

---

**Maintaining Balance, Self-Identity and  
Relationships as the Parent of a  
Special Needs Child**

Kate J. Stone, Psy.D.  
Licensed Psychologist  
Mom of a Special Needs Child

---

*About me.*

*About you.*

Why did **you** decide to come  
tonight?

Why I decided to do this workshop.

What do *you* hope to get out of this  
workshop?

---

# Maintaining Balance

## as the Parent of a Special Needs Child

---

- ❖ **Balance** (according to google): an even distribution of weight enabling someone / something to remain upright and steady
- ❖ So what are we trying to avoid when we talk about maintaining balance?

---

# Maintaining Balance

## as the Parent of a Special Needs Child

---

- ❖ How many people have felt off-balance at times as the parent of a special needs child?
- ❖ When, as caregivers of special needs children, do you think we are most susceptible to being off-balance?



---

# Maintaining Balance

## as the Parent of a Special Needs Child

---

- ❖ #1- When we learn that our child is different from who we expected him/her to be...
- ❖ Most psychologists in this field who have looked at caregivers of special needs children have said that when we learn that our child is different from whom we expected him/her to be... we can experience grief/loss and the various thoughts and emotions associated with that experience.

---

# Maintaining Balance

## as the Parent of a Special Needs Child

---

- ❖ Ken Moses, Ph.D.:
  - ❖ “No one had died. So I asked: what was lost? Gradually the answer emerged, a dream was lost: the dream of a ‘normal child.’ This lost dream... [is] much more than missing a ‘Gerber baby.’ They had attached some of the deepest parts of who they were and who they yearned to be to their yet to be born children... the dreams represented embodied parts of their selves. When their child’s disabilities shattered those dreams, it was the loss of a piece of self in a dream that was grieved.” (1994, p. 2).

---

# Maintaining Balance

## as the Parent of a Special Needs Child

---

- ❖ This loss / grief experience is not limited to when diagnosis first made or differences first learned
- ❖ “Every time I see a little four year-old, blond-haired girl playing, walking with her daddy, pleading with him to buy her an ice cream, I realize a deep and painful sense of loss. I feel cheated...” (Meyer, p. 6).

---

# Maintaining Balance

## as the Parent of a Special Needs Child

---

- ❖ #1 (cont.) - When we learn that our child is different from who we expected him/her to be...
- ❖ What do we do about it?
  - ❖ Reach out - ask for a listening ear - talk to people you trust about your experience - allow yourself to experience the thoughts/feelings associated with the loss
  - ❖ Understand the various “stages” of grief: denial, anger, bargaining, depression, acceptance so that your experience & emotions may make more sense
  - ❖ Avoid isolation & find ways to connect - sometimes Parent to Parent support is particularly helpful & sometimes...
    - ❖ “One of the things that we are the least prepared for is the kind of social isolation that comes with grief / a special kind of camaraderie exists among parents of children with disabilities. Although we are not related by blood, we are deeply related by our circumstances and can offer each other much comfort and understanding” (Naseef, 1997).
  - ❖ Sometimes, seeking professional help may be appropriate
    - ❖ Moses suggests “Transition Therapy”
      - ❖ an existential approach to facilitating growth in light of loss with an ENUF focus, where ENUF stands for: Empathizing Non-judgmentally Unconditionally with Focus on Feelings - received by a “caring, present listener”

---

# Maintaining Balance

## as the Parent of a Special Needs Child

---

- ❖ #2 - When our kids are off-balance & we either can't or don't know how to help them...
  - ❖ “another contributor to emotional stress is the heart-wrenching experience of watching a child suffer and not being able to relieve that suffering” (Seligman & Darling, 2007).
- ❖ So what do we do?
  - ❖ Dr. Marshall Land's words of wisdom

---

# Maintaining Balance

## as the Parent of a Special Needs Child

---

- ❖ #3 - When what we want/expect for our child is not happening because of perceived resistance from the environment / world...
- ❖ So what do we do? “Regardless of the nature of their child’s disability, parents have many similar experiences as they learn to survive and cope. It is the **challenge of a lifetime to do everything possible** to help your child and to **maintain hope and fight off despair** while striving to **live as normal a life as possible**” (Naseef, 1997, p. 9).
- ❖ If you’re finding that you...
  - ❖ don’t have hope
  - ❖ can’t fight off despair
  - ❖ are struggling to accept or figure out your life’s “new normal” ...
    - ❖ this is when asking for help and/or talking to a professional could be of benefit

---

# Maintaining Balance

## as the Parent of a Special Needs Child

---

❖ #4, 5, 6...

---

# Maintaining Self-Identity

## as the Parent of a Special Needs Child

---

- ❖ **Self-Identity** (again, according to google): the recognition of one's potential and qualities as an individual...
- ❖ So what are we trying to avoid when we talk about maintaining self-identity as the parent of a special needs child?



---

# Maintaining Self-Identity

## as the Parent of a Special Needs Child

---

- ❖ Losing sight of our potential as individuals
- ❖ Not nurturing our individual qualities
- ❖ Not recognizing or realizing our individual needs / wants / dreams
- ❖ and / or...

---

# Maintaining Self-Identity as the Parent of a Special Needs Child

---

- ❖ Overidentifying (or identifying *too much*) as parent of special needs child
  - ❖ what is the potential problem with overidentification?
    - ❖ lack of balance / grounding - more susceptibility to suffering with rather than being able to be there for child when needed. Separation/individuation is healthy.
      - ❖ effect on special needs child
      - ❖ effect on other relationships
      - ❖ Naseef: living for myself and “not through my children” (p. 13)

---

# Maintaining Self-Identity

## as the Parent of a Special Needs Child

---

- ❖ How many people have had periods where they felt as though they lost a sense of themselves as individuals in caring for their child / children?
- ❖ When, as parents of special needs children, do you think we are most susceptible to losing a sense of ourselves?

---

# Maintaining Self-Identity

## as the Parent of a Special Needs Child

---

- ❖ Are you still **nurturing** you?
  - ❖ What do I mean by nurturing? google's definition:  
to care for and encourage the growth or development  
of you

---

# Maintaining Self-Identity

## as the Parent of a Special Needs Child

---

- ❖ What did you used to do to nurture yourself before your child was born / children were born that you no longer do?

---

# Maintaining Self-Identity

## as the Parent of a Special Needs Child

---

- ❖ Real-life (and simple) examples:
  - ❖ Exercise - maybe you can't take time to go to 90-minute classes, but can you do a 20-min video at home?
  - ❖ Listening to music - maybe you can't go to concerts as frequently but can you, on that 20 minute ride with no one else in the car, listen to that song you love at a volume no one else in your family likes?
  - ❖ Reading - do you really not have time to read for pleasure anymore? how much time do you spend reading about/for your child? what if you spent half that reading for YOU?
- ❖ \*\*Do these examples sound like self-care or self-*nurturing*?\*\*

---

# Maintaining Self-Identity

## as the Parent of a Special Needs Child

---

- ❖ Filling our own tanks metaphor
  - ❖ as adults, we all have “tanks” that represent individual needs, & it’s our responsibility to figure out what fills our tanks and how to go about filling it.
  - ❖ It’s important that we fill our own tanks and not be dependent on others (including our children) to fill them
  - ❖ If we keep our tanks full, or reasonably full, we are better prepared to deal with with issues that come up in our lives or our children’s lives

---

# Maintaining Relationships as the Parent of a Special Needs Child

---

- ❖ **Relationship:** the state of being connected
- ❖ So we are trying to avoid **disconnection/isolation** when we talk about maintaining relationships.



---

# Maintaining Relationships as the Parent of a Special Needs Child

---

- ❖ How many people have felt like their relationships have been affected just by the mere fact of being a parent/caregiver of a special needs child?
- ❖ How so?

---

# Maintaining Relationships as the Parent of a Special Needs Child

---

- ❖ Partner/Spousal Relationship
  - ❖ Mixed research on whether or not couples with special needs kids are at significantly greater risk of divorce or experience significantly greater marital conflict as a result of having a child with special needs (Seligman & Darling, 2007).
    - ❖ “For a relationship that is fragile or unstable, disability can be ‘the straw that breaks the camel’s back.’ On the other hand, couples with strong cohesive marriages may become closer and more loving and those in / relationships that haven’t yet been tried by adversity may develop increased closeness and strength” (Naseef, 1997, 115/116).
  - ❖ But I think many of us in this room would agree that it is not easy to “maintain” your relationship with your partner/spouse as the parent of a special needs child. Why? Many reasons...
    - ❖ Considerable lack of time, energy, resources
    - ❖ But also:
      - ❖ both parents may be experiencing periods of grief/loss as well as many other emotions & experiences on this journey
      - ❖ often, one or both parents unaware of these emotions/experiences
      - ❖ and often, parents are experiencing things *differently*

---

# Maintaining Relationships as the Parent of a Special Needs Child

---

- ❖ Why else is it hard?
  - ❖ Often I find that 1st thing to go when overwhelmed is prioritizing of self, 2nd is prioritizing of partner relationship
  - ❖ We tend to displace anger / frustration / other emotions onto those closest to us - our partners, then, sometimes / often get the brunt especially if we (often subconsciously) want to keep our children “safe”

---

# Maintaining Relationships as the Parent of a Special Needs Child

---

- ❖ Partner/Spousal Relationship
  - ❖ So what do we do about it?
    - ❖ maintaining your relationship through communicating, understanding each other's experiences, and of course, date nights and time away
      - ❖ but regular communication about each others experiences & what each other is feeling is as important as date nights...
    - ❖ reconnecting, seeing yourselves as "on the same team" again even if you have different ways of experiencing & coping
    - ❖ understanding each other's individual "needs tanks" and supporting each other in keeping them filled up
    - ❖ Sometimes... couples therapy? individual therapy for one or both of you? ... when problems are getting in the way of your / your partner's functioning or the functioning of the relationship
  - ❖ Good news? Some marriages can really do well if not, thrive in the face of such challenges (Seligman & Darling, 2007).

---

# Maintaining Relationships as the Parent of a Special Needs Child

---

- ❖ What other relationships are we talking about?
  - ❖ Your relationship with your other “typically-developing” children
  - ❖ Peers / Friends / Parents of “typically-developing” kids
  - ❖ Extended family
  - ❖ Others?

---

# Maintaining Relationships as the Parent of a Special Needs Child

---

- ❖ Your relationship with your other “typically-developing” children
  - ❖ understanding your **unique family** and the **unique individuals** and **unique relationships** in it
  - ❖ using the “filling the tank” metaphor - what does each child need and how do we help achieve that as a “team”?
  - ❖ what do **YOU** want from your relationship with your other children and how do you go about getting that, too.

---

# Maintaining Relationships as the Parent of a Special Needs Child

---

- ❖ Rel'p between special needs child & typically-developing sibling = unique to family & *particular* relationship
  - ❖ Importance of being open to the sibling's experiences
    - ❖ Examples: some typically-developing sibs may at times experience
      - ❖ sense of loss - not having a typical playmate / sibling
      - ❖ embarrassment of sib
      - ❖ jealousy of parents' attention & may express their desire for attention through somatic complaints (Seligman & Darling, 2007)
      - ❖ need to be the "easy" child because their sib is so "hard"
    - ❖ "Similar to their parents, siblings share in the anticipation and excitement of a new child in the family. However, they also share in the grief, pain, and challenges that may accompany the birth of an infant with a disability" (Seligman & Darling, 2007, p. 233).

---

# Maintaining Relationships as the Parent of a Special Needs Child

---

- ❖ Also, typically-developing sibs can experience future care taking responsibilities / expectations differently...
- ❖ “Parents can place future care taking responsibilities and expectations on their non-disabled children, which can be... problematic, though not always. The assignment of responsibility for a child with a disability is taken with aplomb by some children and deeply resented by others” (Seligman & Darling, 2007, p.22).
- ❖ So again, know your kids, be open to their experience, avoid making assumptions or put responsibilities or expectations on them related to your children without listening to their needs & understanding them



---

# Maintaining Relationships as the Parent of a Special Needs Child

---

- ❖ What is important?
  - ❖ 1) Communication with the typically developing child as developmentally appropriate and in an honest and gradual way
  - ❖ 2) Being open to all of his/her experiences & being there for him/her to help with navigating
  - ❖ 3) Fostering a relationship & family environment where he/she can express these to you without feeling shamed for what he/she is expressing
- ❖ What else is important? Your attitude and adjustment: “children’s adjustment to having a sibling with a disability is related to their parents’ attitude and adjustment” (Singer & Powers, p. 346). Another reason to focus on your balance & overall adjustment!
- ❖ Sibling Support Groups or Sibshops when child school-aged can also be helpful to the typically-developing child... & sometimes family therapy appropriate.
- ❖ For any parent interested in reading about the sibling experience, I recommend the book, Thicker Than Water: Essays By Adult Siblings of People with Disabilities - edited by Don Meyer (2009).

---

# Maintaining Relationships as the Parent of a Special Needs Child

---

A friend is one to  
whom one may pour out  
all the contents of one's  
heart, chaff and grain  
together, knowing that the gentlest of hands  
will take and sift it,  
keep what is worth keeping  
and  
with the breath of kindness  
blow the rest away.

- Arab proverb, quoted by Naseef (2001)

---

# Maintaining Relationships as the Parent of a Special Needs Child

---

- ❖ Ideal = having a friend like that described in this Arab proverb ...
  - ❖ but sometimes we don't or we don't *think* we do or we just struggle to maintain our friendships because of lack of time, energy, resources, or ?avoidance
- ❖ What else contributes to our disconnection from friends / peers?
  - ❖ “Professionals, relatives, and friends rarely seemed to know what to say or how to say it” (Naseef, 1997, p. 5).
  - ❖ What about us? What about:
    - ❖ our fear of judgment
    - ❖ our envy

---

# Maintaining Relationships as the Parent of a Special Needs Child

---

- ❖ So how do we stay connected since “families who remain embedded in positive social networks appear to cope better with adversity than do isolated families. Disability in the family can pose a threat to social integration... resilient families work at maintaining social links despite these challenges” (Singer & Powers, 1993, p. 13) ?
- ❖ Help others understand our experiences & be open to the idea that they CAN
- ❖ Imagine being them & invite them into your world instead of putting wall up
- ❖ Like with grief, when people don't know what to say or how to say it they can sometimes shy away or avoid... sometimes we have to be the aggressor, I would argue, and if they continue to shy away, well, then we know we've tried.

---

# Maintaining Relationships as the Parent of a Special Needs Child

---

- ❖ Dealing with unsolicited advice
  - ❖ why does this hit such a nerve?
  - ❖ how do we stay connected?

---

# Maintaining Relationships as the Parent of a Special Needs Child

---

- ❖ Extended family
  - ❖ every family is unique
  - ❖ dealing with disappointment, loss of expectation
  - ❖ inviting members into your world if shying away
  - ❖ dealing with overinvolvement / suffocation / loose boundaries

What did we leave out?

Maintaining...

Review of our “hope for” list



---

# References

---

- ❖ Moses, K. (1994). Grief groups: Rekindling hope. In *Voices, Journal of the American Academy of Psychotherapists*. Evanston, IL: Resource Networks, Inc.
- ❖ Meyer, D. (Ed.). (2009). *Thicker than water: Essays by adult siblings of people with disabilities*. Bethesda, MD: Woodbine House, Inc.
- ❖ Meyer, D.J. (Ed.). (1995). *Uncommon fathers: Reflections on raising a child with a disability*. Bethesda, MD: Woodbine House, Inc.
- ❖ Naseef, R.A. (1997). *Special children, challenged parents: The struggles and rewards of raising a child with a disability*. Secaucus, NJ: Birch Lane Press.
- ❖ Powers, L.E. (1993). Disability and grief: From tragedy to challenge. In G.H.S. Singer & L.E. Powers (Eds.), *Families, disability, and empowerment: Active coping skills and strategies for family interventions* (pp. 119-148). Baltimore, MD: Brookes.
- ❖ Klein, S.D. & Schive, K. (Eds.). (2001). *You will dream new dreams: Inspiring personal stories by parents of children with disabilities*. New York: Kensington Publishing Corp.
- ❖ Seligman, M. & Darling, R.B. (2007). *Ordinary families, special children: A systems approach to childhood disability* (3rd ed.).
- ❖ Singer, G.H.S. & Powers, L.E. (1993). *Families, disability, & empowerment: Active coping skills and strategies for family interventions*. Baltimore, MD: Paul H. Brookes Publishing Co., Inc.

---

# Resources

---

- ❖ Ashland Parent Advisory Council (ASHPAC) or *your* local Special Education Parent Advisory Council (SEPAC)
- ❖ Federation for Children with Special Needs, [fcsn.org](http://fcsn.org)
  - ❖ “provides information, support, & assistance to parents of children with disabilities, their professional partners, & their communities”
- ❖ Family TIES of Massachusetts - [massfamilyties.org](http://massfamilyties.org)
  - ❖ “provides information & referral services, emotional support, & trainings to parents of children & youth with special needs”
- ❖ Shirley Riga - [conqueringyourfears.com](http://conqueringyourfears.com) - Metrowest Caregiver Support Group 1x/month
- ❖ Massachusetts Sibling Support Network [www.masiblingsupport.org](http://www.masiblingsupport.org)
- ❖ [abilities.com](http://abilities.com) : “the resource for the disability community”
- ❖ Exceptional Parent magazine [ep-magazine.com](http://ep-magazine.com) & website: [eparent.com](http://eparent.com)
- ❖ Each other!!! Fellow Parents of Special Needs Children - Local Mental Health Providers

Questions?

though we are not related by blood, we are related  
(Naseef, 1997, p. 161).