



Saturday, August 3, 2019

Breakout Session C13 • 2:45-3:45 pm • Grand Ballroom A/B

## Counseling Parents of Children with CHARGE

Timothy Hartshorne, Central Michigan University

### Presenter Information

Tim Hartshorne is a professor of psychology, specialized in school psychology, at Central Michigan University. His doctoral degree is from the University of Texas at Austin. He also has a master's degree in counseling and is a licensed professional counselor. He is the grant holder for DeafBlind Central: Michigan's Training and Resource Project, which provides support to children who are deafblind in Michigan. Much of his work is influenced and motivated by his son Jacob, who was born in 1989 with CHARGE syndrome. Tim's particular interests include understanding the challenging behavior exhibited by many individuals with deafblindness, CHARGE, and related syndromes, and also how severe disability impacts the family. He is the lead developer of a deafblind intervener training module on behavior for the National Center on Deaf-Blindness. He has been awarded the Star in CHARGE by the CHARGE Syndrome Foundation. His research was recognized in 2009 with the Central Michigan University President's Award for Outstanding Research. He is a frequent presenter on CHARGE and deafblindness.

### Presentation Abstract

Early research suggested that families of children with severe disability were likely to be hopelessly damaged by the experience, with depression, anxiety, low self-esteem, loss, guilt, feeling overwhelmed, and marital troubles predominating. However, many researchers have begun to recognize that many families do quite well, and many report positive experiences and perceptions and even personal transformations. Some parents may turn to counseling for assistance. The question is, how counselors can work with families, and parents in particular, to help them cope with the negatives, and come to appreciate the unique, positive aspects of raising a child with severe disabilities. To accomplish this, counselors need to understand that personal transformation is possible, and that what on the surface appears to be an overwhelmingly negative experience, can develop into something very positive. For the general conference, this presentation will emphasize the potential benefits of going to counseling for support in coping with the guilt and stress of raising a child with CHARGE. Issues addressed include guilt, stress, siblings, marriage, the future, and behavior. Pitfalls for counselors include misunderstanding the nature of this kind of grief, not understanding the parent experience, mistaking courage for denial, and seeing "specialness" in the parents (you are so strong).

### Learning Objectives

- Participants will be able to identify some of the major issues parents are likely to bring to counseling.
- Participants will recognize the kinds of pitfalls counselors who do not understand disability and CHARGE might fall into.
- Participants will understand the overall objectives of counseling and potential outcomes.

# Counseling Parents of Children with CHARGE

Timothy S. Hartshorne  
Central Michigan University

## Issues

- Stress
- Guilt
- Siblings
- Marriage
- Parenting
- Managing
  - Time
  - Tasks
  - Careers

## Stress

- Parenting stress
  - Parenting a more typical child is hard enough
- Child stress
  - It is hard to see your child struggling
- Child impact on the family stress
  - How is it impacting other family members
- Daily stressors
  - These do not go away

## Guilt

- I am not the parent for this child
  - Other people seem to do better with their child
  - Other people are not as miserable as I am
  - Someone else could have helped my child much more
- I failed in having this child
  - What went wrong?
  - I let down myself and others
- Shame

## Siblings and spouse

- Cheating siblings
  - Missed out on a typical sibling life
  - Ignored
  - Restrictions on what the family can do together
  - "Am I damaging them?"
- Spouse (Blanton, 2000)
  - Equality vs. hierarchy
  - Cooperation vs. competition
  - Commitment vs. evasion (divorce rate slightly elevated)

## Parenting

- How do you not spoil a child with a significant disability?
- Communication
- Routine
- Discipline
- Good enough parenting

## Time, Tasks, and Careers

- Time management
  - There will never be enough time
- Task management
  - Expectations for what you can accomplish
- Careers
  - Smearing friendly?
  - Insurance
  - Is it what you dreamed of?

## Pitfalls – counseling gone wrong

- Grief and mourning
- Not getting it
- Mistaking courage for denial
- Specialness

## Grief and mourning

- The child is not dead
  - Addressing grief can elevate the sense of loss and take away from the living child
  - Most parents are so busy taking care of the tasks that they do not have time for grief
  - I would prefer this be discussed as sadness, but moving it away from sadness for ourselves to sadness for our child and family
- The loss of a dream
  - How many dreams are lost in a life time?
  - Finding meaning and purpose in the life we are leading

## Not getting it

- Counselors need to get it – to really understand
  - Parents do not need sympathy
  - We are not raising heaven's special child
  - We are knee deep in feces (often literally)
  - You may have trouble making sense of our moods
    - Day one: I am going to conquer the world from fighting like hell for my child
    - Day two: I get that my child is who they are, and I am OK with that
    - Day three: I need help!!!
  - Don't expect consistency or try to pigeonhole us

## Mistaking courage for denial

- Most of us are not in denial – we know what we are dealing with
- Most of us are realists. Sure we want the moon for our child, but we get the limitations. You don't need to remind us.
- Questionnaire on Resources and Stress

## Specialness

- "You are so strong."
- Weirdness is pretty universal
- We adjust our concept of "normal"
  - It's normal to have your child puke in public
  - It's normal to have to find a babysitter when your child is 20
  - It's normal to be on first name basis with most of the medical providers in your area
  - It's normal to worry if this ER visit might be the last
- Allow us a moment to scream

## Objectives

- Strengths based
- Making connections and networking
- Marathon skills
- Post-traumatic growth

## Strengths based

- We see it in the other parents we meet
- It is harder to see it in ourselves
- We are not exceptional, but we are battle tested
- Help us to recognize all that we have learned

## Making connections

- When you see another parent tube feeding, you don't have to say anything, the connection is there
- But not all parents allow this to happen
  - Some parents withdraw
- There are networks of parents and professionals in most communities who "get it." Find a way to tap into this resource
- Social media has been a lifeline for many parents. Figure out how to use it and use it helpfully

## Marathon skills

- Meet basic needs - food, shelter, health, security - may want to raise parent expectations
- Know yourself and your family - explore feelings, options, preferences in order to learn about themselves as a family - knowing what their growth needs are
- Love your child unconditionally - avoid being in love with who their child might be some day if only work hard enough
- Establish relationships - social support network (network orientation)
- Experience and benefit from emotions - emotion can be healthy, can be energizing, are human - professionals needs to allow feelings
- Take charge - families must take charge of services to get immediate results, but it is a professional cop-out to expect parents to always be the catalysts and implementers of innovation
- Anticipate the future and learn transitional planning - must anticipate skills and resources needed and then develop them
- Establish balance - fair allocation of finite family time and resources early intervention can work against

## Post-traumatic growth

- Has some of this been traumatic?
- We have choice. We can be beaten down by our circumstances, or we can choose to grow because of it
  - It is not as easy as it sounds
  - It is not a constant – we do go back and forth
- Relating to others
- New possibilities
- Personal strength
- Spiritual change
- Appreciation of life