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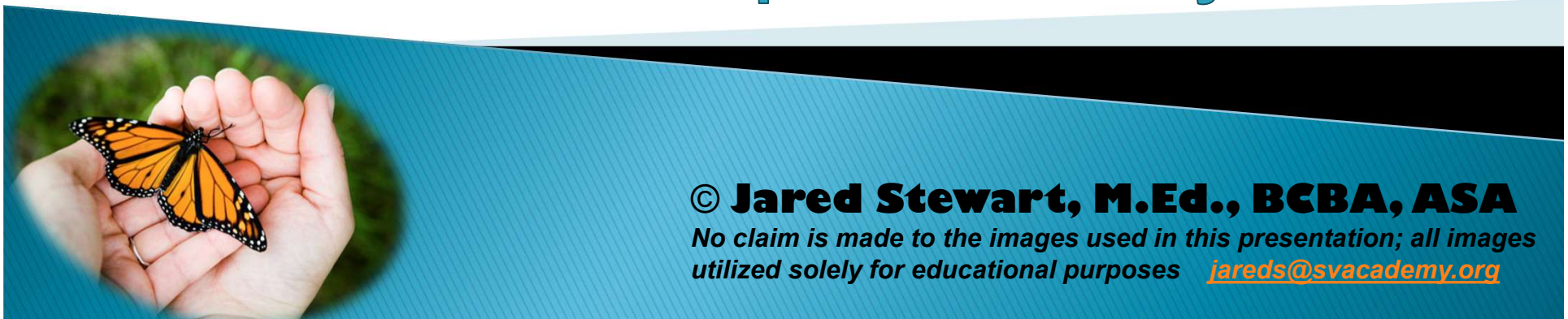
(song by the Lonely Island)



# The Dignity of Risk

*Balancing Rights with our Duty and Desire to Care*

**AKA “Too Much Help Can Actually Harm”**



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Kodiak Island, Alaska

ScenicView Academy,  
Provo



Jared Stewart, M.Ed, BCBA

- Program Director, SVA
- Adjunct Professor, UVU
- UDDC Chair, UAI, etc...



# Introduction

- **Working with Neurodiverse adults since 2002**
- **Father of three children with special needs**
- **Neurodivergent myself from birth... ☺**
- **Today's Objectives:**



1. **WHAT**– What is Belonging? And what is it's connection to the “Dignity of Risk?”
2. **WHY**– Why are Belonging and Boundaries such important considerations?
3. **HOW**— How do we best balance the Right To Risk with the Duty To Care?

# Belonging

- ▶ Think of a time where you knew you didn't belong
- ▶ Maybe you were picked last, picked on, or never picked at all
- ▶ Maybe you were left out, laughed at, or overlooked
- ▶ Maybe you had to hide your religion, accent, sexual orientation, true thoughts, or true feelings



# Belonging



- ▶ **Exclusion Hurts**; and thinking of times when you didn't fit in because of something you couldn't control can teleport you right back into that sad, pit-in-your-stomach feeling.
- ▶ And yet, true Belonging is extremely difficult to actually achieve!
- ▶ *Just because someone is included, it doesn't mean they feel they belong.*

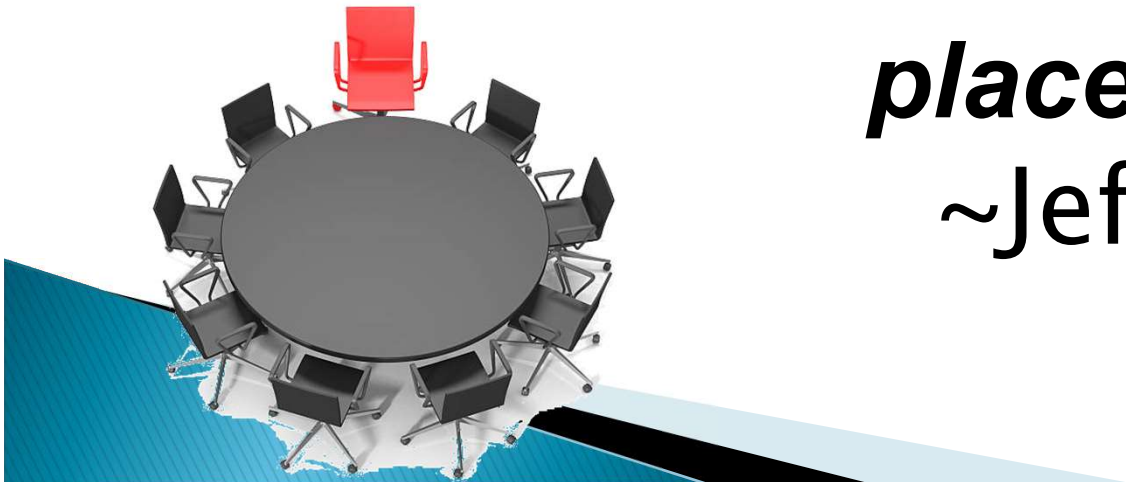


# Belonging



***“**Inclusion** is having a seat at the table. **Belonging** is not only being at the table but **having a voice that matters in the conversation and decision-making that takes place at the table.**”***

**~Jeffrey Peterson**



# Belonging



- ▶ Would you have felt belonging if you didn't have a voice?
- ▶ If you didn't have a say in the decisions made by the community? (especially the decisions about YOU?)
- ▶ **Question:** would you actually feel SAFE in a place like that?
- ▶ How can we be safe if other people are in charge of everything for us???

# Belonging???



- ▶ **What if some well-meaning folks, who are more experienced, successful, and intelligent than us (or who at least think they are) , decided that they were just going to go ahead and start an ABA or some other therapy program for us?**
- ▶ **Or that they would permanently take control of our finances, living arrangements, transportation, or ability to enter into contracts?**
- ▶ **What would make that OK (even possibly positive)?**
  - ▶ **Answer = ONLY Safety or Autonomy!!!!**

**Based on what is  
MEANINGFUL TO YOU!**



# Belonging???



## Without Choice and Consent, How Can We Feel Like We Belong?!

- ▶ **Imagine for a moment if your significant other wanted you to change one of your behaviors... Maybe you forget to do the dishes, or you talk during movies...**
- ▶ **Now imagine that they refused to acknowledge you if you didn't do the behavior they wanted you to do. Or if they refused to hug you, or talk with you, or stopped you from watching TV or using your phone until you followed through with their "target behavior".**
- ▶ **Wouldn't it make you feel uncared for? Like you were being manipulated? Like you didn't matter; that all that mattered was complying with whatever they wanted?**

*Adapted from George, K. (2019) Five Important Reasons Even "New ABA" is Problematic*

*How often do we, WITH GOOD INTENTIONS,  
end up doing this to people with disabilities?*

# Belonging



- ▶ Now think about a time or place where you DID belong!
- ▶ How did you feel?
- ▶ Peaceful? Understood? Appreciated? Supported? SAFE?
- ▶ ***We all want to feel safe!!!***
  - ▶ *To never be hurt*
  - ▶ *To never see our loved ones get hurt*



# Belonging and Safety

- ▶ Safety is terribly misunderstood!
- ▶ We look at the world, and we see how unprepared our children are, and how vulnerable. We see their very real limitations.
- ▶ It's so easy to think that keeping our loved ones with disabilities safe is the most important thing...



# Belonging and Safety



*Finding Nemo*; © Pixar 2003

# Riddle Number 1:

► What do you call a place where you always:

- Have 3 meals a day,
- Have clean clothes picked out for you,
- Have a full daily schedule decided for you,

► And you can only:

- Go where other people take you
- Use “screens” with permission
- “Play” only when and for how long you are told to
- Eat what and when you are allowed to
- Do the work other people choose for you

► But you are always watched over?

**PRISON!**





# Riddle Number 2:

- ▶ What do you call a person who is absolutely safe;
- ▶ Who never has to worry about getting abused, exploited, hurt, embarrassed, harassed, offended, disappointed, or made fun of;
- ▶ Who never has to worry about injury, accident, other people, money, finances, relationships, transportation, housing, identity, education, illness, employment, or failure?

**DEAD!**



# Who Here Has Ever...

- ▶ Made some choices you wouldn't want your mom to know?
- ▶ Signed a contract without understanding every part of the fine print?
- ▶ Made a purchase that turned out to be financially irresponsible? (Ran up debt on a credit card?)
- ▶ Gotten physically injured doing some everyday task? (Or done something physically risky?)
- ▶ Gotten hurt in a relationship?
- ▶ Done or eaten something unhealthy?
- ▶ Gotten ticketed or fined?
- ▶ Jaywalked? Trespassed?
- ▶ Been late on a bill?
- ▶ **ETC!**



# We All Should Have Guardians! 😊

- ▶ How many risks have YOU taken in the past week? How many risks have you taken today?
- ▶ Situations where you might have:
  - Made a choice that could have long-term costs?
  - Hurt your feelings (or someone else's)?
  - Gotten injured?
  - Gotten embarrassed?
  - Gotten killed???



**Scary Stat:** In 2022, just in the state of Utah, over 26,000 people were injured, and over 320 people were KILLED as a result of automobile accidents!

*Are you planning to give up driving???*

# Concept: The Dignity of Risk



- ▶ There is RISK in every aspect of real life!
- ▶ Every individual has the right to make choices!
- ▶ Some choices will inevitably be mistakes...
- ▶ Every individual has the **RIGHT to FAIL!**
- ▶ It is in failure, learning from failure, and adjusting that we eventually find success!
- ▶ We can't RISE more than we RISK!
- ▶ Everything involves RISK!
- ▶ Our job is to make it SAFE to FAIL, and then to
- ▶ Learn to **LET GO!**
- ▶ **THIS IS KEY!** *(favorite stories; my story)*



# Concept: The Dignity of Risk



**“All people have the right to eat too many donuts and take a nap!**

**Teaching clients how to express their freedoms responsibly should be an integral part of the habilitation process. While learning, clients should be encouraged to make as many choices as their abilities allow... service providers should challenge themselves to work harder at teaching and providing opportunities for choice...**

**Although extra time and teaching are needed to help clients learn to make choices, this liberty may facilitate habilitation...”**

*Bannerman, D. J., Sheldon, J. B., Sherman, J. A., & Harchik, A. E. (1990)*



# Concept: The Dignity of Risk



## Definition:

- ▶ ***The idea that Self-Determination and the right to take Reasonable Risks are essential for Dignity and self esteem and so should not be impeded by excessively cautious caregivers, who are legitimately concerned about their Duty of Care.***
- ▶ **Cornerstone of the ADA and the Disability Rights and Self-Advocacy Movements!!!**



# Developmental Disability Act (1963)



The 1990 ADA  
Guarantees  
EQUAL  
OPPORTUNITIES!

- ▶ *“Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently,*
- ▶ *to exert control and choice over their own lives, and to*
- ▶ *fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society...”*
- ▶ *“People with even the most significant disabilities are capable of:*
- ▶ *Independence, Self Determination, Productivity, Integration and Inclusion in all areas of community life.”*

**Max Barrows, ASA, Vermont**

**Dignity Of Risk**

*Why is this so hard for us???*

*What are we so scared of???*

# Dr. Tony Attwood:



“Professionals and service agencies tend to see children and adults with [Neurodiversities] who are having problems that are highly conspicuous and difficult to treat or resolve, *and this may lead to an overly pessimistic view of the long-term outcome.*”

~The Complete Guide to Asperger's Syndrome

*“We were surprised... in the scientific literature [that] there are young people who have minimal verbal skills who do lead, at age 19 or 21 or even later, quite happy lives.”* ~Dr. Catherine Lord



# What Are We Afraid Of?

- ▶ Thinking about our special needs children and their unique situations, **what are some of our biggest worries about their adulthood?**

Dr. Sean Stephenson, 1979-2019

- ▶ **The “Terrible Questions”:**
  1. Will my child ever be able to live on their own?
  2. Will my child ever have a job?
  3. Will my child ever be “normal”?
  4. Will my child have caring people around them? (friends?)
  5. What will happen to them after I die?
- ▶ These are REAL concerns.
- ▶ But our kids are going to grow up.
- ▶ What then???





# The Reality:



- ▶ “Failure to Launch” is common...
- ▶ A 2010 study by Easter Seals analyzing outcomes for 1,714 adults over the age of 18 found that:

Area of Independence Examined:	ND Young Adults	TD Young Adults
Live with Parents/Guardian	69%	17%
Employed Full Time	11% (19%-PT)	58% (24%-PT)
Manage their own Finances	34%	82%
Have ADL Skills	30%	83%
Has Friends	50%	88%
Recreates Regularly	40%	69%
Who will take care of them when the parents are gone? 39% = Sibling; 31% = “No Idea”		

Source: [Easter Seals Study \(2010\)](#)

- ▶ ***But there is NOWHERE in the DSM that says that people with Neurodiversities CANNOT become independent adults!***

# Donald Triplett — “Case 1”

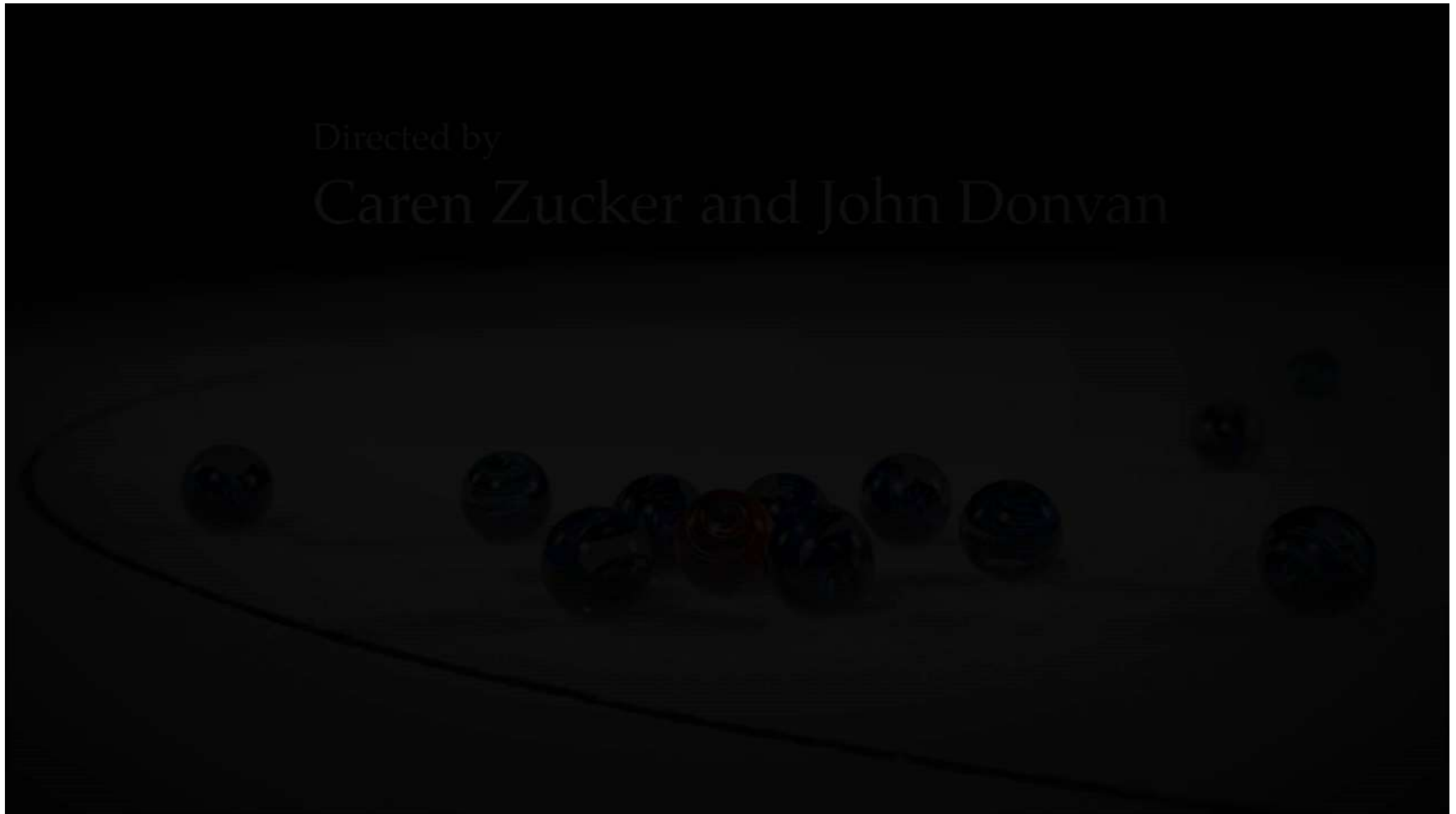
- Diagnosed in 1938 at the age of 5 by Dr. Kanner
- **The FIRST diagnosed case of autism**
- Fixated on spinning objects, spinning himself, and rolling nonsense words around in his mouth
- **Rarely listened to/obeyed his parents**
- Awkward movements/motor coordination
- **No apparent interest in other people or socializing**
- Poor eye contact
- **Assigned everyone numbers in place of names**
- Wrote letters in the air with his fingers
- **Institutionalized at age 3 as “hopelessly insane”**



*The Atlantic*, October 2010  
In A Different Key, 2022

# Donald Triplett — “Case 1”

Directed by  
Caren Zucker and John Donovan



*The Atlantic*, October 2010  
In A Different Key, 2022

# Donald Triplett — “Case 1”

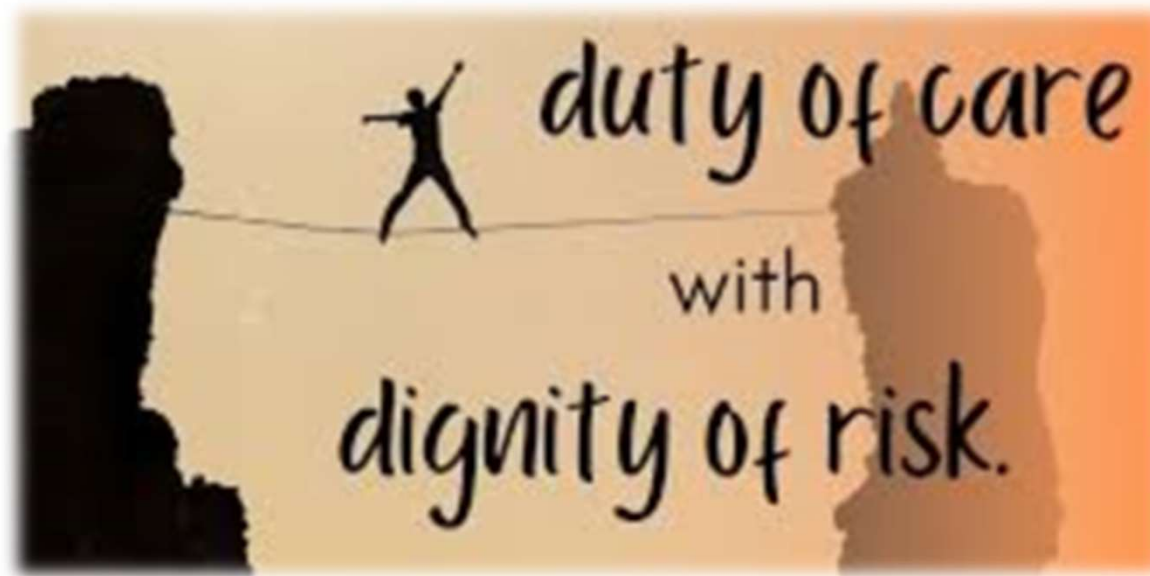
Lived to be almost 90! (9/1933-6/2023)



- ▶ Graduated High school!
- ▶ Graduated College! (and active frat member!)
- ▶ Worked as a bank teller!
- ▶ Lived on his own! (and loved to send postcards)
- ▶ Learned to Golf, drive, & travel the world —all independently!  
*(First developed these skills at respective ages of 23, 27, and 36)*
- ▶ Always had a fairly rigid routine (but it was HIS and it involved people and positive goals: exercise, recreation, and scrapbooking)
- ▶ Had early childhood “interventions” (farming, mainly)
- ▶ Had life goals tied to his areas of preoccupation
- ▶ Had neighbors and friends who would “not only shrug off his oddities, but openly admire his strengths”
- ▶ Had Community Support (“Acceptance”)
- ▶ Check out the PBS Documentary!

*The Atlantic*, October 2010  
In A Different Key, 2022

# The Balancing Act...



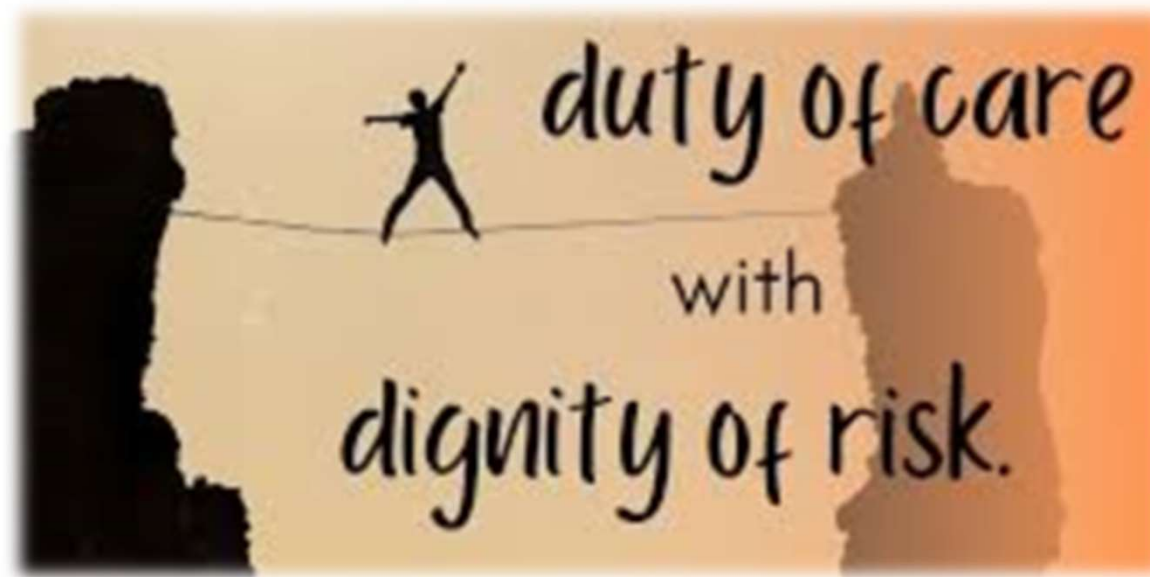
- ▶ **Duty of Care** = The requirement that we “do no harm” and act towards others with a reasonable standard of watchfulness, attention, caution, and prudence. The opposite of negligence.

*“Our Starting Point must be from Dignity of Risk!”*

~Dr. Emi Golding



# The Balancing Act...



**Duty of Care trumps Dignity of Risk ONLY  
when there is threat of “Death or  
Permanent Serious Disability”!!!**

*“Our Starting Point must be from Dignity of Risk!”*

~Dr. Emi Golding

# Duty of Care does NOT Mean:

- ▶ **Infantilization** (“but they’re just a 3 year old in a 24 year old’s body”)
- ▶ You have to protect the person “**from themselves**”
- ▶ That the person is **100% safe** at all times

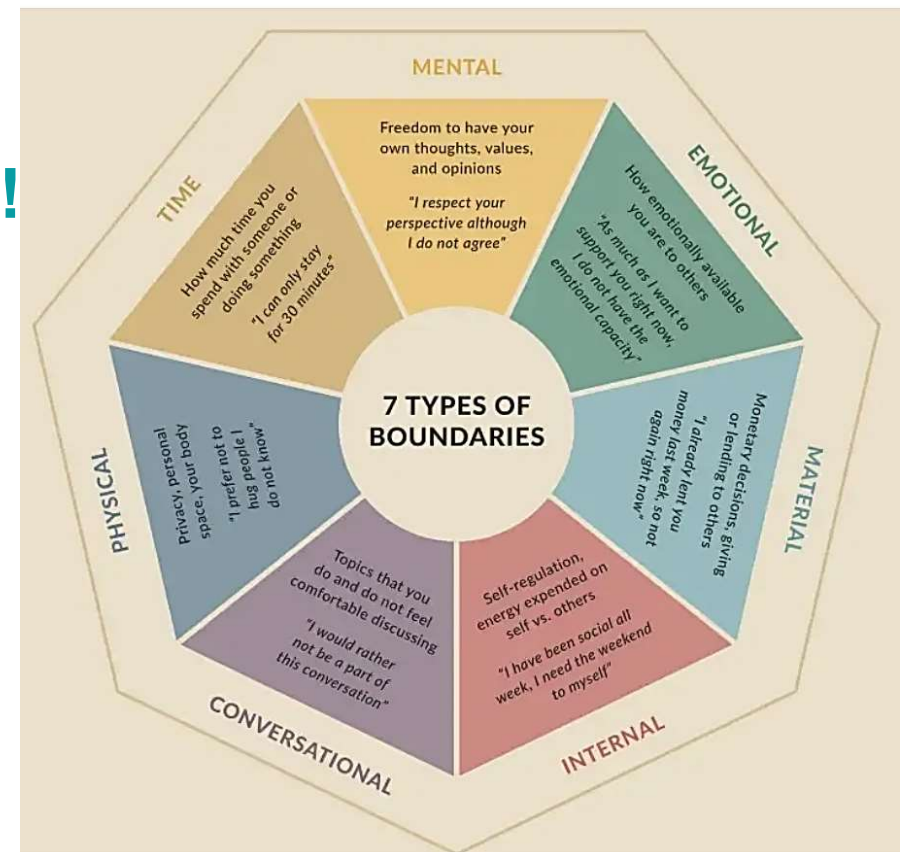
## But it DOES mean:

- ▶ We teach
- ▶ We push
- ▶ We mentor
- ▶ We trust
- ▶ We **CARE!**



# But What About Boundaries?

- *Ok, so I want to give the Dignity of Risk, but don't there have to be limits on what I let someone do?*
- **Boundaries = Lifesaving!**
- **Boundaries = Empowering!**
- **Boundaries = Scaffolding!**
- **Boundaries = Teaching!**
- *“Give a man a fish...”*



**Dr. H. Wong:**

***“Whoever does the work  
does the learning.”***



**(Who is doing “the work”?)**

**Dr. Peter Gerhardt’s Question:**

***“Is this outcome more the result  
of their diagnosis, or more the  
result of their never having been  
taught a reasonable cohort of  
actual living skills?”***



# Self Determination

- ▶ *Freedom to live as one chooses, or to act or decide for oneself without consulting others*
- ▶ **It's about letting individuals CHOOSE what they want to work on, what they want to achieve**
- ▶ *It's about handing control back to the individuals we provide care for*
- ▶ **Our job is NOT to decide what everyone is working on, or what is best for them**
- ▶ *Our job is to ensure proper supports are in place as people exercise their **AUTONOMY***

*Good Rule of Thumb = What choices are non-disabled people allowed to make?*





# Supporting Self-Determination

1. Assumed Capacity (“Ability Mindset”)
2. Tolerance for Risk (No Risk = No Reward!)
3. Reasonable Supports (“Safe to Fail”)
4. Deference to Preference (Even when we don’t think that the choice is for the best!)

- Self-Determination→
- Self-Reliance→
- Self-Discipline→
- Self-Esteem! (**Dignity**)



# Self Determination = Affirm Autonomy



- ▶ A word on Supported Decision Making [www.supporteddecisionmaking.org](http://www.supporteddecisionmaking.org)
- ▶ Guardianships are not inherently bad...
- ▶ But they should not be your first or only choice if independence is your goal!
- ▶ *Guardianship = Civil Death!*

*Power of attorney, advance direction letters, or even limited guardianship can be better alternatives!*



# Self Determination = Affirm Autonomy



Keeping in mind that the freedom to make decisions defines all of us as human beings and plays an important part in determining our quality of life, ask yourself, "What kinds of decisions do I make every day that I value the freedom to make for myself?"

*"What kinds of decisions do I make every day that I value the freedom to make for myself?"*



In order to promote independence, dignity and freedom of choice, it is important to remember that **all adults are presumed competent to make choices about their lives**. Simply because a person has a developmental disability, mental illness or is aging is *not* a reason to assume the person cannot make decisions. Sometimes, because of limited cognitive or communication skills, a person may simply need help with making decisions.

They may be as simple as the following:

- What you wear
- What you eat
- What time you get up in the morning or go to bed at night
- Where or with whom you live
- Who your friends are
- When and where you may go in your community
- How your money is spent

They can also be significant, such as the following:

- The right to vote or obtain a driver's license
- The ability to consent or object to medical care
- The ability to enter into contracts like marriage or home ownership

**It is critical to find the least restrictive way!**

<https://moguardianship.com/>



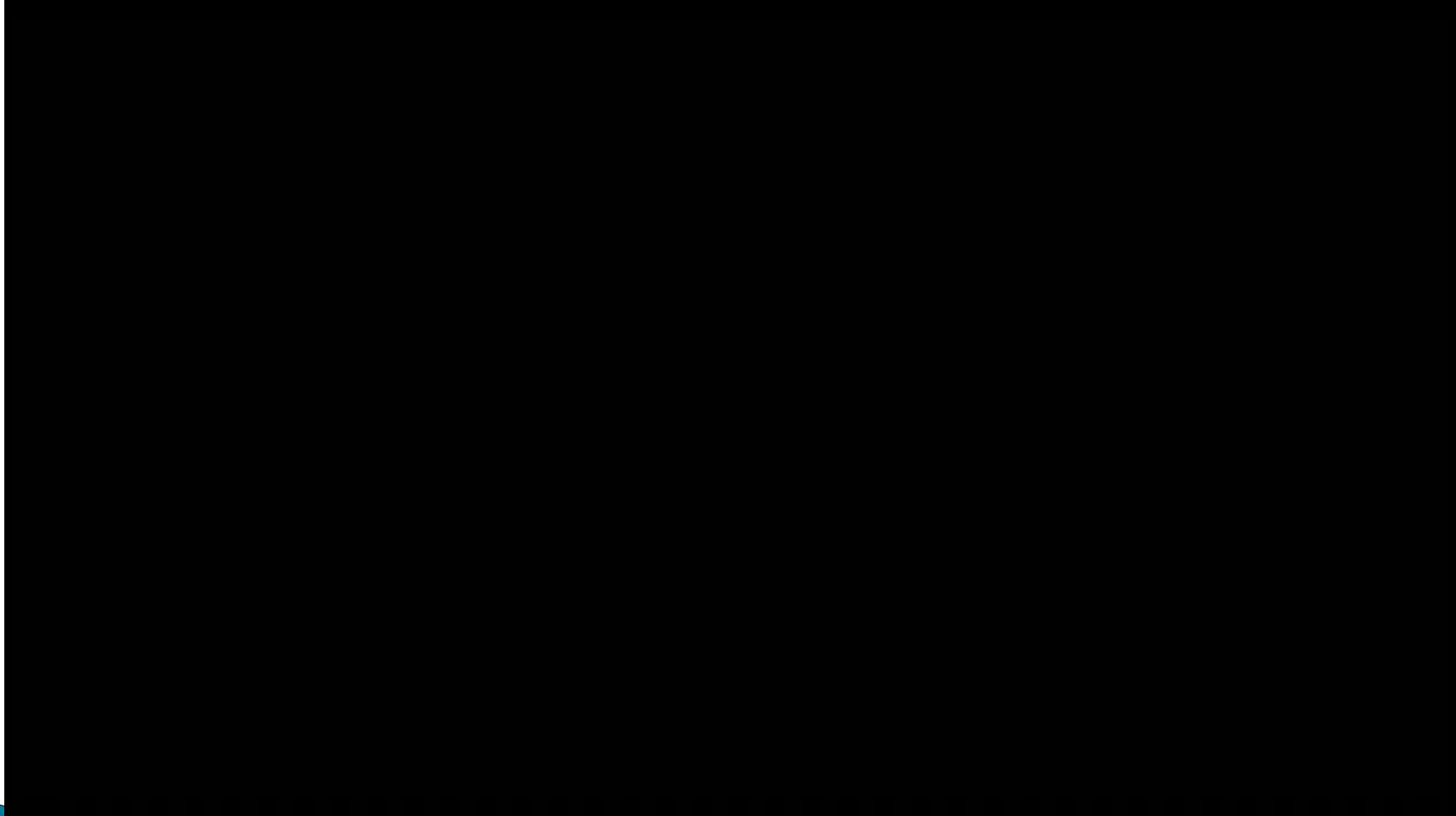
# Self Determination = Affirm Autonomy



- ▶ A word on Supported Decision Making [www.supporteddecisionmaking.org](http://www.supporteddecisionmaking.org)
- ▶ **“My Voice Counts”**
- ▶ Free guide from the UDDC
- ▶ Great place to start!
- ▶ [www.UtahDDCouncil.org](http://www.UtahDDCouncil.org)
- ▶ **Speaker’s Network page** has the downloadable guide...
- ▶ **Resources page** is a gold mine!
- ▶ *How would you want to live?*



# **Justice for Jenny—Dignity Wins!**

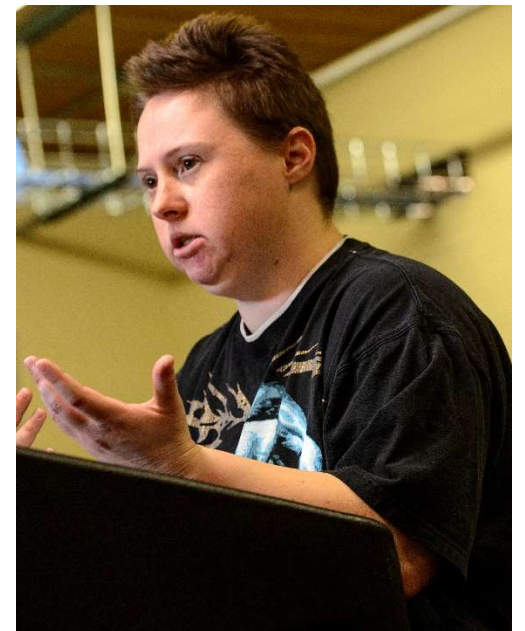




# Staci Christensen– Risk for Utahns

## People

- ▶ “Sometimes, [living in the ICF] feels like a prison, and that makes me sad and frustrated. I’d like to have more freedom and be able to have more control over my choices. I’d like to be able to do things on my own, without following so many rules and being told what to do...But that’s impossible to do when I’m living like this.”
- ▶ “If I had my own place, I’d have my mom or my friends over for dinner, and I’d make fried chicken, mashed potatoes and gravy, and maybe some corn or carrots. For dessert, I’d make something chocolate. *It would be my decision, not somebody else’s.*”



**Staci sued to win the right to self-determination in 2018!**

<https://le.utah.gov/interim/2019/pdf/00002613.pdf>

EXPLORE People

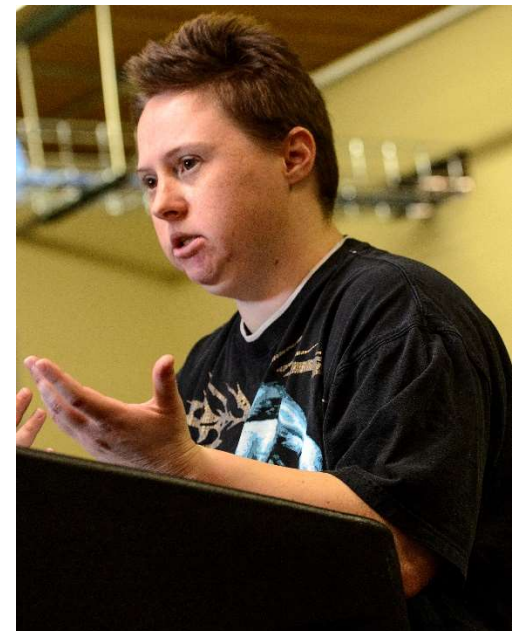
PEOPLE.COM > HUMAN INTEREST

Utah Woman with Down Syndrome Hopes Lawsuit Will Lead to a More Independent Life: 'It's My Dream'

# Staci Christensen– Risk for Utahns

People

- ▶ “Where I live now, I like to sleep in, but I have to get up at 6 when they announce that it’s time to eat breakfast. And everybody has to be in bed by 10. I’m tired of living by rules like that. I’d love to get an education, I’d love to go on my first date and learn how to drive.”
- ▶ “My biggest dream, I guess, is that *I just want control of my own life.*”



**Staci won her case and Utah settled on May 15, 2019!**

<https://le.utah.gov/interim/2019/pdf/00002613.pdf>

EXPLORE People

PEOPLE.COM > HUMAN INTEREST

Utah Woman with Down Syndrome Hopes Lawsuit Will Lead to a More Independent Life: 'It's My Dream'



# Staci Shared a Poem...



• **"SPECIAL" NEEDS POEM** •  
THEY SAY THAT I HAVE "SPECIAL" NEEDS,  
AND WHILE THAT'S PARTLY TRUE,  
• THE NEEDS THAT MATTER MOST TO ME •  
ARE THE SAME ONES YOU HAVE, TOO.  
**I NEED TO BE ACCEPTED.**  
I NEED FRIENDS THAT MAKE ME SMILE.  
• I NEED A CHANCE TO LEARN AND GROW •  
FEELING VALUED ALL THE WHILE.  
**SURE, I NEED SOME EXTRA HELP,**  
**AND SOME THINGS I CAN'T DO,**  
• BUT I HOPE YOU'LL SEE BEYOND ALL THAT... •  
INSIDE, I'M JUST LIKE YOU.  
**-APRIL VERNON**

**People**

# The Loving Push...

## WHO HELPED PUSH YOU?



- **When you were starting out as a young adult, WHO and WHAT prepared you and stretched you to be able to handle adult responsibilities?**
  - How did you feel about it at the time?
  - How do you feel about it looking back?



"I had people in my life who didn't give up on me: my mother, my aunt, my science teacher... I cannot emphasize enough the importance of a mentor...

The most important thing people did for me was to expose me to new things... I think sometimes parents and teachers fail to stretch kids. My mother had a very good sense of how to stretch me just slightly outside my comfort zone... Parents need to let go and give careful, **loving pushes** to get their child to try new things" ~Temple Grandin

# The Loving Push...

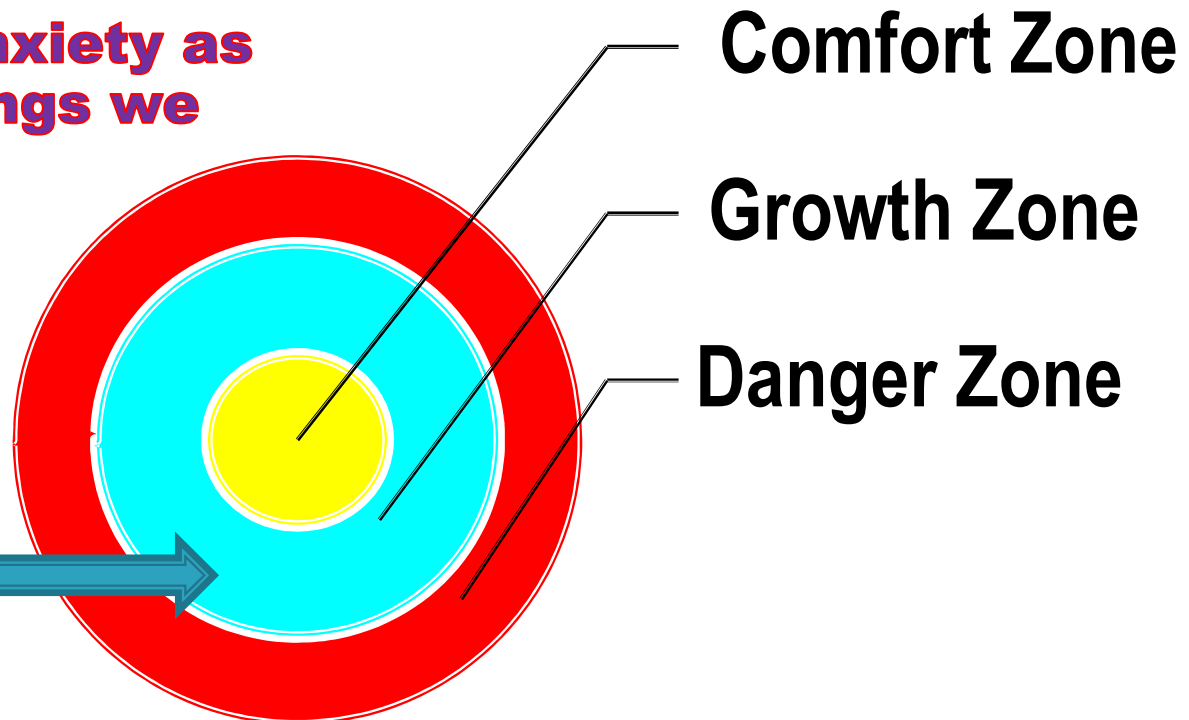


**Growth** = “Zone of Proximal Development”

- **We are going to naturally feel anxiety as we try to do things we don't feel 100% certain about**

- **But that's the ONLY WAY TO GROW!** 😊

**ZPD = Where you want to Be!**



“One common denominator [of Neurodiverse youth who successfully made the transition to adulthood] was that each person was encouraged and “stretched” just outside their comfort zone by at least one adult in their life.” ~Dr. Debra Moore

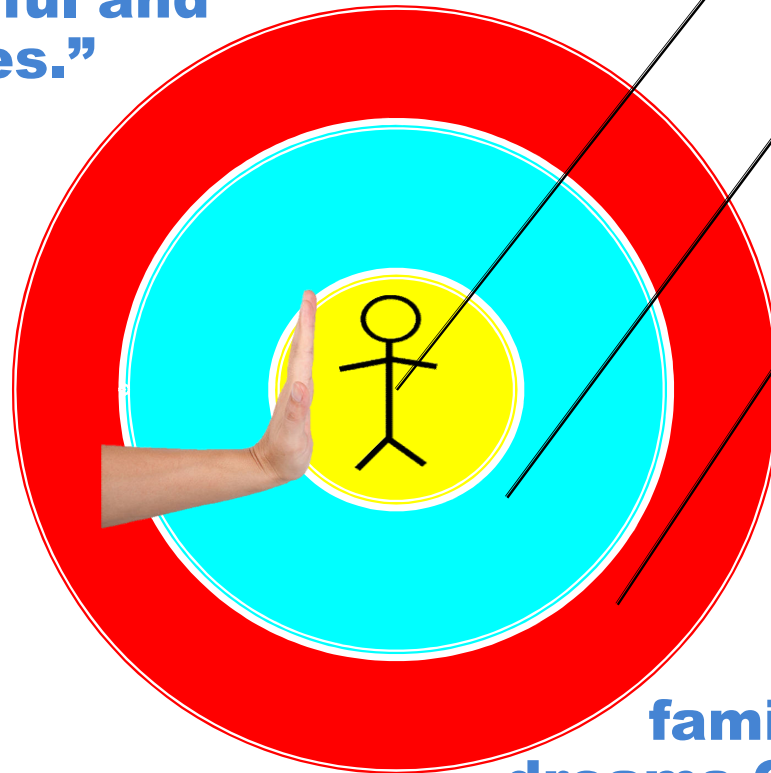


# The Loving Push...

**Growth = Comfort Zone + 1**



**“All children should have hopes and dreams, and the opportunity to chose and lead meaningful and satisfying lives.”**



**Comfort Zone**

**Growth Zone**

**Danger Zone**

**“With the support, Intervention, and “loving pushes” of family and others, those dreams CAN come true.” ~xv**



**THE LOVING  
PUSH**

How parents and professionals can help  
spectrum kids become successful adults.

# Lovingly Push Toward Transition



- What future do you picture for them?
- What do you want them to be able to do?  
*(If they can't do it, who will do it for them?)*
- Prioritize ADAPTIVE skills over ACADEMIC skills as age increases
- Vocational, Social, and Navigational skills
- Prioritize multiple–environment skills
- Prioritize safety/survival skills
- Prioritize skills that REDUCE dependence
- **Allow the RISK required for mastering these skills!**
- Address ALL areas of Transition!

*Adapted from Wehman, 2012*

# Top 7 Transition Areas



According to Wehman (2012):



1. Employment/Education
2. Living and Participating in the Community
3. Getting Around (Transportation)
4. Money Management/Financial Literacy
5. Friendships/Social Skills
6. Sexuality/Self Esteem/Personal Identity
7. Fun! (what to do in leisure time)

<http://www.autismspeaks.org/sites/default/files/documents/family-services/wehman.pdf>

# Questions to Consider when creating Boundaries of Belonging:

1. Are you considering my safety and protection without making me overly dependent or taking away my right to be self-determined?
2. Are you giving me a chance to experience the full variety of life—including appropriate risks?
3. Are you exposing me to new things, people, and places?
4. Are you letting me make as many decisions for myself as possible?
5. Are you letting me take responsibility for as many daily living tasks as possible?
6. Are you helping me learn how to say no or tell someone if I feel uncomfortable or am being abused?
7. Does my transition plan include learning how to take charge of my life so I won't require full guardianship unless absolutely necessary?



# Overwhelmed?



Here are some Tips:

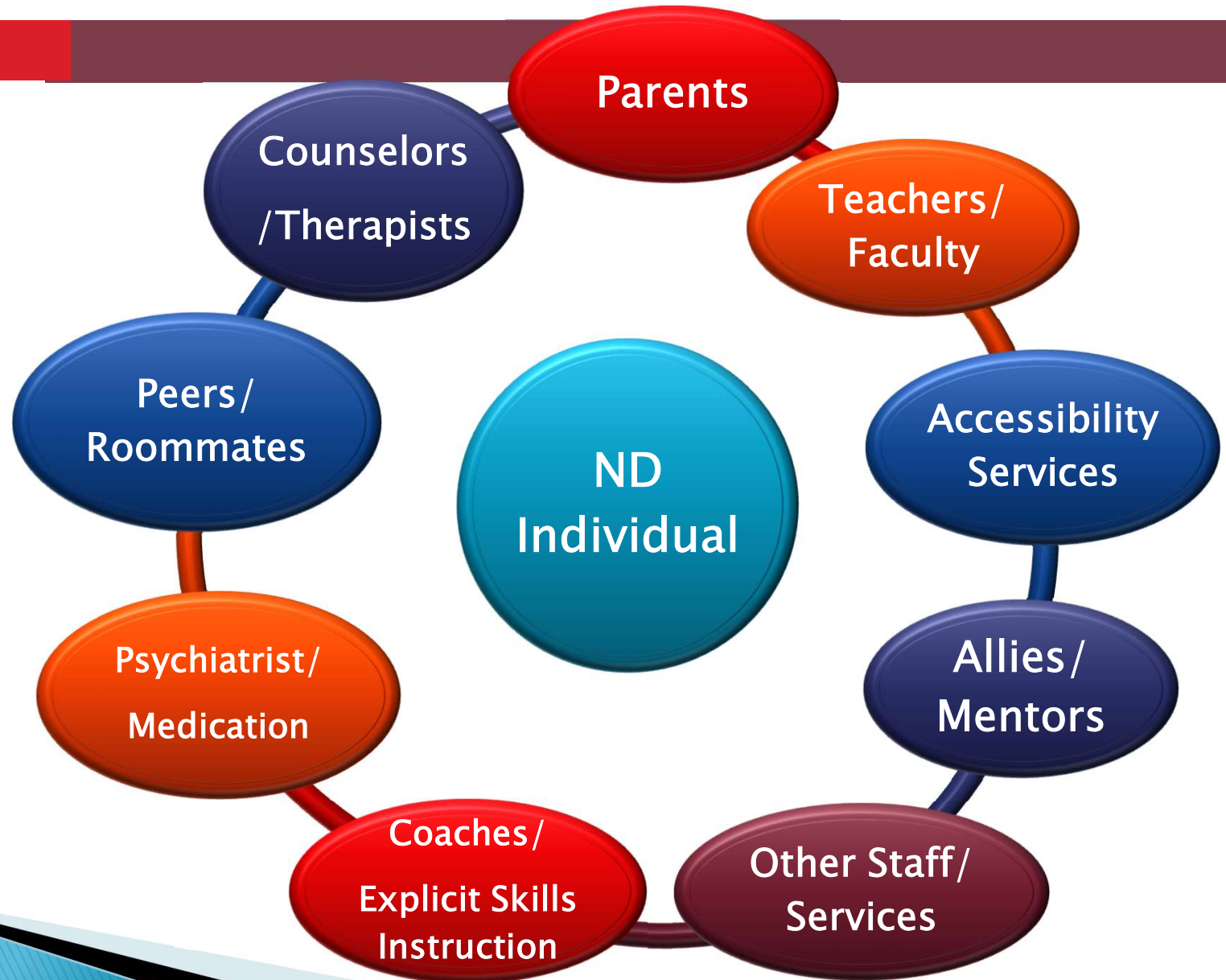
1. Know and Use your Resources!
2. Don't try to address all of them at once!
3. Learn from those who have been there before!
4. Know your Rights! (and fight if necessary)
5. Watch for Natural Teaching Opportunities!
6. Don't Overlook Sexuality! (that's not delayed...)
7. Don't try to do it all alone! (ask for help!)





# Empower Them to Assemble a Support Team!!!

## Support Team for Neurodivergent Individuals



# The 2 “Cliffs”:



- ▶ **1<sup>st</sup> Cliff (22 Cliff): IDEA cuts off**
  - No more IEP or IEP Team
  - No more guaranteed government services!
- ▶ **2<sup>nd</sup> Cliff (Care Cliff): Parents unable to care**
  - Old age, poverty, ill-health, death...
  - What will they do when that “system” is gone?
- ▶ *“It’s like giving someone a wheelchair on a one-month rental, and at the end of the month, they have to give it back—and walk.” ~Dr. Peter Gerhardt*
- ▶ **Will they be ready to “walk”?**



# “Walking” = Maximizing!



**GOAL = *Maximization* –not *Normalization***

- ▶ **NORMALIZATION** springs out of the belief that neurodiversity is somehow inferior or “wrong”; something to get rid of
- ▶ **NORMALIZATION** seeks for “indistinguishability” from NT’s
- ▶ **MAXIMIZATION** accepts the neurodiverse person for who they are and where they are– and where they want to go
- ▶ **MAXIMIZATION** seeks to actualize potential; to grow someone’s capabilities as an neurodiverse person
- **NORMALIZATION asks:** “How can they become the best approximation of everyone else?”
- **MAXIMIZATION asks:** “How can they become their best self and achieve their best future?”

***Note: Maximization Does Not Mean  
Doing Everything Alone!***

# Conclusions: So What?



- ▶ **Abandon** our preconceived limitations on potential!
- ▶ **Acknowledge** that DD is not a “death sentence,” but that it is a lifelong condition demanding unique interventions
- ▶ **Have a Plan!** And include steps to prepare each individual to live their **BEST LIFE** and to live it in a **Community of Inclusion AND Belonging!** (*Create the Community if needed*)
- ▶ **Expect Successful Transition!** (*5x more successful!*—Carter, 2018)
- ▶ **Focus on *strengths*: success doesn't come from our weaknesses!**
- ▶ **Surrender the “1-Up”:** gradually let the individual take control of more and more of their life decisions
- ▶ **Develop Support Networks** that you can hand over to the individual and which will mitigate necessary risks
- ▶ **Aim for Quality of Life!** (*There is no Perfect Life!*)
- ▶ **Marathon Mindset— Every timeframe will be unique!**
- ▶ **Involve individuals** in all their treatment decisions!

***(“Nothing About Me Without Me!”)***

"If they don't  
give you a  
seat at the  
table, bring in  
a folding chair."

- Shirley Chisholm





# THANK YOU FOR YOUR TIME!

## Any Last Questions?



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