Identifying and Addressing the Needs of Adolescents and Adults with Autism

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“Metal Sky”
www.forrestsargent.com
Overview

- Adult autism in Washington State
- Review factors impacting ASD adult outcomes
- Highlighting “case management”
- Areas of need
  - Health and Behavior
  - Employment and Continuing Education
  - Housing and Community
  - Social and Recreation
Adult Autism in Washington State

Andrew Mito
mitosanpaints.com
- 50,000 individuals with ASD enter adulthood in the US annually based on current CDC estimates of 1 in 68 (Wang, 2014)
Autism in Washington State

• **Question** – *how many individuals are currently living in Washington State with ASD? How many are adults?*

• **Answer** – *we don’t know*

• **6,984,900 estimated population in 2014 (over 100,000?)**
Autism in Washington State

- Based on 2010 DDA and OSPI State Needs Project
  - DDA totals (age 3 to 21) – 1,421
    - Incomplete database for age 22 and over
  - OSPI totals (age 3 to 21) – 8,974
    - Even accounting for 51% with intellectual disability (4,577),
      discrepancy still of 3,156 between OSPI and DDA numbers

- Seattle Children’s Autism Center
  - Over 16,000 patient visits in 2014-15

- UW Medicine Adult Autism Clinic
  - 1,589 new patient visits since opening (9/2012 – 6/2015)
UW Adult Autism Clinic (Tolson, 2015)

- Retrospective Chart review
- 385 Individual patients selected randomly from a list of all patients in the clinic since its opening in August 2012 through June 2014

- Demographic data
- Primary and secondary diagnosis history
- Service utilization
- Medication use at presentation
- Education level
- Work status (full, part, paid, volunteer)
- Living condition status (supported vs independent vs homeless)
- Communication ability (verbal, not-verbal, uses a device)
Results: Who is using the clinic

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (yrs)</td>
<td>27 (17-72)</td>
</tr>
<tr>
<td>Male</td>
<td>68%</td>
</tr>
<tr>
<td>Private insurance</td>
<td>49%</td>
</tr>
<tr>
<td>Government funded insurance</td>
<td>47%</td>
</tr>
<tr>
<td>Living independently</td>
<td>16%</td>
</tr>
<tr>
<td>Communication: words or signs</td>
<td>82%</td>
</tr>
<tr>
<td>Communication device</td>
<td>7%</td>
</tr>
<tr>
<td>Behavioral medication</td>
<td>68%</td>
</tr>
</tbody>
</table>
## RESULTS: Clinical Care needs

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Well-established care</td>
<td>93%</td>
</tr>
</tbody>
</table>

## RESULTS: Diagnostic needs

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD diagnosis</td>
<td>50%</td>
</tr>
<tr>
<td>ASD with a genetic or psychiatric condition</td>
<td>18%</td>
</tr>
<tr>
<td>Seeking a diagnosis</td>
<td>25%</td>
</tr>
</tbody>
</table>
# Results: Seekers vs Non-Seekers

<table>
<thead>
<tr>
<th></th>
<th>Seeking</th>
<th>ASD</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years</td>
<td>29 (18.5)*</td>
<td>22 (6)*</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>In person visits</td>
<td>1.6 (1.8)*</td>
<td>2.3 (2.3)*</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Phone visits</td>
<td>0 (0)*</td>
<td>0 (1.9)*</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Independent Employment</td>
<td>36%</td>
<td>13%</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Living Independently</td>
<td>41%</td>
<td>8%</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Well established care</td>
<td>85%</td>
<td>95%</td>
<td>=0.002</td>
</tr>
<tr>
<td>Behavioral Medication</td>
<td>46%</td>
<td>75%</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Antipsychotic</td>
<td>7%</td>
<td>38%</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Antidepressant</td>
<td>36%</td>
<td>52%</td>
<td>&lt;0.01</td>
</tr>
</tbody>
</table>

*Median (interquartile range)
Factors impacting Adult autism Outcome

“Party Boy”
Wil Kerner
Wilspapercutouts.com
Outcome Trajectories

- 3-25% optimal outcome (Helt, 2008)
- Approximately 60% make progress but continue to require some types of support
- Approximately 20% remain severely impacted requiring 24/7 support (Seltzer, 2004)

Identifying trajectory by early teens critical for transition planning
Factors Impacting Outcome

- **Intrinsic**
  - Cognitive and adaptive ability
  - Severity of core autistic deficits – communication, social, restricted interests (motivation)
  - Disruptive behaviors
  - Mental health (depression, anxiety)
  - Medical health (epilepsy, sleep disorders, obesity)

- **Extrinsic**
  - Socioeconomic
  - Access to services/early intervention
  - “Case management” (Myers, 2015)

Where can we have the greatest influence?
Extrinsic Factors Impacting ASD Outcomes

- National Longitudinal Transition Study (NLTS-2)
  - Household income and “case manager” at wave 1 influenced community participation as an adult (defined as ANY participation outside of school in prior 12 months)
  - “case manager” at wave 1 influenced social participation as an adult (defined as ANY get together, social event, or phone call to friend in prior 12 months)

CP - “has youth participated in community activities in the last 12 months”
SP – “get togethers, invitations, or phone calls in the last 12 months”

Myers, 2015
Who are the “case managers?”

- DDA
- Educators
- Medical personnel
- Psychologists/therapists
- Parents and family
- The individual
- The community?
Areas of Need (and opportunity)

- Health and Behavior
- Employment and Education
- Housing and Community
- Social and Recreation

“Love in Action”
Guy McDonell
Mental health in ASD

- **Inpatient hospitalization**
  - tripled between 1999-2009 for adolescents with ASD (Nayfack, 2014)

- **Suicidal ideation**
  - Suicide attempts 4-fold increase in ASD (Croen, IMFAR, 2014)

- **Depression and anxiety**
  - increased in ASD vs. DD-nonASD (Gotham, IMFAR, 2014)
Medical Health in ASD

- Loss of adaptive skills after 30s
- Premature death
- Increased medical conditions
- Lower QoL than age matched DD ages 19-79
  - (interpret with caution – preliminary, small numbers, cohort effect?)

Geurtz, IMFAR, 2014
ABA services

- WA Health Care Authority, Group Health, Regence
- Established “Centers of Excellence” for Dx (31 statewide as of 10/5/15)
- Washington Autism Advisory Council (2014)
  - 250 BCBA providers statewide (50 in academics, 100 contracted with Medicaid, 45 graduating this year)
  - 160 children receiving service (but 1400 approved awaiting services)
- State plan limited to < 20 yo
Barriers/Opportunities

• Lack of adult providers
  o Physicians serving adults with ASD, only 20% received training during residency (Bruder, 2012)
  o Parents view pcps as unable to assist vast majority of autism-related problems (Carbone, 2013)
• Lack of transition tools for pediatric providers
• Lack of adult BCBA training/experience
• Parents/caregivers delay; anxiety about future planning ("case manager burnout?")
• Collaboration between medical, mental health, and the “autism expert” (telehealth?)
Employment and Education

- Lower rates of employment, vocational training, and post-secondary education compared to other DDs (Shattuck, 2012)
- Employment rates 4.1% – 11.8% regardless of intellectual ability (Taylor & Selzer, 2011)
  - Decline in employment status over time – decline is 15x greater for women (Taylor, 2014)
  - Demand for vocational rehab services for transition age youth with autism is increasing steadily (yet success in achieving employment outcome rate is declining)
- Failure in higher ed due to cognitive inflexibility, exec fxn deficits, poor study strategies (Tops, 2014)
ASD Employment

- Greater vocational independence relates to subsequent reduction in autism symptoms and maladaptive behaviors as well as increase in ADLs – the reverse did not hold true (Taylor, 2014)
  - *The job is the treatment!*
Intrinsic factors hindering work participation (Holwerda, 2012)

- Cognitive ability
- Severity of autism related symptoms
- Co-morbidity of psychiatric disorders
- Oppositional personality
- Epilepsy
- Maladaptive behaviors
- Lack of drive/motivation

- Factors improving – higher education/family support
Success in Supported Employment

- Supported employment programs with successful competitive employment in 27 of 33 (Wehman, 2012) and 21 of 24 (Wehman, 2013) vs. 1 of 16 in control group
Barriers/Opportunities

• Employment Specialists training (need identified in Road to Community Living grant)
• Employer education/support – change culture in the workplace
• Post-secondary education opportunities – restore “master-apprentice” teaching
• Post-secondary educator support
Defining Success

- Parents in “Next Steps” class – asked “What are your long term goals for your son/daughter?”

- Living –
  - “Live in a group home with a caretaker to oversee him and insure he is OK”
  - “Live independently and have positive social relationships”
  - “Find permanent housing and learn to manage money”
  - “Safe and well cared for, eating healthy food and functioning as independently as possible”
Defining Success (cont.)

- **Social/Recreational**
  - “More face-to-face in person rather than online over the computer”
  - “Make friends who are understanding and avoid people trying to take advantage of him”
  - “Possible relationship with a female partner”

- **Occupational**
  - “A job that paid enough for him to live on with health care”
  - “A meaningful job challenging to him while he is able to support himself financially”
  - “Continue opportunities for learning”
“Not everything that steps out of line, and thus ‘abnormal,’ must necessarily be ‘inferior.”

Hans Asperger, 1938