

Institution: University of South Wales
Unit of Assessment: A4
Title of case study: Autism Spectrum Disorder in Later Life
<p>1. Summary of the impact</p> <p>Autism Spectrum Disorder (ASD) is a lifelong condition, but has almost never been examined in adults over the age of forty years. Following an earlier bid for funding to examine this issue, Prof. Stuart-Hamilton was commissioned by the Welsh Assembly Govt (WAG) via the charity Autism Cymru to conduct a quantitative survey of problems faced by older adults with Autism Spectrum Disorder (ASD). A companion qualitative survey, involving interviews with a small sample, was conducted by colleagues at Bangor University. A formal report (consisting of Prof Stuart-Hamilton's and Bangor's findings) and a refereed paper (solely of Stuart-Hamilton's findings) have been published, predating other studies in this field that have since begun to appear in the UK and internationally. The report was formally adopted by WAG, leading to a national awareness-raising publication campaign and presentation of the report as part of WAG's ongoing strategy. Integration of the report's recommendations into government policy is anticipated when the ASD policy is revised in early 2014.</p>
<p>2. Underpinning research</p> <p>The prime driver for this work was Professor Stuart-Hamilton's on-going research and scholarly publications on ageing and Autistic Spectrum Disorder, which came to the attention of Autism Cymru.</p> <p>Relatively modest funding (£20k) precluded a demographically representative sample. Instead, the highest functioning people with ASD were targeted, with the reasoning that if significant problems were found in this group, then other, lower-functioning groups can logically be expected to have similar or greater problems. The study was thus from outset intended as exploratory research to test the need (or not) for further, more detailed studies.</p> <p>Participants were recruited via advocacy and online discussion groups, to participate in an online survey, consisting of the 'Asperger Quotient' test, EuroQOL, and further biographical and health measures. Participants formally diagnosed, plus those who believed they had ASD, but were awaiting formal diagnosis, were recruited. No payment was offered, thereby deterring symptomless claimants from fraudulently claiming money.</p> <p>The results showed both the formally diagnosed and those awaiting diagnosis had significantly higher levels of depression and anxiety, plus assorted physical complaints (e.g. hypertension, digestive disorders) than the general population. Both the diagnosed and awaiting diagnosis groups scored significantly above threshold on the Asperger Quotient test, but the diagnosed group had significantly higher scores than the awaiting diagnosis group. This and further significant differences on other measures always fell in this direction. Employment was overall significantly lower than the population mean, although there was a small sub-group of participants with very high incomes in high status jobs (e.g. GP, head teacher). Although the risk of fraudulent representation is always possible in anonymous online studies, the overall pattern of results concurs very well with what little is known about ASD in later life, and would have required mass collusion by the participants to produce the pattern of findings.</p> <p>Furthermore, the results replicate the findings of the Bangor part of the study, which interviewed some of the Stuart-Hamilton study participants in detail. The study can thus be accepted as an accurate overview of the problems facing high-functioning older adults. This indicates potentially much graver problems for older adults with ASD who are not high-functioning, and indicates a possible causal path to explain the already-documented finding that people with ASD are significantly over-represented in the prison population.</p>

The study thus highlights a need to identify older people with ASD, and since ASD became a popular diagnosis in the 1990s, the majority of children and teenagers currently with the condition have been identified. But relatively few (under 5%) of people over 40 with ASD have a formal diagnosis. This means that circa 1% of the older population has a condition in need of treatment, but who are unaware of this. The study points to an urgent need to increase awareness amongst professionals who regularly treat older adults (GPs, residential care workers, etc) and to ensure that national authorities are aware of the need to identify and treat older people with ASD, and also to recognise that ASD identified in young people will need lifelong follow up. Finally, the study also points to new and potentially fruitful areas of research.

3. References to the research

Stuart-Hamilton, I., Griffith, G., Totsika, V., Nash, S., Hastings, R.P., Felce, D & Kerr, M. (2009) The circumstances and support needs of older people with Autism. Report for the Welsh Assembly Government. Cardiff: Welsh Assembly

Ian Stuart-Hamilton, Hugh Morgan, (2011) "*What happens to people with autism spectrum disorders in middle age and beyond? Report of a preliminary on-line study*", *Advances in Mental Health and Intellectual Disabilities*, Vol. 5 Issue: 2, pp.22 – 28

4. Details of the impact

- 1) This was the first such research, which has since been followed by significantly increased focus elsewhere in Europe and the UK.
- 2) Led to a WAG publication on raising awareness of older people with ASD, available online and distributed to appropriate groups and individuals.
- 3) Led to a conference (incl. keynote address by Ian Stuart-Hamilton) funded by WAG in 2010 to discuss older adults and ASD. Inter alia, senior WAG officials and ministers, and representatives of 18/22 of local authorities and all health boards attended.
- 4) The report is an integral part of the continuing WAG ASD policy.
- 5) Led to WAG adopting the report, pursuing further study and consideration for inclusion in strategy for care of older adults.
- 6) Formal adoption of the recommendations as WAG policy is expected, but the WAG revision of the same is not expected before early 2014. Hence, no evidence can be provided at this time.

5. Sources to corroborate the impact

- (1) The report's publication in 2009 predates other publications on this topic. This is a simple matter of record.
- (2) The WAG publication referred to above may be found at:
<http://www.wales.nhs.uk/documents/110127asdolderadultsen.pdf>
- (3) Details of the conference referred to above may be found at:
<http://wales.gov.uk/docs/dhss/report/100805adultaautismen.pdf>
- (4) The report is cited as part of the on-going strategy on the following WAG webpage:
<http://wales.gov.uk/topics/health/socialcare/disability/adults/?lang=en>
- (5) Evidence for WAG adopting the report, pursuing further study, etc is provided at:
<http://wales.gov.uk/topics/health/publications/socialcare/reports/Olderpeopleautism/?lang=en>

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