Moving from Awareness to Acceptance

O By Alex Kimmel AKA The SelfDeterminator

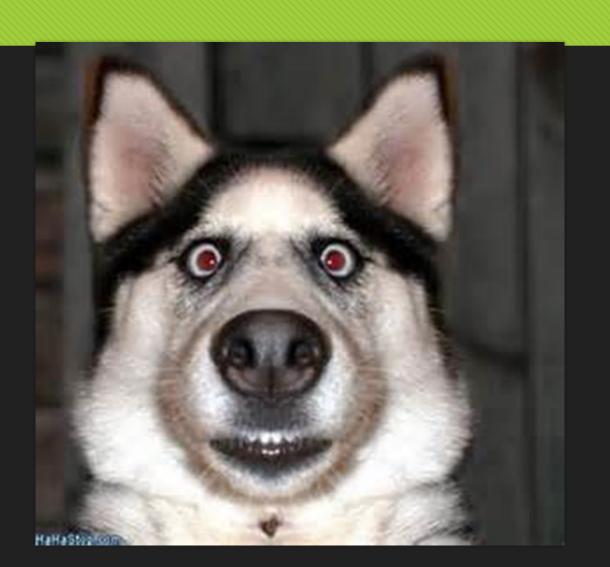
O Make sure you have a worksheet or something to write on.

O (Because I like to really think of how to best answer your questions, I appreciate you emailing your thoughts to alex.kimmel@hotmail.com instead of the traditional questions and answer session.)

- OAh.....
- OCulture of Gentleness.



QUIZ TIME!!



Pre-session check-in

Get Out your Worksheet!

- Identity First Language is...
- Neurodiversity is.....
- Culture of Gentleness is.....
- special needs are......

O Just a little check-in of your thoughts on these concepts. Please write out your current thoughts on these topics. It is ok if you do not finish. You will have 1 minute. Go ahead and start!





SD

"Self-determination incorporates a set of concepts and values which underscore a core belief that people who require support from the public mental health system as a result of a disability should be able to define what they need in terms of the life they seek, should have access to meaningful choices, and control over their lives."

Michigan Department of Community Health

Overview of today:

- "1. Self-determination incorporates a set of concepts and values which underscore a core belief that people who require support from the public mental health system as a result of a
- 2. disability should be able to
- 3. define what they need in terms of the
- 4. life they seek, should have access to meaningful choices, and control over their lives."

Michigan Department of Community Health

- 1. Self Determination definition
- O 2. Disability concepts
- O 3. SD personalized needs
- 4. SD and life, meaning and control
- O And # 5.....

SD

• 5. You are not done hearing my wise thoughts so you write down my contact info and ask me to come speak to your group



1. Self Determination defined

"Self Determination is really an inalienable right that all have, with or without disabilities, to have control on how they spend their life."

Alex Kimmel

In 2013, I was a Michigan Partner for Freedom local leader and member of the statewide steering committee.

I was asked to monitor and engage our listserve.

Thought I would challenge members to finish this statement with just five words:

"Self Determination is...."

Here's mine: Self-determination is ... my life on my terms.

What's your 5 word definition of SD? Take a minute to write out your 5 word definition.

You have 1 minute, so get started!





O You are invited to type your 5 words into the chat. I will read the first 10. Go ahead and start!





O These are the responses other Partners for Freedom gave from across Michigan of their 5 word definitions:

- O " A life of ones' choosing"
- "Life, liberty, pursuit of happiness"
- "The first step to selfadvocacy"
- "The freedom to be me"
- O "A life like anyone else"

OI want you to gain an understanding that having a disability in and of itself has no bearing on how successful and fulfilling life can be.

OThe thought that I have disability pride does battle with my strong philosophy that inclusive communities are places all are worthy, just because they were created, with or without a disability

One of the things that has to change would be the portrayal of autism as a disease in need of a cure.

OWhile that may stimulate income from a charity model,

it sure as hell stifles the promotion where autistics have respect as equals.

• Who is creating these campaigns? Sharing from a hunch that it is not autistics



OHow about promotions that highlight the many adults that have successful and meaningful lives.

OWhat about letting the focus be about how these successes are possible

often because supports that respect each individuals' specific wiring are provided.

- OThis could occur only with the most careful planting and cultivating of seeds of self advocacy and that of self determination
- OThis is something that has to be sown to the autistic community along with the community at large.

- The pursuit of power to change how autistics are perceived must first address how autistics view themselves.
- The majority that I have met have struggles with esteem either currently or in the past.

O The steps of autistics modulating from awareness that they have the power and right to govern their own lives

to acceptance of that power and right to govern change in policy in their community

has to precede that of the community as a whole holding them as equals.

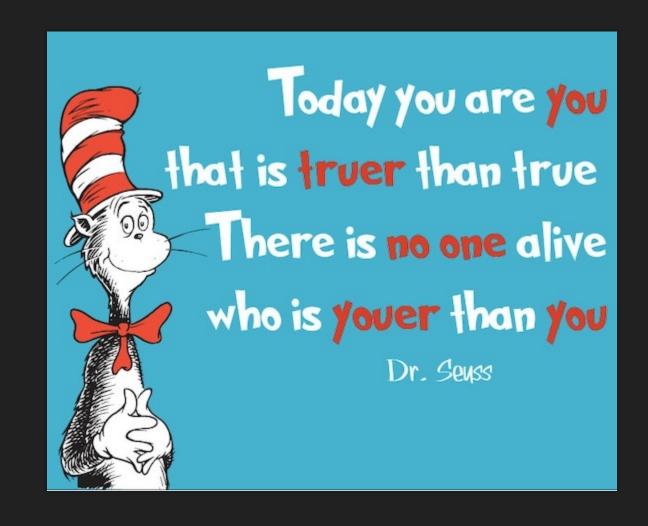
- OHolding as equals is a big part of what neurodiversity is.
- OHere is what www.believe-nd.org says about neurodiversity:
- What is neurodiversity? Neurodiversity recognises that people have a different way of thinking, seeing and interacting with the world around them.
- Specifically, it relates to variations within the brain that can affect sociability, learning, attention, mood and other cognitive functions.

O I also like Sonny Jane Wise words.

"Identifying as neurodivergent isn't just another label; it's also an identity, it's a reclamation, it's a song. When we call ourselves neurodivergent, we are reclaiming our differences that society calls abnormal or wrong.

When we call ourselves neurodivergent, we are challenging you to consider what 'normal' actually means and perhaps even realize that maybe our normal isn't your normal. When we call ourselves neurodivergent, we are rejecting the concept of disorders."

There is one more great philosopher I have been following for decades that can give insight into the power of neurodiversity.



- OThere are differing ideas of how to refer to people. Some are fans of the person first language, as in, "person with autism"
- OSome prefer identity first language, such as "autistic person"
- O You can visit http://autisticadvocacy.org/home/aboutasan/identity-first-language/ for a more in depth briefing on identity first language.

OI prefer identity first language and will use terms like autistics.

Of course, calling me "Alex" or "Your majesty" works for me, too



3. SD and personalized needs

OSelf-Determination is about personalized needs, NOT "Special Needs"



3. SD and personalized needs

- O To me, the only way to be able to accept me is to respect my needs to feel safe and loved
- The Culture of Gentleness is a philosophy I embrace because it lets ME decide what I view as safe and loved

3. SD and personalized needs

- The culture of gentleness official resources do not often mention selfdetermination by name but the essence of selfdetermination and the practice of culture of gentleness have similar root elements
- I use the tools of selfdetermination and culture of gentleness to create a very personalized plan that drives my supports and services for my life.

SD and personalized needs

Culture of Gentleness is an important kind of approach because....

- It is a philosophy that requires the person providing the support to change rather than placing the emphasis solely on the individual being supported.
- There is an emphasis placed on "us" and "equality" rather than the typical one in control/one controlled relationship
- The purpose is to build safe, loving relationships where all feel valued.

• I participated in an interview where I was asked to reflect on self-determination and my culture of gentleness ideas.

One of the interesting thoughts that I have regarding culture of gentleness and self-determination is the practice of great difference of who is a more likely recipient of each

OThere seems to be great alignment of those that are perceived to have impaired intellect to have the gentle teaching applied while the self-determination philosophy is reserved for those perceived as having met a threshold of cognition

 Those philosophies should not be mutually exclusive and are rights that we all have and are certainly not conditional on intelligence. Placing the presumption that the ability to orally communicate as the prime indicator of intelligence is a gravely faulty premise that pollutes many professionals and parents.

OThe philosophies of culture of gentleness and self-determination are elements that all of society are worthy to claim, having entry simply by virtue of being created

 How this impacts those of us that society would have labeled as "special" is to erect barriers to these rights others in society have access to.

 Those who have less obvious differences from the mainstream tend to procure the right to live selfdetermined lives that have meaningful goals that line up with societal expectations such as: full time employment, making more than minimum wage, living with whom they want/where they want, getting to be part of society as a whole and not relegated to special activities only with access to others with disabilities.

• This ability to have oversight of setting your own goals is powerful; however, that power is frequently usurped.

- Too often those society categorizes as "high functioning", those that are more likely to look and behave as "normal" as gauged by neurotypicals, tend not to get the right to have the personalized respect for individual neurological preferences that gentle teaching provides.
- (fyi: I am not of fan of these labeling terms of "high-functioning" and "normal")

OThose that more readily tend to receive culture of gentleness have similar outcomes of life unfulfilled but for opposite reasons

 Those termed as disabled, displaying as further from the societal norm, have less likelihood of authoring their person centered plan and life goals and overseeing the other aspects of selfdetermination. Their life goals are likely to have relevance more about their behavior and less about their hopes and dreams.

OOften there is not much self-authority in choices regarding housing and sexuality. On the optimistic perspective, this same population is more likely to be offered patience and supports

 The culture of gentleness asks to respect the person on their terms, not on societal or other "norms".



The pillars have a hierarchy. You can't feel loved till you feel safe. You can be loving and engaged once you are safe and loved.

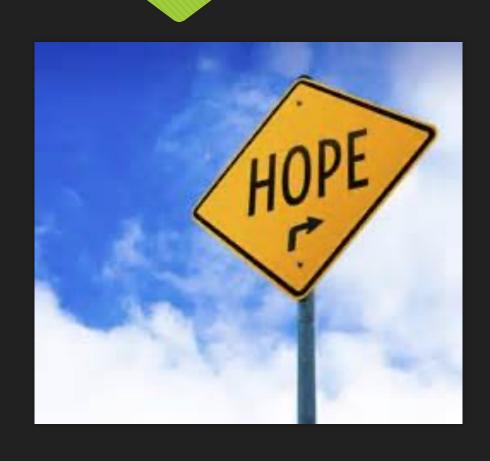


- Every person has a different idea of what it takes to be safe, loved, loving and engaged. This is the foundation of a Culture of Gentleness (or COG)
- A big component to how we move toward these positive places is how we are approached.
- From the start it is about investing time in the relationship

OWhat makes me feel safe?

One of the things that I have to consider is how the people in my life **think of my intelligence** when I do not have access to assistive technology and I cannot fully communicate with them.

OThis respect is greatly important in my ability to let me get to the point where I can trust them. For me, then, it is important that I am talked to as an equal.



OWhat makes me feel safe?

O Top of the list for me is keeping positive: to keep me having hope and help me to remain optimistic. This is helpful to let my anxiety keep submerged.

OWhat makes me feel safe?

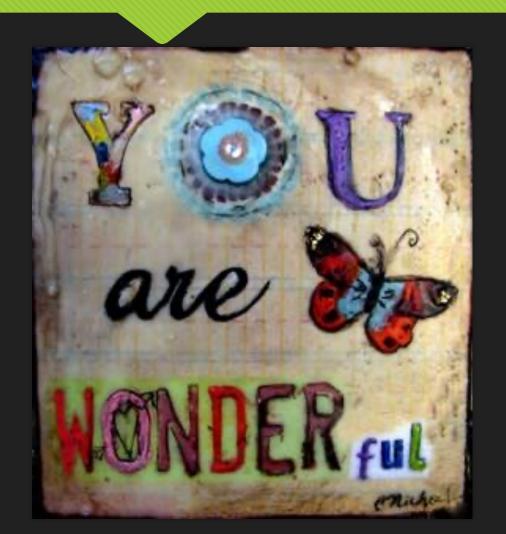
Thinking that **keeping promises** is honoring the elevation of trust and therefore accessing safety.





OWhat makes me feel safe?

O I am wanting to respect words if they are positive. They have the way to utter feeling of being accepted and there is hope for me to then share love.



OWhat makes me feel safe?

People who tell me that I am helpful or wonderful keep giving me the idea that the possibility is growing that more will have positive assessment of my mind.

GET OUT YOUR WORKSHEET!!

SD and personalized needs

Who, what and where make you feel safe? Take a minute to think about what you would put on your worksheet. You have 1 minute. Go ahead and start!

WHO AND WHAT

- People who talk to me as an equal
- People who use positive words
- People who keep promises

WHERE

- Grandma's house
- In the water
- Not too loud

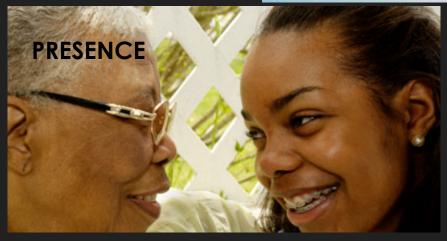




SD and personalized needs: The 4 tools of







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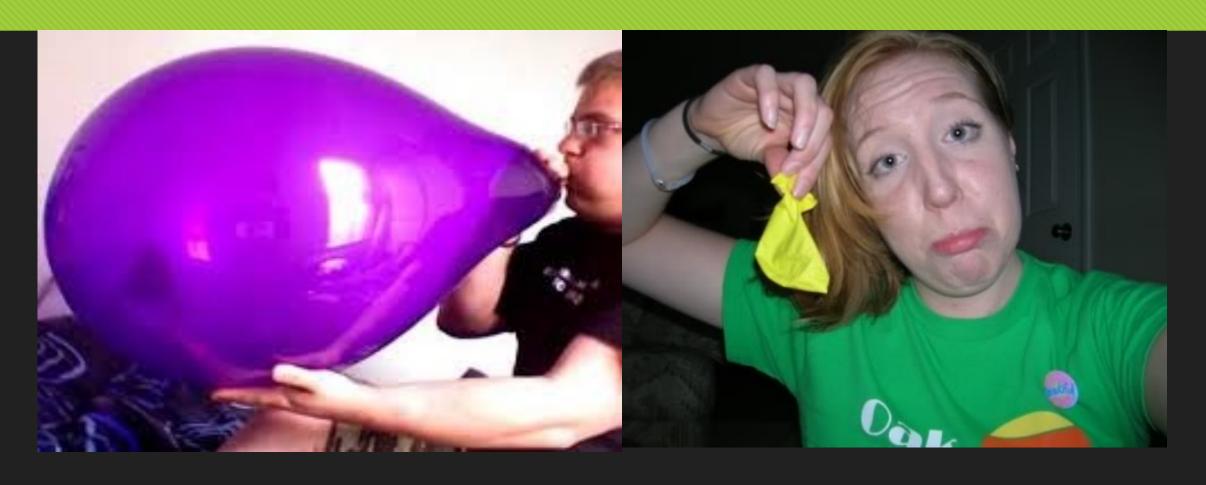
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Each tool can be used in a positive or negative manner.



Culture of gentleness: positive use of tools



What about your thoughts of **positive** use of the four tools? Go ahead and write them out. You have 1

minute . Go ahead and start!

Eyes

Touch

Words

Presence



01:00

www.interventioncentral.org



Culture of gentleness: positive use of tools

- O Eyes: soft, engaged
- O Touch: gentle, encouraging
- O Words: respectful, positive
- O Presence: genuine, acceptance



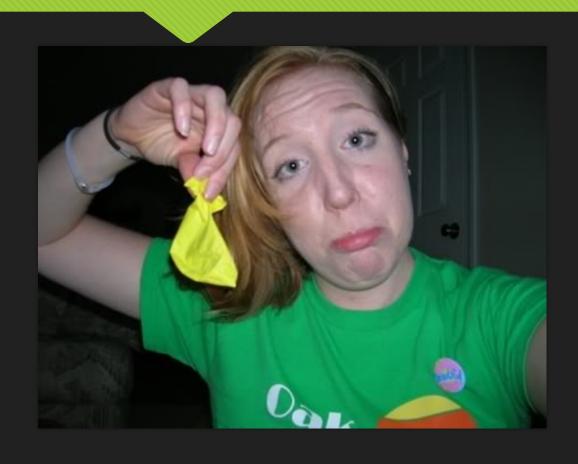
Culture of gentleness: negative use of tools

- What about your thoughts of negative use of the four tools?
 You can write them out. You have 1 minute. Go ahead and start!
- O Eyes
- O Touch
- O Words
- O Presence





Culture of gentleness: negative use of tools



- Negative use of tools can convey
- O Eyes: rolling, impatience
- O Touch: control, intolerance
- O Words: demands, belittling
- O Presence: disrespect, indifference

O How one person desires a tool to be used and calls positive another may see as negative. It is very important to respect each individual and not assign your filter or desires on their perception.

O It is very important to keep in mind that safety is different for every person and that the person being supported defines what safe looks and feels like.

O The same goes for demands: let them define what is demanding or draining. Let them lead as to what supports and structure are needed to remain feeling safe, loved and positive.



One thing that I would have to get those who are interested in conversations with me is to **respect** that when people ask to keep eye contact with me I have challenge to hear their words.

Allow me to have right to have eye contact according to my comfort knowing that I thrive on connecting and am carefully minding everything you say.

One thing that would help is getting more safe offers from people to join them that often helps have more confidence about inferior me Initiating eye contact.



DON'T MAKE EYE CONTACT

DON'T MAKE EYE CONTACT, DON'T MAKE EYE CONTACT, DON'T MAKE EYE CONTACT, DON'T MAKE EYE CONTACT

- OThe access to words will get the anxiety diminished with helping me to have trust that what I want is understood.
- OI would prefer the words that I have to hear speak **only** about positive and keep optimistic.

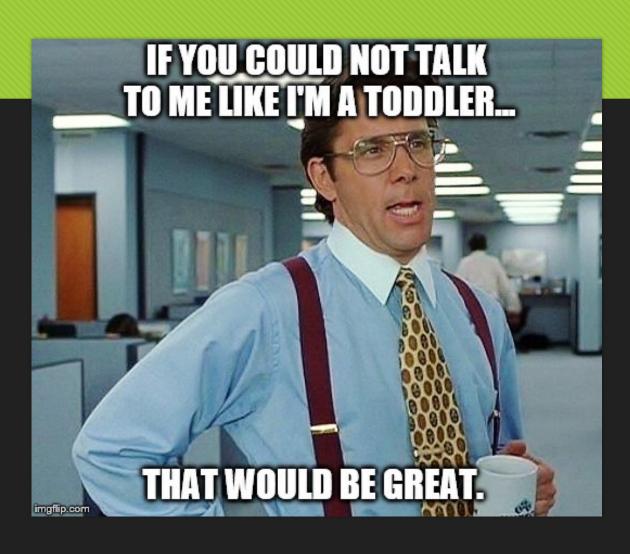
SD and personalized needs

One thing that I would change in a heartbeat is how hard it is to communicate with everyone.

- O More often than not I am either talked to like I am a preschooler or even worse I am ignored.
- O I should be having conversations that respect that I am an adult and that would be great...

SD and personalized needs

....to **not** have tone that totally makes me think that you are thinking that I am just a baby that I require that half singing voice typically reserved for preschool teachers.



Get Out your Worksheet!

- What about you? What are ways that you prefer people TO (WANT) and prefer them NOT TO (DON'T WANT) use....
- Their eyes?
- Their touch?
- Their words?
- Their presence?

O Write down some of your thoughts. It is ok if you do not finish. You will have 1 minute. Go ahead and start!





SD and personalized needs

Self Determination is not just about rights, though.

Self Determination is a balance of rights **and** responsibilities



SD and personalized needs

- OSelf Determination to me is about a *right* to a life based on my goals, my interests, my strengths and my schedule.
- Self Determination also leaves me with a responsibility to take the steps needed to keep my end of the deal.

4. SD and life, meaning and control

- All over the United States there are champions of selfdetermination. I am trained by Michigan Partners for Freedom and am proud to call myself a local leader.
- Local leaders teach about the five principles of selfdetermination.

SD and life, meaning and control

The principles of Self-Determination are:

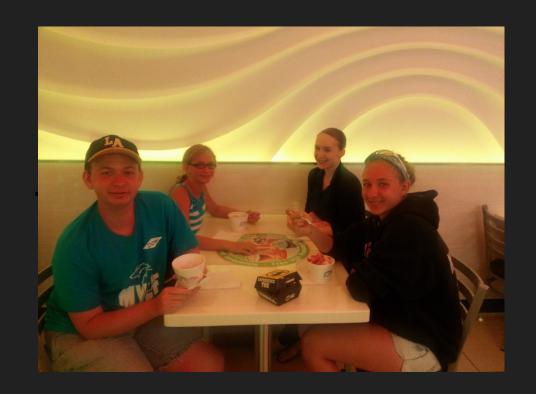
- Freedom: to choose a meaningful life in the community
- Authority: over a targeted amount of dollars
- Support: to organize resources in ways that are life enhancing and meaningful to the individual with a disability
- Responsibility: for the wise use of public dollars and recognition of the contribution individuals with disabilities can make to their communities
- Confirmation: of the important leadership role that individuals with disabilities and their families must play in a newly re-designed system and support for the self-advocacy movement

Source: Michigan Partners For Freedom

Principle #1: Freedom

The way that this core value of freedom shines in my life reflects how I do what I want, when I want, with whomever I choose.

Those things include parties, work, church, volunteering, community band and family.



- O Friendships, relationships and **community belonging** are critical aspects, if not the most universally valued condition, of quality of life.
- National Core Indicators
- O July 2015



Ol I have been on paid staff at Frontier Distributing since 2007

- I use the North Oakland Transportation Authority (NOTA) to get to and from work most days.
- This has helped me increase hours because it is not based on my mom's availability.
- Plus, they are never late (sorry mom).

- I am contracted by Macomb Oakland Regional Center to provide training for new employees on selfdetermination
- O Universities and community groups hire me to present on neurodiversity and inclusion through my business The SelfDeterminator



Principle #2: authority

- O The core value of authority has me in charge of my life and gives me the financial backing to correctly run my person centered plan.
- My plan funds goals I chose that help me become more independent in both work and social dealings



Principle #3: support

OIn my mind this is about people that help me carry out my goals and help make my transition towards independence an accountable reality

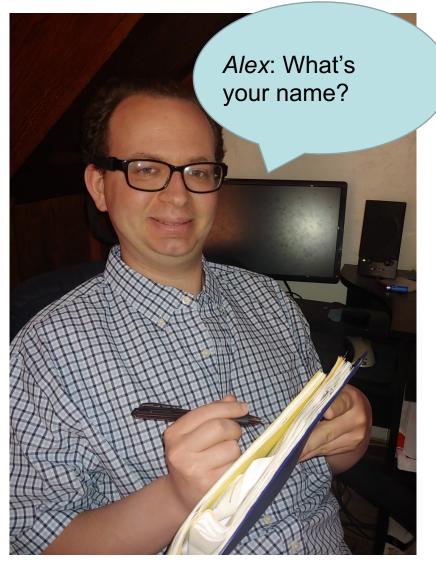
support

- O I have hired Sarah to help me with building my speaking business, cooking, laundry, shopping, hair cuts, going to the library or whatever else I need to take care of.
- O This past year I have worked on skills to make me able to actually do a task we have practiced even when staff are not there.

O We have put written step by step directions in my IPAD so I can do laundry, chores, and cook even when I don't have staff right there.

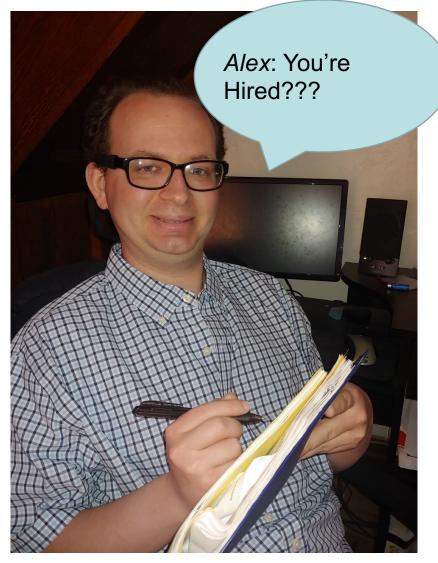
support

OI am an Employer of Record. This means that I am the boss and I hold the interviews and I hire and I fire staff. Interviewing staff





Interviewing staff







Principle #4: responsibility

OThis core value respects individuals with disabilities having the responsibility as well as the capacity to be making contributions to the communities where they live.

Worship assistant



responsibility

The ways that this has shown to be evidenced currently in my giving is at my church and with animal shelters

Volunteering at an animal shelter



Principle #5: confirmation

OThe core belief of confirmation relies on me and other Partners for Freedom finding ways to educate on inclusion and self-determination for everyone.

Alex Kimmel receives the Dan Moran, Rights and Advocacy Award

By Oakland Community Health Network, Community Contributor Oct 30, 2017 3:27 pm ET

Like 81

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Lake Orion resident, Alex Kimmel is one of five Oakland County citizens presented with a 2017 Oakland Community Health Network (OCHN) Achievement Award. Kimmel was recognized during the agency's recent "Your Voice, Your Value" conference.

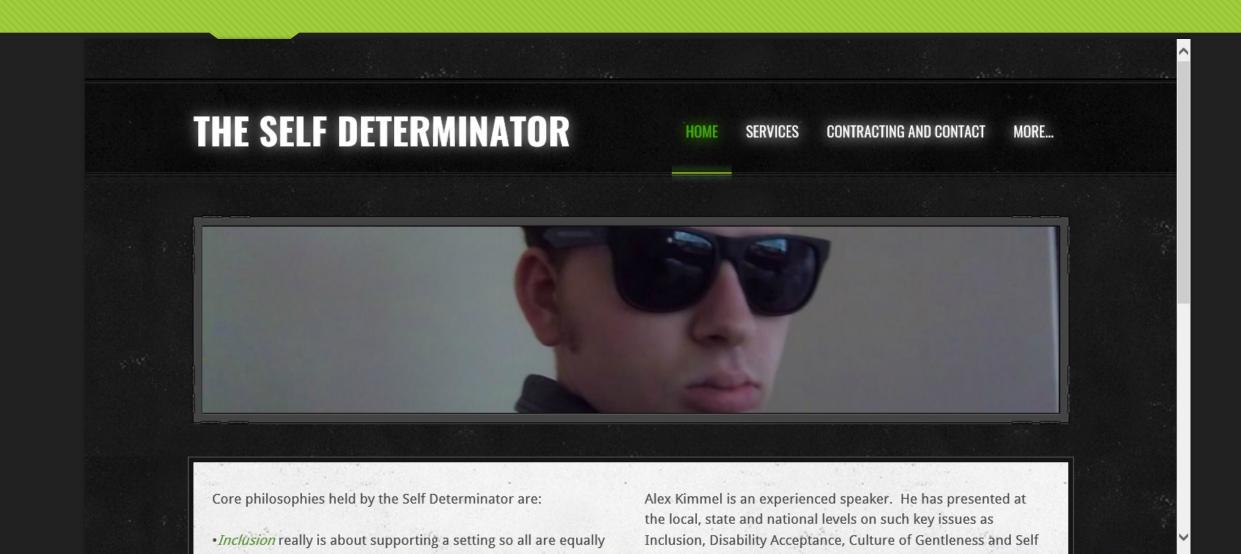
- I am a peer mentor, available to contract with via community mental health.
- I'm a graduate of Michigan Youth Leadership Forum.
- I am a trainer for Developmental Disability Institute.
- I am content trainer for "By, With and For Autistic Adults"







Shameless plug: www.alexkimmel.com



- OI strongly hold onto Self Determination as a right all have.
- For those with disabilities, making self determination a reality sometimes has barriers.

OUnderstand that I get nervous that I am going to be perceived and treated like someone who is not fully human or someone who is inferior and lesser.

The greatest challenge I have personally

is that before I am given the right or powerful opportunity to make my own first impression of my own choosing

- othere are too many that dismiss me merely based on my use of technology for communicating
- O which is ironic to me as they are apt to be tethered to their smart phone.

• The nicest thing that someone can do is to slow down and invite me into conversation and really get to know me before there is judgement made.

• The most important thing that would make for world of difference

is to quell the silent blaring of fear that I will be rebuffed or ignored when I do take the risk of wanting to team up with universal need to connect and belong

OThe things that I am terming as positive would be times when I was treated as welcome equal and having the desire to have me included.



One challenge for individuals with disabilities is that too often we would have people in society focus on how the short list of characteristics for diagnosing people warps into grossly over-homogenizing an entire demographic to be impersonal and stereotypical.

The lesson for people regarding inclusion is more than time allowing access or tolerating someone's presence. The real thought about inclusion that is meaningful has to start first by communicating that **all** are welcome and **all** are valued.

Get Out your worksheet!

- Reflect individually or turn to a partner or group of three and respond to the following questions:
- 1. How might social norms impact enacting selfdetermination?
- O 2. How would you explain neurodiversity to someone? Why is it important to know?
- 3. How can these concepts of Self-Determination, neurodiversity, acceptance, culture of gentleness and inclusion influence you in your life or career?
- You have 5 minutes, go ahead and start.





It's all about the Possibilities....

Thank you to MI-DDI, Wayne State University and the Pure Michigan commercial film crew for putting together this video.



Post-session check-in

Get out your worksheet and go back to the top for the post session check-in

- O Identity First Language is...
- Neurodiversity is.....
- Culture of Gentleness is.....
- special needs are......

O Just a little check-in of your thoughts on these concepts. Please write out your updated or renewed thoughts on these topics. It is ok if you do not finish. You will have 1 minute. Go ahead and start!





OThe focus should be each person should be left to define themselves. This lesson is true whether there is a disability or, *heaven help them*, they are neurotypical.

O Here is a poem I wrote a few years ago called **Respect**:

Let me think that power of treating with dignity

Where you treat currently with words of distance and apathy out of ignorance that

I am hungry for how people focus with presence that there is something that is within me

Enticing, exciting

Evoking our time together

From strangers

To mutually diverse entities

To friends

Which we offer the world to see that it is respect that really lights the path we all travel

Each of us helping to

And hoping for

The give and take of safe, valued and loved

Alex Kimmel 2014

Get Out your Worksheet!

- Please take out your phone for a text to yourself or a memo or something to write with or use your worksheet.
- O Please take a minute to write out, very specifically, what you are going to do differently in your life, work or personal, that reflects something you learned about the culture of gentleness or self determination.
- Feel free to email me with your strengthened or changed perspective!





- O Thank you for having me share about the values that empower all of us and for letting me lend you my philosophy of self determination and inclusion.
- You could tell that I am passionate about these topics and would welcome an invitation to speak to your circle of influence.

- You can contact me at:
- O Alex.kimmel@hotmail.com
- O <u>www.alexkimmel.com</u>
- TheSelfDeterminator on facebook



If you are walking away today with a stronger understanding of COG, inclusion and acceptance, I would be honored if you could leave an endorsement on my LinkedIn page. #SelfDeterminator Thank you!