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
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 BCBAs
- Use of evidenced-based treatments such as ABA
- Recreational Opportunities
- Socialization Opportunities
- Support for Establishing Meaningful Relationships
- Community Education
The 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?
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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