework (Henderson, Johnson, & Moodie (2014)

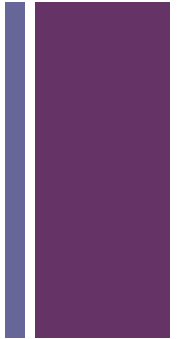
- Proposes a conceptual framework of parent-to-parent support based upon extensive literature review.
- Components include:
 - well-being: parent, family and child;
 - knowledge: advocacy, system navigation & education;
 - empowerment: confidence and competence. Learning Parents (child recently diagnosed) and Supporting Parents (lived experience) are described related to mutuality and connectedness.
- The article discusses key predictors of well-being for parents and families and for DHH children based upon scoping study of 39 peer-reviewed articles published 2000-2014

Figure 2. Parent-to-parent support for parents of children who are deaf or hard of hearing: A conceptual framework.





Keys to Parent-to-Parent Support



■ Mutuality

- Mutual exchange of information, thought, resources
- Experiences that are beneficial to both supporting and learning parents
- Access to mentors & role models

■ Connectedness

- Shared experiences
- Supports identity, sense of belonging, affirmation
- Belonging

■ Sustainability

- Must have community of mentors & role models

Constructs	Predictors of Success	
Well-Being:	<ul style="list-style-type: none"> • Child • Parent-Family 	<ul style="list-style-type: none"> • Autonomy, Participation, Goals • Relational, Emotional, Adaptational
Knowledge:	<ul style="list-style-type: none"> • Advocacy • System Navigation • Education 	<ul style="list-style-type: none"> • Legal rights, funding, representation • Professionals, services, transitions • Resources, information, skills
Empowerment:	<ul style="list-style-type: none"> • Competence & Confidence 	<ul style="list-style-type: none"> • Engagement, decision-making, parenting, self-awareness, problem-solving



Constructs	Predictors of Success	
Well-Being:	<ul style="list-style-type: none">• Child• Parent-Family	<ul style="list-style-type: none">• Autonomy, Participation, Goals• Relational, Emotional, Adaptational

- Feelings associated with grief
- Bonding, family dynamics, communication
- Adjustment to hearing loss, grieving, developing awareness and new skills to create optimal environment for raising child



Constructs	Predictors of Success	
Knowledge:	<ul style="list-style-type: none">• Advocacy• System Navigation• Education	<ul style="list-style-type: none">• Legal rights, funding, representation• Professionals, services, transitions• Resources, information, skills

- Parents indicated they received inadequate, outdated, biased, and incomplete information from their child's specialist. (JCIH 2013, p 5)
- Supporting Parents share information with learning parents that is more authentic



Constructs	Predictors of Success	
Empowerment:	• Competence & Confidence	• Engagement, decision-making, parenting, self-awareness, problem-solving

- **Exchange of parenting information**
- **Parents provide authentic experiences to help with decision-making**
- **Self-awareness builds from strength, learning, confidence**



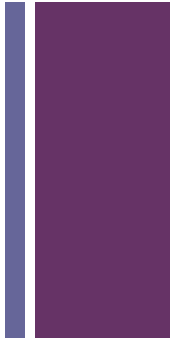
Conclusions

Parent-to-parent support is a central tenet in family-centered care for families with children who are DHH...

that must be provided by experienced parents, and...

that cannot be replicated by health care [or educational] professionals.

+ Positive Psychology



■ Values

- Well-being, contentment, and satisfaction (in the past);
- Hope and optimism (for the future);
- “Flow” and happiness (in the present).

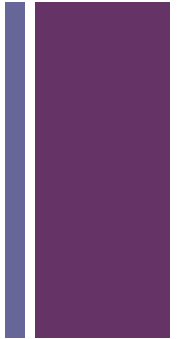
+ Positive Psychology and Parenting a Deaf or Hard-of-Hearing Child



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



Positive Psychology and Parenting a Deaf or Hard-of-Hearing Child (cont.)

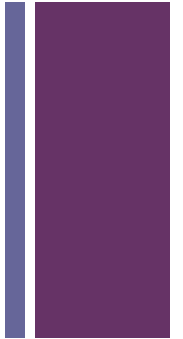


Szarkowski and Brice (2016)

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

+ Lessons Learned

- Child first – who happens to have a unique communication and learning style and may introduce another language into the home
- Education – knowledge is power
- Have confidence in your providers and the school system
- Be responsible for raising your child – schools are responsible for educating your child, same responsibilities as for a typically hearing child, a partnership
- Parent-to-parent support
- Unique responsibilities of parents:
 - Facilitate friendships
 - Be vigilant to insure access
 - Explain behaviors, incidental communication, social nuances
 - Promote self-determination, self-advocacy and personal responsibility
 - Provide guided failure



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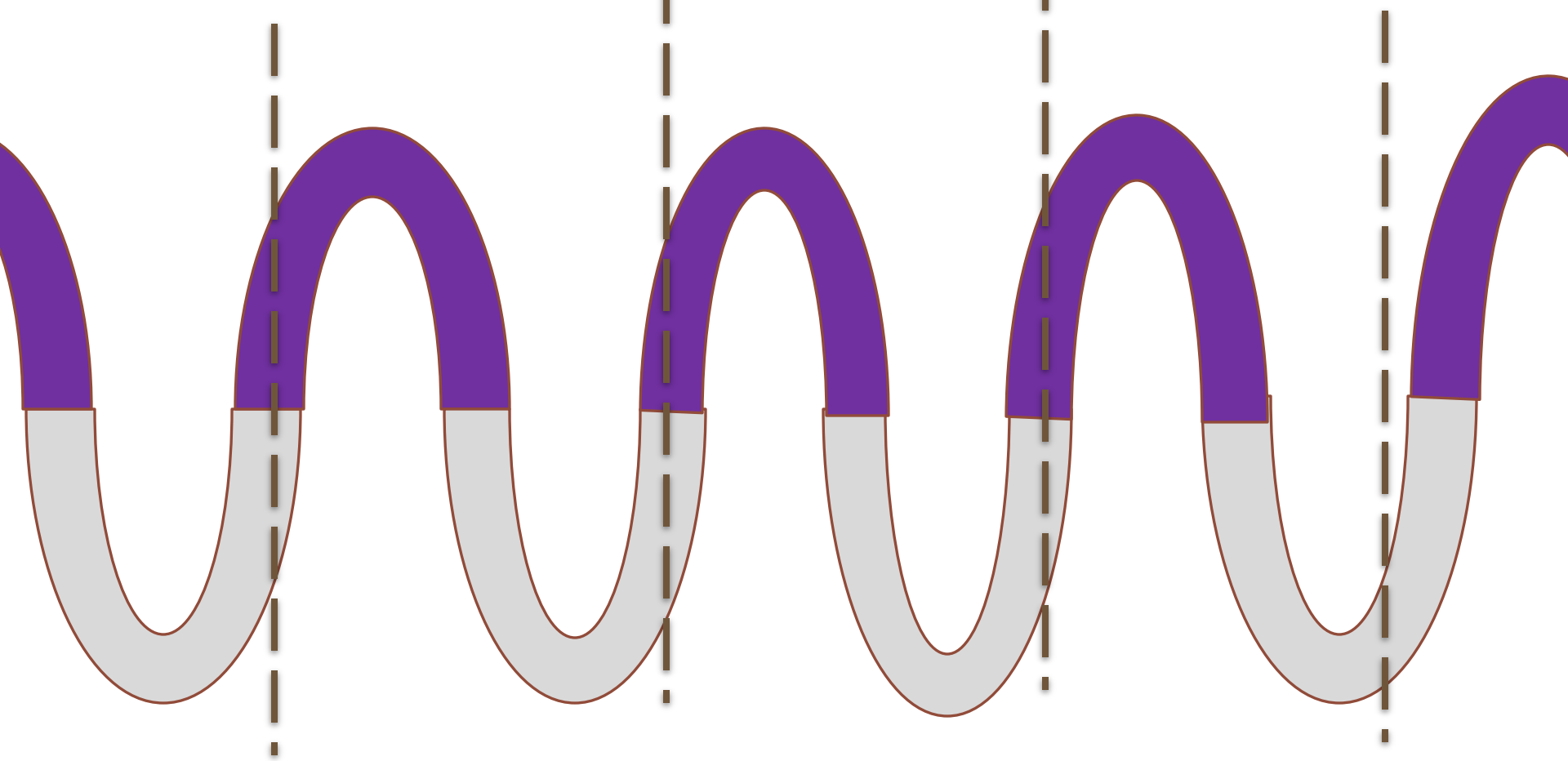
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“I wouldn’t change it for the world!”



Mother and daughter



Daughter as mother



Daughter as college academic support advisor