



*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



*AdultAutism in
Washington State*

Andrew Mito
mitosanpaints.com

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***
 - (David Maltman, Policy Analyst, Washington State Developmental Disabilities Council, 5/2014)
- 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



Characteristic	Percentage
Age (yrs)	27 (17-72)
Male	68%
Private insurance	49%
Government funded insurance	47%
Living independently	16%
Communication: words or signs	82%
Communication device	7%
Behavioral medication	68%

RESULTS: Clinical Care needs



Characteristic	Percentage
Well-established care	93%

RESULTS: DIAGNOSTIC NEEDS

Characteristic	Percentage
ASD diagnosis	50%
ASD with a genetic or psychiatric condition	18%
Seeking a diagnosis	25%

Results: Seekers vs Non-Seekers

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

*Median (interquartile range)

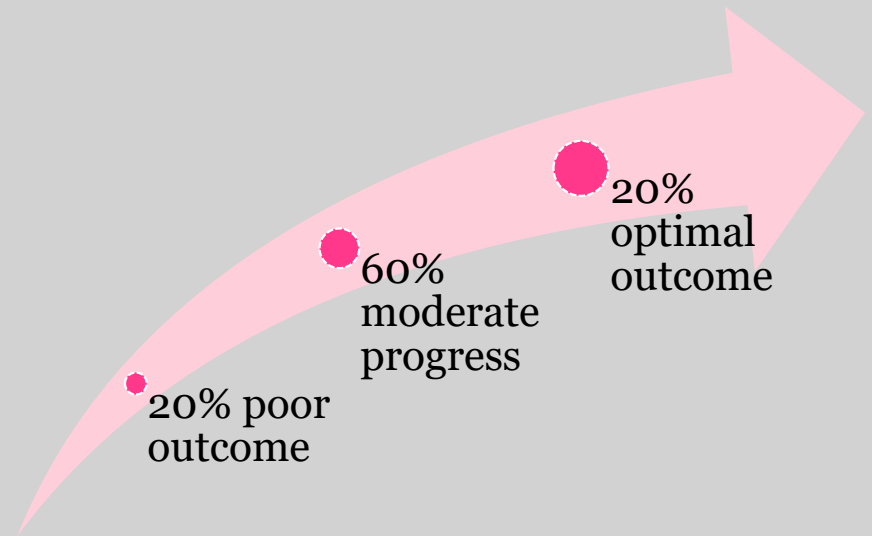
***Factors impacting
Adult autism
Outcome***



“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)



Factors Impacting Outcome



- Intrinsic

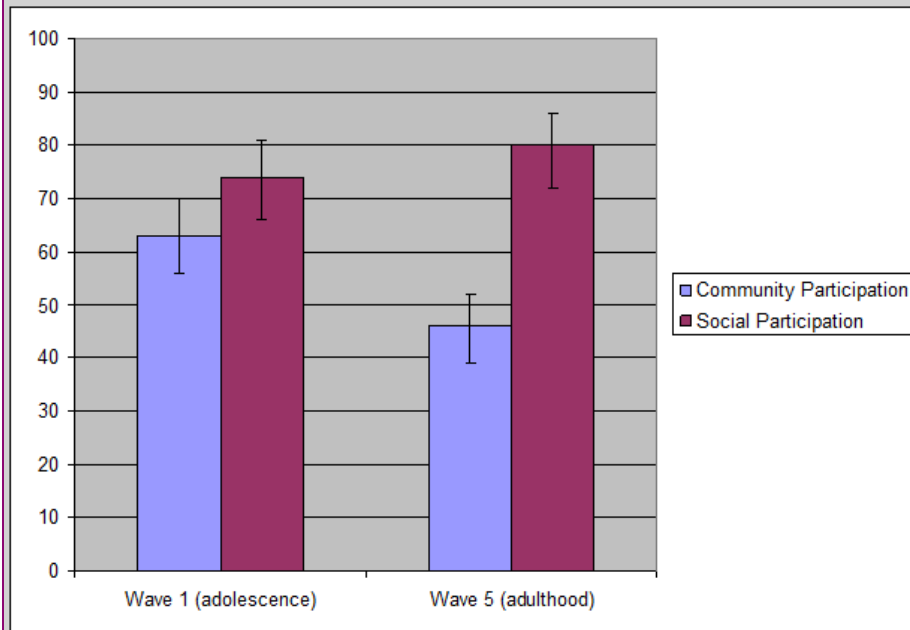
- Cognitive and adaptive ability
- Severity of core autistic deficits – communication, social, restricted interests (motivation)
- Disruptive behaviors
- Mental health (depression, anxiety)
- Medical health (epilepsy, sleep disorders, obesity)

- 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”

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?)

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
 - Physicians serving adults with ASD, only 20% received training during residency (Bruder, 2012)
 - 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**

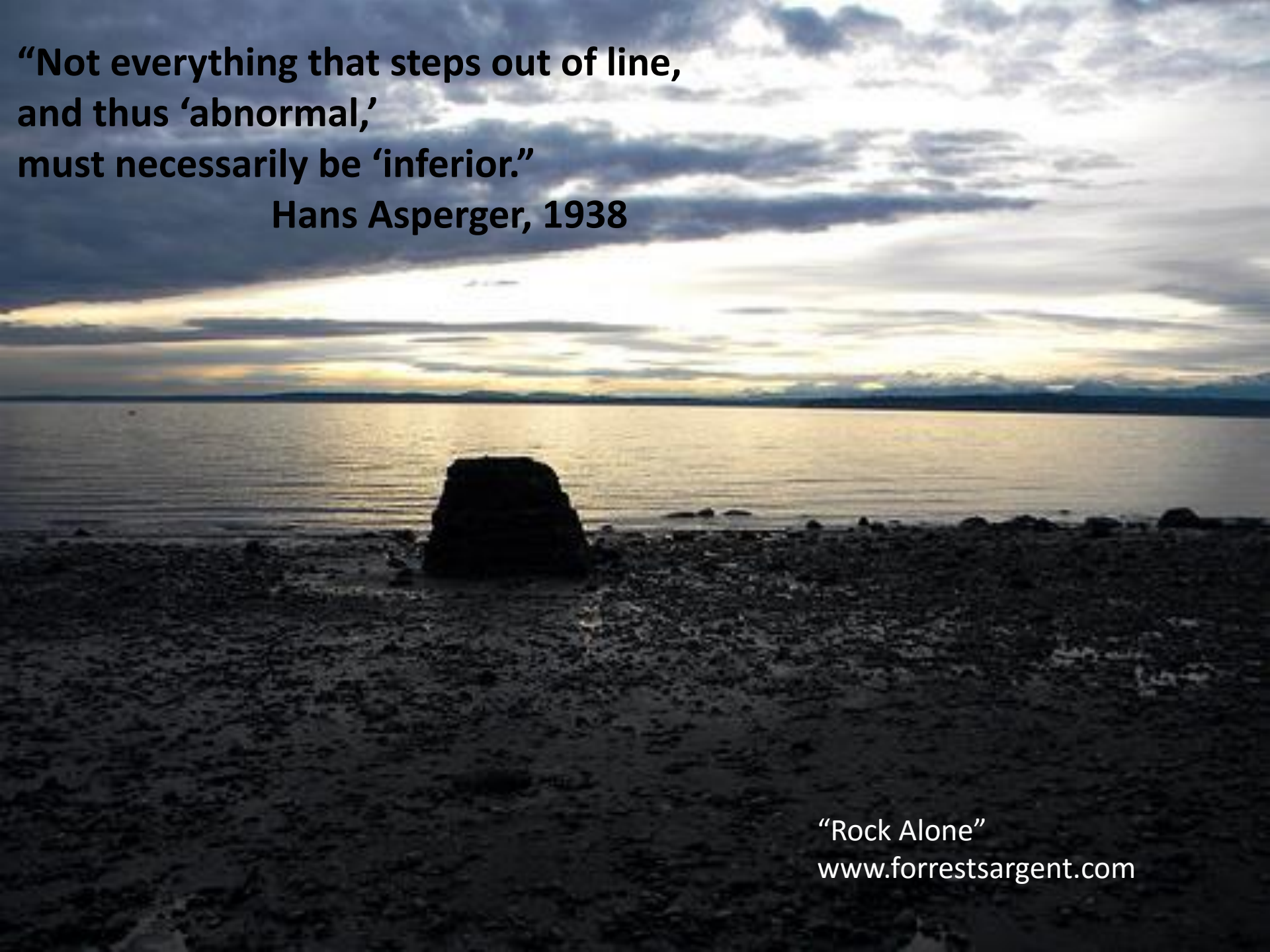
- “More face-to-face in person rather than online over the computer”
- “Make friends who are understanding and avoid people trying to take advantage of him”
- “Possible relationship with a female partner”

- **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



“Rock Alone”

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