This talk is dedicated to the parents with whom we work, who remind us every day in the ways that they interact with their children, the power of joyful interaction.

“Parents (and especially fathers) report relatively higher levels of happiness, positive emotion, and meaning in their life than do nonparents”

(Nelson, Kushlev, English, Dunn & Lyubomirsky, 2012)

Getting the Diagnosis

How did you/the family come to terms with the diagnosis?

• All at once – early on
• Growing concerns and wondering
• Denial
• Confronting your suspicions
• Seeking information/confirmation
• Wait and See?
• More wondering and concerns?
• Formal Diagnosis?
• Pro’s and con’s of a formal diagnosis

When We Grow Up

When we grow up, will I be pretty?
Will you be big and strong?
Will I wear dresses that show off my knees?
Will you wear trousers twice as long?

Well, I don’t care if I’m pretty at all.
And I don’t care if you ever get tall.
I like what I look like and you’re nice small.
We don’t have to change at all.

“From Free to be... You and Me”
Song by Stephen Lawrence, Lyrics by Shelley Miller

Historical Perspectives On Parenting A Child With A Disability

• From the mid 1970’s and 1980’s, professional literature on parenting a child with a disability tended to focus on the negative impact on family life
  • parental sadness
  • Marital problems
  • Family instability
• Turnbull and Turnbull (1993) identified two trends –
  • Focusing only the negative, pathological elements of family life
  • Dismissing positive reports form parents as indicative of “Denial”
• As of 1998, a review (Helff and Glidden) showed a decline in negativity in the literature but no increase in positivity.
Despite this, many parents respond to the challenges of parenting a child with a disability with positive coping and resiliency. (Trute, Hiebert-Murphy, & Levine, 2007)

In a review of over 60 books written by parents of children with disabilities Multens (1987) found that a large majority of parents conveyed a message of lives that had been enriched and made more meaningful as a result of their experience.

Parents of young children with developmental disabilities experience more parenting stress than those in families with typically developing children. (Hauser-Cram, Warfield, Shonkoff, & Kraus, 2001; Smith, Oliver & Innocenti, 2001; Trute, Hiebert-Murphy, & Levine, 2007)

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Stress and Coping

Positive and Negative feelings about the impact on the family can and do exist at the same time. Parental self esteem can be “put on trial”. The meaning that one ascribes to the challenges affects the individual’s sense of well being. Coming to think about the impact in positive ways or in ways that make the situation more manageable can help develop adaptive coping and lessen the negative effects of stressors. Parents who who shoe higher levels of self esteem about their parenting experience less anxiety and depression and lower parental stress. (Folkman and Moskowitz, 2000; Hastings and Brown, 2002; Hassel, Rose, and McDonald, 2005)

Looking at the Other Side

Positive Outcomes

- Parenting experiences (Scorgie and Sobsey, 2000)
  - Emotional growth experienced by family members
  - Improved relations with others
  - Positive changes in spiritual and philosophical values
  - Stronger sense of purpose
- Change seems to occur over time – while things may seem difficult early on, as their children age, parents are more able to take perspective on their experiences and acquire a more positive view. (Behr and Murphy, 1993; Glidden & Johnson, 1999)

No relationship is more important than that between parent and child.

Infant research tells us that developmental growth and learning occur best within the context of a relationship. Other important relationships are:

- Grandparents and other family members
- Caretaker and child
- Teacher and child
- Professional/clinician and child
- Parent and Professional relationship

The “R” of DIR

- Affect drives learning. Relationships are the primary vehicle for creating and organizing learning situations.
- Interactions need to be tailored to child’s individual processing differences so the child can master core functional developmental capacities
- Caregiving patterns + individual differences influence the development of the Functional Emotional Developmental Capacities within the relationship
- Parents and children grow together; intervention focuses on their interactions to mobilize development

Kathiresan and Osten, 2015

Wieder, S, 2007
OBSTACLES TO MORE JOYFUL INTERACTIONS: A PERSONAL ASSESSMENT

DIR Is For Parents Too

- Understanding one’s own individual differences and developmental levels can promote more joyful relationships.
- DIR can be a personal journey for you too.

Individual Differences

- As you learn about your child’s individual differences, you can also learn about your own individual differences.
- Do you know your sensory profile?
- Winnie Dunn Sensory Profile for Adolescents and Adults

Engagement

- Are you included in your child’s therapies?
- Do you blame yourself for your child’s challenges in engagement, or for your reactions to this challenge?
- Does knowledge about your child’s profile help you to understand his challenge with engagement, result in steps toward increased engagement, and toward fewer negative feelings about oneself?

Engagement Around a Full Range of Feelings

- Sharing in a full range of feelings promotes joyful interactions.
- Are you able to engage in a full range of feelings with your child?

Initiation

- Are you able to initiate your feelings and ideas with your child?
- Do you initiate your feelings and ideas with other family members and professionals? Are you able to voice your opinions?
### The Developmental Process
- Developmental progress involves many small steps that can lead to change.
- Do the small steps of developmental progress lead to feeling joy? Do you relish in the small changes?
- Are you preoccupied only with the outcome, rather than the process of small change?
- Are you too focused on needing to move your child up the developmental ladder?
- Repetition is needed.

### Complex Problem Solving with Your Child
- Becoming a problem solver will help you experience more joy during those unpredictable experiences with your child. Helping parents become problem solvers should be a therapist’s goal.
- Do you feel as if you have become a problem solver as you approach the daily activities and interactions with your child?

### Complex Problem Solving with Professionals
- There are so many decisions to make as a parent of a child with developmental challenges.
- Can you share your opinions and remain in a problem solving interaction with professionals who may share different opinions?
- You are the team leader.

### Aggression Activates the Developmental Process
- At some point, all children define their own boundaries while opposing adult rules and guidelines, in the hope of becoming more independent. This is a more difficult and prolonged process for children with developmental challenges, but a necessary one.
- Can you non-verbally remain in a problem solving interaction when your child expresses his own opinions which are contrary to yours?
- Can you remain regulated and engaged while a child is angry and upset?
- Can you tolerate the ambivalence in your child and yourself?

### Pretend Play
- Do you enjoy the pretend play with your child?
- Are you able to create ideas in play with your child?
- Are you able to associate feelings and ideas in play with your child?
- Do you become too logical?

### Ghosts in the Nursery
“In every nursery there are ghosts. They are the visitors from the unremembered past of the parents: the invited guests at the christening. Under all favorable circumstances the unfriendly and the unbidden spirits are banished from the nursery and return to their subterranean dwelling place... In still other families there may be more troublesome events in the nursery caused by intruders from the past. There are, it appears a number of transient ghosts who take up residence in the nursery on a selective basis. Even when the bonds between parent and child are strong, the parents may feel helpless before the invasion and may seek professional guidance.” - Selma Fraiberg
The Process of Mourning

- Parents often need to mourn the child they hoped for to enjoy the child that they have.

Angels in the Nursery

“Angels emerge from childhood memories deeply connected to the phenomenology of care-receiving experiences that are characterized by intense shared affect between parent and child and provide the child with a core sense of worth and security. These messages of intrinsic goodness and unconditional love constitute the essence of the angel.”

- Alicia Lieberman and colleagues

You can seek help.

Bibliography


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Osten and Selinger, 2015