



Understanding Parent Perspectives

CARD



Receiving A Diagnosis





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

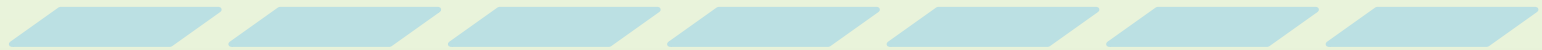
- Level 1- Ostrich phase
- Level 2- Special designation
- Level 3- Normalization
- Level 4- Self-actualization

*Ulrich, M.E., & A.M. Bauer. 2003. Levels of awareness: A closer look at communication between parents and professionals. *Teaching Exceptional Children* 35 (6): 20–24.

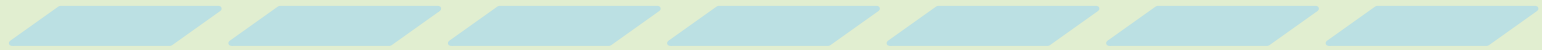


Ostrich Phase

Lack of awareness



No prior experience with a disability



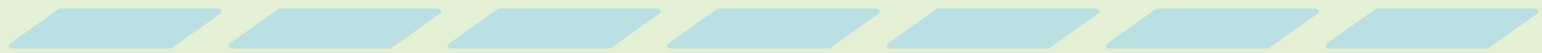


Special Designation

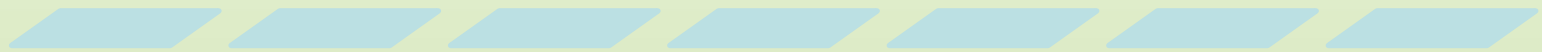
Awareness sets in



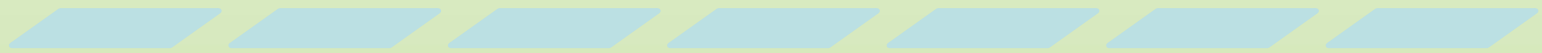
Seek special services



Want to “fix” the disability



Look for a cure



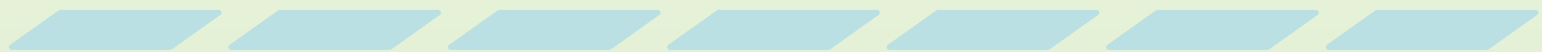


Normalization

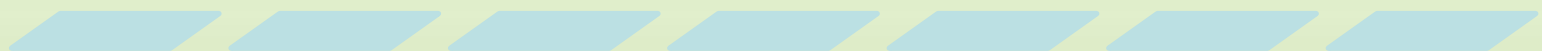
Want to make disability less apparent



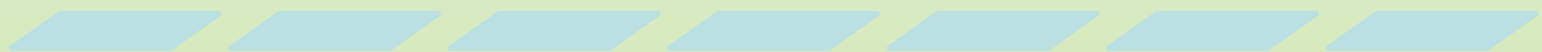
Request a decrease in services



Request inclusive classroom/services



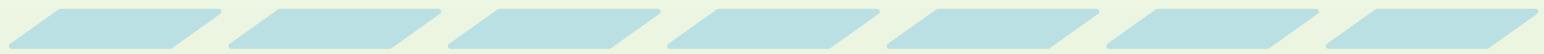
Assert peers will benefit



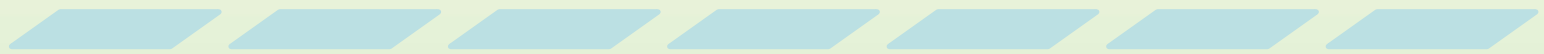


Self-Actualization

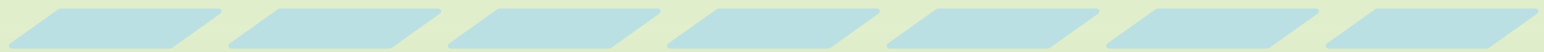
Different not less



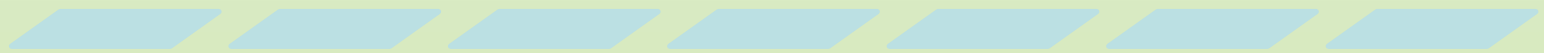
Support child in a self advocate



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

by Susan F. Rzucidlo



Autism and Beirut

by Susan F. Rzucidlo



Autism and Beirut

by Susan F. Rzucidlo



Autism and Beirut

by Susan F. Rzucidlo



Autism and Beirut

by Susan F. Rzucidlo





“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

Center for Autism and Related Disabilities
University of South Florida

<http://card-usf.fmhi.usf.edu>

813-974-2535

1-800-333-4530