The New Look at the Needs of Teens and Adults on the Autism Spectrum

by Michael John Carley
Founder, GRASP
and author, “Asperger’s From the Inside-Out”
Setup—"The Situation on the Ground"

Brief History of Autism + Myths

Potentially Redundant Charts


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?
- Problems
Figurative Fights ("The Politics")

- Language (ex: "Cure,")
- The Vaccine Debate
- Aversives
- Research? What kind of research?
- First-ever Congressional Hearings on Autism
- DSM-5
A Brief History of Autism
(or of a stigma)
Dr. Leo Kanner—Autism
1943

- Inability to communicate verbally
- Preference of objects to people
- Disliking of breaks in routine
- High intelligence
Dr. Hans Asperger—Asperger Syndrome 1944

- Inability to pick up non-verbal communication
- Passionate interests
- Motor skills deficits
- Oddly exhibited use of the spoken word
Before the 40’s?
Kanner’s work spreads
Asperger’s work does not

Asperger not translated into English until the early 1980’s by Lorna Wing
The 1950’s

Kanner’s belief that intelligence lies within the autistic brain is eventually discounted (only today is it being revived)

Kanner starts to think that placements outside the home would be better for autistic children
1960’s-early 1970’s
Bruno Bettelheim
The Iconography of Autism: Bettelheimian Version

- Suggestion of bad mothering
- Forced separation
- Logical then to avoid the diagnosis of Autism
- Impactful today (Sacks and grant)
Late 1970’s and 1980’s
“Why do you want to put a label on him?”
Anti-Labelism
The Iconography of Autism: Anti-Labelist Version

• Intentionally vague description of all diagnoses as “special”
• By keeping the aura surrounding the individual undefined, no one could prescribe anything harmful to the family
• Avoidance of stigma?
So did these two eras really contradict each other as much the anti-labelists hoped?
• Both prevented individuals from having a say in their care—Denying self-advocacy, if not the concept altogether

• Demonization of diagnosis itself

• Both attached negative iconography to words like “autism” and “Asperger’s”
The seeds of where we are today began in the 1960’s

• First autobiographical accounts
  — Donna Williams, Temple Grandin, and Thomas McKean challenged the idea that all autistics were incapable of communication
The seeds of where we are today began in the 1960’s

• Clinicians Like Sacks who brought the world’s attention to the beautiful works by autistics
The 1990’s

• 1993-Don’t Mourn for Us

• 1994-The DSM-IV

• Late 1990’s-More books by people like Liane Holliday-Willey, Jerry Newport, Stephen Shore. Plus, 2nd and 3rd books

• Opinions, not just experiences
And they dispelled the notion that one size fit all
Myths Since Dispelled

- Passionless
- Humorless
- No sexual appetite
- We’re all great at math
- Bullies are eventually punished by life
- 65%-85% girls
- Happiness = ability to communicate
“The New Look”

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<td>Focused on being clear in what is being said by utilizing a strength, text.</td>
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<td><strong>Penchant for interrupting others.</strong></td>
<td>The individual is rude.</td>
<td>The individual has something to say, another indicator that social contact is indeed desired (and that desire needs to be encouraged).</td>
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Socialization:

Do We Really Want To?
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
• Confidence
• No slight to the arts :-)

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Families

• Master’s Degrees in Neuroscience
• Stigma of the aforementioned history
• They don’t get a break from one another — Accumulated frustrations
• Genetic nature
The “Work Spectrum”

The 9-5 office job

The Arts & University Life

The military
Disclosure?

- Who
- How
- When
- Why
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
“Failure”
The biggest obstacle . . .
...is that no one wants to please more than us.

And “wants to please,” will always be “can’t handle rejection” to some people.
Two Wonderful Words:

1. “So”
2. “what”
Because life is going to throw us some punches
Temple Grandin
Perspective
Our Makeup

• Gender
• Race
• Economic Background
• Sexual Orientation
• Neurological Makeup
• Quality of Supports
• Culture
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
If you really want someone to change, then you have to change.

—Freud
PDFs?

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Thank you for listening!!!