

Transition to Adulthood for Teens and Adults on the Autism Spectrum

Presented by
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*“Asperger’s From the Inside-Out,” “Unemployed
on the Autism Spectrum”* & the Huffington Post
column, *“Autism Without Fear,”*

Outline

- Setup: The Situation on the Ground
- The Autism Job Mess
- The Schools That Prepare Us?
- Side Issues:
 - Socialization/Relationships
 - Sports
 - Disclosure
 - Libraries
- Closing (Perspective)
- Q&A?

The Situation on the Ground

- The complexity of the Spectrum + DSM-5
- Nowhere near adequate school placements available
- A plethora of butcherous clinicians
- 1 in 68?
- What's out there for adults?
- We have "Problems"



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**Albert Einstein, Isaac Newton, Henry Cavendish,
Thomas Jefferson, Vincent van Gogh, Ludwig van
Beethoven, Wolfgang Amadeus Mozart, Emily
Dickinson, Ludwig Wittgenstein, Alan Turing, Hans
Christian Anderson, Herman Melville, William Butler
Yeats, Lewis Carroll, Arthur Conan Doyle, Erik Satie,
Bela Bartok, George Orwell, Patricia Highsmith, Andy
Warhol, Glenn Gould, Alfred Kinsey, Bertrand Russell,
Immanuel Kant, Piet Mondrian, Wassily Kandinsky,
Barbara McClintock, Paul Erdős, Nikola Tesla, Sophie
Germain, Dian Fossey, Andy Kaufman, Julia Bowman
Robinson, Joseph Cornell, Benedict de Spinoza . . .**



Pro-Cure
Research
Organizations

(Very) Pro-Cure
Vaccine Theory
Organizations



Other Peer-Run
Groups and Blogs



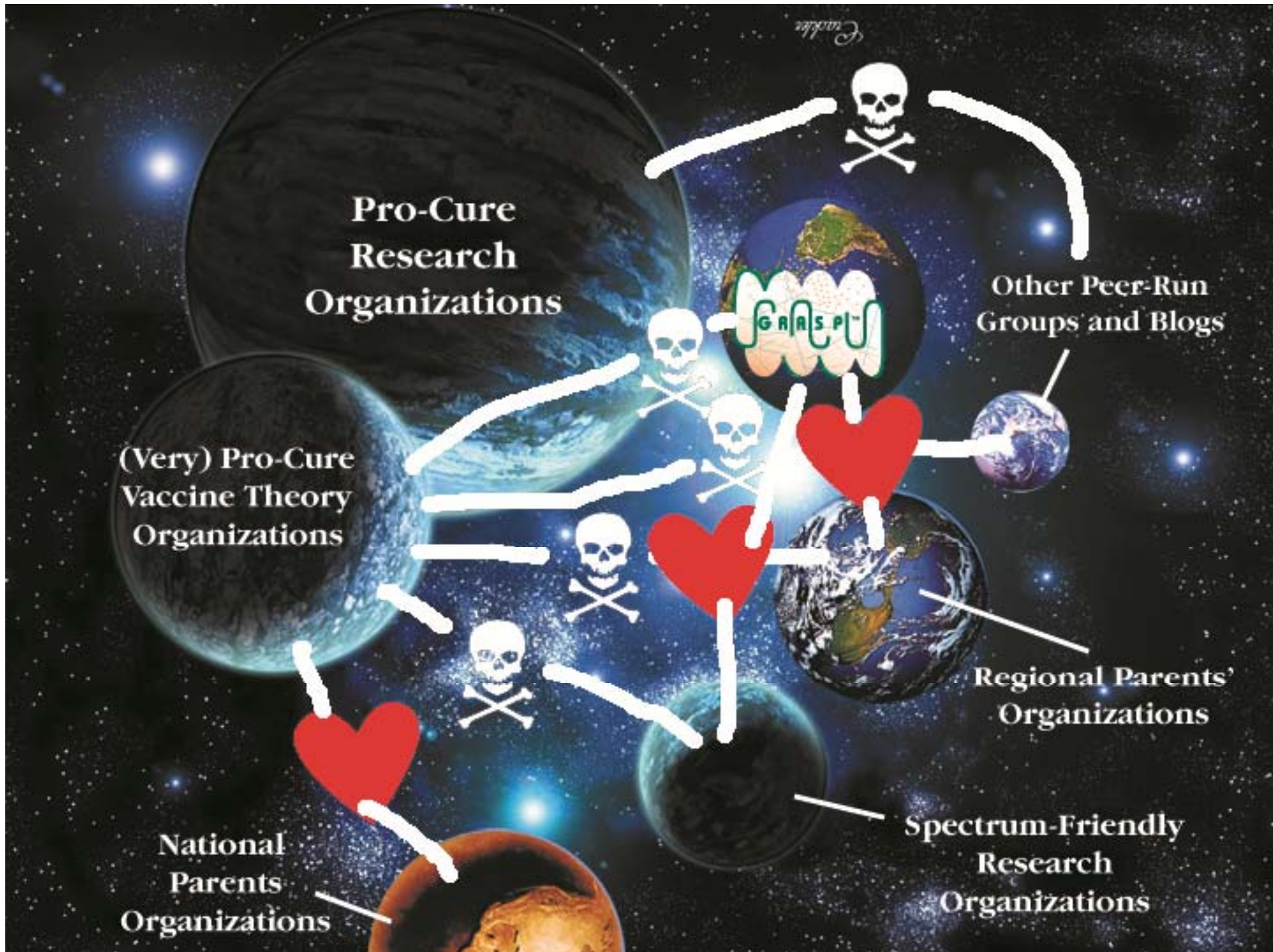
Regional Parents'
Organizations



Spectrum-Friendly
Research
Organizations

National
Parents
Organizations





Figurative Fights (“The Politics”)

- Language (ex: “Cure,”)
- The Vaccine Debate
- Aversives
- Research? What kind of research?
- First-ever Congressional Hearings on Autism
- DSM-5

The Autism Job Mess

The New Frontiers in Personnel Agencies

- Specialisterne
- Aspiritech
- Ultra Testing
- Nonpareil Institute
- ASTEP

“What do you mean by ‘mess’?”

- A handful of programs serving...100 per year?
- Working age is 21-65
- 75-85% unemployment number
- A nation of 319 million
- Prevalence rate is 1 in 68
- = over 2.6 million needing to be served

Ouch.

Large companies...

Large companies have entire departments dedicated to preserving civil rights, inclusive practices, and equality on their jobsites.

They are called
“Diversity & Inclusion” departments.

How did we once (or how do we still) define “Diversity & Inclusion?”

- Gender
- Race
- Ethnicity
- Religion
- Sexual Orientation
- Disabilities
- Veteran Status

With one exception, the unifying principle is legal compliance

And in practice? (My guesswork only) How many are focused on...

- Gender 95%
- Race 98%
- Ethnicity 65%
- Religion 70% (predominantly Christian)
- Sexual Orientation 45% (but growing)
- Disabilities (10%)
- Veteran Status (8%)

Employee Resource Groups (ERG)

How do we define Disability?

Visible Disabilities:

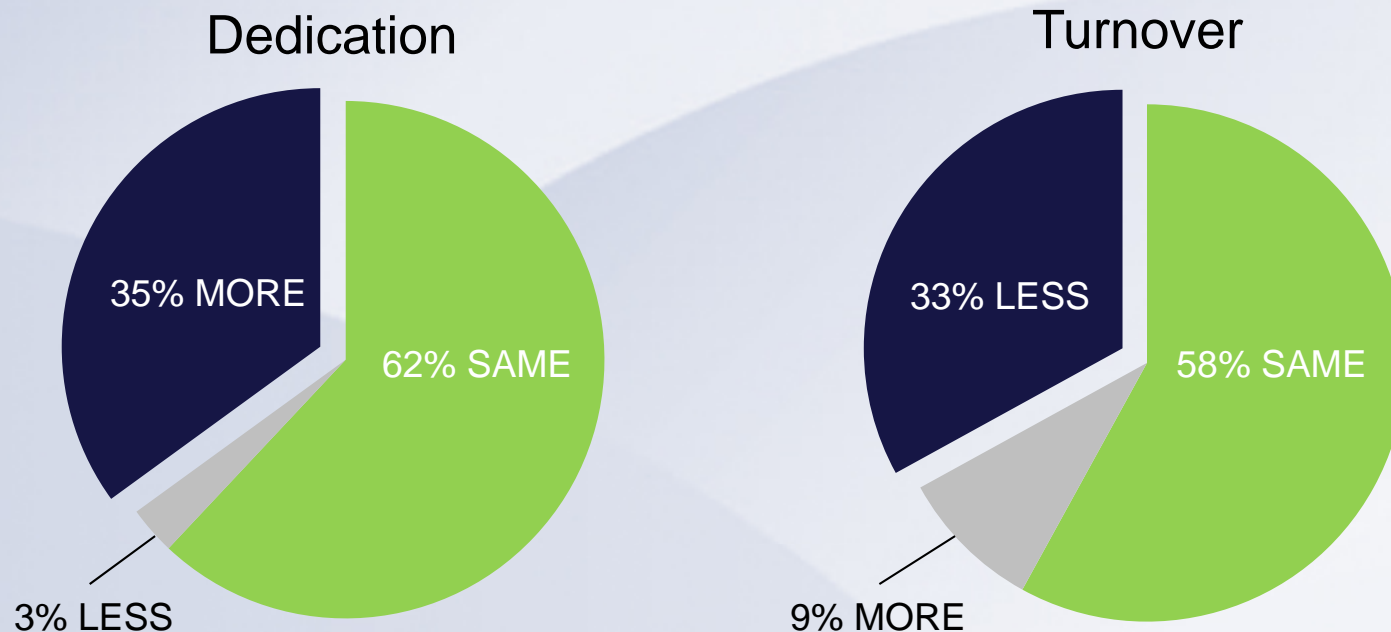
- Physical – mobility limitations...
- Sensory – hearing, vision...

Non-Apparent Disabilities:

- Mental health – depression, anxiety...
- Physical health – diabetes, epilepsy...
- Learning – dyslexia, ADD...
- Developmental – autism spectrum disorders...

Slide developed with Marcia Scheiner and ASTEP.

In 2010, 411 Fortune 5000 employers were asked about employees with disabilities. A third perceive employees with disabilities to be more dedicated and less likely to leave the job.



Slide developed with Marcia Scheiner and ASTEP.

Source: "The Employment of Americans with Disabilities" survey sponsored by the Kessler Foundation & NOD, October 2010

Silicon Valley Anyone?

And why is there fear of non-apparent disabilities?

- Disclosure
- Accommodations
- ADA

Slide developed with Marcia Scheiner and ASTEP.

ADA and Non-Apparent Disabilities

- Must be qualified for the job
- Must be able to perform the essential functions of a job with or without a reasonable accommodation
- Must disclose the disability to receive accommodations
- Accommodations must be reasonable and not present an undue hardship
- Not IDEA

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Other Laws (in the US)

- “100,000 Federal Workers!!!” from the U.S. Office of Personnel Management, 2011.
- “7%!!!” US – Office of Federal Contract Compliance Programs – Changes to Section 503 of the Rehabilitation Act: proposed requirement, 2013.
- Section 504 of the Rehabilitation Act

Crisis = Opportunity

75-85% Unemployment rate

So why aren't large businesses HIRING?

- Lack of Training (strengths, challenges, accommodations...etc.)—Confidence
- They don't get commended for nobly “trying”
- Top-down Initiative
- Love of leadership? Ha!
- They Don't Have to + our salesmanship _ _ _ _ _
- The elephant in the tub... “professionalism”

Retention

Three Types of Non-Apparently Disabled Employee

- Undiagnosed
- Diagnosed and undisclosed
- Diagnosed and disclosed

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So why aren't businesses **RETAINING** them?

- It's still too close to the "Don't ask, don't tell" days
- They don't know the warning signs (that someone might have a non-apparent disability)
- Legally cannot suggest a condition exists
- They're not certain of what accommodations they can maneuver (cost, co-worker resentment...etc.)
- Can't successfully tap into increasing D&I numbers because they can't earn the employee trust needed for disclosure
- Fear of what to do when an employee discloses

Why should businesses *want* them to disclose?

- The cost of accommodation is so much lower than typically feared– employers estimate that workplace accommodations cost on average less than \$500 for an employee with a disability
- The ability to discuss solutions with them
- Every study indicates that companies that are more diverse have been proven to outperform their peers

What would help convince an employee to disclose?

- Trainings for managers and colleagues, thus convincing the employee that their differing behaviors and histories will not be used against them
- Supervisors/ colleague/ HR staff demonstrating an understanding of—maybe even a respect for—their condition
- Seeing other elements of D&I accommodated, valued, and respected

The secret to businesses addressing 90% of the challenges...

- Communicate
- Communicate
- Communicate

Slide developed with Marcia Scheiner and ASTEP.

Challenges on our end: “Getting”

- Job skills training
- College programs not addressing the social
- Keywords
- Innovative materials? Baloney. Be boring!!!
- Interviews! But seriously...
- Networking—Who hires strangers?
- The LinkedIn generation
- Like campus recruitment...all social.

Challenges on our end: “Keeping”

- The Hidden Curriculum
- Executive Functioning
- Sensory
- Inability or discomfort towards Disclosure

The Hidden Curriculum...

Understanding unstated rules in social situations that make us fit in.

- Information that most people learn without having to be taught
- “Non-Verbal Communication” such as gesture, or tone
- Unwritten rules that most people understand
- Knowing what other people might be thinking

Management Strategies for the Hidden Curriculum...

- Clear communication – write it down
- Detailed job descriptions
- Limited use of idioms
- Mentoring
- Rules help (and the importance of how they're delivered)
- Structured work environment

Slide developed with Marcia Scheiner and ASTEP.

Executive Functioning...

Mental processes that allow us to plan, organize, strategize, and pay attention to and remember details.

Includes:

- Organizational skills– Time management
- Multi-tasking – Transitions
- Prioritization – Focus
- Emotional Regulation

- Can be seen as short-term memory challenges

- Not prevalent in all spectrum individuals

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Management Strategies for Executive Functioning

- Clear communication – write it down
- Detailed job descriptions
- Flexible work hours
- Mentoring
- Structured work environment incl. breaks
- Solutions revolve around going slow, employees taking notes, and supervisors providing written instructions

Slide developed with Marcia Scheiner and ASTEP.

Sensory...

- Sight
- Sounds
- Touch
- Smell
- Taste

Possible Accommodations for Sensory Challenges

- Lighting adjustments
- Other workspace adjustments
- Noise cancelling technology
- Flexible work hours
- Telecommute

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Stinks to be on the spectrum, but...

Everyone's challenges at getting a job
(6.0-6.5% is nonsense)

- Long-term unemployed (includes 55+)
- Discouraged workers
- High % seeking disability
- Job growth? Salaries?—Barely above the poverty line
- Changing professions vs. inadequate high school + college curriculums
- Global economy

Everyone's challenges at keeping a job

- No job protection
- “Adapt or die”

Will these large businesses be the entities that save us?

Meanwhile...(if unemployed)

- The woman from the Philippines
- Forgiveness vs the cowboy culture
- Learn a trade!
- “Lesser work” – Minimum wage, volunteer
- Small biz (REAL growth), non-profit...
- Exercise, meditate, eat well, sleep well...

Meanwhile...(if unemployed) 2

- Take your freaking benefits!
- Move?
- Budget
- Opportunity??? Self-employment, startups, back to school, get in a car...?
- Momentum

Parents should...

- Plan 15 years ahead, not 5
- “Adapt or die”
- Work it with your head, not your heart (politics example)

The Schools That Prepare Us?

Inclusion Does Not Magically Work Out Without Effort

- “No Dogs! Dogs Bite!”
- “No Recess!”
- Evan and the License Plates
- Jack at the Mall
- Understanding a Student’s Perspective and Experience, Rather Than Simply Try to Manage Behavior.
- Understanding What is NOT Within a Teacher’s Ability to Control . . . And what is
- Trust

The New Yorker's Perspective

- Pro: Inclusion WAY ahead.
- Con: Self-identification, and Self-Advocacy
- Pro: We New Yorkers think we know everything.
- Con: Money—Unsupported inclusion environments...
- Pro: Greater sense of community
- Con: Midwest not behaviorally pluralistic
(GRASP study, emphasis on behavior [vs. rebellion], aides)

See any eccentric people running businesses?

Colleges

- Distance
- Socially
- Academically realistic
- Office of Student Disabilities

Ideal Self-Advocacy is spiritually portrayed in schools and work as:

Ideal Self-Advocacy is spiritually portrayed in schools and work as:

“I need help.”

Ideal Self-Advocacy is spiritually portrayed in schools and work as:

“I need help.”

“I’m sorry.”

Ideal Self-Advocacy is also:

Ideal Self-Advocacy is also:

“Your only duty on God’s green earth is to get the hell out of my way.”

Confidence

Starting as early as possible...

Opportunities to
practice independence

Socialization/Relationships

Socialization:

**Do We Really Want To?
(my Chinese-
American friends)**

Socialization:

Different Learning Styles

Visual Learner?

Non-Visual Learner?

Socialization:

Different Learning Styles

All autism? Special Ed?

Inclusion? Mainstream?

Socialization: Common Connections

Sports

- Obvious physical benefit + motor skills
- Arena where certain emotions are appropriate (and where it is safe to apply them)
- Notions of competition
- Hayley Wickenheiser and the school in Houston
- Confidence
- No slight to the arts :-)

Disclosure

Why Do We Disclose?

Who to Tell, Who Not to Tell

HOW to Tell

WHEN to Tell

Obstacles

- These are judgment calls—
We might make a few bad decisions about who to tell, how, when..etc.
- The other person

Libraries

- Usually, we like to read
- Sensory-friendly
- Merging away from just the place where you check out books. GRASP chapters...
- And if the libraries are smart...redefining...

No Diagnosis is “the Bad Guy”

- Anxiety
- Anger
- Depression
- And for us? Distrust

“I know what’s going on with you, you’ve just got too many wires...”

“No, doctor. My problem is that the wires aren’t insulated well enough.”

--- A 5-year old boy with AS

Two Wonderful Words:

1. “So”
2. “what”

Perspective

Our Makeup

- Gender
- Race
- Economic Background
- Sexual Orientation
- Neurological Makeup
- Quality of Supports
- Culture

A Supportive and Practical Guide
for Young Adults and Adults with
Asperger's Syndrome

Asperger's from the Inside Out

Michael John Carley
Executive Director, GRASP
The Global and Regional Asperger
Syndrome Partnership

Foreword by Peter F. Gerhardt, Ed.D.,
President, Organization for Autism Research

Unemployed ON THE Autism SPECTRUM

How to Cope
Productively
with the Effects of
Unemployment and
Jobhunt with Confidence

MICHAEL JOHN CARLEY

Perspective

“Security is a superstition. It does not exist in nature. Life is either a daring adventure, or nothing.”

Perspective

“Security is a superstition. It does not exist in nature. Life is either a daring adventure, or nothing.”

—Helen Keller

Perspective

If you really want someone to change,
then you have to change.

—Freud

Thank you for listening!!!