

Honoring the Grief Process: Supporting Families When a Child is Identified with a Disability

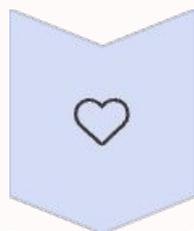
This training provides essential tools for professionals supporting families navigating the emotional journey after a disability diagnosis. Together, we'll explore grief stages, challenges, and compassionate support strategies.

by **Cassie Scott and Julissa Romero**



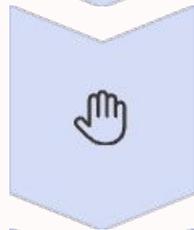


Our Journey Together



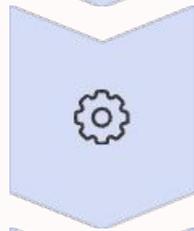
Understanding Grief

Explore the emotional responses families experience



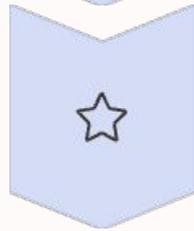
Recognizing Challenges

Identify unique obstacles families face



Building Support

Develop practical strategies for compassionate care



Fostering Resilience

Help families discover strength and hope

“ In the journey towards a more inclusive and respectful world, it's essential to recognise that 'disabled' isn't a bad word. It's a word that encapsulates strength, resilience, and the rich diversity of the human experience. By embracing this term, we contribute to a culture that values every individual, regardless of their abilities, and fosters a society where everyone can thrive.



Why We're Here

15%

Families

Percentage of families with
children who have disabilities in
the US

70%

Emotional Impact

Parents reporting significant
emotional distress after
diagnosis

3.5x

Support Gap

Increased risk for family
breakdown without proper
support

Understanding Grief



Not Just Death

Grief happens with any significant loss, including loss of expectations.



Universal Experience

All cultures and communities experience grief, though expressions vary.



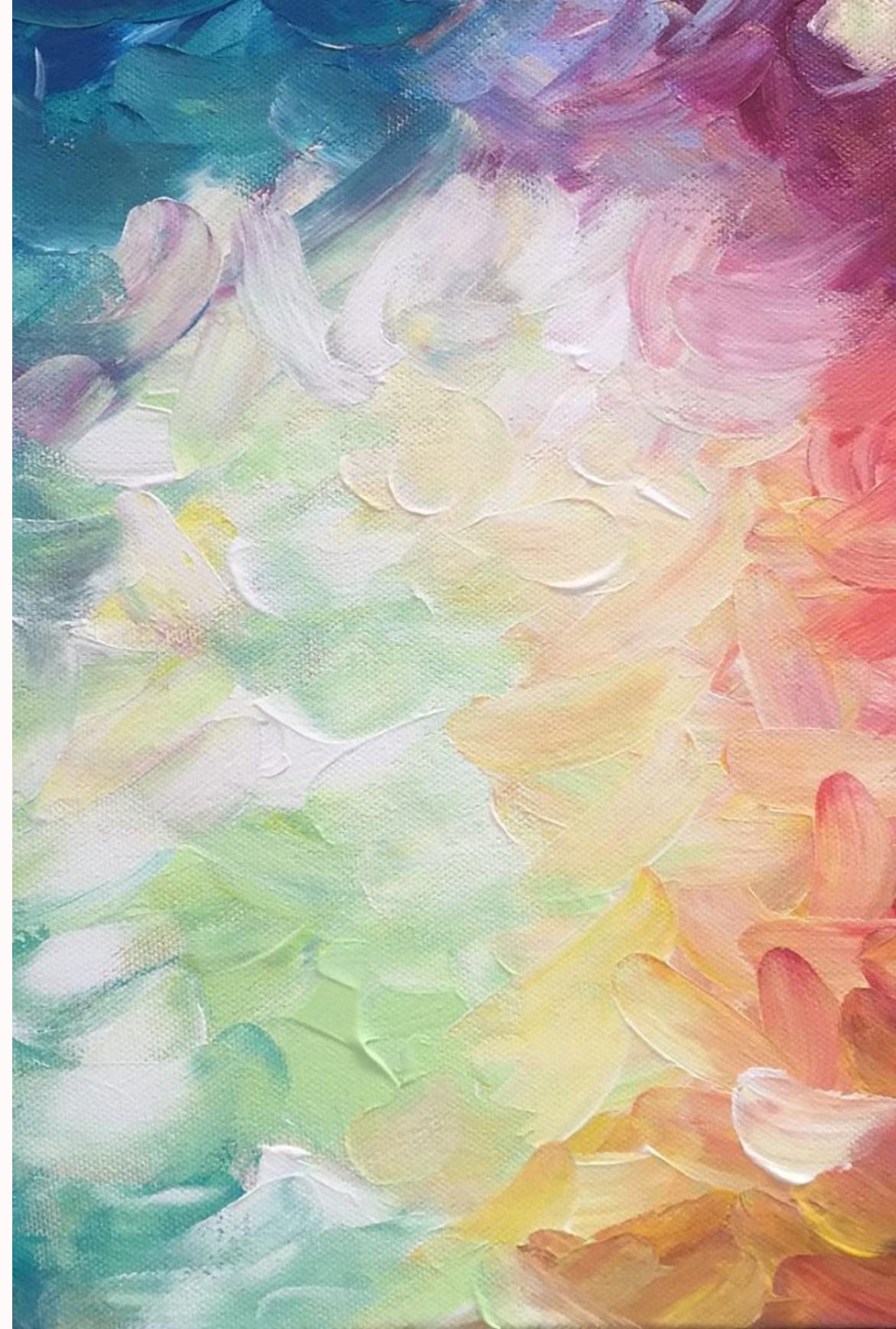
Ongoing Process

Grief isn't linear or time-limited. It evolves and resurfaces.



Deeply Personal

Each family member's grief journey is unique and valid.





Types of Loss Families Experience

Loss of Expected Future

Dreams and plans for their child's life may need to be reimagined.

Loss of Normalcy

Daily routines, social connections, and family dynamics change dramatically.

Loss of Control

Medical decisions, therapy schedules, and new systems feel overwhelming.

Loss of Identity

Parents take on new roles as advocates, caregivers, and medical coordinators.

Common Stages of Grief

Shock & Denial

Initial disbelief and difficulty processing the diagnosis

Acceptance

Integrating the reality into a new vision of family life



Anger

Frustration at the situation, healthcare system, or perceived unfairness

Bargaining

Seeking alternative outcomes or second opinions

Depression

Sadness, withdrawal, and mourning the imagined future

Honoring the Non-Linear Journey

1

Initial Diagnosis

Families often experience intense shock and confusion.

2

Developmental Milestones

Grief may resurface when peers reach milestones their child cannot.

3

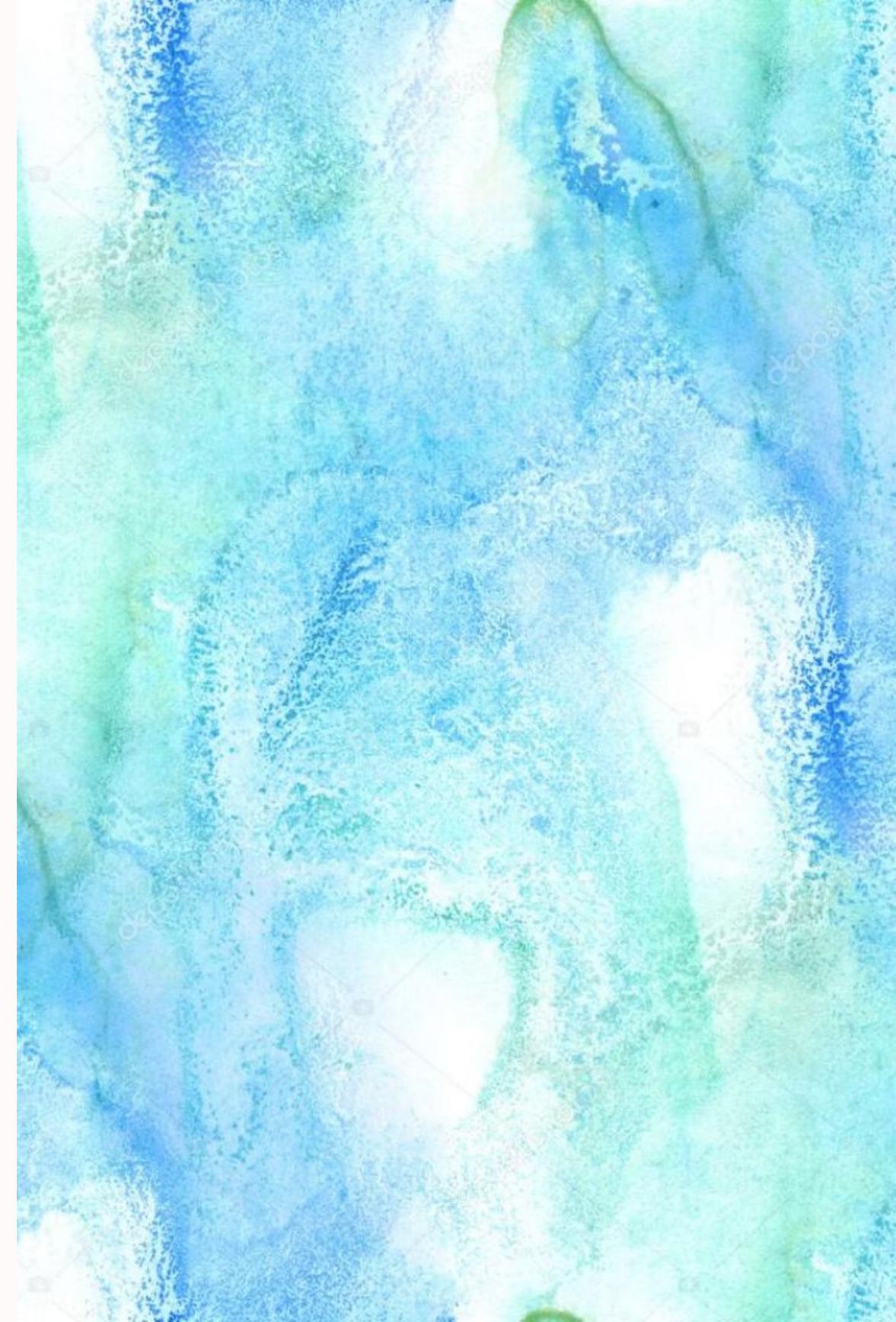
School Transitions

New environments highlight differences and trigger fresh grief.

4

Adult Planning

Future independence concerns bring another wave of emotions.



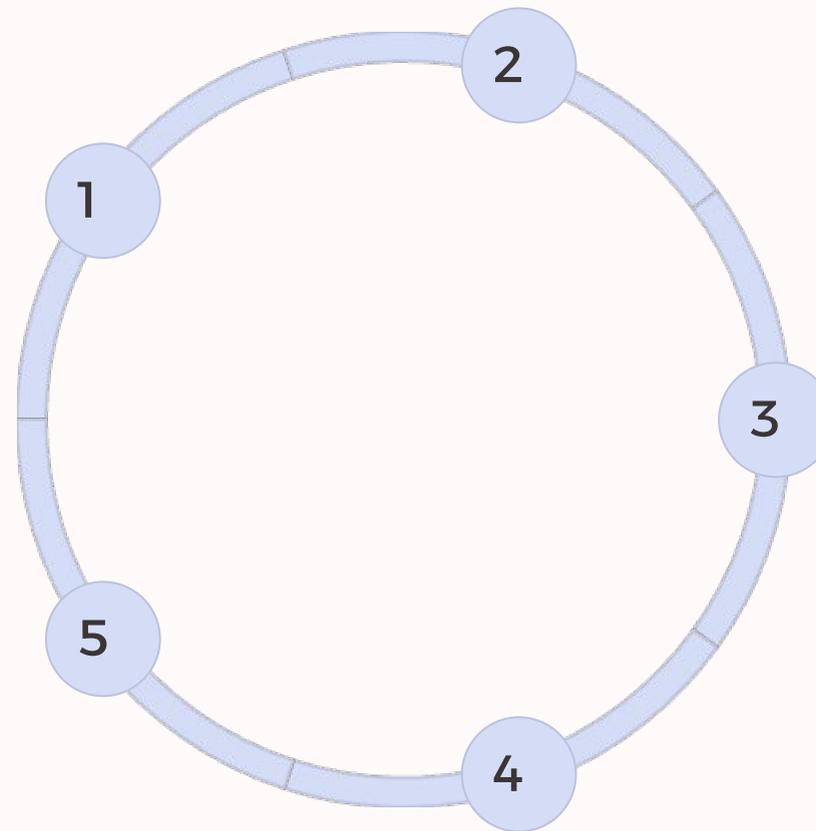
Factors Influencing Grief Responses

Cultural Background

Cultural beliefs shape how loss is understood and processed.

Family Dynamics

Pre-existing relationships impact how families cope together.



Support Networks

Strong social systems can buffer emotional impact.

Prior Experiences

Previous losses influence how new grief is experienced.

Disability Type

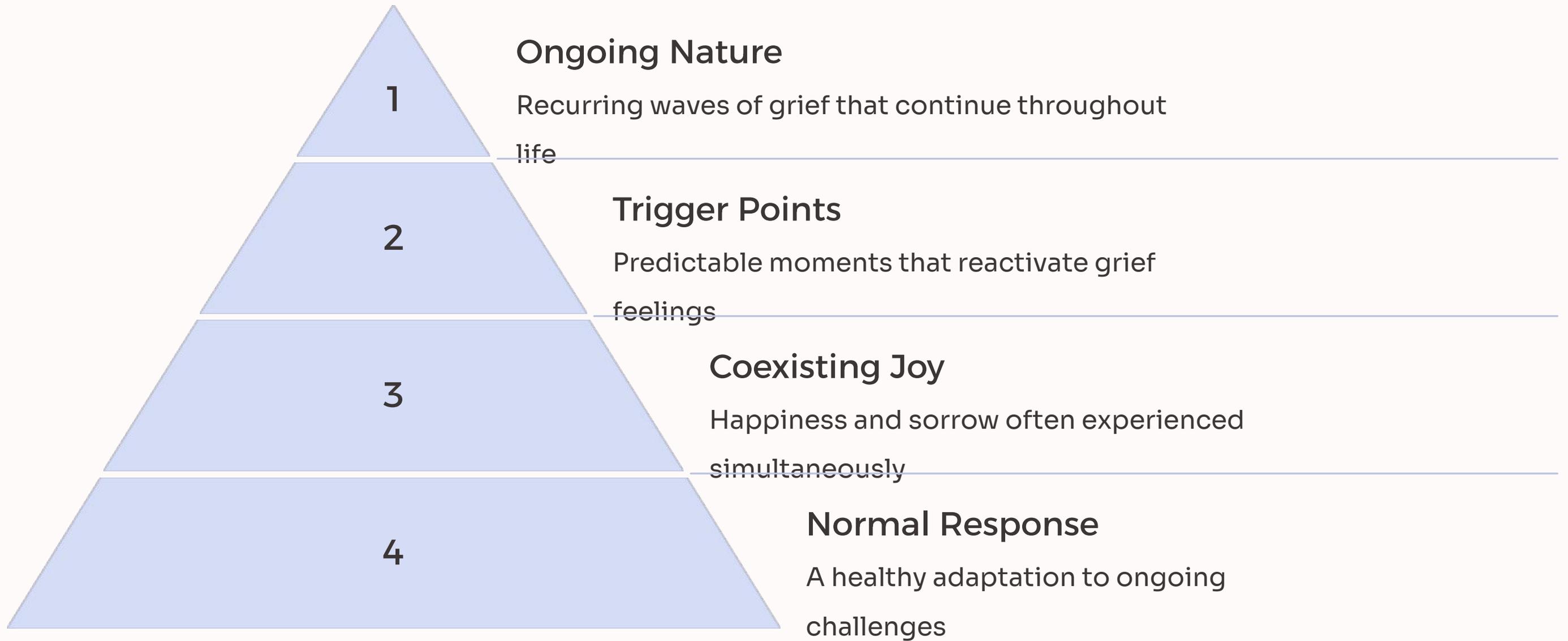
Visible vs. invisible, progressive vs. stable conditions affect adjustment.

Recognizing Grief Expressions

Emotion	Examples of how the parent might display the emotion
Denial	Parent denies his or her child has a disability.
Anxiety	Parent goes through dramatic change that might affect his or her attitudes, values, beliefs, and routines.
Fear	Parent may feel concerned about letting his or her child with a disability do certain things (protective).
Depression	Parent may experience uncontrollable tears, sadness, and feelings of hopelessness.
Guilt	Parent may feel he or she is somehow to blame for the disability or the situation.
Anger	Parent may act out his or her anger or direct it toward another person.

(Adapted from Childhood Disability: A Parent's Struggle, by K. Moses, 1987, and You Are Not Alone: For Parents When They Learn Their Child has a Disability, by P. McGill Smith, 2010.)

Understanding Chronic Sorrow





Ella, 19 years old

“Chronic Grief.

They say that “time heals,” but in my world “time creates new wounds.” Chronic Grief. The idea of layered hurts without there being a real healing each time. Imagine the scar tissue after 17 years.

I mentioned joy and grief being able being able to coexist. THIS is our truth. That while we cry out to in pain and seemingly drown in tears, we can also laugh loudly, cheer for our friends, and SMILE bigger knowing that the joy around us lightens the internal pain. We are not victims of Ella’s brain damage. we are LIVING A FULL LIFE in spite of the challenges of this world.

So if you see me tear up and possibly lose it at an otherwise cheerful and joyous occasion, just know my grief might be getting another layer, but so is my joy.”

Nia, 13 years old

The initial diagnosis of AU brought on some relief because it gave us somewhat of an explanation for her behavior and allowed us to start better navigating her support. My heart broke because I felt like I had to let go of my initial hopes and dreams for her. Everything has been a bit more difficult and challenging and it hurts to watch her struggle.

We constantly carry guilt about what more we could or should do but aren't always able to. We know that teachers are busy and that they have a lot on their plates but I wish they understood how much we try to do so that our kids aren't a burden to them. I have felt that some educators would rather not have to deal with the "extra" work a child with disabilities may add to a teacher's day.



Family-Wide Impact



Siblings

May feel overlooked, responsible, or confused about family changes.



Marital Relationship

Partners may grieve differently, creating potential disconnection.



Extended Family

Grandparents experience double grief—for grandchild and their own child.



Social Circles

Friendships often change as families navigate new priorities.

Sibling Experience



Emotional Complexity

Love, resentment, guilt, and pride often
coexist



Identity Formation

Developing self-concept intertwined with family
situation



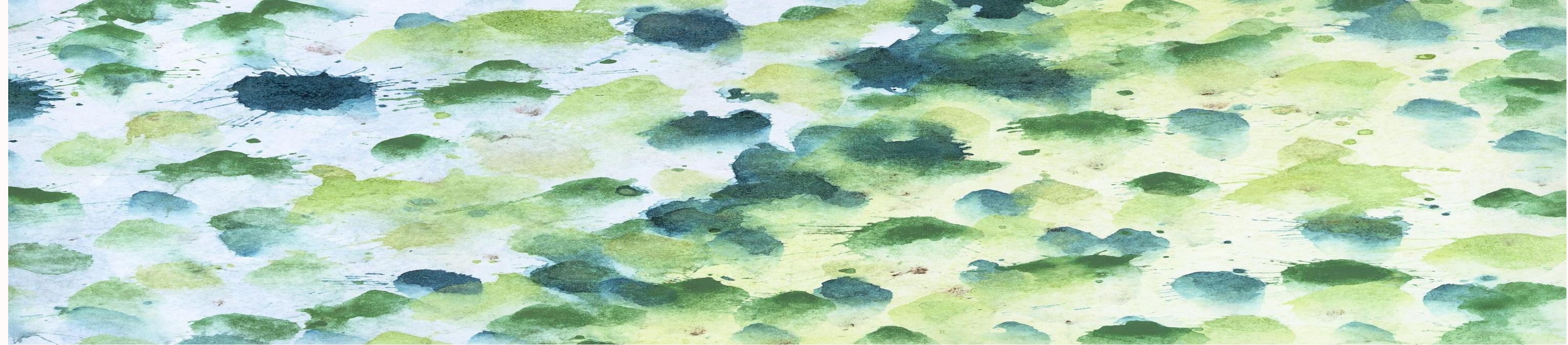
Knowledge Needs

Age-appropriate understanding of disability assists
coping



Individual Attention

Requiring dedicated time and acknowledgment of their
experience



Cultural Perspectives on Disability

Cultural backgrounds significantly influence how families interpret disability. Understanding these perspectives helps professionals provide culturally responsive support.

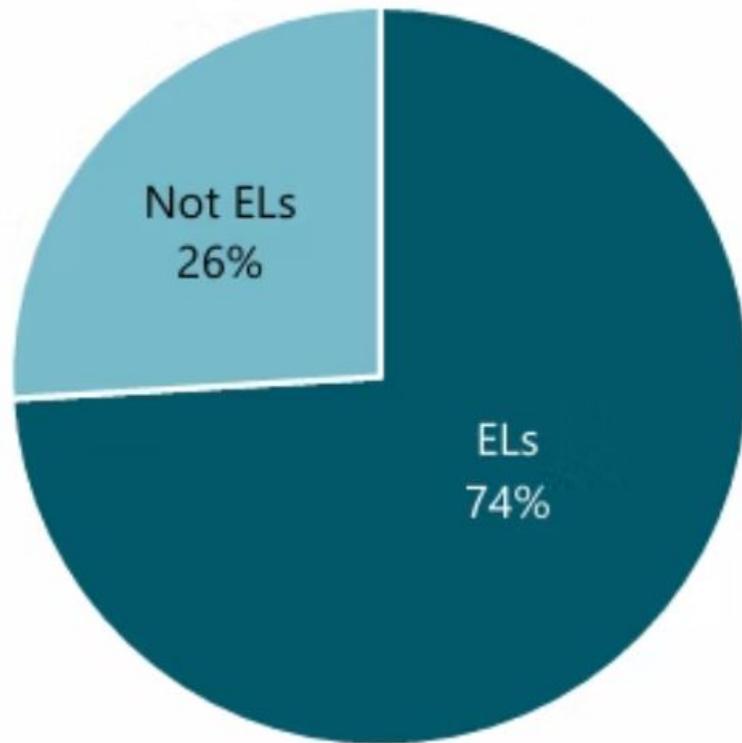
For families of multilingual learners with disabilities, this process can be even more complex as they navigate cultural beliefs, language barriers, and systematic challenges.

Honoring their grief means providing culturally responsive support, clear communication in their native language, and resources that empower them to advocate for their child.

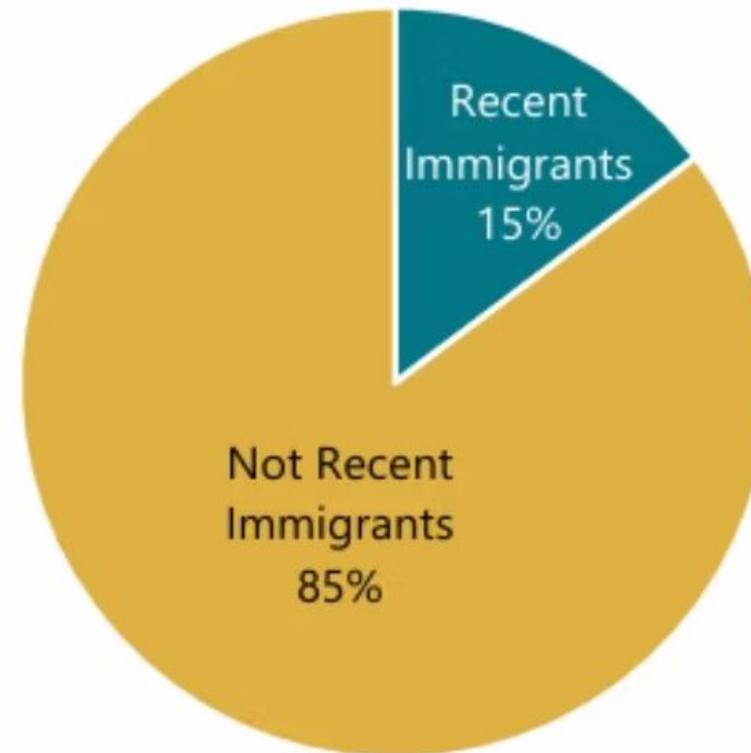
Current Trends and Statistics

Federal Count of Recent Immigrants Who Are English Learners in U.S. Schools, School Year 2020–21

All Recent Immigrants



All English Learners



Notes: In this figure, “recent immigrants” are those who have been in U.S. schools for three years or less. In the second chart, “not recent immigrants” includes immigrants who have been in the U.S. schools for four or more years and some native-born students. U.S. Dept of Education, “ED Data Express.”



Creating Culturally Responsive Support



Language Barriers

Difficulty understanding assessments, reports, and special education terminology.



Cultural Perceptions of Disability

Some cultures may stigmatize disabilities or believe in alternative explanations such as lack of discipline, spiritual beliefs.



Fear of Labeling

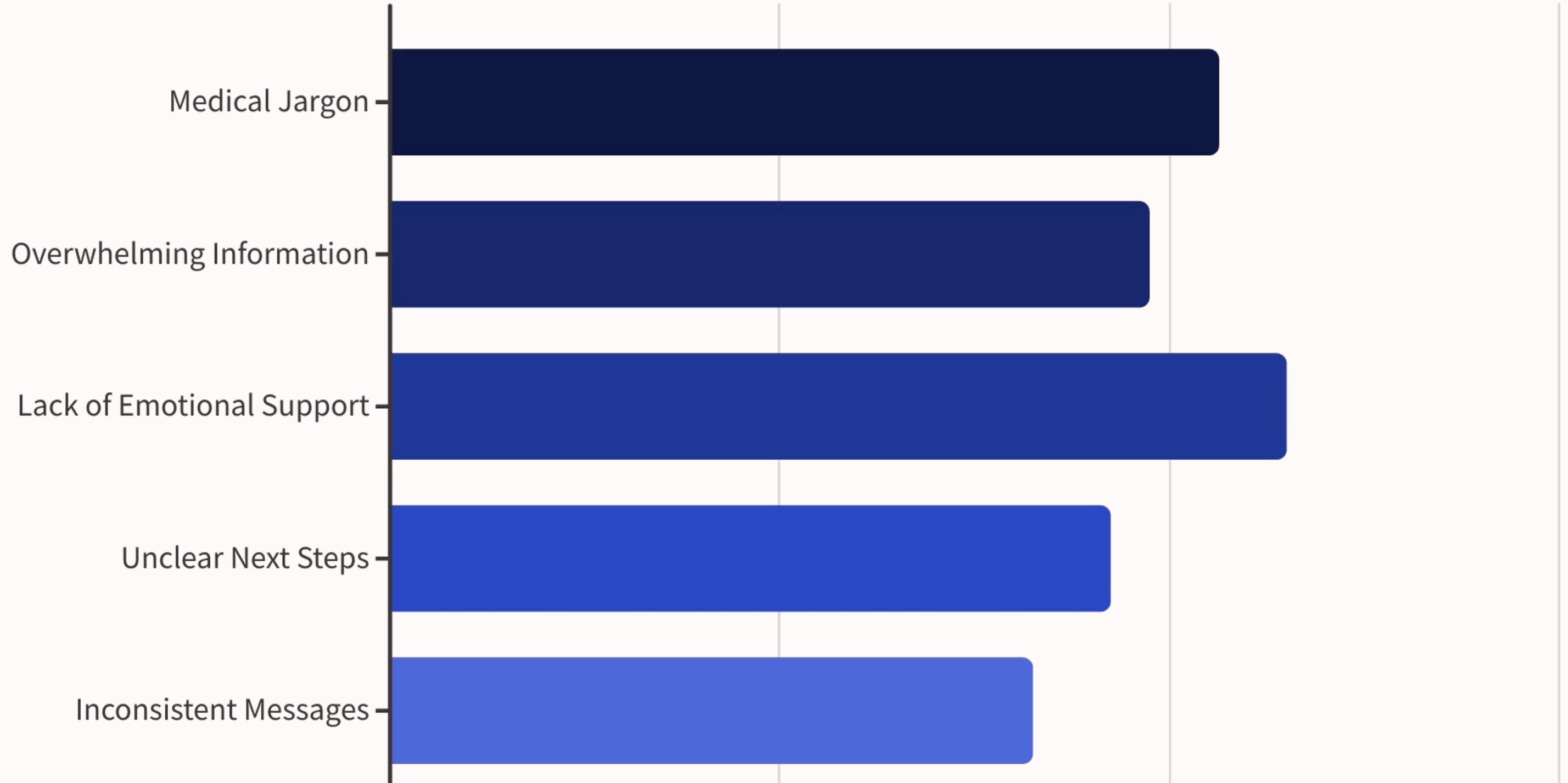
Families may worry that special education will limit their child's opportunities.



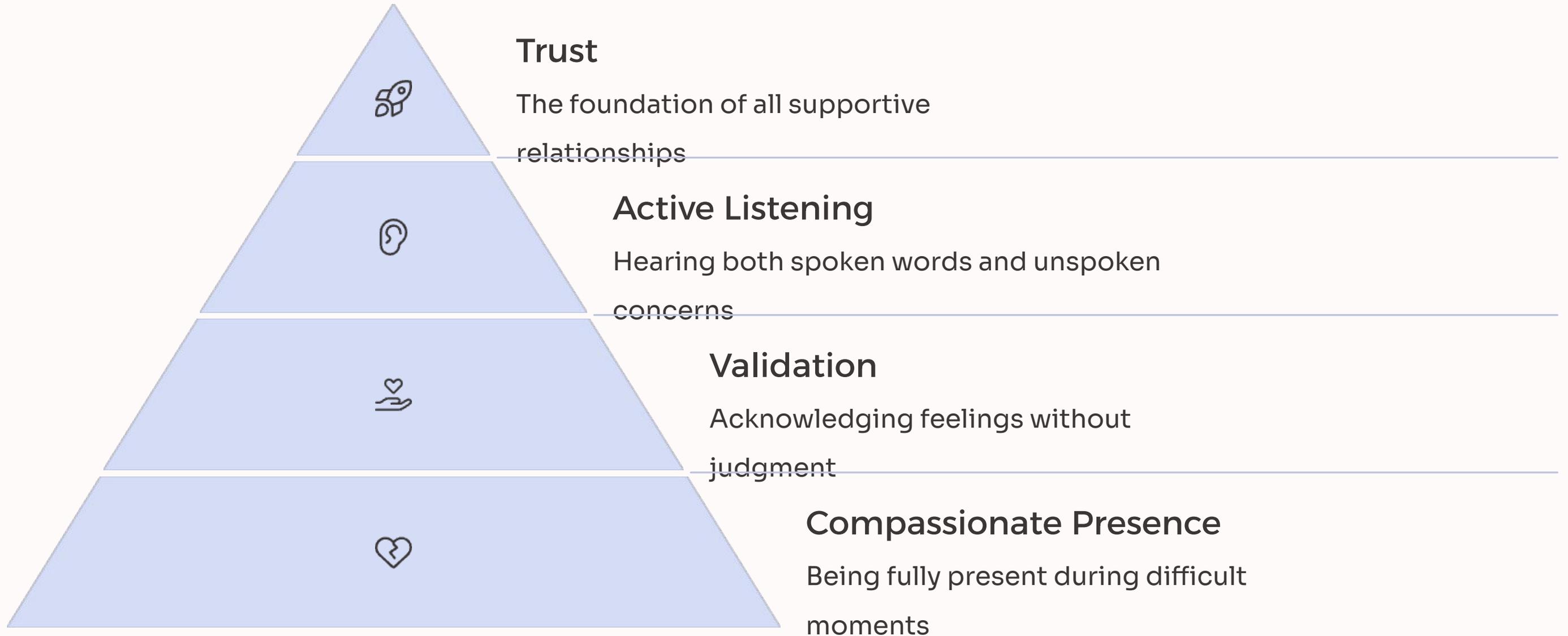
Lack of Representation

Limited access to bilingual professionals who can explain the process in a culturally responsive manner.

Communication Challenges



Building Supportive Relationships



Communication That Helps

- **Person First vs. Identity First Language**
 - Honor the preferences of the person with a disability
- **Avoid Euphemisms**
 - Be clear and direct
 - Don't minimize reality
- **Balance Honesty & Hope**
 - Acknowledge challenges
 - Highlight possibilities
 - Be careful about using absolutes
- **Check Understanding**
 - Ask for reflections and questions
 - Follow up after meetings
 - Provide open door for communication



Delivering The News

1

Allow Adequate Time

Never rush these critical conversations.

2

Create Private Space

Ensure a comfortable, interruption-free environment.

3

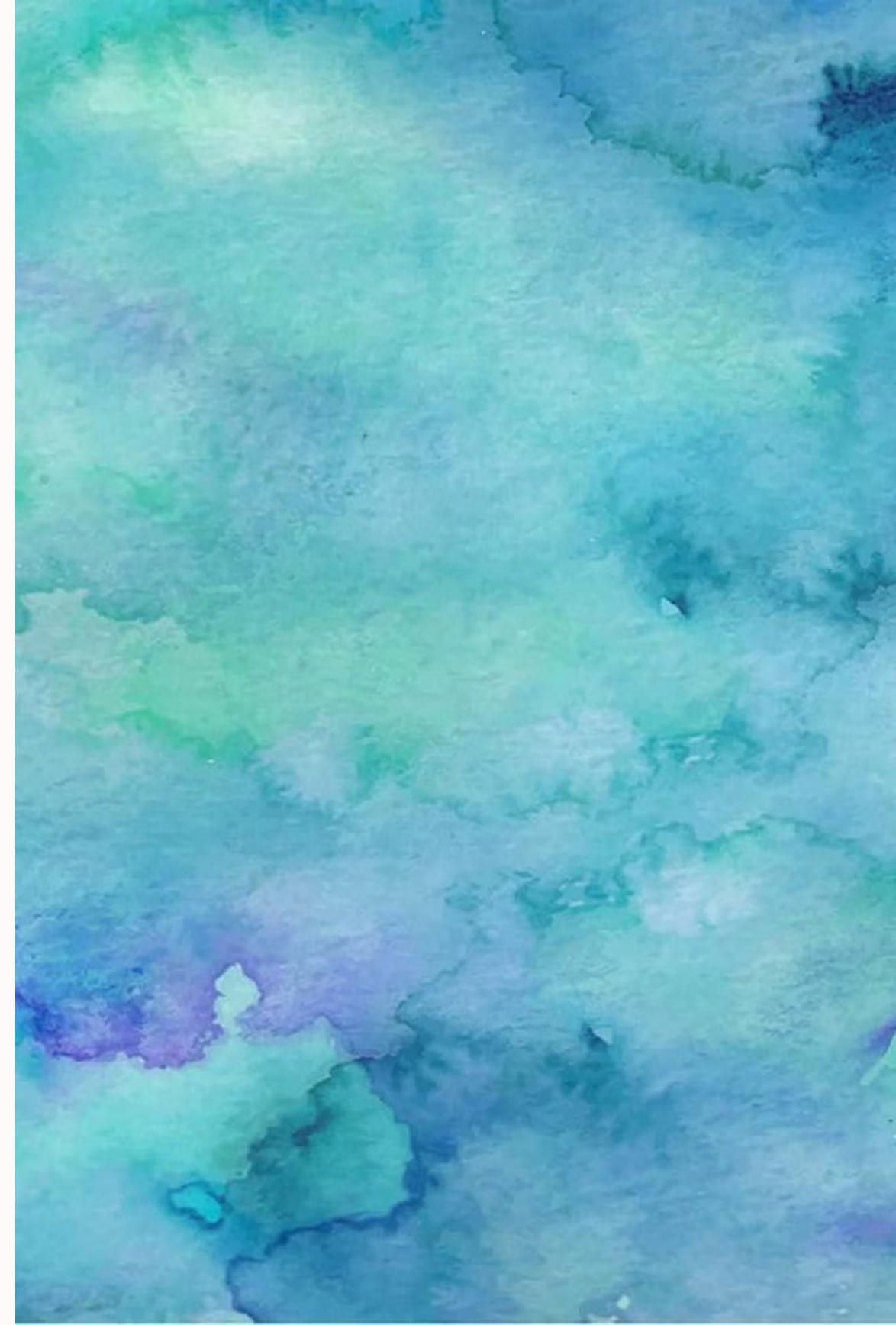
Provide Written Information

Supplement verbal discussions with take-home resources.

4

Schedule Follow-Up

Review information again with parent during IEP meeting and be available for questions



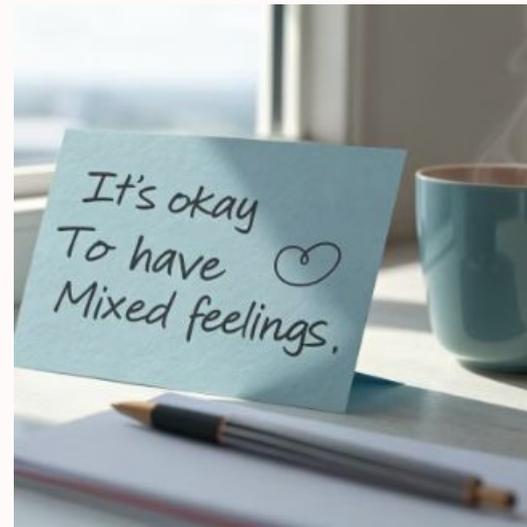
ARD/IEP Process

“The older she gets the less I feel like the support actually helps her and the less the teachers are truly invested. The process in general is pretty standard.

Regardless of how many meetings I have attended, I always feel nervous and like I have to go in ready to fight for her not to lose supports.” -Nia’s Mom

- **Strengths based approach**
- **Honor parents’ expertise about their child**
 - **Provide a draft and actually seek input!**
- **Validate feelings**
- **Be patient and flexible**
 - **Be open to rescheduling meetings or allowing breaks when emotions run high**
- **Use clear, compassionate communication**
 - **Be careful of being condescending**
 - **Limit acronym use (even for the most seasoned parents)**

Powerful Validation Statements



Supporting the Whole Family



Sibling Support

Age-appropriate information and special time together help siblings adjust.



Partner Check-ins

Encouraging couples to maintain communication and personal connection is vital.



Extended Family Education

Helping grandparents and relatives understand supports the whole system.



Creating Supportive Environments

Physical Space

- Private conversation areas
- Comfortable seating
- Accessible facilities
- Family-friendly amenities

Policies

- Flexible scheduling
- Family presence options
- Clear communication channels
- Feedback mechanisms

Team Culture

- Empathy training
- Strengths-based language
- Collaborative approach
- Emotional awareness

Create Compassionate School Environments

1

Staff Training

Educate all school personnel about disability issues, including grief processes. Help them recognize triggers and provide appropriate responses.

2

Family Partnerships

Create welcoming spaces for family involvement. Regular check-ins help address emerging needs.

3

Peer Education

Teach classmates about differences with appropriate information. Foster inclusion through structured activities.

4

Inclusive Programming

Ensure programming is inclusive. This includes open house, field day, and clubs and events on campus. Don't be quick to shut an idea down because of logistics.

Helping Families Build Resilience

Acknowledge Reality

Facing challenges honestly creates foundation for moving forward.

Identify Strengths

Helping families recognize their capabilities builds confidence.

Connect to Resources

Knowledge and support networks reduce isolation and stress.

Develop Coping Skills

Practical tools help manage difficult emotions and situations.

Find Meaning

Discovering purpose within challenges transforms the experience.

Hope-Based Approach

- Celebrate Strengths
- Set Realistic Goals
- Find the Joy
- Build Community
- Embrace New Dreams





Connecting Families to Resources



Medical Support

Specialized care providers, care coordination, and health education.



Community Programs

Support groups, recreational activities, and respite care options.



Educational Resources

School supports, advocacy training, and transition planning.



Financial Assistance

Insurance navigation, benefit programs, and planning tools.

Parent-to-Parent Support



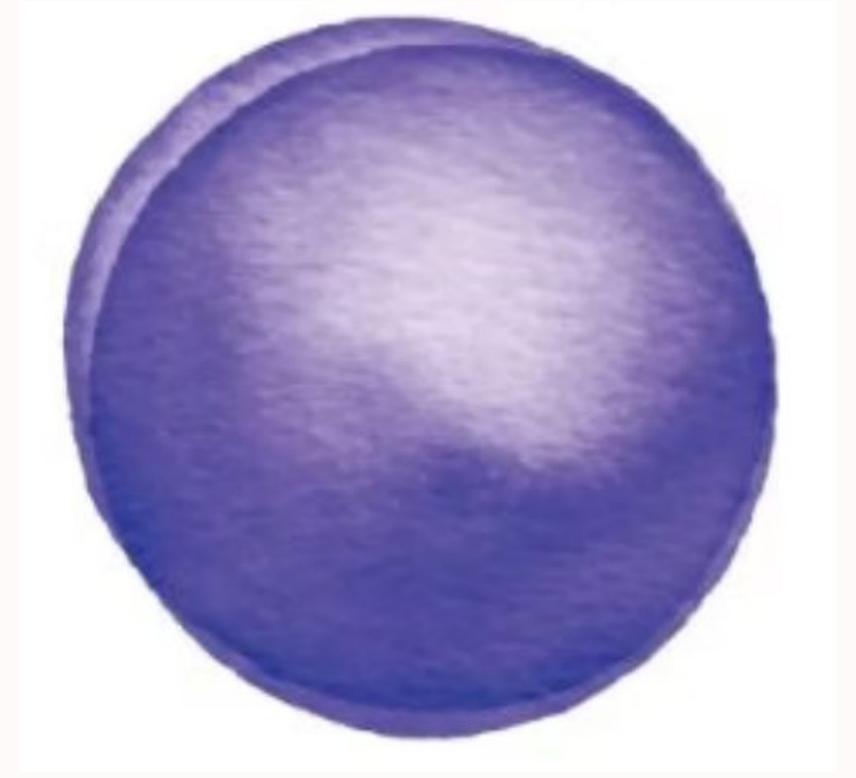
Shared Experience

The power of connection with someone who truly understands cannot be overstated.



Practical Wisdom

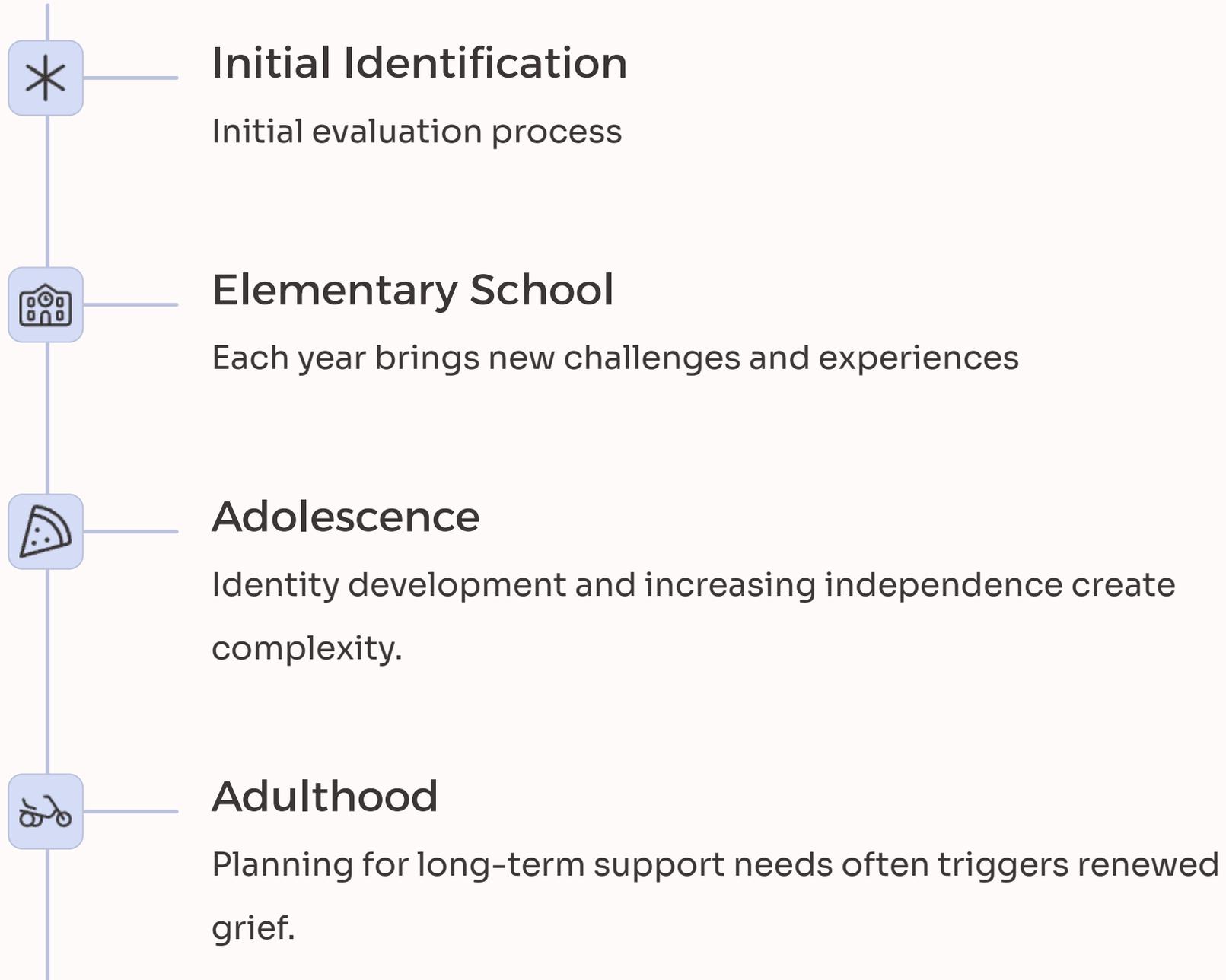
Veteran parents offer navigation tips that professionals may not know.



Hope Modeling

Seeing others who have adapted successfully provides powerful reassurance.

Supporting Transitions



Case Studies: Putting It Into Practice



The Garcia Family

Parents of 2-year-old newly diagnosed with autism spectrum disorder.



The Wilson Family

Divorced parents navigating complex medical decisions for their teenager.



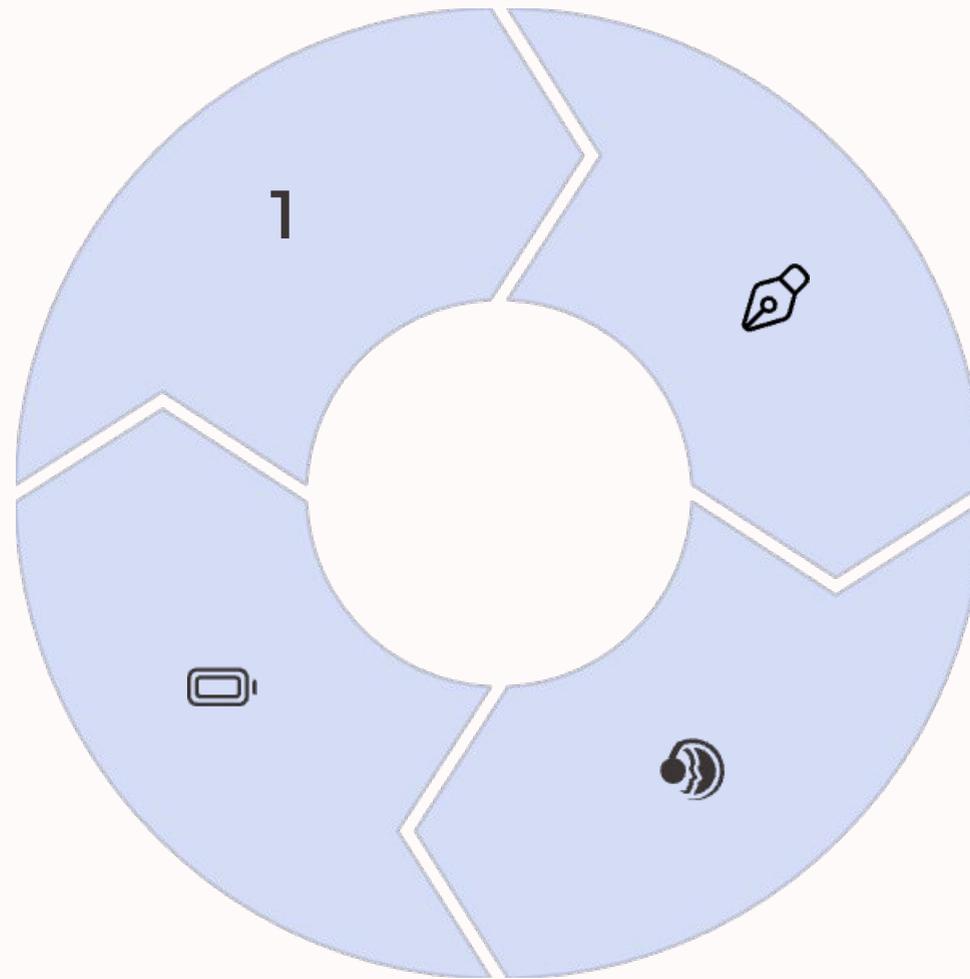
The Nguyen Family

Recent immigrants facing language barriers while seeking services.

Professional Self-Care

Recognize Impact
Acknowledge secondary trauma
and emotional toll

Practice Renewal
Develop personal restoration
practices



Set Boundaries
Create healthy work-life separation

Seek Support
Engage with peers for processing
and validation



Your Journey Forward

1

Grief is a normal, ongoing process that deserves recognition.

2

Your compassionate presence matters more than perfect words.

3

Supporting whole families creates sustainable resilience.

4

Self-care enables you to maintain compassionate support.



For More Information

<https://tinyurl.com/disabilitygriefjourney>

“When we listen with the intent to understand, we create a bridge to the hearts of families navigating a diagnosis.”

~Amy McCarthey



Thank you!



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