

"Autism, Bourbon, Perspective and Resilience"

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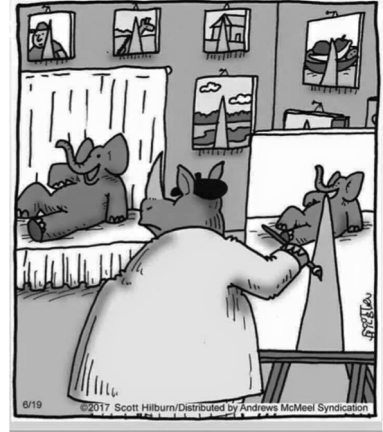
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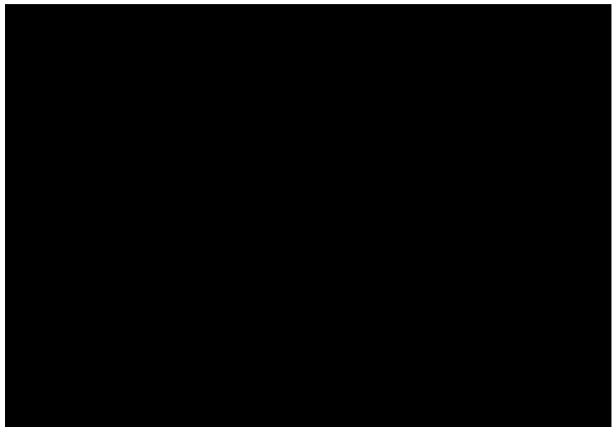
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Perspective is
Everything



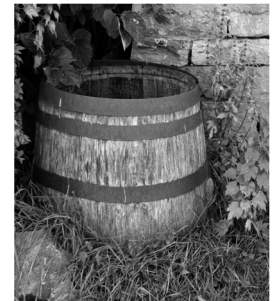
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Perspective is Everything



Cognitive Energy

Everything we do;
Everything we
experience;
Every step we take;
Everything we learn;
Are all spigots draining
from our rain barrel of
cognitive energy



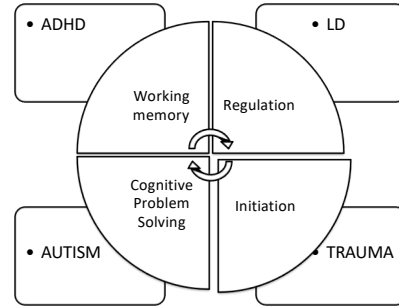
Why should autism be the priority?

Autism:

- **Heterogeneous combination of manifestations**
- **ADHD, LD, MH, sensory, trauma, addiction, eating disorders**
- **All populations benefit when ASD is understood.**
- **We are the reflection of and the predictors of the implications of a non-resilient society.**



Resilience Factors in Varying Populations



Kaiser Permanente

• ACEs

- chronic physical illness like lung disease, heart disease, liver disease, diabetes, obesity and hypertension.
- 30 -70% percent higher risk of heart disease
- correlation with teen pregnancy, divorce, depression, suicide attempts, PTSD, chemical dependency, school failure and unemployment.
- [Three top causes of death in autism- Seizures, suicide and cancer/heart disease]

(Anda, R. F., Felitti, V. J., Bremner, J. D., Walker, J. D., Whitfield, C., Perry, B. D., . . . Giles, W. H. (2006). The enduring effects of abuse and related adverse experiences in childhood: A convergence of evidence from neurobiology and epidemiology. *European Archives of Psychiatry and Clinical Neuroscience*, 256(3), 174-186. doi:10.1007/s00406-005-0624-4)

Evidence of Need #1: Suicide

- **Stress and coping** ^ (41% reported 3+ coping challenges; Milovanov) and (Hirvikoski)
- **Suicidal ideation** ^^ 66% reporting ideation, 35% plans or attempts, 31% reported depression of 374 (Cassidy)
- **Hirvikoski**: Shorter life spans* (37)
- **Croen/Kaiser Permanente (1507)**
 - 5X rate of suicide attempts
 - Half reporting suicidal thinking did not have a depression diagnosis

Evidence of Need #2: Access

- **Croen (1507) KP study**
 - Conditions: immune disorders, psychiatric disorders, gastro, sleep, seizures, obesity, hypertension, diabetes
- **Burke and Stoddard (Canada) Access**
 - Higher mortality rates
 - Delays in treatment
 - Increased complications upon presentation
- **Barriers to care**
 - Executive function
 - Overmedication
 - Communication
 - Depression/anxiety
 - Lack of providers

Evidence of Need #3: Poverty

- Note: Poverty line for a single adults is \$11,770; **on SSI the annual income is \$8,830.84**
- U.S. Census: Overall poverty rate is 14.5%; **Disabled is 28.8%.**
- 17% of autistic adults 21-25 ever lived independently compared to 34% of non-autistics with ID

(Anderson KA, Shattuck PT, Cooper BP, Roux AM, Wagner M. Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder. *Autism*. 2014;18(5):562-70.)

Evidence of Need #4: Incarceration

- Research suggests as much as **13%** of forensic populations may be Autistic.
- A London study of prisoners "neurodevelopmental disorders and difficulties"
 - Neurodivergent prisoners 3 Xs as likely to have been homeless before coming to prison
 - 80% of neurodivergent prisoners had previous convictions.

(Mccarthy J, Chaplin E, Underwood L, et al. Characteristics of prisoners with neurodevelopmental disorders and difficulties. *J Intellect Disabil Res*. 2016;60(3):201-6.)

Evidence of Need #5 Non-suicidal Self-Injurious Behavior

- **50%** reported a history of non-suicidal self-injury.
- Adults with autism spectrum disorder have ^ risk for NSSIB
- Women with autism spectrum disorder were significantly more likely to endorse non-suicidal self-injury
- Lack of research
 - Autistics have ^ rates of risk factors for non-suicidal self-injurious behavior
 - Depression
 - Poor emotion regulation skills

(Maddox, B. B., Trubanova, A., & White, S. W. (2016). Untended wounds: Non-suicidal self-injury in adults with autism spectrum disorder. *Autism*, 1362361316644731.)

Evidence of Need #6: Research bias against women

- 2014 review of thousands of sports and exercise studies that found that of over 6 million participants, only 39 percent were women
- “women were perceived as more physiologically variable.”
- “The complexities of the menstrual cycle are considered major barriers to the inclusion of women in clinical trials,” the researchers argue

<http://thinkprogress.org/health/2016/06/08/3785632/> menstruation-clinical-research/

Diagnostic misconceptions

Attwood: “...we diagnose autism based on a male conceptualization of the condition. We need a complete paradigm shift. We need to draw up a female version of Asperger’s that identifies girls on the spectrum on the basis of the way they present...undiagnosed Asperger’s can create devastatingly low self-esteem in girls.

(The Observer; Amelia Hill, April 2009)

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Women’s issues

- “Girls form friendships through sharing their identities and relating to each other’s emotions...they form **their very identity** based on how well they navigate.”

(Zaks, 2006)



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Consistencies for diagnosis

- Pretend play is “deceiving”
 - Rigidity
 - Ritualistic
 - Less stereotypical
 - Less receptiveness
 - May reflect her idiosyncrasies
- “...qualitative impairment in their play...lacks reciprocity and is too controlling... the **dominance and intensity**...is out of the norm.”

(Attwood, 1999)

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Barriers to diagnosis

“...girls exhibit potential subtleties that are not detected by traditional assessment instruments and direct observations”



(Girls Under the Umbrella of Autism Spectrum Disorders Ernsberger and Wendel- Published by AAPC)

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The bottom line...

“According to Miller (2003), the under-diagnosis of women contributes to the marginalization of females on the spectrum...women will continue to stay in the background and live in seclusion”



(pg 22; Girls)

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Childhood abuse



- Sexual abuse
 - treatment for the men/nothing for the victim
- Unintentional neglect from mother with undiagnosed autism

Hiding

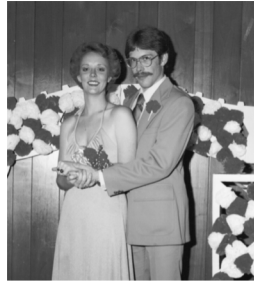
- Academics seen negatively
- Hid with parties and theater
- Low self-esteem and body dysmorphic tendencies



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Public persona....

- Homecoming candidate
- Class officer candidate (asked to back down)
- 4.0 student first semester



Promiscuity and Consent

"...is frequently observed in women with AS... factors include lack of experience and boundaries, poor judgment, and deficits in theory of mind. *Some women...accept all sexual offers in an attempt to obtain affection and intimate contact, and people take advantage of their naivety and vulnerability.*"

(Henault; 2006)

Who are we?

- ***Often women who are grieving***
 - Poverty of therapies
 - Loss of workplace identity
 - Loss of friends, family
 - Loss of position in a cultural community
 - Their own feelings of inadequacy, shame and internalized blame
 - Isolation



Evidence of Need #7 Anorexia/eating disorders

- Zucker, Spectrum; 2015
- Not about fat / wanting to be a model
- Theories:
 - Food refusal = Muting of sensory/processing
 - Shifts focus to basic, simpler needs
 - Predictability/control
 - Limited or extreme body awareness
 - When the body slows, "heart beat slows, stomach motility slows, menstruation stops"

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Evidence of Need: #8 Sexuality Training

- Inadequate information on sexuality/intimacy/reproduction
- Lack of explicit information specifically around grooming
- Sexual information given prior to interest and/or context capacity
- Clinical language versus street language

(Penwell & Maticka-Tyndale (2015))

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Shame Train



- Limited validation
- No adaptations
- Whispers
- Autism as something separate from self
- Unable to name it
- Unable to own it
- Unable to integrate self
- Unable to ask for support



How did we get off of HERE? Shame Train...



Shame Train



- When does shaming begin?
- Where is it reinforced?
- How does it escalate?
- What are the consequences?



Our History

- Autistic culture and the human services fields continue to be influenced by the scientific method and medical model.
- ***This is the language that surrounds us***
- Deficits
- Abnormality
- Disorder
- Disease
- Disability
- Vulnerability
- Victimization
- Shame
- **Cure**

Shame Train



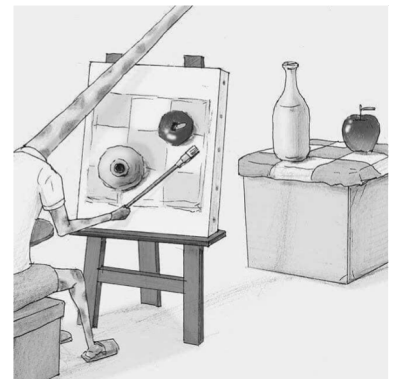
- Issues with diagnosis
 - Deficit model begins
 - Psychological assessment focuses on deficits; they do not measure strengths
 - Diagnosis is conveyed in a grief driven manner

Where do we see this?



- Marginalization and segregation in families, schools and community
- Evaluation results
- IEPs
- Rehabilitation programs
- Post-secondary programs
- Employment
- Community

Perspective is Everything



Compensation

"Compensating for AS difference, ...comes at a very high cost in terms of effort, and many times, in the privacy of their home adults are not willing or able to make the considerable effort it would take to function as well there, as they do at work or out in the world."

Lovett, J. P. (2005). *Solutions for Adults with Asperger's Syndrome: Maximizing the Benefits, Minimizing the Drawbacks to Achieve Success*. Fair Winds Press.

How do we keep it full?



- Understanding autism
- Understanding self and our individual "expression" of ASD
- Identify needs and triggers
- Using strategies
 - *resilience building curriculum*
 - *disclosure, scripting, accommodations and adaptations*
 - support from programmatic &/or informal partnerships—to provide "translation" support to bridge the gaps

The First Resilience Strategy: The Connection Process[©]

- How does ***the individual*** experience their unique expression of ASD?
- How do ***others*** experience their ASD?
- How can the individual ***express*** what is happening?
- How does disclosure ***level the playing field?***
- How does one use accommodation, adaptation and modification to ***maximize productivity while maintaining personal wellness?***
- How does all of this sync together to insure the ***maximum productivity balanced with the highest quality of life?***

Integrate the diagnosis

- What IS autism?
- How do I experience the world differently because of MY autism?
- How do OTHERS experience my autism?
- What can I achieve?
- What will I leave behind?
- What will require adaptations, accommodations, modifications?
- How will I find my own "normal"?
- When and how will I use language to disclose the things that I cannot address with any of the above items?

My Personal Barriers

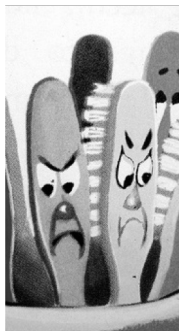
- Failure to be Identified until 38
- Difficulty Finding Support
- Overwhelming Others with Details
- Emotional Dysregulation
- Lack of Personal Integration of Diagnosis
- Trusting and Naiveté
- Executive Function
 - Inability to prioritize information
 - Organize written information
 - Overburdened participants

How do I Experience my own Expression of Autism?

- **BODY**
- Sensory
 - Touch
 - Sounds
 - Smells
 - Gastro
 - Vision
 - Pain
 - Loss of motor control
 - Seizure



How does *the individual* experience their unique expression of ASD?



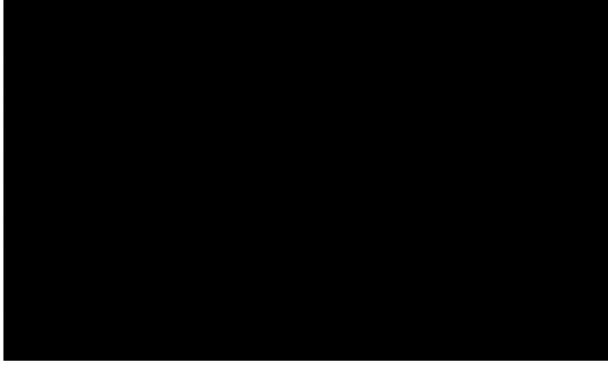
- **SENSORY & MOTOR**
- Visual processing
- Auditory, olfactory, tactile etc.
- Photophobia
- Handwriting limitations
- Keyboarding limitations
- Large motor issues (standing, walking, sitting)
- Fear of public transportation
- Hygiene
- Uniforms

How does *the individual* experience their unique expression of ASD?

- **Cognition**
- Sequencing & balancing hygiene, clothing prep, work equipment, lunch, keys, phone
- Transportation use/preparation
- Maintaining independent living employment tasks
- Maintaining auto
- Bills
- Executing emergency plans



How does ***the world*** experience their unique expression of ASD?



New Adult Trajectory

- When we focus on normalcy, parents, teachers and the individual struggle to focus and capture strengths
- Nothing on the “white board” in the minds of autistics or collaborators



Shifting to a Strengths Based Approach

- Puts stuff on the whiteboard!
 - Perception within
 - Perception from others
 - Strategies for connection



Saleebey, D. (1996). The strengths perspective in social work practice: Extensions and cautions. *Social work, 41*(3), 296-305 (p. 297).

Shifting to a Strengths Based Approach

- Capacities
- Talents
- Competencies
- Possibilities
- Visions
- Values
- Hopes and dreams
 - Nurse?



Saleebey, D. (1996). The strengths perspective in social work practice: Extensions and cautions. *Social work, 41*(3), 296-305 (p. 297).

“A dynamic process encompassing positive adaptation within the context of significant adversity”.



Masten, A. S. (2001). Ordinary magic: Resilience processes in development. *American psychologist*, 56(3), 227.

***Resilience is Relative
Resilience is not Static
Resilience skills can be Learned
Resilience can Evolve at ANY TIME***

Harvard Working Paper 13



- One stable, caring and supportive relationship
- Sense of mastery as compared to feelings of helplessness
- Direct instruction for strong executive function skills (with adaptations, modifications and tools)
- Direct instruction for strong self-regulation skills (knowing signs, asking for break)
- Where possible, having a strong faith and/or cultural support (hockey counts) or that of a pay for fee support

Center on the Developing Child at Harvard University (2015). *Supportive Relationships and Active Skill-Building Strengthen the Foundations of Resilience: Working Paper No. 13*. Retrieved from www.developingchild.harvard.edu.

We know resilient autistic people



What do they share?

- They are “out”
- They use accommodations
- They are using their strengths
- They’re continuing to grow and consistently solicit “feedback” (not criticism)
- They use family—home and families of choice—for support



What tools are in your chest?

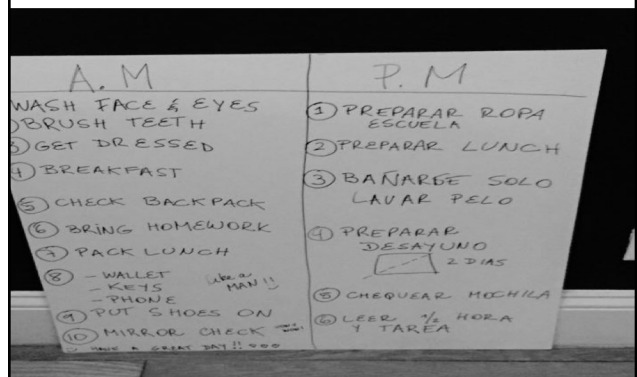


Chloe Talks: Tools to Cope

- Friends on line
- Fidgets
- Breaks
- Weighted blanket/lap pad
- More processing time
- Social scripts
- Visuals & Schedules
- Headphones (NC)
- Ear buds (listening to music, sometimes the same song on loop)



Schedules



Schedules

	Monday	Tuesday	Wednesday	Thursday	Friday
7:00					
7:30					
8:00	Wake up, get ready for class, eat	Wake up, get ready for class, eat	Wake up, get ready for class, eat	Wake up, get ready for class, eat	Wake up, get ready for class, eat
8:30	breakfast, walk to campus for class	breakfast, walk to campus for class	breakfast, walk to campus for class	breakfast, walk to campus for class	breakfast, walk to campus for class
9:00					
9:30	Meet with Kerrie	email MuOnline	Meet with Kerrie	email MuOnline	Meet with Kerrie
10:00					
10:30	CJ 200 -11-11:50 Smith Hall 416	Meet with GA	CJ 200 -11-11:50 Smith Hall 416	Meet with GA	CJ 200 -11-11:50 Smith Hall 416
11:00					
11:30	Lunch Campus	History 434	lunch Campus	History 434	Lunch Campus
12:00					
12:30	email MuOnline	12:30-1:45 pm Harris Hall 130	email MuOnline	12:30-1:45 pm Harris Hall 130	email MuOnline
1:00					
1:30	Tutoring with Kenny 2-4 pm	Tutoring with Kenny 2-4 pm	Tutoring with Kenny 2-4 pm	Tutoring with Kenny 2-4 pm	Tutoring with Kenny 2-4 pm
2:00					
2:30					
3:00					
3:30					

What others say...



- Sensitivity to particular levels of illumination or colours, or a distortion of visual perception occur in ...one of five children with AS

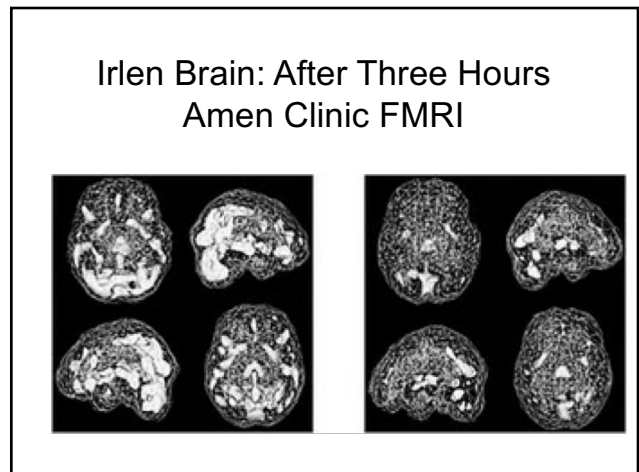
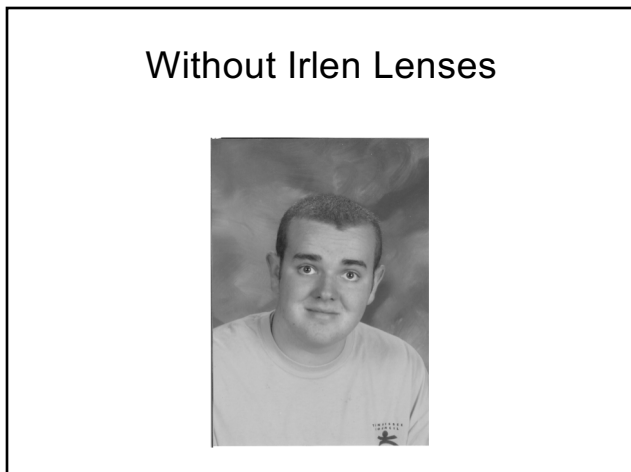
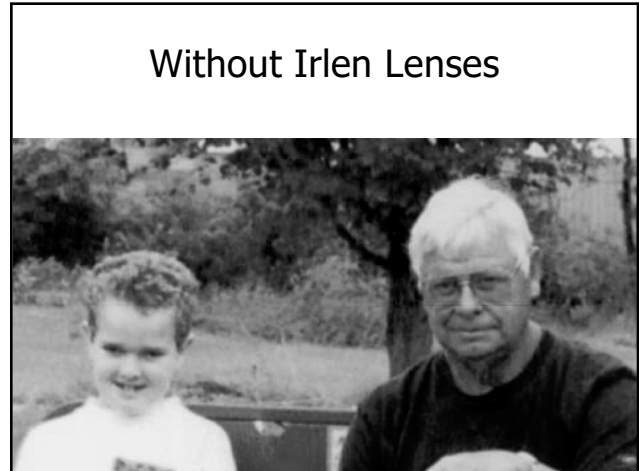
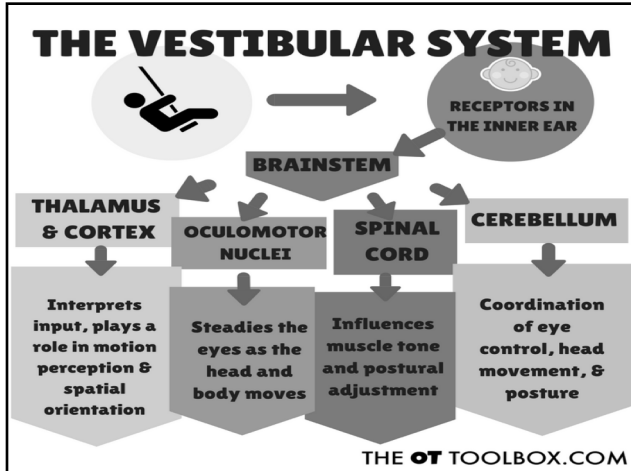
Attwood, T. (2006). *The complete guide to Asperger's syndrome*. Jessica Kingsley Publishers.

- “Responses to visual stimuli such as light, color, shadow, or reflection may cause increased arousal of the nervous system in persons with autism.”

Baron, M. G. (2006). *Stress and coping in autism*. Oxford University Press, USA.

By Thursday after noon,
 was not entirely surpris
 no one knew was there
 group. He only saw his cla
 after that they were spli
 Maths with x English w
 which was mysterious
 end of that period he was
 been at the beginning, it
 on page 135 of book 2 whil
 135 of book 3 as both book
 the lesson was over befor

We all see things
 We see words
 The print is ma
 bac kgr ound ..
 (more text)



With Lenses



Rehabilitation Services/College Accommodations

- Irlen Lenses
- Kurzweil Reading Software (2nd version)
- Dell Laptop
- Notetakers in classes
- Separate testing
- Read aloud
- Teacher notes/slides
- Adapted tests
- Communications supports



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Regulation Tools

- Irlen Lenses
- Communications supports
- GABA
- iPod
- "Stuff" (Generals, books, DVDs)
- Control over all of it
- Predictability
- Consistency
- Schedules



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Dena's Supports

- *Air Travel*
- *Lighting*
- *Earphones*
- *Space to work*
- *Executive Function*
- *Quantitative Research*
- *Statistics*
- *Comprehensive Exams*
- *I want Rosie!*



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Going forward:

- Targeted skill development for “students, parents, job seekers and community members” (WP 13)
- Expand 18-21 training with off campus locations to encourage less externally manifesting students to utilize transition support/ parallel with academic goals
- Maximize instruction for EF and Self-regulation with coaching scaffolding and practice.
- Realize that with the right supports and services, and practice insights, that these skills can evolve over time
- Accept that the capacity to develop these skills is individualized and while some can learn autonomy, others may require surrogate representation but rarely will anyone have mastery



Redefine my marriage



Redefine Family



Cultivate professional relationships

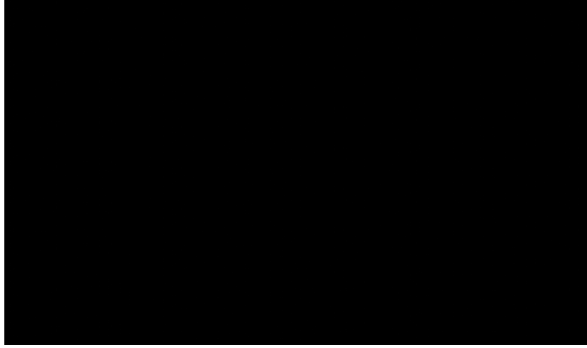


You Don't Outgrow your Autism

- ❖ You don't **outgrow** your accommodations.
- ❖ You don't **outgrow** your autism.
- ❖ You grow **INTO** it.



What is Possible



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c4ucontact@gmail.com