

My Life: How an Autism Diagnosis Helped To Create a Nonprofit Program and More Opportunities

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My Life: How an Autism Diagnosis Helped to Create a Nonprofit Program and More Opportunities

What we will be covering today.....



1. My life story with Q&A from Scott/Jamie
2. How my life story resulted in GCA and more opportunities




My Life: How an Autism Diagnosis Helped to Create a Nonprofit Program and More Opportunities

Purpose Statement and Learning Objectives

Purpose statement: The presenter will share his inspirational life story and how his story created the GCA Centre for Adult Autism and the opportunities that came from it

Learning Objectives:


- 1. Learn how you can deal with and overcome very tough obstacles
- 2. Learn how you can take the skill set you have and do amazing things
- 3. Realize that opportunities can come when least expected



My Life: How an Autism Diagnosis Helped to Create a Nonprofit Program and More Opportunities

LO 1 – My Life Story and Overcoming Very Tough Obstacles – Scott/Jamie

- Born on the southside of Chicago in Chicago (native Chicagoan)
- Diehard Chicago Cubs fan (since mid-1970s) “Go Cubs Go!!!”
- Was NOT diagnosed on the autism spectrum as a kid (tools not available until the early 1990s)
- Happily married to current wife, April (best friends, “treehouse buddies”)
- Her three youngest grandchildren live with us



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LO 1 – My Life Story and Overcoming Very Tough Obstacles

I wanted to learn more about my own experiences growing up, my life story, and the obstacles I had to face.

Question 1 – **“What type of education did I receive.... elementary and up... public or private. If public did I have an IEP in place? and if so what services most benefited you.”** (remember, we’re talking late 1960’s to mid 1980’s here for Scott)

My mom: “K teacher: do not pass go, do not go to regular 1st grade”

- Attended rehabilitation school in 1st grade, didn’t think I should be there
- No IEP at the time, special education = strong stigma at time



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LO 1 – My Life Story and Overcoming Very Tough Obstacles

2. What other diagnoses were you given if you were just recently diagnosed with autism?

Me: AD/HD. Attacked that first, then autism

Two ways of dealing with very tough obstacles

- A. Feel a strong sense of relief
- B. Play the “woe is me” game and feel sorry for myself all the time



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LO 1 – My Life Story and Overcoming Very Tough Obstacles

Discovered that I did not have AD/HD...

- But that I had “tunnel vision” (autism) in which I was hyperfocused

Advantage – got me to where I am today

Disadvantage – my wife wasn't exactly the happiest at times



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3. What type of health professionals worked best for you?

Family doctor: “boys slower at learning things..to wait it out. Communication problem.”

Research project @ Chicago hospital: “Diagnosis of brain damage, no autism diagnosis was made...no head banging, endless rocking”

Psychologist in project: “Picture of me drawing family eating at table, eating...guessing some kind of food connection”

Rehabilitation school: “Had OT/ST. Given possible diagnosis of cerebral palsy.”




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4. When was I diagnosed and what prompted me to seek an evaluation – did I suspect autism?

- I was “different” and just been fired from yet another job in 2007
- Licensed physician told me I could be autistic & AD/HD but didn’t give me written confirmation
- Waited three years to get a written confirmation, but only after a psychologist confirmed I was highly likely to be autistic after psychological evaluation



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5. What was your school experience? Did you feel that you were "different"? Do you think other kids and teachers perceived that you were? Was bullying an issue?


My mom: "I really do not remember any specific comments other than you would not be recommended for 1st grade. The specific reason for that I do not recall. Probably due to the language issue."

However.....

Scott: - 3rd grade: first one done with math assignments and tests, "different"

- college: first one done with tests in music history class, "math/music" – Grandin

- taunted by two neighbor kids during summer between 3rd and 4th grade




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5. What was your school experience? Did you feel that you were "different"? Do you think other kids and teachers perceived that you were? Was bullying an issue? Continued...

- Moved around a lot, teachers may not have known who I was
- Taunted briefly as high school freshman by high school seniors
- Struggled during ST sessions with therapist in high school

Wouldn't trade what I went through because it made me stronger (military family)




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6. What do you wish your parents knew about Asperger's when you were growing up? What advice would you offer to a parent of a child with AS or ASD?

My mom:

- I knew nothing and apparently neither did professionals
- Never heard about it until had client at VR (she worked for Indiana VR for 15 years)
- Parents: be the advocate for your child, you know child better than doctor
- Parents: keep plugging away in best interest of child



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6. What do you wish your parents knew about Asperger's when you were growing up? What advice would you offer to a parent of a child with AS or ASD? (continued)

Scott:

- Talk with someone with experience of developing an IEP plan

If student going to college:

- Qualify for services with Georgia VR
- Attend New Student Orientation/Disability Resource Center, ask lots of questions
- Become part of a group on campus he/she comfortable about being involved



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7. Was he ever given any kind of medication? If so, at what age and for what?

Childhood – Phenobarbital, Dilantin, Depakote, Tegretol

Adulthood – Carbamazepine (generic for Tegretol), meds for colon cancer

Anti-convulsants

Meds available to treat autism, never took anything for it




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LO 1 – My Life Story and Overcoming Very Tough Obstacles

1990s:

- A. Greater stability – lived in one city the entire decade
- B. Graduated with associate's degree in accounting - 1992
- C. Got driver's license at 25 in 1992 (epilepsy)
- D. Worked towards bachelor's degree in financial planning - 1996
- E. Had several girlfriends during this decade
- F. Worked underemployed type jobs mainly: dishwasher, custodian, cook
- G. Run of being fired from jobs began




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2000s:

- A. Graduated from Purdue with bachelor's in financial planning (2000). Hired. Let go due to not having enough manpower to train further. Couldn't land another financial planning related position.
- B. Started and completed master's in higher education administration from the University of Kansas (2005). Hired. Had micromanager. Would have been fired one day later if I had not submitted resignation. Couldn't land another administration position at a college or university.
- C. Got divorced the first time in 2002 (married in 1999). More hirings and firings.




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2010s:

- A. Received written documentation of diagnosis. Started GCA Centre for Adult Autism (the nonprofit program). Later in presentation on GCA.
- B. Started and completed bachelor's in accounting (2014). Hired, then fired eight months later.
- C. Reflected on previous experiences of my life to determine where my strengths and limitations were.
- D. Met current wife in 2011, married in 2015.
- E. Developed Stage 3 colon cancer in 2017, Stage 4 in 2018



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LO 1 – My Life Story and Overcoming Very Tough Obstacles

How to deal with and overcome very tough challenges:

- A. Always keep as much hope as possible, realize not everything is fair
- B. Stay close to your spiritual source (whatever it is)
- C. Develop skill set: Given your set of skills, what kind of jobs are out there?
- D. Understand that the hare won, not the rabbit – easy to overanalyze things and have “tunnel vision”, need to develop and maintain long-term perspective
- E. Volunteer, volunteer, volunteer – does two things
 1. Gets the focus off of you and onto others
 2. Can help lead to employment opportunity (who, not what you know)

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My Life: How an Autism Diagnosis Helped to Create a Nonprofit Program and More Opportunities


2. How my life story resulted in GCA and more opportunities

2010 began my search for adult only support groups in the Chattanooga area. None in Chattanooga, none in Metro Atlanta (important to know for 2018)

“Do you know of any adult only support groups in Chattanooga?” “Sorry we don’t know of anything like that Here...good luck to you”

– “BAM! It’s time to kick it up a Notch!” (Emeril Lagasse)





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2. How my life story resulted in GCA and more opportunities

Timeline 2010-2015


2010: Founded GCA on December 31 as an inside joke to New Years 2011

Jan 2011: Named Greater Chattanooga Aspies (later shortened to GCA, with Centre for Adult Autism added after that)

Feb 2011: GCA became part of the Chattanooga Autism Center to present. First meeting. Advisory board about one year in 2011.

Mar 2011: Met current wife in person the first time, has been with GCA the longest as Parents Outreach Coordinator.

2011- Summer 2015: monthly adults-only adult support group. People hear more about it, telephone calls and emails start pouring in over time. Marries current wife on May 31, 2015 after dating for over four years.



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2. How my life story resulted in GCA and more opportunities

Timeline 2015-early 2019

Fall 2015: GCA establishes a set of groups in GA


2016: Newsletter, founding of Southeast Adult Autism Symposium, website

2017: First annual symposium. Scott gets diagnosed with colon cancer and recognized as North Georgia volunteer of the year. First ever reverse job fair takes place.

2018: Scott working on bed between rounds of colon cancer. Recognized as Chattanooga Autism Center volunteer of the year. Does search on adult autism support groups (approximately 30+) in Metro Atlanta. How many? 0.

GCA goes into Metro Atlanta. Hire program coordinator for Chattanooga. Volunteer for Metro Atlanta program coordinator joins. 2 reverse job fairs.

2019: Adult social support groups meet at two locations in Metro Atlanta



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2. How my life story resulted in GCA and more opportunities

The moral to the story?

- A. Never give up and always believe for the best
- B. You may find your niche later in life, not when you turn 18
- C. You never know who you will run into that could be your next opportunity
- D. Volunteer, volunteer, volunteer – volunteering a gateway to opportunity




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LO 2: Learn how you can take the skill set you have and do amazing things

1. Needs to start in freshman year of high school, no later than 2nd year HS
2. Vo Tech programs need to make a comeback to the high schools
3. Not everyone is cut out for college (autism community included)
4. If under 18, may want to contact guidance counselor at high school for guidance and direction...also consider autism FB groups
5. If graduated from high school, may want to get GVRA's assistance

<https://gvs.georgia.gov/find-location>



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LO 2: Learn how you can take the skill set you have and do amazing things

Someone who has expertise in the area of skill set development needs to sit down with student/individual.


E.G. Let's say that you have an interest in airplanes.

1. Do you have 10,000 hours of registered flight time? No
2. Do you have a degree in aeronautical engineering? No

Flying a plane may not be for you. What is it about airplanes you like?

"I like watching planes being fixed while they are on the ground"

1. How much mechanical experience do you have?
2. What has your mechanical experience been like to date?



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LO 2 – Learn how you can take the skill set you have and do amazing things

8. "What advice would he give a young teen about finding a job and preparing for an interview."


What kinds of things might interest a young teen in wanting to work?

Any interests a parent might notice in his child that stands out? That might be an area to explore.

If the child has a special talent that might be valuable to an employer, even at a young age, definitely a possibility.

Wouldn't worry a lot about the interview process with a young teen.

"How will he be able to function if around a lot of noise and customers?"




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LO 2 – Learn how you can take the skill set you have and do amazing things

Strengths

- Develop interest → full-time job
- Strong truth, social justice values
- “Systems and Research People” - logic statisticians/mathematicians/accountants
- “Big picture types” inventors, creators, great visualist, painters
- Funny way of looking at life, dry humor
- Compliance-based, whistleblowers
- “Good with foreign languages/speech” interpreters, linguistics



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LO 2 – Learn how you can take the skill set you have and do amazing things


Limitations

- Inflexible, way too structured
- Fascination with one particular topic
- Dealing with loud noises & odors
(hypersensitivities)
- With Facial Expressions/Body Language
- Strong amount of being taunted
- Usually the last one picked on teams

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2. How my life story resulted in a nonprofit program





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3. How Nonprofit Program Resulted in GCA and More Opportunities

2010 → GCA starts as adults-only support group


2015 → GCA expands like a mushroom

Today → GCA focused mainly between Chattanooga, TN and Atlanta, GA

Mission statement: “Empowering autistic adults and young adults and their parents/caregivers by serving as a resource center to provide mutual opportunities, information, and activities”

Values: transparency and building community – what are they?

“Four main areas” based on transparency and building community



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3. How Nonprofit Program Resulted in GCA and More Opportunities

**say
what.** “ ”

1st area – social support groups (early 2011)

2nd area – social events (2011)

3rd area – adult autism conference (2016)

4th area – employment initiatives (2017)

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3. How Nonprofit Program Resulted in GCA and More Opportunities

1st area – social support groups (early 2011)

- Builds community between people
- Transparency: we come as we are
- May or may not have a speaker
- Often people come to share experiences
- **Great way to meet new people**



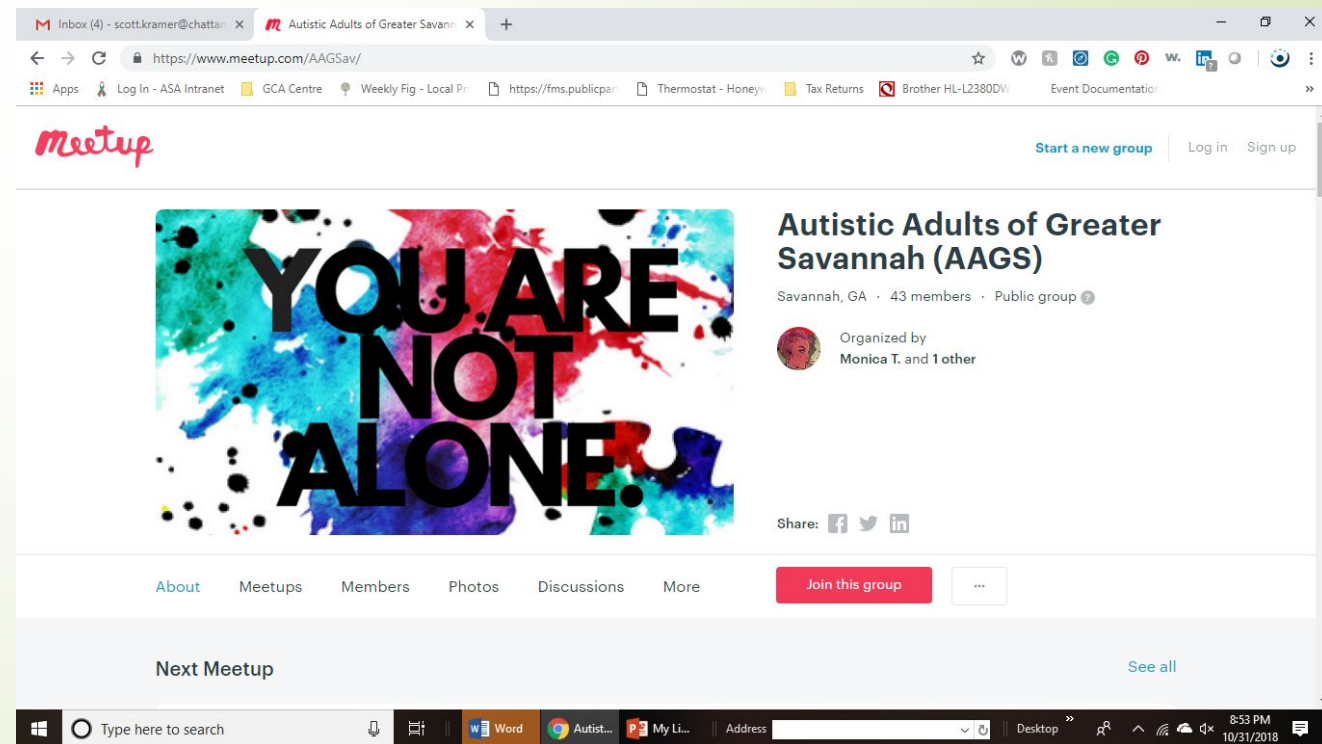
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3. How Nonprofit Program Resulted in GCA and More Opportunities

- Autistic Adults of Greater Savannah (local social support group in Savannah)

<https://www.meetup.com/AAGSav>

Founder, Monica Tye



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3. How Nonprofit Program Resulted in GCA & More Opportunities

2nd area – social events (2011)

- Builds community between people
- Transparency: we come as we are
- Keep costs reasonable
- Have fun!!!!!!!
- **Great way to meet new people**
- Others: Potlucks, movies, Bluff View Art District, more



Setting the Scene



“PREMATURE MORTALITY IN AUTISM SPECTRUM DISORDER”

The British Journal of Psychiatry (2016)

Longitudinal Study (1987-2009) – ASD adults dying an avg. of 17 years earlier

Karolinska Institutet, Stockholm, Sweden - Matched Case Cohort Study (ASD and non-ASD cohorts)

| COHORT STUDIED | TOTAL NUMBER IN STUDY | NUMBER OF MORTALITIES | MORTALITY % OF COHORT STUDIED | MOST LIKELY TO DIE SOONER |
|--------------------|-----------------------|-----------------------|-------------------------------|-------------------------------|
| General Population | 2,672,185 | 24,358 | 0.91% | |
| ASD Population | (Diagnosed) 27,122 | 706 | 2.66% | 2.92 time higher ¹ |

¹ Suicide - leading cause of HFA deaths


Setting the Scene

Relation to Approximate Adult Autism Population in TN,GA, AL, AND NC

CDC (2018) says 1 in 40 on the autism spectrum (2.5%) (2)

| | TN | GA | AL | NC |
|--|--------------|--------------|--------------|--------------|
| U.S. Census Bureau: Population Estimate, 2017 (1) | 6,715,984 | 10,429,379 | 4,874,747 | 10,273,419 |
| % Who Are ASD Individuals, 2018 (2) x | <u>2.5%</u> | <u>2.5%</u> | <u>2.5%</u> | <u>2.5%</u> |
| Approximate # of ASD Individuals | 167,900 | 260,734 | 121,869 | 256,835 |
| % of people, 18 and Over in US, 2017 (1) x | <u>74.0%</u> | <u>75.9%</u> | <u>77.5%</u> | <u>77.6%</u> |
| Approximate # of Adult ASD Individuals | 124,246 | 197,897 | 94,448 | 199,304 |

(1) https://www.census.gov/data/datasets/2017/demo/popest/state-detail.html#par_textimage_2063038847



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3. How Nonprofit Program Resulted in GCA and More Opportunities

3rd area – adult autism conference (i.e. “Southeast Adult Autism Symposium” – 2017)

- 3rd year of event is Saturday, July 27, 2019
- Location: Downtown Chattanooga, TN @ Chattanooga Hotel
- Starts at 9:00 AM EST, ends at 4:40 PM EST – ice cream social following
- Online registration starts in late March 2019 at www.gcaspies.org



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3. How Nonprofit Program Resulted in More Opportunities

3rd area – adult autism conference (i.e. “Southeast Adult Autism Symposium” – 2017)

What makes Symposium very special from other autism conferences?

1. Founded by an autistic adult (me)
2. Founded with independent living, social relationships, employment, and health & wellness in mind
3. First autism conference in the Southeast focused entirely on the adult side of autism
4. Welcome Reception and Closing Reception opportunities to network and make new friends

Won't find anything having to do with ABA or anything under the age of 18 at the Symposium, per the Symposium Planning Committee



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3. How Nonprofit Program Resulted in More Opportunities

4th area – employment initiatives (2018)

A. Chattanooga Area Employment Consortium

B. GCA and Employment

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3. How Nonprofit Program Resulted in More Opportunities

4th area – employment initiatives (2018)

Chattanooga Area Employment Consortium
Reverse job fairs in 2017, 2018, and 2019 in
Chattanooga; reverse job fair 2019 in Savannah
and Atlanta (GCA and Employment)

The CAEC is an employment consortium of various service providers and other interested individuals who get together to discuss how the consortium can further employment opportunities for individuals with various disabilities in the Chattanooga, TN and Northwest GA area




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LO 3 - Realize that opportunities came come when least expected

GCA Metro Atlanta – Jamie



1. Social support groups – East Roswell and East Atlanta locations
2. Social events (e.g. Game Days, GA Aquarium, JapanFest 2019)
3. Adult autism conference – Inaugural Autism South Conference
Atlanta, GA – Location/Cost TBD & Date (approx. mid-February 2020)
4. Employment initiatives – quarterly reverse job fairs




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LO 3 - Realize that opportunities came come when least expected

1. Where is there a need that exists and no one else is filling it?
2. Are you ready to be called on if no one else is filling that need – even if you don't know what you're doing or how it will get done?
3. It's all about networking in the community – the more people who know you, the more you'll be able to help others
4. Referrals: phone calls, emails, FB groups, FB messenger, LinkedIn, etc.

See a need in your community and would like to brainstorm about it?

Email me at Scott.Kramer@chattanoogaautismcenter.org



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If you go to the Matthew Reardon Autism Center website at matthewreardon.org, you will see this PowerPoint presentation there.

Thank you for coming to this presentation. Please see Jamie, April, or me afterward or at the GCA Centre for Adult Autism exhibitor booth if you have questions.