

Life, Liberty & the Pursuit of Happiness: Embracing Choice and Expanding Living and Work Opportunities for Young Adults with Moderate to Severe Autism



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Who Are We Talking About?

Moderate to Severe Autism

- DSM-5 Severity Level Descriptors
- Level 2
- Requiring Substantial Support
 - Marked deficits in v/nv social communication
 - Social impairments apparent even with supports in place
 - Limited initiation of social interactions
 - Reduced or limited response to social overtures from others
 - RRBs and/or fixed interests are frequent and noticeable to a lay person; interfere with functioning in multiple contexts
 - Distress when RRBs interrupted; difficult to redirect from fixed interests

Moderate to Severe Autism

- DSM-5 Severity Level Descriptors
- Level 3
- Requiring VERY Substantial Support
 - Severe deficits in v/nv social communication severely affects global functioning
 - Very limited initiation of social interactions
 - Minimal response to social overtures from others
 - RRBs markedly interfere with functioning in ALL areas
 - Marked distress when RRBs and routines are interrupted
 - Very difficult to redirect from fixed interests; returns to RRBs and fixed interests quickly after interruption

Moderate to Severe Autism

- Additional Challenging Behaviors
 - Aggression – at times extreme
 - Self-injurious behaviors

The Autism Epidemic

A Public Health Crisis

National Incidence of ASD

1970 ~ 1 in every 10,000 births

1993 ~ 1 in every 1,000 births

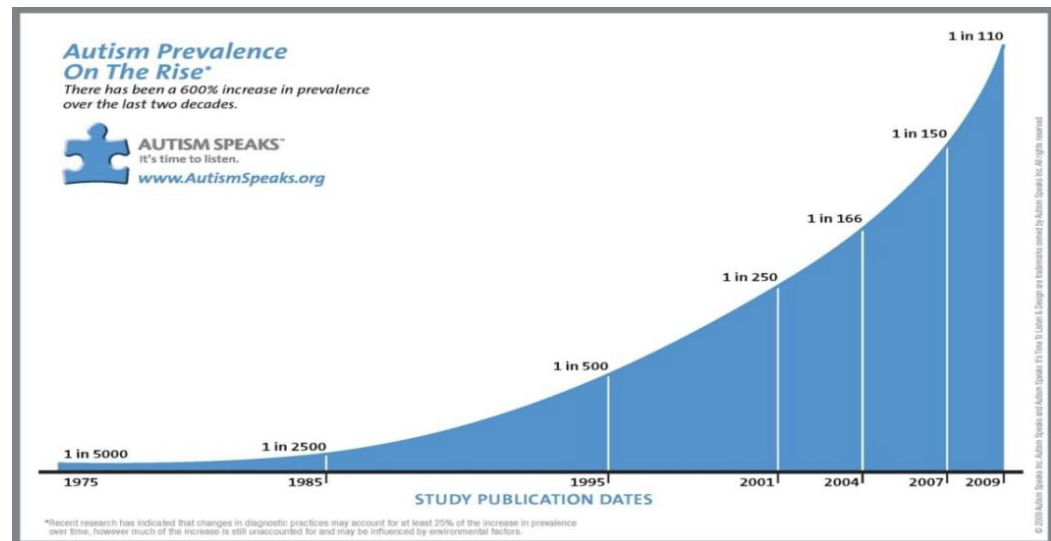
1995 ~ 1 in every 750 births

1998 ~ 1 in every 500 births

2008 ~ 1 in every 150 births
(1 in 94 males)

2010 ~ 1 in every 88 births
(1 in 54 males)

2013 ~ 1 in every 50 births
(1/31 males; 1/143 females)



Question: What happens to kids with ASD?

Answer: THEY GROW UP!

- **CURRENT STATUS OF YOUTHS & ADULTS WITH ASD**
 - Youths with ASD ~ poor education & employment
 - 61% of adults rely on their families
 - 40% live at home with their parents.
 - 82% ~ isolated.
 - 67% ~ anxiety 55% ~ depression because of a lack of support.
 - Lack of support (60% of youths with ASD) ~ higher long-term needs

The Tsunami of Young Adults with Autism

- Currently 6,000 adults with ASD are Regional Center (RC) consumers
- By 2018, there will be more than 19,000 adults with ASD in the RC system
- Most Regional Centers will see more than a 300% increase in the numbers of adults with ASD during the next decade
- Purchase of Services: Costs related to age & diagnosis
 - children without ASD.....\$3,447
 - children with ASD.....\$6,993
 - adults without ASD.....\$15,935
 - adults with ASD.....\$36,704



Quality of Life

Quality of Life

- A Definition

A major study by the Centre for Health Promotion of the University of Toronto, published in 1997, defined Quality of Life as:

“...the degree to which a person enjoys the important possibilities of his or her life.”

Quality of Life for those with Moderate to Severe Autism

- Nonverbal people with higher QOL were associated with:
 - having an occupational activity of some kind
 - not having marked behavior problems
 - having leisure activities in community
 - having community access
 - being more independent
 - making own decisions
 - having opportunities available from which decisions can be made
 - having practical support from other people
 - having emotional support from other people

Other Components of Quality of Living for those with Severe Autism

- Emphasis on Self-determination
- Well-trained staff; Supervision by BCBA's
- Use of evidenced-based treatments such as ABA
- Recreational Opportunities
- Socialization Opportunities
- Support for Establishing Meaningful Relationships
- Community Education

The Proust Questionnaire

The Interactive Proust Questionnaire | Vanity Fair - Windows Internet Explorer

http://www.vanityfair.com/culture/features/proust-questionnaire

File Edit View Favorites Tools Help

Favorites Kindergarten at CHIME Los Angeles Unified School...

Gimme Shelter: Housing for A... The Interactive Proust Q...

0/20 QUESTIONS ANSWERED

Proust Questionnaire

10. When and where were you happiest?


11. If you could change one thing about yourself what would it be?

12. If you could change one thing about your family what would it be

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

◀ PREVIOUS QUESTION | NEXT QUESTION ▶

TOD'S



Done

start Tool Kits | Autism Sp... Definitions of Wellbe... The Interactive Prou... Summit 2012 PP - Mi... Inbox - jbolton@the... Summit_2012_Broch... 3:20 PM

The Proust Questionnaire

- #10: When and where were you happiest?
- 47 year old man with Autism who was playfully answering the Proust Questionnaire with a housing program staff member at The Help Group's Project Six Adult Residential Program answered:

“Three years ago when I came to live here.”

- That's a testament to QUALITY OF LIFE.

Meet the Panel

- Judy Mark: Self Determination
- Pamela Clark: Preparation for Employment and Career Development
- Victoria Berrey: Community Involvement

Contact Information

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