Disclosures

• SIG #15 – first literature review prepared for the May 2012 issue of *Perspectives in Gerontology*. There is a fee reimbursement associated with editorship.

• Bloomsburg University – full time employee. Resources for literature review and partial reimbursement of travel. No other relationships.
Who is here today and why?

• Perhaps you:
  • Work with autism with pediatrics and are wondering what all the fuss is about... or perhaps are relieved that we are finally thinking about it.
  • Work in a SNF and you have residents that “if I didn’t know better, I’d think this person was on the spectrum.”
  • Are fascinated by autism and are curious about what we are going to talk about.
• Those who know me, know that.....
Objectives: We Will:

1. Discuss the general behavioral manifestations of ASD.
2. Describe the aging process in other special populations.
3. Review data about aging in autism (demographics)
4. Discuss communication and socialization and how autism may affect these in aging.
Objectives

5. Discuss appropriate screening/assessment tools for geriatric patients that may be sensitive to autism.

6. Discuss three cases from skilled nursing facilities which, although never diagnosed with ASD, presented special challenges to their caregivers as a result of the communicative, social and other behaviors.
Autism defined

• Autism (autism spectrum disorders, or ASD)
• Wide range of developmental disorders
• Impairments in 3 behavioral domains
  – social interaction
  – language, communication, and imaginative play
  – range of interests and activities (Muhle, Trentacoste, & Rapin, 2004).

• New definitions will alter which individuals may “qualify” for the label.
Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:

1. Deficits in social-emotional reciprocity;
   – (ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction)
2. Deficits in nonverbal communicative behaviors used for social interaction;
   - (ranging from poorly integrated verbal and nonverbal communication, through abnormalities in eye contact and body-language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures.)

3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers);
   - (ranging from difficulties adjusting behavior to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people)
DSM-V language

• Restricted, repetitive patterns of behavior, interests, or activities as manifested by **at least two of the following**:  

• 1. *Stereotyped or repetitive speech, motor movements, or use of objects*;  
   – (such as simple motor stereotypies, echolalia, repetitive use of objects, or idiosyncratic phrases).

• 2. *Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change*;  
   – (such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes).
DSM-V language

• 3. **Highly restricted, fixated interests that are abnormal in intensity or focus;**
  – (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).

• 4. **Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment;**
  – (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects).
DSM-V language

• C. *Symptoms must be present in early childhood*
  – (but may not become fully manifest until social demands exceed limited capacities)

• D. Symptoms together *limit and impair everyday functioning.*
A Syndrome, not a Disease

• Estimates of the prevalence of ASD vary.
• Increase of over 550% from 1991 to 1997 (Muhle et al., 2004).

• Prevalence has increased from 5-10 per 10,000 in the 1990s (Newschaffer & Curran, 2003) to various current estimates approaching 1%, or 1 in 100... or even more.
  – Is the actual population of individuals with ASD increasing?
  – Has society become more adept at recognizing the symptoms of this disorder?
Are all people with ASD the same?

• Of course not.
• But often a need for life-long assistance

• Higher level ASD may be able to live independently and well
• Lower functioning individual likely to need long term support
They will age.

- Most of what is known about ASD comes from pediatrics.
- Only recently that the maturational (adulthood) and aging (geriatric) aspects of ASD have been considered (*Harrison, 2010*).

- Our profession and society must prepare for:
  - Changing demographic
  - Poorly understood demographic (even in youth)
  - LESS understood in terms of its senescence.
Care is Expensive

- Provision of necessary services is expensive.
- Over $35 billion annually (estimate)
- This does not take into account all therapies or lost income (Harvard School of Public Health, 2006).
- Has not been able to encompass the potential costs of managing life span issues.
Identification

• DSM-V classifications of ASD *(American Psychiatric Association, 2012)*

• ↓qualification for services at all points in the life span?? Debated.

• Lower functioning individuals → more likely to qualify

• More likely to require lifelong support.
Appropriate Services

• Special education services until the age of 21
• Afterwards, special community programs, group home placements, etc. Not mandated through legislation.
• Funded either privately or through Medical Assistance.

• Recent focus in life planning (adulthood): How can we...
  – Meet their need for assistance and support?
  – Integrate them as much as possible while preserving their individuality and preferences?
  – Accomplish this with the numbers that we expect in the future?
Normal Aging

• Physical, psychological and social (Kane et al., 2008)

• Physical:
  – *Decrease in Physical Strength, Endurance, and Flexibility*
  – *Decline in Efficiency of Body Organs*
  – *Loss of Bone Mass*
  – *Slower Reflexes*
  – *Sensory Decline*
Normal Aging

• Physical, psychological and social (Kane et al., 2008)

• Psychological:
  – Secondary to changes in the brain (cortical as well as microstructural)
  – Slower processing time
  – Longer learning time
  – Mild memory reductions
  – Often improved vocabulary, general knowledge.
Normal Aging

• Physical, psychological and social (Kane et al., 2008)

• Social:
  – *Known benefit from maintenance of social interaction*
  – *Greater need for social supports*
  – *Bereavement/grief*
Aging of other Special Populations

• Down Syndrome, for example.

• Brain Structure: Similarities between the brains of individuals with Down syndrome and those with Alzheimer’s disease (Burger & Vogel, 1973)

• (Known genetic mutation present in Down syndrome)

• No single genetic cause for ASD, but possibly multiple genetic interactions plus environmental factors (Muhle et al., 2004).

• Complicates predictions about aging in ASD.
The continuum of ASD aging: Adulthood

• Vocational Services: From 2003 to 2008, 337% increase in ASD referrals nationwide.
  – Comparable to rates observed in other special education children...1993 to 1998.
  – ...a rate increase that reached 800% *(Standifer, 2010, in Harrison, 2010)* *(Illuminations)*

• Caregivers = continually aging parents
  – (end of state-funded educational services)
  – These parents worry about what will happen to their son or daughter with ASD as they (the parents) age.
The continuum of ASD aging: Middle age

- UK survey of older adults with ASD (n=29); mean age 48.5 (sd 4.27)
- Over half reported problems with mobility, daily activities, pain and discomfort, and anxiety and depression (Stuart-Hamilton & Morgan, 2011).

- Consistent with other findings:
  - Levels of unemployment, anxiety and depression all higher among older adults with ASD.
  - Anticipated increasing need of expertise in the psychiatric management for adults and older individuals with ASD. (Mukaetova-Ladinska, Perry, Baron, & Povey, 2011)
<table>
<thead>
<tr>
<th>Category and % response for each</th>
<th>UK Typical</th>
<th>Formal ASD Dx</th>
<th>Self-identified</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No problem</td>
<td>90</td>
<td>64</td>
<td>75</td>
</tr>
<tr>
<td>Problem</td>
<td>10</td>
<td>36</td>
<td>25</td>
</tr>
<tr>
<td>Self Care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No problem</td>
<td>95</td>
<td>79</td>
<td>94</td>
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<tr>
<td>Problem</td>
<td>4</td>
<td>21</td>
<td>6</td>
</tr>
<tr>
<td>Usual Activities</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No problem</td>
<td>90</td>
<td>43</td>
<td>56</td>
</tr>
<tr>
<td>Problem</td>
<td>10</td>
<td>57</td>
<td>44</td>
</tr>
<tr>
<td>Pain/discomfort</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No Problem</td>
<td>74</td>
<td>42</td>
<td>56</td>
</tr>
<tr>
<td>Problem</td>
<td>26</td>
<td>58</td>
<td>44</td>
</tr>
<tr>
<td>Anxiety/Depression</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>No Problem</td>
<td>81</td>
<td>21</td>
<td>19</td>
</tr>
<tr>
<td>Problem</td>
<td>19</td>
<td>79</td>
<td>81</td>
</tr>
</tbody>
</table>

Stuar-Hamilton & Morgan, 2011
The continuum of ASD aging:

Older age

• First individuals identified with ASD were labeled in the 1940s (Kanner, 1943).

• Donald: now in his late 70s.
• Lives in the southern community where he has lived all his life (Donovan & Zucker, 2010).
• Family wealth/trust fund. Worked in the family bank.
• Socially: community accepts him as he is.
• Life skills development well into his 30s
• Supporting the need for ongoing support for individuals with ASD.

• http://bcove.me/j586fr34
Not all individuals with ASD will be like Donald

- Financial resources
- Family support
- Community and familiarity
- Vocational opportunity
- Support and acceptance
The continuum of ASD aging: Older age

- Little is known how the older ASD brain will age.
- Studies show that young children with ASD have a significant increase in total brain volume compared to normal controls.

- MRI data:
  - ASD show age-related differences in cortical anatomy from controls (↓ volume and thickness)
  - These changes persist into adulthood.

- Not clear if the differences in the older ASD brains were structural differences or a result of environmental response (Raznahan et al., 2010).
Executive Functioning, Autism and Aging

(Guerts & Vissers, 2011)

• Compared neuropsychological profiles on 46 individuals aged 51-83; 23 ASD, 23 typical.
• Working memory, cognitive flexibility, planning, and fluency.

• *Premise*: In normal and ASD, there are different developmental patterns for different aspects of EF.
• Will this remain stable, become more severe, or become less severe in aging?
• Participants matched for age, gender, education, IQ; classified as ASD with scores on Social Responsiveness Scale (SRS) (Constantino & Todd, 2005)
Executive Functioning, Autism and Aging
(Guerts & Vissers, 2011)

• No significant overall differences in:
  – Processing speed, attention, cognitive flexibility, planning, visual memory, or verbal memory.
  – All declined with aging, but no more so in ASD.

• Significant differences in:
  – Visual memory, verbal fluency
Attention: Mean Reaction time in a digit response task (respond on cue except when a specific digit is noted)
Verbal Fluency: Number correct
(name as many words starting with a particular letter)

Regression analysis to determine impact of aging specifically with ASD on this skill.

(Guerts & Vissers, 2011)
Visual Memory: Reproduce geometric figures viewed for 10 seconds. Aging had a greater effect for ASD

Regression analysis to determine impact of aging specifically with ASD on this skill.

(Guerts & Vissers, 2011)
Caring for Older ASD patients

• When people with ASD reach Medicare eligibility (via aging or through documented disability), the system must be able to provide their needed care.

  – What supports will they need?
  – How should supports be provided?
  – Would they benefit from the same kinds of interventions provided to children with ASD? (Piven & Rabins, 2012)
Intervention and Support: It is not known:

- WHAT
- BY WHOM
- TO WHAT DEGREE
- WHERE
- WHEN
- HOW

- Virtually no research yet defining what those needs might be so that these important issues can be addressed. (Happé & Charleton, 2012; Perkins & Moran, 2010; Piven & Rabins, 2012).
Is anyone trying to determine LT needs?

• Task forces and societies in the UK, Canada, The Netherlands
  – projections for numbers of citizens
  – estimates about costs of care within their social support systems
  – It should be noted that their social support systems differ from ours
Demographic Data

• Stable *percentages* of ASD across the life span.
• Screening of over 7400 individuals (England) across the life span
  • 1.1% at age 16-44
  • .9% age 45-74
  • .8% above age 75 (*Brugha et al.*, 2011)
• Few adults with ASD live alone; many live with family members.
• Lower rates of marriage and parenthood
• Cannot depend upon younger family members to care for them as they age (*Pivin & Rabins*, 2012).
D’Arc at the University of Amsterdam

• D’Arc = Dutch Autism and Attention Deficit and Hyperactivity Disorder (ADHD) research center
• “Aging and Autism: Double Jeopardy” (Guerts, 2011).
• Hypothesis: Aging has a different trajectory in autism.
  – Began with interviews; individuals with ASD ages 53-83.
  – “How has aging affected your life?”
“How has aging affected your life?”

• For some, life is easier – less societal pressure to conform
• Some abatement of sensory issues... but some with greater sensory issues.

• Much variability across individuals
  – The sensory decline often a part of normal aging may benefit some (not all) individuals with ASD
  – May lessen environmental triggers and lessen anxiety and agitation.
Are we ready?

• NO. Emphatically.
• Our care facilities are not prepared and appropriately staffed to manage the issues coming with ASD.
  – language
  – communication
  – socialization
  – behavioral issues
• Resources/training needed - “highest practicable level.”
Assessment/Screening

• MDS 3.0 – no separate category listed for autism, (MDS 2.0 did) (Center for Medicare and Medicaid Services, 2012).

• MDS 3.0: nursing interviews are part of the tool, patient/resident’s diagnosis that affects communication and socialization
  – Not necessarily predictable communication
  – This is a complex group of residents
  – Never DID fit a social model
Assessment/Screening

• Use of questionnaires may help identify possible ASD (James, Mukaetova-Ladinska, Reichelt, Briel, & Scully, 2006).
  – *Mini Mental Status Exam* (Folstein, Folstein, & McHugh, 1975)
  – *Saint Louis University Mental Status Exam* (Tariq, Tumosa, Chibnall, Perry, & Morley, 2006)

• Sensitive to cognitive changes

• Neither normed for disorders seen in ASD.
Possible Tools

• **Autism Diagnostic Interview-Revised** (Lecouteur, Lord & Rutter, 2003)

• **Social Responsiveness Scale** (Constantino, 2005)

• **Autism Spectrum Quotient** (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001)

• **Friendship Questionnaire** (Baron-Cohen & Wheelwright, 2003)

• **Empathy Quotient** (Baron-Cohen & Wheelwright, 2004)
Autism Diagnostic Interview - R

- Audiotaped interview with parent/caregiver.
- Tool relates responses to DSM-IV categories
  - (91% of samples still identified with DSM-V; Huerta, 2012)
- Sample question from the form:
  - “Can you tell me about _____’s family? Was there anyone in the family with problems with development?”
- “Tell me about his early childhood. When was their first concern?”
Social Responsiveness Scale

*Constantino, 2005*

- Parent/teacher/family member/caregiver rating scale.
- A sixty-five item scale where behaviors are rated on a 0-3 scale (3 = always true).
- Higher scores indicate greater social impairment. Initial edition normed 4-18.
- SRS -2 normed through adulthood.

- Social Awareness
- Social Cognition
- Social Communication
- Social Motivation
- Restricted Interests and Repetitive Behavior
Sought to compare if the SRS (questionnaire) was valid when compared to the ADI-R interview format.
Correlation - .7

SRS determined to be a valid tool to quantify behaviors associated with ASD.

Clinical and Research use.
Autism Spectrum Quotient

• Self-report, 50 items.

The Autism-Spectrum Quotient (AQ): Evidence from Asperger Syndrome/High-Functioning Autism, Males and Females, Scientists and Mathematicians

Simon Baron-Cohen,¹ Sally Wheelwright,¹ Richard Skinner,¹ Joanne Martin,¹ and Emma Clubley¹

Currently there are no brief, self-administered instruments for measuring the degree to which an adult with normal intelligence has the traits associated with the autistic spectrum. In this paper, we report on a new instrument to assess this: the Autism-Spectrum Quotient (AQ). Individuals score in the range 0–50.
You can take it online!

- [http://glennrowe.net/baroncohen/autismspectrumquotient/autismspectrumquotient.aspx](http://glennrowe.net/baroncohen/autismspectrumquotient/autismspectrumquotient.aspx)

Pam’s score: 27

- 0 - 10 = low
- 11 - 22 = average (most women score about 15 and most men score about 17)
- 23 - 31 = above average

23 - 31 = above average

- 32 - 50 is very high (most people with Asperger Syndrome or high-functioning autism score about 35)
- 50 is maximum
Friendship Questionnaire

• Self-report, 35 items.

The Friendship Questionnaire: An Investigation of Adults with Asperger Syndrome or High-Functioning Autism, and Normal Sex Differences

Simon Baron-Cohen\(^1,2\) and Sally Wheelwright\(^1\)

Friendship is an important part of normal social functioning, yet there are precious few instruments for measuring individual differences in this domain. In this article, we report a new self-report questionnaire, the Friendship Questionnaire (FQ), for use with adults of normal intelligence. A high score on the FQ is achieved by the respondent reporting that they enjoy close, empathic, supportive, caring friendships that are important to them; that they like and are interested in people; and that they enjoy interacting with others for its own sake. The FQ has a maximum score of 135 and a minimum of zero.
Friendship Questionnaire


• Higher scores by respondents who report enjoying close, supportive friendships, who like and are interested in people; who enjoy interaction with others

• Women scored significantly higher than men

• ASD scored significantly lower on the FQ than unaffected males
Empathy Quotient

• Self report, 60 items
• Assesses the ability to understand the feelings of other people.

• Correlates negatively with the Autism Quotient and positively with the Friendship Questionnaire.

• ASD score lower on the Empathy Quotient than controls.
In addition to Questionnaires

• Thorough case history
• Corroborated by a relative who has known the resident for at least 10 years *(van Niekerk, Groen, Vissers, van Driel-de Jong, Kan, & Oude Voshaar, 2011)*.

• Must include reports about childhood
• (Problematic)
Differentiating ASD from Dementing Conditions

• ASD is a lifelong condition
• NO insidious OR sudden onset

• Most difficult: Dx ASD from psychiatric conditions
• Need early development info
• Need info re: psychosocial functioning prior to adolescence (van Niekerk et al., 2011).
Differentiating ASD from Dementing Conditions

- Disorders of mood, anxiety and depression occur more frequently in patients with ASD (Happé & Charleton, 2012).

- IMPORTANT! Characteristics seen in ASD – inappropriate behavior, impairments in socialization, etc.
  - Often trigger a psychiatric referral
  - Often leads to medication request if staff does not consider ASD as a potential diagnosis (van Niekerk et al., 2011).
Institutional Care

• LTC residents should ideally maintain levels of function in all domains.

• Irony:
  – Socialization is often a common goal for residents in institutions
  – Persons with ASD may never have been able to socialize normally.

• Unrealistic to assume they can function at their optimal level in this setting.

• Few options exist, even before these people become geriatric.
Institutional Care

• Two issues/two kinds of residents:
  1. The higher functioning resident, who was a community dweller, needing few supports but perhaps a bit “peculiar,” who then suffers a CVA or hip fracture and requires rehabilitation or other care.
  2. The lower functioning resident, who, when his parents or other caregivers can no longer care for him, needs someone and somewhere else.
Institutional Care

• There are no data to examine how patients/residents with ASD respond:
  
  – To new onsets of disability?
  – To the need for 1:1 assistance by strangers in a strange environment?
  – To the intensely social approaches to rehabilitation that are commonplace in our models of care?
  – To physical assistance?
  – To the lack of routine?
  – To inconsistency of care?
Institutional Care

• Many individuals with ASD prefer consistent routine, prefer to be alone and are uncomfortable with change (Happé & Charleton, 2012).
Institutional Care

- Caregiver training in our SNFs: Public policy/company guidelines
- State certification requirements for CNAs.

- Programs HAVE ADAPTED to meet the changing SNF demographics
  - No longer just a “convalescent home.”
  - Higher acuity
  - Closing of state hospitals
  - Etc.
Institutional Care

• Training re: ASD will be needed:

• Must know how they age and respond to new disability, as well as to supportive medical and rehabilitative care.
What are we to do?
As SLPs working with older people...

- What is our obligation?
- MUST become aware of the behaviors associated with ASD
- Advocate for these individuals in work settings and our communities
- Help meet their socialization and communication needs.
- Educate, document, educate, document, etc.
Is anyone researching this here?

nih.gov

University of Wisconsin-Madison
Waisman Center

Aging with Autism and Mental Retardation: Challenges and Rewards of Caregiving by Older Parents and Adult Siblings R2.1
Is anyone researching this here?

Aging with Autism and Mental Retardation: Challenges and Rewards of Caregiving by Older Parents and Adult Siblings R2.1

This study is shaped by our goal of providing scientifically credible information about a vastly under researched topic of immense importance to persons with autism, their families, and the public/private resources that sustain them. This study is timely in light of the fact that the population of adults with autism is now increasing in size, as the first cohorts diagnosed in 1943 (the year when autism was first described in the literature) have reached middle age and their parents approach or are in old age. Given the lack of research addressing these questions more research is needed to inform public policy and social services for adults with autism and their families.

A critical need exists to conduct longitudinal studies of these issues in order to describe, understand, and convey the unfolding and changing nature of the lives of adults with autism and their families during the later decades of the life course. The deepest worry in every family of a person with a lifelong disability, such as autism, is what will happen to the family member in the future. Where will he or she live? What kind of support will be available? Will his or her functioning improve, stay the same, or deteriorate? By studying a cohort of 400 families of adults with autism over a 5 year period, we will address these pressing concerns.
(1) How do the symptoms of autism change over the life course and how do these changing symptoms affect the well-being of parents and siblings?

(2) What roles do mothers, fathers, and siblings take in the provision of care and support?

(3) What resources (social, familial, psychological) are most important in maintaining parental and sibling well-being?
(4) What community resources are the most important in supporting the individual with ASD to maintain as independent a life as possible?

(5) What are the major policy issues that need resolution to ensure appropriate services and options for adolescents and adults an ASD?
Objective:

• The primary objective of the proposed studies is to utilize neuroimaging... and neuropsychological tools... to identify cognitive idiosyncrasies (e.g., social-cognitive deficits, visual perceptual assets, and savant skills) characteristic of individuals on the autism spectrum and their neural underpinnings across childhood and adulthood.

• A secondary aim is to ... identify subtypes that may inform genetic studies

• Ages: 5 - 89
How do WE start? No data!

• Document cases of suspected ASD in facilities
• Work with medical staff toward proper identification
• Work with nursing and other staff toward appropriate care planning for these individuals.
• Educate staff about ASD.
Help With A Hallmark of Autism: Communication Difficulties

Amidst Rising Rates of Autism, Speech-Language Pathologists Can Help—Early Intervention Is Key

(Rockville, MD - April 24, 2012) In the wake of a new Centers for Disease Control and Prevention (CDC) report that states the incidence of autism has risen dramatically, speech-language pathologists (SLPs) can play a critical role helping children with autism who have language and social communication difficulties.

"Given that early intervention is critical, it is important that parents are aware of the help that is available from our professionals," according to Shelly S. Chabon, PhD, CCC-SLP, President of the American Speech-Language-Hearing Association (ASHA).

One in 88 children in the United States has autism, according to the CDC—nearly a 78% increase in prevalence since 2002.

Because delayed language and limited social interaction often are the first symptoms of autism, SLPs play a key role in evaluating and diagnosing children who have the condition, and they should be involved in the evaluation process from the start. SLPs use tests and observational tools to determine communication and social skills and needs. They also rely on information from parents and caregivers.

Ultimately, SLPs develop intervention plans that meet the needs of children and families. Typically, those plans include activities designed to improve language and social communication. Additionally, they may call for the use of augmentative and alternative communication systems. Also, for children with limited speech, SLPs can develop individualized communication systems and strategies that use hand signals, picture/symbol recognition, and/or electronic devices.

Through intervention plans like these, SLP services help children develop and improve:

- Early communication skills, such as recognition of sounds, words, and gestures
- Comprehension, speech, and reading and writing skills
“But Autism is a pediatric disorder!”

- Not forever.
- Those of us working with the geriatric population MUST assure quality care

- Follow the lead of our colleagues working with the younger age groups.
- Needs: Share resources. Be open to differences across age groups. Be open to existing intervention models, but respect the differences that come simply with age.
- These residents are not just bigger ASD kids.
Article reviews suggested assessment procedures, reviews five case presentations, and discusses the issues related to identification of AS in older people.

Advantages and disadvantages of acquiring the label later in life.
James *et al.*, 2006

- SUMMARY
- There are many older adults who may have met the criteria for AS as children, but never received such a diagnosis due to the fact it had yet to be established. What happened to these people as they aged?

- Conclusion: Older patients with undiagnosed AS may currently be receiving inappropriate treatments.
- Greater awareness of AS in the older population would enable better management of such patients.
Case Presentations

• Caveat: None of these residents were ever officially diagnosed with ASD. (two are deceased).
• No way to obtain permission to review records.
• Interview with SLPs who participated in their care.
• Changed names, other potentially identifying information.
• Retrospective in nature.
“Adam,” “Ronald,” and “Stan.”
Commonalities (*similar to James et al. 2006*)

- Male*
- Admitted for falls plus generally other comorbidities.
- Lived alone with varying types of community assistance*
- Poor relationships with family*
- Disconnections with children, either no marriage or multiple marriages/divorces (unlike several of James et al. 2006)
Commonalities (*similar to James *et al.* 2006)

- Lack of insight into needs*
- Inflexibility*
- 2 of 3 well above average intelligence.
- One unable to interact in society on any level.
- Others considered “peculiar” by family for many years.
VERY LIMITED “N,” but...

• ...staff seriously questioned in all cases whether this type of facility (SNF) could meet the needs of this (type of) patient.

• Never diagnosed with AD.

• (Would having had the diagnose help them?)
“Adam”

• PERSONAL/FAMILY HX:
  • Early 70s. Divorced x3; one son, little information (poor relationship)
  • Worked for a federal agency – investigative.

• MEDICAL HX: Admitted to SNF after a fall, multiple fractures. No neurological diagnoses on his chart.

• SLP INITIAL OBSERVATIONS: Screened as a new admit... Odd.
“Adam”

• Eye contact good. Social, but with tangential responses - but primarily on two topics.
• Either talked about food, or talked about math and science.
• Really unable to hold conversations outside of these topics.
• Disliked and refused to interact with other residents.
• Refused participation in any activities.
• Exceptions: Discussion groups, but could not participate well as he monopolized on his own tangent.
• Had multiple roommates, all of whom requested room changes.
“Adam”

• CARE ISSUES:

• Nursing staff became quite annoyed and sometimes avoided him because they didn't have time to “deal with him.”

• Social but “just odd.”

• Described as a “hoarder of sorts.” Saved everything.

• Enjoyed attention from females, but it was borderline inappropriate.

• Enjoyed assistance while at the SNF but did not want it at home….despite the need for it.

• “Very set in his ways.”
“Adam”

- THERAPY ISSUES: Insisted upon specific times for therapy...facility staff accommodated this.
- SLP goals included functional problem solving in preparation for discharge.
- Professionally had been involved in research (unclear to what extent) so more interested in that.
- Had no insight into cognitive and pragmatic issues.
- Enjoyed coming to talk and felt that the SLP was intellectual and thus his equal.
- Couldn't get through a structured therapy task without tangential responses.
- (Symbolic dys 784.69)
“Adam”

• SLP could not approach him as they might with other cognitive pts (thought he was essentially confabulating).
• Therapy attempts: Games, problem solving, etc....No.
• ADL tasks like cooking or anything functional... No.
• “He was really good at refusing and had enough tact so it wasn't perceived as disruptive, just odd.”
• Was d/c’d home (alone) with home health services.
“Ronald”

- **PERSONAL/FAMILY HX:** Late 80s. Admitted with UTI and falls.
- Initial plan was for him to go home to his own house but it was condemned...deemed to be an unsafe discharge (hoarder)
- Never married, no children. Sister POA.
- Resident lived in a cabin in the woods. He was a laborer and did odd jobs from time to time as needed.
- Had a lot of books about gardening, farming; could discuss this at length.
- Prior to admission he had someone deliver groceries so he wouldn't have to go shopping.
- Much evidence of social isolation prior to admission.
“Ronald”

- MEDICAL HX: UTI, falls; (behavior/”cognition” did not improve after UTI resolved)
- Nothing neurological, no dementia ever in dx.
- Hospitalized (respiratory issues) and returned on 12 L O2. Continued a general decline and eventually was put on dementia floor and then hospice.
“Ronald”

- CARE ISSUES
- Would not let nursing touch him, nor OT to work on ADLs.
- Did let PT touch him but repetitively demanded the rationale for all PT activities.
- Did own AM care.... All AM. Refused showers and there were hygiene issues.
- All tx had to be scheduled in the afternoon.
- Ate all meals alone in room.
- No dementia dx but was placed in dementia unit.
- Roommate → increased anxiety.
- Continued to decline and placed on hospice.
“Ronald”

- SLP/THERAPY ISSUES
- Lack of participation or acceptance of SLP
- Perseverative so if something happened in the AM, that was his focus all day.
- With medical decline: more perseveration.
- Interfered with eating and became a choking risk... SLP back on the case.
- Perseveration on law enforcement issues ("Call the police!"")
- Hospice nursing staff did BEST to meet his needs on individual basis.
- Passed away in the facility.
“Ronald”

• One SLP felt that the care received by Ronald was so inappropriate for his personal needs (it was not inappropriate care... but not appropriate for HIS needs) that his CARE contributed to his decline and eventual death.
“Stan”

- PERSONAL AND FAMILY HX. Late 70s as well. Admitted for falls.
- Ophthalmologist. “Weird and pompous.”
- “Had to become an ophthalmologist because my father was also one, so it was my duty.”
- "My brothers were the smart ones, not me, so I had to memorize the textbooks in order to pass."
- Married and divorced twice. Had two sons in a distant state
- Tried to move closer to them to mend his relationships with them and his "sons’ children" (they were his grandchildren)
- Hated it and moved back.
- His home was half house and half his practice. Still in the same house in a wealthy downtown location.
“Stan”

- Was only the facility for one week and signed himself out AMA.
- This was his 11th SNF AMA discharge.
- Relied on caregivers (former office asst.) but repeatedly assured everyone that this was platonic.
- OT/speech discussed ADLs/driving with caregiver, recommended that he not drive, etc.
- He had run his BMW into the neighbor’s garage and was not concerned about this.
- Caregiver laughed – “He’s going to do what he wants to do anyway.”
- “I could probably take the keys away for about a week.”
“Stan”


• No insight into his own interaction issues.

• Very condescending to other staff and residents.
• Achieving Emotional Literacy (2003) by Claude Steiner.

• This step-by-step program opens the door to achieving emotional power. Instructions are given on how emotional literacy -- intelligence with a heart -- can be learned through practising specific exercises that foster the awareness of emotion in oneself and others, by increasing capacities to love others and oneself while developing honesty, and by taking responsibility for one's actions. Provided are instructions on how to reverse the dangerous self-destructive emotional patterns that can rule a person's life. This program shows individuals how to open their hearts and minds to honest and effective communication, how to survey the emotional landscape, and ultimately how to take responsibility for their emotional lives.

• [http://www.bookdepository.com](http://www.bookdepository.com)
• Just wait. There will be!

• We owe it to these residents to prepare for them. It is a clinical, ethical as well as a human obligation.

• Our colleagues in pediatrics have done so, admirably, in those settings.

• We look forward to collaboration and continued learning about aging with autism.
Special Thanks

• ...to the clinicians who granted interviews about their residents....
• ...to all caregivers who work so tirelessly meeting the needs of our older citizens...
• ...to the researchers who are working toward finding answers...
• ...to you, for your attention and care.
Questions, comments, thoughts?

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References


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