

TIM HARTSHORNE

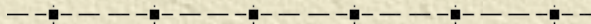
The Challenge of Parenting Children
with CHARGE



*The Challenge of
Parenting Children with
CHARGE*

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The World of Disabilities

✧ Difference – leading to a felt minus

✧ Work

- Limitations due to time and resources
- An escape

✧ Friendship

- Lack of social support
- Change in participation

✧ Love

- Expectations
- Commitment



Typical Characteristics of Child

- ✦ Communication difficulties
- ✦ Sensory and motor impairments
- ✦ Intellectual disability
- ✦ Fragile health, pain, & limitations





Parent experiences

✧ Parental Guilt: The Courage to be Imperfect

“How do you know if you have the right doctors and therapists doing the right things and enough of them? How do you know if you’re doing all the right things and enough of them? I have been avoiding phone calls and insurance stuff, etc, because I just want us to be normal.”

Parent experiences

✦ Need to defend and protect the child

“Our first battle was over getting deafblind consultative services. We fought and fought. Now we are going through it again. Maybe it’s just the looming battle, but I feel like weeping. Yes, it can be necessary to fight like the devil, but that doesn’t make it right.”

Parent experiences




✦ Capability of the child

“When she was an infant the hospital sent out evaluators. They sat me down and told me she would never walk, talk, or be independent. After he left I cried and had such terror my world spun. Then I thought “Baloney.” She ended up learning lots. Her performance always goes above and beyond potential. Always.”

Parent Experiences

✦ Can I cope?

“Tonight I am so very tired of being the person figuring out what’s going on. It’s been awhile since I’ve felt so isolated, scared, on and on. Right now it’s as though nothing is enough to really help. I’m damned tired of this. I would like some help, too. I need it now. My daughter needs it now.”



**The problem is how to love
your child with no need for
your child to be any
different, AND without
giving up hope that your
child may progress with
time and resources.**



COURAGE IS NOT DENIAL

**BUT SOMETIMES COURAGE LOOKS
LIKE DENIAL TO OTHER PEOPLE**

Hartshorne, T. S. (2002). Mistaking courage for denial: Family resilience after the birth of a child with severe disabilities. *Journal of Individual Psychology, 58*, 263-278.

Genetic Component of Behavior

✦ Behavioral Phenotype

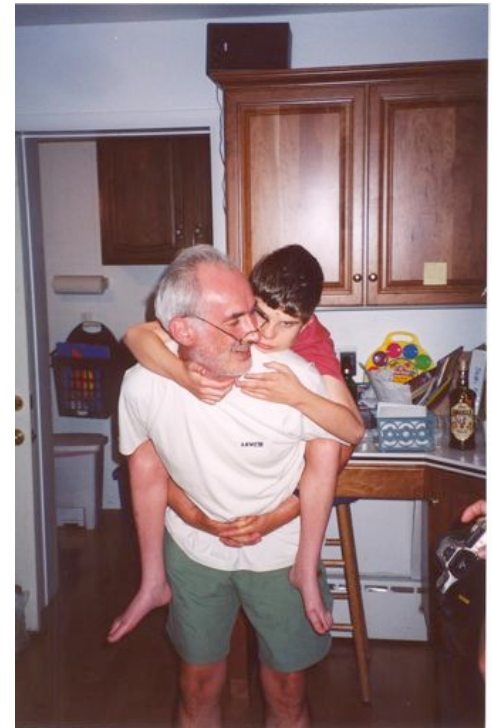
✦ Executive Dysfunction

✦ Self-Regulation



“A pattern of behavior that is reliably identified in groups of children with known genetic disorders and is not learned.” (Harris, 1995)

If I behave like this, I probably have CHARGE syndrome



Executive Functions


- ✦ Inhibit
- ✦ Shift
- ✦ Emotional Control
- ✦ Initiate
- ✦ Working Memory
- ✦ Plan/Organize
- ✦ Organization of Materials
- ✦ Self Monitor



Self-Regulation

- ✦ Poor self-calming with irritability
- ✦ Sleep problems
- ✦ Feeding problems
- ✦ Inattention
- ✦ Mood regulation problems
- ✦ Sensory processing problems





*The problem is how to parent
when...*

- ✦ You exist in the world of disability
- ✦ You struggle with problems of acceptance and hope
- ✦ Your child exhibits behavior which is related to a syndrome
- ✦ You are exhausted by it all


After the Birth

✧ Aaron



✧ Jacob





It is hard enough to cope with raising a child who does not have obvious disabilities. Why in the world would you think you should know how to raise a child with tremendous needs?

Parenting Skill #1

- ✦ Have the courage to be imperfect
 - Because you are!
 - Because everyone else is too!
 - Even the presenter! [just ask Aaron]

Parenting Skill #2

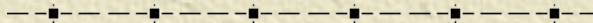
✦ Understanding behavior

- All behavior has a purpose
- All behavior is communication
- Behavior reflects solutions that are effective for the child even though they may be a problem for the parents



Goals of Misbehavior

Attention
Power
Revenge
Inadequacy



Parenting Skill #3

✦ Encouragement

- We learn by making mistakes
- We learn by the consequences of our actions
- Avoid discouragement

Parenting Skill #4

- ✦ Avoid the use of rewards and punishments
 - Invite cooperation
 - Teach other methods to solve problems
 - Use natural and logical consequences
 - Be authoritative, not dictatorial or permissive
 - Be sympathetic but set limits

Parenting Skill #5

✦ Build Communication

- Read behavior as communication
- Take turns when interacting
- Let the child know that you have heard and understood, even if your answer is “no”




Parenting Skill #6

✦ Family Meetings

- Raising a child is a family challenge
- Cooperation rather than competition
- Getting on the same page
- Sharing and working together

If Only it were that Simple!!!





“I have a question. I struggle with this. The OCD obsessions are our biggest battles. One is water. She has to get her clothing wet before she can take them off. And she needs to change her clothes often. I have tried making her stop both but she just goes over the edge. I have finally come to the approach that I can't stop her, but I need to just try to control the amount of water she gets when she soaks her clothes. If we take the water away, she will pee on them so we have our choice of water supply there. It's going to happen one way or another, from the well or from her. Is it wrong to help her with the water? I am saying it is ok and feeding the obsession. But I have little hope of getting her to stop, and so I don't know what to do and what harm I am doing by allowing it. Jessica's obsessions seem to have come from routine. Then they turned into habits, rituals and then true obsessions. If I had noticed that earlier in life, do you think that I could have prevented some of this?”

Where to Begin?

- ✦ Anxiety is a basis for OCD, except perhaps in autism
- ✦ Genetics – does not mean it happens without a reason
- ✦ What does it solve?
- ✦ What is it communicating?



All Behavior is Communication

- ✦ Look what I know how to do
- ✦ I really enjoy the feel of wet clothes
- ✦ If I change my clothes I can avoid something
- ✦ I am in pain, and this really helps
- ✦ I am anxious, and this really helps
- ✦ I like having you engage with me

Parent Issues

- ✦ Is it OK to participate in the ritual?
- ✦ How do you prevent a power struggle?
- ✦ Guilt about not having prevented this.
- ✦ Remember, you have an exhausted mom.



Parenting Objectives

- ✦ Communication skills development
- ✦ Choice making
- ✦ Self-regulation
- ✦ Independence

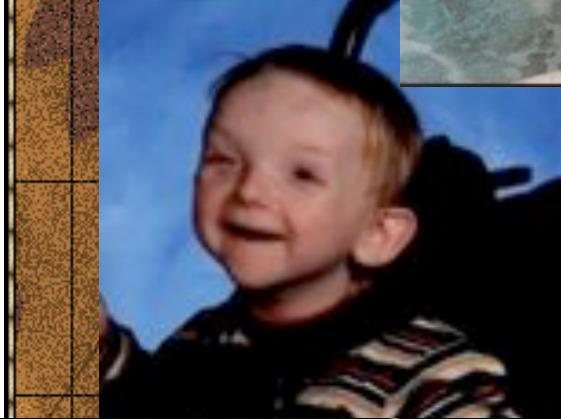


In Crisis

- ✦ Read behavior as communication
- ✦ Consider pain and health
- ✦ Look for sensory overload
- ✦ Look for any changes in life space
- ✦ Respect choices
- ✦ Provide reasonable limits

In General

- ✦ Medication should not be the first choice
- ✦ Work on optimal eating, sleeping, health
- ✦ Provide choices & RESPECT
COMMUNICATION
- ✦ Provide powerful encouragement
- ✦ Reduce stress
 - Routine/consistency
 - Provide choices
 - Sensory breaks



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