

Proceedings of the 2013 Newcastle meeting on ASD Lifecourse and Ageing

Thursday 12th September 2013

Newcastle University Campus for Ageing and Vitality

About the meeting

The 2013 Newcastle meeting on ASD lifecourse and ageing brought together people with ASD, relatives of adults with ASD, members of local and national charities and organisations involved in supporting adults and older people with ASD, and clinicians and researchers. The meeting was by invitation, and just over 40 people attended. The meeting was jointly funded by the North East Mental Health Research Network, and the UK autism research charity Autistica.

The aims of the meeting were to discuss research opportunities, and strengthen collaborations, to enable the planning of research that will make a difference to the lives of adults with ASD, and their relatives. The day was organised around three main themes:

- engagement and consultation with the ASD community
- research into appropriate health and social care services
- neurosciences research

For each theme there was at least one presentation, but the main focus was on small group discussions, and then groups sharing key information, to promote broader group discussion around the topic areas. To enable this, delegates sat in five groups with around 8 delegates per group. In keeping with INVOLVE guidance, people with ASD, and relatives received honoraria for attending.

Topics discussed at the meeting

Delegates agreed that the meeting had led to them gaining new knowledge, and that it had been useful to meet other people who were interested in ASD lifecourse and ageing and similarly motivated to improve knowledge about this important topic. All agreed that there was a need for more research into ASD lifecourse and ageing, to provide evidence that would lead to improvement in services, and in the lives of people with ASD and their families.

The following document lists topics raised and discussed by delegates at the meeting, indicating that the topics are of some interest and importance to some people. However, not all will agree with its content, and some will think other topics should have been discussed. Topics are listed as 'information useful for researchers' and 'information useful for people planning services'. The topic lists have been edited so they can be easily read and understood, so that others can use them as they wish. This document has been made freely available, and can be cited as 'Proceedings of the 2013 Newcastle University meeting on ASD lifecourse and ageing'.

Information useful to researchers (listed as research questions, research topics or statements about research)

Research engagement

Engage with people about research methods - potential participants may show a real interest in the research process and desire for information. Ensure that people with ASD have access to summaries of research data, that data are publicly available for the community, and that individuals who want to access their own data are allowed and supported to do so.

Identifying 'best research engagement practice' would be useful for researchers working with adults from across the age range.

We need to make research accessible and identify the different ways that people want to engage. How can researchers and the community engage with people with ASD who are not 'linked in with anything'? Postal mailshot methods to reach out to people, with a message 'Do you have ASD and are you feeling isolated'? Many of these adults will not have email access. We need to have data and learn about how to reach other people – for example, what is the utility of sending flyers and posters or using other resources to get people involved?

Researchers could use focus groups for engagement in the very early stages of research. For example, contacting individuals early in research to learn about the challenges they face and some of their needs – these themes can then be built into the research programme.

Many people with ASD connect with specific on-line forums. How can researchers engage? How can researchers signpost particular research processes and ideas to people with ASD that they would like them to be involved in? Maybe a new forum is required, with links to how to participate – this would be part of an initial effort toward recruitment and engagement with people who have had a diagnosis.

We need to think about the methods that would be adopted within the research process to get a whole range of information. We should consider the people who would find it more difficult to speak for themselves and the extent to which this will impact on the research – what are the benefits and drawbacks of having family members being the spokesperson? Also, there are a range of different response methods to use (based on experience from the learning disability field) including electronic/augmentative communication methods, so people who cannot speak for themselves can participate. We should not make assumptions that people cannot do things, but find ways to help them do so. There are also lessons to learn from research with the elderly, about how to approach people, how to ask questions – the key being flexibility and respect.

We need to think more about the needs of people with ASD when designing research, or including people with ASD as researchers, or advisors about the research process. For example, the format of meetings needs to be thought about (for example, size, place, and sensory environment). In the flow of discussion, take account of potential lag in information processing time. Some people with ASD would not like to be involved in group meetings, and it may be better to engage 1-1.

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How can we develop research processes to ensure they are 'friendly' for people with ASD? For example, to avoid the situation where someone 'looks really laid-back but their pulse rate is racing'?

How to engage with people who do not have an official diagnosis (some of whom wouldn't want a diagnosis)? This is important regarding the representativeness of the ASD population with whom research is undertaken. Might some people be willing to engage with researchers if they are prepared to 'self-identify' with some ASD characteristics, and take part for altruistic reasons?

How can researchers be trained to discuss how research participation may help the people who take part, or others, in the future?

Can examples of successful engagement be found from other organisations? For example, have mental health charities/researchers managed to engage with people in the community, or people in institutions? What engagement strategies have the older people's charities/research groups found useful?

Research topics and priorities

Understanding more about the lives of adults and older people with ASD, and relatives

Collect the life-stories of adults with ASD, to pull out similarities/differences between people's lives; also gather evidence about the experiences of parents/carers/siblings/spouses.

We need to know about the lived experience of people with autism. What are the ways of gaining information from adults who are in contact with services? Some people are only in touch with information providers/services at certain times and sometimes only in a social situation.

What are the needs for someone with autism with very limited social or verbal interaction with others? Sometimes their needs may not be recognised at all.

What have been the experiences of parents, siblings and other relatives over the years? Did they get what they wanted (for example, services, support)? How did they learn about ASD lifecourse – through personal experience, the experiences of others, or because information was provided? How should information about ASD lifecourse be provided to parents, siblings and relatives, and what is the utility of doing so?

How should we involve parents, siblings and relatives in research? How should we gather information about their experiences, or measure 'outcomes' for them?

How does ASD change with age?

To what extent does an individual's ASD change with age (development of strengths, relative strengths, and difficulties), and how does this affect them, their lives and happiness?

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Knowing this is important for diagnostic and other service development, and providing effective support in the future.

Is the ASD diagnosis that comes at age five a life-long diagnosis? What proportion of people diagnosed in childhood might not have a diagnosis if reassessed in adulthood?

We need longitudinal research about service use over time, and how this changes. This may show that services should be adapted to meet the needs of older people from the ASD population.

It is important to bring together a range of stakeholders interested in ASD, adulthood and ageing to get some idea about the key priorities for research.

Outcomes and measurement

What would research outcomes look like from an autistic perspective? For example, what would autistic people consider as 'meaningful life outcomes'? Need for researchers to consider planning outcomes 'around the person with autism'.

How we can research whether employment has a positive role in the lives of people with ASD? Might employment result in improved outcomes (for example, improved happiness, mental health outcomes)?

Can we identify appropriate measures of Quality of Life/happiness?

How do adults cope with stress and anxiety, and other co-existing conditions?

Brain and dementia research

Brain Banking is important so researchers can look at the associations between brain changes with ageing from a cognitive testing, imaging and brain anatomy perspective. Does brain structure age differently in ASD to other people? Some centres have lots of 'control' data about brains from other populations, which could be useful in ASD studies.

What is the prevalence and profile of dementia in people with autism? How does dementia affect people with ASD accessing services? In dementia and other conditions of older age, are there existing therapies that can be adapted for the ASD population?

What should be the dementia research outcomes for people with ASD? Outcome could be improvement in quality of life.

Can the research cohorts of older people from the general population provide useful 'control' information for ASD studies?

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In order to investigate brain ageing, imaging studies of groups of adults of different ages could be undertaken. How 'brain health' changes through the years, and how this might relate to general health, and people's progress and outcomes is important.

Increasing research capacity

There was discussion about how to work collaboratively to advance what we know about ASD, develop research and evidence and facilitate service development. Collaboration would ensure progress is made as quickly as possible and allow best use of resources (time of people with ASD, relatives, researchers and funds).

Research databases and cohorts are making a difference to childhood ASD research. How can these be developed for adults and older people with ASD?

Diagnostic process and healthcare

Regarding outcome measures and diagnostic tools, we need to create new measures or alter existing measures so they are valid for use with people with ASD. How should we make diagnoses when a developmental history is not available?

We need to identify research priorities regarding diagnosis during adulthood. For example, how should teams undertake assessments and give diagnoses? How should teams work with adults?

Are there some population groups in whom ASD might be common and undiagnosed? Might these populations be screened for an ASD diagnosis?

How important is an ASD diagnosis? Why do you need a diagnosis as an adult? What are the experiences of people who received a diagnosis as a child, compared with those who were diagnosed in adulthood? How do their experiences compare with adults who have ASD but do not have a diagnosis?

Who are we actually diagnosing in adult life? Are they individuals who are looking for an additional diagnosis? Are they in the cognitively-able end of the spectrum? Who are the people left undiagnosed?

How do people get their diagnosis? How did they cope before diagnosis? Did they develop a really good way of coping? What are the common themes from people about what went well? What precipitates seeking a diagnosis? Have people sought interventions or guidance?

What is the economic impact on the health service of providing or not providing post diagnostic support?

It might be successful and acceptable to signpost people to taking part in research as part of the pathway after diagnosis, i.e. people receive an invitation to be involved in research if they would like to and then keep in contact with people over time.

What are the implications of providing services, compared with not providing them?

Consider researching the implications of services providing diagnostic assessment alone, versus diagnosis and post diagnostic support/follow up. Supporting people may lead to greater future engagement and service use, rather than the social isolation experienced by some – this may improve long term outcomes for adults.

What problems do people with ASD have in accessing the healthcare available to others in the population? How can people with ASD maintain general good health into old age?

Some conditions are screened for in the population – do people with ASD access these screens (for example, breast cancer screening, high blood pressure screening)? What's the health impact of not accessing these? How can they be supported to access 'good healthcare'? How can people with learning disability be supported to receive 'good healthcare'?

Other research areas / questions

How many adults have ASD?

Research output should be written in a form accessible by all groups from society – important that clinical support staff are aware of the evidence, but some (for example, healthcare assistants) may not access research literature. How to get across important research outputs to people across settings?

Information useful to people planning or providing services

Diagnostic services

There was a lot of geographical variability in how adult diagnostic and post diagnostic services have been arranged. In Scotland, one-stop shops have been opened to signpost adults to services. There is support available from the Scottish government for engagement with other organisations. Scottish Autism have worked on a mapping exercise with a view to offering services for adults with ASD.

Many considered that services for diagnosis, and post diagnosis support for adults, are not well developed in many areas. Some people also thought coordination between education, housing, employment, health and social care professionals is not as good as it should be.

Will adult services need to develop criteria to access services? Shouldn't these services be available to all with a diagnosis? What can be available for people who haven't got a diagnosis, or where there is no-one available to make an assessment?

There should be post diagnosis information packs and helpline information.

People need to think carefully about the process of diagnostic assessment for adults. When seeking a diagnosis for a child, parents' question might be "there is something wrong"; however, an adult may be more likely to ask "how can I make sense of all of this?"

Thus the process of making a diagnosis involves forming a relationship, and can be a positive process if it is done well; at best, people will make sense of their experiences and will be better able to resolve problems for themselves.

Engagement with services

We need to think about the resources required by adults with ASD; opportunities for leisure; learning opportunities; social skills development etc.

Some people have difficulties accessing healthcare – for example, some studies have found shorter life span associated with learning disability/epilepsy. We need to ensure people with ASD have good access to healthcare across the lifespan.

There should be really good training for professionals who might come in contact with people with ASD. For example GPs, health, education and social care professionals, police, probation and court services. People need healthcare and other professionals to have the right level of knowledge, and be sensitive to the challenges for people with ASD and relatives.

In order to encourage people to engage with services, could there be a physical place dedicated to autism to serve an area? What would be the benefit for the people with ASD in being engaged? What would they be looking for? When in difficulty people are more likely to be engaged with services. If they knew there was somewhere to go, would they engage earlier, before difficulties are acute?

Equitable services are required – there are fewer services for older people with ASD. We need to ensure older people receive the ‘usual’ healthcare, and identify health inequality – why do individuals with ASD not get the healthcare received by others? How can we ensure people not accessing services are aware of and receive appropriate healthcare?

What is missing from local services? What happens to people able to access services? Who are the people who do not or cannot access services and what happens to them?

How can people be supported to develop life skills? Having the opportunity to work with a personal assistant on a 1-1 basis to work to develop life-skills may be useful.

How can people be encouraged to access services provided by the private sector?

Evidence is needed about what health, education, social care and other services are required, and when these should be provided. Research evidence may lead to service development.

Northern Ireland’s autism strategy became available in November 2013. Funds have been made available to train professionals about adults and ASD, and to develop services.

Are parents satisfied with the support families have received from services? What would they like to have been able to access?

Parents frequently support people with ASD, but how does this change with age? To what extent does the connection between people with ASD and their parents reduce with age?

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Is there a disconnection and what is the impact of this? How can parental support be facilitated, or where necessary, replaced?

Practical support is needed for parents/carers in relation to their mental health needs.

We should be going into the local community to provide information about autism to increase awareness about autism. For example, encourage employers to communicate effectively with the individuals they employ or support.

How can informal support work best for adults? There are some models of drop-in sessions (with a staff-member available for advice and sign-posting to resources) – social groups can then form around particular interests. There are other similar examples, such as Skills for People. However, it can be difficult for organisations to help people to create their own social groups.

Can service providers learn from groups like Age-UK, and how they help/support people? We do not necessarily have to invent new ways of supporting people and, where necessary, combating people's social isolation.

For people who are pro-actively looking for information, a model such as Citizen's Advice Bureau may work, with special sessions for people with ASD to answer their questions and help with practical matters. And provide advice for relatives. But what about those people who might not be so good at asking for help? Examples were given of services being proactive in contacting/visiting people to see them and ensure they are ok.

There is the challenge of needing services to be developed for individuals with a diagnosis, and the large number of individuals who are unknown to services, whilst also developing an evidence base about a best model of service provision.

Take into account how to reduce sensory overload from environmental stimuli to reduce challenging behaviours. Discussion about a community home model for 4-6 people with ASD, and how in that 'ASD friendly setting', this has altered and reduced challenging behaviour.

Other information relevant to service providers

Disorder vs. neurodiversity was discussed, including the fact that the 'disorder' label is often necessary to access services, and a Fair Access to Care assessment.

Local authority professionals are keen to know 'Are we getting services right?' And if not, how to get services right?'

Scottish Autism have been working on an 'End-of-life-care' study.

Will people want to discuss topics such as end of life care? Should the community make people available who would be a resource to discuss this, who could say 'we are here if you want us'?

Arranging legal power of attorney is a huge challenge for families – having ASD specific advice around this would be useful.