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# Adults with Autism Spectrum Disorder (ASD): Service User Perspective on Ageing Transition(S)

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## Abstract

The health, social, educational aspects as well as the research in treatment and diagnosis of Autistic Spectrum Disorder (ASD) have largely focused on the younger population. In contrast, very little is known about ageing with ASD. In order to address both the current knowledge about the ageing in ASD and the real needs of the ageing ASD subjects, we conducted a survey of 45 individuals who were either formal or informal carers of people with ASD or themselves had the diagnosis. Participants identified long-term management, diagnosis and awareness regarding ageing in ASD to be major topics for further work and investment rather than aetiology and treatment. They also identified two major themes for action: person-centred care (to include accurate diagnosis of ASD irrespective of age) and long-term support and care in community.

*Keywords:* Autistic spectrum disorder; Ageing; Older adults; Transition; Survey

## 1. Introduction

Autistic spectrum disorder (ASD) is one of the most widely studied developmental disabilities. It is considered one of the most severe childhood neuropsychiatric disorders. Research into both the treatment and diagnosis of ASD has largely focused on the younger population, with the majority of published studies conducted on children and adolescents (reviewed in Mukaetova-Ladinska et al, 2012). In contrast, very little is known about ageing of individuals with ASD. The recent review papers on ageing in ASD (Povey et al, 2011, Mukaetova-Ladinska et al, 2012, Piven et al, 2012, Happe and Charlton, 2012, Smith, 2012, Wright et al, 2013) have all highlighted the number of unknowns in respect to epidemiological, biological, psychological and social aspects of older adults with this syndrome. Although largely based on empirical observations, these reviews also included studies on prevalence rates (Brugha et al, 2011) and quality of life and psychological distress in

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adults with ASD (Stuart-Hamilton et al, 2010), as well as a small number of published case reports on diagnosing ASD for the first time in older adults and changes in their cognitive abilities, in terms of problems thinking, loss of memory, decreased attention span, and difficulty with word-finding (James et al, 2006).

The children initially diagnosed with the ASD in the 1960s are now well into adulthood and approaching (or having even reached) the age of 60 years or above. Above the age of 60 years, people with learning disability have higher care needs and more frequent age-related impairments characteristic for old age (reviewed in Holland, 2000). All of the current older people with ASD underwent their first transitional period (from childhood to adulthood) several decades ago. Interestingly, only recently this passage has started to be studied and documented by the research community. A recent study drew the attention to the transitional period and support needed for ASD adolescents starting university and work (Schall et al, 2012). Although some improvements in co-morbid behaviour and emotional problems and autism symptomatology have been observed in ASD adulthood, the prevalence rates of these symptoms still remain higher than in the neurotypical population (Gray et al, 2012). Similarly, the mental health needs also remain very high and largely undetected and untreated (Hassiotis and Turk, 2012). The adult ASD subjects have high dissatisfaction in respect to relationships and quality of their life (Cottenceau et al, 2012). This argues that the core symptoms of ASD continue to be florid in adulthood and are further accompanied by additionally socially gained complications in the course of the ageing process.

If the studies addressing adulthood ASD characteristics are redundant, this is even more so for the older ASD subjects. Furthermore, since old age is defined according to reaching chronological milestones which mark life stages and/or when active contribution is no longer possible, the currently accepted definition of old age may not, necessarily, be applicable to individuals with ASD. Ageing with ASD is emerging as an area of key interest. For example, national and international institutions [e.g. National Autistic Society (NAS) and Autism-Europe] have conducted audits on targeting ageing perspectives in ASD, with a number of conferences/workshops being held. However, it is essential that we find out what people want, not just make general statements that 'something must be done'. In order to address both the current knowledge about the ageing with ASD and the real needs of the ageing ASD subjects, we conducted a survey of 45 individuals who were either formal or informal caregivers of people with ASD or who themselves had the diagnosis.

## **2. Materials and Methods**

### *2.1 Participants*

45 working-age participants, of whom 3 declared themselves having a diagnosis of Asperger syndrome (two of them were diagnosed in their 40s) took part in 3 workshops on Ageing in Autism. The workshops were organised as a part of the Scientific Programme of the Wales' Fourth International Autism Conference (Cardiff, 22.06.2011) with an aim to address the needs of the ageing individuals with ASD. The Conference was well-attended (over 800 caregivers, service users and professionals) and the workshops were chosen as a venue to attract participants with a significant interest in ageing with ASD. Thus, the workshop participants were a self-selected, rather than randomly selected sample.

## *2.2 Questionnaire*

The questionnaire (Tables 1 and 2) was devised by both authors according to the gaps identified in the available literature on ageing in ASD (reviewed in Mukaetova-Ladinska et al, 2012).

## *2.3 Description of workshops*

The workshops consisted of four parts: in the first part (10 minutes) participants were asked to fill in a brief questionnaire centred on participants' experiences regarding the care of ASD subjects, and in particular about their opinions regarding the care of adults and elderly with ASD concentrating on physical and cognitive/mental problems and care needs (Tables 1 and 2).

This was followed by a brief (30 minutes) presentation reviewing current epidemiological and clinical literature on adults (IS-H) and older (EBM-L) individuals with ASD. The third component of the workshops was work in small groups (15 minutes discussion; 5 people maximum in groups) facilitated by the two workshop leaders, with participants discussing one of the following topics on ageing with ASD:

- Do older people with ASD provide us with challenges different from older people with other atypical conditions?
- Should we be searching for older people with ASD or just leave things as they are?
- If we had the resources, what form would a service for older people with ASD take?

This was followed by a 20 minutes interactive question and answer session, resulting in producing a chart to aid identifying care provision and obstacles for ageing subjects with ASD (Table 3).

## *2.4 Statistical analysis*

An Excel database was created to store data obtained from the questionnaires. Frequency of response data and their percentages were calculated for each question.

# **3. Results**

## *3.1 Participants' characteristics*

Most of the participants (91%) at the workshops were looking after an ASD individual either as a family member or providing care in care homes. Similarly, all but one (98%) also knew a relative, family, friend or a colleague who had a child or looked after someone with ASD. Surprisingly, one third (31%) knew a child with ASD, whereas the majority (78%) knew adults (32/45) and/or older people with ASD (3/45) (Table 1).

## *3.2 Priorities for ASD management*

The majority of participants (84%) felt that the general public is not aware of contemporary issues in ASD research and health care (Table 1). Nearly half of them (49%) thought that the support the ASD subjects they knew had was adequate or superior, whereas 31% reported inappropriate support. Surprisingly, attendees felt that the most important issue in ASD is a long-term

management (47%), followed by correct diagnosis, including that made in adulthood (22%), as well as education and awareness regarding ASD (20%). None of the participants felt that aetiology is an important issue in ASD research/management, whereas only 4 of the participants (9%) placed treatment as a priority (Table 1).

**Table 1** Participants' involvement and views on care for individuals with ASD. Abbreviation: NA, not available.

Questions	Reply	n	%
1. Do you know anyone (relative, family, friend, colleague etc.) who has got a child or looks after someone with autism?	Yes	44	97.8%
	No	1	2.2%
2. If yes, do you feel that the support they have is:	Adequate	17	37.8%
	Inappropriate	12	26.7%
	Far better than other carers get	3	6.7%
	Do not know	9	20.0%
	NA (3 responded 'varies')	4	8.9%
3. Do you personally know anyone with autism?	Yes	41	91.1%
	No	4	8.9%
4. If yes, where do they live:	Home (independent)	11	25.6%
	Home with family/carers	27	62.8%
	24h care facility	12	27.9%
	Do not know	3	6.9%
5. How old are they?	Child	14	33.3%
	Adult (one subject was 60y old)	32	72.2%
	Older (>65 years) adult	3	6.8%
	NA	3	6.8%
6. In general, do you feel that the support they have is:	Adequate	18	40.0%
	Inappropriate for their needs	14	31.1%
	Eat better than most people with disability get	4	8.9%
	Do not know	5	11.1%
	Do not need help (AS subject)	1	2.2%
	NA (1 'varies')	3	6.7%
7. Is the general public aware of contemporary issues in ASD?	Yes	2	4.4%
	No	38	84.4%
	Do not know	5	11.1
8. In your opinion, what is the most important issue re ASD care:	Aetiology	0	0.0%
	Diagnosis	10	22.2%
	Treatment	4	8.9%
	Long-term management	21	46.7%
	Education and awareness	9	20.0%
	Other:		
	Understanding	4	8.9%
	All	5	11.1%

### 3.3 Ageing in ASD

**Table 2** Participants' views on ageing with ASD.

Questions	Reply	n	%
1. Is ageing an important aspect for ASD?	Yes	40	88.9%
	No	0	0.00%
	Do not know	5	11.1%
2. Do you think ASD subjects age:	Like everyone else	9	20.0%
	Age differently (specify): Late to develop certain skills, life like typical neuro-typicals, sometimes do not learn by their mistakes; depending on age of diagnosis support given to date. Due to cognitive differences their understanding mature at different rate cognitively; less obsessions.	27	60.0%
	Do not know	9	20.0%
3. Does ageing in ASD requires:	More resources	32	71.1%
	No change in resources	0	0.0%
	Less resources	0	0.0%
	Do not know	13	28.9%
4. What problems elderly with ASD face? (tick as many as you think)	Isolation	33	73.3%
	Not understood	40	88.9%
	Social problems	41	91.1%
	Problems in communication	38	84.4%
	Managing money	37	82.2%
	Personal care	36	80.0%
	Lack of advocates	39	86.7%
	Lack of adequate knowledge	37	82.2%
	Lack of adequate support in community and care	24	53.3%
	Other (specify): access to health care	9	20.0%
	social support	7	15.6%
work job availability support	9	20.0%	
5. Do older people with ASD have more physical problems than the younger?	Yes	17	37.8%
	No	1	2.2%
	Do not know	27	60.0%
6. Do older people with ASD have more mental/behavioural problems than younger?	Yes	19	52.8%
	No	2	5.6%
	Do not know	15	41.7% <sup>s</sup>
7. Does ASD require a different approach to care provision?	Yes (specify): Long-term support; health services; understanding; ASD-specific, 24h better communication	35	77.8%
	No	1	2.2%
	Do not know	9	20.0%

Eighty-nine per cent (40/45) of the participants perceived ageing being an important aspect of ASD, whereas the remaining 5 attendees did not have any firm opinion about this (Table 2). According to the participants, ASD subjects age differently (60% response) and this may be due to ASD subjects 'developing certain skills late in life', having 'distinct cognitive differences', 'different maturation', having 'less obsessions' or 'not being able to learn by their mistakes'. In addition, participants felt that the effects of ageing might vary between individuals depending on the age of diagnosis and support given to date. However, 20% of the participants thought that ASD subjects age similarly to the rest of the general population, whereas similar proportion of the interviewed panel (20%) did not know (Table 2).

### 3.4 Physical and mental health problems in ageing in ASD

The majority of the participants (62%) did not know whether ASD subjects have more physical problems than the general population, whereas the rest (17/45) felt that they might well have (Table 2). However, 42% thought that the older ASD subjects have more mental/behavioural problems than the younger ones, with one of the participants stating that the 'behavioural problems in younger adults seem to be more acceptable than those in older adults'.

### 3.5 Care provision for older people with ASD

78% of interviewed participants reported that ageing in ASD requires a different approach to care provision, and this will require more resources (according to 71% of participants). In particular, a number of difficulties older individuals with ASD face were highlighted including: social isolation (73.3%), not being understood (88.9%), variety of social problems (91.1%), problems with communication (84.4%) and finance (82.2%), support with personal care (80%), lack of advocates (86.7%), inadequate knowledge (82/2%) and support in community, inadequate: care (53.3%), access to health care (20%) and social support (15.6%), and lack of work job availability (20%) (for those ASD subjects in the working age) (Table 2).

**Table 3** Identified care provision and obstacles for ageing subjects with ASDs.

<b>Person centred care</b>	<b>Long-term support and care</b>	<b>Person centred care</b>	<b>Long-term support and care</b>
<b>Good care</b>	<b>Obstacles</b>	<b>Good care</b>	<b>Good care</b>
Attention to personal specific needs and interests Communication Diagnosis Empathy Respect Quality of life Time-keeping routine Understanding needs Own home	Challenging behaviour Routines Depression & bereavement Social isolation at home Communication Lack of understanding of wishes and needs Difficulties in communities Lack of family support Death of a parent Financial problems Misdiagnosis of other psychiatric conditions Family support Resources and funding Lack of research into ageing	Social activities Living environment Supported living Social support Planned services Support centred round an individual not the institution Provision for older ASD subjects Health care Humility	Many of staff inadequately trained Lack of understanding Neglect Lack of involvement No specific services Lack of individualised care Lack of social inclusion Resources and funding Lack of research on ageing

The participants also provided their views regarding what good care for older ASD subjects should consist of. Two major themes emerged: (i) person-centred care and (ii) long-term support (Table 3). In addition to these, all participants also identified a number of problems that may occur in the process of caring for individuals with ASD, including lack of information regarding social and psychological functioning, communication, loss of a family support, social isolation, financial problems, access to services, and lack of resources and funding (Table 3).

## 4. Discussion

Our findings confirm that ageing in ASD is a topical issue among people who have either a family member or know someone with ASD. Contrary to expectations, the majority of the participants in our survey felt that long-term management, diagnosis and awareness regarding ageing in ASD are major topics that need further work and investment rather than those pursued for the younger ASD population e.g. aetiology and treatment (reviewed in Blenner et al, 2011) or trajectories of development over the ASD lifespan and identifying factors that may influence the prognosis for people with ASD in adulthood, as suggested by a recent expert review (Howlin and Moss, 2012). In this respect, the latest UK National Institute for Health and Clinical Excellence (NICE) guidance (2012) is welcome news, since it stresses the importance of diagnosis of ASD in adults, and provides recommendations for assessments. Although the most recent review (Fombonne, 2012) puts an accent on diagnosis and pharmacological management of adults with ASD, the findings from our survey highlight that the adult ASD needs are more within the long-term management in terms of long-term support of the vast amount of longstanding and known social and personal needs, all requiring more financial resources.

The participants in the current survey identified two major themes for action: one concentrating on person-centred care, including accurate diagnosis irrespective of the age and another on the long-term support and care in community, similar to those identified in the recent reviews on ageing in ASD (Mukaetova-Ladinska et al, 2012, Piven et al, 2012). In addition, the lack of research and knowledge regarding ageing in ASD was highlighted as one of the major obstacles in delivery of good care and provision for ageing ASD subjects.

Although, undoubtedly, academic research in ASD adulthood is lacking, the needs of the ASD adults in the current climate are more far-reaching than the academic understanding and gaining new knowledge. The participants in this survey highlighted the urgent need to address both the unmet and the increasing needs of both ASD subjects and their families. Thus, the elderly parents of the adults with ASD are also facing the ultimate unknowns for the future of their adult children. The recent National Autistic Society (NAS) initiative *Autism in Maturity* in particular is dealing with the support that the ASD adults over the age of 40 years will require from their second generation of caregivers, their siblings. This second transition will bring also new generation of carers who may well require a different type of support from that of their parents. In particular, since the majority of adolescents and adult ASD subjects continue living with their parents (as high as 40-70%; Taylor and Seltzer, 2011), it remains unknown what will happen to them once their current caregivers (i.e. parents) are not able to look after them. This will, undoubtedly, have an impact on the quality of life of both the older people with ASD and their siblings and put pressure onto the currently available social services to meet the needs of this ASD contingent.



A recent narrative study explored older parents' experiences of living with adult offspring with ASD (Hines et al, 2013). The findings of this study highlight the difficulties parents (aged 60 years and older) have whilst providing care for their adult children with ASD and achieving a degree of fulfilment in their own lives. This raises the need for adequate formal support and tailored intervention strategies, matching each family's unique needs, to be developed to support ageing parents. However, this needs to be extended to the new generation of caregivers, the siblings of people with a SD. The qualitative research study on siblings of people with Autism from the University of York (Atkin and Tozer, 2011) reported that sibling relationships are lifelong, two-sided and characterised by strong feelings and loyalties. However, the significance of these relationships is generally overlooked in policy, practice and research, and very little formal support is available to siblings and their own families. Thus, disruption to siblings' family activities, worries about stressed parents and lack of understanding from peers and other family members were reported by many of the participants in the study.

The recent survey by NAS (de la Cuesta and Michael, 2012) further confirmed the extent of adult sibling involvement looking after their relative with ASD. Thus, 40% of adults with ASD do not have practical support in their day-to-day lives, and the majority of them (40%) live with their elderly parents and/or siblings. Since a significant number of siblings are expected and willing to continue to have an active role in the care for their adult relative with ASD (de la Cuesta and Michael, 2012), they will need more support by statutory services, including social service providers, commissioners and professionals.

These concerns, alongside the well-documented caregiver burden, mainly associated with the ASD person's unmet needs (social relationships and mental health problems, including inappropriate behaviours, depression and anxiety; Cadman et al, 2012) also warrant educating this new generation of caregivers about interventions to reduce their caregiver burden. Atkin and Tozer (2011) provided a number of recommendations including: (i) siblings should be offered the choice to take part in reviews about their sibling with autism to discuss future planning; (ii) social care providers, practitioners from all relevant disciplines and commissioners need to be 'sibling aware' and value and support whatever positive contributions siblings make to their brother or sister's life; and (iii) involvement of a third party to help families (including the new generation of caregivers) negotiate future plans if needed.

The Autism Act (2009), the first disability-specific legislation in England (please note that in Wales, the Welsh Assembly Government Autism Spectrum Disorders – A guide for people working with Older Adults, Dec 2010; in Scotland, The Scottish Strategy for Autism, and in Northern Ireland, The ASD Strategic Action Plan, apply), resulted in statutory guidance (published in 2010), about involvement of both local authorities and the National Health Service (NHS) needs to improve services for the adults with autism, from adequate diagnosis and collecting data about adults with ASD, adequate assessment of their needs to facilitating further service developments. This guidance is in line with the United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD), ratified by the European Union and most of its member states, and echoes the *Recommendations of the Council of Europe on Ageing and Disability in the 21<sup>st</sup> Century* (2009). Autism Europe with Age Europe, in their policy paper 'The Rights of Ageing People with Autism Towards a better quality of life' ([8](http://www.age-</a></p></div><div data-bbox=)

platform.eu/images/stories/Autism\_Europe\_AGE\_Report\_on\_ageing.pdf; 2013) presents a number of recommendations to policymakers, including:

- the right to an independent life and self-determination (article 19 of the UNCRPD);
- the right to maintain or improve the quality of health (article 25 of the UNCRPD);
- prevention of health problems related with ageing;
- accurate diagnosis and accurate information on their specific health condition, prevention of problems related to their specific health conditions, treatment of individual health conditions;
- the right to maintain and improve communication and social interaction (articles 9 and 26 of the UNCRPD) – the older people with ASD should be provided with access to adapted alternative means of communication and visual information;
- the right to appropriate intervention (article 26 of the UNCRPD). Multidisciplinary assessment and co-ordination of interventions throughout the lifespan of the person with autism, including during the old age;
- the right to have services to provide a good quality of life (article 26 of the UNCRPD)

Various research meetings and workshops held in Europe and Middle East (e.g. Autism-Europe workshop on Ageing, 2012, Istanbul; International Autism Conference in Israel, 2012; Autism-Europe meeting on Challenges of Ageing Lyon, 2012; National Autistic Society conference on supporting older people with autism, London, 2012) clearly demonstrate the groundswell of opinion amongst concerned parties that action is taken. Since specialised ASD services for adults and beyond are underdeveloped, further work is needed to determine the socio-economic impact of development of adequate services for this population, taking into account the continuing physical and mental health issues individuals with ASD have. This has been very well summarised by one of the participants (27 years old man with Asperger syndrome) in this survey, who said: 'The first transition was difficult, but the second looks even more worrying.'

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## **Conflict of Interest**

None

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