Autism in Maturity

Carol Povey
Director of the Centre for Autism
National Autistic Society
Outline

• What do we know
• What are the issues
• What is being done – within the NAS and elsewhere
• What do we need to do next?
“We’ve all got in common that we’re all getting older. And so that’s a real worry, ‘cos you think you want to settle your children somewhere or know what’s going to happen in the future sooner rather than later”
Overviews of the research and issues


- Piven, J et al (2011) *Autism Spectrum Disorders in Older Adults: Toward Defining a Research Agenda*


Empirical research

<table>
<thead>
<tr>
<th>Source</th>
<th>Summary</th>
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<tbody>
<tr>
<td>Bowler, D, Gardiner J, Berthollier N, (2004) Source memory in adolescents and adults with Asperger’s syndrome</td>
<td>Memory of adult with asperger syndrome is similar to older people without AS</td>
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</tbody>
</table>
1st / 2nd person accounts - pictures of success

“Supporting Elder Aspies” - Lianne Holiday Wiley, Psychology today

Blogs

Asperger United

books, magazine articles, films

Accept difference. Not indifference.
Case studies

van Niekerk ME et al (2010) Diagnosing autism spectrum disorders in elderly people *Int Psychogeriatr*


**Key issues**

Elderly ASD often referred to psychiatry due to affective disorders – anxiety / depression, but may be missed by less experienced clinician.

Present diagnostic tools highly reliant on early informant.
Prevalence studies


Adults with autism found across the age range, many undiagnosed
Policy and Practice in other countries

- The rights of ageing People with Autism - Autism Europe position paper (2008)

- “Model Programme for residential facilities for the Elderly with Autism” Denmark

- France – Sesame Village; a project for ageing persons with autism

- USA – “Autism in the second half of the lifespan: behavior, daily living, service needs” University of San Diego

- Advancing futures for adults with autism - www.afaa-us.org
UK Policy and Practice

- Rewarding and Fulfiling Lives (2010) (England and Wales only)
- Implementing Rewarding and fulfilling lives (2010)
- The Scottish Strategy for Autism
- Welsh Assembly Government Autism Spectrum Disorders – A guide for people working with Older adults, Dec 2010
- NICE Guidelines
Quality of Life of older individuals with ASD

**Methodology**

- Online survey, 29 adults, mean age 47 yrs
- Measured quality of life & psychological distress
- Compared to previously published data on these measures in general population

**Results**

- QOL significantly poorer in those with ASD vs general population
- High scores on measure of psychological distress in ASD group
- Comparison of self-diagnosed vs formal diagnosis
  - Significantly fewer with formal diagnosis in employment; had no friends and not married
- Problems documented in adolescence/ early adulthood (Howlin 2000; NAO, 2009) persist

“I Exist”

- NAS campaign 2009 to improve services and support for adults with ASD through raising awareness
- Detailed survey asking 1787 adults (18yrs and over) about their lives
- 34% of respondents (that’s 605 people) aged 40yrs or over
- 4% were 65yrs and over
If you live in your own flat or house, who provides most of your support?

If you live in your own flat or house, who provides most of your support?
Parents/Carers

Are you worried about your child's future when you can no longer support them?

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Very worried</th>
<th>Quite worried</th>
<th>Not worried</th>
<th>Don't know</th>
</tr>
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<tbody>
<tr>
<td>18-24 yrs</td>
<td>70%</td>
<td>23%</td>
<td>5%</td>
<td>2%</td>
</tr>
<tr>
<td>25-39 yrs</td>
<td>67%</td>
<td>27%</td>
<td>4%</td>
<td>2%</td>
</tr>
<tr>
<td>40-64 yrs</td>
<td>65%</td>
<td>20%</td>
<td>14%</td>
<td>1%</td>
</tr>
<tr>
<td>65+ yrs</td>
<td>55%</td>
<td>27%</td>
<td>15%</td>
<td>3%</td>
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</table>
Mental health problems

High percentage in over 25yrs report experiencing depression and anxiety
Older people with autism who use NAS services

• Range of services for adults
  – Residential care (group homes)
  – Supported living and outreach
  – Day services
  – Drop in and social groups
  – Befriending / mentoring
National Autistic Society
Understanding and responding

• 2000 working group on ageing and autism first established
• 2005 working group report
• 2006 framework for services developed
• 2008 Action learning group established
  – Training developed
  – Service model developed
  – Resource library on ageing established
• 2008 “I Exist”
• 2009 Newcastle University meeting
Older people with autism using NAS services (2009)

- Number of elderly using NAS adult services is likely to increase in next decades
Issues for service providers

- Understanding the ageing process – many care staff are young
- Lack of understanding of autism in health professionals
- What does dementia / cognitive effects of ageing look like in people with autism
- Understanding and supporting people re changes in benefits and finances
- Impact on other individuals in group homes and day services
- Generic services for older people are cheaper but not autism specific – can we train / build capacity in older people’s services
<table>
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<tr>
<th>SPELL framework domains</th>
<th>Examples of good autism practice</th>
<th>Examples of good practice with people with dementia</th>
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<tbody>
<tr>
<td>Structure</td>
<td>Modified environment</td>
<td>older people in all settings provision of a structured day, including rehabilitative activities</td>
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<td></td>
<td>Visual clarity – timetabled activity</td>
<td>can choose from and participate in a diverse range of stimulating one-to-one and/or group activities.</td>
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<td>Positive approaches and expectations</td>
<td>Respect for the persons strengths- encourage and maintain skills: attention to physical wellbeing and health</td>
<td>respect for all those people who engage with these services, not only those using them but also their supporters and carers.</td>
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<tr>
<td></td>
<td></td>
<td>The importance of health promotion in later life should not be diminished by stereotypical views on older people’s frailty and dependence.</td>
</tr>
<tr>
<td>Empathy</td>
<td>See the world from the (unique) perspective of the individual; advocacy</td>
<td>use empathy skills to help the person with dementia express their feelings and needs</td>
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<tr>
<td>Low arousal</td>
<td>Non confrontational style</td>
<td>A calm, unstressed environment where there is a clear, familiar routine can help avoid excessive reactions.</td>
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<td></td>
<td>Reduce extraneous or distracting noise/ other stimuli</td>
<td>Speak clearly and use simple sentences, allowing time for response. (Do not interrupt the response).</td>
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<td></td>
<td></td>
<td>Give limited choices in order to avoid confusion</td>
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<tr>
<td>Links</td>
<td>High level of consistency of approach: Involvement of close relatives:</td>
<td>good links with local specialist services</td>
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<td>Carers should be recognised as often essential to the well-being of the older person, and supported and empowered to provide this care.</td>
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Autism in Maturity project

• Funded by the Inge Wakehurst Trust

• Project manager – Cos Michael

Cos.michael@nas.org.uk

“I have a daughter who’s 40. She lives alone but she’s very dependent on emotional and practical support. I’m 80 and my husband’s nearly 87. I think when we’re not here, she’ll be a terrible burden for my son, who’s got a young family and that’s not fair.”
Autism in Maturity project

- undertake some research into the needs of people with ASD who are over 40 by surveying siblings

- develop a small advocacy service, using volunteers, who can support people with ASD who are over 40 through difficult times. This is in partnership with Burgess Autistic Trust and Advocacy for all, and will develop a model which can be rolled out nationally.

- develop an online network for siblings of people with ASD who are over 40 to help them to support their sisters or brothers. This will give them information about social services etc.

- provide resources for social workers and other professionals to help them to understand the needs of people with ASD as they are growing older.

- raise awareness of the issue in the press and for the general public
“(my son) has a younger brother but the younger brother has already informed me that he’d rather leave the country than actually have anything to do with X in the future. That really brought tears to my eyes.”
What do we need to find out?

• What is life like for elderly people with ASD?

• How can we develop diagnostic tools which help us to diagnose and assess older people with ASC?

• Are any health problems more common in ASD? – *effects of long tem medication / anxiety / epilepsy*

• How do the characteristics of ASD change with age? – *are there protective factors?*
  *Longitudinal studies needed*

• Is dementia common in ASD? How can it be recognised?

• What are the cognitive / sensory effects of ageing in the ASD population?

• What services, support and resources do older people with ASD want and need?
  *We need to be asking them*

• What about the people who are not known to services?
How do we ensure future generations live “rewarding and fulfilling lives”…..throughout their lives

We need to act now, and plan for the future, rather than pick up the pieces when things go wrong