Understanding Parent Perspectives
Receiving A Diagnosis

Grief

- Denial
- Anger
- Bargaining
- Depression
- Acceptance
- Guilt
- Fear
What is Grief?

• Response to a loss
• Emotional suffering you feel when something or someone you love is taken away
• In 1969, psychiatrist Elisabeth Kübler-Ross introduced what became known as the “five stages of grief.”
Stages of Grief

• Denial: “This can’t be happening to me.”
• Anger: “Why is this happening? Who is to blame?”
• Bargaining: “Make this not happen, and in return I will ____.”
• Depression: “I’m too sad to do anything.”
• Acceptance: “I’m at peace with what happened.”

Elisabeth Kübler-Ross, M.D.
Denial

• Unable to handle reality
• Helps person survive loss
• Protects from being overwhelmed
• Buys time to deal with the impact
• Fix/Cure
Anger

• May occur once parent faces reality
• Shattered dreams
• Internal sense of injustice
• Anger towards child, family, friends, school personnel or oneself
• Can cause parent isolation
Bargaining

- Realization setting in
- Often not noticed
- Negotiate their way out of the hurt
- Prayers that they will do _____ if it goes away
- Remain in the past
Depression/Rejection

• Occurs when reality really sinks in
• Cannot measure ability of parenthood with peers
• Can’t “fix” what is broken
• Are not effective (helpless)
• Things will never get better (hopeless)
Acceptance

• Accepting reality and the fact that nothing can change the reality
• Does not mean parent is okay with loss
• Learning to move on
• Final stage of healing
Levels of Awareness

- Level 1 - Ostrich phase
- Level 2 - Special designation
- Level 3 - Normalization
- Level 4 - Self-actualization

Ostrich Phase

Lack of awareness

No prior experience with a disability
Special Designation

Awareness sets in
Seek special services
Want to “fix” the disability
Look for a cure
Normalization

Want to make disability less apparent
Request a decrease in services
Request inclusive classroom/services
Assert peers will benefit
Self-Actualization

Different not less
Support child in a self advocate
Advocate for supports
Dreams become more realistic
Other Things to Consider

• Fear
• Guilt
• Child stressors
• Outside stressors
Fear

• Knowing that they will be required to change on a fundamental level
• Fear of having more children
• Fear of aging/death
Guilt

- Thinking they are responsible for their child's autism
- Child’s autism is a punishment for past wrong doing
- Child’s autism is caused by regretting the pregnancy sometime during gestation
Child Stressors

- Eating
- Sleeping
- Emotional Regulation/Externalizing behaviors
Outside Stressors

- Time/Schedule
- Advocating for services
- Siblings
- Financial pressures/Inability to work
Autism and Beirut
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“When a parent feels understood, he or she becomes more open to working with you.”

~Jean Cheng Gorman-Working with Challenging Parents of Students with Special Needs
Contact Information

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