

ASD in Older Adults

Summary of talk 19/1/09

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Introduction

There are practically no reliable data on what happens to people with Autism Spectrum Disorder (ASD) in later life, beyond a handful of case studies, which although excellent on their own merits, tell us little about the scope of the problem. The reason for this omission is largely because ASD (particularly Asperger syndrome) is a relatively new condition, and attention has naturally focussed on emerging cases. However, studying the experiences and fates of older individuals with ASD is of great importance, since the information gained is not only valuable in its own right, but also points to likely developmental paths for children and teenagers diagnosed as having ASD.

The present study is the first step to rectifying this problem. It is in two parts:

(1) Mapping out the broad range of issues and problems facing people with ASD. This is being done through an on-line survey offered by University of Glamorgan.

(2) Exploring the experience of growing old with ASD. This is being done through a series of in-depth interviews by University of Bangor.

The survey

The survey is up and running and may be found at:

https://www.surveymonkey.com/s.aspx?sm=rwmRv7jFR56fpuBBHA2wJA_3d_3d

The survey consists of several questions, which can be grouped into: (1) basic biographical information (age, marital status, occupation, etc); (2) measures of quality of life (QOL); (3) the Asperger Quotient (AQ) test (a measure of strength of archetypal ASD symptoms); (4) basic health status information (including whether the ASD is a self-diagnosis or has been made by a qualified person). In total, it takes about 20 minutes to complete, and is strictly anonymised. Participants are invited to indicate an interest in volunteering for further studies, but any information given cannot be linked to responses given in the survey.

The survey is open to anyone aged 40 or older resident in Wales and (if they are interested in taking part) the rest of the UK. Although responses from people in Wales are of prime concern, responses from people in the rest of the UK will be analysed for comparative purposes (and if there is no significant difference between the Welsh and non-Welsh responses, the data may in some cases be pooled for analytical purposes as this may strengthen the validity and reliability of the measures). We are also happy to receive

responses from people without ASD aged 40 and over and resident in Wales who may be used to form an age comparison group.

The survey can either be completed by the person themselves or can be completed on their behalf by someone else acting as their amenuensis.

It is hoped that we will be able to offer printed versions of the survey (though we would prefer people to fill the survey on-line if possible).

The survey is currently only available in English, but a Welsh version is in preparation. Please note that the Welsh version will still have a considerable proportion of text in English as many of the measures used in the survey have only been standardised in English.

The interview study

This section of the study is being conducted by a research team at Bangor University, comprising: Dr Vaso Totsika, Dr Susie Nash and Prof Richard Hastings. The study will recruit a small number of people with ASD and without marked learning difficulties. Participants will be given semi-structured interviews that will be recorded for later analysis using a technique called Interpretative Phenomenological Analysis (IPA). This essentially looks for common themes in the different interviews that enable researchers to identify issues and beliefs shared by individuals with ASD.

Participants for the interviews will be recruited directly by the Bangor team and from the list of prospective volunteers gathered from the survey study.

What the studies will show

It is impossible to predict in detail the outcome of the studies. However, it is envisaged that the following information will at least: (1) inform care providers of the range of needs of people with ASD as they grow older; (2) inform counsellors, school teachers and similar of career choices that appear to offer higher levels of QOL amongst people with ASD; (3) enable counsellors and workers in related professions to recognize potential problems facing people with ASD in relationships; and (4) identify the degree to which people with ASD present as an economically problematic group and whether they are actually an economic asset if they pursue particular lifestyle/career choices.

Notice for NAS

The Universities of Glamorgan and Bangor are being funded by the Welsh Assembly to look at the experiences and lifestyles of older adults with Autism Spectrum Disorder (ASD). There are practically no reliable data on what happens to people with ASD in later life and this study is the first of its kind. We are looking for people to fill in a questionnaire, which should take about 20 minutes to complete. These people must be aged 40 or over and must either: (1) have a diagnosis of ASD (e.g. Asperger syndrome, Kanner's autism, childhood autism, atypical autism, pervasive developmental disorder-not otherwise specified, Asperger's, high functioning autism); (2) currently be in the process of being diagnosed; or (3) think they may have ASD but who have not yet been diagnosed. Although we are particularly interested in hearing from people living in Wales, we will also welcome responses from anyone living in the UK or Northern Ireland. The questionnaire can be completed by the person themselves or by someone else on their behalf if the person finds it difficult to fill in the questionnaire for themselves.

The questionnaire is completely anonymous. If you have access to the internet, the questionnaire can be completed on-line. It can be found at the following web address:

https://www.surveymonkey.com/s.aspx?sm=rwmRv7jFR56fpuBBHA2wJA_3d_3d

Paper copies can be obtained from XX.

Although the survey is completely anonymous, there is the opportunity at the end to volunteer for further research (note that volunteering will not enable us to identify an individual person's responses on the questionnaire). If you have any questions, then please contact Professor Ian Stuart-Hamilton of Glamorgan University. Ian can be reached at istuarth@glam.ac.uk or 01443 654158.

We are also interested in hearing from older people with ASD living in Wales who are interested in being interviewed about their experiences of living with ASD. The interviews, which will be conducted by researchers from Bangor University, will be strictly confidential. If you are interested, please contact Dr Susie Nash (s.nash@bangor.ac.uk).

Notice for older people's groups

The Universities of Glamorgan and Bangor are being funded by the Welsh Assembly to look at what happens to people with Autism Spectrum Disorder (ASD) in later life. ASD is a group name for a set of conditions, the best known of which are Autism and Asperger syndrome. At the moment, we have very little information on what happens to people with ASD once they get past early adulthood, and it is very important that we get a more substantial picture. This study will be the first attempt to examine this issue.

At the moment, we are looking for volunteers to take part in a questionnaire on the internet. This takes about twenty minutes to complete and asks some basic questions about your general health and lifestyle. There are NO

questions that will ask you to reveal your identity and we are NOT electronically tracking people's responses. The questionnaire can be completed by anyone aged 40 or over living in Wales. We especially would like to hear from people with ASD, but we also need comparison data from older people living in Wales who do not have ASD, so if you don't have ASD but have the time to complete the questionnaire, you will be more than welcome to do so. If you know someone who has ASD but who cannot complete a questionnaire on-line by themselves, it's perfectly okay for someone to fill in the questionnaire on their behalf. We are also interested in hearing from people who think they may have ASD but have not yet been diagnosed by a doctor.

Although the questionnaire is confidential, if you are interested in taking part in further research (about ageing or ASD), then there is a contact address at the end of the questionnaire that you can contact on-line or by phone or letter. At the moment, the questionnaire is only available in English. A Welsh version is being prepared, but for various technical reasons, the Welsh questionnaire will still contain sizeable portions in English.

If you have any questions, then please contact Professor Ian Stuart-Hamilton of Glamorgan University. Ian can be reached at istuarth@glam.ac.uk or 01443 654158.

We are also interested in hearing from older people with ASD living in Wales who are interested in being interviewed about their experiences of living with ASD. The interviews, which will be conducted by researchers from Bangor University, will be strictly confidential. If you are interested, please contact Dr Susie Nash (s.nash@bangor.ac.uk).

ASD in Later Life Survey - Some Commonly Asked Questions

I think I have ASD, but I've never had a formal diagnosis - can I take part? Yes.

I'm not sure about taking part yet. Is there someone I can talk to? Yes. Please contact Professor Ian Stuart-Hamilton at Glamorgan University. Ian is responsible for the survey. He can be reached on email at istuarth@glam.ac.uk. Alternatively, you can phone him on 01443 654158 or write to him at Professor Ian Stuart-Hamilton, HASS, University of Glamorgan, Pontypridd CF37 1DT.

I know someone who would like to take part, but they don't have ASD. Can they take part? Provided they are 40 or older, yes. We are interested in the responses of people without ASD as well, for comparison purposes.

I don't live in Wales - can I take part? Yes, provided you live in the United Kingdom or Northern Ireland.

I'm worried about whether I can be identified. Is this possible? The survey is completely anonymous and none of the questions on it ask for any information that would make you easily identifiable.

I know someone who would like to take part but they would need help in filling it in. Is this okay? Yes, this is fine. The survey can be filled in on behalf of someone else.

How long does the survey take? We estimate that it will usually take about 20 minutes. However, there is no time limit, so you can take longer if you like.

I'd be interested in taking part in more surveys and research. Is this possible? Yes. At the end of the survey you will be asked to contact Ian Stuart-Hamilton (at the above address) if you are interested in taking part in further studies. We will NEVER give your details to anyone else, and if we contact you in the future to ask if you'd like to take part in a further study, you are completely at liberty to say 'no' and we won't contact you again.

DO YOU KNOW SOMEONE OVER FORTY WHO HAS OR MAY HAVE ASPERGER SYNDROME OR AUTISM?

The Welsh Assembly Government, through Autism Cymru, has commissioned University of Glamorgan to conduct a survey of people aged 40 and over who have autism spectrum disorder (ASD). This is to increase our understanding of the condition and identify what services people would like to have access to in the future.

If you are 40 or older, and have a diagnosis of ASD (e.g. Asperger syndrome, Kanner's autism, childhood autism, atypical autism, pervasive developmental disorder-not otherwise specified, Asperger's, high functioning autism), we would be grateful if you could give a few minutes of your time to complete an on-line survey. We would also like to receive responses from people who think they may have ASD but have yet to be formally diagnosed.

We are primarily interested in responses from people in Wales with ASD, but we will also be happy to receive responses from people in the rest of the UK and Northern Ireland. If a person aged over 40 who does not have ASD would like to answer the questions, they are welcome to give responses as we also need a comparison group of older people who don't have ASD.

The survey is completely anonymous, takes about twenty minutes to complete, and can be found at the following web address:

<https://www.surveymonkey.com/s.aspx?sm=rwmRv7jFR56fpuBBHA2wJA 3d 3d>

Although the survey is completely anonymous, there is the opportunity at the end to volunteer for further research (note that volunteering will

not enable us to identify an individual person's responses on the questionnaire). If you have any questions, then please contact Professor Ian Stuart-Hamilton of Glamorgan University. Ian can be reached at istuarth@glam.ac.uk