

The Autism Journey

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Utah Valley Psychology

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ScenicView Academy

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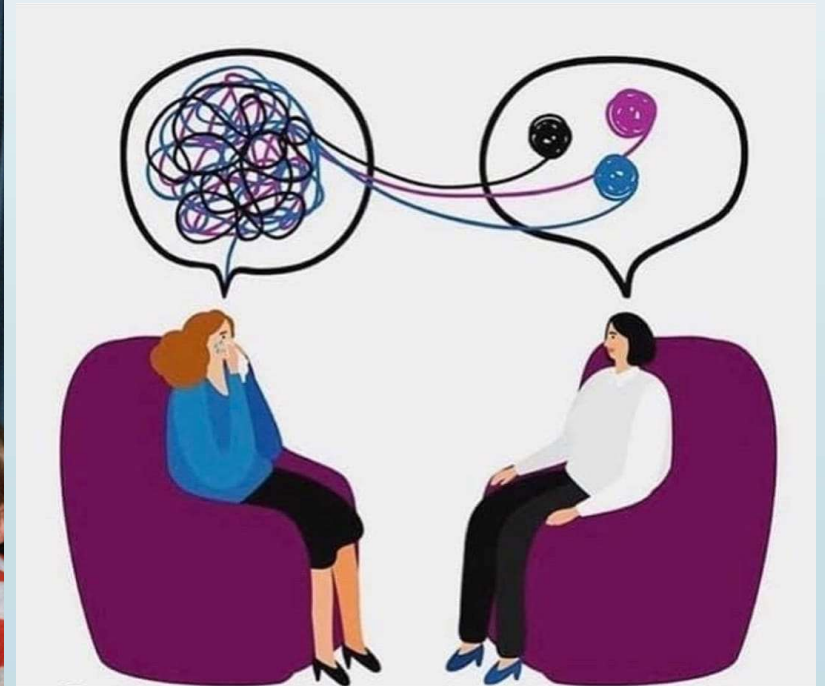


The Autism Journey

Part One: Navigating as a Family



Part Two: Calibrating as a Therapist



Introduction

- Started at a very personal level
- Reluctance to accept designation as “expert”
 - I am learning every day from my family members, my clients and my coworkers!
- Some historical perspective
- I’m for whatever works. I love the word “effective.”

Introduction (con.)

- Honor the individual and their families' lived experience and respect their deeper understanding of their own and their family member(s) with autism.
 - They are the expert on themselves and their family members.
 - I hope to add perspectives, skills, support, and options.
- I use person first language most naturally.

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My mom (1930-2022)



Divisiveness



A Friendly Reminder

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- ➡ There is no majority or “most” in this community.
- ➡ Some like the puzzle piece; some like the infinity symbol; some like an element.
- ➡ Some like blue, some like red, some like gold.
- ➡ Some like Awareness; others Acceptance; and some Action.
- ➡ Some prefer Autistic, some prefer “with Autism”; some like both.
- ➡ To some the name Aspergers is negative and outdated; some prefer it.

A Friendly Reminder (con.)

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- Some don't mind functioning labels; some prefer never to use them.
- Some believe Autism Speaks is damaging; others believe they do good.
- Some like ABA; some do not.
- Autistic voices matter; but caretakers voices matter too.
- No matter what you believe, what you support, or what you prefer, the important thing is that it is YOURS to decide and it is THEIRS to decide.

A Friendly Reminder (con.)

- We should respect each other. We can discuss, but we should never demean or demand.
- Let's advocate and educate for better programs for adults and children, better access to these programs, better accommodations in schools, better job opportunities, better community support, and increased financial support.
- Lets focus on improving what impacts lives the most and try not to argue over symbols and verbiage.
- This is my wish and I hope it can be yours too.

What is Autism?

The essential features of an Autism Spectrum Disorder are the presence of markedly abnormal or impaired development in:

- **social interaction and communication**
- and a markedly **restricted repertoire of activity and interests**

—DSM-5

Social Communication & Interaction

- A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and **manifest by all 3 of the following:**

Social Communication & Interaction (con.)

1. **Deficits in social-emotional reciprocity**; ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction.

Social Communication & Interaction (continued)

- 2. Deficits in nonverbal communicative behaviors used for social interaction;** ranging from poorly integrated- verbal and nonverbal communication, through abnormalities in eye contact and body-language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures

Social Communication & Interaction (con.)

3. **Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers);** ranging from difficulties adjusting behavior to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people.

Behaviors, Interests, Activities

B. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following:

1. **Stereotyped or repetitive speech, motor movements, or use of objects;** (such as simple motor stereotypies, echolalia, repetitive use of objects, or idiosyncratic phrases).

Behaviors, Interests, Activities (con.)

2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change; (such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes).

Behaviors, Interests, Activities (con.)

- 3. Highly restricted, fixated interests that are abnormal in intensity or focus;** (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).

Additional Diagnostic Criteria

- C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities).**
- D. Symptoms together limit and impair everyday functioning.**

Severity Levels

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Severity Level for ASD	Social Communication	Restricted Interests and Repetitive Behaviors
Level 1 Requiring support	Without supports in place, deficits in social communication cause noticeable impairments. Has difficulty initiating social interactions and demonstrates clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions.	Rituals and repetitive behaviors (RRB's) cause significant interference with functioning in one or more contexts. Resists attempts by others to interrupt RRB's or to be redirected from fixated interest.

Jerri Maroney, Andrea Kliss, Edward Toyer, *AmeriHealth Mercy Family of Companies*

Severity Levels

Severity Level for ASD	Social Communication	Restricted Interests and Repetitive Behaviors
Level 2 Requiring substantial support	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions and reduced or abnormal response to social overtures from others.	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions and reduced or abnormal response to social overtures from others.

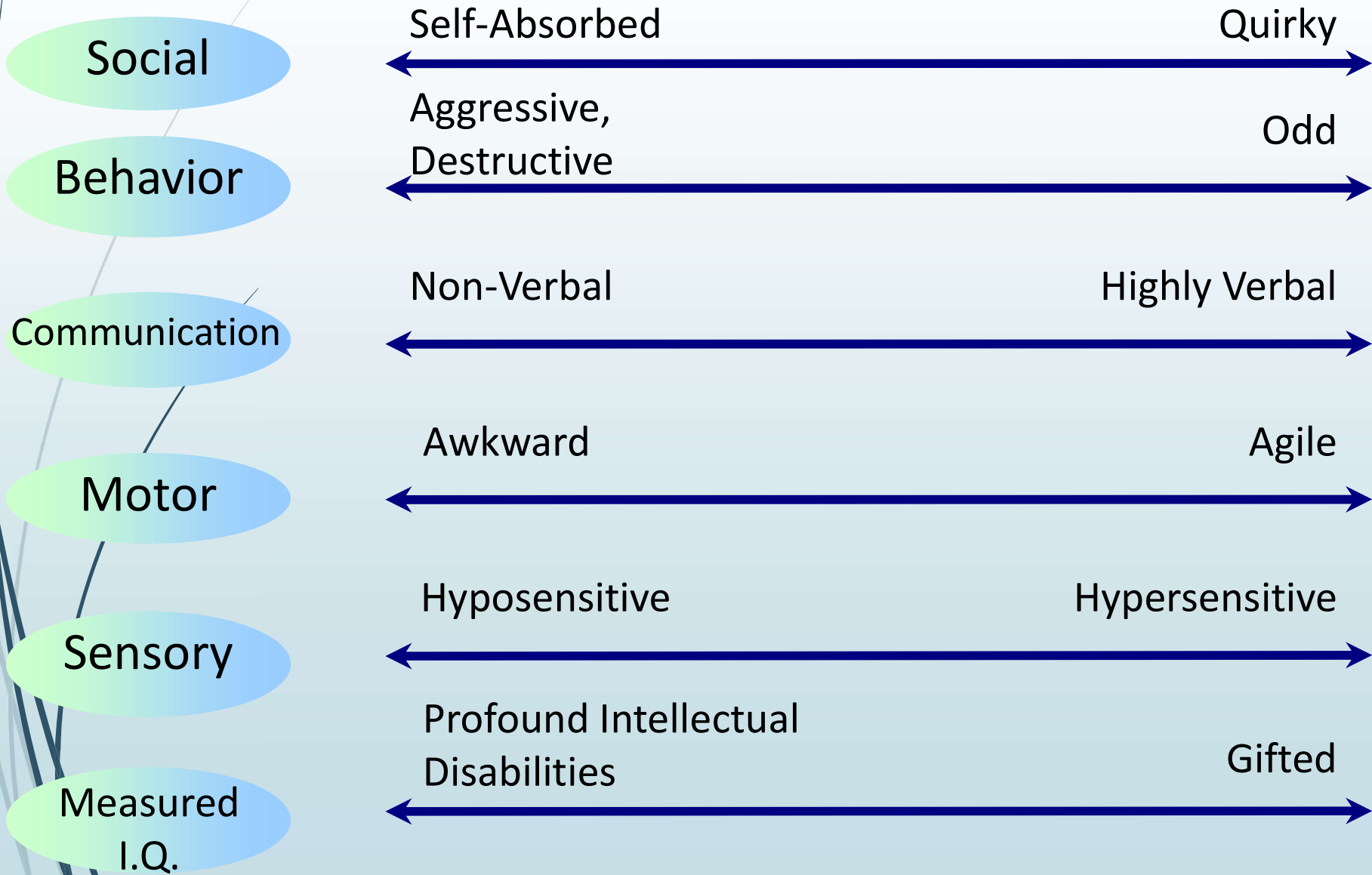
Jerri Maroney, Andrea Kliss, Edward Toyer, *AmeriHealth Mercy Family of Companies*

Severity Levels

Severity Level for ASD	Social Communication	Restricted Interests and Repetitive Behaviors
Level 3 Requiring very substantial support	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning; very limited initiation of social interactions and minimal response to social overtures from others.	Preoccupations, fixated rituals and/or repetitive behaviors markedly interfere with functioning in all spheres. Marked distress when rituals or routines are interrupted; very difficult to redirect from fixated interest or returns to it quickly.

Jerri Maroney, Andrea Kliss, Edward Toyer, *AmeriHealth Mercy Family of Companies*

Spectrum of Autism

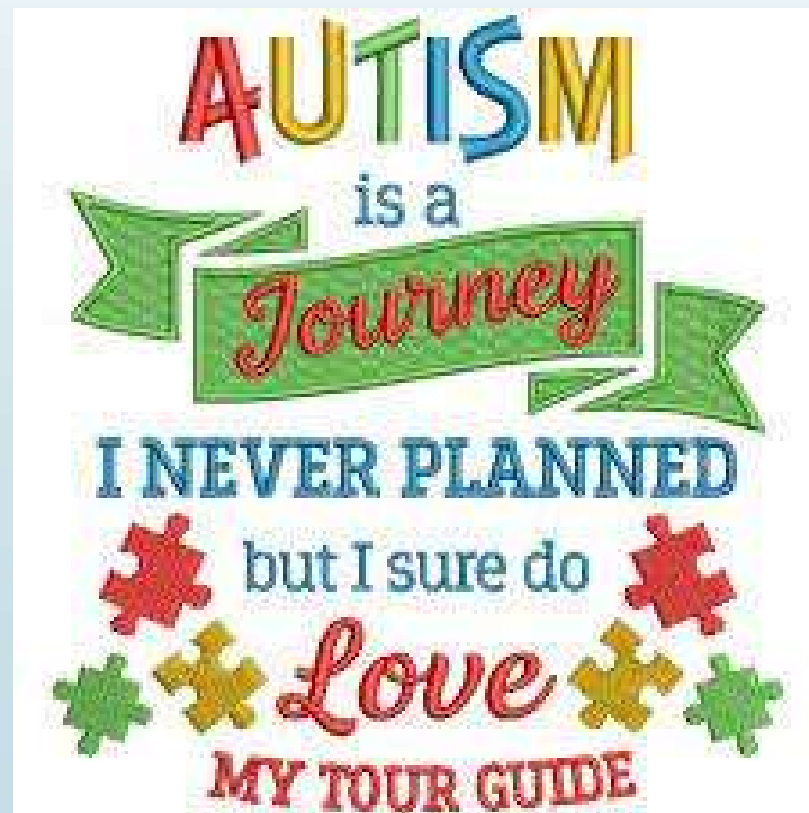


Discuss

What has been your personal experience with autism?

The Autism Journey, Part One: Navigating as a Family

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Some Challenges for Families with Autism

- Family Adaptation
- Marital Relationship
- Sibling Relationships
- Extended Family Relationships
- Delayed Independence

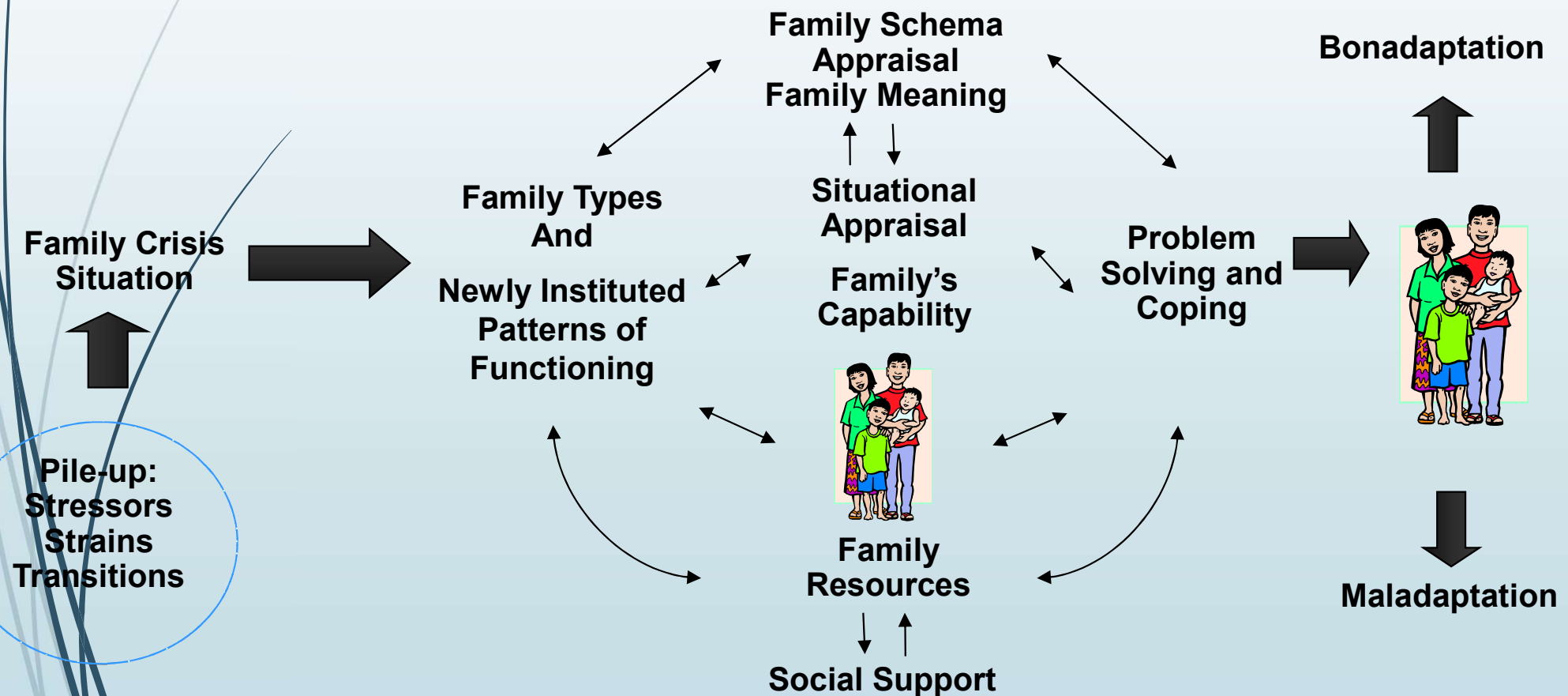


Family Adaptation



Family Adaptation

DEMANDS — over time —→ **PROCESS** — over time —→ **OUTCOME**



Family Adaptation

- Pile Up Stressors
- Family Types/Functioning
- Appraisal
- Family Resources/Support
- Problem Solving/Coping

Family Adaptation (con.)

■ Pile-Up Stressors

- Symptoms and Challenging Behaviors
- Diagnostic Process
- Obtaining Appropriate Services
- New/Unexpected Responsibilities

Major Responsibilities of Parents of a Child with Autism

- Direct teaching of skills and behaviors that other children acquire in more incidental ways.
- Responding to the emotions of the child that surround the disorder. Parents must be prepared to help the child to confront possible negative attitudes imposed by self and others.

- Skill in managing behaviors which result from or are magnified by the disorder (tantrums, lack of initiative, withdrawal).
- Meeting the cognitive and emotional needs of the non-disabled siblings.

- Working to educate extended family members, neighbors, and others in the child's environment about Autism and their role in useful support.
- Attending to the marital relationship so that the stresses of parenting a child with Autism don't jeopardize the needs of the parents.





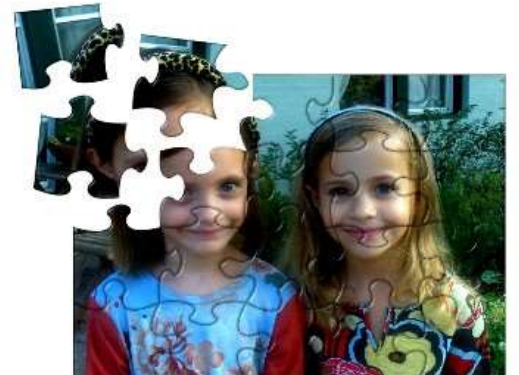
- Participating in school and community events to bring about an awareness, advocacy, and progress in integration.

Source: Adapted from Heward, W.L., Dardig, J.C., and Rossett, A. (1979) *Working with Parents of Handicapped Children*, Columbus, OH. Merrill.

Family Adaptation (con.)

► Family Types/Functioning

- Family composition
- Other family members on the spectrum; spouse on the spectrum
- Unresolved trauma activated
- Relationship difficulties magnified



Family Adaptation (con.)

- **Appraisal--How bad is this?**
 - Uncertainty regarding diagnosis
 - Long-term prognosis
 - Concerns over future caregiving
- **Negative appraisal related to poorest adjustment**
- Feelings of **grief**

Common Emotions related to a Diagnosis of Autism

<u>shocked</u>	anxious	unhappy	fuming	remorseful	joy
<u>numb</u>	worried	sad	furious	regretful	hopeful
<u>dazed</u>	disturbed	blue	disturbed	tainted	determination
<u>uneasy</u>	restless	negative	upset	unworthy	wise
<u>indifferent</u>	fretful	crushed	annoyed	embarrassed	patient
<u>sluggish</u>	nervous	dejected	uptight	victimized	enjoyment
<u>emotionless</u>	afraid	disheartened	touchy	unholy	compassion
<u>half-hearted</u>	pained	gloomy	distraught	culpable	nonjudgmental
<u>dull</u>	tormented	hopeless	agitated	penitent	victorious
<u>drugged</u>	distressed	discouraged	troubled	guilty	
<u>apathetic</u>	worked up	melancholy	grumpy		
<u>afraid</u>	ashamed	hollow	angry		

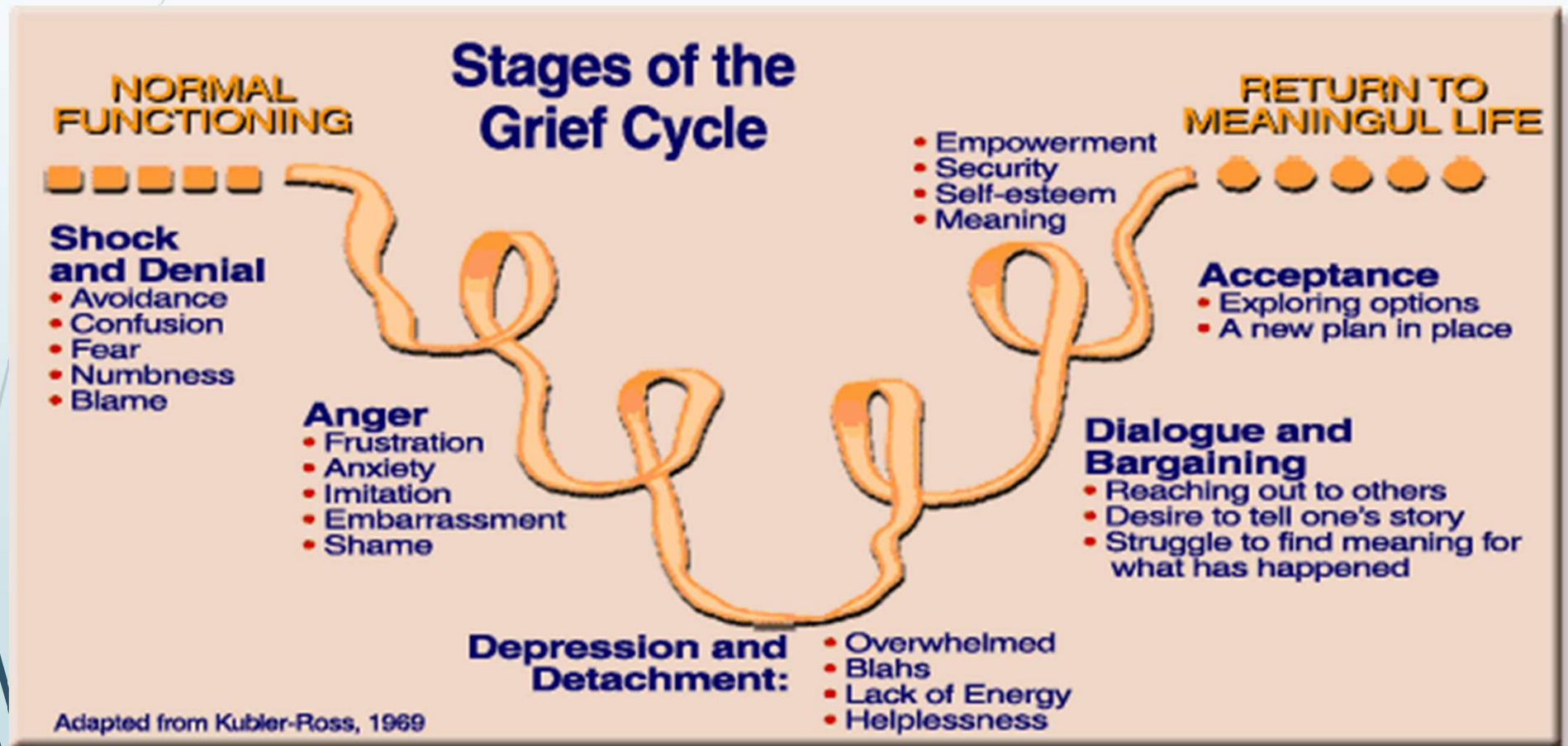
Triggers that can set off Grief

- Milestones
 - Prom
 - Religious Advancements
 - Younger siblings surpass
 - Young Adulthood
- Comparisons
- Comments/Advice
- Unmet expectations (even modified expectations)

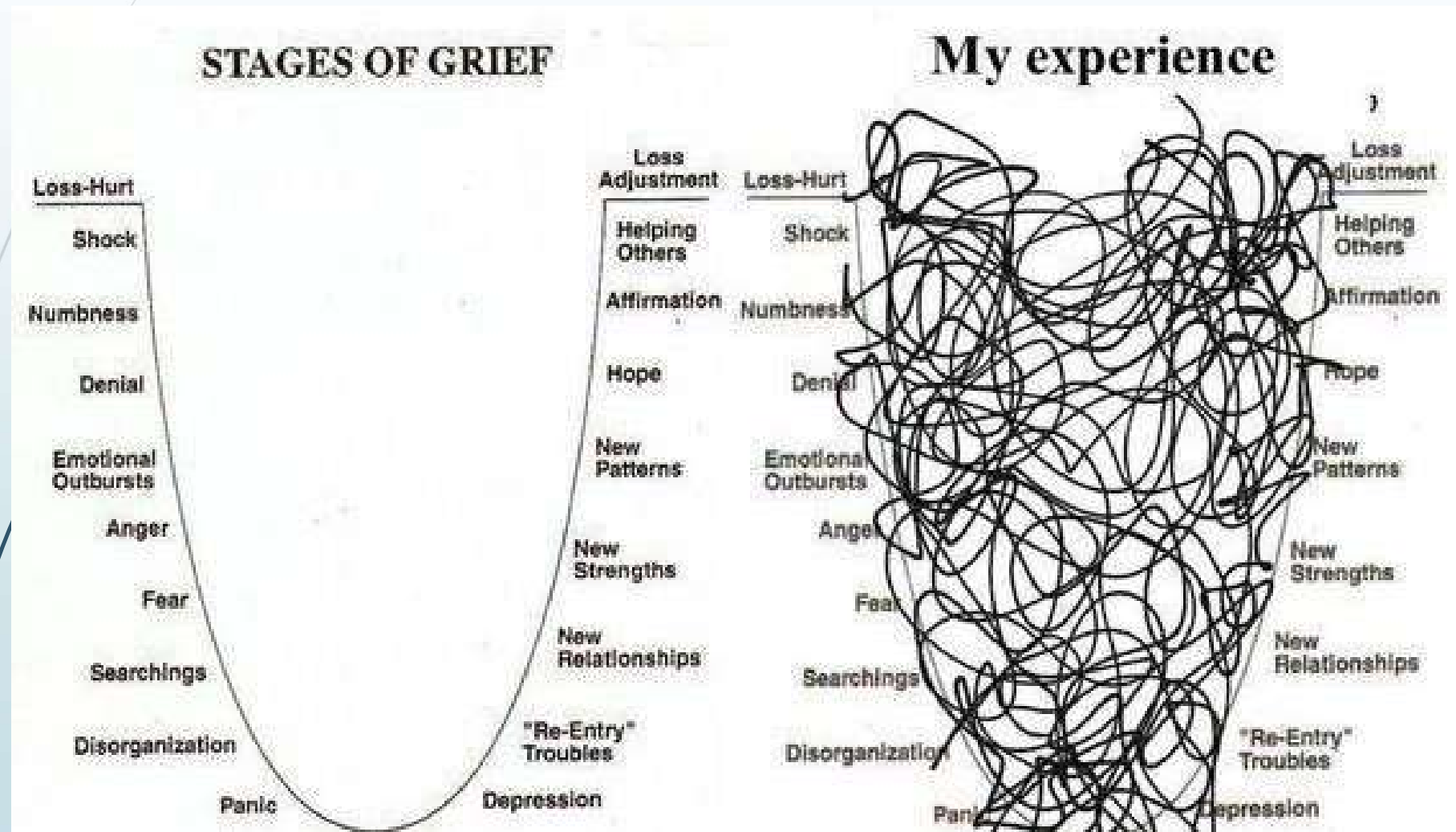
Traditional Stages of Grief



The myth is that it is a cycle and that it ends.



Messy Grief



Family Adaptation (con.)

■ Family Resources/Support

- Feelings of isolation
- Limited resources
- Lack of understanding and tolerance from society, including friends and family

Family Adaptation (con.)

► Problem Solving/ Coping

- Resources, **perceptions**, and behavioral responses interact to restore balance in the family
- More likely to predict adjustment than severity of disability



Marathon vs. Sprint



Marital Relationship



Some answers from the Social Sciences:

Children raised in intact married families:

- are more likely to attend college
- are physically and emotionally healthier
- are less likely to be physically or sexually abused
- are less likely to use drugs or alcohol and to commit delinquent behaviors
- have a decreased risk of divorcing when they get married
- are less likely to become pregnant/impregnate someone as a teenager

<http://www.foryourmarriage.org/married-parents-are-important-for-children/>

Marital Relationship

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- Greater Pressures/Lower Expectations??
- “We had no choice but to throw our marriage overboard.” (Couple in Counseling)
- When raising children with intensified parenting needs, we need to **intentionally** take care of our marriages. (Marshak)

Marital Relationship (con.)

- “The greatest gift you can give your child[ren] is a strong relationship between the two of you.” John Gottman, PhD

Sacrificing the well-being of the family as a whole, does not help the child.



“There is nothing noble in sacrificing yourself for others while you are starving at a psychological level.”

<http://www.peopleskillsdecoded.com/savior-complex/>

What are the characteristics of couples that thrive?

They have prioritized and protected the marriage. They don't assume that they have to put 100% of themselves into their children. (I don't think kids thrive when we put everything into them.) Both partners see each other as more than just parents. They take time to connect each day. They regularly have dates and vacations without the children — without guilt. Amy Baskin

When Autism enters a Family



- The marriage can disintegrate.
 - Sometimes mom and/or dad's life begin to revolve around the disability; they become disability expert/therapist/parent.
 - Sometimes dad falls into traditional role of providing money; he is not included or involved in treatment.
 - Sometimes the marriage turns into a treatment team; a good treatment team is not necessarily a good marriage.
 - Differences in acceptance of the diagnosis and/or treatment can escalate conflict.

When Autism Enters a Family

“We give up our interests and take on a new identity only to feel sorry for ourselves later and blame our spouses.”

(Mother of a child with Autism)--Harshak



When Autism Enters a Family



- A couple can draw closer.
 - Look to one another for strength.
 - Help each other.
 - Provide needed relief for each other.

Marital Relationship (con.)

- Establishing a great marriage is hard work under the best of circumstances.
- Couples who have a child with disability may be more likely to divorce, BUT the 80% divorce rate is a myth!

Don't Hack at your Boat in a Storm

“The advice I give to couples who sail into a storm and are fighting is: Don't hack at your boat in a storm. If you are in the middle of a crisis, don't take the very support you have and start whacking at it, because that is dumb. You should love, nurture, and care for that other person or you are not going to make it through the storm.”

-Parent of three children with fragile X syndrome



Couples including a Spouse with ASD

- Spouse can develop symptoms of emotional abuse—Cassandra Phenomenon
- Firm Boundaries must be maintained, “What’s ok and what’s not ok”—Dr. Brené Brown
- “Gentle Teaching”—Dr. Chelom Leavitt
- $\text{Suffering} = \text{Pain} \times \text{Resistance}$
(opposite of acceptance)

Couples including a Spouse with ASD (con.)

- Wives Support Group
 - Utah Valley Psychology, 801-854-7942
- *The Seven Principles for Making Marriage Work*, Dr. John Gottman
- Marriage with Asperger's Syndrome: 14 Practical Strategies

<https://www.aane.org/marriage-aspergers-syndrome-14-practical-strategies/>

The Book I Believe Saved My Marriage



Sibling Relationships



Siblings of Individuals with Autism



- Challenges
 - Overidentification
 - Embarrassment
 - Guilt
 - Isolation, Loneliness, and Loss
 - Resentment/Jealousy/Anger
 - Pressure to Achieve

Siblings of Individuals with Autism

► Strengths

- Pride in teaching their sibling
- Higher self-esteem, empathy, maturity
- Take lead role in relationship
- Less quarreling and competition than families without disability
- Positive adjustment, particularly for sisters



Recommendations

► Provide Information

- Hold regular family meetings to teach, discuss, and plan.
- Explain Autism to the child and the siblings at developmentally appropriate levels.

http://aspergers.ca/wp-content/uploads/media-library/article/pdfs/should_you_explain_the_diagnosis_to_the_child.pdf

- Teach siblings how to play with each other.

Recommendations (con.)

➡ Clarify Roles and Expectations

- ➡ Foster a culture of respect.
- ➡ Model making repairs and giving yourself a “timeout.”
 - ➡ Model feeling the feeling rather than becoming the feeling.
- ➡ Explain your “why” whenever possible.
 - ➡ Develop an agreement for when it is not possible.
- ➡ Redefine Success



Recommendations (con.)

■ Provide Emotional Support

- Help siblings accept “what is.”
- Provide the right to not be in the role of the parent.
- Provide appropriate share of family resources.
- Demonstrate parental love and attention to all children.



Recommendations (con.)

► **Provide Emotional Support (con.)**

- Challenge and discourage the use of absolutes. (Always, Never, Everyone).
- Provide the right, particularly in adolescence, of access to time unencumbered by obligation to the sibling with Autism.
- Provide the right to plan for and live a life on one's own, including the right to choose whether or not they will take care of the sibling in old age.

Recommendations (con.)

► Provide Emotional Support (con.)

- Set realistic expectations for siblings.
- Spend individual time with each child in the family.
- Model appropriate expressions of thoughts, concerns, and feelings.
- Create an open environment where siblings share thoughts, concerns, and a wide range of emotions.
- Provide the right to be free of guilt regarding sibling with Autism.

Recommendations (con.)

► Provide Emotional Support (con.)

- Help siblings know they have right to their own life.
- Avoid parental favoritism.
- Provide siblings with private space/time.
- Demonstrate positive interactions with child with Autism.



Recommendations (con.)

➤ **Assure Social Support**

- Assure that not everything needs to be done as a family.
- Encourage activities unique to them.
- Allow them to enjoy special outings with others—extended family, friends.
- Solicit help from family, friends, support groups.
- Provide opportunities to meet other siblings. (i.e. Sibshops)

Recommendations (con.)

- Explain concepts of fair and equal.
 - Fair isn't treating everyone the same; fair is treating each person how they need to be treated.
 - In fact, it would be highly UN-fair to treat everyone the same.



Extended Family Relationships



Stressors for Extended Family

- Grief
- Concern for their child
- Don't know what to do
- Disbelief and confusion



Helpful Responses FROM Extended Family

- Ask how you can help
- Seek out your own support
- Be open and honest about the disorder
- Put judgment aside
- Learn more about Autism
- Carve out special time for each child



Extended Family

- “Understanding Jason”
 - Create your own story



Helpful Responses TO Extended Family

- Decide what WILL work for your family and communicate that.
- Set boundaries assertively.
- Avoid all or nothing reactions.
- Consider making an exit plan for family gatherings.
- Allow time and space to catch up.

Helpful Responses TO Extended Family (con.)

- Pre-forgive people.
 - Some people are intuitive and “get it” with no instruction needed.
 - Some people are willing to learn and “get it” with some instruction.
 - Some people are “never” going to “get it.”

Delayed Independence



Delayed Independence

- Social and Emotional functioning often at about 2/3 of chronological age.
- This generation has been called the “boomerang” generation for difficulty in launching.

Delayed Independence (con.)

- For Parents:
 - Decide your boundaries and flexibly enforce them.
 - Don't feel guilty about your limits.
 - Consider considering yourself as a safe harbor.

Delayed Independence (con.)

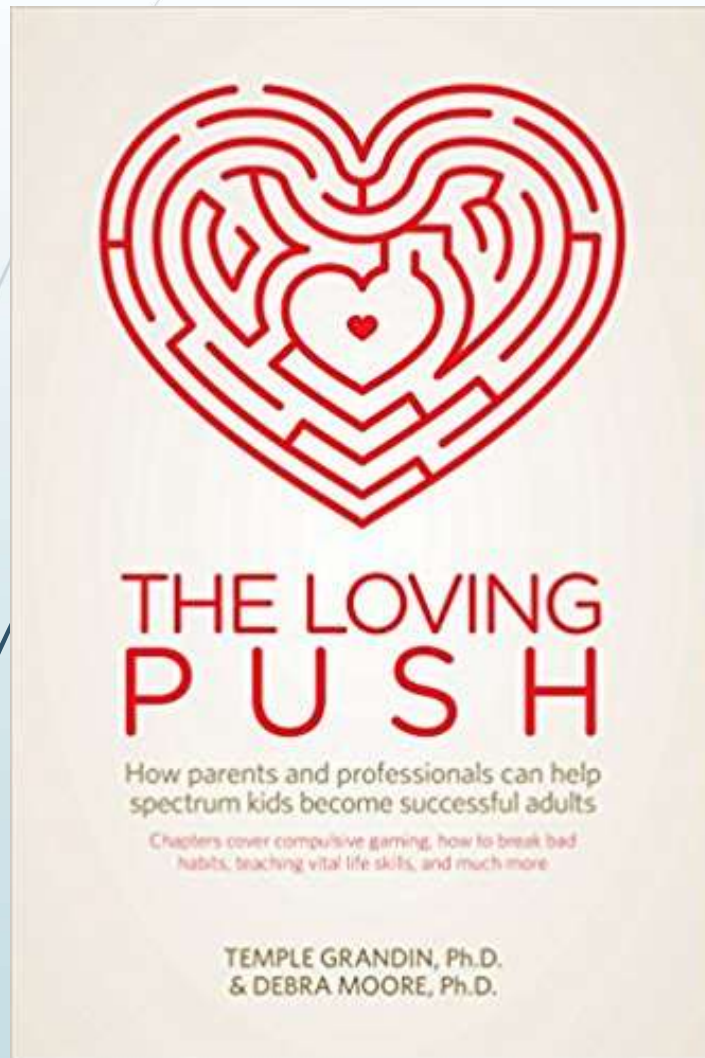
- For Autistic Adults:
 - Aim for growth.
 - Create systems of success for yourself. (Jared Stewart /Passages)
 - Give yourself permission to modify your pace.
 - Compensate for any difficulties with your strengths.



Delayed Independence (con.)

- For Both:
 - Be hopeful yet realistic.
 - Strive for good physical and mental health.
 - Watch your stress levels.
 - Remain open to new opportunities.
 - Give each other lots of grace.

Resource



Take Care of the Caregiver

1. Be gentle with yourself. Be your own best friend.
2. Remind yourself that you are a loving helper, not a magician. None of us can change anyone else—we can only change the way that we relate to others.
3. Find a place where you can be a hermit—use it every day—or when you need to.
4. Learn to give support, praise and encouragement to those around you—and learn to accept it in return.
5. Remember that in the light of all the pain we see around us, we are bound to feel helpless at times. We need to be able to admit this without shame. Just in caring and in being there, we are doing something important.
6. Learn to vary your routine often and to change your tasks whenever possible.
7. Learn to know the difference between the venting that *relieves* tension and the venting that *reinforces* it.
8. Focus on one good thing that happened during the day.

Take Care of the Caregiver (con.)

9. Become a resource for yourself! Be creative and open to new approaches to old things.
10. Use the support you give to others or a “buddy system” regularly. Use these as a support, for reassurance and to redirect yourself.
11. Avoid “shop talk” during your breaks or when you are socializing with colleagues.
12. Learn to use the expression, “I choose to...” rather than expressions like, “I have to...,” “I ought to...,” or “I should...”
13. Learn to say, “I won’t...” rather than, “I can’t...”
14. Learn to say “no” and mean it. IF you can’t say “no,” what is your “yes” worth?
15. Aloofness and indifference are far more harmful than admitting to an inability to do more.
16. Above all else—learn to laugh and to play.

*Author Unknown—NAMI Family to Family Program
5/98*

Summary

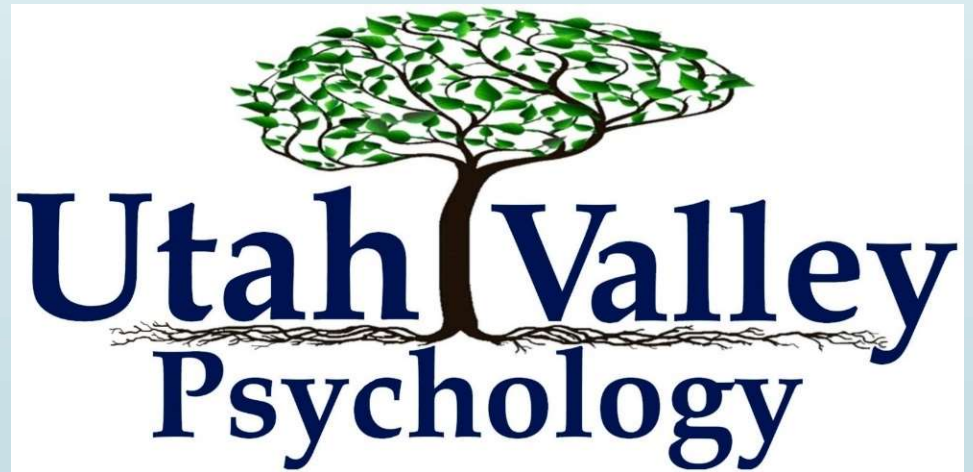
- Families will do better that:
 - Practice acceptance of what is.
 - Continually strengthen their support system
 - Practice not blaming.
 - Save space for their marriage.
 - Honor space for the siblings.
 - Practice not giving energy to what other people may think.

Questions?

► Karen Fairchild, LCSW

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801-854-7942



Resources in Utah County

Melissa Nellesen Center for Autism at UVU

801-863-7620

autismcenter@uvu.edu

Resource Hub for Utah County, including library.

Resources in Utah County (con.)

Autism Resources of Utah County (ARUCC)

<http://www.autismresourcesuc.org/> (local conferences, autism awareness events, local resource lists)—Facebook Group

Wasatch Behavioral Health's GIANT Steps Autism Program

<http://www.wasatch.org/autism.html>

801-226-5437 (preschool, parent training)

Resources in Utah County (con.)

Utah Autism Academy 801-437-0490

<http://utahautismacademy.com/>

(preschool, Kindergarten through secondary education) Private and Insurance pay

BYU Comprehensive Clinic 801-422-7759

(speech therapy)

Wasatch Behavioral Health 801-373-4765

(Medicaid Provider—diagnosis, therapy, groups)

Resources in Utah County (con.)

Orem Pediatric Rehabilitation

801-714-3505 (speech therapy, occupational therapy [sensory processing disorders], physical therapy)

Autism Council of Utah

www.autismcouncilofutah.org

(Website with compilation of community autism resources and information)

➡ Big MAKs Facebook Group

Early Intervention

Kids on the Move (Alpine School District)

Provo Early Intervention Program (Easter Seals)

Kids Who Count (Nebo School District)

- Federally Mandated
- If there are concerns about development, do not hesitate to have a child assessed through early intervention.

Autism Speaks

- Video Glossary
- First Signs
- Tips for Families
- Treatment Recommendations
- Research Updates
- Legislative Updates
- Much more

www.autismspeaks.org

Organization for Autism Research (OAR)

- Research based information for
 - Families
 - Educators
 - Self-Advocates

researchautism.org/

Safety Resources

September 26th Project

<https://www.september26.org/>

- Wandering

- Always check nearby bodies of water first due to high risk of drowning.

- Natural Disaster

- Fire Safety

Orem City Mental Health Response Team

<https://orem.org/mhrt/>

- Register in advance of incident